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## Abstract

**Project Title:** University Center for Excellence in Developmental Disabilities

**Applicant Name:** Board of Regents of the University of Wisconsin

**Principal Investigator:** William E. MacLean, PhD

The mission of the Waisman Center, University Center for Excellence in Developmental Disabilities (UCEDD) is to support the full inclusion, self-determination, independence and productivity of people with developmental disabilities and their families across the lifespan. In partnership with people with developmental disabilities and their families, DD network partners, and key stakeholders we will address the needs of Wisconsinites with DD through a range of programs focused on health, education and early intervention, community supports, and quality assurance. Our goals are guided by the core functions of the DD Act: 1) increase the diversity, knowledge and skills of undergraduate, pre-service, postdoctoral and continuing education trainees in the provision of equitable services, supports and advocacy of people with DD; 2) increase capacity of health, mental health, and community service providers to provide enhanced specialized services, supports and other assistance that are responsive to the needs of individuals with DD and families from diverse backgrounds; 3) strengthen community partnerships to enhance research, dissemination, and outreach practices to address the priorities and needs of individuals with DD and families; 4) conduct applied research and program evaluation activities that positively impact the health, education, and community participation of individuals with DD; and 5) increase access to public awareness materials, research, public policy and other resources that positively impact the lives of individuals with DD and their families. Our goals will be carried out in the context of a UCEDD with numerous community partners, a long history of achievements in the disability field, proven ability to leverage resources to carry out our goals and strong support of our home university.

## **SECTION 1. PROJECT RELEVANCE AND CURRENT NEED**

### **Wisconsin Demographic Information**

Wisconsin ranks 20<sup>th</sup> in population<sup>1</sup> (5,813,568) and 23<sup>rd</sup> in total area<sup>2</sup> (65,496 sq. miles). The population is concentrated in the southern half of the state – primarily in the Milwaukee and Madison metropolitan areas. The northern half of the state is largely rural and relatively distant from the state’s largest cities and the urban influence of Minneapolis and Chicago<sup>3</sup>. Wisconsin’s population is 87.3% White, 6.7% Black or African-American, 2.9% Asian-American, 1.2% American Indian, 0.1% Native Hawaiian and Other Pacific Islander and 1.9% reporting two or more races<sup>1</sup>. With regard to ethnicity, 6.9% of the population identify as Hispanic or Latino<sup>1</sup>. In comparison with the 2000 census, the state has become more diverse with regard to race and ethnicity. Of particular note, the percentage of the population identifying as Hispanic or Latino has doubled while there has been modest growth in non-white populations. Currently, Wisconsin has the third largest Hmong population<sup>4</sup> in the US and the fourth largest Amish population<sup>5</sup>. Wisconsin has eleven federally recognized American Indian tribes – the majority of which are located in the northern portion of the state<sup>6</sup>.

With regard to educational attainment, Wisconsin is above the national average in the population percentage of high school graduates (87.3% vs 91.7%) and just slightly below the national average in the percentage of residents with Bachelor’s degrees or higher (30.9% vs 29.0%)<sup>1</sup>. While the number of people living in poverty in Wisconsin (11.3%) is lower than the national average (12.3%), poverty rates are higher for Black (28.7%) and Hispanic (18.7%) populations<sup>7</sup> as well as households that include children under 18 (16%).<sup>8</sup>

## **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 86,000 people with a developmental disability living in Wisconsin that need one or more services from the publicly funded service system. As of 2015, approximately 31,000 were HCBS waiver participants.<sup>9</sup> At the statewide level, participation in long-term care programs continues to increase as the state works to reduce its wait lists. The final two counties are now entering into long-term managed care, resulting in elimination of wait lists in those counties and an end to wait lists for long-term supports in Wisconsin. In addition, recently passed legislation will eliminate the children's long-term care wait list. This means Wisconsin will soon be one of the only states in the country without wait lists for long-term supports. Within adult long-term care, self-direction continues to expand with more than 18,000 participants statewide choosing to fully self-direct their supports, of which nearly 50% are people with I/DD.<sup>10</sup> Yet true self-determination continues to be challenging for many people with I/DD in Wisconsin. In 2015, almost 25,000 people with I/DD lived in supervised residential settings and only 6,193 (less than 25%) lived in their own homes.<sup>11</sup> Even among those in our self-directed long-term care program (IRIS), more than 71% of people with I/DD are under legal guardianship: their guardians sign their service plans.<sup>12</sup> The UCEDD is working with a statewide coalition to train and equip individuals and families to use more supported decision-making strategies before seeking guardianship.

Dane County, where the Wisconsin UCEDD is located, has one of the highest integrated employment rates in the country (approximately 65%) and a sophisticated accessible transportation system linked to employment. The challenge has been to extend this success statewide where the integrated employment rate is 20%.<sup>13</sup>

## **Planning Process**

The UCEDD utilized a variety of methods to identify the critical need areas it proposes to address over the next five-year period. First, we relied on the members of our Constituent Advisory Committee (which is the name of the Waisman Center's Consumer Advisory Committee) to identify critical needs based on their unique perspectives (See Appendix B for a listing of the CAC membership). Second, as a member of the Wisconsin Board for People with Developmental Disabilities (WBPDD), the UCEDD participated in the five-year renewal of that organization and had access to a variety of data sources (focus groups, interviews, and community conversations) and reports employed in that planning effort. Third, the UCEDD draws from reports written by various agencies (e.g., Family Voices of Wisconsin<sup>14</sup>, Survival Coalition of Wisconsin Disability Organizations<sup>15</sup> and The Arc of Wisconsin<sup>16</sup>) to gain a snapshot from the consumer perspective about the accessibility and quality of services. Of note, the Waisman Center, in collaboration with our DD Network partners, is currently conducting a five-year longitudinal study on the quality and availability of long-term care services in Wisconsin. A specific focus of this study is the level of self-determination reported by participants. Fourth, as shown in Table 1, UCEDD staff serve on many in-state committees related to intellectual and developmental disabilities. The needs of individuals with DD emerge during the deliberations of these committees and this information feeds into the annual and 5-year UCEDD planning process. Fifth, UCEDD staff and faculty routinely document the needs that individuals with developmental disabilities and their families report during the course of their involvement with UCEDD programs. Given that the UCEDD has contact with more than 10,000 people with disabilities and their families each year, this is a rich source of information based on the lived experience.

<b>Table 1: UCEDD Faculty and Staff Participation on State Agency and Organization Boards, Councils and Committees Relevant to the Renewal Application</b>	
<b>Name of Agency or Organization</b>	<b>Nature of UCEDD Involvement</b>
Dane County Dept. of Human Services	Member, Developmental Disabilities Coalition Member, Restrictive Measures Committee
Family Voices of Wisconsin	Co-director
Greater Wisconsin Agency on Aging Resources, Community of Practice on Supported Decision Making	Member
Survival Coalition of Wisconsin Disability Organizations	Member
Wisconsin Act Early State Team	Member
Wisconsin AmeriCorps	Grant Reviewer
Wisconsin Association of Perinatal Care	Member
Wisconsin Board for People with Developmental Disabilities	Member
Wisconsin Community of Practice on Cultural and Linguistic Competence in Developmental Disabilities	Member
Wisconsin Department of Children & Families	Member, Committee on Child Welfare Services for Children with Disabilities
Wisconsin Department of Health Services	<ul style="list-style-type: none"> <li>• Division of Public Health Chairperson, Newborn Screening Program: Metabolic Subcommittee Member, Council on Birth Defect Prevention and Surveillance Member, Newborn Screening Advisory Group Member, Maternal Child Health Advisory Committee Member, CSHCN Regional Center Directors Council</li> <li>• Division of Long Term Care Member, Children's Long Term Support Council Member, Community Options Program Work Group Member, Long Term Care Advisory Council Member, Long Term Care Advocates Advisory Group</li> </ul>
Wisconsin Department of Workforce Development	Member, <i>Wisconsin PROMISE</i> Executive Committee
Wisconsin Interdisciplinary Network on Guardianship Supports	Member

### **Stakeholder Involvement**

The planning process for the five-year renewal began during the summer 2018 UCEDD CAC meeting. The CAC, under the leadership of Maria Nogueron from Milwaukee, held a brainstorming session to generate an initial list of statewide needs (see support letter in Appendix H). The CAC reviewed the initial list, and priorities were discussed at the October 2018

meeting. Simultaneously, UCEDD staff reviewed survey results (Family Voices of Wisconsin, National Core Indicators) and reports from state agencies (e.g., Department of Health Services), state organizations (Survival Coalition) and foundations (Annie E. Casey, Kaiser Foundation) as well as the strategic plans of our DD Network partners (BPDD<sup>12</sup> and DRW<sup>17</sup>). The resulting data were reviewed at the October UCEDD Steering Committee meeting and that group identified additional needs based on the members' project level experience as well as participation on various state agency boards, councils and committees. The resulting list of priority needs was presented to a joint planning subcommittee of the CAC and UCEDD leadership in early December for discussion and final ranking. The highest priority needs clustered into the health, education and early intervention, formal/informal community supports, and quality assurance areas of emphasis and are presented in Table 2.

<b>Table 2 High Priority Needs Identified for Individuals with Developmental Disabilities in Wisconsin through the UCEDD Planning Process</b>
<b>Health</b>
<ul style="list-style-type: none"> <li>✓ Improve access and equity for underserved groups</li> <li>✓ Increase workforce capacity (quantity, diversity, and skill of professionals) for the full range of health and mental health services across the lifespan</li> <li>✓ Increase awareness of, and capacity to address, co-occurring conditions (mental health and secondary medical conditions)</li> <li>✓ Promote health and wellness for people with DD</li> <li>✓ Leadership training related to health and health systems for self-advocates</li> </ul>
<b>Early Intervention and Education</b>
<ul style="list-style-type: none"> <li>✓ Increase statewide capacity for inclusive early intervention, including raising awareness of empirically-supported early intervention approaches</li> <li>✓ Increase access to early intervention services for autism</li> <li>✓ Increase availability of post-secondary supports and opportunities</li> </ul>
<b>Formal/Informal Community Supports</b>
<ul style="list-style-type: none"> <li>✓ Increase support for families through education, information and referral</li> <li>✓ Improve availability and retention of quality direct care staff</li> <li>✓ Research the effectiveness of community based navigators</li> </ul>
<b>Quality Assurance</b>
<ul style="list-style-type: none"> <li>✓ Training in guardianship alternatives: Supported decision making</li> <li>✓ Increase awareness of best practices for competency evaluations</li> <li>✓ Promote personal safety of individuals with DD through behavioral self-monitoring</li> <li>✓ Document baseline quality of long term care programs</li> </ul>



## Goals and Objectives for the Five-Year Plan are Directly Related to Identified Needs

Given the extensive process undertaken in this planning effort, we are confident that our goals, objectives, and activities delineated in the 5-year plan will address the urgent needs that currently exist within Wisconsin. Table 3 identifies the goals and objectives that were developed from the planning process. The goals reflect the core functions described in the DD Act while the objectives relate to the needs identified in the planning process. Over the next five years, our efforts address the emphasis areas of education and early intervention, health, informal and formal supports and quality assurance. However, our primary area of emphasis will be health. Waisman Center CAC, staff and faculty will review and revise the goals and objectives annually to address the emerging needs of our state.

<b>Table 3: Waisman Center Goals and Objectives for 2019-2024</b>
<p><b>Goal 1 (Interdisciplinary Training and Continuing Education): Increase the diversity, knowledge and skills of undergraduate, pre-service, postdoctoral and continuing education trainees in the provision of equitable services, supports and advocacy for people with developmental disabilities</b></p> <p>1.1 Annually, trainees from multiple disciplines will increase their knowledge and skills in leadership, interdisciplinary practice, research advocacy, and public policy related to developmental disabilities</p> <p>1.2 Annually provide discipline specific training and practicum experiences for trainees in the context of ongoing direct service programs and for students in UW-Madison courses</p> <p>1.3 Increase the number of trainees recruited from underrepresented backgrounds (race, culture, ethnicity and/or disability)</p> <p>1.4 Increase the knowledge and skills of health and mental health practitioners, educators, and community professionals on a variety of disability topics through continuing education</p> <p>1.5 Modify CE trainings so that they are available in multiple formats and publicized statewide</p> <p><b>Goal 2 (Community Services: Training and Technical Assistance): Provide community training and technical assistance to people with disabilities and their families and service providers to increase the accessibility and responsiveness of Wisconsin communities to the needs of people with developmental disabilities and their families and enable full and active participation in community activities.</b></p> <p>2.1 Increase the knowledge and skills of professionals, individuals with DD, and families, on best practices, policies and resources in health &amp; wellness, education and early intervention, postsecondary education and community living</p> <p>2.2 Modify trainings so that they are available in multiple formats and publicized statewide</p> <p>2.3 Provide direct problem-solving services to assist programs, agencies, or other entities in improving their services, outcomes, and/or policies</p>

**Goal 3 (Community Services: Model Services): Provide model services to meet unique community needs, to support training and research and serve as exemplary programs of interdisciplinary, family-centered, and culturally appropriate services.**

3.1 UCEDD faculty and staff provide specialized clinical services to enhance the well-being and status of individuals with developmental disabilities and their families

3.2 UCEDD faculty and staff provide other direct model services to enhance the well-being and status of individuals with developmental disabilities

3.3 UCEDD engages in demonstration services that field test promising or other exemplary practices.

**Goal 4 (Research): Conduct research and evaluation activities that impact the health, education, and community participation of individuals with developmental disabilities**

4.1 Conduct research on prevalence of and risk factors for various developmental disabilities

4.2 Support inclusion of people with developmental disabilities in the development, implementation, and dissemination of research

4.3 Conduct research on the special health care needs, co-occurring conditions, services and QOL among individuals with developmental disabilities

4.4 Develop and evaluate new interventions for adolescents and adults with developmental disabilities

4.5 Produce evaluation reports of the impact of each UCEDD project on individuals with developmental disabilities and their families

**Goal 5 (Information Dissemination): Disseminate and increase access to public awareness materials, research, public policy and other resources that positively impact the lives of individuals with developmental disabilities and their families.**

5.1 Promote public awareness and visibility of the Waisman UCEDD

5.2 UCEDD will develop and disseminate information products on the purpose of the DD Act of 2000 to the Wisconsin legislature and to the Wisconsin congressional delegation

5.3 UCEDD will maintain an accessible, current website and utilize social media to provide information and resources to the public

5.4 UCEDD will develop and disseminate products that translate current research into practice

5.5 Each UCEDD project will disseminate information annually

## **SECTION 2. APPROACH**

### **Work Plan**

The proposed work plan describes a 5-year effort with measureable and attainable goals, specific objectives, activities, and timeline for the implementation of 5 core functions of interdisciplinary training and continuing education; community services training and technical assistance; community model services; research and information dissemination related to four areas of emphasis, Education and Early Intervention, Formal and Informal Community Supports,

Health, and Quality Assurance. The Waisman Center work plan is presented in Appendix C. The goals and objectives were developed with the following criteria: 1) each goal is intended to be consistent with the provisions of the DD Act, 2) each objective addresses a need or barrier identified through our comprehensive planning process, 3) the objectives and activities are complementary or build on those of the Wisconsin Developmental Disabilities Network Partners; 4) each goal is built upon the mission, expertise, programs, projects, and services of the Waisman Center UCEDD; 5) each goal is intended to implement innovative approaches to address current and emerging needs, and 6) each goal will be achieved through the implementation of community and state agency partnerships and collaboration with the Wisconsin DD Network to effect systems change, whenever possible. The work plan provides quantitative projections of the accomplishments to be achieved for each core function expressed in terms such as the number of people to be served, the number of activities to be accomplished, or the number of products developed each year. It also provides a chronological order of approach expressed in quarters of years designated by an “x” in the annual columns.

### **Interagency Collaborations and Strategies to Effect Systems Change**

The Waisman Center relies on collaboration to achieve the broad missions of advocacy, capacity building, and systems change. The UCEDD has a history of collaboration with the Board for People with Developmental Disabilities (BPDD), Disability Rights Wisconsin (DRW) and virtually all State of Wisconsin departments and divisions that relate to children and adults with developmental disabilities, focusing on identified needs of common interest in improving outcomes. In Education and Early Intervention, we collaborate with the Department of Human Services (Birth to 3 programs) and the Department of Public Instruction for older children. Employment related projects are conducted in collaboration with the Department of Workforce

Services – particularly the Division of Vocational Rehabilitation. Projects related to Health typically involve the Department of Health Services and the Department of Children and Families. Given the UCEDD’s mission of community inclusion, we have had a long-standing relationship with the Dane County Department of Human Services and the Division of Medicaid Services of the Wisconsin Department of Health Services. In addition to our project work, UCEDD staff often serve on advisory committees relevant to developmental disabilities. These appointments are presented in Table 1 on page 7.

Equally essential are collaborative relationships with other disability organizations, including the ARC of Wisconsin, Autism Society of Wisconsin, Family Voices of Wisconsin (see Appendix H for support letter from Barbara Katz, co-director of Family Voices), Madison Area Down Syndrome Society, People First Wisconsin, and the Survival Coalition of Wisconsin Disability Organizations. A full list of our collaborations with community organizations and state agencies is presented in Appendix F. All of these organizations have been partners in training and educational events, technical assistance activities, model services and disability-related policy initiatives. These relationships help us to remove barriers and improve systems to support the quality of life of people with developmental disabilities.

#### **Five-Year Plan Complements/Furtheres DD Council and P&A Goals and Priorities**

The UCEDD five-year plan complements and furthers the BPDD five-year plan<sup>12</sup> and the DRW Statement of Goals and Priorities<sup>17</sup>. There is considerable overlap in the areas of emphasis as well as the specific needs identified among the three DD Network Partners. The areas of intersection are Education and Early Intervention, Formal and Informal Community Supports, Health, and Quality Assurance. For example, within the Education and Early Intervention area of emphasis, all of the partners are engaged with transition issues. DRW is concerned with

monitoring implementation of transition planning requirements while the BPDD and UCEDD are focused on post-secondary opportunities and outcomes. Within the Health area of emphasis, the DRW and the UCEDD seek to improve outcomes for children with DD that require pre-authorization for specialty health services and increased availability of mental health services for people with IDD while the BPDD does not have a specific priority in this area of emphasis. With regard to formal/informal community supports both the UCEDD and BPDD share a goal of increased availability and retention of quality direct care staff for community programs and greater community inclusion of people with intellectual disability. Within the quality assurance area of emphasis, all three partners have goals related to increased emphasis on supported decision making in Wisconsin and the BPDD and UCEDD share goals related to leadership training for self-advocates and training in behavioral self-monitoring for personal safety. The latter priority was the basis for a Living Well grant from ACL that begins in early 2019. Moreover, the three network partners have a strong focus on cultural and linguistic diversity as well as the need for greater inclusion of people with developmental disabilities generally. The latter priority emerges from the participation of the BPDD, DRW, and the UCEDD in an AIDD/ACL sponsored five-year Community of Practice on Cultural and Linguistic Competence in Developmental Disabilities and the Disparities Leadership Academy held in 2017. We are proud to be among the states selected to participate in these initiatives. Finally, the UCEDD furthers the DD Network efforts for the next five years with a number of related activities – such as supporting families through education, navigation, information and referral, increasing the number of health providers with training and experience in health and mental health issues for DD, and increased access to early intervention services for autism spectrum disorder – to name just a few.

## **AIDD Funding is used to Leverage Additional Funding to Achieve Projected Goals**

We use core funds to maintain an infrastructure for leveraging additional funds. The infrastructure includes the leadership of the UCEDD, coordination of activities associated with the core functions, administrative support, collection of NIRS data, as well as the activities and leadership of our CAC. Over the past four years, we have leveraged over 30 projects and more than \$9.3M per year. These projects fund activities for all core functions. The UCEDD will strive to its current funding partners while seeking funding from new other sources. Program expansion into new program areas related to the proposed five-year work plan will require collaboration with additional UW-Madison faculty. These collaborations will not only bring additional expertise but also an opportunity to leverage more funds to produce broader impact.

### **Interdisciplinary Pre-service Preparation and Continuing Education Activities**

Consistent with its position at a major university, the Waisman Center UCEDD has provided pre-service and continuing education since its inception in 1973. Also since the beginning, the Waisman Center UCEDD has received significant support for interdisciplinary training from the Maternal and Child Health Bureau (MCHB). The WI MCH Leadership Education in Neurodevelopmental and related Disabilities (LEND) program is currently the largest interdisciplinary instructional training program at the UCEDD though there are other instructional programs that integrate knowledge and methods from two or more disciplines –

## **Wisconsin LEND Disciplines**

- Audiology
- Genetic Counseling
- Human Development & Family Studies
- Medicine
- Nursing
- Nutrition
- Occupational Therapy
- Physical Therapy
- Psychology
- Public Health
- Social Work
- Special Education
- Speech Language Pathology

the Genetic Counseling Masters degree program, student teaching at the Waisman Early Childhood Program (WECP), behavior management training that occurs through the Community TIES program (primarily for social work and rehab psychology students), as well as other interdisciplinary clinical fieldwork, internships and rotations in partnership with graduate, post-doctoral and resident training programs (Objectives 1.1, 1.2). Trainees from the thirteen academic disciplines listed above receive training along with family members (parents, siblings) and self-advocates (persons with disabilities). As the WI LEND program has developed more options to include short-term and intermediate-term trainees, UCEDD trainees in other instructional programs also participate in curriculum activities organized and taught by LEND faculty, so that almost all UCEDD trainees are also considered LEND trainees at the Waisman Center UCEDD. Therefore the curriculum described here will include all of the WI LEND program components, many of which are available to all UCEDD trainees in addition to short, intermediate and long-term LEND trainees.

***Contributions made by people with disabilities and family members:*** The UCEDD interdisciplinary pre-service preparation programs, particularly the LEND program, depend on the participation of people with disabilities and family members to carry out their training mission. This integration is achieved in several ways. First, the UCEDD's CAC provides input regarding curriculum issues and the participation of people with disabilities and family members in the program. Second, WI LEND faculty include four parents of children with special needs, and WI LEND also employs disability advocates every year to provide peer mentoring and to inform program development for the trainees with intellectual and other developmental disabilities. People with disabilities and family members have been included as long-term LEND trainees since 2011 and 2006 respectively. These trainees contribute not only their

expertise gained from lived experience, but participate in the training program for the purpose of becoming disability advocate leaders in their chosen areas. Finally, the WI LEND modular curriculum (Appendix D) includes a minimum of seven panel presentations per year that are composed of individuals with a range of disabilities and family members from a variety of cultural, language, racial, social/economic, immigrant, and geographic backgrounds.

***Examines and advances professional practice, scholarship and policy impacting lives of people with disabilities and is designed to advance an individual's academic/professional credentials:*** The WI LEND curriculum is designed to increase knowledge and skill of interdisciplinary trainees based on three sets of competencies – the MCH Leadership Competencies (v. 4.0); WI LEND –specific competencies addressing best practices in screening and identification, diagnosis, intervention and care coordination for people with disabilities; and discipline-specific competencies for best professional practices.

The UCEDD policy specialist, Elizabeth Hecht, is also the LEND Policy Preceptor, and in that role, guides the development and implementation of pre-service training components which increase the policy competencies of UCEDD/LEND trainees. Activities for all long-term trainees include background and basic training in the policy-making process, discussions and case-based training which includes how families' experiences are both shaped by and serve to inform disability policy-making, and completing educational visits with policymakers to inform them about how proposed policy changes will affect the lives of people with disabilities. Feedback from trainees participating in these activities consistently reflects how the training received at the UCEDD/LEND is different from, and often perceived as better than, training they receive in their other academic programs.



***Academic setting for interdisciplinary training:*** The UCEDD/LEND programs at Waisman Center have relationships with thirteen academic programs, schools or departments at the University of Wisconsin – Madison that are defined through a formal “memorandum of understanding” (MOU) signed by the UCEDD and LEND Directors, Department chair or dean, and the training faculty in each discipline. Departmental MOU are reviewed and renewed/signed every five years as part of the LEND program re-application process, current MOU were signed in 2016. Other academic partners include the five academic departments at UW-Milwaukee that participate in the LEND Milwaukee-Link program (Occupational Therapy, Psychology, Communication Sciences, Special Education, Nursing); and at Edgewood College in Madison for the UCEDD WECP with the early childhood educator program, and with LEND for the Cutting Edge program (post-secondary certificate program for individuals with IDD).

***Reflects the diversity of the community:*** While a large majority of students and faculty at UW-Madison, as well as in the population of Wisconsin, is categorized as “white,” efforts to recruit a cultural mix and promote opportunity and inclusion of students and faculty from underrepresented groups are ongoing for the UCEDD training programs. In the 2017-2018 training year, UCEDD trainees were 81% white and 19% other/mixed races (nonwhite) which reflects the diversity of the community. Recent efforts to increase the proportion of students and faculty from diverse cultures are described in the following section on recruitment (page 21).

***Contributes to discipline-specific and cross-cutting degrees, certificates and professional education:*** Long-term LEND trainees receive a certificate of completion reflecting achievement of core competencies in 1) leadership development, 2) knowledge of neurodevelopmental and related disabilities, 3) clinical services, 4) applied research and 5) public health systems. Long-term training experiences in the LEND program and for other

UCEDD trainees at the Waisman Center often complete degree requirements, such as fieldwork, internship or other pre-service and research training requirements, through placements in the Waisman Center clinics, WECP, center-based research teams and community-based programs. Discipline-specific training coordinators in 13 academic disciplines work with faculty in the academic programs to assure that the knowledge and skills addressed in UCEDD training programs align with and contribute to the achievement of graduate and undergraduate degrees and professional certificates at the universities.

*The core curriculum for interdisciplinary pre-service instruction* is based on the WI LEND program that has a modular structure spread over two academic semesters and includes a variety of activities, both didactic and experiential. The instructional content of this program is described in Appendix D as a curriculum matrix linking the five WI LEND competency areas (listed previously) with the modular topic focus. Instructional methods include eight primary groups of training activities. Long-term trainees working toward a WI LEND certificate complete training in all of these activity areas, while other UCEDD/LEND trainees participate in one or more selected training activities.

- 1) Friday Learning Modules (3+ hours/week which includes seminars, case-based learning in interdisciplinary teams of 5-7 trainees with 2 faculty/advanced trainee co-facilitators, and reflective discussions as outlined in the table for each module below)
- 2) Leadership Development Workshops (total of 16 hours/year)
- 3) Individualized Leadership Training Plan (developed with a primary mentor – trainees meet with their mentors at least 12 times and develop 3 individualized training goals to complete over the year)

- 4) Practicum (includes clinical or community work depending on trainee's discipline training needs and whether departmental or clinical fieldwork or internship requirements are being met)
- 5) Family Mentor (trainees pair up and visit with a paid mentor family at least four times in their home or community)
- 6) Research (trainees are assigned in teams of 2 or more disciplines to a UCEDD or IDDRRC research project for a minimum of 30 hours to complete activities which advance their understanding of research)
- 7) Policy (trainees track policy development, receive coaching and then complete an educational visit with a policymaker)
- 8) Other (includes a variety of activities such as attending state and national conferences)

All trainees completing training at the Waisman Center are required to complete a UCEDD trainee orientation that includes an introduction to the AUCD network of UCEDDs, LENDs and IDDRRCs (links with the trainee orientation videos produced by AUCD) and core content on the 4 guiding principles for services that are family-centered, evidence-based, and interdisciplinary and promote community inclusion. In addition, core curriculum components that address each of the following areas are described here:

- 1) *Incorporates cultural diversity and demonstrates cultural competence* – The UCEDD trainee orientation materials introduce the concept of cultural diversity and appreciation of differences at the beginning of the training year/experience. This foundation is then built on through a series of activities which include case-based learning with specific examples of families from different racial/ethnic backgrounds; clinical and community observations and practice; and leadership workshops to build competency in a) self-reflection through

assessments of learning styles and implicit bias, b) communication, conflict resolution and team participation, and c) understanding of systems that promote and support the inclusion of people from diverse backgrounds as employees, students and populations served. Long-term trainees complete self-assessments of cultural competency at the beginning and end of the training year, and work with their mentors and clinical/community preceptors to identify and address areas for improvement in their training experiences.

2) *Address the needs of individuals with DD and families in a culturally competent manner –*

The core knowledge and training experiences just described at the UCEDD/LEND for cultural competence always include the perspective of individuals with DD and their families, which is what makes these experiences unique for this training program (versus other academic programs). Individuals with DD, parents and siblings all participate as trainees, panelists, and contribute to the development and implementation of the core curriculum. Family and individual feedback is incorporated to improve the curriculum. Diverse families and individuals with DD tell their stories and offer advice to trainees through regular panel discussions, case-based learning groups, and in the Family Mentor community experiences. These are always the most highly rated activities from UCEDD/LEND trainees, which has led to an increasing proportion of these experiences in the core curriculum. Graduates state that the perspectives gained contribute long-term to the way they choose to practice as professionals.

3) *Trainees are active participants in research and dissemination -*

Through their practicum and research experiences, UCEDD/LEND trainees are involved with research and dissemination activities. Long-term LEND trainees work with UCEDD and IDDRC research teams to focus on interdisciplinary research approaches to issues for people with IDD and their

families. Examples of projects in which trainees have taken both a significant formative role as well as contributed to wide dissemination of research results include the “Transitioning Together” (TT) program for adolescents/young adults with autism and their families.

UCEDD trainees helped to design and implement the original TT intervention, have presented results through presentations and posters at national and international conferences, and have participated in adapting the curriculum for Hispanic and school-based settings.

- 4) *Trainees as consumers of research* – UCEDD/LEND trainees gain an appreciation for research methods, how to critically evaluate evidence, and how to discuss and implement evidence-based practices with people they serve, through attending the Wiley seminar series, the LEND seminars and research training, and through their clinical, community and research placements. While the research expertise of UCEDD/LEND trainees is quite varied, ranging from none (initially) to advanced (post-doctoral), the goal is for every UCEDD/LEND trainee to advance their research skills applying an evidence-informed approach to best practices in serving people with disabilities. For trainees who will be practicing in the community, this includes understanding how research informs program and policy development. For trainees who are becoming researchers, this includes understanding how lived experience should inform the development of relevant research questions and programs, and how research is conducted along with those affected by the issues being researched.

***Recruitment of UCEDD trainees to increase the numbers of racial and ethnic minorities:***

As stated earlier (page 17), the diversity of UCEDD trainees is greater (19%) than that of the UW-Madison campus, which is 12% nonwhite. However, we seek to increase the diversity of our trainees over the next five years. Given that the WI LEND program is the largest contributor of trainees to the UCEDD, we focus on the WI LEND strategy in this section of the application.

In Madison, outreach to undergraduate and graduate students from diverse backgrounds is achieved through partnerships with campus multicultural groups: the McBurney Center (for disability), Multicultural Student Center and Multicultural Graduate Network. We also benefit from recruitment efforts conducted by the graduate academic departments that partner with our training programs. While these methods have allowed us to maintain a steady rate of recruitment of trainees from underrepresented racial/ethnic backgrounds that mirror the UW-Madison rate of approximately 1 in 10, we propose additional strategies as a part of our 2019-2024 work plan. Specifically, we are adding Activities 1.3.3, 1.3.4, 1.3.5 as new strategies. Other programs have shown these methods to be effective and we believe they could be successful at the UW-Madison.

The most effective strategy to increase racial/ethnic diversity of WI LEND trainees since 2013 has been offering the WI LEND program at a more diverse campus (UW-Milwaukee) in addition to trying to increase diversity at the UW-Madison campus. An additional recruitment focus for LEND Milwaukee-Link is to attract individuals who will stay and work in the Milwaukee area, where there are large disparities in access to services for children with ASD and DD. During the first five years of adding UW-Milwaukee as a WI LEND training site, the overall diversity of the WI LEND trainees increased, with about 1/3 of Milwaukee-Link trainees from underrepresented racial/ethnic groups, including African-American and Asian (Hmong, Chinese, East-Indian).

### **Continuing Education**

The UCEDD provides a rich environment for continuing education strengthened by similar activities in the WI LEND and IDDRC. The IDDRC John D. Wiley Seminar Series brings 25 speakers, from throughout the US and internationally, to conduct research seminars

related to ASD and DD (Objective 1.4.5). In collaboration with the UW Health Office of Continuing Professional Development, the Waisman Center provides CME for health practitioners attending these events. Similarly, the UCEDD Community Training and Consultation Program provides education related to supporting people with disabilities in the community (Objective 1.4.6). Topics include Managing Threatening Confrontations, Safe Medication Administration, the Self-Directed Health Care Kit and Managing Pain. Attendees include family members, volunteers, direct care providers, special education teachers, transportation providers, para-professionals and professional service providers. The Waisman Center UCEDD provides certificates of completion for these events. The UCEDD also provides continuing education to clinical practices, educational programs (teachers, parents, counselors, support personnel), and professional organizations (e.g., Wisconsin Early Childhood Association, Wisconsin Head Start, Wisconsin Court Appointed Advocates Association) on discipline-related or topic-specific training.

The work plan related to continuing education also addresses four additional areas related to our strategic planning process for this application (Objectives 1.4.1, 1.4.2, 1.4.3, 1.4.4). These programs address the need for greater service delivery capacity related to augmentative and alternative communication, empirically supported interventions for ASD, and health and mental health conditions that co-occur with intellectual disability and ASD. We plan to phase these programs into our offerings in Years 2 and 3 of the renewal period. The participation of individuals with developmental disabilities and families will be crucial to the development of the curriculum for these new continuing education offerings.

### **Participation in Broader University Academic Programs**

The University of Wisconsin-Madison is dedicated to the discovery, development,

communication and application of knowledge in a wide range of academic and professional fields and providing the highest quality undergraduate and graduate programs. The Waisman UCEDD participates in the broader university academic programs by directly contributing to undergraduate and graduate programs by teaching university courses (Appendix E), practicum and internship training, and research mentoring. UCEDD affiliated faculty and staff teach courses that will be taken by students from various academic programs and participate in university and college academic committees to set and implement academic policies. The UCEDD also provides training to university academic communities on disability awareness and effective instructional strategies for teaching students with disability. In addition, the UCEDD collaborates with various student organizations on issues related to disability inclusion and with the McBurney Disability Resource Center to broaden the campus focus on diversity to include disability.

### **Description of Community Training and Technical Assistance Activities**

The UCEDD continues to provide training and technical assistance in the areas of emphasis of health, education and early intervention, quality assurance, and formal and informal supports. On average, the UCEDD annually provides 115 community training activities reaching over 7000 participants and over 1000 hours of technical assistance. The UCEDD addresses both universal and unique needs in the state by providing a core set of repeated community training and technical assistance activities as well as developing new trainings, tailoring existing trainings to specific audiences, and responding to emergent technical assistance needs. Training and technical assistance activities routinely reach professionals and paraprofessionals, family members, individuals with developmental disabilities, students, policymakers, other members of the community, and state and national partners.



The UCEDD will continue to provide training and technical assistance activities that meet ongoing needs, and will develop activities to address new needs. Training will be continued on transition, post-secondary options, health care systems, self-determination and supported decision-making, and personal safety for families (Objectives 2.1.2, 2.1.3); on screening and assessment, behavior and health management, and formal and informal community supports for professionals (Objective 2.1.5); and on current evidence and best practices across multiple developmental disabilities for a range of community members (Objective 2.1.1). To meet identified needs, leadership training will be developed and offered in health systems for self-advocates in years three through five (Objective 2.1.4).

#### **Description of Innovative Designs and Methods in Community Training and Technical Assistance Activities**

In order to promote the inclusion and integration, productivity, and human rights of individuals with developmental disabilities and their families in all aspects of community life, community training and technical assistance activities target the knowledge and skills of professionals as well as individuals with developmental disabilities and families; cover lifespan issues; and address health, education, and community living (Objectives 2.1, 2.3). Ongoing training and technical assistance on specific conditions and screening, assessment, diagnosis, and treatment in primary care and educational settings that foster early inclusion and integration of individuals with developmental disabilities in their natural community settings will continue (Objectives 2.1.1, 2.1.2, 2.1.3, 2.1.5, 2.3.2, 2.3.4). The UCEDD will address the identified need to promote quality acceptance, retention, and inclusion for children with DD in early childhood settings statewide by providing technical assistance to early childhood programs (Objective 2.3.1), and will address the need for empirically supported early intervention by providing

technical assistance on the statewide integration of the Early Start Denver Model (ESDM) into early intervention programs (Objective 2.3.5).

The integration of ESDM into existing early intervention programs is also an example of how the UCEDD integrates training and technical assistance activities into community settings. Community members, agencies and other organizations are involved in the planning of these activities so that empirically supported practices can be sustainably and effectively integrated into community-based settings. Another key example of training activities that involve community members are the Waisman Center Day with the Experts events, which are designed to meet the learning needs of a mixed audience of professionals and other community members (Objective 2.1.1). Each year, Day with the Experts events are offered on four different topics: autism, cerebral palsy, Down Syndrome, and cochlear implants. Each event is developed in collaboration with family organizations and individuals with developmental disabilities. Family members and self-advocates participate as expert presenters alongside clinicians and researchers. Day with the Experts events, which accommodate a live audience of over 200 participants, are simultaneously live streamed and recorded for online statewide access. This innovation in training delivery has also enabled local community organizations to host synchronous live group viewing opportunities, as well as viewing by participants outside of Wisconsin.

Community training and technical assistance activities serve to increase knowledge, skill, and capacity to meet universal needs among individuals with developmental disabilities and families as well as emergent and community-specific needs based on the best available evidence. Regularly offered trainings--such as those concerning the management of threatening confrontations, augmentative and alternative communication, self-determination, supported decision-making, transition to adulthood, and disability advocacy--address needs experienced by

many individuals with developmental disabilities are routinely tailored to meet the unique needs of a particular agency or local community. Training and technical assistance activities draw upon empirically supported content and training methods, and are evaluated and revised to target needs most effectively.

Needs assessments indicate that community members from ethnic and racial minority and other backgrounds experience barriers to access and use of community services for individuals with developmental disabilities and their families. Therefore, innovative training strategies are utilized to improve access to training content by community members in these populations. The UCEDD will draw on current research, evaluation findings, and stakeholder input to identify best practices in training and technical assistance.

Finally, our community services training events are accessible and responsive to the needs of individuals with developmental disabilities and their families. For example, a very popular community-training event entitled “Did you know? Now you know” was designed to meet parental needs for ideas on how to manage transition issues with their youth. Similarly, the idea for the Waisman Center “Fashion Show for All Abilities” came from a young woman with developmental disabilities who had wanted to be a model from a young age. The fashion show attracts more than 500 people each year – the goal of which is to change attitudes and support inclusion in the community.

The UCEDD collaborates with Milwaukee community partners, family organizations, and the Wisconsin LEND Program to host an urban autism summit in the Milwaukee city center so that families can access evidence-based practice and service system information in a familiar, local setting with childcare provided. Another innovative training approach, developed through the Wisconsin PROMISE grant, is being integrated into other community training projects.

Specifically, we embed community training into community conversations whenever possible and into home visits conducted by family navigators. These strategies allow navigators to provide just in time training that is responsively adapted to the local and cultural needs of community members.

### **Community Model Services**

The Waisman Center provides a variety of clinical and other direct/model services for children, youth and adults that meet unique community needs, to support training and research and serve as exemplary programs of interdisciplinary, family-centered, culturally-appropriate services. The goal of these services is to enhance well-being and the status of the individual. The model services include information and referral to families regarding services to enhance well-being (Objective 3.2.4), specialized assessment, diagnostic and genetic treatment services (Objective 3.1.1, 3.1.2), an inclusive early childhood education program (Objective 3.2.3), autism treatment (Objective 3.1.3), behavioral supports for challenging behavior (Objective 3.2.1, 3.2.2), individualized non-clinical services related to post-secondary education, job training and competitive employment (Objective 3.2.6) and community based nursing (Objective 3.2.5). Some of these services are provided within the Waisman Center while others are offered directly in the community. Our model services, presented in Table 4 are person and family centered with a focus on promoting skills, self-determination, and learning that will promote inclusive participation of persons with developmental disabilities in their home, school, workforce, and community. These services are informed by collaboration with the CAC as well as project-specific advisory groups so that individuals with developmental disabilities and family members can provide input regarding the services provided. Simultaneously, these services provide unique training opportunities that fulfill the Waisman Center's mission to build capacity

in professional service delivery in the field of developmental disabilities. Furthermore, these service programs support the Waisman Center's research mission. Waisman UCEDD model services are subject to the same continuous quality improvement methods described in Section 4 (see page 39). This system determines project impact and allows us to be flexible to address new needs as they emerge in our state and ensure alignment with the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

TABLE 4 – Waisman Center Model Services

- Autism and Developmental Disabilities Clinic provides diagnosis and clinical care for children with or at risk for a developmental disability.
- Autism Treatment Programs provide comprehensive and focused behavioral treatment services for children, teens, young adults with autism and their families.
- Biochemical Genetics Clinic is an interdisciplinary clinic for people of all ages who have suspected or known hereditary metabolic disease.
- Bone Dysplasia Clinic provides interdisciplinary clinical care for individuals who have or suspect may have bone growth disorders and bone structure abnormalities.
- Cerebral Palsy Clinic addresses the complex needs of children up to 21 years of age with cerebral palsy and other neurological conditions that affect motor development.
- Communication Aids and Systems Clinic provides highly specialized, cutting-edge augmentative and alternative communication (AAC) for children and adults.
- Communication Development Program provides AAC and computer access services for individuals living in Dane County, Wisconsin
- Community TIES is a behavioral and psychiatric support program serving children, adolescents and adults with developmental disabilities and challenging behaviors.
- Down Syndrome Clinic provides clinical care of children, youth and young adults with a diagnosis of Down syndrome.
- Medical Genetics Clinic is an interdisciplinary clinic for people of all ages who have suspected or known hereditary conditions, malformation syndromes or birth defects.
- Neuromotor Development Clinic evaluates the needs of young children with motor disability including early cerebral palsy and other neurological conditions.
- Newborn Follow-Up Clinic provides assessment, diagnostic evaluation, and treatment recommendations for families of high-risk infants and toddlers.
- Pediatric Brain Care Clinic provides services for infants, children, and adolescents with, or at risk for, developmental disabilities associated with an acquired brain injury
- Waisman Early Childhood Program is a center based inclusive early childhood program for a developmentally diverse group of children ages 1 through 6.
- Wellness Inclusion Nursing provides assessment, consultation and training to community agencies and individuals with developmental disabilities.

## **Community Services – Demonstration Projects**

Three of the Waisman Center UCEDD's objectives include new projects or activities that are innovative and serve as demonstration activities. Through Objective 3.3.1, the UCEDD will determine the effectiveness of community based navigators in decreasing health disparities. The most likely focus of this project will be the use of navigators to improve access to appropriate screening, referral, diagnosis, care coordination and services for autism spectrum disorder. The issue regarding ASD is that a significant number of families, especially those who are low income or live in rural areas of the state, experience barriers in accessing services – thus leading to diagnoses at older ages compared with other children and delayed referrals for early intervention services. The hypothesis is that navigation will overcome these barriers and reduce the associated health disparities. In addition, the UCEDD will determine the feasibility of a statewide positive behavioral support program for challenging behavior. This project (Objective 3.3.2) will benefit from the knowledge already gained from the Community Training, Intervention and Evaluation Services (TIES) program in Dane County and its Managing Threatening Confrontations Curriculum. The challenge will be to replicate this county-based program on a regional basis. Alternatively, we are considering the START Model (University of New Hampshire UCEDD) which is already being implemented in 10 states and has demonstrated efficacy with adults with intellectual disabilities and psychiatric disorders. Finally, we plan to pilot a statewide partnership program to expedite access to evidence-based, high quality augmentative and alternative communication evaluations and treatment (Objective 3.3.3). There is a very long waiting list for AAC evaluations and treatment in Wisconsin – a situation made even worse by the recent closure of an AAC Center in Milwaukee. This program seeks to train speech-language pathologists already in practice throughout the state to conduct preliminary

evaluations, using established protocols, in partnership with UCEDD clinic staff and, when possible, to begin interventions based on those evaluations without a visit to the Waisman Center. This potentially innovative project could have significant implications for capacity building in Wisconsin for AAC services.

### **Research Core Function Activities**

The Waisman Center is a long-standing national and international leader in research in developmental disabilities. Investigators come from multiple disciplines, 25 academic departments and utilize a wide range of qualitative (e.g., focus groups, Photovoice) and quantitative (e.g., randomized control trials, prospective longitudinal designs) methods with the ultimate aim of enhancing the lives of individuals with DD. We will continue this work as part of our 5-year plan. Notably, individuals with DD and their families will be active participants in the research process at all levels including design, application and dissemination of the findings. Project activities reflect our current and future program of research that includes applied research, program evaluation, and analysis of public policy. In all of our research and evaluation activities, we take steps to include individuals from culturally and linguistically diverse backgrounds as well as to recruit from rural, urban, and other underserved regions.

Leveraging our strengths in public health and epidemiology, we will examine prevalence of developmental disabilities and risk factors associated with autism and other developmental disabilities (Objectives 4.1.1, 4.1.2). Importantly, these research activities address the identified need for improved access for those who are underserved by elucidating inequities and areas for policy and system change through population-level research that includes individuals from all racial/ethnic groups in Wisconsin and across socioeconomic strata. Consistent with our larger theme of inclusion, our work plan also involves a focus on the inclusion of individuals with DD

in the development, implementation, and dissemination of research (Objectives 4.2.1, 4.2.2).

Through this work we will address the identified need for improved health/wellness for individuals with DD as well as training self-advocates in leadership. We note that the Waisman Center recently received one of the only awards from the Patient-Centered Outcomes Research Institute's (PCORI) focused on individuals with intellectual disability.

As noted earlier in the application, our state currently has a need to increase awareness and capacity to address co-occurring conditions. In response, we have a series of research projects to address this need by describing trends and examining associations related to co-occurring conditions, quality of life, services, and public policy ( Objectives 4.3.1, 4.3.2). As part of this objective, we will also address the need for establishing a baseline of quality of long-term care programs in the state (Objective 4.3.2).

We also will conduct studies to develop and test interventions for adolescents and adults with DD (Objectives 4.4.1, 4.4.2), addressing critical needs for promoting health, addressing co-occurring conditions, and improving access, particularly later in the life course. Our past work has documented the benefits of multi-family group psychoeducation for teens and young adults with ASD on behavioral outcomes for the individual with ASD as well as outcomes for parents; this work, in turn, has resulted in new treatment programs offered not only at our UCEDD but also at other UCEDDs/LENDs within the network. We will continue this work, considering ways to improve access (e.g., telehealth options, cultural adaptations for Spanish-speaking families) as well as developing other novel interventions focused on other underserved DD populations.

In addition to our research studies, the UCEDD actively engages in evaluation and quality improvement activities. As part of the 5-year plan, all UCEDD projects will develop an annual evaluation plan (Objective 4.5.1) and will meet with the evaluation specialist annually to



review progress, outcomes, and timeline (Objective 4.5.2). Finally, for all research and evaluation projects, we will give careful consideration to translation of research to practice and potential policy implications of the work. Project teams will meet with the UCEDD policy specialist on an annual basis to discuss policy implications and strategies for next steps in the knowledge translation work.

All UCEDD research and evaluation activities will benefit from the guidance and support of our CAC. The CAC offers feedback to investigators on recruitment and consent documents, surveys, protocols, and other study documents. Investigators also have the opportunity to present results during CAC meetings and hear consumer input to help contextualize and interpret findings and gather ideas for next steps with the work. CAC members also serve a valuable function of sharing about UCEDD research opportunities and awareness of evidence-based practices within their respective communities. We also note that many research projects at the UCEDD include individuals with DD and/or family members as research study team members. For example, for a recently completed project to evaluate the Healthy Communities initiative of Special Olympics, co-researchers (individuals with intellectual disability who were themselves Special Olympics athletes) participated as members of the study team, conducting interviews (with support) and helping with interpretation. As another example, in past intervention studies for youth with ASD, young adults with ASD participated as study team members, making suggestions for research questions, collecting and coding data, and assisting with the creation of products for dissemination.

### **Information Dissemination Core Function Activities**

The Waisman Center serves as an accessible resource for information for individuals with developmental disabilities and their family members, service providers, advocacy groups, federal

and state policy makers, state agencies and the public. The UCEDD benefits greatly from the contributions made by the Waisman Communications team. Led by Teresa Palumbo, that team oversees a range of media relations, multimedia, outreach and development activities for the Waisman Center. They provide assistance with media relations, writing and editing, graphic design, content management web maintenance, marketing and special events planning. In recent years, we have seen a need to supplement the UCEDD infrastructure with regard to information dissemination and are adding a part-time coordinator position to fill that need. We intend to hire that coordinator in July 2019 once the renewal funding begins. By designating a coordinator for information dissemination activities, we will have someone to oversee our work plan and look for opportunities to reach new and more diverse audiences.

***Strategies for translating research into practice for communicating and facilitating replication of best practices in-state and out-of-state to diverse audiences:*** Because this UCEDD is integrated with an IDDRC, we are experienced with communicating research findings to promote evidence-based practices. An example illustrates our diverse strategies. Dr. DaWalt conducted a federally funded program of research named *Transitioning Together*, a family psychoeducation intervention for adolescents with ASD and their parents. She and her colleagues developed the intervention curriculum based on (a) past findings from her research group and (b) findings from focus groups with parents and service providers. Findings were published in academic journals. Waisman Communications staff reported study findings via a news release disseminated statewide and nationally. Dissemination resulted in numerous requests for training to implement the groups and led to a workshop. Waisman Communications also informed individuals, families, disability organizations about the study through Waisman Center

publications, which are disseminated broadly throughout Wisconsin and nationally. As a final step, the curriculum has been adapted for clinical use in five states.

Going forward we intend to produce at least one product annually that translates Waisman Center research into practice and to disseminate it to a statewide audience including consumers, families, and the general public through online and printed materials (Objective 5.4).

***Resource for individuals/families, community, State agencies, and other provider/advocacy organizations:*** The Waisman Center has a 45-year history in Wisconsin and nationally, and a well-established reputation as a trusted resource for reliable, current disability information. UCEDD activities and products are promoted broadly through (a) print publications, a comprehensive website, videos, social media and community training events; (b) dissemination of news releases in collaboration with University Communications; (c) DD Network members' publication and newsletters of WI disability organizations; (d) policy papers written by the Survival Coalition of WI disability organizations; and (e) NIRS and AUCD.

*Variety of products to promote public awareness and UCEDD visibility.* Waisman Center dissemination involves the use of multiple platforms including, the Waisman Center Resource Center, centralized help desk, email distribution lists, websites, webinars, publications, peer-reviewed articles, reports, flyers, fact sheets, social media and extensive community training each year. The Waisman UCEDD website has primary sections associated with our priority areas of autism, community inclusion, early childhood, family support and leadership, health and youth transition. It also features recent news and activities such as the Wiley Conference Series, Days with the Experts, and continuing education/community training events.

***Targeting a wide range of audiences:*** Individuals with disabilities and their families, including those who are culturally and linguistically diverse, are a primary audience. The

UCEDD also targets professionally diverse audiences, with policymakers as a high priority. Professional audiences include educators, early intervention providers, physicians and other health care providers, behavioral health providers, psychologists, psychiatrists, speech-language pathologists, direct support staff, disability advocates, faculty and trainees in varied disciplines, university administrators and the public.

***Dissemination to legislators:*** The UCEDD educates and disseminates information related to the purposes of the DD Act of 2000 to the Wisconsin Legislature and to Wisconsin's Congressional delegation on an annual basis. (Objective 5.2) Two years ago, we began an Issue Brief series that addresses practice and policy issues related to developmental disabilities. Those briefs are distributed to legislators in print and in electronic format. UCEDD staff and LEND trainees meet with legislators and policymakers during AUCD sponsored events (Annual Conference and Disability Policy Seminar) and the Wisconsin Disability Advocacy Day sponsored by the Survival Coalition of Wisconsin Disability Organizations. The UCEDD is also a member of the Survival Coalition and contributes to policy position papers and proposed changes to legislation that could potentially affect individuals with developmental disabilities on a variety of topics of importance in Wisconsin.

***Response to community requests and use of a variety of networks:*** UCEDD staff respond daily to phone and email to requests for information and refer to the Waisman Resource Center when appropriate. The Waisman Resource Center serves as a Regional Center for the Wisconsin Title V Children and Youth with Special Health Care Needs program (CYSHCN) and provides information, assistance, and parent-to-parent support to families with children with disabilities and other special health care needs. We are responsive to, and share information with,

the University of Wisconsin, Wisconsin DD Network, state agencies, disability and social service organizations, the national network of UCEDDS, LENDS, and IDDRCs and the public.

***Involvement of individuals with intellectual and developmental disabilities and families:*** In planning, writing and disseminating products, the UCEDD seeks advice primarily from persons with disabilities and family members in the CAC. A role and responsibility of the CAC is to support and contribute to the development, review, and dissemination activities of the UCEDD including, but not limited to products, publications and research findings.

***Universal design and accessibility:*** The Waisman Center UCEDD is committed to using principles of universal design both as it applies to the physical environment as well as in our approach to our information dissemination activities. A primary guiding principle is to make the content accessible to everyone. In addition, UCEDD faculty and staff are trained in published guidelines so that they use the principles of universal design for learning when providing classroom instruction and training or making a presentation. We are increasingly translating our materials into Spanish and, for specific projects, other languages upon request. We also utilize sign language interpreters, Spanish translators for community events and closed captioning for video products. The UCEDD has adopted person centered practices and person first language and serves as a model for such practices within the Waisman Center and in our contacts with community partners and other organizations.

***Promotion of strengths and positive qualities:*** The UCEDD always promotes positive images of individuals with DD in inclusive environments. We have an extensive library of photographs of children, youth and adults with DD and their families for inclusion in our webpages, electronic products and print materials. These photos portray participation in a variety of Waisman sponsored activities including model services, community education, and

research. Images and stories of people with disabilities participating and enjoying themselves illustrate products, websites and social media posts. The Waisman Center is also the home of the Harvey A. Stevens International Collection of Art by People with Developmental Disabilities. The collection, which includes more than 200 pieces representing artists from 16 countries, was featured in two-month public exhibition in 2018 at the Chazen Museum of Art.

### **SECTION 3. BUDGET**

We present a detailed 5-year budget and budget justification (see Appendix K) on our proposed use of the AIDD funds to support our interdisciplinary preservice preparation and continuing education, community services, research, and information dissemination activities. The AIDD grant funds will supplement and not supplant funds available to accomplish all of the activities of the Waisman Center UCEDD. AIDD funding provides infrastructure, which includes the leadership of the UCEDD, coordination of activities associated with the core functions, administrative support, collection of NIRS data, as well as the activities and leadership of our CAC.

#### **Leveraging our AIDD Grant**

The Waisman Center UCEDD prides itself in its success over the years in leveraging our AIDD grant to obtain considerable funds from a variety of sources to accomplish our 5-year plan and mission goals and objectives. The degree of leveraging has ranged between \$17 and \$21 for every AIDD grant dollar received over the past 4 years. We have maintained a constant and diversified portfolio of grants and contracts that funds our work on behalf of individuals with intellectual and developmental disabilities (24% Federal, 33% State and Local, 42% Fee for Service, 1% University, Foundations, donations and other sources). We have the necessary structure and supports in place to ensure that we will continue to leverage additional private and

public funds to achieve the goals for our five-year plan and to build systemic capacity in the state of Wisconsin.

#### **SECTION 4. PROJECT IMPACT**

In response to the high priority needs in our state, we have developed a detailed 5-year work plan reflecting goals, objectives, activities, and timelines related to each core function. Although we have projects addressing multiple areas of emphasis, our primary area of emphasis is health. Guided by the logic model (presented below) and the work plan for each core function, the Steering Committee will meet quarterly to monitor, track, and evaluate programmatic progress through ongoing assessment of the processes and outcomes of the UCEDD with the intent of furthering the overall work. Other UCEDD staff and CAC members will be invited to attend these meetings as appropriate. Data will be analyzed and discussed by the team and then shared back with the CAC and other UCEDD members in order to address any barriers and to refine approaches to better meet our objectives. This iterative process of tracking, analyzing, and revising activities and objectives will allow for continuous quality improvement. Notably, our system for determining project impact will allow us to be flexible to address new needs as they emerge in our state and will ensure that work is in alignment with the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

##### **Logic Model**

Our plan for determining project impact is linked directly to the components of the logic model (Table 5) and follows the overall 5-year timeline. We will systematically examine the extent to which the UCEDD, while leveraging *inputs*, has implemented and managed activities to produce the expected *outputs* and the extent to which these programmatic activities have achieved our objectives to create the desired *initial and intermediate* outcomes. As part of our

<b>Table 5 Waisman Center UCEDD Logic Model</b>				
<b>Inputs</b> Resources used to support activities	<b>Activities</b> Processes; what the program does	<b>Output Measures</b> Products of activities	<b>Initial Outcome Measures</b>	<b>Intermediate Outcome Measures</b> <i>Reported every 5 years</i>
<ul style="list-style-type: none"> <li>• UCEDD core faculty and staff</li> <li>• Constituent Advisory Committee</li> <li>• Core grant funding from AIDD</li> <li>• Leveraged funds (federal, state, community funded grants and contracts)</li> <li>• Wisconsin agency collaboration</li> <li>• Collaborative partners</li> <li>• 5-year plan</li> <li>• Reporting and data systems</li> <li>• Website</li> <li>• Equipment and supplies</li> <li>• Waisman Center collaborating staff and investigators</li> <li>• University resources</li> <li>• Waisman Center resources Administration, Communications, IT, HR, Business office</li> </ul>	<ul style="list-style-type: none"> <li>• Leverage funds for partnerships to carry out core functions</li> <li>• Provide exemplary interdisciplinary preservice preparation</li> <li>• Provide continuing education and community training throughout Wisconsin</li> <li>• Provide direct problem-solving technical assistance to agencies and entities to improve services and outcomes</li> <li>• Provide model services for individuals with DD and their families</li> <li>• Conduct basic and applied research and evaluation</li> <li>• Disseminate knowledge-based information through UCEDD developed products and activities</li> </ul>	<p>Annually</p> <ul style="list-style-type: none"> <li>• Leverage \$5M</li> <li>• Provide preservice training to 1000 trainees</li> <li>• Increased diversity among trainees</li> <li>• Increased knowledge and cultural competency of 1000 practitioners working with people with DD</li> <li>• Provide community services training to 5,000 participants</li> <li>• Provide technical assistance activities to 70 agencies and organizations</li> <li>• Provide model services to 2,700 individuals</li> <li>• Conduct 6 research studies</li> <li>• Involve 5 people with ID as collaborators in research annually</li> <li>• Develop and disseminate information in published papers, issue briefs/best practice reports and other products</li> </ul>	<ul style="list-style-type: none"> <li>• 90% of long-term trainees report an increase in knowledge or skills</li> <li>• 90% of community services trainees report an increase in knowledge or skills</li> <li>• 90% of agencies who receive direct problem-solving assistance report enhanced resources, services, or networks</li> <li>• 80% of model service recipients report satisfaction with the services received</li> <li>• 90% of model service recipients report enhanced well-being and status</li> <li>• UCEDD adopts research and evaluation findings by modifying activities in other core functions</li> <li>• 30 conference presentations</li> <li>• 30 peer-reviewed publications</li> </ul>	<ul style="list-style-type: none"> <li>• More leaders statewide who support community inclusion</li> <li>• Greater number of professionals, individuals, and families who use best practices</li> <li>• Improved access to and quality of services for people with DD</li> <li>• Research findings are cited in the literature</li> <li>• Instances of research translating into practice and/or policy including systems change and the adoption of evidence-based practices</li> <li>• Policymakers turn to UCEDD as reliable source of information</li> <li>• Improved health, mental health, and quality of life for people with DD</li> </ul>



continuous quality improvement approach to evaluation, we will measure *process* aspects of activities as noted in the logic model including the number and types of core function activities, alignment of activities with proposed goals, and the timeliness of the activity. We also will obtain numbers and demographic characteristics of trainees, practitioners, clients, organizations, etc., to measure the extent to which we reached our targeted audiences, particularly individuals from culturally and linguistically diverse backgrounds. Finally, we will measure *outcomes* of activities in terms of both initial outcome measures and intermediate outcome measures (reported every 5 years).

### **Methodology to Gather Data to Report Annually**

For each UCEDD project, project directors will be responsible for ensuring that all activities and products related to their project are recorded in the National Information and Reporting System (NIRS). Tailored reports of NIRS data will be generated quarterly for key metrics across core functions and projects such as grant and contract dollars, number of participants in training activities, consumer satisfaction, publications, presentations, and other products. Julie Schears, our NIRS data coordinator, will work closely with UCEDD leadership to ensure timely, complete, and accurate data entry and reporting each year. Annually we will create a dashboard of key data elements in order to track progress and review with faculty, staff, and stakeholders.

### **Innovative Methods to Evaluate our Program**

In addition to entry and evaluation of project data through NIRS, each UCEDD project has its own plan for evaluation. Each project director will provide quarterly updates to the core function coordinator who will then report to the Steering Committee on the status of project activities and share evaluation data consistent with the project's plan. Across projects, a range of

both qualitative and quantitative methods are employed as is appropriate for the objectives of the work including pre/post assessments, progress monitoring on implementation indexes, surveys on satisfaction and learning, listening sessions, focus groups, and case reports. For example, WI LEND program is one of five LEND programs that implemented the LEND Outcomes Study starting in 2015, a case-control research protocol developed and initiated by Dr. Robert Noll from Pittsburgh LEND. The study follows LEND trainees and matched peers using the NIRS data collection system but also provides participating LEND programs the option to ask other qualitative and/or quantitative questions about core competencies, leadership impacts, etc. As another example of innovative measures of project impact, the Wisconsin Long Term Care Survey is designed to understand changes over time in services and quality of life for individuals who receive adult long-term care supports in the state of Wisconsin. We are longitudinally following individuals and family members by administering an online survey every year of our 5-year plan, allowing us to detect fluctuations in key indicators and linking them with changes in service systems. We also note that the UCEDD Associate Director 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.

### **CAC Role in Evaluation**

CAC plays a critical role in evaluation of the work of the UCEDD. CAC members will provide guidance in three primary ways. First, one CAC meeting each year will focus on a review and discussion of annual progress on project activities, products, and outcomes. During this meeting, the CAC will receive the dashboard and related data including case studies/family stories. CAC will give input and make recommendations in response to these updates. Second,

CAC will also receive and review needs assessment data each year and provide guidance regarding any emerging trends in the state that are not currently being addressed in the 5 year plan. This feedback will guide the UCEDD leadership in revising work plan objectives and activities. Third, as appropriate, CAC members will attend Steering Committee meetings as well as specific project meetings to provide guidance including input on evaluation tools and the interpretation of data.

## **SECTION 5. ORGANIZATIONAL CAPACITY**

### **Mission and Vision**

The mission of the Waisman Center, University Center for Excellence in Developmental Disabilities (UCEDD) is to support the full inclusion and self-determination of people with developmental disabilities and their families through the lifespan by:

- Increasing the diversity, knowledge and skills of undergraduate, pre-service, postdoctoral and continuing education trainees in the provision of equitable services, supports and advocacy for people with developmental disabilities
- Providing community training and technical assistance to empower people with disabilities and their families and service providers so that Wisconsin communities can be accessible and responsive to the needs of persons with developmental disabilities and their families and enable full and active participation in community activities
- Providing model services to meet unique community needs, to support training and research and serve as exemplary programs of interdisciplinary, family-centered, culturally-appropriate services

- Conducting research and evaluation activities that develop new knowledge and service approaches that enhance the health, education, and community participation of individuals with developmental disabilities
- Disseminating and increasing access to public awareness materials, research, public policy and other resources that positively affects the lives of individuals with developmental disabilities and their families.

Our programs reflect a life-span and interdisciplinary approach, rely on active participation of individuals with developmental disabilities and their families, and address the current and emergent needs of individuals with developmental disabilities, particularly those who are culturally diverse, unserved or underserved, and those on waiting lists for services.

### **Organizational Structure and Independence of the UCEDD**

The Waisman Center serves as a bridge for training, research, service and outreach activities in the University of Wisconsin System that are related to human growth and development, developmental disabilities, and neurodegenerative diseases. It is the largest research and training center at the UW-Madison and connects with 25 academic departments through its education and research programs. The Waisman Center mission and goals support those of the university – particularly the Wisconsin Idea. The Wisconsin Idea is one of the longest and deepest traditions surrounding the University of Wisconsin. It signifies a general principle that the university has a commitment to public service and that the university should influence people's lives beyond the boundaries of the classroom. It should reach every family of the state.

The Waisman Center is an interdisciplinary education, research and public service unit of a public, land grant, university. 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). See Appendix A for the Waisman Center organizational chart. The Waisman Center is one of only nine research and academic centers in the nation that house both an IDDRC and a UCEDD. The IDDRC is a comprehensive interdisciplinary program focused on IDD spanning biological, behavioral and bio-behavioral sciences designated by the National Institute of Child Health and Human Development (NICHD). Seventy-nine research projects headed by 46 principal investigators address three broad themes relevant to IDD: 1) nervous system development and pathogenesis, 2) IDD conditions, and 3) assessment, interventions and therapeutics. The ultimate focus is on discovery, prevention and treatment for IDD conditions and improvement of the quality of life of individuals with IDD and their families.

The UCEDD is designated by the ACL/Administration on Disabilities and is organized by five core functions defined in the DD Act (Interdisciplinary Pre-service Preparation and Continuing Education, Community Services: Training and Technical Assistance, Community Services: Model Services, Research, and Information Dissemination) to address needs related to Education and Early Intervention, Formal and Informal Community Supports, Health and Quality Assurance. 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.

As shown in the Organizational Chart (Appendix A), William E. MacLean, Jr., PhD is the UCEDD Director and is responsible for the direction, coordination and administration of all aspects of the UCEDD. MacLean reports to Qiang Chang, PhD, Director of the Waisman Center. Dr. Qiang reports directly to the Interim Vice Chancellor for Research and Graduate Education (VCRGE) of the University Wisconsin-Madison, Norman Drinkwater, PhD.

Appendix J presents the signed agreement concerning the role of the Waisman Center UCEDD within the University of Wisconsin – Madison.

***Managerial structure:*** The UCEDD has six committees that plan and oversee its activities: a steering committee and five core function committees chaired by the core function coordinators. The UCEDD Steering Committee meets monthly and is composed of the Coordinators of each of the UCEDD core functions as well as the Director, Associate Director and NIRS Data Coordinator. The Chair of the Constituent Advisory Committee also attends these meetings when appropriate. The UCEDD Core Function Coordinators monitor and report to the other steering committee members on progress, barriers, and any other updates related to their mission/core function area. The Steering Committee establishes and reviews center policies, HR matters, budget issues, core function matters, strategic planning efforts and other mission related issues that might arise and need immediate attention.

The Core Function coordinators maintain five additional UCEDD committees, each composed of 3-5 project staff engaged in activities representative of each core function. These groups meet regularly to address the activities of specific projects, to discuss progress toward UCEDD goals and objectives, to analyze relevant evaluation data, and to consider new project opportunities.

Additional resources are available to UCEDD programs from Waisman Center Core Services. Those of particular importance to the UCEDD are within the Administrative Core – such as communications (media relations, development activities, marketing and special events planning), financial services (management and accounting), human resources, and IT support. Over the past five years, the UCEDD has strengthened its linkage with the IDDRC Clinical Translational 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. This began with the formation of a Clinical Research Committee, a centralized study review process overseen by the manager of the Clinical Translational Core. This past July, the UCEDD Director (MacLean) assumed responsibility for directing the IDDRC Clinical Translational Core – thus establishing a direct link between the UCEDD and IDDRC. The UCEDD’s extensive service system provides a useful link in facilitating translation of research findings into clinical settings.

### **UCEDD Planning Capability to Leverage Resources and Conduct Long-Range Planning**

For 45 years, Waisman Center faculty and staff have had a strong record of leveraging funds for our projects and programs, first as a University Affiliated Facility and later as a University Affiliated Program, and UCEDD. The UCEDD has leveraged, on average \$9,275,000 per year of additional funding toward our training, technical assistance, service, research and information dissemination activities over the past four years. Nearly all of the grants and contracts that we leverage are multi-year awards or are annually renewed by the partnering organization. The predictability in funding levels from one year to the next affords a degree of stability necessary to maintain the workforce needed to accomplish our mission as well as compete for new funding without loss of staff. Our strong funding history and planning capabilities are evidence of our ability to be responsive to emergent and future developments in the field.

### **UCEDD Diversity**

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. Thirty percent of the UCEDD staff and faculty are parents or other family members of a person with a disability or special

health care need. Five percent of UCEDD staff and faculty report being a person with a disability or special health care need. Approximately 14% of the faculty and staff are from underrepresented populations. The Waisman Center also employs seven individuals with significant disabilities in part-time program assistant positions. Several of these employees have worked at the Waisman Center for more than 15 years.

As a part of our work with the Wisconsin Community of Practice on Cultural and Linguistic competence for Individuals with Developmental Disabilities, we have adopted a practice of using interviews and performance evaluations that include questions regarding cultural competence and experiences with diversity.

### **Qualifications of the Director**

William E. MacLean, Jr., Ph.D., FAAIDD is an associate director of the Waisman Center and has overall administrative responsibility for the University Center for Excellence in Developmental Disabilities. He provides leadership for the UCEDD, determines strategic directions for its programs, oversees the core function coordinators and supervises administrative staff. His resume is in Appendix G.

Dr. MacLean is a clinical psychologist with nearly 40 years of experience in academic settings. He earned a doctoral degree in clinical psychology from George Peabody College for Teachers of Vanderbilt University in 1980 and completed a clinical internship in pediatric psychology at the University of North Carolina at Chapel Hill in 1981. He was a faculty member at Peabody College of Vanderbilt University for 15 years and for 18 years at the University of Wyoming. He has an extensive record of leadership in clinical and research training at the doctoral and post-doctoral levels. He served as director of graduate programs in clinical psychology for 16 years. He also co-directed NIH supported research-training programs in



behavioral pediatrics and intellectual disability at Vanderbilt University. MacLean was editor of the *American Journal on Intellectual and Developmental Disabilities* from 2002-2008 and is currently a member of the editorial board of the *Journal of Mental Health Research in Intellectual Disabilities*.

He has been actively engaged in the field of developmental disabilities for over 40 years – beginning with his honors thesis research as an undergraduate at Emory University. His research and scholarship has focused on stereotyped and self-injurious behavior, depression and behavioral phenotypes of genetic etiologies as well as health care access and voting participation of adults with intellectual disability. MacLean served as executive director of the Wyoming UCEDD from 2009-2014. He has been director of the Wisconsin UCEDD since 2014.

He is an experienced grants manager who has received over \$14 million in external funding for research, training and service. He is an author of over 100 peer-reviewed articles, book chapters and other scholarly products. MacLean is a past president of the Division of Intellectual and Developmental Disability of the American Psychological Association. He is a Fellow of the American Association on Intellectual and Developmental Disabilities, the American Psychological Association, and the Society for Pediatric Psychology.

### **Qualifications of Staff Assigned to the UCEDD Grant**

The following paragraphs provide a short description of staff with leadership roles in the UCEDD. Their resumes are included in Appendix G.

Leann Smith DaWalt, PhD (Associate Director) assists the UCEDD Director in carrying out the mission, core functions and federal requirements of the UCEDD; maintaining collaborative relationships with the Wisconsin DD Network partners and other state organizations and community service providers; preparing continuation applications and annual

reports; developing the 5-year strategic plan in consultation with the Consumer Advisory Committee; participating in hiring, supervision and mentoring of UCEDD staff and faculty; and fostering evidence-based practice within all programs and activities of the UCEDD. She is an IDDRC investigator focused on understanding the impact of having a child with a development disability on the family as well as the role of the family in supporting healthy development of individuals with disabilities.

Jody Bleck, MS (Waisman Center Associate Director for Finance & Administration)

Bleck provides fiscal management, budgeting and accounting, business services, human resources, facility and overall administrative support for all Waisman Center grants. She directs all human resources and personnel activities for UCEDD projects and oversees grants administration, business services and information technology.

Anne B. Harris, PhD, MPH, RD (Interdisciplinary Preservice Training and Continuing Education Coordinator) Dr. Harris has considerable experience working with MCH-funded programs focused on improving systems of care for children with special needs, first as a trainee, then as a nutritionist at USC UCEDD Children's Hospital Los Angeles, and currently as the Director of the WI LEND. She is deeply committed to the vision of training emerging leaders who will continue to improve and transform the landscape of health care for children with developmental disabilities and their families through interdisciplinary training; family centered care provision and coordination; translational and systems integration research. Dr. Harris is also a co-chair of the Wisconsin Community of Practice on ASD/DD, member of the AUCD National Training Director Council, program administrator of several contracts from the Wisconsin Department of Health Services, Title V Block Grant, and a co-PI of the Wisconsin

Care Integration Initiative the goal of which is to increase family-centered, integrated systems of care for children with ASD/DD.

Gail Chödrön, PhD (Community Services Training and Technical Assistance Coordinator) Dr. Chödrön brings over a decade of experience in education and outreach related to autism spectrum disorders (ASD) and other developmental disabilities. Drawing on her graduate training in social and behavioral sciences in public health and subsequent training in the WILEND program, she has focused her work on program evaluation and quality improvement initiatives that support community integration of evidence-based and best practices for early identification of ASD and other developmental disabilities. She has taken a lead on community education and technical assistance on numerous projects over the past eleven years, and has served as Chair of the UCEDD community training and technical assistance committee since 2016, prior to which she served as co-Chair for five years (2011-2016). Her strong record in working with a range of community audiences—including early care and education professionals, health care providers, public health professionals, families and the general public—has been recognized through invitations to serve in roles such as training faculty on the state home visiting continuous quality improvement initiative (2018-2019), the CDC’s Act Early Ambassador to Wisconsin (2011-present), and various advisory groups.

Amy Whitehead, (MPA) Community Model Services Coordinator). Over the past 27 years, Ms. Whitehead has influenced the Center’s work through sharing her lived experience as a parent of an individual with a developmental disability, as well as through her management skills in leading model service programs. Her family was a recipient of UCEDD model services (early childhood program and clinics), which contributes to her effectiveness in her professional role of ensuring that services are family-centered. She was on the lead state Children and Youth with

Special Health Care Needs team that established a set of regional resource centers, so that no matter where families live in Wisconsin, they have easy access to quality information, training and linkages to Family Voices and Parent to Parent. Most recently, she manages the UCEDD Clinics, ensuring that the model services benefit individuals with IDD and their families. Ms. Whitehead has been instrumental in integrating training, research and information dissemination into the clinical model service programs.

Research and Evaluation Coordinator (TBD) – This position was created in the last five-year award. Leann Smith DaWalt, PhD, currently the UCEDD associate director, served as the Director of Research from 2014-2018. 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 and evaluation into the work of the UCEDD. Beginning in July 2019, we will be recruiting a new coordinator for this core function area. Dr. DaWalt is serving as the Interim Research Coordinator until a permanent appointment is determined.

Dissemination Coordinator (TBD). This is a new position for the UCEDD – one that will greatly benefit internal as well as external communication. The Dissemination Coordinator will manage and schedule the distribution of communication assets on behalf of the UCEDD. The individual in this position will work with the UCEDD Director, Associate Director and project staff to coordinate information sharing/communication as well as dissemination of information (e.g., such as issue briefs, newsletters, social media concerning UCEDD events and activities, internal email communication, and communication with AUCD).

Julie Schears serves as the NIRS Data Coordinator for the Waisman Center. She also provides administrative and technical support for the Constituent Advisory Committee.

Liz Hecht, public policy specialist, works across UCEDD programs and links with several local, state, and national organizations and agencies to engage with them to define and advance public policies and system changes that support the purposes of the DD Act. Ms. Hecht is the UCEDD representative to the Board for People with Developmental Disabilities as well as the Survival Coalition of Wisconsin Disability Organizations.

Lynn Hrabik, program evaluation specialist, has been a public health evaluator for nearly 20 years. Originally trained as a nutritionist, Hrabik earned an MPH degree in community health education in 2009. Since that time, she has been involved in a variety of initiatives related to obesity and tobacco use. More recently, she served as the evaluator of the Wisconsin Medical Home Systems Integration Project and a UCEDD program, funded by MCH, to increase family-centered, integrated systems of care for children with ASD.

Cheri Sanders is a media specialist that develops and updates webpages, project reports and other UCEDD products. She has expertise in graphic design useful in various UCEDD products such as brochures, training guides and curriculum, newsletters, fliers, and diagrams.

Pao Lee, grants specialist, assists in the development of contract and grant applications.

James Mulder, Ruth Munz, Sonja Oetzel, and Savanna Seel are university services associates that provide UCEDD administrative and clerical support.

The UCEDD maintains sufficient faculty and staff necessary to support its projects and programs through leveraged funding from grants, contracts, fee-for-service agreements, gifts, and other sources. They are highly qualified and dedicated to the UCEDD mission as well as the programs that they support.

## **Constituent Advisory Committee**

The CAC is a vital part of our UCEDD. The primary function of the CAC is to participate in the development and review of our 5-year plan and provide advice and guidance to the UCEDD Director as we implement our programs and projects. CAC members play an instrumental role in communicating important community priorities to the UCEDD and promoting UCEDD activities in the community. The CAC currently has 13 members, 11 of whom are persons with developmental disabilities or family members. Four of the members are from underserved or underrepresented communities. The current membership of the CAC is presented in Appendix B. The membership includes a representative from the Board for People with Developmental Disabilities (State Council) and Disability Rights Wisconsin (Protection and Advocacy), members affiliated with various state organizations (Autism Society of South Central Wisconsin, People First, Special Olympics), self-advocates and family members as prescribed by the DD Act. As stated in the bylaws, the Waisman Center CAC has a minimum of 12 members and a maximum of 20. Each member has a term appointment of three years with an additional three-year term if desired. Three members are currently completing their final year on the committee. The Nominations Committee, a subset of the CAC, is actively recruiting new self-advocates or family members from underrepresented groups to fill the available positions. Members are eligible to receive a stipend to assist with costs to attend each meeting.

The CAC chair receives an honorarium given in three payments over the course of the year as well as travel funds to attend the annual AUCD conference as the COLA representative. Maria Nogueron is currently serving a three-year term as chair. Maria is the parent of a young adult with Down syndrome and lives in Milwaukee. She taught in the Milwaukee Public Schools and was co-chair of the Bilingual Education Teachers Association. She is a champion for science

and technology education among girls and underrepresented minorities in Milwaukee. She was also the Milwaukee parent representative on an advisory committee that created the Wisconsin Birth Defects Surveillance System. More recently, Maria was appointed to the External Advisory Committee for the Waisman Center IDDRC.

The CAC meets in-person three times a year (October, February and June). Each meeting is 3.5 hours in length. One meeting each year is devoted to review of progress in completing the five-year plan, evaluation of impact, and discussion of emerging needs. Julie Schears, a senior outreach specialist and the NIRS Data Coordinator, provides coordination and administrative support for the CAC.

### **Collaborative Relationships with Wisconsin DD Network Partners**

Evident from the letters of support/commitment appended to this application (Appendix H), we have strong ties with the Board for People with Developmental Disabilities and Disability Rights Wisconsin, as well as Family Voices, one of our state partner organizations. The three DD Network Partners meet regularly to discuss current issues relevant to the Wisconsin developmental disability community. The network partners also engage in a variety of collaborative projects. Table 6 lists the collaborative projects that occurred in 2017-18. The first section lists the projects in which all three DD Network Partners participated while the second and third sections represent UCEDD collaboration with only the Board for People with Developmental Disabilities (BPDD) or Disability Rights Wisconsin (DRW), respectively.

**Table 6 Waisman Center UCEDD - DD Network Collaborations****BPDD, DRW and UCEDD**

AIDD – Community of Practice on Cultural and Linguistic Competence in DD  
 AIDD – Disparities Leadership Academy  
 Department of Health Services Advocate Advisory Group  
 Disability Advocacy Day – Sponsored by the Survival Coalition  
 Disability Policy Seminar – Capitol Hill Visits  
 Supported Decision Making Initiative  
 Survival Coalition of Wisconsin Disability Organizations  
 UCEDD Family Action Network  
 Wisconsin Council on Children with Long-Term Support Needs  
 Wisconsin Long Term Care Survey  
 Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) – Wisconsin

**BPDD and UCEDD**

Family Network Project  
 Mind and Memory Matters Project  
 Promoting Readiness of Minors in Supplemental Security Income (PROMISE)  
 Wisconsin Let's Get to Work Project  
 Wisconsin Self-Determination Annual Conference

**DRW and UCEDD**

Analysis of Changes to the Wisconsin Adult Long Term Care Functional Screening Measure  
 IDD – Mental Health Focus Group  
 Medicaid Prior Authorization Improvement Initiative  
 Milwaukee Strategic Planning for Children with Disabilities  
 Workgroup for Children with Disabilities in the Child Welfare System

**Participation in Community Networks**

In addition to the previously described partnerships with the Board for People with Developmental Disabilities (BPDD) and Disability Rights Wisconsin (DRW) described in the previous section, the UCEDD works with many local, state, and national organizations to achieve the goals and objectives of our 5-year plan (Appendix C). These organizations include state and local government agencies, local non-profits, state non-profits, national organizations and federal agencies, and other universities and organizations. Appendix F provides a listing of the Wisconsin partnerships that support the UCEDD's advocacy, capacity building and systems change activities through participation in councils, boards and committees, leveraged funding for specific projects, requests for technical assistance, opportunities to participate in community

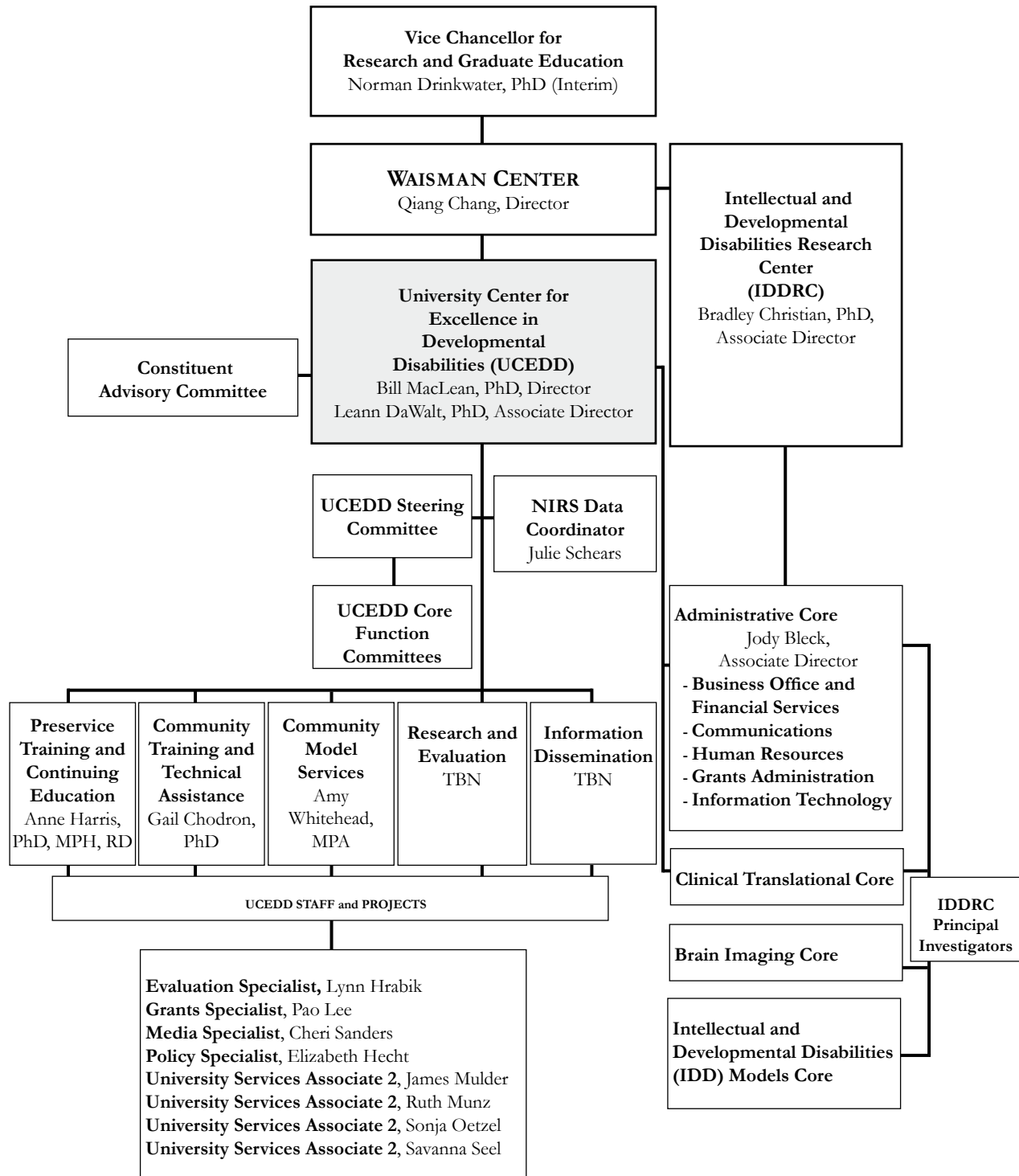


education events and contributions to analysis of public policy. The success of our efforts is dependent upon these meaningful and effective collaborations and partnerships.

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# University Center for Excellence in Developmental Disabilities



**2017-2018 Waisman Center Advisory Committee Membership**

Nancy Alar is a parent of a child with ASD.

Dan Bloomgren is a self-advocate.

Maria Corazon Holloway is a parent of a young adult with Down syndrome.

Jeanne Fehr is a parent of a young adult with Down syndrome.

Mitch Hagopian is a Supervising Attorney with Disability Rights Wisconsin.

Corie Klaustermeier is a parent of two children with developmental disabilities.

Ruth Martin is a parent of a young adult with a developmental disability.

Erin Miller is a self-advocate.

Jenny Neugart is the Disability Grassroots Organizer for the Wisconsin Board for People with Developmental Disabilities Disability.

Maria Nogueron is a parent of a young adult with Down syndrome and Chairperson of the CAC.

Abby Tessman is a self-advocate.

Sandy Tierney is a parent of a child with cerebral palsy.

Tom Veek is a waiver support broker.

	Nancy	Dan	Maria H	Jeanne	Mitch	Corie	Ruth	Erin	Jenny	Maria N	Abby	Sandy	Tom
PWDD & Related Disabilities		X						X	X	X	X		
Family Member of PWDD	X		X	X		X	X			X		X	
AIDD Network Partner					X				X				
Community Support Provider													X
Self-Advocate Organization		X						X		X	X		
Represents Underserved or Underrepresented Communities			X	X				X		X			

<b>Goal 1 (Interdisciplinary Training and Continuing Education): Increase the diversity, knowledge and skills of undergraduate, pre-service, postdoctoral and continuing education trainees in the provision of equitable services, supports and advocacy for people with developmental disabilities</b>						
<b>Areas of Emphasis:</b> Health, Education and Early Intervention, Formal and Informal Supports, Quality Assurance						
<b>Measureable Initial Outcomes:</b> Number and type of trainees, number of interdisciplinary training programs, number of discipline-specific training programs, diversity of UCEDD trainees, number of pre-service preparation training activities conducted outside the UCEDD, number of professionals participating in UCEDD continuing education programs, number of continuing education programs, length of CE program						
<b>Person Responsible:</b> Anne Harris, PhD, Coordinator						
<b>Objectives</b>	<b>Project Activities</b>	<b>Year 1</b>	<b>Year 2</b>	<b>Year 3</b>	<b>Year 4</b>	<b>Year 5</b>
1.1 Annually 80 trainees from multiple disciplines will increase their knowledge and skills in leadership, interdisciplinary practice, research, and public policy related to developmental disabilities	1.1.1. Mentor trainees in leadership skills, communication skills, cultural competency, and policy	xxx	xxx	xxx	xxx	xxx
	1.1.2. Provide core knowledge of ASD and DD through didactic training and case-based learning	xxx	xxx	xxx	xxx	xxx
	1.1.3. Mentor trainees in research, evaluation and dissemination	xxx	xxx	xxx	xxx	xxx
	1.1.4. Mentor trainees in interdisciplinary and family-centered practice	xxx	xxx	xxx	xxx	xxx
1.2 Annually provide discipline specific training and practicum experiences for 85 trainees in the context of ongoing direct service programs and for 1000 students in UW-Madison courses	1.2.1 Provide Masters level training for 16 students in genetic counseling	xxx	xxx	xxx	xxx	xxx
	1.2.2 Provide practicum training for undergraduate and graduate students in 9 early childhood education, educational psychology and social work	xx	xx	xx	xx	xx
	1.2.3 Provide clinical fieldwork experience for 60 speech/language, audiology, social work, medical residents, and psychology trainees	xxx	xxx	xxx	xxx	xxx
	1.2.4 Provide coursework for 1000 undergraduate and graduate students in UW-Madison courses related to audiology, human development and family studies, nursing, nutritional science, occupational therapy, physical therapy, population health sciences, psychology and social work	xx	xx	xx	xx	xx
1.3 Increase the number of trainees recruited from underrepresented backgrounds (race, culture, ethnicity and/or disability)	1.3.1 Recruit students from UW-Milwaukee campus through LEND’s “Milwaukee-Link” program	x	x	x	x	x
	1.3.2 Inform undergraduate students from underrepresented backgrounds to consider graduate programs related to children with ASD and DD and other MCH populations (e.g. Pipeline)	xx	xx	xx	xx	xx
	1.3.3. Use health-science recruitment mechanisms on the UW-Madison campus to reach out to prospective students from underrepresented backgrounds	xxxx	xxxx	xxxx	xxxx	xxxx
	1.3.4 Showcase projects and activities of trainees from diverse backgrounds on our website, products and recruitment materials		xxxx	xxxx	xxxx	xxxx
	1.3.5 Describe success in preparing leaders from diverse backgrounds in the field of DD on our website, products and recruitment materials		xxxx	xxxx	xxxx	xxxx
1.4 Increase the knowledge and skills of 1000 health and mental health professionals, educators, and community professionals on a variety of disability topics through continuing education	1.4.1. Provide a CE certificate program in alternative and augmentative communication for Speech-Language Pathologists to build service delivery capacity in WI		xxxx	xxxx	xxxx	xxxx
	1.4.2. Provide CE for early childhood educators on empirically supported interventions for ASD			xxxx	xxxx	xxxx
	1.4.3 Provide CE courses on health and mental health conditions that co-occur with ID and ASD			xxxx	xxxx	xxxx

	1.4.4 Provide training on specific diagnostic and intervention approaches for children with ASD		XXXX	XXXX	XXXX	XXXX
	1.4.5 Conduct 25 seminars annually on research in ASD and DD; provide CME for health practitioners	XXXX	XXXX	XXXX	XXXX	XXXX
	1.4.6 Conduct 20 trainings annually for direct service providers	XXXX	XXXX	XXXX	XXXX	XXXX
1.5 Modify at least 2 CE trainings (annually) so that they are available in multiple formats and publicized statewide	1.5.1 Offer multiple trainings through on-line technology			XXXX	XXXX	XXXX
	1.5.2 Make video recordings of training events available on the Waisman Center UCEDD website		XXXX	XXXX	XXXX	XXXX
	1.5.3 Annually, develop and implement a marketing plan to promote training events	x	x	x	x	x
<b>Goal 2 (Community Services: Training and Technical Assistance): Provide community training and technical assistance to people with disabilities and their families and service providers to increase the accessibility and responsiveness of Wisconsin communities to the needs of individuals with developmental disabilities and their families and enable full and active participation in community activities</b>						
<b>Areas of Emphasis:</b> Health, Education and Early Intervention, Formal and Informal Supports, Quality Assurance						
<b>Measureable Initial Outcomes:</b> Number of people trained by participant type, number of discrete training events, number of hours of technical assistance provided by area of emphasis, number of hours of technical assistance per type of organization						
<b>Person Responsible:</b> Gail Chödrön, PhD, Coordinator						
<b>Objectives</b>	<b>Project Activities</b>	<b>Year 1</b>	<b>Year 2</b>	<b>Year 3</b>	<b>Year 4</b>	<b>Year 5</b>
2.1 Increase the knowledge and skills of 5000 professionals, individuals with DD, and families on best practices, policies and resources in health & wellness, early intervention and education, postsecondary education and community living.	2.1.1 Provide community training through the Waisman Center Day with the Experts forums on ASD, Down Syndrome, Cerebral Palsy and Cochlear Implants	XXXX	XXXX	XXXX	XXXX	XXXX
	2.1.2 Conduct trainings for families of CSHCN on transition, employment, and post-secondary education	XXXX	XXXX	XXXX	XXXX	XXXX
	2.1.3 Conduct trainings for families on supported decision making, self-determination and personal safety	XXXX	XXXX	XXXX	XXXX	XXXX
	2.1.4 Provide leadership training in health systems for individuals with DD			XXXX	XXXX	XXXX
	2.1.5 Conduct trainings for professionals on screening and assessment, competency evaluations, behavior and health management, and community living	XXXX	XXXX	XXXX	XXXX	XXXX
2.2 Modify trainings so that they are available in multiple formats and publicized statewide	2.2.1 Offer multiple trainings through online technology		XXXX	XXXX	XXXX	XXXX
	2.2.2 Maintain an online library of video-recorded trainings, online modules, and other training content on the Waisman Center UCEDD website	XXXX	XXXX	XXXX	XXXX	XXXX
	2.2.3 Develop and implement a marketing plan to promote live and online trainings (annually)	x	x	x	x	x
2.3 Provide direct problem-solving services to assist 70 programs, agencies, or other entities in improving their services, outcomes, and/or policies.	2.3.1 Provide TA to early childhood programs to promote acceptance, retention and inclusion of children with DD		XXXX	XXXX	XXXX	XXXX
	2.3.2 Provide TA to support transition of CSHCN	XXXX	XXXX	XXXX	XXXX	XXXX
	2.3.3 Provide TA to self-advocacy organizations to promote health and wellness of self-advocates			XXXX	XXXX	XXXX
	2.3.4 Provide TA to primary care practices and schools to support ASD screening, diagnosis, and treatment		XXXX	XXXX	XXXX	XXXX
	2.3.5 Provide TA to disseminate Early Start Denver Model curriculum to early intervention programs			XXXX	XXXX	XXXX

<b>Goal 3 (Community Services: Model Services): Provide model services to meet unique community needs, to support training and research and serve as exemplary programs of interdisciplinary, family-centered, culturally-appropriate services</b>						
<b>Areas of Emphasis:</b> Health, Education and Early Intervention, Formal and Informal Supports						
<b>Measureable Initial Outcomes:</b> Number of specialized services provided by the UCEDD and number of individuals who received specialized services to enhance their well-being and status						
<b>Person Responsible:</b> Amy Whitehead, MPA, Coordinator						
<b>Objectives</b>	<b>Project Activities</b>	<b>Year 1</b>	<b>Year 2</b>	<b>Year 3</b>	<b>Year 4</b>	<b>Year 5</b>
3.1 UCEDD faculty and staff provide specialized clinical services to enhance the well-being and status of 2500 people with developmental disabilities and their families annually	3.1.1 Provide diagnostic and evaluation services in eleven medical specialty clinics in cooperation with UW Health	xxxx	xxxx	xxxx	xxxx	xxxx
	3.1.2 Provide ongoing treatment services to children and adults with genetic conditions associated with DD	xxxx	xxxx	xxxx	xxxx	xxxx
	3.1.3 Provide treatment services for children, youth, and young adults with ASD	xxxx	xxxx	xxxx	xxxx	xxxx
3.2 UCEDD faculty and staff provide other direct model services to 200 individuals to enhance the well-being and status of the recipient annually	3.2.1 Provide community-based consultation and positive behavioral support services	xxxx	xxxx	xxxx	xxxx	xxxx
	3.2.2 Provide behavioral crisis response services in the community to prevent placement in more restrictive settings	xxxx	xxxx	xxxx	xxxx	xxxx
	3.2.3 Provide inclusive early childhood education to children younger than 5	xxxx	xxxx	xxxx	xxxx	xxxx
	3.2.4 Provide information and referral to families regarding services to enhance well-being	xxxx	xxxx	xxxx	xxxx	xxxx
	3.2.5 Provide community nursing to promote, improve and maintain health of adults with DD	xxxx	xxxx			
	3.2.6 Provide coaching to youth and family members to support pursuit of postsecondary education, job training and competitive employment	xxxx				
3.3 UCEDD engages in demonstration services that field test promising or other exemplary practices	3.3.1 Determine the effectiveness of community based navigators in decreasing health disparities			xxxx		
	3.3.2 Determine the feasibility of a statewide positive behavioral support program for challenging behavior		xxxx	xxxx		
	3.3.3 Pilot a statewide partnership program to expedite access to evidence-based, high quality augmentative and alternative communication evaluations and treatment	xxxx	xxxx	xxxx		
<b>Goal 4 (Research): Conduct research activities that impact the health, education, and community participation of individuals with developmental disabilities</b>						
<b>Areas of Emphasis:</b> Health, formal and informal supports, quality assurance						
<b>Measureable Initial Outcomes:</b> UCEDD adopts research and evaluation findings by modifying activities in other core functions and the number of products disseminated (e.g., peer-reviewed publications, presentations, research briefs)						
<b>Person Responsible:</b> Leann Smith DaWalt, PhD, Interim Research and Evaluation Coordinator						
<b>Objectives</b>	<b>Project Activities</b>	<b>Year 1</b>	<b>Year 2</b>	<b>Year 3</b>	<b>Year 4</b>	<b>Year 5</b>
4.1 Conduct at least 2 research studies on prevalence of and risk factors for various developmental disabilities	4.1.1 Monitor the prevalence of autism spectrums disorders, cerebral palsy, and co-occurring intellectual disability as part of the Autism and Developmental Disabilities Monitoring (ADDM) Network	xxxx	xxxx	xxxx	xxxx	xxxx
	4.1.2 Conduct the Study to Explore Early Development (SEED) study to understand early risk factors for autism spectrum disorder and other developmental disabilities	xxxx	xxxx	xxxx		



4.2 Support inclusion of at least 5 people (annually) with developmental disabilities in the development, implementation, and dissemination of research	4.2.1 Develop training tools and networks to support individuals with IDD to engage as research partners	xxxx	xxxx			
	4.2.2 Conduct comparative effectiveness studies of health promotion interventions with community research partners			xxxx	xxxx	xxxx
	4.2.3 Include 2-3 self-advocate LEND trainees in the implementation of ongoing Waisman research studies	xxx	xxx	xxx	xxx	xxx
4.3 Conduct at least two research studies on special health care needs, co-occurring conditions, services, and QOL among individuals with developmental disabilities	4.3.1 Conduct needs assessment to determine what issues affect access and quality of health care for adults with Down syndrome in Wisconsin		xxxx			
	4.3.2 Utilize the Wisconsin Long Term Care Survey to conduct research on changes over time in services and quality of life for adults receiving long term care supports in WI	xxxx	xxxx	xxxx	xxxx	
4.4 Develop and evaluate at least two interventions for adolescents and adults with developmental disabilities	4.4.1 Conduct studies of <i>Transitioning Together</i> , <i>Working Together</i> , and other related psychoeducation interventions		xxxx	xxxx	xxxx	xxxx
	4.4.2 Conduct development and evaluation studies of sex education programming	xxxx	xxxx			
4.5 Produce evaluation reports of the impact of each UCEDD project on individuals with disabilities and their families	4.5.1 Each project leader will develop a project impact plan each year	x	x	x	x	x
	4.5.2 Each project leader will meet with the of Research and Evaluation Coordinator annually to review their project impact plan and timeline for completion	x	x	x	x	x

**Goal 5 (Information Dissemination): Disseminate and increase access to public awareness materials, research, public policy and other resources that positively impacts the lives of individuals with developmental disabilities and their families.**

**Areas of Emphasis:** Health, Education and Early Intervention, Formal and Informal Supports, Quality Assurance

**Measureable Initial Outcomes:** Number of products developed, number of products disseminated, number of conference presentations

**Person Responsible:** Dissemination Coordinator (TBD)

Objectives	Project Activities	Year 1	Year 2	Year 3	Year 4	Year 5
5.1 Promote public awareness and visibility of the Waisman UCEDD	5.1.1 Submit 3 UCEDD news items each year to AUCD publications	xxx	xxx	xxx	xxx	xxx
	5.1.2 Provide information on research opportunities, services, and educational events to the general public through email distribution, social media, and internet website	xxxx	xxxx	xxxx	xxxx	xxxx
	5.1.3 Disseminate research findings at 30 professional conferences and publish 30 papers in peer-reviewed journals each year	xxxx	xxxx	xxxx	xxxx	xxxx
	5.1.3 Support engagement of at least 3 CAC members as UCEDD ambassadors by developing “Talking Points” and basic UCEDD PowerPoint slides to assist members as they engage with communities on behalf of the UCEDD	xxxx	xxxx	xxxx	xxxx	xxxx
	5.1.4 UCEDD will present information at 5 statewide and regional conferences on the latest activities and resources of all UCEDD projects	xxxx	xxxx	xxxx	xxxx	xxxx
	5.1.5 UCEDD will maintain a current DD Network Directory and provide updates to DD Network partners quarterly	xxxx	xxxx	xxxx	xxxx	xxxx
	5.1.6 Maintain current information on AUCD website and AUCD directory	xxxx	xxxx	xxxx	xxxx	xxxx



5.2 UCEDD will develop and disseminate information products on the purpose of the DD Act of 2000 to the Wisconsin legislature and to the Wisconsin congressional delegation	5.2.1 Create at least 1 policy brief/best practice report annually on topics such as health, education, early intervention, or community inclusion and distribute to legislators	x	x	x	x	x
	5.2.2 Policy specialist will coordinate meetings of UCEDD staff and LEND trainees with legislators and policymakers during AUCD Hill Visits, AUCD Disability Policy Seminar, and Wisconsin Disability Advocacy Day and disseminate materials related to various UCEDD projects, annually	xxx	xxx	xxx	xxx	xxx
5.3 UCEDD will maintain an accessible, current website and utilize social media to provide information and resources to the general public	5.3.1 Project leaders will provide up to date information annually on their project for posting on the UCEDD website	xxxx	xxxx	xxxx	xxxx	xxxx
	5.3.2 Dissemination Coordinator will update the project web pages as needed and add web pages as new projects are funded	xxxx	xxxx	xxxx	xxxx	xxxx
	5.3.3 Dissemination Coordinator will monitor and analyze visits to UCEDD web pages, monitor satisfaction survey response to improve functionality and maximize dissemination via UCEDD websites	xxxx	xxxx	xxxx	xxxx	xxxx
	5.3.4 Dissemination Coordinator will test UCEDD website with web accessibility evaluation tools two times each year, and make required accessibility updates	x x	x x	x x	x x	x x
	5.3.5 Dissemination Coordinator will distribute information on UCEDD projects through social media outlets and evaluate engagement	xxxx	xxxx	xxxx	xxxx	xxxx
5.4 UCEDD will develop and disseminate products that translate current research into practice	5.4.1 Produce one product annually that translates Waisman Center research into practice	x	x	x	x	x
	5.4.2 Dissemination Coordinator will distribute the Research to Practice product to a statewide audience including consumers, families, and the general public through online and printed materials	x	x	x	x	x
5.5 Each UCEDD project will disseminate information annually	5.5.1 Each project leader will develop an annual project dissemination plan	x	x	x	x	x
	5.5.2 Each project leader will meet with the Dissemination Coordinator annually to review their product dissemination plan and timeline for web updates	x	x	x	x	x

**Figure 3. Curriculum Overview and Module Content: Friday Seminars and Case-Based Learning (CBL)**

<b>PROGRAM AREAS</b>	<b>Leadership Development:</b> Throughout the curriculum, trainees develop leadership skills in the areas of self, others, and the wider community; including team-building skills, verbal and written communication (leading discussions and presenting material), engaging in critical thinking, self-reflection, ethics and professionalism.					
	<b>Core Knowledge of ASD and DD</b>		<b>Interdisciplinary and Family-Centered Practice</b>		<b>Research, Evaluation, and Dissemination</b>	
<b>Module #: TITLE (weeks)</b>	<i>Age range; examples</i>	<i>Developmental domain; risk factors; public health perspectives, systems of care</i>	<i>Family experience; cultural &amp; linguistic considerations; community contexts</i>	<i>Assessment, diagnosis, and intervention; clinical skills</i>	<i>Research and dissemination practices</i>	<i>Current focus of evidence and research</i>
ORIENTATION and FOUNDATIONS (Weeks 1-2)	Prenatal-12 mos.	Life Course Model; Social determinants of health; Social ecological context; Early child development; Medical Home	LEND Orientation; Discipline roles, including family, self-advocates Strengths-based approaches	Newborn screening; Developmental monitoring; Developmental screening; Autism screening	Evidence-based practice; Standardized, validated tools	Prenatal diagnosis; Infant mental health; Health disparities
Module 1 NEUROMOTOR DEVELOPMENT (Weeks 3-6)	Birth-3; Cerebral Palsy (CP); Latino family	Newborn follow-up; IDEA part C; Title XIX (Medicaid/ EPSDT); Disability policy in historical perspective	Feeding issues; Family experiences with receiving diagnosis; Family goals & IFSP; Natural environments	Role of ID team; International classification of functioning; Sharing concerning results	Leadership in research to practice Researching family experience	Developmental trajectories; Early indicators of CP; Baclophen and Botox;
Module 2 COGNITIVE DEVELOPMENT (Weeks 7-10)	Ages 2-5; Down syndrome	Genetics Primer; Developmental vs intellectual disability; IDEA part B; Medicaid waivers	Grieving process; Family support; Cultural perceptions of normal dev't and disability	Functional assessment; Stigma and the cultural meaning of disability;	Research ethics; Research with vulnerable populations	Assessment of early intervention outcomes
Module 3 COMMUNICATION DEVELOPMENT (Weeks 11-14)	Ages B-6; Genetic hearing loss; Cochlear implants	Disorders of hearing, speech, and language; Long-term supports; Policy impact on services; Community inclusion; Universal design	Early hearing detection and intervention (EHDI); Deaf culture; Parent with disabilities	Using interpreters; How to foster communication; Use of assistive technology; Individual and family goals	Community research partners; Disseminating research	Unilateral vs bilateral cochlear implants

<b>PROGRAM AREAS</b>	<b>Leadership Development:</b> Throughout the curriculum, trainees develop leadership skills in the areas of self, others, and the wider community; including team-building skills, verbal and written communication (leading discussions and presenting material), engaging in critical thinking, self-reflection, ethics and professionalism.					
	<b>Core Knowledge of ASD and DD</b>		<b>Interdisciplinary and Family-Centered Practice</b>		<b>Research, Evaluation, and Dissemination</b>	
<b>Module #: TITLE (weeks)</b>	<i>Age range; examples</i>	<i>Developmental domain; risk factors; public health perspectives, systems of care</i>	<i>Family experience; cultural &amp; linguistic considerations; community contexts</i>	<i>Assessment, diagnosis, and intervention; clinical skills</i>	<i>Research and dissemination practices</i>	<i>Current focus of evidence and research</i>
Module 4 AUTISM SPECTRUM DISORDERS (ASD) (Weeks 15-18)	Ages 5-12; ASD; African- Amer. family	Social communication; Challenging behaviors; Cultural and linguistic biases in standardized tools; Stigma and labeling	Disparity in access to services and supports; Families seeking alternative therapy; Peer supports	Distinguish clinical diagnosis from determination of IDEA eligibility; Health literacy and communication	Implementation science; Cultural adaptation of evidence- based practice	Epidemiology of autism; Intensive and non-intensive behavioral interventions;
Module 5 GENETIC CONDITIONS and CHRONIC ILLNESS (Weeks 19-22)	Ages 10-18; PKU; Cystic fibrosis; Latino family	Medical genetics and inheritance; Life expectancy; Title V (children and youth with special health care needs) initiatives	Ethics of genetic testing; Reproductive decision making; Living with chronic conditions; Sibling experiences	Prenatal diagnosis; Genetic testing and counseling; Preventative intervention	Clinical research; Patient-centered outcomes research	Medical advances; Clinical trials
Module 6 WELLBEING and TRANSITION TO ADULTHOOD (Weeks 23-26)	Ages 14-21; ASD with co- occurring mental health concerns	Wellbeing and health promotion; Sexuality and disability; Psychological interventions; Transition planning in education, health care	Lifespan planning; Supported decision making; Post-secondary options; Community living; Adult service system	Differential diagnosis Intervening in communities and systems; Behavioral supports;	Translational research Dissemination formats: poster, "brief" professional publications	Quality of life outcomes; Transition; Family and individual stress and coping
"Next Steps" LEADERSHIP PRESENTATIONS and NEXT STEPS (Weeks 27-29)	<b>Trainee Research Posters and Leadership Presentations</b> – trainees present a research poster based on their placement on an interdisciplinary research project, and give an oral presentation on their progress towards achieving competencies in all 3 domains (MCH leadership, LEND-specific and discipline-specific) as planned in their ILTP, with examples of activities that demonstrate competency in each of the curriculum components: Leadership Development; Core knowledge: Interdisciplinary and family-centered practice; and Research, evaluation, and dissemination					

**Examples of Courses Taught by UCEDD Staff and Faculty in the Previous Two Years**

- CS&D 202** - Normal Aspects of Hearing
- CS&D 250** – Inter-Professional Communication in the Health Sciences
- CS&D 688** - Evaluation and Diagnosis in Speech-Language Pathology
- CS&D 705** - Motor Speech Disorders/Augmentative And Alternative Communication
- CS&D 791** - Research Experience in Communication Sciences and Disorders
- CS&D 834** - Counseling in Audiology
- CS&D 846** - The Human Balance System: Laboratory
- CS&D 863** - Implantable Auditory Prostheses
- CS&D 921** - Seminar - Problems in Audiology
- ED PSYCH 844** - Childhood and Adolescent Psychopathology in Schools
- ED PSYCH 947** - Evidence-based Child and Adolescent Psychotherapy
- EXCEDUC 601** - Behavioral Supports
- EXCEDUC 671** - Behavior Support and Intervention for Mid/High Students with Disabilities
- EXCEDUC 770** - Seminar: Research on Individuals with Special Needs
- HDFS 363** - Development from Adolescence to Old Age
- KINES 245** – Client Diversity in Health Science
- KINES 508** - Workshop in Kinesiology
- MED SCI-M 773** - Human Family Tree
- NUTR SCI 421** - Nutrition in the Life Span
- NUTR SCI 626** - Experimental Diet Design
- NUTR SCI 631** - Clinical Nutrition 1
- OCC THER 623** - Adolescent and Young Adult Occupations and Therapeutic Interventions
- OCC THER 672** - Scientific Inquiry in OT: Research Design
- OCC THER 673** - Scientific Inquiry in OT: Data Collection and Analysis
- OCC THER 720** - Application of Occupational Science and Occupational Therapy Theory
- OCC THER 811** - Applied Leadership and Management in Occupational Therapy
- OCC THER 812** - Current Trends Shaping Occupational Therapy Practice
- OCC THER 890** - Inter-Professional Development for Leadership
- PEDIAT 713 & 714** - Practicums in Genetic Counseling
- PEDIAT 731** - Advanced Clinical Genetics Concepts
- PEDIAT 737** - Contemporary Professional Issues in Genetics Counseling
- PEDIAT 741** - Interviewing and Counseling for the Genetic Counseling
- PEDIAT 742** - Clinical Embryology and Prenatal Genetics
- PEDIAT 744** - Applications of Biochemical Genetics for Genetic Counselors
- PEDIAT 745** - Seminar in Medical Genetic Counseling Research
- PEDIAT 814** – Advanced Practicum in Genetic Counseling
- PHY THER 635** - Motor Control Dysfunction: Examination, Diagnosis and Management I
- PHY THER 636** - Motor Control Dysfunction: Examination, Diagnosis and Management
- POP HLTH 803** - Monitoring Population Health
- POP HLTH 904** - Special Topics in Epidemiology
- PSYCH 711** – Current Topics in Psychology
- PSYCH 822** – Practicum in Assessment II
- RP & SE 200** – Issues in Special Education
- RP & SE 300** – Individuals with Disabilities
- RP & SE 330** - Behavior Analysis: Applications to Persons with Disabilities
- RP & SE 465** - Language and Reading Instruction for Students with Disabilities
- RP & SE 660** - Special Topics
- RP & SE 715** - Equity and Full Participation for Individuals with Significant Disabilities
- SOC WORK 400 & 401** – Field Practice/Integrated Seminars I and II
- SOC WORK 644** - Issues in Developmental Disabilities
- SOC WORK 800 & 801** – Field Practice/Integrated Seminars III and IV

### Examples of UCEDD Collaborations with Community Organizations and State Agencies

Act Early State Team	Milwaukee Center for Independence
Alianza Latina Aplicando Soluciones (ALAS)	Milwaukee Public Schools
American Family Children's Hospital	Padres e Hijos
ARC Wisconsin	People First Wisconsin, Inc.
Americorps	Parent to Parent of Wisconsin
Autism Society of South Central Wisconsin	Responsive Solutions, Inc.
Autism Society of Southeastern Wisconsin	Southwestern Wisconsin Community Action Program
Autism Society of Wisconsin	Special Olympics of Wisconsin
Board for People with Developmental Disabilities	Survival Coalition of Wisconsin Disability Organizations
Central Wisconsin Center	The ARC Wisconsin
Children's Health Alliance of Wisconsin	UW Health
Community Work Services Incorporated	University of Wisconsin Medical Foundation
Cooperative Educational Service Agency	Wisconsin Aging and Disability Resource Centers
Create-Ability	Wisconsin Community of Practice on Cultural and Linguistic Competence
Dane County Department of Human Services	Wisconsin Department of Children and Families
Dane County Developmental Disabilities Coalition	Wisconsin Department of Health Services
Dane County Family Support and Resource Center	Wisconsin Department of Public Instruction
Dane County Health Watch	Wisconsin Department of Workforce Development
Dementia Capable Wisconsin	Wisconsin Early Autism Program
Disability Rights Wisconsin	Wisconsin Early Childhood Association
Family Voices - Wisconsin	Wisconsin Early Childhood Collaborating Partners
Gigi's Playhouse	Wisconsin Family Ties
Headwaters, Inc.	Wisconsin Independent Living Centers
Ho-Chunk Nation	Wisconsin Statewide Parent-Educator Initiative
Madison Area Down Syndrome Society	
Madison Children's Museum	
Madison Metropolitan School District	
Mental Health America of Wisconsin	