

**Five Year Closeout Report 2016 - 2021**  
**University Center for Excellence in Developmental Disabilities (UCEDD)**  
**Five Year Closeout Report to the**  
**Office of Intellectual and Developmental Disabilities (OIDD)**

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<b>Period of Performance</b>	2016 - 2021
<b>Approved Project Period</b>	2016 - 2021
<b>Project Title</b>	CEDD at the UC Davis MIND Institute
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## Five Year Closeout Report. Part 1A. Final Report on UCEDD Accomplishments

Describe the extent to which each goal was achieved by providing qualitative and quantitative information about major accomplishments and outcomes for the five-year time period. It is not necessary to describe all activities implemented to achieve a goal. Instead, you can describe major activities over the five-year period. Where possible, describe the use of capacity building, advocacy, and systemic change activities to achieve a goal.

This section provides a progress report on the UCEDD work plan. Use the work plan from the 5-year application, or the most recently updated workplan submitted with a continuation application, to provide annual updates along with a narrative report of progress for each section of the work plan that has activities planned for the time period. Activities not planned for during the reporting period should not be included in this section.

1:	<a href="#">Appendix A Workplan 5 year closeout.docx</a>
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## Five Year Closeout Report. Part 1B. Final Summary of Evaluation Results

The UCEDD provides an evaluation plan in its 5-year core grant application. This section will be used to provide a summary report of the results of the evaluation for the full 5-year core grant period of performance.

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

UCEDD Annual Report for FY 2016-21

### Introduction

The Center for Excellence in Developmental Disabilities (CEDD) at the UC Davis MIND Institute is working to leverage the translational impact of research from MIND Institute investigators, expand on initiatives in the areas of training and community service, and develop links between the university and the community to address the needs of Californians with disabilities. We have ongoing activities in all the core functions specified by the DD Act, including pre-service interdisciplinary training, community service, research, and information dissemination. CEDD embraces self-determination as a core value and strives to include people with developmental and other disabilities (D/OD) and their families in all our core functions, and as participants in the design of our project activities that promote independence, productivity, integration and inclusion in the life of the community.

This report covers our completed five-year strategic plan to address the needs of Californians with disabilities 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 early identification and intervention and post-secondary education and employment. We have maintained our focus on these areas of emphasis throughout this five-year period.

Our Consumer Advisory Committee (CAC) has an active, diverse membership and plays a key role in determining the direction of the CEDD. The Committee had three face-to-face meetings annually for the first 3.5 years of the award. During the final 1.5 years of the award the CAC met via video technology (Zoom) 3 times annually.

Our Center leadership is firmly established and active. The relationship between the Center and the University is stable and productive. Staff morale is high. We have had changes in leadership and staffing during course of this 5-year plan. Staff members Lori Llewelyn, Cathryn Mikitka and Angie Rivera retired in June 2020, April 2021, and June 2021 respectively. Staff member Elizabeth Morgan has received her PhD and taken a faculty position at California State University, Sacramento. She continues part time with the CEDD to continue her advocacy and outreach roles to the Black community of families of children with autism and other NDD. Robin Stewart, MSW, has joined our team to coordinate the family navigator program (formerly Cathy Mikitkas role). We recently hired Cecilia Corral to replace Angie Rivera in her outreach and support to Latinx families and communities. Kris Wallman, MSW, will be taking on the role of data coordinator and program manager with a focus on community outreach and engagement. She will also coordinate the CAC (formerly Lori Llewelyns role).

We are on track with our five-year plan for each of our five goals. This year we met or exceeded the benchmarks for all our annual performance measures in our evaluation plan, and we met or exceeded the benchmarks for 38 of the 40 performance measures in our annual workplan. Given the extreme challenges of the COVID-19 pandemic over the past year and a half, we feel we have done quite well in adapting our programs to meet the changing needs of our community and have been able to continue to meet the commitments we made in our 2016-2021 five-year plan.

We recently completed the strategic planning process that culminated in a new five-year plan proposal which was submitted to OIDD in early 2021 and subsequently approved. The strategic planning process provided the opportunity to review the states needs, in collaboration with our federal DD partners, and CEDDs strengths and opportunities, as well as all of CEDDs current projects, in great depth and from the perspective of many different individuals and groups. As a result, we have updated and refocused our efforts in pursuit of our mission.

#### Part 1B. Summary of Evaluation Results

CEDD is committed to data-driven strategic planning as a creative and participatory process that helps us focus our efforts in pursuit of our mission and promotes accountability and customer satisfaction. Our workplan helps us set priorities and build commitment, and it guides funding acquisition and allocation. Our workplan and evaluation plan enable us to monitor achievements and assess results.

The CEDD CAC advises and guides the work of the CEDD and serves as a bridge between the community and the university. Members are selected to ensure that the CAC includes a majority of consumers and is representative of Californias geographic, racial/ethnic, socio-economic, and rural/urban diversity. In addition to monitoring progress towards the goals and objectives in our five-year plan, the CAC reviews emergent issues and concerns and provides input on priorities, product development, potential partners, outreach strategies, and ideas for strengthening the participation of people with disabilities and their families in our activities. Between CAC meetings, staff and CAC members are in communication by way of other meetings, phone calls and e-mails.

Progress toward priorities, as well as emerging trends and needs, are assessed continually and in various venues, including the CAC, the DDNP, and CEDD workgroups (Training, Early Intervention, CAPTAIN, Assistive Technology, Transition to Adulthood). CAC members participating in CEDD workgroups/projects have direct, ongoing feedback on progress towards goals/outcomes related to the specific workgroup or project on which they are participating, including customer satisfaction data. The full CAC reviews the annual report, which includes summary customer satisfaction data by project. The Directors of each of the DDNP members meet regularly together, either in person or by phone, to discuss collaborative activities, emerging needs and strategies for maximizing the use of collaborative resources to address identified needs.

At the end of this fifth year of our five-year strategic plan, we are pleased to report that we are on track with the strategic plan for each of our five goals. This year we met or exceeded the benchmarks for 36 of our 38 performance measures in our annual workplan. Two goals for the number of conference presentations were not met and were impacted by the cancellation of academic conferences due to Covid-19 and the retirement of one of our researchers.

Following is a summary of our performance during this five-year period by core function.

Interdisciplinary pre-service training and continuing education

Interdisciplinary graduate-level DD training program (including DBP Fellowship Program)

Number of trainees: 66

Type of trainees: Developmental Behavioral Pediatrics 16, Education 4, Family/Parent/Youth Advocacy 2, Psychology 13, Physical Therapy 2, Social Work 1, Other 28.

Trainees from diverse backgrounds: African American 3; Hispanic/Latinx 14; Asian 16. Person who speaks a language other than English at home: 24. Parent or family member of people with disabilities: 24.

Percent of trainees reporting an increase in knowledge or skills and/or change in attitude about supporting those with DD in the community: 100%

Number of pre-service training events outside of the CEDD: 44 (811 hours)

Number of students at pre-service training events outside of the CEDD: 2808

Number of people with DD receiving services from former trainees, as measured in the survey of former trainees at 1, 5, and 10 years post-training: 12,961 (NIRS generated report notes 18 in this field which does not align with figures in past PPRs).

Percent of long-term trainees in leadership positions, as measured in the survey of former trainees at 1, 5, and 10 years post-training: On average: 73% increasing annually from 57% in 2017 to 100% in 2021

Training on neurodiversity and DD to (other) graduate students

Number of events: 336 seminars/lectures

Number of students: 54 students

Training on neurodiversity and DD to undergraduate students

Number of events: 146 lectures

Continuing education

Number of programs: 236 programs, 854 hours of training

Number of participating professionals: 48,993

#### Community services

Community training (not counting continuing education events)

Number of people who received training by emphasis area:

- o Education and Early Intervention: 9119
- o Employment-Related activities: 145
- o Health-related activities: 191,325

Number of training events and/or training series: 715

Percent of recipients who reported satisfaction with training: 95%

Percent of recipients of regular on-going trainings who reported an increase in knowledge or skills: 98%

#### Technical assistance (TA)

Number of hours of TA provided: 2746 total hours

Percent of TA recipients with a sustained relationship with the UCEDD who reported enhanced resources or services, strengthened networking, increased awareness of evidence-based practices, and/or identification of needed policy changes: 100%

#### Model clinical services

19,500 people received clinical services.

95% of survey respondents reported satisfaction with services received.

#### Research

53 research projects in the areas of autism spectrum disorders, fragile X syndrome, chromosome 22q11.2 deletion syndrome, ADHD, and other subjects related to neurodevelopmental disorders

Research findings were presented in 383 peer-reviewed journal articles.

Research findings were presented in 402 conference presentations.

## Information Dissemination

124 educational videos with a total of 956,000 web hits

Seven conferences (5 in English and 2 in Spanish) were held for dissemination of research findings and evidence-based best practices. 95% of conference attendees reported satisfaction with the events overall.

See summary of dissemination of research findings through peer-reviewed journal articles and conference presentations in the Research section above.

The MIND/CEDD Resource Center provided assistance to 8595 people, including 745 people with DD.

The CEDD website received 478,0230 hits. 95% of the surveyed sample of website users reported satisfaction with the website.

## Leveraged Funding Summary

Number of grants, contracts, and other funds leveraged: 23 annually on average

Total amount of funds leveraged: \$67,866,896 million

Seventy-five percent (75%) of CEDDs funding comes from federal grants, and the other 25% from a variety of sources, including state grants, foundation grants, fees for service, and university funding.

The CEDD Program Manager and 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.

The CEDD Director, Associate Directors, and Program Manager review progress towards goals with the Executive Committee, the CAC, and the staff. The CAC reviews progress towards goals and objectives at every meeting, and CAC members are encouraged and supported to provide feedback at the meetings and/or directly to staff in person or via phone or e-mail at any time. The CEDD Annual Report is also made available to CAC members for review and comment.

1:	<a href="#">Conceptual Framework 2016-2021.doc</a>
2:	<a href="#">ORG Chart 2016-2021.docx</a>
3:	<a href="#">Part 1b Final Summary Eval 5 yr closeout rpt 10_4_21.docx</a>

**Measures of Improvement and Outcomes**

**CORE FUNCTION: Interdisciplinary Pre-Service Preparation**

Instructional program offered by the UCEDD that: (1) integrates knowledge and methods from two or more distinct disciplines; (2) integrates direct contributions to the field made by people with disabilities and family members; (3) examines and advances professional practice, scholarship and policy that impacts the lives of people with developmental and other disabilities and their families; (4) is designed to advance an individual's academic or professional credentials; and (5) takes place in an academic setting or program.

It may: (1) lead to the award of an initial academic degree, professional certificate, or advanced academic credential; and (2) contribute to a discipline-specific course of study offered by the UCEDD or by another academic department.

<b>UCEDD Long-Term Trainees Data</b>	
<b>Trainee data is not unduplicated across years.</b>	
Percent of UCEDD long term trainees who report they applied knowledge and skills one time or more (data collection started in FY2021):	24%
Percent of former UCEDD long-term trainees working in areas of high need - underserved or vulnerable populations.	84%
Number of individuals with DD receiving services from former UCEDD long-term trainees	18
Percent of former UCEDD long-term trainees in leadership positions	100%

<b>Output Measures</b>		
<b>Number and type (discipline, intermediate, long-term) of UCEDD trainees trained in the DD field</b>		
<b>Discipline</b>	<b>Trainee Type</b>	<b>Trainees #</b>
Education/Special Education	Long-term	2
	Intermediate	0
Education: Early Intervention/Early Childhood	Long-term	2
	Intermediate	0
Family Member/Community Member	Long-term	1
	Intermediate	0
Family/Parent/Youth Advocacy	Long-term	0
	Intermediate	1
Health Administration	Long-term	1
	Intermediate	0
Medicine-Developmental-Behavioral Pediatrics	Long-term	15
	Intermediate	1

Medicine-General	Long-term	0			
	Intermediate	15			
Medicine-Other	Long-term	0			
	Intermediate	1			
Medicine-Pediatrics	Long-term	0			
	Intermediate	3			
Mental and Behavioral Health	Long-term	1			
	Intermediate	0			
Nursing	Long-term	1			
	Intermediate	0			
Nursing-General	Long-term	1			
	Intermediate	0			
Other	Long-term	1			
	Intermediate	2			
Physical Therapy	Long-term	2			
	Intermediate	0			
Psychology	Long-term	10			
	Intermediate	3			
Public Health	Long-term	1			
	Intermediate	1			
Social Work	Long-term	1			
	Intermediate	0			
Total Long-term		39			
Total Intermediate		27			
<b>Total number of UCEDD trainees</b>		66			
<b>Number of UCEDD interdisciplinary training programs</b>		13			
<b>Number of UCEDD discipline specific training programs</b>		53			
<b>Diversity of UCEDD trainees (e.g., gender, person w/disability, family member, race/culture/language spoken)</b>		66 total trainees			
Race		Ethnicity		Gender	
White	37	Hispanic	14	Female	60
Black or African American	3	Non Hispanic	52	Male	6
American Indian and Alaska Native	0	Unrecorded	0		



Asian	16				
Native Hawaiian and Other Pacific Islander	0				
More than one race	6				
Unrecorded	4				
<b>Personal Relationship with Disabilities</b>		<b>Primary Language</b>			
Person with a disability	1	<b>Do you speak a language other than English at home?</b>		<b>How well do you speak English? (only trainees who answer YES to the previous question "Do you speak a language other than English at home?" will be answering this question).</b>	
Person with a special health care need	1	Spanish	9	Very well	23
Parent of a person with a disability	11	Another language	15	Well	1
Parent of a person with a special health care need	5	No	42	Not well	0
Family member of a person with a disability	13			Not at all	0
Family member of a person with a special health care need	13				
Unrecorded	1				
None	39				

<b>Regarding pre-service preparation trainings conducted outside the UCEDD:</b>	
<b>Number of training events</b>	44
<b>Total number of hours for training events</b>	811 total hours
<b>Total number of participants/students trained</b>	2808

<b>Initial Outcome Measure</b>	
Total Number surveyed	350
Total Number responding	226
<b>Number responding</b>	
Strongly Agree	194
Agree	32

	Disagree	0
	Strongly Disagree	0
<b>Percent of UCEDD long-term trainees reporting an increase in knowledge or skills and/or change in attitude</b>		<b>100%</b>

**Measures of Improvement and Outcomes**  
**CORE FUNCTION: Continuing Education**

Seminars or courses of instruction offered by the UCEDD that: (1) serve to maintain professional credentials; (2) encourage professionals to expand their knowledge base and stay up-to-date on new developments; and (3) offer certificates of completion or CEUs (or their equivalents).

<b>Output Measures</b>	
<b>Number of professionals participating in UCEDD continuing education programs</b>	48993
<b>Number of UCEDD continuing education programs</b>	236
<b>Length (amount of course time) of CE program</b>	854 total hours

**Measures of Improvement and Outcomes**  
**CORE FUNCTION: Community Services: Training**

Training provided by UCEDD faculty/staff to enhance knowledge of a variety of community members (individuals with developmental and other disabilities, their families, professionals, paraprofessionals, policy-makers, students or others in the community).

<b>Output Measures</b>		
<b>Number of people trained by participant type (e.g., individuals with D/OD, family members, Service providers, professionals, paraprofessionals, Policy makers, Community members) IN AREA OF EMPHASIS</b>		
<b>Area of Emphasis</b>		
Education & Early Intervention	<b>9119 total</b>	
	Trainees Total	98
	Classroom Students	3640
	Professionals & Para-Professionals	4957
	Family Members/Caregivers	415
	Adults with Disabilities	0
	Children/Adolescents with Disabilities/SHCN	5
	Legislators/Policymakers	0
	General Public/Community Members	4
Employment-Related Activities	<b>145 total</b>	
	Trainees Total	0
	Classroom Students	0
	Professionals & Para-Professionals	120
	Family Members/Caregivers	25
	Adults with Disabilities	0
	Children/Adolescents with Disabilities/SHCN	0
	Legislators/Policymakers	0
	General Public/Community Members	0
Health-Related Activities	<b>191325 total</b>	
	Trainees Total	79854
	Classroom Students	30393

	Professionals & Para-Professionals	68972
	Family Members/Caregivers	6443
	Adults with Disabilities	136
	Children/Adolescents with Disabilities/SHCN	5
	Legislators/Policy makers	0
	General Public/Community Members	5522
Quality of Life	<b>15682 total</b>	
	Trainees Total	82
	Classroom Students	601
	Professionals & Para-Professionals	10259
	Family Members/Caregivers	3817
	Adults with Disabilities	632
	Children/Adolescents with Disabilities/SHCN	52
	Legislators/Policy makers	20
	General Public/Community Members	219
<b>Number of discrete training events and/or training series IN AREA OF EMPHASIS</b>		715
<b>Area of Emphasis</b>		
Education & Early Intervention		19
Employment-Related Activities		3
Health-Related Activities		533
Quality of Life		160

<b>Initial Outcome Measures</b>		
<b>For recipients of regular, on-going trainings, percent reporting an increase in knowledge gained IN AREA OF EMPHASIS:</b>		
<b>Area of Emphasis</b>	<b>Initial Outcome Measure</b>	
Education & Early Intervention	98%	
	Total number of activities	3
	Total number surveyed	117

	Total number responding	117
	<b>Number responding</b>	
	Strongly Agree	83
	Agree	32
	Disagree	2
	Strongly Disagree	0
Health-Related Activities	97%	
	Total number of activities	49
	Total number surveyed	1687
	Total number responding	877
	<b>Number responding</b>	
	Strongly Agree	582
	Agree	274
	Disagree	20
	Strongly Disagree	1
Quality of Life	98%	
	Total number of activities	31
	Total number surveyed	2111
	Total number responding	1357
	<b>Number responding</b>	
	Strongly Agree	871
	Agree	462
	Disagree	20
	Strongly Disagree	4

## Measures of Improvement and Outcomes

### CORE FUNCTION: Community Services: Technical Assistance

Direct problem-solving services provided by UCEDD faculty/staff to assist individuals with developmental and other disabilities, families, programs, agencies, or other entities in improving their outcomes, services, management, and/or policies. This includes TA provided to self-advocacy organizations, family support groups, and other organizations.

#### \*Impact statement(s) for at least one TA project/activity over the 5 years.

CEDD works to strengthen advocacy 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. The advocacy projects in our 2016-2021 Five Year Plan focused on our partnerships with Warmline Family Resource Center and Apoyo de padres para padres, (or Parents supporting parents), with special emphasis on the Latino and Asian communities. We have continued to expand our projects in this area to include outreach in the African-American community; participation in the Statewide Self-Advocacy Network (SSAN); our Resource Center; and our Family Navigator Program.

We place a high priority on self- and family-advocacy efforts in the Latino, African-American, and Asian communities. Our staff reflects this racial/ethnic (and language) diversity and have many connections in the related communities. As staff have retired, we have continued to hire diverse team members with personal connections to the disability community and those with NDD themselves. Projects involve strategic outreach into underserved communities through partnering with community leaders and organizations to engender disability awareness and the importance of early intervention. CEDD promotes self- and family-advocacy via outreach, workshops, networking, training, technical assistance and website resources, with many resources in Spanish as well as English with new languages being supported based on the population of our State. Self- and family-advocacy is a high priority for our CAC.

We have adjusted to the COVID-19 pandemic by moving most of our programs on-line. Our parent support and advocacy groups, sibling workshops, Spanish and English webinars and transition support workshops and our family navigator program have all successfully transitioned to a distance format. For some of our programs that has increased participation, especially for families and practitioners in rural areas of our state.

Highlighting our Family Navigator Program. We piloted the Family Navigator program in our first year of this funding period and during year two, leveraged funding from our Autism Center of Excellence to expand the program. 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,

**Impact statements briefly summarize, in lay terms, the difference the project's teaching/learning, research/discovery, and extension and outreach/engagement efforts have made. They state accomplishments and create strong support for programs.**

and access needed resources. Our family navigator program, staffed by family members and individuals with disabilities who are experienced advocates themselves, provide support and advocacy to other families; participate in training medical students, residents, fellows, and clinic/hospital staff in providing person- and family-centered care for people with disabilities; and develop advocacy skills in the individuals and families they support to create systems change. Participants learn how to access community-based services for their child, based on provider recommendations and family goals. Peer Coaches provide peer-to-peer support in helping families navigate service systems and act as mentors reducing feelings of stigma and social isolation and increase advocacy skills.

Family Navigator is now a fully developed manualized program receiving referrals from both the medical and research clinics and includes people with autism, global developmental delay, language delay, attention deficit hyperactivity disorder and other concerns. The program has served a total of 300 families through 8 peer coaches who are linguistically and culturally diverse. The program serves families in 19 counties throughout Northern California, including rural areas. Children range in age from 1-18 with a majority of children ages 0-5 (55%). Approximately 10% of participants speak a language other than English (primarily Spanish). On average, families remain in the program for 5.4 months with 35% continuing some consultation beyond 6 months from diagnosis. All families reported receiving support directly related to their referral. From a grateful parent: "...checking in I've recognized is something I look forward to more than most anything else! So many little things you have helped with keeping me on track with... and the support of having someone who understands that emotional mom connection that I have to all of this!"

The program has expanded to provide Parent Education Groups to create a supportive learning environment for families on community-based treatment and resources. The program offers approximately 6-10 parent education sessions annually, available to the public. Groups topics have focused on guiding parents through accessing key community-based resources and services such as Regional Centers, Education Services, and Family Resource Centers, coping with COVID-19 distance services and accessing care during the pandemic. Participating families report increased knowledge on accessing services (67%), and high rates of satisfaction (89%) with groups.

Some parent comments from the groups include:

Very helpful to hear from other parents and trade information

This was great, thank you! I would love to continue attending more of these especially meetings tailored to specifics such as: understanding the roles of IEP professionals; local resources; local activities within special needs community

The open discussion really helped

Great resources- very helpful having "experts" and people with experience



available for questions

One of our peer coaches shared her story. She started participating in the family navigator program as a LEND trainee and took a position as a permanent navigator. She says that her hardest and most important job is being a mom to two amazing kids, Samantha and Sharif. Sharif was diagnosed with Fragile X Syndrome and Autism at 10 months old. She found navigating the service system a huge challenge because the system and number of providers made things very complicated. She initially avoided support groups because of her perception of them as being a place to complain or find pity. However, being a LEND trainee helped stretch her comfort zone and her ability to talk about her sons disability with large groups and individual families and being open to discuss a sensitive topic. She received training as a family navigator and found that parents were so thankful for the support and that giving back gives her a feeling of purpose. She now feels there is a reason for her journey. At the beginning of her participation as a navigator there were moments when it felt a little heavy, perhaps because her son was still young and some of the memories of early diagnosis were fresh. However, she also learned from the families she coached that sharing the experience could provide both for them and for her. She gains resources and learns from them as much as they learn from her.

We are currently working on obtaining sustainable funding to continue to offer the program free of charge. We recently work with the LEND to develop a parent support program called Get Mindful which provides mindfulness training to reduce parent stress in a 6-week program. We have now offered the program 4 times and will continue to do so. All family navigator programs and support have moved to a phone or video format during the COVID-19 pandemic. We are now working on ways to train family navigators to support further community engagement by supporting them as cultural brokers. Additionally, we are recruiting navigators from a variety of cultural backgrounds and who speak a variety of languages.

Highlighting Sibling Workshops:

Panel of Siblings of Disabled Children

Project Lead: Maribel Hernandez, gomhernandez@ucdavis.edu

The CEDD partnered with community partners, La Familia Counseling Center, to host a special workshop for siblings of children with various disabilities. Decades of research highlights the importance of providing an additional layer of support and care for children in the family that are not disabled. During the workshop a panel of siblings discussed their experiences which included the triumphs and challenges of being a sibling in the disability community. This is sibling participant, Erika Gonzalezs account what she appreciated most about attending the workshop: Thank you very much CEDD and La Familia for creating a space where we could express ourselves and get to know more about each other. I really loved this opportunity and I appreciate that they have taken me into account. For those of the panel, a pleasure to meet you all and the great heart that you all have!

**Output Measures**

<b>Number of hours of technical assistance provided in the areas of emphasis</b>	2746 Total hours
<b>Area of Emphasis</b>	<b>Hours</b>
Health-Related Activities	835
Quality of Life	1911
<b>Number of hours of technical assistance per type of organization</b>	2746 total hours
<b>Type of Organization</b>	<b>Hours</b>
State Title V Agency	518
State Health Dept.	718
Clinical Programs/Hospitals	245
	353
Developmental Disabilities Council	230
Another UCEDD	1349
	603
	518
	2168
	1724
	402
	334
State/Local DD/DD Agency or Provider	1827
	240
Mental Health/Substance Abuse Agency	518
Transportation Agency	48
Provider Organization	808
	1850
State/Local Coalition	618
	60
Independent research or policy organization	40

**Initial Outcome Measures**

	Total number of activities	24
	Total number surveyed	181
	Total number responding	129
	<b>Number responding</b>	
	Strongly Agree	88
	Agree	41
	Disagree	0
	Strongly Disagree	0
	For TA recipients with a sustained relationship with the UCEDD, percent reporting an increase in any of the identified or requested item(s):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 evidenced-based approaches, Identification of policy changes needed within the areas of emphasis: (Strongly Agreed + Agreed)	<b>100%</b>

## Measures of Improvement and Outcomes

### CORE FUNCTION: Community Services: Model Services

Specialized services delivered with the intention to enhance the well being and status of the recipient and not for testing new practices and may be integrated with training, research, and/or dissemination functions. Includes direct problem-solving services provided by UCEDD faculty/staff to assist individuals with developmental and other disabilities and their families.

#### \*Impact statement(s) for at least one Model Service project/activity over the 5 years.

**Impact statements briefly summarize, in lay terms, the difference the project's teaching/learning, research/discovery, and extension and**

Highlighting Social Skills Groups and SibShop Integration.

Drs. Haener and Tudor, our Child Life Team, including Erin Roseborough and Veronica Tuss, lead groups for weekly intervention using evidence-based intervention for children with ASD, their parents, and their siblings. Children and adolescents between 8 to 18 years of age, participated in groups divided by age (8-10 years, 11-14-years, 14 to 17-years) to learn and practice evidence-based strategies to improve social communication and social skills. Their parents participated in a separate parent group to learn about social communication skills that they could also foster in other environments to support concepts and skills which their children learned, and also to have a supportive parent group. Siblings were invited to participate in a sibling group that included activities adapted from the Sibshop Support program. MIND Child Life Staff receive training this year to increase support to siblings as their families participated in social skills groups. All services were delivered by telehealth during the past two years and participants were pleased with the online delivery of all services, the accessibility of group leaders, and the opportunity for parents and children to continue to connect with others during this particularly challenging year.

Drs. Tony Simon, Kathleen Angkustsiri, and Janice Enriquez lead the 22q Healthy Minds clinic and conduct clinical neuropsychological and medical evaluations on patients diagnosed with 22q11.2 deletion (VCFS/DiGeorge) syndrome. UCEDD research and clinical faculty, led by Tony Simon, Ph.D., Kathy Angkustiri, M.D., and Janice Enriquez, Ph.D., have worked together to create, maintain, and expand the 22q11.2DS Clinic. This past year we included a Psychology Postdoctoral Fellow, Jonathan Bystrynski, within this team, as well as other rotating interdisciplinary trainees (e.g., speech language pathology, family members) within LEND to support this clinic periodically via consultation. The clinic provides developmental behavioral pediatric and neuropsychological assessments of all children with 22q11.2DS participating in Dr. Simons NIH research program, with feedback and follow-up support for families and the professionals providing care in their home communities. 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. One hundred and thirty-nine (139) people received services in the 22q11.2DS Clinic in the five-year period.

**outreach/engagement efforts have made. They state accomplishments and create strong support for programs.**

The Feeding Recovery Clinic, led by Scott Akins, DO, and Meredith Stawicki, CCC-SLP, is an interdisciplinary clinic which provides feeding intervention services for children with behavioral feeding difficulties and their families. The Feeding Recovery Clinic team includes a speech (feeding) therapist, a dietitian, a mental health professional and a developmental behavioral pediatrician. The clinic provides both clinical services and interdisciplinary training, using the S.O.S evidence-based approach. Last year as a LEND trainee Ms. Stawicki conducted a needs assessment of our feeding clinic. Children with autism and NDD have a higher rate of feeding disorders or challenges than typically developing children with an estimated prevalence of feeding difficulties in children with ASD as high as 90%. An estimated 58-67% of parents of children with ASD report selective or picky eating in their child. She surveyed and interviewed caregivers of children under age 7 with ASD or NDD with feeding challenges seen in our clinic during the past year for assessment or intervention for feeding challenges. Results indicated that children had difficulty transitioning to solid foods and had very restricted diets of mostly crunchy foods or liquids and those that did eat solids accepted fewer than 20 foods. Parents reported children were more open to trying new foods with therapist and ate a wider variety of foods at school. Feeding challenges greatly impacted the family including increased stress and worry as well as frustration, difficulty finding childcare and eating out.

I just think its a really hard road that most people don't understand and it does bring a lot of emotions and frustration and heartache for the child and the family, that's not easily remedied. I mean, it's going to take years and years and years.

Parents had concerns about their childrens' nutritional intake. Parents reported challenges in obtaining services for feeding issues as related to insurance.

I am a really strong advocate, and my background is in education, and I kind of already know some of those barriers my background is not in health or insurance, but as a parent, I think you really have to learn not to take no for an answer.

Services were impacted by the COVID-19 pandemic. Data were used to improve and adapt our feeding clinic to support family needs.

**Output Measure**

**Number of specialized services offered by the UCEDD to enhance the well being and status of the recipient**

51

**Initial Outcome Measures**

**Number of individuals who received specialized services from the UCEDD to enhance the well being and status of the recipient**

19500

Area of Emphasis	Number of Individuals
Health-Related Activities	16696
Quality of Life	2804

**Measures of Improvement and Outcomes**

**CORE FUNCTION: Community Services: Demonstration Services**

Services that field test promising or exemplary practices and may be integrated with training, research, and/or dissemination functions.

**\*Impact statement(s) for at least one Demonstration service project/activity over the 5 years.**

Impact statements briefly summarize, in lay terms, the difference the project's teaching/learning, research/discovery, and extension and outreach/engagement efforts have made. They state accomplishments and create strong support for programs.

**Incomplete**

**Output Measures**

Number of services offered solely by the UCEDD that are being field tested as promising or exemplary/best practices

0

Number of services offered in partnership with others that are being field tested as promising or exemplary/best practices

0

**Initial Outcome Measures**

UCEDD and/or partnering agency adopts findings from field test to make at least one modification to the UCEDD services being field tested

Demonstration services provided over 5-year core grant period:

0

Demonstration services resulting in modification to services being tested (total)

0

Demonstration services resulting in modification to services being tested (%)

0

## Measures of Improvement and Outcomes

### CORE FUNCTION: Research

Implementation of basic and applied research, program evaluation, and analysis of public policy on issues impacting individuals with developmental disabilities

#### \*Impact statement(s) for at least one instance of UCEDD- generated research findings.

- **Leading to changes in the systems, practice, policy, at any level (e.g., local, state, regional tribal, territorial, national).**
  - **Translated into practice and/or policy**
  - **Leading to adoption of evidence-based practices**
- Impact statements briefly summarize, in lay terms, the difference the project's teaching/learning, research/discovery, and extension and outreach/engagement efforts have made. They state accomplishments and create strong support for programs.**

CEDD brings a community service and translational focus to MIND research projects. 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 Latino, African-American and Asian communities, serve as advisers to many MIND research projects, including most of those described in this report. CEDD staff also help researchers make other connections in the community, including self-advocates, families, and advocacy groups. We also have bilingual bicultural Spanish assessment available for research projects as part of the IDDRC core, and the CHARGE study, as one example, has recruited a diverse subject population that includes a large Latinx cohort in the ASD, developmental delay and population control groups. Our school-based research studies include over 1/3 Latinx children and families which is representative of our state.

Research findings impact activities in the other core functions, including pre-service training, community service and advocacy, community training, technical assistance, and clinical services, on a regular, ongoing basis. Studies suggest that it takes many years for research evidence to reach clinical practice, but CEDD researchers are focused on a quicker turn-around time for bench to bedside to curbside. Some of our strategies include:

All CEDD researchers are active providers of pre-service training and community training.

Many CEDD researchers provide clinical services, as well as pre-service training and community training and teach undergraduate students.

MIND Institute researchers share their research findings with each other and with clinicians, medical school educators, community educators, and TA providers in bi-weekly seminars.

An example of bi-directional research that has been supported by CEDD staff and contacts and, in turn, has provided evidence-based materials and support to our CEDD programming is the Autism Intervention Research Network in Behavioral Health (AIRB), directed at UCD by CEDD Director, Aubyn Stahmer (overall director is Dr. Connie Kasari at UCLA) and CEDD faculty Dr. Nicole Sparapani and Dr. Peter Mundy. The project also includes CEDD staff Amber Fitzgerald, Maribel Hernandez, Elizabeth Morgan, Angie Rivera, Benita Shaw, and Patty Schetter either as consultants, trainers or part of the research team. Most efficacious interventions for autism have been tested in white, middle class samples seen in clinic settings, with communities of color rarely



reflected as research participants and few tested in under-resourced communities. Almost no research has thoroughly tested the cultural relevance of recommended autism interventions.

The project involves adoption, implementation, and sustainment of interventions to facilitate family engagement in services immediately after receiving an ASD or NDD diagnosis and improving access to high quality education services and transition services. The project involved development, adoption and sustainment of interventions to facilitate family engagement in transitions into service and between service systems to reduce disparities in ASD access, diagnosis and services. The team worked with the CEDD and community partners in California and other states (NY, PA) to develop a family navigation curriculum to support historically marginalized families in accessing services, and a program to support families as their children transitioned between schools. The team completed randomized trials of the family navigator program training peer coaches to assist families upon diagnosis and a randomized trial looking at ways to help families work with school districts to build successful transitions for students with ASD moving from preschool to Kindergarten, elementary to middle and middle to high school. Data indicated that both programs were successful. Specifically, the family navigator program, called Mind the Gap, increased family empowerment. Therefore, the CEDD family navigator program has adopted the curriculum and is working to sustain funding from the program from the Department of Developmental Services. These randomized trials included >75% participants identifying as part of an historically marginalized group based on race/ethnicity or income.

This project has been refunded and now involves implementing three interventions in low resources schools and family resource centers with an aim to reduce disparities in ASD access, diagnosis and services. We continue to work with our community group and our local partners at Warmline and Family Soup Family Resource and Empowerment Centers to implement the program. In fact, we worked with those teams to secure outside funding to implement the program with Spanish and Punjabi speaking families. This is one example of how our partnerships move evidence-based practices quickly into community programs.

Here is a personal story of a participant in an AIR-B family navigator projects who was then linked to a CEDD parent support group.

At 63-years-old Rita became an adoptive parent for a 6-month-old baby named Israel. He [Israel] came to me when he was six months old, and he had already been diagnosed as having several medical conditions, as well as different developmental delays, including 22q Deletion Syndrome, which I had no idea what it was at first. Ritas biological children were all adults and out of the home, but she knew God had brought Israel into her life for a reason. Rita first came to the MIND Institute and took part in several studies and learned so much over the years about Israels unique needs and the supports that will help him thrive, but she still felt disconnected from gaining authentic relationships within the disability community. That was until she signed up for the Mind the Gap (MTG) research project that was an intervention program

designed to provide families of children of newly diagnosed autistic children with peer navigators to coach them on how to access services and supports. That is where she met MTG peer navigator and CEDD program coordinator, Benita Shaw. This is Ritas account of her relationship with Benita and how that led to her ongoing involvement in our Sankofa family support group shed [Benita] came out and helped me to learn about some of the stuff I was going to be facing. Shes a godsend, I said, you know, shes been through all that, Im just getting ready to start. And so, she is the one told me about the support group, Sankofa. And so thats how I started coming to Sankofa. When I first came, you know, I just kind of sit back in the corner, all quiet and everything and just kind of listening. And it was refreshing to be there to see other families, especially families of colors supporting each other and then also being willing to open up and say, hey, yes, I have a child that has some delays, or has some issues, because our culture typically does not do that. It was refreshing to go there and listen and hear other parents talk about their struggles and as well as their successes. Rita discussed how Sankofa has given her valuable information that has allowed her to be an effective advocate for her son during medical visits and special education meetings: I didnt know that I could contest the IEP or that I didnt have to sign it while sitting there at the meeting. I didnt know that until we were talking about IEPs at the [Sankofa] meeting. You dont have to sign anything. You have the right to say no, I didnt know that. I thought, okay, theyre the experts. I have to do what they say. So that was very significant. Because after that, when I went in for IEPs, I had done my research, I said, hey, I need a written report, before I come to that meeting, so I have time to study it and read it. And understand it before I got to the IEP session. I didnt know that I could request that. But thats information that I got from the Sankofa group and listening to the other mothers and parents talk about their experiences in the IEP process. So that was very beneficial to understand that I had power. Rita is now personifying the mission of Sankofa, which is to go back and fetch it, with her outreach efforts to other families passing on the information she learned from the group. Lead on Rita!

**Output Measure**

**Number of active research activities**

53

**Initial Outcome Measures**

**Have you adopted research findings from research activities completed in current or prior years by modifying a fiscal year?**

2016	Yes
2017	Yes
2018	Yes

2019	Yes
2020	No
2021	No

**Measures of Improvement and Outcomes**  
**CORE FUNCTION: Information Dissemination**

Distribution of knowledge-based information through UCEDD developed products and activities.

**\*Impact statement**

<p><b>Discuss how information dissemination plan, as outlined in the 5 year application, was implemented over the 5 years.</b></p>	<p>Spanish Family Conference Story</p> <p>Project Lead: Maribel Hernandez, gomhernandez@ucdavis.edu</p> <p>On October 7-10, 2020, Maribel Hernandez, along with a team of committed volunteers hosted a family conference to provide families whose language is primarily Spanish information about disability advocacy and rights. The conference was hosted via Zoom and had experts from many of our partner agencies such as Alta California Regional Center, Disability Rights California, California State Council on Developmental Disabilities, CREO - CommuniCare Centros de Salud and WarmLine Family Resource Center. The conference was a huge success, bringing participants from all over the Northern California central valley. This is one account from a participant, Ivn Muiz Daz, about her experience during the conference I would like to let you know that your work is excellent with our community! Thank you very much for always inviting me to your meetings, which are very important to me, since they are full of excellent material and your professionalism as well as that of the people who invite each meeting, is worth recognizing! I have learned so much with you! Thank you very much for this material that you just sent me, I have not seen the videos yet, but I have already printed the visuals and they will help me a lot with my son. Again, thank you very much for all your help and excellent work, I thank you with all my heart!./p&gt;</p> <p>Project: Sharing Our Journey DDS Video Modules,/p&gt;</p> <p>Project leads: Elizabeth Morgan, emorgan@ucdavis.edu and Maribel Hernandez, gomhernandez@ucdavis.edu</p> <p>The UC Davis Center for Excellence in Developmental Disabilities (CEDD) at the MIND Institute worked with families to reduce health disparities in early intervention access through a one-year grant from the California Department of Developmental Services Disparity Funds Program. The Disparity Funds Program supports projects that aim to increase equity in service access. Our UCEDD worked with an advisory committee of DD partners and families to develop culturally appropriate video resources for the African American and Hispanic communities of Northern California. The project entitled Sharing our Journey gave first-person accounts for cultural brokers in the African American and Hispanic communities to address the disparities in accessing early intervention services. The goal of the videos was to give underserved communities access to information needed to access early intervention services by giving examples of real-life familys experiences of navigating the interventions and supports available. We created two sets of informational video modules, one for the Hispanic community (in Spanish) and the other for</p>
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the African American community (in English). After completing the video series, the CEDD outreach specialist and project coordinators, Elizabeth Morgan and Maribel Hernandez, conducted community trainings for hundreds of providers to spread awareness of how to access and use the modules for service providers. We conducted trainings in person and via Zoom and included agencies as SCOE, Alta California RC, DDS and as well as to national conferences such as the AUCD and Family Voices National Leadership Conference. Feedback from the Family Voices team included this statement from Bev Baker The wisdom you bring to this field of family and professional partners who work together to improve the lives of children and youth with special health care needs and their families is powerful. Together our voices will have a great impact. Thank you again.

**Output Measures**

<b>Number of products developed in the current Fiscal Year</b>	576
<b>Number of products disseminated (regardless of whether they were created in the current or previous Fiscal Years)</b>	576
<b>Number of conferences and conference presentations</b>	540

**Measures of Improvement and Outcomes  
Leveraging**

Efforts to leverage funds for carrying out the core functions (proposal writing and submission, partnership development.)

**\*Total amount of funds leveraged over the course of the 5-year grant**

Source	Funds Leveraged
Federal	\$45,011,428.00
ACL	\$3,349,919.00
HRSA	\$5,151,027.00
NIH	\$33,996,078.00
ED (US Department of Education)	\$5,866,055.00
State	\$254,196.00
Local	\$0.00
Other > Private Sources (Foundation/Donations)	\$3,325,835.00
Other > Fee-for-Services	\$6,920,520.00
Other > Service Organization, University, AUCD, Other	\$927,183.00
<b>Total</b>	<b>\$67,866,896.00</b>

**\*Average dollar amount leveraged per core dollar across the 5-year period**

5-year Total \$\$ leveraged/ 5-year Total \$\$ core	<b>\$56,439,162.00 / \$3,351,651.00</b>
	<b>\$16.84</b>

## Five Year Closeout Report, Part 3: Measures of Collaboration

### Required Reporting Elements

<p><b>*1. Identify the critical issues/barriers affecting individuals with developmental disabilities and their families in your State that the DD Network (The State DD Council, Protection and Advocacy Agency, and UCEDD) has jointly identified:</b></p>	<p>Emergency preparedness and access to services during an emergency situation such as COVID-19.</p>
<p><b>2. Describe the strategies collaboratively implemented by the DD Network for at least one of the issues/barriers identified above:</b></p>	
<p><b>*a. Issue/Barrier</b></p>	<p>Emergency Preparedness and Access to Information and Services during the COVID-19 workforce disruption</p>
<p><b>*b. Provide a brief description of the collaborative strategies to address issue/barrier and expected outcome(s):</b></p>	<p>Services provided to individuals with ID/DD were substantially disrupted with the onset of COVID-19 and local and state emergency and stay-at-home orders in California. Beginning on March 9, 2020, we saw unprecedented school, day program, employment coaching and community mental health clinic closures, in addition to concerns regarding home health care and virtually all other services for people with ID/DD. This has severely disrupted policies regarding service delivery and the way services are delivered. In addition, data are clearly indicating that COVID-19 is disproportionately affecting individuals with disabilities. People with disabilities and their families report challenges understanding changes to service delivery and regulations and difficulty accessing the services they need. This challenge is even greater for people of color and those for whom English is a second language. Our UCEDD has adapted our programs and worked closely with our DD network partners to improve access to services, information and PPE for people with disabilities in our state.</p> <p>COLLABORATIVE STRATEGIES:</p> <p>1. Development of plain language information about changes in DDS policies and procedures. 2. Survey of stakeholders and community-based organizations to identify gaps and needs and effective methods of communication with various stakeholder groups. 3. Provide resources to consumers, families and providers to support health, mental health and understanding of the COVID-19 crisis and rapidly changing directives. 4. Educate policy makers about the needs of people with disabilities during the COVID-19 crisis. 5. Support people with disabilities and their families in accessing PPE and distance technology. 6. Providing TA in how to move services to an on-line platform and how to safely provide essential in-person</p>

	<p>services, including IEP consultation, guidance documents in supporting educators and families during school closures, etc. and 7. Collaboratively develop strategies to increase vaccine readiness in the NDD population and their caregivers.</p> <p>EXPECTED OUTCOMES: People with disabilities and their families will have access to information about DDS directives and changing state and local guidelines around the COVID-19 response. Families and people with DD will have access to services via distance technology or in person. People with disabilities and their families will know who to contact for support, resources and access to essential needs, including PPE. Individuals with NDD and their care givers will have greater access to COVID-19 vaccines and greater readiness to obtain the vaccine. Ultimately, we hope that every person with a disability in California will receive appropriate access to services during a disaster situation and will have a clear understanding of how to obtain information and support in a time of crisis.</p>
<p><b>*c. Check applicable areas of emphasis</b></p>	<p>Quality of Life</p>
<p><b>*d. Describe the UCEDD's specific role and responsibilities in this collaborative effort. Include any technical assistance expertise you can provide to other States in this area</b></p>	<p>This project takes advantage of CEDDs unique position at the crossroads of the University and community and its access to consumer and family voices, expert medical and legal input, and our diverse consumer advisory board, which includes SCDD and DRC representatives.</p> <p>Since the COVID-19 crisis began to change regulations in California, the CEDD has shifted services and TA quickly and expanded lines of communication with the community. Some examples include: 1) Providing TA to a California Dept of Education sanctioned workgroup called The Innovative Solution Workgroup, charged with gathering and sharing innovative strategies, ideas and resources to educators as they made the shift to distance learning; 2) Developing a Special Edition Autism ECHO series, Helping Educators Use a Distance Coaching Model to Assist Families with Setting up New Learning Routines and Supporting Positive Behaviors for Students with Autism During Home-based Instruction; 3) Working with DRC and SCDD to develop, distribute and analyze a survey of CBO statewide to identify effective communication strategies; 4) Conducting multiple webinars for families and services providers to support their use of telehealth to provide services; 5) Moving clinic services to a telehealth format; 6) Providing family navigator services and parent support groups via distance technology and increasing frequency to respond to emerging issues; 7) Developing a virtual resource center to meet the needs of families with recent diagnoses; and 8) Delivering PPE to families throughout the COVID-19 crisis.</p>
<p><b>*e. Briefly identify problems encountered as a result of this collaboration, and technical assistance, if any, desired</b></p>	<p>Many families who do not speak English or live in low resource areas have challenges with adequate access to free or low cost internet services. Families may feel isolated and driven by fears that their loved ones will become ill or have challenges due to a lack of available services. Providers felt unprepared to move education and other services to a distance format and often, individuals with disabilities had difficulty engaging in services through the internet. Innovative models are needed to ensure access to care during</p>



<p><b>*f. Describe any unexpected benefits of this collaborative effort</b></p>	<p>crises such as this one.</p> <p>Many of our parent support groups and community presentations have moved to an on-line format. This has increased participation and engagement in these programs, both locally and from more rural areas. We will use this technology to support more families in the long term and to provide TA and training to rural regions of our state. Additionally, we have been able to train more general medical providers in strategies to support people with NDD due to increased need for COVID-19 vaccinations. We are developing a toolkit based on our experience in our specialized clinic.</p>
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**Optional Reporting Elements**

<p><b>3. Describe your collaborations with non-DD Act funded programs:</b></p> <ul style="list-style-type: none"> <li>• <b>List which disability populations benefited from your collaborations.</b></li> <li>• <b>Estimate the number of individuals with disabilities, other than developmental disabilities, who were affected by your collaborations with non-DD Act funded programs.</b></li> <li>• <b>Estimate the number of individuals with developmental disabilities who were affected by your collaborations with non-DD Act funded programs.</b></li> </ul>	<p>Our UCEDD has partnered with Family Voices of CA on a few projects in the past year to address diversity within policy and family centered perspectives. One area in which we have partnered has been by including representatives from each partner site in the others organizational efforts to improve diversity, equity and inclusion for people with disabilities and historically underserved communities. FCVA partner, Elaine Linn, was invited to join a cohort of 25 individuals to form a diverse interdisciplinary community of practice (faculty, staff, leadership, clinicians, parents, family, individuals with disability). Elaine Linn participated in a transformative and restorative justice series led by Drs. Maisha and Lawrence Winn from the UC Davis campus to provide a family centered, policy and community perspective of the areas of strength and growth for the MIND in the future in order to improve our diversity, equity and inclusion efforts.</p> <p>In turn, Janice Enriquez was invited by FVCA to participate in a community of practice that was charged with developing goals to improve cultural responsiveness within the FVCA Project Leadership training to reach historically underserved communities and in an effort to promote inclusion. Janice is working with a diverse group of Project Leadership trainers across the state to develop action plans to address three areas of focus: intersectionality, representation, and diverse approaches to advocacy. Each action plan will allow for the curriculum to better serve families that reflect the diversity of California by explicitly addressing the way social identities including race, ethnicity, language, socioeconomic status, and education impact the way that families experience disability and advocacy. These collaborative opportunities have allowed our UCEDD and also our partners to develop and gain expertise that has been mutually and reciprocally shared with both of our organizations.</p> <p>Our LEND Training Program also has a collaborative partnership with FVCA. In January 2020, two LEND faculty members and one LEND trainee participated in a 3-day train-the-trainer workshop for Project Leadership, which was made possible with the support of FVCA and an additional grant. Since then, we have been able to integrate components from Project Leadership into LENDs existing training curriculum to help us build a more robust policy and systems education curriculum that is sustainable and inclusive. This includes support from FVCA partners, Elaine Linn and Ali Barclay, who continue to give presentations to LEND trainees each year on</p>
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topics such as public policy advocacy for systems change and how to harness the power of personal experiences in advocacy. Once in-person conferences are allowed to take place again, we plan to have LEND trainees participate in FVCAs annual Health Summit. Collaboration with FVCA to do disabilities policy training helps us advance policy and practice not only for, but also with, individuals with disabilities, families, and communities.

### Required Reporting Elements

The CEDD has participated with our DDNP to maximize the use of COVID-19 Vaccine funds. DDNP meet at least monthly to coordinated education and outreach activities related to increasing vaccine readiness in the I/DD population, especially those in culturally diverse groups and rural areas, and support for vaccine distribution in our state. These collaborations have allowed different programs to focus their funds on different activities (e.g., educational materials; outreach to specific populations; vaccine access) to maximize funds and impact. The UC Davis CEDD at the MIND Institute hosts a weekly vaccine clinic set up specifically to meet the needs of individuals with IDD and their care providers. Our clinic provides additional time, is sensory friendly, dedicated parking, specially trained staff and materials to prepare individuals with IDD and their families for the vaccine. A video description of the program can be found at

<https://health.ucdavis.edu/mindinstitute/resources/covid-vaccine-clinic.html>

Individuals with IDD ages 12 and older and accompanying caregivers can receive the vaccine. Child Life Specialists developed social stories and other visual supports. They complete an interview with the individual or their family member to determine how to best prepare the environment for a successful visit. A board certified behavior analyst is on site to help individuals who may be fearful or need alternative communication methods. The team has developed materials that are publicly available in English and Spanish to prepare individuals with IDD for a vaccination and provides training to medical professionals at other sites in methods to support individuals with IDD during the vaccination process.

In addition, our Family Navigator program has teamed with the MIND Institute Clinic and CEDD to reach out to families to answer questions about the vaccine, to help them learn where they can access the vaccine and to support transportation access when needed.

Thus far our vaccine clinic has seen 76 people with NDD and trained 12 clinicians to provide vaccines to individuals with NDD. Several patients have had successful second vaccine appointments even in cases when they had to be sedated for their first shot.

Northern California Business Advisory Group.

One result of the collaborative efforts of the DDNP around transition and employment was that CEDD staff member Steve Ruder was inspired by a business advisory group in Southern California to organize a similar group in Northern California. The Northern California Business Advisory Council (BAC) works to strengthen supported employment services and educate potential business partners about employing individuals with disabilities. BAC provides

advice, guidance, and support for the continuing expansion of high quality workforce development programs for people with DD. The BAC is also a vehicle to increase the level of service and coordination among the different agencies supporting people with disabilities with their employment. Planning meetings are opportunities for different support agencies to share information and effective strategies with each other and to discuss practices that are counterproductive. Department of Rehabilitation and local workforce development agencies have the opportunity to provide agency staff with information about their services and also learn about the challenges and opportunities support agencies are experiencing.

Personal Story:

Unleashed: how a doggie day care was the perfect fit for employee and employer

This is a story about hope, opportunity and a chihuahua named Bruiser. It takes place at Cha Chas Doggie Daycare in East Sacramento, where 34-year-old Ashley Robertson has been working since October of 2020.

Im usually more of a cat person, she said, but then quickly added, but I like dogs just as much.

**\*4. Provide a summary of one or more collaborative effort(s) across the five-year period, including a narrative focused on major outcomes resulting from the collaboration(s). In the narrative, be sure to clarify the impact, or outcomes, of collaborations among the DD Network and other partners.**

Robertson has autism, and her job at Cha Chas is supported by Progressive Employment Concepts, which assists businesses that hire people with developmental disabilities. Progressive is a partner of the Northern California Business Advisory Council, part of the Center of Excellence in Developmental Disabilities at the UC Davis MIND Institute. The collaboration introduces business to qualified applicants who have disabilities, which increases diversity, equity and inclusion at regional workplaces. Job options for people with developmental disabilities are very limited. So, the Business Advisory Council acts as a bridge between employers and the agencies that can provide support to businesses through the onboarding and training process. Cha Chas owner, Desalene Jones, was moved to contact the MIND Institute when she noticed that an after-school center next door, where kids with autism used to gather, closed due to the pandemic. I wanted to know how I could help; how I could be the change, she said. The Business Advisory Council discussed her vision and connected her with Progressive Employment Concepts, and they introduced Robertson as a possible hire.

But working at a doggie daycare isnt for everyone, Jones warned. The dogs are loose here and running around and its different from a lot of typical kennels, when you have 30 dogs jumping on you. Ashley walked through and was interested, and it seemed like a good match. And it has been. Robertson now works 16 hours a week. On a recent workday, Robertson described her duties at Cha Chas, while nuzzling her favorite dog at the daycare.

I like this little chihuahua named Bruiser because hes really sweet, she explained, in between cuddles. I like to play with the dogs and I also like to do nap time with them. Theyll lay down in whatever space they can find, and I usually sit with them. I also do leash work, feed the dogs their lunches and I also often clean up their messes, Robertson said.

As part of the arrangement with Progressive Employment Concepts, Robertson makes a regular wage and has a job coach, Marlene Mangabat, who joins her at work part of the time. Cha Chas also receives financial assistance while Ashley is being trained. The goal is to gradually decrease Mangabats role until she's not needed.

#### Long-term relationships

That growth is one of the benefits of the program, said Steve Ruder, community health program supervisor with the Business Advisory Council. He noted that an employees development opportunities often lead to a successful, long-term relationship.

Employers tell us all the time that these hires are incredibly competent, that they are loyal and that they are oftentimes the face of the business, Ruder said. Some have been with their company for a decade or longer.

In 2016, the Business Advisory Council reviewed workers supported by two partner agencies and found that of the 91 employees, 22 had worked for the same company for a decade or longer, and eight had worked for the same employer for at least 20 years. Many of these companies are in the service industry, explained Ruder. The fact that a third of these employees have been at the same company for ten or more years is truly astounding.

Jones noted that Robertson is still in learning mode, and so are her other employees. She's still developing her skills and is doing well with specific tasks, such as cleaning. I think it stretches her a bit when little things happen, like a dog attacking the mop, but she's doing really well, she said. As a business owner it's helpful to have someone that enjoys doing those tasks.

Jones said a recent training session with her whole team and Mangabat via Zoom was very helpful, too. I didnt realize what a benefit that would be. It improved communication between Ashley and my other employees, but much of what we all learned could be used outside of work, too, in terms of communication and universally helpful concepts, she said.

In fact, its been so successful that Jones has now hired a second employee with developmental disabilities through Southside Unlimited, another supported employment agency that works with the Business Advisory Council. Her advice to other employers considering the idea is, Do it!

As for Robertson, she says the job at Cha Chas has helped her to realize how much she enjoys working with animals and plans to continue doing so. The job is very rewarding, and I see it as a blessing and a success, she said.

