

Collaboration: UCEDDs, LENDs, and State MR/DD Agencies

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The Association of University Centers on Disabilities (AUCD) is the national organization representing the national network of 67 University Centers for Excellence in Developmental Disabilities (UCEDDs) and 34 Leadership Education in Neurodevelopmental Disabilities (LEND) programs. UCEDDs are authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 to increase the independence, productivity, and community integration and inclusion of individuals with developmental disabilities. UCEDDs have four broad tasks: conduct interdisciplinary training, promote community service programs, provide technical assistance at all levels (from local service delivery to community and state governments), and conduct research and dissemination activities. The network of LEND programs is funded by MCHB within the HRSA to ensure that health professionals have the necessary knowledge and skills to address the unique needs of children and adolescents with special health care needs and their families. Currently, 34 LENDs operate in 29 states; 30 of the LEND programs are co-located in universities with UCEDDs.

In 2007, AUCD conducted a survey of the membership to discover the extent of the network's partnerships with state mental retardation and developmental disabilities (MR/DD) agencies. Fifty-two Centers responded to the survey; because of the co-location of some UCEDDs and LENDs, respondents represented 78% of the UCEDDs (48 Centers) and 71% of the LENDs (24). The following information reflects the responses received to each question. Not all respondents addressed each question in the survey. This report provides a summary of these activities, but likely under-represents the breadth and depth of the network's impact in the field of developmental disabilities.

The collaborative relationships between UCEDDs and state MR/DD agencies are extensive, reciprocal, and complimentary. A substantial percentage of Centers reported having contracts or grants with their state MR/DD agency to provide training (67.3% or 35) and technical assistance (65.4% or 34). Centers reported that they were awarded grants or contracts to provide training and technical assistance to state employees, Part C providers, and providers of adult services primarily in the areas of person-centered planning, positive behavioral supports, employment supports, family support, communication, and abuse/neglect.

Approximately half of Centers (48.1% or 25) reported having contracts or grants with their state MR/DD agency to provide research/evaluation. Centers most often reported that they were awarded grants or contracts to perform studies on consumer satisfaction (of waiver services and for National Core Indicators), employment outcomes, and service quality, and to conduct program evaluations. Other research projects mentioned included an evaluation of the effects of a rate increase for direct support workers on staff turnover, an outcome study related to adults with dual diagnoses, and a legislatively mandated study regarding services to people with intellectual disabilities.

Approximately half of Centers (48.1% or 25) reported having contracts or grants with their state MR/DD agency to provide policy development/analysis. Centers reported most commonly that they have been awarded grants or contracts to assist in developing language for policies, grants, and contracts to expand opportunities for people with disabilities and to provide support for their family members. Centers also reported being contracted to assist self advocates to fully participate on advisory committees or to otherwise provide input on draft policies. Finally, Centers also noted that their state MR/DD agencies relied on them to provide public commentary in non-contractual areas.

Approximately half of Centers (46.2% or 24) reported having contracts or grants with their state MR/DD agency to provide and direct services. Centers most often reported that they were awarded grants or contracts to provide diagnostic services, early childhood evaluations, nutrition and feeding assessments, occupational therapy and physical therapy services. Centers also reported providing medically fragile case management, mental health services, and geriatric risk assessment for adults with developmental disabilities under grants or contracts.

Most Centers (84.6% or 44) reported that the MR/DD agency in their state administers at least one MR/DD Medicaid waiver. Regardless of who administers the MR/DD Medicaid waiver(s): 14 Centers reported performing direct services for children that are reimbursed under a waiver, 12 Centers reported performing services for adults, and 6 reported performing services for youth in transition that are reimbursed under a waiver. Centers most commonly reported that they performed eligibility assessments, provided clinical, behavioral, and communication-related services, and supplied assistive technology equipment and supports under such waivers.



UCEDDs, LENDs, and State MR/DD Agencies Collaboration Highlights

In **Alabama**, the Sparks Center at the University of Alabama-Birmingham participates in a variety of partnerships with the Alabama Department of Mental Health/Mental Retardation (DMH/MR). The Center provides occupational and physical therapy services to individuals residing at Part-low Developmental Center, a DMH/MR residential facility in Tuscaloosa, Alabama. The Center conducts various early intervention collaborative activities with DMH/MR and is collaborating in efforts to pursue a broad community initiative focusing on the transition needs and challenges for youth and adults with a range of disabilities.

In **Alaska**, the Center for Human Development at the University of Alaska-Anchorage has conducted participant experience interviews for the state MR/DD agency as part of their QA program for the home and community-based waivers. The Center also provides clinical services funded by the MR/DD agency through a grant waiver program.

In **Arizona**, the Institute for Human Development at Northern Arizona University contracts with the state MR/DD agency to bring to fruition the Real Choice Systems Change grant which the Institute wrote with the state agency. The Institute is also contracted to provide services for the agency in the areas of early intervention, assistive technology, and positive behavioral supports and is the agency's primary provider of training in person-centered planning. The Institute also provides community-based training and conducts program evaluations for the agency.

In **California**, three UCEDDs partner extensively with the California Department of Developmental Services (DDS):

The University of Southern California Center for Excellence in Developmental Disabilities connects with the DDS Regional Centers using video teleconference technology to provide continuing education to health care professionals as well as parent training and networking opportunities through the California Family Resource Centers.

The Tarjan Center at the University of California-Los Angeles contracts with DDA to conduct mental health services, an outcome study related to adults with dual diagnoses followed through the Center, and a geriatric health risk assessment of people with Developmental Disabilities. Center staff serve on DDS advisory panels, such as the State Employment Leadership Network and Mental Health Task Force, and DDS staff participate on the Center's Consortium for Postsecondary Education Options for People with Developmental Disabilities.

The University of California-Davis Center of Excellence in Developmental Disabilities at the M.I.N.D. Institute provides policy consultation and training resources to DDS. The Center is also contracted with the DDS Regional Centers to provide diagnostic services to children with developmental disabilities regarding eligibility for services.

In **Delaware**, the Center for Disabilities Studies at the University of Delaware has had a training and technical assistance contract with their state MR/DD agency for over ten years. The Center provides training to all new direct support professionals working through the DD funded agencies.

In the **District of Columbia**, faculty from the Georgetown University Center for Child and Human Development faculty sit on several Developmental Disabilities Services advisory committees, such as Quality Assurance/Basic Assurance, Human Rights Committee, Restrictive Control Techniques Committee, Training Committee and the Mortality Review Committee.

In **Florida**, the Florida Center for Inclusive Communities at the University of South Florida Louis de la Parte Florida Mental Health Institute conducts two employment projects, Start-up Florida and the Micro-Enterprise Training, with collaborative funding from the state MR/DD agency, the state DD council and the Florida Agency for Workforce Innovation. The goals of the projects are to implement and evaluate self-employment training and technical assistance resources.

In **Georgia**, the Institute on Human Development and Disability at the University of Georgia is working with the state MR/DD agency to design a regional system of positive behavior support for the state and to expand customized employment supports for people with disabilities. Through the Children's Freedom Initiative, the Institute is working with the state MR/DD agency and other partners to support children and youth with disabilities to move from institutions to families in the community. The Institute also supports self-advocates to participate as trainers in in-service training programs fielded by the state MR/DD agency.

In **Iowa**, the Center for Disabilities and Development at the University of Iowa has an exceedingly productive partnership with the Iowa Department of Human Services, its MR/DD division and its Medicaid Division. The Center partners on numerous systems improvement grants such as Real Choice Systems Change, Money Follows the Person, and Robert Wood Johnson Cash and Counseling. Center staff sit on advisory committees and personnel recruitment teams for the MR/DD division. The Center also operates several sole source contracts, such as statewide information and referral.

In **Idaho**, the Center on Disabilities and Human Development at the University of Idaho operates numerous programs under partnership with the Idaho Department of Health and Welfare, including providing the training, technical assistance and certification for all developmental specialists and intensive behavioral interventionists working with children with disabilities and their families

in the state. The Center provides a number of other training programs for the state MR/DD agency, including support broker training, through a Medicaid Independence Plus Grant, and the Finding and Keeping a Job training.

In **Illinois**, the Institute on Disability and Human Development at the University of Illinois-Chicago operates its family clinic with funding from the state MR/DD agency. This clinic provides family-focused interdisciplinary assessments and services for children at risk in Chicago's most economically depressed areas. The Institute's Assistive Technology Unit (ATU) provides AT services to state agency clients in the areas of activities of daily living, adaptive equipment, augmentative communication, computer access, environmental control, home modification, seating and wheeled mobility, and worksite modification. AT services are delivered through the ATU's 5000 square foot in-house evaluation and fabrication facility and through the AT Mobile Units, the largest mobile AT program in the country.

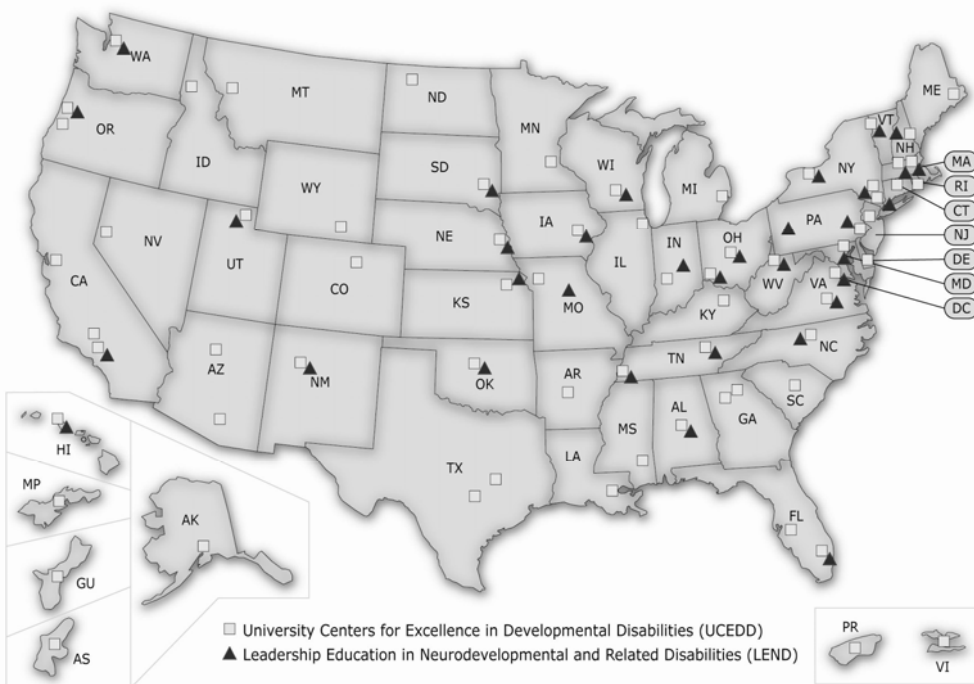
In **Maine**, the University of Maine Center for Community Inclusion and Disability Studies has a long-standing relationship with the state MR/DD agency, including work in the areas of person centered planning, employment, self-advocacy, community living, substance abuse and other health risks, universal design and access, and children's services. The state MR/DD agency is represented on the Center's Community Advisory Council and Center staff sit on committees and workgroups of the state MR/DD agency.

In **Massachusetts**, two UCEDDs partner extensively with the Massachusetts Department of Mental Retardation (DMR):

The Institute for Community Inclusion at the University of Massachusetts-Boston operates a number of contracts with the state MR/DD agency to provide training in person centered planning and benefits counseling, and a number of projects addressing employment and employment supports. The Institute has worked closely with the state MR/DD system in the implementation of the Family Support 360 project that the Institute wrote and jointly implemented with the state. The Institute works with the state agency in the defining of the Medicaid waivers and assists in the development of training for service coordinators, provider staff and senior staff in the state agency.

The Eunice Kennedy Shriver Center at the University of Massachusetts Medical School partners with Massachusetts Department of Mental Retardation (DMR) through the Center for Developmental Disabilities Evaluation and Research (CDDER) to provide research, evaluation and consulting services to DMR for enhancing its systems of community-based health care. The goal of the collaborative relationship is to develop a more systemic and comprehensive approach to identifying and addressing the health and behavioral needs of individuals served by DMR and to develop quality assurance mechanisms to assist DMR in monitoring the health, safety and welfare of the community-based population.

In **Minnesota**, the Institute on Community Integration at the University of Minnesota operates the National Direct Service Workforce Resource Center which supports efforts to improve recruitment and retention of direct service workers who help people with disabilities and older adults to live independently. The program also provides Medicaid agencies, policymakers, employers, consumers, direct service professionals, and other state-level government agencies and organizations easy access to information and resources they may need about the direct service workforce.



In **Montana**, the University of Montana Rural Institute works directly with the state MR/DD agency in early intervention, adult services, and in relation to Montana's Disability and Health Program, Medicaid Infrastructure Grant, and AT Project. The Institute and the state agency are together sponsoring a statewide conference on self directed funding in 2007.

In **New Hampshire**, the Institute on Disability at the University of New Hampshire receives core funding from the state MR/DD agency to conduct professional development and technical assistance in a number of areas, including autism spectrum disorders and employment leadership development. Institute staff sit on a variety of state agency advisory panels including Waiting List and Autism Infrastructure.

In **New Jersey**, Elizabeth M. Boggs Center on Developmental Disabilities at the University of Medicine & Dentistry of New Jersey-Robert Wood Johnson Medical School provides extensive services to the New Jersey Division of Developmental Disabilities to promote practices that will result in higher quality of life for persons with intellectual and developmental disabilities. Major services involve training, technical assistance, and consultation on policy and service provision. Activities in adult services and autism are conducted in collaboration with state agency task forces on aging and workforce development. A major area of collaboration with the Division is the work of The Boggs Center in providing training and technical assistance in self directed services and supports, including training in person centered thinking and essential lifestyle planning.

In **New Mexico**, the Center for Development and Disability at the University of New Mexico has had several long-standing contracts with the state Developmental Disabilities Support Division in projects addressing early childhood evaluation, medically fragile case management, early childhood training, direct support retention, family and community education in autism, self directed family supports, and a feeding and eating clinic.

In **New York**, two UCEDDs partner extensively with the New York Office of Mental Retardation and Developmental Disabilities:

The Westchester Institute for Human Development at New York Medical College provides training and technical assistance to the state Office of Mental Retardation and Developmental Disabilities on positive behavioral supports, employment, person-centered transition planning, self-advocacy, and Medicaid Service Coordination.

The Rose F. Kennedy University Center for Excellence in Developmental Disabilities at the Albert Einstein College of Medicine partners with the state Office on Mental Retardation and Developmental Disabilities on the Developmental Disability Network and co-sponsors two statewide conferences a year on the topics of aging and developmental disabilities and family support for adults with developmental disabilities. Additionally, the Parent, Consumer and Professional Partnership Project has biannually produced the three-time award winning *Directory of Health Services for Bronx Residents with Developmental Disabilities*.

In **Oregon**, the Center on Human Development at the University of Oregon closely collaborates with the state MR/DD agency to meet the needs of children and families, includes representatives from the state agency on their advisory, and has staff members serving on the Oregon Developmental Disabilities Council (ODDC) and other advisory groups. The Center provides education services for birth to school age children with developmental disabilities under IDEA.

In **Tennessee**, the Boling Center for Developmental Disabilities at the University of Tennessee provides occupational and physical therapy services, developmental medicine, and nutrition services for the state's MR/DD agency. Center staff members lead the state agency's Human Rights committee which reviews behavioral and pharmacologic interventions in individuals with severe disability.

In **Utah**, the Center for Persons with Disabilities at Utah State University is leading efforts to improve the state's supported self employment waiver and provides technical assistance to the state agency to improve respire services. Center staff members sit on a statewide coordinating council providing an advisory function to the state MR/DD agency, as well as on two agency advisory panels on autism policy and services and direct service worker policy and training.

In **Virginia**, the Partnership for People with Disabilities at Virginia Commonwealth University and the state Office on Mental Retardation collaborate extensively. Partnership staff sit on the state office Advisory Council, participate in multiple interdisciplinary groups promoting individual supports through waiver services, provide training and mentoring in PBS, jointly co-sponsor person-centered planning and thinking trainings, jointly support self-advocates in participating in state-level meetings, and participate in a legislatively-mandated study in services to individuals with intellectual disabilities.

In **Wyoming**, staff of the Wyoming Institute for Disabilities at the University of Wyoming sit on the state Developmental Disabilities Division Advisory Council and the state IDEA Part C Interagency Coordinating Council. The Institute conducts interviews for the ICAP, which is part of the eligibility for HCB Waivers for adults and children with developmental disabilities and persons with acquired brain injuries, as well as consumer satisfaction interviews for Wyoming's participation in the National Core Indicators Project.

For more information, contact

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