Adoption and Foster Care AFCARS Analysis and Reporting System

Technical Bulletin #14
Disability Information
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This Technical Bulletin provides States with information on how to correctly map certain diagnosed conditions from a State's information system to the Adoption and Foster Care Analysis and Reporting System (AFCARS).

This document is organized into the following sections:

1. Introduction

The purpose of this technical bulletin is to provide States 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 the Adoption and Foster Care Analysis and Reporting System (AFCARS). The Children's Bureau routinely reviews and uses AFCARS data in conducting its various monitoring activities, including the Child and Family Services Reviews (CFSR); 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, and findings from the AARs, indicate that the related data elements are underreported. 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. As data are utilized more frequently for informing child welfare policy and practice, improving data quality increases the accuracy of the numbers used to assess the current status, plan and pursue needed changes, and measure the resulting outcomes. Data are a management tool that allows for better planning, resulting in a better allocation of resources and opportunities to collaborate between various systems in responding to gaps in policies, programs, and services.

This technical bulletin reviews the regulatory definitions for the AFCARS data elements related to disability, provides a discussion on timely and accurate entry of a professional diagnosis, which includes suggestions for improving data quality for the AFCARS files, and provides information regarding disabilities that is specific to the adoption file of AFCARS. Both the adoption and the foster care files contain the same disability category data elements; however, the differences between when a diagnosed condition must be reported for each of these files in relation to a child are also discussed.

An appendix is attached that provides a listing of diagnoses. This diagnoses 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 States when updating or expanding the values used in its information system. Additionally, the appendix provides guidance for mapping a diagnosis to an AFCARS data element. A State 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 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. Many States have within their SACWIS a health section where case workers 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 completing the attached list, the ICD-9 codes were reviewed for possible inclusion. In general, most of the codes are not applicable for mapping to AFCARS. Those that seem more

applicable are included in the list. If a State has a child diagnosed with a medical condition that does not seem to fit one of the included categories/diseases, contact the National Resource Center for Child Welfare Data and Technology for assistance.

1.1 AFCARS Background

AFCARS is designed to collect uniform, reliable information on children who are under the responsibility of the State 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 requirements for AFCARS are codified in Federal regulation at 45 CFR 1355.40. As of October 1, 1994, States are required to collect and submit the AFCARS data semi-annually, in May and November.[1]

AFCARS was established to provide data that would assist in policy development and program management at both the State and Federal levels. The data can assist policymakers in assessing the reasons why children are in foster care and in developing strategies to prevent children from being placed in foster care unnecessarily. 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 Administration for Children and Families (ACF) to administer the Federal title IV-E foster care and adoption assistance programs more effectively. ACF uses 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 DHHS Office of Inspector General (OIG), national advocacy organizations, States, 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;
- Child Welfare Outcomes Report;
- Child and Family Services (CFS) Reviews;
- Title IV- E Eligibility Reviews; and
- Allotment of funds in the Chafee Foster Care Independence Program (CFCIP).

[1] AFCARS report periods are based on the Federal fiscal year. Report periods are October 1 – March 31 (data are due no later than May 15) and April 1 – September 30 (data are due no later than November 14).

2. 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.

2.1. Regulatory Definitions

Appendix A, Section II - Foster Care Data Elements, of 45 CFR 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 the entry of a diagnosis, which is mapped to the appropriate data element #11 through 15. 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 autistic[2]. The term does not include persons who are socially maladjusted, unless it is determined that they

[2] 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.

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
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.

2.2 **Data Discussion**

AFCARS Assessment Reviews have been completed in 26 States over the past six years. 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.

2.2.A Timely and accurate entry of a professional diagnosis.

AFCARS regulations require that a State 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 States 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 an AFCARS Assessment Review, the review teams have uncovered that some children are in foster care for years and the AFCARS data indicate a response of "not yet determined." 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 AFCARS. During the reviews, it is often found the State has a policy that the child must be seen by a health professional within 30 to 60 days of having entered foster care. States may want to consider developing a method to ensure that this information is entered into the information system in a timely manner. One example would be for supervisors and case workers to review this information at the time of the periodic review to ensure its accuracy and if it is up-to-date.

From AFCARS Assessment Reviews, we have also learned of methods States employ to ensure more accurate data. Some States have medical professionals such as nurses enter the medical information into the State's database.

Another method identified is an internal edit check within the information system between the diagnosed disabilities fields to the child's current placement field. States that have employed

this method use an edit check for certain types of placement settings, for instance a therapeutic foster care setting. If a case worker enters this as the child's current placement setting, but there are no diagnosed disability conditions, then an error message is displayed reminding the case worker to update the medical diagnoses screen. Another way to monitor this data is to run 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 not being sure which category of disability to use. A "Help" button to get information on diagnoses could alleviate this problem. Another would be a refresher course 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, and the running of data and frequency utilities, will help identify data errors. The question to answer is "Do the data make sense?" Do the numbers in the frequency report reflect what is generally known about the children in the State's foster care system?

2.2.B Mapping and Program code/screen design.

Another reason for incomplete or inaccurate information is incomplete or erroneous mapping. Mapping is the matching of the State's code for specific information to the appropriate AFCARS value. Mapping is included within the program code that extracts the State's data. For example, information is entered in client characteristics, which is then mapped to answer the disability data elements. Specifically, if a child is professionally diagnosed as having Down Syndrome, the entry of that diagnosis should match to data element # 11, mental retardation. 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 State already has a comprehensive data system where all medical information is entered, this is the area that the AFCARS data should be extracted from the system to the proper five AFCARS data elements. Some State information systems have a comprehensive health section and on another screen (for example, a child's characteristics screen) the system also has the AFCARS disability categories. This results in duplicate data entry and may contribute to an underreporting of the data. In general, the program code extracting the data pulls it from the characteristics screen and not the comprehensive health screen.

The AFCARS Assessment Reviews conducted so far have found instances in which the response to data element # 10, regarding whether a child has a diagnosed disability, is determined by the computer 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 State systems select "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.

Besides the above default[3] 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, one cannot be positive that the child actually has no health conditions that are mapped to AFCARS, or that the case worker has not completed the fields on the system.

In the above two examples, the choices of "yes," or "no," or "not yet determined" needs to 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.

In reviewing States' codes used for these data elements, we have found that States' incorrectly map screenings for conditions, medical equipment (including prostheses), family history of a condition, and childhood diseases such as the measles, chickenpox, etc. None of these conditions are to be mapped to the AFCARS values. In the case of medical equipment, the State needs to map the diagnosed condition that warrants the medical equipment.

3. Adoption Special Needs Information

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

3.1 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 State agency. The data elements and definitions involved are:

Adoption #9, Has the State Agency Determined That the Child has Special Needs?
Use the State 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 State. The valid responses are the following:

> Racial/Original Background -- Primary condition or factor for special needs is racial/original background as defined by the State.

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

Age -- Primary factor or condition for special needs is age of the child as defined by the State.

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 State.

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 State, but clinically diagnosed by a qualified professional.

Other [State defined special need]

Types of Disabilities -- Data are only to be entered if response to [#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 for foster care (foster care data elements #11-15) and the same 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.

Also, 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.

In the adoption file, the guiding question is "Has the agency determined the child to be special needs? Consequently, if 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. The only time that any of the categories of diagnosed disabilities are to be reported in the adoption file is if the primary basis for special needs is "medical conditions or mental, physical or emotional disabilities." In this case, all applicable disabilities should be indicated by selecting "applies" where appropriate for adoption data elements #11-15.

3.2 **Data Discussion**

In regard to adoption data elements #11 - 15, the issues and approaches to good data entry are the same as those discussed in the foster care section. This section will focus on issues found through the AFCARS Assessment Reviews for data elements #9 and #10.

Many States do not include the question "has the agency determined special needs (adoption data element #9)?" 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 State needs to ensure that the numbers are consistent between the two data elements. For instance, if there are 50 responses to "no" in data element #9, then there should be 50 responses to "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 there are more responses indicating that the child is receiving a monthly subsidy, then the records should be reviewed for accuracy and completeness.

One error that is often found when reviewing States' 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.

In regard to data element #10, an error often found in States' program logic is the programming of a hierarchy into the extraction logic. This is often due to the State's information system not identifying on the input screen a field for a "primary" basis. Instead, the screen lists all of the possible options available to a case worker in the State and he/she selects all that apply. While we recognize this is valuable information for a State's use, it does not meet the reporting requirements for AFCARS. Additionally, the case worker, not the computer logic, should be determining what the biggest barrier was to the child's adoption.

Enclosure: AFCARS Disability/Special Needs Table