

THE ADD UPDATE

VOLUME ONE • DECEMBER 2009



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Pennsylvania's dentists take Medicaid. (more – page 2)

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about how to become... (more – page 4)

MESSAGE FROM THE ACTING COMMISSIONER

I hope that you all had a very happy Thanksgiving, and I send you best wishes for the upcoming holiday season.

Unfortunately, holiday season is also flu season. Two strains of flu, seasonal flu and the H1N1 (Swine) flu, are currently circulating in the United States.

I encourage you to stay informed and healthy this season. The Department of Health and Human

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with Disabilities" Youth LEAD provides teens and young adults with developmental disabilities with (more – page 8)

COLLABORATION CONTINUES IN KENTUCKY



On August 21, 2009, the Kentucky DD Network conducted its 5th Annual

Collaboration Meeting. (more – page 9)

SPOTLIGHT ON SELF-ADVOCATES: ROBERT DENTON

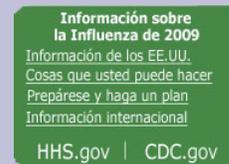
Hi, My name is Robert and this is my story. I grew up in Louisville with my family. I enjoyed hunting and fishing with my dad and...(more – page 10)



LINKS



Visit Flu.gov for up to date information on the flu and H1N1.



Visita Flu.gov para información actualizada sobre la influenza y el H1N1.



Click on the image to the left to view an up-to-date map of H1N1 activity

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Unfortunately, holiday season is also flu season. Two strains of flu, seasonal flu and the H1N1 (Swine) flu, are currently circulating in the United States. I encourage you to stay informed and healthy this season. The Department of Health and Human Services has created the website www.flu.gov to provide accurate, up-to-the minute information about the flu and its prevention.

The link to the flu.gov website can also be found on the first page of the ADD Update. This month's Update is the inaugural electronic Update. We plan to use this format moving forward, and hope that it makes the Update more accessible and easy to read. Please feel free to contact writer/editor Rebekah Yeager at Rebekah.yeager@acf.hhs.gov with any suggestions, and well as to submit stories and ideas for future issues.

In addition, ADD continues to be in search of photographs from our grantees that depict individuals with disabilities living and thriving in their communities. Please send pictures to Rebekah at the address above, or contact her for details.

I also want to take the time, as we near the end of the year, to thank you for all of your hard work in 2009.

Because of what you do, barriers have been broken down and stereotypes have been countered through education. Individuals with disabilities have had new opportunities to receive quality care and education, protect their health, excel in the careers of their choice, travel freely, live independently, participate

in activities they find fulfilling, and make informed choices about the kinds of services and supports they receive. You have shaped attitudes and created access.

By listening to and caring about individuals with developmental disabilities you have played a central role in bringing the American Dream to Americans with developmental disabilities and their families.

It has been a year of economic and political changes. Needs and expectations continue to rise, and you continue to meet them.

Thank you for all your hard work. I wish you all the best in the coming year.



NEXT ADD UPDATE:

The next ADD Update will focus on collaboration. Please submit your stories on collaborative projects to Rebekah.Yeager@acf.hhs.gov. Please also share with us stories about self-advocates and any other projects with which you're having success. We want to hear about programs making an impact in your communities, about the people you're reaching and the work you're doing.

We look forward to hearing from you!

ACCESS TO DENTAL CARE IN PENNSYLVANIA: STAKEHOLDERS TAKE ACTION

“For years now, we have heard the frustrations of people with disabilities and their families about how difficult it is to find (and keep) a dentist. Now we know beyond a shadow of a doubt, that this is not just a Pennsylvania problem, but a national one.”

- Nancy Murray, President of the Arc of Greater Pittsburgh/ACHIEVA

Most people with disabilities rely on Medicaid for their health insurance. In Pennsylvania only 25% of Pennsylvania’s dentists take Medicaid. On top of that, many dentists don’t feel they have sufficient training and therefore will not treat people with disabilities.



Elwyn, a human service provider who operates full service dental clinics, produced the first project on access to dental care for people with disabilities funded by the Pennsylvania Council, noting that approximately 75% of people with disabilities can be seen by a typical dentist.

During the last several years, key strategies have been devised to support people with disabilities in their efforts to receive dental care. Last year, thirty-six stakeholders from across Pennsylvania participated in a forum hosted by ACHIEVA to look at the most promising strategies and determine which are most viable. The participants were self advocates and family members, dentists, dental associations, insurance companies, government agencies and advocates. The stakeholders’ meeting, “Strategies to Solutions,” was part of a larger project at ACHIEVA, entitled, “Advancing Oral Health,” a project supported

by a grant from the Pennsylvania Developmental Disabilities Council and the FISA Foundation. As a result, six committees have been working toward actionable solutions to change the way oral health care is delivered for people with disabilities.

The six strategies are: Loan Repayment , Levels of Care (tied to repayment), Dental Professional Education (all health care providers), Dental Coordinator Position, Education for Consumers and Families, Legislation & Education.

Some resulting work of the project:

- A website about oral health www.achieva.info/advancingoralhealthcare which offers information for people with disabilities and their families, information for dentists and information about legislation. Key information translated into Spanish and information on cultural competence in health care.
- A report to Pennsylvania’s legislators, “Access to Dental Care for People with Disabilities: Challenges and Solutions.”
- A DVD and brochure that was mailed to 8,300 dentists in Pennsylvania. The DVD is dentists talking to dentists about why they treat people with disabilities and the brochure copy breaks down myths about people with disabilities and gives current information about Medicaid in Pennsylvania.

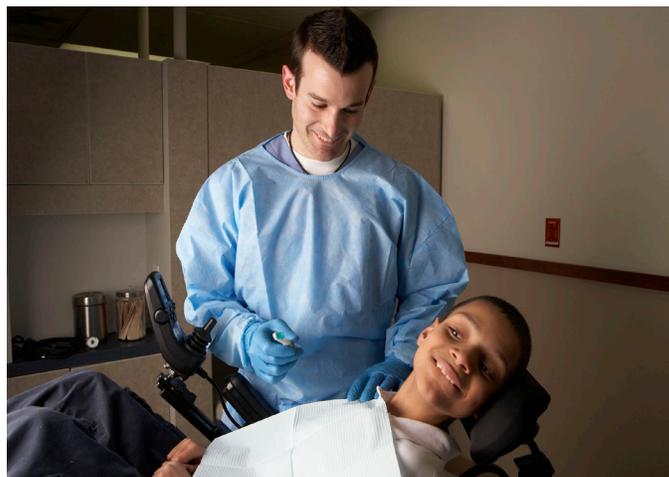
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ACCESS TO DENTAL CARE IN PENNSYLVANIA: STAKEHOLDERS TAKE ACTION (continued)

- Focus groups looking at the specific issues experienced by cultural groups and the challenges faced by people living in rural areas.
- Work has begun to develop an on-line curriculum on dental care for people with disabilities and their families with the help of the state's Department of Public Welfare's Health Care Quality Units. This will be translated into Spanish.
- The Levels of Care committee is developing a comprehensive system to match people with dentists based on the level of dental care needed by the patient as well as a pre-assessment form that documents the support needs of the patient.
- Statewide efforts are underway to encourage the Pennsylvania state dental board to require mandatory training for dentists on treating patients with disabilities.
- The project is looking at ways to support dentists who work with people with disabilities to be supported through increased payments (where necessary) as well as more flexible loan repayment programs at the state and national level.

<http://www.paddc.org>

contact Mary Hartley: mhartley@achieva.info



UTAH UCEDD COLLABORATES ON YOUNG SELF ADVOCATES TOOLKIT

A new toolkit brings the voices of young self-advocates into the discussion about how to become more independent.

The DVD and its accompanying guidebook, the Youth Leadership Toolkit, will provide training to families and to service providers who work with youth with disabilities, and most importantly, to young adults themselves.

“The biggest thing I hope somebody would gain from it is to understand that someone else has dealt with everything that they’re dealing with,” said Andrea Pitts, a young self-advocate who appears on the Youth Leadership Toolkit DVD.

Pitts is a member of the Becoming Leaders for Tomorrow (BLT) project, which helps youth and young adults with disabilities transition into adulthood. The project is a collaboration between the Utah Parent Center and the Center for Persons with Disabilities at Utah State University, under the direction of Judith Holt and Sue Olsen. BLT participants wanted to embed youth perspectives into existing training, said Jeff Sheen, training coordinator for the BLT project. The young advocates worked with partners from the Independent Living Research Utilization, the Center for Persons with Disabilities and seven other entities to produce the toolkit.

On the DVD, young self-advocates address topics like employment, independent living, relationships, self-advocacy and physical exercise. Pitts, who is now a graduate student, spoke about her experience learning to ride a bike.

“I was probably 18 or 19 when I found out about the National Ability Center and the hand bikes,” she said on the DVD. “It sounds simple but that was actually one of the most independent kind of situations I had because I was the one that found it, I was the one that implemented

it, and then I was able to ride that sort of bike ... It’s kind of like scratching it off the life list.”

The message is that young people with disabilities can be leaders and advocates, not only for other youth with disabilities but for themselves. Too often, young adults don’t know the best way to contribute to their own individual education plans, Sheen said.

“It’s hard a lot of times when you have protective parents that want to do everything for you,” said Chris Dodds, a young advocate who spoke on the DVD. “That kind of hinders your success in that area of advocating for yourself and being able to tell someone what you want.”

The youth on the DVD acknowledge their parents’ support but also express their plans to be as independent as they can. The toolkit can serve as a conversation-starter for some important discussions on growing up, Sheen said.

<http://www.cpd.usu.edu>

Contact: Judith Holt 435-797-7157



Cameron, one of the self advocates who appears on the DVD

DISTRICT OF COLUMBIA P&A PROTECTS THE RIGHTS OF GROUP HOME RESIDENTS

The P&A in DC, University Legal Services, has been at the center of a high-profile legal battle to protect the rights of individuals with disabilities living in group homes in the District.

In September, the P&A, along with a federal court monitor, went to the District regarding serious instances of abuse and neglect at two group homes managed by the same nonprofit organization. The P&A was monitoring the homes in order to ensure adherence to court orders to provide minimum-standard services for plaintiffs with developmental disabilities in a 30-year-old *Evans v. Fenty* class action lawsuit.

Among the P&A's concerns about the provider were the death of three residents and a woman who lost 29 pounds in a single month.

One case raising concerns about the provider's standards of care was that of a woman who died in 2007 of an infection that appeared to be related to a misplaced feeding tube. Another case involved a resident who died of a urine-related infection and pneumonia. Investigators found that while it was difficult to directly link her death to negligence, there appeared to be deficiencies in her care, particularly in relation to recurring urinary tract infections.

"If this was our daughter or our sister, we'd all say no," says Sandy Bernstein of the DC P&A.

The deficiencies on the part of the provider, the P&A says, have been pervasive for years, despite frequent reporting and monitoring.

Additional concerns included failure to implement protocols for mealtime (for people at risk of aspiration) and positioning (people left in wheelchairs for hours without a position change). In addition, physician

and consultant recommendations were frequently not implemented, and there was failure to adequately track input and output of bowels, fluids, etc. Residents' weight loss was not properly monitored, and there was inadequate staffing and a lack of community outings. Side effects from psychotropic medications went unmonitored, the staff was unaware of health risks, behavior plans were not implemented, and there were substantiated instances of abuse and neglect.

As a result of the advocacy of the P&A and court monitor, the District went to court in October in attempt to have a receiver put on two of the provider's homes, while halting referrals to other homes managed by the provider. Weeks later, an agreement was reached in which the provider retained control of the two homes and agreed to improve its standards of care, and the Attorney General dropped the bid for receivership.

The P&A will continue to monitor the care provided at these homes. Says the P&A's Sandy Bernstein, "The individuals in these houses deserve and are entitled to better supports."

<http://www.uls-dc.org/>

WASHINGTON ADVOCATES RECEIVE NATIONAL AWARD

On Wednesday, November 11, 2009, advocates from around the country converged on Pittsburgh, Pennsylvania for The Arc of the United States' 2009 National Convention. Some of this year's guests of honor included Emily Rogers, of Olympia, Jason Self, of Greys Harbor, and George Adams, of Bremerton, all representatives from Washington State's Self Advocates In Leadership (SAIL) Coalition who will be receiving The Arc of the United States' 2009 Advocacy Matters! Award.

The Arc of the United States' Advocacy Matters! Award is given annually to an advocate, or group of advocates, who've achieved a significant advocacy victory that improved the lives of people with intellectual and developmental disabilities and their families. The award recognizes advocacy efforts that promote and protect the civil and human rights of people with disabilities or that increase resources, services and/or supports that promote their full inclusion and participation in community life.

The SAIL Coalition received the 2009 Advocacy Matters! Award for their work on the Disability History Month Bill of 2008. This bill designated the month of October as Disability History Month and implemented history courses and lessons focused on disability awareness and education into all levels of education throughout the month of October.

SAIL is a statewide coalition of self advocates, that is, people with developmental disabilities that strive to shape the public policies that affect the lives of people with developmental disabilities.

Every year, SAIL, which is funded and supported by the Developmental Disability Council, works with the Washington State legislature to educate representatives and staffers on the impact that funding, budget cuts, and policy changes have on lives of individuals with intellectual and developmental disabilities. One of SAIL's recent advocacy accomplishments was the passing of Washington State House Bill 1835. This bill,

which is more commonly referred to as the Respectful Language Bill, amended sections of state law to include the term "intellectual disability" instead of "mental retardation".

"In Washington, SAIL was founded on the vision that self advocates must have a powerful voice in the legislative and public policy process at the state level," said Emily Rogers, one of the SAIL representatives who accepted the Advocacy Matters! Award at the Arc of the United States National Convention. "Who better to talk with law makers on issues related to developmental disabilities than people with developmental disabilities who either directly enjoy or bear the consequences of the decisions that are made?"

On Saturday, November 14, 2009, Washington's SAIL coalition representatives also presented the Advocacy Matters! breakout session where they discussed some of their local accomplishments and team other advocacy leaders and self advocates how to affect policy and advocacy efforts in their states.

"This is something that we can do in every state," said Jason Self, also of SAIL. "One of the main reasons we're attending the conference is to teach advocates from other states how they can host advocacy days, talk to legislators and staffers and advocate for change. We're going to teach others how they can make sure their voices are heard."

<http://www.sailcoalition.org/>

GEORGIA SYMPOSIUM ON OLMSTEAD DECISION

On Friday, October 23rd, 2009, The Georgia State University College of Law held “The Long Road Home: Perspectives on Olmstead Ten Years Later” in Atlanta, GA. The Center for Leadership in Disability (the UCEDD at GSU) co-sponsored the event with the Atlanta Legal Aid Society, Sutherland Asbill & Brennan LLP, and the Georgia Advocacy Office (Georgia’s P&A).

The symposium marked the tenth anniversary of the United States Supreme Court’s integration mandate in *Olmstead v. L.C.* (1999), a landmark decision considered by many to be the disability parallel to *Brown v. Board of Education*.

Nationally-prominent experts in the field of disability rights and policy discussed the history, current status, and future of Olmstead initiatives, as well as Olmstead’s potential implications for other areas of law. Attorneys from the Olmstead litigation, which originated in metropolitan Atlanta, also participated in the Symposium, as well as United States District Court Judge Marvin Shoob, who ruled on the original summary judgment motion.

The case began in 1995, when Atlanta Legal Aid filed a suit in federal court on behalf of Elaine Wilson and Lois Curtis, who sought to transfer from Georgia Regional Hospital in DeKalb County to a group home where they would continue to receive state-funded treatment.

U.S. District Court Judge Marvin Shoob and the U.S. Court of Appeals for the Eleventh Circuit both ruled in their favor. The State of Georgia appealed to the U.S. Supreme Court in 1999, arguing that states had the right to continue denying community-based services to people

with disabilities because it historically had been in their best interest to receive treatment in nursing homes and mental health institutions.

“Elaine and Lois were determined to gain as much independence as they could ... and we were determined to support [them].” said Susan C. (Sue) Jamieson, an attorney with Atlanta Legal Aid who served as lead counsel.

Sutherland partnered with Atlanta Legal Aid in 1998 to file the opposition to the state’s petition.



“This was not just any case,” said Judith A. O’Brien, Sutherland’s Partner and Pro Bono Chair. “This was a case that literally changed the world for mentally disabled individuals who were unnecessarily segregated in mental hospitals.”

Following the Supreme Court’s decision, Atlanta Legal Aid continued working to ensure Olmstead was implemented appropriately. Sutherland participated in those efforts and filed a class action seeking to extend Olmstead to residents of nursing homes.

Wilson and Curtis left Georgia Regional Hospital in 1995 after filing suit and moved into group homes in metro Atlanta. Wilson passed away in December 2004. Curtis continues to live on her own in a community-based setting. She has found success as a folk artist.

URBAN LEADERSHIP ACADEMY

Missouri's Youth Information, Training, and Resource Center is "Youth LEAD: Leadership, Education, and Advocacy for Youth with Disabilities"

Youth LEAD provides teens and young adults with developmental disabilities with resources and support to set and meet personal goals. Youth LEAD empowers young people to meet their goals for education, employment and inclusive recreation. Youth LEAD also helps youth-serving community organizations increase inclusive programming for individuals with developmental disabilities.

Youth LEAD's Urban Leadership Academy is a leadership opportunity for Kansas City teens and young adults with developmental disabilities. The Urban LEADership Academy is about leadership and empowerment to achieve dreams.

The Urban Leadership Academy takes place one Saturday month, November through May. It utilizes a framework of youth development and leadership that was developed by The Forum for Youth Investment. This framework organizes and identifies a range of outcomes into five broad developmental areas that include:

- Working: Development of career plans and access to career exploration experiences
- Learning: Development of problem solving skills and planning for continuing education.
- Thriving: Development of skills/behaviors that promote physical and emotional wellbeing.
- Connecting: Development of positive social behaviors, skills, and community connections.
- Leading: Development of civic engagement, conflict resolution, and team building skills.

Participants learn about career pathways; access to continuing education; problem-solving techniques;

opportunities for inclusive recreation; how to seek out community resources, and disability laws, culture and practices. The Academies offer experiential, hands-on learning where the participants work together on projects and create their own resource maps and career and personal development plans.

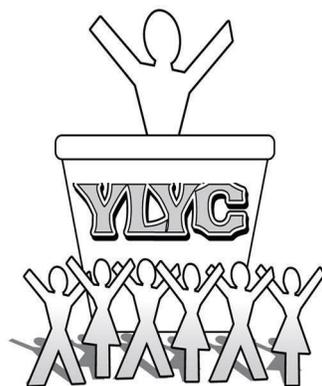
YouthLead reports the following on one Urban Leadership Academy Participant:

It's amazing to see how much growth can occur in a year or over a summer. Of the students last year, Karina was one of the most difficult to understand. She would cry unexpectedly and for reasons she would try and only sometimes succeed to disclose.

After years of living with family members who tended to treat her like a second-rate citizen because of her disability, her self-esteem had dropped so low that the smallest thing would send her to tears. It was a heartbreaking situation. All she ever wanted, she claimed, was to be normal.

She came back this year as a mentor. It was amazing to see the change! Even since the end of the last Urban Leadership Academy in May, she

had grown. When faced with growing anxiety over the prospect of using new technology in the netbooks, something that she'd struggled with the year before, she has seemed to prevail. While last year she may have given up quickly, this year she was determined to learn, and sought help from her brother. She seems to have found her grace in helping others. While still a little quiet and shy, there is hope in her actions. She is even planning on participating in a fashion show that raises money to provide scholarships for young Latina women. Karina seems to have realized that everyone has their own versions of normal.



COLLABORATION CONTINUES IN KENTUCKY

On August 21, 2009, the Kentucky DD Network conducted its 5th Annual Collaboration Meeting. Representatives from the Council, P&A, and UCEDD met to continue their commitment to a collaborative effort to speak with one voice and work together on some of the issues most important to Kentuckians with and without disabilities.

At the inaugural meeting, participants decided to work together on a mentoring project for children with disabilities. Thus, "Project Dream" was born, and at the 2009 meeting, it was evident that this dream has come to fruition. When the DD network initially approached Big Brothers Big Sisters (BBBS) to partner in Project Dream, only 5% of the children served had disabilities. BBBS and Project Dream now serve 80 children with disabilities each year.

The BBBS staff was trained by KDDN staff and other agencies familiar with developmentally disabilities. The staff receives ongoing training and uses a Best Practices guide which is utilized when enrolling Littles and Bigs and when supporting Project Dream matches. Partnerships were created with different agencies already working with this population of children. These partnerships are utilized as a means of volunteer and child recruitment, referrals for families, and educational resources for staff and Bigs.

At the DD Network Meeting, a PowerPoint Presentation provided a thorough explanation of the project, including the story of Conner and his Big Brother Justin, who have been matched for more than a year. Last year Conner's grandmother wrote a letter thanking the agency for

making such a great match.

"Placing him in the Big Brother Program was the best thing I have done for my grandson since his Dad died," she said. "Not every Big Brother will be like Justin. But we can Clone him through the educational process that each person needs to become a better Big Brother for these children. They are our future and the Justins will make them become better through education and understanding."



In addition, the 2009 DD Network meeting included a focus on transportation. As part of the initiative to provide training to transportation personnel on the needs of individuals with developmental disabilities, the UCEDD created and filmed a set of scenarios that individuals with developmental disabilities often encounter in accessing

public transportation. The scenarios were filmed "on location" (in actual transportation situations, such as riding and waiting for busses, with the assistance of the drivers and staff of Lexington public transportation company, LexTran). Each scenario included a "what went wrong" version and a "how to do it right!" version. Discussion and critique of the methods used followed.

Other highlights of the DD Network meeting included the Council's presentation of an interactive "Jeopardy" competition on emergency preparedness and presentations by two P&A Advisory Board members. One of the presenters was Robert Denton; his story is available on the following page.

SPOTLIGHT ON SELF-ADVOCATES: ROBERT DENTON

The following is Robert Denton's story, in his own words. It was adapted from his presentation at the Kentucky DD Network meeting in August.

Hi, My name is Robert and this is my story. I grew up in Louisville with my family. I enjoyed hunting and fishing with my dad and still spend the holidays at home with him.

During a difficult time in my life, I was taken from my home and placed in an institution called Oakwood. It was not a nice place to live. I felt rejected there and wanted to go home. For me life at Oakwood was miserable. I got beat up frequently and did not get to chose the things that make life enjoyable. Others decided what I would eat and when I would get up! There were

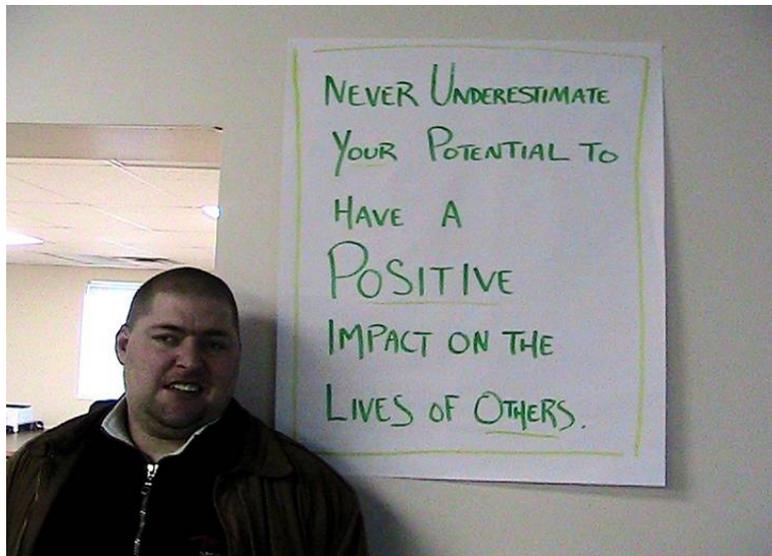
times that I would try to sleep in and I would not get to eat breakfast. Other times staff would beat me up! During the day I was bored. I would sit around watching TV and watching my back! I spoke with someone from Protection and Advocacy in the hallway at the institution. I told them I was being mistreated and wanted to leave.

The P&A helped me move back into the community. I moved to a group home and lived with a housemate that I didn't choose. Eventually I ended up back in the hospital at U of L. My home provider decided to "drop me off" and no longer wanted to support me. I now had a bad reputation and no one wanted to provide services to me.

I was in respite when I met Jill from Community Living Services. We had dinner at my favorite restaurant, Tumbleweed. I like to eat so Jill bought me two dinners.

We became friends. At first I had a difficult time allowing CLS and my staff at Lifelinks to accept me. Because I was rejected by others I rejected myself and my friends.

Now I am doing acts of kindness for other people. I am expressing myself in a new way. I even had a relationship with a woman. Things didn't work out but I learned a lot. I smile now because I have a much more meaningful life. Now I touch people with kindness. I even give people a hug if I really like them.



Now I have a job as a safety coordinator. I check smoke detectors, water temperatures, and fire extinguishers. I also enjoy doing odds and ends to keep things exciting. My friends and I like to go out and enjoy Louisville. We play poker, bingo and to the fair. I am a night owl, so I like to go dancing at the local bars. I like to meet new people, especially good looking women.

As a self advocate equal treatment matters to me. Now people treat me with respect and use words that build me up. I like the way people talk to me and ask my opinion about how I want to live my life. I am learning that I am an important person and people like me. This makes difficult times easier to go through.

The principles of Self Determination, Gentle Teaching and Person Centered Thinking have helped me learn how to live a responsible, joyful life. Now I live the life I've always wanted!