University Center for Excellence in Developmental Disabilities (UCEDD) at the UC Davis MIND Institute, 2016-21

+Core Grant Proposal

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Project Title: University Center for Excellence in Developmental Disabilities (UCEDD) at the UC Davis MIND Institute, 2021-26

A. Summary/Abstract

The Center for Excellence in Developmental Disabilities (CEDD) at the UC Davis MIND Institute, in partnership with people with disabilities and their families, DDNP, and other key stakeholders, will address the needs of Californians with DD through a range of programs focused on improving health and health care, supporting leadership development, and enhancing quality of life, especially in the areas of childhood intervention and transition to adulthood. Our **goals and objectives** are based on the core functions specified by the DD Act: 1) expanding capacity to address the needs of people with DD and their families by providing pre-service interdisciplinary training and continuing education; 2) ensuring access to high quality community services for people with DD and their families through training and technical assistance, including support for self- and community-advocacy in underserved communities; and providing model quality health care services; 3) conducting translational research on treatments for people with DD; and 4) increasing knowledge about resources of the DDNP through information dissemination. Anticipated **outcomes** include: 1) improved quality of life for people with DD and their families consistent with their cultural values, and 2) improved quality of healthcare and intervention services for people with DD that incorporate evidence-based practices (EBP) and reflect individual and family culture, language and traditions. The expected **products** are training (pre-service, continuing education, and community training); annual conferences; educational videos; technical assistance/ partnerships in the Latino, African-American, and Asian communities; Community Engagement and Resource Center; website; Family Navigator; Redwood SEED scholars; advances in state legislation and interagency coordination on DD support programs; clinical services; and presentation of research findings. All activities are conducted in partnership with people with DD and their families.

B. Problem Statement (Problem Relevance and Need)

California (CA) is the most populous state in the nation, with over 39.5 million people.[1] The state is among the most diverse, with Non-Hispanic Whites comprising 38.3% of the total population, compared with 76.3% nationally.[2] The Hispanic population is 39.4% of the population, and sizable proportions are Asian-American (14.8%), African-American (7%), Native American (2%), Native Hawaiian and Other Pacific Islands (0.4%) some other race alone (13.7%) and two or more races (5.0%).[1] Over one-quarter (27%) of CA population (>10 million), were born outside of the US, which is twice the proportion in the US (nearly 14%).[3] About half (45%) of CA citizens are speakers of a non-English language. The most common non-English language in CA is Spanish followed by Chinese and Tagalog. Nearly half (49.1%) of California's under-age-18 population has at least one foreign-born parent.[4]

Key Abbreviations (Terms and Agencies)
DD: Developmental Disability
ASD: Autism Spectrum Disorder
ADHD: Attention Deficit Hyperactivity Disorder
ID: Intellectual Disability
CA: California
DBP: Developmental Behavioral Pediatrics
EBP: Evidence-Based Practice / Promising Practice
CEDD: UC Davis Center for Excellence in DD
SCDD: State Council on Developmental Disabilities
SSAN: State Self Advocacy Network
DRC: Disability Rights California
DDNP: DD Network Partners (SCDD; UCLA and USC UCEDDs; DRC)
DDS: CA Department of Developmental Services
CDE: CA Department of Education
DOR: CA Department of Rehabilitation
FQHC: Federally Qualified Health Clinic

CA has the nation's highest percentage of urban dwellers according to US Census, but, due to the size of the population, the state also has the eleventh largest rural population in absolute numbers.[5] The proportion of Californians living in poverty or near poverty is 18.1%, higher than the US as a whole at 13.2%.[6] The absolute number of Californians living in poverty is the highest in the nation, with more than 7.5 million (1.5 million more than 5 years ago) people living below the poverty line.[7] The size and diversity pose unusual challenges to the equitable provision of health care and educational services to children and adults with developmental disabilities (DD) in CA.

Current estimates are that 9.5 million children, or about one in six children in the US, has one or more DD such as autism spectrum disorders (ASD), cerebral palsy, intellectual disability (ID), and attention deficit hyperactivity disorders (ADHD).[8,9] The CA State Council on Developmental Disabilities

(SCDD) estimates the number of people in CA with DD is currently more than 600,000.[10] CA is unique in the nation because of entitlement legislation, the *Lanterman Developmental Disabilities Services Act*, which established (in 1969) the right to treatment and habilitation services for Californians with DD and created 21 Regional Centers which receive funding from and report their caseloads to DDS. However, because eligible conditions are tied to only four major diagnoses (intellectual disability, autism, cerebral palsy and epilepsy), Regional Centers serve only one third of Californians with DD as defined by the DD Act. Between 1997 and 2015, the number of children under age 3 served by DDS more than tripled, increasing from 15,115 to 41,164, primarily due to increasing identification of children with ASD.[11,12]

B.1. Needs to be Addressed

Meeting the needs of Californians with DD requires effective advocacy and concerted effort by constituent groups working together to maximize each other's strengths and resources. University Centers for Excellence in DD (UCEDDs) play the important role of bridging community and campus in the specific functions of pre-service professional training, community training and technical assistance, community service, research, and information dissemination. The CEDD at the UC Davis MIND Institute (Medical Investigation of Neurodevelopmental Disorders) will continue to address the identified needs of Californians with DD through an expanding range of programs focused on improving **health** and health care, supporting **leadership development**, and enhancing **quality of life,** especially in the areas of early identification and intervention, ASD, post-secondary education, and employment.

Most of our projects serve the entire state of CA. Due to the size of the state (nearly 800 miles long) and the presence of two UCEDDs in the Southern CA, several of our projects focus on Northern CA which spans the state's northernmost 48 counties (21 rural), in contrast to 10 counties in Southern CA. Northern CA accounts for ~ 60% of the geographic area and only 40% of the population.

Health and Health Disparities

The demographics for Sacramento and Northern CA suggest that the challenges in health care and education are exacerbated relative to CA as a whole. A recent report ranked Sacramento the fourth most racially and ethnically diverse large city in the US. The percentage of people living in poverty is substantially higher in Sacramento (21%) compared to the mean for CA (17%). The four lowest ranking counties in CA in terms of health outcomes are in Northern CA (Lake, Siskiyou, Trinity, and Modoc).

With a current rate of 1 in 54 children,[13] the increasing prevalence of ASD strains the availability of quality healthcare resources and urgently needs to be addressed. In 2008, 20% of the DDS caseload had ASD and in 2018 this proportion had risen to 37%.[11,12] Studies of health services for people with ASD and DD in the US have found large disparities across ethnic groups. For instance, African-American and Latinx children are much less likely to be diagnosed with ASD than Non-Hispanic Whites and more likely to be identified later.[14,15] Children of color who have ASD have poorer access to all types of health care and education, are more likely to be misdiagnosed, and receive lower quality care from providers who lack cultural competence.[16] A recent review found no evidence that these disparities declined over time.[17] Individuals of color with ASD are underrepresented in research studies due to the cumulative effect of a range of social disadvantages.[18,19,20]

Two groups in CA, Latinos and Southeast Asians, are more likely to receive poor care for slightly different reasons. Both groups share high proportions of linguistically isolated households, in which no one over 14 is proficient in English. The proportion of linguistically isolated households in CA is more than twice the proportion in the US, 17.1% vs 8.2%.[21] The Southeast Asian population in CA is comprised largely of Vietnamese and Hmong residents, many of whom originally arrived in the US as refugees. In the CA public school system, Asian students are proportionately half as likely to receive special education services as Non-Hispanic White students.[22] Furthermore, even when referrals occur and services are accepted, actual expenditures for DDS services are lower for Southeast Asian clients.[23] The

Latinx population in CA is overwhelmingly of Mexican origin and includes a large number of seasonal workers and undocumented individuals. Undocumented children, raised entirely within the US, are at particular disadvantage in accessing care, likely due to difficulties in navigating bureaucratic systems.[24,25][1,2] One of the most frequent barriers to ASD identification in CA Latinos is limited access to a Spanish language developmental (10%) and ASD (29%) screening and developmental specialists.[24,26] Data from Alta California Regional Center for 2020 indicate that per capita expenditures for non-White clients were considerably lower than for White clients: $11,512 for Latinx, $19,823 for Black/African-American, and $19,534 for Asian clients, compared to $24,564 for White clients.[27] Despite attempts to reduce these discrepancies, they have changed little since data reporting has been mandated.

The shift to tele-services during the COVID-19 pandemic has further exacerbated service disparities given that low income families have lower rate of home broadband access (59%), internet use (82%) and basic digital literacy (53%).[28] Black and Latinx families' disparities in access to behavioral health programs have increased with a shift to tele-services. [29] A survey of CA parents of children with ASD/DD indicated significant unmet service needs. Approximately 50% of non-English speaking families reported not receiving school or therapy services during the COVID-19 crisis (compared to 20% of English-speaking families) and 74% of parents of individuals with ASD/DD reported losing access of at least one therapy or education services and more than a third lost access to a healthcare provider.[30]

Work is needed to identify culturally diverse strategies to effectively support parents of children and adults with DD. In 2018, we conducted focus groups with racially, linguistically and ethnically diverse families, primarily those living in poverty, with children with ASD, and their service providers.[19] Common service barriers included the stigma associated with ASD, lack of culturally matched providers, limited training in advocacy for families and culturally responsive care for providers, and low representation of families of color research. Another recent study found that development of culturally appropriate resources is well received amongst low-income, Latinx families in Los Angeles, with 90% wanting additional materials. Additional work to advance our understanding and implementation of culturally sensitive materials for DD is needed.[31] This is an active area of collaboration across the DDNP.

The transition from pediatric to adult healthcare is especially difficult for people with DD. A child with complex, chronic needs may have been cared for by the same pediatric team for many years and leaving this medical home can be very stressful. The difficulty is compounded by the severe shortage of adult care physicians with any training in DD, and the scarcity of physicians who accept Medicaid. Most health care systems provide little transition support to patients and their families. Training for healthcare professionals rarely includes transition planning for people with DD and their families, particularly around health-care decision making. People with DD experience poorer health than the general population, including higher rates of epilepsy, behavioral/mental health problems, fractures, skin conditions, poor oral health, respiratory disorders, overweight and obesity, and vision and hearing problems. They are subject to "diagnostic overshadowing" in which behavior mental health or physical disorders are erroneously attributed to the disability. Diagnosis and treatment are complicated by communication difficulties, lack of continuity of care, difficulties in accessing care, and inadequate training of health professionals.[32,33] These disparities are accentuated in Black and Latinx adults with DD who have poorer health and mental health than White adults.[33] It is critical these disparities be addressed through innovative measures that address social determinants of health and systems change that addresses the requirements of Home and Community-Based Services in the CA Transition Plan.

Leadership Development

Adequate recruitment and training of professionals and self- and community advocates, especially those who are culturally and linguistically diverse, is critical to the provision of quality services for people with DD. All professionals who work with people with DD, including physicians, nurses, psychologists, other healthcare workers, social workers, advocates, teachers, and others, need to have an understanding of early identification, intervention, service provision, inclusion, cultural responsivity, and other medical, legal, social and policy issues related to disabilities. Additionally, we need to support leaders in these professions, as well as family members and self-advocates, with diverse backgrounds to support our diverse population more effectively.

Severe shortages in developmental behavioral pediatrics (DBP) are adversely affecting patient care. According to the American Board of Pediatrics, less than one DBP is available for every 100,000 children in CA.[34] Most DBPs are located in urban areas, so it is not uncommon for families in outlying areas to face trips of up to 80 miles for an office visit.[35] As DD prevalence increases, it is imperative that health care professionals are well trained to address the complex medical needs as well as physical, emotional and behavioral challenges involved in their care.[36] Children with DD experience more hospitalizations than other children and have more difficulty coping and cooperating in health care settings because of challenges to understanding, communication, mobility, anxiety and behavioral regulation.[37–39] Children with DD experience an increased burden of unmet needs and decreased satisfaction with hospital care compared with typically developing children.[37,39–41] They are more likely to react to changes in their usual routines with aggressive behaviors that impact the provision of care and length of hospital stays, as well as the safety of both patients and staff.

Families of children with DD often feel stressed and isolated in trying to navigate complex systems of health care, education and developmental services. This is especially true for immigrant families, families who have limited English and families of color. Health care professionals routinely report feeling insufficiently trained, particularly in acute care/hospital settings, to provide high-quality care for children with DD and their families even though promising practices are being developed.[36,42,43] Developing strong leaders who can advocate at the personal and system level is key to addressing these challenges. CEDD will develop diverse leaders by partnering with our LEND, Intellectual and Developmental Disabilities Research Center (IDDRC) and Autism Center for Excellence (ACE) to leverage resources and training to interdisciplinary providers and family members of individuals with ASD/DD, students, trainees and self-advocates to become leaders who advocate for people with ASD/DD and work to improve the system of care.

Quality of Life

Early Intervention and Education. CA has a complex system of funding for early intervention services for infants, toddlers and preschoolers. Some services come through DDS, some through Special Education Local Planning Areas (SELPAs). The funds in both are inadequate in most regions for meeting the state's obligations. Because of limited public funding, fewer than half of the 3 and 4-year-olds, eligible for publicly funded programs, are served by those programs.[44] However, recent changes recommended by the CA Health and Human Services Agency may help increase equitable access to care for historically underrepresented groups including those with DD. CA is moving toward universal preschool to advance outcomes for all children by increasing access to care in high poverty areas and growing the quality, size, and stability of the early learning and care workforce through improved and accessible career pathways, and competency-based professional development.[44]

Recent changes to the funding and accountability system (i.e., local control funding and accountability) and the addition of the CA School Dashboard have shone a light on student groups most in need of additional supports. This includes students of color, English language learners, and students with disabilities. In CA, 11.7% of students (>725,000) qualify for special education. According to the Dashboard, students with disabilities perform extremely low in most areas including English, mathematics, and college/career preparation. These gaps may be even greater for students with DD who live in poverty (88%) or are English language learners (84%). CEDD has clear expertise and leadership in developing educational innovation, state-of the-art research and system-wide support.

Quality of Life in Adulthood. People with DD face many obstacles to becoming independent, productive and fully participating members of the community, to living life based on their own personal preferences and attaining physical, emotional, social, and economic well-being. Support services that would enable people with DD to achieve higher levels of education and pursue employment opportunities are currently inadequate. We know this anecdotally from our CAC and the people we work with in the community, as well as from the statistical data. In CA, only 11% of students with disabilities are prepared for the transition to adult life,[45] and only 50% of families report having a transition plan and of those only 55% had a plan that included employment.[46] May people with DD experience further challenges due to language barriers and lack of cultural competence.[47] According to data from CA's DDS, a majority of young adults with DD continue to live at home after high school and remain in segregated services.

Workforce participation is associated with life satisfaction, mental, and physical health for people with DD.[48] Not surprisingly, most individuals (70%) with DD want to work.[49] However, the percentage of working-age people with disabilities in the labor force is about one-third that of persons with no disability. The SCDD provides comparative employment data for CA and the US. While 76.5% of Californians were employed in 2016, only 14.2% of those with DD, were employed. CA employment rates for people with all disabilities are considerably lower than national rates (22.5% and 33.5%, respectively).[3] Workers with disabilities face significant gaps in pay, compared to workers without disability.[4] Of the 160,000 adults served by CA DDS in 2020, only 13.5% worked for wages. CA has prioritized competitive integrated employment and self-determination; however, systemic change requires collaborative, committed, and continuing support and oversight to make significant gains. Our growing CEDD team has provided consultation and growing research in this area.

Emergent Issues.

The COVID-19 pandemic has raised additional emergent issues for people with DD and their families which our UCEDD, along with DDNP, is addressing. For example, people with DD are more likely to have become unemployed due to the pandemic and will likely have a more challenging time finding new employment.[50] At the same time, the shift to working from home has opened up new opportunities for many people with DD.[51] Our CEDD is working with DDNP, DDS and the Department of Rehabilitation to consider ways to support people with DD in returning to work and how to harness this opportunity to reduce reliance on sheltered employment in favor of supporting additional competitive inclusive employment opportunities. DDNP are partnering to ensure equal access to COVID-19 vaccines using recent funding from the federal government. Leveraging our partnership and CA systems of care partners we can make a greater long-term impact on vaccine access. Additionally, issues related to racial and ethnic disparities in our nation have been highlighted and require consistent partnership with cultural brokers with lived experiences who can link CEDD and DDNP to people with DD and their families in historically underserved areas and populations in CA.

B.2. Input from Constituents and Partners in Needs Assessment and Priority Setting

To develop our five-year plan, we conducted a multi-layered needs assessment. In addition to reviewing the current literature, state and national statistics, state surveys, DD partners' strategic plans, and results of planning studies, we assessed our CEDD's strengths and opportunities. We participated in ongoing collaborative planning with DDNP, our CAC, and key stakeholder groups, purposefully including people with DD and families from a multitude of backgrounds. We worked with the MIND Diversity, Equity and Inclusion (DEI) Committee to conduct a needs assessment for historically underserved members of our community, staff, trainees, and faculty.

The CEDD at the UC Davis MIND Institute embraces self-determination as a core value and strives to include people with DD and their families in all our core functions. The primary vehicle for consumer input is our Community Advisory Committee (CAC); see section E.2 for a detailed description. The CAC meets three times a year, and most members participate in CEDD committees and projects as well. Needs assessment and priorities for this application were actively discussed at our CAC meetings beginning in October 2019. This included small and large group discussions and input into goals and objectives, areas of emphasis, and projects. Partner organizations shared their current goals and strategic plans to ensure alignment and ongoing partnership (e.g., DDS, HHS, Family Voices, and State Network of Family Resource Centers). The CAC has strongly endorsed prioritizing community service and training projects, which is reflected in this proposal in continued expansion of activities in these areas.

Community input on needs and priorities was also solicited from a wide array of groups, including CEDD committees and workgroups (Training, Early Intervention, Assistive Technology, and Transition), CEDD staff and faculty, and focus groups in the Latinx, Asian, and African American communities led by CEDD staff who are family members representing those communities. The CA Department of Public Health MCAH Division recently completed its 2016-2020 needs assessment and strategic plan, and review and incorporation of this material was included in our strategic planning.

Our CEDD works with the CA DDNP on needs assessment and strategic planning on an ongoing basis. California's DDNP consist of the SCDD, Disability Rights CA (DRC; protection and advocacy), and California's three UCEDDs, including our CEDD, the Tarjan Center at UCLA, and the USC UCEDD at Children's Hospital LA. The DDNP directors meet regularly to discuss collaborative activities, emerging needs and strategies for maximizing the use of collaborative resources to address identified needs. The directors all serve on the SCDD, and each partner is represented on the CAC of each UCEDD.

Several of the DDNP are in the process of updating their own strategic plans, with the SCDD planning finalized early last year and the other two UCEDDs by next year. Dr. Stahmer (Director) serves as a member of the SCDD State Plan Committee, which is responsible for statewide needs assessment, obtaining input from people with DD and their families through online surveys and town hall meetings, and analysis and development of the next five-year state plan for 2022-26. A total of 5,163 responses from people with DD and family members to the online survey were received and analyzed by the State Plan Committee and received public review. Members of our CAC provided input to the state survey, either online or through town hall meetings, and feedback regarding the survey results and State Plan objectives were shared at CAC meetings as our CEDD's five-year goals were developed. The SCDD needs assessment identified ten areas of emphasis, five of which are closely related to our UCEDD's areas of emphasis: community supports, education, early intervention, employment, health, and advocacy.

The DDNP have leveraged individual agency strengths and resources to promote systemic change to benefit Californians with DD by working closely together and supporting each other's activities to maximally leverage resources and avoid duplication of effort. The DDNP have developed a strategic crosswalk that identifies the shared goals, activities and resources between partners to most effectively address identified state needs and promote attainment of DDNP goals by analyzing the five-year plans of each partner for overlap and divergence. For each of our proposed 2021-2026 goals, we use this crosswalk to be explicit in our collaborative efforts.

B.3. Summary of Identified Needs, Community Input and 5-Year Plan

The goals and objectives for the next 5-year plan arose directly from identified needs, community input from stakeholders including people with DD and their families, and state of the science as they align with the goals of the DD Act. We updated and expanded our curriculum, services and research to reflect increased need for distance learning and leveraging new ideas from the COVID-19 pandemic to increase access to services for stakeholders in rural and underserved areas. We have increased efforts to provide culturally and linguistically responsive programming that increases understanding of the role of systemic racism in disparities for people with DD and their families to support leadership and policy that can improve systems. We are increasing our focus on implementation science and academic-community partnerships and partnership with our IDDRC to ensure the voices of people with DD and their families, especially from historically underrepresented groups, are included in research and clinical services. Our CEDD is strengthened by increased training opportunities with our NorCal LEND program. We increased our peer mentorship programs to provide culturally and linguistically matched support to more diverse communities and to build cultural brokers to improve access to research and care. Our clinical services are expanding outreach to increase capacity in federally quality health clinics (FQHC). We increased training in diversity, equity and inclusion for our CEDD and MIND staff, faculty, and trainees. These changes are reflected in the approach, intervention, logic model and work plan.

C. Approach

The MIND Institute is a collaborative international research center, committed to the awareness, understanding, prevention, and treatment of the challenges associated with DD. Since its inception in 2006, the Center for Excellence in Developmental Disabilities (CEDD) has successfully leveraged the translational impact of research from the MIND Institute, expanded initiatives in the areas of training and community service, and served to strengthen links between the university and the community of people with DD and their families in CA.

The CEDD mission is to work with people with DD and their families to improve quality of life and community inclusion. In the nearly 15 years since the establishment of the CEDD, we have created a successful and expanding infrastructure to support an increasing array of activities in all the core functions specified by the DD Act, including pre-service interdisciplinary training, community service, research, and information dissemination. We will continue this work and increase our focus on implementation science and building expertise in community partnered research. Our areas of emphasis have expanded from the initial primary focus of the MIND Institute on research to include: **Health**, **Leadership development**, and **Quality of life** (emphasizing self-advocacy, early identification, early intervention, education, employment, and transition to adulthood). Based on CAC input, these are areas where we continue to focus our program development efforts, in collaboration with our DDNP and community partners. In terms of research, our CAC has been particularly interested in dissemination of research findings and in developing academic-community partnerships to increase the relevance of research and research participation by historically underserved populations, activities which are complementary to the MIND research activities but not supported by research funds.

C.1. Goal and Objectives

CEDD goals and objectives build on the successes of our prior 5-year plan. We met or exceeded all benchmarks and goals and addressed emergent issues in our state. Each goal includes an emphasis on ensuring cultural and linguistic competence. Our CEDD team and CAC use the AUCD Diversity and Inclusion Toolkit to ensure diversity and equity objectives in each goal. All goals have associated projects and objectives with measurable outcomes that will be reviewed at least annually by the CAC. See **Appendix A** for the complete work plan and section C.2 for project details.

Table 1. CEDD Goals and Objectives

Goal 1. Interdisciplinary pre-service preparation and continuing education: Expand capacity to address the needs of people with disabilities and their families by providing interdisciplinary pre-service and continuing education for trainees and professionals from multiple disciplines.
Area(s) of Emphasis / Activity Type: Leadership Development, Health, and Quality of Life /Capacity Building
Objective 1a: Provide training in serving persons with DD to students in medicine, nursing, special education, psychology, and related fields. Benchmarks: 2-3 DBP Fellows; 8-12 grad trainees annually **Objective 1b**: Participate in broader university academic programs that prepare personnel in a wide range of social and community roles that will contribute to the accommodation and inclusion of people with DD. Benchmarks: 5 lectures or seminars per quarter **Objective 1c**: Provide continuing education courses on DD and support services to enable healthcare/education/other professionals to expand their knowledge base and stay up-to-date on new developments. Benchmarks: 8 CE courses annually
Goal 2. Community Services – Training and Technical Assistance: Expand community capacity to provide quality services to people with disabilities and their families, through training, outreach, and use of implementation science to increase innovative policies and practices in community settings.
Area(s) of Emphasis / Activity Type: Quality of life, Health, Leadership Development / Advocacy, Capacity Building
Objective 2a: Strengthen advocacy skills for people with DD and their families, with special emphasis on underserved communities, through outreach, workshops, parent and sibling groups, networking, training materials, technical assistance, and website resources. Benchmarks: 3-4 events/quarter; mentorship for 100 families annually; 4+ sibling groups annually; TA to 200+ people with at least 30 people with DD; family navigation to 50+ families annually **Objective 2b**: Provide community training opportunities for consumers, families, service providers, and professionals to increase their knowledge and skills in the areas of DD, service provision, inclusion, and other medical, legal, social and policy issues related to disabilities. Benchmarks: 25 community training events/quarter; 4+ Autism ECHO groups annually **Objective 2c**: Provide technical assistance and leadership for development of infrastructure, interagency communication and collaboration to improve early intervention services to children aged 0-5 with DD. Benchmarks: 10-20 hours of TA/quarter

Objective 2d: Provide technical assistance and leadership at the state level for development of infrastructure, interagency communication and collaboration to ensure high quality and equitable intervention services to children and youth with ASD. Benchmarks: 100 hours TA/quarter **Objective 2e**: Provide technical assistance and leadership for development of infrastructure, interagency communication and collaboration to support transition to adulthood for people with DD. Benchmarks: Monthly interagency employment council meetings; 3+ supported decision-making training annually; 10+ family consultations quarterly; support 10+ students with DD at UCD through Redwood SEED scholars program. **Objective 2f**: Expand equitable access to quality assistive technology for people with DD and their families in the community. Benchmarks: 10 + hours TA to new community leader of AT consortium; attendance at consortium meetings; consortium sustainment in community **Objective 2g**: In collaboration with DD Network Partners, identify and take steps to address systemic barriers and issues that impact the full participation, community integration and inclusion of people with DD and their families. Benchmarks: 3 collaborative projects/quarter
Goal 3. Community Services – Model Clinical Services: Provide quality, equitable health care for people with DD.
Area(s) of Emphasis / Activity Type: Health, Leadership Development, Cultural, Linguistic Comp / Capacity building
Objective 3a: Provide quality healthcare in specialty areas, including autism spectrum disorder, fragile X syndrome, 22q deletion syndrome, intellectual disability, High Risk Infant Follow Up, anxiety disorders, ADHD, and feeding disorders. Benchmarks: 1500 NDD Clinic patients; 40 feeding clinic patients; 20 Chromosome 22q11.2 deletion syndrome patients; 40 social skills clinic & ACCESS participants; 80 CIRCLE clinic participants; 20 DBP telehealth partnership patients
Goal 4. Research: Conduct research on etiology, treatment and services for people with DD; and translate research into practical applications with an emphasis on increasing participation of diverse groups based on race, gender identity, sexual orientation, etc.
Area(s) of Emphasis / Activity Type: Health, quality of life, and leadership development; System change, capacity
Objective 4a: Conduct research on etiology, treatment and services for people with autism spectrum disorders. Benchmarks: 15 published articles and 12 conference presentations annually **Objective 4b**: Conduct research on etiology, treatment and services for people with fragile X syndrome and associated conditions. Benchmarks: 12 published articles and 8 conference presentations annually **Objective 4c**: Conduct research on etiology, treatment and services for people with 22q11.2 Deletion Syndrome. Benchmarks: 2 published articles and 2 conference presentations annually **Objective 4d**: Conduct research on etiology, treatment and services for people with ADHD. Benchmarks: 2 published articles and 2 conference presentations annually **Objective 4e**: Conduct research on etiology, treatment and services across neurodevelopmental disorders**.** Benchmarks: 10 published articles and 6 conference presentations annually
Goal 5. Information Dissemination: Increase awareness and knowledge about the resources of the state and federal DD Network Partners through dissemination of research findings, public awareness materials, and other useful information to consumers, families, and professionals.
Area(s) of Emphasis / Activity Type: Quality of life, Health / Advocacy, Capacity Building
Objective 5a: Provide two conferences per year highlighting the translation of current research into clinical and community practice. Benchmarks: One English and one Spanish language conference with 300+ attendees and 3,000+ video hits annually **Objective 5b**: Develop training in community engagement and implementation science for community partners and researchers, with an emphasis on partnerships with diverse communities. Benchmarks:

Community partner database with 10+ new partners/year; 5+ presentations/quarter; 1 community/year

Objective 5c: Provide online resources and reference materials to people with DD, their families, service providers and professionals on topics related to health and wellness, early intervention, post-secondary education, employment, and inclusive volunteerism, so that people with DD can make better informed decisions about their lives. Benchmarks: 11,000 website hits/quarter; culturally adapt resources into 5 threshold languages.

Objective 5d: Disseminate research findings via refereed journal articles and conference presentations. Benchmarks: 50 refereed journal articles and 40 conference presentations annually

Collaboration with Developmental Disability Network Partners

The Directors of the CA DDNP (including USC and Tarjan Center UCEDDs) meet regularly to discuss emerging trends and strategic planning. As discussed in Section B.2., over the past 5 years the DDNP have been strategic in leveraging individual strengths and resources to promote systemic change to benefit Californians with DD in several areas. Examples of collaborative projects include:

(a) Addressing the mandate for linguistically accessible and culturally competent information relevant to the diverse communities of people with DD in CA, DDNP have worked to reduce service access barriers and decrease disparities in information describing services and supports that may be purchased (POS) through CA Regional Centers. Materials have been developed in plain language English, Spanish, Chinese and Vietnamese. The project tracks statewide POS data for Spanish-speaking self-advocates and families. This will expand in the coming strategic plan to examine disparity data beyond POS and work with diverse communities to improve access to care in CA.

(b) All partners participate in a Community of Practice to improve equity and diversity. This includes work with Georgetown National Center for Cultural Competence to develop diversity and equity plans in two CA Regional Centers, with a goal of expanding this model throughout the state.

(c) State partners quickly activated during the COVID-19 pandemic to collaborate with state agencies to support people with DD and their families in accessing services, personal protective equipment, health care, and most recently, vaccinations. We conduced stakeholder needs assessments, educated legislators about distance care and the special health care needs of people with DD to support timely access to vaccines. The DDNP support bi-monthly meetings with DDS to develop plain language resources detailing pandemic funding and service changes, COVID-19 and vaccine information, etc. We are developing a statewide plan for access to vaccines for people with DD.

Additional collaborative projects for which CEDD will continue to provide primary leadership include the CA Autism Professional Training and Information Network (CAPTAIN) and the CA Early Start Support Network (CESN), both in collaboration with DDNP, state, and community agencies (details in Section C.2. In the coming five-year plan, we have a primary role in the Redwood SEED Scholars project, the first residential college program for students with IDD in the UC system.

In addition to partnerships with the DDNP, the CEDD has a large and complex network of partnerships at the local, state, and national levels which enable us to accomplish the goals, objectives, and activities in our five-year plan, including reaching and supporting individuals with DD and their families across racial, ethnic and cultural groups, including limited-English speaking groups.

Our primary partnerships include:

1. Various departments and centers of UC Davis and California State University, Sacramento (CSUS);
2. State and local agencies, such as DDS and the Regional Centers; CA Department of Education (CDE), Diagnostic Centers, Special Education Local Plan Areas (SELPAs), local educational agencies (LEAs), schools; the Department of Public Health, the Department of Rehabilitation (DOR) and the Sacramento Employment Training Agency; research partners including the Autism Intervention Research Networks in Behavioral and Physical Health (AIR-B and AIR-P both have sites at UC Davis), local and state self-advocacy networks and family organizations, and a long list of community organizations. Details in Section E.2 and the work plan in **Appendix A**.
3. To further improve our impact related to diversity, equity and inclusion we work closely with the Georgetown National Center for Cultural Competence and the Transformative Justice in Education Center in the UC Davis School of Education to embed restorative and transformative justice

strategies in our CEDD programs and to integrate DEI strategies into our curriculum content with the goal of ensuring a clear focus on cultural responsiveness, diversity and equity. We partnered with UC Davis Health's Office of Health Equity, Diversity and Inclusion, UC Davis faculty (e.g., Dr. Johnson) and those from other institutions (e.g., Drs. Belcher and Stone from Kennedy Krieger Institute, Dr. Nadal from Columbia University) to further develop staff and faculty knowledge related to diversity and equity and to improve inclusion of people with DD from diverse backgrounds.

Utilization of Core Funding and Leveraging of Additional Resources

CEDD prioritizes the use of AoD core grant funds to support the infrastructure functions of staff leadership, the CAC, administration, communication, evaluation, and support to core staff to develop partnerships and proposals for additional funding. All expenses are related to the implementation of the four core functions and the administration of the Center. CEDD faculty and staff have a strong record of successfully leveraging core grant dollars. In the past five years, CEDD has leveraged more than $11 million per year in external funding for research, training, and community service projects. Examples include the Redwood SEED Scholars project, working with our Autism Center of Excellence to expand our Family Navigator program and develop the Autism ECHO project, leveraging our CAPTAIN investment to obtain CDE funding to become the statewide autism trainers, obtaining DDS funds to produce videos for diverse populations, and partnering with the AIR-B network and local Family Resource Centers to obtain DDS funds for implementation of a family navigator curriculum for families living in poverty. We are committed to continuing this pattern in the next funding cycle.

C.2. Proposed Intervention

Interdisciplinary Pre-Service Preparation Programs & Continuing Education

Goal 1. Interdisciplinary pre-service preparation and continuing education: Expand capacity to address the needs of people with disabilities and their families by providing interdisciplinary pre-service and continuing education for trainees and professionals from multiple disciplines.

The over-arching goal of the CEDD training program is to improve quality of life for people with

DD and their families by providing advanced training in interdisciplinary clinical, research and leadership skills necessary to improve health, systems of care delivery and community inclusion of people with DD. CEDD leverages the clinical and educational expertise at the MIND Institute and among CEDD partners, particularly those who represent both diverse interdisciplinary expertise as well as personal experience as a person with DD or family member, to provide interdisciplinary pre-service training and continuing education for students and professionals in medicine, allied health professions, education and educational administration. Over the last five years, we have improved our training programs by expanding the racial, ethnic and linguistic diversity and competence of our trainers and trainees. This is evidenced by (1) the proportion of our trainees from diverse backgrounds such as African American, Hispanic, and Asian, people who speak a language other than English, and family members of individuals with DD; and (2) our partnerships designed to expand DEI training and efforts at CEDD and MIND.

Participation in program planning and curriculum development by people with DD and their family members that reflect the cultural and linguistic diversity of CA is central to ensuring that a personal perspective on disability is included. We have partnered with neurodiverse students on campus and people with DD and their families in the community to share lived experiences in and out of the academic settings and serve as facilitators in training seminars, reflective practices and community site visits. The curriculum includes materials written, produced and shared by people with DD and family members. Our LEND program has further increased participation by family members and self-advocates.

CEDD faculty represent diverse academic disciplines and a mix of cultures that reflect the diversity of the community. Academic disciplines include Community Development, Early Intervention, Human Development, Genetics, Leadership Education, Special Education, Speech and Audiology, Physical Therapy Medicine, Nursing, DBP, Psychiatry, and Psychology; and students from all these departments at UC Davis and CSUS participate in CEDD programs. CEDD faculty reflect a mix of cultures, including African American, Asian/Pacific Islander, Hispanic, Native American, and White; and include people with disabilities and family members.

UC Davis has recruitment policies and strategies which encourage cultural diversity and cultural competence in the faculty and student body. The UC Alliance for Graduate Education and the Professoriate (UCAGEP) holds conferences and summer programs throughout the UC system specifically designed to target and recruit students from historically underrepresented groups, building a pipeline for ongoing recruitment through programs developed to reach promising junior high and high students, who would be the first in their families to attend college, along with our RISE-UP program. Our goal of working with trainees from groups historically underrepresented in universities and in professions is emphasized in all recruitment materials and activities. The UC Davis School of Medicine Strength through Equity & Diversity (STEAD) workshop aims to reduce bias in the hiring process and is attended by CEDD faculty involved in recruitment of faculty and trainees. We work closely with the UC Davis and CSUS Student Disability Centers and the UC Davis Disability Issues Administrative Advisory Committee (Dr. Stahmer is a member), to gain assistance in recruitment and to guide our faculty to maximize supports and resources for trainees with DD. One successful strategy has been to involve existing students in the recruitment process.[52,53] The success of efforts is evaluated annually based on recruitment data and strategies updated based on best practices and trainee input. Across the past 5 years of our program, 56% of our CEDD trainees have identified as Hispanic/Latinx or non-White and 43% have identified with a disability or as a family member, for a total of 75% (unduplicated) from underrepresented groups.

CEDD Interdisciplinary Pre-service Training Program

Objective 1a: Provide training in serving persons with DD to students in medicine, nursing, special education, psychology, and/or related fields.

CEDD has two interdisciplinary pre-service training programs, the Developmental Behavioral Pediatrics (DBP) Fellowship Program and the Interdisciplinary Graduate-level DD Training Program. Our three-year DBP fellowship program, one of 12 funded nationally by HRSA/MCHB and accredited by

ACGME, provides intensive training in DD to 2-3 pediatricians per year. The fellowship includes a didactic curriculum, training in clinical practice, teaching, and research; and has sustained stable funding.

The Interdisciplinary Graduate-level DD Training Program is designed to advance trainees' academic credentials and is open to our pediatric fellows, LEND trainees, and graduate students in medicine, nursing, education, psychology, speech language pathology, occupational therapy, physical therapy, social work and related fields at UC Davis or nearby CSUS. The focus is on the impact of disability and the provision of care to people with DD. Trainees receive instruction and practical experience in all UCEDD core functions, including teaching, community service, research, and dissemination. The program prepares trainees to be advocates, community leaders, and consumers of research as it informs practice and policy. The core curriculum is composed of didactic and experiential components, all of which are competency based. Areas of core competency include values/perspectives, interdisciplinary practice, person and family-centered care and education, research, policy and systems advocacy, and leadership. Trainees increase their knowledge of DD and exposure to medical, legal, social and policy issues related to disabilities. Trainings are co-led by persons with DD and family members, and field work with persons with disabilities is a major training component. Trainees participate in a variety of community programs and in clinics at UC Davis and regional FQHCs serving persons with DD across the age span. Trainees gain experience in partnering with service providers in rural communities by participating in telehealth assessment and virtual therapy programs that serve rural populations.

Trainees participate in a variety of learning experiences, including seminars/discussions, readings, and community experiences followed by interdisciplinary reflection and assignments linked to each activity. The core curriculum includes 1) Orientation to the CEDD and History of Disability, including DD Act, medical vs. social model, concepts of disability, and World Report on Disability; 2) Foundations in Disability, including screening for neurodevelopmental disorders (NDD) and early referral, fragile x syndrome, 22q11.2 deletion syndrome, ADHD, language delay, ASD, and diagnostic evaluation and treatment planning process; 3) Living with Disability, including systems of care (IFSP/Part C, IDEA/Part B, transition to adult services), conservatorship and shared decision making, community inclusion/self-determination, healthcare transition and needs, intimacy/sexuality, and aging with disability.

Each trainee partners with a person with DD and their family/support team to gain experience on living with disability. Trainees have participated with their disability partners in family dinners, sporting events, school and work routines, doctor appointments and other services. Disability partners represent a wide range of ages, race/ethnicities, disabilities, lifestyles, and experiences. Trainees and partners share their experiences with each other and reflect on living with a disability. During the COVID-19 crisis, trainees completed their work with families via video visits and had the opportunity to learn how the crisis affected people with DD and their families, how services changed, and the strategies and resources families accessed for support during the crisis. Each trainee completes a project or product relevant to their discipline. In a new program to expand our reach, CEDD sponsors a Medical Student Special Interest Group, a seminar series focused on the experiences of living with disability, perspectives on the intersection of disability, race and ethnicity, and the impact of disability on care.

Our DBP fellows participate in the NIH-funded Autism Research Training Program (ARTP) and LEND activities, and ARTP and LEND fellows can participate in the CEDD interdisciplinary training curriculum. We are responsible for the ARTP and LEND components on cultural competency and disability. Our LEND program has enhanced our collaborative interdisciplinary training resources with LEND trainees (including family members and self-advocates) participating in CEDD training programs.

Objective 1b: Participate in broader university academic programs that prepare personnel in a wide range of social and community roles that will contribute to the accommodation and inclusion of people with developmental disabilities.

CEDD Participation in Other Academic Programs

CEDD participation in broader graduate and undergraduate university academic programs that prepare personnel in roles that will contribute to the accommodation and inclusion of people with DD:

Training on DD and Neurodiversity to (other) Graduate Students

*1. Learning and Mind Sciences Program / Neurodevelopment and Educational Research Concentration***.** The Learning and Mind Sciences emphasis (LMS) within the UC Davis Graduate Group on Education, developed by CEDD faculty members Drs. Mundy and Sparapani, uses innovative and interdisciplinary research and training on the psychological, social, and neuroscience foundations of human learning. Within LMS, the program provides graduate training in a multidisciplinary integration of research and knowledge on neuroscience, developmental psychopathology, education and intervention science to construct the scientific foundations for improved school-based assessment and treatment of children and adults with DD including working with students with DD in the classroom.

2. Fundamentals of Developmental Behavioral Pediatrics. This small group seminar series for DBP fellows and UC Davis Year 2 Pediatric residents provides educational content covering Accreditation Council for Graduate Medical Education (ACGME) and American Board of Pediatrics (ABP) specifications. The goal is to build a strong foundation in developmental theories, milestones, biological mechanisms in development and behavior, temperament, attachment, family factors and social determinants of health, health inequities, the basics of screening and interdisciplinary developmental assessments, including psychometric properties and administration of developmental and behavioral evaluation tools.

3. UC Davis Nursing and Physician Assistant Programs. CEDD and LEND faculty including Charlene Singh, Ph.D., R.N., provide training to medical trainees in multiple areas related to DD: advocacy for families of individuals with DD across the lifespan, understanding the impact of early recognition and intervention in DD, exploring how community systems hinder or foster development, and issues related to health disparities in children with DD. CEDD faculty and staff support interaction with individuals with DD and their families. Trainees' experiences include implementation of care coordination and the medical care home, dual diagnosis and mental health, special education, community outreach, and advocacy for and with people with DD and their families.

4. Lectures. CEDD faculty deliver lectures on DD, autism, partnership with families etc. as part of the seminars and classes at UC Davis and other universities.

Training on DD and Neurodiversity to Undergraduate Students

1. "Educating Children with Disabilities" Courses & Seminars. CEDD faculty, Drs. Mundy and Sparapani, offer this course through the UC Davis Department of Education. The goal is to prepare general education teachers to deal with the diversity of children in a typical inclusive classroom, including best practices in working with children with DD. Topics include biological and cognitive foundations of exceptional learning needs, assessment and EBP for different types of learning difficulties, and professional and ethical practice with exceptional needs children and families. Students can enroll in an applied seminar in which they apply concepts learned in the course through presentations, reading and discussion to reflect on their teaching practice with feedback.

2. *MCHC/RISE-UP.* Since 2016, our faculty, led by Dr. Enriquez, have partnered with Kennedy Krieger Institute (KKI) and the UC Davis Office of Health Equity, Diversity and Inclusion to participate in this CDC-funded, undergraduate summer program which provides opportunities for enhanced public health leadership training to focus on elimination of health disparities and promotion of health equity. Consortium partners include: (1) KKI and the Johns Hopkins School of Medicine, Bloomberg School of Public Health, and Historically Black Colleges and Universities; (2) University of South Dakota with Tribal Serving Institutions; and (3) UC Davis MIND Institute. MCHC/RISE-UP's goal is to promote a more equitable health system by introducing qualified diverse undergraduate scholars to the field of public health. Our site emphasizes service for culturally diverse groups of children and families who experience health inequities within the community and encourages students to pursue careers caring for children with DD and mental health concerns. Our CEDD staff and CAC members mentor scholars, support research projects, and serve on panel presentations to share advocate, family and policy perspectives.

3. Lectures. CEDD faculty deliver DD lectures, often in partnership with individuals with DD, to various classes at UC Davis and CSUS.

Continuing Education

Objective 1c: Provide continuing education courses on DD and support services to enable healthcare/ education/other professionals to expand their knowledge base and stay up-to-date on new

These continuing education courses offer CME (continuing medical education) or CEUs (continuing education units) and contribute to maintenance of professional credentials. Our primary venues for CME/CEU courses are (1) our annual Summer Institute on Neurodevelopmental Disorders (additional information in Objective 5a); (2) our monthly Hearts and Minds Series, an interdisciplinary forum for clinical case discussions and presentation of translational research and EBP (10 sessions/yr); and (3) our new ECHO Autism program, which reaches providers in rural Northern CA to support access to care (details in Objective 2b). In addition, CEDD staff and faculty participate in Genomic Medicine, Pediatrics and Psychiatry Clinical Grand Rounds (monthly) and the MIND Research Seminar Series (bi monthly). All CE programs have successfully moved to remote learning during the COVID-19 restrictions.

Role of Individuals with DD and Their Families in Pre-service Preparation and Continuing Education

Our pre-service training program directly involves individuals with DD and their families to provide a unique perspective to our trainees. In most courses, trainings are co-led by persons with DD and family members, and community engagement with persons with DD is a major training component. Trainees participate in clinics and community-based programs serving persons with DD across the age span. Trainees partner with a person with DD and their support team to experience what everyday activities are like when living with disability. Individuals with disabilities and their families from diverse background review the curriculum for most courses and co-design and implement the Summer Institute.

Community Services – Training and Technical Assistance

Goal 2. Community Services – Training and Technical Assistance: Expand community capacity to provide quality services to people with disabilities and their families, through training, outreach, and use of implementation science to increase innovative policies and practices in community settings.

CEDD provides a comprehensive program of training, technical assistance, and model services targeted to individuals and families affected by DD, policy-makers, healthcare and behavioral health professionals, teachers, educational administrators, and other professionals, students, and members of the community. CEDD leverages the translational impact of MIND research through training and dissemination of the science of EBP for DD. Model community and clinical services, training and technical assistance activities have been developed directly from our needs assessments and work with DDNP, people with DD and their families, and community agencies. The goal of our programs is to build community capacity to address community needs of people with DD and their families in a culturally and linguistically responsive manner. Advocacy and outreach activities are focused on the meaningful inclusion of persons with DD and their families in all aspects of community life. CEDD is committed to meeting the needs of CA culturally and linguistically diverse communities and working towards effective outreach, education, and support strategies for underserved groups. All programs involve mentorship and training and use of implementation science methods to facilitate community integration and replication of EBP.

Responding to Emergent Community Needs. CEDD works with DDNP and community partners to ensure rapid response to community needs. This past year, we have had the opportunity to highlight this with the collaborative response to the COVID-19 pandemic (also see section C.1). Our CEDD mobilized to provide training and resources for teachers in supporting students during distance learning, move all of our programs into multiple distance formats (video, webinar, text, phone) to meet the varied needs of the community, developed strategies for distance diagnosis and treatment, increased programming to support caregiver well-being, and safe in-person clinical assessment and treatment when appropriate. In addition, our team is consistently responding to potential funding calls and community requests for technical assistance, training and services, as evidenced by new programs related to transition, family navigation for diverse communities, increased clinical services through telehealth and support for children seen in FQHC and other publicly funded programs.

Self- and Family-advocacy

Objective 2a: Strengthen advocacy skills for people with DD and their families, with special emphasis on underserved communities, through outreach, workshops, parent and sibling groups, networking, training materials, technical assistance, and website resources.

CEDD will continue working to strengthen advocacy and leadership skills for people with DD and their families, promoting the inclusion, integration, productivity, and human rights of people with DD and working towards creating a community that is enriched by their full and active participation and contributions. We have several advocacy projects underway, including participation in the Statewide Self-Advocacy Network (SSAN); parent and sibling projects in the Latinx, African-American, and Asian communities; our Resource Center; and our Family Navigator Program.

Robert Levy is a CEDD staff member and self- and community- advocate. He provides leadership on CEDD self-advocacy initiatives and is CEDD's representative to the SCDD Statewide Self Advocacy Network (SSAN), where he has become informed and advocated for issues affecting people with disabilities and has been elected to a leadership position in SSAN as Secretary. Robert continues to be involved in the efforts to implement Employment First and Self Determination legislation in CA, spearheading a letter writing campaign and testifying in support of legislation to eliminate sub-minimum wage employment for people with DD. He is active in California Autistic Self Advocates group. He participates in annual self-advocate panels for LEND and DBP fellows and presents often at AUCD.

We place a high priority on self- and family-advocacy efforts in the Latinx, African American, and Asian communities. Our staff reflects this racial/ethnic (and language) diversity and have many connections in the related communities. Our self- and family-advocacy efforts continue to expand and diversify, from self-help and support groups, to disability-related videos, to radio broadcasts. Projects involve strategic outreach into underserved communities through partnering with community leaders and organizations to engender disability awareness and importance of EBP. CEDD and CAC members promote self- and family-advocacy via outreach, workshops, networking, training, technical assistance and website resources, with many resources in multiple languages. In the next funding period, we will expand the family navigator training to support them taking a leadership role as cultural brokers.

Three community partners are vital to our self- and family-advocacy efforts: Apoyo de Padres para Padres (Parents helping Parents), Sankofa (formerly the African American DD Parent Alliance), and the WarmLine Family Resource Center. Apoyo de Padres para Padres is a support group of Spanish-speaking parents in Northern CA with a 30-year history, and with close ties to CEDD since its inception 15 years ago. Latinx, Spanish-speaking CEDD staff, Maribel Hernandez, supports this program. Sankofa is a group formed during second funding period with leadership from CEDD staff, Elizabeth Morgan and Benita Shaw. The group is working toward replication in rural communities through a mentorship program. They have leveraged funding through AUCD and LEND to support development of mental health resources specific to the Black community. WarmLine is a parent support organization that provides resources and support to families of children with special needs in 26 counties of Northern CA. Warmline provides resources, family activities and our sibling workshops in English and Spanish.

Our *Community Engagement and Resource Center* is user-friendly for people with disabilities and their family members, community advocates, trainees and professionals. The Center provides parent-to-parent support and connections to resources within the MIND Institute, the UC Davis Medical Center, and the community. The Center supports over 1900 families annually (40% Spanish speaking). In the next funding period, we will further develop the Center as a place of community engagement and partnership as we have found the Center needs to evolve as more resources are available on-line. The Center now offers small-group training and networking opportunities for researchers and community members on partnership strategies (see Dissemination goals). We have staff who are bilingual/bicultural in English and Spanish; and staff who support Black families in accessing culturally appropriate care.

Our Family Navigator Program has been extremely successful, serving over 100 families annually. Family members of people with DD who have become experienced, skillful advocates are an important resource for other people with disabilities and families who are still trying to understand a diagnosis, navigate healthcare service systems, access resources, and prepare for and navigate transition to adult life. Our family navigator program, staffed by parents and individuals with DD, provides support and advocacy to other families; participates in training medical students, residents and fellows in providing person- and family-centered care for people with DD; and develops advocacy skills in the individuals and families they support to create systems change. Our program includes staff representing multiple cultural and linguistic backgrounds, including Black, American Indian, Asian (Korean, Chinese, Indian) and Latinx. In the new funding period, navigators will be trained to serve as cultural brokers to various communities to increase engagement in hard to reach populations, and for Covid-19 vaccine access. The program supports families during the healthcare transition from pediatrics to adult medicine. Additional families are supported through monthly parent education groups. We have leveraged funding from our Autism Centers of Excellence and our MIND Clinic to support this program and have partnered with the AIR-B to implement a navigator curriculum for underserved families. We partnered with our LEND program to provide a very popular mindfulness group for parents that address stress. All family navigator services successfully transitioned to a virtual format during COVID-19.

In addition, CEDD will continue to provide financial support, outreach and dissemination for two statewide conferences for people with DD: Supported Life Conference and Youth Leadership Forum.

Community Training

Objective 2b: Provide community training opportunities for consumers, families, service providers, and professionals to increase their knowledge and skills in the areas of DD, service provision, inclusion, and other medical, legal, social and policy issues related to disabilities.

CEDD leverages the wealth of clinical and educational expertise at the MIND Institute and among CEDD partners, particularly those who represent both diverse interdisciplinary expertise as well as personal experience as a person with DD or family member, to provide community training and technical assistance. CEDD will continue to provide training opportunities for people with DD, families, service providers and professionals to increase their knowledge and skills in the areas of DD, early identification and intervention, service provision, inclusion, and other medical, legal, social and policy issues related to disabilities. We anticipate providing 100+ community training events per year. In addition, we have partnered with the MIND Autism Center for Excellence to provide an ECHO Autism program which provides community training to physicians, behavioral health professionals and community providers through a distance, case-based learning platform. ECHO Autism provides continuing education (see above) and community training. For example, in the early days of the COVID-19 shut down, our ECHO Autism team partnered with CAPTAIN to provide a series of trainings for educators on how to engage families and students in distance learning. Echo Autismo, now serves 40 Spanish speaking professionals in CA and internationally. We partnered with our LEND program to develop a speaker and TA support database of MIND/CEDD/LEND faculty, trainees and staff who can provide resources and TA on a variety of topics to meet the emergent needs of the community.

Technical Assistance

CEDD provides technical assistance, using capacity building strategies, to strengthen the capability of communities, systems and service providers to provide high-quality, culturally competent, user-friendly services to people with disabilities. Our staff/technical assistance providers include people from the Latinx, African-American, and Asian communities who are sensitive to the unique needs of people with DD and their families in those communities. During this funding period, we plan to become an ECHO Super-hub so we can provide technical assistance to other groups wishing to use the ECHO model. The CDE has already asked us to support them in this effort.

Our technical assistance efforts fall primarily in four content areas: (a) early intervention services for children aged 0-5 with DD (b) intervention services for children and youth with ASD, (c) services supporting transition to adulthood for people with DD and (d) assistive technology.

Improving Early Intervention Services

Objective 2c: Provide technical assistance and leadership for development of infrastructure, interagency communication and collaboration to improve early intervention services to children aged 0-5 with DD.

1. Early childhood partnerships with state agencies. CEDD staff participate in various state agency-sponsored advisory groups and interagency collaboratives, and provide technical assistance to various state agencies, including Public Health, CDE, and DDS. Examples include:

- The CA Statewide System of Support is one of the central components of CA accountability and continuous improvement system. The goal is to support local education agencies in meeting the needs of students by building local capacity to sustain improvement and effectively address disparities in opportunities and outcomes. Led by CDE and the CA Collaborative for Educational Excellence.
- CA Statewide Screening Collaborative (CSSC). Convened by the CA Department of Public Health MCAH Program to bring together state agencies and other organizations to develop California's capacity to promote and deliver effective, coordinated health, developmental, and early mental health screenings for young children.

2. California Early Start Support Network (CESN). CESN is a collaborative project of our CEDD, the USC UCEDD, the CDE, CA DDS, Local Educational Agencies, Regional Centers, and community groups. We are ensuring sustainability of the program by sharing leadership with the CSUS early childhood special education program and CDE Desired Result Access Program. Video conferencing facilitates training and support for practitioners providing early intervention. Part C programs from 26 counties in CA have participated, along with Regional Centers, Local Education Agencies and Family Resource Centers.

We have successfully transitioned our preschool early intervention supports to our LEND and DBP programs. CEDD faculty and staff continue to provide technical assistance to participating trainees. Additionally, CEDD faculty provide consultation and training in EBP to Part C providers.

<u>Improving Statewide Services for Youth with Autism</u>

Objective 2d: Provide technical assistance and leadership at the state level for development of infrastructure, interagency communication and collaboration to improve intervention services to children and youth with ASD.

1. The California Autism Professional Training and Information Network (CAPTAIN) and other partnerships with state agencies. CEDD has been at the statewide level since 2013 to increase awareness of ASD, use of EBPs and improve interagency communication and collaboration. CAPTAIN consists of over 400 cadre members nominated by their agencies to be Trainer of Trainers throughout the state. The agencies who have nominated trainers include DDS, Regional Centers, SELPAs, Family Resource Centers and Family Empowerment Centers as well as two of the State UCEDDs (USC and UC Davis). CEDD staff Patty Schetter coordinates the project and facilitates an active leadership team from the CDE, the State SELPA and DDS. They develop strategic plans for implementation of EBP and policy and initiatives related to serving individuals with ASD. CAPTAIN was recognized and funded as the SELPA Content Lead for EBP implementation and training in CA. This 4-year project expands the role of CAPTAIN trainers in supporting struggling schools. CAPTAIN is taking a leadership role in a newly formed National Autism Network of State Implementors, a group of similar networks across 6 states working to increase EBP implementation. CAPTAIN leveraged research funding from the Institute for Education Sciences and preliminary results indicate strong EBP use when teachers are trained by a CAPTAIN trainer.

Transition to Adulthood

Objective 2e: Provide technical assistance and leadership for development of infrastructure, interagency communication and collaboration to support transition to adulthood for people with DD.

These programs are designed to strengthen the preparation of teens and young adults with DD for adult life in the community. In our prior funding period, CEDD's Think Transition Workgroup explored opportunities and supports for adults with DD. Information and resources are now shared through the family navigator program. Recommendations led to the development of the new five year plan.

1. Business Advisory Council. CEDD staff member Steve Ruder organized and sustained a Northern CA Business Advisory Council (BAC) to promote collaboration among local businesses and employment and training programs. BAC provides advice, guidance, and support for the expansion of high-quality workforce development programs for people with DD. The BAC is a vehicle to increase the level of service among the agencies supporting people with disabilities with their employment. Planning meetings are opportunities for support agencies to share information and effective strategies and to discuss practices that are counterproductive. DOR provides information about services and learns about challenges and opportunities support agencies are experiencing.

2. Supported Decision Making. Since 2016, CEDD staff have collaborated with the ACLU, DRC, UC San Francisco, Disability Voices United and other leaders in the development and adoption of supported decision-making in CA. The CEDD administered a 2-year WITH Foundation grant that created a series of videos on supported decision-making, curated a toolbox of resources, and provided trainings throughout CA on the overuse of conservatorships and strategies for implementing supported decision-making for people able to communicate their preferences. CEDD continues to maintain a supported decision-making web page, provide trainings, and support initiatives related to supported decision-making.

3. Redwood SEED Scholars Program. MIND recently received funding to support development of the Redwood SEED Scholars program (Supported Education to Elevate Diversity) to support students with DD attending UC Davis in a residential, 4-year higher education program. SEED students will be supported by peer mentors in academics, health and wellness and will participate in career exploration and internships with a goal of competitive employment. CEDD has an active role in engaging community partners and ensuring self-determination and choice will be paramount.

CEDD staff also participate in efforts at the state and local levels with DDNP to develop infrastructure, interagency communication and collaboration to support transition for people with DD.

Assistive Technology (AT)

Objective 2f: Expand knowledge of and access to appropriate assistive technology for people with DD and their families in the community.

The CEDD AT Consortium has successfully expanded knowledge of and access to appropriate AT for people with DD and their families. The Consortium is comprised of representatives of Local Educational Agencies (see work plan for detail), CDE, CA DOR; CA AT Network; Supported Life Institute Communication Technology Education Center; Ability Tools, CSUS, Sankofa, and WarmLine. In an effort to provide sustainable community-run programs, over the first two years of the new funding period, CEDD staff will identify and support an AT Consortium partner who will lead and sustain the consortium.

We will use implementation science strategies to ensure successful transition of this well-established group and will maintain membership in the group post transition. The initial step in this transition is sharing the planning and facilitation of AT Consortium meetings with the California Foundation of Independent Living Centers, a long-time member that has an established project on assistive technology education. The focus will continue to be to train general educators, special educators, resource teachers and other school staff to impact students with high incidence needs such as speech and language processing disorders, learning disabilities, and mild intellectual disabilities with an emphasis on community implementation.

Collaboration with DD Network Partners

Objective 2g: In collaboration with DD Network Partners, identify and take steps to address systemic barriers and issues that impact the full participation, community integration and inclusion of people with DD and their families.

CEDD will continue its close collaboration with the DDNP, as described in Sections B. 3 and C.1. DDNP leverage individual agency strengths and resources to promote systemic change to benefit Californians with DD in several areas, including linguistically accessible and culturally competent information relevant to the diverse communities of people with DD in CA; development of infrastructure and communication between state agencies to improve service delivery in early intervention, education for students with autism, and transition to adulthood; competitive, integrated employment; leadership of self-advocates; access to healthcare; and self-determination and shared decision-making and, more recently, working together to support people with DD in CA during the global COVID-19 pandemic.

Community Services - Model Clinical Services

Goal 3. Community Services – Model Clinical Services: Provide quality health care for people with DD.

The Neurodevelopmental Disorders Clinic, under the leadership of Drs. Akins, D.O., Enriquez, Ph.D., Restrepo, M.D., and Angkustsiri, M.D., provides assessments for ASD, Fragile X syndrome, 22q11.2 deletion syndrome, ADHD, learning disorders, and other DD. The clinic provides interdisciplinary diagnostic evaluations, intervention recommendations and medical management for children referred by primary care physicians as well as through contractual agreements with four Regional Centers. Clinicians provide information to parents interested in MIND Institute research studies as well as information about other community resources. CEDD and LEND trainees are involved in clinical activities and has pre- and post- doctoral psychology training programs.

The Feeding Recovery Clinic is an interdisciplinary clinic led by Dr. Akins, D.O., Meredith Stawicki, MS, CCC-CLP and Staci Collins, RD and provides intensive feeding intervention for children with severe feeding difficulties. The clinic provides both clinical services and interdisciplinary training. The feeding team utilizes the SOS approach and includes a speech therapist, a LEND trainee in speech and language pathology, a registered dietician and a DBP, pediatric residents and DBP fellows.

Chromosome 22q11.2 Healthy Minds Clinic. CEDD research and clinical faculty, led by Dr. Enriquez, and medical director Dr. Angkustsiri support the 22q11.2 Healthy Minds Clinic. Since its inception over 15 years ago, the clinic has provided DBP and neuropsychological assessments to hundreds of children with either deletions, or more recently, duplications at chromosome 22q11.2. The clinicians provide feedback and follow-up support for families and the professionals providing care in their home communities. Dr. Angkustsiri has also developed a series of Chromosome 22q11.2 DS Educational Videos that share individual and family perspectives and information about medical issues common in 22q11.2 DS. Follow-up with families shows a high degree of satisfaction with the clinic, greater understanding of the child's disorder, and an increased ability to advocate for and secure services required for educational and intellectual development.

Social Skills & ACCESS Programs. The Social Skills Program, under the direction of Marjorie Solomon, Ph.D., is a group training program for children and adults with ASD and other social communication disorders who have difficulty making friends, having successful interactions in school and the community, including employment. Groups are organized by age and typically have an average of 8-15 people each. The groups are led by a licensed psychologist and several adult co-leaders. Parent participation is also required (adult participants may bring a friend or caregiver instead of a parent); the parent/ support person group meets at the same time as the children's group and is led by a social worker and a psychologist. Covered topics include non-verbal behavior cues, emotion recognition, stress management, conversation rules, social problem recognition and problem solving, making good choices, and friendship and leadership skills, and for adults, employment skills.

Comprehensive Integration of Resilience into Child Life Experiences (CIRCLE) Clinic. An integrated care model for children and families involved in the child welfare system. Developmental assessments, trauma screening, behavioral health assessments and comprehensive medical care occur in an integrated model within the Pediatric Medical Home at the County Primary Care Clinic. Developmental assessments and ongoing management of ASD, ADHD and other neurodevelopmental disorder are provided by Dr. Akins, DBP fellows, interns and post-doctoral fellows in child psychology and speech and language pathology in partnership with CAARE Center child psychologists, Primary Care Clinic pediatricians and the Sacramento County Department of Child and Family Services.

Developmental and Behavioral Pediatrics Telehealth Partnership Clinic with Northern Valley Indian Health (NVIH) System. DBP and fellows led by R. Scott Akins, D.O. and Kathy Angkustsiri, M.D, partner with primary care providers at NVIH to provide developmental pediatrics assessment and ongoing care for children with ASD and other neurodevelopmental disorders via telehealth.

Partnership Engagement with Federally Qualified Healthcare Centers (FQHCs). We are conducting outreach and engagement with two FQHCs in Sacramento to provide education and consultation, with the goal of eventually implementing DBP support and developing cultural brokers in our community. The Sacramento Native American Heath Center (SNAHC) and Elica Health clinics provide service for MediCal/Medicaid based children and families from historically underserved backgrounds and non-English speaking communities. Twenty-six percent of SNAHC patients are Native American. Elica provides quality, affordable health care through the operation of professional and compassionate health homes for underserved populations, who are confronted with barriers to accessing care.

Research

Goal 4. Research: Conduct research on etiology, treatment and services for people with DD; and provide translation of research into practical applications with an emphasis on increasing participation of diverse (race. Equity, gender identity, sexual orientation etc.) participants.

We propose to continue with basic and clinical research projects, emphasizing a community service and translational focus to MIND research projects. The addition of clinical services for participants in research projects such as the 22q11.2 Health Minds translational clinic and the young adult social skills and employment research by Dr. Solomon, and community implementation studies such as training Part C providers in evidence-based caregiver coaching methods, are examples of the added dimensions that the CEDD brings to the MIND Institute's research activities. MIND Institute research continues to be top in the nation – with three of the Autism Speaks' top ten studies of 2019 coming from our researchers. CEDD supported MIND research efforts during the COVID-19 pandemic by reviewing safe research practices and linking research teams and community programs to develop distance strategies to support diagnostic evaluations and treatment research strategies.

We work to include people with DD and their families, including those from culturally and linguistically diverse groups, as participants in the research process. CEDD staff, representing people with disabilities and their families, as well as the Latinx, African American and Asian communities, serve as advisers to many MIND research projects, including most in this five-year plan. During the new project cycle, we will increase our efforts to improve Community Academic Partnerships by providing training in community partnered participatory research (see dissemination section). Our work plan for Goal 4 (Research), in **Appendix A**, lists partners, including advocacy groups. We have bilingual bicultural Spanish assessment for research projects, and the Re-CHARGE study, as one example, has recruited a diverse subject population that includes a large Hispanic cohort in all study groups. Dr. Stahmer and Dr. Dufek's research focuses on delivering early autism services to underserved, low resourced children and families from culturally diverse backgrounds, and they have a long list of community partners (see work plan). They identified methods to address engagement barriers for telehealth during COVID-19.

The MIND Institute, under the direction of Dr. Abbeduto, is home to a prestigious NIH-funded Intellectual and Developmental Disabilities Research Center (IDDRC), one of 14 such centers across the country. The IDDRC advances an interdisciplinary, translational research agenda, providing resources to its member scientists to support innovative research on Autism, Fragile X syndrome, Down syndrome and other NDD. The MIND Institute IDDRC is noteworthy among the centers in the network for its emphasis on treatment studies. In addition to continuing and expanding many of our past projects, we have added new research with the MIND Institute IDDRC as a collaborative partner. These new projects (described below) include research on increased access to quality ASD services for children and families in underserved, low resource communities including using innovative telehealth strategies; research on EBPs to address anxiety and autism; examining how teacher student interactions affect academic development; and innovative, community partnered research developing mouse models for Angelman's Syndrome and Autism. We are partnering to develop an academic community partnership database.

Autism Research

Objective 4a: Conduct research on etiology, treatment and services for people with ASD.

Increased Access to Quality Intervention Services for Children and Families in Underserved Areas. Dr. Stahmer and colleagues have several projects that involve community-based participatory research aimed at improving the use of EBPs in underserved, low resourced areas. The majority of efficacious interventions for autism have been tested in White, middle class samples in clinic settings with communities of color rarely reflected as participants and few tested in under-resourced communities. Almost no research has thoroughly tested the cultural relevance of recommended autism interventions.

Drs. Stahmer and Sparapani, in a collaborative R01 with Dr. Brookman-Frazee at UC San Diego, have been working with leaders and providers in schools and community mental health clinics to increase the quality of EBP use for autism. Over 40% of enrolled children/families are Hispanic/Latinx and over half of the school districts serve a high percentage of students living in poverty. They are exploring methods for improving EBP implementation by teaching therapists how to support engagement of Latinx parents and improving classroom quality in low resourced schools.

Dr. Stahmer is part of the Autism Intervention Research Network for Behavioral Health (AIR-B) examining methods to implement interventions to engage caregivers of underserved children with autism and other DD. This multi-site project is led by Dr. Kasari at UCLA and involves UC Davis, University of Pennsylvania, University of Kansas, University of Washington and University of Rochester as well as community collaborators in each location. The project involves implementation and sustainment of interventions to facilitate family engagement in transitions into services and between service systems to reduce disparities in access to ASD services in early intervention and adolescent transition.

Drs. Stahmer and Dufek participate in an Autism Treatment Network Center of Excellence, funded by NICHD with Drexel University. The project is designed to answer a question that has major policy, practice and funding implications for early universal developmental screening, public early intervention delivery systems, for professional training and practice, and for children's lives: What is the effect of early universal screening, which includes linkage to evidence-based diagnostic evaluation and high quality treatment, on the developmental progress of toddlers with ASD on Kindergarten readiness and quality of life? Results will inform pediatric screening policies and guidelines. In addition, Dr. Dufek is conducting innovative work related to the use of telehealth in early treatment of DD.

Evidence-based Practices in Academic, Social and Adaptive Functioning Including Transition and Career Readiness. Dr. Solomon is examining, as part of our Autism Center of Excellence (PI: Amaral), better ways to detect anxiety in children with ASD and determine whether cognitive behavioral therapy or medication can better alleviate symptoms. At least 50% of children with ASD exhibit clinically significant anxiety symptoms. She is also beginning to examine community adaptation of an intervention to support competitive integrated employment for adults with autism. The goal of the program is to promote social and vocational functioning, community engagement, and self-care. In addition, Dr.

Lindstrom, who came to UC Davis in 2017 as Dean of the School of Education and a CEDD faculty member, conducts research focusing on college and career readiness for students with ASD and DD. Her research is based in community partnership and focuses on underserved populations of girls with autism and individuals living in poverty.

Elementary and Secondary Education for Students with ASD. CEDD faculty members, Drs. Mundy and Sparapani, are conducting research on educational best practices for elementary and secondary students with ASD. Dr. Mundy has funding to continue research on cognitive and academic development in school age children with ASD. New studies will focus on the preschool predictors of academic achievement in early elementary students with ASD, and a RCT of reading comprehension intervention to mitigate risk for reading comprehension impairment in students with ASD (in partnership with Dr. Emily Solari at the University of Virginia). Dr. Sparapani leads an interdisciplinary team in improving education by understanding the dynamic and translational relationship between students and their classroom environment. Her newest work involves using detailed classroom observation coding systems to examine teacher language in mathematics and literary contexts and how this affects student learning. The knowledge gained from this study will contribute to the improvement of educational outcomes for ASD, an important issue for research, practice, and policy.

Revisiting the CHildhood Autism Risks from Genetics and the Environment (CHARGE & Re-CHARGE) Projects. CHARGE, under the leadership of Drs. Schweitzer and Abbeduto, is a study of approximately 2,000 children, looking at gene-environment interactions that increase the risk for autism and other DD, and targeting environmental exposures that can be modified so as to reduce risk. Currently in its twentieth year of funding, the study has generated a body of new results on prenatal exposures, such as pesticides, air pollution, medications and maternal nutrition, in relation to ASD, ADHD and DD. CHARGE children will be followed up at either ages 8-12 or 13-19, to understand developmental trajectories for children with DD, ASD, or typically developing. Outcomes of interest will be longitudinal change in diagnoses, cognitive and adaptive function, and symptoms of ADHD, anxiety or depression. The CHARGE study has identified potentially modifiable risk factors that have important public health and policy implications in reducing ASD challenges. In addition, the identification of maternal antibodies that target fetal brain proteins in over 20% of mothers of children with ASD who participated in CHARGE, has opened a new line of research for early identification through biomarkers.

Fragile X Research

Objective 4b: Conduct research on etiology, treatment and services for people with fragile X syndrome and associated conditions.

The Fragile X Research and Treatment Center, under the leadership of Randi Hagerman, M.D., performs clinical evaluation and treatment of patients with fragile X mutations including both the full mutation leading to Fragile X Syndrome (FXS) and the premutation which is associated with DD, Fragile X-associated Tremor Ataxia Syndrome (FXTAS) with aging, and Fragile X-associated Neuropsychiatric Disorders (FXAND). Over the next five years, research will focus on treatment including (1) a topical CBD ointment (Zyn002), (2) a multicenter controlled trial of metformin, (3) behavioral studies that examine a combination of medication and Parent Implemented Language Intervention (PILI) in children with FXS, and (4) sulforaphane in those with FXTAS. Recently they have begun to examine medication for women with Rett syndrome (Anavex 2-73 and Trofinetide). Staff includes specialists in molecular biology, pediatrics, genetics, psychiatry, psychology, neurology, neurobiology, pathology and social work.

Chromosome 22q11.2 Deletion Syndrome Research

Objective 4c: Conduct research on etiology, treatment and services for people with 22q11.2 Deletion Syndrome.

The MIND Institute's 22q11.2 Research Center and Clinic is directed by Dr. Angkustsiri. Research involves neuropsychological assessment, neuroimaging, biobehavioral markers and measures of parent-child interactions, to understand the factors that impact everyday functioning. A key goal is to develop a range of intervention techniques that will reduce or even eliminate many of the cognitive difficulties that present challenges to children with DD such as 22q11.2 DS. Our experience from research as well as the knowledge gained from the 22q11.2 Healthy Minds Clinic has generated an new understanding of the behavioral aspects of this disorder and how they might interact with cognitive and psychiatric outcomes. This view led to a recently funded NIMH grant on the cognitive and affective aspects of risk and protection for psychosis in 22q11.2.

ADHD Research

Objective 4d: Conduct research on etiology, treatment and services for people with ADHD.

The ADHD Translational Research Program, directed by Dr. Schweitzer, undertakes research activities in etiology, assessment, treatment, and outcomes, using neuroscience and behavioral methods. It offers both neuroscience research activities in ADHD and evidence-based training and treatment models for ADHD throughout the lifespan. Over the next five years, translational research activities in ADHD will expand to: 1) better understand the neural and behavioral trajectory of ADHD during adolescence and emerging adulthood, and emerging psychiatric co-morbidities, academic and occupational functioning; 2) testing compensatory functional behavioral activities in ADHD and explore ways that this compensatory behavior (e.g., fidgeting) might lead to novel treatments; 3) focus on how technology (e.g., virtual reality therapy) can support improved attention in ADHD; 4) investigate the presence and treatment of attentional symptoms in other neurodevelopmental disorders (e.g., Fragile X, ASD); and 5) explore how the environment relates to ADHD symptoms in the general population.

Other Research on Neurodevelopmental Disorders

Objective 4e: Conduct research on etiology, treatment and services across neurodevelopmental disorders.

Language and Cognitive Development in Neurodevelopmental Disabilities. Drs. Abbeduto and Thurman, are conducting research on language development in children with Fragile X syndrome (FXS), Down syndrome (DS), and ASD. They have found that each of these conditions has a unique linguistic "signature," with different areas of relative strength and challenge. In addition, they have found similarities and differences in the biological, behavioral, and/or environmental factors that influence the ways language develops. They also focus on developing methods for assessment and monitoring treatment efficacy over time. They will continue to examine the efficacy of combining approaches to the treatment of language problems that empower parents to be agents of change and use telehealth technology to decrease the cost and burden and increase the accessibility of treatment.

Preclinical Models of Genetic Neurodevelopmental Disorders. Dr. Silverman joined the MIND and CEDD faculty in 2015 to study rare genetic disorders characterized by intellectual disabilities and pediatric epilepsies. Her laboratory has a large sub-focus on genetic disorders of the chromosomal region 15q11.2-q13, a maternally derived duplication of the 15q11.2-q13 region. It is the second most common genetic variation associated with ASD and a common cause of ID (~1:250-500 of ASD cases; ~1:584 cases of ID). She is leading a project focused on identifying the phenotypes associated with isoform specific Ube3a overexpression in neurons. This is the only NIH-funded work focused on splice variants of the Ube3a gene *in vivo*. She works in collaboration with multiple parent groups and disability organizations to develop genetic models that will translate into clinical practice more rapidly.

Evaluating Assessment and Medication Treatment of ADHD in Children with Down Syndrome. A new assessment study of ADHD in children with Down syndrome led by Dr. Angkustsiri is underway, after some delays in start-up due to COVID-19 restrictions. Children with Down syndrome have a greater prevalence of ADHD than typically developing children. However, rates of stimulant medication treatment are disproportionately low in children with DS+ADHD, even though stimulants are the most efficacious ADHD treatment and are recommended for use in children with ID and co-occurring ADHD. This research tests the safety and effectiveness of stimulant treatment in children with DS+ADHD and develops cardiac monitoring protocols that can be used by health providers. The clinical trial will be conducted in partnership with Pharmacy, Pulmonology, Cardiology, and local Down syndrome groups a. This innovative project addresses unrecognized attention challenges in children with Down syndrome.

Information Dissemination

Goal 5. Information Dissemination: Increase awareness and knowledge about the resources of the state and federal DD Network Partners through dissemination of research findings, public awareness materials, and other useful information to consumers, families, and professionals.

CEDD's information dissemination plan is two-pronged: (1) *To serve as a resource for information for people with DD and their family members, service providers, advocacy groups, federal and state policy makers, state agencies, and the general public, about the DD Act and about issues related to DD, service provision, inclusion, and other medical, legal, social and policy issues related to disabilities*. We do this through our *Community Engagement and Resource Center*, our website, two annual conferences (English and Spanish), development of products such as web-based resources and educational videos in multiple languages, our family navigator program, and extensive community training events. (2) *To spur the translation of research into practice*. We do this by providing links between researchers and people with DD and their families by providing training in research-community partnership and community engagement with the disability community to researchers, by undertaking research to identify best practices, and by disseminating research findings and information about best practices via peer-reviewed journal articles, conference presentations, pre-service training, continuing education, our website, our annual conferences, and our educational videos. In the next funding period, we will increase our focus in community-partnered participatory research.

Many of our information dissemination efforts (pre-service training, continuing education, resource center, community training, translational research) have been described in previous sections. Due to space constraints, we will limit this section to projects which have not been previously described.

Training in Community Engagement

Objective 5a: Develop training in community engagement and implementation science for community partners and researchers, with an emphasis on partnerships with diverse communities.

Community-partnered participatory research increases community participation in research, improves the relevance of research to community priorities, improves translation of research findings to community settings and ensures community members, such as people with DD and their families, are active participants in the research process. CEDD will partner with the UC Davis Clinical and Translational Science Center (CTSC) to expand our current community networks (CAC and AIR-B) to provide input across MIND Institute DD studies from basic to implementation science. We will work with the CTSC to reach out to historically underrepresented populations in the Sacramento region to gather ongoing input for basic, translation, treatment and implementation research focused on DD populations. The group is to develop and implement a community training plan designed to engage potential partners and educate the community about DD. The CEDD, in collaboration with community partners, will provide training to UC Davis researchers in how to respectfully and successfully partner with community groups to ensure research questions and goals meet community needs. Training will include issues related to the intersectionality of neurodiversity and race, ethnicity, gender, sexual orientation, poverty, and mental health. The project includes partnering with the IDDRC in the development of a *Community Partnership Registry* of community members willing to support UC Davis researchers in developing new projects and interpreting research findings. We expect to see increased engagement of diverse stakeholders in UC Davis' DD research, greater diversity of research participants, and increased community collaboration by UC Davis researchers.

Conferences

Objective 5b: Provide one conference per year highlighting the translation of current research into clinical and community practice.

Summer Institute. CEDD hosts the annual MIND Summer Institute on Neurodevelopmental Disorders with a community planning board. This is typically a one-day conference intended for a wide range of professionals, including educators, psychologists, physicians, nurses, occupational therapists, physical therapists, and speech and language pathologists, as well as people with DD, family, caregivers, and students. The focus is to help participants keep pace with the latest advances in DD research and the most current standards for best practices in prevention, assessment, treatment, and support services. In 2020, we moved to a virtual format due to COVID-19 restrictions. The Institute focused on women and included MIND research highlighting girls and women with ADHD and autism, and an incredible panel of women on the spectrum sharing their experiences. We had over 1000 registrants and 2000 people watching live on Facebook, and over 30,000 people have viewed the recordings. We offered Spanish language interpretation. The 2021 Institute will still be virtual, and we are considering a hybrid model in future years to increase access.

MIND Institute CONFERENCIA. In collaboration with Alta California Regional Center, WarmLine FRC, DRC and SCDD, we offer an annual Spanish conference for parents of children with DD. This one day conference began in person in 2019 with 150 Spanish-speaking family members participating. It included a variety of speakers on topics relevant and important for caring for children and adults with DD, and also a resource fair with local DD partners and service agencies. In 2020, the virtual event brought together more than 550 Spanish-speaking families from different states and countries during COVID-19. The videos have had over 800 views. This will now be an annual event.

We make all conference presentations available in video format on our website (http://www.ucdmc.ucdavis.edu/mindinstitute/videos/video_summerinstitute.html) and on the MIND YouTube page (https://www.youtube.com/playlist?list=PLQnwECjj19TroJYJY0rH97Wd_59mZKF4N), and UCTV (www.uctv.tv) often picks up some of them as well.

Online Resources

Objective 5c: Provide online resources and reference materials to people with DD, their families, service providers and professionals on topics related to health and wellness, early intervention, post-secondary education, employment, and inclusive volunteerism, so that people with DD can make better informed decisions about their lives.

Educational Videos. CEDD will continue to develop educational videos and online training programs and make them available, free of charge, on the CEDD website (http://www.ucdmc.ucdavis.edu/mindinstitute/centers/cedd/cedd_products.html). We are currently focusing on culturally and linguistically appropriate translation of primary videos and resources. ,During our past funding period we worked with CA DDS to translate our ADEPT (Autism Distance Education

Parent Training) series, which focuses on behavioral skills training for parents of children with autism, and they are now available in English, Spanish, Chinese, Korean and Vietnamese. It is geared toward enhancing independence and positive behavior of children with autism and increasing their opportunities for community integration. We are currently working with CAPTAIN to use community partnered methods to culturally adapt videos and information related to autism practices. Next, we will adapt and translate our videos for family navigator, health care professionals on shared decision making, using people with DD who speak varied language to develop and narrate the content.

CEDD/MIND Websites. CEDD provides online resources and materials on topics related to DD, health and wellness, environmental health, community resources, government resources, best practices, advocacy, cultural diversity, early identification and intervention, education, transition to adulthood, post-secondary education, employment, assistive technology, and other quality of life related topics. To make the information more accessible to the diverse populations of CA, our website also includes extensive Spanish language resources and some Chinese and Vietnamese translations.

We continually strive to keep our website user-friendly, accessible and up-to-date, and to ensure that it consistently uses person-first (or identity-first when preferred), person-centered language and displays positive, inclusive images of people with disabilities and people from different racial and cultural backgrounds. In this effort, we recently received an external review of the website and made additional changes in collaboration with CAC members, self-advocates, CEDD faculty and staff, and representatives of the Latinx, African-American, and Asian communities to improve our cultural representation. We also solicit user feedback through an online satisfaction survey. We have two Spanish-speaking staff who maintain the Spanish language sections.

In website design and development, we pay particular attention to universal design and 508-accessibility, reflecting the underlying premise that by considering all potential users in the development phase, a more simple and streamlined design can be used to meet multiple needs. We have to work within the confines of University website development software, but the University Information Technology Department is committed to improving accessibility and has recently rolled out new, accessibility-friendly software. Our staff, especially our website coordinators and videographer, are familiar with new developments in multiple accessible formats and in universal design for electronic information and are working to maximize access and usability for a wide range of audiences.

CEDD has been active during the COVID-19 pandemic at working with the University to ensure accessibility of video conferencing methods, including use of closed captioning and simultaneous translation as well as e-reader compatibility. We have also begun using social networking sites, providing Facebook live presentations and outreach for example, to disseminate information more broadly. With the growth and development of the Internet and rapid changes in modes of communication, it is an ongoing task to determine how best to allocate resources among them.

Journal Articles and Conference Presentations

Objective 5d: Disseminate research findings via refereed journal articles and conference presentations.

Through journal articles and conference presentations, CEDD faculty will disseminate research findings and contribute new knowledge to the field of disability research. We expect to produce more than fifty peer-reviewed journal articles and do more than forty conference presentations per year. See benchmarks for research in **Table 1** and **Appendix A** for more information.

C.3. Special Target Populations and Organizations

The CEDD has determined specific populations based on the needs identified in our problems statement, our work with our community partners, our CAC and with DDNP. Our collaborators, goals and objectives, projects and outcomes are based on these target groups. We focus on increasing quality of life for individuals with DD throughout the lifespan, with a special focus on autistic individuals and their families. In addition, based on our most recent needs assessment we have increased our emphasis on members of historically underserved groups, including those who are racially, linguistically, and ethnically diverse, those living in poverty and people with DD and their families in rural areas. We work with our DDNP on projects related to state-wide efforts to improve early intervention (e.g., CESN) and evidence-based autism practices in schools (e.g., CAPTAIN) and meeting the needs of our CA underserved communities with DD (CoP). These efforts are reflected in our goals and objectives, which include emphasis on cultural and linguistic responsiveness, including measurable outcomes to ensure progress in this area. Specific needs, partnerships, goals and objectives are outlined in the workplan.

D. Evaluation (Project Impact)

D.1. Outcomes

Our overall project performance will be evaluated based on two ultimate outcomes: (1) Improved quality of life for people with DD and their families consistent with their cultural values and linguistic preference; and (2) Improved quality of healthcare and intervention services for people with DD that incorporate EBPs and reflect individual and family culture, language and traditions.

These outcomes have been condensed from the ultimate outcomes in the UCEDD logic model (**Appendix B**), based on the principles and expectations of the DD Act of 2000, taking into account an assessment of needs in CA over the past 5 years and CEDD's strengths and opportunities for advocacy, capacity building and systems change to support people with DD and their families in leading inclusive, self-determined lives in their communities of choice. Our work plan (**Appendix A**) outlines our five goals and includes measurable outcomes, both quantitative and qualitative, for each goal, all of which are related to achieving the ultimate outcomes.

All CEDD projects are primarily designed to contribute to one or both of these ultimate outcomes as reflected in both the work plan and logic model. Our interdisciplinary pre-service training curriculum builds on our strengths as an internationally acclaimed academic training and translational research center for ASD and other DD. We have engaged people with DD and their families who reflect the diversity of CA as key participants in developing and providing training resources that are culturally competent, experiential and accessible. Our community service training, technical assistance, and research activities will also expand knowledge, skills and resources in our community to enhance overall quality of life and services for people with DD and their families in CA, particularly those in historically marginalized families for whom English is not the primary language. Successfully adapting and implementing EBP, cost effective services to low-resourced, culturally diverse communities from early intervention through transition to post-secondary education and employment, provides models of care that expand availability of quality intervention which can be replicated in other states and countries.

We are committed to data-driven strategic planning and continuous quality improvement to help us focus our efforts in pursuit of our mission and to promote accountability and customer satisfaction. The CEDD logic model and work plan are critical components of this process. CEDD is committed to achieving the proposed activities in a manner consistent with the principles and objectives of the DD Act. CEDD will apply the DD Act evaluation criteria of cultural competency, equity, participation, and accessibility to its review of all projects and activities.

D.2. Evaluation

Our logic model is based on ACL's logic model for UCEDDs and includes inputs, activities, output measures, outcomes, and outcome measures. Our performance will be evaluated based on two primary, ultimate outcomes, using quantitative and qualitative methods per the logic model. This evaluation method has been successful for us and supported us in adapting our programs to meet emerging needs.

Summaries will be presented of descriptive quantitative data from various sources, including the SDCC National Core Indicators assessment interviews (quality of life indicator data); the CA Autism Professional Training and Information Network (CAPTAIN) data on improvement in the responsiveness of service delivery systems; Regional Center point-of-service data (responsiveness of service delivery systems and disparities in responsiveness by race/ethnicity); the UCEDD National Information and Reporting System (NIRS); follow-up surveys with recipients of CEDD services (quality of life, access to services), and other sources. Case study and interview methodologies will be employed to collect qualitative data regarding the impact of CEDD services. Finally, we will utilize data from federally-funded CEDD-affiliated research projects, which utilize quantitative and qualitative implementation science methods, based on Community Partnered Participatory Research (CPPR) models, to test the effectiveness and sustainment of EBP and to develop tools and guidelines in community settings.

The logic model/evaluation plan reflects the work of the CEDD Executive Committee (described below in E.1.) in taking the goals and priorities developed by the CAC during the past 18-24 months, translating them into quantifiable measures, and committing to their achievement. The core leaders and the Data Analyst, under the direction of the Executive Committee, are responsible for ensuring that standards of quality and consistency are established and maintained with regard to data collection. They work with faculty and staff to ensure regular and comprehensive reporting, regular project progress monitoring, and the collection and reporting of customer satisfaction with multiple methods available to ensure universal access. Progress monitoring will be shared with the CAC at meetings. CAC members participating in CEDD workgroups/projects (Training, Academic-Community Partnerships, CAPTAIN, Website/Dissemination, Early Intervention, Transition) will have direct, ongoing feedback on progress towards goals/outcomes related to the specific workgroup or project on which they are participating.

The evaluation plan will be reviewed annually and updated as necessary to reflect changes in program design and activities approved by the CAC. The evaluation plan will serve as the basis for our review and assessment of overall project success. The data on outputs and outcomes will be reported in the UCEDD annual report, both in NIRS and in the narrative report. The CEDD director and associate directors, with support from staff, will review progress towards goals with the Executive Committee and the CAC on a regular basis. CAC members are encouraged and supported to provide feedback at each of the three annual meetings and/or directly to staff in person or via phone, video conference or e-mail at any time. The CEDD Annual Reports are also made available to CAC members for review and comment prior to submission, in a format most accessible to each member (electronic, print, verbal discussion).

Program evaluation input is solicited from faculty and staff; stakeholder groups (e.g., WarmLine Family Resource Center, the Autism and Neurodiversity Community at UC Davis, Statewide Self Advocacy Network, Apoyo de Padres Para Padres, Sankofa, and project participants). Family and self-advocate CAC members meet with a CEDD staff prior to each meeting to review content, ask questions and provide feedback. All members may attend, receive meeting and evaluaton information in advance, and can follow up with CEDD staff after meetings to ask questions or provide feedback.

E. Project Management (Organizational Capacity)

Vision and Mission. The CAC worked with CEDD staff to update the vision and mission for the new five year plan. CEDD's **vision** is to provide leadership in education, service and research to maximize the self-determination and community inclusion of individuals with DD and their families. Our **mission** is to collaborate with individuals with DD and their families to improve quality of life and community inclusion through advocacy, community partnerships, interdisciplinary training, and the translation of research into culturally and linguistically relevant practical applications.

CEDD's vision, mission, and programs, as illustrated throughout this document, reflect a commitment to: (a) Ensuring the active participation of people with DD and their families; (b) Ensuring that people with DD, across the lifespan, achieve outcomes consistent with the DD Act; (c) Supporting people with DD, families, service agencies and the larger community; (d) Promoting culturally and linguistically competent attitudes and practice that reflect the racial, ethnic and linguistic diversity of the state; (e) Serving as a link between various programs within the University and the community; and (f) Interdisciplinary training and research, and development of new knowledge.

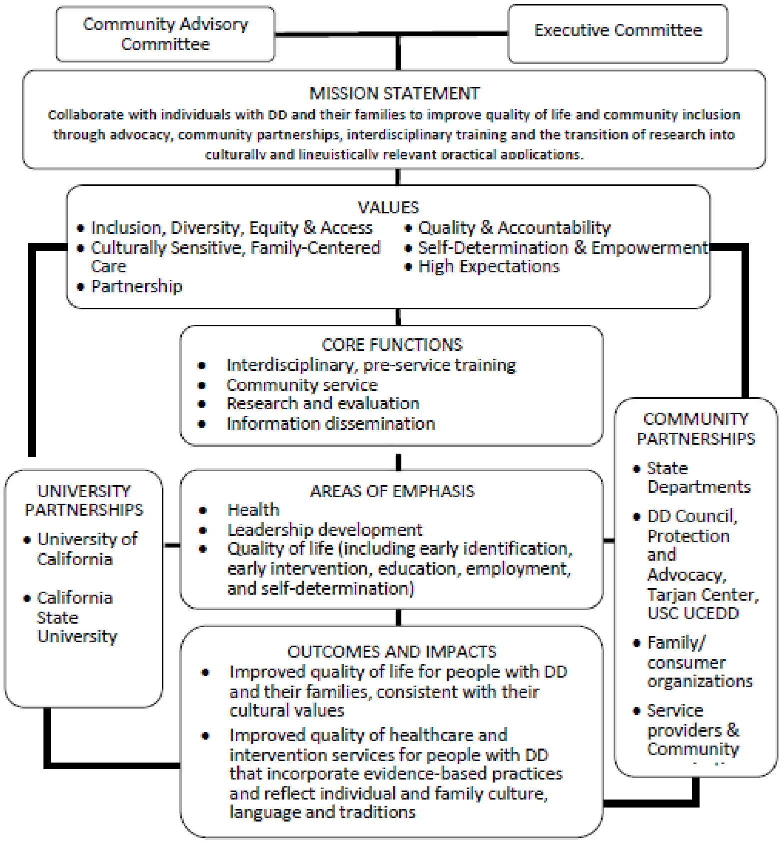
Independence of the UCEDD. See **Appendix H** for a Memorandum of Understanding between CEDD and the UC Davis School of Medicine which confirms CEDD's independence and its authority to carry out the four core functions of a UCEDD.

E.1. Organizational Structure & Capability

CEDD is located within the MIND Institute in the School of Medicine at UC Davis. See Figures 1 and 2 (also in **Appendix C**) for the CEDD organizational chart and conceptual framework. The conceptual framework describes the relationships between our mission, values, core functions, areas of emphasis, and university and community partners. The CEDD Executive Committee, comprised of the CEDD Director and Associate Directors, the MIND Director, the core function coordinators, and liaisons to Education and Community partners, provides internal leadership regarding the CEDD's overall direction and management through quarterly meetings. A subset of the Executive Committee meets weekly and handles day to day operations.

Figure 1

Conceptual Framework
Center for Excellence in Developmental Disabilities at the UC Davis MIND Institute



Organizational Ability to Plan Strategically and Leverage Resources

CEDD faculty and staff have a strong record of successfully leveraging core grant dollars. In the past five years, CEDD has leveraged more than $11 million per year in external funding for research, training, and community service projects, and we are committed to continuing this pattern. Our funders' confidence in our work is evidence of the long-range strategic planning capability which enables us to respond to emergent developments in the field.

Diversity of Staff: Disability/Cultural/Linguistic

We will continue to make the personal perspective of disability and cultural/linguistic diversity prominent in our planning, implementation, evaluation and dissemination activities. Of the 12 current CEDD staff members, one is a person with ASD, four are parents of children with DD, two are Latina and Spanish-speaking, two are African American, and two are Asian. We also have LEND trainees who are family members and people with DD who rotate through every 6-12 months, as well as culturally diverse affiliated faculty and staff. We support two MIND staff with ASD who work on research teams.

People with DD and family members – both on staff and on the CAC – are an integral part of CEDD operations and will continue to assume important roles at all levels of program planning and implementation. Persons with DD and family members serve as project consultants, mentors, product reviewers, and featured speakers in training programs. As an organization that represents the disability perspective, we strive to serve as a model program on disability inclusion and cultural diversity. We are committed to providing support for CAC members, staff, interns, and consultants with DD so that they can be successful in their roles. This includes workplace accommodations, support for personal assistance for travel, schedule adaptations, and adaptation of technologies, with a current focus on participation in distance activities. It also includes having an organizational culture that values diversity.

CEDD is committed to meeting the needs of California's diverse communities. We will continue to promote the practice of recruiting and hiring for diversity. Clinic and other staff receive annual training in cultural competence and incorporating standards of competence into systems of care. Cultural and linguistic competence is a recurring theme throughout all activities, including pre-service training, community service, research, and information dissemination. Staff attend regional, university, and national seminars and discuss content together in an effort to remain current in the cultural and linguistic needs of the disability community; they actively integrate these concepts in CEDD related projects to improve health equity for people with disabilities and their families.

E.2. Project Management

Leadership and Staffing

Director. Aubyn Stahmer, PhD, is a professor of psychiatry and behavioral sciences and clinical psychologist with experience treating children with DD as well as intervention and implementation science research. While she is new to the role of CEDD director, she co-directed the program for 2 years with Dr. Hansen, the founding director. Dr. Stahmer has a strong history of research with expertise in implementation science. She is an internationally respected expert in the use of naturalistic developmental behavioral interventions, validated treatments for autism. Dr. Stahmer leads grants funded through the US DOE, NIMH and NICHD that involve adapting evidence-based screening and

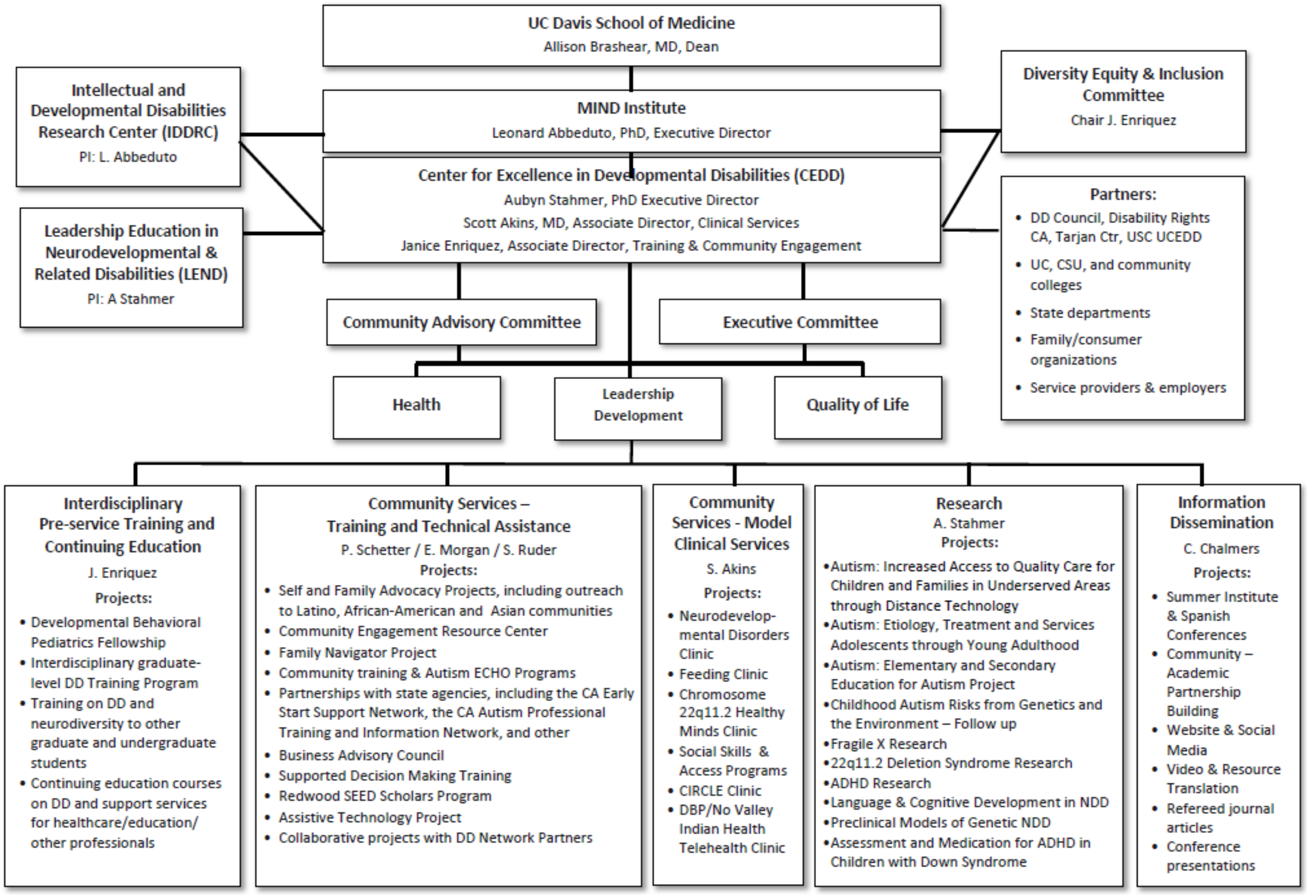


Figure 2
Center for Excellence in Developmental Disabilities
UC Davis MIND Institute
Organization Chart

intervention practices for children with autism in collaboration with teachers and community providers. Dr. Stahmer has served on the Interagency Autism Coordinating Committee Services group, the CA Governor's Improving Special Education Transition Task Force, and the Implementation Mechanism Network of Expertise. Directorship of CEDD fits well with her role as the site director of the Autism Intervention Research Network in Behavioral Health (AIR-B), Director of the NorCal LEND program, and the ACE Community Outreach Core. Leading these programs enables her to integrate opportunities for training and methods to engage diverse community groups in research and dissemination. She is a recognized, effective leader with a strong commitment to serving diverse families and trainees.

Associate Director of Training and Community Engagement. Dr. Janice Enriquez is a Clinical Associate Professor and clinical psychologist in the DBP Division, Associate Director of the NorCal LEND, Co-Director of the MCHC/RISE-UP scholars program, Chair of the Diversity, Equity and Inclusion Committee at the MIND Institute, and part of the leadership team of the AUCD Multicultural Council. She is involved in direct clinical services using evidenced based assessment and treatment for children with DD, supervision and mentoring of LEND trainees, medical residents, and DBP Fellows. She assists in curriculum development, with an emphasis on supporting the cultural and linguistic competence development of trainees and faculty, recruitment and retention of diverse trainees and faculty. She is actively involved in national, university, and MIND specific efforts to address health equity for children with DD and mental health concerns. She co-facilitates Racial Healing Circles within UC Davis. She collaborates with other UCEDDs invested in health equity and mentoring the next generation of leaders.

Associate Director of Clinical Services. R. Scott Akins, DO, Clinical Associate Professor of Pediatrics, is a developmental and behavioral pediatrician specializing in the care of children with neurodevelopmental disorders. He is Chief of Developmental and Behavioral Pediatrics, Associate Director of the Developmental and Behavioral Pediatrics Fellowship and Director of Clinical Programs at the UC Davis MIND Institute. Dr. Akins has developed partnerships with Regional FQHCs and Tribal

Health Organizations that expand access to pediatrics specialists in ASD and other DD within the medical home. Dr. Akins' clinical interests and expertise are in ASD, Intellectual Disability and Trisomy 21. His research has focused on telehealth supports for families of children with ASD and ADHD in remote communities, partnerships between pediatric specialty providers, schools and medical home providers and utilization of complementary and alternative medicine in families of children with ASD.

Core Function Leaders. Each core function (pre-service training and continuing education, community training and technical assistance, model clinical services, research, and information dissemination) has a leader responsible for ensuring successful progress towards goals and objectives. Due to the breath of project in community training and technical assistance, we have 3 co-leaders who each coordinate a specific age group (early intervention, school age, adolescents/adults). Dr. Enriquez supports overall coordination across leaders. Core Function Leaders report to the Executive Committee for progress reviews and feedback and share reports and updates with the CAC for feedback.

Data Collection and Analysis. Caryn Chalmers, our Information Dissemination Core leader, also serves as our NIRS data analyst. She has a master's in public health, training in data analysis, clinical services and information dissemination. She ensures data are accurate and reports are completed.

CEDD Faculty and Staff. CEDD has stellar faculty and staff, whose qualifications are described in various attachments. **Appendix I** provides biosketches of eight key faculty/staff. The personnel narrative **(Appendix G)** includes a brief description of faculty and staff who are fiscally supported by core funding including FTE allocation. **Appendix D** provides a list of CEDD faculty and staff not fiscally supported by the core but working on CEDD projects. CEDD staff have been hired from the community; we recruited individuals who benefited from services or have worked in the community for many years. We strive to hire staff with a personal perspective of disability and who are representative of the cultural and linguistic diversity of CA. They are also highly qualified in their areas of expertise, as illustrated in the above- referenced attachments.

Community Advisory Committee

The CAC is a key part of our organizational structure, advising and guiding the work of the CEDD and serving as a bridge between the community and the University. Members are selected to ensure a majority of consumers and is representative of California's racial/ethnic diversity. The CAC is comprised of 23 members, six self-advocates (two who also represent a state agency or community group), eight secondary consumers (four who also represent community groups), and representatives of our DDNP, the Statewide Self-Advocacy Network, and other advocacy groups and related government agencies. Of the 23 members, nine are African American, Latinx, or Asian. (See CAC membership list in **Appendix E**. The CAC is a resource to CEDD for information, community connections and advice. In addition to providing overall guidance regarding CEDD goals and priorities, CAC members participate in projects and committees of their choice. CAC members participate in interdisciplinary training seminars, serve as mentors in the family navigator program, and provide connections to other community organizations.

Our CAC meets three times a year, in. All meetings are face-to-face (or currently on Zoom), with the option for members to call in or use video technology. At each CAC meeting, the group reviews progress towards goals and objectives, and discusses emergent issues and concerns; between meetings, staff and CAC members are in communication through meetings, calls and e-mails. The CAC provides input on priorities, products, potential partners, outreach strategies, and ideas for strengthening the participation of people with DD and their families in our activities. At our May meeting, we solicit input for any changes to our UCEDD Annual Report and our work plan for the following year. The CAC has been very involved in the 18-month planning process for this 5-year plan proposal, (see Section B.2). Our CAC has remained very engaged in the strategic planning process during the pandemic and has supported efforts to support people with DD in CA to ensure quality services and vaccine access.

Collaborative Partnerships & Networks

The CEDD and the MIND Institute have a large network of partnerships at the local, state, and national levels (see **Table 2**). We will build on these partnerships to accomplish the goals and objectives in this 5-year plan. Working collaboratively to improve and expand services is the surest way to increase quality of life and community inclusion. Additional information about partnerships is in the work plan (**Appendix A)** and letters of support can be found in **Appendix F**.

Table 2. Partnerships

DD Network Partners
UC Davis and UC Davis Health System *Intellectual and Developmental Disabilities Research Center (IDDRC), Clinical and Translational Science Center (CTSC), Center for Reducing Health Disparities, School of Education, Extension, Student Disability Center, and Departments of the School of Medicine: Pediatrics, Psychiatry, Internal Medicine, Neurology, and Rehabilitation*
CSUS (*Nursing, Education, Speech and Language Pathology, Physical Therapy and Other Departments*)
Community Organizations *WarmLine Family Resource Center, Statewide Self- Advocacy Network (SSAN), Communication Technology Education Center (CTEC), California Family Resources Network, Apoyo de Padres para Padres, Sankofa, Progressive Employment Concepts (supported employment agency), Supported Life Institute, CA Foundation for Independent Living Centers, Family Voices of CA, and condition-specific support and advocacy groups*
State and Local Government Agencies *DDS and the Regional Centers, CDE, Diagnostic Centers, Special Education Local Plan Areas (SELPAs) and Local Educational Agencies (LEAs) (county offices of education and school districts), Department of Public Health including the MCAH Division, DOR, and the Sacramento Employment Training Agency*
Other Organizations *California Infant Development Association, WestEd Center for Early Intervention, and ACLU Disabilities Program*

F. Conclusion

This proposal has described current needs in CA that CEDD is uniquely prepared to meet including health care disparities for children with ASD/DD and their families, an extremely large population, poverty in both urban areas and in agricultural areas, people for whom English is not their first language, families from under-represented groups, and a pandemic that has severely disrupted state health, educational and developmental services for persons with ASD/DD. The dedication and diverse portfolios of CEDD faculty and staff, the commitment of the CAC members, NorCal LEND and our IDDRC, and our extensive collaborative partnerships, are the strength and substance of our program and the foundation for the successes of our first 15 years in which we met or exceeded all of our goals and objectives. We look forward to the next five years of working with people with DD and their families in the continuing quest to improve quality of life and community inclusion.

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Appendix A. CEDD Workplan 2021-2026

Goal 1. Interdisciplinary pre-service preparation and continuing education: Expand capacity to address the needs of people with disabilities and their families by providing interdisciplinary pre-service and continuing education for trainees and professionals from multiple disciplines.

Area(s) of Emphasis: Leadership Development, Health, and Quality of Life

Type of Activity: Capacity Building

Measurable Outcomes:

- Quantitative: Number of former trainees in leadership positions, including those from historically underserved groups; Number of people with DD receiving services from former long-term trainees
- Qualitative: Case studies of former trainees and the services they have provided / are providing to people with DD, including those from historically underserved groups

Objective 1a: Provide culturally responsive training in serving persons with DD to students in medicine, nursing, special education, psychology, and/or related fields.

Project 1: Developmental Behavioral Pediatrics Fellowship

Benchmark: 2-3 fellows per year

Leads: Akins, Angkustsiri, Enriquez, Restrepo

Timeline: Years 1-5

Project partners: Curriculum development and presentations - People with DD and their families, Apoyo de Padres Para Padres (Parents helping Parents), Sankofa African-American DD Parent Alliance, WarmLine Family Resource Center, Down Syndrome Information Alliance. Contributing faculty from UC Davis School of Medicine Depts of Pediatrics (including Neonatology and Genetics Divisions), Psychiatry and Behavioral Sciences, Internal Medicine, Neurology, Physical Medicine and Rehabilitation, and the Center for Reducing Health Disparities; UCD School of Education; California State University Sacramento (CSUS) Depts of Education, Physical Therapy, Speech and Language Pathology; Sacramento County Office of Education; Disability Rights CA; Northern Valley Indian Health; Sacramento County Primary Care Clinic; CA Foundation for Independent Living Centers; Communication Technology Education Center; and Progressive Employment Concepts.

Project 2: Interdisciplinary graduate-level DD Training Program

Benchmark: 8-12 trainees per year

Leads: Stahmer, Solomon, Enriquez, Akins

Timeline: Years 1-5

Project partners: Same as Project 1 above and LEND program; Autism Research Training Program

Objective 1b: Participate in broader University academic programs that prepare personnel in a wide range of social and community roles that will contribute to the accommodation and inclusion of a people with DD, including those from historically marginalized groups.

Project 1: Training on DD and neurodiversity to (other) graduate students (including teaching assistants) and faculty

Benchmark: 3 lectures or seminars per quarter

Leads: Mundy, Hagerman, Stahmer

Timeline: Years 1-5

Project partners: Various departments of UC Davis and California State University Sacramento;

Project 2: Training on DD and neurodiversity to undergraduate students

Benchmark: 2 lectures per quarter

Leads: Stahmer, Mundy

Timeline: Years 1-5

Project partners: Various departments of UC Davis and California State University Sacramento; Autism and Neurodiversity Community at UC Davis; RISE Up Program; UC Davis Disability Issues Administrative Advisory Committee and partners as above.

Objective 1c: Provide continuing education courses on DD and support services to enable healthcare/education/other professionals to expand their knowledge base and stay up-to-date on new developments particularly as it pertains to the intersection of DD and historically underserved cultural and linguistic backgrounds.

Project: Continuing education courses on DD and support services for healthcare/education/ other professionals

Benchmark: Eight CE courses per year;

Leads: Stahmer, Chalmers, Heung

Timeline: Years 1-5

Project partners: Represented on Continuing Education Planning Committee - People with DD and their families, Apoyo de Padres Para Padres (Parents helping Parents), Sankofa African-American DD Parent Alliance, WarmLine Family Resource Center, California State University Sacramento College of Education; Alta California Regional Center; Maternal and Child Health Branch of the CA Dept of Public Health; State Council on Developmental Disabilities; Autism and Neurodiversity Community at UC Davis; California Department of Education Statewide System of Support; MIND faculty and staff.

Goal 2. Community Services – Training and Technical Assistance: Expand community capacity to provide quality, culturally and linguistically responsive, services to people with disabilities and their families, through training, outreach, and use of implementation science to increase innovative policies and practices in community settings.

Area(s) of Emphasis: Quality of life, Health, Leadership Development

Type of Activity: Advocacy, Capacity Building

Measurable Outcomes:

- Quantitative data: Quality of life data from the SCDDs National Core Indicators assessment interviews and other sources; Data on improvement in responsiveness of service delivery systems from CAPTAIN, Department of Developmental Services, and other sources

  Qualitative data: Case studies and interviews of recipients of individual and organizational technical assistance and other CEDD services

Objective 2a: Strengthen advocacy skills for people with DD and their families, with special emphasis on underserved communities, through outreach, workshops, parent and sibling groups, networking, training materials, technical assistance, and website resources.

Project 1: Increase community implementation of self- and family-advocacy projects, including projects in the Latino, African-American, and Asian communities

Benchmark: 2-3 events per quarter; mentorship for family or self-advocacy group replication in 1+ new communities annually, 4+ sibling workshops annually

Leads: Enriquez, Hernandez, Morgan, Levy

Timeline: Years 1-5

Project partners: Organizing events and organizational co-sponsorship - People with DD and their families (including both parents and siblings), Apoyo de Padres Para Padres (Parents helping Parents), Vamos a Platicar (Let's talk) Parent Group, Mexican Consulate, Sankofa African-American DD Parent Alliance, Family Navigator Program; Autism Intervention Research Network-Behavioral Health; Family Soup Family Resource Center; WarmLine Family Resource Center, DREDF Family Resource Center, Sacramento Public Libraries, Disability Rights California (P&A) Office of Clients Rights Advocacy, State Council on DD Self-advocacy Council, UC Davis Center for Reducing Health Disparities; LEND trainees and graduates, Valley Mountain Regional Center Parent Group, MIND Child Life, Supported Life Institute, California Autistic Self-Advocates, TASH.

Project 2: Community Engagement and Resource Center

Benchmark: Provide culturally and linguistically appropriate individual TA to 200 people per year, including 30 people with DD.

Leads: Enriquez, Hernandez, Ruder, Shaw

Timeline: Years 1-5

Project partners: WarmLine Family Resource Center; MIND Child Life. Other integrally involved partners include Apoyo de Padres Para Padres (Parents helping Parents) and Sankofa African-American DD Parent Alliance; LEND program. Many other organizations contribute resource materials.

Project 3: Family Navigator Project

Benchmark: Provide individualized support to 50+ families per year in at least 3 languages; and provide 4+ group parent support sessions supporting system navigation and access.

Leads: Stahmer, Stewart, Shaw

Timeline: Years 1-5 for ASD; Expand program beyond ASD in Years 1-2, implementation in Yr 3

Project Partners: Program development - People with DD and their families, Apoyo de Padres Para Padres (Parents helping Parents), African-American DD Parent Alliance, WarmLine Family Resource Center; UCD Child Life; LEND Program; Autism Intervention Research Network – Behavioral Health; Help Me Grow – Sacramento and Yolo Counties; Rochester UCEDD; Family Resource Centers.

Objective 2b: Provide community training opportunities for consumers, families, service providers, and professionals to increase their knowledge and skills in the areas of DD, service provision, inclusion, and other medical, legal, social and policy issues related to disabilities.

Project: Community training and Autism ECHO Programs

Benchmark: 25 community training events/quarter and 4+ Autism ECHO for providers and families

Lead: Stahmer, Restrepo

Timeline: Years 1-5

Project partners: Most of our partners (people with disabilities and their families, DD Network Partners, University partners, state agencies, and community organizations) have participated by organizing or co-sponsoring events or providing speakers, Project ECHO programs, CAPTAIN, MIND Clinic, MIND Autism Center for Excellence, LEND trainees and graduates.

Objective 2c: Provide technical assistance and leadership for development of infrastructure, interagency communication, and collaboration to increase equity and improve early intervention services to children age 0-5 with DD.

Project 1: Early childhood partnerships with state agencies

Benchmark: 6-8 hours of TA per quarter

Lead: Morgan, Fitzgerald

Timeline: Years 1-5

Project partners: Various offices of the CA Depts of DDS, CDE, and Public Health; interagency groups related to early childhood (Statewide Screening Collaborative, the Interagency Coordinating Council) Help Me Grow Sacramento and Yolo counties, and taskforces convened by the state legislature, such as the Statewide Special Education Task Force and State Inclusion Collaborative; LEND trainees.

Project 2: California Early Start Support Network (CESN)

Benchmark: 10 hours of TA per quarter, including diversity, equity and inclusion at least annually

Lead: Morgan

Timeline: Years 1-5

Project partners: Cal State Sacramento Early Childhood Special Education Program, CDE = Desired ACCESS Project, USC UCEDD, CA Dept of Education / Office of Special Education, CA Dept of Developmental Services, 28 Local Educational Agencies (LEAs), 6 Regional Centers, WestEd Center for Prevention and Early Intervention, Family Resource Centers throughout CA, CA Infant Development Association, and parents of people with DD, CA Early Start providers throughout CA.

Objective 2d: Provide technical assistance and leadership at the state level for development of infrastructure, interagency communication, and collaboration to ensure high quality and equitable intervention services to children and youth with ASD.

Project 1: CA Autism Professional Training and Information Network (CAPTAIN) and other state agencies.

Benchmark: 40 hours of TA per quarter including training and supporting 400 trainer of trainers across CA from Schools, Regional Centers and State and Federally Funded Family Support Agencies. including TA on diversity, equity and inclusion at least annually

Lead: Schetter

Timeline: Years 1-5

Project partners: The Leadership team includes a representative from CEDD, the USC UCEDD, CA Dept of Education, CA Dept of Developmental Services, Regional Centers, and the Family Resource Center Network. The 400 participating members represent the Dept of Developmental Services, Regional Centers (Part C service coordinators, Lanterman service coordinators and clinical staff), > 120 Special Education Local Plan Areas (SELPAs), and > 25 of the Family Resource and Empowerment Centers.

Project 2: California Special Education Local Plan Area (SELPA) Content Lead for Autism EBP Training & Implementation

Benchmark: 20 hours per week of TA to 17 SELPAs and their Local Education Agencies to build capacity to implement high quality, equitable programs and services to all students with ASD

Lead: Schetter

Timeline: Years 1-3 (with possible renewal)

Project Partners: CAPTAIN, California Department of Education, California Collaborative for Educational Excellence, Marin County Office of Education, San Diego State University, 17 participating SELPAs, SELPA Administrators of California, California Diagnostic Centers, Supporting Inclusive Practices (SIP) Project and Statewide System of Support Team.

Project 3: National Autism Network of Statewide Implementors

Benchmark: 4 meetings annually with other State Leads working to scale up the use of EBPs for ASD within their educational systems with a focus on equity and inclusion

Timeline: Years 1-2 network development; implementation years 3-5

Partners: CAPTAIN, UNC Charlotte, North Carolina State Education Agency, Indiana Institute on Disability and Community, Texas Statewide Leadership for Autism Training, Kentucky Autism Training Center, CEC-Division on Autism and Developmental Disabilities (DADD), Minnesota Dept of Education

Objective 2e: Provide culturally and linguistically responsive technical assistance and leadership for development of infrastructure, interagency communication, and collaboration to support transition to adulthood for people with DD.

Project 1: Business Advisory Council

Benchmark: Monthly interagency meetings to promote collaboration and best practices for equitable, inclusive, competitive employment opportunities. Recognize 3-5 businesses/year for inclusive hiring practices and replicable inclusive hiring and retention strategies as well as benefits to businesses

Lead: Ruder

Timeline: Years 1-5

Project partners: California Regional Centers, Supported Employment Agencies, CA Department of Rehabilitation; American Job Centers; State Council on Developmental Disabilities; local Businesses (e.g., Sacramento Municipal Utility District).

Project 2: Increased Understanding and Awareness of Supported Decision Making

Benchmark: Maintain and update SDM culturally and linguistically accessible resources on CEDD SDM webpage; Provide 3+ SDM trainings annually; Provide 10+ professional and family consults quarterly

Lead: Ruder

Timeline: Years 1-5

Project partners: Family Navigator Program, LEND trainees and graduates, DRC, MIND Clinic, UC San Francisco, ACLU, Warmline Family Resource Center, Department of Developmental Services

Project 3: Redwood SEED Scholars Program

Benchmark: 10+ students with intellectual disabilities /year from diverse backgrounds admitted to UC Davis for fully integrated college experience. Students will exit Redwood SEED with employment reflective of a program that provided education, support, and internships at UC Davis.

Lead: Abbeduto, Ruder

Timeline: 5 years

Partners:: Regional Centers, CA Department of Rehabilitation, UC Davis, UCD Office of Education, Diversity and Inclusion, regional business leaders, Business Advisory Council, MIND Institute.

Objective 2f: Expand equitable access to quality assistive technology for people with DD and their families in the community.

Project: Transition Assistive Technology (AT) Consortium to Community Agency

Benchmark: Provide 10+ hours of TA to new community leader of AT Consortium. Use implementation strategies to transition and sustain AT consortium. CEDD maintains membership after transition

Lead: Morgan, Ruder

Timeline: Years 1-2

Project partners: Consortium members - Elk Grove Unified School District, Placer County Office of Education, Placer County SELPA, San Juan USD, Sonoma SELPA, Twin Rivers USD, and WestEnd SELPA; CDE Special Education Division; CDE Clearinghouse for Specialized Media and Translations; CA Dept of Rehabilitation; CA AT Network; Supported Life Institute Communication Technology Education Center; Ability Tools, CSUS, Sankofa, and WarmLine Family Resource Center. CA Foundation for Independent Living Centers, UCD AT Center, Communication Technology Education Center (CTEC), Society for the blind, high school AT specialists, NorthState AT, private AT consultants

Objective 2g: In collaboration with DD Network Partners, identify and take steps to address systemic barriers and issues that impact the full participation, community integration and inclusion of people with DD and their families.

Project: DDNP Collaborations

Benchmark: At least three collaborative projects per quarter

Lead: Stahmer

Timeline: Years 1-5

Project Partners: Tarjan Center, USC UCEDD, Disability Rights, CA and CA SCDD

Goal 3. Community Services – Model Clinical Services: Provide quality and equitable health care for people with DD.

Area(s) of Emphasis: Health, Leadership Development, Cultural and Linguistic Competence

Type of Activity: Capacity building

Measurable Outcomes:

- Number of individuals who report that they are satisfied with services received
- Increase number of individuals from underrepresented populations served by 1% annually
- Case studies of patients who have received ongoing treatment, with focus on improvements in satisfaction with medical services and health status

Objective 3a: Provide culturally responsive and linguistically competent, quality healthcare in specialty areas, including autism spectrum disorder, fragile X syndrome, 22q deletion syndrome, intellectual disability, High Risk Infant Follow Up, anxiety disorders, ADHD, and feeding disorders.

Project 1: Neurodevelopmental Disorders Clinic

Benchmark: 1,500 patients per year

Leads: Akins, Enriquez, Angkustsiri, Restrepo

Timeline: Years 1-5

Project partners: People with DD and their families, and clinicians in developmental behavioral pediatrics, psychology, psychiatry, genetics, neonatology, speech and language pathology, social work, and nutrition, family navigator program, MIND Child Life

Project 2: Feeding Recovery Clinic

Benchmark: 40 patients per year

Lead: Akins, Stawicki

Timeline: Years 1-5

Project partners: People with DD and their families, and clinicians in developmental behavioral pediatrics, psychology, genetics, speech and language pathology, social work, and nutrition.

Project 3: Chromosome 22q11.2 Deletion Syndrome Healthy Minds Clinic

Benchmark: 20 patients per year

Leads: Simon, Angkustsiri

Timeline: Years 1-5

Project partners: People with chromosome 22q11.2 deletion syndrome and their families, clinicians in pediatrics, cardiology, psychiatry, psychology, neurology, genetic counseling, and social work

Project 4: Social Skills Clinic & ACCESS Program

Benchmark: 40+ participants per year

Lead: Solomon

Timeline: Years 1-5

Project partners: Parents and siblings of participants with autism, community clinicians, and school (teacher and SLPs) and Regional Center co-leaders, LEND trainees

Project 5: Comprehensive Integration of Resilience into Child Life Experiences (CIRCLE) Clinic

Benchmark: 80+ participants per year

Lead: Akins

Timeline: Years 1-5

Project partners: Youth ages 17 and under involved in child welfare and their Parents, Foster Parents and caregivers, community clinicians, DBP, psychology, social work, general pediatrics and Sacramento Department of Child and Family Services.

Project 6: Developmental and Behavioral Pediatrics Telehealth Partnership Clinic with Northern Valley Indian Health System

Benchmark: 20+ participants per year

Lead: Akins, Restrepo

Timeline: Years 1-5

Project partners: People with DD and their families, community clinicians who care for them and clinicians in developmental behavioral pediatrics.

Goal 4. Research: Conduct research on etiology, treatment and services for people with DD, and provide translation of research into practical applications with an emphasis on increasing participation of diverse (ethnically, racially gender identity, sexual orientation etc.) participants.

Area(s) of Emphasis: Health, quality of life, and leadership development

Type of Activity: Systemic change and capacity building

Measurable Outcomes:

Evidence that research findings are translated into practice and lead to changes in systems or practice and/or adoption of evidence-based practices with a focus on historically underserved populations and multiple languages.

Number of research projects, presentation and publications

Objective 4a: Conduct research on etiology, treatment and services for people with autism spectrum disorders.

Benchmarks across objective: 15 published articles and 12 conference presentations per year

Project 1: Increased access to quality intervention services for children and families in underserved areas through distance technology

Leads: Stahmer, Dufek, Rogers

Timeline: Years 1-5

Project partners: Apoyo de Padres para Padres (Parents Supporting Parents), Sankofa African American Parent Support Group, Solano County Office of Education, Yolo County Office of Education, Folsom Cordova Unified School District, Alta California Regional Center, Sacramento County Office of Education, Help Me Grow Solano/Sacramento/Yolo, San Juan Unified School District, Placer County Office of Education, Sacramento State University, WarmLine Family Resource Center, Elk Grove Unified School District, Sacramento City Unified School District, North Bay Regional Center, Yuba County Office of Education, Partnership Health Plan of California, Family Resource Centers Network of California, Family Soup Resource Center, First 5 Sacramento/Yolo, Autism Spectrum Therapies, Gateway Services.

Project 2: Etiology, treatment and services for people with autism adolescence to young adulthood including transition and career readiness

Leads: Solomon, Lindstrom

Timeline: Years 1-5

Project partners: People with ASD and their families; the UC Davis Student Disability Center; UCLA Tarjan Center; schizophrenia employment researchers; Department of Rehabilitation, supported employment agencies, business advisory council Oregon Youth Transition Program; school districts

Project 3: Elementary and secondary education for students with autism spectrum disorder

Leads: Mundy, Sparapani

Timeline: Years 1-5

Project partners: San Juan Unified School District, Elk Grove Unified School District, Solano SELPA, Yolo SELPA. UCD Teacher education program.

Project 4: Childhood Autism Risks from Genetics and the Environment Follow up (RE-CHARGE)

Lead: Schweitzer, Abbeduto.

Timeline: Years 1-2

Project partners: Parents of people with disabilities, Apoyo de Padres para Padres (Parents Supporting Parents), Sankofa African American DD Parent Alliance

Objective 4b: Conduct research on etiology, treatment and services for people with fragile X syndrome and associated conditions.

Project: Fragile x research

Benchmarks: 12 published articles and 8 conference presentations per year

Lead: Hagerman

Timeline: Years 1-5

Project partners: People with Fragile X Syndrome and their families, National Fragile X Foundation, Fragile X Clinical and Research Consortium, pharmaceutical companies (clinical trials); researchers and clinicians in pediatrics, molecular biology, molecular genetics, psychiatry, psychology, neurology, genetic counseling, speech pathology, occupational therapy, neurobiology, pathology and social work.

Objective 4c: Conduct research on etiology, treatment and services for people with 22q11.2 Deletion Syndrome

Project: 22q11.2 Research Center and Clinic

Benchmarks: 2 published articles and 2 conference presentations per year

Leads: Simon, Angkustsiri

Timeline: Years 1-5

Project partners: People with chromosome 22q11.2 deletion syndrome and their families, and researchers and clinicians in pediatrics, cardiology, psychiatry, psychology, neurology, craniofacial genetic counseling, and social work.

Objective 4d: Conduct research on etiology, treatment and services for people with ADHD.

Project: ADHD translational research program

Benchmarks: 2 published articles and 2 conference presentations per year

Lead: Schweitzer

Timeline: Years 1-5

Project partners: People with ADHD and their families, teachers, and researchers and clinicians in pediatrics, psychiatry, psychology, neurology, social work, epidemiology, neuroscience, CHADD, PEN.

Objective 4e: Conduct research on etiology, treatment and services across NDD disorders.

Benchmarks across objective: 10 published articles and 6 conference presentations per year

Project 1: Language and cognitive development in neurodevelopmental disorders throughout the lifespan

Lead: Abbeduto, Thurman

Timeline: Years 1-5

Partners: IDDRC, AIR-P, People with Down syndrome and their families

Project 2: Preclinical Models of Genetic Neurodevelopmental Disorders: Advancing Therapeutics

Lead: Silverman

Timeline: Years 1-5

Partners: Foundation for Angelman Syndrome for Therapeutics; Autism Science Foundation

Alliance for Genetic Etiologies of Autism (AGENDA) Consortium, NORD (National Organization for Rare Disease); LouLou foundation (Foundation for CDKL5 Research); Dup15q Alliance; Foxg1 Foundation; Syngap Research Trust Organization; Angelina's Foundation (focused on the study of CASK deficiency)

Project 3: Evaluating Assessment and Medication Treatment of ADHD in Children with Down Syndrome

Lead: Angkustsiri

Timeline: Years 1-4

Project Partners: Down Syndrome Alliance; Children with Down syndrome and their families, and researchers and clinicians in pediatrics, cardiology, psychology, pharmacy, and pulmonology.

Goal 5. Information Dissemination: Increase awareness and knowledge about the resources of the state and federal DD Network Partners through dissemination of research findings, public awareness materials, and other useful information to consumers, families, and professionals.

Area(s) of Emphasis: Quality of life, Health

Type of Activity: Advocacy, Capacity Building

Measurable Outcomes:

- Quantitative: Percent of website users who report that they are satisfied with website resource materials; percent of Summer Institute conference attendees who report that the conference met their educational needs and that the material covered will be useful in their practice. Number of people from underserved groups signing up on MIND research registry. Development of diverse academic community partnership registry.
- Qualitative: Case studies and interviews of recipients of technical assistance.

Objective 5a: Provide two conferences per year highlighting the translation of current research into clinical and community practice.

Project: Summer Institute

Benchmark: One English and one Spanish language conference with 300+ attendees and 3,000+ video hits per year on conference presentations which have been video-recorded and posted on the web

Leads: Stahmer, Fitzgerald, Heung, Hernandez

Timeline: Years 1-5

Project partners: Planning Committee members - People with DD and their families, Apoyo de Padres Para Padres (Parents helping Parents), Sankofa African-American DD Parent Alliance, WarmLine Family Resource Center, California State University Sacramento College of Education; Alta California Regional Center; Maternal and Child Health Branch of the CA Dept of Public Health; State Council on Developmental Disabilities; Autism and Neurodiversity Community at UC Davis; ; California Special Education Task Force – State SELPA; MIND Institute faculty and staff.

Objective 5b: Develop training in community engagement and implementation science for community partners and researchers, with an emphasis on partnerships with diverse communities.

Project1. Build academic community partnership capacity

Benchmark: Database of community partners willing to support academic community partnerships – at least 10+ partners added per year. 5+ presentations per quarter to researchers or new community-based organizations to facilitate partnerships; Development of cultural brokers to support engagement in diverse communities – adding one new community annually.

Leads: Stahmer, Chalmers

Timeline: Years 1-5

Project partners: May include any of our partners (people with disabilities and their families, DDNP, University partners, state agencies, and community organizations), varies depending on the academic community partnerships. Will partner with family navigator program, self-advocacy network and parent support groups to develop cultural brokers. UCD Researchers.

Objective 5c: Provide online resources and reference materials to people with DD, their families, service providers and professionals on topics related to health and wellness, early intervention, post-secondary education, employment, and inclusive volunteerism, so that people with DD can make better informed decisions about their lives.

Project 1: Website & Social Media

Benchmark: 11,000 hits per quarter; 1-3 Social Media events per quarter

Leads: Ruder, Chalmers

Timeline: Years 1-5

Project partners: Responsibility for content development for some sections - WarmLine Family Resource Center, Apoyo de Padres Para Padres (Parents helping Parents), Sankofa African-American DD Parent Alliance, LEND trainees, ADHD program, social skills program Redwood SEED Scholars program. We provide links to resource materials from many of our other partners.

Project 2: Community Partnered Translation of Video and Web-Based Resources

Benchmark: Identify and translate and culturally adapt ASD and NDD resources into 5 threshold languages spoken in California

Leads: Schetter, Hernandez

Timeline: Years 1-5

Project partners: CA Department of Developmental Services, State Council on Developmental Disabilities, San Diego State University, Family Resource Center Network

Objective 5d: Disseminate research findings via refereed journal articles and conference presentations.

Project 1: Refereed journal articles

Benchmark: 50 per year

Lead: Stahmer, Chalmers

Timeline: Years 1-5

Project partners: See lists of partners under Goal 4 / Research.

Project 2: Conference presentations

Benchmark: 40 per year

Leads: Stahmer, Chalmers

Timeline: Years 1-5

Project partners: See lists of partners under Goal 4 / Research.

Appendix B. CEDD Logic Model and Evaluation Plan

Ultimate Outcomes and Outcome Measures

- Improved quality of life for people with DD and their families consistent with their cultural values
  - Outcome measures/quantitative:
    - Quality-of-life data from the State Council on DD's National Core Indicators assessment interviews, follow-up surveys with recipients of CEDD services, CEDD research projects, and other sources
  - Outcome measures/qualitative:
    - Case studies and interviews of recipients of CEDD services

- Improved quality of healthcare and intervention services for people with DD that incorporate evidence-based practices and reflect individual and family culture, language and traditions
  - Outcome measures/quantitative:
    - Data on improvement in the responsiveness of service delivery systems from CAPTAIN, Dept of Developmental Services/Regional Centers, and other sources
    - Outcome data from CEDD faculty research projects, such as data on 1) implementation models of evidence-based interventions for ASD in under-represented, low-resource communities, and 2) student engagement and social skills, assessed by structured direct observation, both pre- and post-test-intervention
  - Outcome measures/qualitative:
    - Case studies, focus groups and interviews of recipients of both individual and organizational technical assistance and training
    - New knowledge from research studies that can contribute to the field of community living, such as validated guidelines implementation of evidence-based practices in community programs.

Inputs and Resources

Community Advisory Committee input and perspective, collaborative partners (university partners, DD Network Partners, community partners), CEDD faculty and staff, University resources, core grant funding from AoD, leveraged funding, plans and goals, reporting and data systems

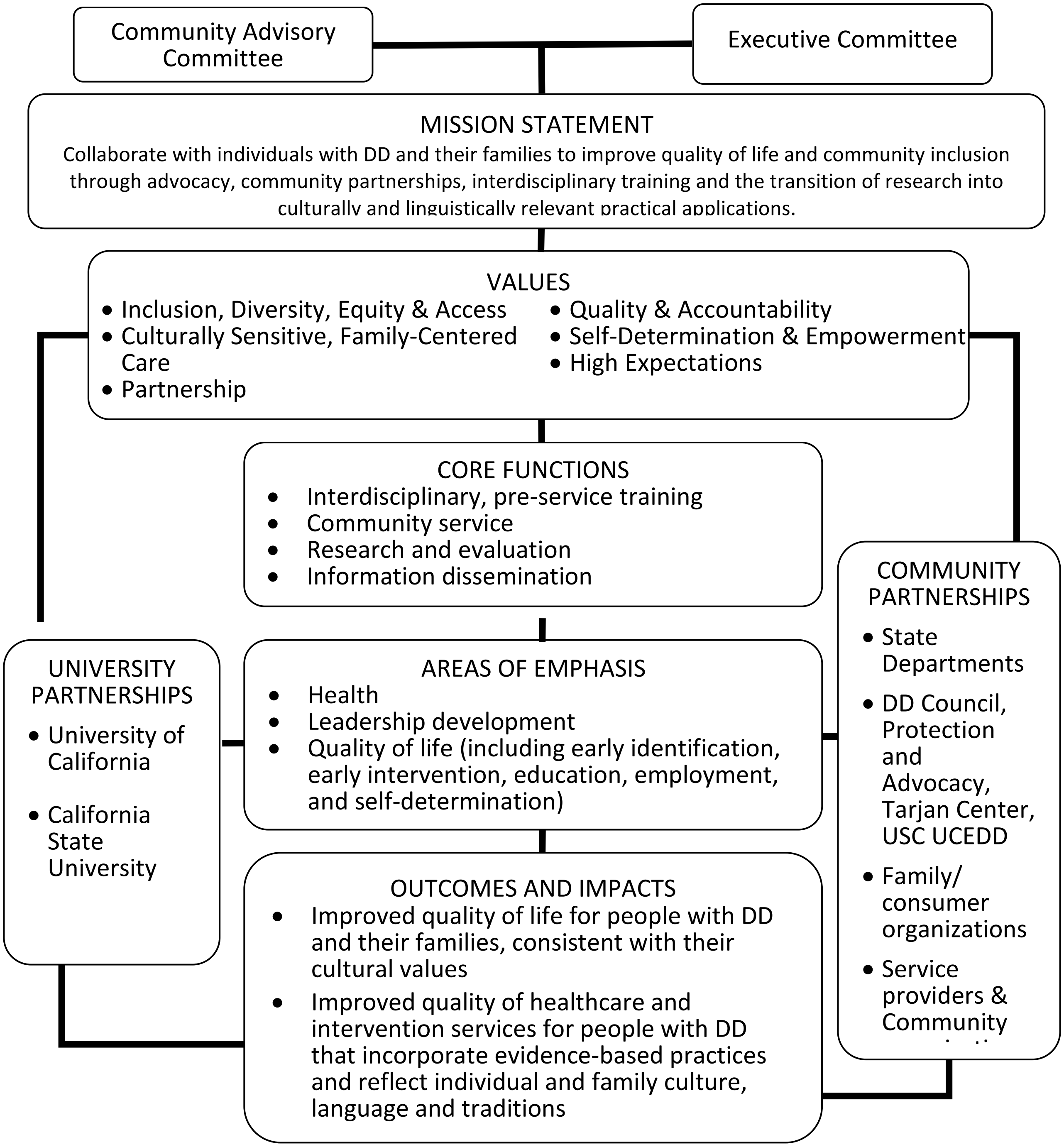
Activities	**Output Measures** (reported annually)	**Initial and Intermediate Outcome Measures** (reported every five years, except as noted)
Leveraging Efforts Proposal writing and submission, and partnership development	• Number of grants, contracts, and other funds leveraged • Total amount of funds leveraged	
Interdisciplinary Pre-service Training	• Number and type of trainees	• Percent of trainees who report satisfaction with the knowledge and skills gained

• DBP Fellowship • Interdisciplinary, graduate-level DD training program • Training on neurodiversity and DD to (other) graduate students • Training on neurodiversity and DD to undergraduate students • Continuing Education	• Percent of trainees from diverse backgrounds • For pre-service training outside of the UCEDD, number of events and number of students • For continuing education (CE), number of programs and number of participating professionals	(reported annually) • Percent of long-term trainees reporting an increase in knowledge or skills and/or change in attitude (reported annually) • Number of people with DD receiving services from former long-term trainees, measured at 1, 5, and 10 years post training (reported annually) • Percent of long-term trainees in leadership positions, measured at 1, 5, and 10 years post training (reported annually) • Case studies of former trainees and the services they have provided/are providing to people with DD
Community Services • Community training • Leadership in self-advocacy and self-determination • Community Technical assistance to community organizations and state agencies to provide quality services to people with DD and improve quality of life • Community supports (early intervention, education, transition, employment, EBP implementation) • Health and wellness services for people with DD	**Community Training** • Number of people receiving training • Number of people from underrepresented groups participating in training • Number of training events and/or training series	• Percent of recipients who report satisfaction with training (reported annually) • Percent of recipients of regular on-going trainings who report an increase in knowledge or skills (reported annually) • Percent of recipients of regular on-going trainings who apply acquired knowledge, attitude, and skills • More people with DD participate in secondary education and employment experiences
	Technical Assistance (TA) • Number of hours of TA provided • Number of hours of TA by type of organization	• Percent of TA recipients with a sustained relationship with the UCEDD who report an increase in any of the following: enhanced resources, enhanced services, strengthened networking of public and private entities across communities, increased awareness of evidence-based practices, enhanced capacity to assess current practices in relation to evidence-based approaches, identification of policy changes needed within areas of emphasis (reported annually) • Percent of TA recipients with a sustained relationship with the UCEDD who report an increased capacity in: utilization of resources, development of community networks, adoption of evidence-based practices, and/or development of

		disability policy at any level - Case studies of recipients of TA
	Model Clinical Services - Number of people who receive diagnostic and/or treatment services	- Number of people who report that they are satisfied with services received (reported annually) - Increase in number of individuals from underrepresented populations served - Case studies of patients who have received ongoing treatment, with focus on improvements in satisfaction with medical services and health status
	Other Model Services - Number of people who receive technical assistance in our Resource Center	- Number of visitors to the Resource Center who report improved ability to access appropriate services and supports (reported annually) - Case studies of visitors to the Resource Center/recipients of individual technical assistance
Research - Research on etiology, treatment and services for people with DD and translation of research into practical applications	- Number of research projects - Number of conference presentations - Number of peer-reviewed publications	- Evidence that CEDD adopts research findings by modifying activities in the other core functions (reported annually) - Summaries of research findings - Number of citations in the literature - Evidence that research findings are translated into practice or policy, and lead to changes in systems, practice or policy and/or adoption of evidence-based practices
Dissemination - Research findings, public awareness materials, and other useful information to consumers, families, and professionals	- Number of products developed and disseminated - Number of peer-reviewed publications - Number of conferences and conference presentations - Number of people from underserved groups participating in research registry	- Number of web hits (reported annually) - Percent of website users who report that they are satisfied with website resource materials (reported annually) - Percent of conference attendees who report that the conference met their educational needs and that the material covered will be useful in their practice (reported annually) - For product dissemination which is integrated into other core functions (such as peer-reviewed publications and conference presentations in Research), outcomes are measured under the other core function

Figure 1

Conceptual Framework
Center for Excellence in Developmental Disabilities at the UC Davis MIND Institute



Community Advisory Committee

Executive Committee

MISSION STATEMENT

Collaborate with individuals with DD and their families to improve quality of life and community inclusion through advocacy, community partnerships, interdisciplinary training and the transition of research into culturally and linguistically relevant practical applications.

VALUES

- Inclusion, Diversity, Equity & Access
- Culturally Sensitive, Family-Centered Care
- Partnership
- Quality & Accountability
- Self-Determination & Empowerment
- High Expectations

CORE FUNCTIONS

- Interdisciplinary, pre-service training
- Community service
- Research and evaluation
- Information dissemination

UNIVERSITY PARTNERSHIPS

- University of California
- California State University

AREAS OF EMPHASIS

- Health
- Leadership development
- Quality of life (including early identification, early intervention, education, employment, and self-determination)

COMMUNITY PARTNERSHIPS

- State Departments
- DD Council, Protection and Advocacy, Tarjan Center, USC UCEDD
- Family/ consumer organizations
- Service providers & Community

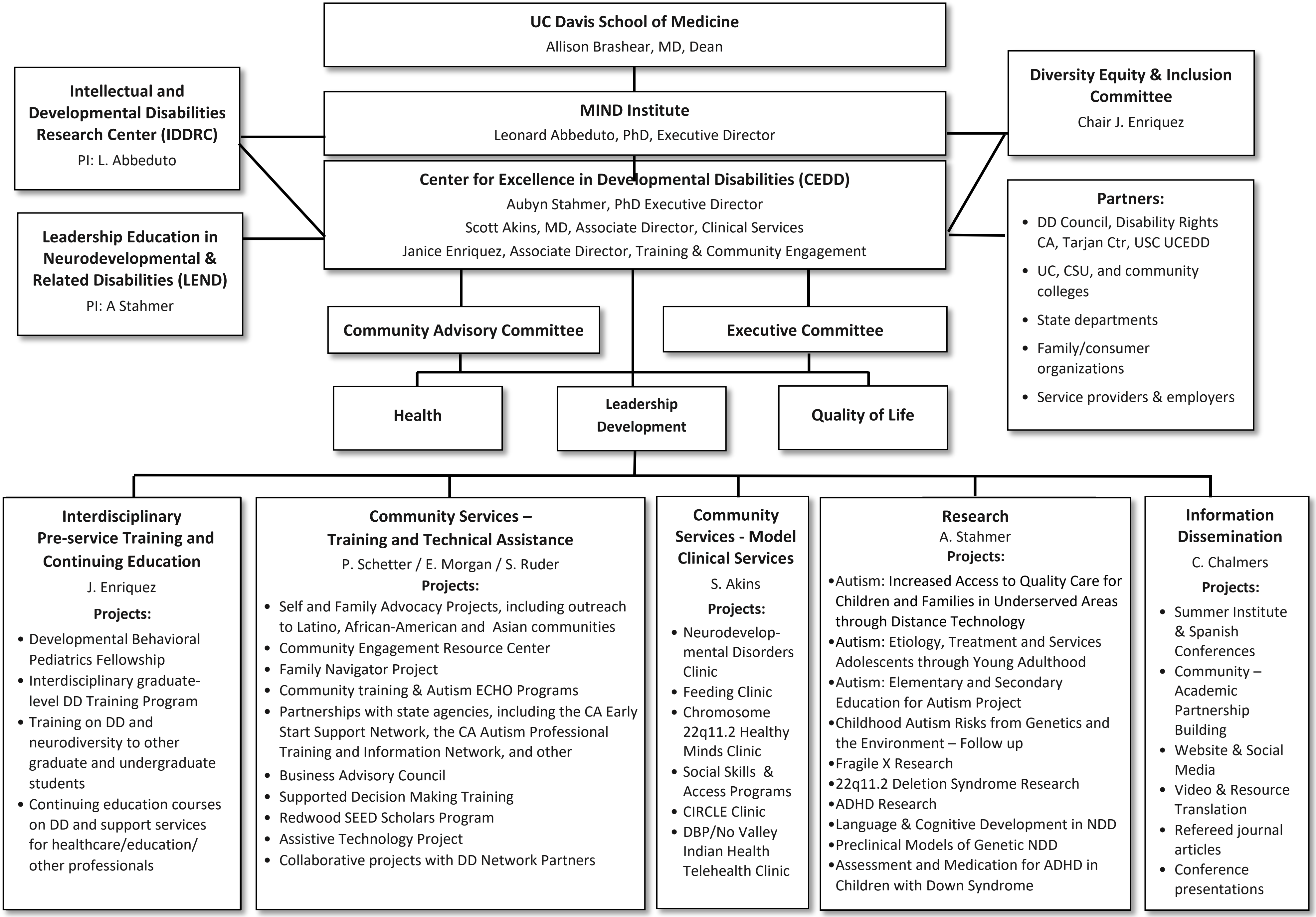
OUTCOMES AND IMPACTS

- Improved quality of life for people with DD and their families, consistent with their cultural values
- Improved quality of healthcare and intervention services for people with DD that incorporate evidence-based practices and reflect individual and family culture, language and traditions

Figure 2

Center for Excellence in Developmental Disabilities
UC Davis MIND Institute

Organization Chart



UC Davis School of Medicine
Allison Brashear, MD, Dean

MIND Institute
Leonard Abbeduto, PhD, Executive Director

Intellectual and Developmental Disabilities Research Center (IDDRC)
PI: L. Abbeduto

Leadership Education in Neurodevelopmental & Related Disabilities (LEND)
PI: A Stahmer

Diversity Equity & Inclusion Committee
Chair J. Enriquez

Center for Excellence in Developmental Disabilities (CEDD)
Aubyn Stahmer, PhD Executive Director
Scott Akins, MD, Associate Director, Clinical Services
Janice Enriquez, Associate Director, Training & Community Engagement

Partners:

- DD Council, Disability Rights CA, Tarjan Ctr, USC UCEDD
- UC, CSU, and community colleges
- State departments
- Family/consumer organizations
- Service providers & employers

Community Advisory Committee

Executive Committee

Health

Leadership Development

Quality of Life

Interdisciplinary Pre-service Training and Continuing Education
J. Enriquez
Projects:

- Developmental Behavioral Pediatrics Fellowship
- Interdisciplinary graduate-level DD Training Program
- Training on DD and neurodiversity to other graduate and undergraduate students
- Continuing education courses on DD and support services for healthcare/education/ other professionals

Community Services – Training and Technical Assistance
P. Schetter / E. Morgan / S. Ruder
Projects:

- Self and Family Advocacy Projects, including outreach to Latino, African-American and Asian communities
- Community Engagement Resource Center
- Family Navigator Project
- Community training & Autism ECHO Programs
- Partnerships with state agencies, including the CA Early Start Support Network, the CA Autism Professional Training and Information Network, and other
- Business Advisory Council
- Supported Decision Making Training
- Redwood SEED Scholars Program
- Assistive Technology Project
- Collaborative projects with DD Network Partners

Community Services - Model Clinical Services
S. Akins
Projects:

- Neurodevelopmental Disorders Clinic
- Feeding Clinic
- Chromosome 22q11.2 Healthy Minds Clinic
- Social Skills & Access Programs
- CIRCLE Clinic
- DBP/No Valley Indian Health Telehealth Clinic

Research
A. Stahmer
Projects:

- Autism: Increased Access to Quality Care for Children and Families in Underserved Areas through Distance Technology
- Autism: Etiology, Treatment and Services Adolescents through Young Adulthood
- Autism: Elementary and Secondary Education for Autism Project
- Childhood Autism Risks from Genetics and the Environment – Follow up
- Fragile X Research
- 22q11.2 Deletion Syndrome Research
- ADHD Research
- Language & Cognitive Development in NDD
- Preclinical Models of Genetic NDD
- Assessment and Medication for ADHD in Children with Down Syndrome

Information Dissemination
C. Chalmers
Projects:

- Summer Institute & Spanish Conferences
- Community – Academic Partnership Building
- Website & Social Media
- Video & Resource Translation
- Refereed journal articles
- Conference presentations

Appendix E

Faculty and Staff affiliated with CEDD but not fiscally supported by the core grant

For the list of CEDD faculty and staff who are supported by the core grant, please see the budget narrative and (for key staff) the biosketches.

All the following are affiliated with the UC Davis MIND Institute, unless otherwise noted. A brief description of their CEDD participation is provided.

Leonard Abbeduto, PhD, Director of the MIND Institute and Professor of Psychiatry and Behavioral Sciences. *Executive Committee, Redwood SEED program, Fragile X research.*

Faria Ahmed, MS, LCGC, Genetic Counselor. *Neurodevelopmental Disorders Clinic.*

Sergio Aguilar-Gaxiola, MD, Ph.D., Director of the UC Davis Center for Reducing Health Disparities, and Professor of Clinical Internal Medicine. *Advisor to training programs and other projects.*

Kathy Angkustsiri, MD, Assistant Professor, Department of Pediatrics. Developmental Behavioral Pediatrics Fellowship Director. *Neurodevelopmental Disorders Clinic, Chromosome 22q11.2 Deletion Syndrome Healthy Minds Clinic.*

EunMi Cho, EdD., Professor, College of Education, California State University Sacramento. *Training programs and annual conference.*

Shawn DePeralta, administrative staff. *Neurodevelopmental Disorders Clinic.*

Nicole Diab, LVN., *Neurodevelopmental Disorders Clinic.*

Faye Dixon, PhD., Psychologist. *ADHD Programs. Diversity recruitment.*

Sarah Dufek, PhD, Assistant Clinical Professor, Psychologist. *Neurodevelopmental Disorders Clinic, autism research with expertise in telehealth; training programs.*

Erin Engstrom, PhD, Clinical Psychologist. *Neurodevelopmental Disorders Clinic.*

Lisa Gaines, Practice Manager. *Neurodevelopmental Disorders Clinic.*

Daniel Haener, PsyD., Clinical Psychologist. *Neurodevelopmental Disorders Clinic.*

Kris Herman, MD, Assistant Clinical Professor of Pediatrics; Genetics Division. *Neurodevelopmental Disorders Clinic.*

Mary Jae Leigh, MD., Associate Clinical Professor, Department of Pediatrics. *Research projects.*

Lauren Lindstrom, PhD, Dean, UC Davis School of Education. *Training programs.*

Julaila Musgrove, administrative staff. *Neurodevelopmental Disorders Clinic.*

Murat Pakyurek, MD, Associate Clinical Professor**,** Department of Psychiatry and Behavioral Sciences. *Neurodevelopmental Disorders Clinic.*

Sally Rogers, PhD, Professor Emeritus of Psychiatry and Behavioral Sciences. *Training programs. Autism early intervention research.*

Dorcas Roa, PhD, Psychologist, Director, Psychological and Behavioral Services. *Neurodevelopmental Disorders Clinic.*

Rosa Rodriquez, MD, Developmental Behavioral Pediatrician. *Neurodevelopmental Disorders Clinic.*

Andrea Schneider, PhD, Assistant Research Scientist. *Fragile X Research & Treatment Center.*

Julie Schweitzer, PhD, Professor in the Department of Psychiatry and Behavioral Sciences and MIND Institute. *Directs ADHD clinical and research programs.*

Suma Shankar, MD, PhD, Associate Professor of Pediatrics, Genomic Medicine Division Director, Precision Genomics. *Neurodevelopmental Disorders Clinic.*

Joseph Shen, MD, PhD, Division of Genomic Medicine, Department of Pediatrics. *Neurodevelopmental Disorders Clinic, RASopathy research.*

Jill Silverman, PhD, Associate Professor of Psychiatry and Behavioral Sciences. *Clinical translational research in NDD, genetics.*

Nicole Sparapani, PhD, Associate Professor, Education. *Research on educational interventions for students with autism.*

Romina Stanislavsky, PhD, Clinical Psychologist. *Social skills program, ADHD parent group.*

Meredith Stawicki, MA, SLP-CCC, Speech and Language Pathologist. *Feeding Recovery Clinic, training programs.*

Robin Stewart, LCSW, Clinical Social Worker. *Family navigator program, Project ECHO.*

Ayaka Suzuki, MS, LCGC, Genetic Counselor. *Neurodevelopmental Disorders Clinic.*

Heather Thompson, PhD., CCC- SLP., Associate Professor, Speech Pathology and Audiology, California State University Sacramento. *Training programs.*

Angela Thurman, PhD, Assistant Professor of Psychiatry and Behavioral Sciences. *Language and cognitive development in NDD programs.*

Megan Tudor, PhD, Clinical Psychologist. *Neurodevelopmental Disorders Clinic. Training programs.*

Veronica Tuss, MS, CCLS, Child Life Specialist. *Neurodevelopmental Disorders Clinic.*

Breanna Winder-Patel, PhD, Clinical Psychologist. *Neurodevelopmental Disorders Clinic.*

Appendix F
CEDD Community Advisory Committee (CAC) Membership List

February 2021

Barbara Boyd	CA Department of Education / Special Education
Aaron Carruthers	State Council on Developmental Disabilities
Pam Chueh	Parent Warmline Family Resource Center
Kim Connor	Parent Retired staff of CA Legislative Analyst's Office
Lisa Cooley	Self-Advocate
Sergio DeCastellanos	Parent
Robin Dewey	Parent
Patrick Dwyer	Self-Advocate Autism and Neurodiversity Student Association
Wilbert Francis	UCLA Tarjan Center
Chioko Grievious	Parent Black Infant Mental Health Program
Charlaine Hamilton	Sibling
Katie Hornberger	Disability Rights California
Matt Ibele	Self-Advocate
Sarah Leff	Department of Public Health, Maternal, Child & Adolescent Health Division
Robert Levy	Self-Advocate State Self-Advocacy Network (SSAN)
Elaine Linn	Parent Family Voices of California
Scott Lorigan	Self-Advocate, Grandparent
Christine Mirzaian	USC UCEDD
Laurie Newton	Parent
Cameron Newton	Self-Advocate
Mary Rettinhouse	Alta California Regional Center
Alvaro Rodriguez	Self-Advocate
Debbie Sarmento	Parent Family Resource Center Network of California
Emily Woolford	CA Department of Developmental Services

Appendix F

Letters of Support

We have letters of support from the organizations listed below. Due to space limitations, we were only able to include the first six letters in the grant application packet. Any letters which are not included in the packet are available on request.

Community Advisory Committee

DD Network Partners:

- State Council on Developmental Disabilities
- Disability Rights California (P&A)
- UCLA Tarjan Center
- USC UCEDD

University partners:

UC Davis

- MIND Institute
- School of Education
- Extension
- California State University Sacramento (CSUS)
  - College of Education

Community organizations

Apoyo de Padres para Padres (Parents Supporting Parents)
Sankofa – African American Parent Advocacy Group
Warmline Family Resource Center
Family Resources Centers Network of California
Family Soup Family Resource Center
Supported Life Institute (SLI)
Autism and Neurodiversity Community at UC Davis
Help Me Grow – Sacramento and Yolo Counties
Family Voices

State and local government agencies

Department of Developmental Services
Alta Regional Center
Department of Education
Department of Public Health / Maternal Child and Adolescent Health Division
Department of Rehabilitation
Sacramento Employment Training Agency
Marin County SELPA
Special Education Local Plan Area Administrators of California (State SELPA)
Valley Mountain Regional Center

Other

California Infant Development Association
Progressive Employment Concepts
Oak Park Preschool
Desired Results on behalf of CA Early Start Videoconference Network

UCDAVIS HEALTH | MIND INSTITUTE
CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

Aubyn Stahmer, Ph.D.
Director, Center for Excellence in Developmental Disabilities
UC Davis MIND Institute
2528 50th St
Sacramento, CA 95817

April 3, 2021

Dear Dr. Stahmer,

As members of the current *Community Advisory Committee (CAC)* for the Center for Excellence in Developmental Disabilities at the UC Davis MIND Institute, we are excited about the new 5-year plan for the CEDD. We have appreciated the thoughtful strategic planning process that began almost two years ago to prepare for the development of the next 5-year CEDD initiatives. The CAC has been involved in the process through quarterly meetings and workgroups, review of materials, goals and objectives, participation in planning meetings and needs assessment review. We began the process in person and after the COVID-19 shut down, transitioned to virtual video meetings.

The CEDD CAC is a diverse group of self-advocates, family members, providers and state agency representatives and we serve as a resource for CEDD faculty and staff, providing information about community needs, programs, and policies, as well as challenges and successes in our community. We review CEDD program progress and make recommendations to the CEDD team. We appreciate the opportunities we have to become engage in specific projects, such as the annual Summer Institute for Developmental Disabilities. During the last 5 years the CEDD has developed innovative programs, such as the Family Navigator program, which now supports close to 100 families a year in better understanding how to access high quality services through the many systems in our state, and the Business Advisory Council, which has brought together local businesses, state agencies and self-advocates to develop systems to support competitive employment for people with developmental disabilities. The CEDD has continued to develop programs and resources to support the cultural and linguistic diversity of our community through parent support, advocacy programs and development of resources that represent multiple cultures and languages. CAC members participate in CEDD training programs, working with medical students, graduate and undergraduate students in many fields and LEND trainees who are becoming new leaders in the DD community. This CEDD and the MIND Institute consistently provide high quality, evidence-based clinical services and are working toward increasing access to care for children living in poverty. The CEDD consistently brings the high quality research taking place at the MIND Institute to the community through training in evidence-based practices, state-wide networks of practice and community events.

The CAC worked closely with the CEDD staff and faculty to revise the CEDD Mission, Vision and Values to fit the changing needs of the community with greater emphasis on cultural and linguistic diversity, self-determination and community engagement in research. As a team, we reviewed and updated the CEDD goals and objectives to meet the current needs of our community. We recommended a focus on supporting the transition of some CEDD activities to new communities through the use of distance technology, as the pandemic has increased access and knowledge about the use of tele-education and tele-health. The CAC is pleased with a focus on increasing community engagement in research and building relationships between researchers, healthcare providers and historically underserved communities. This compliments the research efforts of the MIND and harnesses the CEDD community relationships. The CAC and the CEDD staff used an iterative process to develop the new 5 year plan which builds on the successes of the last 5 years and the strengths of the CEDD and expands to new areas that address specific community needs.

We continue to be pleased with the degree of partnership developed between the CAC and the CEDD team, and the level of collaboration. The CEDD partnered with the CA DD partners (the USC UCEDD, Tarjan Center at UCLA, Disability Rights California and the State Council of Developmental Disabilities) to ensure the safety and health of people with developmental disabilities in our community during the COVID-19 pandemic. Needs assessments identified service and information gaps. The development of plain language materials happened quickly as did processes for providing PPE. CEDD services and programs quickly transitioned to tele-health and distance learning formats with accessibility as a top priority for people with disabilities and their families.

The new strategic plan meets the needs of California, and with continued partnership and collaboration this plan will further reduce health and service disparities in our community. Our CAC has developed a strong partnership and we are pleased to continue to work together over the next 5 years.

The undersigned representatives include family advocates, self- advocates and representatives from numerous service and state agencies across California as well as the DD Network Partners. (see full membership list in Appendix F). We will continue to participate by attending CAC meetings, providing advice and making recommendations, reviewing program outcomes, helping share information with the community and participating in CEDD projects and committees.

We look forward to our on-going work together and our efforts to reduce health disparities and improve community services, quality of life and self and family advocacy in our communities.

Sincerely,
The Community Advisory Committee for the Center for Excellence in Developmental Disabilities at the MIND Institute

*List of CAC members in appendix E
**All CAC members reviewed and signed this letter of support through DocuSign. Signature pages available upon request.

CALIFORNIA
SCDD
State Council on Developmental Disabilities

STATE OF CALIFORNIA

Edmund G. Brown Jr.
Governor

• website • www.scdd.ca.gov • email • council@scdd.ca.gov
1507 21st Street, Suite 210
Sacramento, CA 95811
(916) 322-8481
(916) 443-4957 fax
(916) 324-8420 TTY

April 12, 2021

Aubyn Stahmer, PhD
Director
Center for Excellence in Developmental Disabilities
UC Davis MIND Institute
2825 50th Street
Sacramento, CA 95817

Dear Dr. Stahmer:

This letter is in support of your application for a University Center of Excellence in Developmental Disabilities (UCEDD) grant for 2021-2026. The CEDD has been a critical partner with the California State Council on Developmental Disabilities (SCDD) over the last 15 years in our joint work to enhance the lives of people with developmental disabilities and their families, and we look forward to the continuation of this partnership. We have developed a strong collaborative relationship that is reflected in our joint strategic planning process. We have appreciated your participation on the council and your work on the nominating committee as well as work with the other UCEDDs in developing a statewide training program for community organizations applying for State Council grants.

SCDD is an independent state agency that is federally funded by the Administration on Intellectual and Developmental Disabilities to ensure that people with developmental disabilities and their families receive the services and supports they need to lead integrated, inclusive lives in their communities. The UC Davis CEDD is always responsive to our requests for assistance and regularly provides us with information that helps advance our representation of Californians with developmental disabilities. We especially appreciate CEDD's work/efforts in the following areas:

- Collaboration with individuals with developmental disabilities and their families to improve quality of life and community inclusion through increased supports and training for self-advocates through the Statewide Self-Advocacy Network;
- Participation in the Employment First Committee to increase competitive, integrated employment for people with intellectual and other disabilities
- Support in reaching individuals with developmental disabilities and their families to support access to care and important information during the COVID-19 pandemic, including work with the Department of Developmental Services in developing plain language materials regarding state directives and vaccine information

- Serving as a resource in the areas of education, research, community service and information dissemination, particularly in developing best service models for individuals with autism and other neurodevelopmental disabilities;
- Working together to promote the purposes of the Developmental Disabilities Act to assure that individuals with developmental disabilities and their families participate in the design of and have access to community services and supports that promote self-determination, independence, productivity, and integration and inclusion through joint strategic planning that includes all DD Network Partners

In addition, we and all DD Network Partners are continuing work on our collaborative project to increase linguistically and culturally competent information relevant to the diverse communities of people with DD in California. Together, we are committed to ensure that information and services are provided in a culturally and linguistically competent manner, that we reduce the disparities in purchase of services in our DD system statewide and that we identify best practices for providing services to traditional racial and ethnic minority communities. Together we are developing a description of regional center provided services in multiple language. This would meet the most common request from the community. This is in addition to our work with Georgetown University and CA Regional Centers to improve culturally competent care for our State.

As a long-term collaborative CEDD partner, SCDD endorses your application and will work cooperatively will our other DD Network Partners to ensure the ongoing success of CEDD.

Please do not hesitate to contact me if you have any questions or if I can be of any further assistance.

Sincerely,

Aaron Carruthers
Executive Director
SCDD

Disability Rights California
California's protection & advocacy system

1831 K Street
Sacramento, CA 95811
Tel: (916) 504-5800
TTY: (800) 719-5798
Fax: (916) 504-5801
Intake Line: (800) 776-5746
www.disabilityrightsca.org

March 15, 2021

Aubyn C Stahmer, PhD Professor of
Psychiatry and Behavioral Sciences Director,
Center for Excellence in Developmental Disabilities Director
of Community Based Research
MIND. Institute/UC Davis
2825 50th Street
Sacramento, CA 95817

Dear Dr. Stahmer:

We are pleased to support your application for a UCEDD grant for 2021- 2026. As California's protection and advocacy system, it has been our pleasure to work with the UC Davis CEDD for the past 15 years and we look forward to the continuation of our work together as federal network partners during a time of critical importance for people with intellectual and other disabilities and their families in California.

Over the past 15 years, we have developed a strong collaborative relationship with all of California's Developmental Disabilities Act funded agencies, which is reflected in our strategic planning process and regular communication. Our efforts have included work to ensure that the state developmental disabilities system is responsive to the needs of diverse consumers and families for accessible information and services, collaboration on the needs of individuals with autism and other disabilities and their families, implementation of systems change to increase competitive, integrated employment and self-determination, and joint trainings on issues impacting Californians with developmental disabilities.

The UC Davis CEDD is always responsive to our requests for assistance and regularly provides us with information that helps advance our representation of Californians with developmental disabilities. We especially appreciate CEDD's work/efforts in the following areas:

--Leadership development and training in the areas of early identification, early intervention, education, employment and assistive technology;

--Collaboration with individuals with developmental disabilities and their families to increase knowledge of health care professionals in shared health care decision making to improve quality of life and community inclusion;

--Serving as a resource in the areas of education, community service and information dissemination, particularly in developing best service models for individuals with autism and other neurodevelopmental disabilities;

--Advocacy, community partnerships, interdisciplinary training, and the translation of research into practical applications; and

--Support in educating CA legislators regarding the importance of prioritizing COVID-19 vaccination for people with developmental disabilities and their caregivers.

In addition, we and all Developmental Disabilities Network Partners are continuing our collaborative project to increase linguistically and culturally competent information relevant to the diverse communities of people with developmental disabilities in California. As one of the most ethnically diverse states in the nation, we are committed to ensure that services are provided in a culturally and linguistically competent manner, that we reduce the disparities in purchase of services in our developmental disabilities system and that we identify best practices for providing services to traditional racial and ethnic minority communities.

As a new director of a state partner agency myself, I have appreciated our monthly meetings to better support collaboration, including planning for a conference to support inclusive employment for individuals with developmental disabilities in California.

Disability Rights California looks forward to our continuing collaboration with CEDD. We have confidence in the CEDD leadership to continue our collaborative partnership to advance systems change that promotes the equality, independence, freedom and dignity of all people with intellectual and other disabilities. We enthusiastically support your grant application, and look forward to working with you in the future.

Please do not hesitate to contact me if you have any questions or if I can be of any assistance.

Sincerely,

Andrew J. Imparato

Andy Imparato
Executive Director

TARJAN
CENTER AT UCLA

Aubyn C Stahmer, PhD, Director
Center for Excellence in Developmental Disabilities (CEDD)
UC Davis MIND Institute
2825 50th Street
Sacramento, CA 95817

April 12, 2021

Dear Dr. Stahmer:

The Tarjan Center at the University of California, Los Angeles is pleased to provide a letter of support for your application to the Administration on Intellectual and Developmental Disabilities for a UCEDD grant for 2021-2026. The Center for Excellence in Developmental Disabilities (CEDD) is an important partner of the Tarjan Center and we look forward to the continued expansion of our partnership.

The Tarjan Center, which was founded in 1969, is a federally designated University Center for Excellence in Developmental Disabilities (UCEDD). Today, the Tarjan Center is a bridge connecting the knowledge, expertise, and resources of UCLA to persons with disabilities and their families, the generic and disability service delivery systems, and public policy. Our mission is to serve as a catalyst for collaboration, innovation, and systems change to advance the self - determination and inclusion of people with disabilities. Our faculty and staff represent a variety of academic and research disciplines, but they share a common commitment to and interest in developmental disabilities. The Tarjan Center accomplishes its mission across the lifespan through four overarching and interconnected core programs in the areas of arts, postsecondary education, health and wellness, and social and civic engagement.

The CEDD is a highly valued partner and contributor to the Developmental Disabilities network in California through its programs, resources, and collaborations. We look forward to expanding our ongoing collaborations together, including:

- The sharing of information, resources and collaboration as DD Network Partners to accomplish joint advocacy, policy and systems change activities related to increasing transition to post-secondary education and competitive integrated employment for people with intellectual and other disabilities. The new Redwood SEED project will be an important addition to our State in this area.
- Research and dissemination for best-practice models of support for young children and families in low-resource communities with autism and developmental delays (AIR-B)

- Research and dissemination for best-practice models of social skills training to support youth and young adults with autism spectrum disorders to increase their integration into peer activities, educational opportunities and integrated employment
- Reduction of disparities in access to healthcare service through interdisciplinary training and systems change, particularly for culturally and linguistically underserved communities.
- Membership on each other's Consumer Advisory Committee for strategic planning and ongoing input

The Tarjan Center is pleased with the success of the work with all the DD Network Partners on our collaborative project to increase linguistically and culturally competent information relevant to the diverse communities of people with DD in California. Together, we are committed to ensure that information and services are provided in a culturally and linguistically competent manner, that we reduce the disparities in purchase of services in our DD system statewide and that we identify best practices for providing services to traditionally under/unserved racial and ethnic minority communities. We are happy to continue this work and our work with Georgetown University around our community or practice.

It is important for the state of California, with its extensive geographic size, and racial, cultural, and linguistic diversity to have such a strong and respected academic and community presence in Northern California. The expertise of the faculty and staff of the CEDD and their programs are important to addressing California's complex needs. We look forward to our continued collaboration with the CEDD and strongly endorse their application.

Sincerely,

Olivia Raynor

Olivia Raynor, Ph.D., Director
Tarjan Center at UCLA, University Center for Excellence in Developmental Disabilities
Adjunct Professor of Department of Psychiatry and Biobehavioral Science
Semel Institute for Neuroscience and Behavior
University of California Los Angeles

Children's Hospital LOS ANGELES
USC UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES
USC University of Southern California

3/15/21

Dear Dr. Stahmer:

Subject: Support for your 5-year Application for UCEDD

The USC UCEDD strongly supports your application for 5 years of funding as part of the national network of UCEDDs. Our work with you over the past 15 years has been characterized by collaboration of the highest caliber, with a thoughtful sharing of resources and expertise across our two programs as well as within the California DD Network Partners. Given the diversity of California, the collaborations our programs have developed around issues related to individuals with autism spectrum disorders, healthcare access, early intervention and reduction of disparities in access to services are critical, particularly for culturally and linguistically underserved communities. This has been especially important during the recent COVID-19 pandemic as we partnered across the DD Network to ensure access to services and healthcare for people with disabilities across the state.

Within the state, your efforts to advocate for early intervention services and adapt programs for linguistically underserved populations have been important and effective, and we look forward to continuing our collaborative work on the CA Early Start Support Network (CES), a statewide interagency collaboration between our UCEDDs, CA Infant Development Association, CA Association of Professors of Early Childhood Special Education, county offices of education, and Regional Centers. Your work with self-advocates and families in Hispanic and African American communities are excellent examples of university/community partnership, particularly around access to early identification and intervention services, transition planning for post-secondary education and competitive, integrated employment for people with intellectual and other disabilities. We have also enjoyed our collaboration on the Community of Practice with Georgetown University aimed at improving diversity and inclusion in California. The initial work with two Northern California Regional Centers has been promising and we look forward to expanding this work to new sites. We also look forward to new opportunities in collaboration with you hosting joint trainings and webinars on a number of potential topics including the promotion of self-advocacy, pilot programs to reduce disparities in purchase of service through the state's Regional Center system and other topics promoted through our Community Advisory Committee.

We look forward to continuing collaboration around the goals established by the DD Network Partners and around UCEDD initiatives.

Sincerely,

Larry Yin, MD, MSPH
Interim Division Chief, of General
Pediatrics
Associate Professor, Clinical Pediatrics
USC Keck School of
Medicine
Director, USC University Center of Excellence in Developmental
Disabilities at CHLA Medical Director, Boone-Fetter Clinic
Children’s Hospital Los Angeles

UCDAVIS
HEALTH

UC Davis Health
2315 Stockton Blvd.
Sacramento, CA 95817
health.ucdavis.edu

MIND INSTITUTE
Medical Investigation of Neurodevelopmental Disorders
UC DAVIS HEALTH SYSTEM
2825 50th Street
SACRAMENTO, CALIFORNIA 95817
http://www.ucdmc.ucdavis.edu/mindinstitute/

March 16, 2021

Aubyn Stahmer, PhD, Director
Center for Excellence in Developmental Disabilities at the UC Davis MIND Institute
2825 50th Street
Sacramento CA 95817

Dear Aubyn:

I am writing to express my enthusiastic support for your application for continuation of UCEDD funding for the next five-year cycle. The CEDD has been an important partner over the last fifteen years as we at the MIND Institute worked to understand the causes and develop treatments for neurodevelopmental disorders. Indeed, the CEDD has substantially expanded the activities and impact of the MIND Institute in the areas of interdisciplinary training, community outreach, translational research, and service. The areas of emphasis chosen by the CEDD for the next five years (i.e., health, leadership, and quality of life) are fully consistent with the goals and activities of the MIND Institute. We are also exited about the increased focus on building community partnerships for MIND researchers.

The MIND Institute is a collaborative international research center, committed to awareness, understanding, prevention, and treatment of neurodevelopmental disorders, including fragile X syndrome, autism, ADHD, 22q11.2 deletion syndrome, and Down syndrome. We are committed to identifying the causes and developing better treatments, and preventions for the neurodevelopmental disorders that affect children and families around the world. The MIND Institute collaborates with researchers, clinicians, and parents to achieve our ultimate goals of improved quality of life and full inclusion for individuals with neurodevelopmental disorders and their families.

The UC Davis MIND Institute also provides year-round educational opportunities on research-based, multidisciplinary approaches to assessing, diagnosing, and treating neurodevelopmental disorders. The Institute is committed to extending our research and clinical knowledge to the general public, professionals and students completing undergraduate or graduate studies.

We look forward to the continuation of our partnership and ongoing collaborative work over the next five years. The MIND will commit to ensuring 10% matching funds (based on California's Tier 1 status as CA poverty rate is greater than the national poverty rate) consisting of supporting time for Drs. Stahmer and Akins, several CEDD faculty and administrative staff as outlined in the budget justification. Together, we will work to expand our linkages between the university and the community – locally, at the state level, and nationally – to improve the lives of individuals with developmental and other disabilities.

Please do not hesitate to contact me if you have any questions or if I can be of any assistance. Thank you for leadership and for the enriching impact of the CEDD.

Leonard Abbeduto

Sincerely,
Leonard Abbeduto, Ph.D.
Director, UC Davis MIND Institute
Tsakapoulos-Vismara Endowed Chair
Professor of Psychiatry and Behavioral Sciences

Budget Narrative Personnel Overview for UCEDD Grant FY 2021-26

University Center for Excellence in Developmental Disabilities (UCEDD) at the UC Davis MIND Institute

This budget justification expands on personnel information provided in the budget justification breakdown. Due to space constraints, specifics provided in the budget justification are not repeated here.

Fund available through the CEDD grant are used to support the four core functions and the CAC, and are used to supplement, not supplant, the funds that would otherwise be made available for activities related to interdisciplinary pre service preparation, continuing education, community services, research and information dissemination

Key Personnel:

Aubyn Stahmer, PI, PhD, Director, Research Core Function Coordinator (1.2 calendar months, 10% total FTE, 5% federal share, 5% matching funds), Professor, Department of Psychiatry and Behavioral Sciences and incoming CEDD Director. Dr. Stahmer served as Associate Director of the CEDD with Dr. Hansen for 1 year and assumed the role of CEDD Director last year. Dr. Stahmer is a licensed clinical psychologist and an expert in the translation of evidence-based autism research to community-based practice and delivery. She conducts research on how to take evidence-based interventions that are effective in research settings and deliver them in settings where kids are, in schools and early-intervention settings in the community. Dr. Stahmer is part of the CEDD management team and provides coordination and administrative oversight for the program. In collaboration with the Consumer Advisory Committee (CAC) and the Executive Committee Dr. Stahmer will oversee implementation of the CEDD's new five-year strategic plan, will oversee tasks related to enhancing community participation, and lead seeking of additional funding sources. She represents CEDD at the DD Partners Network meetings and on the State Council for Developmental Disabilities.

Janice Enriquez, PhD, Associate Director of Clinical Training and Community Engagement, Pre-Service Training and Continuing Education Core Function Coordinator (3 calendar months, 25% FTE). Dr. Enriquez is involved in interdisciplinary pre-service training and clinical community services including coordination of training across our LEND and CEDD programs. She plays a lead role in efforts to advance and sustain cultural and linguistic competence and increase cultural diversity within our network of programs that support people with disabilities. She provides supervision to CEDD team members and is a member of the Executive Committee and CEDD management team. She also serves as our representative to the AUCD Multicultural Council.

R. Scott Akins, DO, Associate Director of Clinical Services, Model Clinical Services Core Function Coordinator, (1.2 calendar months, 10% total FTE, 5% federal share, 5% matching funds). Dr. Akins is Chief of Developmental and Behavioral Pediatrics, Associate Director of the Developmental and Behavioral Pediatrics Fellowship and Director of Clinical Programs at the UC Davis, MIND Institute. Dr. Akins has developed partnerships with Regional FQHCs and Tribal Health Organizations that expand access to pediatrics specialists in ASD and other neurodevelopmental disorders within the medical home. Dr. Akins leads our clinical services and supports development of community partnerships with Dr. Enriquez. He will continue to lead efforts to support vaccine access for people with DD in our state.

Caryn Chalmers, MPH, Information Dissemination Core Function Coordinator (7.2 calendar months, 60% FTE). Ms. Chalmers will work closely with Dr. Stahmer to provide coordination and administrative oversight for the program. Responsibilities include grant writing, program evaluation, report writing, and development of public relations materials. She leads coordination and engagement of the CAC and will lead the development of academic community partnerships and the database. She supports information dissemination activities for the CEDD, including ensuring the website is up to date.

Elizabeth Morgan, MA, Early Intervention Training and Technical Assistance Core Coordinator, (3 calendar months, 25% FTE, Y1; 2.4 calendar months, 25% FTE, Y2-5). Ms. Morgan serves as the project coordinator for several key projects and is a member of the Executive Committee. She plays a lead role on early intervention projects, assistive technology projects, support and advocacy projects in the African-American community, and the interdisciplinary graduate-level DD training program. Responsibilities include program development, capacity building and work as an emerging leader with AUCD.

Patricia Schetter, MA, BCBA, Education and ASD Training and Technical Assistance Core Coordinator (1.8 calendar months, 15% FTE). Ms. Schetter is the lead staff member on several projects, including CEDD's autism education initiatives. She has taken the lead role in developing a certificate program in ASD for educators and allied health professionals and a special studies program in ASD for students, professionals, consumers and families. She plays a lead role in the California Autism Professional Training and Information Network (CAPTAIN) a statewide infrastructure, interagency communication and collaboration to improve services to children and youth with developmental disabilities. She recently received funding from the State of California Department of Education to expand this program which funds a majority of salary.

Steve Ruder, BS, Adolescent and Adult Program Training and Technical Assistance Core Coordinator (6.6 calendar months, 80% FTE, $67,526 annual salary, $54,021 grant salary, 50.9% benefit rate). Mr. Ruder plays a lead role in CEDD's youth transition training and mentoring projects and in our Resource Center. He provides individual technical assistance on transition-related and other disability-related issues; and he coordinates community outreach and political action activities. He leads the Business Advisory Council and assists with the ACCESS intervention group as well as grant writing and supports the Redwood SEED Scholar program.

Marjorie Solomon, PhD, MBA, Faculty, Transition to Employment Project Lead (0.6 calendar months, 5% FTE), Professor of clinical psychiatry in the Department of Psychiatry and Behavioral Sciences**.** Dr. Solomon will take a lead in the development of programs for adolescents and young adults with autism and ID/DD, including applying for outside funding to research innovative intervention programs focused on the acquisition of social and life skills for these individuals. She is a member of the Executive Committee. She is also very involved in the CEDD training program. She plays a lead role on several CEDD projects, including the ACCESS program and the Social Skills Intervention Program, which she developed and is cited as one of the few evidence-based social skills programs available for individuals with ASD.

Peter Mundy, PhD, Faculty, Executive Committee Member / Liaison to School of Education (0.6 calendar months, 5% matching funds), Professor and Lisa Capps Chair for Neurodevelopmental Disorders and Education, School of Education. Dr. Mundy serves on the CEDD Executive Committee and he facilitates collaborations between the CEDD and the School of Education. He is working with School of Education and CEDD faculty to develop a Concentration in Neurodevelopment and Educational Research within the Learning and Mind Sciences Program in the Graduate Group on Education. He leads a project developing a virtual reality paradigm for education of children with autism and fragile X syndrome.

Randi Hagerman, MD, MIND Institute Medical Director, Executive Committee Member (0.12 calendar months, 1% matching funds), Distinguished Professor of Pediatrics, Endowed Chair in Fragile X Research. Dr. Hagerman leads our Fragile X research and clinic programs. She supports the MIND Institutes International Training Program and provides training of CEDD medical trainees in supporting individuals with DD and their families throughout the lifespan.

Other Personnel:

Maribel Hernandez, Community Outreach Specialist, Latino Outreach and Advocacy (12 calendar months, 100% FTE,). Ms. Hernandez coordinates the Resource Center and coordinates Latino outreach and advocacy. She is responsible for development of collaborative relationships between CEDD and Latino groups with an interest in DD; Spanish language family support groups; identification of Spanish language resource materials and links for the MIND Resource Room and CEDD website; and consultation and staff training on culturally and linguistically appropriate service delivery.

Patrick Hugunin, E-Media Coordinator (3.0 calendar months, 25% total FTE, 15% federal share, 10% matching funds). Mr. Hugunin formats and programs our website and Facebook page and is photographer/videographer for our public relations materials and training videos.

Robert Levy, Community Advocate (1.2 calendar months, 10% FTE). Mr. Levy is an individual with autism and serves as a self- and community-advocate. He is CEDD's representative to the California Statewide Self Advocacy Network, where he advocates for issues affecting people with disabilities, including Employment First and Self Determination legislation. He also provides mentoring to interns and assists with community outreach, event planning and preparation, and state-wide advocacy and education of trainees.

TBN, Family Navigator, (6 calendar months, 50% FTE). This individual will support the family navigator program and will be a family member or an individual with DD who is an experienced advocate. This person will provide support and advocacy to families of people with disabilities who are attempting to navigate the UC Davis and the CA service systems.

Bibiana Restrepo, MD (0.24 calendar months, 2% FTE). Dr. Restrepo is a developmental and behavioral pediatrician offering care for children with neurodevelopmental problems. She leads our ECHO Autism Project and provides education to trainees regarding family-centered medical care. Additionally, Dr. Restrepo conducts evaluative research of the Autism ECHO program and research related to GI challenges in autism.

Benita Shaw (4.2 calendar months, 35% FTE). Ms. Shaw staffs the Resource Center and assists Ms. Morgan with African American Outreach and Advocacy. She co-leads, Sankofa, a parent support group designed to meet the unique needs of Black families. They are responsible for development of collaborative relationships between CEDD and Black groups with an interest in DD; identification of culturally appropriate resource materials and links for the MIND Resource Room and CEDD website; and consultation and staff training on culturally and linguistically appropriate service delivery.

Shannon Barber, MPH (2.4 calendar months, 20% FTE). Ms. Barber provides administrative support to the CEDD team, supports data collection, meeting and event coordination, managing mailing/email lists, providing backup for the resource center, assisting with web-site maintenance and coordinating calendar events across the center and coordination with LEND.

Amber Fitzgerald, MA, BCBA (1.8 calendar months, 15% FTE). Ms. Fitzgerald supports educational programs and community outreach. She coordinates training programs for medical students, participates on the Autism ECHO hub team and coordinates the Summer Institute.

Erin Roseborough, MA, CCLS (0.6 calendar months, 5% FTE on matching funds) Ms. Roseborough is a Child Life Specialist and leads family support for the MIND Institute Clinic. She also provides opportunities for families to participate in events such as Family Night at the MIND and leads our annual Thank you Party. In addition, she facilitates referrals to the CEDD family navigator program by meeting with families at the time of their diagnostic evaluation to link them to a navigator. She assists with evaluation for Family Navigator.

Memorandum of Understanding (MOU)
between **UC Davis School of Medicine** *and*
Center for Excellence in Developmental Disabilities, UC Davis MIND Institute

This Memorandum of Understanding describes 1) the purpose of the Center for Excellence in Developmental Disabilities (CEDD) at the UC Davis MIND Institute, and 2) the Center's relationship to the University.

CEDD is one of 67 federally designated University Centers for Excellence in Developmental Disabilities (UCEDD) authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000. The centers are funded by the Administration on Disabilities (AoD), part of the Administration on Community Living within the U.S. Department of Health and Human Services. The purpose of the DD Act is "to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under this title."

UCEDDs are mandated to:

- *provide interdisciplinary pre-service training and continuing education*
- *provide community services*—
    - provide training and technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policy makers, students, and other members of the community; and
    - provide services, supports, and assistance through demonstration and model activities;
- *conduct research*, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families; and
- *disseminate information* related to activities undertaken to address the purpose of the DD Act, especially information that CEDD areas of expertise that may be accessed and applied in diverse settings.

The work of the CEDD is guided by its Community Advisory Committee (CAC) and other community input. The CEDD Five Year Plan is based on data driven strategic planning and developed in collaboration with the CAC, and is reviewed and revised annually to address emerging trends and needs. The CAC is comprised of community members, a majority of whom are individuals with developmental disabilities or family members of such individuals.

By signing below, we agree that:

1. UCEDD grant funding will be used to supplement, not supplant, funds that would otherwise be made available for these activities.
2. UCEDD grant funding, and the infrastructure and resources established by way of the grant, will be used to leverage, to the extent possible, additional public and private funds to successfully achieve the projected goals developed in the CEDD Five Year Plan.
3. UCEDD has a director with appropriate academic credentials, demonstrated leadership, expertise regarding developmental disabilities, significant experience in managing grants and contracts, and the ability to leverage public and private funds who reports directly to the MIND Institute director who will represent the interests of the UCEDD within the University; and
4. Adequate staff time will be allocated to carry out the work of the five-year UCEDD grant.
5. The term of this agreement is July 1, 2021 through June 30, 2026.

In concurrence:

03/10/2021
Allison Brashear, MD, MBA
Date
Dean, School of Medicine
University of California, Davis

3/11/2021
Aubyn Stahmer, PhD
Date
Director, Center for Excellence in
Developmental Disabilities

BIOGRAPHICAL SKETCH

NAME Aubyn C Stahmer, Ph.D.	POSITION TITLE Associate Professor

eRA COMMONS USER NAME: astahmer

Education: INSTITUTION AND LOCATION	DEGREE *(if applicable)*	MM/YY	FIELD OF STUDY
University of Colorado, Boulder	B.A.	12/89	Psychology
University of California, San Diego	M.A.	06/90	Psychology
University of California, San Diego	Ph.D.	06/93	Psychology

A. Personal Statement

I have spent over 25 years developing expertise in psychology, applied behavior analysis, multidisciplinary diagnostic evaluation and treatment, parent education and implementation science. My work examines interventions for children with autism and other NDD and their families across multiple service systems including behavioral health, medical health, early intervention and education. Leadership experience includes directing the Nor Cal LEND program, directing over 15 federal and foundation grants, including multi-site intervention and implementation projects, and directing an autism clinic and school program. I am a member of the UC Davis Mentoring Academy. My research is conducted by teams that include researchers, community providers from a variety of disciplines, funding agency representatives and families. I served as the co-director of the CEDD program with Dr. Hansen for 2 years and as Director for the past year. I am very excited to provide leadership for the CEDD and partnership with DDNP to meet the objectives of the DD act.

B. Positions and Honors.

License: Clinical Psychologist, State of California (PSY 15224); Board Certified Behavior Analyst (1-07-3941)

Positions and Employment (most recent)

1997 - 2015	Research Director & Psychologist, Autism Discovery Institute, Rady Children's Hospital.
2002 - 2013	Research Scientist. Child and Adolescent Services Research Center, Rady Children's Hospital.
2013 - 2015	Associate Professor. Department of Psychiatry, UC San Diego
2013 - 2015	Associate Director. Child and Adolescent Services Research Center
2015 - 2019	Associate Professor. Department of Psychiatry, UC Davis
2019-	Professor. Department of Psychiatry, UC Davis
2016-	Associate Director. Nor Cal LEND Program, UC Davis
2020-	Director. UC Davis MIND Institute Center for Excellence in Developmental Disabilities

Representative Honors, Boards and Professional Memberships

2003-2015	San Diego County Infant Mental Health Committee
2005-2010	National Standards Project for Autistic Spectrum Disorders
2006-2014	Interagency Autism Coordinating Council Strategic Planning Group
2008	Leadership in Research and Development Award, Rady Children's Hospital
2009-2014	CA Senate Select Autism Committee Regional Task Force;
2012	California Taskforce on Equity & Diversity for Regional Center;
2012-Present	Editor, Autism Journal of Research and Practice
2019-	California Governor's Improving Special Education Transition Committee
2019-	PACE Policy Research Panel on Special Education
2020	UNICEF/Autism Speaks Committee for Early Detection and Intervention for autism

C. Selected peer-reviewed publications. (Selected from 100+ peer-reviewed publications)

1. **Stahmer, A.C.**, Dababnah, S., & Rieth, S.R. (2019). Considerations in implementing evidence based early ASD interventions in community settings (*Invited for focused issue: Implementing Autism Early Intervention: A Global Perspective*). *Pediatric Medicine. https://doi.org/10.21037/pm.2019.05.01*

2. **Stahmer, A.C.**, & Brookman-Frazee, L. (2019). Utilizing community-based implementation trials to advance understanding of service disparities in autism spectrum disorder. (*Invited*) *Global Pediatric Health, Online First, June 13.* https://doi.org/10.1177/2333794X19854939
3. **Stahmer, A.C.,** Vejnoska, S., Iadarola, S., Straiton, D., Segovia, F., Luelmo, P., Morgan, E.H., Lee, H.S., Javid, A., Bronstein, B., Hochheimer, S., Cho, E., Aranbarri, A., Mandell, D., McGhee Hassrick, E., Smith, T., & Kasari, C. (2019). Caregiver voices: Cross cultural input on improving access to autism services. *Journal of Racial and Ethnic Health Disparities, 6,* 752-773.
4. **Stahmer, A.C.**, Suhrheinrich, J., Schetter, P., & McGee Hassrick, E. (2018). Exploring Multi-level System Factors Facilitating Educator Training and Implementation of Evidence-Based Practices (EBP): A Study Protocol. Implementation Science. https://doi.org/10.1186/s13012-017-0698-1
5. **Stahmer, A.C.**, Brookman-Frazee, L., Lee, E., Searcy, K., & Reed, S. (2011). Parent and Multi-Disciplinary Provider Perspectives on Earliest Intervention for Children at-risk for Autism Spectrum Disorders. Infants and Young Children, 24, 344-363. PMC3779141
6. **Stahmer, A. C.** & Pellecchia, M. (2015). [Editorial] Moving towards a more ecologically valid model of parent implemented interventions, Autism: International Journal of Research and Practice, *19,* 259-261.
7. **Stahmer, A. C**., Rieth, S., Lee, E., Reisinger, E., Connell, J. E., & Mandell, D. S. (2015). Training teachers to use evidence-based practices for autism: The issue of fidelity of implementation. Psychology in Schools, 52(2), 181-195.
8. Brookman-Frazee, L., **Stahmer, A.C.**, Searcy, L. K., Feder, J., Reed, S. (2012). Building a research-community collaborative to improve preventative care for children at-risk for autism spectrum disorders. Journal of Community Psychology, 40, 715–734. PMC3716577
9. Schreibman, L., Dawson, G., **Stahmer, A.C.**, Landa, R., McGee, G., Kasari, C., Ingersoll, B., Kaiser, A., Rogers, S.J., Bruinsma, Y., McNeriney, E., Wetherby, A., Hallaway, A. (2015). Naturalistic developmental behavioral interventions: Empirically validated treatments for autism spectrum disorders. Journal of Autism and Developmental Disorders, 45(8), 2411-2428.
10. Stadnick, N., Stahmer, A., & Brookman-Frazee, L. (2015). Initial findings from a community-based effectiveness study of Project ImPACT: A parent-mediated intervention for children with autism spectrum disorder. Journal of Autism and Developmental Disorders. Advance online publication. doi: 10.1007/s10803-015-2376-y

D. Research Support (representative)

1R01HD093457-01 (Stahmer, Site PI; PI: Robins). 10/1/2017-07/21/2022 NIMH

Connecting the Dots: An RCT Integrating Standardized ASD Screening, High-Quality Treatment, and Long Term Outcomes

1R01MH111981 (Stahmer, AC, PI) 02/01/2017-01/31/2021 NIMH

2/2 Effectiveness of a Multi-Level Implementation Strategy for ASD Interventions (Collaborative R01; Brookman-Frazee; UCSD)

R324A170063 (Stahmer, AC, PI) 09/01/2017-08/31/2020 IES

Exploring Mulit-level System Factors Facilitating Educator Training and Implementation of Evidence-Based Practices (EBP)

Examining the system and teacher level modifiable factors that affect implementation of training in evidence-based intervention for students with ASD in schools.

2UA3MC 1055-077-00 (Stahmer, Site PI; Kasari, PI) 10/1/2020-9/30/2025 HRSA

Autism Intervention Research Network for Behavioral Health 4

Using Community Partnered Participatory Research to increase access to care and parent engagement in services for children with ASD in low resource environments.

R324A190076 (Stahmer, Site PI; Rieth, PI) 07/01/19-06/30/2023 IES

Examining the Efficacy of Project ImPACT for Toddlers

The major goals of this project are to examine the efficacy of a parent-implemented early intervention for children with or at-risk for autism.

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Janice Lyanne Enriquez, PhD

eRA COMMONS USER NAME (credential, e.g., agency login): N/A

POSITION TITLE: Associate Clinical Professor, Training Director LEND, Associate Director UCEDD

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Completion Date MM/YYYY	FIELD OF STUDY
University of California at Davis Davis, California	B.S.	6/1998	Biochemistry & Psychology
Loma Linda University, Department of Psychology Loma Linda, California	PhD	12/2005	Clinical Psychology, Neuropsychology
Harbor UCLA Medical Center	N/A	2002-03	Predoctoral- Clinical Psychology
UC Davis CAARE Center Sacramento, CA	N/A	2004-2006	Predoctoral & Postdoctoral- Clinical Psychology

A. Personal Statement

The NorCal LEND program aims to provide leadership education to improve healthcare access for underserved children with neurodevelopmental disorders and their families. I currently serve as the Training Director of this program and I am uniquely qualified for this position given my experience and interest in clinical training and service, as well as diversity, equity and inclusion. I am a licensed clinical psychologist with specialties in diagnostic evaluation of children and treatment of young children with behavioral concerns. Currently, I provide direct patient care for children within interdisciplinary clinics, and I conduct clinical teaching for predoctoral psychology interns, and medical residents and fellows. I assist in all aspects of our program development, including development of our curriculum, community, and clinical experiences within our LEND program. Furthermore, I am heavily involved and invested in improving health equity for underrepresented children and their families nationally, and within our health system and our program through my work related to diversity, equity and inclusion.

B. Positions and Honors

2020-Present	UCEDD Associate Director of Community Engagement & Training. MIND Inst. Faculty & Diversity Committee Chair.
2019-Present	AUCD Multicultural Council Leadership Team: Secretary
2018-Present	Center for Excellence in Developmental Disabilities (CEDD) Training & Diversity Director
2016-Present	Behavioral Health Psychiatry Professional IV, Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Training Director, Co-Director Maternal Child Health Careers (MCHC) RISE-UP Program, Supervising Psychologist Joint DBP-CAARE Center APA Approved Internship
2006-2016	Psychologist II, U.C. Davis Children's Hospital, Department of Pediatrics, Section of Developmental & Behavioral Pediatrics, M.I.N.D. Institute Clinical Psychologist.

Teaching Experience

2018-Present	UCD Volunteer Clinical Faculty, Associate Clinical Professor, Dept. of Peds.
2006-2018	UCDHS Volunteer Clinical Faculty, Assistant Clinical Professor, Dept. of Peds.

Awards

UCD Health Volunteer Clinical Professor Special Recognition Teaching Award, 2018

Presentations at Annual Professional Meetings

California Best Practices & BPRA Measures Conference. Hosted by the California Area Indian Health Service and the California Rural Indian Health Board, Inc., 2017. Developmental Screening. Enriquez, J. & Weir, A.

Black Infant Health Conference, 2018. Early Developmental Screening and Community Resources. Burns, J., Enriquez, J. & Yamada, E.

California Best Practices & BPRA Measures Conference. Hosted by the California Area Indian Health Service and the California Rural Indian Health Board, Inc., 2018. Early Identification of Developmental Disabilities. Enriquez, J. & Sharpp, T.

The Role of Cultural Diversity in Mentoring. Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities, 2020. Vigil, D. & Enriquez, J.

Preparing Trainees to Engage with and in Culturally Diverse Communities: Addressing the Social-Political Context. Association of University Centers on Disabilities, 2020. Ofonedu, M., Jones, W., Enriquez, J., Graybill, E. & Yarbrough, D.

Pandemic Lessons Learned: Virtual Clinic Training from the PacWest. Association of University Centers on Disabilities, 2020. Costanza Smith, A., Rice, S., Winters, S., Friedman, S. & Enriquez, J.

Consultation

August-September 2020
Association of University Centers on Disabilities Prospective Implementor for UCEDD Resource Center’s Equity Diversity and Inclusion TA Plan

November-January 2020
Association of University Centers on Disabilities TA Institute Directors Conference Planning Committee

C. Contributions to Science

D. Additional Information: Research Support and/or Scholastic Performance

Peer Reviewed Publications:

APPI: Clinical Manual of Neurodevelopmental Disorders, Dyslexia, Dysgraphia, Dyscalculia, and other Symbolic Dysfunctions. Ingrid N. Leckliter, Ph.D., Associate Clinical Professor, and Janice L. Enriquez, Ph.D., Assistant Clinical Professor.

(In Progress) Developmental Behavioral Pediatrics, 5e edited by Drs. Heidi Feldman, Ellen Elias, Nathan Blum, Terry Stancin, and Manuel Jimenez. Autism. Hansen, R., Restrepo, B., and Enriquez, J.

Grant Funded Support

2019-20	*PI* FAST Grant (AUD). Policy and Advocacy within the NorCal LEND Curriculum.
2016-21	*Training Director* (Co-PIs Sally Rogers & Aubyn Stahmer). Human Resources Services Agency (HRSA): 16-031 “Leadership Education in Neurodevelopmental and Related Disorders” University of California, Davis (LEND Program)
2012-present	*Multicultural Council Representative to AUCD, Training and Diversity Director* (PI Robin Hansen). Centers for Excellence in Developmental Disabilities, Education, Research, and Service (UCEDD), U.S. Department of Health and Human Services
2017-2021/2022	*Co-Director*. Maternal Child Health Careers/Research Initiatives for Student Enhancement - Undergraduate Summer Program (MCHC/RISE-UP) at UC Davis (PI Harolyn Belcher). Partnership with Johns Hopkins & Kennedy Krieger Institute, funded through CDC Office of Minority

BIOGRAPHICAL SKETCH

NAME Roger Scott Akins	POSITION TITLE Section Chief, Developmental and Behavioral Pediatrics, Associate Professor, Department of Pediatrics
eRA COMMONS USER NAME (credential, e.g., agency login) RSAKINS	

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	MM/YY	FIELD OF STUDY
Northern Arizona University, Flagstaff, Arizona	B.A.	06/94	
Midwestern University, Chicago, Illinois	D.O.	01/98	Doctor of Osteopathy
Naval Medical Center, Portsmouth, Virginia		01/01	Internship Pediatrics
Naval Medical Center, Portsmouth, Virginia		01/01	Residency
University of California Davis, Sacramento, CA		06/10	Developmental Behavioral Pediatrics Fellowship

A. Personal Statement

I am a developmental and behavioral pediatrician specializing in the care of children with neurodevelopmental disorders. I am the Chief of Developmental and Behavioral Pediatrics and Director of Clinical Programs at the UC Davis, MIND Institute. I also serve as the Associate Director of the Developmental and Behavioral Pediatrics Fellowship and Associate Director of the UC Davis, University Center for Excellence in Developmental Disabilities. I am pleased to lead the model clinical programs core function and support engagement of community clinics and training of medical providers in understanding how to support people with developmental disabilities and their families.

I have special clinical interest and expertise in Autism Spectrum Disorders, Intellectual Disability and Trisomy 21. My research has focused on telehealth supports for families of children with Autism Spectrum Disorders and ADHD in remote communities, partnerships between pediatric specialty providers, schools and medical home providers and utilization of complementary and alternative medicine in families of children with Autism Spectrum Disorders.

B. Positions and Employment

2020-present	**Section Chief, Developmental and Behavioral Pediatrics, MIND Institute** Associate Professor, Department of Pediatrics Associate Director, University Center on Developmental Disabilities Associate Fellowship Director, Developmental and Behavioral Pediatrics
2017 – 2020	**Developmental Pediatrician and Senior Medical Officer, Exceptional Family Member Program**, Department of Pediatrics, Naval Medical Center Portsmouth, Portsmouth, VA
2014 – 2017	**Specialty Leader and Advisor to Surgeon General**, **Navy Pediatrics** Naval Medical Center Portsmouth, Portsmouth, VA
2013 – 2015	**Specialty Leader**, **Navy Developmental Pediatrics** Naval Medical Center Portsmouth, Portsmouth, VA
2010 – 2016	**Section Chief**, Neurodevelopmental Pediatrics Naval Medical Center Portsmouth, Portsmouth, VA
2007 – 2010	**Fellow**, Developmental and Behavioral Pediatrics M.I.N.D. Institute, University of California Davis, Sacramento, CA
2004 – 2007	**Chairman**, Department of Pediatrics Naval Hospital Jacksonville, Jacksonville, FL
2001 – 2007	**General Pediatrician**, Department of Pediatrics Naval Hospital Jacksonville, Jacksonville, FL

Awards and Honors

2018	Honorable Recognition, selected by peers as recipient of the prestigious *CAPT Anthony Delgado Servant Leadership Award*, a lifetime service award which recognizes leadership in the care of military connected children
2014	Meritorious Services Medal, Naval Medical Center Portsmouth
2014	Finalist, Arnold P. Gold Foundation, Humanism in Military Medicine Award
2014	Senior Master Clinician, Naval Medical Center Portsmouth *Reserved for top 3% of faculty members who have demonstrated excellence as clinician educators, high clinical productivity, superior patient satisfaction and academic leadership through GME and professional expertise*
2007	Navy Commendation Medal, Naval Hospital Jacksonville
2005	Meritorious Unit Commendation, Naval Hospital Jacksonville
2003	Admiral Melvin Museles Award, Family Practice Residency Program, Naval Hospital Jacksonville
2002	Navy Achievement Medal, Naval Hospital Jacksonville
2001	Navy Achievement Medal, Naval Medical Center Portsmouth
2000	Outstanding Young Pediatrician Award, American Academy of Pediatrics, Uniformed Services Chapter East

Peer Reviewed Publications.

1. Seritan, A. L., Schneider, A., Olichney, J. M., Leehey, M. A., Akins, R. S., & Hagerman, R. J. Conversion disorder in women with the FMR1 premutation Am. J. Med. Genet. A, 149A(11):2501-2506., 149A(11):2501-2506, 2009.
2. Akins, R. S., Angkustsiri, K., & Hansen, R. L. Complementary and alternative medicine in autism: An evidence-based approach to negotiating safe and efficacious interventions with families. Neurotherapeutics, 7(3):307-319., 2010.
3. Au, J., Akins, R. S., Berkowitz-Sutherland, L., Tang, H. T., Chen, Y., Boyd, A., Tassone, F., Nguyen, D. V., & Hagerman, R. Prevalence and risk of migraine headaches in adult fragile X premutation carriers. Clinical Genetics. Clinical Genetics, 84(6: 546-551, 2013.
4. Akins, R. S., Krakowiak, P., Angkustsiri, K., Hertz-Picciotto, I., & Hansen, R. L. Utilization patterns of conventional and complementary/alternative treatments in children with Autism Spectrum Disorders and children with developmental disabilities in a population-based study.. Journal for Developmental and Behavioral Pediatrics, 35(1):1-, 2014.

Government Publications:

Office of the Secretary of Defense (**Akins, R.**, contributor). *Report to Congressional Defense Committees: Study on health care and related support for children of members of the Armed Forces*. (2015); (RefID: C-1679FB4), Retrieved from https://health.mil/Reference-Center/Reports/2014/07/15/Study-Health-Care-Related-Support-Children-Members-the-Armed-Forces+&cd=3&hl=en&ct=clnk&gl=us

Research Support:

Grant No: 90DD0823 Stahmer (PI) 7/1/2016-6/30/2021
Description: The Center for Excellence in Developmental Disabilities is one of 67 federally designated university centers across the country. The mission of the Center for Excellence in Developmental Disabilities is to collaborate with individuals with developmental disabilities and their families to improve quality of life and community inclusion. The Center accomplishes this mission through advocacy, community partnerships, interdisciplinary training, and the translation of research into practical applications
Role: Co-investigator

Grant No: 12569321 Angkustsiri (PI) 07/01/2018 - 06/30/2023
HRSA Maternal and Child Health Bureau $935,575
Developmental Behavioral Pediatrics Training Program
Our overarching goal is to enhance the overall health and resiliency of children, adolescents and their families by training leaders in developmental behavioral pediatrics through public policy, research, and teaching.
Role: Associate Director

Name: Caryn Chalmers, MPH
eRA Commons User Name: NA
Position Title: Community Education Specialist

Education and Training

Institution and Location	Degree	Completion Date MM/YYYY	Field of Study
Winona State University, Winona, MN	B.S.	05/2014	Exercise and Rehabilitative Science
Oregon State University, Corvallis, OR	M.P.H	04/2018	Public Health

A. Personal Statement

This proposal brings together a team of community members, staff, faculty, and advocate. I serve as the CEDD Data Administrator and Outreach Coordinator. My current payroll title is Community Education Specialist II. I work closely with Dr. Stahmer to provide coordination and administrative oversight for the UC Davis MIND Institute CEDD and the Community Advisory Committee (CAC). My core responsibilities with the CEDD include grant writing, program evaluation, annual progress report writing, information dissemination, facilitating CAC engagement, tracking data, and monitoring online content. Additionally, at the MIND Institute I manage several programs and provide care for neurodiverse children, adolescents, and adults with ASD in a clinical setting. I have experience working for universities, hospitals, clinics, and nonprofits. Moreover, I have several years of experience working on an interdisciplinary team with therapists, physicians, technicians, and researchers. I hold a master's in public health focusing in global health and have a drive to understand health disparities to create an equitable health care system for underserved communities.

B. Positions and Honors

2013-2014 Cardiopulmonary Rehabilitation Student Intern, Meriter-UnityPoint Health
2015-2016 Rehab Technician, Virginia Commonwealth University Children's Hospital
2017-2017 Graduate Research Assistant, Oregon State University
2017-2018 Graduate Intern, United Way
2019-present Community Education Specialist, UC Davis MIND Institute

C. Selected Peer-Reviewed Publications

1. Taylor-Winney, J., **X., C.,** McNab, E., & Krahn, G. (2019). Inclusion of Youths with Disabilities in 4-H: A Scoping Literature Review. *Journal of Extension, 57*(3), Article 22. https://tigerprints.clemson.edu/joe/vol57/iss3/22

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Elizabeth Holliday Morgan

eRA COMMONS USER NAME (credential, e.g., agency login):

POSITION TITLE: Graduate Researcher and Program Coordinator, Center for Excellence in Developmental Disabilities, UC Davis MIND Institute

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Start Date MM/YYYY	Completion Date MM/YYYY	FIELD OF STUDY
Xavier University of LA	BS	08/97	05/01	Psychology
Harvard University	Ed.M.	08/02	06/03	Education
University of California Davis	Ph.D.	09/16	05/21	Human Development

A. Personal Statement

I am currently working part-time for the Center for Excellence in Developmental Disabilities and pursing a PhD in Human and Community Development at UC Davis. My areas of specialization are child development and early intervention services, with a focus on low-resource communities and reducing health disparities. I am a parent of a child with autism. I founded and facilitate CEDD's Sankofa African American parent support group. I am involved in various efforts at the MIND Institute to 1) make our training curricula culturally competent and family-centered, 2) advance and sustain cultural competence and increase cultural diversity, and 3) reduce health disparities. In my position with CEDD, I play a lead role on several projects, including early childhood partnerships with state agencies, support to preschools, support to early intervention practitioners, outreach and support to African American and low-resource communities, and assistive technology; and I organize and present community trainings on these topics. As a graduate student, I am working on an Autism Intervention Research-Behavioral Network III (AIR-B 3) grant aimed at increasing access to care for families of children with autism who are living in poverty, especially families of color.

I represent the UC Davis DBP Training Program, CEDD, and LEND on the Autism CARES national advisory committee. I am an active board member and Vice President for Warmline Family Resource Center in Sacramento, CA. I am also am the Emerging Leader Board member for the Association for Centers in Disabilities.

B. Positions and Honors

Program Coordinator (part-time), Center for Excellence in Developmental Disabilities (CEDD) at the UC Davis MIND Institute, 2014-present

Program Associate, WestEd (Consulting firm, education and human development), 2014-15

Special Education Lead, California Preschool Instruction Network, Sacramento County Office of Education, 2014-present

Distinctions

- Selected to be a Council on Quality and Leadership (CQL) Fellow (deferred to Spring 2021).
- Selected for the 2019-2020 Global Alliance for Training in Health Equity Research (GATHER) Fellowship program from the Drexel University Dornsife School of Public Health.
- Selected for Spencer Foundation's 2-day Pre-Conference Seminar for Early Career Scholars with Disabilities/Disabled Scholars for the AERA 2019 Conference in Toronto, Canada. April 3-5th, 2019.
- Selected to participate in the Critical Educators for Social Justice (CESJ) Graduate Student Forum (GSF) in Toronto on Friday, April 05, 2019

C. Selected Peer-Reviewed Publications

Morgan, E.H., Rodgers, R., & Tschida, J., (in press) "Embracing the intersections of race and disability: The work we must do". *Autism Researcher Review Board Pediatric Journal Supplement*.

Morgan, E.H. & Stahmer, A.C., (2020). Narratives of single, Black mothers using cultural capital to access autism interventions in schools. *British Journal of the Sociology of Education.* 42:1, 48-65. DOI: 10.1080/01425692.2020.1861927

Gulsrud, A., Lee, S., Hassrick, E.H., Pellechia, M., Shih, W., Vejnoska, S., Iadarola, S., **Morgan, E.H.** Hochheimer, S., Crabbe, S., Li, J., Hauptman, L., Castellon, F., Nuske, H., Garcia, C., King, R., Luelmo, P., Carleu, K., Mandell, D., Kasari, C., Stahmer, A. (Under Review). "It's who you know: Caregiver social networks predict service use among under-resourced children with autism". *Journal for Research in Autism Spectrum Disorders*.

Stahmer, A.C., Vejnoska, S., Iadarola, S., Straiton, D., Segovia, F., Luelmo, P., **Morgan, E.H.,** Lee, H.S., Javid, A., Bronstein, B., Hochheimer, S., Cho, E., Aranbarri, A., Mandell, D., McGhee Hassrick, E., Smith, T., & Kasari, C. (2019). Caregiver voices: Cross cultural input on improving access to autism services. *Journal of Racial and Ethnic Health Disparities.* https://doi.org/10.1007/s40615-019-00575-y

Iadarola, S., Pellecchia, M., Stahmer, A. Lee, H.S., Hauptman, L, **Morgan, E.H**.….Smith, T. (2020). Mind the gap: An intervention to support caregivers with a new autism spectrum disorder diagnosis is feasible and acceptable. *Journal of Pilot and Feasibility Studies*, *6*, 124. https://doi.org/10.1186/s40814-020-00662-6

Paper Repository and Abstract Publications

Morgan, E.H. (2019). "And I will tell you this": Single, Black Mothers using Cultural Capital in Schools. Section of manuscript printed in the 2019 American Educational Research Association Paper Repository for the 2019 AERA conference held in Toronto, Canada.

Morgan, E. H. Finding Our Voice: Black Mothers Navigating ASD Diagnosis and Services. Association of University Centers in Disability National Conference: Navigating Change Building Our Future Together. Poster presentation abstract. December 2016.

Publications in preparation

Morgan, E.H., (In preparation for publication). A Review of the Role of Parent Advocacy in Autism Diagnosis and Treatment: How can Schools Address Disparities for Black Children on the Autism Spectrum through Culturally Relevant Interventions. Chapter proposal.

Morgan, E.H., Hassrick, E.H.,(In preparation for publication). Community Cultural Capital used to access services in low-income, BIPOC, communities.

BIOGRAPHICAL SKETCH

NAME: **Patricia Schetter, MA**

POSITION TITLE: Executive Coordinator, CAPTAIN

EDUCATION/TRAINING

California State University, Sacramento	B.A.	12/93	Psychology
California State University, Sacramento	M.A.	6/97	Psychology

A. Personal Statement: My professional career has been dedicated to teaching and providing positive behavioral supports to individuals affected by autism and other neurodevelopmental disabilities and their families and, more recently, providing professional development and support to educators who work to teach these children in the public school system. As the lead instructor for the UC Davis Special Studies in Autism program, and the Coordinator of Autism Education Initiatives for the Center for Excellence in Developmental Disabilities, I have worked hard to translate the research on evidence-based approaches into useable formats for practitioners and families. It is vital that we make the ground-breaking research taking place at institutions such as the MIND Institute accessible and usable to parents, practitioners and educators. As a parent of a child with a disability, I know first-hand how difficult it is to make treatment decisions that are based on reliable evidence and to bring other team members on board to the extent that they can implement what needs to be done for my child. I am currently the principal investigator on a statewide systems improvement grant funded by the California Department of Education. The focus of this grant is on building capacity within the public education system to effective support students with autism through the use of evidence-based practices (EBPs). I am also the executive coordinator of a statewide technical assistance network called the California Autism Professional Training and Information Network (CAPTAIN) for our CEDD. This is a multi-agency network of trainers whose mission is to increase awareness and use of EBPs for autism in schools and community settings. I look forward to continuing my role leading school age programs in technical assistance and continuing education during the next 5 years.

B. Positions and Honors.

1991 – 1992	Intern, Applied Behavior Consultants/California State University Sacramento/UCLA Early Autism Project
1992 - 1997	Assistant Director/Teacher, Applied Behavior Consultants, a Non-Public School for Students with Autism Spectrum Disorders
1997 – 1999	Behavior Analyst, ALTA California Regional Center
1999 – 2003	Program Specialist for Students with Autism Spectrum Disorders, Butte County SELPA
2005 - 2008	SELPA Program Specialist, Yolo County Office of Education

2003 – 2019	Founder and Director of Professional Development, Autism and Behavior Training Associates
2008 – present	Coordinator of Autism Education Initiatives, CEDD at the UC Davis MIND Institute, Sacramento, CA Positions and Appointments: Other Professional
2005- present	Lead Instructor for UC Davis Extension Specialized Studies Program in Autism
2006- 2008	Teacher Educator/Instructor, Bureau of Education and Research
2008-2009	Instructor for Regional and Continuing Education, CSU Chico
2008- 2009	Appointed Member: California Legislative Blue Ribbon Commission on Autism
2013-2014	Appointed Member: California Special Education Task Force. Chair of Early Childhood Education Workgroup
2019-2020.	Appointed Member: California Department of Education Advisory Group for Restraint and Seclusion
2019-2020	Appointed Member: California Students with Disabilities Collective

C. Contributions to Education Research

Suhrheinrich, J., Schetter, P., England, A., Melgarejo, M., Nahmias, A.S., Dean, M. & Yasuda, P. (in press). Statewide interagency collaboration to support evidence-based practice scale up: The California autism professional training and information network (CAPTAIN). Evidence-based Practice in Child & Adolescent Mental Health.

Schetter, P., England, A., Kaniuka, M., Childress, N., Passmore, A., Carico, H. (In Press) Statewide Implementation and Scale-Up of Evidence Based Practices for Autism in Education: From Sea to Shining Sea. DADD Online Journal.

Stahmer, A.C., Oliver, K., & Schetter, P. (2020, January). Improving Education for California Students via Professional Development. Policy Brief. *Policy Analysis for California Education.* https://edpolicyinca.org/publications/improving-education-california-students-professional-development

Schetter, P. (2013). Percy Learns to Fly. Redding, CA: ABTA Publications. Schetter, P. (2003). Learning the ROPES for Improved Executive Functioning. Redding, CA: ABTA Publications.

Schetter, P., & Lighthall, K. (2009). Homeschooling the Child With ASD: Answers to the Top Questions Parents and Professionals Ask. San Francisco, CA: Jossey Bass Publishing.

Schetter, P., & Murphy, V. (2009). Autism Program Development and Review Protocols. Redding, CA: ABTA Publications.

Ozonoff, S. & Schetter, P. (2007). Executive Dysfunction in Autism: From Research to Practice. In Lynn Meltzer (Ed.) Understanding Executive Function. New York: Guilford Publications, Inc.

BIOGRAPHICAL SKETCH

NAME: Peter Mundy

eRA COMMONS USER NAME (credential, e.g., agency login): PCMUNDY

POSITION TITLE: Professor of Education and Psychiatry, University of California at Davis

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Completion Date MM/YYYY	FIELD OF STUDY
Richard Stockton State College, N.J.	B.A.	06/1976	Psychology
University of Miami, FL.	M.S., Ph.D.	05/1981	Dev. Psychology
UCLA Neuropsychiatric Institute	Fellow	12/1985	Child Clinical & Neurodev. Disorders

A. Personal Statement

Dr. Mundy studies the role that joint attention impairments play in the nature, diagnosis and treatment of autism. His research has contributed to identifying the behavioral and neurodevelopmental components of the social and cognitive phenotype of preschool children with autism. His work has contributed to the development of assessments such as the Autism Diagnostic Observation Scale and early intervention methods such as JASPER (Joint Attention, Symbolic Play, Engagement, and Regulation) developed by Dr. Connie Kasari and colleagues at UCLA. Dr. Mundy reported the first observations of the neural networks involved in the development of joint attention that informed research on both autism and typical development. Recently, Dr. Mundy has begun to focus on understanding the development and treatment of autism in school-aged and higher-functioning children. These efforts have involved the development of virtual reality methods for research with older children and a longitudinal test of the hypothesis that problems in reading and writing in 8 to 16 year old students with ASD, without intellectual disabilities is as an outgrowth of their social-communication and social-cognitive disabilities.

B. Positions and Honors

Positions and Employment

1986 – 1989	Assistant Clinical Professor & Adolescent Ward Psychologist, UCLA, NPI
1989 – 1991	Assistant Clinical Professor & Associate Director for Clinical Training, UAP Program in Developmental Disorders, UCLA, NPI
1991 – 1996	Associate Professor & Director, Psychological Services Center, Department of Psychology, University of Miami
1996 to 2007	Founding Director, Center for Autism and Related Disabilities, Department of Psychology, University of Miami (now serving over 9000 families)
2000 to 2007	Professor of Psychology and Director, Child Division, Department of Psychology, University of Miami

2005 to 2007	Co-Director, Marino Autism Research Institute, University of Miami & Vanderbilt University
2008 to present	Lisa Capps Professor of Neurodevelopmental Disorders and Education Research, Department of Psychiatry and School of Education.
2008 to Present	Director for Educational Research, the M.I.N.D. Institute, University of California, Davis

Honors

2019 to 2021	President International Society of Autism Research
2019 to 2020	Member, Lancet Commission of the Future of Care and Research for Autism
2016-Present	UC Davis Distinguished Professor, School of Education
2014	Visiting Professor, Jane and Terry Semel Institute for Neuroscience and Human Behavior at UCLA, April 1st to June 27th .
2013-Present	Associate Editor, *Autism Research*

C. Selected Peer-Reviewed Publications

Zajic, M. C., Solari, E. J., McIntyre, N. S., Lerro, L., & Mundy, P. C. (2021). Observing visual Attention and writing behaviors during a writing assessment: comparing children with autism spectrum disorder to peers with attention-deficit/hyperactivity disorder and typically developing peers. *Autism Research, 14,* 356-368. *DOI: 10.1002/aur.2383.*

Bullen, J.C., Swain Lerro, L., Zajic, M., McIntyre, N. & Mundy, P. (2020) A Developmental Study of Mathematics in Children with Autism pectrum Disorder, Symptoms of Attention Deficit Hyperactivity Disorder, or Typical Development. *J Autism Dev Disorder*, https://doi.org/10.1007/s10803-020-04500-9.

Mundy, P. (2019). Individual differences, social attention and the social-motivation hypothesis of autism. Behavioral and Brain Sciences. http://dx.doi.org/10.1017/S0140525X18002509

Seo, S., Kim, E., Mundy, P., Heo, J., & Kim, K. (2019). Joint attention virtual classroom: A preliminary study. Psychiatry Investigation, 16, 292-299.

McIntyre, N., Oswald, T., Solari, E., Lerro, L., Zajic, M., & Mundy, P. (2018). Social Cognition and Reading Comprehension in Children and Adolescents with Autism Spectrum Disorders or Typical Development. *Research in Autism Spectrum Disorders, 54,* 9-20*.*

McCauley, J., Zajic, M., Oswald, T., Swain-Lerro, L., McIntyre, N., Harris, M., Tresniewski, K., Mundy, P., & Solomon, M. (2018). Brief Report: Investigating relation between self-concept and performance in reading and math for school-aged children and adolescents with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 48*: 1825-1832.

Burrows, C., Usher, L., Becker-Haimes, E., McMahon, C., Jasen-Doss, A. Mundy, P., Henderson, H. (2018). Profiles and correlates of parent-child agreement on social anxiety symptom in youth with Autism Spectrum Disorder. *Journal of Autism and Developmental Disabilities, 48,* 2023-2037*.*

Mundy, P. (2018). A review of joint attention and social-cognitive brain systems in typical development and autism spectrum disorder. *European Journal of Neuroscience, 47(6)*, 497-514.

BIOGRAPHICAL SKETCH

NAME: Randi Jenssen Hagerman

eRA COMMONS USER NAME (credential, e.g., agency login): RJHAGERMAN

POSITION TITLE: Medical Director, UC Davis MIND Institute; Professor of Pediatrics

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Completion Date MM/YYYY	FIELD OF STUDY
University of California at Davis, Davis CA	B.S.	06/1971	Zoology
Stanford Medical School, Stanford, CA	M.D.	05/1975	Medicine
Stanford Medical School, Stanford, CA	PL1 & PL2	06/1977	Pediatrics
University Hospital, UC San Diego, San Diego, CA	PL3, Fellow	06/1979	Ambulatory Peds.
UC San Diego Neurosciences, San Diego, CA	Fellowship	06/1980	Developmental Peds.

A. Personal Statement

I am a developmental and behavioral pediatrician and have studied patients with fragile X syndrome (FXS), premutation involvement including FXTAS, autism, and other neurodevelopmental disorders for my entire career, which is longer than 30 years. I head the Clinical Trials Program at the MIND Institute, where I am also the medical director and hold an Endowed Chair in Fragile X Research. I have carried out significant work regarding treatment and phenotypic involvement in premutation carriers of all ages. I also direct the clinical trials program at the MIND Institute and have carried out numerous trials of targeted treatments in fragile X syndrome, Down syndrome, and autism. I have summarized the field of new targeted treatments in neurodevelopmental disorders in Hagerman RJ and Hendren RL (eds) (2014) Treatment of neurodevelopmental disorders: targeting neurobiological mechanisms. Oxford University Press, Cary, NC, and I have recently published a book on Fragile X Syndrome and Premutation Disorders by Mac Keith Press 2020 for students, physicians, and health care providers. I look forward to mentoring and helping with outreach to the community for the CEDD.

B. Positions and Honors

Positions and Employment

1982-1988	Assistant Professor of Pediatrics, University of Colorado Health Sciences Center (UCHSC), Denver, CO
1988-1993	Associate Professor of Pediatrics, UCHSC, Denver, CO
1992-2000	Section Head of Developmental & Behavioral Pediatrics, UCHSC, Denver, CO
1994-2000	Professor of Pediatrics, UCSHC, Denver, CO
2000-2005	Tsakopoulos-Vismara Endowed Professorship in Pediatrics, University of California, Davis (UC Davis Health), Sacramento, CA
2000-present	Medical Director, MIND Institute, UC Davis Health, Sacramento, CA

2005-present Endowed Chair in Fragile X Research, UC Davis Health, Sacramento, CA
2014-present Distinguished Professor of Pediatrics, UC Davis Health, Sacramento, CA

Honors

1992	Jarrett Cole Award from the National Fragile X Foundation
1993	Award for Science and Medicine, Bonfils-Stanton Foundation
2004	Distinguished Research Award for UC Davis Medical Center
2004	IASSID Distinguished Achievement Award for Scientific Literature, Montpellier, France
2005	Distinguished Scholarly Public Service Award, UC Davis
2008	Lifetime Achievement Award from the National Fragile X Foundation
2013	UC Davis Distinguished Professor
2014	Distinguished Scholarly Public Service Award, UC Davis Office of the Academic Senate
2014	C. Anderson Aldrich Award for Outstanding Career Achievement, American Academy of Pediatrics, SODBP
2014	International Sisley-Lejeune Award for Treatment of Neurodevelopmental Disorders
2017	Emil M. Mrak International Award, Cal Aggie Alumni Association

C. Selected Peer-Reviewed Publications

1. Greiss Hess L, Fitzpatrick SE, Nguyen DV, Chen Y, Gaul KN, Schneider A, Lemons Chitwood K, Eldeeb MA, Polussa J, Hessl D, Rivera S and **Hagerman RJ** (2016) A randomized, double-blind, placebo-controlled trial of low-dose sertraline in young children with fragile X syndrome. *J Dev Behav Pediatr* 37:619-628. PMC5039060
2. Ligsay A, Van Dijck A, Nguyen DV, Lozano R, Chen Y, Bickel ES, Hessl D, Schneider A, Angkustsiri K, Tassone F, Ceulemans B, Kooy RF and **Hagerman RJ** (2017) A randomized double-blind, placebo-controlled trial of ganaxolone in children and adolescents with fragile X syndrome. *J Neurodev Disord* 9:26. PMC5540519
3. **Hagerman R**, Jacquemont S, Berry-Kravis E, Des Portes V, Stanfield A, Koumaras B, Rosenkranz G, Murgia A, Wolf C, Apostol G and von Raison F (2018) Mavoglurant in Fragile X Syndrome: Results of two open-label, extension trials in adults and adolescents. *Sci Rep* 8:16970. PMC6242849
4. Biag HMB, Potter LA, Wilkins V, Afzal S, Rosvall A, Salcedo-Arellano MJ, Rajaratnam A, Manzano-Nunez R, Schneider A, Tassone F, Rivera SM and **Hagerman RJ** (2019) Metformin treatment in young children with fragile X syndrome. *Mol Genet Genomic Med* 7:e956. PMC6825840
5. Thurman AJ, Potter LA, Kim K, Tassone F, Banasik A, Potter SN, Bullard L, Nguyen V, McDuffie A, **Hagerman R** and Abbeduto L (2020) Controlled trial of lovastatin combined with an open-label treatment of a parent-implemented language intervention in youth with fragile X syndrome. *J Neurodev Disord* 12:12. PMC7175541
6. Tassanakijpanich N, **Hagerman RJ** and Worachotekamjorn J (2021) Fragile X premutation and associated health conditions: A review. *Clin Genet*. doi:10.1111/cge.13924
7. **Hagerman RJ** and Hagerman PJ (eds) (2020) Fragile X Syndrome and Premutation Disorders: New Developments and Treatments. Mac Keith Press, London, UK
8. **Hagerman R**, Protic D and Berry-Kravis E (2020) Medical, Psychopharmacological, and Targeted Treatment for FXS. In: Hagerman R, Hagerman P (eds) Fragile X Syndrome and Premutation Disorders: New Developments and Treatments. Mac Keith Press, London, UK. pp 41-58

Official CA Poverty Rate		**11.4%**
UCEDD Project Title	**Description**	**Poverty Indicator**
Of the total UCEDD Project (**50 Projects),** the percent that is targeting individuals with DD living in urban and rural poverty areas **(41 Projects)**.		**82%**
Sankofa / African American DD Parent Alliance	Sankofa is a social network for parents and caregivers of African American children with disabilities. The goals are 1) to educate and empower caregivers, and 2) to provide advocacy and resources.	Serving families in Sacramento designated Empowerment Zones (EZ/EC)
Apoyo de Padres para Padres (Parents Supporting Parents)	Spanish language parent support group for parents of children with disabilities to share their thoughts and feelings in a supportive and confidential environment.	Serving families in Sacramento designated (EZ/EC) Zones
CEDD Website	Online resources (English, Spanish) and reference materials on health. wellness, DD, advocacy, early identification, intervention, education, employment, assistive technology, and other quality of life topics.	Videos and resources to support families in EZ/EC zones and rural areas of CA
Clinic: Feeding Recovery	Intensive feeding intervention services for children with severe feeding difficulties. Interdisciplinary Clinic team provides treatment to children with DD, and training for students from a variety of disciplines.	Serving Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Neurodevelopmental Disorders Clinic	Assessments for autism spectrum disorders, fragile x syndrome, ADHD, learning disorders, and other neurodevelopmental disorders.	Serving Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Clinic: Chromosome 22q11.2 Deletion Syndrome Healthy Minds	Developmental behavioral pediatric and neuropsychological assessments, with feedback and follow-up support for families and the professionals providing care in their home communities.	
Clinic: Social Skills	Group training program for children and adults with ASD and other NDD. Topics include emotion recognition, stress management, conversation rules, social problem solving, making good choices, and friendship and leadership skills.	Medi-CAL (Medicaid) Eligible families/ children participate through DDS
CONFERENCIA 2020 Aprendiendo Juntos	CEDD sponsored Conference for Spanish families to learn about the cutting-edge research for neurodevelopmental disabilities	Serving families in EZ/EC
Conf: MIND Summer Institute	Conference intended for a wide range of professionals (health, education, other) and consumers, family, caregivers, and students. Helps participants keep pace with the latest advances in NDD research and the most current standards for best practices in prevention, assessment, treatment, and support services.	Supports Medi-Cal eligible families through Scholarships
Developmental screening at health fairs & Mexican Embassy	This is a part of CEDD's Latino outreach project.	Occurs in EZ/EC & supports Medi-Cal eligible families

Research: Exploration of Factors Influencing EBP training within CAPTAIN	Understanding how the context of our state SELPAs and Districts affects training of evidence-based practices by the statewide CAPTAIN network	Serving districts and school supported by National School Lunch Program (NSLP)
Family Navigator Program	Staffed by parents and individuals with DD who are experienced advocates themselves, to provide support and advocacy to other families; and to develop advocacy skills in the individuals and families they support to create systems change.	Serving Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Pre-svc Training Program: DBP Fellowship	The fellowship includes a didactic curriculum, training in clinical practice, teaching, and research. Includes the DBP Fundamentals course.	Serving Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Pre-svc Trng Class: Developmental Delays (undergrad)	Supports UC Davis Rise Up Students	Supports students from high poverty families
Pre-svc Trng Course: UCD EDU115 Educating Children with Disabilities	. Goal: Prepare general education teachers to work with the diversity of children in a typical inclusive classroom, including best practices in working with children with DD. Regular and Teacher Edition.	
Pre-svc Trng Course: UCD EDU213: Indiv Diffand Educational Assessment (grad)	Prepare graduate students to understand the implications of research on individual differences in cognitive development that are associated with specific learning disabilities.	
Pre-svc Trng Course: Yr 2 Pediatrics Residents (grad)	Didactic and clinical instruction in child development; NDD; developmental milestones and red flags for infants, toddlers, and school age children; medical, developmental behavioral, and social issues in pediatrics, the transition from childhood to adulthood, and cultural competence and community inclusion.	Increased training for working with Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Pre-svc Trng: Learning and Mind Sciences Program / NDD and Educational Concentration (grad)	On the psychological, social, and neuroscience foundations of human learning. Twelve seminars per year.	
Research: 22q11.2 Deletion Syndrome	Goal: Develop a range of intervention techniques that will reduce or eliminate the cognitive difficulties that present challenges to children with DD such as 22q DS.	
Research: ADHD	Research activities in etiology, assessment, treatment, and outcomes, using neuroscience and behavioral methods.	
Research: Autism / CHARGE (Childhood Autism Risks from Genetics and the Environment)	The CHARGE Study is a case-control study of over 1,000 children with differing patterns of development. These include children with autism, DD, and typically developing children compared with regard to a broad array of exposures and physiologic factors.	Focus on families in rural areas and EZ/EC in

Research: Autism / Elementary and secondary education for students with autism spectrum disorder	Virtual reality technology for intervention and assessment of public speaking, social information processing and motivation in school aged students with ASD.	
Research: Autism / Evidence-based practices in academic, social and adaptive functioning	Development of culturally-competent intervention/services for adults ages 18-38 with a diagnosis of ASD, in an effort to promote social and vocational functioning, community engagement, and self-care.	
Research: Autism / Increased access to quality intervention for children in underserved areas	Projects that involve community-based participatory research methods aimed at improving the use of EBP in underserved / low resource areas. This research expands into communities of color and under-resourced communities.	Serving Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Research: Fragile X	The Fragile X Research and Treatment Center, performs clinical evaluations and treatment of patients with fragile X and studies the association between molecular variations in the fragile X gene and the physical, behavioral and cognitive features of children and adults affected with fragile X syndrome.	Serving Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Research: Neurodevelopmental Disorders / Language development	The biological, behavioral and environmental/family factors that influence the ways in which language develops and the processes that underlie language learning are being examined in individuals with fragile X syndrome, Down syndrome, and autism spectrum disorder, developing methods for assessment and monitoring treatment efficacy over time.	Serving Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Research: Neurodevelopmental Disorders / RASopathies	Research on the association of autism in the RASopathies, how germline Ras/ MAPK pathway dysregulation affects skeletal muscle development and other organ systems, and how germline Ras/MAPK pathway affects functional interactions among glia and neurons in the brain.	Serving Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Resource Center	Parent-to-parent support, creating and supporting connections to resources within the MIND, at the UC Davis Medical Center, and in the community. Bilingual staff - English & Spanish.	Supports families in Occurs in EZ/EC & supports Medi-Cal & TANF eligible families
Resource: Spanish versions of MIND Institute resource materials	Provided Spanish translation of MIND Institute resource materials	Supports families in Occurs in EZ/EC & supports Medi-Cal & TANF eligible families
TA: Assistive Technology (AT)	Quarterly networking and informational meetings for AT professionals in the region to expand knowledge of and access to appropriate AT for people with DD and their families.	Supports families in Occurs in EZ/EC & NSLP schools

TA: CA Autism Professional Training and Information Network (CAPTAIN) and other state agencies	CAPTAIN consists of representatives of the CA Departments of Developmental Services, Education, and Public Health, and other stakeholders. The group has developed the infrastructure and interagency collaboration to implement a state plan for improving services to children and youth with ASD.	Work in NSLP schools and districts
TA: Early Childhood Partnerships with State Agencies and Community Organizations	Includes 1) the Interagency Coordinating Council; 2) the Training & Technical Assistance Collaborative; 3) CA Statewide Screening Collaborative; 4) CA Early Start Network; and 5) efforts to reduce health disparities in early intervention services.	Supports programs serving Medi-Cal eligible families; Head Start Programs
TA: Preschool Early Intervention Supports	Training and technical assistance in Classroom Pivotal Response Teaching (CPRT), a naturalistic, developmental, behavioral intervention for students with autism to preschools in low resource districts.	Supports schools in EZ/EC & NSLP schools and districts; Head Start Programs
TA: Support for transition to adulthood	TA for development of infrastructure, interagency communication and collaboration to support transition to adulthood and employment opportunities for people with DD. Includes: 1) Think Transition Workgroup, 2) Northern California Business Advisory Council and ; 3) Stanford Business Economic Recovery Recommendation Workgroup.	Supports individuals with DD in Occurs in EZ/EC & supports Medi-Cal & TANF eligible; SSI recipients
Trng Series (Schools): EBP, Child Parent Relationship Therapy, Video Modeling Training	Evidence-based practices, Child Parent Relationship Therapy, Video Modeling Training for CA school district educators and administrators	Supports Medi-Cal eligible families and providers in EZ/EC
Trng Series (SELPA): Implementing EBP Across California	Presentations to State SELPA directors; Marin County, 7/18, 7/29, 8/14, 8/21, 9/06, 9/10, 9/18, 9/26, 9/27, 9/28, 10/18, 12/19, 12/20, 5/14	Serving districts and school supported by National School Lunch Program (NSLP)
Trng Series (TEAMS): TEAMS Leadership Institute	CAPTAIN -based community training to local school districts and public community clinics. TEAMS = Translating Evidence-Based Interventions for ASD: A Multi-Level Implementation Strategy.	Serving districts and school supported by National School Lunch Program (NSLP)
Trng Series: Genomic Medicine Clinical Grand Rounds (UC Davis)	Same as Genomic Medicine Case Conference, different than Genomic Medicine Seminar Series.) Participants are kept abreast of topics in the rapidly changing field of clinical genomics through case conferences.	Serving Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Trng Series: Meeting Hearts and MIND	Monthly training includes various training formats, including 1) Case Conference, 2) Journal Club, and 3) Performance Improvement.	
Trng Series: Pediatric Resident Continuity Care Clinic	Teaching modules in the Continuity Care Clinic UC Davis	Serving Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Trng Series: ECHO-Autism Program	ECHO-Autism is a teleconferencing program, including didactic training and case conferencing, connecting a hub team of autism experts at the UC Davis MIND Institute and practitioners at remote locations.	Supports providers in EZ/EC and those that serve Medi-Cal eligible patients

Trng Series: Sibling Workshops	Workshops for siblings of individuals who have disabilities; 8 local workshops this year	Serving Medi-Cal Eligible families
Trng Series: Special Studies Program (SSP) in ASD	Trains educators and health professionals as well as people with disabilities, family members, and other members of the community.	Trains provides to support Medi-CAL eligible families and TANF eligible families; families in rural areas and EZ/EC
Trng Series: Vamos a platicar / Let's Talk	6-hour training by CEDD staff that is conducted entirely in Spanish for parents of children with DD to share their experiences and to learn about their child's diagnosis and needs.	Serving Medi-Cal Eligible families
Trng: ACCESS (Acquiring Career, Coping, Executive Function, and Social Skills) Program	For adults with ASD to practice and develop skills while meeting others and having fun. Designed to help strengthen social skills, life coping skills, and planning skills to empower adults with autism to access social, work/educational, and community opportunities.	Serving Medi-Cal Eligible individuals and families; SSI recipients
Trng: CAPTAIN Summit North	The California Autism Professional Training and Information Network (CAPTAIN) is a statewide initiative to develop the infrastructure and interagency collaborations to improve services to children with ASD by providing training and support. Oakland, CA	Supports schools in EZ/EC & NSLP schools and districts
Trng: CAPTAIN Summit South	The California Autism Professional Training and Information Network (CAPTAIN) is a statewide initiative to develop the infrastructure and interagency collaborations to improve services to children with ASD by providing training and support in up-to-date evidence-based practices. Camarillo CA.	Supports schools in EZ/EC & NSLP schools and districts
Trng: Covid Let's Talk	Virtual series of "LET'S TALK," an opportunity to share concerns and hear information / resources from professionals supporting people with IDD and their families." given weekly since 4/09/20	Serving Medi-Cal and TANF Eligible families
Trngs: Supported Decision Making (SDM) for Regional Center Professionals	Training for professionals (2 hrs each) presented by Steve Ruder in six Regional Center (RC) areas: Stockton 8/28, Modesto 1/30/20	Supports professionals serving Medi-Cal and TANF Eligible families and those in rural areas
Trngs: Supported Decision Making (SDM) for Families	Training for families (2 hrs each) presented by Steve Ruder in six Regional Center (RC) areas: MIND Institute 7/10	Serving Medi-Cal and TANF Eligible families