



**Technical Bulletin #2
Disability Information
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This Technical Bulletin provides title IV-E agencies with information on how to correctly map certain diagnosed conditions from an agency's information system to the Adoption and Foster Care Analysis and Reporting System (AFCARS).

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I. Introduction

A. AFCARS Background

AFCARS is designed to collect uniform, reliable information on children who are under the responsibility of the title IV-B/IV-E agency for placement, care, or supervision. The collection of adoption and foster care data is mandated by section 479 of the Social Security Act (the Act). The requirements for AFCARS are codified in Federal regulation at 45 CFR 1355.40. Effective October 1, 2009, section 479B(b) of the Act authorizes direct Federal funding of Indian Tribes, Tribal organizations, and Tribal consortia that choose to operate a foster care, adoption assistance and, at Tribal option, a kinship guardianship assistance program under title IV-E of the Act. On January 6, 2012, the Administration for Children and Families (ACF) issued an Interim Final Rule (IFR)² to implement statutory provisions related to the Tribal title IV-E program. The Federal regulations at 45 CFR 1355.40 were amended to apply the same regulatory requirements for data collection and reporting to a Tribal title IV-E agency as are applied to a State title IV-E agency.

AFCARS was established to provide data that would assist in policy development and program management. Data can be used by policymakers at the Federal, Tribal, and State levels to assess the reasons why children are in foster care and to develop strategies to prevent their unnecessary placement into foster care. Specifically, the data include information about foster care placements, adoptive parents, and length of time in foster care, and make it possible to identify trends in particular geographic areas. Also, the data enable the Children's Bureau to administer the Federal title IV-E foster care and adoption assistance programs more effectively. The Children's Bureau and ACF use these data for a number of purposes, including:

- responding to Congressional requests for current data on children in foster care or those who have been adopted;
- responding to questions and requests from other Federal departments and agencies, including the General Accounting Office (GAO), the Office of Management and Budget (OMB), the Department of Health and Human Services' Office of Inspector General (OIG), national advocacy organizations, States, Tribes, and other interested organizations;
- developing short and long-term budget projections;
- developing trend analyses and short and long-term planning;
- targeting areas for greater or potential technical assistance efforts, for discretionary service grants, research and evaluation, and regulatory change; and
- determining and assessing outcomes for children and families.

Additionally, the AFCARS data are used specifically in the

- Adoption Incentives Program;

² 77 FR 896 (January 6, 2012)

- Child Welfare Outcomes Report;
- Child and Family Services Reviews (CFSRs);
- Title IV- E Eligibility Reviews; and
- Allotment of funds in the Chafee Foster Care Independence Program (CFCIP).

B. Overview of the Technical Bulletin

The purpose of this Technical Bulletin is to provide title IV-E agencies with information regarding the data elements related to a child's diagnosed disability (foster care data elements #10 - 15, and adoption data elements #11 - 15) in AFCARS. The Children's Bureau routinely reviews and uses AFCARS data in conducting its various monitoring activities, including the CFSRs; Title IV-E Eligibility Reviews; Statewide Automated Child Welfare System (SACWIS) Assessment Reviews; and AFCARS Assessment Reviews (AAR). AFCARS is also the primary foster care and adoption data source for Federal reporting and policy development.

Review of AFCARS data regarding the characteristics of a child's physical and mental health, findings from the AARs to date, and technical assistance reports indicate that many title IV-E agencies may be underreporting or incorrectly reporting the related data elements. Reliable information about foster and adopted children's disabilities is critical contextual information for assessing, at the systemic and individual levels, the needs and available resources for foster care placements, adoptive homes, services, and other factors required to achieve positive outcomes for children. High-quality data can help inform child welfare policy and practice, ensure efficient use of resources, and establish effective data-informed decision making.

This Technical Bulletin reviews the regulatory definitions for the AFCARS data elements related to disability, provides a discussion on and suggestions for improving timely and accurate entry of a professional diagnosis, and provides information regarding disabilities that is specific to the adoption file of AFCARS. Although both the adoption and the foster care files contain the same disability category data elements, there are differences between when a diagnosed condition must be reported for each of these files and these differences also are discussed.

The appendix attached to this Technical Bulletin provides a listing of diagnoses. This table is populated from two key sources: the International Classification of Diseases (ICD-9) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). Both of these directories are valuable resources to title IV-E agencies when updating or expanding the list of diagnoses used in its information system. Additionally, the appendix provides guidance for mapping a diagnosis to an AFCARS data element. A title IV-E agency is not required to include all of the conditions listed in the appendix. Instead, this listing is a reference for how to map certain conditions to those elements required to be reported in AFCARS.

The enclosed list is not intended to be an exhaustive listing of all medical conditions and whether they should or should not be mapped to the AFCARS values for data elements

#11 - 15. As a part of the AARs conducted in States to date, it was found that most of the State's with a SACWIS have a health section where caseworkers are able to record a child's medical diagnosis, the date it was diagnosed, and the date the child recovered from the disease or received treatment. Also, some States have copied the complete ICD-9 codes into their system. In general, most of the codes are not applicable for mapping to AFCARS, but those that are most likely to be applicable are included in the appendix . If a title IV-E agency has a child diagnosed with a medical condition that does not appear to fit one of the included categories/diseases, contact the National Resource Center for Child Welfare Data and Technology for assistance.

II. Foster Care Disability Information

This section focuses on the collection and reporting of the disability information in the AFCARS foster care file, data elements #10 - 15.

A. Regulatory Definitions

Appendix A, Section II - Foster Care Data Elements, of Part 1355 defines the disability data elements. Data element #10 asks if a child has been clinically diagnosed with a disability. A response of "yes" requires that at least one data element #11 through 15 have a response of "yes" to indicate the applicable disability(ies). If a child has multiple diagnosed disabilities, then all the diagnoses must be entered. The following are the regulatory definitions for foster care data elements #10 through 15.

Element #10 Has the Child been clinically diagnosed as having a disability(ies)?

"Yes" indicates that a qualified professional has clinically diagnosed the child as having at least one of the disabilities listed below. "No" indicates that a qualified professional has conducted a clinical assessment of the child and has determined that the child has no disabilities. "Not yet determined" indicates that a clinical assessment of the child by a qualified professional has not been conducted.

#11 Mental Retardation

Significantly subaverage general cognitive and motor functioning existing concurrently with deficits in adaptive behavior manifested during the developmental period that adversely affect a child's/youth's socialization and learning.

#12 Visually/Hearing Impaired

Having a visual impairment that may significantly affect educational performance or development; or a hearing impairment, whether permanent or fluctuating, that adversely affects educational performance.

#13 Physically Disabled

A physical condition that adversely affects the child's day-to-day motor functioning, such as cerebral palsy, spina bifida, multiple sclerosis, orthopedic impairments, and other physical disabilities.

#14 Emotionally Disturbed

A condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree: an inability to build or maintain satisfactory interpersonal relationships; inappropriate types of behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression; or a tendency to develop physical symptoms or fears associated with personal problems. The term includes persons who are schizophrenic or autistic³. The term does not include persons who are socially maladjusted, unless it is determined that they are also seriously emotionally disturbed. The diagnosis is based on the Diagnostic and Statistical Manual of Mental Disorders Third Edition) (DSM III) or the most recent edition. [Note: the current edition is DSM-IV.]

#15 Other Medically Diagnosed Condition Requiring Special Care

Conditions other than those noted above which require special medical care such as chronic illnesses. Included are children diagnosed as HIV positive or with AIDS.

B. Data Discussion

AFCARS Assessment Reviews have been completed in 41 States since FFY 2001. A review of the reports in regard to disability data indicate there are two key areas in which data can be improved:

- Timely and accurate entry of a professional diagnosis; and
- Mapping and program code/screen design.

B-1. Timely and Accurate Entry of a Professional Diagnosis

AFCARS regulations require that a title IV-E agency report whether a qualified professional has diagnosed a child with a disability. Frequently, this information is not immediately available when a child enters foster care. However, once a child enters foster care, most title IV-E child welfare agencies require that a child have a health assessment. The medical assessment report, if performed by a qualified professional, is one potential source for providing an accurate response to whether a child has a disability and, if so, to accurately determine which category (mental retardation, visually or hearing impaired, physically disabled, emotionally disturbed or other medically diagnosed conditions requiring special care) best captures the type of disability. The reports from mental health visits may be another source of disability information.

During the case file review segment of prior AARs, the review teams have found that some children are in foster care for years and the AFCARS data indicate a response of "not yet determined" for data element #10. However, in the paper case files medical reports are found to indicate the child does indeed have a diagnosis that should be mapped to an AFCARS value, or the child has no conditions that are to be mapped to

³ Due to comments by many State staff during AFCARS assessment reviews and technical assistance visits, we are mapping "autism" to element #15, "other medically diagnosed condition" instead of treating it as an emotional disturbance.

AFCARS. In this instance, data element #10 should have contained a “yes” or “no” value. During the reviews, it is often found the child welfare agency has a policy that the child must be seen by a health professional within 30 to 60 days of having entered foster care. Title IV-E agencies may want to consider developing a method to ensure that this information is entered into the automated information system in a timely manner. One approach would be for supervisors and caseworkers to review this information at the time of the periodic review to ensure its accuracy and timeliness. Another approach, used by some title IV-E agencies, is to have medical professionals such as nurses enter the medical information into the database.

In addition to manual methods, a title IV-E agency may want to develop an automated edit check that can link the diagnosed disabilities fields to the child's current placement field. For example, if a caseworker enters a child's current placement as being a therapeutic foster care setting, but there are no diagnosed disability conditions, then an error message is displayed reminding the caseworker to update the medical diagnoses screen. Another way to monitor this data is to generate a report listing all children in therapeutic foster care settings against the number of children with a diagnosed condition.

Another challenge with data accuracy is overuse of “other medically diagnosed condition.” This may be the result of caseworkers being uncertain as to which category of disability to use. Potential solutions may be to add a “Help” button for the caseworker to get information on diagnoses or provide staff training on when it is most appropriate to select these data elements.

In addition to system checks and supervisory oversight, a review of disability information (as well as other AFCARS data elements) at the time of the child's periodic review encourages improved data quality. A quality assurance review by both program and data staff, in conjunction with the use of data quality and frequency utilities, will help identify data errors. The questions to answer are “Do the data make sense?” and “Do the numbers in the frequency report reflect what is generally known about the children in the title IV-E agency's foster care system?”

B-2. Mapping and Program Code/Screen Design

Incomplete or erroneous mapping can result in poor data quality and misinformation. Mapping is the matching of the title IV-E agency's code for specific information to the appropriate AFCARS value. Mapping is included within the program code that extracts the agency's data. For example, information is entered in client characteristics, which is then mapped to the appropriate AFCARS disability data elements. Specifically, if a child is professionally diagnosed as having Down Syndrome, the entry of that diagnosis should map to data element #11, mental retardation. It is possible, however, that conditions or diagnoses may be mapped to wrong categories. For instance, in this example of a child with Down Syndrome, mapping of that diagnosis to any data element other than mental retardation is erroneous and needs to be identified. Once the errors are identified, a programmer will need to make the necessary corrections.

If a title IV-E agency already has a comprehensive data system where all medical information is entered, the AFCARS data should be extracted from this system and mapped to the appropriate five AFCARS data elements. One common finding of noncompliance in the AARs has been due to in duplicate data entry. In those information systems that have a comprehensive health section some also have another section (for example, a child's characteristics screen) where the five AFCARS disability categories are located. This results in duplicate data entry and may contribute to an underreporting of the data or an increase in data entry errors. In general, the program code extracting the data pulls it from the characteristics screen and not the comprehensive health screen.

The AARs conducted to date have found instances in which the response to data element #10, regarding whether a child has a diagnosed disability, is determined by the information system logic. The system has been programmed to select "yes" if the caseworker has selected any of the categories (foster care data elements #11-15). If none of the categories are selected, then some agencies report "not yet determined" as the response to whether a child has been diagnosed with a disability. This method may result in underreporting of the number of children determined to have a disability. The AFCARS definition for "not yet determined" means that a qualified professional has not yet conducted a clinical assessment of the child.

In addition to the above default⁴ to "not yet determined," another type of default is to "no," if the caseworker does not specify a disability; this method results in a false "no" response in AFCARS. In this instance, the validity of the data would be in question since it cannot be determined that the child actually has no health conditions that are mapped to AFCARS or that the caseworker has not completed the fields on the system.

In the above two examples, the choices of "yes," "no," or "not yet determined" should be added to the input screens on the system. In both of these types of defaults, an automated response of "no" or "not yet determined" may yield misleading data or mask that the caseworker is not properly filling out the screen that lists the types of client disabilities. If foster care data element #10 is reported as "no" or "not yet determined," foster care data elements #11-15 should be reported as "0: does not apply." Missing data in foster care data elements #10 - 15 must be mapped to blank.

Another finding of the AARs has been that agencies incorrectly map screenings for conditions, medical equipment (including prostheses), family history of a condition, and childhood diseases such as the measles, chickenpox, etc. to elements #10 – 15. None of these conditions are to be mapped to the AFCARS values. In the case of medical equipment, the title IV-E agency should map the diagnosed condition that warrants the medical equipment.

⁴ A default is when the computer program code incorrectly maps missing data to a valid AFCARS value.

III. Adoption Special Needs Information

This section focuses on the collection and reporting of the disability data elements in the AFCARS adoption file.

A. *Regulatory Definitions*

Appendix B, Section II – Adoption Data Elements of 45 CFR 1355 define the special needs data elements. In the adoption file, the focus is on whether the child was determined to have a special need by the title IV-E agency. The data elements and definitions involved are the following:

Adoption #9, Has the title IV-E Agency Determined that the Child has Special Needs?
Use the title IV-E agency definition of special needs as it pertains to a child eligible for an adoption subsidy under title IV-E. The valid response is either “yes” or “no.”

Adoption #10, Primary Factor or Condition for Special Needs.
Indicate only the primary factor or condition for categorization as special needs and only as it is defined by the title IV-E agency. The valid responses are the following:

Racial/Original Background -- Primary condition or factor for special needs is racial/original background as defined by the title IV-E agency.

Age -- Primary factor or condition for special needs is age of the child as defined by the title IV-E agency.

Membership in a Sibling Group to be Placed for Adoption Together -- Primary factor or condition for special needs is membership in a sibling group as defined by the title IV-E agency.

Medical Conditions or Mental, Physical, or Emotional Disabilities -- Primary factor or condition for special needs is the child's medical condition as defined by the title IV-E agency, but clinically diagnosed by a qualified professional.

Other -- [title IV-E agency defined special need]

The AFCARS regulation does not provide a definition for the special needs category “other.” However, this category is meant to reflect the policy in the Child Welfare Policy Manual, Section 8.2B.11, question 1.

Types of Disabilities -- Data are only to be entered if the response to adoption element #10 was “Medical Conditions, or Mental, Physical, or Emotional Disabilities.”

For the adoption file, the categories for diagnosed conditions (adoption data elements #11-15) are the same as those listed in the foster care file (foster care data elements #11-15), and the foster care mapping list also applies to adoption. However, there are

differences between the foster care file and the adoption file on the circumstances for reporting this information, as explained below in section 3.2.

In the adoption file, the guiding question is "Has the agency determined the child to be special needs?" If the answer is "yes," and the primary basis for special needs is "medical conditions or mental, physical or emotional disabilities," then all applicable disabilities should be indicated by selecting "applies" where appropriate for adoption data elements #11-15. If, however, the child's primary basis for special needs is *not* "Medical Conditions or Mental, Physical, or Emotional Disabilities," then adoption data elements #11-15 are to be coded as zeroes (condition does not apply).

B. Data Discussion

The data discussion in Section II.B above concerning the foster care data elements pertain to adoption data elements #11 -15 as well. The same issues and suggested approaches to improving data quality apply to both the foster care and adoption elements. Therefore, this section will focus on issues found through the AARs that are related to data elements #9 and #10.

A finding from the AARs to date has been that many agencies do not include the question "has the agency determined special needs (adoption data element #9)?" on any screen in the information system. Instead, the response in AFCARS to this question is based on the response to data element #10, "primary basis for special need." This approach is acceptable; however, the title IV-E agency needs to ensure that the numbers are consistent between the two data elements. For instance, if there are 50 responses of "no" in data element #9, then there should be 50 responses of "not applicable" in data element #10.

Another area to ensure data consistency is between the responses in data element #10 and data element #33 ("Is child receiving a monthly subsidy?"). The response to data element #33 should be equal to, or less than, the aggregate responses to the values for special needs in data element #10. If more children are receiving monthly subsidies than there are children who have been identified as being special needs, then the records should be reviewed for accuracy and completeness. Additionally, a common error that has been found when reviewing the program logic for data element #33 is that Medicaid-only subsidies are not included. This could contribute to an underreporting of the information for data element #33.

Relative to data element #10, it has often been found that the automated information system does not identify a field for a "primary" basis on the input screen. Rather, the screen lists all of the possible options available to a caseworker, and he/she selects all that apply. Although this may be valuable information for an agency's use, it does not meet the reporting requirements for AFCARS. Additionally, the caseworker, not the programming logic, should be determining what the biggest barrier was to the child's adoption.

Appendix A
Resource List of Disability Information

AFCARS DISABILITY/SPECIAL NEEDS TABLE

The following table lists several medical/emotional conditions that may be mapped to AFCARS for foster care data elements #11-15 and adoption data elements #11-15. This is not an exhaustive list of all conditions that a title IV-E agency may be using in an Information System. If a title IV-E agency includes other chronic disease categories, or other mental health/behavior diagnoses, and wants to have its mapping reviewed, contact the National Resource Center for Child Welfare Data and Technology (NRC-CWDT) (www.nrccwdt.org). In some instances, the ICD-9 code is included.

#11 Mental Retardation: "Significantly subaverage general cognitive and motor functioning existing concurrently with deficits in adaptive behavior manifested during the developmental period that adversely affect a child's/youth's socialization and learning."

Down Syndrome
Borderline Intellectual Functioning
Hydrocephalus
Microcephaly
Mental Retardation (all degrees)

#12 Visually/Hearing Impaired: "Having a visual impairment that may significantly affect educational performance or development; or a hearing impairment, whether permanent or fluctuating, that adversely affects educational performance."

Blindness and Low Vision (ICD-9: 369)
Cataracts
Congenital anomaly of the eye
Glaucoma
Diabetic Retinopathy
Retinal Detachment and Defects (ICD-9: 361)
Visual Disturbances (ICD-9: 368)
Deaf
Hearing Loss (ICD-9: 389)

#13 Physically Disabled: "A physical condition that adversely affects the child's day-to-day motor functioning, such as cerebral palsy, spina bifida, multiple sclerosis, orthopedic impairments, and other physical disabilities."

Arthritis
Brittle Bones/Osteogenesis Imperfectus
Cerebral Palsy
Chronic Motor Tic Disorder
Club Foot
Diplegia
Multiple Sclerosis
Muscular Dystrophy

Myasthenia Gravis
Paralysis - Paraplegic, Quadriplegic, Diplegic
Poliomyelitis
Rheumatoid Arthritis (juvenile)
Spina bifida

#14 Emotionally Disturbed: "A condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree: An inability to build or maintain satisfactory interpersonal relationships; inappropriate types of behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression; or a tendency to develop physical symptoms or fears associated with personal problems. The term includes persons who are schizophrenic or autistic. The term does not include persons who are socially maladjusted, unless it is determined that they are also seriously emotionally disturbed. The diagnosis is based on the Diagnostic and Statistical Manual of Mental Disorders Third Edition) (DSM III) or the most recent edition." [Note: the current edition is DSM-IV.]

Adjustment Disorders

Attention Deficit and Disruptive Disorders:

ADD

ADHD

Conduct Disorder

Oppositional Defiant Disorder

Anxiety Disorders:

Agoraphobia

Obsessive Compulsive Disorder

Panic Disorder including Generalized Panic Disorder

Phobias

Post Traumatic Stress Disorder (PTSD)

Separation Anxiety Disorder

Eating Disorders:

Anorexia Nervosa

Bulimia

Impulse Control Disorder

Mood Disorders:

Bipolar Disorder

Cyclothymic Disorder

Depressive Disorders

Dysthymic Disorder

Personality Disorders:

Antisocial Personality Disorder

Avoidant Personality Disorder

Borderline Personality Disorder

Dependent Personality Disorder

Histrionic Personality Disorder

Obsessive Compulsive Personality Disorder

Paranoid Personality Disorder
Schizoid Personality Disorder
Schizotypal Personality Disorder
Reactive Attachment Disorder
Schizophrenic and Other Psychotic Disorders:
Delusional Disorder
Psychotic Disorder
Schizophrenia
Schizophreniform Disorder
Schizoaffective Disorder
Somatoform Disorder
Tourette Syndrome

#15 Other Medically Diagnosed Condition: "Conditions other than those noted above which require special medical care such as chronic illnesses. Included are children diagnosed as HIV positive or with AIDS."

Aplastic Anemia
Asperger's Syndrome
Asthma*
Autistic Disorder
Acquired Immunodeficiency Syndrome (AIDS)
Blood disorder that required hospitalization once a month
Cancers
Childhood Disintegrative Disorder (Pervasive Developmental Disorder)
Chronic Granulomatous Disease
Cleft palate
Coagulation Defects
Congenital cystic lung
Congenital heart anomaly
Crohn's disease
Cushing's syndrome
Cystic Fibrosis
Diabetes
Disorders Involving The Immune Mechanism (code 279)
Encephalopathy
Epilepsy
Fetal alcohol syndrome
Fetal drug addiction
Heart murmur, vigorous activity curtailed
Heart disease
Hemophilia
Hypertension
Human Immunodeficiency HIV Disease (HIV)
Human T-Cell Lymphotropic Virus-III
Other Human T-Cell Lymphotropic Virus-III

Immunodeficiency
Kidney disease
Klinefelter's syndrome
Learning Disability
Leukemia
Liver disease
Lupus
Malignant Neoplasms (Malignant tumors)
Misplaced facial feature
Organic Brain Syndrome
Pancreatic Disease
Pervasive Developmental Disorders Not Otherwise Specified
Rett Disorder
Sarcomas
Seizure Disorder
Sickle cell anemia
Shaken Infant Syndrome
Late Effects Of Tuberculosis (ICD-9: 137)
Nutritional deficiency