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ABSTRACT

This application requests core funding for the Strong Center for Developmental Disabilities (SCDD) at the University of Rochester, continuing its 45 year history of partnering with people with intellectual and developmental disabilities (IDD) and their families. The proposal outlines four long term goals that will promote self-determination, independence, productivity and inclusion in all aspects of community life for individuals who experience developmental disabilities personally, as family members, and members of their communities. The goals include specific and related activities to improve opportunities for all people with IDD to lead self-determined lives by actively influencing, choosing, and participating in individualized, culturally competent community services and supports. The goals and their associated activities address the core functions of UCEDDs described in the Developmental Disabilities Assistance and Bill of Rights Act of 2000. Over this Five Year Plan, our goals are: maximal inclusion for people with IDD in their educational environments and in their transition into the adult world with the appropriate supports and services; maximal health for people with IDD across the lifespan through quality health promotion, wellness, medical care and health services; integrated, competitive community based employment for individuals with IDD; and increased opportunities for inclusive recreation and leisure time activities for individuals with IDD across the lifespan.

PROJECT RELEVANCE AND CURRENT NEED

Portrait of State needs and identified need for assistance based on relevant and current data (4 points)

The Strong Center for Developmental Disabilities (SCDD), Western New York's UCEDD, is located at the University of Rochester (UR). About 1.5 million people live in the nearby 13-county Finger Lakes region, 75% (approximately 1 million) in the Rochester metropolitan area (208,000 in the city of Rochester; Onboard Informatics, 2019). Most of the service region is decreasing in population. The urban counties containing Rochester and Buffalo, paradoxically, have significantly gained population since 2010, although they are the focus of high levels of urban poverty (see below). One contributing factor is movement of families of individuals with developmental disabilities to these counties for better services.

Over the past five years, the region that SCDD serves has continued to expand from its most proximate area, the 13-county Finger Lakes Region of NY State, to a broader region encompassing western NY, central NY, and the Adirondack Mountains, and a service population of about 4.75 million (about 25% of the state's population, but 75% of its area). Contributing factors include improved screening and referral for services related to autism spectrum and related disorders but reduced service availability in the Buffalo, Syracuse, and Albany areas. After a period of relative stability, SCDD's clinic waiting list has climbed back to about 6 months, continuing to grow despite adding providers. This has required creative planning with partners from this larger region to consider local needs, and the growth of telehealth services.

Population. New York, like many northeastern states, continues to have relatively slow growth in overall population, but more substantial change in its demographic and economic makeup. The state's 2018 Census population estimate is 19,542,209, an increase of only 0.8% from 2010 (Census Bureau, 2019). Much of the region, including 95% of its land area and a third

of its population, is rural and poor, with poverty rates about 15%, compared to New York State as a whole at 14% and the US now below 10% (Census Bureau, 2019).

The racial and ethnic breakdown of the region remains fairly constant. Racial, ethnic and cultural minorities, including African-, Hispanic-, and Native Americans, compose about 15% of the proximate region's population, and 53% of Rochester residents (Census Bureau, 2019).

Within the region, Monroe County, including Rochester, has the highest percentage of minority residents, and the highest percentage of Latinx population in the state outside New York City. Of note, two rural counties have remarkably high percentages of Latinx members, one because of a large military base and the other because of a large migrant farm population. Rochester has an estimated 50,000 who are deaf or hard of hearing, including the nation's largest per capita population of Deaf Americans. Census data show that the region's overall rate of people under age 65 with disability (broadly defined) is one-third higher than that of New York State overall. The state Office for People with Developmental Disabilities (OPWDD; 2019) reports that about 22,000 people with significant DD reside in western New York State, about 6,000 within the pediatric age range. NYS Dept. of Health data show 1,800 children under age three (most served for language and behavior problems), 5,100 children ages 3-5 years, and over 15,000 school-aged children in the region receiving early intervention, preschool, or school-based educational services under the Individuals with Disabilities Education Act (DOH, 2019). The remainder of SCDD's larger service region multiplies these numbers by roughly 2.5 times.

Economics. Western New York State's economy is characterized by a diminishing manufacturing sector, continued agricultural focus, and slowly growing technical sector, supported by partnerships with the universities in the region. Despite a generally favorable environment for business and a supportive social safety net, disparities between rich and poor in

upstate and western NY striking. Rochester is the third poorest city in the country, and the poorest among comparably sized cities. It has the highest concentration of poverty of any school district in New York State. Although about 19% of our region's children live in poverty, close to the national average, this rate jumps to 33% for urban Rochester residents. Over 2/3 of single-parent families headed by women with children under age 5 live in poverty in our region, almost equally divided between urban and rural areas. Concentrated poverty adversely affects the academic achievement of students in the Rochester City School District, with 38% of children under the age of 12 living in poverty, the highest rate in the US. Buffalo area statistics are close to those of Rochester.

An additional factor leading to our increased service population and area are the system changes associated with the Affordable Care Act. As health systems organize into Accountable Care Organizations (ACOs), URMC has, with the encouragement and partnership of the Golisano Foundation and Special Olympics International, committed to reducing health disparities in people with IDD, and this population is being welcomed into its evolving ACO for both primary and higher levels of health care.

Meanwhile, NY State, in an effort to reduce skyrocketing Medicaid costs, has undertaken a broad reworking of all of its Medicaid-based services to the roughly 100,000 individuals with IDD served in the state. Spurred by multiple challenges, OPWDD has elected to reorganize its financing of IDD services through a managed care model called People First. The first step in this revision is creating Care Coordination Organizations that will function as Health Homes, managed care entities overseeing services and supports provided by traditional community nonprofit agencies to people with IDD, facilitating access to services, and breaking down barriers between state agencies when possible. A self-direction option has been implemented,

with supports to establish a “money follows the person” model. OPWDD has instituted a “Front Door” process to help individuals and families access needed services. This large-scale reorganization results in confusion and other challenges to individuals, families, and providers.

Needs Assessment Process and Development of Five-Year Plan. Ongoing needs assessments are conducted as part of regular activities for programs within the UCEDD, such as our various community programs, and in concert with our cross-state collaborators. In addition, over the past five years we have integrated a qualitative component into many of our federally-funded research projects, to allow for community voice and to ensure that intervention development is coordinated with identified needs. Appendix A provides a summary of formal focus groups, key informant interviews, and community conversations conducted as part of our regular activities.

To inform the development of the five-year plan, a regional needs assessment was initiated in July 2018, with data collection occurring August through November 2018. Community conversations were scheduled in three major regions within our catchment area, including the two largest metropolitan areas and the rural Southern Tier of New York State. Daytime and evening groups were held, to increase participation of working families. In addition, a teleconferencing option was provided for stakeholders that could not attend in person. Simultaneously, an online survey was disseminated through our various listservs, community partnerships, and social media. Data and associated themes gathered from the formal needs assessment are summarized in Appendix A.

A summary of the data was presented within the UCEDD, as well as within the broader division of Developmental and Behavioral Pediatrics and with the CAC. A webinar was presented to all those who participated in the survey and focus groups to provide feedback on the

data accumulated. These conversations allowed for input into the consolidation and interpretation of data. Using this feedback, the final themes and identified needs were developed (see Table 1). Many expressed needs related to cultural disparities, such as strengthening cultural and linguistic competence (both within the UCEDD and in the broader provider community), providing greater reach of information and resource dissemination to under-represented communities, and capitalizing on peer models of information sharing. Ongoing needs related to community inclusion were highlighted; these included increasing inclusive community experiences for adults and children, and increasing individual and organizational preparation to post-secondary opportunities. Health needs were acknowledged regarding increasing access to care for adults with disabilities, as well as expanding education on disability for medical providers across the community. Finally, the community recognized the need to promote self-advocacy for those with disabilities, as well as addressing advocacy and stress management for families.

How CAC, families, people with IDD, DD Council, P&A, and other UCEDDs were consulted in development of the application (3 points)

Community Advisory Council (CAC). SCDD meets quarterly with our CAC, which provides us with ongoing opportunities to engage in iterative cycles of program planning, vetting, data collection, interpretation, and revision. The SCDD CAC is composed of 50 individuals and includes self-advocates, family members of individuals with IDD, educators, and other professionals from disability-serving organizations in our region. Accordingly we have collected qualitative data from group conversations (documented in CAC minutes) each year. Formal discussions regarding the Five Year Plan launched in July, 2017 and included small and large-group conversations, as well as systematic working groups around our four emphasis areas. In the fall of 2018, SCDD conducted a regional community needs assessment, and the data were brought back to the CAC for input into both interpretation of findings and

subsequent planning based on identified needs. The CAC reviewed the needs and proposed goals and objectives before they were finalized, and our two CAC co-chairs have contributed to the writing of this proposal.

Self-Advocates. Over the past cycle, SCDD has increased self-advocate representation in UCEDD activities, to honor the expertise and contributions of individuals with IDD and their families. The CAC includes several self-advocates from community organizations and our local government offices. To ensure representation and opportunities for input on new and existing projects, SCDD has hired two self-advocates who contribute to and/or lead new initiatives. Many programs and activities also include input from community self-advocates. SCDD offers a variety of family-focused activities and experiences, which highlights the importance of family representation. As such, parent advocates are formally integrated into the development and implementation of these programs. For instance, one of SCDD's programs, the Rochester Regional Center for ASD, has made the inclusion of parent consultants part of their essential staff moving forward; last year they contracted with two parents who are now dedicated team members. Further, for several years our associated Developmental and Behavioral Pediatrics Clinic has included four family navigators, to represent parent voice in interactions with patients.

Developmental Disabilities Planning Council (DDPC) and Disability Rights New York (DRNY). The longstanding, collaborative relationship among SCDD, the DDPC, the other two NYS UCEDDs, and DRNY informs both our planning and our ongoing implementation processes. Together, these groups engage in mutual contribution to our respective planning processes' funding cycles. Members also participate in additional mutual planning activities. For example, the New York State team for the Cultural and Linguistic

Competence Community of Practice (CoP) led through Georgetown National Center for Cultural Competence includes representatives from SCDD, the DDPC, and Disability Rights New York (our state P&A), and the other two UCEDDs. Through this CoP, members across organizations engage in coordinated planning to support individuals with IDD in our state. This relationship also ensures that we interweave priorities related to diversity and inclusion throughout our goals and objectives. Further, DDPC and DRNY have contributed data and perspectives to our needs assessment, and we align our goals for the current proposal with priorities identified through their own needs assessment processes. We are working collaboratively with DRNY and DDPC to develop relationships with, identify needs, and provide information to the Native American communities in Upstate New York. Each of the DD Act partners in New York shares their five year planning or, in the case of DRNY, their yearly Priorities and Objectives. We utilize this information to complement our own planning and implementation.

Community Stakeholders: NY State OPWDD; ACCES-VR; Office of Special Education; Regional Health, Education, and DD Provider Agencies; Parent Groups.

SCDD has worked closely with NYS governmental and non-governmental DD agencies to identify needs, both in their organizations and in the IDD population in NYS. Many organizations also have representation on our CAC. With our partners, we engage in shared activities, such as participation at community boards, engagement in and conducting of collaborative trainings, and information dissemination activities. For example, a groundbreaking Employment Summit was planned and implemented with Starbridge, a community disability organization. Existing relationships allow us to leverage resources to better meet the needs of our IDD community. To highlight, we participate in shared grant-

funded projects with OPWDD, ACCES-VR, and the NYS Departments of Health and Education. Furthermore, representatives from various agencies serve on the community advisory boards for federally-funded research projects. Their involvement ensures that the research goals within SCDD align with community priorities, and the inclusion of community partners is a critical strength in federal grant applications.

The direct relationship between needs identified and feedback from above groups in the goals and activities of five-year plan (3 points)

Table 1

Relevance of Identified Needs to Proposed Objectives

Need	Source	Associated Objective(s)
Increase cultural and linguistic competence for service provision and information dissemination within the community	<ul style="list-style-type: none"> • Focus groups* • CoP • CAC 	E6a, R1b, D1c, D3d, D5b
Promote cultural competence within the UCEDD and increase linguistic access to UCEDD and medical center materials/products	<ul style="list-style-type: none"> • Focus groups • CoP 	E6a, R1b, D1c, D3d, D5b
Disseminate informational and educational products to families and providers in under-represented communities, to reduce disability stigma	<ul style="list-style-type: none"> • Focus groups • CoP • CAC 	R1b, R1c, D1c, D2a, D4a
Increase preparation for transition to gainful, post-secondary opportunities	<ul style="list-style-type: none"> • Focus groups • Surveys • CAC 	E1b, E2b, E4a-e, C1e, C2a-f, R1c, R1d, R2a-d, D3a-d
Educate medical providers on strategies to increase access to appropriate healthcare for children and adults with disabilities	<ul style="list-style-type: none"> • Focus groups • Surveys • CAC 	E1a, E2a, E3a, E3b, E5a-h, R3a, R3d
Support family experiences through addressing caregiver stress	<ul style="list-style-type: none"> • Focus groups • Surveys • CAC • CoP 	E3a, C3a, R4a, R4b, R4c, D1b
Increase inclusive and productive community participation for all individuals with IDD	<ul style="list-style-type: none"> • Focus groups • Surveys • CAC 	E4f, E7a, E7d, C7a-c, R5a-d, D5a, D5b
Promote self-advocacy and leadership skills for individuals with disabilities	<ul style="list-style-type: none"> • Surveys • CAC 	E4f, C5a, C7d, R3b, D1a, D1b, D5b

Provide specific outreach and education on disability and family engagement strategies to community organizations and agencies working with marginalized individuals and their families	<ul style="list-style-type: none"> • Focus groups • CoP 	E6a, E7g, C1b, C1c, C4a, R1b, R5b
Capitalize on the benefits of the promotora model, and increase presence of peer navigators/community health workers/etc., particularly in under-represented neighborhoods	<ul style="list-style-type: none"> • Focus groups • CoP 	R1b, C6a, C7c, C7d

Note. CAC=Community Advisory Council. CoP = Community of Practice. DDPC = Developmental Disabilities Planning Council. * The “Focus Groups” indication includes information gathered from both community conversations and qualitative research projects

Table 1 includes a summary of the primary identified needs, as well as the sources that endorsed the need. The far right column indicates the objectives from each function area (i.e., Tables 4-7) that align with each need.

APPROACH

Strong Center for Developmental Disabilities Five-Year Plan: Areas of emphasis and goals

Quantitative projections of the accomplishments to be achieved for each core function or activity (3 points)

Our UCEDD’s five-year plan is based on the needs of our region as identified by our needs assessment analyses, as well as the mandates of the Developmental Disabilities Act of 2000, and our collaborative relationship with our DD Act network partners. Our mission is to develop partnerships, foster accessibility, translate research to best practice, and promote diversity and inclusion with and for people with intellectual and developmental disabilities in our community. SCDD has four areas of emphasis with a primary goal for each one and associated activities (see Tables 4-7). These emphasis areas were determined by our CAC for our last five-year plan, based on analysis of our needs assessment at that time. Our most current needs assessment, accomplished through a survey, focus groups, and multiple CAC meetings, determined that these four areas should remain as our foci: Education, Employment, Health Disparities, and Recreation. The goals, objectives, and activities of the areas are addressed through the AIDD identified core functions of Interdisciplinary Pre-Service Preparation and

Continuing Education, Community Service, Research, and Information Dissemination. In these areas, we strive to make significant advancements in the field of IDD. This is especially possible when close collaborations are established between IDDRCs, UCEDDs and LENDs at those institutions with all three entities. SCDD is affiliated with a LEND program, which is strongly integrated into our activities. In addition, many of our research goals – particularly those related to Parental Stress, ASD Research, and Sensory Processing – were developed in collaboration with the broader IDD Executive Committee (see Appendix F), which includes leadership from across the medical center. As seen in our Approach (Tables 1-4) and our Logic Models (Figures 1-5), we have articulated our quantitative projections of outcomes, the number of people affected by our activities, and a general chronological approach to achieving outcomes. Our approach to increasing access for diverse populations is grounded in all the work that we do and propose to do. Under our Diversity and Inclusion Forum, data will be collected on outcomes of this work.

The extent to which the UCCEDD’s goals, objectives, and activities reflect interagency collaboration (1 point)

As described previously, SCDD’s goals, objectives, and activities reflect collaboration with the NYS DD Network, community partners, advocates, and especially our Community Advisory Council. This work has led us to effect systemic change around employment, education, and health disparities at the NYS State level. For example, our AIDD Employment Systems Change grant led to a number of changes in that area, including workshop transformation and involvement in the Employment First Commission. In Education, we have worked closely on issues of Early Intervention and family involvement with the Department of Health, as well as consulting on an intensive level with the Rochester City School District on reforming their special education efforts.

How the five-year plan complements and furthers the State DD Council five-year plan, the P&A Statement of Goals and Priorities, and the five-year plans for other UCEDDs in the state (1 point)

SCDD's five-year plan builds on and complements the DDPC's five-year plan, the P and A Statement of Goals and Priorities, and the five-year plans of both the Westchester Institute for Human Development and the Rose F. Kennedy Center. This is most evident in the network's efforts to address cultural and linguistic competence. However, the network has a number of areas in which our goals and objectives intersect and in which we actively support each other.

For example:

- Employment (DDPC, P&A)
- Special education (All UCEDDs, P&A, DDPC)
- Health disparities (All UCEDDs, DDPC)
- Early intervention (All UCEDDs, P&A)
- Self-Advocacy (All UCEDDs, P&A, DDPC)
- Community inclusion (All UCEDDs, P&A, DDPC)

How the infrastructure and resources obtained will be utilized to leverage additional public and private funds (2 points)

SCDD utilizes its center-based funding to derive funding from multiple other sources, including, but not limited to, federal programmatic and research money, NYS Office for People with Developmental Disabilities, NYS Department of Health, NYS Education Department, national and local foundations, and local contracts with agencies and school districts. These funding sources allow us to continue current programs and to develop new programs based on the needs identified through our needs assessment. In the past five-year cycle, we utilized our UCEDD grant to leverage more than \$13 million in additional funding. Our UCEDD funding allows us to strategically identify and analyze the needs of our state and local communities, and to make intentional decisions based on those needs. In turn, we then seek funding to support the programs based on those decisions.

INTERDISCIPLINARY PRE-SERVICE PREPARATION AND CONTINUING EDUCATION

How the UCEDD will carry out Interdisciplinary Pre-service prep core function as an instructional program (3 points)

GOAL: To provide exemplary pre-service preparation to and educational opportunities to people with disabilities, their families, school and agency staff, and leadership at the University and in the community.

SCDD's interdisciplinary pre-service and continuing education leadership training programs address specific state and local workforce requirements and prepare highly qualified professionals for leadership in the developmental disabilities field. Preservice training occurs across multiple programs, the largest of which is its Leadership Education in Neurodevelopmental Disabilities (LEND) program, which has provided long-term leadership training to graduate and post-graduate students in 13 disciplines for 24 years.

Stephen Sulkes, MD, directs Pre-Service Training and the LEND program, with Therese Welch, PhD, as Training Director; Susan Hetherington, PhD, directs Community Education. Responding to the challenges of the Autism CARES Act, SCDD's LEND program continues to focus on training clinicians in screening, diagnosis, and evidence-based treatment of children and adults with Autism Spectrum Disorders. Intermediate term training occurs in medicine, nursing, psychology, dentistry, nutrition, education, and family- and self-advocacy, both through direct clinical and didactic training, and through distance learning. LEND fellows and many intermediate term trainees participate in Family Experiences, each working with a family of an individual with IDD, often also representing underserved minority communities.

All intermediate- and long-term UCEDD trainees receive supervision in SCDD programs and in inclusive community-based settings for at least 40 hours of experience in interdisciplinary team participation and leadership. Over the past five years, SCDD provided training to an

average of 85 students per year (see Table 2). SCDD trainees represent 18 disciplines representing a cross-section of professions associated with services and supports. About 16% of trainees represented ethnic and cultural minority groups. Eighty percent of SCDD's former trainees, who report back in alumni surveys, work in the field of developmental disabilities, while most of the remainder have entered other areas of health and human services or are still in training. Over half of long-term trainee alumni reporting are engaged in leadership activities.

Table 2

Number of LEND Trainees by Discipline and Year

Discipline	2015	2016	2017	2018	2019	Total
Audiology	1	1	1	1	3	7
Dentistry	3	2	2	2	3	12
Education/Special Education		2	3	30	50	85
Epidemiology			1			1
Family/Parent/Self-Advocacy	1		3	2	1	7
Health Administration		1	1			2
Medicine: General	3	2	8	7	24	44
Nursing	2	1	8	1		12
Nutrition		9	11	11	11	42
Occupational Therapy	1		2	2		5
Other	1		1	4	4	10
Psychology	1	8	12	10	10	41
Medicine: Pediatric	38	22	25	23	19	127
Physical Therapy	1	1	2	2	2	8
Public Health	1		1	1		3
Psychiatry				1	2	3
Speech-Language Pathology	1	2	1	2	2	8
Social Work	1	2	2	2	1	8
Total	55	53	84	101	132	425

Description of the Core curriculum for Interdisciplinary Pre-service Prep. (2 points)

Each UCEDD intermediate- or long-term trainee receives an individualized program based on his/her goals. SCDD's Pre-service Core Curriculum emphasizes cross-system

coordination, interdisciplinary services, and attention to the reciprocal impacts of family and cultural difference on disability and provision of supports. Particular attention is given to evolving concepts of disability culture and the intersection of disability and other causes of discrimination and disparity. Trainees are expected to master a core set of learning objectives emphasizing prevention, diagnosis and evaluation, habilitation, self-determination, family support, advocacy, and leadership. Long-term trainees participate in a two-semester Core Course, consisting of presentations by both faculty and students designed to comprehensively examine the interdisciplinary model and contemporary issues in IDD, develop skills in research, teaching, advocacy, intersystem and interdisciplinary coordination, and the unique contributions of families and culture. Please see Appendix B for our Core Course schedule.

How efforts to recruit UCEDD trainees will focus on bringing larger numbers of racial and ethnic minorities into the disciplines (2 points)

Recruitment efforts include work with the University Office for Faculty Development and Diversity to target trainees from underserved communities, particularly the City of Rochester, and to help that office recognize that persons with Disability are an underserved community as well and foster recruitment of students with disability to all University programs. In addition to Center-wide activities to increase diversity of faculty, staff, and trainees, SCDD's Inclusion Forum proposal (see Appendix C), lists specific goals to increase trainee diversity, including recruiting students/alumni of Historically Black Colleges and Universities (HCBU) by listing all job postings and fellowship opportunities on [HBCU Connect](#), and working with University Human Resources Diversity and Community Engagement team.

Description of the continuing education program (3 points)

Continuing Education Activities include workshops, lectures, and sponsorship of national, regional, state and local conferences that cut across all UCEDD missions. Continuing

education is provided to physicians, school personnel, and others via growing use of ECHO technology, as well as traditional in-person and web-based didactic presentation. Between 2015 and 2018 (FY 2019 data not yet available), Continuing Education activities reached an average of about 3,400 professionals and paraprofessionals per year (see Table 3). Another 4,000 individuals participated in other Community Education activities each year, including presentations at the University of Rochester, collaborating academic institutions, and community sites. Community education activities reflect recommendations from our CAC to more directly address the educational needs of consumers and direct care personnel.

Table 3

SCDD Past Trainee Types and Timelines

SCDD Trainee Types	Year					4-year Total
	2015	2016	2017	2018	2019	
Trainees/Classroom Students	54	483	207	546	**	1290
Professionals/Paraprofessionals	5818	2581	1914	3303	**	13616
Family Members/Caregivers	10558	666	746	1020	**	12990
People with Disabilities	37	128	92	219	**	476
Legislators/Policy Makers	30	12	32	95	**	169
General Public	51	313	113	836	**	1313
Total	16548	4183	3104	6019	**	29854
** data not yet available						

Description of the active roles of individuals with IDD and their families (2 points)

Notable among SCDD’s 13 disciplines are Family- and Self-Advocacy, in which individuals with IDD and family members serve on LEND faculty and participate in the planning and delivery of both preservice and community education activities, as well as training leaders from the advocacy community. They coordinate the Family Experience for medical students, post-graduate residents, and LEND fellows; co-teach the Medical Humanities Seminar (below); contribute to LEND Ideal Project and Relevant Topic development; and train preservice trainees

in all disciplines on individual and family perspectives in IDD theory and practice. They lecture to students at affiliated universities on inclusion and self-determination, and collaborate with other UCEDDs in presentations through AUCD.

How the UCEDD participates in broader University academic programs (1 point)

SCDD faculty also participate in preservice programs offering specialized training in the health and education of children with disabilities, within UR's School of Medicine and Dentistry (Medical students, Pediatrics, Dentistry, Public Health, Audiology), School of Arts and Sciences (Clinical and Social Sciences in Psychology), School of Nursing, and Warner Graduate School of Education and Human Development, and with programs at Nazareth College (OT, PT, Speech Pathology) and SUNY College at Brockport (Social Work). In addition to experiences for post-graduate residents in internal medicine, family medicine, psychiatry, physical medicine, neurology, preventive medicine, and palliative care, SCDD faculty offer medical school courses for second year students (Medical Humanities Seminar "Developmental Disabilities Across the Lifespan") and fourth year clinical electives. The Warner School offers a Masters in inclusive elementary education with certification in both elementary and special education, and collaborates with SCDD to provide a Masters in Applied Behavior Analysis to prepare education and allied professionals to work with students with ASDs and other developmental disabilities, and to qualify for certification as Applied Behavior Analysts (BCBA). This program (ProABA) is the fastest growing program in the School of Education and is led by SCDD faculty and staff. There is a special track on developmental disabilities policy and leadership in the Master of Public Health degree program of the University of Rochester.

The Maudie Weeks Endowment program trains providers of adult health care in the knowledge and skills to work with adults with Down syndrome and other IDD conditions.

Family medicine and internal medicine/pediatric residents receive training in the specific health

needs of transition age youth and young adults with IDD and other chronic health conditions across the lifespan. An expanded focus on oral health for people with IDD is in place with collaborators in UR’s Eastman Institute for Oral Health. New funding has allowed Family Experiences to be offered to medical students and residents in pediatrics, internal medicine, family medicine, dentistry, ENT, physical medicine, emergency medicine, and OB/GYN to enable them to better understand the lives of their patients with IDD outside the health care environment. Finally, SCDD coordinates with the new Institute for IDD (which will be applying for an IDDRC; see Organizational Capacity and Appendix F). We are dedicated to promoting translational learning for basic science postdocs and graduate students, and thus preservice education experiences will include trainees from the Institute (noted in Table 4).

Table 4

Objectives and Associated Activities for Preparatory and Continuing Education

Function Area: Interdisciplinary Pre-Service Preparation and Continuing Education	
GOAL: To provide exemplary pre-service preparation to and educational opportunities to people with disabilities, their families, school and agency staff, and leadership at the University and in the community.	
Emphasis Area: Education	
Objectives	Activities
E1: People with intellectual and developmental disabilities will be maximally included in their educational environments and in their transition into the adult world with the appropriate supports and services.	<p>E1a: Interdisciplinary training of pre-service providers, including Institute for IDD trainees, in the importance of inclusive educational environments. <u>Year 1:</u> Train 15 new trainees in a wide variety of disciplines <u>Years 2-5:</u> Train a minimum of 15 new trainees each year</p> <p>E1b: Provide training on inclusive education environments and school cultures to school building administrators using an ECHO model. <u>Year 1:</u> Develop and provide ECHO model training to 15 administrators in the Rochester City School District on developing an inclusive culture, in collaboration with the Warner School of Education <u>Year 2:</u> Provide an ECHO model training on inclusive schools to suburban and rural school administrators, while continuing with training to Rochester City School District, 30 each year until the market is saturated</p>

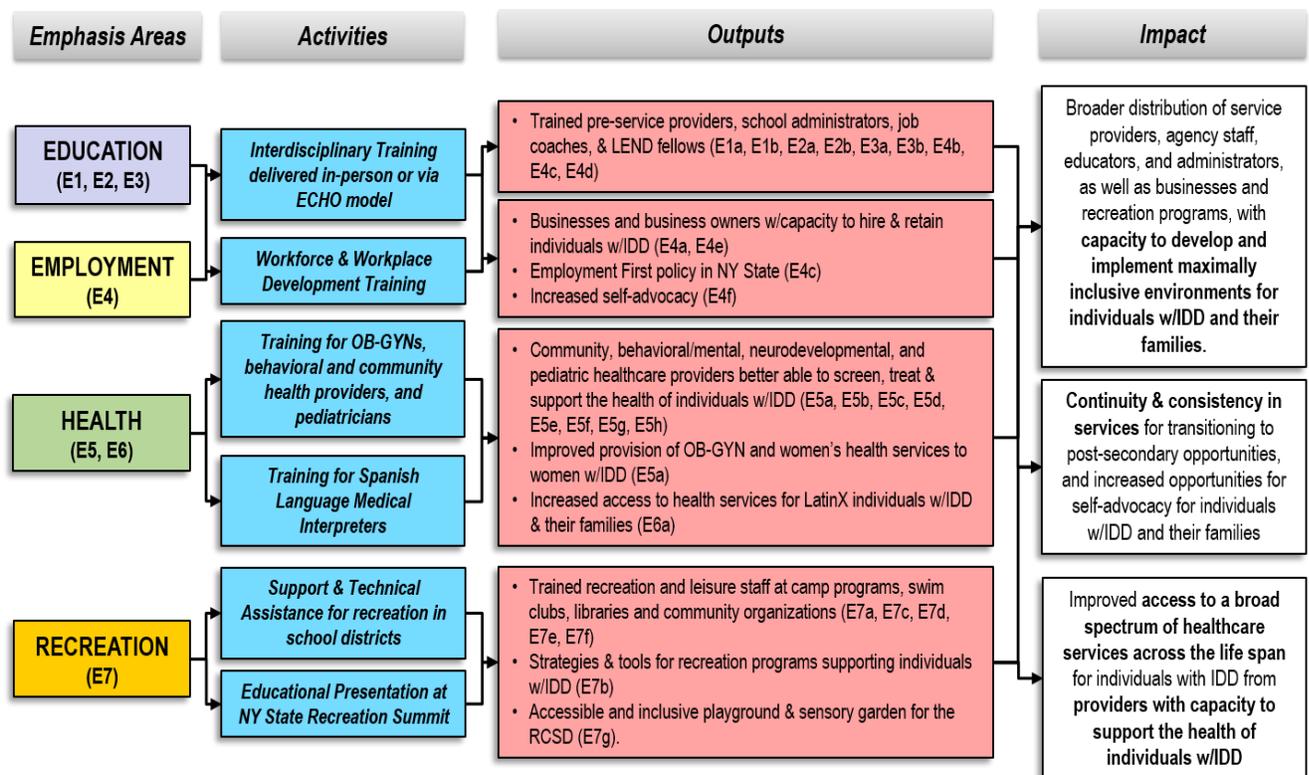
<p>E2: Provide education and support to preservice trainees and community education providers for people with IDD</p>	<p>E2a: Provide intermediate term distance clinical training via ECHO model to at least 10 personnel per year on evidence-based practices in ASDs to improve assessment and intervention for improving behavioral health outcomes.</p> <p>E2b: Provide continuing education training to 50 school and community professionals per year on evidence-based practices in ASD to improve assessment and intervention for improving behavioral health outcomes.</p>
<p>E3: Provide education and support to health professionals to increase awareness about the Family Experience Program</p>	<p>E3a: Develop a community planning activity bringing together families and health professionals to create ways to increase diversity in the Family Experience for health care students, residents, and Institute for IDD postdocs and students. <u>Year 1</u>: Develop activity and pilot with 5 families and 3-5 health professionals <u>Years 2-5</u>: Provide the activity 5 times throughout Upstate New York</p> <p>E3b: Expand residency programs/disciplines at the Medical Center participating in the Family Experience. <u>Year 1</u>: Run 2 new programs <u>Years 2-5</u>: Run 1 additional program</p>
<p>Emphasis Area: Employment</p>	
<p>Objectives</p>	<p>Activities</p>
<p>E4: Provide interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of employment for individuals with developmental disabilities leading to increased integrated, competitive employment options</p>	<p>E4a: Pilot training and supporting businesses in the hiring and retention of individuals with intellectual and developmental disabilities. This will include trainings to business related to effective natural supports to shift some of the emphasis of the support system to the business community as opposed to provider agencies. <u>Year 1</u>: Develop curriculum for businesses and pilot to 1 business; evaluate <u>Years 2-5</u>: Provide training and support to 3-5 businesses per year</p> <p>E4b: Pilot an ECHO for job coaches across the region, particularly related to supporting individuals with challenging behaviors. <u>Year 1</u>: Needs assessment and development of a curriculum; recruitment <u>Year 2</u>: Pilot ECHO with up to 10 job coaches <u>Years 3-5</u>: Present ECHO to 10-15 job coaches <i>*Need identified by self-advocates and families</i></p> <p>E4c: Provide preservice training to 15-18 UR LEND fellows per year and 3-6 Institute for IDD trainees per year on the importance of integrated, competitive employment for people with disabilities, their role in the domain of employment, and the necessity of an Employment First policy in New York State.</p> <p>E4d: Provide training in best practices related to preparation for transition to employment to school districts <u>Years 1-5</u>: 10 presentations/trainings per year</p>

	<p><i>*To be conducted in collaboration with disability self-advocates and leaders</i></p> <p>E4e: Explore relationship with local business schools, including the University of Rochester’s Simon Business School to provide inclusion training to undergraduate and graduate business students who will go on to employ individuals with disabilities.</p> <p>E4f: Provide self-advocacy and leadership trainings related to employment for individuals with disabilities. <u>Year 1</u>: Develop and pilot training with 5 self-advocates <u>Years 2-5</u>: Hold 3 trainings per year <i>*To be conducted in collaboration with disability self-advocates and leaders</i></p>
Emphasis Area: Health	
Objectives	Activities
<p>E5: Provide interdisciplinary pre-service preparation and continuing education on health to future and current professionals in the area of developmental disabilities to provide the skills and knowledge to enhance the health of people with developmental disabilities across the life span</p>	<p>E5a: Provide continuing education to providers to improve women’s health. <u>Year 1</u>: Identify and collaborate with key stakeholders/OB-GYN providers providing care to women with IDD; conduct provider needs assessment for women with IDD utilizing OB-GYN services; develop curriculum <u>Year 2</u>: Pilot curriculum with 5 OB-GYN providers <u>Years 3-5</u>: Train 5 – 10 additional OB- GYN providers throughout region <i>*To be conducted in collaboration with disability self-advocates and families</i></p> <p>E5b: Provide continuing education to Behavioral/Mental Health service providers for people with IDD via an ECHO model. <u>Year 1</u>: Identify & collaborate with mental health providers concerned with behavioral management of individuals with IDD; conduct and analyze needs assessment; develop curriculum <u>Year 2</u>: Train 10 mental health providers <u>Years 3-5</u>: Train 10 – 15 additional mental health providers <i>*To be conducted in collaboration with disability self-advocates and families</i></p> <p>E5c: Provide preservice training to at least 15 LEND fellows chosen from among 13 disciplines and 4-6 Institute for IDD trainees each year on provision and coordination of health services for children with neurodevelopmental disabilities.</p> <p>E5d: Provide specific preservice training in diagnosis and health treatments for ASDs to at least 15 long-term trainees chosen from among 13 disciplines each year.</p> <p>E5e: Provide training to at least 3 advanced post-residency fellows in Developmental-Behavioral Pediatrics over course of grant period.</p> <p>E5f: Provide clinical training to 40 interdisciplinary intermediate-term trainees, including Institute for IDD trainees, each year in health and</p>

	<p>mental health care, and functional skill maintenance of individuals with IDD across the lifespan.</p> <p>E5g: Provide at least 1 continuing education activity per year to community health care providers to enhance health care transitions, maintain health and function, and increase the quality of health care provided to individuals with IDD across the lifespan. <i>*To be conducted in collaboration with disability self-advocates and families</i></p> <p>E5h: Provide lectures or short-term training to at least 30 medical students per year to increase basic skills of providers without IDD specialization in screening for developmental disabilities and in ongoing health care of individuals with IDD across the lifespan.</p>
E6: Improve services for people with IDD to reduce health disparities	<p>E6a: Provide continuing education to Spanish Language Medical Interpreters to increase awareness of and address common problems such as communication and language differences that often exist in relationships between providers and Latinx individuals with IDD and their families. <u>Year 1:</u> Train 10 interpreters <u>Years 2-5:</u> Train 5-19 interpreters per year <i>*To be conducted in collaboration with disability self-advocates and families</i></p>
Emphasis Area: Recreation	
Objectives	Activities
E7: Provide interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of recreation and insure leading to increased inclusive recreation opportunities	<p>E7a: Train camp counselors at the Greater Rochester YMCA’s in supporting children and youth with IDD in their recreation programming. This will include 6 sites throughout the Rochester and surrounding region and will involve training 400 counselors. Training will include an established curriculum, ongoing technical assistance, and the provision of a mobile sensory kit. <u>Year 1:</u> Develop and pilot training with 1 YMCA <u>Years 2-5:</u> Provide trainings to 5 YMCA’s per year</p> <p>E7b: Present at the 2019-2024 New York State Recreation Summits on community inclusion in recreation and leisure settings. Providing strategies and tools for recreation professionals on how to support individuals with IDD in their programs.</p> <p>E7c: Provide inclusion training to the Niagara County Swimming clubs on supporting individuals with IDD within swim programs and teams. In addition to in person training, technical assistance will be provided to coaches through a free webinar. Additional technical assistance and ongoing support as needed and requested by Niagara Swimming. <u>Year 1:</u> In person training on inclusion to swimming clubs <u>Years 2-5:</u> Continued in person training (2 per year) and consultation to swimming clubs</p> <p>E7d: Provide training to the Rochester City Department of Recreation and Youth Services. Train 25 camp counselors per year on supporting</p>

	<p>children and youth with IDD within their recreational camps. Utilize the inclusive curriculum and provide ongoing support. <i>*To be conducted in collaboration with disability self-advocates and families</i></p> <p>E7e: Provide technical assistance to the Monroe County children and youth librarians on enhancing inclusion options at the library. Ongoing TA may involve providing additional trainings, running make and take visual support workshops, or correspondence by email or phone. <i>*To be conducted in collaboration with disability self-advocates and families</i></p> <p>E7f: Continue to offer up to 5 free trainings per year to organizations on increasing access to inclusive recreation opportunities for individuals with disabilities. This is accomplished through a structured curriculum we developed that addresses administrative, programmatic, and individual-level strategies to facilitate inclusion.</p> <p>E7g: Provide ongoing technical assistance to Rochester City School District on planning an inclusive and accessible playground as well as designing an inclusive sensory garden.</p>
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Figure 1. Logic Model for Preservice and Continuing Education Function Area



COMMUNITY SERVICES

Description of Community Services core function activities of training or technical assistance of individuals with DD, families, professionals, paras, policy makers, students, and other members of the community that may be services, supports, and assistance for individuals with DD through demonstration and model activities (2 points)

GOAL: Provide Community Services and Education to promote self-direction, healthy living, inclusive communities, and self-advocacy in a culturally and linguistically competent manner.

Community Services is an essential and consistently increasing component of Strong Center for Developmental Disabilities by providing community programs, technical assistance, and training. As our Community Advisory Council has grown from approximately 5 attendees per quarter to 25-30 participants per quarter, so have the demonstration and model programs of SCDD in the areas of education, employment, health disparities, and recreation. The central components of all of these focus areas are: accessibility, inclusivity, cultural and linguistic competence, and self-advocacy. Please refer to Table 5 for the Community Services descriptions of the Objectives and the activities related to those objectives. All faculty and staff are committed to engaging with the community, both with the larger community to inform and educate about IDD, and with the disability community to learn, collaborate, inform, and serve. Table 5 provides a description of the objectives and activities that were developed based on the needs assessments described earlier in the relevance and current needs section (See Appendix A and Table 1).

How community services offer innovative designs and methods (5 points)

All SCDD community services are based on needs identified by the community needs assessment. See Table 1 for the specific needs identified by the community. A significant concern of the community is the lack of inclusive community opportunities: in education,

employment, health, and recreation. In response, the majority of our programs and activities specifically address that need. Because the Rochester area is rich in services designed to “help” and “support” people with developmental disabilities, we believe that it is our responsibility to provide evidence-based, innovative model programs and activities that are not available in the broader community and that have belonging in the community as a core component. OPWDD is going through a period of transformation, and with that comes the opportunity to develop innovative programs and services that address gaps identified by the community. Thus, we have developed a new program that focuses on young adults trying to transition to employment or maintaining employment. Because difficult to manage behaviors have become the most frequently mentioned reason for segregated education, we work closely with over 30 large and small school districts to support them in enabling classes and programs to be more inclusive and to meet students’ behavioral needs. We have developed and are developing programs to train medical interpreters to better understand and more accurately reflect the needs of people with IDD. Finally, our staff have engaged with the community to develop new inclusive recreational opportunities and to help assess the accessibility and inclusivity of existing programs.

These activities would not have been possible without the active engagement of our CAC, as well as formal focus groups and surveys, and our ongoing engagement and involvement with community allies, collaborators, and programs/committees/task forces. They help us both identify needs, as well as provide feedback on the success and need for continuation of our programs and activities. Beyond informal feedback, each program has an evaluation component that helps us identify whether it should be continued or replicated.

An exemplar of this approach is the ROC Employability Summit that we convened this past fall. This Summit was modeled after the Harkin International Employment Summit and was

based on information derived from the needs assessment survey done as a part of the AIDD funded Partnerships in Employment grant. That survey showed the need for employment services to be more business oriented; to have all employment constituents speaking the same language: and that agencies and businesses need more information on the benefits of hiring people with disabilities. The Summit brought together self-advocates, families, agencies, school, and businesses to discuss needs, barriers, and solutions. Based on the Summit recommendations, a Disability, Poverty, and Employment Task Force has been developed to make further recommendations and implement those and the Summit's recommendations.

A commitment to inclusivity demands understanding and addressing the needs of all individuals with intellectual and developmental disabilities. Over the past 3 years we have worked diligently with the University community to include people with disabilities as part of the diversity discourse of the University. This has been a slow process that has begun to demonstrate results by our faculty and staff actively interacting with the diversity and cultural competence components in the University and in the broader community. In addition, as described in Appendix C, through our own Diversity and Inclusion Forum, we are working to increase diversity in our own UCEDD and the division of the Medical Center in which we "live."

Another commitment that our direct service components have made is to increase self-advocates and family navigators in those services. Our clinical services now employ 4 family navigators who are all parents of individuals with developmental disabilities. A self-advocate coordinates and provides instruction in our extended Employment Discovery Network and another self-advocate provides mentorship in our Project SEARCH™ Medical Center program. We have parents and self-advocates on all of our advisory committees and boards, and they provide constant feedback on the work we are doing and our projected directions.

Description of Community Services Training and Technical Assistance activities (2 points)

In any educational activity we undertake, either community training or technical assistance, it is our intention to “make ourselves obsolete.” While we may advertise those areas in which we hold a knowledge base, we depend on the community’s articulation of needs to inform us of training and technical assistance needs. For example, our Community Consultation Program provides systems, classroom, and individual technical assistance and training on inclusion and behavioral supports. It is our goal in each one of these cases to exit the school district as soon as they are comfortable providing the services themselves. In large districts this may involve organizational management support, developing expertise in behavioral strategies, and special education systems reform, and may last for multiple years. In other districts, needs may be limited to an individual student or teacher and be limited to less than a year.

Continually building and strengthening our community relationships is imperative to supporting both people with disabilities and their families, as well as those programs that work with them. It is by developing these relationships that we are able to identify, prioritize, and address needs through formal needs assessments, but also through those informal relationships in which needs are articulated and gaps identified.

We recognize that as part of an academic institution we must develop relationships if we want to support people with disabilities who have intersecting marginalizations: cultural, linguistic, or ethnic. Employing staff who are from diverse cultural or ethnic communities has supported us in this effort. As discussed earlier, we attempted through our needs assessment to identify areas of needs, but as our CAC has pointed out, those needs do not always reflect the gaps experienced by individuals. Thus, when we begin a new program we strive to provide opportunities for those affected by the service to be involved in the development and evaluation

of the program. Much of our work is done within the City of Rochester, a very diverse area where children are among the poorest in the country, as are people with disabilities. It is our intention to be as involved with as many community resources, task forces, and committees so that we can make people aware of our supports and services, and so that we can listen and react to community needs.

How Community Services demonstration service activities address and provide evidence of an emerging, critical (1 point)

Poverty and under- and unemployment have been identified as huge barriers to an acceptable quality of life for people with disabilities in New York State, and especially in the Western New York area. As identified by UCP/ANCOR's "Case for Inclusion" report (Ankor Foundation, 2019), the unemployment rate of people with disabilities continues to be a significant and widespread problem, as does the issue of disparities in health care. These are areas of national concern that are very real in Upstate and Western New York. Thus, we convened an employment and disability summit which brought together people with disabilities and their families, businesses, community leaders, and disability agencies. The Summit both identified issues to be addressed and provided recommendations on how to address them.

Beyond the urban areas, New York State geographically is primarily rural, and there is a dearth of services which threaten the well-being of people with disabilities and their families. Recently our clinical services have piloted a program in the Southern Tier of NYS (part of Appalachia) in order to both provide diagnostic and ongoing developmental and behavioral pediatric services, and to provide training for providers in that area about autism and other developmental disabilities.

Our collaborations with the NYS DD Council and the Protection and Advocacy agency, and the other NYS UCEDDs continue to inform and support our focus on the critical issues affecting the IDD community in New York.

Table 5

Objectives and Associated Activities for Community Services

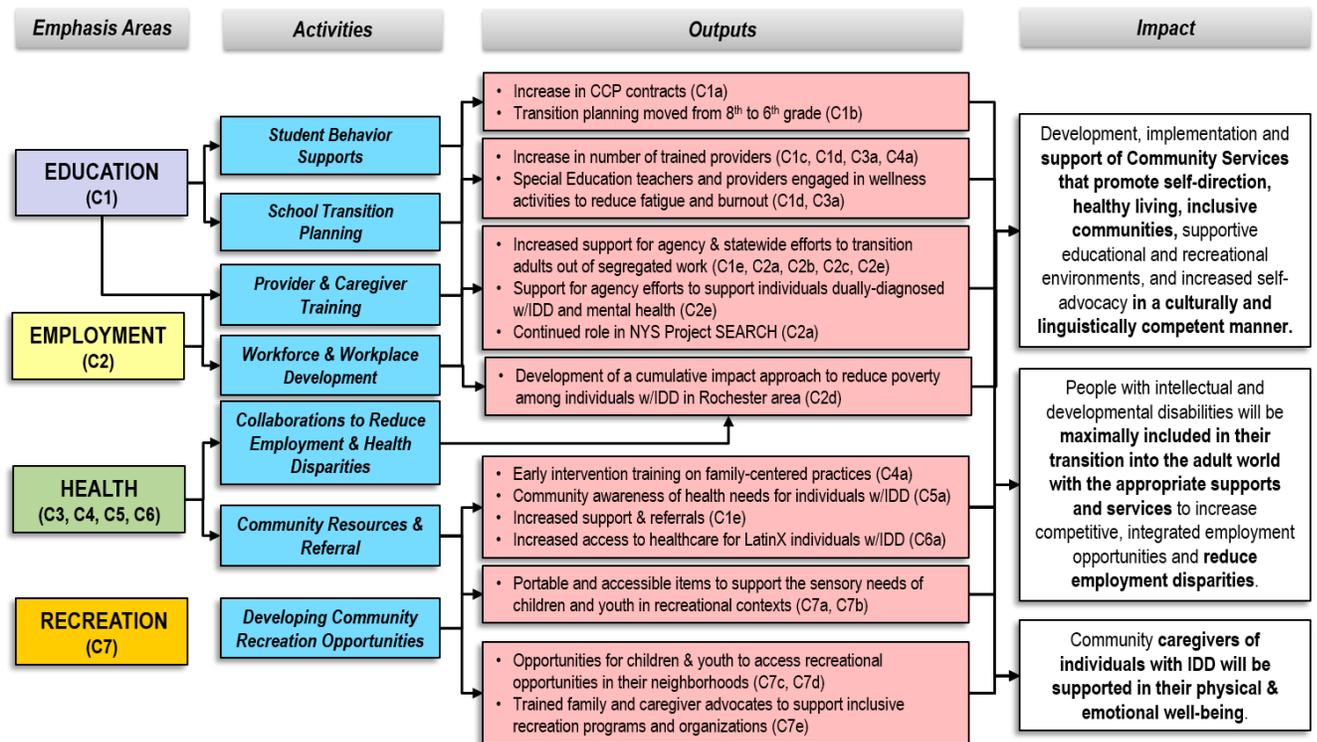
Function Area: Community Services	
GOAL: Provide Community Services and Education to promote self-direction, healthy living, inclusive communities, and self-advocacy in a culturally and linguistically competent manner.	
Emphasis Area: Education	
Objectives	Activities
<p>C1: People with intellectual and developmental disabilities will be maximally included in their educational environments and in their transition into the adult world with the appropriate supports and services.</p>	<p>C1a: The Community Consultation program will consult with additional schools and after school programs on the inclusion of students with autism and behavioral difficulties. <u>Year 1:</u> Will increase contracts by 10% <u>Years 2-5:</u> Will increase contracts by 5% each year</p> <p>C1b: We will consult with school districts, especially Rochester City Schools, to move initial transition planning to middle school years. <u>Year 1:</u> Will move transition planning to 8th grade for districts with whom we have a contract <u>Years 2-5:</u> By year 5 districts will have moved initial transition planning to 6th grade</p> <p>C1c: The Rochester Regional Center for ASD will provide ongoing trainings throughout the year to regional educators and administrators and community members on supporting students with ASD and related disabilities. Trainings will focus on evidence-based strategies to support the behavioral, social, emotional, and academic well-being of students with IDD. <u>Year 1:</u> Provide 5-10 trainings <u>Years 2-5:</u> Provide 10-15 trainings annually <i>*To be conducted in collaboration with disability self-advocates and families</i></p> <p>C1d: Given concerns about teacher burnout in special education, we will provide regular trainings to educators on mindfulness and compassion fatigue, with the goal of both reducing burnout and encouraging authentic interactions between educators and students with IDD. <u>Year 1:</u> Provide 3 trainings to at least 3 school districts <u>Years 2-5:</u> Provide 5-10 trainings annually, to at least 5 school districts <i>*To be conducted in collaboration with teachers</i></p>

	<p>C1e: Continue to provide training in best practices related to preparation for transition to gainful, post-secondary opportunities to relevant stakeholders, including school district staff, BOCES, families, state officials and provider agencies.</p> <p><u>Year 1</u>: Provide trainings to 100 people</p> <p><u>Years 2-5</u>: Provide trainings to 100 people annually</p>
Emphasis Area: Employment	
Objectives	Activities
C2: Provide services and supports to increase competitive, integrated employment of people with intellectual and developmental disabilities	<p>C2a: Serve as the NYS Project SEARCH Coordinator, providing technical assistance and support to existing programs and prospective programs. Explore how adult Project SEARCH can support the state’s greater efforts to transition adults out of more segregated settings into competitive, integrated employment.</p> <p>C2b: Continue to support and provide technical assistance to NYS’s ACCESS-VR and OPWDD in their effort to move sheltered workshop employees to competitive employment by providing technical assistance, as requested.</p> <p>C2c: Expand the Employment Discovery Network pilot, a program that supports young adults to prepare for and acquire competitive integrated employment opportunities.</p> <p><u>Year 1</u>: Develop 3 new sites</p> <p><u>Years 2-5</u>: Develop 2 new sites per year</p> <p><i>*To be conducted in collaboration with disability self-advocates and families</i></p> <p>C2d: Serve in a leadership capacity in a taskforce designed to decrease poverty and increase inclusive, competitive employment for people with disabilities living in the city of Rochester. This initiative will partner with the Rochester Monroe Anti-Poverty Initiative (RMAPI), the Chamber of Commerce, local schools, provider and state agencies.</p> <p>C2e: Support agencies’ efforts to implement customized employment, particularly for individuals with challenging behaviors and individuals dually diagnosed with IDD and mental health.</p> <p><u>Year 1</u>: Conduct and analyze needs assessment regarding customized employment with DD agencies, people with disabilities, and businesses</p> <p><u>Year 2</u>: Develop local training curriculum on customized employment</p> <p><u>Years 3-5</u>: Conduct trainings and provide consultation to 5 agencies and 5 businesses per year</p> <p><i>*To be conducted in collaboration with disability self-advocates and families</i></p> <p>C2f: Pilot a workplace development proposal that focuses on training and supporting businesses in the hiring and retention of individuals with intellectual and developmental disabilities. This will include trainings to businesses related to effective natural supports to shift some of the emphasis of the support system to the business community instead of provider agencies.</p> <p><u>Year 1</u>: Develop and pilot the program with 1-2 businesses</p>

	<u>Years 2-5</u> : Expand program to 3 new businesses a year
Emphasis Area: Health	
Objectives	Activities
C3: Caregivers of individuals with intellectual and developmental disabilities will be supported in their physical and emotional well-being.	C3a: Annual mindfulness-based intervention will be provided to caregivers of individuals with IDD through participation in brief (4-8 session programs). <i>*Need identified through family advocates</i> <u>Year 1</u> : Run 2 mindfulness groups with 30 caregivers of people with IDD. <u>Years 2-5</u> : Run 3-4 mindfulness groups annually, with a cohort of 15 caregivers per group <i>*To be conducted in collaboration with families and caregivers</i>
C4: Promote best practices aimed to increase family engagement outcomes in the early intervention program	C4a: Early intervention providers, county officials, and parents will receive training on family-centered practices identified by learning collaboratives as part of the State Systemic Improvement Plan. <u>Year 1</u> : Hold 10 webinar training sessions for early intervention providers, county officials, and parents
C5: Improve community services to be responsive and accessible to the needs of people with IDD	C5a: Provide at least two community education activities per year directed to individuals with IDD and their circles of support to increase health literacy and self-management of health and wellness. <i>*To be conducted in collaboration with disability self-advocates and families</i> C5b: Provide interdisciplinary clinical diagnostic and support services to approximately 4000 children and youth with IDD each year.
C6: Improve services for people with IDD and their families to reduce health disparities	C6a: Provide education and support to health care providers to increase knowledge and importance of family experiences through initiating meetings with families and health care providers. <u>Years 1-5</u> : Conduct 3 meetings per year <i>*To be conducted in collaboration with families</i>
Emphasis Area: Recreation	
Objectives	Activities
C7: Provide services and supports to increase inclusive recreation and leisure opportunities for people with intellectual and developmental disabilities	C7a: Provide 20 mobile sensory kits to YMCA camp programs throughout Greater Rochester in Year 1 . The sensory kits will include items that engage touch, sight, sound, and smell, and support the sensory needs of children and youth in recreational contexts. C7b: Provide 10 mobile sensory kits to the City of Rochester Department of Recreation and Youth Services, to support the sensory needs of children and youth in their summer camp programs in Year 1 . Replace as needed. C7c: Participate in the implementation of a citywide neighborhood play day each year , by providing supports on including individuals with IDD. This effort is led by HealthiKids, part of Common Ground Health, a regional health systems agency. C7d: Develop training for family and caregiver advocates on engaging with recreation providers and organizations and advocating for inclusion within those spaces. Training will be led by parent partners who have experience with advocating in recreational spaces and can share lessons learned.

	<p><u>Year 1</u>: Develop training and pilot with our CAC parents</p> <p><u>Years 2-5</u>: Provide 3 trainings per year</p>
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Figure 2. Logic Model for Community Services Function Area



PROGRAM OF RESEARCH AND EVALUATION

Description of research program (4 points)

GOAL: Conduct federally and independently-funded research studies and program evaluations to ensure dissemination of evidence-based information and interventions and to gain new knowledge related to best supporting individuals with IDD from diverse backgrounds.

SCDD has a longstanding, federally-funded research program. Drs. Suzannah Iadarola and Laura Silverman are the current co-directors of research, and Drs. Hetherington and Sulkes are Principal Investigators and Co-Investigators on many UCEDD-affiliated projects. Within SCDD, research projects are identified and then vetted through a community partnership before they are initiated through institutional review boards. This partnership, which includes agency and family

advocates, ensures that research projects are relevant to community needs. A full summary of research objectives and related activities are included in Table 6. The SCDD research portfolio primarily includes behavioral intervention research, with some extensions into mechanistic evaluations and implementation science. Education-related projects comprise a small majority of our research and evaluation activities. Several ongoing projects – two of which are network studies – emphasize interventions to increase inclusive educational opportunities for individuals with IDD, as well as education and advocacy for their families. The interventions under study include novel intervention designs as well as novel methodological approaches. Newly-funded applications through NIH and the Department of Defense are initiating, and three additional applications are under review by NIH and the Institute for Education Sciences. As evidenced through our large research networks, focus on under-represented groups, and community engagement efforts, SCDD research is increasingly incorporating implementation science methodology; this ensures that interventions are evaluated in the community, and, by design, examine facilitators and barriers to sustained implementation and dissemination.

Ongoing program evaluation and regional data collection are emphasized for Employment, Health, and Recreation programs. In addition to specific projects SCDD team members conduct, SCDD is an available resource to community organizations seeking support for data collection and analysis. Current and new programs include systematic evaluation of related outcomes that are collected in-person and through online surveys. Data allow us to refine program materials and processes to ensure that they are responsive to community input.

How PWD and families, including from diverse groups, will be active participants in research activities (2 points)

Several of our research and evaluation projects are conducted via community-partnered methodology that includes representatives from agencies, schools, families, and other

stakeholders throughout all stages of the research – from topic identification to design to recruitment to implementation and dissemination. Our research partnership meets monthly to ensure ongoing input into our processes. In addition, many projects are highly focused on those who are traditionally under-represented in research. For example, our Autism Intervention Research Network on Behavioral Health (AIR-B) is funded through the Health Resources and Services Administration, and therefore directly targets individuals from low-income households. This network also supports research on racial, linguistic, and ethnic disparities. Other school-partnered studies are implemented through Title 1, rural, and other low-resourced schools. All of our AIR-B and IES studies involve interventions that are delivered in homes, in schools, in trusted community locations, or via tele-conferencing, to reduce burden and increase participation. In Table 6, asterisks and bolded/italicized text are used to indicate when and how self-advocates, family advocates, and other community partners were involved in research activities.

The nature of the populations we aim to engage require thoughtful attention to developing interventions and evaluations that are culturally and linguistically competent. Our research networks and associated partnerships include racially and ethnically diverse individuals, and we explicitly solicit feedback on cultural competence throughout the process of intervention development and delivery. When using qualitative methodology, diverse raters are used, and we conduct member checks with those in the community to ensure data are interpreted within the context of the relevant communities. With respect to interventions themselves, when possible they are made available in other dominant languages. For instance, two of our AIR-B interventions are available in Spanish and Korean, and each site team has at least one bilingual representative who can conduct consent and study sessions in those languages.

Table 6

Objectives and Associated Activities for Research

Function Area: Research	
GOAL: Conduct federally and independently-funded research studies and program evaluations to ensure dissemination of evidence-based information and interventions and to gain new knowledge related to best supporting individuals with IDD from diverse backgrounds.	
Emphasis Area: Education	
Objectives	Activities
<p>R1: Conduct research and evaluation to enhance the inclusive educational opportunities for people with intellectual and developmental disabilities</p>	<p>R1a: Conclude NIH R01 examining 10-year outcomes of 153 children enrolled in early intensive behavioral intervention, as well as predictors of long-term cognitive, academic, and adaptive outcomes. Data will enhance our understanding of the efficacy of early intervention (EI) services and therefore has the potential to affect NYS policies related to EI service access (approx. 20,000 children in Western New York). <u>Year 1:</u> Completion of data collection and data cleaning <u>Years 2-5:</u> Data analysis, interpretation, and publication submission. Dissemination of findings through national conferences and community meetings. <i>*Conducted in shared leadership with Institute for IDD faculty</i></p> <p>R1b: Continue HRSA/MCHB-funded Autism Intervention Research Network on Behavioral Health (AIR-B), currently in the fourth year of a 5-year cycle. This community-based participatory model evaluates community interventions to increase service access and school transitions for 240 children with ASD. If the programs are successful, they may be disseminated to over 30 school districts in Western New York, in addition to national dissemination through our California and Pennsylvania State collaborators. <i>*Includes community research partnership that contributes to planning, implementation, and dissemination</i> <u>Year 1:</u> Data analysis/interpretation and publication submission <u>Years 2-5:</u> Development, submission, and implementation of new network cycle (to be submitted in 2020)</p> <p>R1c: Initiate new research study: NIH R01 under review to evaluate relative benefits of adult versus child-led interventions to increase communication in 140 children with ASD, as well as learning trajectories and identification of ideal treatment intensity for those who do not respond quickly. <u>Year 1:</u> Study startup and intervention refinement <u>Years 2-5:</u> Data collection, data analysis, and dissemination of results</p> <p>R1d: Initiate new research study: Institute for Education Sciences award under review to fund expansion of a network-wide, modular intervention for supporting 120 students with ASD in public school classrooms and their teachers (n=60), in an effort to increase time in general education. This project has the capacity to be disseminated within up to 10 regional school districts, in addition to districts in our partner regions (i.e., South Florida and Boston). <i>*Intervention developed via</i></p>

	<p><i>community-based participatory model, with feedback from community stakeholders</i></p> <p><u>Year 1:</u> Study startup and development of research partnerships <u>Years 2-5:</u> Recruitment, data collection, data analysis, and dissemination of results</p> <p>R1e: Conduct new 5-year grant from Department of Defense (awarded 2018) to compare standard early intervention strategies with a modular intervention focused on social-communication skills in 130 young children with ASD, aged 18 months-5 years. Results have the potential to significantly affect state and federal policy recommendations for early intervention and applied behavior analysis, as this project will provide important information on both intervention <i>type</i> and ideal intervention <i>dose</i>.</p> <p><u>Year 1:</u> Study startup and intervention development <u>Years 2-5:</u> Data collection, data analysis, and dissemination of results. Develop and disseminate associated recommendations and advocate for policy shifts, if indicated by the findings</p> <p>R1f: Conduct new NIH-funded grant (awarded 2018) evaluating the use of pragmatic language in 25 adults with ASD and 25 without ASD, which has the potential to inform the creation of an automated software tool for analyzing everyday spoken language, and to drive autism-specific language interventions. <u>Year 1:</u> Study startup and data collection <u>Years 2-5:</u> Data collection, data analysis, and dissemination of results</p>
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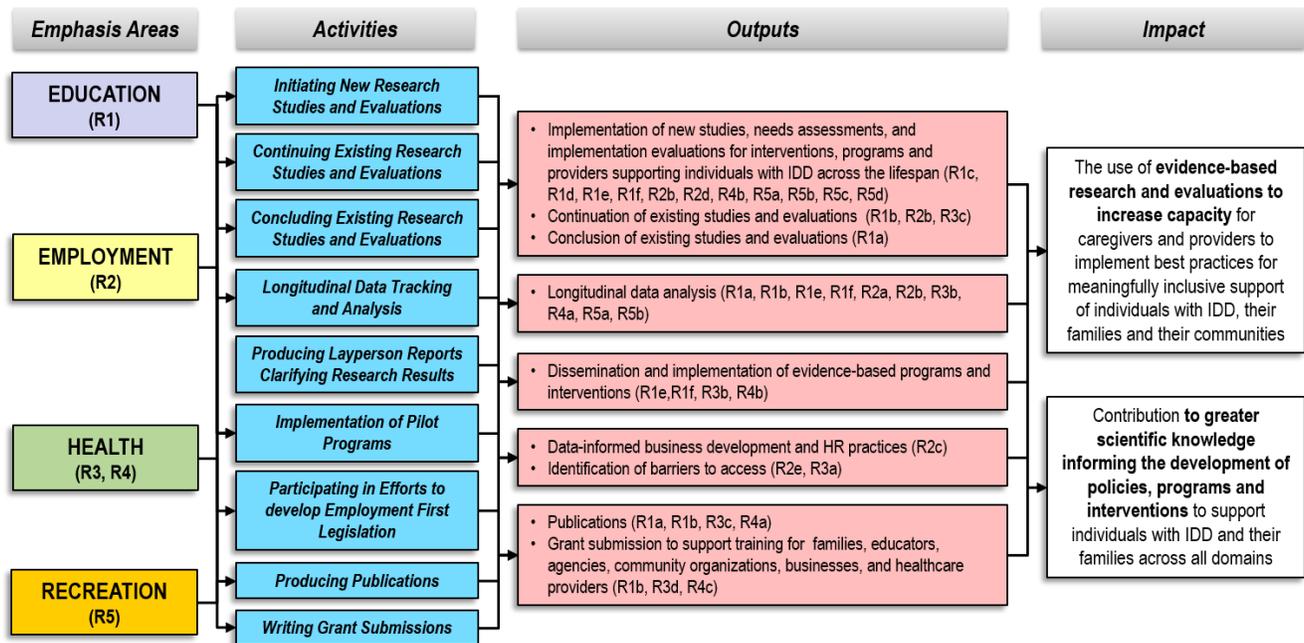
Emphasis Area: Employment

Objectives	Activities
<p>R2: Conduct research and evaluation to enhance the integrated, competitive employment of people with intellectual and developmental disabilities</p>	<p>R2a: Support Project SEARCH data collection and reporting systems across NYS. Analyze longitudinal outcomes of Project SEARCH in partnership with NYS NYESS, while simultaneously supporting analysis of data collected through Cincinnati Children’s Hospital’s new database. In addition, explore a new study of family expectations and involvement and the association to outcomes in Project SEARCH. <u>Year 1:</u> Conduct annual Project SEARCH evaluation <u>Years 2-5:</u> Continue annual evaluations and develop 2-3 community reports</p> <p>R2b: Systematically evaluate new and ongoing pre-vocational programs (e.g., Job Club) implemented for individuals with IDD in two classrooms within our largest school district. Measure outcomes including: employment self-efficacy, employment knowledge, job readiness, family contact with community resources, parent employment expectations. <i>*To be conducted in collaboration with disability self-advocates and leaders</i> <u>Year 1:</u> Finalize and pilot outcome measures and evaluation metrics <u>Years 2-5:</u> Conduct annual evaluations on Employment Discovery Network Activities, including annual evaluations that are cohort dependent</p> <p>R2c: Conduct systematic evaluations on trainings provided to support businesses in the recruitment, hiring, and retention of individuals with disabilities. <i>*To be conducted in collaboration with disability self-advocates</i> <u>Year 1:</u> Conduct evaluation on two employment trainings <u>Years 2-5:</u> Conduct annual evaluations on 3-4 trainings</p>

	<p>R2d: Conduct needs assessment with at least 50 higher education educators/administrators, transition-age adults with IDD, and family members to identify needs, barriers, and facilitators to successful participation in post-secondary educational opportunities.</p> <p><i>*Need identified via self- and family advocates</i></p> <p><u>Year 1:</u> Conduct needs assessment</p> <p><u>Years 2-5:</u> Prepare publication; use findings to inform development of an ECHO on inclusion in secondary education environments</p>
Emphasis Area: Health	
Objectives	Activities
R3: Conduct at least 5 research studies/evaluations per year to enhance the physical and behavioral health of people with IDD throughout the lifespan	<p>R3a: Continue Western NY study geo-mapping of sources of primary health and oral health care for people with IDD across lifespan. Extracted dataset for analysis of all individuals with IDD across the lifespan served by University of Rochester Medical Center; analyzing data for preventive health care markers, disparities in health care delivery, and 30-day readmission data.</p> <p>R3b: Execute planned expansion for the health literacy program for adolescents with ASD. The pilot is completed (publications under review), and a new grant submission is under review.</p> <p><i>*Intervention developed with input from individuals with ASD</i></p> <p><u>Year 1:</u> Secure funding and study startup</p> <p><u>Years 2-5:</u> Recruitment, data collection, analysis, and publication</p> <p>R3c: Complete ongoing, extramurally-funded research study on obesity prevalence in ASD and <u>publish at least one peer-reviewed article in 2019</u></p> <p><u>Year 1:</u> Publish at least one peer-reviewed article</p> <p><u>Years 2-5:</u> Develop study-based recommendations and disseminate within the community</p> <p>R3d: Secure federal funding to support medical provider training for OB-GYN offices on providing appropriate gynecological and prenatal care for adult women with disabilities; research outcomes will include evaluation of training impact on provider self-efficacy, clinical comfort, and disability knowledge.</p> <p><i>*Need identified via self-advocates; to be conducted in partnership with self- and family advocates</i></p> <p><u>Year 1:</u> Develop and submit grant application to NIH/HRSA</p> <p><u>Years 2-5:</u> Study recruitment, data collection, analysis, and publication</p>
R4: Evaluate caregiver stress programs and their impact on family physical and emotional well-being	<p>R4a: Complete ongoing data analysis of study evaluating bio-behavioral effects of mind-body interventions for caregivers of individuals with ASD.</p> <p><u>Year 1:</u> Submit one peer-reviewed publication</p> <p><u>Years 2-5:</u> Plan and submit for federal funding to expand program</p> <p>R4b: Conduct systematic, quantitative evaluation of mindfulness programs on caregiver stress and well-being (n=15 per cohort).</p> <p><i>*Conducted in collaboration with family advocates, from identification of need to implementation</i></p> <p><u>Year 1:</u> Conduct evaluation on two mindfulness cohorts</p> <p><u>Years 2-5:</u> Conduct annual evaluations on 3-4 mindfulness cohorts</p>

	<p>R4c: Secure funding for evaluation of the contribution of race-related stress on caregiving stress in 100 mothers of individuals with ASD.</p> <p><i>*Need identified through family advocates</i></p> <p><u>Year 1:</u> Complete NIH resubmission process</p> <p><u>Years 2-5:</u> Engage in data collection and analysis</p>
Emphasis Area: Recreation	
Objectives	Activities
<p>R5: Conduct research and evaluation in the area of inclusive recreation and leisure options for people with intellectual and developmental disabilities</p>	<p>R5a: Conduct a community-wide needs assessment in partnership with Rochester Accessible Adventures, to better understand the types of programs and opportunities that people with IDD, their family members, and their friends are looking for within the community.</p> <p>R5b: Through the collaboration with the Greater Rochester YMCA, measure key outcomes of the training project, including: 1) camp counselor knowledge of disability and inclusion; 2) camp counselor self-efficacy related to supporting individuals with IDD and creating inclusive environments; 3) parent/caregiver perceptions of disability-related climate; and 4) increased service of children with disabilities in camp programming. These outcomes will be measured through a disability knowledge survey, a self-efficacy survey, parent/caregiver focus groups, and participation data collected through the YMCA.</p> <p>R5c: Provide ongoing inclusivity assessments for community organizations offering recreation opportunities (n=5 annually); results will contribute to a state-wide database on the accessibility of recreation agencies.</p> <p><u>Year 1:</u> Conduct 3 evaluations on recreation trainings</p> <p><u>Years 2-5:</u> Conduct 5 annual evaluations on recreation trainings</p> <p>R5d: Systematically evaluate impact of inclusive recreation trainings (n=3 annually) on agency provider skills and self-efficacy in providing inclusive recreation opportunities.</p> <p><u>Year 1:</u> Conduct 3 evaluations with recreation providers</p> <p><u>Years 2-5:</u> Conduct 5 annual evaluations with recreation providers</p>

Figure 3. Logic Model for Research Function Area



INFORMATION DISSEMINATION

Description of a plan that includes strategies for translating research into practice (5 points)

GOAL: Disseminate culturally competent information, provide advocacy, and promote policies in the service of community inclusion in all of its facets, self-direction, and healthy lives to people with disabilities, their families and communities, agencies, legislators, and others affecting the lives of people with disabilities.

Issues affecting people with disabilities in New York State are complex and ever changing, and we have found it most effective to develop a multi-disciplinary team to disseminate information to a variety of stakeholders. More specifically we will have a staff person with dedicated communications and marketing responsibilities, and a separate staff person with policy and advocacy responsibilities who has governmental relations expertise. The

communications focus will allow us to enhance visibility and reach, while the policy expertise will allow us to broaden impact and strengthen relationships with policymakers at the local, state, and federal level. In addition, all UCEDD faculty and staff are expected to work collaboratively with the policy and communications staff so that our content expertise may be accessed and applied in diverse settings and circumstances.

SCDD has developed a dissemination plan that will share information related to research projects and evaluations by providing a report to the community that is accessible and provides the information both visually and through text. In addition, SCDD will create an annual report each year that provides brief information on programs and activities, focus areas, data collected, and contact information. Physical and electronic materials will be disseminated through SCDD's social media pages, Facebook and Twitter, on the accessible website, by email, to CAC members, and shared with community partners. We will also work to develop an email listserv that is specific to SCDD and reaches a broad audience. In addition to physical and electronic materials, SCDD will be present throughout the community at education, health, employment, and recreation-related community fairs in order to communicate the work of SCDD and build relationships throughout the region. This will also provide additional opportunity for dissemination of the aforementioned materials.

Over the past five years the UCEDD has strategically worked to improve our relationship with the University of Rochester's Government and Community Relations office. Their office and staff exist to help coordinate the University's legislative priorities, work to maintain relationships with elected and appointed officials, and partner with legislators and agencies on legislation or regulations that protect and enhance the missions and operations of the University. We have worked diligently to justify and align our priorities with those of the greater University

so that we can use their expertise and network to further the UCEDD mission and vision. For example, their office disseminates a federal priorities plan annually, and now includes language specific to supporting the UCEDD. In collaboration with their office, we will continue to work with regional and state policy makers to facilitate policy changes and increase the adoption of research-based practices. Through these efforts we will uphold the DD Act's promise that UCEDDs will "serve as a research-based resource for Federal and State policymakers on information concerning and issues impacting individuals with developmental disabilities and entities that assist or serve those individuals" (114 STAT. 1721). Finally SCDD's dissemination plan now includes a specific education for state legislators on the purpose of the DD Act of 2000 to increase recognition and utilization of our expertise over the next five years at the state level.

Our activities related to information dissemination in our four core focus areas of education, health, employment and recreation are consistent with that stated in the Developmental Disabilities Assistance and Bill of Rights Act of 2000: to provide leadership, advise policymakers, and otherwise "promote opportunities for individuals with disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life." Current and future advocacy issues include Employment First related policies, addressing access to transportation, especially as it affects employment and recreation activities, and, with the American Academy of Developmental Medicine and Dentistry and American Academy of Pediatrics, working to enhance health provider training and health service delivery to reduce health disparities for people with IDD across the lifespan. Additionally our LEND trainees attend the Disability Policy Seminar in Washington, DC, each year, learning the elements of federal policy development and how to craft an advocacy "elevator speech," and visiting lawmakers on Capitol Hill to educate and advocate for child and developmental

disability policy change. Trainees report this activity to be one of the most profound of their training.

How the development and dissemination of products and information uses Universal Design (4 points)

We will apply universal design through SCDD's different avenues of information dissemination: social media, physical handouts, email, etc. We will do so by including a text description option or providing a PDF instead of an image, so that it is accessible to screen readers. Furthermore, we will adapt language so it is in the simplest reading level possible, avoids jargon and difficult language, and limits the length of paragraphs. Images and text will have high contrast and clear headings to that the information is clear. SCDD will default to person centered language, while also sharing information directly from the disability community, and may contain identity first language. We will also intentionally share from a variety of sources, including from self-advocacy organizations, family-advocacy organizations, and agencies serving individuals with disabilities. In doing so, we will share the diversity of experiences and better reflect the needs of the region we serve.

Displays positive images of individuals with developmental disabilities (4 points)

SCDD has a commitment to both display positive images in our own materials, but also in the materials of the Medical Center and the University. This includes displaying images that are in inclusive environments, but also ones that demonstrate capabilities, rather than weakness. For example, we have developed two short videos that present people with disabilities engaged in inclusive recreational activities: one video geared towards families and self-advocates, and another video focusing on the business message. Similarly, we developed videos on employment for National Disability Employment Awareness Month, showing people with disabilities engaged in meaningful, competitive work opportunities. The goals of these video campaigns are

to raise expectations of what individuals with disabilities can accomplish in the community and to send a message to the community that inclusion is better for everyone.

SCDD is mindful of diversity within the disability landscape when sharing images of individuals with disabilities in pictures or videos. It is important to reflect a diversity of racial, ethnical, and cultural backgrounds, but also highlight intersectionality as it relates to the lived experiences of individuals with disabilities. In addition, SCDD strives to convey the experiences of individuals with invisible disabilities as well, by using images and videos in materials that show people who may not have visible disabilities, engaging in activities within their communities, like meaningful employment, or inclusive recreation.

Table 7

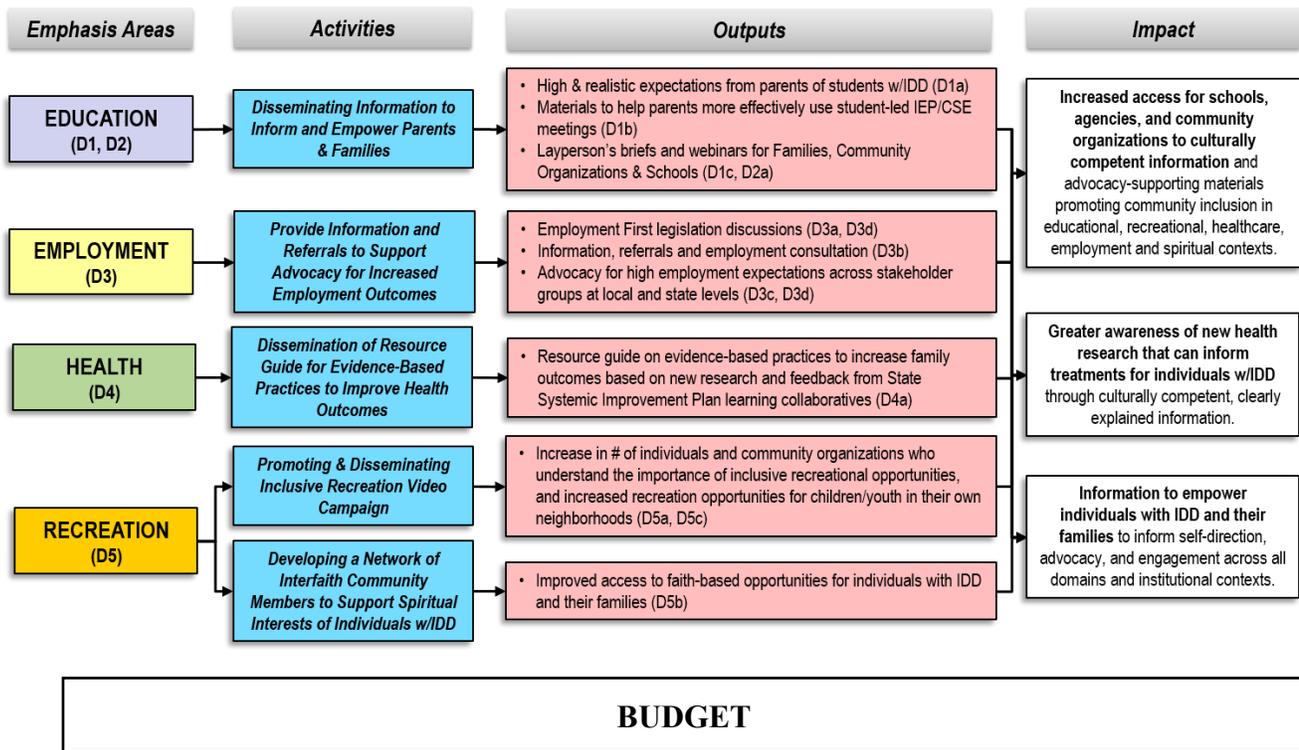
Objectives and Associated Activities for Information Dissemination

Function Area: Information Dissemination	
<p>GOAL: Disseminate culturally competent information, provide advocacy, and promote policies in the service of community inclusion in all of its facets, self-direction, and healthy lives to people with disabilities, their families and communities, agencies, legislators, and others affecting the lives of people with disabilities.</p>	
Emphasis Area: Education	
Objectives	Activities
D1: Engage parents in the process of high expectations and future dreams for their children	<p>D1a: Develop and disseminate information to parents/families on having high and realistic expectations of their children with IDD. <u>Year 1:</u> Develop 1 webinar series and printed materials for parents/families helping them to set realistic expectations for their children, which would include inclusion in their schools, communities, and the work force <u>Years 2-5:</u> Continue developing materials based on family needs</p> <p>D1b: Develop and implement materials for parents to help them engage their children in the IEP process. <u>Year 1:</u> Develop a local student-led IEP process utilizing the approach developed by our sister UCEDD at WIHD and implement in two different school districts <u>Year 2:</u> Provide materials for parents to help support them through the student-led IEP process <u>Years 3-5:</u> Support 2 new districts with appropriate materials a year to more effectively use student led IEP/CSE meetings</p>

	<p>D1c: For each research project, a layperson’s research brief will be created, based upon study findings, and then disseminated throughout our regional communities. This will be accomplished through products such as infographics, brief visual summaries, and webinars.</p> <p><u>Year 1:</u> Develop and disseminate two community research briefs and host two webinars</p> <p><u>Year 2:</u> Develop and disseminate 1-2 annual briefs and 1-2 annual webinars, based upon the number of completed studies</p>
D2: Equitably disseminate evidence-based information, services, and supports for people with IDD to communities	<p>D2a: Through ongoing relationships with community organizations and schools, (including disability and non-disability service agencies) results of SCDD-conducted research and research conducted across the broader network will be shared with community stakeholders during meetings, workgroups, and other table discussions. Links, briefs, and other products will be shared electronically and via social media, when appropriate.</p> <p><u>Years 1-5:</u> Conduct a minimum of 5 sharing opportunities per year</p>
Emphasis Area: Employment	
Objectives	Activities
D3: Provide information dissemination and advocacy to support increased employment outcomes for people with IDD in New York State	<p>D3a: Be actively involved in efforts to develop an Employment First policy and legislation for New York State, and implement the Governor’s E1 report and recommendations.</p> <p>D3b: Provide statewide education, information and referral services to help individuals, families, and other stakeholders understand changes in state systems that impact employment.</p> <p><u>Years 1-5:</u> Conduct a minimum of 5 presentations per year <i>*Based on needs identified through focus groups and surveys</i></p> <p>D3c: Advocate for high expectations related to employment potential of people with intellectual and developmental disabilities across stakeholder groups (state officials, businesses, families, schools, provider agencies).</p> <p>D3d: Advocate at the state and federal level to design creative and culturally responsive employment services for people with IDD. This will include continued advocacy as the state DD agency transforms their employment services and supports.</p>
Emphasis Area: Health	
Objectives	Activities
D4: Serve as a clearinghouse and resource for current research and evidence-based practices to NYSDOH and families on emerging evidence and research on family engagement in early intervention	<p>D4a: Disseminate updated resource guide of evidence-based practices to increase family outcomes based on new research and feedback from State Systemic Improvement Plan learning collaboratives.</p> <p><u>Year 1:</u> Disseminate resource guide.</p> <p><u>Years 2-5:</u> Update and disseminate resource guide.</p> <p>D4b: Disseminate information on Medically Underserved Population designation of people with IDD to policy makers, and a legislative toolkit to advocates to aid in discussions with policy makers</p> <p><u>Years 1-5:</u> Disseminate and periodically update with fresh state and national data</p>

	<p>D4c: Develop and disseminate manualized curriculum for Spanish language interpreters to aid in work with individuals with IDD and their families. <u>Year 1:</u> Develop curriculum <u>Year 2:</u> Disseminate curriculum</p> <p>D4d: Develop and disseminate materials related to women’s health to individuals with IDD and to women’s health care providers. <u>Year 1:</u> Conduct regional needs assessments of individuals, families, and providers <u>Year 2:</u> Develop and field test materials <u>Years 3-5:</u> Disseminate materials in conjunction with preservice, continuing, and community education and technical assistance activities</p>
Emphasis Area: Recreation	
Objectives	Activities
D5: Provide information dissemination and advocacy to support increased inclusive recreation and leisure opportunities for people with Intellectual and Developmental Disabilities	<p>D5a: Disseminate the Inclusive Recreation Video Campaign that was developed in 2018. Continued outreach will include ongoing shares on social media and through listservs, as well as displaying the videos during recreation presentations at conferences and community events at least 5 times per year.</p> <p>D5b: Develop a collaborative network of interfaith leaders and community members to brainstorm how to better serve individuals with IDD in regards to their faith and spiritual lives. The Greater Rochester Faith Inclusion Network (GRO-FIN) will focus on inclusion advocacy and will bring together diverse community leaders and members to better understand the state of the region and how we can address barriers to community inclusion in this area. <u>Year 1:</u> Develop collaborative <u>Years 2-5:</u> Sustain collaborative goals via 5 meetings per year</p> <p>D5c: Disseminate one informational sheet per year on the importance of recreation and leisure opportunities for all individuals. It will explore the physical, mental, and social benefits of engaging in recreation, and will also cover resources available in the community.</p>

Figure 4. Logic Model for Information Dissemination Function Area



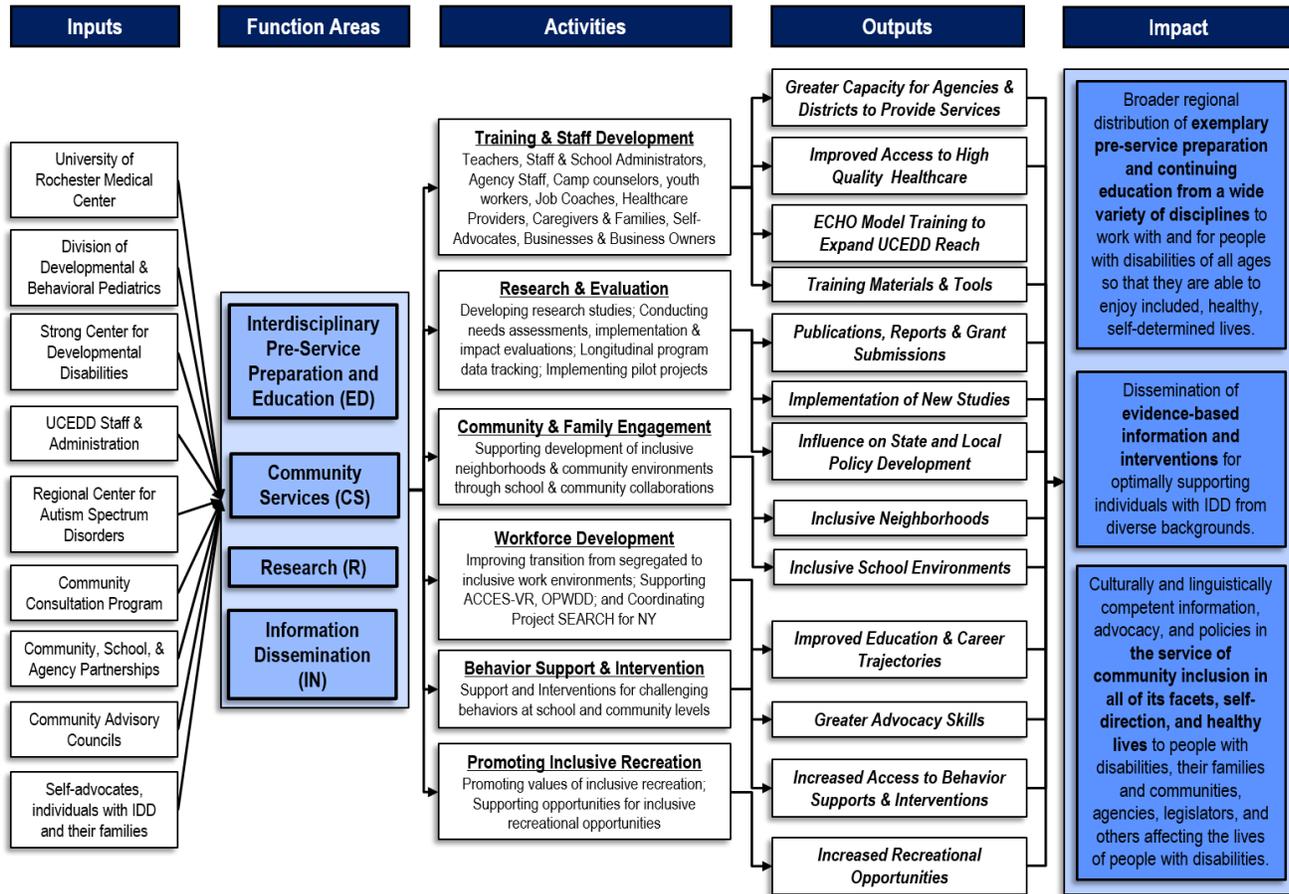
The budget narrative describes the justification for each category of expenses in the administration of the UCEDD and the implementation of its programs (see Appendix K). It provides a detailed breakout of staff effort necessary to meet the goals and objectives of this five-year renewal proposal through AIDD funding, as well as effort supported by leveraged funding. The budget is designed to, as much as possible, reflect changes expected to occur prior to the completion of the five-year period of the grant.

PROJECT IMPACT

The logic model (5 points)

An overarching logic model for all SCDD function areas and activities is included below. Individual logic models are also presented for *each function area* and are included in the earlier narrative on function areas (i.e., Figures 1-4).

Figure 5. Overarching SCDD logic model for all function areas and emphasis areas



The methodology that will be employed to gather data to report annually. (5 points)

SCDD will utilize mixed methods to understand how programs and initiatives are meeting their intended outcomes (Table 8). Quantitative measures will collect data on number of individuals served through a particular program, as well as satisfaction related to the program. We will implement standardized questions on all survey measures for each function area, in order to be able to aggregate program data at the end of each year, and at the end of five years. For example, for the education function area, we will collect data on satisfaction with the educational program as well as a standardized measure on increased knowledge.

Table 8

Summary of Data Collection Methodology and Sources of Information

Method	Type	Respondent(s)
Demographic Survey	Quantitative	Program participants
Engagement in SCDD Programs (e.g., enrollment, attendance, attrition)	Quantitative	SCDD coordinators
Outcome Surveys	Mixed	Program participants
Focus Groups	Qualitative	CAC and program participants
Semi-Structured Interviews	Qualitative	Identified Stakeholders: self-advocates, family-advocates
Needs Assessment Surveys	Quantitative	Self-advocates; family advocates; community stakeholders

In addition to quantitative measures, SCDD will collect qualitative data to understand in depth how the programs are meeting their intended goals. Qualitative data will include open-ended questions on surveys, but also implementing semi-structured conversations and stakeholder interviews. Through SCDD’s CAC meetings, we will annually collect qualitative data on SCDD’s progress towards meeting each year’s goals. In addition, we will conduct in-depth semi-structured interviews with identified stakeholders, specifically self-advocates, to provide more perspective on how we are doing, and gaps we need to fill.

How the UCEDD utilizes innovative methods (1 point)

Stakeholder involvement in program evaluation is best accomplished by the inclusion of those stakeholders in the planning process, from program conception. In this manner, those individuals have input into what outcome measures and other evaluation metrics are important and relevant to the community. Through our inclusion of self-advocates and family advocates on our UCEDD team and by providing them opportunities to both lead and contribute to new programs, we are increasingly integrating stakeholder input into evaluation processes. In addition, for teams that do not yet have self/family advocate representation, we contract with community advocates to provide this perspective. In these cases, program and evaluation planning is discussed during regular team meetings, and written evaluation plans are disseminated to the entire group for feedback.

How the CAC will review and comment on progress (4 points)

Ongoing CAC input on the UCEDD evaluation process will be accomplished in a step-wise fashion throughout the year. At the highest level, SCDD will present annual summaries and reports to the CAC for comments and input, and they will provide approval for all AIDD Annual Progress Reports. The CAC is specifically asked to comment on SCDD’s success in addressing the goals of the DD Act. In addition, the CAC will be provided the initial five-year plan to ensure consistency with the work plan and to re-solidify the overarching vision for each five-year cycle. Funding and recommendations from the CAC will be integrated into the final AIDD Annual Progress Report. On a smaller scale, the CAC will be consulted to provide input on evaluation metrics for new projects and programs before they are launched. Subsequently, evaluation data will be regularly shared with the CAC, both to report on program progress and to ensure that outcome measures continue to be relevant. Finally, following the completion of data collection for both research and program evaluation, the CAC will be asked to provide feedback on the SCDD team’s interpretation of the data. This information will be used to guide research and community reports and will be used iteratively to guide evaluation processes for future projects.

ORGANIZATIONAL CAPACITY

The UCEDD's mission (3 points)

In collaboration with the community of people with disabilities and their families, Strong Center for Developmental Disabilities envisions a world in which people of all ages with intellectual and developmental disabilities are valued and respected, lead self-determined lives in the community of their choice, and have the opportunity to contribute to that community and society at large. The mission of Strong Center for Developmental Disabilities is to develop community partnerships, foster accessibility and inclusion, and translate research into best

practice with and for people with intellectual and developmental disabilities living in our community. SCDD strives to do this work in a culturally and linguistically respectful manner through its service, research, training, community engagement, and dissemination/advocacy work. Our programmatic areas of emphasis are Education, Employment, Health Disparities, and Recreation, and programs and activities cover the lifespan, from birth to aging. Beyond these activities the SCDD both informs and supports, and is supported by, the Division of Developmental and Behavioral Pediatrics (DBP) clinical and research efforts. We believe it is our responsibility to bridge and inform the strong diversity programs and conversations throughout the University by including disability in diversity and cultural competence conversations and by providing specific educational sessions within the University system on disability and inclusion. Our faculty are engaged in teaching classes throughout the University, including the Warner School of Education and the School of Medicine and Dentistry. They also frequently serve on Master's, MPH, and dissertation committees for students in related programs, such as Counseling and Public Health. We also have strong relationships with other institutions of higher education, using our expertise in disability to further the understanding in those institutions of working with and for people with disabilities.

The UCEDD's programs: 1) Reflect a life span a approach; 2) reflect the active participation of individuals with developmental disabilities and their families; and 3) address the needs of individuals with developmental disabilities (3 points)

While Strong Center for Developmental Disabilities' academic home is in a Department of Pediatrics, we have a true life span approach, especially in our employment, health disparities, and recreation areas of emphasis. The CEO of the Medical Center and Dean of the School of Medicine and Dentistry granted our Center a designation as a "virtual center" so that our dissemination materials and relationships could extend beyond the Department of Pediatrics. Our multiple areas of emphasis require that we have an interdisciplinary approach with faculty and

staff who are physicians, educators, policy analysts, psychologists, behavior specialists, public health professionals, and, most importantly, self- and family member advocates. Our training programs include the above, as well as speech, physical, and occupational therapies, nutrition, organizational leadership, audiology, dentistry, nursing, and social work.

Our Center takes pride in our greatly improved recruitment of people with developmental disabilities and their families working in our programs. Nonetheless, we recognize that we have considerable work yet to do in this realm. Currently, we have 3 staff with self-identified developmental disabilities, and 5 family members who are faculty or staff. Just as important, however, is our renewed and actively engaged Consumer Advisory Council with over 60% having a disability or a family member with a disability. Our CAC is our bellwether for the needs of the community. They let us know where there are gaps and whether we are effectively filling those gaps or creating bridges within the community to address them. To promote this model across affiliated programs, we also are in our second year of contracting with family advocates for one of our state-funded grants, which falls under the purview of SCDD. Finally, our research efforts have increasingly relied on the community partnership model, which involves the community in research decisions – from identification of the topic to development to implementation. We maintain active community research partnership boards to provide ongoing feedback. In response to the community’s voice, two of our major research projects have included hiring family members to better disseminate our pediatric research efforts within the community.

Given the critical need to attend to intersectionality, our team is mindful of additional challenges posed by the confluence of disability and other marginalized identities. As such, attention to issues of intersectionality is integrated into our work, particularly with

underrepresented communities. Two of our team members who identify as self-advocates also identify with other underrepresented racial and ethnic groups. They, along with staff members coming from culturally diverse communities, have helped us to reach out to individuals who are under- or unserved in those communities through educational, research, and community service programs. In addition, CAC members from more rural areas have worked with us to provide increasing training, consultation, and service to the underserved in hard to reach regions.

Documentation is provided that the UCEDD has a written agreement (MOU) or charter with the University (3 points)

A Letter of Agreement from the CEO of the University of Rochester Medical Center and Dean of the University of Rochester School of Medicine and Dentistry can be found in Appendix J. The UCEDD at the University of Rochester enjoys a designation as a “virtual center” which enables us to identify and market our programs, research, and training that are focused on adults. The University provides space and other essential resources to the UCEDD, and the Department of Pediatrics and the Division of Developmental and Behavioral Pediatrics provide administrative support, ancillary services, and leadership. The director of the UCEDD, Susan Hetherington, PhD, reports directly to the Chief of the Division of Developmental and Behavioral Pediatrics and to the Chair of Pediatrics.

The application describes an organizational structure of the UCEDD (1 point)

SCDD has been in existence for over 40 years in the Department of Pediatrics at the University of Rochester, in Rochester, New York. The Department of Pediatrics and its Golisano Children’s Hospital are integral parts of the University of Rochester Medical Center. The Medical Center is the largest component of the University with more than 26,000 employees, while the University is the largest private sector employer based in Upstate New York, and the sixth-largest employer in the state. While historically the UCEDD lives in a Division of

Developmental and Behavioral Pediatrics, we have been given wide latitude to fulfill our mission and the mandates of the Developmental Disabilities Act of 2000. The organizational chart for the UCEDD can be found in Appendix E. For many years, the Division and the UCEDD were one entity. When we separated, we maintained the four function areas at that time: Clinical, Research, Training, and Community Education and Technical Assistance. Those four functions have adapted over time to Community Services- Clinical and Community Engagement; Interdisciplinary Pre-Service and Community Education; Research; and Dissemination, Policy, and Advocacy. Each of the functions has a director or co-directors, and our four areas of emphasis, Education, Employment, Recreation, and Health Disparities, either have a director or a coordinator to provide leadership. The UCEDD collaborates with the University's new Institute for Intellectual and Developmental Disabilities which has wide spread responsibility for coordinating research efforts related to intellectual and developmental disabilities (see Appendix F). Led by Dr. John Foxe, PhD and Jonathan Mink MD, PhD, under the Del Monte Institute for Neuroscience, the Institute will be applying to become an IDDRRC in the next round of competition in late 2019. The Foxe and Mink team is well positioned to see the UR successfully join the prestigious group of 14 institutions nationwide with an IDDRRC, and the even more elite group of 8 institutions with an IDDRRC, a UCEDD and a LEND. In preparation for this, leadership of the IDDRRC, UCEDD and LEND (along with other UR leaders) all participate on the University's IDD Executive Committee. The IDD Executive Committee was formed more than a year ago, in anticipation of the IDDRRC application being submitted in 2019, and has been meeting monthly to review, coordinate and enhance the myriad IDD programs at UR.

The ability of the UCEDD to leverage (1 point)

During the time of SCDD's existence, we have leveraged a variety of resources: financial, personnel, and community relationships. Currently, we leverage approximately \$4

million annually in other grants and contracts. Within the Division we have over 90 faculty and staff that include pediatricians, psychologists, behavior specialists, educators, speech pathologists, nutritionists, occupational and physical therapists, nurses, policy specialists, social workers, family members, and self-advocates. Our talented faculty and staff leverage resources through their own research and local, statewide, and national relationships. Our CAC, a vital part of our organization, represents multiple community agencies, family members, and self-advocates, and supports our long-range planning, which occurs both at the five-year renewal period and on an ongoing basis with yearly evaluations of progress and outcomes followed by renewed objectives and activities. Our yearly re-evaluations and engagement with our own interdisciplinary staff, the University, community, and other stakeholders allow us to be aware of and respond to emergent and future developments in the field. In addition, participating in the AUCD Network makes us aware, on a continuing basis, of emergent issues in the field, and being a part of an active DD Act Partnership in New York State, including the DD Council, the P and A, and the other UCEDD's supports continuing dialogue on the current, emerging, and future needs of NYS.

How the applicant does or will employ individuals with developmental disabilities (1 point)

While we know that we can improve immensely in employing people with IDD, their family members, and those from culturally and linguistically diverse backgrounds, we have made significant progress over the last five years. We currently employ two self-advocates and ten family members of people with disabilities. Both self-advocates come from culturally and/or linguistically diverse background, as do 20% of our staff. However, we recognize that this is not sufficient. Our faculty still lacks diversity. Because of this we have implemented an inclusion and diversity plan that requires the division to go beyond the typical University hiring practices. We aim to increase the number of diverse applicants and hires to our division and across staff,

faculty, and trainee positions by 1) sharing job posting with the Associate Director of Staff Diversity & Community Engagement in University HR and requesting that she share our postings with her community listserv, 2) creating an account on HBCU Connect where we will post all job postings and fellowship opportunities. (HR will provide a list of targeted HBCUs that have large populations of students from Rochester), 3) utilizing SCDD's Diversity and Inclusion Forum to assist in developing a workflow for job postings, 4) including the division's mission statement on all job postings, which should emphasize how we value diversity and inclusion, and 5) communicating to potential applicants whether there is flexibility for the position's schedule during the interview process.

The qualifications of the UCEDD director (2 points)

Susan Hetherington, PhD is the current director of the UCEDD at the University of Rochester. She assumed the directorship in 2015 and co-directorship of the University of Rochester UCEDD in 2012. Prior to that she was the deputy director and has been the function director for Community Education and Technical Assistance for over twenty years, and has held various positions at the UCEDD for over thirty years. Dr. Hetherington received her undergraduate degree from Temple University in Early Childhood Education, her Masters in Special Education, and Doctorate in Disability Studies from the University of Rochester. Her career has been diverse, serving as early childhood and special education teachers, an educational diagnostician, a disability trainer and advocate, Education Discipline Coordinator of LEND, and in various leadership roles at SCDD. She is currently the Principal Investigator of the UCEDD grant, a NYS Department of Health Early Intervention State Systemic Improvement Plan grant, and a recently completed NYS Department of Education grant on employment. She was the Principal Investigator of the AIDD-funded New York State Partnerships in Employment Systems Change grant, and is the Director of the Community Consultation Program guiding that

program. Dr. Hetherington has been PI on a number of OSERS and foundation grants and serves as the Associate Director for Community Education, Technical Assistance, Dissemination, and Advocacy for the Division of Pediatrics. She has particular interest and expertise in inclusion of students with disabilities, transition of young people with disabilities into the adult world, and employment of people with disabilities. Her research interests focus on the intersection of race and disability, especially autism. Dr. Hetherington is on multiple community boards and task forces, and has a secondary faculty appointment at the Warner School of Education. She is a member of the NYS DD Council and has been appointed by the Governor to serve on the Office for People with Developmental Disabilities Commissioner's Advisory Council. An abbreviated copy of her current vitae is in Appendix H.

The qualifications of the faculty and staff assigned to the UCEDD grant. (2 points)

Stephen Sulkes, MD, UCEDD Co-Director, is a board certified Developmental-Behavioral Pediatrician, and Professor of Pediatrics in the Division of Developmental and Behavioral Pediatrics. As founding Director of SCDD's Leadership Education in Neurodevelopmental and related Disabilities (LEND) program and Fellowship Director for DBP, he is also function director for Preservice Training. In addition to his clinical and teaching roles, he leads SCDD's focus on Health Disparities through research, advocacy, and dissemination activities, and is a founding member of the University's Institute for Intellectual and Developmental Disabilities. He is also currently President of the American Academy of Developmental Medicine and Dentistry where he created its first joint medical/dental/ nursing trainee chapter in Rochester. He is an honored medical educator at the University of Rochester, speaks nationally on the transition from pediatric to adult health care for individuals with intellectual and developmental disabilities, and advocates for improved health care across the lifespan for people with IDD. As the director of the Developmental and Behavioral Pediatrics

fellowship program at UR, he has mentored 25 developmental pediatricians throughout the country.

Suzannah Iadarola, PhD, BCBA-D is a licensed psychologist, board certified behavior analyst, and Assistant Professor in the division of DBP. She is also the Associate Director of Diversity and Community Engagement for the Strong Center for Developmental Disabilities. As of 2018, she assumed an interim role as DBP Co-Director of Research. Currently, she is the Principal Investigator (PI) on two large, network studies (one funded through HRSA and one through IES), as well as PI on two NIH-funded R01s. In addition to her clinical and research work, Dr. Iadarola is engaged in leadership roles within community organizations. She is the Project Director for a NYS Department of Education grant dedicated to disseminating evidence-based information and programming for individuals with ASD in Western NY. To ensure local and regional services are responsive to the needs of diverse communities, Dr. Iadarola joined the NYS Transformation Team of the Georgetown Center for Cultural Competence Community of Practice; she further supports this mission as a lead member of the DBP Diversity and Inclusion Forum and the Pediatrics Liaison to the University of Rochester Faculty Diversity Committee.

How the UCEDD will maintain a Consumer Advisory Committee (2 points)

SCDD's Community Advisory Council has grown dramatically in the last 5 years, both in terms of number of members and their engagement in our UCEDD's mission, policies, and programs. We have co-chairs, one of whom is the mother of a young man with IDD, and the other the local executive director of Best Buddies. A self-advocate is being mentored to take a leadership role in the CAC. Over 60% of our CAC participants are people with disabilities, or family members. Representatives of the DD Council and the Protection and Advocacy Agency attend our meetings, as well as representatives of the Center for Disability Rights and Rochester

Center for Independent Living. Racial and ethnic diversity is increasing with membership from the Ibero-American Action League and the Urban League. We are working to both maintain this increasingly involved CAC and expand its reach to cover a larger part of our region's rural areas.

How the UCEDD engages in collaborative relationships with the DD Network (1 point)

SCDD works closely and collaboratively with the NYS DD Partners. Susan Hetherington, PhD, the UCEDD director, serves on the NYS DDPC and several of its committees. She also serves on the DRNY Special Education Task Force, which identifies needs and provides training based on those needs in western NY to families, school staff, and providers. DDPC and DRNY staff serve on SCDD's CAC. Network partners meet quarterly to coordinate activities around issues identified as priorities across all three entities, with special attention paid to cultural and linguistic competence. The NYS DD Network has identified cultural and linguistic competence as its highest priority and is working collaboratively to assess statewide needs, identify priority issues, and plan activities that can be addressed collectively. The network has targeted Spanish and Chinese speaking communities as the highest need. We have identified current projects undertaken by each of the partners surrounding cultural and linguistic competency and have assessed network capacity to address the need. Next steps being planned include conducting a needs assessment, identifying priority initiatives, designing a plan for implementation, implementing projects and/or initiatives, and analyzing results. To further this collaboration, SCDD has representatives (along with DDPC and DRNY) on the New York State team of the Georgetown Center for Cultural Competence Community of Practice. With the associated focus of promoting cultural and linguistically competent services for Spanish and Chinese-speaking individuals with disabilities and their families, the team is engaged in a state-wide needs assessment that will drive action planning and the inclusion of a community partnership. SCDD is especially excited about working with Protection and Advocacy and the DD Council to engage

the Native American community in New York State. We have had several presentations and webinars and are currently working on building a relationship with the Haudenosaunee tribal community. In addition, the three NYS UCEDDs are collaborating with the NYS Department of Health to improve family engagement and satisfaction with Early Intervention services.

How the UCEDD actively participates in community networks (1 point)

SCDD sees its mission, in large part, as engaging with the community in several ways:

- 1) Assessing the needs of the disability community;
- 2) Providing services to people with disabilities and their families;
- 3) Providing technical assistance and training to schools, agencies, and other entities;
- 4) Conducting our research in and with the community;
- 5) Building networks and collaborations with other organizations that work with and affect the lives of people with disabilities.

In order to do this, we must collaborate and work with community networks and partners. In our community efforts we work with the Regional Early Childhood Direction Center, PECAN (Parent Engagement CAN), the Rochester- Monroe Anti-Poverty Initiative (RMAPI), the Rochester Area Employment Network, county Departments of Health, United Way, and multiple agencies and school districts. These collaborations have led to a number of new and expanded initiatives. For example, our relationship with Starbridge, an advocacy, training, and disability services agency, led to our collaboratively initiating an Employment and Disability Summit, a unique day of bringing together businesses, families, agencies, and people with disabilities to talk about and address the issue of poverty and un- and under-employment for people with disabilities. This has led to a community task force on the issue that is being co-led by the Chamber of Commerce, RMAPI, and SCDD.

APPENDIX A

Summary of community-identified IDD needs, based on research and community needs assessments.

Topic	Procedures*	Relevant Findings
Services for children with ASD in Title 1 schools (Iadarola et al., 2015)	Focus groups with parents (n=14 ; 64% black, 36% white) and educators (n=24 ; 40% black, 60% white)	-Lack of adequate training in providing services to children with ASD -Limited trust between parents and schools -Lack of positive culture in school around disability and difference
Developmental screening for refugee families (Kroening et al., 2016)	Focus groups (n=16) and key informant interviews (n=19) with refugee families (86% Bhutanese-Nepali; 14% Iraqi) and community stakeholders	-There are cultural barriers and stigma around disability -Participants reported poor healthcare knowledge; language barriers; and reliance on traditional healing practices -Facilitators of screening were trust in healthcare providers, visual supports, education about child development
Parenting stress in mothers of children with ASD from underrepresented groups (Iadarola et al., 2017)	Focus groups with parents (n=17 ; 25% black, 6% pacific islander, 29% white, 59% Latinx; 35% primarily Spanish-speaking; 50% from low-income households)	-Language is a significant service barrier for Spanish-speaking families -There is prevalent stigma against disability in local black communities -There is inequitable distribution of information around disability that limits community awareness in low-income zip codes
Health literacy for adolescents and young adults with ASD (Christensen et al., under review)	Focus groups with individuals with ASD (n=12) and caregivers (n=15)	-People with ASD should be empowered to manage their healthcare, but they often rely on parents -Healthcare management is an important indicator of independence -People with ASD need consistent access to healthcare information
Supporting special education teachers in public schools (Iovannone et al., under review)	Focus groups with educators who serve students with ASD in their classrooms and parents of children with ASD (n=69)	-There is a lack of resources and training in public schools for supporting students with ASD -Educators feel they need to prioritize short-term goals over implementation of systems-wise evidence based practices -Intervention models that include direct coaching for educators are desired and would fit within available resources
Cross-cultural input on improving access to ASD services (Stahmer et al., under review)	Focus groups and key informant interviews with providers (n=55) and parents of children with ASD (n=56 ; 32% black; 25% Asian; 43% white; 46% Latinx; 89% from low-income households)	-There are barriers to ASD diagnosis and treatment based on race and language -Provider training in ASD was highlighted as a significant need -Families experience race-based stigma, which can lead to delays in diagnosis and service referrals -Access issues, such as location and transportation, are barriers to receiving adequate services -Authentic caregiver engagement is a positive facilitator for accessing services and supports

		-Promotora model (i.e., through peer coaching or family navigation) is a viable way to engage families who are wary of the medical system
Identifying priority community needs for individuals with IDD (July, 2017)	<u>Conducted directly with UCEDD Community Advisory Council:</u> Individual work group discussions were completed among members of the CAC, to launch planning process for 5-Year Plan (n=20)	-There are huge employment gaps for those who do not qualify for state services; families need technical assistance to learn how to support their adults with IDD -SCDD needs to expand employment services beyond Project SEARCH -Agencies need support/ training in reducing barriers to inclusive recreation for those with IDD -Subspecialty medical providers need training in IDD -There is a mental health crisis that is being overlooked -Greater education about disability is needed in the community; self-advocates could help with this but would need formal mentorship in self-advocacy
Service needs for families of children with disabilities living in the rural Southern Tier of New York (June-July, 2018)	Six focus groups were completed with parents of children with disabilities, all living within a designated rural county	-Overall consensus for services was positive, with some gap areas identified -Parent groups are a strength, but it is difficult to sustain them over time. Considering parents learn best from other parents, as a result, information dissemination is difficult and inconsistent -Increased access to subspecialty care is severely needed, as traveling to more populated areas results in transportation barriers and significant time missed from work and school -There is a major need for mental health services
Community needs for Spanish and Chinese-speaking families of children with IDD (August-September, 2018)	<u>Conducted in collaboration with the DDPC and the CLC Community of Practice:</u> Four focus groups were completed with caregivers of children with disabilities, all of whom were primarily Spanish or Chinese speaking	-There is limited language access for those with Limited English Proficiency, which drives service delays -Professionals do not generally use linguistically or culturally competent practices -Information that is shared in languages other than English are of poorer quality -Educational campaigns would help address the prevalent disability stigma -People from Spanish and Chinese communities get information from trusted community organizations
Needs for Spanish-speaking families who have a child with IDD (September, 2018)	<u>Conducted in collaboration with the DDPC and the CLC Community of Practice:</u> Focus groups with parents of children with IDD who are primarily Spanish-speaking (n=6)	-Latinos do not get equitable access to information about disabilities -There is a lack of Spanish-speaking providers and interpreters that are barriers to families accessing services -Programs should be advertised in Spanish -Parents expressed high stress and need for support to help manage stressors -Schools should better communicate about all available supports

<p>Community needs assessment around supporting individuals with IDD across the lifespan (September – November, 2018)</p>	<p><u>Conducted directly with UCEDD Community Advisory Council and the Institute for IDD</u>, including agency stakeholders, self-advocates with IDD, and family members; assessments accomplished via quarterly meetings including an annual focus group</p>	<ul style="list-style-type: none"> -IDD-specific Primary Care clinic cannot serve area population; there is need for specialty and community providers to better engage people with IDD -It is critical to provide IDD training to providers across settings (medical, support staff, mental health, schools, emergency responders, government officials) -We need more research on social determinants of health within our local IDD population -Need for improved relationship between providing agencies and families of people with IDD -Benefit from collaboration with Office for the Aging
<p>Community needs assessment focused on facilitators and barriers to quality of life for individuals with IDD (October, 2018)</p>	<p><u>Conducted in collaboration with Community Advisory Council</u>: Focus groups (n=39) with parents, providers, and self-advocates</p>	<ul style="list-style-type: none"> -There is a lack of community awareness/ stigma -There are not enough truly inclusive placements for education, recreation, or employment -Our community needs more pre-vocational options -The lack of specialized medical providers is an increasing concern as individuals age into adulthood -Disparities based on race/ethnicity persist in our community -Existing programs and specialty providers were highlighted as community strengths
<p>Community needs assessment focused on service gaps for individuals with IDD (October, 2018)</p>	<p><u>Conducted in collaboration with Community Advisory Council</u>: Survey disseminated throughout the Western New York region (n=76) to parents, providers, and self-advocates</p>	<ul style="list-style-type: none"> -Recreation and employment were identified as the areas in most need of support -The need for increased choice across areas (recreation, employment, health) was highlighted -Unmet needs were highest in the areas of employment, mental health, housing, and transportation -Parental stress was highlighted as a barrier to getting needs met; associated need to support mental health -For self-advocates, the limited inclusive programs and lack of choice were primary barriers
<p>Reducing education and service-related disparities for students with developmental disabilities (ongoing throughout year)</p>	<p>Community partnership with local organizations and parents of individuals with IDD; assessments accomplished via monthly partnership meetings</p>	<ul style="list-style-type: none"> -Families of children with IDD in low-income areas are unaware of available local resources -There is pervasive mistrust of the medical system among communities of color, which perpetuates lack of access to critical disability services

Note: ASD=Autism Spectrum Disorder. IDD=Intellectual and Developmental Disabilities.
UCEDD=University Centers for Excellence in Developmental Disabilities.

* Projects that emphasized race/ethnicity related disparities include specific reporting on demographics of participants.

APPENDIX B

LEND Core Course Curriculum and Schedule.

Date	Room	Reflection Focus	Core Course Seminars Morning Sessions: 9:00 – 12:30 pm	Faculty Leader(s)
9/7/2018	Buckland Lodge	Reflection Introduction (Dawn & Pam)	Orientation Ideal Project Introduction	LEND Faculty
9/14/2018	1w501	Junk in my Trunk reflection (Terry)	Nuts & Bolts Discipline Overview (speed disciplines) Interprofessional Overviews Ideal project review	Sulkes, Orlando, Burkin, Welch, Vogler-Elias, Brown
9/21/2018	1w501	Ideal Project Reflections(initial ideas for projects) (Orlando)	Ideal Project Budgeting, Business Plans, Business operations, Budgeting	Orlando
9/28/2018	1w501	Reflections on who you are? (Viggiani)	Life Course Theory Risk, Resilience, Baggage Cultural Humility	Viggiani Flores Burkin
10/3/18	Museum of Play		Intelligent Lives A film by Dan Habib	6:00 – 8:30 pm
10/5/2018	Field Trip	-----	Disability Museum Field Trip	Burkin Donahue
10/12/2018	1w501	Reflections on Disability Museum trip(related to life course, diversity, etc) (Burkin)	Ideal Project (Letter of Intent due) Systems Reviewing Research Grants	Orlando Sulkes Silverman
10/19/2018	1w509	No Reflection Due	Health Systems/Insurances Family/Person Centered Care	Sulkes Yingling
10/26/2018	1w501	No Reflection Due	Health Marketing & Advertising QI/PDSA Relevant Topic introduction & group work	Orlando, Flores, Vogler-Elias, Yingling, Burkin, Viggiani
11/2/2018	1w501	No Reflection Due	Clinical Corner – Autism Advocacy	Vogler-Elias, Silverman, Brown, Flores
11/9/2018	1w501	Reflection: Advocacy (Flores)	Policy Relevant Topic group work	Veazie, Richardson, Relevant topic group faculty
11/11 – 11/14	1w501	-----	AUCD conference – Washington, DC	-----
11/16/2018	1w509	No Reflection Due	Shared Vision/Issues with Leadership in DD (Optional Budget Workshop – 12:30 – 1:30 PM)	Hocker Orlando

11/23/2018	1w501	-----	Thanksgiving Break	-----
11/30/2018	1w501	Reflection: Shared Vision/Issues with Leadership in DD (Hocker)	(Optional Budget Workshop – 8:00 – 9:00 AM) Clinical Corner – (Developmental Disabilities) EI preschool/school systems	Orlando Kroening Donahue & Welch
12/7/2018	Field Trip	No Reflection Due	Daystar	Donahue & Welch
12/14/2018	1w501	No Reflection Due	Ideal Project presentations Book Club – Pot luck lunch post session	Orlando
12/21/2018	1w501	-----	Winter Break ***Final Prep on Relevant Topics***	-----
12/28/2018	1w501	-----	Winter Break ***Final Prep on Relevant Topics***	-----
1/4/2019	1w501	-----	Winter Break ***Final Prep on Relevant Topics***	-----
1/11/2019	1w501	No Reflection Due	Domains of Transition (Adult – CCC) Relevant Topic group work	Sulkes Pulcino Ricigliano
1/18/2019	1w501	No Reflection Due	Relevant topic group work OPWDD & Self-Direction	Guest speaker:OPWD D Burkin
1/25/2019	1w501	No Reflection Due	Relevant Topics Presentations	LEND Faculty
2/1/2019	1w501	No Reflection Due	Arena Prep ID Teams	Vogler-Elias Baltus-Hebert
2/8/2019	1w501	No Reflection Due	Accessibility simulations Accessibility simulation activities	Silverman, Hebert, Vogler-Elias, Viggiani
2/15/2019	1w501	No Reflection Due	Arena evaluation Prep work Preparation Policy Discussion	Sulkes, Vogler-Elias, Baltus-Hebert, Chimento, Veazie Richardson
2/22/2019	Nazareth YWRI 255	No Reflection Due	Arena Session 1	Vogler-Elias Baltus-Hebert
3/1/2019	1w501	No Reflection Due	Coaching and Mentoring Communicating Effectively	Hocker

			Changing Team Culture	
3/8/2019	Nazareth YWRI 255	No Reflection Due	Arena Session 2	Vogler-Elias Baltus-Hebert
3/15/2019	1w501	Reflection: Leadership from 3/1/19 (Hocker)	Leadership/DISC	Hocker
3/22/2019	1w501	No Reflection Due	Evidence-based Practice Clinical Corner – (Dual Diagnosis)	Silverman Brown
3/29/2019	1w501	No Reflection Due	Family Presentations	Burkin
4/5/2019	SRB 1412	Reflection: EBP & Dual diagnosis (Silverman/Brown)	Disability Policy Seminar Preparation	Sulkes Richardson
4/7 – 4/10	1w501	-----	Disability Policy Seminar Washington, DC	-----
4/12/2019	1w501	Relevant topic Reflection(DVE/PV/CB/JF/JY)	Clinical Corner – (Cerebral Palsy) Disability Policy Seminar Debrief	Kroening Sulkes
4/19/2019	Field Trip	No Reflection Due	Assistive Technology	Donahue Flores
4/26/2019	SRB 1416	Reflection on Clinical Experiences/Shadowing (Donahue)	Epidemiology	DeLucia
5/3/2019	1w501	No Reflection Due	AADMD Preparation Book Club during core course	Sulkes DeLucia
5/10/2019	Hyatt Hotel	-----	AADMD attendance	Sulkes
5/17/19	TBD	-----	Graduation	9:00 – 12:30 pm

APPENDIX C

Diversity and Inclusion Forum Plan

INCLUSION FORUM PLAN

Proposed activities to improve responsiveness to diversity within our division

GOALS OF THE INCLUSION FORUM

To align with the stated goals of our federal funders and our University, our intention is to:

- Create and promote a safe and inclusive environment in all settings in which we engage in clinical, research, teaching, or community partnership activities
- Develop and nurture partnerships with organizations representing or affiliated with diverse communities
- Develop infrastructure that supports diversity, inclusion, and cultural and linguistic competence; and builds capacity to address and reduce inequities and disparities
- Foster an internal workforce that is more diverse with respect to faculty, staff, and trainees

To accomplish these goals, we recommended the following opportunities for growth and reflection.

I. Diversity Assessment

Regular assessment is critical to our understanding of where we stand with respect to cultural competence, to identify areas in need of improvement, and to recognize gains. Regular, formalized diversity assessment at the organizational and individuals levels will help us remain accountable.

Organizational Assessment

We propose that an organizational assessment is conducted on the division as a whole at least once every two years. The assessment will be completed by a collaborative team, which will be organized by the Inclusion Forum but open to all members of the division for optional participation. One proposed measure is The Cultural and Linguistic Competence Assessment for Disability Organizations (CLCADO): <https://nccc.georgetown.edu/assessments/clcado.php>. Other potential tools are available on the Georgetown National Center for Cultural Competence website. Following the completion of the assessment, the members of the assessment team will consolidate results, develop goals for the next two years, and present back to the entire division.

Self-Assessment

Individual self-assessments are valuable for promoting self-reflection and identifying personal goals toward inclusion. Although we do not propose a required self-assessment for all members of the division at this point in time, the Inclusion Forum will disseminate tools and opportunities for self-assessment, to ensure that these resources are available. Following 1-2 cycles of organizational assessment, and as the division achieves short-term goals related to diversity and inclusion, we may consider whether required self-assessment becomes an appropriate goal for individuals.

II. Faculty/Staff Diversity Education Requirement (CHEC Marks)

For all faculty/staff

We propose a requirement for each faculty and staff member's annual review to complete a total of 2 hours per year on continuing education related to diversity/inclusion. This will be called Cultural Humility Experience Component (CHEC), and the credits will be called CHEC Marks. CHEC Mark opportunities include:

- Attending relevant talks or events (e.g., town hall meeting, conference, cultural experience, etc.)
- Reading and reflecting on position papers, articles, or other media related to diversity

Disseminating CHEC opportunities

- We propose posting CHEC learning opportunities to the DBP event page on Sharepoint. There will be a CHEC button on the main dashboard to link to this page.
- Members of the Inclusion Forum will coordinate one training per year that will take place during the Division Meeting, to make it as easy as possible for all division members to attend.
- The page will serve as a repository for links/documents announcing local or web-based opportunities to earn CHEC Marks (e.g., URMIC talks, Psychiatry Brown Bag Series, webinars, journal articles, resources from the Georgetown National Center for Cultural Competence). It will also include a link to opportunities posted through Psychiatry, in MyPath.
- There will be a central person who posts opportunities to the page.
- The entire division will be responsible for sending opportunities to the central person, as they encounter them.

Tracking CHEC Marks

- Staff and faculty will be responsible for tracking their CHEC marks and providing them to their supervisor or Function Director at their annual review. Staff must complete both (2) learning opportunities to receive a “(5) – Outstanding” rating at their annual review.
- Supervisors are responsible for reviewing and ensuring these events are included in the Annual Review. The Inclusion Forum will remind supervisors of the requirement to review CHEC activities with their direct reports during March of each year (employee review time).

Employee Feedback Collection

- The Inclusion Forum will send optional feedback surveys to DBP staff/faculty who attend any diversity-related events coordinated or hosted by the Inclusion Forum.
- Members of the Inclusion Forum will disseminate a brief, annual survey to all division members, soliciting feedback on the CHEC process and available learning opportunities.

For leadership

For those in leadership positions, we propose a requirement to complete the Safe Space training, a 2-part series offered through the University of Rochester. It is designed to promote inclusivity and sensitivity to diversity in gender and sexual identity and orientation. The foundations on being an ally in this training can be more broadly applied to other diverse populations.

II. Increasing Diversity in Hiring of Staff, Faculty, and Trainees

We aim to increase the number of diverse applicants and hires to our division and across staff, faculty, and trainee positions.

- When job postings are shared with Janice Holland, Associate Director of Staff Diversity & Community Engagement in University HR, specific requests will be made that:
 - She shares our postings with her community listserv.
 - Responses from this listserv be sent directly to the "multicultural email." HR will forward any applications that come in through this email; we can track applicants recruited through this method.
- The Inclusion Forum will assist in developing a workflow for job postings.
- To facilitate recruitment from students/alumni of Historically Black Colleges and Universities (HCBU), we will create an account on [HBCU Connect](#) where we will post

all job postings and fellowship opportunities. (HR will provide a list of targeted HBCUs that have large populations of students from Rochester).

- All job postings will include the division's mission statement, which should emphasize how we value diversity and inclusion.
- If there is flexibility for the position's schedule, this will be communicated to potential applicants during the interview process.
- The Inclusion Forum will apply for at least 1 diversity grant opportunity in the first year of this effort.
- Inclusion Forum can offer assistance in applying for diversity supplements.

We will increase retention of diverse staff, faculty, and fellows.

- A culture of humility and responsiveness will be promoted throughout the Division through required trainings, the provision of learning opportunities, and opportunities for self-assessment.
- Opportunities will be provided for open dialogue regarding diverse populations, such as in clinical supervision and peer supervision groups, in research meetings, and through the LEND program. Resources on having these conversations will be posted on Sharepoint.
- Division activities will recognize the diversity within the entire division and embrace all individuals within DBP. For example, staff celebrations will be seasonal celebrations instead of holiday-specific (e.g., "spring flings", summer cookout, fall harvest, winter wonderland).
- All exit interviews will include a question about the division's cultural sensitivity and responsiveness.
- We will add to the mission statements for DBP, and LEND to include an explicit commitment to diversity. SCDD has already revised their mission statement to reflect this commitment, at the advice of the Inclusion Forum.

Discussion of cultural and linguistic diversity will be integrated into the onboarding/ orientation process.

- For the first few years, this will be accomplished by having new hires complete an on-line learning opportunity.
 - Proposed learning opportunity: "Conscious and Unconscious Bias in Health Care" <https://nccc.georgetown.edu/bias/>
 - Include CHEC requirements in onboarding
- Over time, we aim to develop an in-person training that will be facilitated by members of the inclusion team and may be open to existing employees, in addition to new employees.

III. FTE for Inclusion Learning Opportunity Coordinator (ILOC)

To maintain and disseminate learning opportunities for CHEC and other professional development, we suggest identifying a central coordinator who will:

- Maintain the SharePoint Page that houses learning opportunities
- Forwards learning opportunities to the division
- Send reminder emails to the division to complete CHEC Marks, and for supervisors to review CHEC Marks with direct reports during reviews
- Assist with the development of job descriptions
- Organize and run Inclusion Forum meetings
- Coordinate diversity and inclusion opportunities hosted by the Inclusion Forum
- Disseminate employee feedback surveys
- **Given these multiple responsibilities, we propose a .05 FTE allocation to the ILOC. In the context of AUCD's emphasis on diversity, we propose this FTE is covered by the UCEDD.**

APPENDIX D

PROJECT WORK PLAN														
YEAR 1														
Major Goal	Key Tasks	Lead Person	1	2	3	4	5	6	7	8	9	10	11	12
Provide exemplary pre-service preparation to and educational opportunities to people with disabilities, their families, school and agency staff, and leadership at the University and in the community	1. Provide education to preservice trainees and community education providers on IDD	Steve Sulkes	X	X	X	X	X	X	X	X	X	X	X	X
			Year 1 = Trainings available each month; preservice trainees in months 2-11											
	2. Provide education and support to health professionals to increase awareness about the Family Experience Program	Carrie Burkin			X	X	X	X	X	X	X	X	X	X
			Year 1 = Via LEND trainees, conducted annually and linked to academic year											
	3. Provide interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of employment for individuals with developmental disabilities leading to increased integrated, competitive employment options	Kaitlyn Richardson	X	X	X	X	X	X	X	X	X	X	X	X
			Year 1 = Trainings available each month, with associated outreach throughout the year											
	4. Provide interdisciplinary pre-service preparation and continuing education around health to future and current professionals in the area of developmental disabilities to provide the skills and knowledge to enhance the health of people with developmental disabilities across the life span	Steve Sulkes; Sabrina Smith	X	X	X	X	X	X	X	X	X	X	X	X
			Year 1 = Provider needs assessment and ECHO startup throughout the year; LEND preservice trainees in months 2-11											
	5. Improve services for people with I/DD to reduce health disparities	Steve Sulkes; Sabrina Smith			X	X	X	X	X	X	X	X	X	X
			Year 1 = Spanish Language Medical Interpreter training and evaluation											
			X	X	X	X	X	X	X	X	X	X	X	

	6. Provide Interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of recreation and leisure, leading to increased inclusive recreation opportunities.	Jennifer Ward	Year 1 = Trainings available to direct providers throughout the year; LEND preservice training to occur in months 2-11																									
Provide Community Services and Education to promote self-direction, healthy living, inclusive communities, and self-advocacy in a culturally and linguistically competent manner	1. Conduct trainings for educational and administrative providers on maximal inclusion of individuals with IDD in their educational environments and transition into adulthood	David McAdam	X	X	X	X	X	X	X	X	X	X	X	X	X	Year 1 = Execution of annual consultation contracts and offering of ad-hoc workshops/technical assistance sessions												
	2. Provide services and supports to increase competitive, integrated employment of people with intellectual and developmental disabilities	Kaitlyn Richardson ; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	X	X	Year 1 = Execution of annual contracts for Project SEARCH, as well as state funders; startup of Employment Discovery Network												
	3. Support caregivers of individuals with IDD in their physical and emotional well-being	Suzannah Iadarola												X	X	Year 1 = Conduct Spring mindfulness sessions for caregivers												
	4. Share best practices aimed to increase family engagement outcomes in the early intervention program with providers, county officials, and families	Susan Hetherington		X	X	X	X	X	X	X	X	X	X	X	X	Year 1 = Hold 10 monthly education sessions of family-centered practices												
	5. Improve community services to be responsive and accessible to the needs of people with I/DD	Sabrina Smith			X	X	X	X								Year 1 = Conduct community education for individuals with IDD to increase knowledge to support physical and behavioral health												
				X	X	X	X	X	X	X	X	X	X	X	X													

	6. Improve services for people with I/DD and their families to reduce health disparities	Lynn Cole; Sabrina Smith	Year 1 = Conduct annual cycle of Spanish interpreter training; conduct healthcare provider training on knowledge of family experience																						
	7. Provide services and supports to increase inclusive recreation and leisure opportunities for people with intellectual and developmental disabilities	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	Year 1 = Execute contracts and annual training commitments with recreation providers; coordinate around annual inclusive play events											
Conduct federally and independently-funded research studies and program evaluations to ensure dissemination of evidence-based information and interventions and to gain new knowledge related to best supporting individuals with IDD from diverse backgrounds	1. Conduct research and evaluation to enhance the inclusive educational opportunities for people with intellectual and developmental disabilities	Suzannah Iadarola	X	X	X	X	X	X	X	X	X	X	X	Year 1 = Study startup for IES and NICHD grants; recruitment closeout for HRSA grant; data analysis for IES grant; execution of ongoing studies (e.g., DoD)											
	2. Conduct research and evaluation to enhance the integrated, competitive employment of people with intellectual and developmental disabilities	Kaitlyn Richardson	X	X	X	X	X	X	X	X	X	X	X	Year 1 = Conduct annual Project SEARCH evaluation; finalize Employment Discovery Network Curriculum; evaluate employer trainings conducted throughout the year; conduct post-secondary needs assessment											
	3. Conduct at least 5 research studies/evaluations per year to enhance the physical and behavioral health of people with IDD throughout the lifespan	Steve Sulkes; Sabrina Smith	X	X	X	X	X	X	X	X	X	X	X	Year 1 = Continue with annual Geo-Mapping; receive funding and study startup for Health Literacy grant; data analysis for obesity in autism study; development of pregnancy grant submission											
	4. Evaluate caregiver stress programs and their impact on family physical and emotional well-being	Suzannah Iadarola	X	X	X	X	X	X			X	X		Year 1 = Analyze data on bio-behavioral stress profiles in caregivers; submit one publication; conduct evaluation of caregiver mindfulness program in Spring; submit caregiver stress-focused grant application to NIH											
	5. Conduct research and evaluation in the area of inclusive recreation and leisure options for	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	Year 1 = Conduct community recreation needs assessment; provide training to recreation providers throughout the year and conduct program evaluation											

	people with intellectual and developmental disabilities													
Disseminate culturally competent information, provide advocacy, and promote policies in the service of community inclusion in all of its facets, self-direction, and healthy lives to people with disabilities, their families and communities, agencies, legislators, and others affecting the lives of people with disabilities	1. Engage parents in the process of high expectations and future dreams for their children	Susan Hetherington; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	
			Year 1 = Develop webinar series and infographics on family expectations; develop curriculum for engaging students with IDD in IEP process; develop layperson research summaries											
	2. Equitably disseminate evidence-based information, services, and supports for people with IDD to all communities	Suzannah Iadarola	X	X	X	X	X	X	X	X	X	X	X	X
			Year 1 = Develop process for sharing research results with community (e.g., webinars, infographics); share evolving evidence-based findings and information at community meetings throughout the year											
	3. Provide information dissemination and advocacy to support increased employment outcomes for people with IDD in New York State	Kaitlyn Richardson ; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	
			Year 1 = Develop Employment First policy; provide statewide education on systems change in employment; engage in state and federal-level advocacy for culturally responsive employment services											
	4. Provide information dissemination and advocacy to support increased inclusive recreation and leisure opportunities for people with IDD	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	
			Year 1 = Disseminate inclusive recreation campaign videos; identify partners for Interfaith Inclusion Network; continue relationship with local advocacy groups supporting safe, inclusive play environments; develop information sheet about importance of inclusive recreation											

PROJECT WORK PLAN YEAR 2															
Major Goal	Key Tasks	Lead Person	1	2	3	4	5	6	7	8	9	10	11	12	
Provide exemplary pre-service preparation to and educational opportunities to people with disabilities, their families, school and agency staff, and leadership at the University and in the community	1. Provide education to preservice trainees and community education providers on IDD	Steve Sulkes	X	X	X	X	X	X	X	X	X	X	X	X	
			Year 2 = Trainings available each month; preservice trainees in months 2-11; Develop ECHO training for school administrators												
	2. Provide education and support to health professionals to increase awareness about the Family Experience Program	Carrie Burkin			X	X	X	X	X	X	X	X	X	X	
			Year 2 = Via LEND trainees, conducted annually and linked to academic year												
	3. Provide interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of employment for individuals with developmental disabilities leading to increased integrated, competitive employment options	Kaitlyn Richardson	X	X	X	X	X	X	X	X	X	X	X	X	X
		Year 2 = Trainings available each month, with associated outreach throughout the year													
		Steve Sulkes; Sabrina Smith	X	X	X	X	X	X	X	X	X	X	X	X	
		Year 2 = Conduct needs assessment for OB-GYN ECHO and Behavioral/Mental Health ECHO and analyze data; engage medical trainees in education sessions throughout the year; LEND preservice trainees in months 2-11													
		Steve Sulkes; Sabrina Smith			X	X	X	X	X	X	X	X	X	X	
		Year 2 = Conduct annual Spanish Language Medical Interpreter training and evaluation throughout the year													
			X	X	X	X	X	X	X	X	X	X	X	X	

	6. Provide Interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of recreation and leisure, leading to increased inclusive recreation opportunities.	Jennifer Ward	Year 2 = Conduct trainings for direct providers throughout the year; LEND preservice training to occur in months 2-11													
Provide Community Services and Education to promote self-direction, healthy living, inclusive communities, and self-advocacy in a culturally and linguistically competent manner	1. Conduct trainings for educational and administrative providers on maximal inclusion of individuals with IDD in their educational environments and transition into adulthood	David McAdam	X	X	X	X	X	X	X	X	X	X	X	X	X	Year 2 = Execution of annual consultation contracts and offering of ad-hoc workshops/technical assistance sessions; conduct teacher burnout prevention sessions in school districts
	2. Provide services and supports to increase competitive, integrated employment of people with intellectual and developmental disabilities	Kaitlyn Richardson ; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	X	X	Year 2 = Execution of annual contracts for Project SEARCH, as well as state funders; finalize Employment Discovery Network curriculum and begin pilot of the program
	3. Support caregivers of individuals with IDD in their physical and emotional well-being	Suzannah Iadarola			X	X							X	X		Year 2 = Conduct Fall and Spring mindfulness sessions for caregivers
	4. Share best practices aimed to increase family engagement outcomes in the early intervention program with providers, county officials, and families	Susan Hetherington		X	X	X	X	X	X	X	X	X	X	X		Year 2 = Hold 10 monthly education sessions of family-centered practices
	5. Improve community services to be responsive and accessible to the needs of people with I/DD	Sabrina Smith			X	X	X	X								Year 2 = Conduct community education for individuals with IDD to increase knowledge to support physical and behavioral health
				X	X	X	X	X	X	X	X	X	X	X	X	

	6. Improve services for people with I/DD and their families to reduce health disparities	Lynn Cole; Sabrina Smith	Year 2 = Conduct annual cycle of Spanish interpreter training; conduct healthcare provider training on knowledge of family experience																						
	7. Provide services and supports to increase inclusive recreation and leisure opportunities for people with intellectual and developmental disabilities	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	Year 2 = Execute contracts and annual training commitments with recreation providers; coordinate around annual inclusive play events											
Conduct federally and independently-funded research studies and program evaluations to ensure dissemination of evidence-based information and interventions and to gain new knowledge related to best supporting individuals with IDD from diverse backgrounds	1. Conduct research and evaluation to enhance the inclusive educational opportunities for people with intellectual and developmental disabilities	Suzannah Iadarola	X	X	X	X	X	X	X	X	X	X	X	Year 2 = Finalize interventions for IES and NICHHD grants and begin to engage with community research partners; finalize data analysis and writeup for HRSA and IES grants; execution of ongoing studies (e.g., DoD)											
	2. Conduct research and evaluation to enhance the integrated, competitive employment of people with intellectual and developmental disabilities	Kaitlyn Richardson	X	X	X	X	X	X	X	X	X	X	X	Year 2 = Conduct annual Project SEARCH evaluation; evaluate preliminary outcomes from the Employment Discovery Network pilot; evaluate employer trainings conducted throughout the year; analyze data from post-secondary needs assessment											
	3. Conduct at least 5 research studies/evaluations per year to enhance the physical and behavioral health of people with IDD throughout the lifespan	Steve Sulkes; Sabrina Smith	X	X	X	X	X	X	X	X	X	X	X	Year 2 = Continue with annual Geo-Mapping; receive funding and study startup for Health Literacy grant; manuscript submission for obesity in autism study; submit OB-GYN provider-focused pregnancy grant											
	4. Evaluate caregiver stress programs and their impact on family physical and emotional well-being	Suzannah Iadarola	X	X	X	X	X	X			X	X		Year 2 = Conduct evaluation of caregiver mindfulness program in Spring; receive external funding for caregiver stress grant and engage in study startup											
	5. Conduct research and evaluation in the area of inclusive recreation and leisure options for people with	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	Year 2 = Conduct community recreation needs assessment; provide training to recreation providers throughout the year and continue with annual program evaluations											

	intellectual and developmental disabilities													
Disseminate culturally competent information, provide advocacy, and promote policies in the service of community inclusion in all of its facets, self-direction, and healthy lives to people with disabilities, their families and communities, agencies, legislators, and others affecting the lives of people with disabilities	1. Engage parents in the process of high expectations and future dreams for their children	Susan Hetherington; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	
			Year 2 = Execute webinar series and disseminate infographics on family expectations; conduct trainings on engaging students with IDD in IEP process; continue development and dissemination of layperson research summaries											
	2. Equitably disseminate evidence-based information, services, and supports for people with IDD to all communities	Suzannah Iadarola	X	X	X	X	X	X	X	X	X	X	X	X
			Year 2 = Begin engaging in regular sharing of research results with community (e.g., via webinars, infographics); continue to share evolving evidence-based findings and information at community meetings throughout the year											
	3. Provide information dissemination and advocacy to support increased employment outcomes for people with IDD in New York State	Kaitlyn Richardson ; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	
			Year 2 = Develop Employment First policy; provide statewide education on systems change in employment; engage in state and federal-level advocacy for culturally responsive employment services											
	4. Provide information dissemination and advocacy to support increased inclusive recreation and leisure opportunities for people with IDD	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	
			Year 2 = Disseminate inclusive recreation campaign videos; begin meeting process for Interfaith Inclusion Network; continue relationship with local advocacy groups supporting safe, inclusive play environments; disseminate information sheet about importance of inclusive recreation											

PROJECT WORK PLAN YEAR 3															
Major Goal	Key Tasks	Lead Person	1	2	3	4	5	6	7	8	9	10	11	12	
Provide exemplary pre-service preparation to and educational opportunities to people with disabilities, their families, school and agency staff, and leadership at the University and in the community	1. Provide education to preservice trainees and community education providers on IDD	Steve Sulkes	X	X	X	X	X	X	X	X	X	X	X	X	
			Year 3 = Trainings available each month; preservice trainees in months 2-11; Pilot ECHO training for school administrators												
	2. Provide education and support to health professionals to increase awareness about the Family Experience Program	Carrie Burkin			X	X	X	X	X	X	X	X	X	X	
			Year 3 = Via LEND trainees, conducted annually and linked to academic year												
	3. Provide interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of employment for individuals with developmental disabilities leading to increased integrated, competitive employment options	Kaitlyn Richardson	X	X	X	X	X	X	X	X	X	X	X	X	X
			Year 3 = Trainings available each month, with associated outreach throughout the year												
	4. Provide interdisciplinary pre-service preparation and continuing education around health to future and current professionals in the area of developmental disabilities to provide the skills and knowledge to enhance the health of people with developmental disabilities across the life span	Steve Sulkes; Sabrina Smith	X	X	X	X	X	X	X	X	X	X	X	X	
			Year 3 = Refine curriculum development for OB-GYN ECHO and Behavioral/Mental Health ECHO; engage medical trainees in education sessions throughout the year; LEND preservice trainees in months 2-11												
	5. Improve services for people with I/DD to reduce health disparities	Steve Sulkes; Sabrina Smith			X	X	X	X	X	X	X	X	X	X	X
			Year 3 = Conduct annual Spanish Language Medical Interpreter training and evaluation throughout the year												
			X	X	X	X	X	X	X	X	X	X	X	X	

	6. Provide Interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of recreation and leisure, leading to increased inclusive recreation opportunities.	Jennifer Ward	Year 3 = Conduct trainings for direct providers throughout the year; LEND preservice training to occur in months 2-11																									
Provide Community Services and Education to promote self-direction, healthy living, inclusive communities, and self-advocacy in a culturally and linguistically competent manner	1. Conduct trainings for educational and administrative providers on maximal inclusion of individuals with IDD in their educational environments and transition into adulthood	David McAdam	X	X	X	X	X	X	X	X	X	X	X	X	X	Year 3 = Execution of annual consultation contracts and offering of ad-hoc workshops/technical assistance sessions; conduct teacher burnout prevention sessions in school districts												
	2. Provide services and supports to increase competitive, integrated employment of people with intellectual and developmental disabilities	Kaitlyn Richardson ; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	X	X	Year 3 = Execution of annual contracts for Project SEARCH, as well as state funders; continue execution of the Employment Discovery Network curriculum												
	3. Support caregivers of individuals with IDD in their physical and emotional well-being	Suzannah Iadarola			X	X								X	X	Year 3 = Conduct Fall and Spring mindfulness sessions for caregivers												
	4. Share best practices aimed to increase family engagement outcomes in the early intervention program with providers, county officials, and families	Susan Hetherington		X	X	X	X	X	X	X	X	X	X	X	X	Year 3 = Hold 10 monthly education sessions of family-centered practices												
	5. Improve community services to be responsive and accessible to the needs of people with I/DD	Sabrina Smith			X	X	X	X								Year 3 = Conduct community education for individuals with IDD to increase knowledge to support physical and behavioral health												
				X	X	X	X	X	X	X	X	X	X	X	X													

	6. Improve services for people with I/DD and their families to reduce health disparities	Lynn Cole; Sabrina Smith	Year 3 = Conduct annual cycle of Spanish interpreter training; conduct healthcare provider training on knowledge of family experience																					
	7. Provide services and supports to increase inclusive recreation and leisure opportunities for people with intellectual and developmental disabilities	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	Year 3 = Execute contracts and annual training commitments with recreation providers; coordinate around annual inclusive play events										
Conduct federally and independently-funded research studies and program evaluations to ensure dissemination of evidence-based information and interventions and to gain new knowledge related to best supporting individuals with IDD from diverse backgrounds	1. Conduct research and evaluation to enhance the inclusive educational opportunities for people with intellectual and developmental disabilities	Suzannah Iadarola	X	X	X	X	X	X	X	X	X	X	X	Year 3 = Begin recruitment and intervention for IES and NICHD grants and continue relationships with community research partners; publish peer-reviewed papers for HRSA and IES grants; execution of ongoing studies (e.g., DoD)										
	2. Conduct research and evaluation to enhance the integrated, competitive employment of people with intellectual and developmental disabilities	Kaitlyn Richardson	X	X	X	X	X	X	X	X	X	X	X	Year 3 = Conduct annual Project SEARCH evaluation; develop community reports on post-secondary needs assessment; evaluate ongoing outcomes from the Employment Discovery Network; evaluate employer trainings conducted throughout the year										
	3. Conduct at least 5 research studies/evaluations per year to enhance the physical and behavioral health of people with IDD throughout the lifespan	Steve Sulkes; Sabrina Smith	X	X	X	X	X	X	X	X	X	X	X	Year 3 = Continue with annual Geo-Mapping; begin recruitment for Health Literacy grant; manuscript submission for obesity in autism study; obtain funding for OB-GYN provider-focused pregnancy grant and engage in study startup										
	4. Evaluate caregiver stress programs and their impact on family physical and emotional well-being	Suzannah Iadarola	X	X	X	X	X	X			X	X		Year 3 = Conduct evaluation of caregiver mindfulness program in Spring; begin recruitment and data collection for caregiver stress study										
	5. Conduct research and evaluation in the area of inclusive recreation and leisure options for people with	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	Year 3 = Conduct community recreation needs assessment; provide training to recreation providers throughout the year and continue with annual program evaluations										

	intellectual and developmental disabilities													
Disseminate culturally competent information, provide advocacy, and promote policies in the service of community inclusion in all of its facets, self-direction, and healthy lives to people with disabilities, their families and communities, agencies, legislators, and others affecting the lives of people with disabilities	1. Engage parents in the process of high expectations and future dreams for their children	Susan Hetherington; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	
			Year 3 = Execute webinar series and disseminate infographics on family expectations; conduct trainings on engaging students with IDD in IEP process; continue development and dissemination of layperson research summaries											
	2. Equitably disseminate evidence-based information, services, and supports for people with IDD to all communities	Suzannah Iadarola	X	X	X	X	X	X	X	X	X	X	X	X
			Year 3 = Continue engaging in regular sharing of research results with community (e.g., via webinars, infographics); continue to share evolving evidence-based findings and information at community meetings throughout the year											
	3. Provide information dissemination and advocacy to support increased employment outcomes for people with IDD in New York State	Kaitlyn Richardson ; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	
			Year 3 = Continue education and advocacy around Employment First policy; provide statewide education on systems change in employment; engage in state and federal-level advocacy for culturally responsive employment services											
	4. Provide information dissemination and advocacy to support increased inclusive recreation and leisure opportunities for people with IDD	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	
			Year 3 = Disseminate inclusive recreation campaign videos; continue meeting process for Interfaith Inclusion Network and identify shared goals/objectives; continue relationship with local advocacy groups supporting safe, inclusive play environments; disseminate information sheet about importance of inclusive recreation											

PROJECT WORK PLAN YEAR 4															
Major Goal	Key Tasks	Lead Person	1	2	3	4	5	6	7	8	9	10	11	12	
Provide exemplary pre-service preparation to and educational opportunities to people with disabilities, their families, school and agency staff, and leadership at the University and in the community	1. Provide education to preservice trainees and community education providers on IDD	Steve Sulkes	X	X	X	X	X	X	X	X	X	X	X	X	
			Year 4 = Trainings available each month; preservice trainees in months 2-11; Pilot ECHO training for school administrators												
	2. Provide education and support to health professionals to increase awareness about the Family Experience Program	Carrie Burkin			X	X	X	X	X	X	X	X	X	X	
			Year 4 = Via LEND trainees, conducted annually and linked to academic year												
	3. Provide interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of employment for individuals with developmental disabilities leading to increased integrated, competitive employment options	Kaitlyn Richardson	X	X	X	X	X	X	X	X	X	X	X	X	X
			Year 4 = Trainings available each month, with associated outreach throughout the year												
	4. Provide interdisciplinary pre-service preparation and continuing education around health to future and current professionals in the area of developmental disabilities to provide the skills and knowledge to enhance the health of people with developmental disabilities across the life span	Steve Sulkes; Sabrina Smith	X	X	X	X	X	X	X	X	X	X	X	X	
			Year 4 = Pilot curriculum for OB-GYN ECHO and Behavioral/Mental Health ECHO; engage medical trainees in education sessions throughout the year; LEND preservice trainees in months 2-11												
	5. Improve services for people with I/DD to reduce health disparities	Steve Sulkes; Sabrina Smith			X	X	X	X	X	X	X	X	X	X	X
			Year 4 = Conduct annual Spanish Language Medical Interpreter training and evaluation throughout the year												
			X	X	X	X	X	X	X	X	X	X	X	X	

	6. Provide Interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of recreation and leisure, leading to increased inclusive recreation opportunities.	Jennifer Ward	Year 4 = Conduct trainings for direct providers throughout the year; LEND preservice training to occur in months 2-11																									
Provide Community Services and Education to promote self-direction, healthy living, inclusive communities, and self-advocacy in a culturally and linguistically competent manner	1. Conduct trainings for educational and administrative providers on maximal inclusion of individuals with IDD in their educational environments and transition into adulthood	David McAdam	X	X	X	X	X	X	X	X	X	X	X	X	X	Year 4 = Execution of annual consultation contracts and offering of ad-hoc workshops/technical assistance sessions; conduct teacher burnout prevention sessions in school districts												
	2. Provide services and supports to increase competitive, integrated employment of people with intellectual and developmental disabilities	Kaitlyn Richardson ; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	X	X	Year 4 = Execution of annual contracts for Project SEARCH, as well as state funders; continue execution of the Employment Discovery Network curriculum												
	3. Support caregivers of individuals with IDD in their physical and emotional well-being	Suzannah Iadarola			X	X								X	X	Year 4 = Conduct Fall and Spring mindfulness sessions for caregivers												
	4. Share best practices aimed to increase family engagement outcomes in the early intervention program with providers, county officials, and families	Susan Hetherington		X	X	X	X	X	X	X	X	X	X	X	X	Year 4 = Hold 10 monthly education sessions of family-centered practices												
	5. Improve community services to be responsive and accessible to the needs of people with I/DD	Sabrina Smith			X	X	X	X								Year 4 = Conduct community education for individuals with IDD to increase knowledge to support physical and behavioral health												
				X	X	X	X	X	X	X	X	X	X	X	X													

	6. Improve services for people with I/DD and their families to reduce health disparities	Lynn Cole; Sabrina Smith	Year 4 = Conduct annual cycle of Spanish interpreter training; conduct healthcare provider training on knowledge of family experience																						
	7. Provide services and supports to increase inclusive recreation and leisure opportunities for people with intellectual and developmental disabilities	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	Year 4 = Execute contracts and annual training commitments with recreation providers; coordinate around annual inclusive play events											
Conduct federally and independently-funded research studies and program evaluations to ensure dissemination of evidence-based information and interventions and to gain new knowledge related to best supporting individuals with IDD from diverse backgrounds	1. Conduct research and evaluation to enhance the inclusive educational opportunities for people with intellectual and developmental disabilities	Suzannah Iadarola	X	X	X	X	X	X	X	X	X	X	X	Year 4 = Continue recruitment, intervention, and data collection for IES and NICHD grants and continue relationships with community research partners; execution of ongoing studies (e.g., DoD)											
	2. Conduct research and evaluation to enhance the integrated, competitive employment of people with intellectual and developmental disabilities	Kaitlyn Richardson	X	X	X	X	X	X	X	X	X	X	X	Year 4 = Conduct annual Project SEARCH evaluation; develop community reports on post-secondary needs assessment; evaluate ongoing outcomes from the Employment Discovery Network; evaluate employer trainings conducted throughout the year											
	3. Conduct at least 5 research studies/evaluations per year to enhance the physical and behavioral health of people with IDD throughout the lifespan	Steve Sulkes; Sabrina Smith	X	X	X	X	X	X	X	X	X	X	X	Year 4 = Continue with annual Geo-Mapping; continue with recruitment and data collection for Health Literacy grant; manuscript submission for obesity in autism study; begin recruitment and data collection for OB-GYN provider-focused pregnancy grant											
	4. Evaluate caregiver stress programs and their impact on family physical and emotional well-being	Suzannah Iadarola	X	X	X	X	X	X			X	X		Year 4 = Conduct evaluation of caregiver mindfulness program in Spring; begin recruitment and data collection for caregiver stress study											
	5. Conduct research and evaluation in the area of inclusive recreation and leisure options for people with	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	Year 4 = Conduct community recreation needs assessment; provide training to recreation providers throughout the year and continue with annual program evaluations											

	intellectual and developmental disabilities													
Disseminate culturally competent information, provide advocacy, and promote policies in the service of community inclusion in all of its facets, self-direction, and healthy lives to people with disabilities, their families and communities, agencies, legislators, and others affecting the lives of people with disabilities	1. Engage parents in the process of high expectations and future dreams for their children	Susan Hetherington; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	
			Year 4 = Execute webinar series and disseminate infographics on family expectations; conduct trainings on engaging students with IDD in IEP process; continue development and dissemination of layperson research summaries											
	2. Equitably disseminate evidence-based information, services, and supports for people with IDD to all communities	Suzannah Iadarola	X	X	X	X	X	X	X	X	X	X	X	X
			Year 4 = Continue engaging in regular sharing of research results with community (e.g., via webinars, infographics); continue to share evolving evidence-based findings and information at community meetings throughout the year											
	3. Provide information dissemination and advocacy to support increased employment outcomes for people with IDD in New York State	Kaitlyn Richardson ; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	
			Year 4 = Continue education and advocacy around Employment First policy; provide statewide education on systems change in employment; engage in state and federal-level advocacy for culturally responsive employment services											
	4. Provide information dissemination and advocacy to support increased inclusive recreation and leisure opportunities for people with IDD	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	
			Year 4 = Disseminate inclusive recreation campaign videos; continue meeting process for Interfaith Inclusion Network and work toward shared goals/objectives; continue relationship with local advocacy groups supporting safe, inclusive play environments; disseminate information sheet about importance of inclusive recreation											

PROJECT WORK PLAN YEAR 5														
Major Goal	Key Tasks	Lead Person	1	2	3	4	5	6	7	8	9	10	11	12
Provide exemplary pre-service preparation to and educational opportunities to people with disabilities, their families, school and agency staff, and leadership at the University and in the community	1. Provide education to preservice trainees and community education providers on IDD	Steve Sulkes	X	X	X	X	X	X	X	X	X	X	X	X
			Year 5 = Trainings available each month; preservice trainees in months 2-11; Pilot ECHO training for school administrators											
	2. Provide education and support to health professionals to increase awareness about the Family Experience Program	Carrie Burkin			X	X	X	X	X	X	X	X	X	X
			Year 5 = Via LEND trainees, conducted annually and linked to academic year											
	3. Provide interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of employment for individuals with developmental disabilities leading to increased integrated, competitive employment options	Kaitlyn Richardson	X	X	X	X	X	X	X	X	X	X	X	X
		Year 5 = Trainings available each month, with associated outreach throughout the year												
	4. Provide interdisciplinary pre-service preparation and continuing education around health to future and current professionals in the area of developmental disabilities to provide the skills and knowledge to enhance the health of people with developmental disabilities across the life span	Steve Sulkes; Sabrina Smith	X	X	X	X	X	X	X	X	X	X	X	X
			Year 5 = Train additional providers in the curricula for OB-GYN ECHO and Behavioral/Mental Health ECHO; engage medical trainees in education sessions throughout the year; LEND preservice trainees in months 2-11											
	5. Improve services for people with I/DD to reduce health disparities	Steve Sulkes; Sabrina Smith			X	X	X	X	X	X	X	X	X	X
			Year 5 = Conduct annual Spanish Language Medical Interpreter training and evaluation throughout the year											
			X	X	X	X	X	X	X	X	X	X	X	X

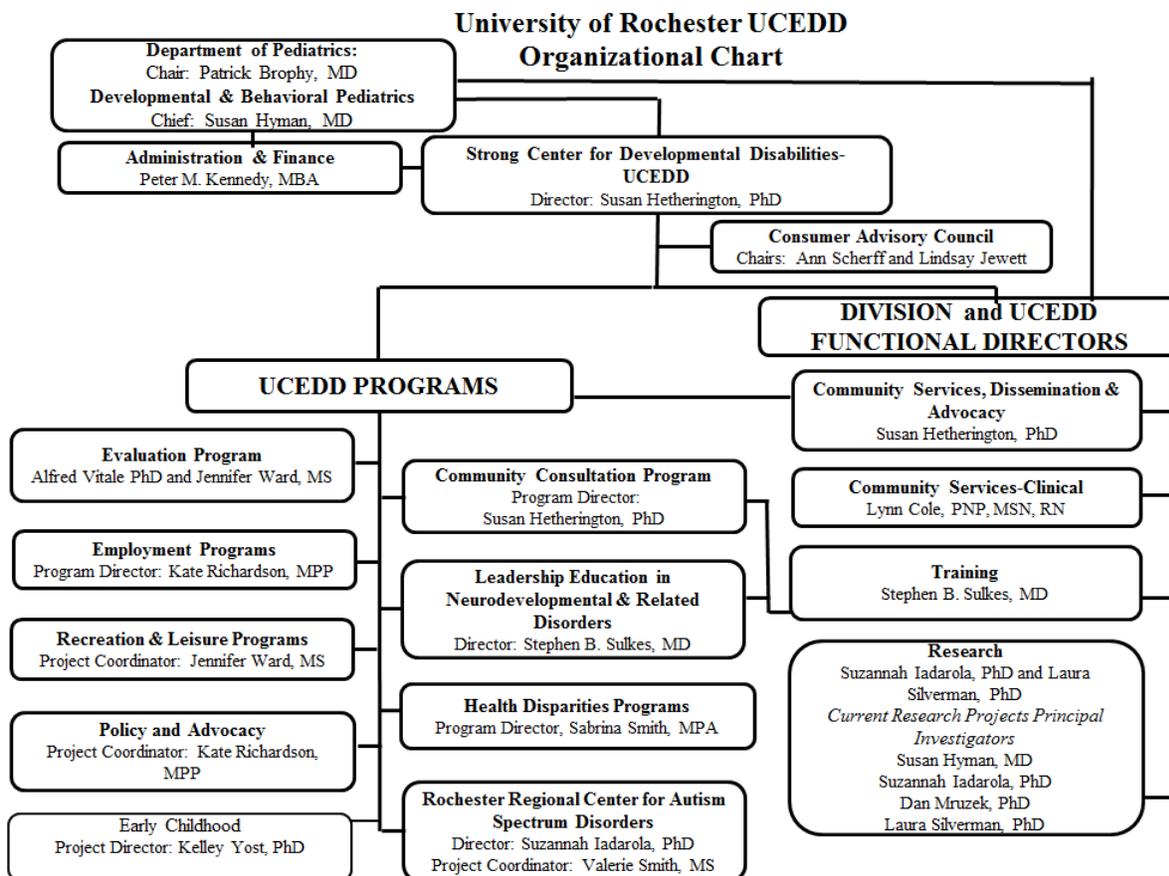
	6. Provide Interdisciplinary pre-service preparation and continuing education to current and future professionals in the area of recreation and leisure, leading to increased inclusive recreation opportunities.	Jennifer Ward	Year 5 = Conduct trainings for direct providers throughout the year; LEND preservice training to occur in months 2-11												
Provide Community Services and Education to promote self-direction, healthy living, inclusive communities, and self-advocacy in a culturally and linguistically competent manner	1. Conduct trainings for educational and administrative providers on maximal inclusion of individuals with IDD in their educational environments and transition into adulthood	David McAdam	X	X	X	X	X	X	X	X	X	X	X	X	Year 5 = Execution of annual consultation contracts and offering of ad-hoc workshops/technical assistance sessions; conduct teacher burnout prevention sessions in school districts
	2. Provide services and supports to increase competitive, integrated employment of people with intellectual and developmental disabilities	Kaitlyn Richardson ; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	X	Year 5 = Execution of annual contracts for Project SEARCH, as well as state funders; continue execution of the Employment Discovery Network curriculum
	3. Support caregivers of individuals with IDD in their physical and emotional well-being	Suzannah Iadarola			X	X							X	X	Year 5 = Conduct Fall and Spring mindfulness sessions for caregivers
	4. Share best practices aimed to increase family engagement outcomes in the early intervention program with providers, county officials, and families	Susan Hetherington		X	X	X	X	X	X	X	X	X	X		Year 5 = Hold 10 monthly education sessions of family-centered practices
	5. Improve community services to be responsive and accessible to the needs of people with I/DD	Sabrina Smith			X	X	X	X							Year 5 = Conduct community education for individuals with IDD to increase knowledge to support physical and behavioral health
				X	X	X	X	X	X	X	X	X	X	X	X

	6. Improve services for people with I/DD and their families to reduce health disparities	Lynn Cole; Sabrina Smith	Year 5 = Conduct annual cycle of Spanish interpreter training; conduct healthcare provider training on knowledge of family experience																						
	7. Provide services and supports to increase inclusive recreation and leisure opportunities for people with intellectual and developmental disabilities	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	Year 5 = Execute contracts and annual training commitments with recreation providers; coordinate around annual inclusive play events											
Conduct federally and independently-funded research studies and program evaluations to ensure dissemination of evidence-based information and interventions and to gain new knowledge related to best supporting individuals with IDD from diverse backgrounds	1. Conduct research and evaluation to enhance the inclusive educational opportunities for people with intellectual and developmental disabilities	Suzannah Iadarola	X	X	X	X	X	X	X	X	X	X	X	Year 5 = Continue recruitment, intervention, and data collection for IES and NICHD grants and continue relationships with community research partners; execution of ongoing studies (e.g., DoD); prepare and submit new grant for external funding											
	2. Conduct research and evaluation to enhance the integrated, competitive employment of people with intellectual and developmental disabilities	Kaitlyn Richardson	X	X	X	X	X	X	X	X	X	X	X	Year 5 = Conduct annual Project SEARCH evaluation; disseminate community reports on post-secondary needs assessment; evaluate ongoing outcomes from the Employment Discovery Network; evaluate employer trainings conducted throughout the year											
	3. Conduct at least 5 research studies/evaluations per year to enhance the physical and behavioral health of people with IDD throughout the lifespan	Steve Sulkes; Sabrina Smith	X	X	X	X	X	X	X	X	X	X	X	Year 5 = Continue with annual Geo-Mapping; engage in ongoing data collection for Health Literacy grant; manuscript submission for obesity in autism study; continue recruitment and data collection for OB-GYN provider-focused pregnancy grant											
	4. Evaluate caregiver stress programs and their impact on family physical and emotional well-being	Suzannah Iadarola	X	X	X	X	X	X			X	X		Year 5 = Conduct evaluation of caregiver mindfulness program in Spring; begin recruitment and data collection for caregiver stress study											
	5. Conduct research and evaluation in the area of inclusive recreation and leisure options for people with	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	Year 5 = Conduct community recreation needs assessment; provide training to recreation providers throughout the year and continue with annual program evaluations											

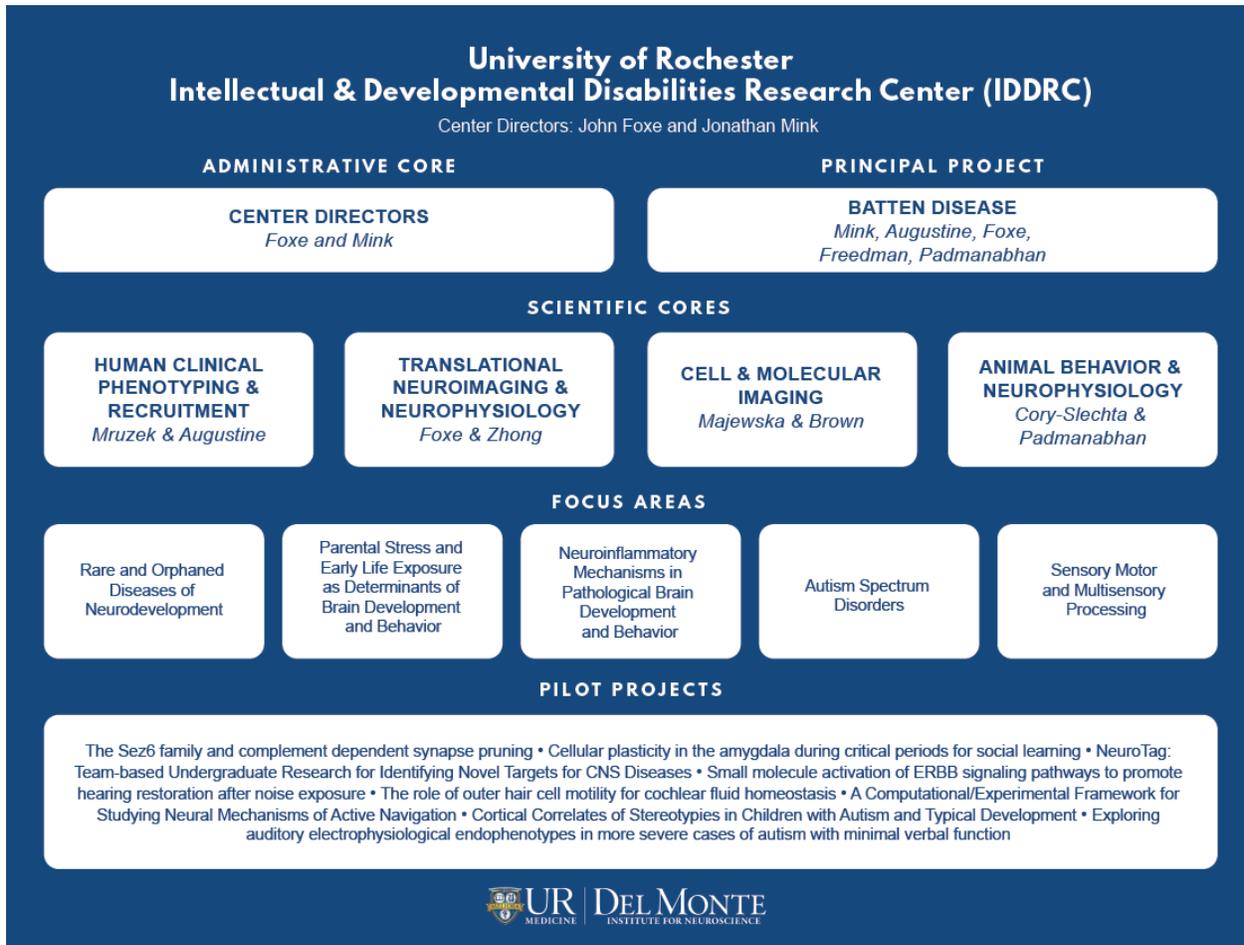
	intellectual and developmental disabilities													
Disseminate culturally competent information, provide advocacy, and promote policies in the service of community inclusion in all of its facets, self-direction, and healthy lives to people with disabilities, their families and communities, agencies, legislators, and others affecting the lives of people with disabilities	1. Engage parents in the process of high expectations and future dreams for their children	Susan Hetherington; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	
			Year 5 = Execute webinar series and disseminate infographics on family expectations; conduct trainings on engaging students with IDD in IEP process; continue development and dissemination of layperson research summaries											
	2. Equitably disseminate evidence-based information, services, and supports for people with IDD to all communities	Suzannah Iadarola	X	X	X	X	X	X	X	X	X	X	X	X
			Year 5 = Continue engaging in regular sharing of research results with community (e.g., via webinars, infographics); continue to share evolving evidence-based findings and information at community meetings throughout the year											
	3. Provide information dissemination and advocacy to support increased employment outcomes for people with IDD in New York State	Kaitlyn Richardson ; Jeiri Flores	X	X	X	X	X	X	X	X	X	X	X	
			Year 5 = Continue education and advocacy around Employment First policy; provide statewide education on systems change in employment; engage in state and federal-level advocacy for culturally responsive employment services											
	4. Provide information dissemination and advocacy to support increased inclusive recreation and leisure opportunities for people with IDD	Jennifer Ward	X	X	X	X	X	X	X	X	X	X	X	
			Year 5 = Disseminate inclusive recreation campaign videos; continue meeting process for Interfaith Inclusion Network and work toward shared goals/objectives; continue relationship with local advocacy groups supporting safe, inclusive play environments; disseminate information sheet about importance of inclusive recreation											

APPENDIX E

Strong Center for Developmental Disabilities Organizational Chart.



Institute for Intellectual and Developmental Disabilities Proposed IDDRC Organizational Chart.



APPENDIX I

Glossary of Acronyms

ACO = Accountable Care Organization
AIDD = Administration on Intellectual and Developmental Disabilities
AIR-B = Autism Intervention Research Network on Behavioral Health
ASD = Autism Spectrum Disorder
AUCD = Association of University Centers on Disabilities
CAC = Community Advisory Council
CoP = Community of Practice
DBP = Developmental and Behavioral Pediatrics
DDPC = Developmental Disabilities Planning Council
DRNY = Disability Rights New York
ECHO = Extension for Community Healthcare Outcomes
HBCU = Historically Black Colleges and Universities
HRSA = Health Resources and Services Administration
IDD = Intellectual and Developmental Disabilities
IDDRC = Intellectual and Developmental Disabilities Research Center
IES = Institute for Education Sciences
LEND = Leadership and Education in Neurodevelopmental Disabilities
MCHB = Maternal and Child Health Bureau
NIH = National Institutes of Health
NYS = New York State
OPWDD = Office for People with Developmental Disabilities
P&A = Protection and Advocacy
PECAN = Parent Engagement Collaborative Action Network
PWD = People with Disabilities
RMAPI = Rochester-Monroe Anti-Poverty Initiative
SCDD = Strong Center for Developmental Disabilities
URMC = University of Rochester Medical Center
UCP = United Cerebral Palsy

APPENDIX O

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