DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office of Human Development Services
President's Committee on Mental Retardation

A Presidential Forum:
Citizens with Mental Retardation and Community Integration

Forum Proceedings
February 3-5, 1989
Washington, DC

The President's Committee on Mental Retardation acknowledges and extends appreciation to the following organizations, agencies and private individuals for their financial co-sponsorship of the national conference, "A Presidential Forum: Citizens with Mental Retardation and Community Integration:"

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PREFACE

The foundation of the President's Committee on Mental Retardation was established in October, 1961, when President John F. Kennedy announced the formation of the Presidential Panel on Mental Retardation with the charge to review the status of programs for persons with mental retardation.

As the Panel's recommendations began to be implemented, it became obvious that some overview and coordination of the public and private effort in mental retardation, on a continuing basis, was necessary. The need for a coordinated effort formed the basis for establishing a national alliance of government and private citizens who could provide an ongoing review and coordination as well as advise the President of the varying needs of persons with mental retardation.

On May 11, 1966, by Executive Order 11280, President Lyndon B. Johnson, established the President's Committee on Mental Retardation; hereafter referred to as the PCMR. The Executive Order mandates the PCMR to provide advice and assistance in the area of mental retardation as the President or Secretary of the Department of Health and Human Services may request.

Today, there are over six million Americans of all ages directly affected by mental retardation. It is estimated that the mental retardation experienced by approximately 1.5 million of these individuals is attributable to causes and origins of diseases which are biomedical in nature, and that the remaining 4.5 million Americans with mental retardation experience this disability because of environmental/ psychosocial or multi-factorial contributions.

The purpose of the Presidential Forum was to examine the national effort to promote maxi mum community integration of citizens with mental retardation and to highlight the experiences of educators, service providers, community planners, Federal/State officials, parents, advocates, etc. that have achieved success in planning, designing, evaluating, and/or implementing diverse community integration projects serving persons with mental retardation. Each participant was also requested to address one or more of the following "Partnership Themes" in their presentation: a) Federal/ State, b) State/Local, c) Public/Private,
and; d) Family/Service Delivery System.

Along with the President's Committee on Mental Retardation, an impressive 22 Federal, public and private organizations and individuals provided co-sponsorship in the form of fiscal support for this timely initiative. They are as follows:

ACTION

American Association of University Affiliated Programs for Persons with Developmental Disabilities
American Foundation on Mental Deficiency
American Nurses' Association, Inc.
Carter, Hawley, Hale Stores, Inc.
DoE-Office of Special Education and Rehabilitative Services
DHHS-Administration for Children, Youth and Families
DHHS-Administration on Developmental Disabilities
DHHS-Health Resources and Services Administration Bureau of Maternal and Child Health and Resources Development
DHHS-National Institute of Child Health and Human Development
DHHS-Social Security Administration

Fairview Families and Friends, Inc.
Goodwill Industries of America, Inc.
Miriam and Peter Haas Fund
Maine Department of Mental Health and Mental Retardation
Marshall's Department Stores
Minnesota University Affiliated Program/Center for Residential and Community Services
National Association for the Dually Diagnosed
National Council on the Handicapped
National Foundation for the Handicapped
WEMCO, Inc.
Mrs. Jefferson Patiterson of Washington, D.C.

Presidential Forum participants included: parents, Federal, State and Local representatives, educators, service providers, experts in the field of mental retardation and representatives of 18 states and the District of Columbia.

In attendance were over 350 persons from 40 states, 3 territories and the District of Columbia, from all walks of life, educational backgrounds and expertise representing a wide variety of agencies and organizations, as well as parents and advocates, all of whom were interested and/or involved in programs and services that promote community integration for persons with mental retardation.

This Presidential Forum Proceedings document seeks to accomplish the following significant community integration objectives:

a) provide contacts and resources regarding programs and services which have made maximum community integration for persons with mental retardation a realistic objective;
b) provide a sampling of programs and services that currently exist nationwide in the areas of: zoning and real estate, financing of community integration models, transition into the community, living arrangements, employment, transportation, education, recreation, family supports, respite care, life services planning, quality assurance, medical and dental health care and citizen advocacy;
c) enhance the PCMR's ability to provide the President and the Secretary of Health and Human Services needed information relative to where the nation is in its efforts to promote maximum community integration and suggested recommendations that may enhance the improved quality of life of persons with mental retardation; and,
d) identify the potential of various Federal and public and private program models for achieving maximum community integration.

Papers contained in this Presidential Forum Proceedings document are the views, experiences, and opinions of the authors and do not necessarily reflect the views of the PCMR or any other part of the U.S. Department of Health and Human Services.

In conclusion, the PCMR is very proud to present this Presidential Forum Proceedings as a reference and resource document.

Albert Leroy Anderson, D.D.S.
Vice Chairman
President's Committee on Mental Retardation

OPENING PLENARY SESSION
February 3, 1988

Remarks
Opening Statements
PCMR Community Integration Initiative
Drug Abuse, Mental Retardation and Community Integration
Public Awareness/Public Acceptance
Family Role, Financing and Trust Planning
Family and Real Estate
Financing of Community Integration Models
Promoting Maximum Community Integration Through People Management of Transition into the Community

Remarks

by Sydney Olson
Deputy Assistant Secretary
for Human Development Services
Department of Health and Human Services
Washington, D.C.

Thank you, Dr. Anderson, and good morning, everyone.

Welcome to Washington! And welcome to this important forum, whose potential to improve the lives and futures of millions of American citizens with mental retardation can indeed be momentous, even historic.

This week, you will share experiences as well as expertise on successful ways to achieve our national goal of integrating citizens with mental retardation into the mainstream of community life.

America's public policy, articulated by President Reagan on many occasions, is to move toward this goal with special vigor during the Decade of Disabled Persons. We know that people with mental retardation comprise a significant portion of that special population.

These meetings are justifiably called, "A Presidential Forum." The President's Committee

on Mental Retardation has among its many responsibilities that of advising the President on matters related to mental retardation in all its aspects.

Out of this meeting will come a series of reports and recommendations to the President and to the Secretary of Health and Human Services, addressing the issue of community integration.

The Office of Human Development Services has four major programs which have a relationship to mental retardation, as well as to community integration. OHDS serves citizens with mental retardation who are also persons with:
1) developmental disabilities;
2) Native Americans with mental retardation;
3) children, youth; and, 4) elderly persons with mental retardation.

So our Office has a very real role and interest in this Forum, and its results.

I note among the themes to be discussed this week are a series of partnerships between the Federal government and State government, as well as the public/private sectors and service delivery partnerships with the family.

Implicit in these themes is a partnership at the Federal level bringing together the various Departments and programs which impact upon those with mental retardation, their families, friends and advocates. Much has been achieved already, including cooperative agreements between HHS and the Departments of Labor and Education.

It is my intention as head of the Office of Human Development Services — assuming my confirmation hearing goes well tomorrow! — to build upon these partnerships. And I want to reach out to still other Federal agencies, including the Social Security Administration, not only to remove existing barriers to community integration, but also to find new paths to reach that goal.

And I want to pursue, as well, an initiative already well begun by Secretary Bowen, called "Family Caregiving." I believe Family Caregiving to be a rational and workable response to the needs of many persons with disabilities, including mental retardation. It stresses the important role of family members in caring for them, not only by making physically and financially possible for them to do so, but also by giving them the training, knowledge, and even equipment and respite they need to cope with the physical and social needs of the person with a disability. I recognize that family care giving can't be a total solution, but it could be a giant step toward resolving many such family situations. And it will contribute toward the mainstreaming process, because someone who lives with his or her family at home is, indeed, living in the community in a far more normal setting than some alternative living arrangements.

My welcome duty this morning is to introduce to you someone who surely needs no introduction. As Chairman of the President's Committee on Mental Retardation, he is the President's direct representative on that body. At the same time, he is the chief executive officer of the Department of Health and Human Services, whose programs play such a vital part in the lives of citizens with mental retardation, and their families

Dr. Bowen knows well, from his personal experience as a family practitioner, how deeply having a child with mental retardation affects the whole family. As a former lawmaker, he knows how difficult it is to make the variety of laws and regulations — often seemingly at odds with the goal of rationalizing the service delivery system — work together. As a former Governor, he knows how hard it is to administer a network of programs that sometimes prefer to work separately, rather than together. As a teacher, he knows how important it is to inculcate upcoming generations of service providers in the holistic approach, bringing together the various resources of a community to deal with the medical, social, economic, and rehabilitative needs of each individual who is sick or disabled. And, as Secretary of such a vast Department, responsible for our nation's major health, welfare, medical research and income security programs, he has worked tirelessly to strengthen programs that strengthen the family, and to serve those most truly in need.

I am pleased to introduce the Honorable Otis R. Bowen, Secretary of the Department of Health and Human Services.

Opening Statements

by Otis R. Bowen, M.D.
Secretary
Department of Health and Human Services and
Chairperson
President's Committee on Mental Retardation
Washington, D.C.

Sydney Olson, thank you.

Welcome, all of you. Coming to Washington in mid-winter may mean snow in the Capitol city, and in Washington that may result in a stand-still in the Capitol. Well, we don't want to stand still. The weather has helped us.

Your groups are well-known for your tireless devotion to the well-being of our Nation's six million citizens with mental retardation. Although most of our citizens with mental retardation reside in the community today, community integration is not complete for most of them. And many of the 100,000 persons in large public residential facilities can benefit from community services. Also, there are some who need 24 hour health or nursing services in special facilities because of their profound or multiple handicaps.

Whether you're urging more community living arrangements, or better vocational training programs, you're saying: "Look, this is what disabled people can do. How about giving them a chance?" And every time you go out and try to convince another employer to hire a disabled person, that's the message.

For my own part, I have committed this Department to ensuring that people with mental retardation have the opportunity to live, learn, work and play in their communities.

As I see it, our job spans three key areas:

- to provide the supports that caregiving families need;
- to enhance community living arrangements;
- and to help open up education and employment opportunities.

Of course, there are a number of other basic areas, such as health and social services, and leisure and recreational opportunities that are needed to assure community integration.

Let's look at family support needs first. And let me begin by praising those families that have achieved near-miracles with a severely disabled child or adult. Their strength is awesome. To the rest of us it seems like they face impossible demands on their physical, emotional and financial resources.

But they do it — with love and devotion. These parents give what it takes to help their child realize his or her full potential.

But parents need help, too. Sometimes they become exhausted. That's when they need the relief that respite care and homemaker services provide. Sometimes families need financial help and some States provide this.

And they need a range of support services that aren't always available; they also need to know where to get help, and how to get information about teaching techniques to use with their child.

That's why your efforts in these areas are important. And we want to help you. So we've launched the Family Caregiving Project.

It's a cluster of research and demonstration projects funded by various agencies in our Department. The projects that deal exclusively with mental retardation and developmental disabilities address topics such as respite care, recreation and bartering of services.

It's information you can put to use in your work.

Our second emphasis is to enhance community living arrangements. We're making progress here, too.

Twenty five years ago, when disabled children moved into adulthood, they were often

moved out of the family home and into institutions. This often meant that years of special education and training in independent living were lost. For many, the institution became the place:

- where self-confidence was drained away;
- where skills and knowledge painstakingly acquired were forgotten;
- and where hope for the future was lost.

Thanks to people like you, that's changing.

Our goal now is to integrate as many persons with mental retardation as we can into every aspect of community life. Today, each State is developing community-based services for the disabled. They're putting strong emphasis on living arrangements and the transition services that people need to become self-sufficient.

The kinds of services required at this juncture are many. They include family support, health services, transportation, education, employment, recreation, life services planning and advocacy.

They must be initiated long before the young people finish school, so when they do leave, they leave with the expectation and self confidence that they can support themselves.

Indeed, we now know that most persons with mental retardation can learn and work at jobs. We also know that the longer people are jobless, the harder it is to place them in gainful work. And they are at greater risk of becoming dependent on public support.

Here are some figures that indicate the challenge we face to move persons into living and employment in the community:

- About 500,000 mentally retarded adults are receiving public assistance from the SSI and SSDI programs. Virtually none of them are employed at jobs paying more than $300 a month.
- About 140,000 persons are living in intermediate care facilities for the mentally retarded. Almost none are employed.
- Of 185,000 persons with mental and developmental disabilities served in state-supervised day and vocational programs, only 3% hold jobs.

Coordinated and comprehensive transition services from school and family to community and workplace are a tall order.

But remember, years ago our goal was to provide appropriate schooling for these children. We've largely achieved that now.

The big challenge today is to get them into jobs. We're making progress on that front, thanks to the Administration's employment initiative. Since it began in 1983:

- We have received over 102,000 pledges for private sector employment;
- Nearly all State Developmental Disabilities Councils have begun State employment campaigns;
- And over 87,000 persons have been placed in competitive employment.

These new employees have earned wages of about $400 million.

And our employment initiative campaign is opening still more doors. It has brought on board the American Bus Association, the American Hospital Association, the National Restaurant Association, McDonalds and Denny's and the Marriott and Radisson Hotels.

We'll continue these efforts to open doors for the disabled by targeting our sales effort on new industries and individual corporations. We'll be banking on you to help out in this effort.

These are exciting times for people in your field, and I'm glad to have this chance to meet with you. I know you're ready to start talking with each other and with us, so let me close with some personal observations.

As a physician I've seen firsthand what disabled people can do. Later, as governor of Indiana, I pushed for employment and fair treatment of the disabled. And it didn't take me long to see that people with handicaps were some of the most dependable employees around. And, in my book, the greatest ability is dependability!

Success means so many different things to different people. All of us have a chance to succeed, using our God-given talents. Our philosopher of self-reliance, Henry David Thoreau said: "Whoever you are, life is a battle in which you are to show your pluck, and woe be to the coward. Whether passed on a bed of sickness or in a tented field, it is ever the same. Despair and postponement are cowardice and defeat. We men and women are born to succeed, not to fail."

Al Anderson, I'll turn the program back to you now. Thank you.

Overview of the President's Committee on Mental Retardation's Community Integration Initiative

by Vivian Bricklin Levin
Executive Director
President's Committee on Mental Retardation
Washington, D.C

The topic of the conference: A Presidential Forum: "Citizens with MR and Community Integration" is very challenging. Twenty-two cosponsors have joined with PCMR to produce this conference. You will find their names listed on the inside cover of the program booklet. I want to thank each of them for their support.

The PCMR has had a commitment to the furthering of community integration efforts since the early 1970's. On November 16, 1971 President Nixon, following a White House Meeting with members of the PCMR, issued a statement inviting all Americans to join him in commitment to two major national goals:

> To reduce by half the occurrence of mental retardation in the United States before the end of this century.
>
> To enable one-third of the individuals with mental retardation in public institutions to return to useful lives in the community.

The PCMR established a Subcommittee on Family and Community Services and went to work on community integration issues by collaborating with other organizations planning and implementing national conferences, and publishing numerous reports, including Annual Reports to the President and Secretary of the U.S. Department of Health and Human Services in support of community living for persons with mental retardation. The 1971 goal in the area of community integration was reached. But, the PCMR continued beyond the goal.

The PCMR is still working on a community integration initiative, as we note today in our Presidential Forum on community integration and will continue to do so after this Forum. Our goal is to foster the continuing development of strategies emphasizing integration into the community, independence and employment, while still providing support and protection for those persons who need such assistance.

Let me provide you with an overview of this Presidential Forum beginning with a restatement of its purpose which is "to examine the national effort to promote maximum community integration of citizens with mental retardation.

The Forum theme focuses on partnership among Federal, State, and local agencies; between the public and private sectors; and between family and service delivery systems.

The major focal areas under community integration will be covered in 10 concurrent panels. These include: (1) living arrangements, (2) employment, (3) transportation, (4) education, (5) recreation/leisure/socialization, (6) family supports/respite care, (7) life service planning, (8) quality assurance, (9) health care, and (10) citizen advocacy. These are the areas that are of special importance to us to ensure comprehensive community integration.

Great changes are taking place in the field of mental retardation. New Federal legislation has attempted to address the needs and concerns of people with mental retardation. In particular, the Education for all Handicapped Children Act of 1975 which requires that handicapped children be educated in the "least restrictive" environment has challenged us. What we will learn about in our concurrent panel sessions, what we discuss and the recommendations which we will make at the end will assist us in fulfilling our mandate: Promotion of appropriate services for the population of individuals with mental retardation to enhance self-sufficiency through exploration and advocacy of the most effective methods."

This is our great hope and our ultimate goal.

Now, let us go to work on behalf of our fellow citizens with mental retardation.

Drug Abuse, Mental Retardation and Community Integration

by Donald Ian Macdonald, M.D.
Special Assistant to President Reagan
and Director, Drug Abuse Policy Office
The White House
Washington, D.C.

Dr. Donald Ian Macdonald brought greetings from the President and Mrs. Reagan. He is a pediatrician, a national leader in the parents' movement against drug abuse and a member of the White House staff. The following is a summary of Dr. Macdonald's speech presented at the Opening Plenary Session of the *Presidential Forum: Citizens with Mental Retardation and Community Integration:*

- The number one cause of post, neonatal or perinatal mental retardation is meningitis and encephalitis brain infection. With the new numococci vaccine, it is our hope that we can further dramatically decrease the occurrence of mental retardation.
- The number two cause of mental retardation during the post-perinatal period is trauma.
- Another leading cause of mental retardation is fetal alcohol syndrome. The baby becomes "at risk" due to low birth weight and underdevelopment of vital organs as a result of alcohol consumed by the mother during pregnancy.
- Twenty-five percent of drug users with AIDS have been infected by a needle. Babies born of mothers with AIDS usually are addicted to the drug that the mother has taken and the baby most likely will be born with a drug addiction and suffer profound mental retardation.
- A growing number of infants and children involved in highway related accidents sustain head injuries that cause mental retardation.

Public Awareness/Public Acceptance One Parent's Experiences

by Emily Perl Kingsley
Chappaqua, New York

This presentation will attempt to summarize my activities in the area of Public Awareness/ Public Acceptance of the Mentally Retarded through the media — 1972 to present.

BACKGROUND

I have worked in television since 1963 in various capacities — research, production, talent, writing. Since 1970, I have been a writer for SESAME STREET. In 1985-1987, I co-wrote a television movie-of-the-week, KIDS LIKE THESE.

My son was born in 1974. He has Down syndrome. Personal experiences coming out of that occurrence have shaped and directed my volunteer efforts ever since.

SESAME STREET

I joined the writing staff of SESAME STREET in 1970, at the beginning of the show's second season.

In 1972, I was sent to check out the Little Theatre of the Deaf for possible inclusion on SESAME STREET. I was enchanted with their style and imaginative presentation and recommended that they be booked immediately. LTD made several appearances on SESAME STREET and I was the writer who prepared all of their early material for the show. Writing material for the deaf, and becoming friendly with the performers, necessitated my learning sign language — and those growing relationships sensitized me to many disability-oriented issues.

On the show, hearing impaired performers were depicted as having unique talents and abilities and the ability to communicate fully and beautifully and sign language was portrayed as a valuable skill Hearing children were encouraged to learn signing and the signing segments were communicated in entertaining and imaginative ways — to both hearing and non- hearing children.

Response to LTD was wonderful and SESAME STREET started exploring the idea of expanding the curriculum again — this time for "slow learners/mentally retarded" viewers. Mail had indicated that mildly mentally retarded children were enjoying the show and learning from it. Producers realized that the target age for SESAME STREET of 3-5 years represented a *mental age,* not necessarily a chronological age. Material aimed at educating "normal" pre-schoolers would be just as appropriate for developmentally delayed children who were somewhat older.

During this period, I became pregnant. Because of my deepening involvement with the deaf and some awakening awareness of the problems of the disabled. I attended all the planning meetings for this new curriculum. When my son was born with Down syndrome, what was up until then a fairly academic interest, suddenly became a passionate commitment.

The original curriculum exploration involved a connection with the Kennedy Foundation Play-To-Grow program. Some early tapes were made of some of the Play-To-Grow activities (feather blowing, balloon basketball, etc.) and were aired on Wednesday mornings.

As my son Jason grew older, he began to make appearances on SESAME STREET. When he was three, he taped a series of segments with the Cookie Monster demonstrating his ability to identify and label letters of the alphabet and then to identify a word beginning with that letter. This, I believe, was the first time that a child with Down syndrome was seen on television exhibiting specific academic capability.
In addition, we started integrating children

with Down syndrome and other disabilities into the regular activities of the show without regard to disability and without regard to content material.

Response to this comfortable mainstreaming was wonderful. Mail indicated that we were reaching people with several very important messages. Children with disabilities, including children with Down syndrome, were seeing themselves represented on television in a normal way for the first time ever and the joy of self-recognition was apparent. Siblings were proud to see their brothers and sisters portrayed in a relaxed and non-judgmental way. Disabled youngsters were seen doing the same things, academic and non-academic, as their non-disabled peers and, as a result, a lot of stigma was reduced.

This experiment was acknowledged to be a huge success and the commitment to this concept of normalization continues to this day. It is one of the areas of which SESAME STREET has been most proud.

As in many other areas, it was the hope of the producers of SESAME STREET that other programs would follow their example — but only now, 20 years later, are we beginning to see performers with disabilities routinely mainstreamed without regard to their disability.

ALL MY CHILDREN

When Jason was five, a friend called and told me that one of the soap operas, ALL MY CHILDREN, was doing a story on amniocentesis. Already there has been some potentially damaging, inflammatory dialog about "an impending tragedy" if the pregnancy in the story-line were to produce a fetus with "a problem."

I called the production office of the show and asked to speak to the producer. I suggested that they had an obligation to present the most up-to-date and accurate information possible about amniocentesis and the possible results and options implicit in this procedure. An appointment was set up and I spoke with the producer in his office for 2-1/2 hours.

Soap operas feel strongly about presenting current attitudes about current issues and they were grateful to receive an education regarding amniocentesis and Down syndrome.

During the meeting I suggested that it might be very graphic and dramatic to have the pregnant character, who was awaiting the results of her amniocentesis, meet with a neighbor or friend who actually had a child with Down syndrome. The producers were very receptive to this idea and asked me to portray the neighbor. I agreed on the condition that they'd allow me to write the scene.

Jason and I appeared on ALL MY CHILDREN in October 1979. About 7 million soap opera viewers saw a real live child with Down syndrome — who talked and responded and was cute, polite and entirely "non-threatening." They heard his mother (me) acknowledge that while there are special challenges involved in raising a child with Down syndrome, it needn't destroy your life by any means and such a child can bring great joy to a family.

I received a great deal of mail afterwards, some of which related incidents of pregnant women who had seen that episode of ALL MY CHILDREN who were better prepared when their babies with Down syndrome were born months later.

ADVERTISING

After my son was born, one of the most excruciatingly painful experiences was watching the media and finding that nothing on television reflected my life or my experience any more. If anything, the media seemed to conspire to flagellate me with experiences I would never have in my life. Everywhere I turned, all I saw were depictions of healthy normal children, families enjoying college graduations, weddings, and grandchildren. No one was speaking to me anymore.

It made me extremely angry.

In 1976 I wrote 133 letters — to the top executives of the top 35 advertising agencies in America handling "family"-oriented clients. I expressed the idea that there were about 36 million people with disabilities in this country — plus their families, spouses, children, parents, and concerned friends — adding up to considerably more than the original 36 million — who were consumers and users of their products — but who never saw themselves represented in their print or television advertising.

I pointed out to them that they had been responsive to the existence of other minority groups by including blacks, hispanics, women, senior citizens, etc. in their advertising — obviously recognizing that those groups represented specific consumer blocks which warranted direct appeal. As America's largest minority, I suggested that "the disabled" should be included in the same comfortable way — and that I was sure that disabled consumers would be economically responsive to this inclusion.

The responses I got from the advertisers were shocking to me. They felt that they were not interested in incorporating people with disabilities into their ads because:

1. viewers would be so distracted by the presence of a disabled person in a commercial, they would miss the name of the product.

2. they could not justify the "exploitation" of people's "misfortunes" in order to make a profit.
3. they believed that most disabled people are living in Veteran's hospitals and so are not really consumers at all.
4. while it might be a "noble" idea, they didn't believe that Americans were *ready* to view disabled people as living normal lives.
5. advertising does not set trends, it follows them. They suggested that we contact them again in 2 to 3 years!
6. they saw the disabled community as a bunch of disorganized splinter groups without any central organization, therefore not having any real cohesiveness or economic clout.

Finally, the advertisers said that they were in business to make money for their clients. If the *clients* suggested this approach, they'd be more than happy to adopt it in their ad campaigns. They passed me off to the clients, happy to get rid of me.

Another letter-writing campaign followed, this time aimed at the major family-oriented "clients" — (General Foods, Coca Cola, Nabisco, etc.) — in which the same basic suggestions were made. The response to this campaign was somewhat more positive and a few companies promised to explore the idea — but no real progress was made.

In 1977, I conducted an informal research project, questioning participants at the annual convention of the National Down Syndrome Congress. The questionnaire asked people if they would like to see disabled people portrayed in television and print advertising. Would they support companies who advertised in this way?

Of 350 responses to the questionnaire, 349 answered that they would *love* to see disabled people in commercials — and that they would go out and buy the product *whether they needed it or not!* The single dissenting response was from a person who thought that *all* advertising was foolish!

One interesting aspect is that it doesn't seem to matter *which* disability is portrayed. The depiction of *any* disability is perceived as helping the public's perception of *all* disabled.

Since that time, I have contacted advertisers directly on 3 other occasions. I have appeared in numerous interviews, including two with Betty Furness on NBC LIVE AT FIVE NEWS, addressing this issue — and recently was quoted in a first-page interview in the WALL STREET JOURNAL which discussed this matter. Admittedly, things are improving — ever so slowly. Wheelchairs have appeared in commercials for Levi's, McDonalds, and Wheaties and McDonalds produced its now-famous commercial using only sign language and captions. The wheelchair has become synonymous with "disability" and we have yet to see a mentally retarded person in a commercial. [NOTE: This presentation predates the historic inclusion of a young person with Down Syndrome in a Crest toothpaste commercial during the summer of 1988!]

I believe that this is simply another frontier of civil rights — comparable to the time when black people never saw themselves represented in the media.

On the back of my car is a bumper sticker. It reads:

DISABLED AMERICANS: UNITE!

I believe if we were able to "get our act together" and indicate to America that we are a united effort, once advertisers could see us as a powerful unified consumer block — with considerable economic clout — I believe that these representations would start to appear more regularly.

THE FALL GUY

We were fortunate to get to know Lou Shaw, a television writer and producer who had a daughter with Down syndrome. Serving together on the Board of Directors of the National Down Syndrome Congress, Lou often said, "Someday I'm going to write a show for Jason."

Imagine our surprise when Lou called one day to announce that he had gotten network approval on a Down syndrome story idea for the TV action series THE FALL GUY, starring Lee Majors.

Two weeks later we were in Hollywood auditioning for the series director, Ray Austin. Ray felt confident that Jason (at that time 10 years old) could take direction and learn material well enough to play the part planned for him. In fact, Ray suggested that Jason's part be *expanded* since he felt that once the audience saw him, they'd want to follow his storyline more than the other subplots being proposed.

A 63-page script was written, with Jason's part appearing on 47 of the 63 pages. Jason had about a month to learn his part. It was written in THE FALL GUY genre, about a young boy with Down syndrome who runs away to Los Angeles to participate in the Special Olympics. Accidentally viewing a murder, the boy hides in the truck belonging to the stunt man (Lee Majors) who then tries to learn his identity and return him to his family.

The role required following specific directions, playing long scenes with varying emotions and content. Jason was given complicated material which included counting in Spanish, French and Japanese, correcting Majors' spelling and doing an elaborate stunt

(Jason refused to use a stunt-double, completing the complicated stunt himself).

On the two main airings of this episode of THE FALL GUY, it is estimated that over 29 million people say this self-reliant and clever little boy explode countless myths about Down syndrome in the period of one hour!

THE FALL GUY has been dubbed into many foreign languages and has been seen all over the world. Now in syndication, it continues to be viewed all over America on a regular basis.

On a recent trip to Jerusalem, Jason was recognized in the airport by several people who had recently seen his FALL GUY episode run on Jordanian television!

KIDS LIKE THESE

Over three years ago, I felt I was ready to put my feelings and experiences into a piece of dramatic work that would explore the challenges and the rewards of raising a child with Down syndrome. I proposed the idea for a TV movie to an old friend who is a seasoned and acclaimed television writer, Allan Sloane.

Allan was excited about the idea and we started to work together to draft and plan an outline. We determined that this was going to be the "true story" and not some standard sugar-coated "triumph-over-adversity" movie.

When the outline and treatment were completed, they were sent to Allan's agent in California. The afternoon that he received it, the agent called to say that he was hand-carrying it across the street to Tyne Daly. He felt it was perfect for her. She bought it that first day.

But it was still fully three years before the project saw fruition and was aired on national television.

There were many network complications, having to do more with executive shuffling than with our project — but we got tossed around depending on who was in and who was out.

At one point we reached the top of the executive ladder of approvals and expected to go into production within hours. Instead, the top executive who was supposed to give final approval, disappeared and left to work at another studio and our project was shelved by the man who replaced him.

The film was saved by Tyne Daly and her husband, Georg Stanford Brown who marched into CBS and announced that they believed in this film and were going to make it — either for CBS or for some other network! The network calmed down and promised to reconsider their shelving of the movie and, after several months of deliberations, reinstated it.

The network was dubious about the feasibility of using real children with Down syndrome in the film — but we insisted that the integrity of the project demanded using real children. No child actor with elaborate makeup could accurately convey the totality of the Down syndrome experience. But the CBS casting department had no idea where to find five children who could learn material, take direction and who all resembled each other! We made their job easier by promising to cast all five of the children ourselves.

We screened over 400 children — photos, write-ups, videotapes — and finally decided on the five children we needed plus a set of understudies. The newborn baby in the film, amazingly, was cast prenatally — from a mother who had had amniocentesis and knew she was due to deliver a child with Down syndrome right around the time our filming was scheduled to begin!

The film starred Tyne Daly, Richard Crenna and Martin Balsam and was given a full top budget production. I was hired as Technical Advisor and was allowed to be a part of every major content decision. The producers, actors — all the way down to set decorators — had a deep commitment to the honesty and integrity of the film and the result, I believe, was a film that portrayed the experience of raising a child with Down syndrome in a fair and true light. It presented neither a glamorized, romanticized picture, nor a depressing, discouraging picture. It showed the ups and downs, the joys and disappointments, the challenges and the rewards.

The ratings for the night of last November 8 were excellent and the network was thrilled that 21 million people tuned in to see KIDS LIKE THESE. Yes, it was difficult sharing my innermost feelings, pain, fears and heartaches with the world — but I am pleased and proud that 21 million people now have a fuller, more accurate idea of what goes into parenting a child with a disability, any disability.

Most exciting was the radiant performance of the five youngsters with Down syndrome — who demonstrated *incontrovertibly* that "kids like these," who have suffered for centuries under the burdens of their labels, their stigmas, their myths and stereotypes, can indeed be charming, capable, delightful and unique individuals!

KIDS LIKE THESE was just given the prestigious Christopher Award, which recognizes media efforts which "affirm the highest values of the human spirit" and attempt to "change the world in which we live for the better." [NOTE: Since this presentation, the film "KIDS LIKE THESE" has been honored with:

1. The ARC of Excellence Award from ARC of the United States.

2. First Prize in the Rehabilitation International Film Festival.

3. National Media Award from the National Down Syndrome Congress.

4. Certificate of Appreciation from the National Conference for Christians and Jews.

5. The National Easter Seals Communication Award.

6. Media Award — ARC Tidewater VA and is a finalist in the National Media Access Awards, to be given out in Hollywood in January 1989.]

SUMMARY

Our accomplishments in raising public awareness about mental retardation have been as a result of many things, including:

- being in the right place at the right time.
- knowing the right people.
- not being afraid to pick up the phone or write a letter.
- a healthy dose of anger, frustration, pride, perseverance.
- not getting discouraged with each defeat.
- a lot of luck, help, support and encouragement.

It is important, however, that each of us see ourselves as permanent working public- relations ambassadors, taking every opportunity possible to educate and enlighten the public. The cumulative effective of all those small efforts made by individuals will ultimately add up to major accomplishments in improving public awareness and acceptance of the mentally retarded.

General Family Role, Financing and Trust Planning in Community Integration—Now and the Future

by James H. De Ore
Executive Director
National Foundation for the Handicapped
Elmhurst, Illinois

The National Foundation has been involved with various causes primarily mental retardation for the last 26 years. We have locations in Washington D.C., Boston, and main headquarters in Elmhurst, Illinois.

The National Foundation for the Handicapped is an unusual foundation in the sense that within its family of corporations, there are some for-profit corporations. The profits are used by the National Foundation to make grants to include organizations who provide services to the disabled; we do not fund the local type organizations. We do provide banking relationship for not-for-profit organizations who are looking for capital dollars, as well as for loans for short-term purposes at low interest rates.

On the national level, one goal is to bring to the forefront the need to make the community and country aware of the problems associated with mental retardation, as well as other disabilities. The National Foundation has hired the producer and director of "Cosmos" to heighten community awareness. Cosmos by Dr. Carl Sagen, as you know, was one of the most watched series by national television. The result of that series was the one or two years of coverage of the scientific community on concerns they had surrounding the dispute between NASA, as well as the concerns of the general country.

We expect to produce a series which will include six thirty-minute segments, concerning all areas of disability. They will be oriented toward trying to create national awareness of the disabled population. The current state of the art activities ranging from brain research to genetics, to the everyday issues surrounding different causes and problems faced by parents with disabled children and adults. We hope the series will occur in the next One and a half years. We did an archives search of the television and movie productions over the last ten years to see if there had been any national series of this type done and found there was not.

One of the major philanthropists that supported the National Foundation for the Handicapped was Anna Emery Hanson who was the mother of a retarded child. She had a great ambition and was concerned about enhancing the lives of the disabled in many areas. One of the areas of her concern was that of the lack of housing. Tax dollars were not there for parents in sufficient amounts. Her goal included exploring new ways of developing alternative funding sources so that additional dollars could be found for services.

Over four years, a team of people from the public and private sector looked at this problem. We received great cooperation from the Reagan Administration primarily from Kaye Rairdin from the White House who is involved in State/Federal relations and affairs, as well as the Vice President's council. We also received cooperation from the Social Security Administration (SSA) and from the Health Care Finance Administration (HCFA). However, we had a very difficult task since what we were trying to research were areas where there were insufficient dollars available, and enhance them with non tax dollars. We are very pleased to announce that we have finally received the approval from HCFA two weeks ago. We had earlier secured the Social Security Administration's approval.

The National Foundation was looking at ways of developing funds from the private sector which met essentially five different criteria. The first was that we did not want to rely on

State and Federal tax dollars. Second, the dollars had to be significant in scope. Third, whatever was developed had to have a cost of living concept associated with it so that dollars would grow over a period of time. Fourth, the system should be voluntary not mandatory. Finally, whatever mechanism was created had to meet all Federal and State requirements.

A substantial amount of research was done. I am familiar with a lot of the original founding fathers' papers and one of the things I happened to stumble on was a paper by Alexander Hamilton. What Hamilton was about to propose to Congress was essentially the idea of a financial trust. His idea was that tax dollars, which in those days were very very small, would be essentially placed in a bank institution and the interest from those tax dollars would be expended by Congress to expand its needs. The Congress would not be able to spend the dollars that were in the banking institution, that is, the principal. They could only spend the interest on the dollars. It is very interesting that if this would have been done, we may not be paying taxes today.

This idea was presented to a number of financial experts. The up side is this certainly will work and the down side is that it is going to be slow. What the National Foundation is interested in looking at is a solution to long term care and a solution to a population of disabled such as the retarded who are going to be living their lives over a sixty to eighty year span of time. We then started looking at the possibility of whether or not a trust fund concept could be used to help provide these services. We looked carefully at what incentives were at work between parents of disabled children and adults, and between the private providers of care and the state. Additionally, we wanted to know what were the set of inducements that would make someone want to use the mechanism.

On the State side obviously one of the needs was enhancement, since the taxpayer has sent a message that there are only so many taxes they can afford to pay. The states need more dollars to meet the needs of the disabled population. The same is true for Federal funds. The second is that the State needs a way for planning for its citizens. As many of you know, in most states the State knows who needs services that are currently in the state system, however, they do not know the populations outside the system that are coming up as an impact to the State system.

I was amazed to find out that the Department of Education for instance does not make a regular report on a community basis of the children who are in Special Education classes who will be passing the age of 21 and going into the adult world as mentally retarded disabled people. Therefore, there is not a planning process possible by which the legislature or Congress can determine specifically who those people are and when they will impact the system.

Another issue was that private sector participation was required. Over a period of years there has been a basic kind of rights issue movement between the disabled, Congress and the State legislature that has led to mistrust. It is one of the issues with which we are trying to deal, as to "how will parents be able to gain the security of knowing that the state is able to maintain services?".

It was also necessary to insure low income provisions so that parents of disabled children or adults who are unable to provide dollars would be able to access the system.

Finally, we wanted the system to stabilize income. Providers were looking for ways of generating additional dollars for care. They were also concerned with the cost of living because it was eroding constantly the amount of services they could provide each year through State government income which was being effected by lower tax collections thereby recession. They were unable to withstand the demands. Also in the same way, the result of high quality care was being jeopardized. The stabilized income situation also was critical for a provider because they have to meet the needs of the residential populations they serve each year. That population is going to be there whether or not the tax dollars increase or the cost of living goes down.

Parents were looking for services that they were not able to receive. The condition they were looking for was not only services, but additional protection so that those services were high quality, and the ability to participate in those services. Many parents told us time and time again that they had felt they had been forced out of the participation with the provider for the care of their dependent. Also parents are looking for long-term security. "What happens after I pass away, to my son or daughter?" "How do I know that person can care for them?" We try to take these needs and we try to look at them in light of this concept.

A great deal of time was spent in concern for the low income disabled. We wanted a system with low income provisions which would allow families to participate through various contractual ways. One way a family can participate is through life insurance. We also wanted to have a way which the state could monitor funding since one of the concerns was as distribution of the dollars for this program occur,

how do you know whether the worthy people that are out who actually need the services and are receiving access to those services. We wanted to make sure that the people who were involved in these services in the low income area had the same rights and access to services as everyone else.

A family is permitted now for the first time in this country to leave to their son or daughter a sum of money which can be used to supplement their care without loss of entitlement/benefits. In other words Social Security Supplemental Income (SSI) and Medicaid eligibility would not be jeopardized with the creation of the Self-Sufficiency Trust. In the past we have read the National Association for Retarded Citizens pamphlets and have gone to attorneys about the issues surrounding our sons or daughters care. What they have been told is that you should disinherit your child or make certain that no dollars appear in your child's' name otherwise they will lose benefits. As a result, millions and millions of dollars that parents wanted to use to provide services for their sons and daughters were forced out of the system. They were not able to be used for care so the approach we have been using is to say, let the parents bring their money in to provide for care.

We also did not want the state legislature to control the parents' money. Therefore, a pooled trust receives the parents' money. This would impact the private sector similar to what I had mentioned with the Alexander Hamilton concept. The legislative law has nothing to say or do with those dollars. Only the interest earned from those dollars is passed through the state to the provider of care on behalf of the handicapped person. In a supplemental fashion the dollars cannot be used for rent nor clothing since this would supplant the Social Security entitlement program. The dollars will not be used to replace Medicaid dollars. However, dollars can be used to supplement care in a variety of ways.

Perhaps the easiest way to describe how the dollars can be used is a staffing pattern for a small group home. In a staffing pattern for a small group home you have different components of dollars. Part of the dollars are committed by Social Security for room and board, part are Medicaid dollars for basic care for the person. The dollars that the parents would be able to enhance would be those for specialized staff, education, training, as well as other kinds of services inside the facility. The way it works essentially is that after the parent makes the trust, 50% upon the death of the handicapped person will go to their heirs. The other 50% goes to a charitable fund and that charitable fund makes grants to low income families who have handicapped children.

The law in Illinois and Maine is for the disabled which included mentally retarded, as well as the mentally ill. It is a very complex concept that was developed in order to meet these needs. We are extremely excited about this program. We have met many parents that have said, I put my son John through college and I am very proud of him. And I bought my other son a hardware store and he is thriving. My other son who is mentally retarded I had to go down and disinherit. I asked how long ago was this that you had to take guardianship? They answer, about 15 years ago.

What we are trying to address is that for the first time a parent can leave money or give money for the care of their son and daughter just like they send them to school. The program is an exciting one because it should for the first time provide for a self participation concept in the country. To allow for the generation of substantial dollars for increased services, we are very proud of it and we hope all of you in all the states are able to move forward and participate with us in this activity.

To illustrate the National Foundation for the Handicapper's role in the development, as well as the operations of the Self-Sufficiency Trust model, I have provided a detailed narrative as follows:

The Self-Sufficiency Trust and the National Foundation for the Handicapped

The National Foundation for the Handicapped (the "National Foundation"), a charitable foundation serving physically and mentally disabled persons and their families, developed a financing mechanism to facilitate the coordination and integration of private financing for the disabled with governmental funding programs. This mechanism, the Self Sufficiency Trust of Illinois ("SST"), was established to facilitate the flow of money from private sources. It is designed to help the state of Illinois fund expanded government sponsored programs for the disabled and to supplement government sponsored programs for the disabled with privately funded programs.

The SST was enacted by the Illinois State legislature in 1986 in response to an initiative to provide a means for the parents of disabled persons to secure financing arrangements for the life of their disabled children, especially if those children survive their parents. This arrangement was intended to avoid further conflict with rules which in some states may penalize families for providing direct services to persons eligible for Federal assistance under the Supplemental Security

Income program and Medicaid.

The SST is governed by seven Trustees appointed by the National Foundation who serve as volunteers and control the two private sector parts of the SST's three funding mechanisms. The SST Private Fund is a revolving funding mechanism, in which families may contribute monies designated for life-care services of named beneficiaries. The SST Private Fund is used to either donate monies to the state in support of expanded State programs, or to directly fund activities supporting the life-care plans of named beneficiaries. A Charitable Trust is operated under the SST, in which charitable contributions from private contributors and the SST Private Fund transfers are used to serve impoverished disabled persons covered through the programs of the Illinois Department of Mental Health and Developmental Disabilities (DMHDD). A third fund is the State of Illinois' Self-Sufficiency Trust Fund (which is referred to in the law as the "Trust Fund" referred to in these materials as the "SST State Fund"). It is the repository for donations to the state from the Charitable Trust or SST Private Fund and used to expand existing governmental supported services of the Illinois DMHDD.

The National Foundation's role in relation to the SST is to administer the private funds, promote the formation and implementation of the SST, and provide supporting services needed to integrate and coordinate public and private sector programs to the disabled. The State of Illinois has contracted directly with the National Foundation to study the needs of mentally disabled residents of the state, to conduct demographic studies and evaluations of the service requirements of the population, to assist the state in planning for future service expansion and to staff operation and planning for the SST. The National Foundation is involved in developing a joint public and private sector case management system for the mentally disabled. The SST enhances the joint public/private planning process by using available private sector dollars to support and supplement government programs as needs are identified.

In conjunction with the SST, the National Foundation assists in planning services for the mentally disabled including: coordinating residential services; arranging clinical assessments and evaluations of beneficiaries; developing life-care plans for beneficiaries; and serving as advocates for disabled persons with appropriate government entities.

In addition to the SST project, the National Foundation conducts other projects in support of disabled persons, including the following: providing grants to disabled individuals;

2. funding of not-for-profit corporations serving the disabled;
3. developing a special program supporting performing and fine arts for the disabled through the Anna Emery Hanson. Center in Illinois;
4. furnishing capital for housing disabled persons; and
5. funding activities through charitable organizations serving the disabled including the President's Committee on Mental Retardation, the Boy Scouts of America Camping for the Handicapped, and projects coordinated with the National Association of Centers for Independent Living.

Relationship of the SST to Medicaid*

TREATMENT AS INCOME OR RESOURCES

Under current Medicaid law and regulations, the income and resources of parents and relatives who live apart from their disabled family members generally are not counted as the income and resources of such disabled recipients for purposes of Medicaid eligibility. Where income or resources are given to a Medicaid eligible recipient in the form of cash, tangible assets, or support (in the form of food, clothing, or shelter), the benefits received are counted as income and may jeopardize the status of that recipient for Medicaid. Transfers of assets or income from parents or relatives to a Medicaid eligible recipient are also treated as income or resources under these rules, even if held in a trust.

The SST is *not* established to provide cash, assets, or support to disabled Medicaid eligible recipients. Instead, the income and assets of the SST are intended only to supplement Medicaid covered services and to expand state governmental services in coordination with Medicaid. The Supplemental Security Income (SSI) program does not treat health care and social services, which are paid for directly by parents to a provider, as income or resources in determining SSI eligibility. (See 20 C.F.R. §416.1103(a) and (b) and §416.1201(a) (1987).

In some states with more restrictive eligibility rules than SSI, health and social services paid for by private parties may be counted as in-kind support for purposes of Medicaid eligibility. Where states continue to treat such in-

***/ This document provides a description of the applicable Medicaid law and regulations the facts involving relationships and arrangements under the SST, and our opinions of how Medicaid rules apply.**

kind services, medical care, and benefits as income to Medicaid disabled recipients, they are jeopardizing available benefits under Medicaid.

Federal recognition of the services funded by the SST as benefits provided by a governmental program may help to avoid counting such in-kind support as income. Further, since Medicaid allows SSI recipients to receive non- covered supplementary services when donated directly by parents without adversely affecting Medicaid eligibility, it likewise should recognize that such arrangements may continue through the SST when parents become elderly, move out of state, or die.

THIRD PARTY LIABILITY

Medicaid coverage is secondary to all other third party payors, which cover services included in a Medicaid State Plan (See 42 U.S.C. §1396a(25)). Federal reimbursement to a state will be denied if the state failed to properly determine third party payor liability and recover payment in advance of Medicaid monies (See 42 C.F.R. §433.140). Medicaid regulations define a third party at 42 C.F.R. §433.136 as: "any individual, entity or program that is or may be liable to pay all or part of the expenditures for medical assistance furnished under a State Plan." This definition excludes two categories from third party payors: first, *state programs* themselves are not considered third-party payors; second, private entities furnishing services *outside of the scope* of Medicaid are exempt from recovery by Medicaid based on third party payor rules.

In the case of the SST, when monies are *held* by the SST Private Fund or Charitable Trust, they are not being *spent* for any services and therefore, not considered a third party payor source. Second, when the SST disburses payment to a vendor to provide services directly to a designated beneficiary, such services are intended to be *outside of the scope* of Medicaid covered benefits and should not be subject to recovery as a third party payor. Finally, when the SST contributes to the SST State Fund, the monies are then appropriated by the State of Illinois and constitute *State funds* not subject to third party payer recovery.

FEDERAL MATCHING

Federal regulations at 42 C.F.R. §433.45(b) permit funds donated from private sources to be used as the State's share in claiming matching Federal financial participation under Medicaid. To be used as the State's share, the private funds must satisfy two conditions that: first the funds are under the State Medicaid agency's administrative control; second, the private funds do not revert to the donor's facility or use (unless the donor is a nonprofit organization and the Medicaid agency of its own volition, decides to use the donor's facility).

In the case of the SST, once monies are disbursed from the SST Private Fund to the SST State Fund, they remain in the custody of the State Treasurer and under the control of the Illinois DMHDD. This constitutes administrative control of the state. Further, neither the SST nor the National Foundation are service providers under Medicaid. Thus, funds donated to the SST State Fund will not revert to the SST or the National Foundation through provider contracts. Reversion of monies from the SST State Fund may occur only if the Illinois DMHDD is unable to apply the monies to the purposes designated by the SST Trustees, in which case the monies reverting to the SST Private Fund would not be used for the State's share in matching with Federal financial participation

AMOUNT, DURATION, AND SCOPE OF SERVICES

Medicaid regulations at 42 C.F.R. §440.240 require that services furnished under a state plan be comparable in amount, duration, and scope to all Medicaid recipients. The SST provides for individual accounts for designated beneficiaries of the SST. It also requires that monies from the SST pay for at least one low income disabled person, not designated by a Private Fund Trust account for each designated beneficiary. Although the SST is intended to be a funding source for the State's share of Medicaid financing it does not relieve the state from financing a comparable amount, duration and scope of services to *all* similarly situated Medicaid recipients.

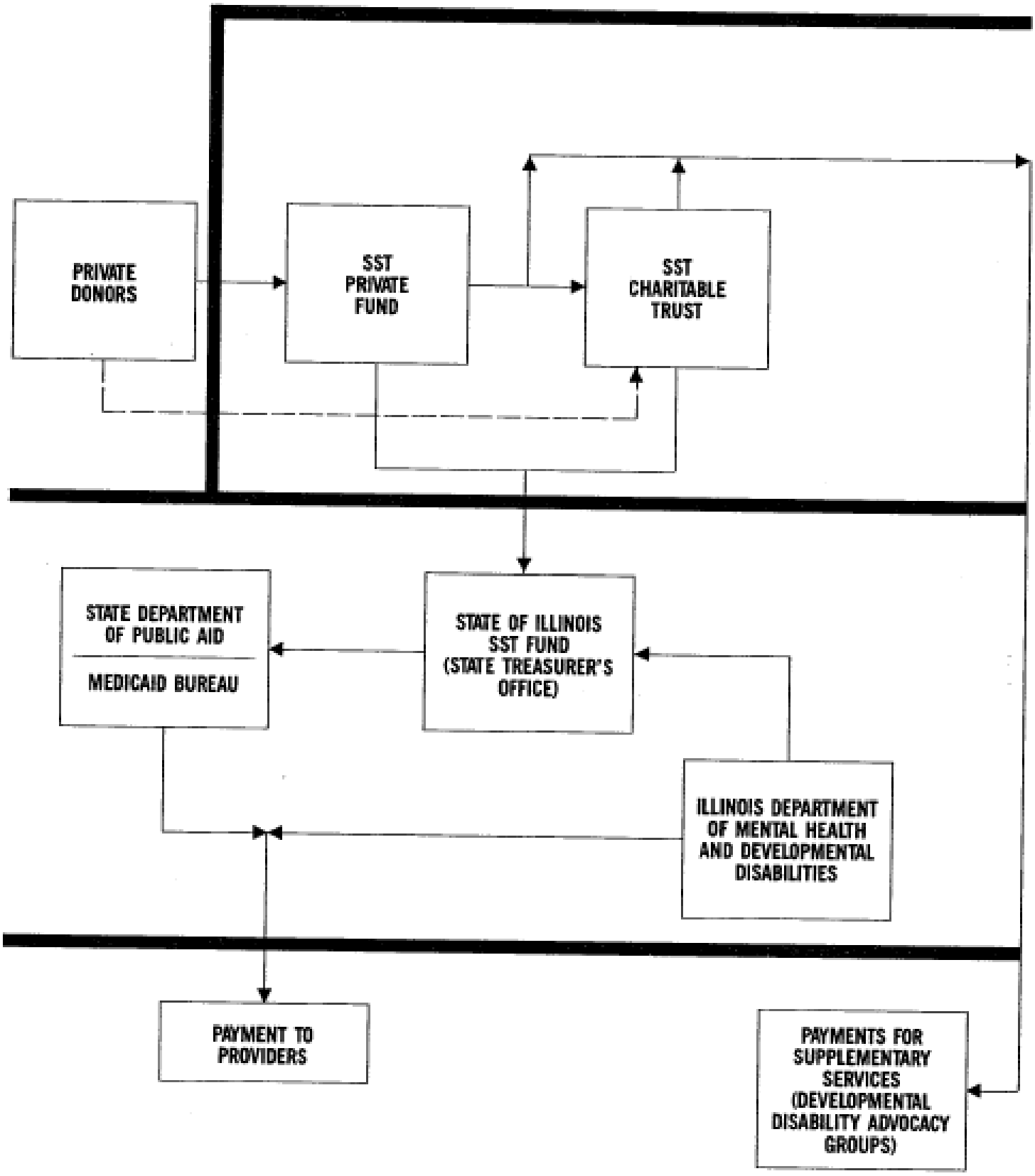
STATE MAINTENANCE OF EFFORT

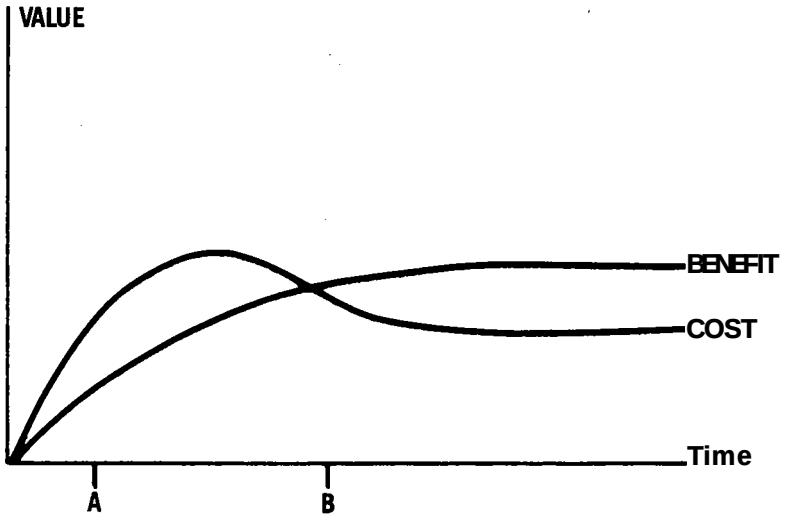
One critical feature of the SST law passed in Illinois was to assure State maintenance of effort in funding services to the disabled. The SST law includes two key requirements: first, to maintain separate accounts for each named beneficiary in order to monitor the level of effort; second, to assure that no diminution of existing services would occur by receipt of benefits through the SST. These provisions of the Illinois law enacting the SST will assure that the State at least will maintain the level of effort in the State support for Medicaid services as was made available prior to the funding from the SST.

Flow of Funds Under the Self-Sufficiency Trust

Step 1: A donor, usually a parent of a participating beneficiary, contributes capital or other tangible financial assets to the SST Private Fund and designates a primary beneficiary for use of these funds. The donor is also named co-trustee

Self-Sufficiency Trust of Illinois
Flow of Funds Diagram





of the SST Private Fund account established for the designated beneficiary.

Step 2*:* Although deposited on a commingled basis in the SST Private Fund, investment income is credited separately to the account of each named beneficiary. Initially, a life-care plan is developed by the National Foundation tailored to each SST beneficiary. During this period the co-trustee/donor retains the right to disapprove or delay implementation of the designated beneficiary's life-care plan. Until disbursement for services is made from each respective beneficiary's SST Private Fund account, the donor and designated beneficiary may withdraw from participation in the SST Private Fund and recover their original contribution, if reduced by an amount based on a formula related to the number of years of participation in the SST Private Fund. (See Article 4, section 9 of the SST Agreement.)

Step 3: The Trustees of the SST Private Fund make disbursement decisions when a life- care plan is developed for the designated beneficiary, and the co-trustee assents to its implementation. Disbursements from the SST Private Fund can be made in any of four ways. First, monies in the SST Private Fund (whether interest or principal) may be donated by agreement to the SST State Fund. Second, monies in the SST Private Fund may be disbursed to vendors, such as developmental disability advocacy groups who will monitor the status and condition of the designated beneficiary. Third, if the designated beneficiary dies or withdraws from the SST after receiving services, up to 50% of the remaining monies in the designated beneficiary SST Private Fund account will revert to the donor. Finally, the remaining monies in the SST Private Fund will be paid to a related Charitable Trust, operated by the National Foundation, if the designated beneficiary either dies or withdraws from the SST. This Charitable Trust is operated as a service funding mechanism of the SST to pay for services to poor persons for whom no donor has contributed money to an SST Private Fund account.

Step 4*:* After monies are donated to the SST State Fund (by either the SST Private Fund or the Charitable Trust) they are deposited under the control of the State Treasurer. The SST State Fund is subject to appropriation by the state legislature and disbursement based on vouchers approved by the Department of Mental Health and Developmental Disabilities (Illinois DMHDD).

Step 5: Disbursements by the Illinois DMHDD are made on the basis of individual accounts to facilities serving the mentally and physically disabled. Each individual account is maintained for each beneficiary entitled to benefits from the Illinois DMHDD.

Step 6: Disbursements by the Illinois DMHDD are made to its regular service providers. Once monies are deposited with the state, they will not revert to the SST Private Fund nor to the Charitable Trust, unless the Director of DMHDD *determines* that the monies donated can not be used to provide care, support, and treatment of the designated beneficiaries in accordance with the SST donation agreement. The decision to return donated monies to the SST Private Fund may be initiated within the Illinois DMHDD or by the SST Private Fund Trustees.

Control Over the Funds Deposited in the Self-Sufficiency Trust

Generally, control over the monies set aside for the SST will vary depending on where the monies are deposited.

***Parents/Donors/Co-Trustees* —** exercise some degree of control over the monies deposited into the SST Private Fund until a life-care plan is developed for the designated beneficiary and is approved by the individual donor/co trustee. While monies remain in the Private Fund, they may be withdrawn based on a schedule of limits (appearing at Article IV, Section 9 in the SST Agreement). The individual donor/ co-trustee may *not* exercise any control over the monies disbursed by the SST Private Fund to vendors, to the Charitable Trust, or to the State of Illinois.

***Trustees of the SST* —** have full control over both the Charitable Trust and SST Private Fund. The Trustees will not exercise the right to disburse monies from the SST Private Fund until agreement has been reached with the co- trustee over the life-care plan and its purposes, implementation, and start-up schedule for disbursements on behalf of the designated beneficiary. Once such services to the designated beneficiary begin, the SST Trustees have wide latitude to make disbursements. Such disbursements made to the State on behalf of designated services and beneficiaries will not revert to either the SST or the Charitable Trust due to powers or authorities exercised by the Trustees. As a matter of practice, donations to the State of Illinois by the SST Trustees will only be made based on an agreement in which such donations are consistent with the state's own mental health service plan. Once donations are made to the State of Illinois, they are in the sole possession and control of state officials.

***National Foundation for the Handicapped* —** will administer the SST Private Fund and Charitable Trust at the direction of the Trustees. No control may be exercised over monies deposited with either the SST Private Fund or the Charitable Trust.

The Illinois Director of Mental Health and Developmental Disabilities (DMHDD) — has full control and authority to disburse monies in the SST State Fund donated by the SST's two private funds, as if the monies were raised through State taxes. The Director may obligate himself voluntarily to use of the monies for designated services and beneficiaries, so long as it is consistent with the needs and uses approved by the Illinois DMHDD's mental health plan. The State's mental health plan must furnish comparable services statewide in order to comply with Medicaid so that the same services will be furnished to other recipients of State services even if they are not participating in the SST. If the Director determines that the uses designated by the SST Trustees' agreement with the State are inconsistent or contrary to purposes of the Illinois DMHDD, the Director must return the money to the SST where it will be redeposited in the SST Private Fund or Charitable Trust.

***Designated Beneficiary* —** has no direct use, control, or power over the monies deposited in any of the funds of the SST. The designated beneficiary receives benefits from the SST to the extent that it does not reduce entitlement to other Federal or State benefit programs.

***State Treasurer* —** maintains accounting for the SST State Fund when monies are deposited with the State. The Treasurer is obligated to disburse funds based on vouchers submitted by the Illinois DMHDD.

Purposes and Limitations of the Self-Sufficiency Trust

Article IV, Section 15 of the Self-Sufficiency Trust of Illinois states that, “No distributions from the Private Fund shall be used to pay for the support of a Participant as the term support is defined under Federal or State benefit pro-grams, including but not limited to, Social Security, [and] Medicaid.... In particular, no distributions shall be used to provide for food, clothing, shelter or items which are considered support under Federal or State benefit programs." These limitations on the use of monies deposited with the Self-Sufficiency Trust (SST) are reflected as well in the donor's transfer agreement, the State law authorizing the SST State Fund, and the policy of the state, in a letter from Ann Kiley, Director, Illinois DMHDD to the Social Security Administration.*/ Furthermore, no funds from the SST Private Fund or Charitable Fund may be used to pay for medical or health services covered by the Illinois Medicaid program except for those emergency or other services which are not covered or paid for by the State Medicaid program.

Consistent with these limitations, monies in the SST Private Fund and Charitable Trust may be spent on behalf of designated SST beneficiaries for: social services, rehabilitation and remedial services, educational services, recreational programs, respite services, habilitative services, and training programs to assist disabled persons in managing activities of daily living. Additionally, monies may be transferred from the SST Private Fund to the SST State Fund. As so supplemented, the SST State Fund may be expanded, in combination with State general revenue funds, for: (i) a portion of the costs of residential facilities and services where SSI and Medicaid disabled recipients reside; and (ii) as the State's share of required I.FP to pay per diem rates to residential facilities are Medicaid providers; and (iii) to expand services

offered by the Illinois DMHDD. Finally, monies from the two private funds of the SST may be used to pay for advocacy services which consist of monitoring visits by private sector ombudsmen who assure that appropriate care and treatment are being made available to designated beneficiaries receiving medical support and maintenance from State funded facilities.

The actual distribution of monies from the SST Private Fund will depend upon the life- care plan developed for each designated beneficiary and participant.

Zoning, Real Estate and Related Issues

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I. AN OVERVIEW OF THE LEGAL AND SOCIAL ISSUES CONCERNING ZONING AND THE DEVELOPMENT OF HOUSING FOR PEOPLE WITH MENTAL RETARDATION:

> At 23, Joanie had spent 9 years in an institution for people with mental retardation. She exhibited minimal capacity for language and personal care, suffered psychological problems due to large doses of tranquilizers she had received over the years, exhibited aggressive outbursts and had an I.Q. of 24 which placed her in the category with severely-to-profound retardation. In 1977 Joanie moved in to a community home called "The Residence" in a small town in Minnesota. Two years later Joanie had become capable of caring for her personal needs; improved substantially her language skills; almost never had aggressive outbursts and experienced a 30-point increase in her I.Q. which places her in the category of mild retardation. Several residents of the town had attempted to prevent the establishment of "The Residence" but failed after a two year legal struggle. ("Exclusionary Zoning," *North Carolina Central Law Review*, 1981, pp 167-190).

This example is obviously not unique nor outdated. Since the early 1970s, when large numbers of children and adults were released from institutions — mental hospitals, mental retardation facilities and correctional facilities — communities have sought to prevent these people from living next-door.

Thus, the fact that the development of group homes and community residences has not kept pace with the dramatic increase in need that has occurred in the last two decades may be attributed in part to funding problems But community opposition, evidenced by the enactment of exclusionary zoning laws, is often an even more insidious cause.

In the next few minutes I will discuss the following. First, I will review briefly the history of the relationship of zoning laws to group homes for people with mental retardation. Then I will ever so briefly discuss how zoning laws work for those of you who do not know. Finally, I will discuss the three strategies that I have found to be effective in overcoming restrictive zoning laws. They are litigation, advocating for effective State and Federal legislation and community education or conciliation. None of these strategies, of course, are mutually exclusive.

II. HISTORY OF THE APPLICATION OF ZONING LAWS TO RESIDENCES FOR MENTALLY DISABLED PEOPLE

The number of CRF's has grown dramatically in the last decade. A survey of small facilities (fewer than 15 residents) for developmentally disabled people alone showed 611 such facilities existed in 1972, 3,225 in 1977 and by 1982 the number had nearly doubled to 6,414.

Although the numbers have increased, the opposition has not decreased. The introduction of living environments for people with mental retardation into communities has been met with rebellion and indignation. And, although initial success by those who oppose mentally retarded

people from living in the community has waned, and a majority of states now support the establishment of group homes in the community, even in the more liberal jurisdictions, the threat of neighborhood resistance and prejudice remains strong. In fact, a 1985 study of the American Planning Association indicated that "zoning is the major stumbling block to the deinstitutionalization movement." (Jaffe, M. & Smith, T *Siting Group Homes for Developmentally Disabled Persons,* Planning Advisory Service, Report No. 397).

Zoning laws originated with the industrialization and urbanization of the late nineteenth century as a way to accommodate the competing demands of protecting the community's health and safety and the economic needs of the new industries. Zoning laws were, and are today, recognized as a proper exercise of the State's police power. Generally, they contain few substantive provisions and typically seek to "promote the general welfare" by affording localities the power to zone to "prohibit activities considered harmful to the community."

In 1926 the United States Supreme Court upheld the right of municipalities to enact zoning laws. In *Euclid v. Ambler Realty Co.,* 272 U.S. 365 (1926), the Court defined zoning as a legitimate exercise of a locality's police power so long as the particular ordinance bore a rational relationship to a permissible State objective. According to the Court, zoning laws cannot be used as a license for otherwise unconstitutional or unreasonable actions by a municipality and cannot be "clearly arbitrary or unreasonable, having no substantial relationship to the public health, safety, morals or general welfare"

Despite the Supreme Court's pronouncement in *Euclid* that zoning laws cannot be used "for otherwise unconstitutional actions," some communities, relying on prejudices and fears, have seized upon local zoning laws to discriminate against certain groups of people by excluding them from residential neighborhoods. As we know, zoning laws have been used to exclude certain racial minorities and religious groups from certain neighborhoods. Yet such zoning laws have been struck down, one by one, as unconstitutional.

Efforts to "zone-out" group homes for people with mental retardation have continued, however. From the local government perspective, the community residence in a residential area is an anathema. Residents fear that the homes will lower property values and destroy the character and tranquility of a neighborhood. Accordingly, zoning authorities (often at the instigation of affluent residents) have employed a variety of methods to exclude this "unwanted" land use.

Typically, the local zoning ordinance will designate certain areas of the municipality as "single family residential" zones. The exclusionary nature of these zones is often premised on an extremely restrictive definition of family, limiting occupancy in such zones to persons related by blood, marriage or adoption. Other ordinances treat a residence for mentally retarded people as a boarding home, permissible only in commercial zones. And still others treat them as hospitals or nursing homes and permitted only in zones "suitable" for such use.

III. HOW ZONING LAWS WORK

Most zoning laws divide property into three districts: residential, commercial or mixed use. There are three basic ways in which zoning ordinances may regulate the opening of homes for people with mental retardation in residential districts. These define the facility as a "permitted use", "special-use", or by construing the definition of "family" to include nontraditional, congregate living arrangements, such as congregate housing facilities.

A permitted use is a use of land which the zoning ordinance specifically authorizes in a certain zoning district. In other words, a permitted use is one for which local officials can issue a permit to construct or occupy a structure on the basis of an application, without further consideration at a public hearing. Providers seeking to open homes for people with mental retardation in an area in which such a facility may be considered a "permitted use" would have no zoning difficulties at all. So long as the facility satisfied all applicable code and licensing requirements, the facility would be permitted to open automatically.

A "special-use" or a "conditional-use" is a use of land for which the zoning ordinance specifically requires that a special- or conditional- use permit be obtained before a residence can be established. Such a requirement often even applies in multiple-family areas. And before the permit is granted, the local government is commonly required to conduct a public hearing on the permit application and approve the application before the city can issue the permit to construct or occupy a structure on a certain parcel of land. In addition, even if the permit is granted, it may include certain conditions including compliance with elaborate building code standards and may even include a restriction on the number of residents.

An example of a recent case involving a challenge to a denial of a special-use permit is *Cleburne v. Cleburne Living Center Inc.,* 473 U.S. 432 (1985). In this case, the Supreme Court was asked to consider whether the city of

Cleburne, Texas had acted properly in denying a special-use permit to the operator of a group home for 13 mentally retarded adults. The Court upheld the right of the group home to open,
although it rejected the plaintiffs' claim that people with mental retardation should be treated the same as black people, women, and other minorities who are afforded greater protection under constitutional analysis. According to the Court, the city's ostensible justifications for denying the permit were either impermissible or unworthy of belief The Court found that "mere negative attitudes of fear, unsubstantiated by factors which are properly cognizable in a zoning proceeding, are not permissible bases for treating a home for mentally retarded people differently from apartment houses, multiple dwellings, and the like.

IV. STRATEGIES

There are, in my view, three ways to overcome exclusionary zoning tactics, and it is these strategies which I would like now to address. They are litigation, legislation and conciliation/ education, as I will call the third.

A. Litigation

Most cases challenging exclusionary zoning practices pit a group home operator against the city which has denied a permit to open. These cases more often than not turn on the question of whether the home at issue should be construed to meet an ordinance's definition of family. Other cases involve constitutional challenges, alleging that by denying a permit to a particular group home, the constitutional rights of the prospective residents are violated.

1. *State Court Cases*

Perhaps as many as 90 percent of zoning cases are heard in state courts since a zoning case heard in a federal court must involve federal constitutional issues or meet other constitutional requirements. Thus, while advocates for people with mental retardation have traditionally favored bringing cases in federal courts, in most cases, state courts will have jurisdiction. This may not be a disadvantage, since advocates have found that state judges are increasingly well-informed and sympathetic to the rights of disabled people.

There are four types of theories or legal claims which have been used in state courts to uphold the right of a group home to open:

- A state law preempts local zoning law, and the action taken by a locality has violated the state law. Thirty-four states now have such laws.
- Unrelated residents of a group home meet the definition of a "family" as required in the local zoning ordinance. This is the most common type of legal claim made in state court. In the vast majority of zoning cases, state courts have agreed that residents and staff of a group home do constitute a family, although not related by blood, marriage or adoption. States which have made favorable rulings in this area include Colorado, Connecticut, Georgia, Iowa, Kentucky, Louisiana, Missouri, Minnesota, New York, North Carolina, Ohio, Pennsylvania and Rhode Island. (One notable exception to this trend was the *Omega* case in Virginia, which involved a covenant forbidding four or more unrelated people from occupying a house. The presence of live-in staff members was determined to make the group home in question of a commercial establishment rather than a family residence. However, to date this case has had little impact as a precedent nationwide.)
- A residence is operated by the state, or by an agency under contract to the state, or receives 100 percent funding from the state. Since states are immune from local regulation, local zoning ordinances do not apply to the residence in question. This is a relatively new approach to zoning cases, but one which has met with considerable success.

2. *Federal Court Cases*

The case of *Cleburne v. Cleburne Living Center, Inc.* remains the seminal Federal case, since it was decided by the U.S. Supreme Court. In *Cleburne*, the Court ruled that the prospective residents of the group home had been discriminated against and treated differently under the city's zoning law solely because of their mental retardation. Thus, their constitutional right to equal protection under the law had been violated.

Inf. W. *v. City of Tacoma*, 720 F. 2d 1126 (9th Cir. 1983). the Ninth Circuit Court of Appeals held that mentally ill people are entitled to a higher level of review and that the local zoning authority failed to pass a stringent test to prohibit mentally ill individuals from living together in a group home. The case involved eight individuals with histories of psychiatric hospitalization.

Another relevant suit was recently settled in U.S. District Court in Ashland, Kentucky, by MHLP, the Kentucky Civil Liberties Union, Pathways, Inc. (a group home developer and operator) and four prospective residents. In this case, the city responded to the provider's application to open a group home by rezoning the street on which the home was to open so as to prohibit multi-family uses. When Pathways, Inc. then tried to build and operate an

apartment complex for people with and without mental illness, the city essentially rezoned the entire city to prohibit the proposed apartment building. Thus, Pathways was left without any potential sites. The case was successfully settled after MHLP argued that the city's actions constituted blatant discrimination against mentally ill people. The result of the settlement is that the city was ordered to rescind the changes to the zoning laws and to grant Pathways the necessary permits to open.

Other cases involving Federal constitutional issues are:

- *Lieberman v. Board of Tax Review* in Greenwich, Connecticut. A group of property owners who were unsuccessful in preventing the opening of a group home for adults with mental illness in their neighborhood petitioned the tax review board to lower assessments on their homes. The tax board agreed to lower assessments, based solely on the neighbors' fear that the presence of the home justified the reduction. Connecticut's attorney general, Sen. Lowell P. Weicker, Jr. (as a Greenwich taxpayer) and MHLP (on behalf of an association of group home operators) filed suit against the tax review board, charging that its decision was motivated solely by prejudice and fear. This case has yet to be settled, but it is hoped that it will alert other tax review boards to the fact that similar actions may fall under legal scrutiny. (Since this speech was presented, the case was settled with the town agreeing to do new assessments on all the homes without using the group home as a factor in its calculations).
- *People v. 11 Cornwell Company* in New York. A group of neighbors, upon hearing that a group home was planned, bought the property on which the home was to be located. The state sued the property owners on the grounds that their action violated the civil rights of the prospective residents and the New York human rights law. The Second Circuit Court of Appeals upheld the district court's decision in favor of the state and even ordered the payment of attorneys-fees against the law-breaking neighbors.

3. *Cases Involving The Right of People with Mental Disabilities to Live in Independent Housing*

There is only a very small body of law protecting the rights of people with mental disabilities living in independent housing. In one case, a mentally ill woman who claimed reliance on a pet could not gain access to public housing because the lease forbade pets. A suit was brought in Federal court, claiming that forcing her to comply with the lease was a violation of the anti-discrimination clauses contained in Section 504 of the Federal Rehabilitation Act of 1973. The court ruled in her favor.

MHLP is beginning to develop cases aimed at preventing evictions from public housing (as a means of preventing homelessness) under various anti-discrimination laws and state statutes.

Most such challenges will rely on Section 504 of the Rehabilitation Act of 1973, which, for the first time in our nation's history, guaranteed the civil rights of people with disabilities. In the 14 years since enactment of Section 504, all of the Federal agencies responsible for enforcing the law in regard to the programs they fund (schools, libraries, health centers, etc.) have published regulations to implement it — with the sole exception of the Department of Housing and Urban Development.

In 1978 and again in 1983, HUD proposed regulations that never became final rules. Proposed rules that were published in 1983 provoked a storm of protest by the civil rights community and by groups representing the elderly, children and low-income tenants.

A primary cause of the protest was HUD's failure to issue regulations recognizing that recipients of Federal dollars have a statutory responsibility to accommodate the needs of disabled people. For example, all other agencies' regulations require recipients to review the physical accessibility of their buildings and to develop transition plans for appropriate architectural changes. By contrast, HUD's draft rules impose no requirement on public housing projects (the largest source of housing for low- income tenants, whether disabled or not) to conduct any such review, much less to develop transition plans or make architectural changes. All other agencies' regulations also require recipients to review and amend any of their policies and practices that result in discrimination against people with disabilities by denying them an equal opportunity to benefit from the recipient's program. The HUD draft, by contrast, absolves recipients of HUD funds from altering any policies they find inconvenient to change.

As a result of the public outcry, HUD substantially revised its proposed rules. A new version is currently circulating within the agency and we understand HUD plans to publish it as final regulations without providing any further opportunity for public comment. Although an improvement on the 1983 proposed rules, we have reason to believe that the current version is still gravely flawed and inconsistent with the rules adopted by the other Federal agencies 10 years ago.

Without question, housing regulations for Section 504 are long overdue. HUD has delayed enforcing the 1973 antidiscrimination law with-

out them. As long as the agency continues to stall, thousands of disabled adults and children will remain inappropriately and unnecessarily consigned to institutions, nursing homes and shelters. Yet the HUD rules will control both access by tenants to housing assisted with Federal tax dollars and the policies and procedures that housing managers and owners must follow. It is therefore most important for the HUD regulations to fulfill the intent of Section 504, of protecting disabled people from discrimination. (Since this speech was presented, on June 2 HUD issued its final regulations. They do reflect a dramatic improvement over the version proposed in 1983).

B. Legislation

1. State Statutes

The second, but not mutually exclusive, way in which restrictive zoning laws may be fought is in the legislature. In recent years approximately 34 states have enacted State statutes, preempting local zoning laws.

The statutes vary in their approach. Generally they restrict the number of permitted occupants. Some define group homes as those occupied by six or fewer residents, while others allow additional residents and may permit live-in staff as well.

Some simply define residents of group homes as a "family" for zoning purposes. Others say such homes constitute a single-family residential use, and still others say group homes are a permissible use in all zoning areas. None of these provisions are mutually exclusive, however, and the statutes in many states contain language incorporating all of them.

Some State statutes also require that a group home not be located within a certain distance of other similar homes. These "dispersal requirements," as they are known, are accomplished in different ways. Some prohibit "undue concentration", others require specific distances between group homes and some, like New York's Padavan Law afford the State discretion in determining whether the existence of a group home would cause "over concentration" of such facilities in a given neighborhood.

2. Federal Statutes

In addition to State statutes, attention is being paid recently to the role of Federal legislation. As you may know the Fair Housing Act was enacted in 1968 to prohibit discrimination in all public and private housing-related activities. The law was enacted specifically in response to the death of Martin Luther King, Jr., and addressed discrimination based on race, color and national origin. Since 1979, Congress has debated amending the law to expand its coverage to include families with children and individuals with disabilities.

The law will likely be amended this year to include protections for people with disabilities. The effect of such an amendment will be enormous since it will give people with mental retardation and others the right we all take for granted: the right not to be turned away or evicted from housing simply because someone may not like the way we look.

Yet there is deep concern that, without energetic advocacy, the amendments might not adequately protect the rights of tenants and home buyers who have mental disabilities. For example, the law will address the extent to which local health, safety and zoning laws may be used to limit the development of housing programs for disabled people. It would be sadly ironic if the Federal law were to protect the rights only of mobility-impaired tenants, limiting the advances that many localities have already made in prohibiting the use of zoning requirements to exclude people with mental disabilities. (The Fair Housing Act was amended on September 13, with an effective date of March 12, 1989).

3. *Federal Housing Policies*

HUD controls the funds that Congress annually appropriates under Section 202 of the Housing Act to encourage the development of appropriate community housing for elderly and disabled people. It also controls the management policies for all federally assisted housing.

The agency is well-known for frustrating the intent of the funding laws by making it impossible simultaneously to develop housing and comply with HUD's administrative requirements. Many developers have spent two or three years meeting the agency's continuing demands for approvals and revisions only to find that changes in fair market rents and financing policies have made completion of their projects impossible.

In addition, HUD has made little or no attempt to coordinate the policies of its housing and community development divisions with those of the Fair Housing and Equal Opportunity Office. As a result, agency policies are internally inconsistent. They often perpetuate discriminatory practices and unnecessarily restrict the number, location and type of housing available to tenants with disabilities.

For example, with two or three exceptions, HUD's program regulations prohibit discrimination on the basis of race but not on the basis of disability or age. As a result, the agency does not consider that accommodation of the needs of elderly or disabled people is required in any of the housing it funds except those specifically designed for these populations.

The result is both to limit housing opportunities for elderly and disabled people and to promote the segregation of these populations.

C. Conciliation/Education

The third strategy to overcome restrictive zoning laws is by "persuasion" or conciliation. This method may take many forms.

1. *Property Values*

The most common concern expressed by opponents to group homes is that establishment of a group home or halfway house nearby will devalue their property. It will not. Numerous studies have established conclusively that the location of a group home or community residential facility for mentally disabled people does not adversely affect property values or destabilize a neighborhood. I have personally reviewed every available study on the subject and, without exception, each study shows that location of a group home does not have the feared affect.

These studies, approximately 30 in all, were conducted in a range of neighborhoods — from upper-middle-class to low-income, from single-family to multi-family housing and apartment complexes, from black to white to racially mixed and from older to younger to mixed-age communities.

The most recent study on this issue was completed in the District of Columbia for the D.C. Association for Retarded Citizens. It establishes, unequivocally, that neighborhood property values are not in any way adversely affected when group homes open.

In Lansing, Michigan, another study reaches the same conclusion. It shows that the average sale price after a group home was established was equal to or *higher* than the sale price of a home in the control neighborhood. In Philadelphia, property transactions were tracked in a six-block radius of several residential facilities. The number of transactions actually diminished by 2 percent after the opening of a group home.

Similarly, an Ohio study found the following. First, property values in group homes had the same increase or decrease in market price *as* homes in neighborhoods without group homes. Second, close proximity to a group home did not significantly alter the property's market value and that adjacent properties did not decline in value. And third, the study found that group homes did not generate more turnover of property than in other similar neighborhoods. Finally, another Ohio study found property values increasing less as distance from the facility increased, indicating that a group home can be a *positive* factor in upgrading a neighborhood.

2. *Character of the Neighborhood*

In addition to neighbors' fear about property values, some neighbors are concerned simply that location of a group home or half-way house will change the nature or character of the neighborhood. This fear is equally unfounded. Studies reveal that group homes are maintained at least as well if not better than surrounding homes and that such homes are not conspicuous in their neighborhoods. Further neighborhood activity patterns do not change nor is there greater noise or traffic associated with group homes than other private homes.

2. *Mentally Disabled People Pose No Threat*

The third most common concern expressed by opponents of group homes is that mentally disabled people will be dangerous as neighbors. This stereotype is simply wrong. People with mental retardation are no more likely to commit violent acts than members of the population at large. In fact the numerous studies which have been done on this subject show that they are less likely.

Residents of group homes who are mentally retarded are rarely involved in behavioral or criminal incidents. In a two-year study of nearly 2,000 developmentally disabled people, fewer than one percent were reported to have been in the custody of the law. A second study of 20 family-care homes reported that 96 percent of the mentally retarded residents had no recorded behavioral difficulties in the community. And one of the most recent studies has found that it is probably *safer* to be a neighbor of a group home since the arrest rate for adults in the general population is 60 per 1,000, significantly higher than the rate among mentally retarded residents of group homes, which is 3 per 1,000.

Despite the unequivocal showing that mentally retarded people make good neighbors and that a residence for them does not devalue neighboring property or otherwise adversely affect the neighborhood, opponents of these homes continue to embark on various strategies to block the opening of group homes, but with limited success.

V. CONCLUSION

People with mental retardation can be found in every State, at every age level and among all races, ethnic groups and economic classes. Indeed, most mentally retarded people live, learn, work and play in our neighborhoods — as children living at home and attending public schools and as adults living independently if they are able, or if they are not, with relatives

friends or group homes, if they are available. Yet fear and prejudice of people with mental retardation have resulted in prolonged debates over amendments to zoning laws and even longer legal battles over the rights of these people to live in the community — in my neighborhood, in your neighborhood.

Just as a community has no legal right to exclude specific racial minorities or ethnic groups, it has no right to keep out people who seem different. Stated another way, people with mental retardation have the same right as you or I to live in the community. And we should all take responsibility for accomplishing that goal.

A parting note. Seldom are judges quotable. However, I would like to leave you with a statement made by one judge who held that a community had no right to "zone-out" a group home for mentally disabled people:

> "The concept of the king and his court living within the castle and the serfs residing outside the walls was never contemplated to be the social order of this country."
> *Russell Knee v. Town of Atkinson* (Rockingham Superior Court, New Hampshire, Oct. 30, 1984, Case. No. E-36-80).

Financing of Community integration Models

by Vincent D. Pettinelli, ACSW, FAAMR President and Director
VOCA Corporation
Columbus, Ohio

VOCA Corporation is a privately-held company based in Columbus, Ohio. We serve approximately 650 persons with mental retardation and developmental disabilities in three states and in the District of Columbia. Most persons whom we serve have severe and profound disabilities, and most persons are served in 8-bed facilities or less. VOCA employs approximately 1,100 individuals, representing all paraprofessional and professional levels of service. We have been operating for 10 years.

Prior to starting the company, I worked in South Carolina, Pennsylvania, and in Ohio in various state government positions. In South Carolina, I served as assistant superintendent and director of regional services and developed the first community programs in that state. In Pennsylvania I served as commissioner, and in Ohio I worked in a governmental and a joint governmental agency. So my early experiences were based in the public sector, and I believe I'm sensitive to the realities of public funding.

Deinstitutionalization is becoming a reality in most States. Early costs associated with providing community care to persons with disabilities were substantively less than they are today. Why? Because earlier, the persons who were exiting State facilities were more mildly handicapped and could be served for fewer dollars. Today, as more and more persons are exiting State institutions with more and more severe disabilities, the true costs associated with providing those community services are approaching the levels of costs associated with providing institutional care. Why? First of all, sites are small and scattered. Small, scattered sites are more difficult to manage than large facilities. Second, there are specialized habilitation needs of individuals with dual diagnosis or substantive handicaps. These are also specialized day program needs. Not only must a provider be responsible for the services that are in the facility, but he or she also must be responsible to assure that the services provided in day treatment programs are, in fact, meeting the same standard of quality. There are specialized transportation needs — wheelchair lifts, the kinds of transportation needs that accommodate people with special handicaps. There are special medical and dental interventions as well.

And there is liability insurance coverage. Ladies and gentlemen, I pay $360,000 a year for liability insurance coverage. When the persons we serve were in State facilities, there were not costs for liability because most states have sovereign immunity. In order to sue a state, in those states that allow you to sue them, you have to go through such a cumbersome process that few people ever make the effort. But providers today are easy targets for ambitious lawyers who are making a name for themselves in the disability area. We serve medically fragile individuals, individuals with special needs, and individuals who are easily victimized. The litigation in this area is soaring, and it's something that has to be addressed.

I've known Arlene Kanter for a while, when I was in Pennsylvania; in fact, I think she's one of the people who made sure I was named in the Pennhurst lawsuit. The Mental Health Law Project is doing a great job. The point is, for those of us who are involved with zoning and other litigation, how many Arlene Kanters are there out there, that we can hire to help fight our zoning battles? Who will pay their fees? How many people who provide services have the wherewithal to hire attorneys to litigate all kinds of complaints that people have to deal

with, let alone the typical business issues of hiring and firing staff. We employed last year, and I never thought I'd do this, our own in- house general counsel. We are paying this person $70,000 a year, and he's excellent but if five or ten years ago somebody would have told me that I would have needed an attorney in my own shop in order to provide services to persons with mental retardation, I would have said they were crazy. The clear issue is that we are now dealing with the business of providing the services to individuals in the community, and those special needs cost dollars.

The costs of competent manpower continue to escalate. Community providers compete with state, county, and governmental agencies in hospitals, nursing homes, and retirement centers for paraprofessionals, individuals who provide the day-to-day habilitation needs of the residents in these facilities. Paraprofessional staff is at a premium. This work is hard. All of us who have done it know it is not easy, and if you can't pay enough to where you force somebody to work at this as a second job, they come to work tired, they come to work disgruntled, they come to work unmotivated, and at the same time we're asking them to provide Active Habilitation. It can't continue. We must pay staff a living wage.

Nurses. Everybody knows about the nursing shortage. The hospital down the road from my corporate office is offering a one-week paid vacation to the Bahamas, no fooling, for nurses to sign up to go to work with them. How can I compete with that? Plus, I'm asking nurses to take special training in dealing with persons who are handicapped.

The O.T. and P.T. shortage is even worse. In West Virginia where we are just starting up services, we're having to literally find O.T. and P.T. professionals in other States and contract with them to come into that State to provide services — plane fare plus the special consultation rates. These are some of the special costs.

Now let's talk about the revenue.

Most States set reimbursement rates with little regard to client functioning level or to individually determined needs or to market rates. What are the differentials in costs in Washington, D.C., Columbus, Ohio, Wheeling, West Virginia, and St. Louis, Missouri, for the same type of individual that's going to be sought after by a myriad of other health care providers? And it's going to get worse. As health care providers expand with the AIDS epidemic and other services proliferating year after year, not only do we have a manpower shortage, but it's clear that providers who can pay the most are going to get the best staff. Most states increase rates each year by adding dollars to prior year reimbursement rates. The assumption, of course, is that last year was okay. Well, if last year wasn't okay and you've got an add-on to what was deficient in the first place, what you've got is something that's a little less deficient than it was the year before!

The difficulty in attracting high-qualified staff results in high staff turnover for many of us. In some facilities, we've had staff come to us and say, "we haven't had the kind of raise we know we deserve in the last two or three years. Other people want to employ us. We're going." People are leaving the field in droves. When I was a young kid in college in the 1970s, there were a lot of people who were my colleagues who wanted to get into the human services business. I dare say there are very few people at Harvard Business School thinking, when I get out, I'm going to go into the residential services business. That's a problem. It's something we have to address. We have to get the best talent to solve the myriad of problems that exist today. The field is a lot more complicated now than it was 10 or 20 years ago.

We all applaud the strict application of the Medicaid regulations. Surveyors are requiring more and more. Federal look-behind surveyors are coming in asking for more and more documentation.

Delivery of services today, all across the board, is more expensive because before, we didn't provide Active Treatment. Before, we didn't provide Protective Oversight. Before, the conditions that existed, in people being shut away in institutions for years and years, didn't matter to a majority of the population. Now that persons with mental handicaps are part of society, people are demanding better services. Who will pay for those services, and how much are we, in society, willing to spend?

The challenge is to provide funding agencies with a system by which we can justify reimbursement based on assessed individual needs. We also need to hold all providers of service accountable to meet those needs and, at the same time, provide the fiscal resources necessary. Our company has developed a simple, easy-to-understand instrument which profiles an individual's needs via his or her habilitation requirements. We match needs to the staff necessary to provide services and the support services necessary for those staff individuals to do their job. We then apply that fiscal data, which assures that the needs are going to be met, by valuing reasonable market prices within the area where the service is being provided.

This is how it works: Referring agencies fill out a profile form on each individual they refer to us. That profile form includes things like

functioning level, including the level of mental disability, and adaptive behavioral problems, medical data identifying the special needs of that individual for medical supervision, the individual's ability to communicate expressive and receptive language documentation is made, the level of competence to perform self-help tasks with or without assistance. This is real important when we're talking about basic staffing ratios to provide habilitative services within the units. If an individual needs one-on-one staffing because of the level of his or her disability, in order to be safe, in order to be habilitated, then that's what the person needs; no more, no less. It's that simple. If a person needs special interventions of an orthopedist because of a bone abnormality that needs special attention, if a person has a specialized respiratory problem, if an individual needs special dental services that can only be provided in an extraordinary dental environment, then those costs are documented.

Challenging behaviors may be present, including self-injury, Pica, aggression, unauthorized leave, property destruction, and self- stimulation behavior. Obviously, the goal is to extinguish those behaviors as quickly as possible. It can only be done with consistent staff attention by individuals who are trained in the technology of providing those services. Taking someone off the street and saying, here you are, this is your job, is not enough. We have to demand a level of service, a level of accountability on the part of the persons who are working for us, and we also have to remunerate them for their work so that they can take pride in what they are doing.

We also document the types of intervention that have been used and their effect. What's been tried before and what's worked. Typically, even in the worst conditions, there are individuals who have been working with persons who have had a lot of successes. We talk with paraprofessional staff from the referring agency. Tell us what happens when the behavior occurs, what have you noticed, what kinds of things don't work and what kinds of things work best? Those strategies help in the transition from institution to community residence or from larger facility to small facility, from small facility to semi-independent living. We strive to smooth that transition for each individual. Now, that's habilitation!! That's how people learn skills, by the intervention of those particular strategies on a consistent basis. If a person needs special O.T., P.T., psychological services, psychiatric services, speech services, those are also added to the required list. We determine whether those services are needed daily, weekly, monthly, or bi-monthly.

If a person needs special assistance in transportation and mobility, that also begets a special needs area.

Habilitation staff ratios when awake and when asleep. We can't assume that everybody sleeps at night, obviously. If people have patterns where they're awake at night, they need to have staff attention during that time. The fact that most staff don't want to work at night or it's hard to find staff to work at night doesn't mean anything if the resident, in fact, needs those services.

To these data are added the cost of supplying the physical plant, equipment, and supplies. So what we have is a total per-day per-dollar amount needed to serve each individual who has been referred to us for service. We make a decision with the referring agency. The point is that we can't serve everyone with a fixed rate that's supposed to meet everyone's need. We just can't. And I think we need to bite that bullet, as hard as it is. What does it mean?
It may mean that we can't serve everyone who is referred. It may mean that there are some people who don't get served because we know we can't serve them adequately. Anybody participating in the Medicaid program knows that you don't have the choice to not serve adequately because you lose certification. So the government is forcing us to be accountable, and I think any competent professional would applaud that kind of accountability. Parents demand it. Advocates demand it. And we need to demand it of ourselves. We must also be honest about the resources needed to be accountable.

If assessed needs can be met through the application of sufficient revenues, as determined by this analysis, no one should ever be rejected for placement. Clients' needs have been documented. Needs have been coasted out. Funding agencies can justify each cost, and we've identified the resources that exist to meet each client's need. Programs serving individuals should meet all applicable standards. Whether they're licensing standards, certification standards, special local standards or whatever they are, they are fed into the matrix. The only variable under this system is the ability for each provider to deliver the necessary services.

Accountability is a function of each provider in managing his or her own operation, since all have access to the same necessary resources to meet the documented needs. The ability to choose those providers who can deliver the best services allows us to have increased competition and to assure that the best people are providing the best services. Competition in this business is one of the things that can assure high quality.

Why? Because if everybody's getting the same level of resource, then you can attack or applaud each agency's ability to meet the documented services that they say they're going to be providing. If they meet it, fine. If they don't, they're gone. It's a hard way to look at it, but I don't know that we have a choice today in providing the plethora of community programs that we're developing. Under this documentation of needs system, the excuses for non-delivery of services disappear. Monitoring agencies can measure performance upon an agency's ability to deliver services. Poor providers can be driven out. Providers will have an incentive to expand, if they're good and want to expand and should expand. Competition will be stimulated. More providers will enter the field, availing funding agencies more choices. If all this occurs, services cannot help but improve.

Government funding agencies have four possible options open to them now:

A. Serve everyone with everything they need.
B. Serve less than everyone with everything they need.
C. Give something, less than everything, to everyone,
or
D. Serve no one at all.

Option C is chosen by too many. Expectations from regulatory bodies are not tied to resource availability. This is a dishonest approach.

We have already committed ourselves to advocating for the rights of all persons with disabilities to receive the services that they need. True advocacy, I think, champions the right of persons to receive the resources they need to meet those needs. Under funded programs create fear and doubt amongst parents, guardians, advocates, professionals, and everybody who cares about serving persons with handicaps. We must recognize the problem and deal with it now.

An action plan that I would propose is that each provider must first ensure that they are using the resources that they have efficiently. Waste cannot be tolerated, and should be underscored in any audit or inspection. If you're using government money, my philosophy is clear — your books are open, and you'd better be clear about meeting all the requirements that are imposed upon you.

However we must also demonstrate how assessed client needs can only be met through the application of sufficient resources which ensure continuing compliance with all state and Federal regulations which, in turn, ensure continued funding. If clients' needs are not met and certificates and licenses are pulled, places will close down, therefore, affording fewer service available options for individuals than exist today. When the level of resources is insufficient to meet needs, we must demonstrate the negative effects on client services, the resulting effect of being incapable of meeting standards, and how continued funding is jeopardized, resulting in programs becoming less available We are advocating some legislation in the state of Ohio that takes a first shot at client-based program funding. Our appeal to the chairman of the Senate Finance Committee stated, "Ohio has already lost millions of dollars in the closing of facilities that have become decertified; how many more are you willing to lose by not providing the adequate resources necessary to keep the ones that are open, open, and assure that the new ones that come up stay open because the resource availability is there." I'm not suggesting, ladies and gentlemen, that money is the only answer, but let's start from a common denominator. I'm not negating staff dedication. I'm not negating parent involvement. I'm not negating the client's participation in his or her program. Those are essential, but you've got to all start from a common denominator. And if resources cannot be met or we are constantly depending upon discretionary dollars coming as a charity to keep these types of on-going operations alive, I think we're kidding ourselves.

The people we serve demand service 24 hours a day, 365 days a year, for a long, long time, and they may not be in the same facility or they may not be in the same setting during their lifetime, but will probably be depending upon community resources to meet their needs for a long time to come, especially individuals with substantive handicaps, persons who always will need a high level of Protective Oversight.

We have the technology to educate professionals, legislators, and government leaders about the validity of this approach and how increasing allocations of public resources can ensure increasing quality of care to the persons who need it.

If we decide, as a society, that there is just not enough money to adequately meet everyone's needs, then we have a professional and ethical, and moral responsibility, to adequately meet those needs of the persons we do decide to serve.

The vision for all of us, I think, is to assure that services that are in place are funded adequately. We need to celebrate and publicize our successes. We also need to attack the failures, and we need to self-police our own profession to make sure that only the best providers survive. We need to work together to develop

a full continuum of services so that people demand that the level of services currently being provided are expanded, even if that means tapping more resources. Those revenues have to be consistent, they have to be dependable, they have to be relied upon by people providing the services and, most importantly, the people who are receiving those services.

The vision is that once all services are funded adequately, parents, advocates, and persons with disabilities will demand that service opportunities be expanded. Consumers will demand that they be included in an expanded system that is accountable, that can justify the use of resources, and that is adequately funded to meet the needs of those persons it was designed to serve.

Promoting Maximum Community Integration Through People

by Peter "Skip" Sajevic
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II. BEGINNING DEVELOPMENT.

We have witnessed over the last 20 years a growing and continuing effort to expand and to enrich participation and integration of people who are disabled in everyday community opportunities.

Many of the people who are disabled benefit from services and support that facilitate a full and active community experience. Services and support have been developed to offer housing, education, employment, recreation and health care options.

Many of us are excited about the successful development of creative service options and opportunities *"tailored to individual need"*. Many of us are also frustrated that not enough progress has been made.

WHAT HAVE WE LEARNED SO FAR?

A. Models make people work

Much progress has been made toward the protection of rights for people who are disabled, toward the development of safeguards and remedies as well toward the growth of resources and technologies.

B. People make models work

As more services are developed, they begin to espouse the same words, they begin to sound alike — 'tailored to individual needs.' People who are in primary contact or direct service breathe life into what otherwise becomes a cliché'.

We believe that people develop best emotionally and intellectually from a secure base of interpersonal relationships. This is an unfolding process that occurs throughout each person's life. In addition, we believe that 1) *all* people have the ability to learn, 2) *each* person is unique, and 3) *all* people have the desire to be competent.

CHANGING ROLES

As the world of service and support expands to a broader range of community involvement and experience — a richer quality of life — for individuals who are disabled, the role of the person offering service and support changes not only in language but also in action.

We introduce, accompany, enable, facilitate, mediate, advocate, guide, teach, modify as an active interaction and participation in another person's development.

We build and develop relationships as a foundation for opening doors to further opportunities.

The skills and attitudes involved in these roles may be considered more sophisticated than the skills required previously in the directed care environments and may require a new thinking in attracting and developing people with these qualities.

The challenge to experience givers is to be sensitive to the whole person and to demonstrate a productive valuing that seeks expression, promotes and builds qualities of judgment, curiosity, a sense of humor and the appreciation of beauty.

THE PROBLEMS

A. Lack of Personalization of staff — the forgotten element in service delivery

All too frequently, people who offer service and support are greeted with attitudes of mistrust, questioned about motivation, criticized for training and double-checked for judgment, intelligence and competence.

B. The distress signals are loud and difficult to ignore.

1. Turnover rates are reported at 70% or higher which have traumatic impact on both the continuity of service as well as the stability of secure relationships.

2. The average job tenure reported in the range of six to nine months demonstrates not only inefficient use of valuable resources, but also a nagging negative image of service importance.

3. Service providers report a haunting fear that competent staff are not available in sufficient quantity. This has the effect of slowing and "braking" the creative energy necessary for more ambitious efforts.

4. Services inherently impose significant demands and stress. To perceive a lack of support or more so a lack of trust compounds the stress for people performing on the direct contact level of service.

5. The lack of connection or "team" — feeling alone and isolated — presents a major attitude for agencies to overcome when organizing in small, dispersed service sites.

6. The expectations for job performance and training continue to grow yet compensation levels force competition with labor pools essentially targeted for unskilled personnel, i.e., fast-food.

C. Marketing

The message and appeal must be framed positively if services are to attract, recruit, retain and save valuable human resources. "Saving" versus "losing" motivated and competent staff implemented as a functional concept offers an exciting promise of long-term quality services.

The message and appeal should promote the development of staff talents as a priority for ongoing growth and that training is a focus for self- improvement.

D. Compensation – "Compensation Trap"

Compensation rivals support as critical indicators of job satisfaction. Yet compensation levels generally are at embarrassing low levels—perhaps a result of the perception that people need not be paid for "what they like to do."

There is no economy in low wages. When minimum wage and Department of Labor standards are forefront issues in service delivery, the signal of exploitation should be as clear to policy makers as it is experienced by many that deliver services.

A quick scan of want-ads in most any newspaper would reveal compensation levels for most job "opportunities" to fall far short of poverty levels.

A number of states are to be congratulated for initiatives of wage parity, wage equity or enhancement and comparable worth.

VI. Recommendations

A. Respect and Support -"People-Centeredness"

The fundamental belief of our most successful companies is to treat individual employees as a source of quality with respect.

There are infinite numbers of reasons why we should not trust, but this pre-occupation with maybe 3% to 8% of the total people involved serves to discourage, reduce self-esteem for the people we want to participate.

We motivate on what we think we can be — the potential — the possible. This seeking of possible gives breath to the future and substance to our own existence and uniqueness.

To promote maximum integration and quality of life, we must seek people willing to demonstrate the courage:

- of participation
- of involvement on an individual level
- of an openness to share one's own self by expressing one's own uniqueness, excitabilities, anxieties and enthusiasms as a process to assist another's development of personality and connection to life.

If we can offer respect to individuals offering support and service it is more likely to encourage respect and dignity for people who are disabled — reciprocal people-centeredness.

B. Enlisting the Partnerships

1. Federal-State Leadership Message
   a. Recognize quality staff as important determiner of successful services — valued imaging.
   b. Send clear signals to educational and vocational systems that validate career opportunity and job importance.

c. Establishing compensation guidelines for career development.
d. Develop a practice of linkage or liaison between agencies with overlapping responsibilities, i.e., Department of Labor, Housing and Urban Development, and Department of Health and Human Services to avoid conflicting practice.

2. State-local
   a. Provide community education regarding service and job potential.
   b. Offer assistance to neighborhoods in how to get involved and what to expect from services.
3. Public – Private
   a. Develop value-based criteria for service development.
   b. Cooperate in planning for staff development and staff opportunity.
4. Family-service provider
   Recognize and expect the partnership necessary for quality service depends on accountable trust and communication.

VII. SUMMARY

A. Who gets helped? — Everyone wins with an opportunity to tap rich fund of human energy and potential

B. How much does it cost?

How do we estimate the expense of service breakdowns or disruptions? How do we value the unending cycle of training and retraining, of training and retraining. What is the cost of disillusionment and discouragement? A recent University of Minnesota study estimates the cost of staff replacement at $90,000,000 annually.

We can expend resources or invest in people-potential.

Management of Transition into the Community

by Marcia F. Hill
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I am very pleased to be here today to be able to discuss with you some of Florida's experience in transition.

Transition in Florida can be viewed as a multidimensional concept and, depending upon where you are in your state in the development of community services and where people with mental retardation live, your transition plan activities will be very different.

Transition at one level moves people: from an institution to a community program; from large settings to small settings. At a second level, there is transition that occurs within a program to improve it, focus it, and to keep it appropriate with current technology. And at a third level, there is the transition that all people experience as they move through life stages.

What I would like to do this afternoon is share with you Florida's experience with all three types of transition as it relates to the development of community programs for persons with mental retardation and some suggestions on how to manage successful transition. These are suggestions based upon experience — not necessarily the experience of success, but also the experience of failure.

The first level of transition is where Florida has had the most experience. Florida, as most states did back in the early seventies, began moving people out of state institutions into community programs. Many of these people were quite independent and were able to move into community settings easily. We set up what was considered to be model training programs in our institutions to teach clients how to live in communities. We were particularly proud of our institutional mini mall — a mall built in the early 70's to replicate the real world. It had a bank, a snack shop, a library, a post office, barber and beauty shop and a small department store. We were so proud. Even the most innovative thinkers of us never thought to use what resources the community could offer. As we moved clients into the community, we had a fair amount of success and our share of failures.

Until the 80's most of our community residential programs continued to serve people who were able to function with a fair degree of independence. Then due to a number of circumstances, the primary one being that the buildings were fire traps, the decision was made to close two of our institutions. These institutions housed about 1200 persons with severe/profound mental retardation who were non-ambulatory and had substantial medical complications. The closure of these two facilities was a huge undertaking lasting about 5 years and resulting in moving about 1000 people into smaller community programs. Most of these programs were called clusters. These were small ICF/MR facilities licensed to served 24 clients in 3-8 bed houses. In total, we moved clients from two institutions to about 35 different programs all over the State.

It goes without saying it was a management nightmare. I was a program supervisor in one of the districts where one of the institutions was located the same time we were closing this institution we were also under a legislative mandate to move 100 persons with mental retardation who were inappropriately placed in a Mental Health facility — often into the same facilities. There were periods of time when I lost sight of the individuals' needs and thought in terms of compatible characteristics like ability levels, age and sex. Because we were under legislative mandates and working with providers who were only reimbursed when a client

was placed, logistical considerations were at times overwhelming. Weeks of placement planning had to be reshuffled when chicken pox broke out three days before transfer.

What were some of the things we did to plan and actually accomplish this transition? Many things. We had some 12 different areas which required extensive planning. These were areas such as site selection, facility construction, license and certification, contracting and budgeting procedures. There are two main areas I want to focus on today — Staff Training and Individual Transition Plans.

In the area of staff training we developed an extensive pre-service program for all levels of staff. Because we were moving persons with severe medical problems all over the state, we realized we had to provide an intensive training. We assumed, and correctly so, that many new employees would be inexperienced. We designed a three phase program involving 25 days of structured training. The most valuable part of this training was something we called practicum observation and demonstration, or PODS. This part of the training involved bringing the staff to the institution to actually work with the individuals who would be moving to their facility. Not only did the staff learn new skills but they got to know the individuals, who would be moving to their facilities and could learn about them from the people who worked with them at the institution. This was very important with this population who often could not communicate for themselves. Much was learned about individual likes and dislikes.

Another thing that we did was to develop fairly elaborate transfer agreements on each individual to make sure that every last detail from clothing to medication to records to eligibility applications were handled.

We learned a lot from that experience and we have continued to phase down our remaining four institutions. In 1986 we closed an additional 132 beds, and in 1987, another 60 beds. Our experience with closure has helped us immensely in planning effectively for the actual movement of people.

What has been our experience at the second level — that of transitioning within programs? We have been making steady, if not dramatic, progress in that area. Although I admit it hasn't been as impressive as our deinstitutionalization effort, in some ways it has a more significant impact on persons with mental retardation because it focuses on the appropriateness of programs.

We have seen program transition in our day programs and in our residential programs.

Day programs in Florida are called developmental training programs. In the past we have used a very intensive developmental model that taught skill acquisition and minimized vocational training. For persons who had been institutionalized for long periods or who had not been served in public school, this appeared to be appropriate. Developmental training programs often replicated home/community environments within their training facilities where housekeeping skills like making beds, cleaning dishes and cooking were taught. Programs were set up, data was taken, progress was tracked, and clients moved through a series of objectives. Rarely did we assess whether or not he did the things at home or ever would. Then one day we said to ourselves — does this make sense? — And gradually we have started to be more creative.

We have begun to expand our training approach into actual home settings and into community settings. Money management is much more functional when taught in the community in real stores. Cooking skills are much more functional when taught in the kitchen where the individual lives.

Transition of our day programs into work programs has been another area of transition in Florida. Five years ago, supported employment was a vague concept in Florida. Today it is a reality. By the end of June 1988, over 700 people who were in developmental training programs will be in supported employment settings. Moving from a center based activity program to supported work programs is not easy. There are many skeptics. There is a great deal of money invested in facilities. There are service providers and parents who don't believe supported employment will work. But it does and it will.

We are also experiencing program transition in our residential services. Although we have moved persons with mental retardation from large institutions to community-based programs, we realize that many of these so- called community residential programs are, in fact, institutional. When shifts are used to staff a residential program, the result is an institutional operation. A slow transition is occurring in many of our smaller programs to 24-hour staff. Although it has been difficult to recruit and maintain staff, those who have transitioned to this model feel a strong commitment to it.

The third type of transition, that of the transition that people experience as they move through various life stages, is a concept that we in Florida have just recently begun to consider. We have talked a lot about programs for children, programs for young adults, programs for the elderly. With that, we discuss a continuum that we move people through. Just recently we have begun to think about the individual and

changing our programs to fit the various life stages or transitions that the individual experiences. We are beginning to view transition as we as individuals are experiencing transition.

In Florida we have recently completed a five-year plan. As we developed this plan, we challenged ourselves to think beyond our current programs and technology. We focused, not on programs or funding, but on the individual and his needs — and what has emerged has been a philosophy and a fresh approach that looks at the individual in transition — not the system as it moves people — not the program as it struggles to change — but at the individual as he moves through life — like you and like me.

Presidential Forum: Citizens with Mental Retardation and Community Integration Recommendations

Submitted by Marcia F. Hill
Assistant Director
Developmental Services Program
Florida Department of Health and Rehabilitative Services

1. The Medicaid Reform Act or similar legislation should be enacted.

As individuals with mental retardation graduate from public school and transition into work settings and begin to participate in society as adults, some level of federal funding for ongoing training and support services is necessary. Currently federal funding for community-based services is limited to only a small portion of the population with mental retardation who live in the community. Federal funding for all individuals with mental retardation who need support to remain in community-based programs should be available.

2. Programs for persons with mental retardation should transition as the individual moves through life stages.

Too often program designs for persons with mental retardation have been conceptualized as a continuum through which the individual moves. Rather than moving people through programs, program designs need to change as the individual changes and moves through various life stages.

3. Programs need to be functional and appropriate to a person's life stage, and provided in real settings.

As we develop programs for persons with mental retardation we need to evaluate the functionality of the program and its value to the person. Training programs need to occur in real life settings and need to provide the greatest opportunity for generalization.

4. Program change must be viewed as an evolutionary process.

Program models for persons with mental retardation have and are continuing to change dramatically. As technologies are developed, it_ is important that programs change and adapt. Changing current program models is often more difficult than developing new programs. Model programs which are effectively dealing with changes must be identified. Their techniques must be studied for replication.

5. The development of small supported living facilities should be promoted.

The development of small residential facilities will eliminate many resource development problems associated with zoning difficulties and neighborhood opposition. Further, it will enable persons with developmental disabilities to live in natural environments.

PANEL SESSIONS

February 4, 1988

Living Arrangements
Employment
Transportation
Education
Recreation/Leisure/Socialization
Family Supports/Respite
Life Services Planning
Quality Assurance
Health Care
Citizen Advocacy

Living Arrangements Panel

MODERATOR: "HANK" BERSANI, JR. PH.D.

PANELISTS: JANICE C. SCHIFF
MICHAEL M. MORRIS
GAIL D. JACOB
JEAN W. POWERS

Community Integration for Children With Severe Handicaps?: Let's Be Practical!

by Hank Bersani
Assistant Professor
Syracuse University
Center on Human Policy
Syracuse, NY

The Center on Human Policy was founded by Burton Blatt in 1971. Since that time, we have been committed to the goal that he set down for us: "The promotion of open settings." For the past 4 years, we have been funded by the National Institute for Disability Rehabilitation Research to study the success of community integration for people with severe handicaps, and to develop policies to promote social integration. This paper will present some of the successes we have observed and the lessons we have learned based on our work across the country. Here is a partial listing of the variety of services and locations our staff has visited:

- Institutions ranging from Fairview Center in Oregon; Cloverbottom State School in Tennessee; Bethesda Lutheran Home in Wisconsin to Hammond State School in Louisiana.
- Group homes from Boise and Pocatello, Idaho, to Jackson, Mississippi; from Tulsa, Oklahoma to Nashville, Tennessee.
- Family support programs from Macomb County, Michigan and Dane County, Wisconsin to Calvert County, Maryland.
- Individualized supported living projects from Providence, Rhode Island, to Madison, Wisconsin; from the California Regional Center System, to Greeley, Colorado.
- We have been to major metropolitan areas such as New York City, and Los Angeles, and to rural areas of Vermont and Murfreesboro, Tennessee.

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Quite a variety of settings, and quite a bit of travel in 3 years; we have gathered practical information about real people, living integrated lives in communities across the country.

As a result of our travels I have a list of 5 items to cover here:

1) Basic principles of community integration.
2) A policy statement in support of families.
3) Myths and facts about community integration.
4) Characteristics of the Michigan system that promote integration.
5) Recommendations.

1. Basic Principles of Community Integration. These principles are a statement of values that we formulated with the assistance of consumers, families, and practitioners we have worked with.

- People with developmental disabilities, including those with the most severe disabilities, should be served in their home communities.
- The size of community living arrangements should reflect the scale of other homes in the area.
- Community living arrangements should be located in neighborhoods populated by other people.
- Services should support people to live in typical homes, work in ordinary jobs, learn in neighborhood schools, and play in community recreation programs.
- Services should foster the development of relationships with other community members who do not have handicaps.

- Services should foster the development of practical life skills by using natural environments.
- People with disabilities themselves, and their families should be involved in the design, operation, and monitoring of community services. (Adapted from Taylor, Racino, Knoll & Lutfiyya, 1986)

2. A Statement in Support of Families and their Children. This statement reflects the lessons we have learned from families and successful services across the country.

- All children, regardless of disability, belong with families and need enduring relationships with adults.
- Families should receive the supports necessary to maintain their children at home.
- Family supports should build on existing social networks and natural sources of support.
- Family supports should maximize the family's control over the services and supports they receive.
- Family supports should support the entire family.

These statements are extracted from a longer policy statement by the Center on Human Policy (1986-87).

3. ***Myths and Facts About Community Integration.*** In recent years, the concept of integration has been frequently misunderstood and variably defined. Some people say, "Our services are integrated ... we have people who are Black, some who are Asian ..."
Still others say that "Our program is integrated because we serve people who are blind, physically handicapped, deaf ..." We have learned that these are a number of common myths about integrated community living for people with severe handicaps. Some of these myths are reviewed below along with our responses to those myths.

Myth: Integration is an interesting theory, but it is just not practical yet.

Fact: Community integration is a reality in many places across North America. In many communities, the children and adults with the most severe disabilities are being supported to live, learn, work, and play in the community. Some of the people with the most severe handicaps now live in the community, and the people remaining in institutions are not more handicapped than other people living in integrated settings.

Myth: There is a "research-practice lag." This myth assumes that academics at research centers develop new ideas, and that those ideas are slowly transmitted to universities via professional journals. Then the information is transmitted to university students and finally "trickles down" to direct care staff, families, and consumers. In this myth, the "lag" from research development to practical application is estimated at 5-10 years.

Fact: There is a "practice-research lag." That is, across the country there are innovative practical ideas being applied to offer people integrated lives. The lag exists because the practitioners, families and consumers involved in these innovations are involved in "doing it" and do not publish about it in scholarly journals. The lag exists because between the development of an innovative practice and the recognition of that practice by re-searchers may take several years. In fact, integration success stories are some of the best kept secrets in the field today.

Myth: Community integration is an interesting concept, but realistically we cannot afford to implement it.

Fact: When the full scope of social and economic costs of segregation are tallied, integration is something that we cannot afford to ignore. Among the costs that need to be counted include the market value of large parcels of land and the equity in large buildings currently dedicated to segregation; the cost of maintenance of specialized, segregated buildings, especially old buildings requiring massive expenditures to meet new standards. Social costs of segregation include the disruption of families, and the important cost of non-handicapped children growing up segregated from potential friends, schoolmates, and roommates who happen to have a disability. In a recent review of nearly 100 studies and articles about the economics of integrated and segregated settings (Bersani, H., Knoll, J., & Caruso, G., 1987) there was no evidence that congregated, segregated settings are more cost beneficial.

Myth: Community integration is a good idea — for people with milder handicaps, but people with the most severe levels of impairment cannot be integrated.

Fact: In many communities people with even the most severe impairments are already living, learning, working, and playing in the community. These include people

with G-tubes, T-tubes, apnea monitors, respirators, and serious behavioral challenges. Many of the people remaining in segregated facilities are substantially less disabled than those living integrated lives in nearby communities.

Myth: Only "exceptional" families can cope with a child with a severe disability. Only "saintly" families will be adoptive or foster families for such children. We cannot count on them in sufficient numbers to meet the full need.

Fact: The involvement of natural, adoptive, or foster families is not determined by the disability of the child. It is determined by the availability of natural and human service supports. Given the proper supports, every child can live in a family home. The greatest success nationally has been in the state of Michigan, and in particular, the Macomb Oakland service region. In that region, in the Detroit area, from a population base of 2 million citizens, only 15 children are living in institutional or group settings. All the rest, including those with the most severe handicaps, are living with natural, adoptive, or foster families.

4. Characteristics of the Michigan System that Promote Integration. When people hear of the successes in Michigan, or when they visit and see for themselves, they often ask several related questions: Why Michigan? Why now? How did they do it? After several trips to Michigan, visiting homes, reviewing records, and examining the costs of children returned to families from mental retardation institutions and specialized nursing homes, we have identified 5 characteristics of the Michigan system that promote successful, practical integration:

Value Based Leadership: From the state offices to the counties, from the interdisciplinary teams to the accounting office, people have a sense of values that help set priorities. They understand that small is better, that children need families, and that short term savings may mean long term costs.

Cultural Solutions: Staff looks to the broader culture for direction in problem solving. This is the source of the value placed on small size, families, and permanency planning. They do not ask "What should happen differently because this child is disabled?" Instead they ask, "What does this child need just like other children need?" That means living, learning, and playing in the community and having a family of your own.

General Flexibility: The system bends, conforms, and responds to meet the needs of individuals. Individuals are not made to conform to program or facility demands.
No assumptions are made that medical needs such as apnea or aspiration pneumonia require medical settings. Medical and therapeutic support services are made available to children in their family home and their own neighborhood.

Selective Rigidity: There are some things about which there is no flexibility. Requests to place children in institutions are routinely rejected. Requests for children's group home placements are most often rejected. Proposals for indefinite foster care without a permanency plan are seen as unacceptable. Michigan offers a wide range of family settings and family supports, but settings that are needlessly segregated or unjustifiably large are rejected. Just as we have rejected orphanages for non-handicapped children, Michigan rejects group settings based on disability.

Comprehensiveness: Many locations in the country offer one or more of the features present in the Michigan system. No other state offers such a comprehensive array of supports to integration:

- cash subsidy: families receive $250/month cash if their child meets disability criteria.
- family support: families also qualify for a variety of respite services, in-home therapies, modifications to homes and vehicles etc.
- permanency planning: a statewide system to arrange a permanent home for each child. First choice is for return to the natural home; second choice is for adoption, and as a third choice, placement in a permanent foster home.
- focus on families: within the extensive range of community options, parents wishes are respected, and family involvement is promoted.

Each of these features individually is important. Together they create a system to promote excellence.

5. Recommendations. Based on our pro-integration policy statements, combined with the practical success we have seen, several recommendations are appropriate:

A. Formulate a clear pro-integration policy. The policy should promote full integration for all children regardless of their level of disability.

B. Disseminate information about integration through the publication of a book of exemplary integration projects.

C. Formulate a new national deinstitutionalization policy. PCMR once set a goal for a 50% reduction in our institutional population. That goal has been met. The new policy should set a goal for total national deinstitutionalization by the year 2000.

D. Urge Congress for Medicaid reform. The current Medicaid system is biased toward large, congregated, segregated services, and clearly discourages integration. A reversal of this bias could promote quality integration across the nation.

E. Formulate a national family policy. This policy would state that all children can and should live with families, and that federal and state programs should make family supports their top priority.

Against All Odds: Partnerships for Residential Development

by Janice C. Schiff
Director, Residential Development
Fairfax-Falls Church Community Services Board, Fairfax County, Virginia

I'm going to change the title of my presentation to *"Against All Odds: Partnerships for Residential Development."* For those of you who know something about Virginia ... historically, the funds have not been flowing in Virginia for community residential programs. For several major reasons, the development of residential programs in the State of Virginia has been against all odds.

> Virginia has minimum participation in the Federal Medicaid program for Intermediate Care Facilities for the Mentally Retarded. There are only 200 community ICF/MR beds in the State. There is no Medicaid waiver. Virginia ranks well below the national average in per capita funding for community services for mentally disabled persons. In fact, in 1985, Virginia ranked 44 out of 50 in per capita funding for community residential programs for persons with mental retardation. Virginia is also the State of the well-known Omega case ... the Virginia Supreme Court upheld a restrictive covenant in a community barring group homes for mentally retarded adults in single family residences.

Despite all these odds, the programs that do exist are individualized and community integrated. I consider myself lucky that I had the opportunity to develop my work career in residential services for persons disabled by mental retardation. My husband and I opened the first group home in 1974 for the County of Fairfax. I have held various positions within Residential services in this County, and I am now in the position of Director for Residential Development. I am responsible for the development of a variety of residential programs for persons disabled by mental retardation, mental illness, or alcohol and drug abuse. I am regularly out in the community talking one on one with legislators, neighbors, Realtors, architects, and developers. As I prepared for this morning's presentation, my first thought was that I could spend some time talking about the headlines we've gotten recently in the local papers, like "Not in My Backyard," or "Group Homes Fight for Acceptance." But I would rather spend my time sharing with you what we do to overcome those kinds of headlines. I will begin by talking a little about Fairfax County itself.

Fairfax County has a population base of 700,000 people, 12% of the total State population. The average four-bedroom house is selling at the current time for $214,000. There is a very low vacancy factor. The agency I work for, the Community Services Board is one of 40 Community Services Boards throughout the State. Our annual budget is currently at $35,000,000, 63% of which are local dollars, and only 18% State dollars; 14% are client fees and about 4.8% is from Federal block grant fund. The majority of residential development in the last five years has been through creative use of local tax dollars. But today, I can proudly say to you, that all of the disability advocacy groups joined hands in the State of Virginia last year, and rather than competing against each other for State dollars, they formed a coalition, and in a very sophisticated manner have lobbied State legislators and this next biennium we anticipate receiving a significant amount of new State funding targeted specifically to community residential programs.

In 1974 when we first started developing group homes, we envisioned this ideal continuum. We thought that all individuals with

mental retardation would somehow fit into this ideal continuum; that they would move from their homes or from the local training centers into group homes and then into their own apartments. Several years down the road, we discovered that after we had moved a certain number of people through the group homes and into their own apartments, there were residents who needed the group home level of support all their life who did not fit into this ideal continuum. We also were forced to realize that the funds were not flowing like we had anticipated; that we did not have the funds we needed to open additional group homes. Our waiting list mounted quickly and for the last ten years, we've had an ongoing waiting list of between 200 to 300 mentally retarded individuals who need residential services.

In 1984, our agency, after study and review, determined that we needed to focus energies on residential development. It was at this time that we created a residential development unit that I head. The mission was to leave no stone unturned, dedicate total resources to securing any kind of matching funds, develop any kind of partnerships, etc., to further the number of residences for mentally disabled citizens in our community. This was a significant move and I highly recommend it to any of you in attendance today who find yourselves in the position of being a program manager or supervisor and never having time to dedicate resources fully to development. When we created this new residential development unit, we also evolved a residential plan and a set of principles for developing programs. The salient principles we established included 1) the importance of home first and training and treatment as secondary supportive services; 2) whenever possible, move staff not residents; and 3) seek partnerships whenever possible, and within these partnerships, share the mission and resources to promote the development of community residential programs. This may involve a partnership with another public agency, a public/private partnership with parents or other non-profit organizations. We call it a multi-path approach to residential development.

In 1984 when we began this unit, we had 37 group home beds and 30 semi-supervised or supported residential beds in Mental Retardation Services. In 1988, we now have 107 group home beds and 37 apartment beds. The agency has set a goal for the mental retardation system to add 155 beds in the next five years. One avenue for expansion is through our local Capital Improvement Program. We essentially engaged in a social marketing campaign with other county agency staff and elected officials ... *the message being that community residences for disabled citizens are as important as schools, libraries, parks, etc.* We were able to evolve from a position of zero participation in the Capital Improvement Program to a position of $20,000,000 for this year's advertised plan.

Another strategy is in the area of multi- agency collaboration, particularly with the Department of Social Services, the Area Office on Aging and the Department of Housing and Community Development. Again, through liaison, negotiation, and planned presentations, we are working with the Area Office on Aging to develop residential programs for senior citizens; we are working with the Department of Social Services in developing Licensed Adult Homes, which are funded through DSS auxiliary grants. We have developed special programs with the Office of Housing and Community Development to set aside public housing units for disabled persons. Another resource that we pursued successfully was the use of Community Development Block Grant finds for renovating houses to be used for group homes.

The City of Falls Church, population base 9,000, is one of the jurisdictions with whom we work. Falls Church City serves as a role model for small cities in the use of community development block grant money to renovate houses to be used for group homes. They have been promoted in a recent HUD publication Case Study 86-2 July 1986. *These CDBG projects are model community integration partnership projects.* They had volunteer architects from the community donate the design work; free technical assistance was provided by local engineers; the City waived the building permit fees in order to facilitate this development; they entered into special negotiations with HUD to allow Section 8 Certificates to be dedicated to these particular projects. The furnishings in the homes have been donated. Two of the homes are preservations of large old historic houses, and the one that they just completed this year was not only renovated in keeping with an historical design, but the entire downstairs was renovated to be barrier free. I encourage you to visit Falls Church City and see these group homes.

Public/Private partnerships for residential development are another program that evolved from our residential development initiative. Three years ago through a Developmental Disabilities grant, we hired an Alternative Residential Coordinator for the agency and legal and financial consultants. Our goal was to set up a series of workshops for church groups, parent groups, civic associations, existing non-profit vocational programs ... any type of organization that might be at all interested in developing a community residence. We held a year long

series of workshops that covered a variety of topics ... including fund raising, incorporating, developing policies and procedures, hiring staff, etc. Several viable not-for-profit organizations evolved from this group. We have continued to work with them in a partnership whereby the Community Services Board funds 50% of their annual operation, and through family and resident fees and fund raising, they fund the other 50%, and provide the on-going management of the residential program. The County received an achievement award this year from the National Association of Counties for this initiative.

I would like to end my presentation by posing the question to you, "What really makes for community integration for citizens who are disabled by mental retardation?" I think the answer lies in what feels good for the individual. In terms of a residence ... that might be a condo, living with family, or living in a shared housing situation with other disabled citizens. More important than the type of residence, what's really important is the feeling of belonging, acceptance, involvement and positive interaction with friends.

In closing, I would like to focus on one of the goals of this Forum — to provide recommendations to the Secretary of Health and Human Services regarding the role of the Federal government in the promotion of maximum community integration of citizens with mental retardation:

1. Increased allocation of federal housing funds for disabled citizens to localities which are willing and able to match these funds.
2. Greater subsidy and flexibility with HUD 202 loans so that it is feasible to use these mortgage funds for five and six bed group homes with live-in support staff permitted at no additional cost.
3. HUD low interest loan programs for family- run corporations or cooperatives who want to develop group homes for their own children (this is currently in violation of Section 8/HUD 202 regulations, which mandate "open-participation waiting list.")
4. Promote through media and literature the value of integrated opportunities for handicapped citizens; the People First Movement has to be a daily occurrence — not one week of dedicated recognition per year.
5. Federal support to states for assistance to families who are caring for their disabled family member at home.

I appreciate the opportunity to have participated in the 1988 Presidential Forum.

Implications of Federal / State Policy

by Michael M. Morris
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United Cerebral Palsy Association, Inc. Washington, D.C.

My role on this panel is to look at the implications of community integration in terms of Federal and State policy.

It's always gratifying and enjoyable to watch a presentation such as the one that preceded me that shows people in communities whose lives have changed both as a result of the professional people around them as well as volunteers and other people who provide support and a different quality of life for people with severe disabilities. What I do on a day-to-day basis is try to think of ways that those types of things that happen in Madison and happen in Fairfax County and happen in other pockets of community excellence across the country can be translated into something that isn't just a matter of circumstance where one might live but is in fact an opportunity that is supported by a policy and law, by regulations and legislation. That's not always a very easy thing to do.

All too often it's a minority of people, a small group of people working on policy change and legislative change that affects thousands and thousands of individuals and families across the country. And that isn't so great either.

I think to put in perspective for you where we are today in terms of Federal policy, I'm going to ask you to assist me with what I call a diabolical design scheme. I want you to be the policy maker, whether it be at a Federal level, where you might chair a key Senate or House Committee and have control of making policy about the way we provide support to people with severe disabilities; or suppose you were a State Legislator or a Governor of a State, and you had the decision making power to establish a set of rules that would support people in situations like Madison, Wisconsin (Options in Community Living by Gail Jacobs). If you quickly took a few minutes, you probably could jot down about three to five points that you would like to see as key public policy to create and maintain the support, the nurturing of programs in your community that would benefit individuals with disabilities and their families. What I'm going to ask you to do, though, is to do the exact opposite of that kind of list. I want you to think about the development of the worst possible policy guidelines, the worst possible standards that we could create using our imagination, our creativity, our range of experience. Five points that would deter, that would set up barriers, that would diminish the ability of professionals, of volunteers, of employers, of housing officials, of governors, to provide appropriate support to persons with disabilities and their families.

SUGGESTION: "A requirement that the only type of public funding available would support large residential settings."

SUGGESTION: "Residential placement for persons with severe disabilities is done without consideration for service needs."

SUGGESTION: "People should be kept with their own kind so that the convenience of the program is helped because they will be able to do the same things all at the same time."

SUGGESTION: "Public policy would deny funding for any individuals between agencies."

The reason this exercise is called a diabolical design is that all the points you made are in fact in some way embedded in either State or Federal policy today. So that even with all that we have going, the best of minds, the range of experiences, somehow we've managed to place into law what is the very worst rather than the very best terms of what we know

about things that are going on in communities like Madison. It makes you wonder about how policy is made, who makes the policy, and about how policy is changed.

I begin with that kind of exercise because we have a number of questions that need to be asked about Federal policy and I think many of these questions could also be asked about where we stand today in almost any state. If you were to review your state laws regarding community services or you were to review Federal policy, I would want you to ask several questions: One, does the particular funding source offer opportunities to increase and maximize consumer social and economic independence? Two, does the program support the individual with disabilities with opportunities for increasing self determination or the range of choices that maximize integration opportunities? Three, does the program provide services based upon individual need rather than what is currently available? Four, does the consumer, and when appropriate the parent, have a meaningful voice as a partner in decision making concerning program planning, operation and evaluations? Five, does the program seek to foster and maximize individual growth and development in an integrated setting? Six, does the program support rather than supplant the natural family?

These kinds of questions are still not being asked by decision makers, by the people asking questions of decision makers, by the people who run programs, by parents and by the group that has the least amount of control at this point, obviously individuals with severe disabilities.

If we were to look at changes that could be made in Federal policy, there are several considerations that would very definitely change the Federal policies that we have on the books today related to community services.

First: Evaluate all Federal disability policy as to whether it promotes integrated opportunities.

Second: Examine our Federal laws and regulations in terms of how much they continue to provide incentives to keep people dependent rather than offer opportunities to maximize individual potential, their potential for choices and their potential to become more independent.

Third: Look again at our legislation, our current laws and policies, and recognize how much of it is still based on the medical model and how little has changed in terms of the need to recognize the family unit, and the social nature of program and supports for people with severe disabilities. Stop looking at facilities as the central focal point for the delivery of services and move instead to communities as a larger sense of support with both professionals, volunteers and others who can serve in a supportive role around people with severe disabilities.

Fourth: Look at the emerging benefits of assistive technology as a way to maximize the potential of people with severe disabilities. We know so much more today about how to provide supports to people with severe disabilities with behavioral technology, learning technology, and assistive technology. We haven't refined public policy to ensure technology is accessible to all who need it. Augmentative communication devices, mobility systems, and environmental control systems, enable people with a range of impairments to be able to live more independently. Funding remains a barrier to too many individuals who have not yet benefited from technology related assistance.

Fifth: We must move away from -looking at services, particularly adult services, as some type of privilege or some type of discretionary opportunity to be determined by others and move toward adult services as a right or entitlement.

And finally, Sixth: consider the whole issue of control versus empowerment. Who controls choices for people with disabilities? How much control is actually being allowed for people with disabilities, and what opportunities do we provide for them to become a part of the decision making team, whether that be in their individual program planning, the actual implementation of programs and services, or the evaluation of whatever systems that we have in place across the country? Persons with disabilities as the customer should be valued members of the decision making team.

Obviously, there is a lot to be done in terms of where we are today with Federal policy, compared to what we know is really a State of practice that isn't so isolated any more. It's not just excellence in Madison, Wisconsin. In most every State in the country, we have pockets of excellence. We know the way to provide support in communities for people with disabilities but our funding streams continue to lag behind and our policies continue to create barriers to see that those practices become supported rather than discriminated against by Federal policy and funding. I would like to spend a minute or two with you, on two areas of legislation that presently or in the last year were before the Congress that relate to community living. The first relates to some comments made earlier concerning housing development policy. The funding source in housing under the Department of Housing and Urban Development that most

people are aware of is the section 202 program. It is a program that provides approximately $100 million annually in direct loans to nonprofit agencies across this country to develop new housing opportunities for people with disabilities, whether that be in apartments, in group homes, or in independent living complexes. As a side note, that particular funding source will only allow for development of housing in segregated settings and will not allow housing to be developed in any type of integrated opportunity. In any case, as was mentioned earlier, there are a considerable number of problems with the way HUD regulates the Section 202 program. Congress in the closing days in December passed Senate Bill 825 (P.L. 100-242) which is a major omnibus housing authorization bill, the Housing and Community Development Act of 1987. Why this legislation is so important for you is that it included major changes for the 202 program.

For the first time the program will be separated from the housing development funds for people who are elderly. A separate set of standards, and a separate set of processing forms or application will have to go forward to be developed by HUD that recognizes the unique and specialized needs for the housing of people with disabilities. For the first time the fair market rents that are a part of the section 8 program that couples with the 202 direct loan program is going to be eliminated. As was mentioned earlier, those fair markets rents don't work for small types of housing for people with disabilities. They were set up on a system that was really for the elderly. High rise apartments, with a typical project being seventy-five to a hundred units, did not translate well to the needs of persons with disabilities. Instead of the fair market rent structure under the section 8 system, there will be put in place a new system that will be based on reasonable cost; reasonable cost to be determined by the housing needs for people with disabilities. So for the first time HUD is going to have to really consider accessibility issues, it's going to have to really consider some of the staffing patterns that require additional space within group homes and apartment settings. It could mean a major breakthrough in the way this $100 million a year is going to be used in the future. It's something that I would urge you to watch for and read about and it could mean at least some of the barriers that have prevented the effective use of these dollars in the past will be overcome.

I think many of you are aware of the Medicaid Home and Community Quality Services Act, Senate bill 1673 and House bill 3454. I would like to make three points related to this legislation. If you are in any way involved with people with disabilities in this The reason for my strong feelings about this legislation is that it will impact the use of the major federal funding source we have today that is providing services to people with disabilities. Special education on the Federal level is funded at approximately 1.2 billion dollars a year. Vocational rehabilitation on the Federal level is at a similar level of funding, about 1.2 billion dollars a year. When we discuss the ICF/MR program within Medicaid, we're talking about a funding source that is over 2.5 billion dollars a year in potential home and community services for people with severe disabilities. What this legislation will do is mandate a number of services. It will mandate community and family support services, specialized vocational services and a system of case management. This funding source could be one of the answers to the long term support needs of people now going into supported employment. It can be an answer to many families who need support at home, and would prefer support at home rather than to see their child leave home. It can be the answer to many adults with severe disabilities who are in need of attendants or personal care services to enable them to live more independently. It provides at least the beginnings of an answer to how we assemble the pieces as we try to get different agencies and different people to work together at a local and a state level.

A final point for you to consider is that this is a presidential election year. I'm probably not going to have the time to go over it with you the way I'd like, but I have a political activism quiz that has 5 points to it. I'll just read over the points with you and I want you to think about it. (1) Any time in the last year have you written a letter to a member of Congress? (2) Any time in the last year, the last twelve month period, have you called a member of Congress or their staff? (3) Any time in the last twelve months have you visited with a member of Congress or their staff? (4) Any time in the last twelve months have a member of Congress or their staff invited you to talk with them about a particular issue that relates to people with disabilities? (5) Any time in the last twelve months have you had the opportunity to actually visit with a member of Congress or their staff at a local program that shows what home and community services are all about and why it's so necessary for this

funding stream to become more flexible and provide more choices for people with disabilities and their family. If you didn't answer yes to each of those questions, you need to become more politically active.

Persons with severe disabilities need each of us to become more apart of the political process. A change in public policy and a change in opportunities at the community level is dependent upon your political activism. Thank you.

Options in Community Living

by Gail D. Jacob
Program Director
Options in Community Living, Inc.
Madison, Wisconsin

What is OPTIONS

Options is a private, non-profit agency that supports 94 people with developmental disabilities in their own homes in Madison, Wisconsin. Funding and services are provided through a contract with the local community board County based service delivery system. It began 13 years ago as one of the oldest supported apartment programs in the country. Support is individualized to meet each person's preferences and needs. The amount and types of support vary from person to person and can be anywhere from 24 hours a day to once a week. About 20 people require live-in support. Options provides training, case management and day to day assistance in helping people manage their lives. People live throughout Madison area.

Values/Organizing Principles Which Guide Our Services

A. EVERYONE HAS A RIGHT TO LIVE IN A HOME OF HIS/HER CHOICE IN THE COMMUNITY. NO PERSON SHOULD BE SEGREGATED BECAUSE OF THE NATURE OF HIS/HER DISABILITIES.

We have a zero exclusion policy. Nobody is rejected based on the nature of his/her disability.

People rent their own apartments. The agency doesn't own or lease any housing.

We don't provide group living arrangements. No more than two people with disabilities live in any one home.

Two ways of looking at how services can be designed.

We reject the continuum idea because:

- It puts the burden on the labeled person to earn his/her way through the system rather than on the community to provide the necessary support for people to live in their own homes. Having a home is a basic right. None of us had to demonstrate entry level skills to have one.
- If people have to demonstrate mastery of skills, people with severe disabilities would never reach the end of the continuum.
- The continuum idea wrongly presumes that what you learn in one setting will transfer to another. For many people who are labeled developmentally disabled we know that's not true. (Example: if you learn to use the stove in a group home, you will need to relearn on a different stove in your apartment.) Skills need to be taught in the environments where they will be used.
- The continuum penalizes people for doing well. If you do well enough, you are rewarded by "graduating" to another setting. Often this means leaving your friends, neighbors, places where you feel a part of.

The alternative to the continuum is a support model.

- We start with the presumption that you live in your own home and whatever type of support you need is provided in your home and community- whether it's learning how to prepare a meal or assistance with bathing and personal care.
- If your needs for support change, you don't have to leave; rather the intensity or type of support can be changed.

(Example: you may initially need someone around every day to help with meals. If one year later you can cook meals on your own, that type of support can be faded out.)

- Services are not tied to a physical setting, but rather to the person. This is efficient. People get exactly what they need, not more or less which is often the case in group living arrangements when you're programming for 6 or 8 people.
- You don't have to ask your neighbors permission to live there. People rent their own homes like you and I would.
- We challenge the notion of special places for people with "special needs". I would say the worst place for someone with challenging behaviors to be is in a group home with seven other people who have strange behaviors.

B. PEOPLE WITH DEVELOPMENTAL DISABILITIES HAVE A NEED, EQUAL TO THAT OF ANY OTHER CITIZEN TO CONTROL THEIR OWN LIVES, TO MANAGE THEIR OWN AFFAIRS, TO MAKE THEIR OWN DECISION, AS MUCH AS POSSIBLE.

We believe that the people we support are the best judges of their own needs and progress. They should not have to prove anything first in order for us to respect their rights and autonomy. Our role is to help them gain more control, confidence and competence with things that are meaningful to them. We can do that by helping people to understand and pursue their own choices and by providing opportunities for people to learn and try new things. It means being there to offer assistance and support when they have problems or make mistakes.

Why is a consumer directed approach a good idea?

- It builds self-esteem and self-confidence that carries over into all parts of a person's life.
- It sends positive messages about the person to other people in his/her life and in the larger community.
- It helps people learn, because when people define their own goals, they take more responsibility for achieving them.
- It helps protect people's legal rights.
- It creates growth-producing challenges and opportunities.
- It produces "surprises" and fresh solutions where past attempts at changing people's behaviors have failed.
- It allows us to assist people who insist on a higher degree of autonomy and will not accept needed help on any other terms.

Translating principles into practice for people who have difficulty understanding or pursuing their own choices.

- Many of the people we support who are labeled "severely handicapped" are very limited in their abilities to know what their choices are or what consequences might result from the choices they make. They are people who rely totally on others to make their decisions and structure their lives. It has been the most challenging to interpret our principles of consumer autonomy for these individuals. Some strategies that have 'worked for us:

  a. Providing opportunities to participate as much as possible in daily routines even when you can't be totally independent.
  b. Using technology and creative adaptations to support independence.
  c. Knowing people well enough so that when they don't communicate in typical ways we can understand their preferences through behaviors.
  d. Providing opportunities for choices and exposing people to a variety of options.

C. PEOPLE WITH DEVELOPMENTAL DISABILITIES HAVE A NEED, EQUAL TO THAT OF ANY OTHER CITIZEN, TO FEEL ACCEPTED WITHIN THE COMMUNITY, VALUED FOR THEIR UNIQUENESS AND CONTRIBUTIONS, AND ABLE TO PARTICIPATE IN INTERACTIONS, ACTIVITIES AND MUTUALLY SUPPORTING RELATIONSHIPS WITH A VARIETY OF PEOPLE IN A VARIETY OF ENVIRONMENTS.

- This principle relates to the importance of achieving a sense of community. We believe it's not enough for people to be physically integrated into the community and to be provided with an array of professional services. We feel our role is to assist people in becoming part of neighborhoods, churches and other community organizations, to develop natural networks of friends and family
- We assist people in using typical community resources rather than those that are segregated or "special". Examples are public transportation, adult education,

home health services and real jobs in real businesses.
- We place a high priority on finding situations where people can contribute and where the focus is on people's capacities rather than deficits or needs.

Key Success Factors

- Small size. Decision to limit size of agency and number of people served.
- High degree of individualization.
- Strong value base.
- High level of accountability to local community. Decision not to expand geographically outside of our county. Community leaders and parents on our Board of Directors, county supervisor is guardian of a person we support.
- Shared values and mission with county and State government. Wisconsin very involved in Medicaid waiver to support individualized services.

Implications for Federal Policy

- Need commitment of funding to make community services an entitlement for all persons with developmental disabilities.
- We need support of Federal policies which prioritize community integration and change the current Medicaid disincentives which promote institutional services and the medical model.
- Federal policy should support local community control and accountability.
- Need to avoid Federal mandates that are too prescriptive and over regulated. We're experiencing the down side of Medicaid funding with the waiver program. We're getting buried in paper.
- Look for opportunities outside of professional services to promote community integration. The national cooperative movement is an example of people working together to build strong communities and citizen empowerment.

Striving for Excellence While Shaped by History

by Jean W. Powers
Administrator, Peppermint Ridge Corona, California

Good Morning, I am Jean Powers, the Administrator of Peppermint Ridge, a spectrum of residential services, located in Corona, California and dating back to a family care home for six boys started in 1959. With me today is John Petrich, who lives in one of our coed homes about four miles away from the main campus of The Ridge.

We want to share some of our experiences with community integration. We do not want to be simply defensive, a posture which is probably inevitable, but we want to contribute some measure of realism. I often wish we were not trapped by our history and by our bricks and mortar, but of course, to a great degree, we have been molded by where we have been and by what we have. On the other hand, our past and our buildings are not all bad.

The Ridge started as a family care home, and we have never forgotten our roots of caring and deep personal involvement. Upon reflection, we see that relationships have proved to be extremely important in the lives of the people we serve. Some peer to peer, resident-staff relationships are 10, 15, 20 and more years old. For instance, John and I have each been part of the Peppermint Ridge community almost 11 years. We have lived together through many experiences, crises and changes.

The people of Peppermint Ridge see The Ridge as a caring, interdependent community, an extended family, a neighborhood within a larger community in which we participate intensely, sometimes with supports and sometimes independently.

Our bricks and mortar, our facilities, are not totally negative either. We have a lovely main campus, built with the aid of PCMR funding in the early 70's and opened in 1975. While The Ridge campus was in the planning stages, it was considered state-of-the-art, because each home is essentially independent, meets safety requirements and is spaciously homey. However, before construction was completed, it was considered passé.

Please allow me to describe the campus briefly so that you can picture the situation out of which our varied programs operate. The main property consists of five acres in a residential neighborhood. On the front 2 1/2 acres are five separate homes, each housing 12 people in single or double bedrooms, and each having its own kitchen, dining area, living room and recreation area. Three of the on-campus homes are licensed separately as ICF/DD-H's (small intermediate care facilities, habilitative), and the other two homes share a community care license with an authorization for specialized services. We have a number of patio areas, a pool, a mini-park and a building that contains offices, a classroom, a central living-dining area, kitchen and laundry. Originally, it was intended that more houses would be built on the back half of the property, but, of course, with the momentous change in the philosophical climate, that has never happened. Now, a large recreation field and a horticulture/nursery operation utilize that space.

The campus blends beautifully in its neighborhood which contains three other clusters of homes — town houses and condominiums — for non-disabled people. (All three of these other clusters use our central living room for their homeowners association meetings.) There is also a retirement complex which only includes non-disabled seniors, because it does not have convalescent facilities. This complex

is brand new and considered to be the ritziest in the area. In other words, Peppermint Ridge is an integral part of a reasonably classy neighborhood.

Incidentally, there is something I want to interject before describing The Ridge's other living arrangements. It is widely recognized that in the United States family style living is no longer the norm for adults in the general population. The majority of adults do not live in primary family arrangements. I dare say that few of us or our friends live in a house with our mothers, our fathers and our siblings. Last year my family's household included four generations with my father, my husband and myself, my daughter, and my grandson living under one roof. Is it not true that, in our society, most adults live with housemates other than their spouses and their children?

Moreover, our main campus serves as a neighborhood, similar to the town house complex next door, within which people have privacy in their own living quarters and freedom to roam in a larger area. This allows our folks much more unrestricted movement and choice of relationships and activities than if they lived in a single group home in some other neighborhoods. The ways of living of these at the Ridge reflect some typical lifestyles which are not currently recognized by the philosophical determiners in the field of developmental disabilities.

I would like to go on with the descriptions of The Ridge's spectrum of living arrangements so that you can see how we decided to expand when it was apparent that we should not add any more residences to the main campus. Peppermint Ridge leases and operates three 6-bed houses scattered in the community. Two of these homes are licensed as community care homes and one is an intermediate care facility for the developmentally disabled-habilitative (ICF/DD-H).

Six years ago, one of these leased houses was a home for two gentlemen, each with profound retardation and a psychotic diagnosis as well. They came to our community directly from a state hospital which was closing its doors to people with developmental disabilities. This living arrangement for the two men provided one direct care staff person per shift with part-time administrative supervision. The men flourished in this situation, but the arrangement proved to be far too expensive for California's community care rate of reimbursement; so the men were moved into a home that had four women living in it and which became an ICF/DD-H. After a short time, one of the men could not be served safely in the six-bed home and was discharged to a larger ICF/DD. The other gentleman continues to live in this off-campus home, but he requires a one-to-one program during the day.

Our friend, John, here now lives in one of the off-campus homes licensed for community care. When he came to Peppermint Ridge eleven years ago, he lived in one of the on- campus homes and later another which seemed more congenial. John's off-campus home is coed with two ladies and three other gentlemen living with him. Currently, this home has shift staff, because the live-in family that guided the home for three years moved away, and we were unable to find anyone suitable who was willing to share this home as a primary residence. Another problem I might mention in conjunction with John's home, as opposed to our on- campus homes, is that Peppermint Ridge finds that expenses for this home and the other off- campus community care home exceed the rate received by about $2,500 per month per home.

Let me share a little of what John has told me about his living arrangement, what I have observed and what I gleaned from reading his records. John was offered the chance to move off-campus to Cypress Point when one of the men that used to live in that household needed to move back to the campus. That gentleman's ability to manage his own behavior had deteriorated in the family atmosphere; he had become very aggressive and expressed a wish to return to his old friends in his previous on-campus home. John was eager to move to Cypress, but his parents, and particularly his mother, were horrified. She literally cried and pleaded that John remain in the relative security of the Ridge campus. Nevertheless, John's whole interdisciplinary team decided that he should take the opportunity which was available. Reading John's old program plans makes it clear that John has benefited from his current living arrangement very much. Just three years ago we were working on reducing his temper tantrums from five times a week to two. Now, it has been six months or a year since he has had a real flare-up. His domestic skills, especially in cooking, have improved tremendously, and because of a running competition with one of his housemates, John has learned to do a fine job of mowing a lawn. That was a task that he always begged to do but quickly got off track and never used to complete. John's parents are still not fully reconciled to his situation, but they see how happy he is and how much more mature he is in many ways.

Besides our licensed homes on and off the main campus, Peppermint Ridge has two vendorized programs in independent living for people who need some training, counseling and crisis intervention, but do not require 24-hour

care and supervision. These programs operate out of a small apartment complex in downtown Corona built for us by two parent couples. The hub apartment complex is typical of others in the area except that the garages have been adapted for meeting/training areas. Additional participants in these programs live in other apartments, duplexes and houses scattered throughout the community.

In Ridgeway, the more basic of the independent living programs, training is offered five days a week in cooking, shopping, cleaning, budgeting, "working the system," social-sexual education, maintaining one's health, enjoying one's leisure, etc. It is likely that a young mother and her baby will soon be admitted to this program.

The V.I.P. (Very Independent People) program is a follow-along service which is tailored individually to the minimum number of hours of training and support services that a participant needs. This program was created, because it was discovered that very few of the Ridgeway participants could survive successfully totally on their own after two years of daily training. Moreover, there were other adults for whom this minimum sort of assistance was crucial. For both these independent living programs, crisis intervention is offered at all times; the participants have local staff friends they can call on whenever necessary. Within these programs, we have had two couples marry, but only one or two individuals have graduated to total independence.

So, you see, The Ridge offers quite a range of options in our community of about 50,000 people. The residential programming we offer is highly individualized even in a home in which twelve people reside. We try to provide the type and the level of programming that a person needs right where he or she lives. Sometimes, however, it must be admitted that the regulatory requirements of the person's living arrangement may be somewhat stifling or that the current level of dependency is too comfortable for all concerned and is fostered unnecessarily.

Peppermint Ridge has long tried to offer some measure of stability and security to the people we serve. Our reluctance to evict someone is only exceeded by their own (and their family's) reluctance to *be* discharged. Nevertheless, people who live at Peppermint Ridge engage in a wide variety of daytime activities which offer a progressive continuum without their needing to move frequently. There are schools, adult education classes, community college programs, workshops, activity centers, supported work, both part-time and full-time jobs as well as senior citizens programs. Moreover, there is a lot of community integration both ways in that, not only do people from the Ridge participate in community activities and utilize community services, individuals and groups from the wider community participate in Ridge activities and utilize Ridge facilities, such as our pool, dining room, classroom and meeting areas. Ridge staff of all ages and interests do not relate just during on-duty hours. Many staff take their Ridge friends home for holidays and other visits. They bring their families and friends for visits, especially when there is an appropriate special event that has been planned by our Resident Council.

Peppermint Ridge has a value system that undergirds everything that we do. (Please see the page following this article "Overall Purpose and Philosophy" which was adopted by our Board of Directors several years ago and which is stressed during each new employee's orientation.) You will note that our first guideline is that every human being is valuable and should be accorded dignity and respect. We believe that wherever people live, among the options The Ridge offers, is *their* home, and we are there to supply whatever supporting services of care and training are required. People who live at the Ridge are not pampered guests nor serfs nor patients nor students; they are fellow members of an extended family, fellow citizens in a common society.

During new employee orientation sessions we also go over two organization charts. One is the usual type which indicates the lines of authority and responsibility, but the other one is called a "Philosophical Orientation Chart." On this one the residents, participants, trainees are placed at the very top, because they are the most important people in the Ridge organization. Just below them are the staff people who work directly with the participants on a daily basis. It is in the relationships between these two top groups of individuals that the real life and work of Peppermint Ridge goes on. All the rest of us are just there to make sure that those relationships go well and fulfill the purposes intended.

I do not want to leave you with the impression that I think Peppermint Ridge provides perfect living arrangements. We recognize many problems. We certainly do not always live up to the ideals we profess. Over the years, we have had some practical problems with our off-campus homes. John's household, called Cypress Point, has had to move three times since 1981 when it was first licensed. One landlord went bankrupt, the next landlord did not like the modifications that were required of us and gave us one month's notice causing us to select an inferior dwelling whose leaky roof drove

us to the current house which seems quite satisfactory. Escalating fire and safety regulations have been expensive and have forced another household to move twice. In establishing a new home with the aid of a HUD loan we have been frustrated by the excessive delays and by the restrictions which forced us to build one twelve-bed home instead of the two six-bed homes we wanted to construct.

Besides all the crises that occur when attempting to serve the needs of vulnerable people 24-hours-a-day, 365-days-a-year there is, for us, the constant problem of being significantly under funded. In the California service delivery system for people with developmental disabilities, residential services are lowest on the totem pole in terms of dollars and esteem. Our host Regional Center is the most penurious in California's system, seeing The Ridge as a vendor from which services should be obtained as inexpensively as possible rather than as a provider of services needing moral and financial support as well as scrutiny and technical advice. Because of this under funding and, thus, the inability to provide the intensive staff ratios or supportive services necessary, we have had to discharge some people who lived there that we were longing to serve properly. To catch a glimpse of the scope of this financial problem, let me interject that it has been continuing for a long time. Rate increases voted by both houses of our legislature were vetoed two years in a row by our governor. In spite of prudent management and constant fund raising from the private sector, Peppermint Ridge has had to place its property up for collateral on a line of credit, and we are having to borrow large sums of money just to keep afloat. Inadequate financial support is our primary problem that leads to many others.

The repressive and regressive system under which we operate penalizes us by reducing our specialized services payments when the people who live at the Ridge make progress. I have already told you that the six-bed off-campus homes lose more money than the on-campus twelve-bed homes, and our independent living skills programs cost $13,000.00 more to operate last year than we were reimbursed.

The biggest problem with being under funded is that the people who reside in the Ridge may not receive the quality and quantity of services they require in the least restrictive setting. The second most serious aspect of the situation is that our staff is underpaid causing some unnecessary turnover and, in my opinion, some exploitation of the people who work the hardest in the system.

On the other hand, because Peppermint Ridge is a non-profit organization without adequate operational support from governmental sources it does exemplify all of the partnerships that this Forum is considering. There is Federal, State, regional and local governmental and agency involvement. Our public-private partnership includes many diverse individuals, groups, corporations, churches, etc. Naturally, families are true partners with us in the service delivery system. Families are often heavily involved in the original placement at The Ridge. All are invited to participate in our Parents' Group and individual program planning meetings. Those who can afford to do so donate regularly to Peppermint Ridge. It takes all the partners we can muster to keep The Ridge alive and thriving.

I am well aware that Peppermint Ridge is not the perfect model of living arrangements with the ultimate in community integration. Because of this and the constant struggle over substandard support, I sometimes get a little paranoid and think that outside forces are trying to eliminate The Ridge and all the hard work, love and voluntary support that have been invested in it. However, when I observe people who are happy and progressing, and think about some of the less desirable living arrangements which might be provided as alternatives, then my determination to do everything in my power to ensure its survival is strengthened.

To finish our presentation I would like to share a story that reveals the character of the Ridge community.

Included in our extended family is a young man, now 26 years old who came to the "old" Ridge when he was 7 going on 8. He had been relinquished at birth and Maintained in a series- of foster homes until that time. He had been confined to a bed or a playpen and, thus, could not walk. Our staff was told that he would not live to adulthood. Jo had a cleft palate (untreated), was hearing impaired, non-verbal, and has an extremely serious lung and heart problem. The Ridge arranged for surgery on his palate, taught him to walk, provided him with a hearing aid for each ear, trained him in sign language and some speech and keeps an oxygen tank at the ready for when he becomes cyanotic. An elderly couple has voluntarily become adoptive grandparents for Jo providing him with many gifts and frequently visiting with him. Staff frequently takes Jo home with them. One staff family took him home so frequently that he was able to complete preparations for his Baptism and First Communion in their church. Jo is one of the most loving and lovable persons I have ever known.

Jo has been living in either A Home or C Home on the campus since it opened in 1975,
but last Friday at our admissions committee

meeting I suggested that we all consider his moving into one of our ICF/DD-H homes on campus, because they will soon have an opening, and that home has people who require a great deal of staff assistance with their challenging behaviors and their intense deficits in self-help skills. Since Jo is so adaptable and adorable, I thought he might provide some relief to the staff in the prospective home. However, later on that day, the Program Specialist in charge of A and C Homes left me the following note which forestalled any movement attempts on my part:

"Dear Jean —

"I want to tell you how I feel about the suggested move for Jo now that I have had a chance to think about it.

"First, let me defend myself. I know when I say this move would not be in Jo's best interest,
I also know it would not be in my best interest, because I *love* Jo! But I've let other clients go knowing that the move would be best for them. In Jo's case, I don't believe this is true.

"I have to refer to A and C Homes as one when I speak of Jo, because even before I came, he moved between the two. He thinks of these as home, because for him *it is* his only *real* home. We, the staff and clients, are his family. Norma, Lee Ann, June, Mary and myself have a combined 50 years with him! Even if we discussed a possible move for Danny, our other parentless client, I could see the advantages of growth and development for Danny. But it's not in Jo's future to live the long life we hope for Danny. I and the other staff have helped and loved Jo through some very low points in his life. We also want to love and help him when it comes to death. I hope you don't think
I am being dramatic, but the thought of him being somewhere else when this happens is unbearable. I realize when his health regresses, he may have to leave the facility. But until that happens, I think he would want to be with "his family."

"I realize that each on and off campus home has loving and committed staff people. I know they would love Jo. And maybe I am asking this as much for myself and my staff as for Jo. But *Jo* is a special case.

"Even though we don't discuss it often, we know that he won't live as long as our other clients. His doctor reminds us each time we visit. Jo is so happy with his loved ones in A and C Homes. Each morning and evening he visits A Home to say "Hi" to his family. When (if) he moves to A it will be as natural for him as changing bedrooms in the same home, because they are family, too.

"Thank you for being willing to listen —.
Gale"

Thank YOU, too, for listening.

Peppermint Ridge
Overall Purpose and Philosophy

The primary purpose of Peppermint Ridge is to provide care and training — lovingly, expertly and with respect — to each and every special person in our charge.

The entire Peppermint Ridge organization is guided by an under girding philosophy:

A. All human beings are valuable and should be accorded dignity and respect.

B. The life styles of persons with special developmental needs should be as normal as possible, and they should have maximum control over their own lives with the right to pursue their individual preferences and desires, and the satisfaction of their needs.

C. Since persons having developmental disabilities are especially vulnerable, care must be taken to protect their rights, health, safety and welfare.

D. Every person has a capacity for development and should be encouraged to achieve his or her highest potential and greatest degree of independence and be allowed to experience the consequences of success or failure.

E. Since a sense of belonging is vital to a person's well being, mutually enhancing bonds are nurtured between those who live and work in each Ridge home.

F. Functional life skills which are critical to one's growth and survival should be taught gently and persistently.

G. All people should have opportunities to experience faith, fellowship and service.

H. People develop best with the least amount of restriction and the greatest possible beauty, comfort, happiness, love and security.

Employment Panel

MODERATOR: WILLIAM E. PITTMAN, M.A., M.ED.
PANELISTS: DONNA D. DOERER
KENNETH J. SHAW
AARON J. PRERO, PH.D.
PAUL HIPPOLITUS

Public / Private Partnership Working Together To Provide Employment

by Donna D. Doerer
Former Regional Director, ARC/US
National Employment and Training Program
Seattle, Washington

The topic of my presentation "Public/private partnership working together to provide employment" could also be subtitled "How to leverage your resources" or even "How to stretch the dollars". In addressing the critical needs facing both service providers and consumers today it is inherent that private enterprise and government be members of the same team.

I would like to share my perspectives with you today utilizing the following format. First I will familiarize you with my own background so that you may have a better understanding of my viewpoint. I will define the term "partnership" and the concepts which surround a "working partnership". Then I will identify the roles each partner assumes with the major categories of public and private including their strengths and needs.

Through projects and proposals I will illustrate examples of cost-effective and innovative methods of cooperative community efforts which focus on employment of people who are mentally retarded. Finally I will offer recommendations for increased facilitation of positive relationships with private enterprise.

As I defined "partnership" I viewed this as the joining together of two or more forces for a common goal. I developed my approach towards the public/private sector coordination based on these premises for effective partnership:

1. Understanding of the needs and forces which drive each player;
2. Partners must be able to work together positively maintaining a relationship which avoids unnecessary conflicts; and
3. The results should be respectful and oriented towards mutual benefits.

An example of private enterprise utilizing partnership is the mutual marketing campaign advertising "Fly United Airlines and use your American Express Card". They both have an investment in each other's identity and products.

I bring to you today the perspective and visions of an individual who has been in the field of mental retardation for twenty years. My background has been both in direct service as a teacher, counselor, job developer, and trainer and more recently as an administrator of employment and training programs for youth and adults with special needs.

The ideas which I will present today are an outgrowth of my past five years with the Association for Retarded Citizens (ARC) National Employment and Training Program (formerly known as ARC-OJT Project). The evolution of the OJT Project into the National Employment and Training Program has paralleled the increase in supportive employment services for people who are mentally retarded.

The ARC received a grant from the United States Department of Labor in 1966 initially to establish on-the-job training opportunities for people whose disability was mental retardation. This grant focused on four states as a demonstration of the potential of these individuals.

In the period when advocacy was addressing the extensive needs and concerns of the many people still in institutions, the ARC-OJT Project emphasized community integration in the workplace. The project success is reflected in its continued financial sponsorship from the DOL today as well as its availability in all fifty states.

Unfortunately national funding has not kept pace with the market for on-the-job training and additional support services for this population. With the Education for All Handicapped Act, Supported Work Initiatives, and emphasis on returning individuals to the community who have been institutionalized there is a growing gap between needs and resources.

The ARC's national program established regional offices throughout the United States. Today there are ten regional offices who serve surrounding States. Each regional director serves as a link to employment and training opportunities within her/his region offering on-the- job training funding to employers who hire and train employees who are mentally retarded.

This concept has been popular and effective particularly today in light of the increasing entry-level labor market shortage. Regional directors have enhanced the initial DOL funding and services by developing local and state job development and placement programs. Due to the positive track record during the last twenty years demonstrating that people who are mentally retarded can be long-term, competent, and productive workers Private Industry Councils in many areas of the United States contracted with ARC to provide specialized employment and training services.

My personal inclination towards the combination of resources has resulted from my involvement with the challenge of putting people to work. We knew we had a good "product" or "service" based on our history of over 70% of our individuals satisfactorily completing the initial training and continuing employment. But the downside was the lack of sufficient existing resources through the normal social service channels.

After initially conducting an analysis of our goals, potential strengths and limitations it was obvious that we could offer additional employment opportunities in competitive, community- based positions if we could find the monies to sponsor these activities. I assessed the following to be the elements in Private and public sectors identities:

THE PRIVATE SECTOR:	Non-profits	Human services Services clubs
	For-profit	
	Community resources	
	Foundations	
	Individual	
	Organizational	Associations
	Business	Corporate Small business
THE PUBLIC SECTOR:	Government	Federal, State, County, Municipal
	Public Schools	K-12 system Community colleges Universities

After recognizing the number and identities of our associates who were also involved in economic development and/or employment, I evaluated what each could bring to a partnership.

PRIVATE SECTOR	**RESOURCES**	**REQUIREMENTS**
SERVE PROVIDERS:	Creativity Training techniques Workforce Proven track record	Financial Technical expertise Labor market Opportunities Training techniques
BUSINESS	Job specific knowledge Jobs Contacts Profit basis	Personnel Opportunities Financial incentives

PUBLIC SECTOR	RESOURCES	REQUIREMENTS
FOUNDATIONS	Initial funding Influence for change	Projects/causes Opportunities
GOVERNMENT	Legislation Initiatives Employment and training programs Employer incentives Rehabilitation and vocational programs	Implementation Outcomes Employment Utilization Employment and reduction in "disability" maintenance" expenditures
PUBLIC SCHOOLS	Training techniques Vocational programs Vocational funding	Successful applications Same Opportunities

It became obvious that both private and public sectors could gain from merging resources which would as a result provide mutual benefits. From there I developed some possible combinations and scenarios of how this linkage could be applied.

A basic example of joining resources across both private and public might have a private, non-profit organization (ARC, for example) which contracts with the local Private Industry Council. ARC could provide services through these federal Job Training Partnership Act (JTPA) dollars which would enable private business to hire and train workers who are mentally retarded.

Through this approach all three entities — ARC, government, and business — would be bringing their assets to the relationship which would result in a win-win situation. To take this illustration to the next level we could involve the schools and vocational rehabilitation. While both are considered public they do not always interface as one serves primarily youth and the other more often adults.

In a more involved partnership the public school, in its Individual Education Planning, involves the Vocational Rehabilitation counselor. The teacher, counselor, consumer, and parent focus on work experience in the community as a goal for the coming year. If the student becomes a client of Vocational Rehabilitation (s)he can receive a detailed vocational assessment as well as needed medical evaluations.

The teacher can then program for the activity which would be in the best interests of the student. With the school district approval and backing the teacher could propose to start a community-based vocational program. Civic groups such as Rotary, Lions, and Civitan often sponsor creative youth skills-enhancement programs such as this. With grant funding the schools could hire a job-coach to train the student to ride the bus to and from work, learn appropriate work-related socialization, and acquire entry-level job skills.

There again the employer would be an obvious contributor as well as the beneficiary of the school's specialized training approaches and follow-along. The student would be connected to both the school and Vocational Rehabilitation effecting enhanced options both now and after graduation.

In a final illustration which comes full-circle to the private sector initiation there is a complex utilization of a consortium of efforts. In this situation a company (such as Marriott) assesses its workforce needs and identifies a significant deficit in the area of sufficient entry-level employees. Fewer applications are being received and there is a greater turnover.

As this company is aware of employer incentives such as OJT and TJTC, and has hired capable workers referred by the local sheltered workshop previously, the company contacts the workshop. The company states that there is sufficient workload to hire in the range of five to seven individuals in a single location. The workshop proposes to establish an enclave and to provide a supervisor from their own staff.

The concept is acceptable to both parties but the administrative expenditures for staffing, payroll, and ongoing support are beyond the current budget of the workshop. The workshop negotiates with the county board for developmental disabilities to allocate funding to this community-based program.

After extensive planning and several months of operation the company finds that the

enclave workers are steadily improving productivity to the point where, on an individual basis, they can become employees of the company. To assist the workers in maintenance of skills and to provide ongoing technical assistance to the company the workshop proposes to the Developmental Disabilities Planning Council a research project which would fund "follow- along" for each worker.

The DDPC provides advocacy and oversight to each worker through federal monies. The company has continued to be an active proponent of hiring people with disabilities through the workshop as well as other private non-profit organizations. The company has given an endorsement at Chamber of Commerce seminars, merchant association meetings, and to colleagues. In addition the company prints the brochures and business cards for the workshop.

This illustration ends here. Private enterprise accessing private non-profit workforce and State and Federal training resources to meet their entry-level personnel requirements. In actuality there are often many partners and creative mixes of resources in each situation.

In Seattle, operational base of ARC's National Employment and Training Program Northwest regional office, the partnership must include a realization of the natural resources based economy and the geography in this region. Alaska, Idaho, Montana, Oregon, and Washington are currently served by this office. There is often a very different viewpoint on public sector involvement when there are more miles between people.

Seattle is the largest metropolitan area in the region with approximately a million and a half people within the city and surrounding county. In 1983, the supported employment concept was already in action. The University of Washington, two community colleges, and private non-profit agencies who were vendors through the King County Board of Developmental Disabilities were providing placement and training to individuals who were previously considered unemployable.

ARC approached the then newly established Private Industry Council of Seattle-King County to propose funding to offer specialized on-the- job training for participants who were mentally retarded and un-served by other JTPA organizations. The PIC awarded the smallest contract of $8,000 to ARC to provide OJT reimbursements to employers.

Since 1983, ARC has continued to contract, on a performance basis, with the Seattle-King County PIC. One of the most recent contracts at the level of $90,000 enabled ARC to place 85 individuals into competitive employment within a single year. ARC partners with other community organizations such as Vocational Rehabilitation, Developmental Disabilities, University of Washington, workshops, parent and consumer groups to develop jobs, provide job and task analyses, transportation and on-the-job training.

At this time ARC in the Seattle area is expanding to join with Vocational Rehabilitation and Marriott in its next venture. ARC will contract with Vocational Rehabilitation to provide referrals, screening, interviewing, coordination with Marriott, client support, and skills training. Marriott will sub-contract with ARC to develop and implement a customized training program. The end goal for all parties will be employment.

In making recommendations for developing this partnership to the fullest extent I would urge that the public sector and private nonprofit service providers take the first step. We must be realistic in our vision, plan for appropriate timelines, and take the viewpoint of the private sector. We cannot base our approach from the expectation that each partner is driven by the same needs, but that there are common goals we share.

We must establish our credibility, assess our service for its effectiveness, and restructure our models to merge with the profile of industry. We should develop our sponsors within business and access their contacts through introductions and references. We must speak to business in their language.

Partnerships should be creative and not limited to one source. I subscribe to the viewpoint of stability as based on planned diversity. We will need to develop a game plan that incorporates many options.

The role of the government, in particular the Federal level, must be one of facilitator. The legislation must enable people with handicaps and must respect the unique needs of people with disabilities as a sizable minority group.

The Job Training Partnership Act has great potential to serve people with mental retardation. As an employment and training program focusing on individuals who are unemployed and economically disadvantaged this could meet a critical need for vocational resource for this population. There needs to be consideration, however, of the fact that people with handicaps are not mandated as a targeted population under this act.

In many local areas it is difficult, if not impossible, for people with significant learning disabilities to enter JTPA programs. Frequently the Private Industry Councils set goals of over $5.00 per hour and 32 hours per week as the standard for each participant. This is not realistic for people experiencing characteristics of mental retardation who are entering the job market for the first time.

In addition, there should be a demonstration of strong support from all levels of government in regards to promoting employment in the public sector. This is still very limited in actual practice. I would urge extensive publicity and endorsement as well as incentives to government agencies hiring individuals who are developmentally disabled.

Federal monies should be focused on practical applications including increasing financial incentives for employers and demonstration models that emphasize actual placement results, not research into feasibility. If the private sector is to be a true partner it will need to be involved in all phases of planning — from local operations to federal policy development.

I will leave you with a phrase which the Association for Retarded Citizens utilizes in our approach to the private sector, from "mom and pop" establishments to offices at the corporate level:

"It's Not Kindness . . . It's Good Business"

Supported Employment Within the Competitive Workplace

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I. Supported Employment and the Rehabilitation Facility:

Supported employment has recently become identified as a series of program models specifically designed for severely disabled individuals. The intent of supported employment programs is not different from the program traditionally provided within rehabilitation facilities. Both facility-based and supported employment programs intend:

- To facilitate the placement of a person with a disability into remunerative employment.
- To provide training in vocational skills appropriate to the local community labor market.
- To provide identified follow-up services to maintain the individual in the job.

The location of the services tends to be the major determination of the differences between the two programs. Facility-based programs tend to be a "place-train" model, which requires the identification of a community job, matching the individual to the job and providing the necessary training and support services at the employer site. Each of the models requires: an established positive relationship with business and industry, to facilitate placements; an understanding of the training needs of the disabled; the ability to identify and respond to service needs of individuals and to access auxiliary services for those served. These areas of expertise presently exist in rehabilitation facilities.

Consequently, it is logical that rehabilitation facilities view supported employment as an extension of existing services and an alternative means of accomplishing their goals. Since supported employment programs (most of the time) offer funding, not previously available, to work with an individual at an employer site, facilities have taken advantage of the opportunity to expand services to existing populations, to facilitate movement into community employment as well as to new populations for whom traditional programs have not been available.

Successful initiation of supported employment program models requires a strong partnership between the facility, funding agencies, individuals served, significant others in the client's environment, and business and industry.

II. Supported Employment: Purposes and Models

Supported employment is characterized primarily by the location in which the work occurs. Generally, in order for a program to meet the requirements of a supported employment program, the work must take place in community settings of business, government or industry. Supported employment programs require a cooperative relationship between the rehabilitation facility providing the supported services and the community-based employer, who must be attuned to the needs of people with disabilities and committed to making appropriate adaptation and adjustments to accommodate the principles of supported employment models.

The overall purpose of the supported employment models is to provide employment opportunities for people with disabilities. In conjunction with this, individual program objectives can be to upgrade the training opportunities for individuals and to expand the array of jobs that might be available. Additionally, objectives can include maintaining the individual's existing work skills and applying them in a real work environment.

The core elements of supported employment include providing real work in a community-based site and conducting training in a specific occupation which is offered by the community-based employer. Support services are also integral to the successful implementation of supported employment program models. The support service can take the form of counseling, assisting with transportation, money management, behavior modification, skills training, or any supportive activity required to assist a person in retaining a job.

ADVANTAGES

- ***Integration:*** The primary intent of a supported employment program is to enable people with disabilities to integrate fully with non-disabled counterparts in the workplace. This process helps the employer, as well as the community-based employees, appreciate the ability of people with disabilities to function in a real work environment and perform jobs that, in the past, may not have been considered appropriate for a special-needs population.
- ***Real Work:*** The use of community-based employment programs has the advantage of offering the person with disabilities an opportunity to participate in a real work environment to work on jobs that actually exist in the community and skills that are readily transferred to other community-based employers.
- ***Real Wages:*** In supported employment models, the community-based employer often will focus on paying the industry wage for work being performed even though the disabled person may not be performing at a competitive production level. Even if a commensurate wage payment system is used as part of the program, the individual has the opportunity to see how his/her wage is established in relation to that of non-disabled counterparts.
- ***Focus on Outcomes:*** Community-based programs have the advantage of helping to focus the service provider on the primary goal: ensuring the client will move toward full integration and permanent employment. Client participation in the community-based job site ensures that the service provider keeps the overall goal of unsubsidized employment as the primary objective, and helps to facilitate the reduction of service and support activities to the individual on a structured basis.
- ***Facilitates Movement:*** The opportunity for individuals to participate in real work in the community and to be held accountable for working at industry standards facilitates the acquisition of skills which assist the individual's efforts to obtain employment outside the training site. Since the procedures used for the training are generally transferable to other employers doing the same kind of work, it does provide an opportunity for the client to expand opportunities for employment with more than one employer.
- ***Expanded Job Market:*** Using community- based employers provides areas of employment not previously available to facility-based trainees. When employment opportunities are provided in a community-based rehabilitation facility, the opportunities for employment are limited to those kinds of jobs available within the facility. By using the community industry sites, the options for employment are as varied as the array of jobs within a given community.

Considerations

- ***Establishing Role:*** In the development of any supported employment model, it is particularly important that the facility establish well-defined relationships with the businesses where the supported employment will occur. Written agreements covering all the aspects of the business relationship established between the facility and the business are critical to the success of the program. Additionally, the facility will have to be assertive in demonstrating concern for the safety of persons with disabilities being served in community- based sites. The facility needs to pay particular attention to the risks and liabilities to which the facility and the community-based employer may be exposed. Insurance requirements should be explored prior to the implementation of supported employment programming.
- ***Communication:*** Since the supported employment program usually will occur away from the facility's normal place of business, good communication must exist between the employer and the service provider, and between the management of the agency and its staff working at the community-based site. Community-based service delivery staff will be responsible for establishing appropriate program objectives for the individuals served, as well as completing all required reports.
- ***Client Concerns:*** Adequate supervision must be provided to ensure that the training and job needs of the individual are met. Support activities necessary to ensure that the individual will have the best opportunity for success at the job site must be provided. Additionally, concerns for full integration at the work site of the person with a disability must be addressed. At no time should the

difference between the workers of the establishment and the clients of the supported employment model be exaggerated. Care must be given to ensure that the role of the client is clearly established before the client is placed at the site. The definition of the role of the client as either an employee of the community business or as a client of the facility must be clearly delineated. Additionally, issues related to accessibility, not only to the job site but to individual jobs and upward mobility, would be reviewed prior to placement of individuals at the sites.

MODEL FOR SUPPORTED EMPLOYMENT

The following are the generally accepted models of supported employment in the rehabilitation community: work stations in industry/enclaves; mobile crew; and job coach or supported jobs.

The bench work model of supported employment has, by design, been omitted from this list because of the inherent lack of integration.

Characteristics Common to All Models

- ***Real Work/Real Pay:*** Each of the supported employment models focuses on the idea that the individuals will be engaged in real work and will be receiving full pay for the work performed. The principles of commensurate wage payment are paramount in each of the models. It is fully expected that each individual engaged in the production of goods or services will be paid at least according to his/her ability to produce.
- ***Community Integrated:*** Each of the models assumes that the individual will be placed in a community-based business or industry around or near non-disabled persons performing essentially the same type of work Each of the models, however, differs in terms of the level of integration offered.
- ***Accrual of Benefits:*** It is assumed that persons engaged in supported employment models will obtain the same benefits as non- disabled persons doing the same type of work. The benefits here are not specifically financial, but rather sociological and psychological. People working in community-based industries will have the sense that they are contributing members of the workplace and society much like their non-disabled counterparts.
- ***Ongoing Support:*** Each of the supported employment models assumes that supportive services will be offered on an as-needed basis to the person engaged in work at a community-based site. Although the level of support and type of support services offered will vary according to the model and the individual being served within the supported employment model, each client will have some form of rehabilitation or support plan.
- ***Employment Model versus Preparation Model:*** Supported employment programs generally assume that the individual will be placed in a job and then receive the services necessary to maintain that job or to upgrade skills for other jobs. This is in opposition to the traditional method of service delivery within a rehabilitation facility where people are trained how to be workers, with the development of generic skills to be applied to any work situation. It is felt by some that the specific support services given in this model are more vital and long-lasting than the training of job skills that may generalize to multiple types of employment.

Choice of Model

- ***Knowledge of Local Job Market:*** Before establishing any particular supported employment model, it is imperative that the facility become knowledgeable about the availability of employment opportunities within its local community. The establishment of the various supported employment models is dependent on the number, type and accessibility of job openings within the community and is affected by the employers' perceptions of people with disabilities and their ability to perform the work within the business and industry community.
- ***Needs of the Individuals Served:*** Before establishing a particular supported employment model, the service provider or facility must understand the characteristics and needs of individuals referred to the agency. The various types of needs, including the amount of supervision required, types of training needed, transportation accessibility, etc., all have an impact on the type of model to be chosen for community-based programming.
- ***Strengths of the Service Provider:*** The type of supported employment model that could be established is largely dependent upon the knowledge, skills and resources of the service provider. If a facility's staff members do not have any particular knowledge in the type of work offered by the employer, it would be difficult for them to establish certain types of employment models where they would be responsible for training as well as producing goods and services at a community- based site.

Work Stations in Industry/Enclaves

Definition: The enclave model features a group of individuals, trained and supervised, who work among non-disabled workers in a community-based work site. The community-based employer provides the work, and the rehabilitation facility generally provides the training and support services. The enclave model is the most common model currently in use by rehabilitation facilities.

Characteristics

- ***Integrated Environment:*** This model integrates individuals with non-disabled, coworkers at the community-based work site. Although the enclave workers may be responsible for a portion of an existing job within the industry, they are working in the same geographic location as the host industry's workers and have access to all the common facilities.
- ***Specially Trained Supervisors:*** The enclave model requires the training of the supervisors in the work to be performed as well as the rehabilitation support services to be offered to the individuals at the work site. The advantage of having the supervisors trained in the work is that it expands their field of expertise to ensure the client will be able to gain the skills necessary to perform the work appropriately.
- ***Pay:*** Since the work will be performed at the community-based site, the client will have the opportunity to be paid on a level commensurate with his or her non-disabled counterpart for essentially the same type, quantity and quality of work. The regulations of the Federal Department of Labor will have a positive impact by ensuring that the pay rate is based on the wage being paid to the non-disabled counterpart at that work site.
- ***Little Downtime:*** Since the work will be coordinated and provided by the community-based employer, the likelihood of having insufficient work to keep the work force busy will be minimized, if not eliminated. Since most community-based employers have sufficient work to maintain their existing work force, and the enclave model simply extracts some work out of the existing work flow, it is assumed that clients will be able to work on a continuous basis.
- ***Access to Company Benefits:*** In using the enclave model, the individuals engaged in work at the community-based business often will have access to the financial and social benefits provided to the regular work force. Opportunities to participate in social functions, to take advantage of medical programs, etc., will be enhanced by using this model.

  Continuous Supervision: Since the rehabilitation facility and the community-based employer probably will have staff assigned to monitoring the enclave program, supervisors will be available for both training and support services on a continuous basis.
- ***Accommodates Severe Disabilities:*** Again, since a combination of supervisors generally will be available, the opportunities for more severely disabled people to work is enhanced. Industry supervisors as well as facility staff, by combining their skills to design appropriate accommodations, can share responsibilities in facilitating the integration of the individual clients into the work force.

Constraints

- ***Skills Required for Supervisors:*** Since the supervisor of the enclave model probably also will be the rehabilitation specialist, a special combination of skills is required on the part of the staff. Staff members have to be skilled in acquiring and teaching job-related tasks, and must apply appropriate behavioral and supportive activities to assist clients in making the adjustment to work an effective one.
- ***Lack of Tolerance of Behavior:*** Since the enclave will integrate the client into the work force, it may be that certain types of client behavior will not be acceptable to the host company. Certain types of behavior may be found to be offensive or intolerable on the part of other workers in the environment and, thereby, reduce the opportunities for employment of some individuals whose behaviors have not been appropriately normalized to function in a community-based setting. This is especially true if there are only one or two individuals out of a group who have inappropriate behaviors and if supervision is insufficient to give the personal attention necessary to ameliorate the identified problems.
- ***Locating Host Companies:*** Locating host companies is a major marketing function, and an existing business often already lacks appropriate work space, so it may be difficult to find employees who are willing to participate in this model.

Mobile Crews

Definitions: The agency provides work opportunities by obtaining service contracts in its community and provides the support services and training necessary within community- based sites.

Characteristics

- ***Van is Office:*** In the mobile crew model, the agency generally purchases a van to take the mobile crew to its various employment locations. In essence, the van becomes the facility's main office for conducting rehabilitation services, as well as offering transportation to employment sites.
- ***Service Jobs:*** For the most part, the mobile crew concept lends itself to the establishment and offering of jobs in the service industry. These most often include janitorial and grounds maintenance types of occupations.
- ***Frequently in Rural Areas:*** The mobile crew model has been most often used in rural areas where centralized employment opportunities do not exist for people with disabilities. Since the facility uses a van as part of its employment program, the transportation problems that are generally associated with providing employment in rural communities are avoided.
- ***Continuous Supervision:*** Like the enclave model, the mobile crew model offers an opportunity for continuous supervision of severely disabled individuals. Consequently, people with severe disabilities have the opportunity to participate in employment with structured, ongoing and intensive supervision coupled with support services.
- ***One Supervisor Per Crew:*** In this model, one supervisor works continuously with the same crew, thereby offering continuity of services and supervision to the clients engaged in the work setting. Consequently, if more than one crew is out doing community-based work, then the facility will have to have more than one supervisor and, generally, more than one vehicle for transporting workers.
- ***Multi-talented Managers:*** This supported employment program model, like the enclave model, requires a multi-talented supervisor or manager. Essentially, the supervisor will be the coordinator of the rehabilitation services, as well as the trainer for the job and the supervisor to ensure that quality work is being performed. Unfortunately, it is sometimes difficult to find a person with all the skills necessary to provide the full array of services and support to a crew of disabled individuals in the community-based sites.

Constraints

- ***High Start-Up Costs:*** Generally, this type of work program requires intensive capital investment in items such as a van for providing transportation, as well as initial equipment and materials to do the work. Equipment may include things like buffing machines, floor scrubbers, cleaning supplies, cleaning carts, garden tools, etc.
- ***Opportunities for Interaction:*** People involved in mobile crew occupations often are working in community-based sites when none of the normal work force is present. Consequently, the opportunity for interaction with non-disabled counterparts is severely limited.
- ***Acceptance of Behaviors:*** When the mobile crew is involved in work in or around other workers in a community-based work environment, there is a reduction in the tolerance of deviant behavior. If the mobile crew is doing work when no other workers are present, then there is an increased ability to accept deviant behavior on the part of the work crew.

Job Coach or Supported Jobs

Definition: The supported job model places people in community-based employment with one-on-one training, supervision and auxiliary support being offered and provided by the rehabilitation facility. The community-based employer provides the work and the agency provides the job coach to assist in the acquisition of skills and appropriate behaviors at the job site.

Characteristics

- ***Service Businesses:*** Generally, the supported jobs occur in service businesses, since high turnover is an inherent characteristic of these occupations in most communities. It is not unusual, however, for agencies to find industry-type occupations that are willing to accept both the disabled worker and the job coach.
- ***Frequently Part-time:*** Unfortunately, many of the service-type occupations are offered only on a part-time basis, even to the non- disabled employee within this industry. Consequently, clients may only have the opportunity to learn and demonstrate appropriate work skills on a very limited or short-term basis, which tends to extend the program time necessary for worker competency to be developed.
- ***Does Not Require Competitive Productivity:*** Especially at the beginning of a work program and with the available job coach at the employment site, the client can learn, at his or her own rate, how to perform the job and to increase his/her productivity level to a competitive standard. The job coach being available at the site offers the opportunity to ensure that the work is done at the industry's expected quantity and quality levels without putting undue expectations or pressures on

the individual until appropriate training and opportunity for practice has been given.

- ***Can Accommodate "Severely Handicapped":*** Since an individual job coach is available at each site for each individual, this model can accommodate people with more severe disabilities. The job coach must have strong skills in behavior modification and management.
- ***Support Fades Over Time: It*** is the intent of the supported job or job coach model that the job coach eventually fade away from the client and allow him/her to become productive on his/her own. Again, this requires strong training and behavioral management skills on the part of the job coach to ensure that each step of job training is fully understood and able to be performed by the individual client.
- ***Focus on Individual:*** The job coach model gives specific and unique attention to each individual engaged in the community-based program. Consequently, an individual with many difficulties in adjusting to a competitive work environment will have access to the full array of support services necessary to facilitate the transition to the work environment.

Constraints

- ***Training Difficulties:*** A job coach often will be responsible for providing job coaching services at multiple locations or in different industries. Consequently, the job coach will have to learn the individual tasks, break these down into appropriate component parts of instruction to the disabled population receiving the training, and then teach the skills in an appropriate manner to the individual client. This requires a job coach with a broad array of skills, able to adjust to various types of occupations, and able to do appropriate training in the various occupations. Since the job coach model will exist in, and be totally integrated into, a community-based employment work area, it is expected that the client will bring with him/her a basic set of social behaviors acceptable to the work environment. Having a job coach on the premises facilitates the teaching of appropriate social skills, but employers often will reserve the right to reject individuals from the work situation if it is determined that their behavior is inappropriate for the work situation or is offensive to other workers.
- ***Level of Supervision:*** In the job coach model, supervision and training must be one-on-one. Consequently, the availability of resources to support one job coach per client over an extended period of time is often restricted.

III. Supported Employment Considerations

Although it is generally accepted in the rehabilitation community that supported employment program models are the wave of the future, several considerations must be taken into account to ensure that this program model has long-term value and to ensure that there is no threat to needed existing service programs or those clients engaged in programs. Following are some considerations that need to be taken into account.

COST

The rehabilitation facility will incur additional costs associated with the development of community-based or supported employment models. The additional costs will include startups for work or labor which will include wages and benefits. If the facility is to maintain the clients on payroll, a second area of consideration is the insurance liabilities that rehabilitation facilities may be incurring as a result of having workers at community-based sites. Rehabilitation facilities are strongly encouraged to check with their insurance carriers to ensure that there will be appropriate insurance coverage in the event of product malfunctioning, damage to goods, etc. There is the additional cost associated with supervision, since many of the staff-to-client ratios are smaller in community-based sites than in traditional, facility-based rehabilitation programs There is also the cost associated with the management of community-based programs, since it is managing over distance. Consideration must be given to issues such as who provides supplies and equipment, transportation that might be necessary either for materials or personnel, and the administrative costs of managing multiple sites.

RESPONSIBILITIES

In a supported employment model, the community-based company generally provides the:

- Space;
- Work and materials;
- Supplies and equipment; and
- Payment for work performed.

The agency provides:

- A guaranteed number of workers to complete the work;
- Appropriate supervision to ensure that both quality and quantity standards are met;

- Training of the clients engaged in the work;
- Pay administration;
- Benefits, compensation and insurance;
- Management of personnel functions.

ADVANTAGES TO THE CLIENT

The community-based program models have many advantages to the person with disabilities engaged in community-based work. Among these is the fact that the client is in situations which put competitive expectations upon him or her. The competitive expectations are not only the requirement of the quantity and quality of work, but the social, communication, and recreational expectations that are normally part of a non-handicapped work environment.

It is also assumed that the work area will be "state of the art" for the type of work to be performed. This definitely has the advantage over traditional facility-based programs which may not be doing machine-assisted work as opposed to manual or hand labor.

It is assumed that there will be a higher placement rate out of a community-based program since individuals will be trained in the work the way industry does it, and industry will have an opportunity to observe individual clients doing work at an acceptable level.

GETTING STARTED

In order to initiate the process, it is very important that a rehabilitation facility involve all persons affected by the program and administrative changes necessary to implement community-based programming. This will include the administration, boards of directors and staff providing existing services. It is likely that the initiation of a community-based program will have an impact on the number of clients served by a rehabilitation facility in existing service programs.

Additionally, the agency must be prepared to make an initial investment either in supplies or equipment and, in many cases, the initial wages to be paid before reimbursement occurs. The final consideration in this area would be to identify appropriate industries that would be receptive to the initiation of community-based programming.

IDENTIFYING INDUSTRIES

Following is a list of factors to consider in identifying industries likely to be receptive to community-based programs:

- Employers who have high turnover and/or absenteeism in certain classifications.
- Under-utilization of skilled workers on routine tasks. (In some instances, community-based employers have skilled laborers doing unskilled jobs as part of their normal functions. If those industries can be identified, the client population often can be used to do the unskilled portion of the labor.)
- Companies which have low productivity due to boredom and/or vandalism. In this case, you would be looking for industries which have repetitive types of tasks and are unable to find appropriate types of workers.
- Companies that have routine overtime pay. This information can be obtained from the chamber of commerce or from the state employment agency. It would be to employers' advantage to add workers managed by a rehabilitation facility to take care of excessive workloads and to manage the payroll personnel functions for the additional manpower.
- Companies that use expensive, temporary manpower contracts. This would include employers who generally call upon the temporary manpower agencies to meet the requirements of their labor force.
- Companies seeking to show good intent for affirmative action.
- Companies considering entering a new area or expanding their existing operations.

ADVANTAGES TO THE COMMUNITY-BASED EMPLOYER

Many advantages can be marketed to the community-based employer to solicit their co-operation in developing supported employment models.

- **Advantages Over Subcontracting**
  The company will have greater product control in that they will be able to monitor the quality and quantity standards being applied by the rehabilitation facility. Additionally, there will be faster turnaround of the work since the company will have access to completed materials without having to provide transportation. The community-based company will also be saved the cost of transportation or shipping from the rehabilitation facility to the community-based site. The community-based concern should also have a lower bid rate from the rehabilitation facility since they will not be paying for the overhead charges normally associated with contract bidding. Finally, the community- based concern will have a personnel selection pool from which to draw competent and trained workers for openings that exist in their company.
- **Advantages Over Regular Hiring**
  The community-based concern will be given the advantage of having a dependable work

force for the completion of the work since the rehabilitation facility will assume responsibility for meeting quality and quantity standards. There also will be the advantage of having extra supervision, provided by the rehabilitation facility, at the community-based site to assist in managing the total work flow within the industry site. The community-based concern also will not be responsible for paying fringe benefit costs or additional insurance for clients.

Downtime costs for the community-based concern will also be limited since the rehabilitation facility will be responsible for the clients' work scheduling. Consequently, if work ceases to exist, the rehabilitation facility will have the responsibility for finding an alternative activity for the client population. Finally, the community-based concern will have the advantage of reducing its hiring and training costs, which are generally substantial. Since the rehabilitation facility will be selecting and training new employees, it will be bearing all the front-end costs of recruitment selection and of training.

PLACEMENT CONSIDERATIONS

Rehabilitation facilities, prior to engaging in an agreement to provide community-based services, should take the following criteria into consideration:

1. Is the company easy to reach by public transportation?
2. Are facilities accessible?
3. How well is the industrial plant kept up?
4. Do the client workers learn marketable skills?
5. Will clients follow the same work schedule routine as the industry site workers?
6. Do clients work in the same area and use the same facilities?
7. Do clients comprise only a small percentage of the total?
8. What is the common company image?

DEVELOPING CONTACTS

It is important that the rehabilitation facility, in starting a supported employment model, develop and write contracts with the community-based concern to ensure protection for the facility, the industry and the client. The following are parts of a written contract that should be developed:

- **Services**
  The agency, along with the community industry, should define what quality and quantity standards are to be maintained and met by the rehabilitation facility and the client workers. Additionally, there should be a clear determination of who is responsible for the maintenance of any equipment used for the production of goods or services. The contract also should contain a statement as to who is to purchase the raw materials to be used as part of production and who is responsible for the delivery of materials to the work site and to the point of shipping.
- **Personnel**
  The contract for the rehabilitation facility should indicate that no fixed number of individuals will be assigned to the site, but rather the rehabilitation facility will have discretion in assigning the number of people it needs to have to achieve the work agreed to. The rehabilitation facility also should take responsibility for assigning the workers, although the community-based concern would have the right to reject workers they did not feel were advantageous to have at the work site. The contract should define clearly who is responsible for the training of the client workers. There should also be a statement as to who is responsible for the payroll administration and insurances that might be necessary to protect the facility, industry and client.
- **Equipment**
  The contract should contain a definition of what equipment is going to be used and allowed on the work site, who is going to provide the equipment, who provides maintenance and on what schedule.
- **Work Schedule**
  It is important to include as part of the contract what the normal work hours will be and when the rehabilitation facility has access to the work area. Holidays, vacations, etc. may be different between the rehabilitation facility and the community-based industry. This is particularly true of industries associated with school systems, which have a tendency to have more holidays off. It is equally important that the rehabilitation facility have access to the work area so as to assure that they will be able to meet production requirements of the contract.
- **Payment**
  Contracts should clearly define the mechanism by which the community-based concern will reimburse the rehabilitation facility for work performed. This could be done either through payment for number of units produced or a fixed number of worker hours assigned to the contract at a competitive level.
- **Term of Contract**
  Finally, the written contract with the community-based concern should clearly identify the starting date of the contract, the cir-

cumstances under which the contract can be cancelled, and the procedures to be used in the event of a need to re-bid the costs associated with conducting the contract.

IV. Supported Employment Policy Issues

The issues to be fully addressed on supported employment relate to definition, coordination and funding.

DEFINITION

Unfortunately, there is not yet a clear definition of Supported Employment. Each federal agency concerned with the vocational needs of mentally retarded citizens should come together for the purpose of clearly defining this topic in terms of length of program time, who has responsibility for funding, what are service components, who is it intended for, what are the projected outcomes and who are the service providers.

Presently, within a specific state, a program can exist providing for all of the components of a supported employment program model but be time limited, and therefore not eligible for supported employment funding.

- **Coordination**

  Once the definition of supported employment is clearly stated, the various agencies within the states must determine what components of the supported employment model are their responsibilities. This determination should then be communicated to the service providing community, consumers and parents of consumers. Preferably, the definition of responsibility would be included in state plans submitted to the federal authorities, reviewed for consistency to the federal definition and intent and then approved for implementation. Agencies within states should not have duplicate responsibilities for the vocational rehabilitation of mentally retarded citizens.

- **Funding**

  Clearly, additional funding is going to be necessary if a full transition is to be made to supported employment. The existing individuals being served within rehabilitation facilities have a right to have their program maintained, even if only until placement can be arranged.

  As with the topic of coordination, agencies within states must identify the components of the supported employment program that they must fund. There needs to be clear communication regarding what are the services for which funding is available, how long is the funding to last, who is the population the funding is intended for and who is eligible to provide services. Again, responsibilities for funding should be identified in state plans submitted, for approval, to the federal authorities.

Some Initial Findings of the Transitional-Employment Training Demonstration

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The Social Security Administration's Transitional-Employment Training Demonstration provided transitional employment (TE) services to 375 recipients with mental retardation of supplemental security income (SSI) during the period June 1985 to June 1987. The experiences of this training group are being compared with those of a control group of 370 such SSI recipients who did not receive training. The objective is to determine the costs and benefits of these services and to analyze various important issues in the implementation of programs of TE placement and training. This SSI demonstration was conducted under authority of Section 1110(b) of the Social Security Act. (This section was placed into the Act by the Social Security Disability Amendments of 1980, Public Law 96-165, Section 505(b)).

Some results of the demonstration are now available. Other outcomes of the demonstration such as changes in earnings, reduced SSI payments due to earnings, and cost-effectiveness of TE cannot be fully measured as yet, since they depend on job retention rates over time. A report on those issues will be prepared in 1989, when data on the job retention rates of the recipients involved in the demonstration are available.

Description of the Demonstration

PURPOSE

The demonstration tested the effectiveness of TE training for SSI recipients with mental retardation. Training was offered to recipients in 13 localities around the country through 8 organizations which received Social Security Administration grants.

The questions addressed by the demonstration were:

- What does TE training cost?
- To what extent can TE lead to long-term employment, to reduced SSI payments due to earnings, and to other benefits?
- What characteristics of clients make them more likely to succeed?
- What characteristics of programs make them more or less effective? Can TE programs be operated at policy-relevant scales?

Although some prototype transitional-employment programs for persons with mental retardation have existed for almost 15 years, they have generally not produced reliable data on clients who are sufficiently disabled to meet SSI criteria. This demonstration project was conducted on an adequate scale and with the appropriate scientific analysis to produce valid results on TE training especially for SSI recipients.

DEFINITION OF TE

There are three key elements of TE, as implemented in this demonstration.

- Training is provided on a real job consisting of tasks that another worker would otherwise perform for the same employer. The environment is integrated in that the trainee interacts with non-handicapped coworkers and/or the public.
- A job coach provides training both in job skills and in the social and life skills necessary to retain a job.
- Training is provided for a limited time, a maximum of 1 year in this demonstration.

Ongoing, less intensive services may be provided to promote job retention. Ongoing services generally consist of monitoring for crises on the job and occasionally retraining and placement in another job.

Placement in a potentially permanent job was a responsibility of the grantees. At least some of the training had to be provided on *that* job. However, grantees were permitted, if they chose, to provide the greater part of the necessary training before the permanent placement, on another real job that was for training only and had no potential for permanence.

SERVICES

All sites provided job development and placement and job coaching services. Job coaching is training at the job site by a job coach who is employed by the TE training organization. Sites varied in the amount of job coaching they provided a participant. The amount of full- time, one-on-one coaching varied across sites from up to a month to up to 3 months before being gradually reduced in intensity. Some participants needed little or no job coaching.

All urban sites provided travel training for participants who were not able to travel by bus independently. Some sites provided transportation.

Sites varied in the extent to which they provided other social services and case management services.

Sites were required, under the terms of the grants, to provide or arrange for follow-up of permanently placed trainees. This service is not being financed under the grant and is not limited to the term of the demonstration, however, the evaluation of the demonstration will include a review of this service. The follow-up will consist of periodic contacts with the worker and the employer to ensure that no concerns arise that might lead to loss of the job. Problem solving, retraining, and other similar services will be provided as necessary to preserve the job.

ORGANIZATION OF THE DEMONSTRATION

The demonstration was designed with the primary objective of yielding reliable results. A contractor with experience in TE programs, Mathematica Policy Research, Inc., was engaged to design the demonstration in detail, based on requirements specified by the Social Security Administration. The contractor was also responsible for:

- developing the requirements for applications for grants to operate demonstration sites, and reviewing the applications,
- developing the data collection instruments and procedures,
- monitoring the training operations and collecting the data from the grantees, and
- evaluating the results.

The grantees were three universities and university affiliates, three local units of the Association for Retarded Citizens and Goodwill Industries, and two independent rehabilitation organizations. Four of them operate sheltered workshops. The grantees were:

- Children's Hospital, Boston, Massachusetts
- University of Washington, Seattle, Washington; serving Portland, Oregon, in cooperation with Portland Community College
- The University of Wisconsin-Stout, Menomonie, Wisconsin; serving a rural area in west central Wisconsin
- Association for Retarded Citizens-Monmouth Unit, Monmouth County, New Jersey
- Exceptional Children's Foundation, Los Angeles, California (a unit ,of the Association for Retarded Citizens)
- Goodwill Industries-Milwaukee Area, Milwaukee, Wisconsin
- AHEDD, Inc., Lemoyne, Pennsylvania; serving Harrisburg, Lancaster, Philadelphia, Pittsburgh, and York, Pennsylvania, and Dover, Delaware
- The Center for the Rehabilitation and Training of the Disabled, Chicago, Illinois

Grant application guidelines specified certain features of the operations and left other, features to the discretion of the grantees. As a result, the styles of the sites differed in some important respects. Observation of differences in methods and of differences in site performance, together with analysis of site data, are the basis for most of the initial conclusions described in this paper.

SAMPLE DESIGN

A sample of 745 SSI recipients were enrolled, about half (375) in a treatment group, which received TE services, and half (370) in a control group. Participants were randomly assigned to one of these groups *after* they were accepted into the program by the site and after they (or their representative payees) consented in writing to participate.

The size of the sample was established to permit comparison of the effectiveness of TE within subgroups of the population, such as persons with severe retardation, those who were previously institutionalized, or people with multiple disabilities. The control group method was used in order to determine what portion of the sample would have become employed even without receiving TE services, since it is known that many persons with mental retardation do obtain employment.

DATA COLLECTION

The site interviewed each participant by questionnaire before the research contractor designated the individual as a member of the treatment or control group. The same questionnaire was used at all sites, permitting pooling of the data. Information was collected on household, health, vocational experience and training, education, and the interviewer's observations of the participant.

Detailed records on hours and cost of direct services provided to a sub sample of participants were kept by all sites in a uniform manner prescribed by the contractor.

Data on earnings and reduced SSI payments due to earnings will be derived from periodic review of SSI administrative records and from a re-interview of the participants which the contractor is scheduled to perform in the summer and fall of 1988.

CLIENT RECRUITMENT

The Social Security Administration mailed informational materials on the demonstration to some 12,000 recipients and their representative payees during the first 8 months of the demonstration. Most of those who did not respond received a second letter from the site in their area. A pool of names for the mailing list was initially drawn from SSI computerized administrative records and consisted of recipients age 18 to 40 who lived in the zip code areas served by the sites. Diagnosis is shown on the computer record only for recent awards of SSI payments and in cases of recent continuing disability reviews. In order to limit the mailing list to persons with mental retardation, the claims folders of over 30,000 recipients whose names were selected from the computer record were checked for the nature of the impairment. When the primary or secondary diagnosis was retardation, the name was added to the mailing list. IQ scores of persons on the list were recorded when present in the folder for purposes of the statistical analysis.

When it appeared that enrollment would be insufficient to meet sample size requirements based on this method of recruitment alone, sites were permitted to solicit referrals of SSI recipients from other agencies.

WAIVERS

Trainees in the project were granted waivers that protected their SSI status. These waivers were superseded by the revision of section 1619 of the Social Security Act which took effect in July 1987.

The waivers did not alter the provision of section 1612 of the Social Security Act that, at certain wage levels, the SSI payment is reduced based on earnings. None of the waivers in the demonstration applied to social security benefits, for those who were concurrently entitled to both SSI and social security benefits.

Initial Findings

Overall, 127 of the 375 members of the training group were working in potentially permanent jobs when they completed the project. This is evidence that TE is a valuable training technique. Nevertheless, although the technical aspects of TE are well developed, lack of public awareness and understanding remain major barriers to the full effectiveness of TE for the retarded.

Acceptance by two major segments of the public, the client community and employers, is crucial to the success of TE. The demonstration found reluctance on the part of the parents and social workers of persons with mental retardation to permit and encourage participation. This was unexpected, since advocacy groups had expressed the conviction that parents were eager to use TE services. In fact, the proportion of enrollees at some sites who were *not* being served by other agencies was a surprise to those sites and led to the conclusion that parents who were more active and successful in arranging services for their children were satisfied with the status quo and were not receptive to considering a quick change to TE.

Acceptance of TE by employers is not widespread in any industry, as this demonstration confirmed. Relatively speaking, however, the food service and hotel industries are the most open to TE placements. These "hospitality industries" commonly hire workers who do not fit the full-time, long-term, reliable-worker mold, and are, therefore, also more amenable to hiring workers who are unusual in other respects, like mentally retarded TE workers.

Although placement in non-hospitality jobs was difficult, it was not impossible. Over a third of the demonstration's participants who got and held potentially permanent jobs were working in light manufacturing, clerical, and similar jobs. Clients showed that they could perform such jobs successfully, as well.

EMPLOYMENT OUTCOMES

The 127 participants who were holding potentially permanent jobs when they completed the project represent 34 percent of the 375 members of the treatment group. Another 57 participants (18 percent) also were placed in one or more potentially permanent jobs but failed to retain those jobs. An additional 70 participants (19 percent) were placed in training jobs but could not be subsequently placed in potentially permanent jobs.

The average holder of a permanent job was earning $111 per week for 27 hours' work as of the end of his enrollment in the program. This had the potential for reducing the individual's monthly SSI payment by about $175. However, this initial finding alone is not an adequate basis for projecting future reduced SSI payments based on earnings. Even the most optimistic expectations of job retention allow for some decay over time in the number of persons employed. And an important preliminary finding of the demonstration is that there is some (as yet unmeasured) tendency for recipients living in the household of another to move to independent living arrangements after they become employed. This tends to raise SSI payments.

Hours of employment, earnings, and reduced SSI payments based on earnings will be followed over time through a re-interview of participants in late 1988 and periodic review of SSI administrative records. It is by this means that the Social Security Administration will be able to accurately estimate the overall cost- benefit results of the demonstration.

COST ISSUES

Demonstration services cost about $7,650 per participant. This includes costs that were borne by the grantees in the form of grant matching. Somewhat more than $2,000 of these per person costs are attributed to the resources used in starting up and terminating the program. It is estimated that the same service could have been provided for about $5,600 per client by similar organizations operating in a steady state over the long run. This includes expenditures on job coaching, job development, outreach, and other tasks performed by direct service personnel, as well as program administration and an allocated portion of agency overhead.

These figures are a weighted average of the experiences of the demonstration sites. Cost per participant can be much lower or higher, depending on the resources which an agency devotes to job coaching and job development, the efficiency of management, success in placing clients for training, and similar considerations.

One cost issue is the professional background needed by job coaches. Some practitioners of TE for persons with mental retardation advocate that job coaches have advanced degrees in relevant disciplines and broad responsibilities for task analysis, job development, counseling, and other services, as well as coaching. Since such personnel generally command higher salaries, and since job coaching is a particularly time-intensive part of TE services, the issue of the formal training needed by job coaches has significant cost implications.

The demonstration found that TE services can be delivered effectively even if many staff members have little formal training in rehabilitation and education, so long as a professionally prepared and effective service coordinator designs the training plan and monitors the coaches. One site that had employed only coaches with formal education changed its policy while the project was in progress. The qualities that the sites valued most in a prospective job coach were experience with business and industry, maturity, enthusiasm, patience, communication skills, and a good attitude toward persons with mental retardation.

Costs might also be reduced by better methods of screening participants, to target TE training only to persons who have a strong likelihood to succeed in the program. This demonstration did not itself employ targeted screening, in part to determine specifically what sort of clients are particularly *unsuitable* for the service. That is, one goal was to discover strong correlations between particular characteristics of the individuals and *success or failure* in the program, so that screening methods could be recommended for use in future programs.

PREDICTING SUCCESSFUL OUTCOME

The finding of the demonstration in this regard was that success in achieving permanent employment was not well correlated with IQ score, secondary handicaps (except behavioral, as noted below), or any other characteristics measured. However, a subjective prediction by the intake worker of the likelihood of success in the program was recorded at the time of enrollment. This prediction showed a correlation with client success.

One likely interpretation of the intake worker's ability to predict success is that, as is frequently asserted, the trainee's motivation to succeed, or at least to cooperate, is of overwhelming importance; and this is what the intake worker's subjective prediction measured.

A second interpretation is that a client who is weak in some few areas can still succeed, as long as he/she has some compensating strengths. Further research might develop an index for weighting the strengths and weaknesses of clients and produce more objective and accurate evaluations of success potential.

Another client characteristic which was — like motivation — difficult to ascertain objectively was the level of family support and encouragement, or similar support from elsewhere in the community. Family support was

suspected of being an important factor in determining employment success.

A characteristic possibly related to client failure was emotional disturbance or mental illness. As the demonstration progressed, sites discovered they could work with almost any low level of functioning presented by a trainee who was able to get to the job, but that it was more difficult to work with many of the behavior problems presented. It was frequently but not always possible to modify behavior that was unacceptable in the workplace.

The extent to which the behavior was subject to improvement was difficult to predict. Inappropriate workplace behavior exhibited in a sheltered, segregated environment does not reliably indicate that the client cannot be trained to conform to the requirements of an integrated workplace. One of the principal advantages of TE training in a real job is that the examples and expectations of co-workers greatly influence the behavior of the trainee.

In any event, nearly one-third of the training group members were not placed in a single permanent or training job, either because they dropped out of the program or because the site could not serve them. This is an indication that there is a need for better screening procedures than the demonstration sites used in evaluating clients.

Site personnel have expressed the belief that their predictions would have gained in accuracy over the first 4 to 8 weeks of service to the point of being quite reliable by that time. This assertion is as yet not verified, but it suggests an approach to the use of screening criteria related to motivation, family support, behavior, and other characteristics that are difficult to measure.

REFERRAL

While clients enrolled in the demonstration largely in response to the informational material mailed to them by the Social Security Administration, sites also solicited referrals from other agencies serving the retarded. Relationships among agencies vary from place to place and over time, so it is difficult to generalize about them. But it can be said, at the very least, that most of the demonstration's sites did not gain the full cooperation of the sheltered workshops in their areas, despite strong attempts. The possible reasons vary from simple competition for clients to workshops' pessimistic assessments of what their clients might achieve through the TE method to a feeling of being threatened by the TE movement. Changes are taking place, however, in this area of social service, so this situation is subject to improvement.

There is reason to believe that the sites would have placed a larger proportion of trainees had there been more referrals from sheltered workshops. This is because:

- workshops have a better opportunity to screen for the clients who are more motivated, and
- clients enrolled in workshops are more likely to have better family and community support systems than persons who are not receiving services from any agency.

TRANSPORTATION

The outcomes of the demonstration would have been very different if not for limitations on the availability of transportation to worksites. Clients who could have been successfully integrated into available full-time jobs that matched their abilities were frequently relegated to part-time work, jobs for which they were not as well suited, or no placement at all, because of transportation problems.

Bus routes and schedules that did not accommodate a prospective job, or the client's inability to travel by bus, were the main limitations. Bus service is simply unavailable at worksites in some rural and suburban areas.

Furthermore, an unknown but possibly substantial number of eligible recipients declined to *enroll* in the program because of inadequate transportation opportunities, inability to travel by bus independently, or fear of the risks to a retarded person traveling by bus.

TRAINING-ONLY JOBS

The experience of the demonstration suggests that training on a potentially permanent job from the start is a more effective method than training in a training-only job, from which the worker will be transferred once he has mastered the necessary job and social skills.

Training-only jobs are frequently found in restaurants and cafeterias, hotels, hospitals, and mobile janitorial crews. Typically one job coach supervises a few trainee positions. In this demonstration, the locations of training-only jobs included a college cafeteria, a hospital cafeteria, and a hospital housekeeping department, all of which belonged to grantees, and similar operations in outside for-profit and not- for-profit organizations. Employers are usually induced to allocate positions to training-only jobs by, among other things, a guarantee that the agreed upon production levels will be maintained, even if it requires the job coach's doing the work. Wages can be less than the

normal legal minimum.

THE ADVANTAGES OF TRAINING-ONLY JOBS ARE:

- They can be recycled as trainees graduate into permanent placements. Agencies' job development needs are then primarily for clients who are job-ready. It is much easier, of course, to find jobs for such clients.
- Clients with disruptive behavioral problems, or whose productivity is extremely low at the start, can be accommodated more easily in a training-only job, especially in the agency's own facilities.
- Job coaching is less costly when a number of trainees are in training jobs at the same location and can share a job coach.

DISADVANTAGES OF TRAINING-ONLY JOBS ARE:

- Moving from the training-only job to the potentially permanent job demands greater client adaptability because of new responsibilities, the layout of a new workplace, new work rules (like when and where to take breaks, how to arrange leave time), and new personalities of supervisors and helpful co-workers. Features of the former work environment that the job coach had incorporated as cues to the trainee are usually lost.
- There are very few opportunities to develop groups of training-only jobs in light manufacturing occupations rather than food service and cleaning occupations. The abilities of many persons with retardation are not as well matched to food service and cleaning jobs as to the more repetitive tasks that frequently comprise a light manufacturing job. Agencies that routinely put all trainees through a food service or similar curriculum may foreclose the possibility of successfully serving some clients.
- Moving clients from job to job can deprive them of on-the-job friendships, leading them to drop out, just as some have quit their TE jobs and returned to their sheltered workshops because they missed their old friends.
- Transportation must be feasible to both the training-only job and the subsequent permanent job for a successful outcome to be realized.

Summary and Conclusion

TE is an effective method for training persons with mental retardation to work in regular market place jobs. Persons with a wide range of IQs and levels of functioning, including those whose performance in sheltered workshops and work activity centers had been mediocre, are succeeding on integrated jobs through TE training.

A number of difficulties remain, however, in the implementation of TE programs. First, caregivers of persons with retardation and employers are largely unaware or unconvinced that TE is a key to successful performance in market place jobs. Second, unmet special transportation requirements of many jobs and of many people with retardation frequently prevent clients from being placed in full-time jobs which match their abilities. Third, it is difficult to determine in advance whether a given candidate for TE training is likely to succeed. This uncertainty raises the costs to providers and the risks to trainees.

The Transitional-Employment Training Demonstration addresses these and other issues in the implementation of TE training. Issues of costs and benefits and of employment impacts are being further studied through a survey of demonstration participants in late 1988 and periodic review of SSI administrative records.

Through TE the objective of moving people from the benefit rolls to the labor force can be achieved, while helping those persons achieve greater community respect and self- respect and generally more productive lives.

Utilization of the Nation's "Job Training Partnership Act" Program

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The "Job Training Partnership Act (JTPA)" Program offers citizens with mental retardation an excellent opportunity for employment related training. Each year, over 100,000 persons with disabilities successfully complete this program. While we don't know how many persons with mental retardation are being served, we do know from anecdotal data that many already take advantage of this community program.

It's important for all of us who are supporting the community integration of persons with mental retardation to understand and utilize this vast program as we strive to meet the employment related needs of this population. The purpose of this paper is to describe the operation of the Nation's JTPA program and to offer the reader ideas on "how to" improve this program's ability to serve persons with mental retardation.

It's important to realize that the JTPA program is a locally governed program. It's ability to serve persons with mental retardation is all too often in direct proportion to our involvement in its decision making process. Therefore, we all need to be both knowledgeable and involved at both the State and local levels. It's the hope of the author that this paper helps us in this regard.

JTPA PROGRAM STRUCTURE

The "Job Training Partnership Act" consists of four (4) titles. *Title* I outlines the JTPA administrative structure, as described above, sets forth accountability procedures to prevent misuse and fraud and creates two (2) special funding programs. These two programs are as follows: *Section 123 — 'State education grants"* — a program administered by the governor whereby JTPA monies available under section 202 (b) (1) of the Act can be awarded to state education agencies to provide education and training, including vocational education services, and related services to eligible youth. Such services (related services) may include services for offenders and other individuals whom the *governor determines require special assistance.* The state education agency must, however, match the JTPA funds under such an agreement. The other special funding program under Title I is *Section 124 — "training program for older individuals".* This program is likewise administered by the governor and utilizes monies available under section 202 (b) (2) of the Act. Program participants must be over the age of 55 and economically disadvantaged.

Title II of JTPA establishes employment training programs for the disadvantaged. Here, two basic programs are described. The first under Title II is Part A — *"Adult and Youth Programs".* This program is designed to provide unemployed disadvantaged youth and adults with employment training. Services that may be provided include but are not limited to the following:

1. job search assistance,
2. job counseling,
3. remedial education and basic skills training,
4. institutional skill training,
5. on-the-job training,
6. programs of advanced career training which provide a formal combination of on- the-job and institutional training and internship assignments which prepare individuals for career employment,
7. training programs operated by the private sector, including those operated by labor

organizations or by consortia of private sector employers utilizing private sector facilities, equipment, and personnel to train workers in occupations for which demand exceeds supply,

8. outreach to make individuals aware of, and encourage the use of employment and training services,
9. specialized surveys not available through other labor market information sources,
10. programs to develop work habits and other services to individuals to help them obtain and retain employment,
11. supportive services necessary to enable individuals to participate in the program and to assist them in retaining employment for not to exceed 6 months following completion of training,
12. upgrading and retraining,
13. education-to-work transition activities,
14. literacy training and bilingual training,
15. work experience,
16. vocational exploration,
17. attainment of certificates of high school equivalency,
18. job development,
19. employment generating activities to increase job opportunities for eligible individuals in the area.
20. pre-apprenticeship programs
21. disseminating information on program activities to employers.
22. use of advanced learning technology for education, job preparation, and skills training,
23. development of job openings,
24. on-site industry-specific training programs supportive of industrial and economic development,
25. follow-up services with participants placed in unsubsidized employment,
26. coordinated programs with other Federal employment-related activities,
27. needs-based payments necessary to participation in accordance with a locally developed formula or procedure, and
28. customized training conducted with a commitment by an employer or group of employers to employ an individual upon successful completion of that training.

The President's Committee on Employment of the Handicapped
Washington, D.C. 20210

A Review and Analysis of
The "Job Training Partnership Act"
Public Law 97-300

I. The Review

PURPOSE

"To establish programs to prepare youth and unskilled adults for entry into the labor force and to afford job training to those economically disadvantaged individuals and other individuals facing serious barriers to employment, who are in special needs of such training to obtain productive employment."

JTPA ADMINISTRATIVE STRUCTURE

The governor of a State will determine the number and location of independent *"service delivery areas"* within the State. Each service delivery area will be directed by one or more units of local government and have the responsibility to promote within its jurisdiction the effective delivery of job training services authorized under this Act. Also, each service delivery area will establish a *"private industry council"* (PIC). The private industry council will be responsible for providing policy guidance and oversight with respect to activities under the job training plan of its service delivery area. And, each service delivery area is required to develop and maintain a *"job training plan"* which will, among other things, describe the employment problems of the area, describe the services to be rendered, identify procedures for identifying and selecting participants and offer program performance goals. The job training plan will be approved by the State governor.

At the State level, the governor shall annually prepare a statement of goals and objectives for all of the State's job training and placement programs authorized under this Act. This statement is called the *"governor's coordination and special services plan"*. It will, among other things, establish guidelines for the preparation of local job training plans. Additionally, the governor will establish a *"state job training coordinating council"*. The purpose of the council will be to plan, coordinate and monitor programs funded within the State and through this Act. The council will also recommend to the governor an annual governor's coordination and special services plan, review the operation of local programs, make an annual report, and perform other duties as determined by the governor.

Lastly, each administrative entity, contractor and grantee, under this Act, shall establish and maintain a grievance procedure for complaints about its programs and activities from participants and other interested persons. A hearing on a complaint shall be conducted within 30 days and a decision made within 60 days of the grievance. Complaints can be made within one year of the alleged occurrence.

Also authorized under *Part* A are a series of four *"exemplary youth programs"* (section 205) which may be made available, at the discretion of those responsible for preparing the *job training plan* for a *service delivery area*. These four exemplary youth programs are as follows:

1. *"Education for employment program"* — for eligible youth who have not obtained a high school diploma, with priority given to high school drop-outs. Under this program a network of learning centers can be funded designed to prepare these youth to meet State and locally determined general education diploma and basic education competencies.
2. *"Pre-employment skills training program"* — for eligible youth and individuals aged 14 and 15, with priority given to those individuals who do not meet established levels of academic achievement and who plan to enter the full-time labor market upon leaving school. This program can provide these youth with up to 200 hours of instruction and activities in such areas as: assessment, counseling, career exploration, job search assistance, job holding skills, basic life skills, remedial education, job seeking skills training and more.
3. *"Entry employment experience program"* — this is a work-study program providing up to 20 hours a week of work, not to exceed a total of 500 hours.
4. *"School-to-work transition assistance program"* — for eligible youth who are seniors in high school. Transitional services which may be provided under this program are: the provisioning of occupational information, short duration job search assistance, job clubs, placement and job development and follow-up.

The second basic program under *Title II is Part B — Summer Youth Employment and Training Programs.* Programs under this part

permit similar types of activities, as described under Part A, to be funded for eligible youth during the summer months.

Title III of the "Job Training Partnership Act" establishes employment training programs for dislocated workers. This program is designed to provide training, retraining, job search assistance placement, relocation assistance and other aid (including pre-layoff assistance, job development and job clubs) to individuals who are affected by mass layoffs, natural disasters, Federal government actions (such as relocation of federal facilities) or who reside in areas of high unemployment or designated enterprise zones.

Title IV of the "Job Training Partnership Act" establishes employment training programs for Native Americans, migrant and seasonal farm workers. Also, the "Job Corps" is reestablished, and in Part C of Title IV, a special veterans employment program is created. All programs under Title IV, including veterans, are to be administered by the Federal government on a grant basis.

JTPA DEFINITIONS RELEVANT TO DISABLED PEOPLE

The term "economically disadvantaged" means an individual who (A) receives, or is a member of a family which receives, cash welfare payments under a Federal, State or local welfare program; (B) has, or is a member of a family which has received a total family income for the six-month period prior to application for the (JTPA) program involved (exclusive of unemployment compensation, child support payments and welfare payments) which, in relation to family size, was not in excess of the higher of (i) the poverty level determined in accordance with criteria established by the Director of the Office of Management and Budget, or (ii) 70 percent of the lower living standard income level; (C) is receiving food stamps pursuant to the Food Stamp Act of 1977; (D) is a foster child on behalf of whom State or local government payments are made; or *(E) in cases permitted by regulations of the Secretary of Labor is an adult handicapped individual whose own income meets the requirements of clause (A) or (B), but who is a member of a family whose income does not meet such requirements*.

The term "handicapped individual" means any individual who has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment.

The term "youth" means an individual who is aged 16 through 21.

The term "adult" means an individual who is 22 years of age or older. (Note how this modifies the advantage afforded handicapped individuals under the term "economically disadvantaged" above).

The term "support services" means services which are necessary to enable an individual eligible for training under this Act, but who cannot afford to pay for such services, to participate in a training program under this Act. Such support services may include transportation, health care, special services and materials for the handicapped. …

The term "community based organizations" means ... vocational rehabilitation organizations, rehabilitation facilities (as defined in Section 7(10) of the Rehabilitation Act of 1973, agencies serving youth, agencies serving the handicapped. ...

JTPA FEATURES OF SPECIAL RELEVANCE TO DISABLED PEOPLE

Section 108 of the Act describes limitations on certain costs. For example, not more than 30 percent of the funds available to a service delivery area may be spent on administrative costs. Administrative costs include, among other things, supportive services (see definition above). However, expenditures may be made in excess of this 30 percent limitation if "the job training plan for the service delivery area proposes to serve a disproportionately high number of participants from groups requiring exceptional supportive services costs, such as handicapped individuals ..."

Section 106 of the Act sets forth general requirements with respect to the setting of *performance standards,* which must be met by programs operating with JTPA funds. While the final performance standards will be developed by the Secretary of Labor, the Act suggests they include such factors as: numbers of placements in unsubsidized employment, retention in unsubsidized employment, increase in earnings, etc. Subsection 106 (d) (3) says, however, "The Secretary of Labor shall prescribe variations in performance standards for special populations to be served, including Native Americans, migrant and seasonal farm workers and ex-offenders, taking into account their special circumstances". While handicapped individuals are not listed here, their special employment problems would seem to be significant enough to warrant variations in performance standards. If this is not done, program operators might avoid involving those handicapped people whom, they believe, would hinder achievement in the area of general performance standards.

Section 167 of the Act sets forth the civil rights obligations of program operators. It says, "For the purpose of applying the prohibitions against discrimination on the basis of age under the Age Discrimination Act of 1975, on the *basis of handicap* under Section 504 of the Rehabilitation Act, or on the basis of sex under Title IX of the Education Amendments of 1972, or on the basis of race, color or national origin under title IV of the Civil Rights Act of 1964, programs and activities funded or otherwise financially assisted in whole or in part under this Act are considered to be programs and activities receiving Federal financial assistance."

Section 167 goes on to say, "No individual shall be excluded from participation in, denied the benefits of, subjected to the discrimination under, or denied employment in the administration of or in connection with any such program because of race, color, religion, sex, national origin, age, *handicap* or political affiliation or belief."

Section 203 of the Act describes eligibility for services. It states, "except as provided for in *paragraph (a) (2),* an individual shall be eligible to participate in programs receiving assistance under this title (Title II programs) only if such individual is economically disadvantaged."

Paragraph (a) (2) does offer some interesting possibilities for handicapped individuals; it states, "up to 10% of the participants in all programs in a service delivery area receiving assistance under this part may be individuals who *are not* economically disadvantaged if such individuals have encountered barriers to employment. Such individuals may include, but are not limited to, those who have limited English language proficiency, or are displaced homemakers, school dropouts, teenage parents, *handicapped* older workers, veterans, offenders, alcoholics, or addicts."

Eligibility under *Title III — Employment and Training Assistance for Dislocated Workers,* is outlined in *Section 302*. It states, "each State is authorized to establish procedures to identify substantial groups of eligible individuals who: 1) have been terminated or laid off or who have received a notice of termination or lay-off from employment, are eligible for or have exhausted their entitlement to unemployment compensation, and are unlikely to return to their previous industry or occupation; 2) have been terminated, or who have received a notice of termination of employment, as a result of any permanent closure of a plant or facility; or, 3) are *long-term unemployed and have limited opportunities for employment* in the same or similar occupation in the area in which such individuals reside, including older individuals who have substantial barriers to employment by reason of age."

Full implementation of the new Act's systems and program requirements is required by October 1, 1983. The transition provisions outlined in Section 181 of the Act include requirements for the early publication of those regulations necessary to structure and implement the planning system under Title I of the Act and all aspects of programs under Title II.

Proposed rules were published in the *Federal Register* on January 18, 1983 governing the implementation to programs under Titles I, II and III. The introductory section sets the tone of the regulations. It states, "The Secretary believes that the Act is sufficiently clear and, therefore, requires only limited and select interpretation via regulations. *Governors* and other participants in the delivery system will need to be guided principally by the Act, as supplemented by the regulations." No major points are made in these regulations which might impact on handicapped individuals vis-a-vis the Act.

How to Get Involved With JTPA

II. The Analysis
CONSIDERATIONS

While it has been widely reported that the new "Job Training and Partnership Act" (JTPA) will not be funded at anywhere near the highest levels of CETA, it's important to remember that only 17% of CETA's funds were actually spent on training. JTPA requires that 70% of its funds be spent on training. Thus, even if JTPA is only funded at the 3.8 billion level, the last and lowest appropriation level for CETA, actual training dollars may triple! And, the high levels of unemployment facing our country may persuade the Congress and the Administration to increase the appropriation beyond the anticipated 3.8 billion dollar level.

Another consideration to keep in mind as we prepare to do business with JTPA is the open-endedness of the program. Unlike CETA, the JTPA legislation does not limit the life span of the program. Theoretically, it can continue indefinitely.

The last general point or consideration worth noting before we explore how to become involved with JTPA relates to the latest statistic describing the participation rate of handicapped people in CETA. The Department of Labor reports that for the last three quarters 10.6% of all CETA participants have been identified as handicapped. If this is true, our

Nation's public training program has become a vital programming element in the work preparation of handicapped people. This advance must not be lost.

ACCESSING JTPA

It appears as though we're going to have to modify our approach as the new JTPA law takes over. Unlike the old CETA program where by virtue of the disability, a handicapped person was eligible for services, under JTPA the program applicant must be economically disadvantaged* in order to be eligible. True, there remain some minor exceptions to this rule, to the benefit of handicapped persons; but, in the main, it's a program for the economically disadvantaged. Consequently, our primary approach or "sell" has to shift from fostering opportunities in CETA for handicapped persons to fostering opportunities in JTPA for *economically disadvantaged persons who are handicapped*

It seems to make sense that economically disadvantaged persons who are Handicapped should, whenever possible, strive to access the JTPA slots for economically disadvantaged — where 90% of all the training slots exist. And, the special programs for handicapped persons, like Section 203, paragraph (a) (2), should be reserved for those handicapped persons in need of job training who might not otherwise qualify. This *conservation technique* should help to enhance the participation of disabled people in JTPA.

A good example of this technique in action might be the utilization of whatever number or percentage you are able to obtain of the 10% set aside for non-economically disadvantaged *(Section 203, paragraph (a) (2)* for an area's handicapped youth program under Title II. Since handicapped youth who are from families who are *not* economically disadvantaged are not otherwise eligible for JTPA, their involvement can only be secured in this manner.

Another example of conserving training slots for handicapped persons who might not otherwise qualify under the regular eligibility criteria (economically disadvantaged) seems to exist in *Section 123* of JTPA. Here 8% of a Service Delivery Area's (SDA's) money can be matched by the local education agency and used to provide education and training, including vocational education services, to participants under Title II. The Governor has the discretion to determine who can participate in this program, based on a particular group's need for "special assistance". The JTPA law does stipulate, however, that not less than 75% of Section 123 funds be spent on economically disadvantaged youth. Hence, up to the maximum of 25% of Section 123 funds can go for programs designed to serve handicapped youth and adults, if the Governor so decides. Again, in this example, any effort to target JTPA slots for handicapped individuals should be directed toward disabled youths and adults who would not otherwise qualify. This conservation technique can pay off with a larger overall involvement of handicapped people in JTPA.

In addition to the suggested shift in emphasis to economically disadvantaged persons who are handicapped, and the conservation technique suggested above, accessing JTPA will depend on the direct involvement of handicapped persons and their representatives in *two councils.* The first council that should be courted is the *State Job Training Coordinating Council.* The purpose of this council will be to plan, coordinate and monitor programs funded within the state and through the JTPA Act.

According to the Act, representation on the *State Job Training Council* shall be as follows: *1) one-third* representatives of business and industry; 2) not less than *twenty percent* representatives of the State legislature, State agencies and State organizations (such as the State education agency, State vocational education board, State vocational education advisory council, State public assistance agency, State employment security agency, State rehabilitation agency, State veterans affairs agencies, State postsecondary institutions, and any other which the Governor determines to have a direct interest in employment and training and human resource utilization within the State); 3) not less than *twenty percent* representatives from local government, including PIC's; and 4) not less than *twenty percent* representatives from eligible population and of the general public, representatives of organized labor, community- based organizations (see definition for "community-based organizations" in definition section above) and representatives from local education agencies.

Certainly the prescribed make-up or composition of the State council provides many possible entry points for those concerned with the training needs of handicapped persons. For example, an effort might be made to get the Governor to appoint a particular employer on the State council who has been active in and is familiar with the employment needs of handicapped people. While this person would occupy one of the employer slots, he or she could also be counted on to support the needs of handicapped persons. Additionally, representation on

*NOTE: Governor may declare handicapped youth as family of one, according to a subsequent determination by the Secy. of Labor (see attached memo).

behalf of handicapped people could be gained under the remaining categories, i.e. State rehabilitation, State employment security, State education agency (special education), etc. In other words, more than one ally should become directly involved in the State Council.

Apart from the obvious value of becoming involved with this council in the statewide planning, coordinating and monitoring of JTPA funds, many close to the situation are predicting that these councils have the potential to do much more. It is anticipated with these bodies which will involve all the segments of the employment and training field in the particular State, can become excellent vehicles for the promotion of interagency cooperation. Additionally, they can become excellent platforms for the expressing of the statewide employment and training concerns of handicapped people. Obviously, we must get involved in the State councils.

The other *council* that we are going to need to get involved with is the *private industry council* or PIC. Each State will have, perhaps, one or two dozen PIC's. Nationwide, it is anticipated that there may be more PIC's in business than there were CETA Prime Sponsors (360). And, they will be powerful.

According to the JTPA law, one of the first acts of a State governor as he implements this program, will be to determine the number and location of independent *s*ervice *d*elivery *a*reas, called SDA's. However, cities with a population of 200,000 or more, consortium of contiguous units of local government with a population of 200,000 or more and any concentrated employment program grantee for a rural area which served as a prime sponsor under CETA can demand from the governor that they be designated a SDA. Each SDA will have a PIC and the PIC will have the responsibility to provide policy guidance for and exercise oversight with respect to activities under the *job training plan* in effect for the SDA.

The initial membership of the PIC will be determined by the chief elected official of the SDA. Thereafter, the PIC itself will determine its membership. Initial recommendations for membership on the PIC may be made to the chief elected official.

JTPA does require that a certain ratio be observed with respect to the make-up of the PIC. *Fifty-one percent* of the members on a PIC must be from private industry. And, the chief elected official is required to select these initial members from a nomination list developed by the "general purpose business organization of the SDA". (i.e. the Chamber of Commerce). The remaining positions on the PIC will go to representatives of education agencies (all education agencies in the SDA), organized labor, rehabilitation agencies, community based organizations (see definition), and public employment service.

Again, it would seem advantageous to attempt to have nominated for PIC membership employers who are involved in and understand the problems associated with the training and employment of handicapped people, as well as special educators, rehabilitation representatives, special educators, and local groups representing handicapped people.

According to officials with the National Association of Private Industry Councils (NAPIC), it is anticipated that SDA's will be determined by States' governors during the period of March and April, 1983, and the PIC's will begin forming sometime during April and May, 1983. Hence, time is short if we hope to get involved from the beginning.

One last word about the PIC's. In addition to their duties associated with the JTPA law, PIC's will be directly involved in completing area reviews or assessments of job training and employment systems. An effort should be made to insure that these area needs assessments specifically address the job training and employment needs of both handicapped youths and adults.

In addition to the two councils (the State council and the PIC) there are *two plans* that need to be monitored. The first is the *statewide coordination and special services plan*. This plan will be prepared by the State's governor for the period of two program years and will establish criteria for coordinating activities under JTPA with programs and services provided by State and local education and training agencies (including vocational education), public assistance agencies, the employment service, rehabilitation agencies, postsecondary institutions, economic development agencies and such other agencies as the governor determines to have a direct interest in employment and training and human resource utilization within the State. It appears that this objective of the statewide plan would seem to offer those interested in the training for employment of disabled people an excellent opportunity to integrate JTPA programs with existing services so that they support or augment them.

Another function of the statewide coordination and special services plan is to indicate any adjustments made by the government with respect to *performance standards*. Performance standards are important because they set the ac-

countability for local program operations. And, variations in performance standards are possible and may be necessary for certain special populations (see Section 106 above). Hence, this dimension of the statewide plan will be important to monitor.

Related to the governor's responsibility with respect to the preparation and implementation of the *statewide plan is statewide 121 (c).* Here examples of the governor's coordination and special services activities associated with this plan are offered. Two of them seem to hold a potential to groups interested in improving employment related services to handicapped youth and adults. They are item (3) and item (9). Item (3) suggests that the governor may, "provide programs and related services for offenders and *other individuals whom the governor determines require special assistance".* Item (9) States, "provide pre-service and in-service training for planning, management and delivery staffs of administrative entities and PIC's, as well as contractors for state supported programs." Item (3), if the governor so desires, could provide the basis for a statewide special program for handicapped persons based on their need for special assistance. And, item (9) could become an important element in a more general effort designed to prepare JTPA program operators to serve economically disadvantaged persons who are handicapped. The concepts and particulars of environmental and program access could be taught, on a statewide basis, utilizing item (9).

One last point, concerning the statewide plan, while the law does require that the State council recommend to the governor a statewide plan, it is the governor himself who is the final authority on the matter. Consequently, close association seems to be necessary both with the State council and with the office of the governor.

The other plan that should be monitored as we strive to involve handicapped persons in JTPA programs is the *job training plan.* This plan is the local service delivery area's (SDA) plan spelling out how JTPA funds will be utilized for the next two program years. Responsibility for the preparation of the job training plan is shared between the SDA's chief elected official (i.e., the mayor or county executive) and the private industry council (PIC). Specifically, the law states, "the council (PIC), in accordance with an agreement or agreements with the appropriate chief elected official or officials shall determine procedures for the development of the job training plan, which may provide for the preparation of all or any part of the plan by the council (PIC), by any unit of general or local government in the SDA ... or any other *agreed* upon entity."

The *job training plan* will include, among others, the following features: a description of the services to be provided; procedures for identifying and selecting participants and for eligibility determination and verification; performance goals in accordance with those established by the Secretary of Labor and the governor (including any variations in performance standards for special populations); the budget for two program years; a description of methods for complying with the coordination criteria established in the governor's statewide coordination and special services plan; and procedures for the preparation and submission of an annual report to the governor.

In view of the importance of the *job training plan, it* would seem advantageous to identify the agreed upon entity in each service delivery area responsible for the development of the plan and to insure that someone appropriately represents the needs of economically disadvantaged persons who are handicapped as well as other handicapped youth and adults who might benefit from JTPA services.

At the same time, groups concerned with the employment needs of handicapped persons should attempt to become involved in the review and approval process of each service delivery area plan. As prescribed in JTPA, a job training plan shall be published and made available for public review and comment not less than 120 days before it is to go into effect. Also, each house of the State's legislature, appropriate education agencies, and other public agencies in the SDA, and area labor organizations involved in the areas where training is proposed to be completed, are to be afforded the opportunity to review the job training plan. The final plan will be submitted to the governor not less than 80 days before the plan's beginning date.

SUMMARY

JTPA can serve both economically disadvantaged persons who are handicapped as well as other handicapped youth and adults, if persons or groups representing their needs make these needs known through direct involvement in the state and local decision making process.

At the *State* level this means delivering input to:

1. The Office of the Governor (and those on his staff responsible for developing the Governor's Coordination and Special Services Plan).

2. The State Job Training Coordinating Council. At the *local* level this means delivering input to:
1. The chief elected official* of the SDA (i.e. mayor or county executive).
2. The Private Industry Council* (PIC) of the SDA.

*One or the other has lead responsibility for the SDA's Job Training Plan, the critical document determining how JTPA's monies are allocated for programs.

Transportation Panel

MODERATOR: **PAUL A. MARCHAND**
PANELISTS: **ROBERT C. ASHBY**
ANDREA FARBMAN, PH.D
BRUCE M. OKA

Transportation Considerations for Citizens with Mental Retardation

by Paul A. Marchand
Director
Governmental Affairs Office
Association for Retarded Citizens/U. S. Washington, D.C.

As I was thinking this morning about my opening comments, I began that discussion on the bus, which I take every morning and I thought, "Well, we're going from here, we're going to there" And I think that's really what this issue is all about, getting from here to there, whether we're going to work, whether we're going to school, whether we're going shopping, whether going out to play, whether we're going to go out and meet friends or relatives, it's a fact that you've got to go from here to there. Unfortunately for many persons with disabilities, the well known theme of "you can't get there from here" is all too frequently employed. I'm sure that PCMR has picked this topic because in fact you can't get here from there in many places. We've got to solve that problem. You cannot have full access to the community. You cannot have much independence if you cannot get from here to there, no matter what the circumstance is. Therefore, transportation is an absolutely critical part of the service system, the life system that must be in place for people, all people, whether they are handicapped or not. We can have a hundred people next door talking about special education and another hundred down the street talking about living environments, but if they can't get there without transportation, all of that can easily fall apart.

For the majority of people who are mentally retarded, transportation may not be problematic. That is because most people who are mentally retarded are mildly retarded, and are identified as such primarily during their school years. School systems generally are responsible for transportation, either through specialized transportation or some other arrangements. While the children are special education students, they get to school. When they leave the school system, these individuals are basically assimilated into our general society.

They are the people who will likely be able to obtain driver's licenses. They will be the ones who will potentially own cars and be able to get around on their own. Some won't, but the majority will. For those who won't, and for the remainder of the population which is mentally retarded, those from the moderate level to the most profound levels, will likely be transportation dependent, and they will likely be transportation dependent from the day they're born until the day they die. Transportation has to be arranged in order for them to access society, to access their community.

There is, unfortunately, no national policy on transportation for people who are mentally retarded. In fact there is no general policy, generally, for people who are handicapped. There is no entitlement to transportation, as there is an entitlement to special education, or to cash benefits in this nation, if you are poor and so disabled that you cannot work. Since there is no such entitlement for transportation, something must be planned in order for people to profit from this service.

We know that throughout this country there are places where transportation is probably the biggest issue, despite the fact that there is a variety of programmatic services available. If you can't get there from here, the services are irrelevant for you. Transportation is a key issue, a necessary issue that must be solved. There are many ways that one accesses transportation. There is private transportation, there is public transportation, and there is personal transportation. Who's responsible for all of that? This is a major issue that I hope we will discuss today,

because there is no pinpointed responsibility. Who's going to pay for it? Again, no pinpointed responsibility. Is access assured?

Who is going to train individuals to be able to use whatever transportation is available. Transportation workers themselves need some training in order to understand the special circumstances that a good number of persons with. mental retardation present in order for them
to get from here to there. We will discuss access to mainline transportation. We will discuss door-to-door para-transit type services that are necessary for some, as well as other transportation modalities. Since there is no national policy, one has to look, then, at what is the Federal role.

There is a Federal role on this issue, and Bob Ashby of DOT will deal with that. I'm sure Andi Farbman of the National Council on the Handicapped will address that as well. We have at the moment several major controversial and exciting issues facing us in regard to the Federal government's policy towards transportation in regard to mental retardation. Bob Ashby can now pick up from there and talk to us about what DOT is or is not doing for this population. I hope you'll all be prepared to enter into dialogue with Bob at the appropriate time. Bob...

DOT Legislation / Regulations and Their Resultant Affect on Mentally Retarded Citizens

by Robert C. Ashby
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Regulations & Enforcement
Department of Transportation
Washington, D.C.

What I basically want to do this morning is give an update on development in our regulatory activities with respect to transportation to persons with disabilities.

First thing I want to talk about is some litigation that is currently in process in Pennsylvania. As you know a year and a half ago, in 1986, the Department came out with some new and controversial regulations concerning transportation provided by mass transit agencies which get funding from the Urban Mass Transit Administration, or UMTA.

That regulation briefly, in implementing the statute Congress passed a couple of years previously, listed a series of service criteria which transit authorities had to meet whether they provided service by acceptable bus or parent transit or some other kind of special service or some combination of all the above. But, then said pursuant to another court's decision of 1981 vintage that a transit authority in order to avoid having undue burdens imposed on it by this regulation would not need to spend more than 3% of its overall operating budget, in order to meet Federal requirements. Even if that meant that the service criteria were not fully implemented.

We were sued on that issue by a couple of disability organizations, ADAPT and Eastern Paralyzed Veterans of America and early in January a district court again in Philadelphia found in favor of the plaintiff on the cost cap issue. The court saying that since the statute required minimum service criteria the cost cap provision, by permitting the service criteria to be complied to less than fully, resulted in the criteria not being truly minimum criteria and consequently, the regulatory framework that we had established according to the 1986 regulation was not consistent with the statute.

The court ordered us to redraft the regulations consistent with the court's opinion. We have 60 days after a court decision like that to decide whether to appeal it. We are still in the process of deciding whether or not as an agency we want to appeal it. The decision on whether or not to appeal it will be forthcoming in probably a few weeks.

Pending either the completion of an appeal or the expiration of the 60 day period for filing an appeal, if we decide not to, we aren't told by the court that we have to stop enforcing the existing regulation or that in any way it's been vacated. The order as it now stands is, that if we don't appeal or if subsequently we lose an appeal, simply to rewrite the regulations consistent with the court's opinion, which means you don't have an across the board cost cap of this sort.

There are a number of ways in which the regulation could be redone if that court decision goes into effect. One of them, the simplest, is to draw an X through the cost cap provision rule. That would result in a regulation that had a set of service criteria applicable to each of the modes providing transit, but did not have any limitation on the requirement that one comply with the service criteria even if it costs 10 or 15 or 20 percent of the transit authority's operating budget.

The problem with doing that is that such a result falls inequitably on cities depending on what size city it is and what kind of transit we want to provide. Typically, according to the information that we've developed, it appears that providing paratransit service is in total dol-

lar terms more costly than providing accessible bus service, especially for the operating cost. It's also however, a way of providing service that generates substantially more trips by people with disabilities than accessible bus services have done and consequently, while more costly, is also more cost effective if you have a cost unconstrained set of service criteria. One unintended adverse consequence may be that by saying you have to provide paratransit services that fully meets the service criteria without any cost constraint you may give some cities an excuse to switch to a less aggregate expensive form of providing service like accessible buses which, however, will provide less services to people with disabilities than a paratransit system with the cost constraint, so that is a policy consideration which we will have to look at.

There's also an intermediate approach we might take which would be to remove the cost cap, as the court said, and to some degree lower the service criteria. So the service criteria are not as demanding in terms of costs for paratransit systems in small cities. You lessen the disincentive for providing paratransit on the other hand, that may have the unintended adverse consequence of allowing cities that are now providing special service at or near the service criteria level by enabling them to cut back on the quality of service that they provide. So, none of the choices is by any means a panacea.

We are going to have to do some thinking and probably get some comments on what the best way to react to a non-cost cap situation if indeed the court decision goes into effect. So reacting to the 504 litigation on the cost cap issue is, now the first issue that we're dealing with.

A couple of issues are near the larger scheme of things subordinate in importance to the cost cap issue but of particular interest to folks interested in mental retardation.

First of these is the service criteria for eligibility for paratransit under the rule. To redefine it, what it briefly said in response essentially to concerns about costs and a quality between the cost of different service options was brought up to us in the development of the regulation.

We said that you have to provide service if you're running a special service system to folks who by reason of disability, are physically unable to use the regular bus systems. Providing service to people who by reason of a mental disability, but not a physical disability, aren't able to use the system is optional. So consequently there's a requirement service in effect for physically disabled folks; there is not a competent requirement for service to people who solely by reason of a mental disability are unable to use the regular bus system. For example, someone who may be moderately retarded, whose functional disabilities are such that he or she cannot remember where a bus stop is or how to get from point A to point B using the regular bus system.

That obviously has been the source of substantial controversy. Some legislation has been dropped in the hopper vote the last session of Congress. A House member from Memphis dropped in a bill trying to address this subject. It was a bill to amend the definition of handicapped in Section 16 of the Urban Mass Transportation Act to include mental disabilities. The problem was the definition already included mental disabilities and amending the definition does nothing to amend the service criteria and this is where the problem is.

Third item, is an advanced notice of proposed rulemaking, which the Department of Transportation wanted issued back in October asking questions about what kinds of additional accommodations, if any, should we require for mass transit systems in terms of better serving people with mental disabilities. And, for that matter people with other non-mobility disabilities, such as vision apparent, on the regular mass transit systems, better training for drivers, announcement of stops, different stops, those kinds of accommodations.

We got back, I would estimate and I haven't been through all of them yet, about 200 or 250 comments on that subject from a variety of commenters, including disability groups and State and local transportation agencies, State rehab agencies and such.

I've been through about 50 of the comments so far and if they are representative, what we have gotten in the comments is a statement of people's preferences, but not a lot of information which is exceedingly useful in helping us make regulatory decisions. That is to say, people have said, "Gee, yeah, we think better training is a great idea, we think announcing stops is a really good thing, we think bigger and better signs on buses to help people who have various degrees of vision impairments, for example, it would be really neat", and then you have transit authorities saying things like, "We do lots of this good stuff on our own, don't impose any new regulations telling us to do it."

The problem is that none of these comments that I've seen so far have really addressed to what extent there is a problem which needs to be addressed by regulation, to what extent particular means are feasible, to what extent particular accommodations are really effective

in addressing whatever problem exists. What are the cost implications, if any of the various accommodations are suggested? So if the rest of the comments, I'm hoping this is not the case, turn out to be like the first 50 or so I've been through, I will have information about preferences but not necessarily information about the utilities of particular accommodations that we're thinking of.

Fourth item is air travel. Air Carrier Access Act of 1986 directed us to develop new regulations to ensure non-discrimination on the basis of handicapped in air travel consistent with the safe carriage of all passengers. Most of the specific issues in the rulemaking, and we address these via what's called regulatory negotiation, we had an advisory committee made up of representatives of the major disability groups and the airline industry.

Most of the issues that we addressed in specific terms dealt with accommodations for people with mobility impairment and to some extent vision and hearing impairments. There isn't much in the way of specific issues in this rulemaking that tune indirectly on people with mental disabilities as opposed to people with other kinds of disabilities. We did have one member of the panel who is knowledgeable in the mental disabilities area, Curt Decker from the National Association of Protection and Advocacy Systems.

There are a few things obviously there are general non-discrimination provisions that apply across the board and go to such things as not requiring people to get services they don't want. The old business about the Boy Scout helping the old lady across the street, whether or not she wants to go has been a problem. So folks with disabilities have faith in air travel for a long time. People who are sometimes over-zealously helpful to the point of being patronizing, giving special briefings to passengers who they perceive to be disabled or in some cases giving them a quiz, "Could you show me that you really know how to fasten your seatbelt?"

There is a section that we're working on that would, for example, limit requirements that a disabled person have an attendant to travel with them. The one specifically that might affect some of us, a mental disability, is that someone who could not comprehend or respond appropriately to a safety related instruction to a stewardess or a pilot or whoever, might be required to have an attendant. But aside from that, the fact that they look different or engaged in annoying behavior so long as the annoying behaviors did not rise to the level of creating a safety problem, would not be grounds for requiring an attendant to kick somebody off the plane.

I think one of the most important things that we all very much agreed upon in this rule- making effort is that carrier personnel often will receive more training on how to deal with individuals with disabilities.

One of the biggest problems that persons with disabilities have had in flying is that while more and more people with disabilities do fly, the number of disabled folks who fly is a relatively small percentage of all passengers. There's a relatively high turnover of people at the ticket counter and people at the gate and those who take reservations and so it is not all that uncommon for a person even with a relatively common type of disability to show up at an airport and run into a gate agent who has never seen a person with this type of disability before at least in the context of work.

So we hope that by including training provisions, that we can get the carriers to do a better job by training their employees to assist persons with varying disabilities.

Transportation for Mentally and Physically Handicapped Persons

by Dr. Andrea Farbman
Director of Public Affairs
National Council on the Handicapped Washington, D.C

I am responsible for covering transportation for the National Council on the Handicapped. It's really a pleasure for me to be here. It's a dubious honor to be sitting to the far right of DOT, though.

The first thing I want to do is to refresh your memory about the Council. The Council is an independent Federal agency that's comprised of 15 Presidential appointees who are confirmed by the Senate. It was originally established in 1978 under the Rehabilitation Act as an advisory board under the Department of Education, and I say that literally, under the Department of Education. The Council found that in that kind of hierarchy, it really couldn't get anything done. It couldn't do policy for the Federal government being underneath the Department of Education. In 1984, as an amendment to the Rehabilitation Act, the Council became an independent Federal agency with the authority to or responsibility really, to advise the President and Congress on disability policy issues. We have 5 professional staff members and for Fiscal Year 1989 we'll have just under a million dollars.

Our members' statutory responsibilities are quite broad. At the current time we have 10 statutory responsibilities that range from establishing general policy for the National Institute of Disability and Rehabilitation Research, which used to be the National Institute on Handicapped Research, to advising the President and Congress on any disability issue. For example, if a particular Congressman or the President is interested in employment or transportation or recreation for any disabled person, we might be asked to respond. We're really the only Federal agency who has that kind of cross-cutting responsibility at a policy level. That gives us a huge ball of wax to try to carve out and to try to really do some meaningful work. From time to time we struggle with trying to set priorities in a meaningful way.

In terms of what I'm going to talk about for transportation, I think it's important to remember that transportation policy at the Council has related to not just people with mental retardation or people with developmental disabilities, but has tried to address transportation from the standpoint of all persons with disabilities.

What I want to discuss today is two Harris polls that the Council initiated and was involved with and two of the policy documents that I passed out to give you an idea of what the Council policy is. Paul Marchand, panel moderator, said there is no national policy on transportation, I think the Council believes that we have a national policy on transportation, I think it's fair to say that the implementation of that policy is certainly haphazard and not as consistent, or not as comprehensive as we would like it to be, but certainly in terms of policy issues we feel that we have a policy etched out.

How many of you have heard about the first Harris poll that related to disability? Back in 1986, the Council was mandated by Congress to do an analysis of Federal disability policy. At that time when the Council was looking at a lot of data that existed, and certainly a lot of contradictory data, a number of Council members discussed the fact that what we really needed was a Harris poll, not of service providers, not of bureaucrat like ourselves, but actually trying to find out from persons with disabilities what their perception of their life is in a very global sense. So, the Council initi-

ated a Harris survey and the International Center for the Disabled in New York subsequently contracted with the well known firm of Louis Harris and Associates.

This is a copy of the survey; I'm not going to go into great detail. If you want to get copies, contact ICD at 212 (679-0100).

This survey called "Bringing Disabled Americans into the Mainstream" was the first ever attempt to have a nationwide random sample of persons with disabilities talking about their own lives. The Harris survey team had to screen 15,000 households in their normal way. They actually wound up with a sample of 1,000 people. Within that sample, approximately 3% of the people responded that either they were themselves mentally retarded or that they had a family member who was mentally retarded. So the 3% figure which is commonly used was confirmed by the survey.

In terms of transportation, you might be interested that a large majority, over 50% of the sample, stated that their disability prevents them from getting around, from socializing or just going out as much as other people and that the actual problem of transportation was a deterrent in a lot of daily activities. A majority of respondents, almost 50%, believed that their mobility is limited because they can't use public transportation, because they can't get special transportation, or because they can't even get someone to give them a ride. Fifty percent of the sample is statistically very significant. Also, 3 out of 10 people said that the lack of affordable, accessible transportation is a major reason why they're not working.

Transportation is an important issue. I think a lot of times transportation is seen as a very secondary issue. We tend to focus on education or employment; but I don't think it's quite that simple. I think all of these things are very interrelated and there's actually a complexity. Obviously, transportation is a major ingredient in employment, in recreation and in education.

The second survey was done as a follow-up related to the fact that the first Harris firm survey found out that literally two-thirds of all persons with disabilities were unemployed. A follow-up study on employment was done which again refers to transportation. It doesn't have anything in it particularly relevant to what we're talking about today, so I'll just mention it. As well as mentioning the fact that a third Harris poll is being done right now focusing on education and that sample is going to include children with disabilities, parents of children with disabilities, and educators.

In 1986, the Council had this huge "invitation" really. A mandate, I don't think it's ever been called an "invitation" before, from Congress, to assess incentives and disincentives to community integration and independence of persons with disabilities.

The Council set about quite ambitiously holding a lot of public meetings, public forums, talking to a wide variety and a large number of disabled consumers throughout the country and actually asking them, "What are the problems you're having?", "What are the major issues facing you?" That's when the Council came up with their first report in 1986 called *Toward Independence*.

This report has 10 topics areas, one of which is transportation. The conclusion that was reached in that report was obviously, as we've said several times before, that transportation is a critical ingredient to independent functioning and that people with disabilities are not going to be able to achieve independence in society without accessible transportation.

The Council really went further than that in their report and recommended a national policy of fully accessibility. For example, fully accessible mass transportation. There were 5 areas within transportation and all this is in the handout of recommendations from *Toward Independence*. The first one being Urban Mass Transportation. The second one being Air Transportation. The third one being Inter-City and Inter-State Buses. The fourth one being Private Transportation. And the fifth one being Research.

I'll just go through those and talk briefly about what we recommended. I'll also talk about where we are today in terms of those recommendations. That's really what the second report, *On the Threshold of Independence*, which is just being released this week, is about.

The image of *On the Threshold of Independence* is sort of looking at all of the recommendations, the 45 recommendations, that were made in the first report and saying, given that sort of global picture the Council views persons with disabilities as being on the threshold of independence, sort of being close to independence, but not quite being there. And I think that analogy fits in a lot of different areas, to say that on one hand we have some progress, on the other hand we still have a distance to go and that the progress really shouldn't obscure the fact that there still is a distance to go before we reach total independence or at least independence at a level that is satisfactory to people with disabilities.

Going back to Urban Mass Transportation, the very first recommendation that the Council made was to amend Section 16 of the Urban Mass Transportation Act to require full accessibility within a reasonable amount of time. Bob Ashby, Department of Transportation, mentioned the 504 regulations, the

cap situation which obviously the court has dealt with to a degree.

Another problem that the Council has concern about is a private right of action. When Bob Ashby mentioned that Senator Cranston had dropped a bill in, it had several pieces to it, one of which was a private right of action. Although that hasn't gone any further, at least we have had some discussions with people on Capitol Hill and there is movement in that direction.

Another issue that hasn't been discussed much is the monitoring of the Urban Mass Transportation's 504 Transition Plans. Just this summer several disability organizations did a Freedom of Information Act public information inquiry and were able to get to look at the 504 Transition plans to actually begin to see what is happening. It looks great on paper but how are local transit authorities attempting and planning to comply? To comply in terms of people with mobility impairments, in terms of people who are mentally retarded. What are the plans; and what is the extent of the coverage? That analysis is quite lengthy. Do you have any idea how many plans? I've forgotten their exact number but I know there are several hundred. The number of 504 Transition Plans in rough terms is around 350 to 370 and that analysis is just beginning.

Another recommendation within Urban Mass Transportation that certainly has been suggested is that the Department of Transportation should be a standard setting agency in terms of transportation accessibility under the Architectural Barriers Act of 1968.

Bob Ashby was talking before about regulations. The Architectural Barriers Act does not allow DOT to set standards and that was a recommendation in our 1986 report and, as far as we know, there hasn't been any progress made on that.

The second area is Air Transportation. The major recommendation the Council made related to amending the Federal Aviation Act to prohibit discrimination based on handicap. That was not done per se, what was done, was the passage of the Air Carrier Access Act. I think that the Air Carrier Access Act was a major accomplishment. However, that's not the end of the story. I mean the regulatory process, the process that Bob has been through for the last six months looking at all the specific items that relate to people with mobility impairments, that relate to people with mental retardation and trying to assure that air travel is as accessible as possible for the widest variety of people with disabilities and believe me, that's no small task. I know that the Council is looking forward to seeing the notice of proposed rules that Bob says will come out probably some time this spring to actually see how they're going to implement that Act. The Act winds up being one page and the regulations will probably wind up being over 100 pages.

The third area that the Council commented on was Inter-City and Inter-State buses. Inter- City and Inter-State buses being private are able to, if they choose to, discriminate against people with disabilities. The recommendation was that through interstate commerce that Congress should extend non-discrimination coverage. Interstate commerce would cover interstate buses and therefore, buses would not be able to discriminate against persons with disabilities. In a particular sense that has not been done.

Let me just mention at this point that the Council's major recommendation that came out of *Toward Independence* was the enactment of a comprehensive equal opportunity statute for persons with disabilities. At this point the Council has drafted a bill and it's part of On *the Threshold of Independence*. The title for the bill is "The Americans with Disabilities Act of 1988."

Next week, as a matter of fact, the Council is going to be refining the bill with another group of disabled consumers and professionals and actually putting the finishing touches on what they want to propose and then deal with relevant Congressional people, obviously, the Subcommittee on the Handicapped and others to talk about "actually dropping the bill some time this year".

Within that bill there would be coverage that would include non-discrimination coverage for interstate commerce. Therefore; this provision about inter-state and inter-city buses, would be covered if, the Americans with Disabilities Act as it is proposed currently, were to pass.

The fourth area that the Council recommended in terms of transportation policy related to Private Transportation. Recognizing that not everybody in the world is going to take public transportation, and that for persons with disabilities private transportation is as much an option as for other non-disabled persons; the recommendation was that low-interest loans to assist persons with disabilities and their families to either purchase vehicles and/or modify vehicles and that a low-interest loan program be established. Again, there's no progress, we have had some talks with people on Capitol Hill about this. I think that the climate for having low interest loan programs is not exactly great.

However, I can say that we have talked with a number of automobile companies that are attempting to reach out to customers with

disabilities. Chrysler just met with us several weeks ago and they're doing a plan that involves free modifications. They are very committed to doing modifications on private vehicles. They are within a certain scope. They are wanting to do those modifications for either no cost or a very low cost. In terms of action, there's some action in the private sector, but there hasn't been any action from the Federal Government.

The final area is that of research. I think frankly that one of the problems that has plagued transportation has been that the research has been flawed and the research has been weak. I think it is an area that is difficult to do research in. It's difficult to know how many people are riding the buses, and how many times. I think too often in studies like that they don't get valid data. Because there's been weak data, often people have said, "Well you can't substantiate your claim. You can't substantiate that you need this; you can't substantiate why we should spend this money", and so they say, "So we're not gonna do it." Again, the Council felt very strongly about that. We needed much better research and actually the Council attempted to get some amendments within the Rehabilitation Act for DOT to do some additional studies. But, for a variety of political reasons, that never happened.

We are still hoping at this point that the Compliance Board (ATBCB), whose statute and responsibility clearly falls within the area of doing research in terms of transportations and disabled persons, would hopefully address more valid kinds of research studies. The Council plans to meet with the Board to try to encourage some of this to happen.

In summary, in terms of the policy statement, that the Council made about transportation, there were 6 recommendations in 5 different areas. Our scoreboard tells us that one of those was fully accomplished, three of those were partially accomplished and with regard to two of those, there really has been no substantial activity. Just as the Council said in 1986 that transportation is critical to independence, and it's critical to community integration, and it's critical to the quality of life for persons with disabilities, all of these statements remain true. We have made some progress, but there's still a *long way* to go.

Thank you.

San Francisco Municipal Railway (Muni) Serving the Handicapped

by Bruce M. Oka
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Department of Health and Human Services
Office for Civil Rights
San Francisco, California

What I'm going to be discussing, I'm employed by the Department of Health and Human Services with the Office for Civil Rights and as part of my outreach activities with my office, I have been asked to provide technical assistance on access issues regarding access to community services, transportation being one of those, so I hope this presentation will help you and I'm glad that Bob Ashby is here from the Department of Transportation because a lot of what I'm going to say is going to be rather newsworthy or noteworthy to a lot of you because of the San Francisco Municipal Railway Service (MUNI).

While I'm talking, I'm just gonna have Randy handle the slide show. In San Francisco, we have one of the unique situations where the San Francisco Municipal Railway Service provides fixed route accessibility on 16 of its major routes in San Francisco. What that means basically is that a person like myself, who relies on his independence and ability to get from place to place by himself, can do so.

I use the fixed route transportation every day and throughout the daily course of my job. One of the thing that's unique about the San Francisco Municipal Railway, (and we lovingly call it the "MUNI") is that it has several lines that are equipped with lifts that are 95% reliable, in other words, the malfunction rate is very low on these lift equips. Also, noteworthy is that California is one of only two States in the country that have a legislative mandate that all transportation in this State be accessible.

That legislation specifically says that all buses purchased, all new buses purchased have to be lift equipped and accessible to persons with mobility impairments. My normal day I go from my home, get on the bus to go downtown and if I wanted to, I could get from my home to almost any place, anywhere in San Francisco without any problem whatever.

There are only a few neighborhoods in San Francisco that are not reached by the fixed route.

These buses, if you haven't seen the inside of them, are all set up with securement devices in which the wheelchair locks into and it's perfectly safe. There's no danger of the chair slipping out and one of the keys to providing this kind of access MUNI is one of these transportation systems that not only meets the percentage criteria that shouldn't be there anyway, but it exceeds it in many instances, and it exceeds it by quite a margin.

One of the reasons that MUNI services to the disabled are so good and so reliable is that I'm one of the Co-chairs of the MUNI Elderly and Handicapped Advisory Committee and it took us a long time to get the powers that be to listen to us but the result of their having sat own at the table to discuss this whole thing with us has afforded us with the amount of accessible transportation that we have.

Right now I believe that San Francisco and the San Francisco Bay area has the most accessible transportation in the country, if not the world. We not only work with the MUNI management staff, but we work with the drivers.

One of my fun things to do is every six weeks, MUNI provides training, sensitivity training to its newly hired drivers, and they devote one full day to problems and situations which face the disabled and I think that is the key. You have to provide sensitivity training to your transit operators, the people who actually operate the buses.

This is just showing you how the lift itself works. There are different lifts on the market, but this lift that MUM has on all its accessible

buses seems to be the most reliable, they're rugged, and nobody's complained about them.

I know because, you know, Andi was saying it's kind of hard to estimate how many people ride the bus. Well MUNI sends out surveys on, I believe, a quarterly basis to see how many rides on the bus were taken, which bus lines were used, and we keep statistics like that on a pretty regular basis.

At all times the advisory committee has key input, as a matter of fact, MUNI management doesn't do anything relative to access issues without consulting the advisory committee, and if the advisory committee doesn't agree with something that MUNI proposes, it doesn't happen.

I think that one of the reasons that we have a problem such as we do for disabled, and this is me getting into another mode of our transportation. This is our light rail vehicular travel. We have wayside platforms that make the metro accessible to us, as you can see I've gotten on, and you can wait for the bus, you can see the graffiti. Graffiti is common wherever you go. I haven't seen a city in the United States or over in Europe that doesn't have graffiti on its transit system.

When we talk about fully accessible transportation we have to keep in mind that there are some people that will not be able to use it, no matter how accessible you make the fixed route system. There are going to be some people who are not going to be able to, for whatever reason, use that system. They may not be able to get to the bus stop, or whatever the case may be.

I think one of the points, I think Bob and I- are going to get into a little bit of a discussion later about how to do this, but I think that what MUNI does should be tried all over the country and implemented all over the country in that what MUM does is provides fixed route accessibility and their promise to us and their goal is 100% fixed route accessibility. That includes the trolley coaches, the metro, not all of the metro system is accessible because some of it is above ground and we haven't gotten all of the above ground stops accessible yet, but that will happen. I think that one of the ways to do this is to not have, as the Department of Transportation has, a local option which is the favorite phrase of the American Public Transportation Association.

In 1979, the Congress passed a law mandating on the Federal level that all new purchases of public transport vehicles be lift equipped. That law was rescinded by Congress mainly due to the American Public Transportation Association (APTA's) opposition to it.

APTA's saying to provide full fixed accessibility would be much too costly because they would have to fix all of the old metro stations and the cost would be up in the billions. I don't know where they got their figures, but what the disabled community generally is asking for is and this is our paratransit system which this whole transportation system is managed by the Municipal Railway, and the estimated cost per trip for a paratransit vehicle is $17.00 per person. Multiply that times the number of rides that I would have to take per day, not to mention per week on this system, were it not for fixed accessibility, the cost would be astronomical.

There are, of course, some places where I would not be able to get to and in those cases, I do call the paratransit service to provide that to me, but basically my mode of transportation is by fixed route transit, and I enjoy it.

One of the other things that's harder to do as Co-chair of the Advisor Committee is that I get to go out with the first-time bus users and show them how to use the bus safely, what to do if certain situations arise, what not to do and how to respond to the public who may not know or may be afraid to express how they feel about having us on "their buses" and that's an attitude that a lot of us are going to face. You guys have your own pick-up service, why don't you use it? You know, and if we all took that attitude, nobody would get anywhere. I think this is some of the things that we have to work to break through these kinds of attitudal barriers.

Most of the barriers that are put up for our access to transportation are attitudal. They're not physical, they're not cost, they're, I'm going to tell you an interesting little story.

During the American Public Transportation Association's Annual Conference back in September, which was held in San Francisco, the President of APTA, or the Vice President of APTA, who shall remain nameless because he might come after me if I mention who it was, likened access to transportation to, well, just because I have a million dollars, is it your right to have a million dollars, too?

This is the kind of attitude at the top level of these associations that cause the problems that we have and you know, he also said, "Well, in Buffalo, New York, it wouldn't be practical to have lifts on all these buses because they wouldn't operate in the snow. Well, who operates in the snow? I want you to ask yourself, who can easily operate in the snow, anyway? Whether or not you're disabled or able

bodied, you don't operate well in foul weather. So that's not a good analogy.

You know, and for people to say that air transit is preferable to fixed route accessibility because to provide full access to public transportation would cost too much, let me tell you that to purchase a bus with a lift on it only adds 5% to the cost of the vehicle. Now, when you contrast that and the lifts we have on MUNI require very little maintenance, they don't break down because a system that's used a lot, if you have the system out there, it's gonna be used. The reason you don't have the numbers to show the need is because you don't have good service. If you don't have good service, you're not gonna get used.

I wouldn't use a bus system that only provides me one out of every five buses with a working lift. I'd be discouraged. MUNI ought to be proud and alleviated.

MUNI's attitude was not always this good. It took a lot of fighting. A lot of people had bloody noses and hurt feelings and I went out with my picket signs and blocked buses, so it does take some effort on our part to make this system accessible, and to make people understand that we're part of this society, too. All we're after is an equal opportunity to participate in it.

This, gentleman, is the Manager of the Elderly and Handicapped Program's right hand person and I discuss MUNI's plans with him on a regular basis and the committee meets on a once every other month basis, but my involvement with Access to Public Transportation goes far beyond MUNI, because I'll tell you, if I was living here in Washington, DC, their transit system would be much better than it is, believe me, because I would be in the Senate chambers and the House chambers every day until it was. I think I'd have quite a bit of help.

We took slides to show just how convenient it is to get from place to place. Somebody actually walked with me through a typical day for me. I use the accessible transportation system. The last count they had, I took 135 trips during the course of one month. That's one month. You multiply 135 trips times $17.00 if I were to use the paratransit system and our paratransit system by the way is a very good one. It provides service daily. It runs for 12 hours instead of the normal 9 to 5 or 7 to 5. Some of the paratransit systems close at the close of the business day. That's not when we finish our activities. We do do more than just go to work and come back, or go to the hospital and come back. That's something that I think people need to realize, too.

But I think the key here is first of all to listen when we tell you how we would like to see transportation for us. Also the exchange of dialogue and ideas I think is a very major consideration because without the input from the disabled community and without MUNI's willingness to listen to us, and they weren't always willing to listen to us either, so it hasn't always been, one thing I should mention before I forget to do so, is that these are pictures from the recent APTA convention and one of the things that the Advisory Committee did to help the San Francisco police department deal with the demonstrators that they were going to encounter was to give them sensitivity training on what to expect from a person, like myself in a wheelchair, who might be resistant to being arrested, so we did show them how to handle the wheelchair without breaking it. We made it a point to be very clear that if they broke one of the wheelchairs that they would probably be taking away a person's mobility for quite a while. So it was very important for us to really stress to them the importance of maintaining the equipment without breakage.

This is my office and my office has been very, very conscious about community involvement of this staff and this is why they have told me to take as much time as necessary to provide this kind of, what we call technical assistance to these community agencies and service providers on how to provide access.

Access is not a privilege, it is a right of every human being and we just have to make sure that everybody knows, that I have just as much right to get from place to place as you do. Or that a person with a mental disability has just as much right to ride the bus and know how much change to put in the fare box as you or I do.

Education Panel

MODERATOR: ANN P. TURNBULL, ED.D.
PANELISTS: MARY A. FALVEY, PH.D.
WILLIAM E. KIERNAN, PH.D.
MURIEL W. O'TUEL, PH.D.

The Individual Family Service Plan: What Does It Mean for Families

by Ann Turnbull and Rud Turnbull
(Presented by Ann Turnbull)
Public Policy Fellow in Mental Retardation
Joseph P. Kennedy, Jr. Foundation
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We are excited about the new expectations and possibilities for family support through the individual family services plan (IFSP) and want to share with you the reasons for our enthusiasm. As parents, we have a keen appreciation of what this support will mean for families as they begin their marathon of family life; and as professionals, we know the shared commitment of wanting to make a relevant difference in the lives of youngsters with disabilities and their families. The IFSP provisions enable both families and professionals to meet their goals in the best interests of the children they serve.

We will highlight briefly four aspects of the legislative provisions that converge in the IFSP: goals, service definition of early intervention, nature of assessment, and family outcomes.

GOALS

Two of the four goals stated in P.L. 99-457 particularly pertain to family outcomes. These goals are as follows:

- To minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society, and
- To enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps.

The first goal of maximizing the potential for independent living in society is best accomplished when families are supported to stay intact and to work for community integration. What do we mean by community integration? We mean people with disabilities living, working, socializing, and enjoying leisure in regular community settings where natural interactions with people without a disability occur. The goal then is to maintain family relationships living within family settings so that people with disabilities can have their best access to long-term integration as adults.

The second goal relates to enhancing the capacity of families to meet the needs of their infants and toddlers. We suggest a long-term view of conceptualizing needs. For far too long we have had the tendency to view early intervention as an "era" in and of itself somewhat separated from what happens later on in the child's life. Early intervention is the beginning of the child's education, and most people in society agree that the purpose of education is to prepare citizens to live and work in society across their entire life. Thus, the goal of enhancing the capacity of families to meet the special needs of their infants and toddlers should involve teaching critical skills that will evolve overtime to adult competence and community integration.

The IFSP is the means for translating these two goals into a relevant plan for each family. The plan is designed to serve the child within the context of serving the entire family.

EARLY INTERVENTION SERVICES

One of the particular services to be considered for the IFSP is "family training and counseling". It is significant to note that the word, parent, in P. L. 94-142 has been replaced by the word, family, in P. L. 99-457. This is not just a semantic difference, but rather suggests providing services to a much broader array of significant people in the child's life.

ASSESSMENT

P.L. 99-457 requires that each IFSP include "a statement of the family's strengths and needs related to enhancing the development of the

family's handicapped infant or toddler". The greatest opportunity that we have with this requirement is to move with relevance and rationality into developing a means to assess family strengths. As we have reviewed the state of assessment in early childhood education, we have not found an instrument that has been developed and validated to assess strengths; however, there are a multitude of instruments to assess needs, problems, and stresses. We have an opportunity to move from a pathological focus to one that is balanced, and we should move ahead vigorously to developing our best models of family assessments in the area of strengths, as well as needs. The goals for family support — preventing institutionalization and enhancing the family's capacity to meet the child's needs — must guide the conceptualization and implementation of assessment; simultaneously assessment of family strengths and needs must be linked to the statement of family outcomes as discussed in the next section.

STATEMENT OF OUTCOMES

The IFSP must include a "statement of the major outcomes expected to be achieved for the infant and toddler and the family, and the criteria, procedures, and timelines used to determine the degree to which progress toward achieving the outcomes are being made and whether modifications or revisions of the outcomes of the services are necessary." Thus, outcomes for children *and* for families should be established. Family outcomes can be thought of as the objectives or intermediate steps in accomplishing the family goals of supporting the family to remain intact and avoid institutionalization, and to increase the family's ability to meet the child's needs.

We believe that parenthood of a child with a disability can be likened to a marathon and that a major problem with early intervention in the past is that it has regarded parenthood more as a sprint to the child's first grade year. The outcomes for families incorporated into the IFSP should support the family to remain intact *overtime* and to meet the developmental needs of the child *overtime.* In taking a marathon view of family life, we like to apply the concept of the criterion of ultimate functioning that has been developed in the education of students with severe disabilities to specifying outcomes for families. We need to think very carefully about the expectations of the environments in which families will function, identify critical skills for success, teach those skills early, and enable families to be successful at each stage of the lifespan. The identification of marathon skills, based on the criterion of ultimate functioning, should be a collaborative effort involving families, researchers, and service providers. Examples of marathon skills that we think are important to consider include learning to identify and prioritize family needs; exploring what it means to love unconditionally a family member with a'disability; learning to establish supportive and responsive relationships with family, friends, and professionals; learning to benefit from emotions; learning to solve problems and "take charge" of one's life; learning to plan for the future; and learning to establish balance within family relationships and responsibilities. As the field identifies the crucial marathon skills related to family goals, those skills can then be incorporated into assessment processes for identifying family strengths and needs, and into specific support services.

In summary, we believe that the IFSP can be the catalyst to develop a lifespan and future- oriented perspective of family support. Within this view, early intervention can be thought of as the launching pad to life within the family and community. From this launching pad, infants and toddlers with disabilities can grow, within the context of family life, to become competent adults living as integrated community citizens.

Special Education

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I want to first commend the President's Committee for sponsoring a conference on community integration. This topic is so crucial today. I also want to thank the committee for extending me the invitation to present on special education issues. I thought I would provide you with a historical perspective of educational services from where they have been, where they are, and where they appear to be going. The focus of my comments will more directly apply to those children and young adults with severe mental retardation since the majority of my work has been with those students.

I have not assigned dates to this chronological historical perspective since it has varied and continues to vary across the country. Some time back, in the 1940's and 1950's there were no programs and for many families the only option was an institution. Several factors began influencing services and programs. First, parent advocacy organizations became influential and effective in the development of school programs within local communities so children could remain at home and receive services from the schools. In addition to the development of advocacy groups to influence these changes, researchers were studying the learning characteristics and learning potentials of children and young adults residing in these institutions. Their findings, indicating that persons with mental retardation could learn provided a more scientific rationale for the development of programs in the communities.

These two influences, i.e. parent advocacy and research on learning led to the development of segregated schools, i.e. handicapped only schools that used a "watered-down" regular education and/or developmental curriculum. The curriculum resulted in teaching nonfunctional skills in artificially contrived environments. It placed emphasis on the student's developmental/mental ages while at the same time ignoring that student's chronological age.

Researchers and advocates carefully examined these practices. Advocates took issue with the segregated nature of the services and the undignified and devaluing ways students were treated in a chronologically age inappropriate manner. Researchers began to look at learning characteristics of students in artificially contrived settings and found that they did not generalize very well, and in fact sometimes did not generalize at all. These researchers began to question the use of instructing in artificially contrived environments since students were not able to apply the skills they were learning to their home and/or neighborhood environments. Another group of researchers began to study the effects of teaching social skills to students with mental retardation and found that they learned social skills more quickly and effectively in the presence of socially competent peers, i.e. non-handicapped students of similar age.

These two major findings, i.e. that students did not generalize effectively and that they were more likely to learn social skills in the presence of non-handicapped peers led to development of self-contained classes of students with mental retardation on regular campuses. This service delivery resulted in opportunities to interact with their non-handicapped peers. In addition, the development of a community- based instructional program was emerging. Community-based programs involve providing direct instruction to students in the community environment, e.g. grocery stores, laundromats, banks, restaurants, post offices, integrated work settings, and public transportation. This direct instruction in the community eliminated or at

least reduced the problems with generalization of skills to community environments.

However, researchers were still not satisfied and began to determine if students learning in the school community environments would generalize to their own home neighborhood environments. These researchers found that once again the student's generalization was limited and recommended that instruction occur in the student's actual home neighborhoods.

In addition, several of us have been looking at the research on friendship development and the implications for school placement. There is a very rich body of research that has systematically evaluated the characteristics of childrens' friendships (non-handicapped childrens' friendships). The prerequisite conditions identified in almost all the research on friendships are that *close proximity* and *frequent opportunities* must be made available in order for children to develop friendships. Although the service delivery on integrated sites was to provide education, for administrative convenience the services have generally not been in the students' neighborhoods.

The implications of teaching community skills outside of a student's neighborhood and integrated, but not in the student's neighborhood, have significantly influenced school districts and parents to advocate for and develop quality, cost-effective programs in the student's neighborhood school. This movement should not result in a reduction or elimination of needed specialized services and/or resources. However, it is necessary to use creative efforts to provide neighborhood school opportunities for all students with the needed support. Parents should not have to choose between specialized services and friendship opportunities for their children when faced with placement decisions. I am confident, because of the examples provided by several school districts throughout the country that we can develop the needed services at the neighborhood school without necessarily requiring additional financial resources.

Specifically, I would like to recommend that the President's Committee on Mental Retardation influence schools at the national, State, regional, and local levels to:

1. Develop and create opportunities for students to attend their neighborhood schools;
2. Provide frequent and sustained opportunities to be educated with their non-handicapped peers;
3. Provide specialized services as needed by a student in order to be the best that he/she can be; and
4. Provide direct and frequent opportunities to acquire the skills necessary to participate in integrated living, recreation, and working activities within their own neighborhood.

Thank you.

Future Planning in Education: Critical Issues in Transition

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INTRODUCTION

During the past 5 years, a significant amount of energy has been invested in looking at the transition from school to work. The focus upon movement from school to integrated employment without support, with time limited support, or with ongoing support has been the benchmark of much of the transition activities to date. It is important, however, to look at transition not only as a process from school to a job but also to look at the elements that make up a job and provide satisfaction for the worker on the job. Beyond the specific tasks performed we must look at the level of integration realized (the interactions with co-workers) and the identity that work provides for the individual. The process of transition, the movement from one environment or situation to the next, is not a reflection of the efforts of the educational system during the last years of the student's participation in that system but, rather, should reflect a systemic commitment by the school toward the preparation of the student with special needs throughout his or her educational career for entry in the adult world. This includes developing opportunities for the student to maximize his or her independence and productivity through real work by the utilization of a functional curriculum and realistic career experiences.

It is estimated that 300,000 students with special needs leave school each year. The vast majority are either underemployed or go into unemployment. From 50-75% of all individuals with disabilities have been reported by the U.S. Commission on Civil Rights to be unemployed. A more detailed study of a random selection of 1,000 persons with disabilities was conducted by Lou Harris in conjunction with the International Center for the Disabled. This survey showed that of the 1,000 persons with disabilities randomly selected, 2/3 were unemployed. When asked if given the opportunity to work would they accept employment, 2/3 indicated that they would be willing to enter the labor force. Typically, persons with disabilities are not counted in the unemployment statistics because they are not considered as employable and thus not in the labor force.

Action at the Federal level, including, the establishment of supported employment activities as an initiative through the Department of Educations, Office of Special Education and Rehabilitative Services (OSERS) in conjunction with the Department of Health & Human Services, Human Development Service's Administration on Developmental Disabilities (ADD), has clearly shown that persons with severe disabilities can be employed given sufficient training and support. The developmental disabilities legislation has established employment as a priority in the development of all statewide plans for persons with developmental disabilities. The Department of Education's Rehabilitation Services Administration, through the amendments of the Rehabilitation Act, has established supported employment as an acceptable vocational outcome (Title 6 Part C of the Vocational Rehabilitation Amendments). These Federal movements, though focusing upon supported employment, demonstrate that persons who have been considered unemployable in the past, clearly have potential given adequate training and opportunities for ongoing support.

In the educational process, several States have initiated, either legislatively or administratively, transition planning processes. An analysis of over 1,000 initial plans in Massachusetts has shown that the vast majority of persons moving from school to work are scheduled to enter sheltered employment. A total of 60% of the persons who will be completing their special needs courses in the public schools will be designated as having the Department of Mental Retardation as a lead agency. Of this group, 80% have a long-term goal of sheltered employment.

These statistics show that there is a gap in information between educational and adult services. Initially, a major thrust to establish supported employment was made at the Federal level; however, many States now have extensive supported employment initiatives. Yet, given that supported employment is somewhat established in individual States, the majority of those students with special needs completing their educational program are slated to enter sheltered employment. It might be assumed that there is either a lack of knowledge regarding the employment options available by professionals in schools, or that the educational system is recommending the services that are currently being offered and immediately available rather than those which may be considered as more appropriate but not as readily available. In the latter scenario, students would be referred to an existing service; i.e., sheltered workshop, work activity centers or day habilitation programs though, in fact, the educator may feel that the student has more capacity or greater potential than this type of option. However, given the need to secure a service upon graduation, they may opt for an existing resource rather than the optimal resource.

This problem may reflect a lack of knowledge, as was noted above, among the educators in the area of transition from school to work. However, it may also reflect the limited experiences that some educators have had with industry settings particularly those where special needs students may be placed. Unrealistic expectations regarding the capacity or limitation that the student may possess may inhibit the teacher from encouraging the family or student to strive for greater goals or take risks in seeking out employment. It is important that not only adult services but educators as well, shift their focus from a selling focus, that is preparing an individual with skills that they feel ought to be or have been necessary in the past, to a marketing focus, that is listening to what industry is asking and preparing students to meet those needs.

The above noted issues clearly reflect the need for additional skills among the educators if the movement from school to work is to be successful. Specifically, there needs to be additional training in curriculum and technology development (i.e., task analysis, learning and adjustment, functional curricula), knowledge of industrial environments (i.e., marketing, goodness of fit strategies, ongoing support resources) and enhanced planning capacities (i.e., communication, strategic planning, knowledge of support systems).

The development of these competencies or skills reflect a modification in the more traditional pre-service education training programs with a need to focus upon not only curricula development but industry and marketing skills as well as planning capacities among educators. The outcome of an effective pre-service curriculum for educators in the of transition area would include the development of personnel who are knowledgeable as to employment and industry needs, have a knowledge of the adult service system, are able to design and implement a functional curriculum, and can advocate for employment as an outcome for persons with special needs.

ENHANCED PARTNERSHIPS

The theme of the forum, Citizens with Mental Retardation and Community Integration, reflects a focus upon the movement of persons with mental retardation into integrated work, residential and social settings. This movement focuses upon increasing the productivity, integration and independence of persons with disabilities in the areas of employment, community living and recreation. In order to accomplish this, a number of partnerships must be developed. These partnerships are critical to the success of dealing with the whole person. It is essential that in examining employment opportunities for students with special needs, we consider also recreational and social needs. Other documents in this report will be directing their efforts in these areas. This article will look specifically at the recommendations for enhancing partnerships in the area of integrated employment for students with special needs.

These partnerships will look at the 4 broad areas of Federal/State; State/local; public/private; and family service delivery.

Federal/State Partnerships

- Continue funding of service, training and research in transition and options for employment with support services for students with special needs,

- Encourage cooperative planning between the Department of Health and Human Services and the Department of Education to encourage coordination of resources and planning strategies at Federal and State levels.
- Support for services, not just from school to work but school to adult life including residential and recreational.

State/Local Partnerships

- Define the role for transition specialist in schools; examine certification requirements and have all special education pre-service programs provide adult services and transition curricula materials for students (reinstitute a focus on career education and life-long learning),
- Incorporate other learning environments for students who have left school, i.e., community colleges, adult education and vocational education as mechanisms to support the integration of the student in the work and social areas,
- Require that the IEP (individual education plan) have a focus upon employment not just in the last years but throughout secondary education at a minimum and preferably throughout the entire educational process,
- Encourage the development of functional curricula in school programs including hands-on work experience programs for students in middle school and integrated employment programs for students in high school.

Public/Private Partnerships

- Become knowledgeable, about employer needs and devise a curriculum which helps students respond to those needs,
- Use actual integrated work environments as part of the educational experience for students with special needs,
- Involve adult service agencies in the individual education planning process (Vocational Rehabilitation, Mental Retardation/Developmental Disabilities, Employment and Training Services...),
- Be flexible with the use of staff support on site (not all jobs occur Monday through Friday, 9-5).

Family/Service Delivery

- Make sure that vocational and/or employment recommendations are part of the individual education plan, not just in the final year of high school but throughout high school at a minimum,
- Develop expectations for the child with a disability that will increase the level of independence and productivity both at home and in school,
- Expect that a transition plan will be developed and that the roles of various agencies will be defined,
- Encourage an awareness about the world of work,
- Request work experience both within and outside school as part of the standard curriculum.

CONCLUSIONS

The area of transition is a fast moving and evolving area which includes the working together of those in the educational system as well as those in the adult service field. Likewise, it is essential that families and persons with special needs become active participants in the transition from school to work. It is important that all have an expectation that work is a viable outcome for the student with special needs and that the goal of the educational process is to lead toward increased independence, productivity and integration in real work settings. All individuals in the partnership for enhancing the transition from school to work must be willing to give as well as to receive if the partnership is to be effective. The transition is not just from school to work but from school to adult life. It is this broader transition that the educational system must respond to if we are to maximize the abilities of the student with special needs.

Integration of Children with Mental Retardation into Public Schools

by Muriel W. O'Tuel, Ph.D.
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The first school for persons with retardation was established in 1896 — 200 years after schools were established in our country. At one time people thought nothing could be done for persons with retardation — that the genes were set forever. Also there was much reluctance on part of the parents to acknowledge their child had mental retardation (MR). Some stigma still exists, but, we have come a long way. Most parents aren't prepared to rear normal children not to mention children handicapped by mental retardation. In the old medieval days kids with mental retardation served as court jesters and clowns. Even the great Protestant reformer, Martin Luther, believed that mentally retarded children had no souls. In a feature article (News & Courier, Charleston, SC, 1-31-88), parents of a 16-month old child with retardation said, "Retarded children are just like any other children, they just don't learn as fast. Given the opportunity and some love, these kids can grow up, support themselves and contribute to society." Being accepted by society and being given a fair chance are what parents want most for these children.

In thinking of my topic today, Integration of Citizens with Mental Retardation in the Public Schools, the only objectives we need are: that students with mental retardation learn to support themselves, to contribute to society, and to be accepted by others. Although we have made strides in educating people with disabilities since the passage of PL94-142, we still have a long way to go. We have not, in my opinion, conquered education for people with handicaps.

The best way to truly integrate persons with mental retardation into society is to integrate them as *fully as possible* in the public schools. Our schools are miniature societies. With the total school population learning, living, loving, and laughing together, more acceptance and understanding of the students with mental retardation in the workplace will naturally happen when these students become adults. So many today still feel anxious or uncomfortable around citizens with mental retardation because they look different or have extreme difficulty communicating and many haven't learned to deal with this. You heard Arlene Kanter say yesterday that adults with mental retardation are less dangerous, and less threatening to the neighborhood than most other citizens. Awareness is crucial Part of my responsibility as a school administrator is to improve community-school relations, school board relations, school morale and image building. I must get out in the schools and in the communities. Many central office school administrators/school board members seldom visit the classroom. We must get out and visit with our handicapped students in their learning environment. We must talk with the students, teachers, and parents. We must be educated about the nature and the needs of our handicapped students. This education (awareness training) must include the principals and teachers of non-handicapped students. In my district when one or two of the board members get behind an issue, things happen. Because of the persistence of one board member, our district, in less than one year's time, has produced a comprehensive AIDS curriculum which is the first in our State. With constant awareness before the public, support for citizens with mental retardation can be a reality. At most school board meetings in my school district, a parent or other advocate for the children with disabilities, speaks out during

the public forum for improvements in special education services. This public awareness impacts favorably on programming for children with disabilities in our schools.

In the past we have seen days of readily available public funding for our special education programs, but; we are now seeing days when Federal resources are drying up and State resources are stabilizing at what seems to be unrealistic service levels. Public awareness and support are crucial for funding.

I come to you from Horry County, South Carolina. Some of you may know us better as "The Grand Strand", one of the richest resort and retirement centers in the nation. Though our county's population is expected to triple in the coming twenty years, we find that we have three retired people for every child with a handicap in our school system...and we expect that ratio to increase tremendously in the future in favor of those taxpayers who are living out their "Golden Years" among us. In the area of education in general, not to mention the need to have funding for programs for handicapped children in particular, we live in an area which is already experiencing the "graying" rather than the "greening" of America. Population projections tell me that many of us will be facing similar situations in the future. One of the ways we are dealing with this problem is getting these senior citizens involved as volunteers with our special education students. By forming close alliances with our handicapped students these senior citizens will be more likely to support funding for our programs — vote yes for our school budget and bond referendums. This goes back to the awareness concept mentioned earlier.

We are also looking at ways to expand our *adult* development programs. Because of the tourism-orientation of our area we probably have more restaurants per capita than any other county in our State. We also have more than 50 golf courses. Involving adults with mental retardation in the operation of restaurants and golf course maintenance is something we must get serious about.

Not all of our problems can be cured overnight, but; there are some low-cost/no-cost ways that we educators can explore that will improve the system to persons with mental retardation:

1. We can arrange for dual memberships in PTAs and ARCs so that parents of our students can become involved in looking toward the future.
2. We can work with our administrators to see if we can learn to collaborate with local. mental retardation service agencies and other community agencies in the submission of certain types of budgets so that our constituents can become accustomed to the idea that we work together. We have formed inter-agency councils to deal with this.
3. We can test the waters to see if it's possible to get our local governing boards and our State and Federal legislatures to work to relieve the vacuums they often inflict upon all of us when narrowly defined programs are funded through individual bureaucracies to isolated local programs. Let's ask them for more incentives for us to work together in developing programs, seeking funding, and sharing credit ... and blame!

In conclusion, what I am really here to do is issue a strong call to educators to become involved in the needs of all related community service programs There is no such thing as an isolated concept of "Special Education" which begins when a child stands on our doorstep at the age of 5 and ends when we present him a certificate at the age of 21! We've got to remove the artificial barriers that keep us from knowing what else in this area is going on around us, and we've got to get our parents involved in time to help these adult service agencies improve their long-range predictions of need and planning.

If educators need a selfish motive for changing the way we view these "other agencies", then I offer one: It's pretty simple, really. Across this nation, educators are asking to be judged ... and rewarded ... on the basis of our successes in the classrooms. It comes as no startling truth ... though it is generally more true in the area of special education than it might otherwise be ... that we cannot be favorably judged on how well we've prepared a child with mental retardation for adulthood unless and until there are adequate, challenging support services in the continuum. Special education no longer has the connotation that our job is done when we let an adult with mental retardation out of our system once he/she chronologically reaches the age of 21.

But we've got to do more than look ahead and reach up. There will be times when we must reach down to the pre-schoolers and work hand-in-glove with other agencies to be sure that early intervention and adequate diagnosis are accomplished as soon as evidence of a child's developmental delays become noticeable. There will also be times when we must reach out to find suitable summer services and respite for parents who need vacations from their family circumstances much more often and yet are least likely to get them.

This, then, is the role I see for educators. Think of us as the gentleman who has the second dance on the parent's Dance Card. Usually parents come to the dance with another escort — the human service agency that has helped them identify their children's problems and provided some type of pre-school help.

We in the schools have the Second Dance. We must introduce ourselves and "break the ice", politely offer all the help and support we can muster, and then, some 18 years later, we turn both the parents and our students over to those agencies which offer services for adults with disabilities — work activity centers, sheltered workshops, group community living arrangements. If we in education do our job right, as the traditional role, as the family's Second Dance Partner, we will, when the dance is over, usher them smoothly along to new partners who will already be their old and trusted friends.

The Law of the 85th Monkey also applies to us in education. This story comes from a wonderful book by Marilyn Ferguson called *The Aquarian Conspiracy*. There was this tribe of monkeys that lived close to the shore and ate oysters. The oysters carried a micro-organism that made the monkeys sicken and die. One day, almost by accident, a monkey picked up an oyster and washed it off in the surf before she ate it. She didn't get sick. Several other monkeys began washing their oysters. By the time the 100th monkey washed his oyster, all the monkeys from that point on did it and they were henceforth saved from the deadly microorganism. Now, it is not given to each of us to be the 100th monkey. We may be the 85th monkey, and important to a pattern that we don't know about and can't see. But the efforts of each of us are important, in ways we can't imagine. We educators can make a difference; we have the power and the capacity. We can provide an integrated society where our citizens with mental retardation can live, learn, work, and play successfully. We must make it a priority.

Recreation/Leisure/Socialization Panel

MODERATOR:	STUART J. SCHLEIEN, PH. D.
PANELISTS:	SIRKKU "SKY" HILTUNEN, ED. D.
	JOHN W. CHROMY
	K. J. MOORE

Community Leisure Services and Persons with Mental Retardation

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A historical look at the kinds of recreation programs that have generally been made available to children and adults with mental retardation reveals a substantial gap between the services needed and those available. The recreation programs offered for school-age children, for example, have focused on a small set of activities so predominant in this area that they have become stereotyped. These include bowling, swimming, arts-and-crafts, and field-trips. Summer programs offer a similarly restricted range of options. Most typically, children and youth with mental retardation may attend a handicapped-only camp (which itself is labeled with a "handicappism" such as "Camp Hope") for 1-2 weeks during summer vacation.

Finally, even those recreation events which might be available in community settings require that persons with disabilities be segregated from those who are not disabled or, when interactions with nonhandicapped persons do occur, that they participate in integration experiences characterized by strictly hierarchical role relationships. In these relationships, the nonhandicapped person is the helper and the individual with disabilities receives the help. Special events such as "Special Kids Day" at the county fair, and the annual handicapped- only Christmas party hosted by local service organizations all fall into this category. While such programs are not necessarily detrimental, and often benefit those they serve (there are many, for example, who continue to support segregated programs at a time when integration has otherwise become a widely accepted value which should be reflected in activities and services), their continued dominance does create difficulties.

Just as community integration involves mastering certain skills and activities in the vocational and domestic liying domains, the ability to deal constructively with leisure time has been considered an important predictor of successful community adjustment. There is evidence that difficulties in dealing positively with free time — such as a coffee break at work or evenings in a group home — will impede the success of a community placement even when the individual has otherwise mastered specific job and domestic living skills. Thus, various authors have emphasized the importance of providing systematic instruction to address leisure education needs, and argued that the learning characteristics of persons with mental retardation require that this instruction focus directly on criterion activities and situations as they actually occur in community environments.

STATUS OF COMMUNITY LEISURE SERVICES

In 1977, the National Recreation and Park Association (NRPA) adopted a position statement calling for the application of the principle of the least restrictive environment (LRE) to the design and delivery of recreation and leisure programs for persons with developmental disabilities. The challenge of providing integrated services in this area is not unlike that confronting educational agencies whose existing service delivery pattern involves the segregation of children with handicaps from their peers into separate schools and classes. However, while clear mandates for services and trained professional staff have facilitated the development of integrated public school educational programs in many parts of the country, these and other critical stimulants to similarly integrated programs in recreation are either inadequate or nonexistent.

An examination of the existing service delivery systems in community recreation reveals

a variety of agencies that provide leisure and recreation services to persons with and without disabilities. Schleien and Werder (1985) categorized these into three major groupings: 1) tax-supported municipal or county park and recreation agencies which serve as neighborhood centers providing a variety of recreation and leisure services, 2) community education agencies, also tax-supported, which are generally school-centered (e.g., in a community college) and provide a range of recreational, continuing education, cultural, and social services to all segments of a community in response to presumed needs; and 3) educational and other service delivery systems (such as community mental health and mental retardation boards, state hospitals, and other specialized programs) funded solely or primarily to serve persons with handicapping conditions. In addition to these "public" programs and services, advocacy groups and community service organizations frequently sponsor nonschool activities for children and youth with disabilities. These include programs supported voluntarily by parent groups (e.g., a summer camp or respite service supported by the local Association for Retarded Citizens or Society for Autistic Citizens chapter). Several studies have been conducted to survey such community agencies and assess their respective roles and both actual and perceived responsibilities to provide services to children and youth with disabilities. Schleien, Porter, and Wehman (1979) surveyed both generic community agencies and those funded by the developmental disabilities unit in Virginia, and found that 69% of the agencies offered some form of recreation services to persons with developmental disabilities. Austin, Peterson, Peccarelli, Binkley, and Laker (1977) surveyed a number of agencies, including municipal park and recreation departments and health care and correctional facilities throughout Indiana, regarding the therapeutic recreation services they were providing. Eighty percent of the 50 responding park and recreation departments stated that their agencies should be serving special populations, and 76% did offer such services, although only 5% of the programs were supervised by a therapeutic recreation specialist. Austin et al. (1977) concluded that existing programs were insufficient, and that a majority of municipal park and recreation departments were not providing adequate services.

In a statewide survey of all relevant municipal recreation, public school, and community education agencies, Schleien and Werder (1985) attempted to establish a baseline for future efforts in a shared responsibility system that delivered community recreation services to persons with disabilities in Minnesota. They reported that each agency type believed that one of the other agencies should be primarily responsible for meeting such needs. A large majority of park and recreation agencies believed that community education programs should be primarily responsible, and an even greater percentage of community education agencies maintained that park and recreation agencies must assume primary leadership in this area. Although the public schools assumed a minor degree of responsibility for special recreation services, a majority of the school respondents were not even aware that other recreation service providers were available in the community. Collaborative and cooperative efforts were not likely to occur under such circumstances.

Schleien and Werder (1985) found a gap between the services needed and those provided. Available recreational activities apparently were based on the choices of instructors and the availability of space, equipment, and time, rather than on any systematic assessment of consumer needs and preferences. They concluded that while all three types of agencies were indeed providing some special recreation services, these were limited and typically did not match client service delivery needs. Community education and park and recreation agencies seemed to provide only a few typical recreation services, and schools reported some incorporation of recreation skill instruction into adapted physical education classes. Schleien and Werder highlighted the implications of a lack of clearly consensual and collaborative roles and responsibilities among the agencies involved. In some cases, even an awareness of the services which were and might be provided was found lacking. While the various agencies generally agreed that they were responsible both individually and as a group, redundant services were common. Such duplication of effort by multiple agencies did not appear to reflect any deliberate transagency plan to emphasize certain types of programs. The agencies involved were unaware of similar or identical programs elsewhere.

GUIDELINES AND RECOMMENDATIONS FOR PLANNING COMMUNITY LEISURE SERVICES

The acquisition of functional (i.e., skills which are naturally occurring, frequently demanded and have a specific purpose), age appropriate (i.e., activities typically performed by persons in a particular age group), leisure skills referenced against nondisabled peer performance criteria presents a powerful tool to integrate persons with mental retardation into normal-

ized community environments. The selection of leisure skills should reflect this potential benefit, in that only those skills or activities which have the potential of being performed in the presence of, or in interaction with nondisabled peers should be selected for instruction. Anything short of this goal will do little to mitigate the (unnecessary) longitudinally arranged segregation of persons with developmental disabilities, and could result in the acquisition of leisure skills that meet the substandard performance demands of protective segregated settings (Schleien & Ray, 1988).

Based on survey results and careful analysis of the various obstacles that inhibit leisure skills development and community access, several recommendations for program planning efforts include: 1) distinct networks of communication across agencies must be established to reduce duplication of effort and to complement resources, 2) the range of activity offerings must be expanded, 3) integrated community recreation programs should be encouraged and established, 4) the number of specially trained personnel should be increased and supported across agencies, and 5) in general, access and availability of special recreation programs must be improved. If such lofty goals are to become reality, transagency planning and cooperative sharing of programming responsibility in the provision of these services are critical.

In order to succeed in promoting maximum integration in community leisure environments, an interdisciplinary approach in the design, delivery, and evaluation of these services is necessary. Consumers with disabilities, families/ careproviders, public and private leisure service agencies, and state and federal governments must develop partnerships to instigate changes in the various service delivery systems.

Consumers. These efforts must begin at the individual citizen or consumer level. Greater self-advocacy efforts must transpire to encourage expansion of leisure services and activity offerings. Community leisure service agencies must offer programs that are based on the preferences and needs of persons with disabilities, moving beyond stereotyped activities of bowling, swimming, arts-n-crafts, and field-trips, programs typically offered to persons with disabilities. Citizens inadequately served in integrated community environments, and their careproviders, must communicate their desires and insist on a broader range and more normalizing types of activities such as integrated camping, nature, music, skiing, and cultural arts.

Families. Since we already know that a successful community residential placement in itself does not guarantee a normalized leisure lifestyle (Birenbaum & Re, 1979; Schleien & Meyer, 1988) and that families often shoulder the major responsibility for providing recreation activities and opportunities (Chesseldine & Jeffree, 1981; Wehman & Schleien, 1981), careproviders must also collaborate with the various service delivery systems Families could demand leisure/recreation related goals and objectives in their children's individual education plans during planning meetings in school, and could play more active roles in the delivery of community leisure programs. Examples of these efforts include parents or siblings serving as volunteer advocates or coaches as co-participants in an activity, and families playing active roles in the advancement of their children in organized recreation as are currently performed in scouting programs.

Public-Private Partnership. In order to optimally meet the needs of persons with disabilities, the responsibility for improving and expanding recreation services should rest with professionals, educators, and families in public and private recreation agencies, community education, and school environments. If responsibilities are spread too widely among agencies, however, it is possible that (a) no one organization will guarantee they are carried out, or (b) lack of communication could lead to redundancy or gaps in services. In contrast, a lead agency designated to assume overall programming responsibility could function to insure that comprehensive recreation services were provided in an efficient and effective manner. This responsibility could be assumed on the basis. of the chronological ages of the participants served or on the basis of resources available in the community. For example, the responsibility for training young people in leisure skills could be assumed by public schools and by specific community recreation agencies (e.g., public recreation and park departments, private health clubs, community education agencies) for adults. Or responsibility could fall with the agency best equipped in terms of facilities, staff and funds to provide special leisure services. However, the success of dividing responsibilities depends upon the quality of communication among the agencies.

If, for any of a variety of reasons, public and private agencies fail to share the responsibility for providing quality leisure and recreation services for individuals with disabilities, one agency should assume leadership. It is logical that public park and recreation agencies assume responsibility for delivering leisure services. Since it is the public recreation and park department's responsibility to meet the

needs of all citizens within the political jurisdiction, it is prudent that this agency group assume a primary leadership role in the trans- agency model of special recreation service delivery. As a leader, park and recreation agencies can bridge the gap between public schools, which provide prerequisite recreation skill instruction, and community education and private leisure service delivery systems which provide opportunities to generalize leisure skills in actual community situations. In this vital role, park and recreation departments can provide the practice and experience for individuals with disabilities to develop preferences and refine recreational skills.

Transagency models and shared responsibility for recreation programs are natural theoretical approaches to therapeutic recreation. That such models are uncommon in practice is not surprising, given the complex communication and shared resource networks necessary.

Federal-State-Local Partnerships. From a broader perspective, federal, state, and local governments have important roles to play in the delivery of community leisure services. Agencies within federal (e.g., Office of Special Education and Rehabilitative Services) and state (e.g., State Developmental Disabilities Council) governments must continue to be concerned with the availability and training of program staff to design and deliver special recreation programs. In the Schleien and Werder (1985) study, almost nine of every 10 recreation agencies did not employ a full-time professional. Like other surveys in the past, a scarcity of program leaders with training in therapeutic recreation, adapted physical education, or special education was found in community leisure environments. The lack of such levels of training was indicated to be a primary barrier to offering special and integrated recreation programs. However, research is currently underway to investigate the amount and type of trained leadership necessary to successfully integrate persons with developmental disabilities. Initial findings reveal high levels of appropriate play on the part of the participants with disabilities and increased positive nonhandicapped peer attitudes toward persons with disabilities, with only minimal added expense to the agency.

Also, other federal agencies such as the Rehabilitation Services Administration must frown upon the proliferation of separate, handicapped- only after-school recreation programs, special camps, and segregated social clubs and alter their priorities to support the development of integrated recreation programs. Local education agencies should be encouraged to hire professionally certified Therapeutic Recreation Specialists (i.e., C.T.R.S.) to consult with classroom teachers and physical educators in the schools. Only in this manner will leisure education become a viable component of the daily school and after-school curricula for children with and without disabilities.

SUMMARY

The importance of communication and collaboration across individuals and agencies has become apparent and must be addressed if integrated, accessible community leisure services are to become a reality. While the onus of responsibility for accessible services seems to fall on the public park and recreation agency and staff, the therapeutic recreation specialist, care- providers, consumers, and other key players must assume active roles in this process. These individuals have unique perspectives in that they understand the importance of leisure in the quality of life for everyone, including persons with developmental disabilities. Integration and the development of accessible community leisure services must be approached carefully and systematically if all citizens, with and without disabilities, are to receive successful community leisure experiences and realize a decent quality of life.

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Future Goals of Special Olympics

by John W. Chromy
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BACKGROUND

The future of Special Olympics is being determined by the achievements of one million athletes with mental retardation currently in the program. These athletes, though aged eight through eighty, are very young in spirit, enthusiasm and they delight in the joy of achievement.

Special Olympics set out to give people with mental retardation a chance to participate in sports and to expose people of communities, in a positive way to the achievements of Special Olympians.

The response of the athletes to this opportunity has been overwhelmingly positive. The response of the two-million plus citizens who have volunteered to put on Special Olympics Games has also been enormously positive. But in recent years Special Olympics athletes have pushed the boundaries of our program even further.

- Hundreds of them compete in community 5K and 10K runs, and some compete successfully in the Boston Marathon.
- All across America Special Olympics athletes have been invited to exhibition competitions in high school and college track meets.
- Recently Special Olympics athletes, competing as members of Baton Rouge Weight Lifting Club, won five medals in a Southeast Regional National Strength and Conditioning Association competition.
- Thousands of Special Olympians compete in community bowling leagues.
- In 65 high schools across America, Special Olympics athletes are accepted into the Athletic Letter Club and receive letter jackets for their participation in that, school's Special Olympics team.

The story goes on. We are finding that people with mental retardation, if given a chance to train and compete not only can achieve in Special Olympics sports but are now carving a niche for themselves in community sports organizations. And, wherever our Special Olympians actually are given the chance to compete, those who witness their courage, determination and joy, respond positively to the Special Olympians' participation. So truly the achievements of the Special Olympics athletes are pointing the way for Special Olympics' future.

Special Olympics plans to continue to provide people with mental retardation a place to train, train and train in sports so they develop the confidence, courage and skills needed to play a sport with dignity and pride.

Special Olympics will continue to organize year-round competitions in 14 Olympic sports so those that have trained will always have the opportunity to share in the thrill of competition. These competitions will be organized by age, sex and skill level so that each competitor will have a reasonable opportunity to share in the victory. In organizing training and competitions, Special Olympics will continue, as it has in the past to include non-retarded people in a variety of roles which foster mutual understanding, learning and respect for Special Olympians.

Special Olympics as it now exists fosters integration and normalization in 22 different ways. But there's more to come.

- A heavy emphasis is being placed on arranging peer coaching particularly in the junior and senior high school programs.

- A number of National service clubs have been approached for their assistance in organizing more Special Olympics participation in sports events organized in the community
- Special Olympics is currently experimenting in six sports with teams composed of both athletes with mental retardation and athletes without any handicap.

So the direction of the future of Special Olympics is clear. Provide people with mental retardation with the proper training in competitive sports, lots of opportunity to compete within Special Olympics, lots of exposure to people without mental retardation within Special Olympics programs and lots of encouragement to enter into community sports if Special Olympians so choose. The latter is most important. The choice must be theirs for having choice is the ultimate in normalization.

Providing Art and Drama Therapy Services to Persons with Mental Retardation and Developmental Disabilities

by Dr. S. Sky Hiltunen
The Art and Drama Therapy Institute, Inc. (ADTI)
Washington, D.C.

The Art and Drama Therapy Institute, Inc. (ADTI) was founded in 1985. It is a non-profit organization which offers art and drama therapy services to adults with mental retardation and developmental disabilities in the Washington, D.C. area. Fifty to sixty adults are served by ADTI. They meet in groups of 5-12 approximately two hours weekly. The current program is funded by the Washington, D.C., Department of Human Services, and Mental Retardation/Developmental Disabilities Administration (MRJDDA). The level of clients served ranges from mildly to profoundly mentally retarded. The range of disabilities is as follows: visual, hearing and speech impairments, emotional and psychiatric problems and physical handicaps.

ADTI was founded to meet the growing needs of the deinstitutionalized clients. Their transition from institution into community has presented new demands and expectations, especially on their social skills. ADTI's art and drama therapy program offers a variety of means and media to enhance the participant's socialization skills: peer interaction is encouraged through drama, movement, mime, masked mime, group improvisations and initiation of group discussions. The modeling as well as role playing of appropriate social responses and behaviors is a part of the therapeutic intervention.

Deinstitutionalization efforts locally and nationwide state normalization as one of its major objectives. Sometimes institutional settings have been found to be restrictive, impacting the development of residents' ability to respond appropriately to a variety of social cues in their environment. For effective community integration, maximum social skills are a fundamental prerequisite. Therapy Theatre Company (TTC), which is a side project of ADTI's art and drama therapy program, provides training through process theatre and opportunities for community integration through public performances. TTC has performed since September 1986 a total of six times for a variety of audiences. One of the general goals of TTC is to strengthen rapport between communities and the deinstitutionalized residents with mental retardation. Whereas some of the primary goals of the performances are to inform, educate, and change the perception of the audience more positive toward persons with mental retardation. Actors wearing masks and Japanese style costumes on stage project a positively enchanting image of themselves. With this new image, the perception of the audience on mental retardation will hopefully change and the audience will learn to appreciate the unique talents of the Therapy Theatre Company's ensemble.

The art and drama therapy program is open to all clients who are served by the Mental Retardation and Developmental Disabilities Administration. Initially, a referral can be made by case managers, social workers, psychologists, psychiatrists, parents or other therapists. The primary art and drama therapist will screen and assess each referred client and then make recommendations and referrals for appropriate groups.

Some of the general objectives of the art and drama therapy intervention are as follows:

- to enhance fine motor coordination through drawing, painting, mask making, mixed media sculpture, manipulation of an improvisation with instruments;

- to enhance gross motor coordination through movement, mime and mask pantomime improvisations;
- to enhance expressive and receptive language skills through verbal associations on their visual art work, group discussions, story listening and telling;
- to enhance communication of thoughts and ideas through non-verbal means of visual arts (drawing, painting, mixed media sculpture, mask making, mask collages) and drama (movement, mime and masked mime improvisations);
- to enhance self-awareness, self-esteem, and self-confidence through Therapy Theatre Company training and public performances;
- to enhance the integration of thinking and emotions through visual arts (weaving and collage work);
- to enhance the ability to identify, label, and express feelings through the process of mask and character selection, verbal associations on all of the created art work (drawings, masks, etc.) and the process of creating autobiographical poetry about their childhood, youth and adult life experiences;
- to enhance initiative, independence, decision- making, and problem solving skills through Therapy Theatre Company training and public performance, group improvisations and group discussions.

The Art and Drama Therapy Institute, through its cooperation with the Mental Retardation and Developmental Disabilities Administration, is able to provide its services for deinstitutionalized adults with mental retardation and developmental disabilities. As a result of this public/private partnership the residents with mental retardation are offered this unique opportunity. This program serves as an example of a therapeutic process in which enhanced socialization, communication and community interaction promote normalization and community integration of citizens with mental retardation.

RECOMMENDATIONS

To recognize legislatively art and drama therapy for individuals with mental retardation and developmental disabilities as viable and significant treatment modalities.

To identify sources at Federal level and allocate funding for art and drama therapy in educational, rehabilitative and clinical settings.

To identify, develop and implement private/ public partnership modalities for funding art and drama therapy services/programs for individuals with mental retardation and developmental disabilities in educational, rehabilitative and clinical setting.

Family Supports/Respite Care Panel

MODERATOR: RACHEL D. WARREN
PANELISTS: SHIRLEY COHEN, PH.D.

Respitality: A Unique Private Industry and Service Agency Project

by Rachel D. Warren
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(former Program Consultant, United Cerebral Palsy Associations, Inc.)

Quotes from parents:

"We enjoyed the time off so we could be just two..."

"A rare opportunity to relax, reorganize our lives and gain perspective we needed to remain good parents to a severely handicapped child"

RESPITALITY© is an innovative community-based family support project which has evolved over a nine-year period. The word RESPITALITY© (which has been copyrighted by United Cerebral Palsy Associations, Inc.) is derived from two words — respite and hospitality. "Respite care" has been defined as a period of rest and relief; "hospitality" is defined as the act of being friendly towards guests, and a change of scenery, friendly faces, and a warm inviting room. RESPITALITY© then combines respite care provided by a public or private agency with hospitality donated by hotels, motels, restaurants and entertainment businesses to offer parents of children with special needs a refreshing break — time away by themselves.

RESPITALITY©, by its purposeful design, promotes maximum community integration. Many, many partnerships were forged to permit such family and community support — there were partnerships with families; partnerships with hotel/motel, restaurant and entertainment industries; partnerships with federal, state, and local governments; partnerships with voluntary agencies; and partnerships with media. This paper will briefly describe the history, evolution, processes, and partnerships that we required for UCPA, Inc., to demonstrate RESPITALITY© on a nationwide basis.

First, a little history regarding the development of this project:

The beginning — The year was 1978. A federal national significance grant was awarded to City University of New York by the Administration on Developmental Disabilities. The subcontract granted to UCPA permitted demonstration of urban and rural models of respite care.

The town — Bangor, Maine

The context — UCPA, Inc., consultants were completing site visits to pioneer rural models of respite in northeast Maine. Parents were calling out for a break — time away from their care-giving responsibilities to refresh and renew their families. In 1978, efforts were just beginning to design and evaluate respite care.

The setting — A parent group meeting to discuss the feasibility of utilizing a summer camp as a setting for out-of-home respite care.

The response — Many well-conceived and fun activities were detailed for the children — and then a Dad leaned back in his chair and said: "Wouldn't it be just great if we, as parents, could have that type of weekend getaway — have time together, drink a few beers, and just relax!"

It was just that kind of genuine and deeply felt testimonial that planted the seed that grew and

resulted in designing and demonstrating a service that could address the need for the real, normal "vacation" break that many families take for granted.

This project did evolve very successfully due to activities emerging across three distinct arenas — the respite services arena, the federal government arena, and the private, voluntary services arena. The activities in each of these arenas will be described briefly. First, a brief review of the respite services arena:

- By the early 80s, respite services were defined and families began to accept, utilize, and trust respite services;
- By the mid 80s, requests for using respite began to shift towards fun family-centered activities and away from crisis requests to attend to emergencies;
- By the 80s, respite workers were reporting many other needs of families — transportation, counseling, equipment, loans, etc.;
- By the early 80s, respite staff became advocates for a broader array of family support services;
- By the mid 80s, original definitions of respite were better understood, i.e., respite was seen as one component of a family support service and it was felt respite should not be provided in isolation from other family support services, and finally,
- By the mid 80s, respite services were developing in most states, though availability was still very limited and scattered and budget cuts seemed imminent.

The second arena included the federal perspectives on respite care and the appropriations to support nationwide development. Beginning around 1976 and continuing to the present time, the federal government awarded many grants to develop respite care — first to demonstrate and evaluate respite models, and later to design statewide respite systems. Requests for proposals during the last five years had underlying themes of volunteerism, private sector participation, and cost-effective, easily replicated projects.

The third arena was represented by activities undertaken by a national, non-profit organization, United Cerebral Palsy Associations, Inc. For well over 10 years, program staff were given responsibility to develop respite services as a top national priority. That focus led to participation in varied grant activities, presentations during many meetings, consultations in numerous states, and documenting activities in books, manuals and articles. All of these activities resulted in a rapidly growing interest in respite care. But that interest mounted during a time when established services were competing for scarce funds, making it very difficult to develop a new service like respite.

The themes which emerged in these three arenas provided the basis for designing RESPITALITY©. These themes could be summarized as follows: (1) all families have needs for fun and vacation-type activities; (2) services to families should be integrated, community-based and family-centered; (3) volunteers and neighborly support play a crucial role in our lives;
(4) cost effective designs are critical; and
(5) collaboration is essential during a time of limited resources.

With these themes in mind, the concept of a hotel approach to respite seemed very feasible. Such an out-of-home respite setting would surely be cost-effective, humanistic, participatory, visible, and fun! Preliminary research into the hotel industry seemed to indicate a win- win partnership with families, private industry, service agencies, and communities.

The immediate task at hand was to design a short- and long-range strategy to solicit buy-in from all these partners. The plan included six major strategies — Community Development, Program Development, Family Involvement, Hotel Development, Restaurant/Entertainment Development, and Public Relations.

Many varied partnerships were required to implement these strategies. An extremely high level of enthusiasm was generated by orchestrating activities with the various partners. The pilot project began in August 1985, with UCP of Mobile in Alabama. Two major hotels — Stouffers and Marriott — joined in immediately. The overwhelming acceptance of the project by families, hotels, and communities led UCPA, Inc., to expand its efforts across the U.S. Four additional UCP affiliates were included in October 1986 to field-test the implementation plans drafted in Mobile. The other participating affiliates were UCP of Northeast Maine, UCP of Northwest Florida, UCP of Hudson County, New Jersey, and UCP of Central California. By August of 1987, the following results had been achieved:

(1) Doubled the number of participating hotels to 10 in only 6 months.
(2) Four grants were awarded from both the public sector and private foundations.
(3) Television and newspaper coverage was ongoing at all sites, with many TV and radio stations donating time to us to develop various audio-visual products.
(4) National recognition gave credit to the Stouffer's Hotel general manager — the very first hotel partner.

(5) Restaurant and entertainment partners were on board at all sites.

(6) Families were participating in every phase of planning, designing, implementing and evaluating the project.

(7) Videotapes, brochures, and tapes were prepared for national distribution.

(8) Local hotel general managers agreed to encourage adoption of the project by state hotel/motel associations.

(9) Participating business leaders agreed to serve on local agency boards.

(10) Hotels, entertainment and restaurant partners were recognized in a variety of ways, e.g., news stories, recognition plaques, thank-you letters.

(11) Hotel managers published articles about RESPIRALITY© in their hotel trade magazines.

(12) Staff of Sturgeon PR had coined the phrase RESPITALITY© and U.S. Congressman Coelho facilitated copyrighting the word for UCPA, Inc.

(13) Numerous volunteers had written songs and prepared tapes of those songs. Still others had developed brochures and produced promotional items, and finally

(14) Over 60 UCP affiliates had asked to join in!

These results, then, were achieved through the help of many partners. A few of their contributions follow:

FEDERAL GOVERNMENT

- Initial grant in 1978 awarded to CUNY/UCPA to demonstrate and evaluate respite care and parent training models.
- Subsequent grants made to several states to support respite development.
- Legislation passed to support funding for respite care.

STATE/LOCAL GOVERNMENT

- DD funds granted to numerous local agencies for start-up of respite.
- Respite care vendorized to a variety of agencies to provide respite while families were away for RESPITALITY©.
- Project acknowledged and promoted via numerous government networks.

PUBLIC/PRIVATE

- Grants and contracts approved for both respite services and RESPITALITY©.
- Both sectors participated on local advisory boards and task forces.
- Hotel, restaurant, entertainment industry staff donated numerous in-kind services.
- Media participated wholeheartedly via newspaper, television, newsletter, telethon coverage.
- Entire communities contributed to and recognized needs of their neighbors.

FAMILIES/SERVICE DELIVERY SYSTEM

- Families expressed an outpouring of thanks because "It was exactly what I needed ..."
- Families expressed feelings of true relief, because "The thought of it (RESPIRALITY©) puts me on Cloud 9."

Up to now, a very successful partnership project has been described. Where does this leave us with regard to meeting needs of families? RESPITALITY© is just one piece in the web of intertwined needs of families who have a disabled child. We need to continue to focus on the needs of families and on a systems approach — a holistic approach to the needs of families — be it a need for generic community resources like homemaker or recreation services, be it a need for specialized support services like respite care or adaptive equipment, " or be it a need for crisis intervention services when stresses become insurmountable. These needs must be met in an integrated, systematic and sensitive way.

For a number of years now, the federal government has funded, through the Children's Bureau, a number of National Child Welfare Resource Centers. One of these centers, the National Resource Center of Family Based Services, has a wealth of printed and personnel resources to contribute in building a family-based services model for meeting the needs of families with disabled children. A few models of family- based services focusing on such families have been documented. It would indeed seem advantageous to support financially a project or projects to permit the expansion of a generic family-based services model to meet needs of families with disabled children in a truly humane, systemic and cost-effective manner.

Respite Care from an International Perspective

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I was both pleased and somewhat anxious about the invitation to make a presentation at this conference about respite care from an international perspective. The subject of respite care is one I know well, having studied this topic since 1978 when I directed a project of national significance on respite care funded by the Administration on Developmental Disabilities. What made me feel somewhat anxious was the part about "from an international perspective." My credentials here stem from a World Rehabilitation Fund Fellowship implemented in spring 1987 on the topic of "Child Abuse, Family Support Services, and Disability." But while that study took me (and Rachel Warren) to a conference in Greece as well as to England, my knowledge about respite care from an international perspective stems largely learned from what I learned about respite care in England.

Let me back up a bit and tell you what I knew or thought about respite care before my fellowship study abroad. What I learned during the Project of National Significance from 1978 through 1980, and from the additional work that Rachel Warren and I did in the early to mid 80s in writing our book on respite care, was that respite care wasn't ready and waiting when the deinstitutionalization movement took hold, when families were told, in the mid 70s, that their sons or daughters were being sent home from institutions. In fact, lack of respite care was a major reason for readmissions from natural family homes to state institutions in the mid 70s (Pagel & Whiffing, 1978). Nor was respite care available for parents who couldn't cope with the care needs of their young severely disabled children after institutions closed their doors to children. Families had to de-mand respite care and fight for it. Parents, rather than professionals, were the true originators of this service. In 1978 the Louisiana Development Disabilities Council found that 68 agencies serving individuals with developmental disabilities in that state reported receiving requests for respite care from families although only 16 offered this service.

Professionals had, in fact, allowed a major gap to develop in the wake of deinstitutionalization. It was a gap created by good intentions — to stop, to remove as quickly as possible the damage caused by the warehousing of people. But in their eagerness to undo the harm of warehousing and support a better approach, professionals ignored the needs of families again, or didn't fight hard enough to meet these needs, leaving many families to be strained beyond their coping capacities, barely holding together or not holding together.

By 1980 respite care had gained the recognition of professionals as a sorely needed service. A national survey of state agencies on the problems of children with handicapping conditions and/or their families resulted in respite care being identified as one of the two major problem areas, i.e., as one of the two services most needed but not available (Human Development Program Title XX Training Project, 1980). Yet it took several more years after that for respite care to become a service widely available in most states; and even today there are states in which families that need respite care remain largely unserved.

Every major study of respite care conducted from the late 1970s to the mid 1980s found that allotments of respite care time per family were inadequate. Some families hoarded their limited supply of respite care days lest

they need them for an unexpected emergency. Other families reported that while the allotted time per family appeared adequate, in practice families could often not take advantage of much of this time because the agencies providing respite care were swamped. Other families reported that more generous allotments of respite care would have enabled them to keep their adolescent children at home, something they badly wanted to do. Families had to fight for recognition of respite care as a needed service, and then had to fight further to try to obtain time allotments that were meaningful in terms of individual family needs. And except for a limited number of very good programs scattered throughout the country, one might still characterize the general status of respite care service provision as niggardly in relation to those families with the greatest need. I am thinking, for example, of a family headed by a single parent who has two severely retarded children, both with serious health problems. I am thinking about another family made up of a single parent and her extremely-difficult-to manage young autistic son. These families illustrate not only the need for flexible and, at times, extensive allotments of respite services but also illustrate another principle: Respite care may be ineffective in improving the functioning of families with extremely difficult child care demands, and may be used inappropriately in such cases, unless it is treated as one component of a total family support system. Respite care services cannot answer all family support needs. Homemakers, home health aides, attendants, infant and preschool programs, and after school day care are family support services that may more appropriately answer some ongoing relief needs than would respite care services.

RESPITE CARE IN BRITAIN

If we look at the development of respite care services, we get a different picture in Britain than in the United States. Behind this difference is the concept of "shared care," a concept accepted as a premise in Britain but accepted only in regard to families that are considered deficient in the United States. Shared care is an intermediate state between the government assuming responsibility for the care of a child and the child being considered the exclusive responsibility of his or her family. Institutional care represented an almost pure example of the State assuming responsibility for the care of disabled children. As individuals with disabilities came to be seen in a more humanistic way, and the pendulum swung away from institutional care in the United States, responsibility for the care of children with disabilities came to be relegated almost exclusively to their own families. The concept of shared care, or the shared responsibility of the State and individual families for the care of disabled children, was missing.

In Britain the concept of shared care led to the delineation of "short-term care" as a needed service in a government circular as early as 1952. It was some 20 odd years more before a similar delineation occurred in the United States. In the 1950s and 60s in Britain short- term care was provided in "mental handicap hospitals" (the rough equivalent of our state mental retardation institutions), in pediatric wards of general hospitals, and in some residential centers operated by voluntary organizations. In Britain the deinstitutionalization movement of the 1970s was seen as a shift in the shared care ratio or balance, with families of children who formerly had been institutionalized or who might have been institutionalized assuming greater responsibility for their children's care. It was not perceived as an opportunity for the State to bow out and expect families to do the whole job alone. In this light, the Department of Health and Social Security of the British government promulgated a guidance paper in 1971 advocating the establishment and provision of sitter services and temporary residential care by local governments and voluntary agencies (Robinson, 1984).

It was also because of the concept of shared care that the decrease in the use of institutions for the long term care of children in the 1970s was accompanied by the increasing utilization of these facilities for short term care. As the movement back to community care progressed, some residential schools and small residential homes were converted to respite care centers for children.

The mid 1970s marked the beginning of what may be referred to in Britain as "special fostering schemes," by which may be meant any one of a variety of on-going arrangements between individuals or families serving as respite care providers, and the families that are the recipients of this service. This is a very popular mode for providing respite care services in Britain today.

At this point let me back up a bit. Earlier, in discussing the status of respite care services in the United States, I stated that respite care cannot be considered apart from a framework of family support services. If this is true, then I cannot really elucidate respite care services in Britain without presenting the framework for this service. The "shared care" concept is basic to this framework.

Britain provides a series of non-means tested allowances to families. The "child allowance"

is a cash payment made to all families with children regardless of income or health status. In addition, there are several disability allowances. (Transparency #1) The "attendance allowance" is a benefit paid to an individual from age two up who, because of a mental or physical disability, needs help from another person. A higher rate is paid if the individual needs supervision or assistance at night as well as during the day. Family income is not a factor. The "invalid care allowance" (introduced in 1976) is a cash allotment provided to the child's primary caregiver if this individual spends at least 35 hours a week caring for the child and does not engage in substantial employment or attend school full time. There is also a "mobility allowance" (also introduced in 1976) available to individuals from age five up who cannot walk or who have great difficulty walking. Again, this is non-means tested. If we look at the first transparency you will see these disability benefits. (The child allowance is not included because it is not a disability benefit.) All of these benefits come from Britain's Department of Health and Social Security. The attendance allowance rates as of July 1986 were about $34.00 and $51.00 per week, with the higher figure for more severely impaired children. The invalid care allowance varies depending upon the number of dependents that the primary caregiver has. If the primary caregiver has only himself or herself as a dependent the benefit is about $38.00 per week (as of July 1986). If the primary caregiver has another dependent child another $13.00 per week would be added. The mobility allowance was about $35.00 per week as of July 1986. As you can see, a parent of a severely disabled child might receive $89.00 per week starting with the child's second birthday for serving as the child's primary caregiver. When the child reaches age five, if he or she cannot walk or has great difficulty walking, the benefit would go up to $124.00 dollars per week. We are talking now of about $6,500 per year to the primary caregiver or $4,600 if the child does not have a serious mobility impairment.

In addition, if you look at the transparency you will note that the health and medical care of the child is provided free of charge through the National Health Service. By health care I refer mainly to a system of health visitors who go into the homes of all families of young children, starting in the first month after the child's birth. It is the health visitor's responsibility to identify problems or potential problems and to ensure that appropriate resources are brought to bear. Young children with disabilities get particular attention from health visitors, who visit these babies' homes more often than the homes of children not demonstrating developmental problems.

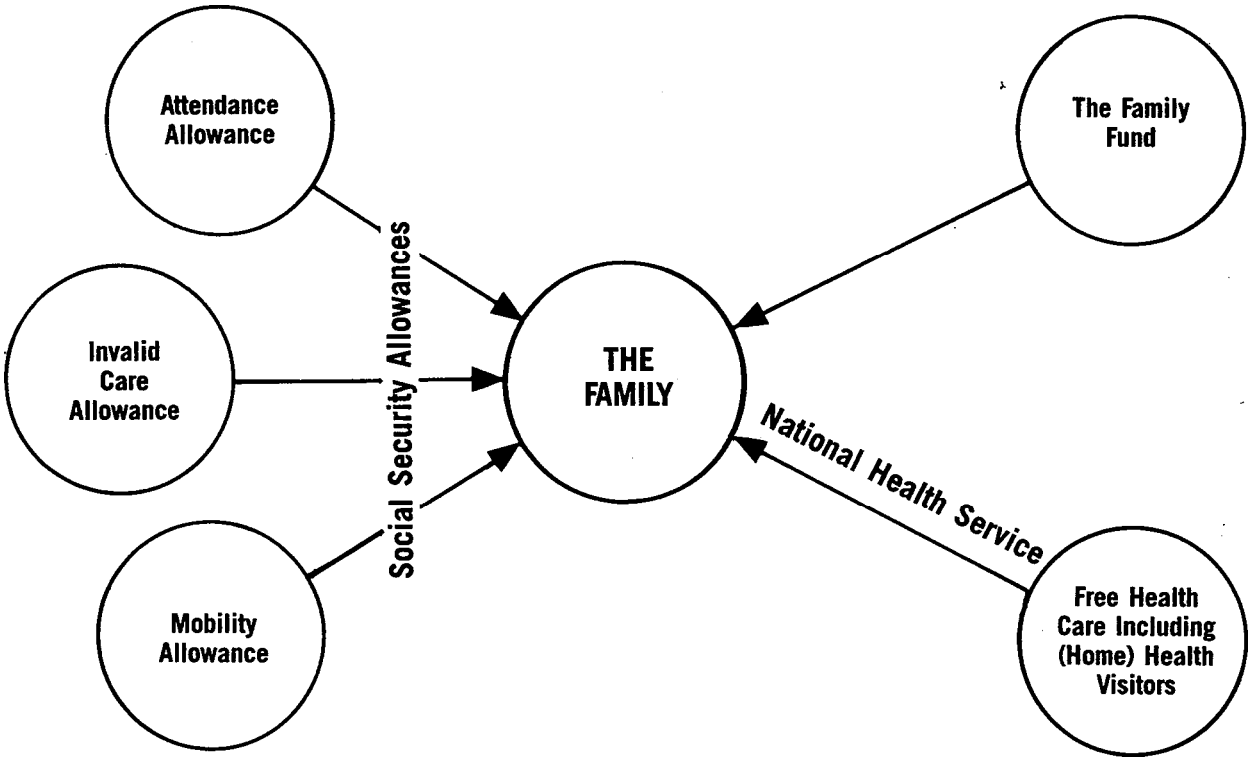
The third item on Transparency #1 is The Family Fund. This is a fund financed by the central government but operated by the Joseph Rowntree Memorial Trust. Its job is to help families with severely disabled children by lump sum grants for specific items, e.g., *washing machines* and *dryers;* a holiday for the whole family.

Now let us compare these benefits to the benefits available in the United States from the federal government for families with severely disabled children. The benefit that comes to mind immediately is Supplemental Security Income or SSI. SSI is available to individuals with disabilities aged 18 and over irrespective of family income. However, in the case of children under age 18, family income is considered in determining eligibility. Thus, while very low income families of children under age 18 may receive SSI, other families will not, except by individual waiver. SSI is not seen as a right of families because of the extra financial and/or care demands involved in raising a child with a disability. It is provided only when a family is considered deficient and therefore incapable of meeting its responsibility. Medicaid reflects this same pattern, being available only to families with extremely low incomes. This is true in spite of the fact that the extra cost of raising a child with a disability might be as high as $95,000.00 when no surgery is involved, $126,000.00 if surgery is involved (United Cerebal Palsy Associations, 1986), and these figures in no way reflect the extra care demands upon the family. There is no concept of shared care reflected here, and no equivalent to the non-means tested benefits available to families of children with disabilities in Britain.

Now let's look at local government responsibility for family support services in Britain (Transparency #2). Disability related services, located on the left side of this transparency, derive from the Chronically Sick and Disabled Persons Act of 1970. This law directs local governments or "local authorities" as they are called in Britain, to assess and provide for the service needs of individuals with disabilities in the areas of help in the home, aids and adaptations, recreational facilities, transportation assistance, and holidays. In practice, there is great variation in the extent to which local authorities provide such services, much as there is great variation between states and even between regions within the same state in the provision of such services in the United States. In fact, families residing in an area where the local authority provides very generous amounts of family support services may be afraid to

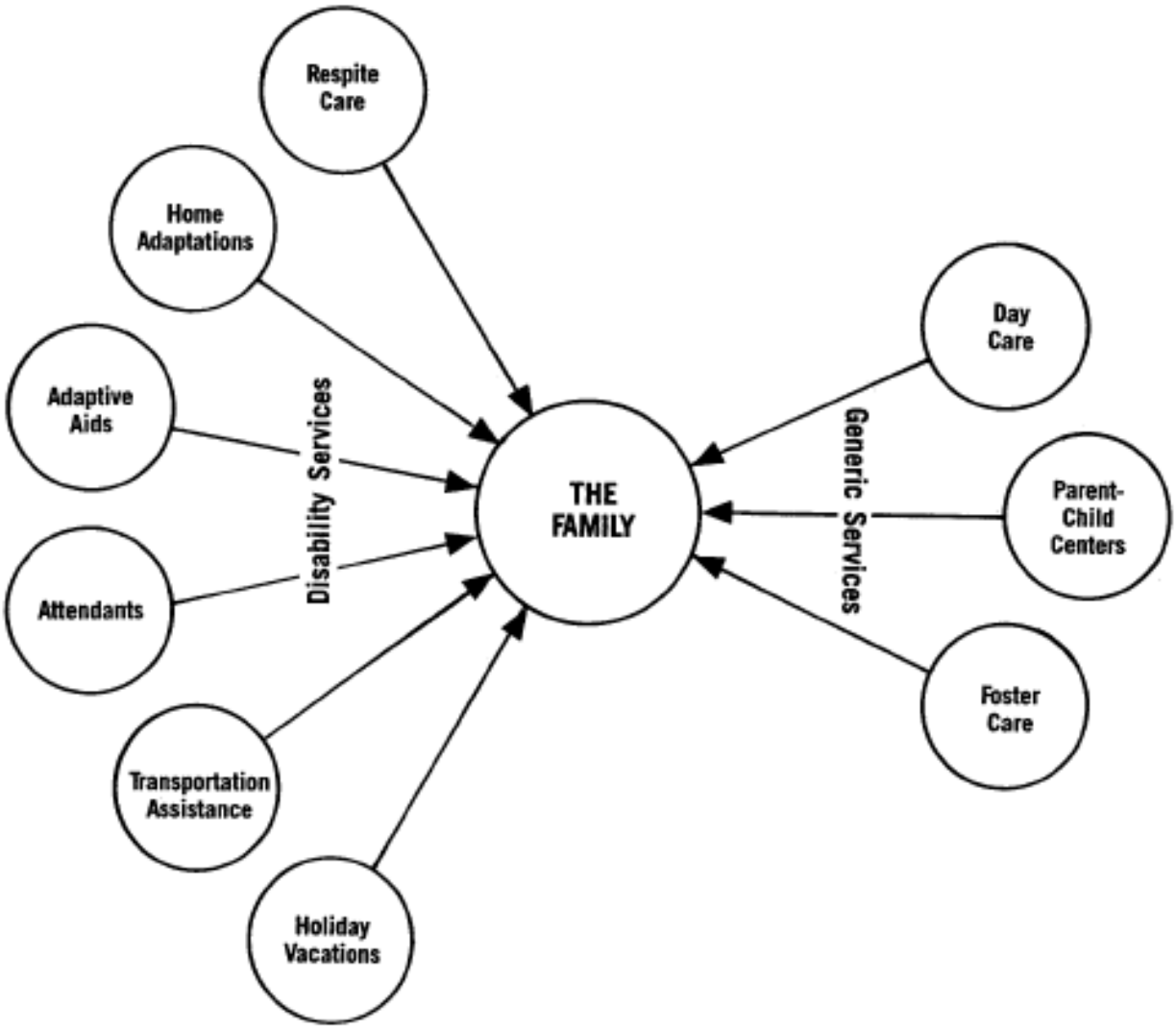
Transparency #1

Support Services for Families of Children with Disabilities
Central (Federal) Government Provision



Transparency #2

Support Services for Families of Children with Disabilities
Local Authority (Government) Provision



move to another area where the allocation of such resources might be less generous.

Now let's take a fuller look at the array of family support services in Britain (Transparency *3). Most of these services are very familiar to us — parent education, parent counseling, day care, respite centers, in-home respite, drop-in centers, respite in the home of the provider. Let me make a few comments about aspects of family support services that may be less familiar. One of these is the concept of family centers which began to take hold in Britain in the late 1970s. The family center may be a center serving all families in a particular community, or it may focus upon serving families of children with disabilities, or it may focus upon serving all families of young children in a community. The defining characteristic of these centers is that they have a commitment to working with parents and children rather than to children alone, and they have as a major objective improvement of the quality of family life (De'Ath, 1985). Family centers operate a variety of services, including many of those services listed on this transparency and others. This is a model we could well emulate in our local communities.

Toy libraries are widespread in Britain. They are a major resource for young handicapped children and their families. Toy libraries may be attached to family centers, special schools, playgroups, or hospitals. They may be operated by parent volunteers. Health visitors, local authority social workers, occupational therapists, and physical therapists often keep in close contact with the toy libraries in the communities they serve. There was a toy library initiative in the United States in the early 1970s focused primarily on the needs of low income families, but with modifications designed for applicability to families with young handicapped children. However, the toy library movement didn't become, in this country, the widespread resource it is for parents of young children in Britain, even though the movement experienced something of a revival in the 1980s. Perhaps the movement failed to take strong hold here because of the narrower focus of toy libraries in the United States. Toy libraries in Britain provide friendship, learning and support for primary caregivers as well as toys for children. It may be time to try this idea within the British sense of a toy library.

Let me just mention that parent self-help groups and help lines for parents — many of the latter run by parent self-help groups — are flourishing in Britain. Self-help groups are often affiliated with national voluntary organizations which nurture and support them.

While we in the United States are very active in providing camp and day camp experiences for children with disabilities in the summer, and there are 11 month school programs for children with severe disabilities, we do very little to provide respite for families during school holidays, such as the winter and spring breaks. Britain responds to this need by the widespread operation of holiday play schemes, usually day recreational programs provided specifically for the purpose of keeping children engaged and giving families respite when schools are closed.

You will also note a circle on this transparency entitled "befriending schemes." This term, and others (Oswin, 1984) are used to refer to what is termed short term fostering in Britain. This may be a service provided on a volunteer or paid basis. The use of terms such as "befriending schemes" was meant to prevent stigma or the implication that this service was needed because the family was inadequate. It was also meant to indicate a desire to foster relationships between families as well as between respite providers and the child with a disability.

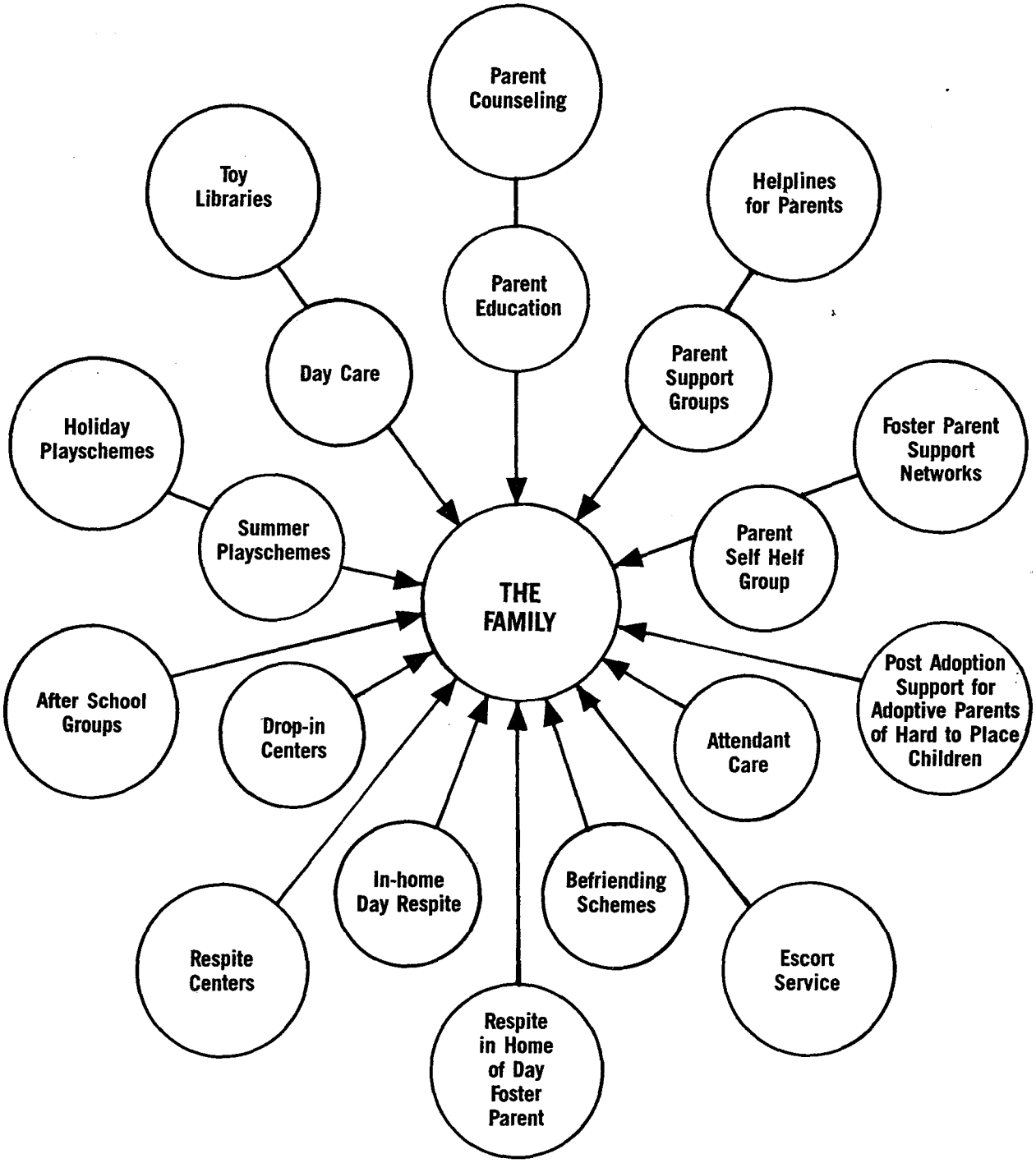
Virtually every major study of respite care programs conducted from the late 70s to the mid 80s in the United States found that the most significant problem or deficiency with these programs was inadequate allotments of service time (Cohen & Warren, 1985). I propose that this situation arose because of the absence of a concept of shared care. In Britain respite care service provision is the responsibility of local government, and both the quantity and types of services vary from local authority to local authority. In addition, in 1984 under Margaret Thatcher's leadership the central government was given power to limit the spending levels and tax rates of local governments, and the central government is holding back funds from local authorities spending above central government targets. There is great concern in Britain about the effects of these actions upon services for families of children with disabilities. However, because the concept of shared care exists, the amount of respite care being allocated to families of children with severe disabilities by some local authorities exceeds that of even our most generous programs. Some families receive up to 12 weeks per year of respite care. Some severely handicapped children may be cared for at a respite facility for two days of each week. Five to six weeks per year of respite care for a family is not uncommon.

After my return from my fellowship trip, I was contacted by a family that had recently moved from England to New Jersey. Their son has mental retardation and behavioral pro-

Transparency #3

*Support Services for Families of Children with Disabilities Voluntary Organizations**

*Often funded by local authorities



*Often funded by local authorities.

blems. This family bemoaned the loss of respite care services which they had received on a regular basis in England. They had contacted all of the appropriate government and voluntary agencies to no avail. There was no respite care program for their son in their area of New Jersey at that time. Just before making this presentation I made contact with these parents again to find out how the family had progressed. Their son was now in a residential school, the mother explained that the only respite care service they had been able to locate was one that would have provided a sitter in their home for $8.00 an hour. This is not what the parents needed. They wanted to be able to rest and relax in their own home. In England they had out-of-home respite care for their son. In New Jersey the only out-of-home respite they had been able to obtain came in the form of summer camp. Nothing was available during the remaining ten months of the year.

CONCLUSION

In concluding my remarks, I will go back again to the concept of shared care. It is time that we gave programmatic recognition to society's responsibility to assist families of children with severe disabilities. We can do this through a benefit, such as a non-means tested SSI benefit, that gives recognition to the extra financial burden borne by families of children with severe disabilities. Apart from the financial assistance such an allowance would provide, it would also bolster the parent's decision making role in obtaining the assistance their child and family needs. The concept of shared care should also be reflected in the establishment of a variety of types of respite care and other family support services in communities in all regions of all states, so that every family of a child with severe disability has access to such programs. The stature of the federal government should back this goal, much as the British central government did in its "White Paper" or "Guidance" in 1952 and again in 1971.

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Living Services Planning Panel

MODERATOR: PAUL L. MEDLIN
PANELISTS: RONALD S. BARBER
MATTHEW P. JANICKI, PH.D.
KENNETH MCGILL

The Self-Sufficiency Trust of Illinois

by Paul L. Medlin
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HISTORICAL DEVELOPMENT AND INTENT

On September 11, 1986, Governor James R. Thompson of Illinois signed into law House Bill 3605 now referred to as Public Act 84-1373 establishing the nation's first SELF-SUFFICIENCY TRUST. After several years of research and development by the National Foundation for the Handicapped, under the direction of James H. DeOre, the Self-Sufficiency Trust Act was unanimously approved by both the House and Senate as an addition to the "Mental Health and Developmental Disabilities Code" (Ill. Rev. Statutes, Chapter 91-1/2, Sections 5-118 and 5-119).

The Self-Sufficiency Trust ("SST") is the first trust of its kind which provides a financing mechanism to facilitate the coordination and integration of private family financing for persons who are disabled while maintaining eligibility for governmental entitlement funding. As a truly private sector initiative, the SST makes possible the flow of private monies into the state's network of publicly sponsored programs to supplement, enhance and expand services to all the disabled of the state.

The SST has removed many of the barriers faced by parents or families with adult or minor dependents who are disabled, when planning financially for a secure future, especially after the death of the parents.

Relatives and families of persons with disabilities have searched for a means by which they could contribute toward the present and future cost of care without the endless penalties traditionally associated with the use of private funds and the resulting negative impact of the loss of the individual's governmental entitlement funding. The SST's intent is to "supplement" these sources and not to "sup plant" them, thus making available new funds to enhance service delivery and meet the special needs of the individual who is disabled.

As a state law, the SST recognizes its mandate to make available its services to all individuals of the state who are eligible for the services provided by the Department of Mental Health and Developmental Disabilities. Charitable provisions are inclusive in the SST model to accommodate the low-income disabled who make application.

The innovative Self-Sufficiency Trust of Illinois is the first program to accommodate the need for private-sector income streams to supplement the limited and often insufficient public dollars available to expand the service delivery system for our citizens who are disabled.

SST: ELIGIBLE INDIVIDUALS

Persons who are developmentally disabled, and/or mentally ill and who are eligible for services under the "Mental Health and Developmental Disabilities Code" and their families may participate in the SST. Additionally, persons with physical handicaps, although not specifically designated in the law, will also become an eligible group as provisions are developed to meet the special needs of this group.

In general any family with an adult or minor dependent may participate in the SST as long as their identified needs can be successfully accommodated by SST programs and services.

SST: PROGRAMS AND SERVICES

As the Self-Sufficiency Trust of Illinois is implemented state-wide, a diverse array of services will evolve based on the identified needs of the SST participants and their families. In general, most services now available through

the current service delivery system will be accessible through the SST. New or expanded services are possible once demand and resources are clearly identified through the DISABLED POPULATION PROFILE SYSTEM. Each SST applicant's data will be input into this unique data base resulting in systemic and individual service needs identification by disability type, functioning level(s), age group, service(s) needs, geographic location, and numerous other socio-economic and demographic fields. From this case information, SST services will evolve to accommodate individual and group needs. The SST cannot promise all services immediately.

The major restriction the SST must place upon such services is that the Private Fund dollars *cannot* be used to meet the same needs as those intended to be met through *available public assistance programs*. Typically included are Supplemental Security Income (SSI) and medical coverage under Medicaid (Title XIX) programs. Basically SST dollars cannot be used to meet food, shelter, clothing or medical needs of persons who are disabled and receive SSI or Medicaid benefits. SST will participate in non-room-and-board cost components of residential service programs.

Individual LIFE-CARE PLANS will define those "supplemental" services which the family wish to fund for their dependent who is disabled, either now or in the future. Any attempt to utilize the private funding for services which would normally be provided under the provisions of SSI or Medicaid will jeopardize the standing of the Self-Sufficiency Trust with the Department of Health and Human Services, specifically the Social Security Administration and the Health Care Financing Administration (HCFA). It is critical during the orientation and initial SST LIFE-CARE PLAN stages that families fully understand these restrictions and their impact on the SST. A LIFE-CARE PLAN - PARENTAL SELF-ASSESSMENT will help families focus on eligible SST services and functions.

Families must be informed that SST Private Fund (and Charitable Fund) monies may be spent on behalf of designated beneficiaries for:

- Social Services
- Rehabilitation and Remedial Services
- Educational Services
- Recreational Programs
- Respite Services
- Habilitation Services
- Training programs to assist in managing activities of daily living

In addition, monies may be transferred to the State Fund and, in combination with state general revenue funds, used for:

- A portion of the cost of residential facilities and services where SSI and Medicaid recipients reside.
- As the state share of Federal Financial Participation (FFP) to pay per diem rates to residential facilities (Medicaid providers).
- To expand services offered by DMH-DD.

Finally, SST monies may be used to pay for guardianship and advocacy services which include home visitation and case monitoring to insure appropriate care and treatment are being provided to SST beneficiaries. The following services may be funded by SST Private Trust dollars (interest income) upon the activation of the SST individual LIFE-CARE PLAN, or, if SST participation is after the death of the family, they may be purchased on a monthly fee-for-service basis through a provider agency:

- Co-Guardianship or Successor Guardianship of Person.
- Personalization Advocacy Services.
- Home Visitation and Monitoring Services.
- Residential Search Services.
- Home Search Services.

SST Advisors will assist families in identifying providers of these services.

SST: THE MODEL:

The Self-Sufficiency Trust is an irrevocable, "pooled-income trust" with spendthrift and discretionary trust language and clearly defined "charitable" and "private" trust provisions. It may take on an Inter-Vivos (Living) Trust or Testamentary Trust (via a will) classification, depending upon when the grantor designates the trust to activate. Regardless of its similarity to other trusts, provisions or classifications, its structure and benefits are uniquely designed to facilitate active parental financing of supplemental care of the disabled without disruption of SSI and Medicaid benefits. Unlike a corporate managed trust, it is *not:*

1. A financial planning model to protect or preserve assets for heirs or remaindermen — *rather*, it is solely to benefit a disabled beneficiary for the duration of his/her lifetime;
2. A tax-avoidance or shelter mechanism — The Grantor's tax obligations must be determined by his or her accountant;
3. A mechanism to set aside large amounts of capital — *rather*, the model is based on a predetermined principal amount which is

necessary to generate a flow of income to pay for specific supplemental service needs for the life of the disabled beneficiary as identified in the LIFE-CARE PLAN.

4. A mechanism to pay for CARE, COMFORT, nor SUPPORT (clothing, housing, food, medicine - medical care) — *rather* it is to supplement day-mode programming and/or education, training and therapeutic service costs within a licensed residential setting. To pay for costs associated with care, comfort or support would be to supplant what Social Security (SSI) and Medicare pays and renders the beneficiary ineligible for these entitlements.
5. A guaranteed source of housing opportunities for the disabled — *rather*, through the Disabled Population Profile System it matches like-family housing needs and refers classes of families with dependents who are disabled to sources of existing or start-up housing assistance.

The structure is as follows:

- Two wholly separate pooled-income trust funds exist as part of the SST structure. Each of the two funds has a counterpart public sector or State Trust Fund by virtue of the public law enacted by each state.
- The Private Trust Fund accepts, holds, and invests the "pooled" assets of each family participating in the SST. Although assets are commingled, all returns on investments are credited proportionately to each "private trust" account. Interest earnings on Private Trust Fund assets are transferred at the direction of the Trustees and the parents or guardians, who serve as Co-Trustee, to the counterpart State Trust Fund which immediately disburses the assets for the *supplemental* goods or services to be provided. The Department of Mental Health and Developmental Disabilities may be designated to hold the State Trust Fund and these funds are generally disbursed by the state treasurer. Technically, funds disbursed from the State Trust Fund become State Trust Fund monies and are not viewed as earned or unearned income to the disabled Trust Beneficiary, therefore not affecting public entitlement eligibility under Supplementary Security Income (SSI) or Medicaid.
- Another trust fund controlled by the Board of Trustees is the Charitable Fund. This fund is a repository to accept residual and donated assets earmarked for low-income and indigent persons with disabilities who are unable to participate in the Private Fund. This important part of the Self-Sufficiency Trust model is supported by:

1. Assets left to the Charitable Fund by grantors of Private Funds at the death of the disabled beneficiary (50% of residual principal of each Private Trust):
2. Contributions from private donors, bequests, corporations or foundations, and appropriations from state general revenue funds;

Earnings on the principal of the Charitable Fund can be transferred to the State Fund for the Developmentally Disabled allowing low- income and indigent disabled individuals to participate in the SST concept.

- A Volunteer Board of Trustees is appointed from the private sector (parents and professionals) to manage and control the Private & Charitable Trust Funds. The parent or family member who establishes a trust is called the Grantor, and his/her dependent is the Trust Beneficiary. The Grantor or his designee serves as Co-Trustee and shares in trust disbursement decisions. As Trustee, the Board of the SST must exercise discretion and judgement and return ownership (legal title) to the property (assets) of each Private Trust. Through the use of agents, it may carry out its obligations to prudently control and manage trust assets. The Self-Sufficiency Trust of Illinois uses three primary agents: a fiduciary agent, Illinois Regional Bank, to invest the pooled assets of the Funds; a SST service agent, PACT, Inc. and selected Case Management Units, to provide intake and orientation services to families and to broker/monitor SST services; and Charter Management Group, Ltd., as technician consultants for SST operations.
- At the direction of the SST Board of Trustees, the state counterpart fund under control of DMH-DD receives the disbursement (interest income) from the Private Fund for each SST beneficiary. These funds are accompanied by specific payout directions in accord with the LIFE-CARE PLAN. After insuring that the specific care, support, or treatment requests are consistent with the rules and agreements of the law, DMH-DD will approve a voucher for payment to the designated service provider by the Comptroller.
- The DISABLED POPULATION PROFILE SYSTEM, is a computerized data base designed to assess the non-clinical functional abilities of the SST beneficiary, to identify specific life- care service and appropriate residential setting needs, and to project present and future costs. Each SST applicant will be input into this system and the statistics will be used

to coordinate service development and provide valid out-year service need and fund appropriation needs. Of course, confidentially is protected in accordance with the law.

- A LIFE-CARE PLAN is developed for each participant which embodies the wishes of the parent (Grantor) and defines the intent and nature of supplemental services to be provided the disabled participant. Trained Self- Sufficiency Trust Advisors provide the direction for parents to develop a realistic and need-specific plan.

In summary, the SST Model is unique in its structure and specific in its intent. As a non-traditional financial planning mechanism, its force is solely to facilitate supplemental funding for service-oriented components of the community-based service system for the disabled, while preserving public entitlement funding. Its purpose will benefit both individual beneficiaries and the system at large, but it may not meet the estate planning expectations of all families

- If you are interested in more information or wish to have an appointment to learn more about the Self-Sufficiency Trust, contact:

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340 West Butterfield Rd. - Suite 3C
Elmhurst, IL 60126
Phone: (312) 941-3498

Finally, as moderator of the Life Services Planning Panel, I want to reinforce the need for innovative and private sector initiatives which eliminate barriers for family's pro-active participants in planning a service future for their disabled dependent.

The Self-Sufficiency Trust model provides a win-win situation for Federal and State governments, community provider networks, families and most importantly the disabled. It is a valid medium by which each of their entities can effectively form partnerships to benefit both the system and the disabled population.

When parents and families with children who are disabled ponder the future, they face concerns that parents of non-disabled children do not. They must provide a life-care legacy which will not render their disabled dependent vulnerable at the parent's death. Innovative research and development in non-traditional estate and future care planning have replaced the usual "catch 22" situations faced by families with means to ensure the disabled the protective legacy they each require. The Self-Sufficiency Trust model removes the disincentives which have traditionally dissuaded viable estate planning efforts by parents and includes the personalized life-care monitoring and guardianship services which significantly reduce vulnerability in the future.

The Trust model was seen as an "estate planning" option which would avoid conflict with existing rules which paralyzed families from providing direct services to their disabled dependents eligible for Federal assistance under the Supplemental Security Income and Medicaid programs. Further, the Trust would encourage the flow of money from private sources focusing on expanding supplemental services to the disabled. This new private- public initiative encourages parents, state government and service providers to work together to plan now for a secure future for the disabled.

My recommendation is simple - each State should look at the merits of the "Self-Sufficiency Trust Model" and how it can benefit the disabled and enhance their life-long service options.

On behalf of the National Foundation for the Handicapped, I wish to extend congratulations to the President's Committee on Mental Retardation on a job well done and appreciation to the PCMR Staff for their individual hard work and cooperation.

Planning for Economic Security

by Ronald Barber
Department of Economic Security
Division of Developmental Disabilities
Phoenix, Arizona

I am pleased to be with you at this important national forum on community integration for citizens with mental retardation. This is a topic of great significance in our field and in our country at this time, and it is to the credit of the President's Committee on Mental Retardation that such a conference has been organized.

During this session I want to share with you ways in which we can most effectively engage in life services planning for people with mental retardation. Before I get to the specifics of this topic, however, I would like to discuss the Arizona context within which we have developed our current thinking, planning processes, and service system.

The history of service development in Arizona is not unlike that of other states. Development has, however, been accelerated over the past ten years due to litigation, legislative attention, and the absence of Federal constraints on how resources should be expended.

We began, as did every other state, with institutions at the center of the service delivery system. Over a period of 30 years, we constructed three institutions and attempted to deliver a full range of services in those facilities. Services included residential programs, vocational training, and even infant stimulation and preschool programs. While it may have been more efficient to locate everything at these sites, it certainly did not advance of opportunities for integration with the community.

In 1977 Arizona developed a five-year plan which called for deinstitutionalization and the creation of community based alternatives. Within a three-year period, over 150 group homes were established statewide. In every community children with disabilities were integrated into regular preschools with non-disabled peers. People with developmental disabilities, who previously had only been served in sheltered workshops, now found employment in the private sector through competitive placement and work stations in industry. In order to support all of this community movement and to ensure proper coordination of the dispersed service system, new statewide case management services were implemented. We are now entering what one could consider the final phase of deinstitutionalization in Arizona. - In August 1988, one of our three institutions will close, and discussions are underway to determine the future of the two remaining facilities.

We are at this time embarking on a new era of development, which hopefully will build on our experiences over the last several years and will capitalize on both the successes and failures of the deinstitutionalization drive. We are calling this the *Family Support Initiative*. It seeks to provide additional supports to families who want their developmentally disabled relative to remain at home and to provide supports to individuals with developmental disabilities so that they can be more independent once they leave their family home. This initiative, like the previous activities of our department, is driven by a strong value system. These values include:

1. A recognition that families do, in fact, have a great deal of power and that systems that serve families and individuals with developmental disabilities should not diminish that power, but instead should enhance it.
2. Services should be developed around the assessed needs of the individual or family, and not driven by what is available. This is a

movement away from "slots" and toward an individualized service array.

3. Greater emphasis should be placed on building interpersonal relationships for individuals with disabilities. I am afraid that too little attention was paid to this important aspect of life services planning when we were engaged in deinstitutionalization efforts. The result across the country has been that people with disabilities are living in communities without friends and without connections to non-disabled peers. Unfortunately, we may well have traded the isolation of institutions for the isolation of living without friends in the community. We seek to change this situation by ensuring that Individual Program Plans include goals for building relationships.
4. We recognize that the delivery of services to people with disabilities cannot solely be the responsibility of government or families. It must also be a community responsibility. As we look to the future, this means that we will be securing services and supports from a variety of community resources, those same resources that are available to you and to me. We will be contacting churches and clubs, and civic organizations, and neighborhood associations, and all of the other groups that make up a part of our life so that people with disabilities can benefit from this kind of access to their community as well. Case managers are being asked to serve as catalysts for the development of family, individual, and community responsibility. Dependence by people with disabilities and their families upon case managers needs to be minimized wherever possible. We need to consider transferring case management responsibilities to family members. Case managers will be the most significant staff player in moving people towards greater independence and community integration.

The new era of service development in Arizona for people with disabilities and their families is designed to enhance opportunities for economic and social security. Initiatives are underway and new ones will begin, in order to demonstrate and explore a variety of options for people with disabilities.

In the area of job training and employment, the state has developed a three-year Adult Services plan, which has as its major goal moving people from sheltered to integrated employment. Various funding sources have been used to advance this concept.

A project known as Structured Training and Employment Transitional Services (STETS) was started with funding from the Manpower Demonstration Research Corporation in New York, and although the demonstration project has ended, STETS continues. Today funding is provided by the Joint Training Partnership Act and state appropriation. Through this program, adults with developmental disabilities are being evaluated, trained and placed in either competitive or supported employment with community businesses. The success rate and cost effectiveness of STETS has been recognized nationally.

Over the past year, the Division of Developmental Disabilities and the Rehabilitation Services Administration have developed joint funding for services to people with severe disabilities. The Division of Developmental Disabilities has provided the match for additional federal funds to Vocational Rehabilitation. These funds have been used by Vocational Rehabilitation counselors to place almost 100 developmentally disabled people in training and evaluation services. These individuals eventually will be placed in either competitive or supported employment situations and will receive ongoing services from the Division of Developmental Disabilities. This is an example of how two state agencies can cooperatively work together to serve people with severe disabilities in innovative ways.

The state of Arizona was one of the first states to be selected by the federal government to receive a supported employment demonstration grant. This grant has complimented the work that was pioneered by STETS and by the joint VR/DDD funded project.

All of these initiatives are moving Arizona steadily towards employment services that are primarily outside of segregated sheltered workshops. Self-sufficiency is replacing dependency for people with developmental disabilities. These advances are being accomplished through a partnership between federal, state, and local governments, in cooperation with the private sector. Planning for economic security, therefore, is increasingly being conducted in an environment that provides real work and real pay for developmentally disabled adults.

In the area of residential and community living alternatives, Arizona is taking steps that will also enhance real economic and social security. Pilot projects are underway across the state assisting people with disabilities to move from provider owned or leased group homes into apartments of their own. This year at least four of the 14 state operated group homes will close and the individuals who reside there will be moving into apartments where they will receive staff support as needed.

Moving to apartments and other small living arrangements is an important step in creat-

ing greater integration into the community, but it also provides the opportunities for greater choice. Every effort will be made to help people with disabilities in choosing their roommates, where they want to live, how the environment should be decorated and furnished, and ultimately, who will be hired as staff. All of these changes are initiated through the Individualized Program Planning Process (IPP) to ensure consumer and guardian involvement in the decisions.

In the past, success in a residential setting such as a group home meant that the disabled person would be "rewarded" by a move to another setting. Success, therefore, brought a loss of friends, a loss of neighborhood and the opportunity to adjust to an entirely new environment. A new approach is now being pursued. Instead of people with disabilities having to move when they achieve greater independence or success, staff supervision, monitoring, or support will decrease. Success in acquiring new skills and greater independence will be rewarded by stability in new environments and relationships.

The idea of service continuum is also being challenged under the new Arizona approach. Traditionally in every state, people with disabilities move from institutions to "intensive" group homes and then to less intensive group homes, and perhaps eventually into supervised apartment or semi-independent living situations. This notion of the continuum suggests that settings, not an appropriate array of services, are critical to the delivery of programs. Efforts are underway to allow people with disabilities "to leap over the continuum". In one such example, a young man with severe disabilities and self- injurious behaviors who has resided in the state hospital for almost eight years, has moved directly into an apartment of his own, which is staffed in accordance with his needs. In time he will meet other people, both with and without disabilities, in order to choose a compatible roommate.

Part of the Arizona dream is that more and more people with disabilities will be able to rent or even purchase their own home. In fact, initial discussions have begun with a national financial institution to look at ways in which low interest mortgages can be made available to developmental disabled people themselves.

Yet another aspect of realistic economic planning has to do with taking a hard look at the ways in which Individual Program Plans are constructed. Typically, in Arizona, and I am sure this is true of virtually every state, IPP's concentrate on specific tasks having to do with activities of daily living or employment training. Rarely do these plans address issues related to the development of friends or interpersonal relationships. Training is now being developed in Arizona that will encourage case managers and other team members to look at this very important aspect of life. All of us count on our family, friends, co-workers and social contacts for support. Why should this be any different for a person with disabilities? And yet we know that for most people with disabilities, their primary support system comes from people who are paid to work with them. We are now building into IPP's objectives that have to do with the establishment of social networks and support systems that go beyond paid employees.

Many people with disabilities live with parents or other family members and in Arizona new emphasis is being given to supporting these families. There are, of course, respite services available, but now a new approach is being employed that allows families to choose their own respite provider and to receive a subsidy from the Division of Developmental Disabilities to cover the cost of care. Additionally, in 1986 the Arizona state legislature authorized the first-ever cash subsidy program for families with developmentally disabled members. This cash subsidy provides up to $400 per month to the family so that the family itself can purchase needed services. The subsidy program is very flexible and there are few items or services that cannot be purchased by the family.

We are also encouraging the transfer of case management responsibilities to family members and to people with disabilities themselves. In our view there is no reason why many families and disabled individuals cannot handle many of the case management functions that have been routinely a part of the case manager's responsibility. This is a recognition that families do have power over their lives and that sometimes state and private providers, with the best motives, end up taking this power away. If families and people with disabilities are supported as being competent to case manage their own affairs, planning for economic security can become more relevant to the family.

The Division of Developmental Disabilities in Arizona is part of an umbrella agency known as the Department of Economic Security. This relationship with public welfare and employment related agencies is being used to enhance One economic security of people with developmental disabilities. Special agreements are in place that facilitate access to food stamps, general assistance, supplemental payments, day care and other services that are available to the population in general. In the near future, an agreement will be finalized to enable the Job Service to conduct job development and placement for people with developmental disabilities.

Ensuring economic security for people with disabilities requires that we must expand and enhance the integration of service delivery with programs such as these. The key, of course, is a strong and competent case management service.

In October of 1988, Arizona will become the last state in the union to utilize Title XIX funds for services to people with developmental disabilities. Being the last gives us an opportunity to break new ground and to explore different approaches to service delivery. This opportunity, also, is being seen as a way to enhance the economic security of people served by our agency.

The Arizona Title XIX demonstration will utilize a pre-paid and capitated funding approach to the delivery of acute and long-term care services. This is very similar to the Health Maintenance Organization (HMO) approach to medical services in which many people in this country are enrolled.

Arizona has chosen to establish very few Intermediate Care Facilities for the Mentally Retarded (ICF/MR). In fact, less than 300 residential placements will be certified as ICF/MR. The emphasis instead will be on funding home and community based services. There will not be a cap on the number of people who can be enrolled, but there will be a cap on the costs that will be reimbursed by Title XIX. This obviously puts the onus on the state to find cost effective and highly integrated services.

A new rate setting methodology for services will be driven by the individual needs of people with disabilities. There will be incentives to providers for moving people towards greater integration. Essentially, money will follow the client, providing choices to the client and/or family that have never been available before.

Needless to say, this approach to funding and service provision provides for considerable economic security, in that providers do not own the resources. Instead, resources are controlled by people with disabilities or their guardians.

All of these innovations, which hopefully strengthen families and move people with disabilities to greater self-sufficiency, require state and private service providers to think outside traditional parameters. Bureaucracies have difficulty with this. Through training and pilot demonstration projects, and the encouragement of risk-taking, we are moving Arizona into an era where planning for services is largely controlled by families and individuals with disabilities.

None of this will be possible without public accountability. The Division of Developmental Disabilities, therefore; has organized a planning process which relies heavily on consumer input and community participation. This process is attempting to clarify the vision and the values of this evolving system and to seek community ownership of the new steps that are being considered.

Additionally, the Department's Office of Evaluation is being asked to look at specific aspects of the new system and evaluate the outcome. Evaluation will be conducted around consumer satisfaction, cost effectiveness, the level of integration of people with disabilities, and the attainment of goals such as family support and self-sufficiency.

Having shared all of this Arizona history and current and future activities, I would like to close with some recommendations that come out of our experience which might be useful to consider in your state. These recommendations are also directed at bringing about changes in federal and state practices. Some or all of these recommendations are directed at ways in which public and private sector resources can most effectively be used to bring about true community integration for people with disabilities.

SUMMARY AND RECOMMENDATIONS

1. Planning for economic security must be conducted in a larger context that includes an assessment of needs for the whole individual and/or family. Economic security cannot be ensured in a narrow sense. It is part of an overall plan for a person with mental retardation and their family.
2. State and local systems that provide services for people with mental retardation must implement training for staff such as case managers to ensure that certain principles form the foundation of life services planning. These principles include:
   a. Recognizing that families are empowered to make decisions that affect their lives and that involvement by public and private agencies should enhance, rather than diminish, that power.
   b. Services for individuals and/or families should be driven by the assessed needs as articulated by individuals or families. Too often case managers and others decide what they believe is in the best interest of the mentally retarded person or their family.
   c. The job of providing life services planning and, consequently, supports and services, is not solely a governmental responsibility. In addition to the individual with mental retardation and/or their family, community organizations must be involved in the

development and delivery of services. For example, case managers should assist mentally retarded people in communicating with social and recreational services, churches, civic organizations, and other entities that people without disabilities routinely use as part of their overall support system.

d. Life services planning must pay attention to the development of interpersonal relationships and supports and not solely concentrate upon the delivery of specific services for economic benefit.

3. State government should enact laws that will assist in the establishment of mechanisms that will assist in the financing of services and homes for people with mental retardation. A housing authority, for example, could be established to provide low interest loans to mentally retarded people so that they would be able to purchase their own home. This is not the same as providing a low interest loan for provider organizations to purchase property. Ownership of property by people with disabilities should be a goal that will help enhance their ability to make important life decisions and build economic security. Additionally, state sponsored trust funds that permit families and disabled individuals to pool resources for the common good should also be encouraged by state government.
4. The federal government should consider changes in laws and regulations that will permit greater flexibility for states in the use of federal resources that are directed toward people with mental retardation. This would suggest, for example, major changes in the way in which Medicaid funds are authorized for state and local use. Currently, federal laws and regulations encourage the development of institutional services as opposed to home and community based programs. This is neither cost effective nor in the best interests of community integration. A proposal that has been submitted by the State of Arizona to the federal government for the implementation of Title XIX funded long term care contains the kind of flexibility that is being recommended here for all states.
5. The federal government should consider national zoning legislation which would prohibit state and local ordinances from limiting the ability of people with mental retardation to live in neighborhoods. Many states have such zoning override laws, but consistency is lacking and some states have no such protection. A federal mandate would significantly advance the cause of integration.
6. Technical assistance should be made available to states, local government, and public and private agencies, so that planning for the future of a person with mental retardation truly includes the key stakeholders in that person's life. Currently, most individual program plans are not individualized, do not address the needs of the Whole person, and are more system focused than person focused. This results in the purchasing of slots rather than an array of services for people with disabilities. Training, consultants, and technical assistance should be provided to address this important problem. Efforts such as "Personal Futures Planning", which is conducted by Dr. Beth Mount, Dr. John O'Brien, Dr. Joe Patterson and Dr. Bud Wetzel, would be one approach that could bring about the necessary change.
7. State and local government should receive technical assistance and training in changing contracting systems. These contracts typically are agency driven, and tied to slots. If we wish to empower people with disabilities and their families, funding should be tied to the person and not to the agency. This will enable people with disabilities to have the power of the purse and will create a system that is more responsive to consumer needs than to agency needs.

Transition from Worklife to Retirement for Older Persons with Mental Retardation

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BACKGROUND

In the United States, the size and continued growth of the overall elderly population are becoming a source of concern for administrators, program providers, and public officials. The nation's population of elders has doubled since the beginning of the century and is expected to triple within the early part of the next century.

According to the US Bureau of the Census, in 1960 there were approximately 16.7 million persons in the United States age 65 and older, comprising slightly more than 9% of the population. In contrast, the same age population numbered 25.5 million persons in 1980, representing slightly more than 11% of the nation's total population — a 55% increase in just 20 years. Expectations are that by 2000 and 2040, this same age group will have grown to represent 13% and 20%, respectively, of the population.

Further, there has been a dramatic growth among older generational groups. In this same 20-year period, the number of individuals aged 75 to 84 rose 65%, whereas the number of those age 85 and older increased by 174%. Indeed, the age group 85 + is the second fastest growing segment of the nation's population. Currently, over 60% of all older persons are between the ages of 65 and 74, 30% are between the ages of 75 and 84, and about 9% are aged 85 and older. Because women tend to outlive men, the majority of the nation's older population are women, and this disparity in longevity increases with advancing age. Many of these same trends hold true for older individuals with a life-long disability such as mental retardation.

Estimates of the size of the population_ of older persons with mental retardation in the United States have ranged up to 500,000, depending upon the age-related definition of "older persons". Using the age break of 60 and above, one projection of the number of older mentally retarded persons is for 4 out of every 1000 older individuals. This results in, at minimum, 150,000 older persons with mental retardation. Studies have also shown that up to a fifth of the populations of state registries of mentally retarded individuals are composed of seniors. Of this older group, about 50% comprise the "young-old" group, about 32% comprise the "middle-old" group, and about 18% comprise the "old-old" group. Problems of transition generally affect those older mentally retarded persons who are in age from the fifties to the seventies.

According to a recently issued report from the National Institute on Aging (NIA), "Personnel for the Health Needs of the Elderly in the Year 2020", expectations are that the nation's population of older mentally retarded persons will double over the next 30 years. Age trends also show that women generally outnumber men among mentally retarded persons over the age of 50 and while the life expectancy of men is increasing the predominance of older women will continue. Further, current information indicates that many older mentally retarded persons live with their families and continue to work well beyond the typical retirement age of the early to mid-sixties; how this will look in the future remains open to speculation.

In terms of the older mentally retarded population, the National Institute on Aging report cited above identified three major groups, each with a different demand upon transitional services planning and development:

- The first group is generally made up of those individuals with minimal mental or physical handicap who have been fairly independent all their adult lives and only because of impairments associated with aging have they again become dependent upon special assistance from social services agencies or the aging network.
- The second group is made up of those individuals with moderate mental or physical impairments, who have a need for supervision or special training, and who as they age become more dependent upon a range of special mental retardation/developmental disabilities, social services, and aging network services.
- The third group is made up of those individuals with severe or profound mental and/or physical impairments, whose gross dependency calls for a range of very specialized long-term care and habilitation services, and who have been the life-long responsibility of mental retardation/developmental disabilities agencies and for the most part will remain so as they age.

ISSUES AFFECTING THE NATION'S OLDER MENTALLY RETARDED POPULATION

Two significant factors contributed to the historical lack of awareness or concern about the aging of older adults with mental retardation: (a) in the past, persons with severe mental retardation had a relatively short lifespan; and (b) many adults with mental retardation spent much of their lives in public institutions. However, both more readily available medical services and improved overall health status have now contributed to increase longevity. Further, with the nation's deinstitutionalization efforts over the past 20 years and an increased emphasis on the availability of community living and support programs, many more mentally retarded older adults are visible and present in the community. Consequently, the combination of greater longevity as well as an increase in the number of known individuals with mental retardation residing in community settings has begun to contribute to the greater awareness of aging among this population.

Further, Congress recognized the special needs of older persons with mental retardation when it passed the Older Americans Act Amendments of 1987 (PL 100-175). Special provisions were included for "individuals with disabilities" which include persons with mental retardation. These provisions recognize the special transition needs of older disabled persons and call for closer collaboration and coordination of planning activities and services between the aging network and disability agencies and the inclusion of persons with life-long disabilities within the gamut of special services available and provided to the needy elderly.

The increased number of older adults with mental retardation has posed a number of problems that relate to transition:

- First, increased longevity has created a demand for services and special attention that many states are ill-prepared to address. Whereas, many states had developed child- oriented developmental and remedial educational services, and adult-oriented vocational and social developmental services, the new demand for senior-oriented retardation services was unanticipated. Further, there is a lack of agreement among Mental retardation policy makers and administrators as to whether to create a parallel senior services track within mental retardation services or to collaborate with the aging network in the use of existing or augmented senior services within that network.
- Second, increased longevity in some cases has also resulted in unexpected problems. In the instance of older persons with Down syndrome, both the occurrence of premature aging and the often co-occurrence of Alzheimer's disease has left agencies with unique challenges in area of developing transitional services to accommodate middle age adults who are aging prematurely and/or who are experiencing progressive mental debilitation.
- Third, two-generation-elderly families in which an elderly parent (or parents) continues to bear the burden of care for an aging mentally retarded adult son or daughter. Many states have yet to link the services generally available to the at-need elderly with more traditional mental retardation services in such special situations or to be sufficiently robust in their service offerings to address this special situation.
- Fourth, the "aging in place" of older mentally retarded adults currently living in a variety of community residential situations (such as foster family care homes, group homes, board and care homes, supportive apartments, and the like) who, to prevent unnecessary institutionalization, need either a shifting in the types of services provided or new and broader support services. Many states have not yet developed the flexibility to adapt their current services models to pre-

clude having seniors move from their "home" simply by virtue of their age and the lack of preparedness on the part of the staff or inability by the home's administrators to effect simple building adaptations.

- Fifth, older mentally retarded persons who need retirement-oriented senior programs in lieu of their current vocational involvement. However, the available alternatives may not compensate for the loss of the social and financial supports associated with continued involvement in vocational services. Further, the transitional supports normally available to non-disabled persons (such as pre-retirement counseling, pensions, and bridging opportunities) have not been available to sheltered workers and those in developmental training programs.

BARRIERS IN THE TRANSITION PROCESS

Attempts to use the aging network for a variety of age-appropriate services usually are confounded by a number of barriers posed both by the aging network's programs and by the mental retardation system's administrators and providers. Within the aging network, these include the following:

- "Handicapism" — This is the expression of negative attitudes by officials, administrators, and other older persons toward individuals with a disability; this attitudinal bias manifests itself by these individuals not wanting the person who is disabled to use their services or to be in their program.
- Economics — Limited monies are usually available to groups that provide special services for persons who are elderly; these monies are carefully guarded. Officials and administrators may resent having to spend these limited monies when the group having primary responsibility for mentally retarded persons should, in their thinking, be spending its own monies on older mentally retarded persons.
- Inexperience and Fear — This is rooted in the notion that staff working in a program serving older individuals will not know how to respond to a person who is mentally retarded. In some regards this barrier is based in reality; as staff working with older citizens are rarely trained to serve persons with disabilities such as mental retardation. As a consequence, they may overestimate the extent of problems they may face and not want to admit an older mentally retarded person into their program.

Similarly, there are a number of barriers that are found in the mental retardation system; these include: Territoriality — This is when mental retardation agencies and providers believe that they must do all for their older clientele, because, "They are our responsibility." This barrier is evident when working with the aging network is dismissed outright due to a belief that the sole responsibility for providing services lies with the mental retardation agency.

- Elitism — This is when the mental retardation agency contends that its services or those generally available within the mental retardation system are grossly superior to any available within the generic aging network. It is characterized by the attitude, "We can do it better" so why look to what's available in the aging network.
- Denial — In some instances, agencies and providers have not yet come to grips with the special needs posed by the population of their older and elderly clientele, nor do they recognize the possible size and scope of the population. This barrier is evident, not because information is lacking, but because when contrary to reality, there is a denial of interest. The feeling expressed here is "It's not a special concern and we need not attend to it."

POINTS OF TRANSITION AND THE OPTIONS AVAILABLE

Transitions occur at various points in the lifespan. One point occurs in the late teens or early twenties, when the focus of services changes from school or education to independence building or work. Another occurs in late middle age or early old age, when the focus changes from work age to retirement activities. Such transitions among disabled persons can pose special challenges for service providers. For older adults with mental retardation, these transition problems can be found in a number of situations, including in later age instances of moving from home or an institution, "aging in place" in a community residential setting, and retiring from a vocational or developmental activity. Each of the transition situations is associated with special problems. What follows is an explication of the problems and some possible solutions.

- ***Moving from Home***

In the general population, it is primarily the family that provides most "services" for elderly persons. Because of the efforts of family members, as many as 60% of the extremely impaired elderly live outside of institutions and fully 80% of their service needs are met by an informal support network. In most cases, such supports are provided by a spouse or by adult daughters, daughters-in-law, or sons. Unlike most elderly

persons, older mentally retarded persons generally do not have children or a spouse on whom they can depend for support. In some cases, they live with very old parents who still provide their day-to-day supports; this creates a situation of a two-generation elderly family. In other instances, it is siblings or the children of siblings that provide care. A small proportion of those mentally retarded individuals who receive state-supported services continue to live with their families into old age, but the percentage of elderly mentally retarded persons who live with their families declines with advancing age.

Movement from the home occurs usually in two circumstances, precipitous or planned. In the precipitous situations, the parent (or parents) may die or become hospitalized and no one is left to care for the retarded older person. Consequently, immediate emergency housing has to be found, oftentimes not in the most ideal setting. With the increase of home caring situations, this circumstance is becoming more frequent. In planned situations, the family has worked with an agency to identify acceptable options for housing; the older mentally retarded adult participates in the decision making process and goes on visits to the option chosen; and movement finally occurs upon prearrangement.

In either of the two instances noted above, movement takes special planning by agencies so that both emergency placement options are available and a sufficient number of community living spaces are developed to anticipate the annual demand presented by the growing elderly population. To address such future planning needs of families, it would be helpful if the Administration on Developmental Disabilities would advise the state developmental disabilities councils that they should consider how their state is addressing the issue of its elderly mentally retarded/developmentally disabled population and establish statewide task groups to address barriers and problems found to be present that impede the community integration of elderly mentally retarded/developmentally disabled persons and families with permanency planning.

- ***Moving from Institutions***

Some studies have indicated that a large proportion (sometimes up to 60%) of known older mentally retarded persons are institutionalized. In most instances the institutionalization took place when the individuals were young; not many older mentally retarded persons are now admitted to public institutions. These individuals may pose a special problem with regard to transitions. Their length of stay in the institution has often acculturated them to the facility and movement to another, less well known, setting can pose special problems.

The problems faced by agencies in such situations, include addressing the willingness or unwillingness of the individual to move, finding the "right" residential and day programs in the community, and attempting to keep intact the friendship network that the individual has developed and upon which he/she relies. Moving intact groups of older persons to a common setting, such as a group home in the community, can do much to alleviate adjustment problems. Finding a day program that offers new and interesting experiences that are age- appropriate and typical of activities that other, non-disabled, seniors engage in can also do much to aid in the transition.

"Senior friends" models that pair a non-disabled elderly volunteer with a mentally retarded person moving from home or from an institution have been shown td be very effective in aiding in transition situations and in affecting successful community integration. One such national program that could be used more frequently to provide such "senior friends" is the Senior Companion Program authorized by the National Domestic Volunteers Services Act. Steps should be taken to expand the applicability of this program to address this transition issue.

- ***"Aging in Place" in Community Residential Settings***

"Aging in place" means growing older while remaining in the same residential setting. Generally this notion refers the problem of the growing frailty of older individuals already living in a community setting and the changing demands that growing frailty makes upon the staff and the environment. Many now older mentally retarded persons living in group homes and other similar settings began to reside in the settings as young or middle age adults. With the passage of time they have aged and their abilities and needs have changed.

Some are experiencing medical complications or frailty that accompanies the normal aging process. Such frailty has been defined in PL 100-175 (the Older American's Act) as having a physical or mental disability that restricts the ability of an individual to perform normal daily tasks and which threatens the capacity of an individual to continue to live in the community setting. This growing frailty may necessitate admission to a long-term care setting; however, in many instances it can be accommodated by special building structure provisions that can be included that compensate for the older individuals difficulties in ambulation, sensitivity to

temperature changes, diminished vision and hearing, and impairments in fine motor dexterity. Further, pre-service and in-service training offered to staff in the facets of aging and special medical and nursing care can also help in re-defining the residence's program.

Activities directed toward adapting the residence and re-training the staff rather than forcing movement are much more functional means to address the transition associated with "aging in place." Further, the revised definition of active treatment in the new ICF-MR regulations issued by HCFA should provide relief from regulatory constrictions. These changes would go far to ensure that a home remains a home. The former federal regulations governing the ICF-MR program (often a source of small group homes in the community), tended to inhibit, rather than facilitate this end. Countless instances of forced movement to accommodate the program rather than the residents were recorded. The Health Care Financing Administration (HCFA) has gone for to interpret these new regulations in favor of facilitating seniors programs (i.e., allow for aging and the special problems fared by older residents who "age in place." Now what is needed is for HCFA to ensure that operators and surveyors use this flexibility effectively.

• ***Retirement***

Of all the transition issues related to aging, the most vexing is retirement. The problem most agencies face is that while it is easy to effect "retirement from" it is not that easy to effect "retirement to." Among non-disabled persons, the *primary gain* associated with work, a salary, is usually substituted by Social Security benefits or a pension. Further, most persons, when considering what to do upon leaving the workforce, also think in terms of what will replace work and the *secondary gains* associated with the work place, such as friendships, a place to go, and the personal identity that is defined by one's job. This notion of replacement leads to "retiring to."

Often the social and personal changes associated with retirement can be traumatic when bridging does not occur as part of the transition process. The loss or change of friends when moving to a new program can pose a significant barrier. Selecting among options available to seniors in the community can help to plan the "retirement to." Some other strategies that could mitigate problems associated with retirement for persons with mental retardation include the use of pre-retirement counseling, partial retirement (where the individual slowly transitions from work to retirement), and increasing socialization through the use of non-disabled "senior friends" and involvement in socialization programs. A "senior friend" can help the retarded person acclimate to new settings that offer retirement activities as well as serve as a bridge to the friends he or she may have left in the work setting.

Most disabled individuals do not receive earned social security benefits or pensions to use as income in retirement. For those mentally retarded individuals attending sheltered workshops or earning money in some type of day program, the lack of money upon retirement can become a major problem. Many older mentally retarded workers are reluctant to retire when they are faced with the loss of their cherished income. This results in a dilemma: when faced with a desire to stop working and relax but lose income, or continue to work and lose the freedom that may come from retirement, most elderly workers chose to continue to work.

There is another side to this problem. Involvement in senior group activities that are offered at senior centers, such outings or a trip, may include a nominal fee. Further, even participating in the congregate meals program involves some expense since sites ask for a donation of on the average of $1.50 per meal. An older person should have the dignity associated with "paying your own way" since many senior activities are peer oriented. This consideration of maintaining the older individuals' dignity and self-respect when they move from the work setting to a seniors program is very important. A mechanism that permits the receipt of a pension or old age benefits would go far to aid in the transition to retirement. Although the issue of introducing social security deductions in a workshop is fraught with complexities, it is worth exploring given the growing numbers of older mentally retarded persons living into old age and the need for some type of pension income.

Lastly, certainly one of the avenues of retirement should be the blending of services available within the mental retardation system with those available to other seniors in the local community. There is a range of services available such as activities in senior centers, congregate meals sites, and adult day care. Any of these options could be used for individuals who are relatively capable. For individuals who are severely mentally impaired programs need to be provided in the mental retardation system. The aging network does not have the capacity to serve very impaired individuals, regardless of handicap. Mentally retarded senior citizens could and should partake of the local senior citizens center's programs.

This, however, does not come without its problems. Because integration of disabled seniors into the local seniors programs could be greeted with resistance, referrals to senior programs should be based upon the age of the resident, not their diagnosis or status in the mental retardation system. Non-disabled seniors may not have ever encountered a disabled person before, especially since when they were growing up it was the practice to institutionalize mentally retarded individuals. Both the expectations derived from continual use of generic aging network services and education campaigns with staff of senior programs should aid in eliminating such bias.

Further, to address such barriers in attitudes and to aid in providing special transition services associated with movement, "aging in place," and retirement, the Administration on Developmental Disabilities and the Administration on Aging, jointly, should commission the development of a series of training and education packages on aging and life-long disabilities that address the issues noted above. These training materials should be made broadly available to both aging and mental retardation/developmental disabilities agencies.

RECOMMENDATIONS

1. To address problems associated with moving from home or institutional settings and the development of appropriate community services:
   The Administration on Developmental Disabilities should advise the state developmental disabilities councils to address the issue of the state's elderly mentally retarded/developmentally disabled population and establish statewide task groups to address barriers and problems found to be present that impede the community integration of elderly mentally retarded/developmentally disabled persons and family planning for long term care.
2. To aid in more effectively using non-disabled seniors as volunteers as "senior friends":
   The National Domestic Volunteers Services Act should be amended to include expanded provisions for the use of Senior Companions to specifically address the transition problems faced by older persons with mental retardation.
3. To ensure that older persons with mental retardation are not capriciously forced to leave their "homes":
   The Health Care Financing Administration (HCFA) should ensure that its new regulations governing the ICF-MR program are flexibly applied to allow for aging and the special problems faced by residents who "age in place."
4. To ensure that a lack of information and training is not a barrier to the successful integration of older persons with mental retardation in the aging network and that mental retardation providers can realistically adapt their programs to serve an aging clientele:
   The Administration on Developmental Disabilities and the Administration on Aging, jointly, should commission the development of a series of training and education packages on aging and life-long disabilities and that these training materials should be made broadly available to both aging and mental retardation/developmental disabilities agencies.
5. To place in the public domain concerns over the aging of persons with lifelong disability: The Administration on Aging should ensure that the interests and needs of older persons with lifelong disability are included on the agenda for the 1991 White House Conference on Aging.

The Supplemental Security Income (SSI) and Social Security Programs for People with Mental Retardation

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BACKGROUND

Supplemental Security Income (SSI) is a Federal program that provides monthly payments to aged, blind, and disabled people who have little or no resources and income.

The Social Security Administration administers the SSI program. It determines eligibility of claimants, makes the basic payments to recipients, and maintains a master record of recipients.

States are required to supplement the Federal payments to people who received a higher amount under certain State assistance programs that existed before 1974. They have the option to supplement the Federal payments to all recipients. Most States also provide Medicaid, food stamps, and various social and rehabilitation services.

Even though the Social Security Administration runs the program, SSI is not the same as Social Security.

SSI is financed from general funds of the U.S. Treasury — personal income taxes, corporation taxes, and other taxes. Social Security is funded through the Social Security taxes paid by workers, employers, and self-employed people. The two programs also differ in other areas, such as the conditions of eligibility and the method of figuring payments.

BASIC ELIGIBILITY CONDITIONS

To be eligible for SSI, a person must be 65 or older or disabled or blind, have limited resources and income, and meet certain other requirements.

Disabled or blind children, as well as adults, may be eligible. It makes no differences how young a person is.

A person 18 or older is considered disabled if a physical or mental impairment prevents him or her from doing any substantial gainful work and is expected to last for at least 12 months or to result in death.

A child under 18 may be found disabled if he or she has a physical or mental impairment that is comparable in severity to one that would prevent an adult from working and is expected to last at least 12 months or result in death.

Disabled and blind claimants are referred to appropriate agencies for rehabilitation services.

In 1988, the resource limits are $1,900 for a single person and $2,850 for a couple. Not all resources are counted in determining if a claimant meets the resource limit. Items which do not count in most cases include: a home, personal effects, household goods, an automobile, life insurance policies, burial funds and plots.

The income limits in 1988 for a Federal payment are $354 a month for a single person and $532 for a couple. The income limits may be higher if a State supplemental payment is involved. Not all income is counted in determining if a claimant meets the income limit. A number of different exclusions are allowed for earned income (wages) and unearned income (pensions, interest, cash benefits). Parental income is partially counted for a child under age 18 who lives at home. An adult child's payment may be reduced if he lives in the parent's household, but the parent's income is not counted.

MEDICAID

In most States, SSI recipients are eligible for Medicaid, which can pay health care expenses.

In some cases, children may be eligible for SSI and Medicaid while institutionalized but be ineligible when living at home, either because of their parents' income and resources or be-

cause they receive support and maintenance in kind. At the State's option, children 18 or younger who live at home may retain Medicaid eligibility while receiving home care at less cost to the Government.

For more information about Medicaid, contact the local medical assistance office.

WORK INCENTIVES

Recent legislation modifies and makes permanent certain work incentive provisions — Section 1619 of the Social Security Act — which were due to expire on June 30, 1987. These rules provide special cash benefits and Medicaid coverage to SSI recipients who work despite severe impairments. The new provisions became effective on July 1.

Begun as a pilot 3-year demonstration project in 1981, and since extended, the program has two parts:

Section 1619(a) allows disabled recipients who work to keep receiving SSI cash benefits until their earnings reduce their SSI payments to zero.

Section 1619(b) continues Medicaid protection for disabled people whose earnings are too high for SSI payments as long as they remain medically impaired, need Medicaid in order to work, and cannot afford to replace the Medicaid benefits. SSI recipients can be eligible for Section 1619 benefits in any month after the first month they join the SSI rolls.

The new provisions require all States to continue Medicaid coverage to recipients who were receiving Medicaid coverage in the month before qualifying for Section 1619 benefits. This coverage was not available in all States under the old law.

Under the old law, recipients who had been receiving Section 1619 benefits often had to reapply for regular SSI benefits if their work attempts failed. Recognizing that severely impaired recipients who make work attempts may not be able to show steady improvement, the new provisions allow relatively free movement between regular SSI benefits and 1619 eligibility. Even people who have worked their way off the SSI rolls can go back to cash benefits and/or Medicaid, if their income drops to eligibility levels within 12 consecutive months.

The new legislation is based on the demonstrated potential of the work incentive rules for helping recipients return to work and leave the payment rolls. A small but growing number of people have participated in the program since it started in 1981 as a demonstration project. The project results indicated that a significant number of participants began working or increased their earnings only because they know they would continue to receive Medicaid and would also receive SSI if their work effort failed.

PLANS FOR ACHIEVING SELF-SUPPORT

Under a plan for achieving self-support, a disabled person can set aside income and/or resources for a work goal such as vocational training, education, or starting a business. A person can even set aside funds to purchase work- related equipment. Income and resources that are set aside are excluded under the SSI income and resources tests.

The person must have a feasible work goal and a specific savings or spending plan. He also must provide for a clearly identifiable accounting of the funds that are set aside. The person must then follow the plan but can negotiate revisions as needed.

A vocational counselor, social worker, employer, Social Security representative, or anyone else may help a person develop his or her plan for achieving self-support. Social Security will evaluate the plan and determine its acceptability.

It is important to remember that, as earnings go up, a person who doesn't need a plan for achieving self-support may need one next month to remain eligible or to increase his or her SSI payment amount.

Quality Assurance Panel

MODERATOR: VALERIE 1. BRADLEY

PANELISTS: LINDA TOMS BARKER
RONALD W. CONLEY, PH.D.
MARY C. CERRETO, PH.D.
C. KAYE PEARCE

Assuring and Enhancing Community Integration of Persons with Developmental Disabilities Through Quality Assurance Mechanisms

by Valerie J. Bradley
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What does quality assurance have to do with community integration and the continued reform of services to people with mental retardation and other developmental disabilities?

1. Quality assurance systems spell out our expectations for services provision. The norms of community integration and community presence, therefore, must be reflected in our standards and evaluation criteria.
2. Community integration assumes that individuals with disabilities will lead more normal and participatory lives. Quality assurance systems should provide the feedback necessary to determine whether these promises are in fact kept.
3. Because community integration for persons with disabilities assumes that lay persons as well as professionals have important roles to play, quality assurance systems must reflect a range of contributions both insofar as setting standards and monitoring services.
4. Because community integration stresses client choice, quality assurance systems should include the perspective of the individual receiving services as a critical element.

Today, we have an impressive panel made of people who can reflect on quality assurance issues from very personal and direct experience. Though quality assurance has become somewhat trendy in the last several years, these individuals have been involved in the design of oversight mechanisms and evaluation systems for several years.

In addition to the individuals on the panel, I hope that others in the audience — especially family members and self-advocates will also contribute to the discussion.

As I am sure you are all aware from the agenda, our mission is to identify state-of-the- art techniques and to make policy recommendations regarding the multiple relationships among federal, state, and local governments, families and consumers and private providers that can be forged to facilitate community integration.

With respect to this panel, our task is to identify the multiple strategies that can be employed at all levels of the system to ensure the well-being of people with disabilities and their maximal integration into the life of the community.

Before we proceed, I would like to provide a general context for the discussion by covering the following areas:

- What is quality in this field?
- What is wrong with the way that we currently measure quality?
- What is the role of a quality assurance system?
- What are the components or aspects of quality assurance?
- What are some innovative techniques for enhancing and ensuring quality?
- Who can carry out quality assurance activities?

WHAT IS QUALITY?

The term "quality" is increasingly used not only in human services, but also in business. Advertisements for automobiles in particular stress the virtues of their products in statements such a "Quality is Job 1" and others claim the "the quality goes in before the label goes on."

"Too bad we don't have a high hurdles event in this track meet!"

"There's got to be a better way!"

These concerns are the result of a desire for standards that yield a product whose performance is reliable and predictable. These are clearly criteria that should be part of the expectations for services to persons with mental retardation. The added dimension in human services is the desire to find out whether the service that is delivered has the intended effect. In other words, quality is the promise that is made to the client and quality assurance is necessary to ensure that the promise is kept.

To ensure that the promise of community integration — a full life in the mainstream of the world of work and leisure — is kept, quality assurance systems must be available that both monitor the fulfillment of the integration goal and that assist in facilitating the implementation of the concept. Notions like community integration are not self-implementing — they need to be nurtured and supported. The field of mental retardation and developmental disabilities is fairly good at housing and training people with mental retardation but the skills needed to encourage integration are not necessarily taught in professional schools.

Our notions of quality are dependent on a variety of inputs including ideology (the values that govern the system), empirical knowledge (research regarding best practices), and professional training. These viewpoints all become relevant in the design of standards. Turning conceptions of quality into standards is a complex process in the human services field. The following figure depicts the differences between inputs into health standards versus standards in the human services.

In the health field, there is a linear relationship between developments in practice and research and the evolution of standards, and consequently to outcome expectations and the application of standards in practice. In the human services field — and particularly the developmental disabilities field — multiple entities and perspectives contribute to notions of quality and to the setting of standards. The application of these standards is also complicated by the diversity of the provider community and the approaches applied to service intervention. The recognition that notions of quality are multi-faceted leads us to the conclusion that quality assurance systems must also employ multiple perspectives in assessing and applying quality standards.

CRITIQUE OF QUALITY ASSURANCE APPROACHES

There are several problems with the way in which quality assurance is currently carried out:

Minimum Standards

The following drawing illustrates the dilemma of minimum standards. The standards used to judge services for persons with developmental disabilities tend to perpetuate mediocrity because they represent minimal compliance thresholds. Clearly, there are basic requirements that all services should meet and that are unlikely to change over time including minimum health and safety standards. Standards, however, should not mark only minimal achievement, but should contribute to the dynamic character of a system by constantly exhorting providers to higher levels of attainment. The provider in the drawing is neither being challenged by the event she is in nor can she expect any rewards for her exemplary performance.

Burden of Documentation

The quality regulator in the next drawing is in the midst of a paper blizzard typifying the problem of paper compliance. As services have proliferated and become more decentralized, quality assurance has become a more time consuming and difficult task. As a result, many public agencies have increasingly used paper "proxies" for quality. As the task has grown, it has become easier to monitor those things that can be counted or observed easily. Staff are inadequate in many agencies and their ability to spend time getting to know programs first hand has diminished.

Reactive vs. Positive

Further, traditional quality assurance systems use techniques that are more reactive than positive. Reactive mechanisms investigate service quality problems post facto and are generally negative and targeted to past practice. Positive monitoring mechanisms assist service providers in order to improve practice, and to head off potential problems before they develop.

Clearly, ferreting out abuses in services delivery is an important activity in any quality assurance system. The problem arises when the system becomes dominated by negative oversight and sanctions. When this happens, providers begin to see the public monitors as adversaries concerned only with finding fault. As a result, the mutual support and cooperation necessary for service quality is undermined.

Implications

The result of these structural problems in quality assurance systems is that the communication of policy or a vision of what the service system should be is blocked both by the adversariness of the process and by its narrow focus. The solution is a better balance between

the aims of quality regulations (e.g., auditing, licensing, etc.), and quality enhancement (e.g., technical assistance, self-assessment, etc.).

Role of Quality Assurance

There are six objectives that characterize the role of quality assurance:

- To assure that providers of human services have the capability to provide an acceptable level of service;
- To assure that client services are provided consistent with accepted beliefs about what constitutes good practice;
- To assure that a commitment of resources produces a reasonable level of service;
- To assure that the services that are provided have the intended effect;
- To assure that the limited supply of services is provided to clients most in need;
- To assure that the legal and human rights are protected;

Contemporary quality assurance systems are fairly effective in meeting those objectives having to do with capacity and practice — usually through licensing and accreditation. They are less effective in assessing cost effectiveness and service outcomes. The protection of legal and human rights has improved substantially over the past decade, but improvements are still needed.

ASPECTS OF SERVICE QUALITY

There are many facets of the delivery of services that must be taken into account when designing a quality assurance system.

- ***Components of a Quality Assurance System*** — Those elements that comprise the quality assurance process including standard- setting, monitoring, and control/enhancement.
- *Standard-setting and measurement* — The development of programmatic norms or benchmarks for the determination of program performance. Standards must be clear and easily communicated, flexible enough to allow for innovation, and uniformly and consistently applied across settings.
- *Monitoring* — The process of assessing the performance of service providers using pre-determined standards. Monitoring must be cost effective, reliable, and valid.
- *Control/enhancement* — The process of responding to information generated through monitoring mechanisms. Such response can either be regulatory (e.g., development of a plan of correction, withdrawal of funds or license, etc.), or enhancing (e.g, provision of technical assistance). Control and enhancement responses must be creditable and constructive.
- ***Service Dimensions*** — Those aspects of provider performance that are the targets of quality assurance including: (the following drawing graphically depicts the service dimensions)
- *Outcomes* reflect what happens to the client as a outgrowth of the service. Outcomes correspond to the client-related goals of the service and measure the extent to which the service has been effective in meeting its goals.
- *Inputs* (or "structural" measurements) refer to the descriptive characteristics of facilities or providers. Included in this category of criteria are client characteristics, staff qualifications, staff-client ratios, and the condition of physical facilities.
- *Process* refers to the interaction between the client and the organization providing the services and to the administrative and support activities integral of the delivery of the service. Process criteria refer to the quality of the interaction between client and provider, and to how well the client moves through the service delivery system.
- *Outputs* refer to the "products" of the service process including number of clients, number of staff trained, number of IHPs completed, and so forth.

INNOVATIVE QUALITY ASSURANCE TECHNIQUES

There are numerous techniques for ensuring the quality of mental retardation services that can improve the responsiveness of quality assurance systems to service planners and providers alike, and that can extend quality assurance capabilities at a moderate cost in most instances.

Pre-Screening and Self-Assessment

Pre-screening coupled with self-assessment is a quality enhancement method by which an organization voluntarily monitors its own operation using a pre-designed set of standards.

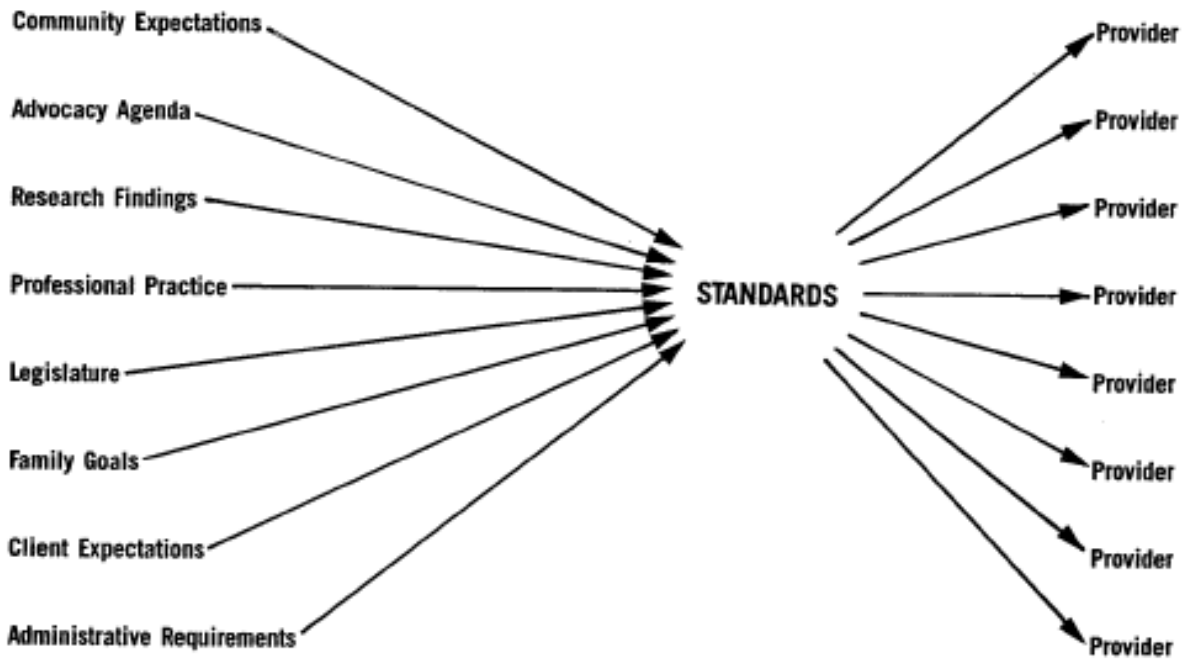
These methods are usually spelled out in manuals and are composed of checklists that organizations can use to assess their own operations. Self-assessment is a non-intrusive and non-threatening way for agencies to assemble and organize information about strengths and weaknesses and to make comparisons with pre-determined norms.

Outcome Monitoring

As noted earlier, quality assurance systems are not very good at measuring whether services have the intended effect. There are some

Quality Assurance in Health

Quality Assurance in Human Services



models of outcome monitoring systems in our field including the work of Temple University Developmental Disabilities Center in designing a continuing outcome monitoring system for the Commonwealth of Pennsylvania. Once a year, the individual progress of persons receiving services in assessed and is compared to previous norms. If an individual's skills have declined below a particular level or if other things about the individual's environment are noted (absence of an IHP on the living unit), then the state or county makes a follow-up visit to determine if there is a problem.

Community integration issues can be built into outcome monitoring schemes so that it is possible to determine whether individuals are remaining isolated in the community or whether they are truly leading active and varied lives.

Case Tracking and Exception Reporting

This technique relies on regularly reported data on individuals receiving service which in turn permits agencies to follow clients through various programs. Exception reporting uses case tracking to identify deviations in individual cases based on predetermined norms.

Consumer Satisfaction

The assessment of consumer satisfaction is important not only because it provides another source of information about service quality but because it is a recognition of the value of client choice and judgement. It is a particularly important method of assessing the extent of community integration.

Observation

Observation involves physically looking at the service delivery process. Observation is a versatile method that can be applied in a variety of residential and work settings. It is one of the only ways in which to assess the actual service process. It is, however, a potentially intrusive method, especially in the residential setting.

Performance Contracting

Performance contracting is in many ways a preferable quality assurance technique since a range of individually-tailored criteria can be built into the contract. Sanctions for non-performance may include some payment penalties and/or may provide for some immediate corrective action.

Accreditation

Accreditation organizations in mental retardation and developmental disabilities by and large include all of the relevant vantage points (with the exception of actual consumers in some instances) on standard setting panels. Many states have "deemed" private accreditation standards as equivalent to state standards and have therefore eliminated the necessity of developing a concurrent set of standards. Other states have allowed private accreditation as an alternative to state certification. The use of private accreditation mechanisms by public agencies is an efficient way of expanding quality assurance resources. The more that accreditation is used as a public requirement, however, the more the field should be concerned about the possible compromise of such standards over time and the gravitation of such standards to the lowest common denominator.

Training and Technical Assistance

Though not conventionally regarded as quality assurance mechanisms, training and technical assistance should be integral aspects of any oversight system. Merely uncovering problems in the service system is not sufficient, public agencies need to have the capability to respond and enhance performance.

QUALITY ASSURANCE ACTORS

As noted previously, quality assurance is a multifaceted activity that should involve the perspectives of a variety of actors in the system and should involve as many perspectives as possible.

Citizens and Volunteers

Citizens can be used to conduct a variety of quality assurance functions including reviewing the results of an evaluation or quality assurance report, collaborating with professionals to carry out evaluations and carrying out independent reviews of a mental retardation program or service system. Citizens and volunteers can bring an important point of view to quality assurance, they can enhance an agency's connection with the community, and they provide an alternative source of manpower for quality monitoring.

Peers

The use of peers to assess the quality of services involves an assessment of the professional practices of individuals providing services within the agency by professionals external to the agency. Peer review can be used for both quality regulation and quality enhancement. It is a reasonably inexpensive mechanism but is sometimes criticized because of its over-reliance on professionalism and the possibility of "cronyism."

Private Evaluation Services

Another option is the use of private evaluation services. Private evaluators can serve as interviewers or trained observers, as designers

of quality assurance instruments, creators of automated client information systems, and developers of data analysis procedures that may be beyond the technical competence of small providers or over-taxed public oversight agencies.

Individuals with Disabilities and Families

Like citizens and volunteers, consumers and their families can extend the capabilities of quality assurance agencies. Using individuals with disabilities and families has several advantages: they have a unique point of view, they tend to focus more on the service environment than on abstract programmatic techniques, they are likely to be sensitive to issues of client rights and abuse, and they may be more successful at soliciting relevant information from other clients and/or family members. Examples of family monitoring can be found in the Macomb Oakland program as well as in the mental retardation program in Ohio. Self advocate monitoring is also growing around the country. One People First program in California did its own evaluation of the service system including interviews with other individuals with disabilities.

Advocacy Groups

Typically, conventional quality assurance agents cannot guarantee that the conduct of a program on a day-to-day basis will enhance the well-being of individual clients and protect their rights while they are receiving services. Because of their unique relationship to their clients, many advocates have a better chance of soliciting quality-related information from service recipients. There are a number of ways that advocates can contribute to quality assurance: they can seek enforcement of existing quality assurance regulations, they can provide a forum for complaints, they can conduct independent assessments, and they can serve as spokespersons for individual complaints.

RECOMMENDATIONS

- Standards at all levels of the service system need to be continually revised and updated to reflect changes in ideology and the state- of-the-art.
- The federal government needs to support research to document the best ways to assess the outcomes of services.
- States and localities should supply the resources necessary to guarantee the inclusion of families and individuals with disabilities at all stages of the quality assurance process.
- Federal, state and local governments should make resources available for a range of training and technical assistance activities.
- The quality assurance provisions of the current Chaffe legislation should be supported.
- Federal funds should be made available to support the dissemination of information on best practice in the area of community integration.

Assuring the Quality of Community Integration Through a Focus on Outcomes: Consumer, Community, and Federal Government Roles

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(Presented by Linda Toms Barker)
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The obvious place to start in any discussion about quality assurance is with examining our definition of "quality". Then we'll look at the importance of focusing on outcomes in order to assure program quality. We'll briefly explore some of the work being done to identify quality outcomes in the area of community integration and where there is a need to improve ways to measure outcomes. Finally we'll examine some issues about the process of quality assurance and the possible roles of different actors in the system to put it all together into something that works.

WHAT IS "QUALITY"?

"Quality" is a concept that is based on ideology — it's something that's very personal and often means different things for different people. One of the potential difficulties that evaluators encounter in measuring quality is a natural tendency to place our own values on the outcomes that we think other people ought to achieve. It's very important in developing systems of standards and mechanisms for monitoring quality, to closely examine the values and range of perspectives that need to be reflected and not only those of the practitioner or evaluator assessing quality.

Quality is a concept that is often used in the context of reinforcing the current way of doing things. One might consider something to be of good quality when it reflects our understanding of the way things are commonly being done. If it's different, especially if it's significantly different, then we might call it "innovative", but still question its quality. So one of the first things we need to look at as we examine our notions about quality, is whether or not we want to reinforce the current ways of doing things or whether we want to look for new ways of doing things.

Quality is also a concept that can be used to help bring about or reinforce what we consider to be "models" of the way things ought to be — to move the system toward what is believed to work best. This presupposes that we know what the model ought to be and the direction in which changes should be made. However, if we focus on the way things are currently being done, or we focus on some notion of where we think they ought to go in the future, we can get ourselves locked into certain ways of thinking about things.

We may want to step back from all of that and start to think about quality in a much broader sense, as a concept that focuses on "the way we get the best results." Then when some new idea comes along, that's neither our current way of doing things, nor the model we've chosen as the best direction to move into, we still have criteria we can use to judge the quality of the new idea.

THE CASE FOR FOCUSING ON OUTCOMES

So what are the best criteria to use to judge quality? It turns out that most quality assurance systems have tended to focus on things like prescribing the kinds of staff roles and qualifications that are most appropriate, or the kinds of services that should be delivered and the timelines, the amount or intensity of those kinds of services, the characteristics of the physical facilities in which those services should be provided, or even detailed sequences of activities staff should carry out in delivering services. These kinds of standards focus on "inputs" and "processes" as the keys to quality services. Certainly, there is a role for under-

standing and valuing certain kinds of processes and inputs, and it is not our intent to down play those. However, it is important to emphasize the need for understanding what the intended outcomes are to be. If you know where you're ultimately headed, it's much easier for you to know if you're going in the right direction, and to assess some new process or input in light of how it contributes to a high quality program.

Consider the experience of a trainer at a computer training program in Georgia who recently went to his director and insisted that the records showed the wrong diagnosis on one of his trainees. "You told me he has Down Syndrome but he's doing elementary computer programming and other things that people with Down syndrome can't do, so the diagnosis must be wrong." In fact, the trainee does have Down Syndrome and he really can do some very simple computer programming. Here was a new "input", a type of client not generally included in this training program. He wasn't the kind of person thought to be capable of these activities. But the outcome is that this person is learning skills that will enhance his employability and potential for community integration. Staying focused on the outcome we can say that this is a good program for this individual.

The major problem with quality assurance systems focusing on detailed prescriptions and monitoring of processes and inputs, is that we often don't know whether the processes and inputs will in fact lead to the kinds of outcomes we desire. We think they will, based on our theories and beliefs about good programs but we may not have had enough experience over time to be sure. Bradley et al., observed that

"The major drawback to using "inputs" as measures of quality is that they measure only the capability to perform and not actual performance" (1984). Other limitations of focusing exclusively on inputs and processes include:

- These systems can inhibit program operators from responding to the unique or special needs of individual clients who are unlike the "typical client," through their overspecification of what a program must do and the processes to be used in carrying out these activities.
- These systems can inhibit programs from responding effectively to the different requirements that may arise at different localities or at different times. Given variations in the resources and environments of different communities, the right mix of inputs in a program may appropriately need to vary. Indeed in some communities, ideally desired facilities or staff with certain backgrounds may not exist. To develop such facilities or move such staff to the community may be prohibitively expensive or otherwise infeasible. To insist on them may be to condemn the community to no program at all, or to requiring clients to relocate or travel great distances. This could result in less desirable outcomes than if the community adapted its facilities and staffing patterns to suit its local needs and resources.
- Because standards will favor some types of staff hiring and program designs over others, the process of erecting the standards risks capture by interest groups wanting to protect their self-interests professionally or in the service market. While the standard- setting process would be carried out in the name of what's best for the client, it can become a political exercise to create job protection for certain types of professionals or market protection for certain types of providers.
- Such a system of standards if quite extensive could be very expensive for the quality assurance component to monitor. Yet poor monitoring could lead to disdain by providers and communities unconvinced of the appropriateness of the standards or unwilling to conform, and ultimately erode the credibility of the quality assurance component altogether.
- And finally, as we focus on community integration, it is important to recognize that the movement away from institutional programs means a movement away from standardized service delivery approaches and a single centralized quality assurance system. The broad diversity of services, providers and service settings involved, may simply not lend themselves to quality assurance approaches that focus on inputs and processes.

An alternative approach to defining quality, which is usually superior to "inputs" and "process" definitions, is to foci's on the "outcomes" actually desired for clients. Under this approach programs are held accountable for achieving results for clients, and a program of "high quality" is one which achieves desired results with consistency. The use of such outcome measures shifts the process of quality assurance by permitting different communities and providers more room for experimentation with different modes and mixes of service as they try to find out what works best, and as they respond to differing client needs and local community situations.

Quality assurance systems driven principally by a focus on client outcomes can, of course, also include standards relating to inputs and program processes. These latter standards would be included where there is clear evi-

dence that those inputs and processes are consistently, strongly, and perhaps uniquely associated with good client outcomes. Also, it may be judged that certain types of client experiences are important outcomes in their own right — e.g. access to certain kinds of services, timeliness of service delivery, the opportunity for client participation in service planning, the right of the client to privacy or confidentiality, or simply sensitive treatment that respects their dignity. In this situation, process standards become appropriate because the experience and protections they guarantee are outcomes desired for clients.

Finally, there remains a place in a quality assurance process for guidelines and suggestions for "best practice" models as currently identified by individuals knowledgeable about programs around the country. The key is that such models be put forward as recommendations, and not as requirements or definitions of "program quality." Today's "best practice", especially in the emerging field of community integration, may become outmoded quickly. Moreover, there will usually not merely be a single model of "best practice", but several alternative models. Rather than elaborate highly complex sets of standards and requirements reifying such contemporary "best practice", the quality assurance component would do far better to identify, describe, and disseminate information about "best practices" to communities, and rely on the sincere concern of those in the local communities to find the best way of serving clients (and on the focus on outcome- focused performance measures) to prompt the communities to emulate such practice.

WHICH COMMUNITY INTEGRATION OUTCOMES ARE MOST IMPORTANT?

A review of the literature shows that there are almost as many different ways of looking at community integration outcomes and different values placed on different kinds of outcomes as there are people writing about them. There certainly is not consensus. While many consumer advocates and service providers have been concerned about community integration for a long time, relative to the whole history of services for individuals with developmental disabilities, the formal assessment of outcomes in this field is still very much in its infancy. Thus, concepts about what to measure are still very varied.

According to Janell Haney, for example, much of the research to date on the outcomes of community integration efforts focuses on the issue of adaptive behavior. We know when we've had a good outcome with someone with a severe disability when their adaptive behavior is improved including in areas such as "... independent functioning skills, physical development, economic activity, language development, number and time skills, prevocational activity, self-direction, responsibility, socialization, and trustworthiness. Maladaptive behavior would include aggressiveness and rebelliousness." A good quality program would be one that offered a combination of services and supports that resulted in increased adaptive behaviors and decreased maladaptive behaviors. (Haney, 1988.)

James Martin suggests that acquisition of specific community and domestic daily living skills are critical to the success or failure of community integration. Since research has shown that individuals who don't have various kinds of community and domestic skills are the ones that tend to fail, a quality program might be one that provides training in specific skill areas including at a minimum the following (Martin, 1988):

Community Skills

Mobility — pedestrian skills, bus riding, car driving

Money Management — equivalency, counting, computation, banking, purchasing in restaurants, grocery stores, vending machines

Telephoning Skills — phone dialing, emergency calls, everyday use

Domestic Skills

Menu Planning

Meal Preparation

Housekeeping

Clothing Care — selecting clothing, sewing, laundry

Home Safety

While these skill areas represent the kind of listing that can be useful in developing a curriculum, they are less useful in defining the quality of a program. After all, the outcome is not so much whether one knows how to sew (not a skill that many of us have time to exercise in our daily lives, even if we do know how), as it is whether one is appropriately dressed in clothes that are clean and in good repair and appropriate to the given occasion. Also, it's extremely difficult to be sure that such a listing truly represents the most important skill areas. For example, what about teaching how to purchase durable clothing less likely to need repair or how and when to take clothes to the dry cleaners?

Richard Schutz stresses the importance of employment as a community integration outcome (Schutz, 1988). He cites Studs Turkel who has pointed out that besides monetary rewards, work offers a person less tangible rewards such

as opportunities to interact with others, develop self-worth, and contribute to society (Turkel, 1972), and C.F. Obermann who has claimed that from a societal perspective, work has become the measure of both worth and social status, with unemployed individuals viewed as less socially acceptable (Obermann, 1965).

Many providers may view employment as a totally separate issue from community integration. There may be a tendency to think of community integration as a program or service approach rather than as a set of outcomes, as being a residential and day treatment concern, with employment being some other agency's problem. But in our society, community participation includes work. Employment and community living are all part of the same big picture as we chart the success of our community integration efforts.

Laird Heal reaffirms the importance of focusing on outcomes and stresses the need for empirical research to establish which kinds of residential changes produce beneficial outcomes. The deinstitutionalization movement has been fueled to date largely by ideology. But at this stage of development it becomes important to bring empirical evidence to the task of refining community integration strategies to ensure that our efforts are having the desired effect. Heal proposes six conceptually different clusters of variables that he considers reflective of the effectiveness of community living arrangements: 1) levels of individual and social competence (e.g. independent living skills, problem-solving skills, adaptive behaviors, socialization), 2) approximation to normalization (geographical location, environmental blending with the neighborhood, comfort and appearance), 3) individuals' satisfaction with their placements, 4) others' satisfaction with the placement, 5) residential climate (e.g. how highly structured, extent of achievement orientation, nature of interpersonal relationships, and 6) cost of services (Heal, 1988).

THE CASE FOR INCLUDING THE CONSUMER'S PERSPECTIVE

Heal points out that among these various measures of success, clients' satisfaction with their living situation may be the most neglected outcome measure of all, and yet it is perhaps the most important. A variety of different attempts have been made to include client satisfaction measures in evaluating outcomes, demonstrating that residents can provide reliable information concerning their level of satisfaction with their community placements. Unfortunately, these studies have generally involved individuals considered mildly or moderately retarded. If all individuals labeled retarded, including those with severe disabilities, are to have a voice in their destiny, the methods of measurement will have to be improved. Evaluators and practitioners will need to develop ways to capture people's perspectives, even if they have limited language skills.

This may require approaches such as in- person interviews, observational techniques, or inter-peer self-report. The support of research to develop better measurement methodologies may be an area where the federal government can make a significant contribution to furthering the state-of-the-art in assuring quality community integration programs. Another outcome area that has been given increasing attention in recent literature is what's referred to as "quality of life". Bob Schalock, for example, has been developing, testing and refining quality of life measures for several years in an effort to capture the extent to which individuals who participate in innovative employment and community integration efforts are really better off as a result of the services they receive and the changes they experience (Schalock, 1983). One of the criticisms of efforts such as these is that again, they may tend to focus on the service provider's perspective on what constitutes quality living, rather than that of the client (Heal, 1988).

A good example of the insights that can be gained from seeking out the clients' perspective comes from BPA's recent work for the U.S. Department of Education to develop performance measures for supported employment programs. We began with simple constructs such as hours worked and wages earned, and then began to tackle more difficult areas such as kind and amount of support, and level of integration achieved. We ran into concerns that some programs might be moving individuals from an environment they actually preferred into an environment in which they wouldn't thrive. It became important to look at a bigger picture than simply what goes on at the job site. Many practitioners have stressed the value of social networks, self-esteem and self-direction as outcomes of quality supported employment programs.

In our efforts to develop national consensus on the appropriate measures, we brought together key experts from around the country. Consensus was reached in a range of areas, but the piece that was missing was the consumer perspective. So we asked People First, a consumer organization of individuals with developmental disabilities, to designate some one to talk to us about what consumers value as outcomes of supported employment. At first we had difficulty getting meaningful input; it was easy to agree that all of the things we had identified as

outcomes were important. Then we found a new way to ask the question — How would you help a friend choose a job? What would you look for? The results were surprising and insightful:

First, whether the supervisor treats us like grown-ups;

Second, whether they judge us on how fast we work — we're not fast, so why do they always put us in jobs where we're judged on speed?

Third, whether there is good light and fresh air and it's a comfortable place to work.

The fourth priority was wage level, followed by all the other outcomes identified by the researchers such as number of hours per week and job stability. These priorities reflect individual values that were influenced by the kinds of job placements often typical for individuals with severe disabilities. But fortunately, there are exceptions. We learned of an individual whose job was taking care of the salad bar in a fast food restaurant. He had a model sparkling salad bar, with every item always filled to the top and other employees came to visit his site during their training. This worker had been through sheltered work, he'd tried competitive placements and failed, but was fortunate enough to be eligible for supported employment. He was also fortunate to be able to communicate his need for work that took advantage of his strengths rather than highlighting his weaknesses. Although it may take more effort to understand the consumers' perspective about which outcomes should be valued, we mustn't fool ourselves into thinking that they can't tell us, just because we haven't learned how to ask the questions.

Having talked to some consumers about what they value, and reviewed the literature, its possible to begin formulating some ideas about what a set of outcomes might look like that cuts across professional and consumer perspectives. Much more work is needed to develop and validate a definitive set of measures, but the following represent some areas that can be proposed for consideration as measures of the quality of community integration efforts:

1. Community Participation — one of the most important indicators of how effectively individuals function in the community is their ability to access community resources. This includes whether individuals are personally aware of what resources are available and able to make their own choices and initiate their own activities in terms of accessing those resources; if not, whether someone else is available to provide the appropriate level of guidance or assistance. Too often only two options exist, either an individual has the ability to independently access one's own resources, or the choices are simply made by someone else. It is also important to consider how much individuals actually make use of their local resources and how accessible they are (in terms of hours available, proximity to transportation, etc.). Mobility is also an important aspect of community participation — can individuals use mainstream transportation effectively or drive their own car? Are they safe pedestrians? Another extremely important aspect of community participation and one that affects many other areas as well is the extent and nature of individuals' social networks and friendships. The kind of activities that friends participate in together (civic clubs, YMCA, churches, etc.) and developing relationships with non-disabled acquaintances as at churches, YMCA and other kinds of places.

2. Employment —while individuals certainly can enhance their quality of 'community living without employment, the opportunity to participate in the workforce dramatically expands an individual's horizons in today's society. Employment brings about a sense of satisfaction and fulfillment, and it also provides an opportunity for making friends, sharing resources and enhancing skills. Characteristics of employment important to measure include hours worked, earnings, job retention, how the supervisor treats the worker, the appropriateness of the job, match, (e.g. whether they are judged on speed, whether the work matches the individual's skills), the work environment etc.

3. Expandable Income — this is a concept sometimes much more meaningful than simple earnings, and focuses on the portion of income (whether it comes from earnings or other sources) that an individual has personal control over. It addresses whether an individual is financially better off. Money can be very empowering and expendable income is a very important aspect of quality of life. Increased purchasing power can increase the kinds of activities people can participate in, the kinds of things they can purchase for themselves, and their sense of self-worth and self-esteem.

4. Family Relationships — the more effective the community integration program, and the better the support that's provided, the more that stress on the family is relieved. The more opportunity family members have to get on with the rest of their lives, the healthier the relationships among family members. Effective community integration may mean enhancing the ability of families to stay together, or it may mean independent living in settings away from parents. In either case the strength and nature

of family relationships can be good indicators of the success of community integration efforts.

5. Personal Growth — one of the biggest challenges in community integration efforts centers around the concept of choice — how to help people understand the concept of choice, how to help them practice making choices, how to help them understand how to use choice skills to make choices that really do meet their own needs, and how to put them in a position where they actually have some options to choose from. Another important aspect of personal growth is the chance to fail. For most people the least restrictive environment is one in which the freedom to try and fail is not unnecessarily limited by overprotection or narrow views of individual potential. Equally important are opportunities to build self-esteem through achieving personal goals and developing new skills.

6. Cost — While some would argue that cost is not a legitimate quality concern, human service professionals are constantly fighting the battle of limited resources. The traditional conflict between the best available options for an individual and society's interest in distributing scarce resources as widely as possible, is increasingly the focus of public debate regarding the most effective allocation of resources available for human service programs. Though improvements in service quality do not always result in increased costs, "there can be little doubt that costs and quality are generally interdependent" (Bradley, 1984).

PUTTING IT ALL TOGETHER: WHO SHOULD DO WHAT?

Once an array of desirable outcomes has been chosen, such as those mentioned above, the next challenge is to build a system for ensuring that these outcomes become the target of community integration services, We've already stated that services to promote community integration don't comprise a single service system that is easily regulated through a single agency or system of standards. Obviously one first important step will be to develop consensus on the aspects of quality we want to stress. Through a common understanding of what comprises quality in community integration, the various regulating agencies that already participate in the quality assurance process with many of the existing providers of service can help to ensure that quality assurance is used as a mechanism to enhance quality rather than simply requiring minimum performance.

Developing this kind of common understanding will require additional research. An important role of the federal government in this process will be to fund further research into areas such as:

- service practices associated with success — establishing empirical evidence that valued inputs and processes do, in fact, lead to desired outcomes;
- developing reliable measures of some of the more complex qualitative outcomes such as extent of choice, self-esteem, and measures of community participation;
- developing better ways to elicit information from consumers with severe intellectual and communication impairments to maximize their involvement in the process and ensure that "quality" is being defined on the basis of what they value as well as on the values of practitioners and researchers;

It's absolutely critical that families and consumers be involved in the process. It's not enough to simply provide licensing and accreditation of providers, because ensuring high quality outcomes involves many decisions along the way. Decisions need to be made about where an individual gets services, how much of the services should come from the social services system, which services can appropriately be provided by an individual's own family and relatives, and what kinds of support can be offered by their church or local independent living center. The interrelationship of a whole network of specialized services and generic supports suggests the local community itself can be a very important vehicle for enhancing the quality of the services available, but with adequate information.

A look at other human services systems suggests a rapidly growing movement towards the private market place — uses of vouchers for buying health care, for example. Theoretically consumers regulate quality through the influence of their purchasing power. In the context of community integration for individuals with developmental disabilities, this approach does have some inherent limitations:

- There is some question about how many DD adults have the personal capacity to evaluate information about programs and make informed, reasoned choices. Where their ability to self-advocate and select services is limited, family members or guardians may not be sufficiently well-informed about the state-of-the-art and most effective service approaches;
- In many communities there simply aren't multiple providers of services such that a true "market" exists whereby consumer choice can be exercised to ensure high quality services;

- Even where multiple choices are available, some kind of oversight is needed — the "marketplace" cannot itself be expected to evaluate different approaches, nor can each individual reasonably be expected to gather widespread information about a wide range of programs from which to choose.
- If all programs available in a given community need improvement, a mechanism is needed to stimulate change. Program self- assessment is one tool, but may not be sufficient to bring about program improvement if system disincentives exist; so certainly going solely to a private market place approach wouldn't work.

In spite of these reservations, there remains an important role in any national quality assurance effort for the simple provision of good information about best practices and client outcomes. For example we have seen how simply publishing the results of educational tests for local schools, for districts, and for states leads to increased public attention and awareness, and often to community-based pressure and movement for improvement.

Thus, another very important role of the federal government is dissemination of current and timely information that can enhance the quality of community integration efforts by maximizing the ability of consumers and local communities to play an active role in the quality assurance process. Only when information about best practices is readily available can individuals and practitioners make effective choices about the service delivery approaches most likely to fill a need in their community or for a particular consumer.

Dissemination of current information about outcomes and best practices will also serve to enhance the effectiveness of state and national accreditation efforts. In addition to existing regulating mechanisms there may be an increasing need for other organizations to become involved in the process such as state DD councils.

How can such a quality assurance system possibly extend to the many communities across the country? Clearly development of any quality assurance system will take 5-10 years before most communities could be directly examined in terms of their quality assurance process. In the short run, the process would be enhanced by development of better measures and better measurement procedures, consensus building on values to be targeted, empirical evidence of links between practices and outcomes, and strong efforts to disseminate information about the current-state-of-the-art and future directions in promoting community integration for individuals with developmental disabilities.

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Quality Assurance from a Service System Standpoint

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When I was invited to participate in this panel, I was asked to prepare a paper on the topic of the work disincentives that are inherent in most of the programs that provide services and/or support to persons with developmental disabilities. My initial reaction was that the subject had been extensively discussed in recent years and I wondered what I could add to the topic that had not been discussed previously. Nevertheless, I agreed to participate because I believed that it was important that this topic be addressed at this conference. It is important because the issues surrounding work disincentives are numerous and complicated and few people fully understand them, and because a major reduction in these work disincentives is necessary in order to assist service providers to achieve their objectives, particularly employment.

I was also initially puzzled as to how to relate the subject of work disincentives to the topic of the panel - quality assurance. After considering the issue, it became apparent to me that the way to relate my subject to the topic of this panel was to consider "quality assurance" from the standpoint of a systems perspective. One of the problems with methods of assessing quality assurance is that we usually consider doing so from the standpoint of individual programs, or some part of the total service system, such as residential care, but we rarely examine the effects of the entire set of programs in the service system on clients.

THE SERVICE SYSTEM

What is the "service system" and why is it important to consider "quality assurance" from this broad perspective? There are numerous programs providing support and/or services to persons with developmental disabilities. As examples, income support may be provided by Social Security Disability Insurance program or the Social Security Childhood Disability Beneficiary program (SSDI/CDB), the Supplemental Security Income program (SSI), private disability insurance, civil service, or railroad retirement. Health care financing may be obtained from Medicaid, Medicare, and numerous private plans. Social Services may be received from agencies funded by the Social Services Block Grant. Vocational rehabilitation services are available from state vocational rehabilitation agencies. Residential care may be funded by the Medicaid Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) program or Housing and Urban Development (HUD) programs.

For the most part, these programs function relatively independently of each other. These programs are operated both publicly and privately, and by different levels of government - Federal, State, and local.

During the past forty years, there have been enormous changes in this services system. In brief:

- It has become very large, serving millions of people and spending hundreds of billions of dollars.
- It has become increasingly comprehensive encompassing a wide range of support and services.
- At the same time, it has become complex, partly because of its size, and, as a consequence, is poorly understood by most people.
- Of great importance is the fact that there has been a major shift towards the use of Federal funding by State and local governments,

largely due to the rapid growth of the social security, SSI, Medicare, and Medicaid programs - these programs account for the bulk of the resources expended by the service system.

- Finally, there has been rapid and dramatic changes in the goals that are set for persons with developmental disabilities, in particular, the service system has changed to stress increasing independence and integration through education programs in public schools, employment in integrated work settings, and community care for persons with severe disabilities, many of whom would formerly have been excluded from schools, placed in institutions, and would have been considered unemployable.

Two essential points about this service system must be stressed:

First, many clients will receive services from multiple programs, both at a point in time, and over time. As an extreme case, it is conceivable for an adult person who is severely disabled to receive both SSI and SSDI, Medicare and Medicaid, social services, food stamps, vocational rehabilitation, HUD supported housing, and other services, all at the same time. As a child, the same person may have been in special education programs and received other services as well.

Second, it is the combined and interacting effects of all of the programs in the service system that determines how successful clients will be in achieving the goals of the service system. Whether or not a person with severe disabilities becomes employed, for example, may depend upon the quality of the education programs that were provided during his or her youth, the availability of vocational and supportive services as an adult, the effects of work disincentives in the income support and health care financing programs, as well as other programs.

From these observations, it necessarily follows that in assessing the effectiveness of programs, we should assess the combined and interacting effects of all of the programs in the service system on the goals set for clients, rather than any one program alone. It is hardly fair to blame the vocational rehabilitation program for failing to place a client on a job, if the client is discouraged from working by work disincentives inherent in the income support and health financing programs.

SYSTEM GOALS

In order to assess effectiveness, however, there must be a set of goals by which to measure the attainments/effectiveness of the service system. If such goals existed, this would constitute a national policy on disability. A fundamental characteristic of such goals would be that each program in the service system would be expected to support each of them and each program would be evaluated on the basis of the extent to which they assisted in the attainment of these goals, or impeded their attainment.

Unfortunately, Congress has not yet legislated a set of national goals. Nevertheless, we can identify some goals that would certainly be a part of a national goal structure if one were to be established. These goals can be divided into those that should be established for individuals being served, and those that should be established for the service system as a whole. Goals that should be established for individuals are:

1. Employment, whenever possible and feasible. In general, employment should be in integrated work settings (with support provided by the service system to maintain such employment, if necessary).
2. Least restrictive care. Community-based residential care (rather than institutional care) should be provided if protective oversight is needed, and must be provided away from the family of the client.
3. Family stability. In particular, children with disabilities should be assisted to stay with their families.
4. Avoidance of poverty.
5. Encouragement of savings.

In general these first five goals should apply to all individuals being served. The next three goals represent aspects of the entire service system that are beneficial both to the individuals being served, and society as a whole. The service system should be:

6. Equitable, in the sense that people with comparable disabilities should be entitled to the same support and services.
7. Coordinated, that is, the programs should reinforce and complement each other.
8. Efficient and dynamic. Not only should the service system achieve its goals at the lowest cost, but it should also be impelled toward seeking even more cost-efficient and more effective ways of achieving social goals. Only a naive optimist would argue that the current state-of-the-art represents the best possible way of providing services.

ASSESSMENT NEEDS

A meaningful assessment of the service system for persons with disabilities is a complex and difficult task that will require numerous simultaneous efforts. There must, of course, be measurement of what the system actually

achieves, i.e., how many people are placed on jobs, how many are placed in community-based housing, the size of such housing, the types of persons placed in different types of housing, how much is saved by persons who are disabled, etc. This type of assessment requires a comprehensive, on-going data system which, as you are aware, does not exist.

But this is only part of what needs to be done. Further questions must be asked as to whether the job placements, the community placements, and other accomplishments result in the maximum level of productivity, independence, and general enhancement of the client's well-being. These questions may be partly answered by an on-going data system, particularly questions about the extent of community involvement by clients. But a more accurate and comprehensive assessment will require more sophisticated analyses of the data, particularly comparisons among States, and the use of special, controlled studies in which clients are placed in different types of employment, or housing, or other situations to see which alternative procedures results in the greatest gains and the least costs.

The conduct of these data analyses and controlled studies will be greatly complicated because of the extreme heterogeneity among clients. Clients vary by the severity of their primary disability, by the number, type, and severity of additional handicaps they have, their attitudes, the amount of training they have, etc. The array of services that is most cost-beneficial for one group of clients may not be so for another group. Some clients may do well in small, semi-independence apartments while others may require far more supervision and it may be more cost-effective to place these more dependent clients in larger residences. It is extremely difficult to carry out data analyses or set up controlled studies in which we can be certain that these differences do not create problems in interpreting the data.

It should be clear that when we discuss evaluation in these terms, then the terms "evaluation" and "quality assurance" become synonymous.

Unfortunately, we lag far behind where we should be in our understanding of the effectiveness of the service system in terms of achieving goals which we outlined above. It is, surprising that there has been so little effort to empirically determine which types of housing are most appropriate for which persons with different severities of developmental disabilities, and different types of additional handicaps, or which types of supported employment systems are best suited for different clients. The lack of ability to determine the most cost-effective and beneficial forms of residential placement is a particularly vexing problem in residential care where some States persist in placing persons with mental retardation in large institutions and then arguing that they could be placed in less restrictive care if they had more flexibility in the use of federal ICF/MR funds.

ASSESSMENT OF PROGRAM POLICIES

There is one type of assessment that is immediately possible for the service system. We can examine the policies and operating practices and procedures of the various programs to determine whether or not they support the suggested national goals that we outlined. If they do not, then we can be reasonably confident that the system does not assure the appropriate quality of services. In fact, it will frequently assure that services will be inappropriate. Although the bulk of the following discussion is devoted to work disincentives, the discussion will extend to other ways in which the system inhibits the attainment of social goals. Let us take each of the national goals in turn.

1. Employment: Most of the resources expended by the service system are for income support and health care—approximately 90 percent of total expenditures. Although recent years have seen reductions in the work disincentives in these programs, major work disincentives still remain to discourage persons with developmental disabilities from accepting employment.

One way in which programs in the services system impede employment is to foster the development of adverse work attitudes and dependency. In order to establish eligibility for SSDI or SSI, and, in most cases for Medicare or Medicaid, applicants must demonstrate that they cannot earn over the Substantial Gainful Activity level, currently set at $300 per month. This is relatively easy to do if they have not worked on a job with earnings above the SGA level since the onset of their condition, and if they fall on a long checklist of disabling conditions established by the Social Security Administration as presumptive evidence of inability to work. If they cannot meet this test, then they must qualify for these programs on the basis of medical evidence, with some account taken for the effects of limited education, advanced age, previous occupation, and work experience. This process takes from two months to a year, and is often characterized with appeals by unsuccessful applicants and litigation. It is almost inevitable that the net effect is destructive to the worker's morale and reduces his or her willingness to return to work.

A second way in which the service system impedes work is by creating massive work disincentives. Acceptance of a job by persons receiving income support and/or health care financing may result in their receiving little net gain, and sometimes a substantial loss in income. The ways in which these work disincentives operate have been discussed extensively in recent years. They are briefly summarized as follows.

Although it is convenient to examine work disincentives on the basis of individual programs, it must be emphasized that it is the total loss of benefits from all programs that an individual must consider when deciding whether or not to risk a return to work.

Work disincentives are particularly severe in the SSDI program. Any beneficiary who earns over $300 per month is placed on a trial work period of 9 months and then, if found capable of earning over this amount, terminated from the program. Since benefits may range as high as $2000 per month, and the average benefit is over $450 per month, there are obviously situations in which substantial financial loss will be incurred by a return to work. Certainly, many beneficiaries would have little incentive to accept the low-paying and insecure jobs that are likely to be available to them.

Work disincentives are less severe in the SSI program, largely because of recent legislation (usually referred to as the Section 1619(a) program) which, after a $85 disregard, causes benefits to be reduced by 1 for each $2 of earnings so that a person is almost always made better off, in terms of net income, by a return to work. In fact, in 1989 individual recipients may earn up to $821 per month before losing entitlement to all Federal SSI benefits and a couple may earn up to $1191 per month. In some States with State supplements, they may still continue to receive a State payment even after losing entitlement to Federal benefits.

Health care benefits have a value that is often as great, or greater, than income benefits to recipients of SSDI or SSI. Since 1981, persons who qualify for Medicare continue to be eligible for Medicare for three years after the termination of the trial work period, reducing, but not eliminating the fear of loss of this benefit.

The potential for loss of Medicaid benefits have been greatly reduced as a consequence of recent legislation (usually referred to as the Section 1619(b) program) which enables persons on SSI who return to work to continue to receive Medicaid benefits as long as annual earnings remain below a threshold income which can be as high as $20,000 (and even higher).

The Section 1619(a) and 1619(b) programs have another feature which greatly reduces work disincentives. Obviously, people can receive extended medicaid benefits under the Section 1619(b) program even though they are no longer eligible for the extended SSI payments under the Section 1619(a) program. Moreover, such an individual will now become automatically re-entitled to Section 1619(a) SSI payment if his or her income falls below the breakeven point. This was not true prior to the renewal of these programs in 1987. If a person lost his or her entitlement to Section 1619(a) benefits before this revised legislation, he or she would have to re-establish eligibility under the basic SSI program before receiving any SSI payments. This required demonstrating that he or she could no longer earn $300 per month, a proof that might be difficult in the case of a former recipient who had been earning above this level for any significant period of time.

A third way in which the service system impedes work is by providing recipients with income security as long as they do not return to work. After all, we all attempt to protect our basic income by insisting on seniority provision at work, or tenure at universities, or bailout provisions by executives, and by other means. Why should we expect that disabled people, often with limited work alternatives, would be less willing to give up income security?

Apart from these work disincentives, we should note the lack of sufficient vocational programs in the service system to provide on-going support to severely disabled persons who need such assistance in order to work.

Although, there are other ways in which the service system impedes employment, these are the most important.

2. Least restrictive care: The second national goal is least restrictive care. The ICF/MR is the major source of federal funds for providing housing for persons with developmental disabilities. Unfortunately, this program, which was designed to reform and improve institutional care, creates major financial disincentives to community-based residential care. One way in which it has done so is to induce States to make enormous capital investments in large institutions in order to qualify them as ICFs/MR and therefore eligible for Federal support. They could recapture this investment only by remaining in operation and charging Medicaid for depreciation on this investment. We should note, however, that the ICF/MR program also stimulated community-based care since

States had to reduce their institutional populations in order to meet the space requirements of the ICF/MR program. A more serious institutional bias on the part of the ICF/MR program is created because only persons who are in need of 24-hour-a-day care are eligible for the program. Lacking standards to determine who should require such an intensive level of care, States have had few restrictions on who they could place in institutional care and a large financial incentive to place persons in ICFs/MR. Since even small community-based ICFs/MR must meet these eligibility conditions, they often become, in effect, small community-based institutions. This condition of eligibility contradicts the basic rationale for providing care in the community which is to maximize independence and community involvement.

3. Family Stability: Family stability is also jeopardized by some features of the service system. The care of some children, particularly those who have serious medical problems, or major care needs, is beyond the financial and physical capability of many families. Unfortunately, funds to assist families to keep their children at home are limited. In consequence, some families have had to institutionalize their children in order to qualify them for Medicaid so that they can obtain medical and other services that they need.
4. Avoidance of Poverty: Often the service system requires what amounts to a vow of poverty in order to qualify for services or other support. For example, in order to receive SSI or Medicaid benefits in 1988, recipients had to meet an asset test which allowed them to own a home, personal possessions, a car, a burial plot, and no more than $2,000 in countable assets if an individual and $3,000 if a couple. The effect of this is to cause some families to spend down into poverty in order to become eligible for the programs.

Even the SSDI/Medicare programs have features which are likely to cause poverty despite the absence of an asset test to qualify for these programs. In the case of SSDI, applicants must wait 6 months after the onset of disability before becoming eligible for benefits, a period that is ample to spend down a large part of one's assets. In the case of Medicare, disabled SSDI beneficiaries must wait 24 months after becoming eligible for SSDI before becoming eligible for Medicare. Beneficiaries who lack private insurance and who have substantial medical problems will probably be poor before the two and one-half year wait to become eligible for Medicare is over.

5. Encouragement of Savings: Few people on SSI have any incentive to save since the most identifiable reward for savings is a one dollar reduction in the SSI benefit for each dollar of interest. Moreover, if savings exceed the asset limit, eligibility for SSI and Medicaid will be terminated. These restrictions are likely to become increasingly onerous as more people make use of extended Medicaid benefits and have earnings as high as $20,000 and even more per year.
6. Equity: There are numerous instances where people with similar conditions are treated differently within the service system. One obvious inequity is that payments to SSDI beneficiaries are not phased down gradually as earnings rise as are payments to recipients of SSI, even though conditions of eligibility and the process of determining eligibility is identical. Persons receiving SSDI will lose all entitlement to benefits if their earnings exceed $300 per month. In contrast, persons receiving SSI may still receive payments even when earnings are double and triple this amount.

Another inequity is that the individual who establishes eligibility for SSI may return to work and still receive both SSI and Medicaid benefits while another, similarly disabled person with the same earnings, will not be eligible for these benefits if he or she went to work prior to becoming eligible for SSI. One consequence of this latter inequity is that students with disabilities who are leaving school are sometimes encouraged to prove inability to work in order to become eligible for SSI and Medicaid rather than being encouraged to seek work immediately after leaving school.

7. Efficiency and Dynamism: There are major impediments to efficiency and rapid development and adoption of new and improved ways of providing services in the service system. Perhaps the greatest impediment is the system lacks a comprehensive and ongoing data system that will document the strengths and weaknesses of the system and enable policy to be developed on the basis of positive knowledge rather than intuition and philosophy. Without such a comprehensive data system, there can be no assurance that the most appropriate services are actually provided. Our lack of knowledge of the costs and benefits of various forms of residential care is scandalous and has greatly contributed to the slow pace of deinstitutionalization.

The availability of large amounts of Federal funds has become another major factor inhibiting the efficiency and the dynamic tendencies

of the service system. Some States organize their service systems in such a way as to assure the receipt of large amounts of Federal funds rather than in ways that would optimize the wellbeing of their clients. In consequence, clients are sometimes placed into inappropriate, inefficient, and old fashioned residential care arrangements that qualify for ICF/MR funding, or they are left in day care arrangements that also qualify for ICF/MR funding rather than being placed in substantial employment.

8. Coordination: The importance of coordinating services has been discussed for as long as more than one program has existed. Many initiatives and research has been carried out on this issue. Nevertheless, the service system is continually criticized for its failure to assure that the various programs re- enforce and support one another. There are many factors causing poor coordination. One way to approach this problem is to note that the service system generally lacks the following aspects, each of which is essential to effective coordination.
   a. The service system does not have clear cut and realistic goals which each program is *required* to support.
   b. The service system lacks a unified service plan for each client that would include Federal (SSDI, SSI; Medicare) as well as State and local programs. It should be noted that some States have established procedures for a common service plan among State controlled agencies. However, States cannot compel Federal participation - a major problem since Federal programs control a large percentage of the funds that are made available to the client. States may find it hard to convince persons with severe disabilities to return to work when this would jeopardize Federally provided income support and health care.
   c. Finally, the service system generally lacks a unified intake procedure that would insure that clients will not fall between the cracks, e.g., to assure that if they are assessed as too disabled to qualify for vocational rehabilitation, they are not also assessed as insufficiently severely disabled to qualify for SSI.

Clearly there are major problems in the service system for persons who are disabled. Nevertheless, there are solutions to all of these problems. There have been much legislation enacted by Congress in recent years designed to ameliorate these problems and there is every indication that this trend will continue. There is widespread support for reform of the ICF/MR program, and growing support for reform of the SSDI program.

In ending this paper, I wish to make one vital observation. We need to develop the mechanisms for emphasizing accountability for the service system as a whole. This requires a comprehensive ongoing data system supplemented with detailed controlled studies of the effectiveness of services. In no other way can we assess the quality of services that are being provided, and learn how to take the steps that will assure the provision of high quality services. Clearly, we need major reform of many parts of the service system. I believe that the more we emphasize accountability for the service system as .a whole, the more rapidly these reforms will take place.

Accreditation Standards: The Public/Private Partnership

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ACDD is a national, comprehensive quality assurance program that develops standards for services of quality to individuals with developmental disabilities, offers training and technical assistance to persons who provide those services, conducts professional, on-site, observational surveys to assess compliance with the standards, and awards accreditation to those agencies found to be in substantial compliance with the standards. The views expressed in this paper do not necessarily reflect the position and/or policies of ACDD and no official endorsement of ACDD should be inferred.

Alternately in developing the concepts for this presentation I contemplated descriptive titles such as "No Malice in Blunderland," the "Crisis in Accountability," "Assuring Quality of Accountability," "Quality is Free," and "Regulation: Have We All Gone Mad?" And lest some day I run for public office, let me credit the No Malice in Blunderland to Professor Robert Reish in his book TALES OF A NEW AMERICA, the concept of assuring quality of accountability instead of quality of life to the New York State Association for Retarded Children, the title QUALITY IS FREE from the book of the same name by the industrial quality assurance expert Philip Crosby, and the idea that maybe we've all gone mad with regulation to Clarence Sundram, the Chair of the New York Commission on Quality of Care.

This paper will address accreditation standards with particular attention paid to the theme of public/private partnership by

- briefly reviewing the purposes of quality assurance,
- assessing the role of accreditation standards in achieving the purposes of quality assurance,
- examining the public/private partnership in relation to accreditation standards and the assurance of quality in the provision of services for persons with developmental disabilities, and
- provide food for thought, if not recommendations, for future policy directions to enhance the ability of providers to provide aggressive, accountable habilitation services, including family and community support services, to individuals with disabilities and their families.

PURPOSES OF QUALITY ASSURANCE

Prior to discussing the purpose of quality assurance, it might be helpful to begin by noting what it is NOT — it is not "quality control." Webster defines quality control as "an inspection for defects." While there is little argument that this is a component of quality assurance, it is by no means its essence. Combining the definitions of "quality" and "assurance" results in the concept of an on-going process of "feeling confident in the coming or attainment" of "a degree of excellence" based upon "inherent features" or "distinguishing attributes" of a given program of services for persons with disabilities.

While quality assurance has been equated with regulation and the meeting of minimal requirements in the public sector, the private sector is increasingly focusing on the concept of quality enhancement of maximal standards for the assessment of the well-being, growth, autonomy, productivity and community integration of persons with disabilities.

Several of the purposes of quality assurance have been clearly elucidated by my colleague Val Bradley of the Human Services Research

Institute Who has noted that quality assurance systems are designed to serve five fundamental governmental responsibilities:

- to assure that providers of human services have the capability to provide an acceptable level of service;
- to assure that client services are provided consistent with accepted beliefs about what constitutes good practice;
- to assure that a given commitment of resources produces a reasonable level of service;
- to assure that the services that are provided have the intended effect; and
- to assure that the limited supply of services is provided to persons most in need.

Advocates, consumers and their families, and providers further explicate these purposes in terms of the values that underlie a quality assurance system, such as those found in the ACDD STANDARDS FOR SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES.

- to assure that each individual has access to services that enhance his or her development, well-being, and quality of life,
- to assure that each individual has access to the most normal and least restrictive social and physical environments consistent with his or her needs,
- that the rights of each person with disability are affirmed and protected, and
- to assure that services are designed and implemented with the full participation of the individual and his or her family in ways that foster the individual's autonomy and productivity in community settings and enhance his or her social relationships with peers who are disabled and peers who are not.

Let's review then for a moment the words and phrases you have heard in relation to the private sector concept of quality assurance: capability, beliefs about good practices, commitment of resources, intended effects, persons most in need, development, well-being, quality of life, least restrictive social and physical environments, affirmation and protection of rights, autonomy, productivity, social relationships, and community integration.

With these concepts in mind let's examine the role of accreditation standards in achieving the purpose of quality assurance.

THE ROLE OF ACCREDITATION STANDARDS

The reality is that they have no role. It is the public sector that determines the regulations or standards that define quality assurance, and not the accreditation standards of the private sector.

By virtue of state or federal regulation, quality is defined in terms of the expectations for performance of a funding source and measured in terms of the performance of the service provider. There is no enforceable definition of quality that exists apart from the requirements set forth for a provider to meet as a condition for receiving payment for the services provided. While empirical research and clinical practice may daily provide us with information and guidelines on, for example, the appropriate use of medication with persons who have developmental disabilities and emotional problems or the proper way to conduct case management services, quality assurance for purposes of a funded program can rely only on what the service providers have been legally required to do.

What legal system then do we currently have in place in relation to quality assurance mechanisms?

LOCAL AND STATE LICENSING are the most typical systems for permitting programs that serve persons with developmental disabilities to operate. These systems use regulations which specify operating criteria against which programs are assessed. The attainment of a license permits programs to operate and permits funds to be claimed and paid.

Programmatic licensing regulations vary widely among regions, states, counties, and local settings. Some focus primarily on health and safety issues, while others regulate the fine details of program operation and implementation. States also variably license some of the professionals who work in programs for persons with disabilities.

While most organized programs are licensed, the smaller the unit of service and the more independent the person with disabilities (e.g., an individual living in an apartment), the less likely the program is to be licensed or regulated. The present public approach to quality assurance and the implementation of standards or regulations in this case is illustrative of one of the most critical current fallacies, that the programs of persons who may be more competent and can exert more independence and control in their own lives do not need the same conceptualization of quality assurance as do persons with more severe disabilities. There are few assurances for persons who may need a wide range of sequenced and coordinated support services such as information and referral, instruction on the hiring and firing of attendants, and transportation to work.

At the licensing level we begin to see the illusion of the public/private partnership in re-

lation to accreditation standards. Some States require, for example, that programs must be accredited by ACCD before they can be licensed.

A second quality assurance mechanism is the STATE MEDICAID SURVEY AND CERTIFICATION process. If a program that serves persons with developmental disabilities receives Medicaid funds under the intermediate care facilities (ICF/MR) program, it must be licensed (in States that require Licensure) and certified by the State survey agency. The survey agency certifies that the program either meets Federal ICF/MR standards or operates with deficiencies that do not pose a threat to the health and safety of individuals nor preclude the provisions of "adequate" care to individuals served. Federal regulations address a wide range of aspects of the individual's life and service provision: rights, active treatment, behavior management, health care, safety and sanitation, physical environment.

When the State survey agency certifies the facility, the State Medicaid agency then executes a provider agreement with the program providing the services. The provider agreement binds the agency to pay the facility for providing care at a set per diem rate as long as the facility remains certified. ICFs/MR must be resurveyed at least annually and recertified annually.

Under the Home and Community Based Waiver program, those agencies that claim Medicaid payment must submit a plan to HCFA which assures that individuals receive quality programs.

In this quality assurance system we also see the illusion of a public/private partnership. The former Medicaid regulations were based in the early 1970's edition of the ACDD STANDARDS and the current regulations are based solidly in the 1983 Edition of the ACDD STANDARDS, especially in the areas of active treatment and behavior management. Additionally, several states utilize verbatim sections of the ACDD STANDARDS as the basis of the regulations for the quality assurance plan of their Home and Community Based Waiver programs.

The next level of quality assurance mechanisms to be addressed is that of FEDERAL MEDICAID MONITORING AND OVERSIGHT, conducted by desk reviews of survey and certification materials submitted by the States and by direct, onsite, and Federal surveys of participating facilities. HCFA's authority under the MEDICAID ICF/MR program is limited to promulgating facility standards and "looking behind" the procedural and substantive correctness of the State's survey and certification activity. This is quite different from the federal authority in the MEDICAID program in which HCFA certifies providers directly and in which the Secretary has the authority to deem private accreditation body standards as equivalent to federal regulations for the provision of quality services.

Each of the three public quality assurance mechanisms and the standards or regulations attendant to them exist to define the conditions of payment to providers of services.

THE PUBLIC/PRIVATE PARTNERSHIP

Continuing along the same vein, while the private sector may assert a particular set of values and a particular set of quality service delivery practices, there is no public assessment of the performance of a program against those standards unless they have been legally promulgated by the State licensing body or by HCFA. The federal government does not currently have the authority to directly deem agencies that have attained accreditation by a national quality assurance body such as ACDD as in compliance with the certification requirements of the Medicaid program. Should States decide to utilize the ACDD process, the professional survey staff of ACDD would be required to survey agencies under the current federal regulations. During the time that it has taken HCFA to develop, disseminate for review, revise and obtain approvals on its soon to be released new regulations for participation in the ICF/MR program, ACDD has published a 1987 Edition of its STANDARDS FOR SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES and has released the Field Edition of its 1990 STANDARDS.

The current public quality assurance system and standards function primarily as a mechanism for payment for services. The Medicaid program is not an entitlement program for individuals; it is an entitlement program for States. An individual cannot walk in and request Medicaid funds unless a State deems that person eligible for services and has a bed. Should the State not do so, services can be denied, and are.

Current legislation is strongly biased in favor of the public sector which pays itself first, views the private sector as a way to reduce costs, and increasingly relies on that sector to provide aggressive and accountable services. An all too frequent scenario has been the obtaining of ICF/MR funds for the proposed purposes of higher per diem rates to provide higher quality services through mechanisms such as enhanced staffing patterns, and the resultant utilization of those funds in meeting the increased demands of paperwork to comply with the regulations that are stipulated for payment.

The history of public regulation is one of dictating highly structured processes. Such a process assumes that if a program is organized in a certain way and does certain things, then the product will be "quality" service. All of us can cite programs that meet process and structure requirements and still do not meet the real needs of the individuals with disabilities whom they serve.

In relation to accreditation standards, the public/private partnership is one of master/ servant. There is no role for private accreditation standards without the expressed approval of the States for licensing purposes. And there is no direct role at all for private accreditation standards in the current Medicaid ICF/MR program. A facility or program cannot independently choose to meet national accreditation standards as an assistance in the development, implementation, and monitoring of a quality assurance system designed to enhance the quality of services to persons with developmental disabilities and their families and as a requisite for payment of the services delivered. There is therefore little incentive for any provider to adopt an enhancement model of quality assurance as opposed to a minimum standard, deficit, regulatory model.

This situation exists despite factors in the "state of the art" of accreditation standards and quality assurance mechanisms that would predict benefits from a truly equal public/private partnership.

RECOMMENDATIONS

1. Current proposed reform of the Medicaid program does not go far enough to assure the provision of quality service that truly meet the needs of individuals with developmental disabilities and their families. While provision after provision has been added to assure a wider range of community and family support services and coordination through case management, the basic conceptualization remains the same, that of an entitlement program to States.

   The perspective of "reform" should instead be one of "creation" — the boldness to develop and implement a NEW system in which the individual and his or her family is the focus. This is a system in which funding is provided on a per capita basis to individuals by virtue of meeting eligibility criteria for which an array of services is mandated. This is a system based in the Office of Human Development Services, a home which has the input from advocates, consumers, providers and professionals in the field and experience in research and demonstration projects to meet the current and changing needs of children and adults with developmental disabilities.

2. Legislation should provide for facility or program choice within a range of rigorous accreditation standards and monitoring processes. Currently HCFA quality of services regulatory involvement occurs either in the highly regulated ICF/MR facility based program or the Home and Community Based Waiver authority that relies entirely on State assurances that quality services will be provided. Neither type of involvement has a future. It can be predicted that the facility based model of quality assurance will become more cumbersome and less prevalent and that as community services become increasingly disbursed, current methods of quality assurance will not be sufficient to provide knowledge about what persons with disabilities are receiving and what services are being funded.

3- ACDD has long recognized that regardless of the nature of the service provided, the vehicle for providing it, or the environment in which it is provided, there are core standards of performance that are pervasive. For example, whether persons with disabilities live in a small apartment and work in a supported employment program or whether they live in a public residential facility that provides comprehensive training and treatment, if the agency serving them has control over important aspects of their lives, the individuals have certain rights that must be protected and asserted.

   As we focus on community integration and quality assurance mechanisms to serve a dispersed population in a diverse service delivery system, the opportunity arises for public/private sector collaboration in the development of a quality assurance system that has the following characteristics:

   - It should operate out of a core set of standards, applicable to all settings, with specialized requirements for discrete settings as necessary to meet the needs of the individual served.
   - The system should identify critical predictors of desired outcomes of the service delivery system.
   - There should be an explicit relationship between the funding source and the contracted service resource for outcomes being purchased.
   - The primary quality assurance role should be assumed by the State, but within authorities that are more independent of political and fiscal pressures than the present system.

- Voluntary accrediting bodies should assume a greater role in quality assurance. Private agencies competing with each other and together competing with States would have the desired effect of generally increasing the quality and effectiveness of the State's quality assurance mechanisms.

4. And finally, a concerted public/private partnership is conducive to a productive approach to enhancing the *science* of quality assurance: the study of the relationship between accreditation standards and direct outcomes to individuals; the association between particular clusters of standards and knowledge about leisure, work or residential environments that foster optimal growth; the determination of the empirical basis of current accreditation standards and regulations; and the reliability and validity of the survey processes used to assess the implementation of accreditation standards and the quality of services. The scientific aspects of such a partnership will come to fruition only with a government commitment to funding public/private sector collaborative research initiatives.

Only with a new paradigm of the conceptualization of the public/private partnership in standards development and implementation and the meaning of quality assurance will we progress in our search for excellence in the delivery of services to persons with developmental disabilities and their families.

Accreditation Standards for Industries that Offer Competitive Employment for Citizens with Mental Retardation within Community Programs

by C. Kaye Pearce
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The very title of this presentation, one which probably would not have appeared on an agenda even five years ago, reflects the tremendous importance of the growing public/private relationship that has so increased employment opportunities for people with developmental disabilities over the past few years. The success of the supported employment effort which was initiated at the federal level and implemented at the state and local level has created an enthusiasm and zest in the field that has not been seen since the deinstitutionalization efforts of the last decade.

Thousands of people with mental retardation who would have had, just a few short years ago, employment options with an N of 1 — sheltered employment — are now able to find their place in the world of work alongside workers who do not have a disability. The result — increased productivity; increased independence; and certainly increased opportunities for community integration.

Along with the clear successes and positive outcomes, voices of concern have been raised especially by parents, advocates, community based providers, and others. The concern is not with the concept of supported employment or with the values that it upholds — rather the concern is one for the potential abuses of a capitalistic system ... well-known abuses manifest in the phenomena from the sweatshops of the 1800's to the Ivan Boesky's of the 1980's.

For a profit oriented business, those businesses in which most people with mental retardation find employment, the basic focus of accountability is the bottom line — has a profit been turned? Fortunately, most such businesses also operate according to an industry code of ethics and according to federal, state and local laws and regulations. However, the sad fact is that there are businesses throughout this country that take every advantage they can of those they perceive as vulnerable including women, illegal aliens, the poor, and, yes, people with disabilities including those with mental retardation. And, as much as we hold community providers of supported employment in esteem for their accomplishments, just as there have been historical abuses in institutions and facility based programs, providers of supported employment are not immune to inept, insensitive, or at worst abusive staff. Given these concerns, it is necessary to look at accountability from the perspective of the needs of persons, with mental retardation who are working in a supported employment site. There are a variety of approaches that can be taken to the accountability issue: vigilance by managers of supported employment services, input from those served and their family members, and standards applied by third party funding agencies.

Another option that more and more funders are looking to in terms of accountability for supported employment programs is independent third party accreditation. The value of using national accreditation standards for supported employment duplicate those that have motivated funding agents to use such standards in other program areas: independent, unbiased reviews; standards that are current and reflect a national consensus; enhancement of resources available for quality assurance; and cost effectiveness.

In response to these concerns, the Commission on Accreditation of Rehabilitation Facilities established, in 1985, the first national standards for Programs in Industry which were standards for programs that were designed to

enable people with disabilities to obtain, retain, and/or upgrade employment in the community. In response to the constituency that is specifically concerned with supported employment, CARF subsequently developed standards within the category of Programs in Industry specifically designed for supported employment programs.

The discussions among national experts that resulted in the supported employment standards reflected the need to have a system of accountability that was reflective of the needs of people with mental retardation but that were not so intrusive that the private sector would slam the door to such programs if CARF's standards were used. These discussions resulted in a consensus that certain issues must be explicitly addressed in the standards:

- that those working in the private sector have every opportunity to be integrated into the community work setting
- that the decisions affecting the person served be reflective of both the person's needs and desires
- that there are a variety of activities that need to take place to assure that there is a common set of expectations on the part of the person served, the provider, and the private business
- that knowledge of functional teaching techniques and behavior management are critical for staff who work directly with the person with mental retardation and the private
- that training does not need to proceed placement
- that assessment can take place on site and does not need to meet CARF's standards for vocational evaluation
- that, where appropriate, the family is a part of the decision making process and receives ongoing communication from the supported employment provided regarding the employee's status
- that appropriate follow-up services be provided
- that, given the health and safety requirements that most businesses must now meet, issues of safety be approached on a "common sense" basis
- that career ladders be a part of planning for individuals so that the supported employment placement is not viewed as "terminal," "the end of the road"

Such discussions which shaped CARF's standards for supported employment reflect the unique three way relationship found in the supported employment environment: the person served/employee, the community based provider, and the private business. Each has their own needs, their own bottom lines. What accreditation standards strive to do is assure that a "win" ... "win" ... "win" situation is the ultimate outcome for everyone —

The Employee:Work, Income, Status in the Community
The Provider: Work, Outcomes
The Business: Productive Employees, Profits

In our competitive society "win-win" is rarely the desired outcome. Yet the consensus of those who shaped CARF's standards for supported employment is that "win-win" is the only acceptable outcome — the only outcome that will assure that supported employment will continue to be a successful model. Perhaps the ultimate irony is that, as more and more people with mental retardation find competitive employment in the community, those who historically have been among the most devalued will demonstrate, as they become valued, productive members of our society, that the greatest successes of all come from cooperation, equitable human interaction, and respect for individual empowerment.

RECOMMENDATIONS:

1 Federal policy regarding supported employment needs to assure that accountability mechanisms for such programs are in place, including national accreditation.

2. Federal policy for supported employment programs must not take the unidimensional approach of only providing fiscal incentives for one outcome — placement in community work sites, any community work site, for any wage, under any conditions. Quality of life issues including the desires of individuals served must be reflected in any definition of desired outcomes.

3. Federal employment initiatives should provide specific funding to assure that job stagnation does not occur and that the concept of career ladders is built into supported employment.

4. All Federal agencies must come together to resolve the current funding absurdities that exist. OSERS, ADD, Medicaid, SSA and others must evolve a policy that supports appropriate employment options for all people with developmental disabilities in non-institutional, community settings.

Health Care Panel

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GEORGE H. DANIELS

Dental Care for Persons with Mental Retardation

by Albert L. Anderson, D.D.S.
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Good Morning. During the last two months I have wrestled with myself as to the subject matter of presentation today, wondering whether I should be scholarly and give a lot of statistics or should I be straight forward and talk to you of my personal problem in attempting to provide dental service to persons with mental retardation (MR) in the community. Since my professional life has been mainly in private practice rather than teaching, I chose the second alternative to explain the problems as I have experienced them and then suggest some solutions.

First of all, I question if the researchers and even many of the health planners and providers really believe that dentistry is part of the overall health plan for people with mental retardation. An example is the magnificent work done by Field, Smith and et al. They did a national profile on changes in services for adults with developmental disabilities. This extensive profile covers every aspect in the life of the adult person with developmental disabilities but, unfortunately, in their health summary they state "the most common health problems among the developmentally disabled population are seizures, skin disease, behavior problems, and obesity." Not one mention of dentistry in the report. You can eat a lot of steaks with seborrhea dermatitis, but; it becomes a real problem with chewing on any kind of steak if you have no teeth.

I received a letter from an outstanding pediatrician who is also a Ph.D. and Director of the Pediatric Division of a hospital that is one of the largest in the United States. This was in regard to a child with mental retardation who was desperately in need of dental care. I requested the child be cared for under general anesthesia at that hospital. He stated, "The only way we could take care of the general anesthesia portion of this hospitalization is in conjunction with an overall medical problem." From this statement, it is quite obvious that they do not believe that oral pathology is considered to be a medical problem.

A few years ago, a large hospital in the city near San Diego, California refused to schedule a dental patient with mental retardation because he was on Medi-Cal. Fortunately, I was a member of the State Health Commission at the time and had some background in the Hill-Burton hospital funding. This happened to be a community hospital which had benefited from Hill-Burton funds. I called the Executive Director of the hospital the next day and explained some of the rules and regulations of Hill-Burton funding — the fact that any Hill- Burton hospital should take care of the total community, not just those who are fully financed. He called me back and said that it was not really the hospital's fault but the anesthesiologist refused to take the case because it was Medi-Cal. I changed hospitals.

This gives you some idea of some of the hospital's and some physician's attitudes toward people with mental retardation, especially if they are on the Medi-Cal Program. But what about the dental provider?

At the present time there is a class action suit going on in the State of California. Although I'm not fully acquainted with the details, the media stated that only 12% of dentists in the state will accept a new Medi-Cal patient. I would suggest to you that when the patient has mental retardation this drops down to one half that percentage. In my own area we have about 20 pediatric dentists and I know of only 2 or

3 who will accept new Medi-Cal patients. My staff spends about 20% of its time trying to find oral surgeons, endodontists, periodontists who will take care of people with mental retardation.

To let you know where I am coming from let me tell you a little bit about myself so that you know that I am not some wild-eyed rebel rabble rouser but that I have training as a pediatric dentist. I have been the National President of the American Society of Dentistry for Children, National President of the American Academy of Pediatric Dentists, International President of the Consejo de Panamericana de Otologia Infantil which covers all of North and South America. My practice is about 80% exceptional people. In fact I have 365 people in my practice who have Down syndrome. As a consequence, my practice is about 80% Medi-Cal, Medicaid, CCS, Regional Center, SSI, and SSDI. All of these programs are based on MediCal fees which are about one-eighth to one- third of the regular fee charged in the average dental office in the State of California. I tell you this because I did not want you to think that dentists are all bad people with no love for their fellow man. In essence, there is no way that a young man with a family and the cost of starting a practice can afford to care for the Medi-Care patient in the State of California. The delivery of care is not the total fault of the profession nor is it all on the part of the individuals who administer the State and Federal programs. The main culprit of poor or no dental care for persons with mental retardation is the fee schedule and the bureaucratic mumbo-jumbo that lays down the rule of care.

The biggest problem we find is good oral hygiene. They should have a good dental prophylaxis every four to six months, the rule says once a year. Many of the young people have deep calculus in need of special scaling. Rule — no one under 18 years of age can have a scaling because scaling doesn't occur on teeth if a person is under 18 years of age. Another problem, an adult is missing a front tooth and no way to get funding for a bridge. The patient will not wear a partial. So I make an inexpensive space maintainer that is attached to the back teeth with a wire that runs around behind the upper front teeth and then attach a false tooth onto that wire. It is then completely cemented in and gives the patient a nice smile and holds that space. The rule — no one over 12 can have a space maintainer. I have a lot of group homes I care for with non-ambulatory patients. There are usually 6 youngsters to a home. I make house calls to these homes for their yearly exams so they don't have to come into the office. They usually have to be trans- ported by ambulances which are a very expensive affair for the State. The rule — if you make a house call you are only paid for the first person you examine which is $18.00. The others are on the house, free-of-charge.

If I have a patient who is manageable enough to do a small filling in the office, but still cannot hold still for x-rays, the rule says that they cannot pay for the filling without x- rays, but we can hospitalize that patient, put him to sleep, do x-rays and one filling. The cost to the state is about $1,018.00. Of that I am reimbursed approximately $25.00. The rest goes to the hospital and a pittance to the anesthesiologist.

Sometimes, for some unknown reason, you are lucky enough to get an O.K. for a bridge or a ceramco crown on one of your special patients. You spend two hours in the hospital with two of your own assistants working. They pay about $125.00 per tooth. I have to pay the lab bill of $100.00 then go back to the hospital once again for another one hour session to cement the crowns in a period of one month. So actually what we are doing is subsidizing the State for doing dental care.

There are thousands and thousands of other problems and I can assure you that this is not only a problem in California, but is true throughout the United States. I am getting old, but I can't find anyone who wants my practice. I am sure the medical and dental care will become a major deterrent to community care in the next two years. But all is not bad. There are some bright spots on the horizon. First, we have in the United States today a small cadre of dedicated people who care for people with mental retardation in the community. We have many in our town. I would like to give you an example of two. First, Rita Sexton has a six-bed facility in her home for non-ambulatory children. Rita lives and breathes for her kids and I know that on many occasions gives her own funds for things that she feels are important to her children that the State will not provide. I drop in anytime and the children are always immaculate, well nourished, and with a look of really tender loving care. And I tell you if I'm not there at the right time to check their teeth each and every year, she is on my back requesting that I immediately come in. When she first got the children, we were doing at least two per year in the hospital. These youngsters change as they get older and move onto other facilities so it is not the same six people that we see all the time, but right now I have not had to care for any of her children in a period of two years. The reason for this is that she is doing a good job of oral hygiene with them.

Secondly, I would like to talk about Children's Convalescent Hospital. It has 60 beds, all non-ambulatory. When I first started working with Joyce Turner 20 years ago, the average was about 15 hospital cases every year. I just finished examining all 60 and none will have to be hospitalized at this time. Why? Because both facilities have well trained personnel who believe good oral hygiene is tantamount to good health.

The saddest people I have are the small six-person group homes for adults who have just returned to the community from large institutions. These are all ambulatory adults. In almost all cases, we find missing teeth, periodontal disease, rampant caries, and a terribly poor oral hygiene program. The following is a good example of what can be done. There is a home in Alpine, California about 30- 40 miles from San Diego where I provide dental care. In one year's time this fine couple has transformed a wandering, non-caring mass of humanity into a warm, loving family. The oral hygiene has changed in the same direction. The large facility had warned this couple about one of the gentleman who was to be stationed in their home. He's 42 years old. They said that he deficated in the corner, urinated on the furniture, was terribly combative and that it was absolutely impossible to brush his teeth. I met him a year ago and I agreed. We had to do him in the hospital. I saw him again a month ago. He gave me a hug. He is going in the potty and brushing his teeth at least three times a day.

I hope with these examples you are beginning to understand the problem we have right now in the United States. I'm telling you that without proper dental care for the six million persons with mental retardation we have in the U.S. today, we will certainly move back to the days when the usual treatment for a carious tooth, in a person with retardation was removal.

We have a problem now but what is going to happen in the next few years? The institutions are cutting back and three to six thousand new people are added to the community each year. Every five minutes in the U.S. a child with retardation is born and now it appears that this number could even become higher with the fetal alcohol syndrome, drug abuse, and a statement made by Duane F. Alexander, M.D., Director, National Institute of Child Health and Human Development, National Institute of Health at the PCMR's Prevention Conference of February, 1987, that in the early statistics, it appears that 90% of women affected by the AIDS virus who became pregnant will deliver a child with mental retardation and/or developmental disabilities. We all admit that prevention is the answer, but what are we going to do right now?

We have been talking about individuals who live in well-staffed group homes or small community facilities. What about the people who live in independent housing and those thousands that live on the streets that we now know have a high percentage that are dually diagnosed, i.e., mental retardation and mental illness. If it is so difficult to have good dental care for those who have good social service, think of the bureaucratic obstacles facing those who are on their own.

There are those in government who would like to contract to take care of all individuals with mental retardation in a massive H.M.O. type clinic I say no. Contract clinics stay in business by not seeing patients. They are paid so much per capita each year whether the patient makes an appointment or not. Secondly, they must produce on a volume in order to stay in business.

Both of these concepts are in direct opposition to good care for people with retardation. A lot of us are here today because we believe a community setting is the best place for most people with mental retardation, integrating them into schools, affording them opportunity to meet "normal" people, and make them a part of the community. I think the private dental office is one of those teaching tools. In our office we do not separate our appointments. A good example is a wife of a prominent orthopedic surgeon at Scripps Clinic in La Jolla. They have seven "normal" young children. She says, "My children have never had a better learning experience than they have in your office. They now know and understand persons with mental retardation and hopefully our children will be much better members of the community because of this experience."

I have several suggestions for change:

1). Medi-Care, Medi-Cal, SSI need to be reformed. Medical care should be extended to all people in the eighteen to fifty- five age range who are developmentally disabled, mentally retarded, children or elderly. This they say is impossible because it discriminates against the 18 to 55 year old. I think there should be some change in that law.

2). Provide a funding program for dental hygienists to set up oral hygiene programs for all community facilities throughout the United States. Have them go into the facilities, do a six-month recall, clean their teeth, therefore, setting up oral hygiene programs that could alleviate many of the problems that we see in the office.

3). Make some good oral hygiene video tapes featuring persons with mental retardation, stressing brushing, rinsing, good nutrition, so they can be played every few months for the staff of the facilities.

4). Have the U.A.P. go back to one of their charges under public law 19583 to train personnel for community facilities. It was one of the major topics in our joint mental retardation—mental health meeting that the PCMR held two years ago. It was emphasized that in many community facilities we had entry level people providing care. It does seem ridiculous that we have entry level people taking care of these special individuals with the most complex social and health problems known to man. The owners of the facilities always say that it is funding. If this is so, we must increase that funding to ensure a more helpful atmosphere.

5). Dental schools must provide more training in the care of persons with mental retardation. Without the help of the dental profession we absolutely have no hope.

Let me thank you for letting me talk with you today, but I would be remiss in concluding my remarks without thanking all of you who take care of people either in institutions or in community facilities, for your dedication, self- sacrifice, and devotion. All of you give to people who are mentally retarded. Whether you be parent or staff, there is no other calling on this earth that gives so much with so little thanks. You are a very special breed of human beings and I for one am honored to be able to work with you on a daily basis.

Health Care for Persons with Mental Retardation Living in the Community: Addressing the Gaps and Fragmentation in Services

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BACKGROUND

Surveys of consumers, community agencies and state and local governmental units confirms the widely held impression that the delivery of comprehensive health care services (medical, surgical, psychiatric, dental, etc.) to persons with mental retardation living in the community has not kept pace with advances being made in other areas of human services.

While great strides have been made in development of community living arrangements, special education services, supported employment and similar areas since the major efforts at deinstitutionalization began, there is yet to be developed a response by our nation's health care establishment to the special needs of persons with mental retardation. In many cases an absence of appropriate health services in the community has precluded the transfer to the community of persons still living in public residential facilities (especially persons considered "medically fragile" or behaviorally impaired) or has necessitated the institutionalization of an individual who has grown up in the community.

Perhaps in very few other ways can PCMR be more helpful in influencing Federal policy makers and legislators on issues relating to community integration and fostering partnerships among all segments of our society than in helping to bring about a more rational and carefully thought out policy on health care for this extremely vulnerable and medically complex population. The present reliance on the system of generic health care services available in most communities is just not working in anything like an optimum fashion. The reasons for this are multiple and include insufficient training and experience with persons with mental retardation by the majority of physicians and dentists practicing in the community, the impatience and difficulty of individual physicians interacting with a large bureaucratic system of multiple agencies, and the real disincentive represented by the medical reimbursement scheme (principally Medicaid) which sets fees which are far lower than other third party health insurance payors.

The author proposes the development of a system of regional health care resource centers to be located in major community/university hospitals modeled after a prototype in existence in Morristown, New Jersey since 1982. Such centers would provide the full range of general and specialty health care services which children and adults with mental retardation require and would provide back up services to practicing physicians, dentists and other human service agencies in the community.

Patients with especially complex handicapping conditions could come to such centers for coordinated, comprehensive treatment of medical, surgical, psychiatric and dental conditions, while the centers would act as a resource for medical education for medical students, residents and community practitioners. Funding for such centers would be based on a supplement to existing Medicaid reimbursement to offset the cost of telephone consultation and follow up, prevention services, outreach, education and other client contacts not involving a "patient visit" and therefore not reimbursable by the usual insurance mechanism. Such supplementation could take the form of special contracts, higher Medicaid reimbursement rates to the hospital program or other measures which would underwrite the support of such regional programs and guarantee their viability.

FEDERAL/STATE PARTNERSHIP

Federal policy and legislation should see to the development of a nationwide network of community/university hospital based regional health care centers in every state, based on populations of persons at risk, and should provide incentives for the states to develop such programs based on local needs and health care patterns.

STATE/LOCAL PARTNERSHIP

The states, through their governmentally based developmental disabilities agencies and health departments, would promulgate guidelines for establishment and operation of such regional health care resource centers and contract with qualified local community/university hospitals in the private or public sector for such services.

PUBLIC/PRIVATE PARTNERSHIP

Though the core costs of the center should be underwritten by public agencies in State and local government, the local hospital program may expand the basic nature of its program to provide for special services unique to its setting.
It may gain support for these special endeavors through charitable foundations, local industry, private agencies (such as Association for Retarded Citizens', United Cerebral Palsy, etc.) as well as through traditional third party health insurance companies.

FAMILY/SERVICE DELIVERY SYSTEM PARTNERSHIP

Families of persons with mental retardation will be among the principal beneficiaries of such a system. A regional health care center that coordinates all necessary medical and dental services, and provides high quality, responsive care in a cost effective manner is currently lacking from the case management system. It will relieve a considerable degree of anxiety on
the part of parents as to who will take responsibility for their family members with mental retardation when they are no longer able to care for them, and will help them negotiate the difficult and complex health care system looking for the doctor, dentist, or hospital that can address the health care needs of a patient with mental retardation in a competent and dignified manner.

Planning for Children and Adolescents Who are Mentally Retarded and Have Substantial Medical Needs

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Increased community integration opportunities during the last two decades have enhanced the lives of many people who are mentally retarded. People for whom community living opportunities are less available include children who are mentally retarded and who have substantial medical needs.

There are a number of reasons why children who are mentally retarded may have substantial medical involvement. Prematurity, congenital anomalies, birth trauma, or postnatal events, coupled with the increased likelihood of survival are causes for increasing numbers of children in this population. Other children may have multiple disabilities, including substantial medical complications, as a result of trauma or injury.

Medical needs play a central role in placement decisions for these children. Infants who are born with severe and multiple disabilities, including medical complications, may live for an extended time in hospitals. When released, they may not be able to go home to their natural family; they may be placed in foster care or adoptive homes. In addition, institutionalization rates are increasing for children under two years of age.

The capacity of families to cope with the complex needs of a severely and multiply disabled child varies substantially. Families are at high risk for "burnout" due to isolation and the tremendous demands that are placed on family resources. Support needs vary and, in all too many instances, are inadequately attended to. Institutionalization may appear to be the only viable option to many families when little else seems to be available. Once their child is placed in an institution, the strongest predictor of willingness to support community placement efforts is the family's perception of medical need.

Thoughtful attention must be given to children with mental retardation with complex medical needs as a part of State and national planning. Definitions for use in planning for this population were developed in the State of Washington and are presented in this paper. The recommendations will be discussed and presented.

I. Introduction

The last two decades have been a time for considerable advances in the national effort to assure people with mental retardation the right to live in the least restrictive environment. Such an environment promotes a person's growth, developmental skills and social integration in community life. While the principal residence of people with mental retardation continues to be their own home (Meyers and Blacher, 1987) there has been a substantial shift in regard to living in other types of residential settings.

The number of people living in institutions is declining although the rate of decline has slowed. The movement out of large institutional settings and into smaller, community- based service networks has occurred in stages. Individuals who were relatively self-sufficient and problem free were chosen first for alternative placement. While severe and profound mental retardation is found in less than 5% of the entire population of mentally retarded individuals, it is estimated that about eighty percent of public institution residents are severely or profoundly retarded (Eppel, Jacobson and Janicki, 1985).

People residing in institutions are more likely to have significant medical complications in addition to the cognitive impairment. The more severe levels of mental retardation are primarily a result of brain damage, chromosomal abnormalities and other neurobiological factors (Dingman and Tarjan, 1960). Hence, there is an increased incidence of medical problems (Wright, Valen & Tarjan, 1962) and higher mortality rates among people living in institutions as compared to those of the general population (Tarjan, Wright, Eyman & Keeran, 1973.)

Substantial efforts to prevent institutionalization have also contributed to the declining numbers of people residing in institutional settings. As our knowledge and ability to establish community based alternative residential options for people grew, it became apparent that community equivalents to institutional settings can be created for the vast majority of people. Hence, national and State policy has often been directed towards the creation of community alternatives as a means of preventing institutional placements.

Under the Reagan Administration, the development of a Medicaid Waiver program is a good example of a Federal/State partnership which is intended to ensure people with disabilities the option to live in the least restrictive environment. This program enables states to request the option of utilizing funds authorized under Title XIX of the Social Security Act (Medicaid) for the purpose of developing community placements as an alternative to institutionalization.

Significant medical complications accompanying mental retardation are a major concern in planning residential environments and other services for children and adolescents. This paper will address policy and planning issues and recommendations specific to children and adolescents typically referred to as "medically fragile" although new terms will be introduced. A definition for use in statewide planning for people of all ages, developed by a group in the State of Washington, will be offered and used to more clearly identify the population under discussion.

II. Overview of the Issues

The development of alternatives for children and adolescents which enable them to live in their own or another family has been of particular concern. As a result of successful community integration efforts nationwide, many more children and adolescents with disabilities remain at home. Foster care as a residential alternative for children with special needs has grown exponentially during the past five years and continues to be viewed as an important alternative to placement in an institution when children are unable to live with their own families. The adoption of children and adolescents with a wide range of disabilities is on the increase.

Despite successful efforts to keep children and adolescents in families and out of institutions, one of the more challenging dilemmas is planning services for children who are mentally retarded and have substantial medical problems. The number of children with significant medical problems are increasing in general.

The survival rates of infants born prematurely or with other birth trauma has increased. Survival is enhanced due to major transformations in medical technology, such as the development of oxygen life support systems, intravenous methods of nutrition, vital function monitoring devices, and new antibiotics or other drugs. While the vast majority develop normally, a small percentage experience major developmental problems. As the sheer number of babies who survive increases, so does the number of babies who ultimately experience major difficulties.

Children and adolescents who require a medical device, such as a ventilator, to compensate for the loss of a vital body function, (children described as technology dependent), are increasing in number. The office of Technology Assessment estimates that there are up to 17,000 children, although not all are mentally retarded, who depend at least part of each day on a ventilator, intravenous nutritional substances or other medical equipment. The estimate is greatly expanded if children who require apnea monitors to ensure they are breathing, or who need renal dialysis as a result of kidney failure, urinary catheters, colostomy bags or substantial nursing care are included.

Advances in technology have affected the survival rates of those who have severe disabilities as a result of environmental events such as trauma. For example, a number of children and adolescents with severe and multiple disabilities are survivors of accidental drowning, vehicular accidents or other, similar trauma.

The medical needs of children who are mentally retarded play a central role in determining placement in or out of institutions. Findings of a study by Seltzer and Krauss (1984) suggest that placement decisions for children who cannot live at home are increasingly being affected by medical, even more than behavioral, factors. An alarming trend, despite efforts to reduce the institutionalization of children is the increase in placement of children under the age of two in selected institutions (Eyman, et al, 1986).

Readmission rates, higher among all people with significant medical problems (Keyes, Boroskin & Ross, 1973; Pagel & Whitling, 1978), reveal a significant number of young people of school age returning to institutional settings (Bruininks, et al, 1981). In a study of community placements out of institutions for 761 children by Seltzer and Krauss (1984), only 6.6% returned to natural families. A significant factor was the degree of medical involvement.

Nationally, the services which are generally less likely to be available to all people with more severe disabilities are educational/adult day programs, medical care and behavior management programs (Sheerenberger, 1981). These services, particularly medical care, are critical for successful community placement of children who are multiply and severely disabled, including substantial medical involvement.

General medical hospitals, including childrens hospitals are another intensive care environment in which children who are born mentally retarded and with significant medical problems are likely to live for extended periods of time. If they are unable to go home with their families when they leave the hospital and no other alternative is available, they may be placed in public or private institutional settings including nursing homes and large State funded mental retardation facilities.

III. Effective Service Planning

A. PARENT/SERVICE DELIVERY SYSTEM PARTNERSHIP

There are a number of decision factors which enter into planning which determines where a child or adolescent will be able to live. An important partnership for successful planning for children who are mentally retarded and have substantial medical problems is between the family and the service delivery system. The impact on families of the birth of a multiply disabled child with critical medical needs is substantial (Thomas, 1986) and their ability to meet the complex care needs of their child are limited without adequate support. Supports to families keeping their child at home are sometimes the most difficult to obtain.

Care decisions, including placement, must truly reflect the spirit of partnership between the family and the care providers. This is especially true as children make transitions — from home to school; from school to work; from home to another setting; or between settings other than the family home. Parents, especially those who have made the very painful decision to place their child out of their home, need understanding and an opportunity for meaningful involvement in all decisions regarding the care of their child.

Transitions from an intensive care environment, such as a hospital or institution, back to the family or a foster care home are especially sensitive. When a person has been placed in an institution there is generally high parental satisfaction with the placement. Payne (1976) iterated several reasons for this satisfaction including the permanency of the institutional placement and the availability of multiple specialists.

Keating et al (1980) found the strongest predictor of family opposition to placement outside the institution was the family's perception of the degree of need for medical care. Conroy (1985) cites serious discrepancies between the perception of families and care providers, with families perceiving more intense medical needs. However, we must not overlook the ability of parents to recognize subtle signs and have a special understanding of their child.

B. EFFECTIVE USE OF EXISTING SERVICE RESOURCES

The factors which contribute to the intensity of medical needs are complex and unique to the individual Planning must consider the optimal living environment as well as the availability of needed, often expensive, medical care resources. Medical care needs are, by themselves, complex. They are further compounded by cognitive and developmental impairments.

Deciding which settings are most appropriate and successful for children and adolescents with multiple and severe disabilities, particularly those with the most intense medical needs, is challenging. The quality of care which is provided to each child is dependent upon the quality of the caregiver more than the setting in which it is provided. Thus placement decisions, regardless of setting, must carefully attend to all the care needs, especially the medical care.

If children with intense medical needs were able to communicate how they are feeling or what is happening to them, they would be better able to participate in quick, appropriate intervention at the time of a potential crises. However, severely disabled children are least able to communicate their physical needs and problems. Hence they depend on attentive, well trained care givers to assess their physical situation and stand ready for quick, appropriate intervention.

What remains to be determined is what options are available. The current service system includes an array of residential options that range from living at home to alternative family placements such as foster care or adoption, to congregate living environments both small

and large. The intensity of services provided in those environments, and the availability of medical care, varies substantially as does the degree of integration with normal family and community life.

In the best of all possible worlds, every child would live at home and that home would be loving, caring and supportive. Sometimes, even the most loving and caring parents are unable to cope with the complex needs of their multiple and severely disabled child on a day to day basis. In other instances, families simply don't provide a nurturing environment.

In order for a child with complex and multiple problems to live anywhere, there must be an assessment of potential risk. Often, there is a lack of medical specialists trained in the care of individuals who are severely and profoundly mentally retarded. It may even be difficult in some communities to find a provider, whether appropriately trained or not, willing to serve that individual at all. This is especially problematic in smaller communities with fewer health care resources of any kind.

Equally important is the capacity to develop satisfactory support services in a way that contributes to greater integration for the child or adolescent rather than hampering it. Children need access to educational, social and spiritual opportunities. Their families and caregivers must have in-home supports, respite care and other similar support services which allow them to meet the potentially intensive demands.

All too often, family based services are not only viewed as the healthiest environment for children and adolescents, it has the potential for being cheaper. The reason families can provide less expensive services is that they often provide free round the clock monitoring and care in lieu of paid staff. As a result, families are liable to burn out or, at the very least, be substantially limited in participating in normal life events. Under these circumstances, children (and their families) are far more isolated than they might be in many congregate care environments normally seen as "isolating" and restrictive.

Children who are the most profoundly retarded and with very demanding medical needs are perhaps the most difficult to plan for. Home care requires the creation of an intensive care environment in the family home. In those instances when doing so enables a child to benefit from enhanced social, recreational and spiritual opportunities the effort can be justified. However, when a child's disabilities are so profound and complex as to significantly impair his/her capacity for greater integration regardless of where he/she lives, the impact must be carefully evaluated.

A child with no observable environmental awareness, who requires intensive round-the- clock medical care, is likely to be isolated in any environment regardless of the quality of care provided. The real outcome of home placement may be disruption and isolation for the family with little or no benefit to the child. Some health care specialists would argue that there are still a few children who are likely to live longer in a more intensive care environment and that placement out of an institutional or intensive care setting creates a risk to the child's survival.

Further, in a time when many people who are mentally retarded receive few or no services, the allocation of resources must be thoughtfully considered. Planners find themselves faced with difficult resource decisions. They must consider the allocation of limited resources to more and, perhaps, more expensive services for people with complex problems while the service system remains unresponsive to many others with less immediate needs.

The decision making, therefore is complex. Each child and family is unique and with their own needs and desires. The availability of resources, and the conditions under which they are accessible, is another significant issue. Our capacity to effectively design the ideal option for each individual, while advancing rapidly, still has a ways to go. The dilemma that remains is to develop a flexible and responsive system of services, which builds upon all the resources that are available and uses them creatively. This was certainly the challenge in Washington State and prompted a statewide study of people who are mentally retarded and have substantial medical needs.

IV. Identifying Individuals Who Are Mentally Retarded and Have Intensive Medical Needs.

Managers in the Division of Developmental Disabilities in Washington State were concerned with developing an effective planning process for addressing the needs of individuals with severe and multiple disabilities. An important part of the planning process was the development of definitions which could be used for broad planning purposes. The definitions, once developed, allowed for a general assessment of which people, currently residing in State operated institutions, nursing homes and/or other hospital-like settings, are good candidates for immediate community placements and which individuals might be able to live comfortably in a community placement if more supports and services were available. (This, however, does not preclude the need for careful individualized planning in all placement decisions.)

The definitions developed in Washington, although applicable to children and adults, will be used in this paper to provide a common understanding of who we mean when we talk about children who are mentally retarded and have significant medical complications. The definitions and the process by which they were developed will be presented.

A. DEVELOPING A DEFINITION FOR STATE PLANNING PURPOSES

The approach taken by the Division of Developmental Disabilities truly reflected a State and local partnership. Participants of the statewide planning group included parents of children with multiple handicaps, developmental pediatricians including two who were based at a State facility serving people with intense medical needs, a pediatric nurse, staff from a State facility and the State Division of Developmental Disabilities, a specialist in service systems for persons with chronically handicapping conditions, and a social worker. It was recognized that defining medical need focused on only one aspect of a person's life. Therefore another workgroup concurrently addressed other important needs such as educational, social and environmental.

Participants in the "definitions" workgroup expressed concern about the use of the term "medically fragile". They felt it was depersonalizing to the individual to whom it was applied. Hence a new term, persons with intense medical needs, was utilized initially the workgroup developed only one definition, which was for individuals with "intense medical needs" As the definition was tested at various sites, it became clear that there was one additional category.

Originally, it was assumed that an individual would fall into the "intense medical needs" category or would not. What the group learned was that a person could have very demanding physical problems but not fall into the "Intense" category. Rather, their needs were such that a lack of appropriate medical and nursing care would cause them to decline and they would ultimately require "intense medical care".

Once definitions were developed, a group composed of a developmental pediatrician, a social worker, a parent and the systems planning specialist visited two other State Schools and the Regional Community Services office in a highly populated area in the State. The person responsible for each individual's medical care at each site was included in the review of the individual's chart.

Records of all individuals with significant medical problems were evaluated and the relevance of the definitions tested. Modifications were made to the original definitions as the process went on. The findings supported the use of the definitions that were ultimately developed for *planning* purposes. It must be strongly emphasized that these definitions cannot be viewed as diagnostic tools nor do they substitute for the professional judgment of trained medical personnel in determining appropriate services for any given individual.

It is important to note that the definition for Individuals with Intense Medical Need was substantially influenced by the excellent work already done by a national organization for children — Sick Kids (Need) Involved People (SKIP). The categories ultimately developed and their definitions are as follows:

I. Individuals with Intense Medical Needs

Individuals whose chronic health related dependence continually or with unpredictable periodicity necessitates 24 hour/day skilled health care supervision and the ready availability of skilled health care providers for the individual's survival. Further, if the technology, support and services being received by the individual are interrupted or denied, he or she may, without immediate health care intervention, experience irreversible damage or death.

Further elaboration of key components:

a. Chronic Health Related Dependence: Ongoing vulnerability to an individual's physical health.
b. 24 Hour/Day Health Care Supervision: 24 hour basis observation by skilled health care providers who are within sight and/ or sound of the individual being monitored
c. Skilled Health Care Providers: Licensed health care providers (e.g. nurse, physician); Specially trained family members knowledgeable in the care of the specific individual (The specially trained family member in this context is described in Washington State Statute)
d. Immediate Health Care Intervention: Skilled health care assistance or treatment necessary to prevent death or damage to individual. Chronology of the need for treatment must be unpredictable.

II. Individuals at Risk for Medical Vulnerability

Individuals whose chronic health related dependence does not require 24 hour supervision by skilled health care provider, but for whom life threatening incidents are unpredictable. Without regular monitoring and the availability of licensed providers, deterioration

will be such that the intensity of medical needs will increase.

III. **Individuals With Significant Medical Needs**

Individual whose chronic health related dependence is predictable but necessitates regular monitoring by licensed health care providers.

The following descriptions are composite of people characterizing individuals who fall into each of the categories addressed by the planning definitions. They are not all inclusive and are meant to assist in a better understanding of the nature of the categories:

INTENSE MEDICAL NEEDS

Art is a young man of 14 whose medical complications typify individuals who fit in this grouping. He has a mixed type of cerebral palsy, scoliosis, microcephaly, and profound retardation. In addition, Art has complications associated with feeding, such as severe reflux, causing aspiration pneumonia and secondary acute respiratory distress. Severe feeding problems which lead to malnutrition require rigid monitoring. In addition the inability of Art to handle oral secretions exacerbates the problems of aspiration. Daily monitoring of medication and possible alterations are also required. Art requires total care as regards feeding, dressing, bathing, toileting, turning and positioning.

AT RISK FOR MEDICAL VULNERABILITY

Paul is a 10 year old boy who is non-ambulatory, microcephalic, and blind. He has a seizure disorder. In addition, he has a problem with emesis after eating and bruxism (teeth grinding) which the staff has not been able to fully control. Paul has a moderate-severe hearing impairment and his left arm is in a splint. He needs careful monitoring of his nutrition, feeding and seizure problem. Without monitoring he may experience weight loss and poor nutritional status, and/or an increase in seizures which at times, can be life threatening. Paul requires total care as regards feeding, bathing, toileting, turning and positioning.

SIGNIFICANT MEDICAL NEEDS

Brenda is a 3 year old girl who is blind and profoundly retarded. She has cerebral palsy and is non-ambulatory. Because of her inability to move and turn herself she needs regular positioning to prevent bed sores and severe contractures. In addition, her lack of mobility causes Brenda to be predisposed to respiratory infections and thus, requires careful monitoring in order to prevent pneumonia and other, similar complications.

The study completed in Washington State underscored the notion that most children and adolescents now living in intensive care environments including institutions, can live — albeit at higher risk in some instances — in smaller alternative residential settings including natural homes, specialized foster care settings, adoptive homes, and group homes. The study team visited institutions, nursing homes, foster care homes, group homes and families who cared for their own child at home. Children from all definitional categories were found living in all the residential environments we visited.

V. Recommendations

RECOMMENDATION I. PLACE A HIGH PRIORITY ON PREVENTING INSTITUTIONALIZATION, INCLUDING MINIMIZING A CHILD'S STAY IN GENERAL MEDICAL HOSPITALS SUCH AS CHIIDREN'S HOSPITALS

In order to prevent children and adolescents from institutional placement several things need to happen.

1. Financial incentives need to line up with philosophical goals

Fiscal structures which support programs are complex and, all too often, counterproductive to the philosophical goals of creating a more normal life experience for individuals regardless of their disability or handicapping condition. Families of children with intense medical needs or who are at risk for medical vulnerability are often dependent on Federal insurance programs and/or other third party reimbursement to pay for care. The condition of reimbursement may be living in an institutional/ hospital-like setting.

The proposed Federal Medicaid Home and Community Quality Services Act Of 1987 which is designed to amend the Title XIX Medicaid program is an excellent example of Federal/ State partnership which will assist people with disabilities in maintaining maximum potential for independence. As it stands now, financial resources may be substantially limited or even curtailed when an individual leaves an institutional setting to go home or into a foster care situation unless special waivers are obtained.

Linda and Tommy, who live in Washington, are examples of this quixotic situation. Both children fit the definition of "Intense Medical Need". Linda is two and now lives with Mr. & Mrs. Ross, a foster family, having moved recently from the Children's Hospital. Linda is eligible for the State's Medically Intensive Home Care program, a Title XIX waiver program which

provides special services in an effort to maintain individuals in community environments.

Tommy also lives with Mr. & Mrs. Ross but is not enrolled in the Home Care program. Linda receives sixteen hours a day of federally and State funded nursing services in the foster home while Tommy, who needs oxygen regularly, does not. In theory, the nurse caring for Linda must not care for Tommy even though they share a bedroom. Tommy's life is dependent on the ability of the foster family to adequately monitor and respond to his health care needs. Fortunately Mrs. Ross is a trained nurse and the fire station personnel nearby are alerted to the possibility of medical emergencies. The alternative if this wonderful family were not available would likely be institutionalization for Tommy.

2. **Actively seek partnerships between State and local communities, and private and public agencies which ensure adequate community based support structures, including respite care and other in-home services, which will help prevent institutionalization.**

Services for children with intense medical needs, including those at risk, which permit and promote their retention in a natural, adoptive or foster home remain inadequate and essentially unavailable through the United States. Families, including foster families, of these children are at considerable risk for becoming isolated and "burned out" without supportive services such as respite care and in-home assistance. Yet examples abound of situations in which supportive services are only marginally available and in danger of being further reduced. It also seems that supportive services are more likely to be available to foster families while natural or adoptive families are more at risk for not receiving any support services.

Danny is ten years old and lives in the Pacific Northwest. He has severe contractures, no ambulation or speech and severe respiratory problems. He fits the planning definition of Intense Medical Need. Danny's home has been modified as much as possible to accommodate his special equipment needs. He receives quite a few services through the school system although his parents assume the financial burden for a number of things for which there is no assistance available. Danny now weighs close to 80 pounds and his mother, a diminuitive 5'0" tall, is finding it nearly impossible to physically care for him by herself. Respite care is rarely available to this family. More critical to this situation, there is no other in-home service available for even the few hours that another family member is not there to physically assist the mother. However, another financial source would pay for out-of-home placement. It is only through the family's adamant advocacy on behalf of their son that he has not been placed in an alternative (and more expensive) care situation by community case-workers.

The development of community services systems in general in this country have lagged behind. Currently they are overburdened and under funded. Waiting lists are long, in many instances, and may not even reflect the true numbers of people getting by with less than optimal or no services at all. It is difficult to prevent the institutional placement of people who fit in any of the three definitional categories described in this paper when community support services are not even adequate for those with less complex disabilities. Lack of adequate medical care is a substantial problem in many communities and a real barrier to maintaining children and adolescents with substantial medical need at home. Without the necessary services the risks to the life of the child are substantial.

3. Encourage and support effective interagency partnerships and critically evaluate alternatives which are developed.

Foster care is often seen as the viable alternative to institutionalization when families cannot care for their child at home. Foster care in most states is administered by State agencies who do not have primary responsibility for children with disabilities. Little planning and interagency coordination exists between agencies responsible for foster care, and developmental disabilities or mental retardation State agencies.

Further, there are too few foster families like Mr. & Mrs. Ross, the family in the previous vignette. A recent national study of the status of children with developmental disabilities in the child welfare system (Richardson, M., West, M., Day, P. & Stuart, S.; In Press) reveals a foster care system that is overburdened and under prepared for children with even mild disabilities. Foster care workers are poorly trained in regard to mental retardation and other disabilities; foster families are not generally trained to deal with the complex needs of a child with medical problems regardless of severity; the level of reimbursement for foster care generally assumes a volunteer status on the part of the foster parent making it difficult to recruit a person with the professional skills necessary to care for this special group of children.

Philosophical differences are substantial. Foster care systems are traditionally organized to step in when a family fails. Families with

mentally retarded children should not have to fail to receive help in raising their child. All too often, the involvement of foster care requires relinquishment of rights on the part of natural parents rather than providing a shared parenting option.

More attention has been accorded to specialized adoption. Specialized recruitment and training is more likely to occur. However, careful attention needs to be given to the needs of the child, the natural and the adoptive family. Support services, including respite and other in-home care supports are necessary and must be available.

4. **Recognize that community placements may not be less expensive than a State operated institution.**

Movement out of public institutional settings has been generally believed to lead to lower costs of care. Much of that belief appears to have been based on the early movement of more functional individuals, requiring fewer and less intense services, from institutions and the assumption that a significant number of people would return to live in their family homes. The population that remains in institutions and other protected environments including children's hospitals require intense, expensive care. Placement in a community will not necessarily lessen the intensity of care needed and overdependence on families to provide low-cost or no-cost care substitutes will contribute to their inability to cope.

RECOMMENDATION II: ENSURE FLEXIBILITY AND RESPONSIVENESS IN THE SERVICE SYSTEM

1. Work together to determine how to effectively utilize all the valuable resources that exist

The more complex the problem faced by an individual who is mentally retarded, the more flexibility is needed in the ability of the system to respond. Children who fit any of the three definitions presented require an array of health, educational and social programs. A system with multiple options and ease of movement in any direction is going to be most responsive.

A significant impediment to effective planning has been the philosophical rift that has occurred within the community of families, advocates, and providers of services to individuals who are mentally retarded. Institutions have in many ways become the symbol of the denial of human rights to disabled people. They have become very controversial as a residential option. In fact support for community program has often been secured by decrying the evils of institutions.

Considerable controversy exists regarding the role of institutions in the total system. This controversy has, in many instances, polarized families, clinicians and other people who are often the decision makers regarding services for individuals with chronic disabilities or handicapping conditions regardless of age. In our desire to ensure a home in a "good" setting for the children which are the focus of this paper we may lose track of attending to the critical needs of the child as we debate "goodness" or "badness" of setting type.

Opportunities to enhance a *child's life* as well as *where they live* may get lost in an argument about setting types. Institutions and other protected environments such as hospitals have staff with considerable experience serving children who have complex medical needs. They also offer a significant resource in terms of available technology. We mist be creative in utilizing these important resources regardless of where a child lives.

2. **Assure access to any part of the system which will best meet the needs of the child and family involved**

The need for adequate supporting services has been mentioned in this paper and will be addressed in greater depth by another panelist. However, it is important to note the lack of community resources in this country in general is especially problematic to the individual with intense medical needs or one who is at risk for medical vulnerability.

In the State of Washington, the State Habilitation Centers (Institutions) are staffed by well trained and experienced developmental pediatricians and other health care specialists with considerable experience caring for children whose medical needs fit all three definitions. Habilitative staff are especially creative and innovative in developing positioning and other adaptive equipment for these children. The Centers have the potential for serving as a diagnostic and specialty care center for people living in the community for whom specialized services may be difficult to find. They also have the capability of offering emergent care and providing short term stays for people who need acute intervention in order to achieve medical stabilization.

Many institutions seem to have a moat around them and a bridge that only allows movement one way. Once you get in it is hard to get out and if you are on the outside it is hard to get in regardless of how long you might plan to stay. The poor use of the skilled and knowledgeable staff within the institution is

difficult to defend in the face of limited resources in general.

An example, not unique to Washington State, offers some insight into the dilemma. The capacity of many families to maintain their family member at home is often dependent on the availability of in-home supports and respite care. Yet funds for respite and in-home care are inadequately funded in many states. Empty beds in State operated institutions, staffed by experienced personnel, offer a respite option. The availability of this option may be limited by regulations and/or the philosophical position of system planners, providers and advocates, who feel that it is better to let families muddle through with no respite than to use the available bed and trained staff for even an overnight stay. The result may ultimately be the inability of the family to cope with the complex demands of their family member.

3. **Acknowledge that our knowledge and technical sophistication is not yet great enough to assure survival for some children except in institutional or hospital like settings.**

There are still some individuals for whom the risk of moving into a less intensive care environment is simply too great. The severity of their disability coupled with the intensity of their medical need requires the highly specialized care which may only be found in a hospital- like setting.

Institutional or other hospital like environments are more likely to have sophisticated and expensive medical or other types of equipment immediately available for children with the more intense medical needs or children who are substantially at risk. They may have the advantage, also, of affording expensive staff on a regular basis, including physicians and therapists. Communication among caretakers, particularly in regard to health status, may occur more readily since they are routinely on the same site.

With expanding knowledge and technological capacity, however, alternate residential options for these children may increase. Computer technology and the enhanced monitoring and communication capacity it offers may hold real promise.

In the meantime, creative planners in Washington and other states have developed small, homelike facilities which are clustered on the grounds of larger institutions. They offer the critical mass of highly specialized and life saving services necessary. More personalized attention and highly specialized care are provided at the same time. In one of Washington's facilities a hospice program is being developed in order to address the needs of individuals who are terminally ill and their families.

A creative addition to homelike settings offered in some institutions would be space for family members to stay on site and participate in providing care if they wished to do so. These family residences could also be used for assistance in helping families plan for moving their family members home in instances where that is an option.

RECOMMENDATION III. ASSURE FAMILY/ SERVICE DELIVERY SYSTEM PARTNERSHIP IN ALL PLANNING ACTIVITIES, INCLUDING SYSTEMS PLANNING AND ESPECIALLY IN REGARD TO FAMILY MEMBERS

1. Acknowledge and understand family concerns

Without a doubt the major concern of parents and other family members of the population in all three of the categories is the need for assurance of continuing services. Institutional services are somewhat protected by legislative mandate. Community based services may be less predictable over an extended period of time. It is important that assurances be made that services would continue beyond the life span of the parents after a move into a community setting, whether from the family home or a larger, institutional setting.

Parents on the Washington statewide planning team especially asked for understanding and meaningful participation in the transitions their child experiences as they move from one setting to another. Among the parent generated recommendations was the creation of transition teams made up of parents and advocates. Their responsibility would include approaching families and providing support and information in any placement planning decision, particularly with regard to individuals with intense medical needs or who were at risk for medical vulnerability. In addition, parents often feel the need for a "back up" plan in the event the community placement does not work well. This may be for short stays in a larger residential environment or, in some instance, the option of placement of a more permanent nature in that larger setting.

The capacity of the family to care for their family member is not a measure of their concern. Over and over, parents reminded our study group not to assume parents did not care even if they were not immediately involved with their children. The ability to cope with grief and loss varies from one person to the next. We saw single parent families, for example, who were remarkable in their ability to manage the care of a child with intense medical needs. At the same time we are aware that

other families, perhaps with both parents living together, simply could not cope with caring for a child whose disabilities were less intense. Yet both families were very concerned about their child.

An important part of the statewide planning in Washington is the environment of parents of individuals with multiple and complex needs. They made substantial contributions to the development of the definitions used in this paper and the subsequent assessment of the people living in State operated facilities. They strongly advocated for the involvement of parents in all phases of planning whether system wide or individually focused.

2. Planning for the Life Span

Services for individuals with disabilities become less available as the person ages. Services for school aged children tend to be the most abundant, with a decline in services occurring as children become adults. However, existing service providers may not be adequately prepared to meet the more immediate and demanding needs of a child with intense medical needs or one who is at risk for medical vulnerability. Children who are technology dependent, for example, will be entering school systems in increasing numbers. Adequate preparation needs to be made for their special needs.

Adolescents, who have services through educational programs, may be less likely to have health care and social services routinely available that address the special concerns of physical maturation and adolescent development into adulthood. Adult programs are not nearly so available in community based services. It is imperative that day programming, transportation, social and recreational alternatives be made available in addition to the necessary specialized medical care services.

3. Ensure adequate monitoring and evaluation

Lastly, but certainly not least, is the need for ongoing planning, monitoring and evaluation of appropriateness and quality of service choices for each individual. Planning should take into account that we all progress and change developmentally. What is a good plan for today may not be adequate later in our life. As our needs change, we need flexibility and availability of options. Monitoring should be systematic and include input from all participants of a service system including consumers/family members, service providers, planners and administrators.

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Access to Health Care

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I am privileged to serve on a couple of Boards of Directors, the one in particular the NDSC. I want to say hello to my friend and compatriot of many years, Mr. Frank Murphy, the current president of the National Down Syndrome Congress (NDSC), sitting over here. I was fascinated by your comment that advocates and consumers indeed consider professionals be trainable. I sort of was amused by that, I remember early on when I started speaking in front of professional groups, I was a little bit unsure, and I talked to my dad about it, and I said "you know, I'm walking up there, I have a BA and all, and I'm not really professional", he put his arm around my shoulders and he said, "you always remember something", he said, "fifty percent of the doctors graduated in the bottom half of their class." I never felt bad after that.

Anyway, I speak in different forums on access to health care, not specifically with regard to the mentally retarded but indeed to all individuals who might have some sort of a chronic or disabling condition that causes them to be somewhat more at risk for being in need of health care services, and I have big numbers, how many millions of people aren't covered and these sorts of things and, but it was sort of funny, I talked to Frank last night, he was very kind when he got in town and gave me a call. We were chatting about some of the things we've done in the National Down Syndrome Congress and whatnot over the years and I thought I might start, rather than talking about big numbers, maybe talking about one person. A number of years ago, and not very many, it was in the early 1980's, there was a mom that brought a youngster into an HMO in a major metropolitan area of the United States for a well baby checkup. The child was about a year and a half or two years old and they were fairly new to this plan at this HMO. And as is the protocol of course she took the youngster's clothes all off and he's sitting there on the table and the doctor walked in. And he looked at the child and he shook his head and he said, "there must be some mistake." And she said "well, what is this mistake" and he said "well, we don't take those here": See that child had Down syndrome and the mom said "I don't understand" and he said "well there must be some kind of mistake, we wouldn't be that foolish" and she was very upset and put the boy's clothes back on and left and went home, and made a phone call to the folks that run this particular facility and said "I just don't understand how you can accept a family into your program and then have a doctor say that you don't take care of certain patients". And the individual who was in charge of consumer complaints said something like, "well, the doctor sounds like he was a little bit abrupt, but, sure, isn't that obvious, you know, why would you intentionally take on a risk like that if you are in our position". And she was astonished, she said "isn't there some level of recourse here" and was given another phone number and made another phone call to a director of, I don't know, complaint services or something, in the main office and basically was told the same problem. That's just the way it is. That's not an unfamiliar scenario for those of us who sit as I have for a number of years on the NDSC or in the Alliance in a position where we receive letters of complaint from consumers who are unable to get health insurance for people who have serious problems. Some of the problems are resolved nicely and some are not, but from a very

personal standpoint, you know, not the quantification of the millions of people who don't have insurance but from a very personal standpoint those individuals who deal with these problems are a lot more affected than simply thinking about how to get from day to day, how to deal with us in public service. You are already in a position, in mind set, in a place in their lives that they didn't see, they are dealing with a condition they didn't want to deal with and are doing as well as they might and very personally, that's a difficult situation from a personal and family standpoint, we will finish this story in a while. Anyway.

In the United States today, there are somewhat over 38 million people that don't have any kind of health insurance at all. Any kind of health insurance, and a very large percentage of those folks are people that have mental retardation because indeed they are identified as being somewhat more at risk than many other segments of the population. And of those 38 million people with no insurance at all, that doesn't take into account the other millions of people that are significantly underinsured, those who have very high deductibles, those who have particular services written out or ridered out of their policies, etc. There is a significant level of under-service with regard to how this society is set up dealing with financing of health care in the country. Now it's said that it's in a sense an employment driven system. The employment driven meaning that basically if you have a job that's typically where you are going to get your benefits package or health care. Well if you look at those 38 plus million people you will find that over two-thirds of them are employed, indeed, full time, part time, and seasonal labor. You know, maybe it's not like working at a fancy hospital or having a government job but they are fitting into the basic concept of the system where they have a job, they are making a living, they aren't indigent per se, but they can't get insurance because the way policies are written. It's a particular kind of group you don't necessarily have a "group" for: a small company that might only have ten people in it or for farm laborers who are around for a couple of months and go away. There are a number of those kinds of situations that simply by the nature of the system as it exists right now, very difficult to get insurance unless you apply for it on an individual basis. Well, if you do that you have to qualify, you have to be underwritten, as they call it individually, and that means if you have someone in your family of special health care need there's a very good chance they aren't going to be covered. And I hear it said in a lot of Forums that that's a significant problem. Yet if you look at the actual numbers, if there are, and this is a very rough number, but if there is somewhere in the range of fifteen or sixteen million people in the country that would fall into that category of being in a special health care need category and you look at the quantification of people in that thirty-eight million who are of that same category, that special health care need, you will find that it's only in the range of about two and a half million people. That means that somewhere, somehow, twelve, thirteen million folks are somehow covered within the system. The argument that we hear from industry, industry meaning the insurance industry, the financers of health care, simply does not hold. It simply is not true that people are uninsurable. What it is is that the nature of the system as it is designed, in other words one that is employment driven, one that is, we won't say financed, but encouraged by Federal tax policy of being able to write off payments to, an insurance company off of your corporate profits, does not cover a significant portion of the people, but it's not because they're uninsurable, it's because the nature of the system itself is not covering this thirty-eight million chunk, and that's a significant problem. It's in effect what I call a defacto policy. It's a policy that exists not by design but by default and because of the nature of that policy there are significant complications in the delivery of dollars to finance health care. For instance, all those people being employed, and being able to hold down jobs and not being able to get insurance. So as we, in the advocacy community look at the situation and how to access health care for those of our constituency who have problems we recognize that indeed we aren't dealing only with this particular community, we are dealing with an overall health care financing policy that we feel needs a reexamination and perhaps a little bit of change.

We have some factors going on in health care today that are rather significant. You know it's funny you mentioned "Sick Kids Need Involved People" (SKIP) a while ago, I know Julie Becket and very early on in their situation which is I think a lot of what lead to the formation of SKIP. What happened was their youngster was hospitalized for a long period of time, being very, very dependent on a ventilator and couldn't leave the institutional setting. And when she got better, this was Katie, it would have been significantly less expensive to take care of the youngster at home, but because of the nature of the laws if they had taken the child home they would lose all benefits. Whereas if they left the child in the hospital setting, the benefits were taken care of by Medicaid. And simply another example, there is

a misdirection of policy that somehow, you know, it doesn't make sense for the government to waste money, and yet they were doing it. It doesn't make sense to split families apart, and yet the policy dictated that that would be the case, and it took intervention by a guy named Reagan to stop that. It took a phone call from the President of the United States to the head of HHS to say, "this is dumb, do something about it", you know, it's a policy problem.

So again, factors that are currently impacting upon health care financing in the country in particular today that will not alleviate but indeed will worsen the condition we are looking at. The increasing prevalence of transplant in treatment of problems, whether it be heart, or liver, or kidneys, or whatever, there is an institution in New England, some of you folks may know, whether it's the University of Connecticut or Harvard or what I'm not sure but they have a rate something like the last thirty heart transplant patients of them, twenty-nine are back at work. It's obviously a viable intervention medically and is therefore going to be reimbursed as an appropriate non-experimental treatment. Well that's a very expensive procedure. It's going to run dollar costs up very much. Trauma care in the United States is undergoing over the last few years an astonishing increase in the ability to maintain the lives of individuals who a few years ago might of died from a serious accident or illness. You know, the medivac helicopters and the special medical units at certain hospitals, what that does is number one, means that there is a relatively expensive series of procedures that takes place for this person and that the person might take instead of leaving us, as they formerly would have, might take six months to recover. And because of the nature of subsequent disability, can't necessarily go back to work in the same capacity they could before. So you have a person who has been receiving medical benefits, who if they go back to work will lose their eligibility for the benefits, so you have a built in glitch in the system that says we're learning to save people but we aren't going to let them live their lives and go back to work. It's a policy problem that has to be addressed.

Certainly, the increasing prevalence of AIDS in this country and the treatment of individuals who will come down with that particular disease is going to run the cost of health care up dramatically over the next couple of decades. It's already beginning to have a significant impact in certain parts of the country.

Testing. Testing for anything, blood tests, whatever anybody might go in for, because of the number of law suits that you see for malpractice and the kind of settlements that are being acquired by people that win those law suits, it was estimated recently, I guess it was in Inquiry Magazine, put out by Blue Cross/Blue Shield that somebody estimated between thirty and fifty percent of the tests done in this country for medical reasons are utterly unnecessary, it is simply covering yourself, in case you get sued. Do four extra tests, well that runs costs up.

The area that I'm particularly involved in, in the area of genetics, some of you I'm sure are aware of the evolving technologies that are coming to bear in the field of genetics today where we aren't just learning how to test and find out about what a person's condition might be, or what they might develop over a period of years, but indeed we are evolving into an area where we can intervene.

There's a fellow who happens to be the Secretary of our organization who is the first human recipient of genetically engineered Factor 8 for hemophilia, instead of being human serum they are getting us Factor 8 out of these little hampsters or something, I don't know what, but, it's very expensive, but it's also an AIDS free intervention that takes care of his disease and it won’t be but another ten or twenty years that they're going to find the technology to where they can inject him with a particular genetic substance that will cause his own body to develop its own Factor 8 and he in effect will be cured of his condition, and that's going to recur in many other conditions that we find the genetic linkage for. And that level of technological advances is advancing just geometrically, it's amazing, and again, very expensive.

Right now in the United States we are spending somewhere in the range of eleven percent of the gross national product on health care. That's up very significantly over the last couple of decades. In fact, private insurers are looking at somewhere in the range of six times the dollar outlay that they were just twenty- five years ago for taking care of health care costs, and with all of the pressure upward for how many dollars are going to be spent, and for in a sense, the desire of the financers of health care to hold the cost down, you have a conflicting situation. You have on the part of the government things called Diagnosis Related Groups (DRG's), I'm sure most of you folks are real familiar with those, where there's a desire to capitate the level of reimbursement for particular procedures. Certainly in the industry level, you're seeing higher deductibles, you're seeing riders existing more than they used to, in general a trend toward purging either people or particular conditions out of the system that finances the payment for these kinds of treatments. And as a result, as we look at increasing

costs on the one hand, as we look at the ability of either the government or private insurers to not pay for increasing amounts of that reimbursement. What you do, in effect, is you begin to impact upon those family units that have already a greater level of jeopardy economically because of the fact of having a family member that is significantly affected by a chronic condition or disability. I have to say, and I enjoyed many of your comments, but I have to say that I object to the idea of looking only at children as the people that we need to look at, in fact, one of the large problems right now is that we have for the mentally retarded an educational system that is able to take people that twenty- five years ago might have to be institutionalized, and we are teaching them enough that they can go out and be functioning members of society. They can be wage earners, they can be tax payers, and yet we are not developing a health care financing system that will permit them to go out and earn that wage. We have again a policy situation to look at; we need to address it not just on the level of how we deal with kids but what we do them at age twenty- one. And what are we going to do with all these folks with all this wonderful special-ed that we give them. And so we have those kinds of factors play additionally.

Over the years the government, whether it be state or federal government has done a number of things that begin to address this kind of policy consideration we talked about. Medicare and Medicaid, two very obvious areas where particular problems were addressed by means of particular legislation. Certainly universally it did not take care of all the people that don't have the ability to finance their own health care, but they were significant steps. You will have noted in the last year or so the catastrophic insurance that was proposed on down here on Capitol Hill for elderly individuals that Medicare wasn't taking care of, so there was this little glitch in that Medicare system that somebody decided they would address with a little factor right here.

There are States around the country that say, you know, we realize that people can't get insurance so whether it be through Blue Cross/ Blue Shield or some similar type of plan in the state there will be a given month of every year wherein you can just sign up even if you have a member of your family that would not otherwise be eligible. If you can afford the insurance, you can buy in. There aren't many of these, only two or three that I know of.

There are hospital taxes that take care of indigents. Florida, being one of the most not plus every year, that hospitals finance the care able, right now runs a multimillion dollar surfor indigents that are taken care of in those facilities. But again that's a little nitch of the population, that's not the population in general.

There are things called risk pools, I don't know if you all are familiar with those, in about a dozen States in the country. There are plans sponsored by a given State that if you're turned down for insurance for whatever reason, you can buy into this State sponsored pool and be insured, for health insurance. The only problem is that the average cost per year per individual runs between four and seven thousand dollars per year, including your premiums and the initial co-payments, based on what State it's in, and there is always a waiting period. So it's again not a perfect answer. And to give you some idea of the quantification of those dozen States that have it in place, and remember we're looking at thirty-eight million who don't have insurance, about twenty thousand people in the country have joined risk pools. So truly there is not a full answer with this particular mechanism.

There are a few states in the country that have actually played with the idea of having State health insurance plans. Sort of like insurance for everybody funded out of State revenues. Wisconsin has been playing with three or four pilots now for about a year and a half or two years and they don't have any of them in place yet. And Massachusetts right now is batting one back and forth in their legislature. They are probably more likely to have it in place before anyone else.

Other little things people have thrown out, there is a thing called Med-America, I don't know if you all have heard of that, that was a bill proposed this past year wherein there would be a graduated buy-in available to people, into the Medicaid program. In other words, if you are at X income per year, you would pay a certain amount and be covered by Medicaid benefits as opposed to not having insurance at all. It didn't go through but it's something that's being looked at.

There are many other things that cross Capitol Hill or a number of the other States. The primary factor that is common to all of them is that none of them really focus on what the problem is. And the problem is simply that the increasing cost pressures that exist with health care as it exists today, in particular for populations such as the mentally retarded, in fact all of us who deal with family members who have a person with a special health care need, with those increasing costs, the increas-

ing ability of financers of health care to purge from their systems those individuals who are at higher risk.

We really need to begin to focus on what we can do on a legislative level, on an advocacy level, on an industry wide level of how to cause the funding to flow without necessarily tipping over every single boat that's already in the pond. We who participate in these things, and I have met with industry folks over the last couple of years, don't necessarily say there shouldn't be any private health insurance, all there should be is a national health care plan. There are many ways that you could integrate a plan whether it be on a state wide basis or on a Federal basis that would utilize existing industry. But indeed something is going to have to be done, and it's going to have to be done nation wide, it's going to have to be done comprehensively, it's going to have to be done with the participation of all the various individuals involved with this, consumers, industry people, providers of health care, policy planners, because if it isn't done all there's going to be is fifteen other little bandaids that are going to get dropped on a problem and there is still going to be great big cracks that people are going to fall through.

So what we advocate for, what we speak for, is the concept that let's figure out, number one, are we spending enough money on health care in the country, or should we recognize the fact that maybe eleven percent is not a large enough chunk of the GNP. Maybe we need to trade off some guns for a little bit more butter. Maybe that should be an appropriate area of discussion. What makes one eligible for being able to get certain kinds of services, should there be a minimum mandated service level for people.

We heard some comments a while ago about how important it is to include genetic services in certain kinds of delivery of primary care, because if you don't do that you aren't dealing with prevention aspects that are potentially there, and if you don't fund that it's not going to happen. And we need to do it on a policy level incorporating those individuals that indeed write the policies, meaning governmental officials. I really see us at a crossroads right now, at a point where if we don't begin to do something other than the bandaids that have been done for so many years, there's going to be a huge dropping of those populations that are more in jeopardy. Because in fact that is the very basis upon which certain health insurance companies in this country today are starting to make contracts with individuals who can do genetic probes and find out individuals propensity toward later disease even if they don't have symptoms right now. So if there's a chance you're going to get lung cancer, they're going to know when you're born and you might not be able to get your insurance. And that's not going to be something that will disappear unless it's addressed universally, on a national level, by people who are going to write this as policy as opposed to as a response to a particular interest or pressure group. And we very much hope that those in the provider community as well as those' in the policy community recognize that this is not something that is static, that it's going to be getting worse, and that it should be addressed soon in an appropriate fashion.

The mom came home from that HMO and she made those phone calls and got very, very discouraged, and spent the rest of the day wondering how that family *was* going to hold itself together if that youngster could not get insurance. And the dad came home and they talked about it. And the next morning he made one phone call. He called that particular HMO and said, "I'm going to make you an offer you can't refuse". The Executive Director said "this is a thing called open season, it's November in Washington, D.C. And in Washington, D.C. in November all the government workers can change to any other plan they want, it was an approved plan for as long as employees." And the dad said, "I don't care what your policy is, you and I are going to discuss this in the Washington Post," and my son got his insurance. See I don't believe in taking that first no, I think that you take a situation and you deal with it constructively, and you find a way to get around whatever corners you might meet.

Health Services to Children with Mental Retardation in the Community, Schools and Home

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Health Services to many children with mental retardation are similar to those for other children. There are some, however, who need special services because of the varied health problems they experience. Because the American health care delivery system is undergoing revolutionary changes, it is timely that health services to children with mental retardation in the community, schools and home be considered. This is particularly important for those who receive residential care and those who need in-patient hospital care.

FACTORS IN THE HEALTH CARE DELIVERY SYSTEM

The decision of the Federal Government to discontinue retrospective reimbursement for hospital services and to pay prospectively on the basis of diagnostically related groups (DRG's) and emphasis on cost containment in health care delivery are two factors that no doubt triggered some of the changes that are emerging and are evident in the health care delivery system. To minimize cost of hospital care, more services will be provided in ambulatory care centers, out patient urgent care and surgical centers. Health Maintenance Organizations (HMO's) are expected to grow and provide services to millions of individuals. In 1985, more than 300 HMO's were providing health care to 15 million people. In addition greater emphasis is being placed on health care service in the home. The move toward managed health care has implications for the health care delivery system to all children. This is important because the third largest industry in the U.S. is health care. Depending on the nature of the child's retardation, he or she may or may not be cared for in these managed health care services.

Other factors that indicate dynamic change in the health care delivery system are the technological advances which have revolutionized diagnosis and treatment of some conditions, liability claims and increased cost of malpractice insurance.

Those children who would receive care in the hospital may now receive care in an ambulatory care setting. Hospital stays are likely to be shorter than in the past. Exactly how this will affect children with retardation is not clear. I recall reading the findings of a study - where the responses of children prepared for surgery in the hospital and children prepared for surgery in an ambulatory care setting were compared. Responses of children who had surgery in the hospital indicated that they adapted better following surgery than those prepared in the ambulatory care setting. The investigator concluded that the hospital was the better place for surgery. Time may be an important variable which was not considered as a probable reason for the findings. This study is mentioned because time would be a critical factor in working with children with retardation in helping them to understand and cope.

FACTORS IN SOCIETY

There are factors in society that are evident which also may have implications for health services to children who are mentally retarded. They are: 1) the average age of Americans is increasing. People are living longer and Americans over 45 years of age are a fast growing cohort. Further, there is a great deal of advocacy for the elderly; 2) a more culturally diverse population is emerging with an increased number of Hispanics, Blacks and Asians in society; 3) more women are in the work force. It is projected that by 1990 the

number of children under six whose mothers work outside of the home will increase to 11.5 million, and the number between the ages of 6 and 13 will increase to 17 6 million; 4) consumerism values appear to be changing. With more information being available to individuals, there seems to be greater emphasis on helping one's self. Toffler suggested that this rush to treat one's own problems, instead of paying someone else, reflects a substantial change in values, our definition of illness, and our perception of body and self

Education of health professionals so they can competently provide care to persons with mental retardation is another factor that needs to be considered. With the tremendous amount of information needed to function as a health professional, critical questions are: What will be removed from the curriculum of health professionals? What is the basic information needed to adequately educate health professionals to care for people with mental retardation? Are there strategies that will enhance student learning? The University affiliated programs have provided a model for training of team members who provide care to children with disabilities. All of these factors have implications for health services to mentally retarded children.

ANALYSIS OF FACTORS

A brief analysis of the factors identified, from the perspective of health services to mentally retarded children, suggests several trends. Deinstitutionalization of mentally retarded individuals will continue because of the costs of institutionalization. Economics and technology play a definitive role in health services that are delivered. Further, the belief that individuals can benefit to a greater extent in community and family based facilities than in large residential facilities also plays a role in deinstitutionalization.

More family centered, community-based, coordinated health care services will evolve. In Kentucky's fourteen regions for Mental Health and Retardation there are preschool, day care, home and center based programs designed for children with handicapping conditions. These services are provided in clusters (or systems) which serve up to 45 people, by meeting their individual needs which they, their families, and communities cannot otherwise fulfill. The services include case management, an individual living environment tailored to the clients' special needs, day habilitation, in-home support, habilitation and respite.

A greater emphasis on preventive services seems evident if more individuals use HMO's. Early intervention and preschool programs for children with handicapping conditions are evident in some States. Some families, whose children are dependent on medical devices for which reimbursement can be given only if the children receive care in the hospital, will benefit from legislation which has been introduced whereby insurance plans would cover in-home medical technology services for children. Prevention will be viewed broadly and not simply from the perspective of primary prevention. Secondary and tertiary prevention also will be emphasized.

Changes in society suggest that more funds likely are to be provided to support activities for the elderly because the population is getting older. The question becomes how funds can be made available for both of these vulnerable groups of individuals.

It seems logical to conclude that more children with retardation from the minority groups mentioned earlier in this paper are likely to come to society's attention, if the population increases in these groups.

More mothers will work outside of the home. Presently, child care is not available to handle the number of children of working mothers. The likelihood of there being adequate services that are concerned with the health needs of children with mental retardation is small.

The fact that a child is retarded may compound the issue of the availability of health services. Will health services be available for all children with retardation and their families, regardless of their ethnic background and socioeconomic status? In the *Health Policy Agenda for the American People,* two principles are stated which are pertinent to this question — a general principle and a specific one. The general principle reads: "The primary purpose of health care facilities should be to serve community needs by delivering health care." The specific principle reads: "Health care facilities and health professionals should fulfill their social responsibility for delivering high quality health care to those without resources to pay." These principles suggest policies that assure access to quality care to vulnerable populations such as children with mental retardation and all segments of the population regardless of race, religion, social or economic condition.

INFLUENCE OF THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

The President's Committee on Mental Retardation can:

- foster prevention. Primary, secondary and tertiary prevention is critical in providing health services to children with mental retardation. Support to local health departments, private physicians, and other community health agencies to assure that children receive

their immunizations and other specific health needs is important. Vaccine prices are increasing because of litigation costs against manufacturers. Since 1980, the price of diphtheria, tetanus and pertussis vaccine has risen from 14 cents to $7.49 per dose, an increase of over 5,000 percent. It is important to assure that no child is ever deprived of needed vaccine.

- advocate and demonstrate commitment to assuring that health services are available for children with mental retardation. There is an increasing number of families and individuals in this country who cannot afford medical care or health insurance. These individuals do not qualify for Medicaid. There seems to be an increasing advocacy on behalf of the elderly, and this is certainly positive. "Gray Power" is on the increase. It is equally important that advocacy on behalf of children be strengthened. It is important that "Kids Power" also increases.
- maintain and enhance the essential services that are now available to mentally retarded children. Mentally retarded children's health care needs vary. Some have need of several special services, while others' needs are typical to those of many children. Support of the University affiliated programs for screening, evaluation and care of children has proven effective and should be continued. The use of a team of health professionals to work with these special needs children reflects a commitment to working from a holistic perspective with the child and his or her family.
- encourage coalitions, collaboration and cooperation among groups that have interest in children. There are many public and private national, regional and local groups interested in children with various types of problems. An approach worth considering is the provision of incentives to groups and health care professionals who work together to provide services to children with mental retardation and other handicaps.
- promote the conduct of research on the delivery of health services to children with mental retardation in the changing health care system and other clinically relevant aspects of care of these children.
- stimulate opportunities for families of children with mental retardation to help themselves. The use of Care By Parent units, where parents learn to help their children, may be one way to provide opportunities.
- assume leadership in promoting health care professionals who are prepared to provide family based health services to children with mental retardation. Universities and colleges need to assure that the curriculum for health professionals includes information on developmental disabilities. It is conceivable that many retarded children can be mainstreamed in the public schools, given adequate support systems. Appropriate preparation and emphasis on a team approach will facilitate the development and implementation of care plans that will aid in meeting the health needs of these children.
- encourage a greater emphasis on follow-up and evaluation of children with mental retardation diagnosed and treated in the health care system.
- foster partnerships of local school districts with other community health agencies that provide services to children with mental retardation. The importance of coordinating services so that the child can ultimately benefit cannot be overstated. Encouraging the building of community based service systems with schools to prevent fragmentation and gaps will enhance the services to these children. Many need basic health services, as well as a variety of other health services such as mental health. The school nurse could be a valuable resource.
- promote the development of alternative strategies and systems for delivery of health services to children with mental retardation, similar to the immediate alternative program in Kentucky which is described above.
- promote the provision of incentives to both-public and private child care facilities that serve children with mental retardation and demonstrate that a component of health services is included in the program of the facility. Get employers to include in health care packages specialized health services where needed.
- use its influence to get group insurers to include as one of their product packages health services for people with mental retardation.

SUMMARY

Several factors that may have implications for health services to the people with mental retardation were highlighted, and a brief analysis provided of these factors. Suggestions for the President's Committee on Mental Retardation were provided. Private and public facilities are necessary to provide adequate health services to children with mental retardation. Leadership to impact health services for these children likely will result from a combination of family, health professionals and public spirited working together to assure that these children receive the care that is needed.

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Health Services in a Rural Setting: Sometimes the D.D. in Mental Retardation Stands for Delights and Dilemmas

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HISTORIC PERSPECTIVE

Sunmount Developmental Disabilities Service Office (DDSO) main office is located at the Developmental Center in Tupper Lake, 35 miles from the site of the 1932 and 1980 Winter Olympics in the heart of the Adirondack Mountains. Sunmount also provides a full range of treatment and habilitation services to people who are mentally retarded and developmentally disabled who reside in Clinton, Essex, Franklin, Jefferson and St. Lawrence Counties. This covers approximately 10,000 square miles or is roughly the same size of Vermont, New Hampshire, Massachusetts, Connecticut and Rhode Island combined.

It is primarily rural with only a few widely scattered population centers. The largest single employer is the government through Mental Health, Mental Retardation, prisons and universities.

Sociologically, the area is as impoverished as Appalachia with high unemployment, high alcoholism rate, high suicide rate, a high number of recipients on social service benefits and a high mental illness rate. It also has a high tenacity for ruggedness, New England frugality, and a sense of camaraderie and cooperation for survival instincts.

We currently have approximately 3500 clients on record for services. These services include residential care at the developmental center, alternative care or service in voluntary and state operated day treatment and day training, community residences, community ICFs, family care, personal care and various forms of supervised apartment living arrangements. The developmental center has approximately 300 clients who are working for alternative placement; within the facility live approximately 300 clients. The rest are in the community.

Within the past five years, we have moved from a custodial model of care to an active treatment service with individualized, integrated programming through an interdisciplinary team process. Our current focus is to go beyond basic services and significantly improve the quality of service throughout the DDSO.

MEDICAL AND RELATED HEALTH SERVICES: THE DILEMMAS AND DELIGHTS

In our attempt to provide a full range of services throughout the DDSO, we did a need assessment that started with the identification of each client's profile (see Developmental Disability Information Services and Developmental Disabilities Plan) for if we were to remain dedicated to the idea that this should be a client driven system, we needed to know what our client's needs were. When this information was generated, we then could compare the needs against current services provided, to determine new services needed, and then begin the budgeting process for providing these services. We also needed to examine each community to determine if appropriate private providers existed to provide the services being generated.

Obviously, the list of needed providers included physicians, dentists, nurses, PT, OT, speech and hearing, psychologists and dietitians, all of which are often lacking in both quantity and quality. This became our "hit list" for recruitment and retention. This also became one of our most difficult obstacles and currently remains a problem.

A second issue of staffing is in having an adequate number of paraprofessionals who

could be hired at basic entrance levels and work with relatively complicated care issues on a day-to-day basis without burning out, by having the capacity and skills to perform within the individualized program plan.

A third major, concern was for the integration and coordination between other institutional bases, such as, the school systems, local hospitals, local governments, departments or social services, departments of vocational services and State offices of aging, etc.

Our conclusions at this point were that we would never have enough of either quantity or quality; and they always come in disproportionate amounts; and that the current fee for service is not flexible enough to capture the true cost of innovation; and therefore limits most services to mediocrity. We also found that the reward for doing a good job is often more regulation and paperwork that is a significant resource thief.

INNOVATIONS — THE DELIGHT

One of our earliest decisions was that there will never be enough of the appropriate staff available to handle the expansion of services we planned to do. Also, we realized the large amount of money we were spending in advertising wasn't producing significant results. We decided then to try to grow our own. We developed a 200-240 hour training curriculum that formed a standardized training package for all of our direct care staff. We then approached all of the community colleges through their continuing education department and/or where they already had a human services worker program and worked with them to develop a special tract in MH/MR that included our training materials. We told them of our recruitment needs and how this would be an excellent recruitment program for them in that this program could easily lead to employment. We now have active college programs which pre-train direct care staff for us. It is also a way for our current staff to turn their in-service training into college credits through life-learning contracts with the college.

We also worked within our own system so that those students who were trained at the college could have a leg up in the hiring process or advance in pay scale faster than usual.

Part of our negotiations with the colleges include a 6-15 credit clinical practicum which we agreed to host. This allowed us to see potential employees and their work habits and gave them a real work experience in program concepts and client interactions. This has proved very beneficial and cost efficient.

We also arranged some mutual exchanges for our staff to become professors and their professors to be teachers for other staff. We also exchanged other soft services such as training materials, library resources, etc. With the success of this program, we began widening our circle to other professions. As we gained academic credibility, we offered field placements, practicums, student teaching, internships and residences to all sorts of students. This included special education teachers, social worker placements, OT and PT trainees, speech and hearing students, graduate psychologists, etc. We began to see immediate benefits in that our staff became sharper as the students discussed current practice questions and the students improved their skill levels from this richer experiential base. We also found some wanted to work for us when they graduated. It took about 3 1/2 years for the program to mature.

We currently are in draft stages of considering a rural medical program in which connections between two schools of medicine (Albany and Syracuse) will build into their programs an intern/residency in mental retardation which would be facilitated at our agency. We would see this as helping medical students to be more aware of our needs and services and may help us recruit physicians. By using our agency as a base, a teaching program would be established and experts would offer lectures, etc. to which local physicians could participate, thus bringing together a core of experts to help our current providers as well as bring new providers into the system. At this point, we have conceptual approval within central office and have had positive contacts with the academic portion and are beginning to recruit others to facilitate this process. Again, funding for this project remains a question at this point in time, but in keeping with our positive attitude we are proceeding as if the money will be there when we are ready.

A SECOND DELIGHT

We have several types of clients that are in need of more supportive help than others. They are people who are low functioning, multi-handicapped, medically frail, explosive behaviorally and older. This is especially true when they are placed in a community-based program.

1. Medically Frail — As we provide no acute medical services other than ongoing services, all acute care is responded to in a community as you would in your own home. The emergency rooms and general hospitals have several problems in addressing the needs of the above clients. We have found that by providing in-services, better transference of information and having some mobile crisis

teams with high levels of expertise available to meet or train their staff, services are more cost effective than sending specials to "baby sit" just in case something goes wrong, or not having a client admitted until the condition is morbid, or in having an early discharge which leads to read-mission. Here is a sample of some of the training required:

a) Medication — The advisability of not giving neuroleptics to control behavior rather than working with the client.

b) Feeding — Training staff so that they use appropriate specific therapeutic feeding procedures including positioning, allowing appropriate time for client to take in food, chew, swallow before giving more food, and appropriate social interaction. These procedures avoid aspiration, dehydration and malnutrition.

c) General Behavior Problems — Know the philosophic differences in care. In general, our clients model the rhythms of the day, get up, go to work or school, etc. The routinization is not something we want changed and the clients don't accept change either. When they feel better, they get out of bed, straighten the room, take trays back and even get brooms out and start sweeping. To this, a general hospital labels our clients as disruptive, confused, and ultimately behavior problems. They fail to see the difference in the habilitative construct or to modify their institutional practices.

d) Moving, Lifting, Transporting and Positioning — Some actions can wipe out a programmatic gain in three days. We have had fractures, bruises and malalignment problems. Our persistence in positioning has allowed many to sit upright and become mobile through wheelchairs only to see six months of work disappear after a short hospitalization.

We now aggressively in-service and provide general teaching days for general hospitals and nursing home staff. Such titles include "How To Get Information From A Non-Responding Client", "Normalization and Humanization in an Institutional Setting", etc.

2. Behavioral Problems — The unusual behavior problems that do not respond to behavioral shaping programs give us the most grief from the community. Those tend to be the low frequency but high intensity types. You can only tear up the local grocery store once. Self-abusive behaviors also fall into this class they shock the general public. I would like to report a huge success in these areas, but I can't — they still remain a problem. However, I can tell you some of the things we are doing that are having some impact. The formation of a talented crisis team who are mobile has turned many crises, that would have returned the client to the institution, into manageable episodes allowing the client to remain in the community. We have also attempted to turn small communities into learning labs. Community staff have gone to movie houses, grocery stores, malls, independent shop keepers and asked them to be part of a program to help clients gain community skills. Most stores are cooperative and when an incident occurs they are not offended by the incident. We also form neighborhood committees where residents of the neighborhood are part of an advisory council and help the management of the house in their community. Programatic ownership often dispels the myths, and we all profit. This is especially true of local governments when they see an economic gain and employment in their town, their tolerance for deviancy (difference) goes up. The clients get a better chance to practice life skills and obviously we shop at cooperative stores. Clients as consumers can have consumer power!

3. ***Geriatrics —*** This is still relatively new to us, but with the advent of better medical care, nutrition, earlier identification of problems, our clients are living longer and are in need of specialized geriatric services. This would be one area for study and granting. The literature is still very sparse. We have just begun to work with our local offices of aging to integrate our clients into normal services for the elderly. Perhaps if I come back next year, I can have more information for you. One key we have identified is in preserving as much of a network as possible for our clients. We have done this to a point that in moving one client to a different part of the service continuum, we have moved up to three clients with him to preserve a social network of friends. We have also worked very hard at preserving as much of their mastery over the environment as possible, even if this means allowing two hours to eat! We also work with nursing homes along these same lines. We encourage staff to be creative in helping clients do for themselves, not to do it for them. This has been a very hard thing to get across when staff feel that there is pressure to do other agency things (mop, clean, do charting, etc.) within any given eight-hour shift. There is also pressure in the fee-for-service structure that when a client shows no progress, they want them moved to another level of care.

With geriatrics, no progress is often significant progress for it means we have halted a regressive process. Thank goodness some of the revised regulations are reflecting this.

4. Multihandicaps — Thank God for the progress of science and electronic gadgets. There are so many things that can assist a multi- handicapped individual today. However, the expense is still often prohibitive, so you have to learn very quickly how to get it through the Medicare red tape jungle. I wish there would be a faster recognition of Medicare to technological advances that do improve the quality of life for clients. Let me share one inventive example. We have Clarkson University within seventy miles of our main campus. This is a recognized engineering school. With one especially perplexing problem we made contact with them, and asked if they would like to take us on as a special graduate project. The engineers did an excellent job in helping us. They designed a wheelchair you wouldn't believe. We now have an ongoing relationship for graduate students, not only in engineering but in business and psychology. They have been especially helpful in communication boards, adaptive equipment for active stimulation, etc.

A THIRD DELIGHT

With the closure of our institutional school system, all sorts of support was needed in working with local school boards, handicap committees and the teachers themselves. Here is an area in which special education programs could do a curriculum overhaul. Most special education teachers are not prepared for the level of clients now in their program. We adopted a consultative/collaborative relationship and provided mini-consultations, visits by experts and direct in-service training, as technical assistance. The training has been from care of ringworm to management of aggressive behaviors, from understanding wheelchair maintenance to special dietary needs, from managing pica conditions to toileting programs. These are also the activities that are hard to include in the fee for service schedule.

THE DILEMMAS:

Our biggest dilemma is in robbing Peter to pay Paul for some of the creative things we've done. The fee for service structure does not allow for originality and creativity, but consists of only basic service components. If you have made a decision to go beyond basic services and want to improve the quality of life of a client there is no mechanism to do so. Let me graphically show you what we attempt to do.

We, as a care/service agency, believe in certain treatment values and within those values the benefit of the care or service over time can be cost effective. Between points A and B is where current policy and regulations fail us most. This is where start-up and often front-end loaded projects fail to get off the ground. This is where we need more grant originality for projects like our rural medical plan, or for mobile dental clinics or long-term training grants to help us grow our own expertise.

I do want you to hear that many things can be done to improve the quality of life for retarded citizens within the spirit of cooperation and collaboration with little resources, but I also want you to hear that you can't provide services where there are no resources and that offering second rate services as better than nothing is not acceptable to us. Unit costs do concern us, but not as much as the dedication to the value to improve the quality of services provided.

2. A second dilemma involves clients with multiple problems (diagnosis) who we can place in a program based on client needs, but do not fit the approved level of care for ICF, SNF, etc. For example, clients who meet most of the ICF regulations, but because of medical frailty cannot participate in regular day programming so that criteria standards are met, or because of aging are self-preserving for 10 out of 15 days, or a child who ages out of a profitable school program. How do you count a therapeutic intervention that does not ring an auditor's bell?

3. A third dilemma is transportation. There is little to no public transportation available in the North Country. While clients are still being seen and do make all appointments, this is an expensive burden the agency must absorb. As there are no major medical centers in our area, special consultations often involve a four to five hour drive to receive service. In fact, simple consultations often involve up to two hours of travel for every hour of service provided.

We have developed satellites of outpatient services, provided vans and automobiles to our houses, arranged to bring consultants to convenient meeting spots, etc. However, this is not adequate and cannot always be reflected in the fee for service provided.

We see little resolve in the future. There is some movement toward mobile services. For example, two hospitals that are sixty miles apart have bought a mobile cat scanner and it travels between the hospitals. Perhaps some other innovative mobile services could be provided in the future. A good example of this would be a mobile unit of habilitative/rehabilitative experts that includes OT, PT and speech and hearing staff and equipment that visits specific sites on a monthly basis. We have also talked about

a mobile dental clinic, which is certainly a very high need.

Well, these are some of the delights and dilemmas of our system of service, and if there is a summary, it goes like this:

1. We spent a great deal of time and management energy in preparing staff to believe in client centered services.

2. To become a service oriented agency by answering every call, saying yes as much as possible, saying no as little as possible and responding to even little events which diffused situations, before huge resources were consumed.

3. By rising expectations of clients and staff and having faith that people will respond positively.

4. Grow your own — training and networking, through consortiums, collaboration and cooperation can work.

5. Provide technical assistance to change dependency to independency.

6. Change the fee for service to better reflect current unit costs.

7. Advocate through alternative systems when your own system is unresponsive.

Citizen Advocacy Panel

MODERATOR: CURTIS L. DECKER

PANELISTS: BERNARD J. CARABELLO
GLENDA DAVIS
COLLEEN A. WIECK, PH.D.
TERESA SMITH
MARGARET A. HOVEN, M.A.

SELF ADVOCACY

by Bernard J. Carabello & Amy Bittinger, M.P.H.
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New York, New York

I. History of Self-Advocacy

Self-advocacy for people with developmental disabilities grew out of the Civil and Consumer Rights movements of the 1960s:

> Through their slogan, "Power to the People," black leaders forever altered the political landscape. They taught those perceiving discrimination to band together to advocate on their own behalves as the experts and owners of their conditions. Spearheaded by Ralph Nader, the Consumer Rights movement was officially sanctioned in a 1962 address to the House of Representatives by President Kennedy. He embraced "the right to be heard . . . to be assured that consumer interests will receive full and sympathetic consideration in the formulation of government policy and fair and expeditious treatment in its administrative tribunals."

Encouraged, citizens with developmental disabilities, among others, pressed for their civil and consumer rights. It took a decade. But in 1973 Congress passed the landmark Rehabilitation Act.

In particular, Sections 501 through 504 of this Act banned discrimination on the basis of handicap, mandated affirmative action programs within the Federal government and organizations contracting with the government, and created the Architectural and Transportation Compliance Board. These four sections, comprising Title V of the Act, are popularly referred to as the Civil Rights Act for the Handicapped.

Several provisions of the Act pertain directly to self-advocacy. Each state vocational rehabilitation agency is required to develop a plan showing how the views of consumers, as well as providers and other concerned persons, are being taken into account in policy making. Consumer participation for mentally retarded people is specifically spelled out in the Individualized Written Rehabilitation Program.

Other legislation from this period recognizing the value of self-advocacy and requiring it in various ways includes:

> Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94- 103).
> Education for All Handicapped Children Act (Public Law 94-142).
> Title XX - Social Services (Public Law 93-647).

This body of legislation mandated consumer input at all programming levels and established consumer satisfaction as a means of assessing the quality, effectiveness, and appropriateness of services.

Almost overnight, publicly funded institutions caring for people with developmental disabilities found themselves under intense scrutiny. Flagrant instances of inadequate care and abuse were uncovered.

But funding to improve care was not forthcoming. Taxpayers, at this moment of history, were caught in the double bind of inflation and recession.

Simultaneously, studies were beginning to document the validity of a new approach toward "treating" the developmentally disabled: normalization. This approach asserted that "the least restrictive environment" was the most conducive to the ultimate ability of those with

disabilities to become fully contributing members of their communities.

For all these reasons normalization was embraced by Congress in legislation mandating opportunities for those with disabilities to be cared for in their homes and communities.

Deinstitutionalization was the result. Thousands of people with developmental disabilities were released from institutions. In waves, they poured back into communities and families inadequately prepared to assist. They were unskilled at finding jobs and housing, unable to deal with prejudice and its side effect: low self- esteem.

Then in 1973 in Salem, Oregon, one such handful of people banded together with three social worker advisers and formed a group. Their goal was to demonstrate to the world that they were "people first" and handicapped second. In so doing, they invented the self- advocacy movement for the developmentally disabled as it is today . . . based on the fundamental human right of all people to be considered first class members of society with a constitutionally guaranteed opportunity to achieve their highest potential.

Thus, developmentally disabled people *must* secure their rights as consumers in order to help create the services and opportunities which so influence their ability to contribute. Self-advocacy is the proved effective route.

H. Why Self-Advocacy Works

Self-advocacy groups have been proved effective in three areas:

1. Protecting Rights. When confronted with situations in direct conflict with the policies and procedures of their employers, service providers tend to side with those paying their wages rather than their developmentally disabled clients.

Unfortunately, many developmentally disabled people don't know how to express a meaningful voice regarding the services they are to receive or are too intimidated to do so. This is true despite legislation requiring consumer input in the development and review of services created for them. The U.S. Senate, for example, in its report on the Developmentally Disabled Assistance and Bill of Rights Act, explicitly recognizes an inherent conflict between a State's role in delivering services and in protecting the human and legal rights of those served. Self- advocacy mitigates this conflict.

In a recent national profile of self-help/self advocacy groups for people with mental retardation, 71% were found to spend most of their time learning about rights and responsibilities. Special attention is focused on:

Contributing to Individualized Program Plans - these are the written documents demanded by law which contain service goals, objectives, strategies, timeliness and evaluation measures and are supposed to include the developmentally disabled in their creation and review.

Participating on advisory boards and planning groups for such service organizations as Developmental Disabilities Planning Councils, the local Association of Retarded Citizens, and public transportation committees.

Learning to evaluate their own services.

2. Demonstrating Capabilities. Parents and professionals tend to perceive themselves as benevolent benefactors for people who are retarded or disabled, frequently undermining opportunities for autonomy and self-worth through their good intentions. Self-advocacy, however, clearly demonstrates that people with developmental disabilities are capable of advocating for themselves.

In a 1984 study underwritten by the U.S. Department of Education of over half the population of developmentally disabled citizens participating in self-help/self-advocacy groups, the findings were conclusive:

— Over 90% of those surveyed met at least once a month for approximately one to one and-a-half hours.

—An average of 23 people per group attended regularly scheduled meetings.

— Meetings were structured, agenda-directed, instructional and oriented to group vs. individual concerns.

— Meetings focused on learning about rights and responsibilities, developing self-help skills such as finding jobs and the process of advocating or collectively speaking for their own rights.

— Activities included social, recreational, recruiting, fund-raising and political. An annual state convention was considered important.

— Most groups elected their own presidents.

— Advisors (those without disabilities who work as consultants on behalf of the groups) noted "moderate" to

"much" change in the majority of cases for personal, social and information skills among member individuals and observed group change in the areas of cohesion, interaction and communication, leadership role and organizational development.

3. ***Creating Social Opportunities***. Finally, research suggests that those with developmental disabilities who do not enjoy friendships and benefactors are not as personally or socially satisfied as those who do. This impacts negatively on social adaptation, contributing to stigmatization. Unfortunately, the research also shows that social opportunities for such people are generally limited.

Self-advocacy, therefore, can fulfill this need, emphasizing the power of group members to assist one another rather than depending entirely upon the direction of professionals. The self-advocacy process includes:

— Open and permissive communication with persons who have experienced the same condition.
— Enhanced opportunities for socialization for those who are frequently isolated and alienated.
— Learning coping abilities from peers who are successfully living with their conditions.
— Experiencing intimacy vs. the "distance" maintained by professionals.
— Learning from peer role models and reinforcement.

In the course of participation in this process, members develop a strong sense of empowerment and competence. They often step forward as leaders, shedding negative self- perceptions. Through sharing with peers they see that the stigma and prejudice they feel is not their fault, but rather the result of society's ignorance . . . which can be changed. They learn how to band together to bring about such change.

III. The Leadership of Bernard J. Carabello

In their groundbreaking work on self-advocacy, the University of Oregon's Rehabilitation Research and Training Center uses R.D. Hooper's historic model of social change to predict four stages in the successful march of a movement toward competency:

PRELIMINARY STAGE. A period of restlessness and antagonism between groups, insufficient and ineffective efforts to resolve difficulties ... agitation without focus.

POPULAR STAGE. Marked by collective awareness and initial attempts to organize, a charismatic leader steps forth to focus discontented, disorganized individuals and groups on more global problems and solutions.

FORMAL STAGE. Ideologies are developed, values and goals are clarified, organizational structure gels, policies are articulated, specific programs are created.

INSTITUTIONAL STAGE. The movement achieves competency, an accepted fact of society with efficient, deliberate, ongoing administration.

Self-advocacy in New York State has arrived at the Formal Stage!

Reason: The "charismatic leader" stepped forth to advance the cause and has created a structure for its fulfillment. This leader is Bernard Carabello. Creating opportunities for disabled people to take charge of their lives is the purpose of his.

BIOGRAPHY

Bernard was born with cerebral palsy. He has been told that doctors let his frightened, immigrant mother sit unattended too long in an emergency room where she had gone for help to ease the pain of premature birth. Three years later those same doctors misdiagnosed Bernard. They told his mother he was mentally retarded and advised her to place him in the Willowbrook State School on Staten Island. She did. He remained there for the next 18 years of his life.

With nearly 6,000 inmates, Willowbrook typified the overcrowded, understaffed institution communities relied on to "handle the problem" of the developmentally disabled.

Then in 1972, while Congress was debating landmark legislation which would create, for the first time, civil rights for disabled people, a TV news reporter aired a series of brutal exposes showing a nationwide audience the extent of abuse at Willowbrook. Geraldo Rivera was the investigating reporter. Bernard was his point man. It gained him his freedom.

"I was starting a new life," says Bernard. "It was like being reborn. But I had to go through a lot of pain and hell." Since then, Bernard has transformed himself into a major force in the movement for self-advocacy in New York and across the nation. "Self-advocacy should not even exist. But society makes it exist," he says.

In September, Bernard was a featured speaker along with Governor Cuomo at the official closing of Willowbrook, a cause he had fought long and hard for. He shocked reporters,

however, by refusing to gloat over the end of his bedlam. Instead he focused on the need to educate the public. The differences in people, including their disabilities, don't have to become handicaps. Bernard believes people who are treated as capable are capable.

For this reason he is counting on the self-helping and image-boosting strengths of local self-advocacy groups. It's local group members who make the difference, according to Bernard. They're the only ones who can sell the movement to potential newcomers. But they don't get started on their own. Statewide planning is necessary to "seed" the effort.

Bernard Carabello wants to make sure this happens. His experience, summarized on the following page, has prepared him for this task.

IV. Policy Statement

Self-advocacy means knowing your rights, speaking up for them, and exercising them.

We believe self-advocacy should not have to exist; it goes against everything we believe in because all people should be treated as human beings entitled to basic human rights. But, because society has difficulty accepting people with disabilities as human beings, we must develop more self-advocacy groups to make sure persons with developmental disabilities can get all that they are entitled to and grow to their full potential.

As a start in the right direction, labels such as mentally retarded, retardates, mentally disabled and mentally handicapped must no longer be used. These labels keep alive the images of persons with disabilities as being crazy, idiots or totally incompetent.

Society must stop concentrating on the limitations of individuals who may have difficulty learning, but concentrate on the positive aspects of people, look for and at the positive values of human beings who may incidentally have a disability.

Citizen Advocacy

by Glenda Davis
Executive Director
Citizen Advocacy Inc.
Grand Island, Nebraska

CITIZEN ADVOCACY creates and supports relationships between citizens of a community and people who have a developmental disability and are isolated from the community or are otherwise *AT RISK*.

CITIZEN ADVOCACY must belong to the community and must be independent of any Federal or State ties. If it does not belong to the community it is something else and is not *CITIZEN ADVOCACY*.

In addressing the Forum Theme, in what way does the Federal/State Partnership assist or burden community services for mentally retarded citizens, I would like to talk to you about a gentleman who lives in Grand Island, NE In telling you about his life, I hope to explain the need for *CITIZEN ADVOCACY* programs and address the following pertinent questions:

Are there certain characteristics of social security programs or other entitlements that help or hinder service delivery?

Are there policy conflicts that hinder or, if resolved, would improve quality of care? Has Federal or State leadership changed public commitment or prejudice toward persons with mental retardation?

Do conditions or participation in certain programs impede a continuum of care?

In talking about community integration for people who have mental retardation, we were asked to address the above issues related to partnerships. These partnerships are governmental and service oriented. It is a closed network of partnerships and does not include the community nor does it include people who have mental retardation. If we are truly talking about community integration, we need to talk about partnerships within *school buildings,* within *business* and *industry* and within *neighborhoods*. This is where *community* is.

In the last day and a half, I have heard words like; clusters, facilities, beds, special education, sheltered workshops, and day programs. These are not words of the community these are words of isolation and segregation. If we are really talking about community integration, we will begin using words like; *home, neighborhood, church, school,* and *job*. Let's not talk about partnerships but about friendships.

Now, let me tell you about Lafayette. He was born in Ravenna, Nebraska in 1938. When he was *seven* years old he was placed in the Nebraska School for the Deaf. The school is located in Omaha, 180 miles from Ravenna. He was there for eight years and was then transferred to the Beatrice State Home for the Mentally Retarded. He lived there until he was *thirty- three*.

In 1971, he was moved by the system, back to Central Nebraska. He came to Grand Island because of a vocational rehabilitation program for independent living. Ironically, Lafayette was not mentally retarded *enough* to qualify for the local community based mental retardation services. He was given a brief period of training and then placed in a job. Unfortunately, the amount of follow-along and support provided was minimal and Lafayette has spent 17 years drifting from job to job and from one substandard living situation to another.

I think it is important to add that in addition to having mental retardation and a major hearing impairment, Lafayette does not have the gift of speech and in spite of having spent *seven* years at the School for the Deaf, he does not sign nor read lips. It would be easy to assume

that his lack of communication skills have prevented him from being able to keep a job for any period of time. Most of his jobs have been well-meaning employers who out of the goodness of their hearts have offered him employment. Without any support to them or to him, the jobs are short-lived because he doesn't always understand what is expected of him and thus appears to the employer to be irresponsible and unreliable. He lost his last job in December of 1986 because he didn't always know when he was supposed to be at work. He was fired from and rehired for that particular job four different times. The employer was more than willing to give him a fair chance, but could no longer deal with the unreliability.

In the last 17 years, alcoholism and diabetes have been added to Lafayette's list of disabilities. He is often the victim of streetwise people and has been robbed of both food and money frequently. The Grand Island Police Department is very familiar with his problems of victimization. The local bank has even cashed checks on an account that he once had with other's signatures on the checks.

In the late spring of 1987, this situation came to the attention of the Citizen Advocacy office. In June, a gentleman was recruited who was willing to take Lafayette to apply for Supplemental Security Income and to be his conservator. The process was begun in July, 1987 and to date has not been completed. The complications of getting the necessary information from someone who has not kept personal records and who cannot speak and who has no available family member is a difficult process, indeed. Social Security required a hearing test but refused the results because the subject would not cooperate with the testor. A psychological evaluation was scheduled for him on Saturday, January 2, 1988 at 5:30 in the afternoon. The psychologist was traveling from North Platte, Nebraska, a town 138 miles from Grand Island. Lafayette was notified of this appointment by letter. The good doctor was ill on the day of the test and the notification of the rescheduled appointment was again sent to him by letter. Lafayette does not read.

Since he has made application for Supplemental Security Income, he has existed month to month on Emergency General Funds from the Nebraska Department of Social Services. Each month his friend/conservator has to call Lafayette's landlord and ask for a letter of eviction. He then has to take it to the Social Services office so Lafayette's rent can be paid. Initially the utilities had to be incorporated into his monthly rent bill because Social Services does not pay these items separately. The landlord was somewhat reluctant and Lafayette's friend had to become quite persuasive in order to get that task accomplished. He has been receiving food stamps since July, so he is able to eat. He has had no cash for necessities like haircuts, shaving supplies and other personal hygiene and household cleaning products.

Lafayette's new found friend, Charles, has had many opportunities to question the difficult system of services for people who are the least able to deal with them. He has frequently asked how people in Lafayette's situation are able to survive without a spokesperson and an advocate. The answer to that question is that sometimes they *don't.* He has also observed that the indignity of negotiating the services system may be as dehumanizing for Lafayette as being "ripped-off" by one of his neighbors. It would be hard to argue with that observation.

In order for Charles to bring value and invulnerability to Lafayette's life, his ties and the ties of the Citizen Advocacy structure must be independent of the service system. The concept of Citizen Advocacy must belong to the community so that its citizens can regain a lost sense of responsibility to all of their neighbors.

The President's Committee on Mental Retardation should pursue the insurance of financial independence for all people with mental retardation who live in the community. To insure *true* community integration, an emphasis must be made on partnerships in the community. These partnerships must be outside the existing "service system". Services are necessary, but are not the community.

It is time to move beyond geographical location. People who live in the community can be locked into a network of services and, therefore, are not of the community. We suffer under the myth that an individual must be specially trained in order to be involved in the life of someone who has a disability. Therefore, we have lost faith in the competence of the community. Have we built a separate community within the intricate service system?

Advocacy and Community Integration From a DD Council Perspective

by Colleen Wieck, Ph.D.
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The President's Committee on Mental Retardation has posed a series of questions for each panelist. The purpose of this paper will be to address three of those questions:

- Do State agencies encourage or enable family members to affect the design of local services?
- Do local school systems strengthen the role of families in special education?
- Do families have a meaningful role in the interdisciplinary team meetings?

In the first section, a new leadership training project, Partners in Policymaking, will be described. This project encourages family members and individuals with disabilities to be involved in the design of local services.

In the second section, two themes, integration and quality of IEPs, will be discussed including a description of flyers designed for families to use in influencing local schools.

In the third section, the planning process will be described and how to improve the family's involvement.

Finally, a set of recommendations will be presented for PCMR consideration.

I. Do State Agencies Encourage or Enable Family Members to Affect the Design of Local Services?

The purpose of this section will be to describe a new parent and self-advocate project sponsored by the Minnesota Governor's Planning Council on Developmental Disabilities.

A frequent problem identified by advocacy groups is the lack of "young parent and self-advocacy" participation in voluntary organizations. Several reasons are given for this lack of involvement including:

- Young parents are guaranteed services for their children from birth to age 21 years. Young parents do not have to fight for services like the early parent leaders in the 1950s, 1960s, and 1970s.
- The structure of the family is changing. There are more single heads of households; there are more two-earner couples; and so volunteer activity is declining.
- Self-advocacy has not been adequately supported.
- Training programs have not been developed to meet the needs of young parents and self-advocates. Conferences are aimed at topics of interest to older parents (wills, trusts) or to professionals.

Partners in Policymaking is a program designed to provide information, training and skill building to consumers, parents, and guardians so that they can obtain the most appropriate state-of-the-art services for themselves and others. This is accomplished by delivering eight of two-day sessions to a limited number of highly motivated, interested participants.

Partners in Policymaking involves and empowers people with developmental disabilities and their families in the policymaking arena. The program acquaints and connects people with organizations, opportunities, and possibilities in the area of developmental disabilities. The program educates the participants about current issues and state-of-the-art approaches. It also familiarizes participants with the policy- making and legislative processes in Minnesota.

The overall goal is to achieve a productive partnership between people needing and using services and those in a position to make policy and law.

Each session of Partners in Policymaking is devoted to a specific service or level of government. The presenters are nationally known experts in their field. Participants are expected to complete assignments between sessions. Participants are also expected to work with a mentor who is, or was, a policy maker.

The program is designed to give participants exposure to, and contact with, nationally known experts in the field of developmental disabilities. Participants attend two-day sessions, approximately eight times a year. During each of the sessions, experts in specific areas present and interact with the participants. Each session begins on Friday shortly after noon and concludes Saturday late afternoon. This allows time for the participants to converse with the experts in small groups or on a one-to-one basis.

The topics include: history, philosophy, values; best practices in education; policy- making at the county and local level; policy- making at the Federal level; funding, rules, laws, policymaking at the State level; best practices in employment and living; and organizations, programs, and opportunities.

As a result of being in this program, participants have acquired:

- A knowledge of state-of-the-art services;
- The ability to present a strong, well-reasoned case for the most appropriate state-of-the-art services for themselves or others to policy- makers, media, providers, and others;
- A knowledge of organizations that are available to assist them to obtain appropriate state- of-the-art services;
- A knowledge of the systems that fund and deliver services and how to influence the systems; and
- The ability to represent their interests and the interests of others to policymakers.

The impact of the leadership problems is as follows:

- There is no leadership development program that will prepare persons for positions of leadership in local/State/national organizations. There is a need for new leadership to assume positions in these organizations.
- Grass-roots advocacy leadership exists but has not been systematically trained on how to write, call, and meet with public officials. There is a need to have persons in the grass-roots advocacy movement in each community who can write, call, or meet with public officials when necessary or when requested through action alerts.
- The young volunteer movement does not have a shared vision. Individuals need an opportunity to share and develop a collective vision. There is a need for motivated, well- informed, active (energetic) volunteers who share a vision about the year 2000.
- There is no current mechanism for State and national leaders to meet with young parents and self-advocates. There is a need for State and national leaders to develop a reciprocal relationship with young parents and self- advocates in order to discuss current problems and issues.
- There is no speakers' bureau available throughout State. There is a need to have spokespersons available throughout the State who can speak on a wide range of issues.

The impact of the problem on services is as follows:

- There have been only modest incremental changes in family support. Minnesota has the third highest ICF-MR placement rate. Our State spends 99 percent of its public funds to support State institutions and group homes. There is a need for a new group of people to advocate for family support as a basic entitlement and to push for reallocation of funding.
- There is a high level of segregation in public schools in Minnesota. There has not been a major initiative in Minnesota for age-appropriate, community referenced, functional curricula in integrated settings. Minnesota has received a critical review from a Federal OSERS auditing team.
- In order to advocate changes to match *A New Way of Thinking*, a new group of advocates is needed who:

— share this vision;
— are motivated;
— are informed;
— are skilled;
— will speak up; and
— will be leaders.

Partners in Policymaking is a solution for leadership problems and service system problems. We hope this idea is replicated in all the States and territories.

II. Do Local School Systems Strengthen the Role of Families in Special Education?

If we were to issue a report card on P.L. 94-142, we would give an:

"A" for access for all students regardless of severity of disability;

"A" for preventing out-of-home placements of thousands of children and youth.

We cannot give A's in two subjects:

- integration; and
- quality of individualized education plans.

Parents and students should not have to choose between integration and quality. Let me describe in greater detail each of these themes.

Integration: The arguments against integration of individuals with disabilities are the same regardless of age, setting, or the year. *Segregation* can occur because of separate buildings or in regular schools if students are kept in *isolation* in separate halls, separate lunch rooms, or separate classes:

- Placing students in regular settings with no support or the wrong support isn't integration — it's dumping.
- Placing students in separate wings or separate clusters of classrooms isn't integration, it's tokenism.
- Pitting one parent against another parent over the amount of resources to be expended for students isn't fiscal responsibility. It's dirty politics.

Here are the typical statements made against integration:

1. "It is not possible because these individuals would be the subject or object of ridicule, teasing, and harassment."
2. "There would be dumping — placement without supports."
3. "Segregated settings provide superior services because the students are with specially trained professionals."
4. "Therapy services can be delivered more efficiently in a segregated setting,"
5. "It is more cost-efficient to have individuals congregated together. There is an economy of scale."
6. "We can't do it, we don't know how."
7. "Students need to be in segregated placements to get ready for less restrictive settings."
8. "There is stability and security in special buildings and special classes. Our rules and regulations tell us how to operate."

As a counterpoint to these statements, here are the arguments used in support of integration:

1. "Ridicule and teasing come from separation." Friendships and relationships start early in life. The earlier integration occurs, the better to enable both students with and without disabilities to benefit from friendships/relationships.
2. "Least restrictive environment is the right of the students with a disability." Supports should be both integrated and appropriate to avoid dumping. Students and families should not have to choose between integration and quality.
3. "There is a difference between placement and program." Often the concepts are intertwined. By attaching services with buildings, the intent of P.L. 94-142 is violated. Placement means *level* — whether it is a *segregated or integrated settings.*

   Program means type and amount of supports. It is possible to be integrated and to have an appropriate program. Integration can only begin in *regular schools and regular classrooms* — where opportunity exists for interaction.
4. "Therapy services can be delivered efficiently wherever the student is located." The new approach to delivery is to teach other staff to teach the student when the opportunity is correct and to make the supports relevant and functional. Students and families should ask four questions about delivery of therapy services:

   — Who can provide services? Program staff, parents, and peers of same age who are not disabled. Remember the lessons of modeling people learn by imitation.

   — Where are skills taught? Teach skills in natural settings where the skills are needed or will be used. Natural settings offer opportunity for policy-makers of today and the future to be with individuals with disabilities.

   — When are skills taught? During the school year or year round? During school hours or during off hours?

   — What skills are taught? Use functional materials, assure that plenty of time is allowed to learn skills, provide many opportunities to build new skills and new experiences.
5. There is no evidence to suggest economy of scale. There is evidence of disincentives for integration. Depending upon how special education is funded, there may by incentives for segregated classes.
6. "We can't do it usually means *we won't do it."* The "how to's" exist, but schools and teachers may not be up to date on the emerging technologies.

7. "Pre means never." Placement rarely exists to get students back to integrated settings once they have been segregated. There are often preprinted reasons on IEPs for placements in segregated settings.
8. "Stability and security exist with mandates, funding, advocacy, and vigilance." *Parents* have the *power*. Parents must understand the rights they have and exercise those rights.

We need to hold schools accountable to that single standard of honor of least restrictive environment. There must be consequences for performance — there must be rewards for good performance, and there must be sanctions for nonperformance.

Students and families are encouraged to use a flyer produced by the Minnesota Governor's Planning Council on Developmental Disabilities entitled *Test Your School's IQ: Integration Quotient* to determine the extent of integration practices in local schools:

ADMINISTRATIVE COMMITMENT:

1. Has the school administration taken a position emphasizing preparation of students with disabilities to live and to work in community settings?
2. Has the school administration demonstrated leadership in promoting integration of students with disabilities through letters, written materials, building accessibility, presentations, conferences, scheduling flexibility, or written plans?
3. Have administrators, teachers, related services staff, paraprofessionals, etc., received in-service training on integration values and implementation techniques during the past year?

LOCATION/TRANSPORTATION:

1. Does your son/daughter attend the same school or other natural setting (early childhood center, job site) that he/she would attend if not disabled?
2. Does your son/daughter use the same transportation that he/she would ride if not disabled?
3. Does your son/daughter use the same arrival and departure times if he/she were not disabled?

INTEGRATED TIME AND ACTIVITIES:

1. Does your son/daughter participate in extra-curricular activities with students who are not disabled?
2. Does your son/daughter spend time in the community receiving instruction, services, or other activities (independent living, leisure, job)?
3. How much time during the instructional day does your son/daughter spend with students who are not disabled?
4. Does your son/daughter participate in activities with students who are not disabled? Check those that apply:
   — lunch;
   — library/media center;
   — free time;
   — assemblies/programs;
   — regular classes (art, music, physical education, electives);
   — vocational education;
   other.
5. Does your son/daughter receive support in settings with students who are not disabled? Check those that apply:
   — modified curriculum;
   — peer/buddy support;
   — adaptive equipment;
   — support staff;
   — augmentation/communication devices;
   — testing accommodations;
   — interpreter;
   — other.

QUALITY INDIVIDUALIZED EDUCATION PROGRAMS

In a humorous approach to reviewing the quality of IEPs, several individuals such as Phil Ferguson, Barbara Wilcox, and Barbara Troolin have categorized plans in the following ways:

1. **The McPlan:** Over 30 billion are served with identical ingredients or slight variations (hold the pickle — hold the physical therapy):
   — You can walk up or drive through to get your portion;
   — All the items on the plan (fine motor, gross motor, receptive language) are *prepackaged,premeasured,preweighed,* and are just sitting around waiting to be warmed up;
   — Anyway you like it requires more time;
   — The team is happy to deliver with smiling faces saying "have a nice day."
2. **Wheel of Fortune:**
   — As a family member contestant, you guess at programs that are not terribly important:

   S T R N G
   B D S

   — You may need to buy vowels to fill in "string beads."
   — You can spin the wheel; and depending upon your luck, you can

hit one of several options — "call Legal Advocacy"; "we would be happy to help you"; "move to the suburbs"; "of course, we will do that."

3. Back to the 50s: Back to the 50s influence is everywhere — music, art forms (flamingos), colors (mauve, aqua, pink), sunglasses, haircuts, and even IEPs:

— You can learn to label the parts of a standard phone;
— You can tie shoelaces on a simulated board;
— You can make change for a dollar, although no one can eat in a restaurant for under a dollar.

4. Advanced Algebra: This mathematical approach gives the impression of *precision, soundness, and well-written objectives* that are meaningless:

— Cindy will jump with *50 percent* accuracy.
— Bryan will say cup *10* times.
— Peg will butter *35 percent* of her bread.

The curriculum at the local level must prepare students for living, working, and enjoying life in the community. Parents are winning the war of inches by demanding that school activities must be age-appropriate, must provide opportunities for interaction with non-handicapped peers, and must have tasks that are functional. We can no longer have classrooms called "preliving," and we can't have behavioral psychologists characterize friendships as "reciprocal horizontal interface."

The Minnesota Developmental Disabilities Council has published another flyer to assist students and families in assessing the quality of individual plans. The questions include:

AGE-APPROPRIATE:

1. Would these materials be used by a non-disabled person of the same chronological age?
2. Would these skills be performed by a non-disabled person of the same chronological age?

COMMUNITY REFERENCED:

1. If objectives are met, will there be participation in a variety of integrated community settings?
2. Are objectives meeting basic skills needed in the future?

FUNCTIONAL:

1. If the person does not learn skills described in the objective, will someone else have to do those activities?
2. Do the activities involve mutual interaction with nondisabled peers?

GENERALIZATION:

1. Are skills taught or performed with natural cues and reinforcement?
2. Are the skills taught in the natural settings where they will need to be performed (home, community settings)?

CHOICE:

1. Are the objectives based on a comprehensive assessment that emphasize strengths of the individual?
2. Do the objectives reflect individual's choices and interests?
3. Do the objectives reflect family's choices and interests?

III. Do Families Have a Meaningful Role in the Interdisciplinary Team Meetings?

There are four components to the interdisciplinary process: assessment, planning, implementing, and evaluating.

ASSESSMENTS

Professionals have been trained to write assessments that tend to be very oriented to needs, deficits, problems, or negative statements. Anyone can pick up a case record and read a summary of physical condition, family history, problems, diagnoses, what the person doesn't do in the developmental sequence, and then at the end, there may be one or two sentences — Joe has a good sense of humor or Mary likes people.

Let us think about this assessment approach.

Every employee has a performance appraisal at least once a year. Performance appraisals even for people we do not like tend to be fairly positive. We probably work our way through a performance appraisal and then say, "Oh, by the way, could you please show up for work?" or "I don't want to mention it, but could you please stop stealing from the company?"

Perhaps all keynote speakers should be introduced in the same way we write about individuals with disabilities. Picture one of our national leaders described in the following way. Today, our keynote speaker is:

Male, Caucasian, who is overweight, has hypertension, is on a low calorie diet, is

currently on medications, has occasional outbursts according to his family, and needs to control his temper tantrums according to staff members.

Our guest speaker enjoys eating and drinking coffee. He does not sleep well at night. (He slept through the entire night only 94 percent of the time last month.

Staff report that he needs to be provided with activities to keep him busy, but he does have difficulty adjusting to change in his schedule.

He needs to have his hair cut short to prevent him from pulling it out.

He needs help in choosing appropriate attire for social engagements.

When he thinks no one is watching, he entertains himself by blowing fuzz balls around on his desk.

All of these statements are direct quotations from case records. Compare these statements with the typical glowing introductory remarks about keynote speakers.

Parents already know the written word is devastating. Professionals must be sensitive to this important lesson.

The challenge for all of us is to build on strengths; to write statements that you would say about yourself or family members; to get away from describing people in terms of stacking, stringing, and pointing behaviors to functional approaches. We need to know what can this person with a disability do in the regular environment?

The challenge is to read books, listen to speakers, and experiment with a different approach to assessment that is more functional.

PLANNING

In the old days, we had one person in charge, usually a medical doctor who would prescribe what would occur to individuals with disabilities. We would refer to that person as God or Dr. God depending upon preference.

The medical model did not work. Other professionals had a stake and different view of the person and what should be occurring. A team was created. The team formed, and the team grew, and now we have the Cecil B. De Mille approach to planning with thousands of people sitting around a table, each with a part of the script to recite. After the script is ended, the spotlight goes on; and everyone turns to the end of the table to the individual with disabilities and his/her family; and the chair of the team says, "Now, what do you think?"

The challenge today is to make the team approach work without intimidating every individual and family. First, can the size of the team be reduced? If not, can the room be filled with relatives, friends, and advocates so the balance of power is shifted back to the individual and the family? Second, can jargon be eliminated? Through peer review, can team members become sensitive to the language problems? Third, can a positive, strength orientation replace the typical negative approach of team meetings? Can we reorient our approach to a positive approach?

IMPLEMENTATION

At the forefront of the implementation are two words — respect and dignity. We have all lived through several phases of special education such as gross motor, developmental, and behavioral. Each of these special methodologies led us down a path of activities and tasks that may not have given people respect and dignity. During those periods, we did not think about what people needed or what people wanted. We did not think about styles of learning — some people learn best through sensory/tactile means. Some learn intellectually, some learn through emotional experiences, and some through psychomotor approaches.

Implementation will be revolutionized by the use of technological aids and devices in combination with our human resources. New technological advancements will allow people to communicate for the first time in their lives; to move around their environment; and to read, write, and handle arithmetic problems with personalized computer devices.

The challenge will be to keep up to date, to track down resources, to assist people to be as independent as possible by modifying the environment. Parents and professionals must keep up to date and know what is possible.

EVALUATION

At the top of the list of evaluation criteria should be friendships and relationships for individuals with disabilities. In addition to this criterion, are the items listed in the previous section of this paper.

RECOMMENDATIONS

1. What needs to be accomplished at the Federal level to achieve integration, independence, and productivity while providing support and protection for those who need it?

   In a few short years since we were all introduced to the theory of trickle- down economics, advocates have become quite fluent in discussing the economics of inclusion, not exclusion; the economics of integration rather than segregation; and

the economics of productivity, not inactivity.

Funding must match policy. At the Federal level, we need to reallocate funds from institutional settings to community integrated supports. The funding shift must occur in Medicaid. PCMR should endorse S.F. 1673 and H.F. 3454 and work toward passage in 1989.

2. What is the specific role of the Federal government in promotion of maximum community integration?

The year 1987 was the 200th anniversary of the Constitution, and isn't it amazing that we continue to talk about fighting for rights of people with mental retardation? These individuals seem to be the last to be accorded rights and the first group to have their rights threatened.

Persons with mental retardation cannot be abandoned. At the Federal, State, and local levels, we must use:

— legislation,
— litigation,
— agitation, and

we also need to bury dinosaur practices.

There is a clear Federal role for rights issues. We need a single standard of honor to assure respect and dignity for people regardless of any label carried or any place of residence.

We must hold state and local entitles responsible to eliminate violations of human, civil, or legal rights.

In 1985, Senator Lowell Weicker released a lengthy report describing institutions for people with mental retardation or mental illness. These facilities were heavily regulated, licensed, or certified. Yet, the descriptions of conditions were reminiscent of the 1950s:

— isolation;
— depersonalization;
— overmedication; and
— neglect and abuse.

As a result of that report, the Federal role in look-behind audits was increased. Monitoring efforts must be in place, but we will always be concerned about the qualifications and training of any Federal monitor.

Monitoring should reveal who is doing a good job and who is not. Those who are should be rewarded; those who are not should have sanctions imposed.

3. What are the specific technical assistance recommendations to be included in a technical assistance manual for design, delivery, and evaluation of exemplary program models to promote community integration?

Before preparing a technical assistance manual, the authors need to be clear about, "What do people with mental retardation want?"

— People with mental retardation want to be treated and addressed as people not "the retarded," and not "the disabled."
— People with mental retardation want to live in their own homes, not in concrete dormitories with hundreds or dozens of other people.
— People with mental retardation want love and friendships, not paid care- giving.
— People with mental retardation want continuity in their lives, not hundreds of hands touching them because of shift patterns or staff turnover.
— People with mental retardation want respect and dignity, not treatment as objects of abuse, charity, or pity.
— People with mental retardation want access to opportunities, the right to make choices, and the opportunity to answer four questions — I need, I want, I like, and I dislike.
— Children with mental retardation do not live in institutions in a civilized society, and that is why national advocacy organizations have passed strong resolutions supporting children living with families.

PCMR needs to make strong statements regarding self determination.

In 1950, Mildred Thomson gave her President's speech at the American Association on Mental Deficiency Convention regarding the need for Association for Retarded Citizens:

> There is a need for unity, for working together, and building bridges over chasms of prejudice, ignorance, and indifference.
>
> We must work with parents — parents are highly motivated and are most effective is pressuring public officials for programs and research funds.

Her advice is still valid today.

Self Advocacy

by Teresa Smith
Garden City, Michigan

I wish to thank the President's Committee on Mental Retardation for inviting me here today. I am real excited and nervous. I couldn't believe I was chosen and feel honored for this great opportunity.

In Michigan, many groups and individuals have helped people with developmental disabilities to speak up for themselves. They have also encouraged people to become more involved in the community. Consumers, mental health agencies, service providers, local support groups and others have worked together to think of new ideas. As a result, some really good things have happened in Michigan and the metropolitan Detroit area. I will talk about how a number of organizations have helped consumers become better advocates. I will also tell you about my own personal experience.

I lived at home with my parents until I was twenty-six years old. Before leaving home permanently, I did live at Hawthorne Center in Livonia, Michigan for one year. When I was about nine years old I also lived at Our Lady of Providence in Northville, Michigan, at a private school, for a year when I was about twelve years old.

During my years at home, I attended school and was involved in various training programs.
I also held two "real" jobs. One was at a nursing home doing dishes and laundry. The other was at Detroit Quality Brush. I worked there very successfully for two and one half years until my seizures became uncontrolled. The company was fearful for my safety and didn't want to continue to allow me to work.

I moved into Community Opportunity Center's Plymouth House located in Plymouth, Michigan when I was twenty-six years old. This is a group home for sixteen adults, eight men and eight women. I shared a bedroom and we did many things as a group. I liked living in this group home because I was with my peers. We had the opportunity to do many different activities and go places I had never been before. Because my parents tended to be over protective, I had not had these experiences while living at home. As time went by, I felt more confident and began to do more on my own.

While living in the group home, I became involved with an organization called People for Independence. People for Independence was formed in 1980. It was initiated through the efforts of the Northwest Communities Association for Retarded Citizen to encourage people with handicaps to become more independent. At our People for Independence meetings, we discussed what we could do to help others with the same problems. These group discussions also helped one feel more confident in talking about my problems. During my involvement with People for Independence, I also began to speak to other groups about self-advocacy and being independent. During the past six to seven years, I have made many presentations to various groups.

At the end of one year at Plymouth House, I moved into a semi-independent apartment setting called Whole Life. Again, I shared with a roommate, but we were much more on our own. We had to do our own shopping and arrange our transportation. However, staff were available on a 24-hour basis. We also saw them a few hours almost every day. They helped us plan meals, activities, do grocery shopping and learn to manage our money.

After six years of the Whole Life Program, I realized I was ready for even more independence.

I had heard about the Supported Independence Program. This program is funded by the Michigan Department of Mental Health. Supported Independence Program gives people the help they need to live as independently as they can. People in Supported Independence Program live in small homes or apartments. Each person has their own bedroom. No more than three people live in one home. Typical services to help include staff, transportation, counseling or medical support. I live in a three bedroom home in Garden City. I have one housemate, Sharon. We have one cat and one bird.

Sharon and I saved our money to buy everything we needed except for appliances for our home. The State could have brought the furniture. I am proud to be able to say these are my things. I own them. Sharon cuts the grass. I rake leaves, grass, pull weeds and we share household chores. We split the bills. I write the checks.

I like living in a Supported Independence Program because I can do my own thing and make my own decisions. There is less confusion and we are part of a regular neighborhood rather than a segregated program. I work as a secretary/receptionist for A. R. Home, Inc. I have been there for three years. Since I moved into my home, I have become better at bookkeeping, cooking skills, bargain shopping, and communication on the phone.

I enjoy my independence, but it is a struggle sometimes, too. Transportation is a big issue for me. I have to call a transportation service to get a ride. I have to plan these rides one week in advance. That is hard to do. Sometimes something comes up and I cannot give them enough notice to get a ride. Then I walk or call for a taxi. Some of my friends use wheelchairs. When they cannot get a ride, then they are really stuck. It is harder for them to find people to give them rides.

Another big issue is Social Security. Sometimes people with disabilities can get a job but they are afraid to go to work because they lose their benefits right away. I do not receive any Social Security because my epilepsy is not severe enough. The government feels that I could work at a regular job. Yet employers do not want to hire me because of my seizures. The job I have is a trainee position. My employer gets funding through Wayne Community Living Services to train me. Without that funding I would be sitting at home. My paycheck barely covers the bills. I do not feel this is fair for me. I fall in the cracks. I am not disabled enough to get the Social Security, but employers will not hire me because of my seizures.

As people like me moved out of group homes, a group of people who believed in independence began to get together in 1982. They became the Interdependent Living Council. Department of Mental Health Agency representatives, service providers and consumers make up the Interdependent Living Council. In 1985 they sponsored their first consumer conference. They called it "Making It On Our Own." About fifty people attended. Each summer a conference has been held. More and more people from across Michigan came to the conference. It is now called "We're Making It On Our Own." At the 1987 conference, approximately 250 people attended. I have attended four conferences. Last summer I was a workshop moderator. I like to go because I like meeting new people and seeing people I have met over the years.

The 1987 conference had more than twenty different workshops. Each workshop is moderated by a consumer. Some of the workshops are run by a consumer panel and moderated by a professional. We meet new people, see old friends and learn more about ourselves. Consumers are encouraged to speak up. For some people, it is the first time they have spoken in front of a group.

Back in 1980, another network of people were getting together. They were public relations people from Michigan Department of Mental Health agencies, Executive Directors of local Association for Retarded Citizens and some service providers. They became the Awareness Communication Team for Developmentally Disabled. They wanted to promote what is good about group homes. Each year, they have highlighted the successes of community living by holding an awards luncheon. They give awards for Statewide Awareness Leader of the Year and Local Awareness Leader of the Year. Neighbor of the Year awards go to neighbor of a group home and to a group home that has been a good neighbor. They give awards to the media for good news coverage. They also give awards to consumers. This award is called the John Furtaw Inspiration Award. It goes to someone who made a contribution to their community. I received an honorable mention in 1986 and won this award in 1987. I was nominated because I am a board member of the Northwest Communities Association for Retarded Citizens, also a board member for Community Opportunity Center, serving on the advisory board for Wayne State University's Developmental Disabilities Institute and a member of the Ladies Auxiliary of the V.F.W. Post 6695. Sometimes I am so busy I think I am burning the candle at both ends.

In 1987, Awareness Communication Team/ Developmentally Disabled held a public hear-

ing on the need for more homes. More than 200 parents attended to testify that their son or daughter needs a group home. Three members of the Consumer Advisory Committee testified at the public hearing for more homes.

The Consumer Advisory Committee was organized through Wayne Community Living Services in 1984. Wayne Community Living Services is a Department of Mental Health agency that provides housing for people with developmental disabilities. The Consumer Advisory Committee runs a Peer Support Project and speaks out for people with developmental disabilities. The members live in Supported Independence Programs and group homes in the metropolitan Detroit area. I recently joined the Consumer Advisory Committee.

In Peer Support Project, committee members visit people with developmental disabilities in group homes and Supported Independence Programs. Committee members meet with the home residents and their staff. They talk about how to help each other and how to make independent decisions.

The committee is very busy. They have spoken to local Association for Retarded Citizens and ran a workshop. One person on the committee recently was appointed to a committee on the State Developmental Disability Council. Another person sits on the Independent Living Council. Two members sit on the Wayne Community Living Services Citizens Advisory Committee. They will speak at the Michigan Chapter of the American Association on Mental Retardation next month. I plan to go with them.

Most of the programs that I have been talking about came about because people talked to each other and shared ideas, dreams and goals. People working in the field of developmental disabilities formed groups and worked together to benefit people with developmental disabilities.

The Supported Independence Program is a State funded program. People should look at what we have done in Michigan and encourage other states to develop their own Supported Independence Programs. I brought some pamphlets and people should look at our organizations, like the Interdependent Living Council, the Consumer Advisory Committee, People for Independence, and Awareness Communication Team for Developmentally Disabled and try to make those groups develop in other states. It is a matter of people working together.

I would like to thank you again for the opportunity to speak with you today.

RECOMMENDATIONS

I can tell you about my own experiences as a person with a disability. In the most part I have been a very lucky person. The Department of Mental Health of the State of Michigan has helped me out numerous times and still does. My biggest advantage was having Dr. Harold Wright from Hawthorn Center in Northville, Michigan. He guided my footsteps along the way. He helped me to cope with my disability. He was always making sure I had every opportunity to get into work shops and skill centers. He also made sure that I had the chance at an education and to have medical attention for my seizures and other medical problems.

Now I receive help from the State of Michigan. I do work and receive Pr over minimum wage, but it isn't enough to make rent, food, utilities and personal care needs.

I am grateful for the Mental Health Department for the supplements from Wayne Community Living Services. My only wish is that every one would have the opportunities to learn as I have.

I disagree with the way Social Security, payments are made to clients. I know of people that are in need of the Social Security money and can't get it. I have been told that they test too high. While others receive and are capable of working and performing much better than some of my peers. It is hard to understand.

Maybe Social Security should go back to those that retire. A special fund should be set up with more equal guides for everyone. This could be paid for by a national lotto or cuts in the defense spending and aid to countries that are our enemies.

I enjoyed the President's Committee on Mental Retardation forum. I would have liked to be able to hear all of the panels. I understand that this would be hard and costly to have the panels on different days or times.

Thank you for the opportunity to have been a part of this forum.

Volunteers with Severe Mental Retardation

by Margaret A. Hoven, M. A. Executive Director
Life Skills Center
Washington, D. C.

The Life Skills Center is a small day program in the District of Columbia serving 13 adults with severe and profound mental retardation. The Center began in 1974 in an attempt to offer training to adults with this level of mental retardation, adults, who were left sitting at home because they had "no vocational potential." At that point, even if an adult was young enough and lucky enough to have received some kind of public education, the only training available after the age of 21 was through Vocational Rehabilitation, and they took only higher functioning people.

The Center began with free space, donated materials, a budget of $1,800 and a lot of faith. The dream was to offer our students training in everyday living skills which would enable them to be more independent. This wider independence would help not only the student, but also reduce the tension and burden at home and, thus, help enable the family in its effort to stay together. The idea was to offer these skills with respect in a home-like setting, in a neighborhood where shopping and services were available.

The fact that we are small is very deliberate. We believe that the students learn better in a small setting where they can receive large amounts of individual attention and can develop a sense of community, of belonging. We also believe that a small setting is a far more pleasant place to spend such a large part of each day. The fact that we are small also enables us to be flexible and adapt more easily to the needs of each student and their family because we get to know everyone more intimately.

Part of the Center is set up in a very homelike manner with a kitchen, dining room, living room and bedroom. It is here that the students learn and maintain he skills We plan, shop and prepare meals, set tables, clean up the kitchen, sweep and mop the floors, clean the bathroom, learn self-care skills, make the bed, dust. Each student also learns functional academic skills, such as printing or recognizing his/ her own name, recognizing signs such as which bathroom to go into, using the telephone and just plain getting along with each other.

We are located on a neighborhood commercial street. This means we shop at the grocery store, pharmacy, thrift shop and 7-11. There are several bus lines near us. There are many Hispanic stores on the street which means that our Spanish speaking students can learn to shop in stores in their own language. We are the only program in the City which is able to fully integrate Spanish-speaking students into our program.

Our philosophy has evolved over the years to include not only helping our students learn life skills, but also helping the students to have a more well-rounded life, through offering a richer program at the Center. One way in which we do this is through our enrichment component which includes art, drama and music.

I want to mention the art just briefly, because it is a good example of how we came to broaden our philosophy to try to address the needs of the whole person. The art program began eight years ago when a woman came to volunteer, but didn't know what she could do. When we found she was a painter we decided to try art. The art work created by the students was astounding, it was a revelation. Our energies had gone so fully into teaching the basic everyday skills needed for living that we had

neglected internal needs — the need for creative expression. The art work is far from child-like. While not all the students are great artists, what they create is art not "arts and crafts." It is art work that most of us could never hope to equal. It is art work that says to the community, "We have something to offer, do not ignore us; we are your equals."

Most often when people from the larger community see the art work there is a response that transcends or shatters the pity and even the empathy that so often is expressed toward people with mental retardation and instead affirms and says "yes" this is truly art. The students now have at least five professional group shows a year and the art work sells very well. Everyone participates. While the methods may not be traditional, the results are exceptional. Last week Walton, who is a very low-functioning man, was painting with a brush in each hand with the look of total concentration and satisfaction on his face. Without the art program I doubt that he would have the opportunity for that kind of very personal internal experience.

Being small also allows us to get to know each family and some of their problems. We try to make the family a priority. I do a lot of informal counseling, listening to the caretakers and the problems they face. We often help deal with the city bureaucracy. By knowing family circumstances, we can often advocate for services that will truly be useful to the family.

The families are also involved in our goal setting process. If the Center is to help the students to grow and change the family must be involved in the process in order to accept the changes as well as to help facilitate them.

We also can do some of the little things that help families: going with Johnny down the street once a month to get his hair cut; going along on a crucial doctor's appointment; helping a single brother understand women's clothing sizes for his sister.

The other aspect of the whole person that we try to address is that of a work life and this is done through our work program component which we call work awareness.

Our students have been consistently passed over for vocational training in favor of higher functioning individuals who require less supervision. We began to realize that moving into a sheltered workshop for some of our students would mean loosing much needed reinforcement of their survival skills. In addition, their day activities would be impoverished by the absence of art, drama and music. The work awareness component is the natural outgrowth of our philosophy that our students learn better in a small setting and that they enjoy a sense of community and of being useful.

Our work awareness component was funded this fall by a grant from the federal volunteer agency, ACTION, which administers the Foster Grandparents Program, RSVP (Retired Seniors Volunteer Program), VISTA and Senior Companions. The grant is a demonstration grant to help prove that adults with severe mental retardation can be good volunteers. While ACTION is funding a large part of the program for one year, the most important thing they offer is technical assistance, to help us successfully accomplish our goals and produce a manual at the end that will help show other programs how to replicate what we have done.

To be volunteers has given the students the perfect opportunity to train in a variety of different skills, which we hope will become marketable after this initial training period.

The work awareness students go out from the Center as a crew with a teacher to volunteer in community organizations that may not be able to pay for the work they need done. The biggest industry in D.C. is paper shuffling, so the crew most often assists with mailings. A teacher goes with the crew each time. Before she goes, she evaluates the work that needs to be done, and then assigns each student to work at a task that is appropriate for their present skills or the skills they need to learn. Most of the jobs are small, no more than 2,000 pieces. The students are developing skills such as folding, stuffing envelopes, labeling, collating, sealing, packaging and sorting. The fact that the students go out of the Center to the agency that actually needs the work done, significantly changes the dynamic of the training. The students get to spend time at a real work setting and they see right away that their work is valuable and useful and they are exposed to a wide variety of different kinds of mailings, as well as other tasks. Last week, for example, the students went to a church and a senior citizens' center to help with newsletters, and to a shelter to help sort clothing for people who are homeless.

Each time we go to a new community agency, we find two mentors within the agency who are our contacts and arrange for the work to be done. The mentors also have a new experience in their own work life, meeting and working alongside adults with mental retardation. We all know the stereotypes people hold, yet here is a group of individuals with very severe handicaps coming to do the work that an agency badly needs done and needs done in a hurry. AND the work crew does it well and with enthusiasm and pride. The mentors learn what we already know: that people with mental retardation can be good productive workers, but most of all they learn that they are just

people — good at some things and not so good at others. One mentor commented on how Jean and Joan can work the postage meter, but that she has tried for years and has never been able to master it. That mentor has learned a huge lesson about humanity in general and about people with mental retardation in particular.

With the help of ACTION we can now expand and refine the project as part of our own three year expansion plan which will result in our being able to serve 12 additional clients, as well as develop a fundraising plan to sustain the work awareness program in future years. We are trying to find a balance. Right now we are doing the work as volunteers, thus, we emphasize agencies who do not have funds to pay for the work. We are, however, at the same time trying to make forays into the larger business world where after a year we could also find paid work doing the same kind of thing.

As part of this project we are documenting the training experiences, carefully focusing on such things as the kinds and sizes of organizations that need and use our service, the variety of tasks the community organizations are most likely to need help with, the level of supervision necessary, and the degree of job satisfaction the students exhibit toward different tasks. This information will be written into a small manual which will be produced by the end of September.

We hope this manual will help non-profit organizations realize that volunteers who are handicapped have something to offer in exchange for the opportunity to gain work experience and feel useful.

CONCLUSION

In conclusion, I don't mean to imply that all programs should be small or even that a small program would be right for everyone, but perhaps smallness should be an option, a choice. On the other hand, the Life Skills Center, through its smallness, is able to do a special kind of advocacy, one that helps to meet some of the needs that all humans have — the need for basic survival skills; the need to feel useful, the need for work, enrichment, friendship and a sense of belonging to a community.

Summary of Panel Recommendations
February 5, 1988

PANEL	RAPPORTEUR
LIVING ARRANGEMENTS	Hank A. Bersani, Jr., Ph.D.
EMPLOYMENT	William E. Pittman, M.A., M.ED.
TRANSPORTATION	Paul A. Marchand
EDUCATION	Ann P. Turnbull, Ed.D.
RECREATION/LEISURE/SOCIALIZATION	Stuart J. Schleien, Ph.D.
FAMILY SUPPORTS/RESPITE	Rachel D. Warren, M.S.
LIFE SERVICES PLANNING	Paul L. Medlin
QUALITY ASSURANCE	Valerie J. Bradley
HEALTH CARE	Albert L. Anderson, D.D.S.
CITIZEN ADVOCACY	Curtis L. Decker

Living Arrangements Panel Recommendations

by Panel Moderator
Henry "Hank" A. Bersani, Jr., Ph.D

Federal/State Level

- To formulate a clear pro-integration policy at the Federal level. This policy should promote full integration for all people regardless of the level of disability.
- The President's Committee on Mental Retardation (PCMR) should disseminate information about excellence in integration by the publication of a book of exemplary integration projects.
- The PCMR should formulate a new National deinstitutionalization goal as it has in the past. If the value base is in place, then it would be a reasonable goal to have an end to Federal participation in institutionalization by the year 2000.
- The PCMR should urge Congress and the Administration for dramatic Medicaid reform. Only full scale restructuring of Medicaid can eliminate the current bias towards segregation.
- The PCMR should work with other national leadership organizations to formulate a National policy in support of families. The policy should state that all children *need* to live with families, *can* live with families, and that families need to be assisted by a national priority of funding of family support systems.
- Restore HUD cuts that were sustained during the recent Administration, to increase the maximum amount of HUD loans and change the rules to allow for live-in assistance.
- Examine all federal policies relative to promoting integrated options.
- Move from services to people with disabilities as a privilege to publicly-paid service as a right.
- Move from policies which seek to control consumer and families, to policies that empower consumers and families.
- Allow and encourage multiple funding streams not linked to label, diagnosis or facility.

Agency Level

- For agencies, leasing homes is often preferable to owning. It provides the kind of flexibility that we see as being essential to integration.
- Actively seek and use multiple funding sources.
- Work with local citizens groups, local housing projects, etc., in our home communities.
- Use a full range of management options to operate some services, and subcontracting for other services.
- Seek voluntary collaboration with other groups and agencies in our home communities. Not limiting ourselves to just disability groups.

- Encourage heterogeneous mixing of people with varying disabilities and dissimilar service needs.

Family Level

- Recognize families as the primary source of progressive changes.
- Follow the lead of programs that were started by parents which have often encouraged more integration.
- Promote ways for families to continue to lead the way to integration.
- Consumers themselves need to take a greater leading role in determining what services are needed and wanted.

Employment Panel Recommendations

by Panel Moderator
William E. Pittman, M.A., M.Ed.

- Need to assist community agencies in the identification of barriers that prevent persons with mental retardation and other developmental disabilities from achieving their full employment potential.
- Develop policies and programs at the national, State and local levels which will help to remove those barriers in efficient and effective ways.
- Need to assist persons with mental retardation/ developmental disabilities, and their families, benefit from, as well as contribute towards, an improved quality of life.
- To achieve an improved quality of life, efforts must focus on creative approaches at the community level where persons with mental retardation/developmental disabilities live, work and achieve individual successes.
- PCMR's focus on coordinated services for persons with mental retardation/developmental disabilities should be at the community level.
- Important leadership roles must be given to State agencies, such as: the Governors' Committees on Employment of the Handicapped, Developmental Disabilities Planning Councils and Protection and Advocacy Agencies, Private Industry Councils and Rehabilitation Services Administrations.
- PCMR must encourage and support programs which build community capacities which effectively lead to independence, productivity and integration for all Americans with mental retardation.
- A national review of the role (as well as training) of agency "Placement Specialists" is needed, which would lead to the possible development of a national credentialling process for acceptable performance and/or competencies.
- There is a need to develop a computerized "state of the art" *National Directory of Training and Placement Resources* (by state) designed for private sector use in accessing our mutual network of services.
- Demonstration projects based on the Supported Work and JTPA models are needed which develop and enhance industry specific community based employment activities.
- Working with the Administration on Developmental Disabilities "Employment Initiative Campaign", PCMR could assist in the establishment of a national public-private sector sponsored toll fee "(1-800) Employment Hotline" to respond (as well as follow up) to employer requests for placement agency/service information.
- PCMR should work with state level networks in the development of "Supported Employment" marketing (standardized employer/employee surveys) and public information plans, as well as follow up private sector training activities.
- Further linkage is needed between PCMR and State Governors' Committees on the Employment of the Handicapped with respect to activities that encourage mutual support and cooperation (Re: for example, discussions on ways PCMR could influence the role of Private Industry Councils with respect to increased utilization of DOL's Job Training Partnership Act).

Transportation Panel Recommendations

by Panel Moderator
Paul A. Marchand

- The PCMR must be at the forefront in establishing a national mandate of full accessibility of transit systems in our nation by endorsing and supporting the efforts of the National Council on the Handicapped.
- The PCMR should plan a more active role in conjunction with the Department of Transportation (DoT) to eliminate existing discriminatory DoT policies and assure accessibility to persons with mental retardation within all transit systems.
- The PCMR should advocate that new vehicles approved for mass transit be fully accessible.
- The PCMR should be working toward policy recommendations that remove the three percent cap in regulations and assure that persons with mental impairments are fully covered.
- The PCMR should support nationwide research efforts about the needs of individuals with mental retardation.

Education Panel Recommendations

by Panel Moderator
Ann P. Turnbull, Ed.D.

- Placing of students in neighborhood schools using natural proportion criteria, and offer maximum opportunities for peer interaction while maintaining the provision of special services.
- Increase opportunities for students with all levels of mental retardation to participate in regular classroom programming with chronological age peers.
- Replicate some of the benefits of special classes placements from the perspective of students and families who have experienced success in that setting into the creation of more integrated options.
- Heighten research and programmatic attention on supporting students to develop a range of friendships with peers with and without a disability.
- Ensure that early intervention programs are located in the same setting as generic child care services, enabling opportunities for integration and access to full day services for working parents.
- Ensure that administrators respect the values of special education and have a thorough understanding of program priorities and alternatives, plus strategies such as required certification.
- Provide state of the art pre-service and in-service training to teachers, all teachers, in fact all school personnel, on integration, because these people are vital to student's success.
- Establish integration in after school programs that are operated by the educational system.
- Teach self-advocacy skills from the earliest years of school; starting in pre-school.
- At the national policy level, the PCMR should become actively involved in the debate and dialogue concerning quality education and establish that an essential criteria of a quality school is that it must be able to effectively teach all of its students in integrated settings.
- Conduct longitudinal research on students whose needs are not adequately being addressed by the present service system.
- Provide continued funding for transition training.
- Identify marathon skills for families and develop options for supporting families to develop these skills beginning in early intervention,
- Investigate the availability of continuing education for adults and expand its availability to provide a full continuum of continuing education services throughout adulthood and into the elderly years.

Recreation/Leisure/Socialization Panel Recommendations

by Panel Moderator
Stuart J. Schleien, Ph.D.

- Greater self-advocacy efforts to encourage an expansion of activities and friends and to move away from stereotyped activities that we usually associate with individuals who are mentally retarded.
- The need for careproviders' support and collaboration with the existing leisure/ recreation service delivery system.
- The need for careproviders and families to advocate for leisure skills programs and leisure education, including leisure education in schools. It is never too early to begin teaching children how to make choices, play with others and make friends.
- The need for individualized education and habilitation plans that reflect leisure goals and objectives.
- The need for therapeutic recreation specialists to work as consultants in schools and communities with teachers and recreation professionals to help develop leisure skills programs.
- The need for clear networks of communication between the public sector, private sector, municipal parks and recreation departments, community education agencies and physical educators in the schools.
- Regarding the states' and federal government's roles, the U.S. Department of Education's, Office of Special Education and Rehabilitative Services, needs to continue to support the training of therapeutic recreation specialists to work in integrated community environments.
- The Rehabilitation Services Administration must prioritize integrated recreation programs that serve persons with and without disabilities. Federal funds for the development of special recreation programs are available once every 3 years. Monies should
  be made available annually to develop exemplary program models that are integrated.
- On a system-wide basis, leisure/recreation facilities and programs must become programmatically, as well as architecturally, accessible (i.e., equal access; zero exclusion policy).
- The development of more integrated, versus segregated, leisure services in the community.
- A necessary corollary of an improved quality of life for all citizens includes friends with same-age peers, access to community leisure environments, and independent and age-appropriate leisure skills.

Family Support and Respite Care Panel Recommendations

by Panel Moderator
Rachel D. Warren

- PCMR should take a lead role in recommending cohesive Federal policy to support families.
- Family support should be perceived as entitlements for families of children with disabilities and that unless we view family support as an entitlement program, we would never have the stability of that program or those services that we need.
- Suggested approaches to achieving stability are: (1) a child allowance, that could go directly to the families and not be directed only to poor families; and (2) is the Chafee bill that would divert funding from segregated facilities to supporting families to keep their children in their own homes.
- Coordination between Federal, state, local, public and private agencies, coordination within States and coordination with families would provide funding stability
- The need for personnel preparation and training to match a major shift in how we work with families.
- In order to implement family support activities, paraprofessionals and professionals need to be trained in a different way around "enabling" role for the families and away from the being "in charge" role of the professional.
- A need for orientation for families in terms of the changing of viability and possibility within family support services.

Life Services Planning Panel Recommendations

by Panel Moderator
Paul L. Medlin

- Professionals and the system must change their traditional mindsets by fostering self-sufficiency and reducing dependency if citizens with disabilities are to become truly integrated in the society.
- Professionals must enhance and reinforce the rights of citizens with disabilities and their families to make choices without having decisions imposed upon them.
- Partnerships must be formed to ensure accountability and progressive changes which maximize the lifelong benefit to citizens with disabilities.
- Providers and families and persons with disabilities themselves must work closely together to develop a life plan toward economic and self support.
- Social Security Administration and other agencies need to look into some type of an IRA, for productive individuals that are employed to set assets aside for their future needs.
- Address problems associated with moving from home and institutional settings and the development of appropriate community services: (1) the Administration on Developmental Disabilities should advise State Developmental Disabilities Councils to address the issue of the State elderly mentally retarded and developmentally disabled population, and (2) establish Statewide task groups to address barriers and problems found to be present that impede the community integration of elderly people who are mentally retarded or developmentally disabled.
- Aid in more effectively using non-disabled seniors as volunteers or senior friends: the National Domestic Volunteers Service Act should be amended to include expanded provisions for the use of senior companions to specifically address the transition problems faced by older persons with mental retardation.
- Ensure that older persons with mental retardation are not capriciously forced to leave their "homes". The Health Care Financing Administration should ensure that its regulations governing Intermediate Care Facilities for the Mentally Retarded (ICF/MR) programs permit utmost flexibility to allow for aging and special problems faced by residents who "age in place."
- Ensure that the lack of information/training is not a barrier to the successful integration of older persons with mental retardation, into the aging network and that mental retardation providers can realistically adapt their programs to serve the aging clientele.
- The Administration of Developmental Disabilities and the Administration on Aging jointly should commission the development of a series of training and education packages on aging and lifelong disabilities; and, that these training materials should be broadly available to the Aging and the Mental Retardation and Developmental Disabilities Agencies.

- Need for innovative private sector initiatives, which eliminate barriers for families to pro-actively participate in planning a service future for their disabled dependent.
- Each State needs to look at the merits of the "Self-Sufficiency Trust" model, how it can be implemented and benefit persons with disabilities, in each State, to enhance their lifelong service options.

Quality Assurance Panel Recommendations

by Panel Moderator
Valerie J. Bradley

Federal Level

- More research is needed to document best practices in the area of community integration.
- Research is necessary to determine the relevance of program standards to positive outcomes for people in the community.
- The Federal government should adopt a coherent national policy on community integration.
- The Federal government should develop a national policy on disability that eliminates current disincentives to community integration.
- Mechanisms should be developed to assess the accountability of the service system as a whole.
- Federal support is needed for the dissemination of information on best practices.
- Federal research funds should be made available to assist states and other program monitors to assess outcomes.
- Federal support is required to assist in the development of assessment techniques to determine the level of satisfaction of persons with disabilities and their families regarding the services they may or may not be receiving.

State Level

- States should support standard-setting and monitoring options that involve people with disabilities and their families.
- State standards should be reviewed frequently to ensure relevance to emerging values and program trends.
- Standards should embody and express community integration objectives.

Public/Private Partnerships

- The most important partnership is between those in the public sector and families and persons with disabilities.
- Any partnerships between public monitoring agencies and private accreditation agencies should have the following characteristics: (1) they should be directed at a core set of standards; (2) the system should identify critical predictors of desired community integration outcomes; (3) there should be explicit expectations from the funding source for outcomes purchased; and (4) quality assurance should be a mixture of state and Federal oversight and external third party overseers including advocacy and family groups.

Health Care Panel Recommendation

by Panel Moderator
Albert L. Anderson, D.D.S.

Federal/State Partnership

- Federal policy and legislation should see to the development of a nationwide network of community/university hospital based regional health care centers in every state, based on populations of person at risk, and should provide incentives for the states to develop such programs based on local needs and health care patterns.
- Encourage and support effective Federal and State interagency partnerships, and critically evaluate alternatives which are developed.
- Appropriate affordable and accessible health care for all persons with out discrimination and higher rates for persons with disabilities.
- The President's Committee on Mental Retardation should use its influence to:
  1. Foster prevention of mental retardation;
  2. Advocate and demonstrate commitment to assuring that health services are available for mentally retarded children;
  3. Maintain and enhance the essential services that are now available to mentally retarded children;
  4. Encourage coalitions, collaboration and cooperation among groups that have interest in children;
  5. Promote the conduct of research on the delivery of health services to mentally retarded children in the changing health care system and other clinically relevant aspects of care of these children;
  6. Stimulate opportunities for families of mentally retarded children to help themselves;
  7. Assume leadership in promoting health care professionals who are prepared to provide family based health services to mentally retarded children;
  8. Encourage a greater emphasis on follow-up and evaluation of mentally retarded children diagnosed and treated in the health care system;
  9. Foster partnerships of local school districts with other community health agencies that provide services to mentally retarded children'
  10. Promote the development of alternative strategies and systems for delivery of health services to mentally retarded children, similar to the immediate alternative program in Kentucky;
  11. Promote the provision of incentives to both public and private child care facilities that serve mentally retarded children and demonstrate that a component of health services is included in the program of the facility.
  12. Use PCMR's influence to get group insurers to include as one of their product packages health services for the mentally retarded.

State/Local Partnership

- The States, through their governmentally based developmental disabilities agencies and health departments, would promulgate guidelines for establishment and operation of such regional health care resource centers and contract with qualified local community/university hospitals in the private or public sector for such services.
- Place a high priority on preventing institutionalization, including minimizing a child's stay in general medical hospitals such as children's' hospitals.
- Financial incentives need to line up with philosophical goals.
- Actively seek partnerships between State and local communities, which ensure adequate community based support structures, including respite care and other in-house services, which will help prevent institutionalization.
- Staff is specifically prepared and trained in client centered services.
- Provide training and networking, through consortiums, collaborations, and cooperation can work;
- Provide technical assistance to change dependency to independency.
- Change the fee for service to better reflect current unit costs.
- Advocate through alternate systems when your own system is unresponsive.

Public/Private Partnership

- Though the core costs of the center should be unwritten by public agencies in State and local government, the local hospital program may expand the basic nature of its program to provide for special services unique to its setting. It may gain support for these special endeavors through charitable foundations, local industry, private agencies (such as Association for Retarded Citizens, United Cerebral Palsy, etc.) as well as through traditional third party health insurance companies.
- Actively seek partnerships between public and private agencies which ensure adequate community based support structures including respite care and other in-home services

Service Delivery System Partnership

- Families of persons with mental retardation will be among the principal beneficiaries of such a system. A regional health care center that coordinates all necessary medical and dental services, and provides high quality, responsive care in a cost effective manner is currently lacking from the case management system. It will relieve a considerable degree of anxiety on the part of parents as to who will take responsibility for their family members with mental retardation when they are no longer able to care for them, and will help them negotiate the difficult and complex health care system looking for the doctor, dentist, or hospital that can address the health care needs of a patient with mental retardation in a competent and dignified manner.
- Ensure flexibility and responsiveness in the service system:
  1. Work together to determine how to effectively utilize all the valuable resources that exist.
  2. Assure access to any part of the service delivery system which will best meet the needs of the child and family involved.
  3. Acknowledge that our knowledge and technical sophistication is not yet great enough to assure survival for some children except in institutional or hospital-like environments.
- Assure family involvement in all planning activities, including systems planning and especially in regard to their own family members:
  1. Acknowledge and understand family concerns.
  2. Plan for the Life Span.
  3. Ensure adequate monitoring and evaluation.

Citizen Advocacy Panel Recommendations

by Panel Moderator
Curtis Decker

Federal Level

- The PCMR must examine its own understanding of the role of persons with disabilities including reviewing language in its publications and how its members and staff publicly deal with this population.
- The PCMR needs to place a stronger emphasis on self advocacy and citizen advocacy as viable alternatives to helping persons with disabilities protect their rights.
- A person with a disability should be a member of the PCMR.
- The PCMR needs to regain its leadership role in the field of mental retardation and take on the role of a visionary in the development of services to people with disabilities.

State Level

- Each State should develop self advocacy and citizen advocacy programs using existing Federal funding sources such as; the Developmental Disabilities Councils.
- Assure that the various forms of advocacy are conflict-free, organized and delivered by the most appropriate body.
- Recognize the expertise of persons with developmental disabilities to do as much for themselves as possible.
- Commitment to client-directed advocacy.
- Encouragement of professionals and parents to "let go" of the control of the decision- making process regarding major life plans of persons with disabilities.

Appendices

A - Presidential Forum Program Agenda Including Co-Sponsors
B - Exhibitors
C - Participants and Attendees
D - PCMR Members and Staff
E - Contributing Authors

PROGRAM AGENDA
A Presidential Forum:
Citizens with Mental Retardation and Community Integration
February 3-5, 1988
Mayflower Hotel
1127 Connecticut Avenue, N.W.,
Washington, D.C. 20036

STATEMENT OF PURPOSE

The purpose of this Presidential Forum is to examine the national effort to promote maximum community integration of citizens with mental retardation.

The Forum will highlight the experiences of community planners, service providers, educators, Federal/State officials, parents and self-advocates that have achieved success in planning, designing, evaluating and/or implementing exemplary community integration models serving citizens with mental retardation, including personal experience profiles.

"Themes" to be addressed by the participants are: Federal/State Partnership
State/Local Partnership
Public/Private Partnership
Family/Service Delivery System Partnership

Potential Presidential Forum products include:

Recommendations to the Secretary of Health and Human Services and a Report to the President regarding the role of the Federal government in the promotion of maximum community integration of citizens with mental retardation;
a Presidential Forum proceedings document;
a video tape summary of the Forum proceedings; and,
a technical assistance manual to be used by State and Local governments and public and private agencies in the design, delivery and evaluation of exemplary program models that promote maximum community integration of citizens with mental retardation.

The President's Committee on Mental Retardation acknowledges and extends appreciation to the following organizations, agencies and private individuals for their financial co-sponsorship of the national conference, "A Presidential Forum: Citizens with Mental Retardation and Community Integration":

ACTION
American Association of University Affiliated Programs for Persons with Developmental Disabilities
American Foundation on Mental Deficiency
American Nurses' Association, Inc. Carter, Hawley, Hale Stores, Inc.
DoE-Office of Special Education and Rehabilitative Services DHHS-Administration for Children, Youth and Families DHHS-Administration on Developmental Disabilities
DHHS-Health Resources and Services Administration Bureau of Maternal and Child Health and Resources Development
DHHS-National Institute of Child Health and Human Development DHHS-Social Security Administration
Fairview Families and Friends, Inc. Goodwill Industries of America, Inc.

Miriam and Peter His Fund
Maine Department of Mental Health and Mental Retardation
Marshall's Department Stores
Minnesota University Affiliated Program/Center for Residential and Community Services
National Association for the Dually Diagnosed
National Council on the Handicapped
National Foundation for the Handicapped
WEMCO, Inc.
Mrs. Jefferson Patterson of Washington, D.C.

Tuesday, February 2, 1988		EAST ROOM
5:30-7:00 P.M.	Pre-Forum Reception (Cash Bar) and Exhibits Forum Registration	
Wednesday, February 3, 1988		
8:00-8:45 A.M.	Forum Registration and Opening Plenary Session	EAST ROOM
9:00 A.M.	Welcome and Introduction of Speakers	Albert L. Anderson, D.D.S. Vice Chairman President's Committee on Mental Retardation San Diego, California
9:15 A.M.	Greetings and Introduction of the Secretary of DHHS	Sydney Olson Deputy Assistant Secretary for Human Development Services Washington, D.C.
9:30 A.M.	Opening Statements	Otis R. Bowen, M.D. Secretary, Department of Health and Human Services and Chairman, PCMR Washington, D.C.
9:45 A.M.	Statement of Occasion "Overview of PCMR's Community Integration Initiative"	Vivian Bricklin Levin Executive Director President's Committee on Mental Retardation Washington, D.C.
10:00 A.M.	Drug Abuse, Mental Retardation and Community Integration	Donald Ian Macdonald, M.D. Special Assistant to President Reagan and Director, Drug Abuse Policy Office
10:30 A.M.	Refreshment Break	
11:00 A.M.	Public Awareness/ Public Acceptance	Emily Pert Kingsley Writer, Sesame Street (PBS) Chappagua, New York
11:30 A.M.	Parental/Family Role in Community Integration Planning - Now and the Future	James H. DeOre, Exec. Dir. National Foundation for the Handicapped Elmhurst, Illinois
12:00 Noon	Forum Luncheon	GRAND BALLROOM
1:30 P.M.	Zoning, Real Estate and Related Issues	Arlene S. Kanter Professor, Syracuse University School of Law Consultant and Former Staff Attorney at the Mental Health Law Project Washington, D.C.
2:15 P.M.	Financing of Community Integration Models	Vincent D. Pettinelli, ACSW, FAAMR President, VOCA Corporation Columbus, Ohio

2:45 P.M.	Labor and Staffing	Peter "Skip" Sajevic Vice Pres. for Policy Natl Association of Private Residential Resources St. Paul, Minnesota
3:15 P.M.	Management of Transition into the Community	Kingsley R. Ross Director, Developmental Services Program Office Health and Rehabilitative Services for the State of Florida Tallahassee, Florida
3:45 P.M.	Closing Comments and Adjournment	Albert L. Anderson, D.D.S. Vice Chairman President's Committee on Mental Retardation
5:30-7:00 P.M.	Forum Reception Sponsored by: The National Foundation for the Handicapped Exhibits	STATE ROOM

Thursday, February 4, 1988
CONCURRENT PANEL SESSIONS

PANEL 1 LIVING ARRANGEMENTS	9:00 A.M.-Noon	PENNSYLVANIA ROOM
		Topic of Discussion
Moderator:	Hank A. Bersani, Jr., Ph.D. Assistant Professor on Special Education Syracuse University Syracuse, New York	Community Integration Project
Panelists:	Janice C. Schiff Director, Residential Development of the Fairfax/Falls Church, Virginia Community Services Board Vienna, Virginia	Partnership for Residential Development
	Michael M. Morris Associate Executive Director Community Services Division United Cerebral Palsy Association, Inc. Washington, D.C.	Implications of Federal/State policy
	Gail D. Jacob Program Director Options in Community Living, Inc. Madison, Wisconsin	Options in Community Living

	Jean W. Powers Administrator Peppermint Ridge Corona, California	Residential programs for persons with developmental needs

Thursday, February 4, 1988
CONCURRENT PANEL SESSIONS

PANEL 2 EMPLOYMENT	9:00 A.M.-Noon	RHODE ISLAND ROOM
		Topic of Discussion
Moderator:	Robert E. Stovenour Deputy Commissioner Administration on Developmental Disabilities Washington, D.C.	Overview of the ADD Employment Initiative
Panelists:	William Pittman Administration on Developmental Disabilities Washington, D.C.	ADD Employment Initiative
	Donna D. Doerer Fmr Regional Director, ARC/US National Employment and Training Program Seattle, Washington	Public/Private Partnership working together to provide employment
	Kenneth J. Shaw Director, Rehabilitation and Research Goodwill Industries of America, Inc. Bethesda, Maryland	Supported employment within the competitive workplace
	Aaron J. Prero, Ph.D. DHHS-Social Security Administration Baltimore, Maryland	Transitional employment
	Paul Hippolitus Acting Director, Office of Plans, Projects & Services President's Committee on Employment of the Handicapped Washington, D.C.	Joint Training Partnership Act

Thursday February 4, 1988
CONCURRENT PANEL SESSIONS

PANEL 3 TRANSPORTATION	9:00 A.M.-Noon	SOUTH CAROLINA ROOM
		Topic of Discussion
Moderator:	Paul A. Marchand Director Office for Governmental Affairs, Association for Retarded Citizens/U.S. Washington, D.C.	
Panelists:	Robert C. Ashby Deputy Asst. General Council Regulations & Enforcement Department of Transportation Washington, D.C.	DoT legislation/regulations and their resultant affect on mentally retarded citizens
	Lex Frieden Executive Director National Council on the Handicapped Washington, D.C.	Transportation for the mentally and physically handicapped
	Bruce M. Oka Equal Employment Opportunity Specialist Department of Health and Human Services Office for Civil Rights San Francisco, California	San Francisco Municipal Railway (MUNI) serving the handicapped Transportation considerations for mentally retarded citizens

Thursday, February 4, 1988
CONCURRENT PANEL SESSIONS

PANEL 4 EDUCATION	9:00 A.M.-Noon	VIRGINIA ROOM
		Topic of Discussion:
Moderator:	Ann P. Turnbull, Ed.D. Public Policy Fellow in Mental Retardation Joseph P. Kennedy, Jr. Found. Washington, D.C.	Future planning in education
Panelists:	Mary A. Falvey, Ph.D. Professor Division of Special Education California State University, L.A.	Special education

William E. Kiernan, Ph.D. Director of Training and Research Institute for Adults with Disabilities Children's Hospital Center Boston, Massachusetts	Master's Program for training specialists in special education and rehabilitation
Muriel W. O'Tuel, Ph.D. Assistant to the Superintendent Horry County School District Conway, South Carolina	Integration of mentally retarded children into public schools
William R Langner Education Program Specialist U.S. Dept. of Education Office of Vocational and Adult Education Washington, D.C.	Adult Education programs
Howard P. Blackman, Ed.D. Executive Director LaGrange Area Department of Special Education LaGrange, Illinois; Member PCMR	Working with students without disabilities to foster accepting school climates for mentally retarded students

Thursday, February 4, 1988
CONCURRENT PANEL SESSIONS

PANEL 5	RECREATION/ LEISURE/SOCIALIZATION	9:00-Noon	NEW JERSEY ROOM
			Topic of Discussion:
Moderator:		Stuart J. Schleien, Ph.D. Associate Professor School of Physical Education and Recreation Univ. of Minnesota-Twin Cities Minneapolis, Minnesota	Community recreation for persons with disabilities
Panelists:		John Chromy Director, Special Olympics Joseph P. Kennedy, Jr. Found. Washington, D.C.	Future Goals of the Special Olympics
		Dr. Sirkku "Sky" Hiltunen The Art & Drama Therapy Institute, Inc. Washington, D.C.	Providing art and drama therapy services to mentally retarded and developmentally disabled persons

	K. J. Moore Chairman, Scouting for the Handicapped National Capital Area Council Washington, D.C.	Scouting programs for mentally retarded children and adults

Thursday, February 4, 1988
CONCURRENT PANEL SESSIONS

PANEL 6	FAMILY SUPPORTS/ RESPITE CARE	1:30-4:30 P.M.	PENNSYLVANIA ROOM
			Topic of Discussion
Moderator:		Rachel D. Warren Director National Resource Center on Family Based Services University of Iowa School of Social Work Iowa City, Iowa	"Respitality" and respite care procedures in the context of family based services
Panelists:		Susan Brooks Parker Commissioner, Main Dept. of Mental Health and Mental Retardation Augusta, Maine	Family support as a focal program area of State policy to actively promote community integration
		Shirley Cohen, Ph.D. Associate Dean Hunter College of The City University of New York Division of Programs in Education New York, New York	Respite care from an International perspective
		Allan I. Bergman Deputy Director for Governmental Activities United Cerebral Palsy Association, Inc. Washington, D.C.	National policy and program perspectives on family support

Thursday, February 4, 1988
CONCURRENT PANEL SESSIONS

PANEL 7 LIFE SERVICES PLANNING	1:30-4:30 P.M.	RHODE ISLAND ROOM
		Topic of Discussion
Moderator:	Paul L Medlin Senior Vice President Corporate Development Charter Management Group, Ltd. Oak Brook, Illinois	State financial planning and the family's role
Panelists:	Ron Barber Department of Economic Security Division of Developmental Disabilities Phoenix, Arizona	Planning for economic security
	Matthew P. Janicki, Ph.D. Director of Aging Services Office of Mental Retardation and Develop. Disabilities Albany, New York	Transition from worklife to retirement
	Kenneth McGill Acting Director, External Affairs Office of Governmental Affairs DHHS-Social Security Admin. Baltimore, Maryland	Supplemental Security Income (SSI)/Medicaid eligibility

Thursday, February 4, 1988
CONCURRENT PANEL SESSIONS

PANEL 8 QUALITY ASSURANCE	1:30-4:30 P.M.	SOUTH CAROLINA ROOM
		Topic of Discussion
Moderator:	Valerie J. Bradley President, Human Services Research Institute Boston, Massachusetts	State support for individuals/ families by assessing and enhancing residential services
Panelists:	Linda Toms Barker Berkeley Planning Associates Berkeley, California	Process and staffing
	Ronald Conley, Ph.D.	Quality assurance from a

	Special Assistant Administration on Developmental Disabilities Washington, D.C.	system perspective
	Mary C. Cerreto, Ph.D. Director of Psychology Franciscan Children's Hospital and Rehabilitation Center Brighton, Massachusetts	Accreditation standards
	C. Kaye Pearce Associate Director, Programs Commission on Accreditation of Rehabilitation Facilities (CARE) Tucson, Arizona	Accreditation standards for industries who offer competitive employment for citizens with mental retardation within community programs

Thursday, February 4, 1988
CONCURRENT PANEL SESSIONS

PANEL 9 HEALTH CARE	1:30-4:30 P.M.	VIRGINIA ROOM
		Topic of Discussion
Moderator:	Albert L. Anderson, D.D.S. Vice Chairman, PCMR San Diego, California	Dental and general health care of mentally retarded citizens
Panelists:	Philip R. Ziring, M.D. Chairman, Department of Pediatrics, Pacific Presbyterian Medical Center San Francisco, California	Medical care for patients of all ages and levels of mental retardation
	Mary Richardson, Ph.D. Administrator Clinical Training Unit Child Development and Mental Retardation Center National Resource Institute on Children & Youth with Handicaps Seattle, Washington	Services to medically fragile children
	Gregory P. Weigle President Alliance of Genetics Support Groups Vienna, Virginia	Access to health care

	Juanita W. Fleming, Ph.D. Professor and Associate Vice-Chancellor Academic Affairs, Medical Ctr University of Kentucky Lexington, Kentucky	Health services to children with mental retardation in the community, schools and home
	George H. Daniels Director of Staff Development & Training at Sunmount DSSO Tupper Lake, New York	Health care provided by nurses serving mentally retarded and developmentally disabled individuals

Thursday, February 4, 1988
CONCURRENT PANEL SESSIONS

PANEL 10 CITIZEN ADVOCACY	1:30-4:30 P.M.	NEW JERSEY ROOM
		Topic of Discussion
Moderator:	Curtis Decker Executive Director National Association of Protection & Advocacy Systems Washington, D.C.	Protection & advocacy systems
Panelists:	Bernard Carabello Director, Self-Advocacy Association of New York New York, New York	Self-advocacy
	Glenda Davis Executive Director Citizen Advocacy, Inc. Grand Island, Nebraska	Organization and funding of advocacy groups
	Colleen A. Wieck, Ph.D. Executive Director Minnesota Governor's Planning Council on Developmental Disabilities St. Paul, Minnesota	Advocacy and community integration from a DD Council perspective
	Teresa Smith Michigan NW Area — ARC Garden City, Michigan	"People for Independence" a self-advocacy group and her own personal experiences and growth in the community
	Margaret A. Hoven, M.A. Executive Director Life Skills Center Washington, D.C.	Severely retarded adults serving as volunteers to gain work experiences in the community

Friday, February 5, 1988 CHINESE ROOM

9:00 A.M.	Opening Remarks and Introduction of Panel Rapporteurs	Albert L. Anderson, D.D.S. Vice Chairman, PCMR
	PANEL REPORTS	RAPPORTEUR
9:10 A.M.	Living Arrangements	Hank A. Bersani, Jr., Ph.D.
9:30 A.M.	Employment	Robert E. Stovenour
9:50 A.M.	Transportation	Paul A. Marchand
10:10 A.M.	Education	Ann P. Turnbull, Ed.D.
10:30 A.M.	Recreation/Leisure/Social	Stuart J. Schleien, Ph.D.
10:50 A.M.	Family Supports/Respite	Rachel D. Warren, M.S.
11:10 A.M.	Life Services Planning	Paul L. Medlin
11:30 A.M.	Quality Assurance	Valerie J. Bradley
11:50 A.M.	Health Care	Albert L. Anderson, D.D.S.
12:10 Noon	Citizen Advocacy	Curtis Decker
12:30 P.M.	Forum Wrap-up	Vivian Bricklin Levin Executive Director, PCMR
12:45 P.M.	Closing Remarks and Forum Adjournment	Albert L. Anderson, D.D.S Vice Chairman, PCMR

APPENDIX B

A Presidential Forum:
Citizens with Mental Retardation and Community Integration
Pre-Forum
Reception and Exhibits
Tuesday, February 2, 1988
5:30 P.M. - 7:30 P.M.
FEATURING
Community Integration Exhibits
Mayflower Hotel
1127 Connecticut Avenue, N.W., Washington, D.C. 20036

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"Developmental Disabilities Awareness Month"	Laura Eblin Judy Moore
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National Association for the Dually Diagnosed	Andrew Levitus, M.D.
National Council on the Handicapped	Andria Farbman
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"Self Sufficiency Thrust"	Dwaine Thompson
Pacific Western Information Systems	Bruce Williams
Social Security Administration	Martha Seabrooks Sheila Jones
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Health Care Mobilizing for Prevention	John P. Scagnelli
Protection and Advocacy A New Way of Thinking	Colleen Wieck, Ph.D.
President's Committee on Mental Retardation	Ashot P. Mnatzakanian
Presidential Forum: Citizens With Mental Retardation and Community Integration	Ashot P. Mnatzakanian

APPENDIX C

A Presidential Forum:
Citizens with Mental Retardation and Community Integration

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