

SSA/AUCD Case Assessment Project: Findings from First Three Years (1998-2001)

Disability Determinations Services Administrators' Letter NO. 596

To: Disability Determination Services Administrators

Subject: SSA/AUCD Case Assessment Project: Findings from First Three Years (1998-2001)

I am pleased to provide you with the following summary of the first 3 years of the joint SSA/Association of University Centers on Disabilities (AUCD) project. We developed the text below together with the AUCD, and they are sharing it with their members.

As you will see below, the project has been very successful, thanks in large part to your cooperation and willingness to try something new. In the near future, you will begin to see even more tangible results from these efforts, as we begin training, revise forms, and provide you with tools that we hope will help in your case processing.

Project Purpose

The Social Security Administration (SSA) Office of Disability began funding an interdisciplinary case assessment project with the American Association of University Affiliated Programs (now renamed the Association of University Centers on Disabilities, or AUCD) in 1998-1999. The project continued in 1999-2000 and 2000-2001, and is still continuing. This report presents an overview of the project's first three years.

The purpose of the project was to determine if interdisciplinary assessments change the outcome of case decisions or improve the adjudication process in selected cases for children. The agency was particularly interested in learning about specific kinds of examinations, assessment instruments and tests that may improve case adjudication and ways to enhance adjudicator training. SSA approached AUCD about the project because of its members' substantive expertise and interdisciplinary approach to assessments. An added benefit was the ability of the programs to recommend services for participating children even if they did not qualify for SSI benefits.

AUCD represents the 61 University Centers for Developmental Disabilities (UCDDs, formerly called University Affiliated Programs or "UAPs") and 35 Leadership Education in Neurodevelopmental Disabilities (LEND) programs across the country. UCDD/LEND programs are interdisciplinary centers that provide pre-service and continuing education as well as technical support to professionals working in the field of developmental disabilities and to individuals who have developmental disabilities and their families. UCDD/LEND programs provide training and technical assistance, conduct research, perform diagnostic and assessment services, and link individuals and families to community services and supports.

Project Overview

In the project's first three years, 28 UCDD/LEND programs conducted interdisciplinary assessments in 23 States. The sites saw over 500 children of different ages who were applying for benefits or whose continuing eligibility was in question, and recipients at age 18 who were undergoing review for continuing eligibility. Each individual referred for an assessment would have been denied SSI eligibility, or would have lost eligibility, based on the file information that the Disability Determination Services (DDS) had at the time of the referral. DDSs are State agencies that make disability determinations for SSA.

Each year, the sites assessed different groups of children and young adults. They included the following:

School-age children (ages 6-15) classified as having mental retardation, borderline intellectual functioning or speech/language deficit (Year 1)

Continuing disability reviews of children who qualified because of low birth weight (Year 2)

Preschoolers (ages 3-5) with cognitive, psychiatric or emotional impairments (Year 2)

Adolescents (ages 14-17) with cognitive, psychiatric or emotional impairments (Year 2)

School-age children (ages 6-15) with cognitive impairments (Year 3)

Age-18 redeterminations with cognitive, neurological or psychiatric/emotional impairments (Year 3)

Working together, the SSA, AUCD and the UCDD/LEND programs developed standard protocols for each age group. Then each site assembled an interdisciplinary team to carry out the examinations. The sites received a complete copy of the claimant's DDS file before conducting their assessments. The team was required to submit a report to the DDS for each individual who was evaluated. These reports integrated all available information about each child or young adult, resolved inconsistencies between the file data and their own assessments, and provided opinions about the degree and nature of the individual's functional limitations.

The protocols were similar, although there were some variations to reflect differences among age groups. Each assessment included a file review and a developmental pediatric and family history. The assessment evaluated these basic areas:

Psychological
Adaptive functioning
Attention/executive functioning

Academic
Communication, including both speech and language

Assessment teams were allowed to do additional specialty evaluations if they believed they were necessary to determine the full extent of the individual's functional limitation. The adolescent and age-18 protocols also assessed the individual's psychosocial status and cognitive skills.

DDS personnel reported that the UCDD assessments integrated all the information in a very coherent way to describe the child's overall functional capacity compared to most other consultative reports that they receive.

Case Outcomes Using Assessments

The chart below shows project case data that was available as of November 1, 2001. Note that there is very limited data available for Year 3 at this point. "No-shows" are cases of individuals who were referred by the DDSs to the UCDDs but who refused or failed to attend the examinations.

	UCDD Assessments	DDS Decisions	DDS Allowances or Continuances	No-shows
Year 1	108	108	44	n/a
Year 2 (includes cognitive, psychiatric, and low birth weight)	172	172	53	45
Year 3				
School-age Age	137	115	22	29
Age 18	121	48	15	56
Total	258	163	37	85
TOTALS	538	443	134	130

Family Services

AUCD requested information from sites about the kinds of referrals provided to children and their families. Although the first year data was incomplete, the second year data indicates that 69 percent of the children who were assessed were currently receiving services. However, 79 percent were referred for additional assistance such as community, educational, family, medical or mental health services.

Participating UCDD/LEND programs reported that sometimes the project assessments provided families with the most complete picture of their children's impairments despite having had previous evaluations.

Key Issues/Recommendations

After each year's assessments, the UCDD/LEND sites met with SSA Central Office staff to review their observations and suggest ways to enhance the adjudication process. Additional information came from a case review that SSA conducted in the spring of 2001. Cases were selected from the project's first two years and reviewed by Federal DDS, SSA Regional Office, State DDS, and SSA Central Office policy staff. Many of these case reviewers later met with a small group of UCDD/LEND participants and SSA Central Office staff to share observations and suggestions.

Speech & Language Issues

The most prevalent observation, across all age categories, was the number of previously undetected language issues. Some assessments surfaced these impairments as a significant problem for children that affected whether they qualified for initial or continued benefits. Many UCDD reports clarified the problem's severity or highlighted it in existing school records. Children who had undiagnosed language disorders included some who had been diagnosed with attention deficit hyperactivity disorder (ADHD) and adolescents who had behavioral manifestations.

Suggestions to address language issues included:

Train adjudicators about language disorders and their impact on children's ability to function. The training could help adjudicators recognize when to request language evidence from schools or consultative examiners and when to consult staff speech/language pathologists (SLPs).

Prepare a national adjudicator checklist for language issues, including pragmatics.

Consolidate all information on language in one resource. There are existing models from several SSA Regional Offices.

School Records

There was ongoing concern about the ability of DDSs to obtain appropriate school evidence and the need for training about how to interpret some evidence. Although a few States pay for school reports, SSA does not have data to determine if this practice provides more comprehensive school evidence or decreases the need for consultative exams. Special difficulties obtaining school evidence were noted in large urban areas, especially for children in regular classrooms who do not have individualized education programs (IEPs) or children enrolled in early intervention programs who do not have individualized family service plans (IFSPs).

Suggestions to address issues pertaining to school records include:

Explore ways in which DDS Professional Relations Officers (PROs) can work with specific schools or districts to increase the ability to obtain existing records.

Offer "Special Education 101" training for adjudicators to explore how better to obtain school records and how to interpret them. The training would explain what the special education law requires and how children qualify for services. It would describe the initial multi-disciplinary evaluation and triennial assessments that IDEA requires and how these evaluations can be used for the SSI determination process. It would review the components of an IEP and IFSP, what they describe about a child's functioning and what supporting documents may help disability examiners.

Adaptive Functioning

Participating disability agencies reported that the Vineland and other standardized tests of adaptive functioning provided very valuable information in some cases. This was especially true when the tester included specific examples of the child's ability to function in each category. The adjudicators also reported that, in some cases, having assessment information from multiple disciplines was very helpful to provide a longitudinal perspective about the child.

Suggestions to address the need for adaptive functioning information include:

Explore the use of social workers to perform consultative examinations (CE), especially to obtain detailed information about daily activities.

Expand existing guidance for CE providers to supplement test scores from standardized tests with specific examples of what children can and cannot do in each functional domain. This will provide more comprehensive information about the child's adaptive functioning.

Revise SSA's national age-specific function forms to elicit better information from parents/caregivers. Explore using pictures to illustrate the meaning of some questions on these forms.

Provide appropriate training for examiners to resolve conflicts between school and parent information about a child's functioning. Expand existing guidance for CE providers to emphasize the importance of explaining when their observations differ from the child's caregivers.

Provide appropriate training to help examiners better understand the range of functional information that may be available from existing sources, to identify other sources and to interpret and determine adequacy of file information.

Provide appropriate training for examiners to develop cases when behavioral problems may indicate depression or other serious mental disorders.

Disseminate information from March 1998 Childhood Training Manual on adaptive functioning.

Low Birth Weight (LBW) Continuing Disability Reviews (CDRs)

Participants in the case review reported that the determinations tended to focus on the resolution of the infant's physical problems. Consequently, the evidence about the child's mental development that was provided by the UCDD/LEND assessment was very helpful in many cases. Participants also noted that not all LBW infants were receiving early intervention services to help address their difficulties. This raises the issue whether SSA field offices should have the capacity to refer these applicants to the appropriate local early intervention agencies.

Suggestions to address the issues for LBW infants include:

Develop a pilot initiative to test the outcome of providing developmental and language testing for some children in this age group.

Issue guidance on setting later diary dates for certain infants, especially those born prematurely or with very low birth weights.

Use the functional report for ages 0-1 for population under 18 months.

Use the interview form for initial claims (SSA-3820) instead of the interview form for continuing disability reviews (SSA-454) to capture more appropriate information for the LBW cases. Consider using a developmental inventory when interviewing parents/caregivers.

Develop State-specific resource information to share with families of LBW infants at intake. Share same information with examiners so they know the appropriate agencies to contact for relevant evidence for LBW reviews. Examples include early intervention providers, WIC, and Early Start programs.

Case Development

There were some general observations about ways to encourage the use of "team assessments" in DDSs, recognizing the scheduling and budget constraints that they face. Other avenues to pursue included expanding the use of other medical sources, such as pediatric nurse practitioners, and increasing the pool of specialized examiners with childhood expertise in other ways. Examples may include school psychologists and new professionals who are training at UCDD/LEND programs.

Action Steps

Through the first three years of the project, the AUCD and its Centers developed unique expertise in working with the DDSs and shared their child development knowledge with the DDSs and SSA Central Office staff.

SSA acknowledges that the knowledge gained from working with AUCD and its Centers was extremely helpful when developing the final childhood regulations that were published on September 11, 2000. Several features of the final rules were shaped by knowledge that SSA gained from the UCDD assessments. These included: evaluating the "whole child," using the same number of domains for all children, separating the cognitive/communicative domain, increasing emphasis on the importance of early intervention, pre-school and school evidence, interpreting test results, and increasing emphasis on tests of adaptive functioning.

In addition, the UCDD assessments helped the agency support related regulations (issued June 1, 2000) that now recognize qualified speech-language pathologists and certain other specialists as "acceptable medical sources" for evidence of impairments that are within their areas of specialty.

To help SSA move ahead on some of these recommendations, the agency awarded AUCD a new contract to continue the SSI Project for another two years. Based on feedback and observations from the first three years, SSA expanded the scope of the AUCD project to have UCDD/LEND staff perform the following activities:

Develop training modules for DDSs and all other adjudicators and quality reviewers in SSA. The first two training modules will focus on "Working with School Records" and "Obtaining Adaptive Functioning Information." These modules should be ready by fall 2002. SSA will select additional training materials for the project's second year.

Develop case adjudication materials and tools for DDSs and other adjudicators. The first item will be a new set of age-specific function forms to use with childhood applicants. SSA will request additional adjudication materials for the project's second year.

Organize demonstration projects in two selected sites to work with DDS and State/county education and early childhood systems. The demonstration projects will run for the entire two years. The sites selected are in Ohio and Tennessee.

Conduct selected case assessments to test specific hypotheses for further analysis. UCDD/LEND staff will perform approximately 150 case assessments by the end of 2002 and a similar number in the following year.

Review interdisciplinary assessments to identify key issues and possible recommendations for policy and procedural changes for how SSA processes childhood disability claims.

The project's current phase began in late fall 2001. More specific details about the work plan will be posted at www.aucd.org as they are available.

For more details about the project, contact George Jesien, PhD, AUCD Executive Director, at [**gjesien@aucd.org**](mailto:gjesien@aucd.org) or Rhoda Schulzinger, Project Director at [**rhoda705@earthlink.net**](mailto:rhoda705@earthlink.net). You can reach them by telephone at 301/588-8252. You may also contact Barry Eigen, Executive Program Policy Officer at [**Barry.Eigen@ssa.gov**](mailto:Barry.Eigen@ssa.gov) (410/965-2528).

/s/

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