

Waisman Center

PROJECT NARRATIVE

5-YEAR APPLICATION – 2014-19

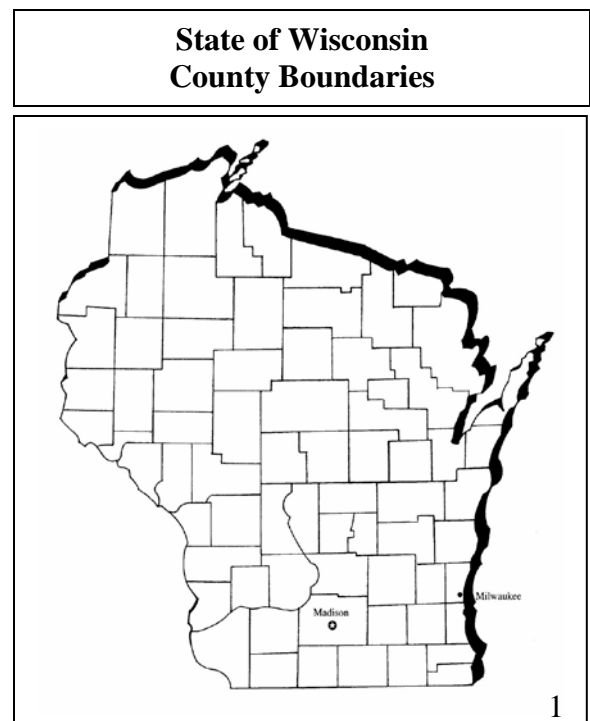
Administration on Intellectual and Developmental Disabilities
for continuation of the
University Center for Excellence in Developmental Disabilities

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Waisman Center – University of Wisconsin-Madison

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I. PROJECT RELEVANCE AND CURRENT NEED

IA. State Demographic Information. As of June, 2013 Wisconsin's population was 5,726, 398, which represents an increase of 2.8% since 2008.¹ It ranks as the 20th largest state in the U.S. Over one-half of the population resides in the Madison or Milwaukee areas which are located in the south-central and southeast portions of the state respectively. The rest of the population is spread across the 72 counties in Wisconsin which spans approximately 310 miles in length and 260 miles in width. Of Wisconsin's population, 82.8% is White, 6.5% African-American, 6.2% Hispanic, 2.5% Asian-American, 1.1% American Indian and 0.9% other. While the combined minority population is approximately 17%, that number has grown substantially since the 2000 census. The Hispanic population has increased by 74.2%, the Asian-American by 49.8%, and the African-American 17.9%. The American-Indian population has remained relatively stable with a 1.1% increase. The minority population is not evenly distributed around the state. Eighty percent of the African-American population resides in three counties in southeast Wisconsin (Milwaukee, Kenosha, Racine). Dane County, the location of the Waisman Center UCEDD has traditionally had a small minority population. However, this has increased from 4.9% to 13.4% since 2000 with the African American population at 5.4%, Asian 5.1%, and Hispanic 6.1%. Within the general population in Wisconsin, 12.5% live in poverty, which compares to the national percentage of 14.9%. Of children in Wisconsin, 18.6% live in poverty compared to the national percentage of 23%².



IB. Individuals with a Developmental Disability: Based on a conservative estimate that 1.5% of the population has an intellectual and developmental disability, the UCEDD estimates that there are approximately 85,895 people with a developmental disability³ living in the state that need one or more services from the publicly funded service systems. As of March, 2014 approximately 67,129 of those are receiving community-based services from either the Birth to 3 Program (9,583), school system (35,763)⁴ or from County and Family Care funded programs (21,846). Approximately 2,119 children and adults are on waiting lists to receive either long term or family support services. This leaves approximately 15,447 individuals with DD who are living in the community who are potentially eligible for services, but are not on waiting lists or being served. As of March, 2014 there were 370 individuals with DD living in one of the two state Centers for DD. This compares to 3900 who were living in the DD Centers in 1969; 971 in 1998; 751 in 2004; and 461 in 2008. 230 individuals with DD are currently living in county and private ICF/MRs.⁵

IC. UCEDD Guiding Principle: The basic principle that grounds and guides the work of the Waisman Center UCEDD is that communities throughout the state and nation have a responsibility to assure that their organizational structures and community programs are designed in ways that acknowledge, welcome and incorporate all citizens as valued members of the community and give them equal opportunities to make continuous contributions into the stream of community life. This principle of community inclusion that is stated in the purpose of the DD Act⁶ serves as the reference point from which the Waisman Center UCEDD identifies the needs of the DD population in the state and develops corresponding core function activities to work with communities throughout the state to address those needs.

ID. Data Sources for Planning: The UCEDD utilized a variety of methods to identify the critical need areas it proposes to address over the next five year period. First, as a member of the

Board of Directors of the Wisconsin Board for People with Developmental Disabilities (WBPDD), the UCEDD has access to and reviews the variety of data sources and reports that are prepared by state and local agencies that are directly serving and/or funding the services that are being provided to individuals with a developmental disability in the state. Most prominent among these is the Long-Term Care Expansion Report⁷ which is completed annually by the Wisconsin Department of Health and Services to track utilization of and satisfaction within the Family Care managed care program. This long term services program began as a pilot with 6 counties in 2000, expanded to 57 of the 72 Wisconsin counties, and plans are currently underway to extend into 6 more counties in 2014. Second, the UCEDD draws from surveys of those using DD services that are periodically conducted by the WBPDD, Family Voices Wisconsin, People First Wisconsin, the Wisconsin Survival Coalition and others to gain a snapshot from the consumer perspective about the accessibility and quality of services. Third, as shown in **Table 1**, the UCEDD serves on several in-state committees and study groups related to developmental disabilities. The needs of individuals with DD are continuously identified during the deliberations of these committees and this information feeds into the annual and 5 year UCEDD planning process. Fourth, UCEDD staff and faculty routinely document the needs that individuals with developmental disabilities and their families speak to and encounter during the course of their receiving UCEDD services. Given that the UCEDD provides direct service to over 6000 families each year, this is a rich source of information based on the lived experience.

IE. Role of Consumer Advisory Committee: The UCEDD Constituent Advisory Committee (which is the name of the Waisman Center's Consumer Advisory Committee) is charged to review and comment on the work of the UCEDD throughout the year and has been closely involved in the development of this application. Input from the CAC was given in several ways. First, as a regular agenda item for each of the 3 CAC meetings, the UCEDD Associate Director

Table 1: Waisman Center UCEDD involvement with Wisconsin based external agencies & organizations that provide input to planning of UCEDD programs and services.	
Name of External Agency	UCEDD involvement to receive input
Wisconsin Department of Health Services	<ul style="list-style-type: none"> • Division of Public Health <ul style="list-style-type: none"> -Member, Statewide CYSHCN Committee -Member, MCH Advisory Committee -Member & Staff, Youth Transition Hub -Member & Staff, Genetics Hub -Grant Recipient, Sound Beginnings Program -Grant Recipient, Southern Region CYSHCN Center • Division of Long Term Care <ul style="list-style-type: none"> -Member, Children's Long Term Support Council -Member, Birth to 3 Interagency Coordinating Council -Member, Restrictive Measures Committee -Grant Recipient, Katie Beckett Consultant Program -Grant Recipient, Wisc Personnel Development (Birth-3)
Wisconsin Board for People with Developmental Disabilities	<ul style="list-style-type: none"> • Member, Board of Director • Member Long-term care committee • Subcontract supports 2 Staff working at DD Board offices
Wisconsin Department of Public Instruction	<ul style="list-style-type: none"> • Member, Early Childhood Collaborating Partners • Member, Community of Practice on Youth Transition • Grant Recipient, Race to the Top Grant
Dane County Human Services	<ul style="list-style-type: none"> • Member, DD Crisis Response Advisory Committee • Grant Recipient for (1) DD Training & Consultation, (2) Challenging Behavior, (3) Wellness Inclusion Nursing, (4) Sound Response.
Wisconsin Survival Coalition	<ul style="list-style-type: none"> • Member, Steering Committee and full Coalition
Wisconsin Department of Administration	<ul style="list-style-type: none"> • Member, Disability Inclusion Advisory Committee
Wisconsin Committee for People with Disabilities	<ul style="list-style-type: none"> • Member of Committee.
American Family Children's Hospital	<ul style="list-style-type: none"> • Member, Family Advisory Committee • Co-sponsor and conduct clinical services
CESA 5 Wisconsin	<ul style="list-style-type: none"> • Member, Birth-3 RESource Quality Improvement Team

provides a "UCEDD Update" during which time selected programs are reviewed based on interests of CAC members and the needs expressed by UCEDD program directors to solicit CAC advice. As one example of advice being sought, at the winter 2013 meeting the committee was asked to offer its advice on how the UCEDD should approach entering into discussions with consumers about whether they and/or their family members would like to be involved in research

projects at the Center. The CAC members were asked, “what information would they want to know about the research and how would they like that information presented to and discussed with them? What advice do they as consumers have to offer the UCEDD as it further considers consumer involvement in research efforts?” The typical schedule for CAC input throughout the year is for the CAC to review the previous year UCEDD Annual Report in July (as it is being prepared for submission to AIDD by July 30th), a midyear report in the winter, and the upcoming annual workplan draft in the spring. Because the 2014-19 UCEDD renewal application was anticipated to be due to AIDD in early 2014, the CAC discussed a preliminary draft of the 5 year plan at its June 6, 2013 meeting, and a more comprehensive review of the full plan at its January 13, 2014 meeting. The conclusion of the CAC at that meeting was that the workplan continues to reflect a wide range of programs and services that correspond to the needs of those with developmental disabilities in the state. They particularly encouraged the UCEDD to continue its efforts to support inclusion of individuals with DD in the early childhood and school systems, as well as within the broader community based programs and systems. The CAC continues to have concerns about how the Family Care model of service delivery that is being advanced in the state will impact services to those with DD, particularly with regard to fostering independent living and integrated employment. For that reason, the CAC encouraged the UCEDD to continue to be involved with monitoring implementation of Family Care and assisting Family Care agencies to serve those with DD. **Appendix A** includes a letter from CAC Chairperson Carl DuRocher that further describes the role the CAC played to review and develop this application.

IF. Problems and Needs Identification:

Based on progress that has been made over the past 40+ years to create policies that support community based services, the vast majority of individuals with developmental disabilities now live in the community along with their fellow citizens without disabilities. While the state and nation can and should be proud of the progress that has been made, all is not well. As the following paragraphs in this section explain, the challenges that individuals with DD in Wisconsin face are similar to those that many others face for social and economic reasons. These challenges include support and development during the early childhood years, equal and appropriate educational opportunities, post school employment, primary and specialized health care, safe and appropriate housing, and meaningful use of social and leisure time. As the UCEDD identified the various needs during the planning process, it grouped

Examples of Major Disability-Related Policy that has Supported Individuals with DD to live in the community.

1963: Mental Retardation Facilities Construction Act authorized construction of MR research centers; university affiliated training facilities and community service facilities.

1965: Elementary and Secondary Education Act Amendments authorized aid to state agencies to support schools for children with disabilities.

1970: Elementary and Secondary Education Amendments created The Education of the Handicapped Act authorizing grants to states to improve education of children with disabilities.

1970: DD Services and Facilities Construction Amendments set broad responsibilities for state councils to plan and implement program of services for persons with developmental disabilities.

1975: DD Assistance and Bill of Rights Act created a bill of rights for persons with DD, and established a system of protection and advocacy organizations in each state.

1975: Education for All Handicapped Children Act mandated a free and appropriate education for all children with disabilities in a state, regardless of the nature or severity of the child's disability.

1978: Rehabilitation, Comprehensive Services and DD Amendments established new programs including independent living centers, pilot programs for employment.

1981 Omnibus Budget Reconciliation Act authorized home and community based waivers to enable states to furnish personal assistance and other services to enable individuals with disabilities to live in the community rather than an institution.

1990: Americans with Disabilities Act guaranteed civil rights of people with disabilities.

1991 Individuals with Disabilities Education Act enhanced infants and toddlers programs.

1999 The Olmstead Decision of the U.S. Supreme Court that affirmed the right of individuals with disabilities to live in their community per the Americans with Disabilities Act.

2000: Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000 that consolidated and updated related federal legislation dating back to 1963.

2010: The Patient Protection and Affordable Care Act, created a range of insurance related policies to promote access to community based health care, e.g., eliminating denial of coverage based on pre-existing conditions, ending annual and lifetime limits and other policies.

those needs as falling within one of three categories:

- Early childhood and education needs,
- Health related needs,
- Other needs to promote inclusion at all levels of community life.

The needs documented within these areas then served as the basis for developing the UCEDD Goals for the next five years and for designing the organizational framework within which the UCEDD will carry out its work to meet those goals.

Early Childhood and Education Related Needs:

The earliest years in a child's life set the foundation for success at all stages of later life. To make the most of these exciting early years, early childhood practitioners, researchers and families have defined a generally accepted *Unified Theory of Practice in Early Childhood*⁸ that identifies the fundamental tenets of early childhood programming and the evidence-based practices that should be incorporated into programming to assure that children with developmental and other special needs are provided with appropriate education, health, and other developmental services so that they are prepared to enter school ready to learn*. ⁹ This theory, which is summarized in **Table 2**, serves as a reference for the UCEDD and its many partners as they work to promote understanding and application the evidence based practices that everyone should be working to assure across the state. The UCEDD carries out this work as a lead member of the Wisconsin Early Childhood Collaborating Partners (www.collaboratingpartners.com/screen_assess.htm) which is a network of state, regional, and community public and private agencies, associations, and

*There is agreement that *school readiness is a two-dimensional concept* and that both elements of readiness are equally important. In addition to *children being ready for school, schools also need to be ready to receive all children*. From the child perspective, school readiness focuses on health and physical development, emotional well-being and social competence, approaches to learning, communicative skills and cognition and general knowledge. From the schools perspective, school readiness refers to schools that have strong leadership, strive for continuity between early care and education programs, promote smooth transitions between home and school, are committed to the success of every child as well as every teacher and adult who interacts with children at school, uses approaches that have been shown to raise children's achievement and alter practices and programs if they do not benefit children.

individuals who work to promote effective early childhood programming. Within this network, the UCEDD and its partners have identified 2 primary challenges that interfere with Wisconsin's ability to implement the tenets and practices spelled out in the Unified Theory.

Challenge #1: Schools, colleges and departments of education across the country are finding that they do not have the capacity to meet community needs for early childhood professionals and are understaffed and under resourced at all levels.¹⁰ This includes staff to serve both typically developing children as well as children with developmental delays and disabilities. States must identify new and efficient ways to meet the staffing needs to plan, administer and deliver high quality early childhood programming to children of all abilities.

Challenge #2: Parents of children with disabilities throughout the state continue to report that it is very difficult for them to identify and become enrolled in inclusive early childhood programs that meet the three key principles for early childhood inclusion which are: access to a wide range of learning opportunities, participation that includes individualized supports to participate fully in play and learning activities with peers and adults, and supports that undergird the efforts of individuals and organizations providing inclusive services.¹¹

Implication of Documented Early Childhood Needs on UCEDD Planning: Based on the documented needs that have been summarized, the Waisman Center UCEDD should work to increase the number of well-trained early childhood professionals by supporting preservice training of early childhood professionals, to include initial preparation and continuing education of those providing Birth to 3 early intervention services. The UCEDD should also continue to advance inclusive early childhood programming by continuing its model demonstration program, and having that serve as the basis for providing technical assistance to community based early intervention programs to assist them to be inclusive.

Table 2: A Unified Theory of Practice in Early Childhood/Early Intervention: Fundamental Tenets and Evidence-Based Practices – Odem and Wolery	
Fundamental Tenet	Evidence-Based Practices
✓ Families and homes are the primary nurturing environments.	<ul style="list-style-type: none">• Family-centered practices• Social support and resourced based models• Parent-implemented teaching models
✓ Positive relationships must be established between the child with the disability, his/her parents or other caregivers, and professionals working with the family.	<ul style="list-style-type: none">• Parent-infant interaction programs• Peer-interactions programs• Professional collaboration programs
✓ Children learn through acting on and observing their environment.	<ul style="list-style-type: none">• Natural learning opportunities• Classrooms employ evidence based practice• Contingently responsive environments.
✓ Adults mediate children's experiences to promote learning.	<ul style="list-style-type: none">• Activity based intervention• Routine structuring• Prompting and prompt-fading strategies
✓ Children's participation in more developmentally advanced settings is necessary for successful and independent participation in those settings.	<ul style="list-style-type: none">• Learning opportunities in community and home• Inclusive preschool play groups• Social integration in inclusive settings
✓ Early childhood/early intervention is individualized and goal oriented.	<ul style="list-style-type: none">• Goals linked with learning strategies• Parent input solicited by routine-based interviews• Environment source of goal identification
✓ Transitions across programs (NICU to home, home to EI, EI to school, etc.) are enhanced by developmentally instigative adult.	<ul style="list-style-type: none">• Assess demands of next setting & teach needed skills• Prepare personnel & family for transition• Interagency agreement for smooth transition
✓ Families and programs are influenced by the broader context.	<ul style="list-style-type: none">• Family-centered planning• Resource-mapping• Culturally sensitive programs

Health Related Needs

The Waisman Center UCEDD has been very involved in addressing health related issues of those with developmental disabilities since it was initially organized in the early 1970s. Its work has included sponsoring several low incidence diagnostic and follow along clinics, preservice training programs, and community based health education programs for professionals and consumers. Based on the fact that over 3500 families seek out clinic and other health related services from the Waisman Center each year, the need for those services is clearly demonstrated. Also, because of the increasing rates (1 in 68 children, age 8) of autism spectrum disorders being reported during the early childhood and school years¹², the Waisman Center has been

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encouraged to expand its clinical diagnostic capacity to serve more individuals, to reduce the waiting time to receive services from two months to one month or less, and to develop treatment services. Because the Waisman Center is recognized as a highly sought after clinical resource to confirm the diagnosis of a developmental disability, the UCEDD teamed with faculty in the UW-Madison Department of Population Health in 2002 to develop a capacity to conduct epidemiologic studies in the area of developmental disabilities. Since that time it has been involved with the CDC funded Surveillance of Autism and Other Developmental Disabilities System that is a multiple-source investigation to determine and monitor the number of eight year-old children in the population with an autism spectrum disorder (ASD), an intellectual disability, and/or cerebral palsy. In 2003 the UCEDD expanded beyond its clinical and surveillance work and assumed a leadership role that continues to this day to design a statewide systems change effort to identify and address the range of health needs of individuals with DD of all ages living in the community. This effort built upon efforts of former Surgeon General David Satcher and Special Olympics to bring attention to these unmet needs. Initial UCEDD work involved convening a Wisconsin Conference on Health Disparities and Developmental Disabilities which resulted in creation of a *Wisconsin Blueprint* that includes a series of health related training and service efforts that the UCEDD and its partners are working to implement.¹³ The Statewide Health Disparities and DD Steering Committee¹⁴ which the UCEDD leads, completed a series of five in-state regional conferences during which consumers, health care providers and others further studied the recommendations in the statewide report and discussed specific concerns and steps to take to address key concerns that are summarized in **Table 3.**¹⁵ To further document the health status of those with developmental disabilities, in June, 2011 the UCEDD convened an invitational meeting of representatives of the health and disability fields to consider developing a *Health and Disabilities Data Plan* to help those interested in health and

disability to more effectively capture, analyze and utilize health and disability data to inform policy development, program planning and evaluation. This effort continues to be developed and is underway at 3 levels:

1. Further Documentation of Needs: First, with leadership from the Wisconsin Division of Public Health a case definition of disability was formulated and utilized to analyze public health databases to document the health of individuals with a disability living in the state. Based on their analyses, individuals with disabilities in Wisconsin are twice as likely to have trouble paying medical bills, four times as likely to not get needed medical care, less likely to have had dental care in the past year, and have significantly higher levels of major health risk factors including more likely to smoke, be obese, have high cholesterol, and have high blood pressure.¹⁶

2. Promotion State Planning to Address Needs: For the first time since the publication began, *The State Health Plan, Healthiest Wisconsin 2020* identifies individuals with disabilities as a population group that is experiencing health disparities which must be addressed.

3. Creation of Collaborative Capacity to Promote Health and Wellness: With leadership from the Waisman Center UCEDD, the WI Department of Health Services, UW-Madison Department of Population Health Sciences, Family Voices Wisconsin and numerous health and disability related agencies and organizations, efforts are underway to secure funds to create a planning process to create a Wisconsin Center for Health and Disability. The UCEDD would assume a major role to coordinate the work of the Center that would: (a) further strengthen efforts to document health needs: (b) identify relevant evidence-based health care practices and assess the degree to which those practices are being implemented for individuals with disabilities in Wisconsin: (c) make information on evidence-based practices more readily available in the community and support efforts to apply those practices: (d) foster health care and systems changes to improve the health of individuals with disabilities, and; (e) encourage and assist to

facilitate research and the generation of new knowledge that can be used to improve health care practices and systems.

Implication of Documented Health Related Needs on UCEDD Planning: Based on the documented needs that have been summarized, the Waisman Center UCEDD should organize its workplan to continue its direct services to families in UCEDD Clinics, its preservice and continuing education of individuals who are preparing themselves for or are currently functioning as a health related professional, and its efforts to better understand the distribution and determinants of health for those with developmental disabilities and use that information to inform public health planning.

**Table 3: Health Issues of Individuals With Developmental Disabilities in Wisconsin
Primary Concerns Reported During Regional Conferences**

Attitudes and Assumptions

- ✓ About disabilities and people with disabilities – inaccurate, negative, low expectations.
- ✓ About care and service providers – what constitutes good care, role of providers?
- ✓ About the way the system should work – be open to doing things in different ways.
- ✓ Ethics and risks – What is ethical? Who is at risk?

Specific Health Issues for People with Developmental Disabilities.

- ✓ Availability of initial diagnostic services, particularly for children age 2-7 years.
- ✓ Health Promotion, Wellness and Safety – apply this to individuals with DD.
- ✓ Recognize and address specific health issues that are more challenging for individuals with DD., e.g., dental, mental health, aging, etc.

Care and Service Coordination

- ✓ Integrate health with other supports.
- ✓ Partnerships – between disciplines and across programs.
- ✓ Transitions – across programs, systems.

Financing - Insurance and Access

- ✓ Insurance, including special issues with Managed Care.
 - Preauthorization – simplify
 - Access to specialists – assure access, especially in managed care organizations.
 - School and Health System Responsibility – clarify how to work together.

Training – of Everyone

- ✓ Training to advance best practice and assuring cultural competency.
- ✓ Understanding consumer choice, preferences, needs.
- ✓ Specialty training.
- ✓ Parent training.
- ✓ Self-advocacy.
- ✓ Integration of health care, behavioral and other community supports.

As the UCEDD studied the range of issues that impact full inclusion at the multiple levels of community life, five issues areas received particular attention.

1. Need for Resource Information and Assistance: Families with children and adult members with disabilities consistently report on their need for information and assistance in two areas;¹⁷ first, information to help them better understand the cause and nature of the health issue or disability that they are dealing with, and second; for assistance to access community based services and supports to live meaningful and integrated lives in the community. These are not newly expressed needs, as they had been documented in surveys for many years. But, they remain areas of high need which the UCEDD is committed to being responsive.

Implication of Documented Information and Assistance Needs on UCEDD Planning:

Based on the documented needs that have been summarized, the Waisman Center UCEDD should organize its workplan to meet the information and assistance needs of families with children and adult members with developmental disabilities.

2. Need for Behavioral Supports for Children and Adults with Challenging Behavior:

According to NADD, which is a National Association that promotes understanding of and services for individuals who have developmental disabilities and mental health needs, approximately 30-35% of all persons with intellectual or developmental disabilities have a psychiatric disorder.¹⁸ And between 12-17% of those defined as having a cognitive disability will reportedly display challenging behavior such as physical aggression, self-injury and destructiveness towards the environment. These behaviors often appear to develop in childhood and continue into adulthood. The co-existence of intellectual disability, challenging behavior, and a psychiatric disorder can have serious effects on the person's daily functioning by interfering with educational and vocational activities, by jeopardizing community based living arrangements, and by disrupting family and peer relationships. In short, the presence of

behavioral and emotional problems can greatly reduce the quality of life of persons with intellectual or developmental disabilities. It is therefore necessary that accurate diagnosis and appropriate treatment be obtained in a timely manner. Positive Behavior Support, which is based on the premise that individuals exhibit behaviors for a reason and that those behaviors serve a useful, communicative purpose, has been shown to be an effective, values-driven approach for supporting individuals with challenging behavior.¹⁹

Implication of Documented Need for Behavioral Supports on UCEDD Planning:

Based on documented needs that have been summarized, the Waisman Center UCEDD should organize its workplan in order to perform core functions that support the availability of Positive Behavioral Supports.

3. Employment Related Needs: Historically, in Wisconsin and across the nation, participation in employment, and particularly integrated employment, has been limited for adults with developmental disabilities. Based on 2012 data, only 22% of Wisconsin adults with a developmental disability, age 18-64 are employed in an integrated work setting.²⁰ Key factors that contribute to these low rates include: (a) individuals with DD have an incomplete understanding of integrated employment opportunities and believe they risk losing publicly-funded benefits if they become employed, (b) disability related service providers have limited knowledge and capacity to provide integrated employment services, and (c) employers have limited experience and expertise in employing individuals with developmental and other disabilities. Given that employment is one of the primary ways that individuals participate in the community, the UCEDD made a special effort to become more actively involved in the employment area of emphasis in 2001 when Wisconsin successfully competed to receive multi-year funding from the Centers for Medicare and Medicaid Services (CMS) to explore how public policies could be revised to support, rather than to discourage employment of individuals with

disabilities. As part of that project, the Wisconsin Department of Health Services formed a Managed Care and Employment Task Force in 2007 and charged it to “recommend a comprehensive strategy to expand work options for adults who rely on the community-based, long-term, care system” and whose services and supports are being shifted to the expanding Family Care – Managed Care program in Wisconsin. This task force was composed of 28 members including the UCEDD Associate Director. Their final report that was issued in 2008²¹ includes 17 major recommendations that are divided into two groups; one directed to improving the managed long-term care system’s infrastructure and broader community collaborations to support employment, and another to improving the experiences and outcomes of individual consumers. UCEDD work with those efforts continued through 2012. In the fall of 2013 the UCEDD became a collaborator on a new 5 year AIDD funded national systems change grant to the Wisconsin Board for People with Developmental Disabilities. Within that *Let’s Get to Work Project*, the team is working to improved community employment outcomes for youth with intellectual and developmental disabilities in transition. The UCEDD employs the overall coordinator for the project and participates as a member of the projects executive and advisory committees.

Implication of Documented Employment Needs on UCEDD Planning. Based on documented needs, the UCEDD should commit a portion of its workplan to support employment of individuals with a developmental disability in integrated employment settings.

4. Education - Youth in Transition Related Needs: IDEA 2004 clearly articulates the commitment to students with disabilities by stating that an overarching purpose of special education is to “prepare them for further education, employment, and independent living” as one component of a national policy aimed at “ensuring equality of opportunity, full participation,

independent living, and economic self-sufficiency for individuals with disabilities” (Sec. 601(c)). Despite this federal commitment, adolescents with developmental and other disabilities face difficult obstacles in making a successful transition to adulthood. Many do not graduate from high school, enter into employment, or pursue postsecondary employment. This is exemplified by the fact that 68.6% of students with disabilities graduate from high school in four years (compared to 90% of students without disabilities), and that number increases to only 78% after six years of high school. This means that 22% of students with a disability never graduate from or drop out of school. Individuals with disabilities also encounter unemployment, underemployment, and segregated jobs after exiting high school, with only 69% of young adults with a disability enrolled in a post-secondary school or competitively employed after one year of leaving high school.²²

Implication of Documented Education & Youth Transition Needs on UCEDD

Planning: Based on the documented needs, the Waisman Center UCEDD should continue to be involved with efforts to increase high school graduation rates of youth with developmental and other disabilities and their successful transition to post-secondary education and work.

5. Needs Related to Broader Public Policy and Systems Change: Wisconsin, like all other states in the nation, is designing, testing and implementing a number of steps to increase the efficiency and streamline the provision of developmental disability related services from birth across the lifespan. While this action is providing the states with exciting opportunities to design community based services and supports that are ever more responsive to the needs and desires of the individuals with DD and their families, there is competition for funds and not everyone is in agreement about how services should be designed and delivered. For these reasons it is very important for the Waisman Center UCEDD, as a member of the national network of UCEDDs to

find its place in the public policy making process and assist others to understand what the evidence is showing with regard to what constitutes best practice, and how those best practices can and should be effectively and efficiently delivered, evaluated and continually improved. Within Wisconsin, the UCEDD accomplishes this by serving as a member of the Survival Coalition of Wisconsin Disability Organizations, which is a cross-disability coalition (that includes Disability Rights Wisconsin and the Wisconsin Board for People with Developmental Disabilities) that works in partnership with others to promote policies, programs, and practices that advance integrated, individualized, community-based supports and services. **Table 4** on the following page briefly summarizes a portion of Survival Coalition's current budget priorities.

Implication of Documented Public Policy and System Change Needs on UCEDD Planning:

Based on documented needs, the Waisman Center UCEDD should organize its workplan to support continuation of its public policy and system change efforts that impact individuals with developmental disabilities and their families in Wisconsin and throughout the nation.

IG. UCEDD Goals for 2014-2019

Based upon the needs that have been documented in this section, the goals of the Waisman Center UCEDD for 2014-2019 will be to:

- Goal 1:** Promote inclusive early childhood education and school readiness for all children with a developmental disability and/or other special health care need.
- Goal 2:** Eliminate health disparities for all individuals with a developmental disability and promote their optimal health and development.
- Goal 3:** Promote the inclusion of all individuals with a developmental disability to live in the community and participate in all streams of community life.

**Table 4: Real Lives. Real Work. Real Smart. Wisconsin
Investing in People with Disabilities
Wisconsin Survival Coalition Budget Priorities, 2013–2015**

Adult Long-Term Care: Expand Family Care statewide. Review and modify Family Care capitation rates to ensure funding is sufficient to allow MCOs to provide the housing, employment and support options preferred by consumers. Consolidate Southern and Central Centers and continue to relocate residents to the community with adequate services and supports.

Children’s Long Term Support Issues: Reduce current waiting time of 2 years for home and community based supports for children with significant disabilities, by increasing funding \$5 million to serve an additional 1,000 children. Provide short-term coordination to 20% (600) of families whose children are on the long term support waiting list.

Special Education: Reform state funding formula to provide adequate and equitable funding to enable all children to be college and workforce ready by the time they graduate High School. Restore overall public education funding to the previous levels, including a fair increase in special education categorical aid funding to raise the state reimbursement to 30%. Prevent future expansion of parental choice (voucher) programs until issues of disability discrimination and full access for children with disabilities are resolved to the satisfaction of the US Dept. of Justice and disability advocates.

Transportation and Housing: Prioritize transit operating aids to help preserve public transit including paratransit services. Adequately fund transportation services in managed care programs.

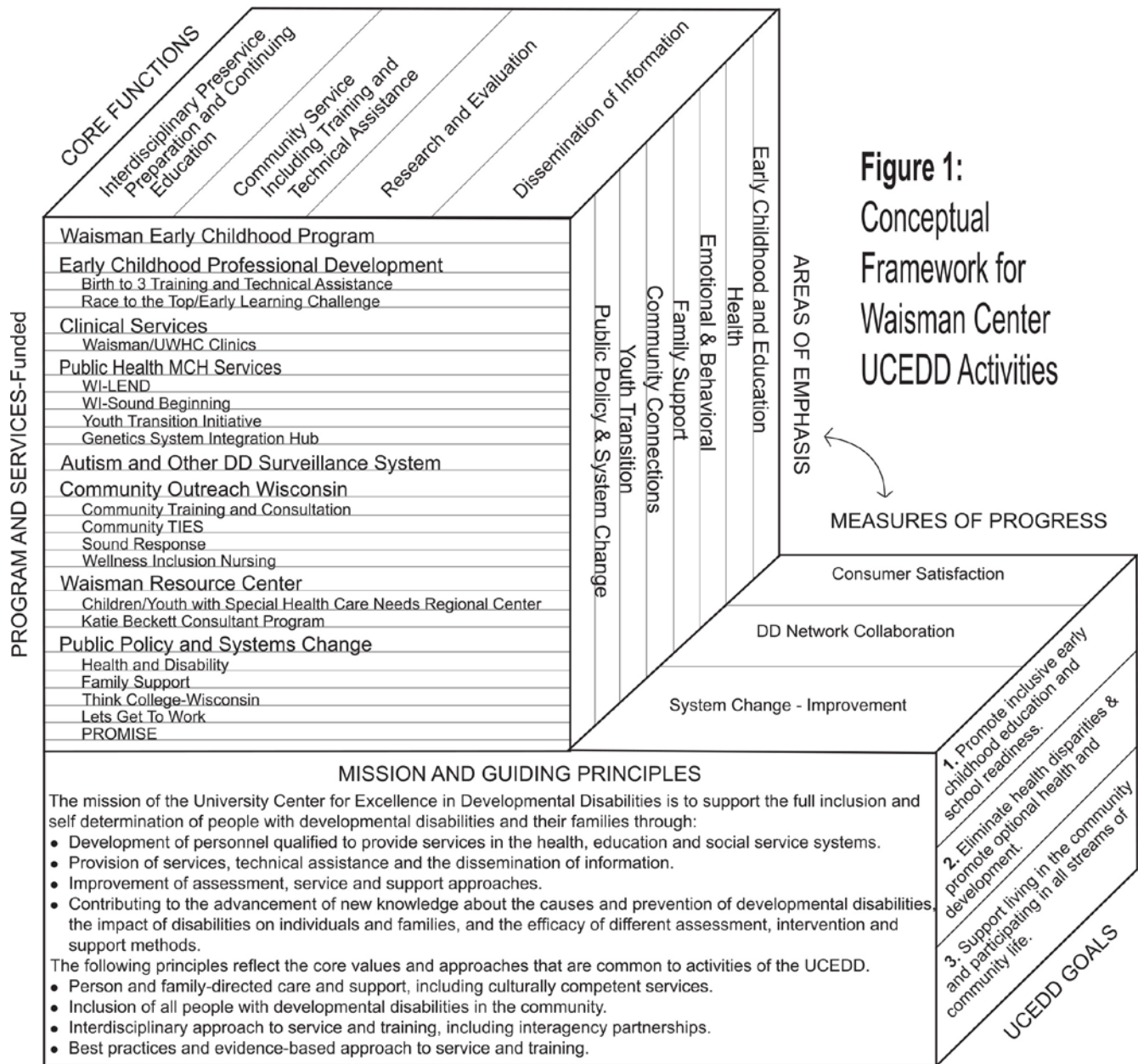
Health Care Reform: Develop a Wisconsin based health care exchange that is specific to the needs of Wisconsin residents and reflects the views and needs of local stakeholders. Focus on expanding Medicaid to the population that remains uninsured below 133% of poverty. Preserve existing insurance mandates as essential benefits going forward (e.g., cochlear implants, autism treatment, mental health/AODA parity). Develop incentives to promote coordination of care across health and community systems, which may include Medical Home models.

Employment: Fully match funding for the VR program with the requirement that DVR set targets for increasing supported employment expenditures and outcomes statewide and in each Workforce development area.

II. APPROACH

This section describes the detailed plan of action that will be undertaken by the Waisman Center UCEDD to carry out its 2014-19 Five Year Plan to address the challenges identified in Section 1. The plan is responsive to the needs expressed by individuals with DD and their families, and the state and federal agencies that make funds available to support the services that the UCEDD provides. The plan was developed in collaboration with individuals with DD, parents, service providers, and representatives of local, state and federal agencies that are involved with various aspects of DD related services. The collaboration to develop this plan took many forms, including soliciting comments from the UCEDD Constituent Advisory Committee (previously discussed in **Section ID**) , engaging in discussion with those who receive UCEDD services, and learning about the needs while serving on the range of governmental and non-governmental committees that were described earlier and are listed in **Table 1**.

IIA. Conceptual framework to address needs: With the previously mentioned documented needs as background, the Waisman Center UCEDD has developed the conceptual framework that is depicted in **Figure 1** to illustrate how various elements of the UCEDD fit together. As shown in the diagram, the MISSION AND GUIDING PRINCIPLES serve as the underlying foundation for the planning and implementation of all UCEDD activities. CORE FUNCTIONS (top of matrix) are performed within a wide array of funded PROGRAMS AND SERVICES, which advance work within one or more of the UCEDD AREAS OF EMPHASIS that are relevant to the needs of individuals with developmental disabilities and their families, and assessed according to the MEASURES OF PROGRESS spelled out in the DD Act.



The proposed UCEDD plan has evolved and become standardized within the UCEDD over the past several years. That plan builds upon the needs expressed by individuals with DD and their families, and the state and federal agencies that make funds available to support the services the UCEDD has organized to address those needs. The plan was developed in collaboration with individuals with DD, parents, service providers, and representatives of local, state and federal agencies that are involved with various aspects of DD related services. The collaboration to

develop this plan took many forms including soliciting comments from the UCEDD Constituent Advisory Committee (previously discussed in **Section 1C**), engaging in discussions with those who receive UCEDD services, and learning about needs while serving on the range of governmental and non-governmental committees that are listed in **Table 1**. Individuals with disabilities and family members are an integral part of UCEDD operations and will continue to assume important roles at all levels of UCEDD planning and implementation. The UCEDD made a special effort many years ago to employ individuals with DD and family members as staff, demonstrated by the fact that the UCEDD staff members listed in **Appendix D** includes eleven parents who have a child or young adult with a developmental disability. In addition, the UCEDD employs five young adults with intellectual disabilities.

IIB. Plan for Interdisciplinary Preservice Preparation: Interdisciplinary Preservice Training activities are guided by the UCEDD Preservice Training Committee (charge on following page) that is chaired by the UCEDD Training Director, Anne Bradford Harris, PhD., RD., MPH. Dr. Harris also serves as director of the federally funded Waisman LEND Training Program within the UCEDD. Preservice training programs within the UCEDD include formal training programs that lead to the award of an initial academic degree or certificate, or an advancement in academic credentials. These include internships, practicums, fellowships and residency activities. For the next five year funding period, formal training programs will include, at a minimum, the Waisman LEND Program that provides interdisciplinary leadership training for graduate students to improve systems of care for children with neurodevelopmental and related disabilities and their families, and the Genetics Counseling Master's Program that combines advanced education in human, molecular, and medical genetics with skills and experience in counseling. Core elements of all UCEDD trainings programs are; (a) person and family directed care and support, including culturally competent services, (b) best practices and evidence based approach to

services and training, (c) inclusion of all people with DD in the community, and (d)

Interdisciplinary approach to service and training including interagency partnerships.

UCEDD Community Education & Dissemination Committee Charge: To serve as a forum for the discussion and coordination of UCEDD efforts in the core functions of community training, technical assistance and dissemination. To fulfill this charge, the committee:

- Facilitates a shared understanding of training and technical assistance activities across projects in the UCEDD.
- Functions as a venue for exploring community training needs and opportunities.
- Explores strategies and mechanisms for effective dissemination of information, resources and practice.
- Serves as a point of connection to the Community Education and Dissemination Council, in order to foster exchange of information and models with other UCEDDs.

Composition: The committee will be comprised of lead staff representing the organizational units of the UCEDD that provide community training, technical assistance or dissemination, with the aim of having representation that allows the committee to link with all relevant projects and areas of emphasis.

Activity: The CEC will meet at least quarterly. Through serving as a forum for cross-project communication and coordination around the core functions of community training, technical assistance and dissemination, the committee supports the UCEDD's capacity to:

- Maintain core information about staff expertise and project activities related to community training and technical assistance
- Increase UW and public access to information, publications, products and expertise within the UCEDD.
- Organize and advertise training opportunities and expertise related to the UCEDD mission and areas of emphasis.
- Coordinate as appropriate for consistent UCEDD and Center branding and messaging.

By serving as a cross-project forum on community training, technical assistance and dissemination, the committee plays a role in exposing needs or opportunities that cut across projects. In this way, the committee may trigger activity in areas including:

Evaluation and Reporting

- Improving documentation of training and technical assistance activities in NIRS
- Developing evaluation strategies to increase knowledge about impact and outcomes

Technological Capacity

- Sharing information about current use of technologies to support training and dissemination, and developing strategies for sharing best practices and lessons learned across projects

Training and Outreach

- Identifying processes to respond to training and technical assistance requests that are not project-specific.

UCEDD trainees come from a variety of disciplines including psychology, social work, medicine, nutrition, public health, regular and special education, OT, PT, and nursing. Family members were added to the array of trainee disciplines several years ago, and self-advocates (individuals with an intellectual disability) were added as UCEDD LEND trainees in 2011. Both

of these trainee disciplines have proven to be significant enhancements to the UCEDD training programs as they not only provide rich training opportunities for the family members and self-advocates themselves, but their participation broadens the scope of disciplines within the training programs so that the various disciplines, including family members and self-advocates, can learn from and with one another. Other family members and self-advocates from the community routinely serve as guest speakers to UCEDD training seminars, and the UCEDD has sponsored a “Family Mentor” experience for the past 20 years, which gives UCEDD long term trainees (those who spend 300+ hours with the UCEDD) an experience with a family in their home environment so that they can learn from the family about the real life experience of raising a child with a developmental disability.

IIC: Plan for Community Services Core Function: The UCEDD carries out its community training, technical assistance and model and demonstration service activities through successfully designing and negotiating an array of grants, contracts and fee-for-service arrangements to provide services, supports and other assistance to individuals with developmental disabilities and their families, professionals, paraprofessionals, policymakers, students and other members of the community. These grants, contracts and programs are summarized within **Table 4** on pages 30-38 which constitutes the UCEDD workplan for the next five years. Based on the current portfolio of grants and contracts, the UCEDD anticipates that each year it will provide clinical services to 3500 families; inclusive early childhood services to 85 children; one-on-one assistance to access local services to 750 families; health and behavioral support to 300 individuals; independent living support to 225 adults; and training and technical assistance to approximately 16,000 community based professional and paraprofessionals, including policy makers and administrators. The UCEDD is continually exploring creative ways to design its training and service methods so that in our delivery of those services we are

demonstrating methods that that promote inclusion and integration of individuals with DD and their families. For example, the UCEDD promotes inclusive early childhood education based in large part on the methods it has designed and is utilizing within its own inclusive early childhood program. In terms of community training events, a particularly creative and cost efficient way to provide training to care support workers and the individuals with DD at the same time, is a community training the UCEDD titles “Info-Share.” These day long trainings are focused on a certain topic such as exploring consumer and provider relationships, supporting good health with food, nutrition and exercise, and dealing with challenging behavior and frustrating times. The trainings then include periods when everyone is trained together, as well as sessions when the consumers can meet with other consumers, and support staff can talk with others who have similar roles and responsibilities. At each of these trainings individuals with DD and family members serve as faculty members. Another creative training method that the UCEDD has used several times is creating scripts that demonstrate some aspect of the training, and then including individuals with DD and family members as actors to role play the scripts. In that way they are involved in the creation of the training scripts and in their presentation to those being trained.

IID. Plan for Research and Evaluation Core Function: The workplan summarized in **Table 4** includes cells that identify specific ways that the UCEDD will be involved with research and evaluation over the next funding cycle, including ways the people with DD and their families will be active participants in the research process at all levels including design, application and dissemination of findings. The activities listed collectively comprise the UCEDD’s current program of research and evaluation that includes applied research and evaluation and the analysis of public policy. In the spring 2014, the UCEDD made the commitment to begin further strengthening its research and evaluation work by creating a new position that is called the Director of Research. The primary purpose of this position is to enhance capacity within and

across each of the UCEDD programs to be more thoughtful and strategic about how to incorporate research into the work of the UCEDD so that the UCEDD can more effectively: (a) contribute new knowledge about the cause and consequences of IDD, as well as strategies for optimizing the quality of life of individuals with IDD and their families; (b) tell the story of its work within the academic, programmatic and public policy worlds; (c) test and apply best practices, in cooperation with the Waisman Center IDDRC investigators, and (d) evaluate its work. Leann Smith, PhD, is an associate scientist at the Waisman Center and assumed the UCEDD Director of Research position 40% time. The remainder of her fulltime position at the Center will be spent with her own research that is focused on understanding the impact of having a child with a developmental disability on the family as well as the role of the family in supporting healthy development for individuals with disabilities. Dr. Smith is currently meeting with each of the UCEDD program leaders to review their work and how they are incorporating research and evaluation into that work. Those discussions will result in creation of a UCEDD Research Plan later this year that will outline steps the UCEDD will take over the next year to build upon current work and expand with additional resources. This UCEDD is confident that it will be able to secure those additional resources based upon the strategic plan that is being developed.

III. Plan for Information Dissemination Core Function: Each of the programs in the UCEDD includes within its charge the responsibility to disseminate information that summarizes the best practices that are being applied in their program so that the UCEDD, the broader Waisman Center and the national network of UCEDDs can clearly show how it is meeting its core function responsibility to translate research into practice. The Community Education and Dissemination Committee oversees information dissemination efforts, and the UCEDD uses the following specific ways to disseminate information: (1) As they carry out their work, each

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UCEDD program is encouraged to develop its own set of products that they believe captures important aspects of their work that would be of interest to consumers, service providers, educators, administrators and policymakers. Funds to support development of these products are incorporated into the various program budgets and additional dollars are secured from other agencies that have an interest in and want to utilize the product being developed. Printed products are then made available to those that supported the initial printing and others can order copies from the initial supply. Still others can simply access the product via the UCEDD website where all products are grouped by Areas of Emphasis and subcategories within those areas of emphasis, for downloading at no cost. At that website, <http://www.waisman.wisc.edu/cedd/products.php> materials are available in a variety of formats including printed materials, CDs, or some form of e-learning opportunity. As the UCEDD creates information and disseminates information, it utilizes the principles of universal design by developing products that are useful to people with diverse abilities and accommodates individual preferences and abilities. The UCEDD contracts with the campus Digital Media Center to create sub captions on videos, and it is creating an increasing number of materials in a non-English format. The most recent of those being “GUÍA DE RECURSOS”, una guía de navegación para las familias de Wisconsin con niños y jóvenes con necesidades especiales de atención de salud y discapacidades.

http://www.waisman.wisc.edu/cedd/pdfs/products/community/FYW_s.pdf

As was discussed in IIC, the UCEDD involves individuals with disabilities and individuals representative of the diverse cultural and linguistic backgrounds within the state in the design of its products. An exciting example of that work within the current 5 year funding cycle was a radio novella that was created in serialized storytelling format in Spanish for airing in radio stations in the Madison and southeastern areas of the state. *Un Nuevo Amanecer Para Ana Y Su Familia* is a story that was told over thirteen episodes from Ana’s diagnosis with cerebral palsy

to her first job as a young adult. The full script is available via CD and at the following link.

<https://www.waisman.wisc.edu/cedd/pdfs/products/family/novela.pdf>

A variety of methods are also used to share information with policymakers, and the most typical methods are issue briefs (created with members of the Wisconsin Survival Coalition that have interest in the given issue) and individual meetings during which the UCEDD can share best practice information and talk more specifically with the policymaker about what they can do to develop and advance policies that help implement those best practices in the most effective and efficient ways that are in accord with the preferences of individuals with DD and their families.

As an example of these type of meetings, earlier this year the UCEDD arranged a series of meetings with a key policymaker in the state who was positioned to help the UCEDD and the families it serves to address the increasing problem with securing prior approval for services within our Communications Aids and Systems Clinic. During the meetings with the policymakers, a Waisman faculty investigator reviewed the scientific literature that explained the purpose and value of the service. Clinic management staff reviewed the problems that were being encountered in the prior authorization process, and a family with a child using the clinic demonstrated how they benefit from the clinic service and how service in that clinic helps their child in school and in everyday life. As a result of those meetings the legislator made contact with the state agency and asked them to explain the basis for the service delays and denials.

Those discussions called into question some of the “evidence” that the state agency was relying on in making their determination (information of questionable scientific base). The UCEDD is beginning to see more approvals for the service and shorter timelines from initial request for prior authorization and the agency decision. While we are pleased to see some level of modest progress with this, we are also very aware that we must be continually prepared to deal with this

situation again, and to be prepared to use similar strategies to work with policymakers on other issues of importance to those with DD and their families.

IF. Plan for Consumer Advisory Role and Recruitment for Maximum Diversity: As stated in **Section IE** and in the Letter of Support (**Appendix A**) from Carl DuRocher, Chair of the UCEDD Consumer Advisory Committee (called the Constituent Advisory Committee), the CAC is comprised of self-advocates and family members and includes representation from People First Wisconsin. The committee is currently in the process of working with each of the UCEDD program managers to encourage them to identify one or two self-advocates and families members who are users of their service and would be interested in joining the committee. The Committee is especially interested in recruiting more members from the rural and distant parts of the state further from Madison, as well as more members from the non-white population, which is approximately 17% of the population in the state.

IIG. DD Network Partnership: The three AIDD State partners (Disability Rights Wisconsin, Wisconsin Board for People with Developmental Disabilities and the Waisman Center UCEDD) have a multi-year history of successfully working together. Supports letters from DRW and WBPDD for the UCEDD 5-year application are included in **Appendix A**. While those letters explain that the partners work together on a range of specific issues that come up at different times in the year, the area of policy and systems change has become a most important area to further channel the network collaboration. Policy and systems change work is an ideal category for network collaboration because each of the partners can then focus on and contribute what their core function work should be on an issue, and those individual efforts can be incorporated within a coordinated strategy to advance the policy and systems changes the partners, self-advocates and family members support. Over the past three+ years the partners entered into a pilot project to fund a policy coordinator to work equally with the 3 partner agencies to help

them design and advance the areas of policy and systems changes they felt important from their individual and collective perspectives. This position was hired at DRW and was very successful in establishing connections and work within DRW and WBPDD. But the position never connected in a meaningful way back to the UCEDD in ways that could justify its continuation from the UCEDD's perspective after conclusion of the pilot. A complicating factor that made it especially difficult to implement as a pilot trial was that shortly after the pilot was initiated the Executive Director of the DD Board resigned and was replaced, and the Executive Director of DRW resigned and was replaced, by someone who shortly thereafter resigned and was replaced. Consequently, from the perspective of the UCEDD entering its new 5 year cycle, the decision was made not to continue the pilot after its scheduled end date of June 30, 2014. Following that time the two partners agencies will likely secure the necessary funds to continue the position to work with them. And when the 3 new directors are in place (see note below), they can talk among themselves about steps they want to take together to support one another to meet their individual core function responsibilities and to channel that individual and collective work into advancing the policy and systems changes that are in the best interest of individuals with DD and their families. *(Note: Current UCEDD Associate Director Daniel Bier will retire in the summer of 2014, and plans are moving forward – not finalized - to have him replaced by William MacLean, current UCEDD Director in Wyoming).*

IIH. Leveraging of Dollars: Table 4 which follows over the next several pages provides a detailed summary of the 2014-10 workplan. Annual funding to implement projects outlined in the plan totals approximately \$9.5 million, of which 32% is from federal sources, 43% from state and local sources, and 25% from fee-for-service. **Appendix D** is a summary of current funding sources, most of which are expected to continue into and throughout the next 5 year cycle.

TABLE 4: ANNUAL WORKPLAN OF PROJECTS AND ACTIVITIES - 2014-2019 Waisman Center – University Center for Excellence in Developmental Disabilities Note #1: While core function activities listed below pertain to the first year of the 2014-19 cycle, activities are expected to continue throughout the 5-year period and any changes would be negotiated each year. Note #2: Timeline: Project activities will be performed on a continuous basis throughout each year.			
GOAL 1: To promote inclusive early childhood education and school readiness for all children with a developmental disability and/or other special health care need.			
Objective 1a: To provide early childhood programming to 90 children age 1 through 6 years of age through the UCEDD based Waisman Early Childhood Program			Area of Emphasis: Early Childhood and Education
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
WECPP will serve as training site for 15 graduate and undergraduate students.	90 children receive early childhood programming. Consultation with area programs; presentation at workshops and conferences	WECPP children participate in 2-4 research studies per year related to child development, early education, and inclusion.	Make WECPP curriculum available for other early childhood programs to adapt. Assist in creation of document that summarizes inclusive practices in early childhood.
Factors that may accelerate/decelerate objective. WECPP is a long standing program of the UCEDD and stable from programming and fiscal perspectives. Inclusive programs requires low staff to student ratios for quality purposed, which are more expensive. But the Waisman Center and UCEDD are committed to continuation of this program.			
Objective 1b: To serve as a lead agency for Early Childhood Professional Development, a component of the Wisconsin Race to the Top Early Learning Challenge			Area of Emphasis: Early Childhood and Education,
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
Support annual community of practice events for the Training & TA Network to ensure knowledgeable content trainers and maximize state, regional, and local resources	Work with the PDI Cross Sector Alignment Workgroup to refine and strengthen the alignment of core content, evidence based practices, and system partners.	Review and revise professional competencies across systems to adequately serve children with special needs in multiple systems	Develop a Professional Development (PD) Implementation Portfolio that describes and collects the components of the WI PD system, the foundation of the system, and impacts made over the course of the project.

PROJECT DESCRIPTION: Waisman Center, University of Wisconsin-Madison

Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
<p>Work with the National Project BUILD's technical assistance initiative to establish more effective and efficient competencies for coaching, mentoring, and consultation</p> <p>Collaborate to refine and strengthen structures that support consistent and knowledgeable trainers and technical assistance providers with the defined framework</p>	<p>Work with the PDI to refine and strengthen early childhood career pathways and structures among departments, higher education, and professional development partners</p> <p>Develop 2-year work plan in conjunction with the Office of Early Learning to develop screening and assessment training related to ongoing assessment and the utilization of the most common tools.</p>	<p>Refine & strengthen the communication & implementation infrastructure for cross department and cross sector alignment of PD for the EC community from birth to first grade</p>	<p>Develop Core Competencies that align across systems of care for children & include content specific to disabilities and inclusive practices.</p> <p>Create a Cross System Consolidated Report of statewide training and TA efforts and activities.</p> <p>Expand and improve the Response to Intervention Practices website to include information and tools on early childhood screening assessment practices that align with other statewide screening and assessment practices.</p>
Factors that may accelerate/decelerate objective: Wisconsin is in the first year of implementation of its federally funded Race to the Top initiative. The UCEDD is closely linked with efforts related to early childhood professional development, and will consider throughout the funding period if and how the UCEDD could assume an even greater leadership role.			
Objective 1c: To serve as lead agency for Wisconsin's Birth to 3 Training and Technical Program		Areas of Emphasis: Early Childhood and Education	
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
<p>-Provide series of training & TA on topical EI issues, e.g., orientation to best practices, Primary Coach Approach to Teaming within Natural Environments, Child Outcomes, transitions, service coordination, etc., (400 cumulative attendance)</p> <p>-Regional Institutes on evidence-based practices.</p>	<p>. -Create on-line learning modules on key topics.</p> <p>-Provide ongoing, technical assistance to county Birth to 3 programs in Southern Region of state.</p> <p>-Participate on Birth to 3 Leadership Advisory Team.</p> <p>-Participate in development of State Systemic Improvement Plan (SSIP).</p>	<p>-Assist with data entry of Family Survey data.</p> <p>-Assist with Birth to 3 Program Review and self-assessment process.</p> <p>-Identify fidelity measures for implementation of evidence-based practices.</p> <p>-Utilize Indicator 3 & 4 to refine data analysis of Child and Family Outcomes.</p>	<p>-Maintain Birth to 3 website, with threaded discussions evidence-based articles.</p> <p>--Implementation Science materials for evidence-based practices on Birth to 3 website.</p> <p>-Variety of on-line learning modules available through Learn@UW</p>
Factors that may accelerate/decelerate objective: No changes are anticipated at this time.			

GOAL 2: To eliminate health disparities for all individuals with a developmental disability and to promote their optimal health and development.			
Objective 2a: To provide diagnostic, treatment and intervention to those with or at risk of having a developmental disability. This will include 14 UCEDD clinics within areas of (1) developmental disabilities, (2) genetics and metabolism, (3) neuromotor, and (4) speech, language & hearing.			Areas of Emphasis: Health, Youth Transition.
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
<p>Provide preservice training for 36 students,</p> <p>Developmental pediatrics rotation for 12 Pediatric residents and observational rotation for 6 Family Medicine residents.</p> <p>Provide outreach training for 250 professionals, paraprofessionals, people with disabilities and family members of people with disabilities</p>	<p>Provide diagnostic, evaluation, services to 3000 individuals with disabilities and their families each year.</p> <p>Provide ongoing treatment services to 200 children & adults with developmental and genetic related disabilities. (e.g., CP, PKU, ASD)</p>	<p>Conduct patient and family satisfaction surveys.</p> <p>For newly developed programs (e.g., ASD in 14/15, designed evaluation to assess 1st year effectiveness and efficiency.</p>	<p>Provide information utilizing a variety of means on the purpose of UCEDD clinics and how to access. (web site, flyers, through ongoing contacts within Waisman Resource Center)</p>
<p>Factors that may accelerate/decelerate objective: In close partnership with UW Hospital and Clinics and the UW School of Medicine and Public Health, the UCEDD has been involved with a significant revitalization and expansion of its clinical services for the past 5 years. This was driven in large part by the increased need for ASD and other DD diagnostic services, and has resulted in a recent infusion of additional dollars to support the UCEDD to hire more clinical staff to serve individuals and families. The Waisman Center expects this expansion to proceed in 2014/15 and within this expansion to begin ASD treatment services. Services will then likely stabilize at a new expanded point, in large part because available UCEDD clinic space at the Waisman Center will have been fully allocated. The UCEDD will then continue its direct service as well as support other community providers to increase their capacity to provide services.</p>			

Objective 2b: To provide preservice training of future professionals who will work in a variety of positions within the DD and MCH related fields (direct service, administration, teaching, policymaking) to increase their skills and competencies to serve children and adults with DD and their families.			Area of Emphasis: Health, Early Childhood
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
<p>Provide interdisciplinary leadership training of graduate level students in WI LEND Training Program. 36 long-term, 25 medium term and 60 short term during academic year.</p> <p>Provide graduate level Genetics Counseling program to serve as Genetics Counselors. 10 each year; 5 first year and 5 second year.</p>	<p>Serve on State MCH Advisory Committee</p> <p>In cooperation with WI Title V design annual leadership training for MCH staff statewide.</p> <p>Solicit and respond to TA request to increase capacity of MCH services statewide.</p> <p>Serve on WI Birth Defects Surveillance Committee</p>	<p>Conduct annual evaluation of WI LEND program, involving each trainee, faculty and staff member.</p> <p>Link each long term trainee to a Waisman investigator to learn from and or assist with their current research efforts.</p> <p>Each genetic counseling students conduct Capstone research project</p>	<p>Participate in overall UCEDD effort to prepare and distribute, electronically and through printed media, a wide array of materials to support the health of those with DD and their families.</p> <p>Share information about all UCEDD training programs on UCEDD website.</p>
Factors that may accelerate/decelerate objective: (1) Wisconsin LEND serves as the foundation grant for interdisciplinary training at the Waisman Center UCEDD. As the federal agency (MCHB) that supports this program secures its funding and sets its expectations each year, the UCEDD adjusts accordingly. Funding has been quite stable of late, and we are expecting that stability to continue through the next 5 year UCEDD funding cycle. However any significant change at the federal level would impact the UCEDD, which is a longstanding LEND grantee. (2) The Genetics Counseling Training Program was recently re-accredited for the maximum number of years through 2020 by the Accreditation Council for Genetics Counseling.			
Objective 2c: To promote university newborn hearing screening and follow up services statewide.			Areas of Emphasis: Health, Early Childhood
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
<p>Provide practicum training to 2 UCEDD trainees within WI Sound Beginnings Program each year.</p>	<p>Provide TA to staff throughout state on how to conduct hearing screening.</p> <p>Provide diagnostic newborn hearing follow-up to 125 children</p>	<p>Evaluate efficacy of involving WIC staff to reducing lost to follow up from Hearing Screening.</p> <p>Assess EI Outcomes of children with hearing loss identified at birth.</p>	<p>Serve as presenter each year to the National EHDI conference to share work and experience in Wisconsin,</p>
Factors that may accelerate/decelerate objective: Program is well established by State mandate , but current training and research efforts are funded with additional short term federal dollars.			

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Objective 2d: To promote person-centered transition planning of youth with developmental disabilities from pediatric to adult health care.			Areas of Emphasis: Health, Youth Transition
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
Include as one component of training within the Wisc LEND curriculum, training to support youth in transition.	Provide staff and other resources to design and support the statewide community training and technical assistance efforts of the Youth Transition Hub within the Wisconsin CYSHCN Program	Implement <i>Transitioning Together Translational Research Project</i> to assess clinical application of <i>Transitioning Together</i> research design.	Through print and electronic means, continue to disseminate youth transition materials developed by the UCEDD with its partners. (e.g., best practice articles, training guides.)
Factors that may accelerate/decelerate objective: Youth transition is a UCEDD Area of Emphasis, and as such work will continue to some degree regardless of changing funding streams .			
Objective 2e: To strengthen capacity for DD epidemiology in order to better understand the distribution and determinants of health for those with developmental disabilities, and to use that information to inform public health planning.			Area of Emphasis: Health
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
Serve as short term training site for LEND students to learn about the design and operations of an operational DD surveillance project.	As member of 14 State ADDM network, implement the CDC Autism Surveillance Project which is a population based surveillance project focused on 8 year olds in special education. Provide community training on various issues related to ASD during Waisman Center Autism Day with the Experts and other community based trainings.	Implement CDC Autism Surveillance Protocol. With CDC and ADDM network partners, conduct further analysis of surveillance data to investigate an array of issues related to ASD and other DD.	In cooperation with CDC develop and distribute electronic and print materials related to ASD and other DD prevalence, as well as information on prevention, intervention and treatment.
Factors that may accelerate/decelerate objective: Funding for ASD surveillance work is provided through a competitive application to CDC. The Waisman Center's current funding will end in 2014, and plans are underway to re-apply for funding to continue the work for another 3 year funding cycle.			

GOAL 3: To promote the inclusion of all individuals with a developmental disability to live in the community and participate in all streams of community life.			
Objective 3a To sponsor a Waisman Resource Center to serve as a Regional Center for the Wisconsin Title V Children/Youth with Special Health Care Needs Program (CYSHCN). The WRC provides information and assistance, and parent-to-parent support to families with children with disabilities and other special health care needs.		Areas of Emphasis: Early Childhood & Education, Health, Family Support, Youth Transition, Community Connections.	
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
<p>Include a minimum of one Wisconsin LEND trainee each year as field experience in the Resource Center serving families.</p> <p>Rotate family practice and pediatric students through WRC to gain familiarity with and understanding of community based resources of importance to families and practitioners.</p>	<p>Provide Info & Assistance via toll-free access. 800 brief contacts and 125 intakes.</p> <p>Assist parents with CYSHCN to link with other parents.</p> <p>Serve on CYSHCN Statewide Committee.</p> <p>Conduct 6 training for parents of CSHCN held on a variety of topics.</p> <p>Conduct 7 continuing education programs to professionals providing services to children with special health care needs.</p>	<p>Conduct satisfaction survey with users of Resource Center (consumers and providers who utilize the Resource Center.)</p>	<p>Provide information to parents, consumers and providers through the 800#, website, the Resource Center at the UCEDD, and during UCEDD trainings.</p> <p>Attend outreach events with project display and resources.</p> <p>Maintain WRC website.</p>
Factors That May Accelerate/Decelerate Objective: The State MCH contract that provides funding to support the WRC is currently on a year-to-year funding cycle. While we are expecting that Title V will continue to support the concept of Regional CYSHCN Centers and the work the UCEDD is doing, we do not operate on that assumption and continue our work in ways that show our service, benefits and value.			

PROJECT DESCRIPTION: Waisman Center, University of Wisconsin-Madison

Objective 3b: To facilitate processing of enrollments and recertification's for MA benefits via Katie Beckett category of eligibility)			Area of Emphasis: Health
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
	Speak with 300 families on the phone for intake purposes. Process 160 new applications with home visits and do 230 recertification's for families currently enrolled..	Work with a State workgroup to monitor implementation of functional screen and other tools for MA determinations	Give a minimum of 5 presentations on Katie Beckett Program.
Factors That May Accelerate/Decelerate Objective: No change is not anticipated at this time			
Objective 3c: To serve as lead agency to provide training to DD Service Providers in Dane County Developmental Disability Service System.			Areas of Emphasis: Health, Employment, Other community services.
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
Conduct approximately 150 community trainings in the Dane County DD system.	Training and technical assistance specific to consumer/agency needs is provided on request	Conduct pre and posttest of trainings held throughout the year.	Maintain Community Outreach Website to promote UCEDD community training events.
Factors That May Accelerate/Decelerate Objective: No changes are anticipated at this time. Community Training has been and will continue to be a high priority of the UCEDD.			
Objective 3d; To provide training and direct service to address needs of individuals with developmental disabilities who are experiencing challenging behavior.			Areas of Emphasis: Health, Employment, Education.
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
An extensive offering of community training events will be provided that focus on Positive Behavioral Supports.	Provide consultation on positive behavioral support to over 200 consumers annually. -Provide Crisis Response services as needed, to approximately 55 consumer per year		Working to offer this behavioral consultation model regionally in the state and assume a statewide leadership role to address the mental health needs of persons with DD
Factors That May Accelerate/Decelerate Objective: No changes are anticipated at this time.			

PROJECT DESCRIPTION: Waisman Center, University of Wisconsin-Madison

Objective 3e: Provide technical assistance and program support to Dane County Sound Response Program as an alternative approach to overnight staffing.			Areas of Emphasis: Community Connections
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
	Ongoing offering of “Sound Response” supports to over 160 consumers annually		Consultations on this innovative service regionally. Presentations at national conferences
Factors that may accelerate/decelerate objective: No changes are anticipated at this time.			
Objective 3f: To provide leadership to follow-up on implementation of recommendations to address health disparities of individuals with developmental disabilities in Wisconsin.			Areas of Emphasis: Health, Public Policy & Systems Change.
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
Include health disparities as one component of training within the Wisc LEND curriculum to 35 long term trainees.	Provide leadership and TA to support workplan to develop a Wisconsin Center for Health and Disability. Implement Nurse Consultant Program in Dane County	Participate in analysis of public health datasets with Division of Public Health to document health status of individuals with disabilities in Wisc.	Maintain UCEDD website on Health and Disability.
Factors that may accelerate/decelerate Objective:			
Objective 3g: To serve as lead agency with Department of Health and Family Services to design and implement options for Children’s Long Term Care Redesign.			Area of Emphasis: Family Support, Public Policy & SC.
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
6 trainings to county staff, providers, families, on the principles and options for community supports and services for children w/ disabilities. 4 trainings provided to committee members and county Family Support Advisory Committee members	Serve as Chair of the Council on Children with Disabilities, Collaborate w/ other state CMS Systems Change grantees	DHFS workgroup member to develop quality assurance and improvement tools for children w/dis. Survey families on specific topics Listening sessions w/ families	Develop information for general public on aspects of redesign. Post to WBPDD, Survival Coalition, and UCEDD websites. Inform Survival Coalition members and others about LTC reform issues related to children and family needs.
Factors That May Accelerate/Decelerate Objective: No changes are anticipated at this time.			

Objective 3h: To support other policy and system change efforts to support transition of youth with disabilities to post-secondary education, work and full integration into the community.			Areas of Emphasis: <u>All 7</u> UCEDD Areas of Emphasis.
Training	Service & Technical Assistance	Research & Evaluation	Dissemination of Information
To develop and deliver policy training component within Wisc LEND Training Program to 35 long term trainees each year.	<p>Serve as member, trainer and facilitator of Wisconsin Survival Coalition of disability organizations.</p> <p>Serve on Think College Wisconsin Steering Committee to advance creation of post-secondary education options for those with DD.</p> <p>Provide staff support to coordinate activities of AIDD funded Let's Get to Work and WBPDD, including LTGW Consortium.</p>	Serve as member of core staff at WBPDD to test an intervention within the 5 year (14-19) Social Security project to increase education, career and income outcomes of youth on SSI.	Develop and disseminate DD related policy briefs in collaboration with policy partners at state and national levels.
Factors That May Accelerate/Decelerate Objective: No changes anticipated at this time.			

III. PROJECT IMPACT

The UCEDD Steering Committee, which is chaired by the UCEDD Associate Director in cooperation with the UCEDD Director, is responsible for overall evaluation of UCEDD effectiveness. To accomplish that evaluation the lead staff and faculty within each UCEDD program design a system of evaluation that includes a workplan and schedule for the timely completion of project activities and information to assess the quality and effectiveness of specific outcomes. A number of evaluation models are considered when developing these evaluation designs including goal, process and outcomes based evaluations, logic models, cost/benefit analysis, studies of effectiveness and efficiency, and formative and summative evaluations. In

addition, the UCEDD gathers descriptive information about how core function activities impacted consumers by creating real life stories that provide the consumer (with appropriate consumer approval and review) perspectives about their experience within each core function area, as either a consumer of services or a consumer who was involved in the design and delivery of those services. A sample of these stories is then included in formal UCEDD reports to AIDD and other funding agencies and they are also periodically posted on the Waisman Center website to help others understand how the UCEDD mission and work translates into something relevant and meaningful within the lives of individuals with DD and their families.

Evaluation reports are submitted to the respective funding agency and they are also reviewed by the UCEDD Steering Committee to assure Steering Committee members understand the work of separate UCEDD projects as well as the collective work across all UCEDD projects. In addition, evaluation results are reviewed with the Constituent Advisory Committee (CAC) as part of its annual review of the UCEDD Annual Report each July.

In order to provide information that can be used to plan, manage and evaluate UCEDD programs, and to report activities and outcomes to outside agencies including AIDD, AUCD and others, the UCEDD has established a UCEDD Information and Reporting System which is built upon the National Information and Reporting System (NIRS) that was developed and is supported by AIDD and AUCD. This system produces management and administrative reports that document such factors as demographic profiles of the population served, specific services offered by the UCEDD grouped by core function and area of emphasis, and the financial status of the UCEDD. Information such as project reports, interviews with key staff, and comments from the CAC and other advisory committees is used to make appropriate administrative and program changes. Other reviews of the UCEDD effectiveness are conducted by external teams of peer reviewers that are convened periodically by UCEDD administration. The UCEDD

PROJECT DESCRIPTION: Waisman Center, University of Wisconsin-Madison

Associate Director served as a member of the AIDD Annual Report Template Workgroup that developed materials for UCEDDs to reference and utilize when designing their respective monitoring and reporting format to document efforts they are involved with to meet their obligations spelled out in the DD Act. The UCEDD Associate Director also serves on the AUCD Council on Research and Evaluation which offers opportunities to talk with staff and faculty from other UCEDDs who are involved with designing evaluation methods so that they can learn from one another.

Table 5 describes the elements of the logic model that the UCEDD utilizes to evaluate the extent to which the goals of the UCEDD are being achieved in a manner consistent with the objectives of the DD Act.

TABLE 5: EVALUATION PLAN - Waisman Center UCEDD, 2014-19 Based on UCEDD core functions set by DD Act and Report Template by AUCD & AIDD						
Inputs	Activities <i>Core functions per DD Act</i>	Goal <i>Initial Outcome per AIDD/AUCD Logic Model</i>	Output Measures	Data Sources for Measurement Annual	Reporting Schedule	Ultimate Outcomes →
UCEDD faculty & staff Core Funding from AIDD Consumer Advisory Input In-kind support from partners Leveraged funds University resources Plans and Goals	Preservice Training: To provide interdisciplinary pre-service preparation and continuing education.	95 % will report increase in trainee knowledge.	135 long term and intermediate trainees will receive training each year	Post training assessments by each training program.	Upon completion of training.	Individuals with DD attain maximum physical, emotional, social and economic well being
		95% will report change in trainee attitudes to support those with DD in community.	75 Short term trainees will receive training each year.	AUCD Long Term Trainee Survey.	For long term trainees, 1,5 and 10 year post training.	
		95% will report increase in trainee skills within areas of emphasis				
	Community Services Training: Provide training to individuals with DD, families, professionals and others.	80% will report increase in advocacy knowledge and skills.	100 self-advocates will receive training.	Post training interviews.	Data collected after each training.	Services incorporate evidence based practices.
		95% will report change in attitude.	14,000 people will receive community training each year. e.g., family, service providers, policy makers.	Post training assessment.	Summary report following each training.	Family members have supports they need.
		95% will report increase in skills within areas of emphasis.				
	Community Services Technical Assistance: Provide community TA to individuals with DD, families, professionals and others.	90% of those received TA will report increase in knowledge, change in attitudes, and increase in skills in areas of emphasis.	70 agencies and organizations will receive TA from the UCEDD each year.	Follow up telephone interview or written feedback form.	Summary report 10 days after completion of each TA event.	Individuals with DD are independent, productive, and fully participating members of community consistent with their cultural values.
	Community Services Direct Services: Provide direct services to individuals with DD, family members and others in the community.	80% of individuals with DD report having increased access to promote improved status, or enhance wellbeing.	2100 individual receive services in UCEDD clinics.	Clinics survey in cooperation with Am Family Children's Hospital.	Annual survey of families served in Waisman Clinics.	Public policy promotes full community participation
		80% of individuals with DD and family members report increased capacity to exercise choice.	750 individuals will receive other direct services and supports each year.	Annual review with individual, family/guardian.	Annually.	

PROJECT DESCRIPTION: Waisman Center, University of Wisconsin-Madison

Inputs	Activities <i>Core functions per DD Act</i>	Goal <i>Initial Outcome per AIDD/AUCD Logic Model</i>	Output Measures	Data Source for measurement	Reporting Schedule	Ultimate Outcomes
						➔
UCEDD faculty & staff Core Funding from AIDD Consumer Advisory Input In-kind support from partners Leveraged funds University resources Plans and Goals	Community Services Model Demonstration: Provide model demonstration services to individuals with DD, family and others in the community.	Evidence based practices (EVP) demonstrated. Models field tested and evaluated. Increased capacity of individuals with DD to exercise choice.	Review of programs to assess use of EVP. Number of model demonstrations.	Annual Survey of WECP Families and summary report. Client/Broker interview and summary report.	May of each year. Annually.	Individuals with DD attain maximum physical, emotional, social and economic well being Services incorporate evidence based practices.
	Research: Conduct basic and applied research, program evaluation, and analysis of public policy.	Contribution of new knowledge to the field.	Assess prevalence of ASD in Wisconsin. Design and test strategies to support increased employment of individuals disability. Six public policy analysis conducted.	Surveillance data per protocol. Data collected per protocol. Written summary of each initiative.	Ongoing throughout the year, with annual report. Final report upon completion of study.	Family members have supports they need. Individuals with DD are in- dependent, productive, and fully participating members of community consistent with their cultural values.
			Assess utilization of WIC to access families lost to hearing screen follow-up.	Survival Coalition reports.		
	Information Dissemination: Dissemination of information based on knowledge through UCEDD developed products.	Research findings inform future research activities.	Build upon research within UCEDD planning.	UCEDD strategic planning notes.	Ongoing throughout the year.	Public policy promotes full community participation
		70% of individuals who report back will report increased awareness.	75 new products developed and disseminated each year. Number of people who received information.	Peer journals. UCEDD internal publications documented in NIRS.	Ongoing throughout the year.	

IV. ORGANIZATIONAL CAPACITY

This profile briefly describes the following; organizational structure including personnel and experience, facilities and core services, and linkages with outside agencies.

Organizational Structure: The Waisman Center serves as the focal point for research, teaching and outreach activities in the UW System that are related to human growth and development, developmental disabilities, and neurodegenerative diseases. It is the largest research and training center within the UW-Madison Graduate School. **Appendix B** is a signed agreement that documents the status of the UCEDD within the UW-Madison and its capacity to perform the required core functions spelled out in the DD Act. Marsha R. Mailick, PhD is Director of the Waisman Center and is responsible for the direction, coordination and administration of all aspects of the Center. Dr. Mailick reports directly to Martin Cadwallader, PhD., Dean of the Graduate School. Dr. Mailick also serves as the UCEDD Director, which is a position she assumes in addition to her positions as full Professor within the School of Social Work and the School of Medicine and Public Health. Daniel Bier, MPA, MSW, serves as full time Associate Director of the UCEDD and reports directly to Dr. Mailick, and in that role oversees all matters within the UCEDD including serving as director of the UCEDD Grant from the Administration on Intellectual and Developmental Disabilities. Dr. Mailick's and Mr. Bier's bio sketches are included in **Appendix E**. **Appendix D** includes a listing of faculty who are associated with UCEDD Programs in a training, service or research role throughout the year, and a listing of UCEDD academic staff members organized by UCEDD employing unit. With regard to its personnel, the Waisman Center works with UW-Madison to recruit and retain faculty and staff who represent the diversity of Wisconsin. As was explained earlier, it has made a successful effort to employ qualified individuals with disabilities and family members in both professional and non-professional staff positions.

PROJECT DESCRIPTION: Waisman Center, University of Wisconsin-Madison

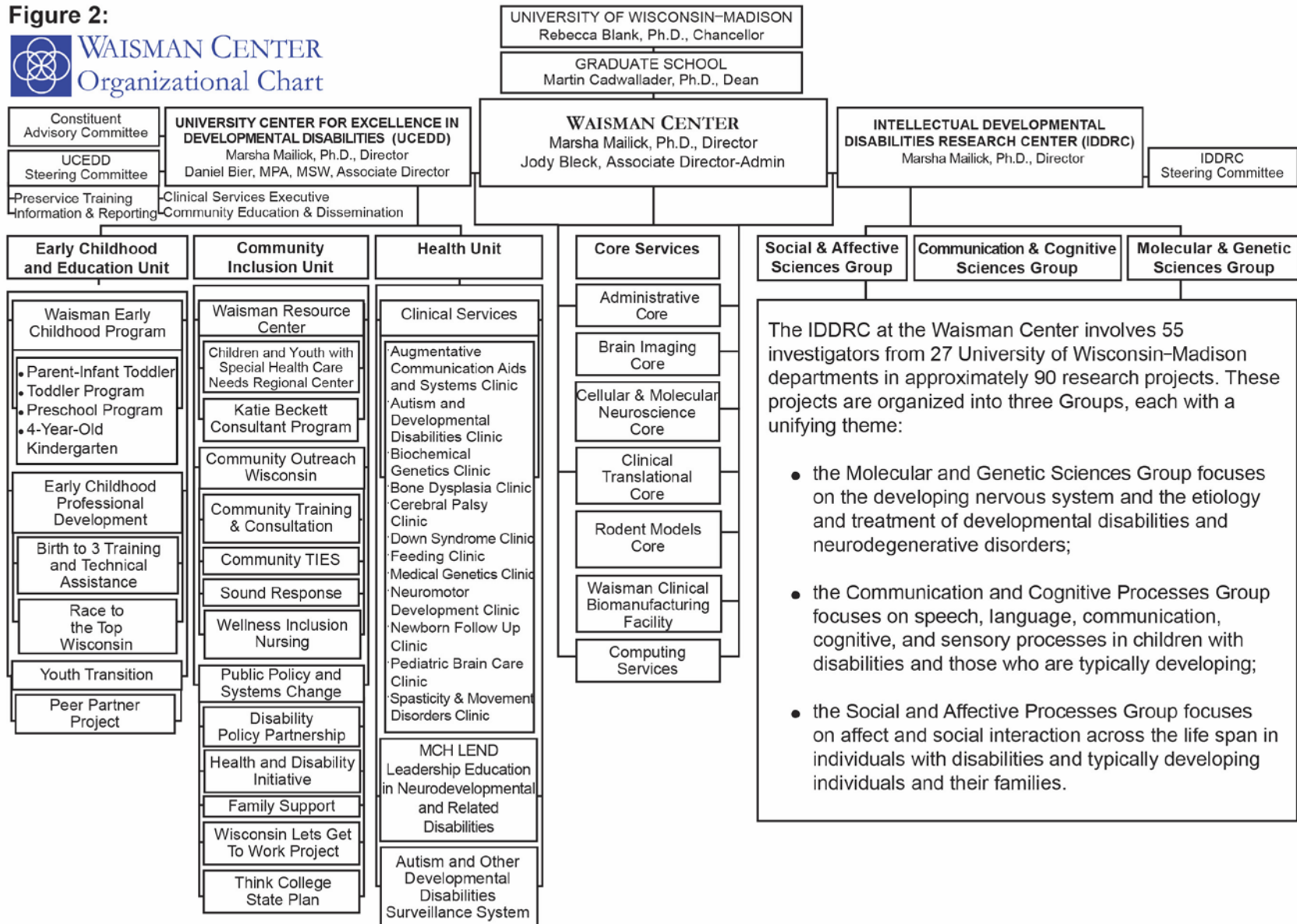
As shown in the **Figure 2** Organizational chart on the next page, the Waisman Center is comprised of two major entities, an Intellectual and Developmental Disabilities Research Center (IDDRC) and a University Center for Excellence in Developmental Disabilities (UCEDD). The Waisman Center is one of only a three research and academic centers in the nation that house both an IDDRC and a UCEDD. The IDDRC is designated by the National Institute of Child Health and Human Development (NICHD) and is organized into three research groups: Social and Affective Processes, Communication and Cognitive Processes, and Molecular and Genetic Processes. Within these units an interdisciplinary team of 55+ faculty affiliated with 26 academic departments campus carry out over 90 scientific investigations, most of which are funded by the NIH and other federal sources. The UCEDD is designated by AIDD and is organized into three units: Early Childhood and Education, Community Inclusion, and Health Services. The Waisman Center has served in the role of a UCEDD since the network of such centers was authorized by federal legislation in the late 1960s.

The UCEDD has five committees that plan and oversee its activities. The UCEDD Steering Committee oversees overall planning. The Constituent Advisory Committee advises the UCEDD on its five year plan and reviews and comments on activities throughout the year. The Preservice Training Committee oversees and coordinates the development and oversight of interdisciplinary preservice training programs across the UCEDD. The Community Education and Dissemination Committee provides direction and oversight to UCEDD community training and TA that is conducted by each UCEDD program. The Clinics Executive Committee coordinates the design and implementation of all UCEDD Clinical services in cooperation with UW Health, including assuring compliance with HIPAA and other regulations. The Information and Reporting Committee coordinates UCEDD data collection and reporting efforts including NIRS reporting to AUCD, ADD and the federal Maternal and Child Health Program.

Figure 2:



Waisman Center Organizational Chart



Facilities and Core Services: The Waisman Center UCEDD has a strong commitment from the UW-Madison and the Waisman Center for space and other resources for its program. The Waisman Center allocates 35,000 square feet of space in the main center facility on Highland Avenue and an additional 5,000 square feet of space in a community-annex for the support of clinical and educational programs. The UCEDD also uses space throughout the university and community as part of training site activities.

The 35,000 square feet at the Waisman Center is located over three floors of the Center. This space includes: specially-equipped evaluation rooms connected to observation rooms with two-way mirrors; interview rooms connected to observation rooms; acoustical and radio-wave shielded sound suites; a demonstration kitchen; a room fully-equipped (e.g., balls, mats, stairs, suspension hook with varied hanging equipment) for therapeutic assessments and treatment; classrooms (regular and theater-style); faculty offices; study areas for trainees; and storage areas for equipment and supplies. In addition, the UCEDD has usage of the Waisman Center auditorium, which is fully accessible and seats 250 people. Also, the entire 8th floor of the Waisman Center consists of two large conference rooms and a complete kitchen which are available for pre-service and in-service training activities. In the 2003 addition to Waisman Center a 90 seat auditorium was added, space for the Center's early childhood program was renovated and expanded, and technological facilities were created to support functional-imaging, genetics and other research.

Additional resources are available to UCEDD programs through Waisman Core Services that are depicted within the middle strand on **Figure 2**. Those of particular value to the UCEDD are the Administrative and Communication Core that provides fiscal and administrative support functions, and the Computing Core that provides service in a variety of areas related to the

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application and development of software, database design and management, and consultation on distance education technologies. Over the past year the UCEDD has strengthened its linkage with the Clinical Translation Core in order to support its efforts to provide individuals with developmental disabilities and their family members the opportunity to participate with Center based research projects.

APPENDICES: The following were entered as a single “optional attachment” into the SF-424 Package.

APPENDIX A: Letters of Support

1. Constituent Advisory Committee (Consumer Advisory Committee)
2. Wisconsin Board for People with Developmental Disabilities
3. Disability Rights Wisconsin

APPENDIX B: Waisman Center UCEDD and UW Madison Agreement

APPENDIX C Summary of Current UCEDD Funding Sources

APPENDIX D: UCEDD Employing Units

APPENDIX E: Curriculum Vitae: Marsha R. Mailick, PhD
Waisman Center and UCEDD Director

Resume: Daniel Bier, MPA, MSW
UCEDD Associate Director

ENDNOTES

¹ U.S. Census Bureau: State and County QuickFacts. (Wisconsin data derived from a variety of Census Bureau reports and estimate), June, 2013.

² The Annie E. Casey Foundation, *Kids Count 2013 Data Book Online*, Baltimore MD.

³ The UCEDD follows the federal definition that is spelled out in the Developmental Disabilities Assistance and Bill of Rights Act of 2000. That law defines a developmental disability as *a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination mental and physical impairments that is manifested before the individual attains age 22 and is likely to continue indefinitely. Developmental disabilities result in substantial limitations in three or more of the following functional areas: self care, receptive and expressive language, mobility, self-direction, capacity for independent living, and capacity for economic self-sufficiency.*

⁴ This figure represents the number of children identified in the IDEA Child Count ages 3-21 with a primary disability within one of the following categories: Cognitive Disability, Emotional Behavioral Disability, Orthopedic Impairment, Autism, Traumatic Brain Injury, Deaf-Blind, Significant Developmental Delay.

⁵ Information on number enrolled in Long Term, Birth to 3, and Family Support services, including number of residents in State DD Centers provided by staff of Wisconsin Department of Health Services, Division of Long Term Care. March, 2014.

⁶ Developmental Disabilities Assistance and Bill of Rights Act 2000, Public Law 106-402. The purpose of this title is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance to promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs under this title.

⁷ Wisconsin Department of Health Services, (December, 2013). *Long-Term Care Expansion Report- P-00590*.

⁸ Odom, S., Wolery, M., (2003) *A Unified Theory of Practice in Early Intervention/Early Childhood Special Education: Evidence Based Practices*, The Journal of Special Education, Vol.37:3. pp 164-173.

⁹ Saluja, G. Scott-Little, C. Clifford, R. (Fall, 2000). *Readiness for School: A Survey of State Policies and Definition*. Early Childhood Research and Practice, Vol 2, No 2.

¹⁰ Washington, V. (September, 2008). *Role, Relevance Reinvention: Higher education in the field of early care and education*. Boston: Wheelock College. (Note: The signatory partners to this special report include National Head Start Association, National Black Child Development Institute, The Council for Professional Recognition, The Cayl Institute, Aspire Institute, Pre-K Now, Wheelock College and the National-Louis University.)

¹¹ DEC/NAEYC. (2009). Early childhood inclusion: A joint position statement of the Division of Early Childhood (DEC) and the National Association for the Education of Young Children (NAEYC). Chapel Hill: The University of North Carolina, FPG Child Development Institute.

¹² Centers for Disease Control and Prevention. *Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network Surveillance Summaries*, MMWR 2014;63(SS02); 1-21.

¹³ Waisman Center, University of Wisconsin-Madison (February 2003). *A Wisconsin Blueprint To Improve The Health of Individuals with Developmental Disabilities: Invitational Conference Report*, Madison, Wisconsin.

¹⁴ Members include: Waisman Center UCEDD, Disability Rights Wisconsin, Wisconsin Board for People with Developmental Disabilities, Arc Wisconsin and the Wisconsin Department of Health Services.

¹⁵ Regional conferences were held in each of the 5 regions of the state during 2005-07. The concerns identified parallel those expressed by consumers and families members during the statewide conference, which demonstrates that the types of changes required to reduce health disparities cannot be quickly achieved.

¹⁶ Seay, J. Miller, R, Pearson K. Siege, A. Buedel, A., (June, 2012) *Health and Disability in Wisconsin – Estimates from Three Population-based Surveys*, Wisconsin Division of Public Health, WI Dept of Health Services

¹⁷ Consensus discussion of meeting of information and assistance staff. (January, 2014). Wisconsin Title V Children and Youth with Special Health Care Needs Regional Centers.

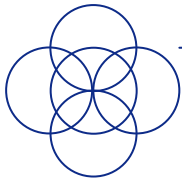
¹⁸ NADD Website (2014). *Information on Dual Diagnosis*

¹⁹ Carr E.G., Horner, R.H., et., al., (1999) *Positive behavior support for people with developmental disabilities; A research synthesis*. Washington DC: American Association on Mental Retardation.

²⁰ Butterworth, J., Hall, A.C., Smith, F. A., Migliore, A., Winsor, J., Domin, D., & Sulewski, J. (2013). StateData: The national report on employment services and outcomes. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

²¹ Wisconsin Division of Long-Term Care, (July 2008). *Managed Care and Employment Task Force Final Report*. Wisconsin Department of Health Services, Madison, Wisconsin. (<http://dhs.wisconsin.gov/WIpathways>)

²² Wisconsin Department of Public Instruction, (2012). *2013 Wisconsin Statewide Summary of Post School Outcomes Survey of 2011-12 Exiters with Disabilities*.



WAISMAN CENTER

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May 9, 2014

Administration on Intellectual Developmental Disabilities
Attention: Review Panel for UCEDD Applications
U.S. Department of Health and Human Services
Washington, DC 20447

CAC Letter of Support

Dear Members of the Review Committee:

The purpose of this letter is to document that the Waisman Center Constituent Advisory Committee (CAC) has been closely involved in the development of the 5 year UCEDD application and that the committee fully supports the proposed workplan. Our committee is comprised of individuals with developmental disabilities, family members, and representatives from People First Wisconsin, the Wisconsin Board for People with Developmental Disabilities, and Disability Rights Wisconsin.

In compliance with the requirements of the DD Act, our committee is charged to review and comment on UCEDD programs and services throughout the year. We accomplish that task during our regularly scheduled meetings which are held three times per year. In addition to reviewing the Annual Report that is submitted to AIDD each July, we review selected projects in more depth each year. Because 2013/14 was the year of resubmission of our 5-year application, during our January 2014 meeting each of the UCEDD program managers either attended our meeting personally or called into the meeting to provide us with a brief review of their program and the plans they had for the program over the next funding cycle. As we review UCEDD programs, our primary interest is to assure that we understand the consumer need that is being met by the program and that the work is being carried out in ways that are sensitive and responsive to consumer perspectives and preferences. I am pleased to report that our committee supports all of the work of the UCEDD and shares the opinion that the work is responsive to consumer needs.

I have been chair of our CAC for two terms and was a member of the committee several years before that. I appreciate the support our UCEDD's associate director has shown the CAC by including its chair in the UCEDD Steering Committee. I also serve as a member of the AUCD Council on Community Advocacy (COCA) and attend its annual meeting each year as part of the AUCD annual meeting. Our committee is currently in the process of reviewing its composition and manner in which it meets its responsibilities. In terms of composition, we have added two new members this past year to increase the diversity of the committee and we have recently asked each of the UCEDD programs to review the consumers they are serving and talk further with a few of those that they think would be interested to join our committee. We are especially interested in recruiting consumers who are from the northern and more rural locations of the state. Because of travel times and the burden of travel, we are also exploring how we can make greater use of telecommunications to involve members statewide. If consumers prefer to attend the meetings in person, their travel, lodging and related expenses are covered by the UCEDD. Each consumer member also receives a \$75 honorarium for each meeting.

On behalf of our CAC, I urge you to support our UCEDD's application.

Sincerely,

Carl DuRocher, Chair
UCEDD Constituent Advisory Committee



WISCONSIN BOARD FOR PEOPLE
WITH DEVELOPMENTAL DISABILITIES

Marsha R. Mailick, PhD, Director
Waisman Center, University of Wisconsin-Madison
1500 Highland Avenue
Madison, Wisconsin 53705

April 18, 2014

Dear Marsha:

I am writing this letter of support for the Waisman Center University Center for Excellence in Developmental Disabilities' application to renew its core grant funding for another five years. The Wisconsin Board for People with Developmental Disabilities (BPDD) takes seriously the charge from the Administration on Intellectual and Developmental Disabilities for the three AIDD partners in each state to communicate and collaborate effectively to achieve our shared goal of improving the lives and supports for people with intellectual and developmental disabilities and their families.

In particular, the recent blended funding that Waisman Center, BPDD and Disability Rights Wisconsin (our Protection and Advocacy organization) contributed toward a statewide public policy partnership has allowed our disability network to influence and change state and federal policies that have affected public education, employment, and long-term care across the lifespan: both at the legislative and state/federal departmental levels. Infusing an evidence base and citing national research studies in our policy briefs and other materials has strengthened our credibility as a network and has resulted in multiple policymakers seeking our collective input when considering policies impacting the disability community.

Additionally, BPDD seeks out the content expertise available at the UCEDD as new opportunities have emerged. Specifically, when BPDD applied as the lead agency in 2011 for a Project of National Significance in youth employment, we sought the expertise of the Waisman Center's Medicaid Infrastructure Team in developing the concepts and in providing staff leadership to the project. Likewise, when the Department of Workforce Development in Wisconsin awarded BPDD with two contracts to provide leadership on parent training and community organizing in its \$32 million PROMISE grant, we solicited the content expertise of specific staff at Waisman who have that background. We frequently seek input from Waisman staff on materials we develop, and team with them on presentations and outreach.

Another joint effort has been our successful Think College initiative to increase the number of post-secondary options that offer college experiences to youth and young adults with intellectual and developmental disabilities. Waisman wrote a planning grant and provided initial staffing, and now we provide additional funds that support an entire team, including Waisman staff, to strengthen the effort.

BPDD continues to partner with Waisman on multiple shared committees and workgroups statewide. We have developed promising initiatives out of initial intervention projects at Waisman, and will continue to seek ways to partner, share successes, and expand and sustain systemic efforts that impact the lives of people with disabilities and their families.

Sincerely,

A handwritten signature in cursive script that reads "Beth Swedeen".

Beth Swedeen, Executive Director
Wisconsin Board for People with Developmental Disabilities

Wisconsin Board for People with Developmental Disabilities
101 East Wilson Street, Room 219, Madison, Wisconsin 53703
Voice 608.266.7826 • Toll Free 888.332.1677 • FAX 608.267.3906
Email: bpddhelp@wi-bpdd.org • Website: www.wi-bpdd.org

Marsha R. Mailick, Ph.D.
Vaughan Bascom and Elizabeth M. Boggs Professor
Director, Waisman Center
University of Wisconsin-Madison
1500 Highland Avenue
Madison, Wisconsin 53705

May 9, 2014

Dear Dr. Mailick,

I am pleased to write this letter of support for the University of Wisconsin - Waisman Center's application to renew its core grant funding as a University Center for Excellence in Developmental Disabilities. As Wisconsin's Protection and Advocacy Agency for Persons with Disabilities, also funded through the Administration on Intellectual and Developmental Disabilities (AIDD), Disability Rights Wisconsin appreciates the partnership that the Waisman Center has developed with our agency. We look forward to building even stronger ties with the UCEDD at the Waisman Center during the next five year grant period. DRW believes it is essential that Wisconsin's three AIDD partners communicate and collaborate effectively in order to achieve our shared goal of improving the quality of life for people with intellectual and developmental disabilities and their families.

The recent joint venture between the Waisman Center, the Wisconsin Board for Persons with Developmental Disabilities, and Disability Rights Wisconsin establishing the Disability Policy Partnership was an extraordinary example of such a partnership. With funding contributed by each partner, including from the Waisman Center's UCEDD grant, the Disability Policy Partnership directly influenced policy-makers and resulted in State policies that have positively affected access for persons with developmental disabilities to public education, employment, and long-term care. Through this partnership we have also worked together to engage with self-advocates and provide training to University of Wisconsin graduate students who have an interest in disability law and policy.

The Waisman Center provides an extraordinary array of research and services expertise. Disability Rights Wisconsin has engaged with Waisman Center experts from the Community Ties program to assist in the transition of long term care residents from Milwaukee County's Mental Health Complex into community residential placements. We have drawn upon the implications embedded in data from the nationally significant longitudinal study of Autism conducted by you and your research partners at the Waisman Center. When seeking expertise in ethical decision-making regarding the medical care and treatment of persons with developmental disabilities, the Waisman Center has provided us with ample support. DRW has also sought to protect funding and access to unique applications of translational research conducted by Waisman Center scientists for people with disabilities.

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DRW also continues to partner with Waisman Center staff members on a number of committees and workgroups affecting long term care and the inclusion of persons with disabilities in the community. We look forward to strengthening our connections, gaining valuable insights from Waisman sponsored research, and working together to affect systemic change that improves the lives of people with disabilities and their families.

Thank you for this opportunity to support and advance the work of the UCEDD at the University of Wisconsin – Waisman Center. We strongly support your application for continued funding and look forward to a long and strengthened partnership.

Very truly yours,

A handwritten signature in black ink, appearing to read "Daniel Idzikowski", with a long horizontal line extending to the right.

Daniel Idzikowski, JD
Executive Director

cc: Dan Bier