

CHILDREN'S SSI INITIATIVE
AUCD/DDS State Collaboration Profiles: 2002-2005

The Social Security Administration (SSA) has awarded annual contracts to the Association of University Centers on Disabilities (AUCD) to provide a variety of pediatric assessment and professional training since 1999. Part of this initiative includes efforts to strengthen and build relationships between state Disability Determination (DDS) offices and AUCD's network of 64 University Centers for Excellence in Developmental Disabilities (UCEDD) and 35 Leadership Education in Neurodevelopmental Disabilities (LEND) programs [hereafter called "the Centers"].

Two pilot state collaborations began in October 2002 in Columbus, Ohio and Memphis, Tennessee. In the first year, the pilots helped DDS offices expand contacts with state/county education and early childhood systems. Each location organized a number of activities such as: joint DDS/Center trainings for early intervention administrators and case managers; working with school systems to improve retrieval of student records; and developing "Child Resource Lists" for parents to help them identify where records may already exist about their children's condition and treatment.

Based on the initial success, SSA approved four new sites and continuation funding for the first two in 2003-2004. In the following year, two sites also received continuation funding. As a result, these six sites were funded in 2003-2005:

- Iowa: Center for Disabilities and Development, University of Iowa, Iowa City [2 years]
- New Mexico: Center for Development and Disability, University of New Mexico, Albuquerque
- Ohio: Nisonger Center, Ohio State University, Columbus [2 years]
- Oregon: Oregon Institute on Disability & Development, Oregon Health & Science University, Portland
- Pennsylvania: UCLID Center, University of Pittsburgh, Pittsburgh [2 years]
- Tennessee: Boling Center, University of Tennessee Health Science Center, Memphis [2 years]

The "state teams" met to discuss the best ways to match DDS needs with the Center's expertise. Each state team designed its own work plan although they were similar. The Children's SSI Project Director organized regular conference calls for which each participating Center prepared a summary of recent activities. These summaries, and other information, were shared through the AUCD web site. Throughout the year, state teams could call AUCD or SSA for consultation. The Project Director provided guidance about what all sites were doing to encourage an information exchange and she visited all sites.

The underlying objectives of the state collaborations were to help improve processing time, case outcomes, quality of evidence and uniformity of decision-making. Both DDS and AUCD participants had very positive reactions to the collaborations: they believed that their activities improved the timeliness and accuracy of DDS work and that there were new avenues of communication between their respective staff. Participants believe that some collaboration will continue because of the mutual benefits.

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The collaborative activities fell into the following broad categories and examples are listed for each group:

- Improve quality of referrals & evidence
 - Develop and present training for variety of child service providers to describe appropriate referrals and documentation for potentially eligible children [Early intervention/early childhood service providers/administrators, Indian Health Services staff, teachers, community nurses]
 - Coordinate SSA field office staff to conduct intake at rural community clinics
 - Develop Web-based distance learning course for speech/language pathologists
 - Require AUCD/LEND trainees to visit DDS as part of Pediatric Intern rotation.

- Improve access to evidence
 - Prepare "child resource lists" to help families identify all appropriate sources of medical/other relevant documentation for children's SSI application.
 - Prepare family-friendly information to ensure parents provide all available medical/other relevant documentation.
 - Assign clinical social workers to obtain standardized assessment of adaptive functioning in selected cases.
 - Work with school administrators to improve access to school records.
 - Work with hospital staff to expedite transmittal of necessary medical records.
 - Pilot electronic transfer of data from major children's hospital.

- Share clinical expertise with adjudicators
 - Provide "curbside consults" for quick questions by e-mail or telephone calls.
 - Conduct case consultations to review difficult cases on regular basis [low birth weight, hearing impairments, speech/language delays, autism, behavioral problems, AD/HD, cognitive impairments]
 - Develop and present skill training – how to interpret evaluation data for specific pediatric specialty areas [speech and language, audiology, cognitive and adaptive behavior in infants/young children].
 - Develop and present clinical training [autism spectrum disorders, AD/HD, language disorders, speech articulation problems, audiology, Neurodevelopmental background for children with disabilities].
 - Conduct selected consultative examinations.

Below are highlights from the state collaboration activities in 2003-2005:

Iowa: Center for Disabilities and Development, University of Iowa, Iowa City

Training: DDS professional staff attended CDD faculty presentations on current issues in brain injury and muscular dystrophy. CDD staff trained DDS examiners about assessing cognitive and adaptive behavior in infants and young children, ADHD, functional implications of cochlear implants, autism, and interpretation of visual and auditory evoked responses. Trainings were conducted both on site and by teleconference. In addition, two DDS staff presented a training session on SSI and the disability process as Grand Rounds at the Center.

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CDD Referrals to DDS: A CDD social worker helped families complete applications.

Consultation: An interdisciplinary team from CDD met with DDS by video teleconference on a monthly basis to share clinical information, offer peer review and provide consultation. Discussions covered case-specific clinical issues, general issues affecting accurate disability determinations, or clinical topics of mutual interest. Specific topics included cochlear implants, autism spectrum disorders and auditory and visual evoked responses. For each session, a Center faculty member made a presentation and then answered specific questions.

Assessments of Adaptive Functioning: In the first year, two CDD social workers performed adaptive functioning evaluations where a diagnosis was already established, but more collateral information was needed. DDS reported that these assessments helped resolve case inconsistencies; provided formal assessment information to help quantify the degree of functional impairment; and described the child's functioning based on direct interaction or observation. In the second year, the approach changed. After receiving a DDS referral, the CDD social workers obtained completed Adaptive Behavior Assessment System (ABAS-II) checklists from parents, scored the checklists, and summarized the information. The Center received 17 case referrals and provided 14 results to DDS.

New Mexico: Center for Development and Disability, University of New Mexico, Albuquerque

Child Resource Directory: A guide was produced to help families submit a more complete SSI application. It is divided into State Department of Health districts to make it user-friendly and includes names and contact information of providers who may have information that will help their child's application. All the information - except the contacts - was provided in English, Spanish and Navajo as both print and CD-ROM versions and was also posted on the Center's web site.

Family Brochure: DDS staff approved a family-friendly brochure in English, Spanish and Navajo with information families need to expedite SSI applications.

Trainings for DDS and LEND Staff: Each agency provided cross training to explain their respective goals and functions. They also met to present cases to each other. Participating staff included DDS medical consultants, other professional staff and CDD faculty, students and clinical staff. Several Early Intervention trainings were held throughout the state for case managers, teachers and administrators with a joint team of CDD and DDS presenters.

Indian Health Services [IHS]: CDD hired a cultural broker to provide contacts, arrange meetings with community leaders and schedule trainings for IHS medical and case manager staff. The CDD project director also met with the IHS National Director to discuss the collaboration's outreach and explore organizing this training at an annual meeting for all IHS pediatricians or in all 12 IHS regions.

Pediatric Intern Rotation: CDD required its Pediatric Interns to visit the DDS office.

Ohio: Nisonger Center, Ohio State University, Columbus [second year of funding]

Speech and Language On-line Course: The Center developed a distance-learning course for speech language pathologists to improve the quality of their evidence for DDS and increase their pool of consultative examiners. The Center prepared a course outline, Power Point

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slides and a video that were posted on the Ohio State Medical School's Continuing Medical Education website. The American Speech-Language Hearing Association (ASHA) granted approval to offer Continuing Educational Credits (CEUs) for completing the on-line training that was available for one year. The course was marketed through SLP newsletters and flyers to clinical training programs.

Rural Outreach Project: The Center completed six outreach rural clinics in four counties. The goals were to increase families' access to SSI and other assistance and to streamline the SSI application process. At the clinics, SSA field office staff interviewed 30 families: 20 applied and 14 received benefits, including four as presumptive disability. Other families were already receiving benefits, did not want to apply or were not financially eligible, or did not appear for scheduled appointments. Baseline data indicated that the clinic improved access for eligible children and decreased case processing time as intended.

Early Intervention Training Materials: The Center helped DDS to expand its outreach to administrators and direct care providers in early intervention and pre-school settings.

Oregon: Oregon Institute on Disability & Development, Oregon Health & Science University, Portland

On-site training sessions: The Center staff traveled from Portland to Salem for four half-day training sessions that participants rated highly. Usually three Center faculty presented didactic topics and led discussions with approximately 30 DDS personnel, both lay examiners and medical consultants. Examples of challenging DDS cases included: twin infants born premature; pre-term infant with speech and language deficits; child with alleged autism and conflicting behavioral descriptions; 17-year-old with behavioral problems, ADHD, emotional difficulties and a borderline IQ. Every participant received documents to review for each case. Center staff provided training on topics such as: neurodevelopmental approach to children who present with a disability; speech and language milestones and speech/language assessments; ADHD; and borderline IQ. The Center staff also presented two cases based on clinic patients to highlight the need to examine the constellation of features that make these children increasingly dysfunctional.

Collaborative Conferences: Working together, representatives from a local Education Service District, the Center, Title V of the Maternal and Child Health Bureau and the DDS designed two full-day conferences. The conference goals were to (1) increase the child providers' understanding of the type of information that is most helpful for DDS to receive and (2) provide educational material to school, DDS and health care staff and providers. Teachers of all levels in the targeted area [early intervention through high school] and community nurses attended. The first program, "Helping Families Through the Maze," shared information about accessing SSI and transition issues. The second program, "The Changing Face of Autism Spectrum Disorder," focused on that disability. Evaluations were uniformly enthusiastic and positive.

Pennsylvania: UCLID Center, University of Pittsburgh, Pittsburgh

Bi-weekly case reviews and consultations: In the second year, the two offices reviewed 67 cases. All the lay adjudicators are encouraged to participate if they have an appropriate case to discuss. Cases included: prematurity and/or low birth weight; speech or language limitations; children under age 5; adolescents age 16-18; transposition of the great arteries; periodic fever syndrome; autism; Pradi Willi syndrome; and learning disabilities. In the first year, case consultations or reviews involved issues including: discrepancy between

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parent and psychologist reports; mild hearing loss in an infant; stuttering severity index; frontal lisp; listing levels for infants; and word recognition testing with non-English speaking adult [not a child issue, but DDS requested assistance].

Specific Trainings: The Center director and professional faculty provided special trainings on speech and language and audiology. About 70 people attended including lay adjudicators, psychologists, physicians and supervisors and videotaped for others to view later. Participants rated the training very highly. The Center presented a second training on audiology that 131 lay adjudicators, psychologists, physicians and supervisors attended. They also created a desk reference and offered Continuing Medical Education Credits and Continuing Education Credits. The training included discussion of three challenging DDS cases.

Training Video: The collaborating offices filmed a training video "*Challenging Cases Concerning Speech and Language: A Training for SSI Adjudication.*" The DDS identified seven challenging cases to use as examples selected from the 67 claims that UCLID helped to review with them. The case-based methodology highlighted indicators of speech delay in SSA forms, incomplete speech and language examinations, and complications from additional impairments. DDS lay adjudicators, the UCLID Director who is a developmental pediatrician and UCLID's senior speech and language pathologist presented the video. It supplements SSA's national training on speech and language disorders developed by AUCD.

Consultative Examiners [CE]: The Center contacted the state chapter of the American Academy of Pediatrics. It learned that some pediatric practices already conduct CEs and others are not interested because of previous rates of "no shows" and the time constraints on their evaluations. The Center did recruit two doctors from Children's Hospital and the Center Director also now conducts CEs.

Quality of Evidence: The Center facilitated a meeting with the Director of Medical Records at Children's Hospital and the subcontractor (Iron Mountain) used to copy and fill requests for medical records for the DDS. As a result, procedures were modified to expedite sending medical evidence to DDS and Iron Mountain designated a liaison for this work.

Expand Outreach Activities: DDS Staff and UCLID speech and language trainees attended a conference by Pennsylvania Speech Language Hearing Association in Pittsburgh. This gave DDS staff the opportunity to educate approximately 60 conference participants about the SSI application process, eligibility requirements and consultative examinations.

Quality Assurance Project: UCLID uses ABAS-II assessment tools to supplement functional information when the files lack sufficient information from a treating source or consultative examiner. The ABAS serves as the next level of screening and if it indicates concerns, UCLID will recommend specific areas for a consultative exam (CE). If necessary, an acceptable medical source at UCLID can do an ABAS as a consultative examiner.

Electronic Folder: DDS is in the early stages of using electronic folders, but wants to get as many medical records as possible in electronic format. Since Children's Hospital is a major provider and already maintains electronic records, BDD asked UCLID to facilitate a meeting with the Medical Records Department.

Tennessee: Boling Center for Developmental Disabilities, Memphis

The project's first year focused on producing informational materials for parents and guardians and increasing outreach to key providers about getting appropriate evidence for

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child SSI applicants. In the second year, the Center continued this assistance, but DDS staff changes affected the project's continuity and the agency had other office priorities.

Transfer of Records to DDS: In addition to continuing its liaison with the Memphis City Schools, the Center facilitated meetings and other contacts with medical records staff in children's hospitals in the state's four largest cities. Center staff also clarified the best method to request records from the University of Tennessee Medical Group in Memphis.

Develop Child Resource Lists: The Center prepared child resource lists for Memphis, Nashville and Knoxville. The resource lists have names, addresses, and other contact information for clinics, educational agencies, mental health agencies, etc. serving children that may have existing records to document disabling conditions. The DDS reported that the list helped applicants provide more information on the initial application and decreased case processing time.

The Center offered to perform adaptive behavior assessments, provide in-service programs for Memphis City School personnel about the disability determination process and the Teacher Questionnaire and arrange appearances for the DDS at appropriate state meetings. However, given other DDS priorities, it was decided to end the collaboration project early.