## Abstract

Sonoran University Center for Excellence in Developmental Disabilities (SUCEDD) developed a five-year plan responding to articulated statewide needs with input from its Community Advisory Council and the Arizona Developmental Disabilities Network. Goals are to: 1) Enhance and expand opportunities for individuals with DD to attain personal life outcomes; 2) Build capacity to achieve inclusive and equitable access for persons with DD and their families from underserved communities; 3) Enhance social inclusion for individuals with DD; and 4) Build capacity to promote promising and evidence-based practices through workforce development of current and future professionals. Objectives serve to: 1) develop interventions and implementation strategies that support life transitions and improve health, quality of life, and employment outcomes; 2) examine and address the needs of diverse populations and promote universal design and cultural and linguistic competency; 3) expand opportunities for individuals and families to make community connections, build relationships, and engage in inclusive, intergenerational programming; and 4) cultivate leaders, advocates, and a diverse, skilled and qualified workforce. Anticipated outcomes are increased: 1) resources and opportunities for individuals to actively engage in personal life choices and outcomes; 2) access to information, services, and supports that are responsive to the diverse values and needs of all individuals with DD and their families; 3) access and active participation by people with DD in all aspects of their communities; and 4) capacity for professionals and systems to effectively support people with disabilities and their families across the lifespan. Highlighted products include training programs for students and support professionals; evidence-based service models and interventions, knowledge translation resources, leadership development strategies, and research/practice/policy briefs.

#### SECTION 1: PROJECT RELEVANCE & CURRENT NEED

## Portrait of the State of Arizona

Arizona (AZ) is a large and complex state. It is characterized by great ethnic and cultural diversity spread over 114,000 square miles of large cities and towns, rural districts, and vast uninhabited desert, forested plateau, and mountain landscapes. It shares long borders with three states (CA, UT, NM), a short border with Nevada, and 326 miles of the U.S.–Mexico border. Twenty-two federally recognized American Indian territories inhabit one-quarter of the landmass of the state, including the majority of the Navajo Nation, the largest in the country. In 2019, the U.S. Census Bureau estimated Arizona's population at 7.3 million, a 13.9% increase since 2010, making it the 14<sup>th</sup> most populous U.S. state. It ranks 35<sup>th</sup> in the nation for population density, 80% of which is clustered in a central corridor that runs through the Phoenix and Tucson metropolitan areas. The rest of the state's population is widely dispersed in smaller cities, towns, and rural lands that are often several hours away from that corridor.

The diversity of Arizona's residents adds to its rich cultural heritage. According to the U.S. Census Bureau (2019), 54.1% of AZ residents identify as White and not Hispanic or Latino, which is lower than the national average (60.1%). Hispanics or Latinos of any race make up the largest ethnic minority (31.7%), and Native Americans or American Indians (5.3% identify as only American Indian/Alaskan Native) make up the largest racial minority in the state. Additionally, AZ is home to a large population of undocumented immigrants, the exact size of which is not fully known. Estimates from 2016 indicate that of the 10.7 billion undocumented immigrants in the U.S., AZ is home to roughly 275,000 (Pew Research Center, 2019). Arizona's southern border presents its own unique and inviting culture characterized by a spirit of family and community influenced by its roots in both Mexico and Arizona. The Tohono O'odham (TO) Nation, whose land is home to the UA, is the size of the state of Connecticut located across both countries with Native TO, Spanish, and English languages spoken. The American Community Survey (2018) reports that 13.2% of Arizonans have a disability compared to 12.6% nationally. Of this number, 5.1% are estimated to represent persons with a cognitive disability. The AZ Division of Developmental Disabilities utilizes the U.S. Administration for Community Living's prevalence rate of 1.58% to determine that there are approximately 111,624 people with developmental disabilities (DD) in AZ. The numbers are correspondingly greatest among those who identify as White/non-Hispanic (64.4%), Hispanic or Latino of any race (22.6%), and American Indian/Alaska Native alone (4.8%) populations (Comprehensive Review & Analysis, 2020).

The Arizona state interagency system of disability services and supports include an array of agencies across the lifespan including the Division of Developmental Disabilities (DDD), AZ Long Term Care System (ALTCS), Area on Aging (AAA), and the Rehabilitation Services Administration Vocational Rehabilitation (VR) Program all located in the Department of Economic Security (DES); AZ Health Care Cost Containment System (AHCCCS) state Medicaid including Behavioral Health Services and Managed Care, the AZ Department of Education (ADE), AZ Early Intervention Program (AzEIP), AZ Department of Health Services including Children and Youth with Special Health Care Needs, and AZ Statewide Independent Living Council. Tribal Vocational Rehabilitation Programs are located on the Navajo, Hopi, White Mountain Apache, Tohono O'odham, and Salt River Native American communities. The Arizona Developmental Disability Network includes the SUCEDD, AZ Developmental Disability Planning Council (ADDPC), AZ Center for Disability Law (the P & A), and the Northern Arizona University UCEDD, Institute on Human Development (IHD). There is considerable collaboration across agencies and organizations as representatives attend mutual meetings, share service provision, and engage in new initiatives. The nature of the state with the majority of the population in the two large cities of Phoenix and Tucson, contributes to frequent opportunities to connect and participate in formal and informal meetings with decision-makers, managers, and direct service representatives.

Conversely, the state structure with an emphasis on local control/implementation creates opportunities to ensure services are responsive for the individual community; however, it also presents problems for people with disabilities and family members seeking services as they may be different than what they have heard about in another part of the state – navigation can be challenging, discrepancies exist across locations, and outcomes tend to vary. Issues around access, service coordination, and disparities in care are often raised. Feedback from our Community Advisory Council (CAC) members while preparing our plan indicated a need to enhance collaboration across systems with policies and practices that work together and breakdown silos. This was evident throughout the AZ DD Network Cultural and Linguistic Competency (CLC) Listening Sessions (2020) where participants shared the need for a centralized source of easily accessible information, service requests to address gaps they were experiencing, shortages of providers in their areas, assistance with systems navigation, and lack of language accessible and culturally responsive services. Similar themes were heard regarding coordinated and accessible services from multiple sources: the AZ Town Hall Strong Families, Thriving Children (2019), AZ Statewide Independent Living Council Needs Assessment (2020), AZ Transition Exploration Study (2021), The Power of Disability Employment: The Impact of Arizona's Economy (2019), and AZ Department of Child Safety Services Citizen Review Panel (2019).

Progressive initiatives, task forces, and work groups suggest interest and effort to promote systemic change that results in best-practice services in response to what people with disabilities and their families would like. Often outcomes are lacking due to an inability to translate strategies into practice, lack of trained staff to provide, a shortage of tools and assistance to help build capacity, and a need for implementation approaches across the state's local communities. Feedback from our CAC members indicates that person-centered approaches, flexible services to accommodate individual choices, self-direction and supported decision-making, and opportunities for personal growth and lifelong learning are often lacking. It is stated that people need to accept what service options they are given which are often

associated with what is available, low expectations, or lack of knowledge about possibilities. Opportunities for individuals with disabilities to learn and practice the skills to advocate for themselves, lead their meetings, obtain desired supports, and make informed choices are not typically available to assist them with actively participating. In addition to input from the CAC regarding these issues, multiple data sources supported the importance of addressing this problem across systems including: AZ Statewide Independent Living Council Needs Assessment (2020), AZ DD Network Division of Developmental Disabilities Support Coordinators Experiences (2020), AZ Self-Advocacy Survey (2019), Supported Decision-Making Pilot Project Overview of Key Findings on Public Understanding (2019), and ADDPC Priority Needs Survey (2020) reports.

Arizona outcomes are not dissimilar to national averages on many evaluation and reporting metrics. For example, according to the Institute for Educational Leadership 2020 State Vocational Rehabilitation Data Report, 59.9% of youth with disabilities received a high school diploma as compared to the national average of 59.7%, while 27.9% had some college as compared to the national average of 28.5%. Similarly, Disability Statistics (2019) report national employment averages for people with a disability at 37.8% as compared to 38.5% in AZ and poverty levels for people with a disability nationally are reported at 26% compared to 24.6% in AZ. The aggregate does not provide a clear picture of the issues as they relate to different population groups in the state. Our CAC members expressed their concerns regarding discrepancies in outcomes particularly for people with significant disabilities or specific disability labels, those who live in rural areas, and individuals from diverse and underserved communities. This was further supported by the AZ DD Network CLC Listening Sessions (2020), the AZ DD Network and Division of Developmental Disabilities Focus Groups (2020), Banner Alzheimer's Institute Outreach Survey (2020), the Graduation Cliff, Improving Post-School Outcomes of Students with Disabilities (2015), and ASPIRE Report (2018).

Of greatest significance are the individual voices of people with disabilities who shared that they were not achieving the outcomes they would like. The ADDPC Priority Needs Survey completed by 245 people with disabilities in AZ identified the following priorities and need areas: a job; travel in my community; health provider who understands my disability and talks to me; training and rules for police; stopping others from hurting me; more training on what to do in emergencies; all medical providers talk to me in ways I can understand; recreation, friends, feeling welcome in my neighborhood; choices and places to live; technology; know laws to protect me; help with disability benefits; to be my own guardian; to have safe and healthy relationships; saving and spending money; voting; what to do after high school, learn with my peers in school, attend college; control over daily decisions; caregivers know how to support me; supported during life changes; and things to do after school. Feedback obtained from participants who attended the SUCEDD Adulting Workshop reported wanting friendships and employment. A survey conducted by the Southwest Institute for Families and Children and the Arc of Arizona to obtain feedback on growing a self-advocacy movement, found that people with disabilities felt it was important and identified the obstacles for participation as transportation, lack of infrastructure to organize selfadvocacy, lack of opportunities to advocate, apathy by self-advocates, poor communication of what selfadvocacy is, and policy barriers.

According to AZ Kids Count Data Book (2020), 23% of the population in Arizona are children and most of them live with their families. An estimated 17% are living in nontraditional families with 9% being raised by grandparents and 8.2% in foster care. One in four children live in an immigrant household. It is reported that 23% of AZ children live in poverty and data indicate that nearly 1 in 2 American Indian children and 1 in 3 Latino/a children are living in poverty in the state. AZ ranks last in the US with the highest proportion of children ages 0-17 who have experienced two or more Adverse Childhood Experiences (ACEs) and 64% of children with special health care needs have experienced at least one ACE by the time they turn 18 compared to 44% of children without special health care needs (From ACES to

Action, 2018). Data indicate that of the 207 new commitments to the Department of Juvenile Corrections in 2020, 79.7% were Hispanic, African American, Bi-Racial, American Indian, or Mexican National. Additionally, 25.6% were reported to receive special education services; 49.7% had a serious mental illness; and 19.8% were dually adjudicated in Department of Child Safety care (AZ Department of Juvenile Corrections Annual Commitments: Demographic Data, 2020). Our CAC members shared with us about the challenges families face and the need for family-centered practices, well-trained early childhood personnel, early intervention and youth transitions, more caregiver support, addressing youth mental health issues, access to medical care, and transition assistance from pediatric to adult health care. These were further substantiated by data sources, including First Things First FY20 Annual Report; First Things First Navajo Apache Regional Partnership Council (2020); Head Start Changes Lives, Creating Solutions for Kids, Families, and Communities (2019); and ADDPC Comprehensive Review and Analysis (CRA) (2020).

National Core Indicators Data Brief (2020) states that the population of older adults with developmental disabilities is growing nationally and is expected to double by 2030. In Arizona, this population growth, combined with the migration patterns of retirees to the state at a rate ranked second in the U.S., indicates that the number of people over 60 will be the same as the number of children under 17 with implications for increased support to address changing health and living needs, dementia planning, and a well-trained direct care workforce (AZ State Plan on Aging 2019-2022). Banner Alzheimer's Institute (2020) survey data reported that respondents needed more information related to day-to-day management strategies, activities to stay connected, and community resources, with their greatest challenges being meaningful activities and maintaining routines. Similarly, the AZ Division on Aging and Adult Services gathered public input data and identified funding for services, caregiver shortages, and navigating and understanding service options as frequently reported concerns. Our CAC members shared with us about the importance of addressing the needs of aging adults with considerations around retirement planning, maintaining lives in their community, transitioning to aging services, caregiver

support, community engagement, and direct care workforce shortages. The Impact of Caregiving on Mental and Physical Health (2020) supports this need reporting higher rates of both physical and behavioral health conditions for caregivers particularly for millennials and members of communities with a majority Black or Hispanic population.

# Stakeholder Consultation and Feedback in Developing Five-Year Plan

A comprehensive needs assessment was conducted to guide our planning for the next five years using a variety of approaches and sources to ensure the voices of people with disabilities, family members, and other stakeholders across the state were heard and included in our work plan. The CAC provided input and feedback throughout the process to guide our activities and help turn the findings into a concrete action plan.

**Community Advisory Council (CAC):** The SUCEDD CAC was actively involved in both the identification of community needs and framing goal areas and activities for our five-year work going forward. Discussion began in early 2020 with plans to hold an all-day in-person CAC planning retreat in early spring. Due to the uncertainties with COVID, the planning meeting was changed to virtual and held in August 2020. CAC members engaged in lively discussion sharing their ideas, experiences, and suggestions to frame our work. Participants first reviewed our previous year's work, reflected on the accomplishments, and shared what was still needed in each priority area, brainstormed additional focus areas of importance, and communicated their perspectives regarding new and emerging issues that should be addressed. A polling of the top three areas of need in Arizona resulted in a variety of responses with employment, advocacy/self-advocacy, transition, and aging being the most frequently reported. Members also contributed their ideas on how the workplan should be approached, other data sources to include, and additional information to inform the needs assessment. Follow-up communications were conducted to gather recommended information from CAC stakeholder representatives.

A review of CAC member input and other needs assessment information generated the following four thematic areas: 1) Opportunities and personal life outcomes across the lifespan, 2) Inclusive and equitable access, 3) Community connections and relationships, and 4) Career and workforce development. A second CAC planning meeting was held in December 2020 to review the themes and insure they were reflective and inclusive of their perspectives. Topical areas crossed over and intersected in each of the thematic areas including aging, community living and participation, employment, health, leadership, and youth transition. Participants identified an area of interest and broke into smaller groups to further explore needs, generate activities, and look at relationships between topical and thematic focus areas. Work groups were established in each priority area with a staff lead and CAC representatives to discuss and frame the objectives and activities. Periodically, the larger CAC came together to revisit the overall plan and provide input into all areas beyond their workgroup topics. During the course of developing the work plan, the CAC met four times in addition to receiving multiple email/phone communications; two scheduled opportunities to check in, ask questions, and receive updates; and completion of a survey to indicate any final feedback and approval.

DD Network/Other Stakeholders (Agencies, Individuals with DD, and Families): The AZ Developmental Disabilities (DD) Network, consisting of the Arizona Center for Disability Law (ACDL), SUCEDD, the Institute on Human Development (UCEDD) at Northern Arizona University (NAU), and ADDPC, meet regularly to discuss initiatives, goals, and activities in joint areas. The Arc of Arizona is considered an honorary member and engages in meetings, advocacy, and policy efforts together with Network partners. DD Network partners participated on our CAC, and were actively engaged in informing our workplan and determining our goals, objectives, and activities. Each director participated on workgroups, provided input at planning meetings, and shared feedback with the SUCEDD director on an ongoing basis. The ADDPC's concurrent work on their Comprehensive Review and Analysis (CRA) was helpful in informing our process and ensuring our collaborative and complimentary focus of our five-year plan goals and objectives. **Other Arizona State Sources:** Multiple formal and informal data and information sources were utilized to contribute to our understanding of the status and unmet needs experienced by individuals with disabilities and family members. The SUCEDD relied on the ADDPC CRA in which we participated in as part of the DD Network. This report used extensive data sources, as well as in-depth interviews, focus groups and surveys reaching over 2,550 people with DD, their families, caretakers, and service providers. We also consulted state reports and data, targeted meetings with state agency officials, and a variety of needs assessments and issue-specific documents produced by disability groups statewide. Additionally, training and event feedback and input gathered through our community connections, partnerships, shared collaborations, and connections with people with disabilities and their families were used to inform the needs in Arizona. The breath and scope of our needs assessment is illustrated in our more than 45 primary document sources summarized in our Portrait of Arizona section.

**Relationship Between Identified Needs and Five-Year Plan:** As part of the process in crafting the SUCEDD five-year plan, we developed a needs assessment summary document to assist the workgroups in framing and prioritizing objectives and activities. The document outlined each of the 45 primary document sources reference above, provided a description of the report or data source, its key outcomes and findings, and the expressed needs or recommendations by topical areas. This document was given to all workgroup leads to share with their team of CAC members and staff ensuring community needs were driving the prioritized objectives and activities identified. Workgroup leads completed and submitted a document outlining the prioritized activities through a template (see appendix B) that indicated the needs each activity addressed with corresponding data source(s) and whether the activity was based on previous center work, was new and based on current need, or was addressing an anticipated emerging issue. These completed templates were used to develop the workplan. Appendix B includes a table that further illustrates the relationship between the objectives and identified needs by area of emphasis.

### **SECTION 2: APPROACH**

**SUCEDD** Five-Year Plan: Four goals organized around thematic topics emerged from our needs assessment process and reflect the input and feedback from PWDD, family members, and other statewide stakeholders. Each goal is representative of one or more areas of emphasis organized into 16 objectives, which demonstrate how all four core functions will be utilized to accomplish the proposed outcomes. A description outlining the measurable goals, objectives, major tasks, benchmarks, persons responsible, and timeline is in the Project Work Plan (Appendix A). A narrative summary of the implementation of the goals and objectives to achieve stated outcomes, our collaborating partners, and how the activities build on the SUCEDD's current efforts are highlighted in this section.

In response to community input and data, prioritized needs were summarized into the following thematic goals and emphasis areas: 1) Enhance and expand opportunities for individuals with DD to attain personal life outcomes (Areas of Emphasis: Quality of life, Health, Employment, Quality Assurance); 2) Build capacity to achieve inclusive and equitable access for persons with DD and their families from underserved communities (Areas of Emphasis: Cultural Diversity, Quality Assurance, Employment, Quality of Life); 3) Enhance social inclusion for individuals with DD (Area of Emphasis: Quality of Life, Recreation, Cultural Diversity); and 4) Build capacity to promote promising and evidence-based practices through workforce development of current and future professionals (Area of Emphasis: Leadership, Quality Assurance, Quality of Life, Health, Employment). These goals further the purpose of the DD Act of 2000 by promoting self-determination, leadership, and opportunities integrated into all facets of community life across the lifespan. We will adhere to the UCEDD requirements pursuant to the law in carrying out our five-year plan.

Our work is guided by our commitment to equity, diversity and inclusion (ED&I) and we utilized the AUCD ED&I Action Plan to help us operationalize this commitment throughout our efforts. All activities are inclusive of all culturally diverse and underserved populations. The documented needs and CAC input necessitated a specific goal focused on addressing systemic issues in Arizona in order for persons with DD and their families from underserved and under-resourced communities to achieve equitable access; this includes activities dedicated to Native American and refugee communities. The CAC also encouraged continuation and expansion of the SUCEDD's many collaborations as reflected in our proposed activities, which are all planned and implemented in partnership with other relevant agencies, people with disabilities, and family members within the state.

GOAL 1 – Enhance and expand opportunities for individuals with DD to attain personal life outcomes across the lifespan (Area of Emphasis: Quality of life, Health, Employment, Quality Assurance): In response to documented disparities in health, employment, and quality of life outcomes for people with developmental and other disabilities, as well as community identified needs throughout the life course that are relevant to individuals leading self-determined lives – a multi-dimensional approach will be applied to enhance and expand opportunities that prepare and support people to have meaningful and satisfying lives. Our work in youth to adult and aging to end-of-life transitions, employment, model clinical programs, and person-centered planning and practices will lay the foundation for activities focused on increasing access to information, resources, and opportunities for individuals to actively engage in personal life choices and outcomes.

*Objective 1.1: Develop supports and model practices that enable individuals with DD and their families to navigate life transitions effectively. (Core Function: community service, research, community education, technical assistance).* <u>OUTCOME: Individuals with DD and their families will have access to</u> <u>information, resources, and strategies to move successfully through key transition points in their life.</u> The SUCEDD will take an ecological approach to understanding and facilitating different life transitions, community living, and independence that promotes the valued role of individuals with DD in society. SUCEDD will examine barriers and attitudes individuals and families experience in different contexts and transition points to implement and evaluate interventions that address the transition needs for specific disability populations, age groups, and topical areas such as children and youth transitions, aging and retirement, and foster or juvenile justice transitions. These interventions and corresponding evaluations will be developed in partnership with persons with lived experience and findings will be translated into practice and usable information. One intervention and translation product will be developed and implemented each year. In year one we will expand our ongoing collaboration with the AZ Governor's Council on Spinal and Head Injuries for person-centered practices in traumatic brain injury (TBI) services by developing an intervention and training focused on the social support TBI survivors need and want in the transition from acute care to independent and community living. With youth to adult transition being one of the major needs identified by families and professionals, major activities will build on current efforts that focus on promoting positive adult outcomes for youth with DD. The SUCEDD will expand development on its innovative Transition AHEAD Roundtable model focused on health, education, employment, independent living, and supported leadership with youth in foster care, middle school, from underserved communities, and field test a telehealth approach to build a sustainable service modality together with our partners including peer mentors; family advocates; benefits specialists; independent living, education, vocational rehabilitation (VR), Tribal VR, and Division of DD Services representatives.

Person-centered and future planning is a cornerstone of the SUCEDD's work. We have spearheaded numerous initiatives conducting person-centered plans with youth and adults with DD in transition planning; developing tools, training and curricula for people with disabilities, their families, and future and current professionals; and most recently, providing technical assistance to our state Medicaid agency, AHCCCS, to comply with the CMS rule for home and community-based services. The SUCEDD will provide at least two annual workshops focused on collaborating with community partners and stakeholders to develop an approach for person-centered and futures planning for persons with DD even if they are not part of the formal DD system. We will facilitate community forums for input on alternative ways for implementation of person-centered approaches and engage in strategic planning with our agency partners on creative and sustainable mechanisms to fund its implementation as person-centered planning is not a billable service in AZ through Medicaid or other systems of support.

Objective 1.2: Develop evidence-based interventions and implementation strategies that promote effective service delivery practices to improve the health and well-being of individuals with DD. (Core Functions: community education, continuing education, direct service, information dissemination, research). OUTCOME: Individuals with DD will have greater access to services and trained professionals that are responsive to and positively impact their overall well-being. Access to health care is challenged by the lack of a comprehensive, coordinated process linking pediatric and adult systems of care. Our previous work in this area suggests that not being "transition ready" and actively participating in one's health care are major factors impacting outcomes. We will develop modules on health-based self-advocacy skills, conduct trainings, and test their application across lifespan systems to improve people with disabilities engaging in their own health care management and decision-makng. The SUCEDD will develop strategies, tools, and training modalities that facilitate health transitions and access by people with DD from adult to aging systems of care. One evidence-based intervention or tool will be implemented each year beginning with a validation study of the healthcare Transition Engagement Guide, a promising practice and tool developed by SUCEDD executive director with the South Dakota team.

Lack of primary care practices trained to provide care for people with DD continues to be a widespread problem, and contributes to the disparity in preventive health services, and higher rates of preventable chronic disease in this population. Building on the evidence-base of our model coordinated primary care program (MCPCP) for adults with DD embedded in the UA university family medicine teaching clinic, the SUCEDD will develop and implement a train-the-trainer approach for disseminating the MCPCP to improve access and equity in health care. The model will expand to our sister UA teaching clinic and two community health centers over the next five years. We will provide four presentations on

standards of care for people with DD, conduct a clinic needs assessment, provide an on-site visit for technical assistance directed at their identified barriers, and on-going support at each site.

The mental health and emotional well-being of people with DD continue to be major concerns due to the shortages of mental and behavioral health professionals who are adequately trained and equipped to support people with DD. Similarly, people with DD are at higher risk of experiencing various forms of abuse and neglect, with sexual abuse and its prevention having statewide attention in AZ due to high profile incidents of sexual assault in health care facilities. The SUCEDD has been engaged with community partners and the DD Network in leading advocacy and research efforts in this area related to sex education in schools, mandated reporting, and developing implementation and evaluation metrics for the state Medicaid agency. We will develop training curricula in year one for supporting emotional wellbeing and integrating trauma informed practices into existing systems of care for people with DD. The SUCEDD will facilitate strategic planning and implementation of recommendations that build capacity in AZ to support individuals with DD who have dual diagnoses of mental health, behavioral, hearing and vision disabilities across systems. In partnership with AZ Behavioral Services, AZ State Schools for the Deaf and Blind, SAAVI Services for the Blind, and AZ Association of Providers for People with Disabilities (AAPPD), a different stakeholder group will be convened each year focused on strategic planning. The SUCEDD will collaborate with our partners to implement recommendations and test new approaches.

*Objective 1.3: Create and expand pathways for people with DD to attain competitive and integrated employment and careers. (Core Functions: community service, research, technical assistance).* <u>OUTCOME: People with DD will have access to the services and supports to become competitively employed in community businesses.</u> Employment continues to be a major area of priority for VR, the DD Network, and Division of DD, and we will continue to collaborate with these organizations and others to develop strategies and opportunities for people with DD to be gainfully employed and pursuing meaningful careers. In collaboration with VR and school communities, we will expand our preEmployment Transition Services capacity building model piloted in Tucson and Phoenix schools to rural, Tribal, and urban schools around the state focused on work based learning leading to post-school employment outcomes. Concurrently, we will adapt and expand work preparation models for middle school students to increase expectations for work.

The SUCEDD will identify approaches that support organizations to implement the transition out of center-based and group employment programs into competitive employment for adults with DD. We will partner with VR and AAPPD to provide intensive technical assistance to support provider transformation and develop and evaluate strategies such as internships, apprenticeships, and work experience opportunities, as well as organizational change practices and evaluate their efficacy for dissemination and use by other organizations.

The SUCEDD has been a leader in the Employment First (EF) AZ Initiative, working closely with state, provider, and business partners to transform policy and implement practices to competitive integrated employment for people with disability, including those with significant support needs. We will collaborate with our partners and state agency administrators to develop a cross-agency data collection system for monitoring employment outcomes and sharing an annual snapshot of competitive employment in AZ. In partnership with ADDPC and VR, the SUCEDD will establish an EF Center as a central point for statewide resources, information, training, technical assistance, support, and networking. The emphasis will be on moving the state from awareness to implementation that results in outcomes and building the capacity and systemic change to make EF a reality in practice.

In collaboration with people with disabilities and community partners, we will explore strategies for ensuring access to meaningful and fulfilling jobs, career transitions and advancements, as well as retirement. The SUCEDD will conduct a systematic review of practices and literature to use in developing an online survey for community providers, professionals, and state agencies to identify resource needs and practices. Each year pilot testing with people with DD will be conducted in one area per year including: 1) career transitions, 2) early-to-mid career transition, and 3) retirement transition.

# *Objective 1.4: Increase opportunities and support of people with DD as leaders, teachers, and advocates. (Core Function: community service, research).* <u>OUTCOME: People with DD will become leaders who are</u> <u>strong advocates for themselves and their communities.</u> The SUCEDD will collaborate with self-advocacy organizations and coalitions to support initiatives that will enable people with DD to gain the skills and opportunities to be strong leaders and advocates while sharing their expertise and insights. We are

committed and intentional in involving people with DD in meaningful roles in the design, implementation, and evaluation of our work; we also look to infuse supported leadership directly into programs and services we offer. To that end, the SUCEDD will utilize the framework and evaluation data of the Transition AHEAD Roundtable operationalizing the components of supported leadership for application across multiple contexts and pilot testing. The methodology for integrating components of supported leadership into programs and services, including training, tools and evaluation, will then be disseminated through multiple modalities for other organizations to use.

A SUCEDD staff with lived experience serves as an advisory council member for the Southwest Institute for Families and Children's project to develop a statewide self-advocacy coalition in AZ. In partnership with this coalition and other advocacy organizations like Diversity Ability Incorporated that is youth-led and provides leadership training to young adults with disabilities, we will design and build capacity for peer support across the state through a qualitative participatory process for framing a vision and identifying the components, roles, and skills needed for peer support. Strategic planning with agencies will be facilitated to establish a career path and training needs. We will also collaborate with selfadvocates to develop and pilot curriculum on healthy relationships in different contexts and settings, such as where someone works, lives, and plays. Self-advocates will teach or co-teach the curriculum with SUCEDD staff. One way individuals can exercise their civil rights is to participate in the electoral process, yet people with DD face challenges in this arena. We will collaborate with the DD Network and other advocacy agencies to conduct research that examines voting participation in group home or other residential settings and develop strategies to increase civic engagement and access to voting. Specific activities presented by AZ Center for Disability Law include working with schools, election officials, and Clean Elections agencies in promoting voting rights.

GOAL 2 – Build capacity within AZ to achieve inclusive and equitable access for persons with DD and their families from diverse, underserved and under-resourced communities (Areas of Emphasis: Cultural Diversity, Quality Assurance, Employment, Quality of Life): The SUCEDD, responding to the articulated community needs of our diverse state, will concentrate efforts in the next five years to address significantly underserved and under-resourced populations. More importantly, we aim to establish new and improved opportunities through trainings, continuing education, curriculum development, and innovative information sharing using culturally inclusive, responsive, and integrated models to increase access for all people with DD and their families throughout the state.

*Objective 2.1: Promote employment, health, and educational opportunities for underserved groups such as those with severe disabilities and from rural, racial, ethnic and culturally diverse communities. (Core Functions: community service, technical assistance, community/continuing education, research)* <u>OUTCOME: People with DD from underserved communities will have access to services and supports that</u> <u>are responsive and conducive to achieving positive outcomes across all aspects of their lives.</u> The SUCEDD will establish an AZ Native Disability Center that will enhance services and supports that assist Native Americans with disabilities with achieving their individual life goals. The University of Arizona resides on the homelands of the Tohono O'odham people; to acknowledge this, we respectfully name the center, the O'odham Circle, which means The People in the Native language of this community in southern AZ. The Native Center is modeled after the Oyate Circle at the South Dakota UCEDD shepherded by Jim Warne, a member of the Oglala Sioux Tribe who is providing consultation and support to establish the O'odham Circle in AZ. The O'odham Circle will be designed with Tribal communities through Talking Circles (focus groups, discussion sessions) held across all reservations and in cities to capture urban Indian perspective. This approach has proven to be an effective strategy to gather data, input, needs assessment, comparative analysis and discussion/listening sessions for inclusion and buy-in from our Native communities and people with disabilities. The resulting outcome will be to build a central point of connection, resources, and support for Native Americans across the state to access. It will be their Center, operated out of the SUCEDD, which will provide infrastructure support for on-going sustainability. As a new CORE element within the SUCEDD, this program will establish a center for additional and diversified funding and partnership development. Due to the extreme representation of disabilities on the twenty-two federally recognized Tribal Nations in Arizona, as well as the urban cities with high Native population centers. The diversity of the Tribal Nations requires a universal indigenous approach to disability and culture. Local representatives would be the ultimate goal and vision for the O'odham Circle that will have a multitude of indigenous staff serving their communities.

Native Americans face the highest rates of disease and disability and lack necessary infrastructure to meet the epidemic demand. In partnership with Mr. Warne, we will investigate the replication of the Arizona Sonoran Border Projects for Inclusion (ARSOBO) community empowerment model to rural Reservation communities. ARSOBO is a social business that provides appropriate, adaptive-technology, low-cost, assisted devices, which improve access and participation for individuals with disabilities in their communities. ARSOBO is a direct result of the SUCEDD's first Border Conference on Disabilities to meet the needs expressed by the community. Not only does ARSOBO train and employ people with disabilities to construct medical equipment they need and use, it has also developed cross-border public private partnerships and networks to support its mission and vision. We have had initial conversations with three tribes in Arizona – Gila River (southern AZ), Navajo Nation (northern AZ), and Hopi (western AZ) – to explore the implementation of ARSOBO's social-enterprise model that will address the inequities and infrastructure needs on three reservations and serve Arizona's tribal communities by establishing fabrication laboratories (wheelchairs, prosthetics, hearing-aids) and Mobile Health Clinics that will expand the geographical range of services for the rural reservations. Tribal members with disability will benefit from services as a replicable model for other tribes to implement.

These initiatives addressing Native communities is an example of approaches to address some of the disparities in our state. It requires relationship building and gaining an understanding of the issues and needs from the communities who are impacted. To apply similar models and develop evidence-based interventions for diverse populations, the SUCEDD will conduct research examining the inequities and resulting disparities experienced by people with disabilities and their families, with a focus on and acknowledgement of the intersectional nature of sociopolitical contexts within which they reside. Areas of current SUCEDD interest based on community needs include health and socioeconomic disparities among specific disability populations (e.g., TBI, ASD, FASD), as well as at the intersections of disability and race, ethnicity, sexual and gender minorities, immigration, refugee status, and foster care. We will conduct five studies and translate the findings by developing corresponding research, policy, and practice briefs to bring awareness and opportunities for change regarding these important issues. We will also increase the capacity of rural and under-resourced communities to effectively support and serve people with DD in their own communities by utilizing remote/virtual approaches such as telehealth and the guided-practice model, Project ECHO. SUCEDD staff have been trained in the "all teach, all learn" ECHO model and will launch hubs to provide essential support and technical assistance that will amplify the capacity for providers and educators to deliver evidence-based and promising practices in areas of dementia capable care, youth transition, health care, and employment.

*Objective 2.2: Increase autonomy and individualized supports for individuals with DD through technological innovations and advancements. (Core Functions: technical assistance, community service, research)*. <u>OUTCOME: Individuals with DD will have greater access to technology resources that enhance independence and participation in the digital world.</u> Due to the COVID-19 pandemic, the last year has shown just how critical it is to have access to technology and finding innovative ways to reach and support individuals in an increasingly digital world. Building from the creative solutions for training and service delivery implemented during the pandemic, the SUCEDD will continue to engage with university and community partners so that people with disabilities and their families have opportunities to learn about, design, access and utilize technological solutions.

In partnership with the state Technology Access Program (AzTAP) and the Coleman Institute on Cognitive Acessibility, the SUCEDD will engage state partners in strategic planning to establish Arizona as a Tech First state and addressing solutions to mainstream technology use across the lifespan. The "Technology First" movement focuses on expanding access to technology for people with DD, where technology is not an add-on feature but used as a natural support in order to live as independently as possible in the community through the integration of technology into home, school, work, and community activities. This initiative will facilitate the shift to viewing technology as the first source of support when addressing outcomes in service planning and integrating technologies into reimbursable services to offer a one-tech solution response in AZ.

The SUCEDD will model this commitment to technology first philosophy through its research, programs and services. Through focus groups and listening sessions, we will identify the issues, challenges and creative solutions for enhancing technology access and use across the state; this will inform the Tech First initiative and implementation of innovative strategies by the SUCEDD in our programs and services. We will develop technological supports, tools and platforms that empower individuals through personcentered approaches to achieve their goals and increase their independence across education, work, and health related settings. This includes providing training to individuals, families and professionals on how to both utilize and support others to do so across contexts. A prime example is within the context of employment. In preparation for the emerging workforce changes of the new global economy, the SUCEDD will develop effective strategies for training people with disabilities on virtual work, use of virtual supports, how to work virtually, and using technology in the workplace. In partnership with the university's School of Information, we will explore application of technology-focused Personal Project Analysis (PPA) for use by people with disabilities to support life goals. This activity will be incubated through expansion of our interdisciplinary training opportunities in objective 4.1 and engage people with disabilities and technology/communication partners to design the technology. Developed by Brian Little, PPA utilizes personality and motivational psychology to tap into what personal activities are salient to a person. We will create personalized technological interventions that provide motivational support for activities of daily living and social relationships for use across settings to assist people with disabilities in achieving their goals.

*Objective 2.3:* Promote and build capacity to utilize principles and values of universal design, diversity, and cultural and linguistic competency to increase access to information, services, and supports by people with DD and their families. (Core Functions: community/continuing education, technical assistance, community service, information dissemination). <u>OUTCOME:</u> Information, services, and supports will be inclusive of and responsive to the diverse values and needs of all individuals with DD and their families. In our last five-year grant, we focused on assessing and building our internal capacity to provide accessible and culturally responsive programming and materials. We acknowledge that it is an ongoing process and we are committed to holding our center accountable while also building capacity in state services and supports to do the same. The Arizona DD Network will continue the work of the Community of Practice on Cultural and Linguistic Competency to address the need for improved language access for people with disabilities and their families in service delivery practices. With community

partners, we will facilitate strategic planning around building capacity and funding mechanisms for interpretation and translation. To assist other organizations to address information access needs, we will develop and conduct community trainings for increasing accessibility of materials and virtual events. These will include practical steps on how to make electronic documents accessible to screen readers and assistive technology, applying principles of universal design in the creation of materials that is inclusive of plain language and use of infographics, as well as considerations and best practices for hosting virtual events.

Another essential piece of making information accessible to individuals and families from diverse cultural and linguistic backgrounds is to receive that information from others who can relate to their experiences. We will create a platform for digital storytelling featuring individuals with disabilities from diverse cultural backgrounds to amplify the voices, needs, and issues important to and from diverse communities. This year our Diversity Fellows created multi-media stories about indigenous students with disabilities pursing higher education; in their project presentation they noted how enabling Indigenous students to tell their own stories and struggles in pursuing higher education could help improve educational equity. We will help individuals share their stories to empower and support leadership for people with disabilities across the lifespan. Also, materials will be designed together with the refugee community in response to their questions for information on how to access disability services, as well as establishing a permanent location and central source for information exchange.

Objective 2.4: Develop and implement innovative ways to share usable and responsive information that promote informed decision-making and quality of life for people with DD. (Core Functions: information dissemination, community/continuing education, research). OUTCOME: People with DD will have the knowledge and resources to enhance opportunities and actively engage in personal life choices and outcomes. The SUCEDD has positioned itself as a "go to" source for technical assistance and resources in areas of critical need for people with DD and families such as employment, developmental medicine and

primary care, person-centered planning/practices, and aging in AZ. In addition to the O'odham Circle (Native Disability Center), we will establish formal Centers within our structure for Employment First (EF) and Fetal Alcohol Syndrome Disorders (FASD). We have led the EF initiative and maintain the current website; a formal center will help to streamline marketing and communications, and creating a distinct home for provider and systemic transformation for competitive and integrated employment. We are inheriting FASD Resource Center from the Arc of Southern AZ and previous DD funded representative for the state. We will serve as a statewide point of contact in these areas and develop hubs for resources, training, and innovative information sharing, readily available and usable.

The SUCEDD will continue to collaborate with community partners on initiatives to promote supported decision-making as an alternative to guardianship. SUCEDD staff participates on the statewide task force led by the Southwest Institute for Families and Children and the Arc of Arizona, and we will assist them in the disseminating existing materials and resources they have developed. The SUCEDD will work with partners to identify strategies that will enhance its utilization by people with DD. We will integrate supported decision-making supports in other SUCEDD initiatives such as employment, health care, and future planning so that people with DD can lead self-directed lives.

GOAL 3 – Enhance social inclusion for individuals with DD by expanding opportunities to make community connections and build relationships (Area of Emphasis: Quality of Life, Recreation, Cultural Diversity): As attitudinal barriers and bias continue to persist, people with DD are more likely to experience social isolation. There is a lack of understanding and minimization of what individuals with disabilities can do, and this affects opportunities to actively engage in communities of their choosing. Individuals with developmental and other disabilities and their families stressed the need for opportunities to make social connections and friendships. During the next five years, we will engage in activities designed to offer inclusive community opportunities for people with DD to grow socially and emotionally, contribute and lead fulfilling lives in communities where they feel they belong. As part of the

Whole Person Care Initiative, the state Medicaid agency (AHCCCS) is considering the development of a new habilitation service model to address social isolation. Our CAC representative from AHCCCS sees these objectives complementing this service, if approved, and noted opportunities for collaboration.

Objective 3.1: Increase opportunities for inclusive recreational, sports, leisure, and volunteer activities for people with DD. (Core Function: community service, community training, technical assistance, research, information dissemination). OUTCOME: People with DD will have greater access to and increased participation in the wide range of activities provided by their communities. For the last two years, the SUCEDD has developed a collaborative partnership with the Reid Park Zoo in Tucson to support their efforts in inclusive programming through their education and volunteer programs. We have provided technical assistance and training to staff and volunteers on disability as diversity, inclusive practices, universal design and engaging diverse guests, and strategies to working with children with behavioral concerns who attend their summer camps and other educational programs. We have a mutually beneficial partnership as the zoo functions as a training site for our trainees and provides work-based learning experiences for high school students with DD. Our partnership with the zoo serves as the foundation on which we will develop and implement strategies to support similar efforts with other community programs and organizations such as museums, scouts, and volunteer organizations. We will develop customizable training and toolkit for enhancing inclusive programming for use by organizations to be welcoming and accessible to all in their communities.

This will also extend to community options for promoting healthy living. There is an interest with 4-H through the university cooperative extension program to make their youth programs inclusive, as well as developing interventions for healthy eating and nutrition through their community kitchen and farm. Additionally, we will examine and pilot interventions that promote physical activity, sleep and the power of sport for people with DD across the lifespan. We will also seek opportunities to collaborate with the UA's adaptive athletic program, the largest and most successful collegiate program in the country, housing seven competitive teams, an adaptive fitness center, and producing 38 Paralympians.

Another aspect to overall well-being through leisure includes opportunities for creative selfexpression through art. During the last year, our community art studio and training program, ArtWorks for adults with DD, piloted fee-based integrated watercolor classes open to the public via a virtual platform, bringing together individuals with and without disabilities while COVID restrictions kept many individuals with DD isolated. We will build on its success by developing addition classes across artistic mediums and evaluate their efficacy. One of our trainees developed and facilitated a weekly virtual session for ArtWorks' members, combining yoga and sketching to process emotions and sensation through movement; it was well received and may be a potential public offering in the future.

Objective 3.2: Increase social relationships and networks for individuals with DD and family members/caregivers. (Core Functions: research, community service, technical assistance, information dissemination). OUTCOME: Individuals with DD and their families will have opportunities to expand their social support and friendships. Individuals with DD, families, and disability organizations want opportunities to network and establish social relationships. We aim to actively engage with self-advocates, community organizations, and systems to identify strategies to share information, increase social inclusion, build social capital, and create a sense of belonging. We will establish a community workgroup inclusive of CAC members and self-advocacy organizations to identify best practices around social inclusion and networking opportunities to develop and pilot interventions and tools with integration of healthy relationships for people with DD. This workgroup will also guide us in efforts to support social clubs and activities to facilitate natural friendships that the SUCEDD could co-sponsor with self-advocacy groups. Currently, a SUCEDD staff member with lived experience serves on the advisory council for an initiative to create a statewide self-advocacy coalition that will support the development of local self-advocacy groups and alternative ways of connecting with other self-advocates across the state. The

SUCEDD will provide organizational support for events and sharing of information; the formulation of social clubs may assist new groups in creating a sense of community throughout AZ.

There are limited opportunities for family caregivers of individuals with DD to network and receive/offer support as individuals age and no longer in school. To increase resources and connectivity of family caregivers of adults with IDD as they age, SUCEDD will develop and implement a social network model for family caregivers, including non-traditional families, that is connected with a community of practice for education/training and technical assistance efforts. We will conduct need assessments regarding what types of networking opportunities family caregivers of adult/aging individuals with DD would like to have, as well as to identify available resources and partners who have existing programs for general family caregivers or those of individuals with DD to build upon existing infrastructures and services. This will in inform model and tool development, which we will pilot with intention to implement the model statewide.

*Objective 3.3: Develop inclusive and intergenerational models for mutual learning and support.* (*Core Functions: technical assistance, community service, research*). <u>OUTCOME: Individuals with and without</u> <u>DD will have access to opportunities and support across generational lines in their communities.</u> People of all ages bring unique perspectives, interests, talents and skills through their life experiences. Common interests and mutually benefiting goals can be catalysts for learning and support regardless of age and ability as everyone has something to contribute. Multiple CAC workgroups for developing our five-year plan noted the potential for intergenerational programming to foster reciprocal relationships. The SUCEDD will examine the concept of intergenerational approaches across cultures to develop strategies for implementation and application that can inform and improve service delivery practices for people with DD. We will pilot the application of findings with SUCEDD program activities and develop a research/policy brief for application within other organizations and systems. This formative work will assist us to create a

community program involving retirees and people with disabilities as teachers and learners across various topics (e.g., photography, gardening, cooking) and ages.

Families and professionals expressed the great need for information, resources and supports. We will also explore innovative options and intergenerational supports to promote aging in place and integrated retirement and community living for persons with DD as they and their family caregivers age. We will conduct a systematic review and comparison of residential options and models for the general aging population and individuals with IDD in collaboration with national partners to offer recommendations for best practice and engage in strategic planning to support implementation of the HCBS setting rule in AZ. To address articulated needs, potential areas for retirement model development include retirement education, caregiver education and support, and recreational activities that preserve functions and maintain socioemotional well-being.

Objective 3.4: Increase community access through creating new opportunities and promoting connections that increase active and valued participation by people with DD. (Core Functions: research, community service, community education). OUTCOME: People with DD will have greater access and actively participate in all aspects of their communities. In response to the expressed desire by people with disabilities to have more friends and relationships, and the greater needs assessment identifying community engagement as a priority, we will examine and develop interventions in the area of social capital to enhance the critical social networks that open doors for individuals to gain access and connect with other people and opportunities. In relation to objectives 3.2 and 3.3, we will conduct a study to examine the participation in hobbies, clubs, and interest groups in areas of passion and interest to enhance social capital. Transportation continues to be a huge barrier to accessing one's community for work, daily living, fun, and appointments particularly in rural and suburban areas. The SUCEDD will conduct focus groups around the state with people with disabilities to state to identify what they have found helpful to get around their communities and bring together community partners who utilize

alternative means of transportation to engage in strategic planning Incorporate a process for assessing transportation options in direct services. Will develop and test creative options for transportation enabling people with disabilities to access a means of travel that works within their communities.

In anticipation of a post-COVID future and acknowledgement of the challenges and "pivots" of the pandemic, we will investigate the needs across diverse communities to support people with disabilities to participate in all aspects of their community as we all adjust to the "new normal." We will work in partnership with communities to develop effective strategies that are meaningful and culturally responsive. People, more than ever, are living their lives online to stay connected and build community; and that seems unlikely to change. In alignment with the Tech First initiative and to ensure people with disabilities can access online communities and benefit from those connections, the SUCEDD will partner with self-advocacy groups to develop multi-medium training modalities to enhance learning and skills to make virtual connections using zoom, social media, and other technology.

GOAL 4 – Build capacity to promote promising and evidence-based disability practices through career and workforce development of current and future professionals (Areas of Emphasis: Leadership, Quality Assurance, Quality of Life, Health, Employment): Enhancing the knowledge and competencies of current and future practitioners in the state across a variety of professional roles was an identified area of need and concern. The issue is compounded by a need for increased numbers of trained providers in some disciplines, inconsistencies in service delivery reported within disciplines across the state, and improved implementation of best practices that promote inclusion for all individuals regardless of severity of disability during all aspects of their lives. The SUCEDD will work in partnership with the university, trainees, people with DD and their families, and community stakeholders to build greater capacity for promising and evidence-based practices throughout AZ.

Objective 4.1: Grow leaders and advocates for disability issues from diverse disciplines and cultural backgrounds through provision of new interdisciplinary educational opportunities. (CORE FUNCTION:

interdisciplinary training). OUTCOME: Future professionals will gain the knowledge and skills to become disability leaders and advocates in their respective fields. Activities will focus on both the expansion of our interdisciplinary training program and infusion of disability content into existing academic programs. We will collaborate with university departments and colleges to offer disability-related content at the undergraduate and graduate level to increase awareness and knowledge of disability constructs and issues as it relates to their disciplines. There are multiple initiatives underway - particularly as UA continues to focus on diversity, equity, and inclusion – that provide opportunities to have disability as part of the curricula. SUCEDD faculty and staff have submitted two upper division interdisciplinary disabilityrelated courses to be included as electives for the new Bachelor of Science degree in Medicine (Disability Perspectives in Research Policy & Practice and Creative Arts in Health, Healing & Wellness). Similarly, the College of Social and Behavioral Sciences has requested disability content from the SUCEDD in their new minor and undergraduate certificate in Justice, Equity, Diversity, and Inclusion. A new course will be developed, Disability & Society, that will help students develop an understanding of the theoretical principles and debates in Disability Studies and how disability is both produced in and shaped by social structures and processes. We plan to develop a course on American Indian/Alaska Native Perspectives of Disability in partnership with Jim Warne, consultant with SUCEDD, which will address disability from Native philosophies through contemporary disability service models. The SUCEDD will develop a course focused on aging and well-being in DD, and plan to offer it as an elective for our certificate program as well as the AZ Center on Aging's gerontology certification. Our courses offer dual enrollment for upper division undergraduate and graduate students to allow us to reach more students and develop topical areas of specialization within our certificate program. We will also be moving towards developing courses to be offered online and intend to launch an online interdisciplinary graduate certificate in disability. The SUCEDD is collaborating with faculty from the School of Information to develop models for tiered

mentorship and learning within Science, Technology, Engineering, and Mathematics (STEM) fields through Vertically Integrated Programs (VIP) focusing on technological solutions for people with disabilities.

Our Diversity Fellowship provides training and leadership opportunities for historically underrepresented students in disability research, practice, and policy. Students participate in activities that promote diversity and inclusion, as well as engage with culturally and linguistically diverse communities as part of their SUCEDD related projects. The program is sustainable through our partnership with a tribal institution of higher education, Tohono O'odham Community College, creating a pipeline of indigenous students as disability advocates in their respective fields. We plan to expand our program to include a Borderlands Fellow. As a Hispanic Serving Institution and our commitment to grow diverse leaders that reflect the racial and ethnic demographic representation of the state, we will seek to recruit students who identify as Hispanic/Latino/a/x and are fluent in Spanish to engage in clinical, didactic and research activities in the Borderlands. We also anticipate developing a refugee fellowship track to support the projected activities of objective 2.3.

Objective 4.2: Increase the number of skilled and qualified professionals who support individuals with DD through robust professional development and continuing education programs. (Core Functions: community/continuing education, information dissemination, technical assistance). OUTCOME: Professionals will have access to information and training needed to effectively support individuals with DD across the lifespan. People with disabilities, families, and professionals all agree that the workforce supporting individuals with disabilities need on-going, additional, continuing education to obtain the necessary skills to provide competent and quality care across the life course. In response to stated needs at critical transition points, the SUCEDD will develop a variety of training modalities and supports to provide the information, resources and effective strategies required to support individuals with disabilities and families well. The SUCEDD will contribute to building a comprehensive system of professional development in early intervention (EI) through training modules and services. In partnership with the national Early Childhood Personnel Center, AZ Early Intervention Program and state leadership team, the SUCEDD will develop in-service online modules and trainings that ensure a well-qualified early childhood workforce. The SUCEDD will address the needs of educators in implementing transition services leading to post-school outcomes through development and provision of modules and workshops that are online for anytime access, practical, and inclusive of youth with disabilities as speakers. As recommended through the SUCEDD AZ transition exploration study, we will develop one resource each year to showcase best practices and effective strategies that are working well in the state. The SUCEDD will develop training modules, virtual technical assistance, and sustainable approaches for enhancing skill development, professionalization, and retention of disability support professionals. We will work together with direct support professionals and the corresponding agencies to develop three career path incentives beginning with one in aging. The SUCEDD will build on our expertise in dementia capable care and aging/health care advocacy to promote workforce hiring and retention and quality care for people with DD as they age.

All of the needs assessment data with responses directly from adults with disabilities stressed the importance of high quality, accessible healthcare and health professionals who are knowledgeable and competent in providing care to people with disabilities. The SUCEDD will explore the feasibility for developing a faculty traineeship by conducting an interest and needs assessment with College of Medicine and junior faculty and if possible, develop a traineeship curriculum for junior faculty in Medicine inclusive of a mentored project in the SUCEDD and clinical practice under the direction of a clinical mentor appropriate to their clinical field to create more teaching physicians who are knowledge about developmental medicine. Formative SUCEDD work identified the need to educate primary health care providers about their role in supported decision-making and not overlooking the "whole person" in favor of the individual's disability. Research with primary care providers indicates they hold biases about people with disabilities and need more information and support in working with patients with disabilities. The SUCEDD will develop, pilot and implement online teaching modalities for continuing medical education

and continuing education units (CME/CEU) to educate primary care providers in the principles of capacity and consent in medical decision-making as it applies to supported decision-making models and on effectively working with individuals with DD to promote their decision-making within healthcare. Future CME/CEU modules for development will include models of sexual health, and best practices in prevention and identification of sexual trauma, and trauma-informed care for people with IDD, as sexual health is not addressed routinely for this population in their encounters with the health care system despite being at higher risk for experiencing sexual violence, less likely to have this identified, and less likely to receive trauma informed care.

*Objective 4.3: Develop innovative ways to collaborate with organizations and systems to build capacity and address the gaps in service delivery practices. (Core Function: technical assistance, community education, information dissemination)*. <u>OUTCOME: Organizations and systems will have access to</u> <u>information and tools to support and address the needs of people with disabilities to live and work in their</u> <u>communities.</u> The SUCEDD will identify and develop strategies and provide technical assistance to disability providers and organizations to support participation by people with DD in meaningful inclusive communities. The need to have choices and engage in activities that facilitate community connections and social networks particularly for those in group homes and other congregate settings is essential. We will partner with Division of DDS and AAPPD to develop tools to assess competencies, such as checklists or surveys, and presentations for organizations and pilot with providers offering technical assistance and evaluation for dissemination broadly.</u>

There continues to be a significant lack of physicians and other health care providers who are knowledgeable about the health and psychosocial needs of people with DD. The National Curriculum Initiative in Developmental Medicine (NCIDM) is a collaborative effort of 18 US medical Schools to provide training to medical students in best practices in the field of developmental medicine. UA is a participating medical school and the SUCEDD will identify best practices in developmental medicine education at the medical school and disseminate through national presentations and publications. We will work with NCIDM colleagues in national and regional working groups to develop technical assistance teams to assist in the dissemination of these practices to US medical schools.

Building on lessons learned through our partnership with the City of Tempe focused on providing support and expertise to assist them with becoming an EF city through development and implementation of the BEST (Building Employment Supports and Training) program with increased hiring of people with DD. In collaboration with Tempe and employers, the SUCEDD will expand employer-hiring practices to promote disability employment through marketing, education, and technical assistance utilizing business driven diversity and support strategies.

An emphasis on center-based and group employment in AZ and the need for competitive integrated employment is a critical priority across the DD Network and VR agency. The SUCEDD will build provider capacity to improve employment services and outcomes through individualized technical assistance and evaluate effective strategies for use by other disability organizations. The development and testing of a provider transformation model will include virtual employment and remote supports as a result of COVID, and inform funding and policy decisions to remove barriers influencing practice.

To effect systemic change in areas identified through this plan, we will develop and disseminate policy and research briefs in collaboration with community partners to educate policymakers and state systems that impact people with DD. For each of the five briefs developed, an accompanying plain language resource will be developed so that individuals with DD can use it in their own advocacy.

*Objective 4.4: Increase educational and leadership opportunities for individuals with DD to gain skills, competitive employment, and career advancement. (Core Function: interdisciplinary training, community service, model demonstration).* <u>OUTCOME:</u> Individuals with DD will have access to opportunities, supports and resources to build leadership skills and navigate their own career paths. The SUCEDD has collaborated with the UA College of Engineering to submit National Science Foundation

grants to develop a high school pipeline and college support (e.g., tutoring, peer mentoring, internships) program for Autistic students to expand meaningful career opportunities, an on-going identified need. In partnership with VR, pilot implementation will begin through our direct pre-employment transition services program with the SUCEDD providing these support services for current Autistic students. The SUCEDD and Tohono O'odham Community College (TOCC) jointly developed a disability services and information, education, and student exchange partnership. Our collaboration with Baboquivari High School and TOCC is focused on building a pipeline from high school on the Nation to TOCC, increase retention and graduation rates, and facilitate transition to UA for students with disabilities, and shared cultural experiences for TOCC students and SUCEDD trainees. We will work together to promote replication of the TOCC pipeline and disability services model to other Tribal colleges in AZ.

During this last year, we launched a new Disability Policy Fellowship for undergraduate and graduate students to enhance students' knowledge of the process of policy development relevant to the community of individuals with DD. Fellows participated in community engagement, leadership, advocacy and scholarly activities throughout the academic year. The SUCEDD plans to establish community fellows (i.e., policy, diversity, and AmeriCorps caregiver fellowships) represented by people with DD within our interdisciplinary training programs. In partnership with the AZ Caregiver Association, we will be an AmeriCorps site for five fellows with a disability who will work on SUCEDD aging projects.

People with disabilities and professionals expressed the need for more disability leaders in the state. The number of active leaders in AZ is relatively small and not representative of disability, diversity and geography across the state. The SUCEDD in partnership with the Self-Advocacy Solutions statewide coalition and Diverse Ability will promote and support development of leadership training for adults with disabilities. We will bring together self-advocates to design training and materials. Our staff with disabilities and partners will be co-trainers. Additionally, we will focus on supporting people with DD in

leadership roles and enhancing opportunities for them to assume new positions. Our partners will assist in determining the best ways to offer and sustain on-going leadership training and support.

#### **Five-Year Plan Compliments and Furthers DD Network Goals**

ADDPC's 2021-2022 workplan targets the following priority areas/goals: self-determination, meaningful careers, inclusion with engagement, safety, and system access and navigation. Similarly, the AZ Center for Disability Law's 2021 focus areas were consulted and reflect the cross-network emphasis of our efforts in key areas including abuse and neglect, access to health and mental health services, access to special education services, access to assistive technology, employment, rights advocacy, and access to the electoral process. The SUCEDD has objectives and activities related to all priority areas of the ADDPC and AZ Center for Disability Law. There is considerable overlap and complimentary focus of priority areas across our Network partners. In addition, many of our dissemination core function activities are collaborative and supportive of one another's work and often completed in partnership particularly across mutual target areas. The Arc of Arizona also targets similar goal areas including 1) access to high-quality healthcare, 2) adoption of person-centered planning, 3) adoption of supported decision-making, 4) relationships and sex education, 5) abuse and neglect prevention, 6) improved transition, and 7) improved early intervention, also complementary and supportive to the DD Network and SUCEDD five-year plan.

#### Leverage Additional Dollars

Our documented track record of successfully obtaining external dollars demonstrates our ability to support and grow our programs and address emerging issues. In the recent past and continuing into the next five-year cycle, the SUCEDD will be leveraging funds to meet its goals and objectives. Currently, the SUCEDD has 33 projects totaling \$8,699,074 dollars in addition to, and leveraged by, our UCEDD core funds. Examples of the diversity of our funding from state, national, and foundation sources across SUCEDD principle investigators include: 1) ACL funded Diversity Partnership Implementation three-year grant, 2) HRSA Autism Intervention Research Network on Physical Health sub-award, 3) NIH R01 funded Intensive Physiotherapies to Improve Function in Children with Cerebral Palsy, 4) ADDPC funded Transition AHEAD Roundtable model development, 5) AZ Medicaid agency funded Sexual Abuse and Prevention Implementation Metrics and Evaluation, 6) AZ RSA funded Pre-Employment Transition Services and Work Based Learning school transformation model development, 7) Kessler Foundation funded Virtual Work and Supports state systems change, 8) NIDILRR Home and Community Based Services Outcome Measures sub-award, 9) NIH National Cancer Institute under the awards for the Partnership of Native American Cancer Prevention Improving Shared Decision Making Regarding Breast and Cervical Cancer Screening Among Native American Women with IDD, 10) National Endowment for the Arts Research funded investigation on Technology use in Creative Arts Organizations, 11) Lejeune Foundation and NIH funded research on sleep and brain development and clinical drug trial in individuals with Down syndrome; 12) Title V - AZ Department of Health Services funded Youth in Foster Care Needs Assessment study, 13) AZ Department of Economic Security Governor's Council on Spinal and Head Injuries funded TBI and Person-Centered Practices, 14) CDC National Curriculum Initiative in Developmental Medicine sub-award, and 15) ADDPC funded Native American Disability Center.

## Interdisciplinary Pre-Service Program

The SUCEDD offers an array of pre-service training opportunities for students at the undergraduate, graduate, and post-doctoral level. These interdisciplinary programs successfully prepare future professionals in a wide range of settings where they will have clients, patients, or even basic science research touching on issues in the lives of individuals with developmental and other disabilities. Our trainees have represented 17 disciplines, including neuroscience and cognitive sciences, psychology, anthropology, special education and rehabilitation, health sciences, and family studies. Current programs include the Undergraduate Certificate in Developmental Disabilities, Diversity Fellowship, Policy Fellowship, and in-depth practitioner and clinical internships. Interns from social work, public health, and occupational and physical therapy programs serve as long-term trainees and are placed in our community-

based and clinic programs. In addition to these structured programs, students from any discipline have opportunities to work in our community-based programs with faculty, assist in SUCEDD based research, and develop skills and expertise in the disability field through innovative projects.

The goal of our programs are to prepare students to become leaders and advocates in disability related and other fields to be proponents of meaningful community inclusion and the full participation of people with disabilities and their families in all aspects across the lifespan. Each of the SUCEDD interdisciplinary training programs has its own set of guidelines, learning outcomes, and activities; however, all programs prescribe to a core set of competencies and modalities inclusive of direct community engagement, didactic learning, leadership development and research. Curricula focuses on understanding the socioeconomic and political contexts that impact the lives of people with disabilities and their families; recognition and appreciation of the strengths individuals and their families bring through diversity in abilities, culture, age, and life-experience; developing a working knowledge of the disability service systems and the available services and supports; application of principles of familycentered, culturally-competent, person-centered services and supports across settings; working in an interdisciplinary team with families and individuals with disabilities; and effective communication with diverse audiences. All programs are designed to be completed in one year, and all trainees participate in opportunities for networking across programs, the annual trainee symposium to present their work, and contribute to our blog (The CACTI). Over the next five years, we will expand our programs to include a disability graduate certificate and multiple tracks for our Diversity Fellowship.

Additionally, we have a three-year developmental medicine curriculum required for family medicine residents at the Banner University Medical Center (BUMC) South Campus. The curriculum includes didactic sessions that focus on issues and topics across the lifespan (e.g., youth transition, aging and dementia, end-of-life) and experiential practice through home and community-based visits. This curriculum will be extended to other BUMC medical residency programs in the coming five-year plan.

**Recruit Diverse Trainees:** While our Diversity Fellowship specifically involves historically underrepresented students in disability research, practice, and policy, we strive to recruit diverse trainees to participate in all of programs. Our current five-year plan had a concerted effort and specific goals for increasing the diversity of our trainees from underserved and underrepresented populations and communities. Over the last four years we engaged in outreach and relationship building through university-wide diversity initiatives and cultural centers, cultural study programs (e.g. Mexican American Studies, American Indian Studies, African American Studies), and student clubs and associations representing the diverse student body. Currently, 52% of trainees are from diverse racial and ethnic backgrounds. This coincides with our effort to ensure the curricula embodies the values of cultural and linguistic competency through infusion of diversity, intersectional, and social justice content, as well as representation of diverse presenters and co-teachers. Through engagement of our CAC members with disabilities, community partners from diverse communities and new SUCEDD hires, presenters in trainee core curriculum reflecting diverse populations increased from 25% to 68% over the last five years; they identified as members of racial and ethnic minority groups, LGBTQ community, people with disabilities, family members of PWDD, and several who identified as having more than one of these identities. We are continuously expanding our connections within the university and around the state, and look forward to spending unscheduled relationship-building time out in communities as COVID restrictions lift. It is anticipated that our proposed activities focused on engaging diverse communities will enhance the involvement of individuals from racial and ethnic minorities in all aspects of the SUCEDD.

## **Continuing Education Program**

The SUCEDD provides educational opportunities for practitioners and other professionals through workshops, webinars, and online modules. Examples include person-centered planning for direct service staff, health care for PWDD training for nurses, and dementia capable care training for community resource workers. At the end, participants receive a certificate of completion. Our work plan reflects an expanded continuing education program building on these experiences to offer increased formats and topical areas across a greater number of disciplines. Meetings have been held with the UA Continuing and Professional Education department to explore options for creating professional development courses for practitioners and state agency personnel. We are also interested in establishing certificate programs and credentialing opportunities that promote workforce development and create new career pathways. It is our intent to offer these through both our pre-service education program for students and our continuing education program for practitioners and community members together. A variety of continuing education events are planned and include in-service professional development for early intervention personnel, skill building content and practicum courses for job coaches, peer support specialists credentialing for PWDD, person-centered and trauma-informed practices as part of state agency personnel required training. SUCEDD has participated in the ECHO training and is partnering with the UA Center on Aging to respond to COVID prevention in nursing homes. We plan on using the ECHO platform and telehealth technologies to expand our offerings using case-based learning through team-to-team approaches. We feel these will be effective strategies for expanding the Transition AHEAD Roundtable to remote satellite sites and replicating the care coordination clinic across community health centers in the state. With COVID, all of our education and training has been provided virtually through zoom or on-line modules. We will continue offering training virtually and anticipate returning to in-person later this year.

**People with Disabilities Included in Education and Training Programs:** Individuals with DD and family members are active participants in our interdisciplinary pre-service preparation and continuing education programs contributing to identification of content, providing input and review of evaluation feedback, and serving as trainers and instructors. The SUCEDD has multiple staff with disabilities who participate on the overall program planning teams. Additionally, individuals with disabilities and family members serve on our CAC, providing input and sharing their knowledge and expertise to guide our education and training programs. We conduct trainings with people with disabilities as co-presenters and/or sponsor and support

trainings provided by those with lived experience. This has had a powerful impact on students and professionals who participate as indicated by the satisfaction evaluation feedback we receive. In our next workplan, we plan to add a Community Fellow to our interdisciplinary training program for a person with a DD. Multiple trainings are focused on individuals with disabilities as participants and will be led by persons with disabilities who are trainers including leadership development, health-based self-advocacy, healthy relationships, and peer mentoring support. Trainings for family members, including those from non-traditional families, are planned in collaboration with the Parent Training Information Center (PTI) Raising Special Kids or other family members in the community. Topical areas include employment possibilities, pre-employment transition services, FASD support, personal futures planning, and caregiver stress. Family members participate in our resident education program as teachers providing residents the opportunity to learn directly from the family on how best to provide medical care through a home visit.

Participation in Broader University Academic Programs: The SUCEDD offers courses, guest lectures, practicum, and research supervision that are available for students across disciplines. This year a new course HPS 408/508, Public Health and Disability, was developed in the College of Public Health and taught by SUCEDD faculty with an enrollment of 42 students. We plan to expand disability-related courses on campus through the development of five additional courses that are cross-listed and/or infused in existing academic programs. The SUCEDD has recently hired a Clinic and Education Coordinator who functions as liaison with university academic departments and offices to increase our connections with other programs on campus and promote opportunities for collaboration and joint teaching. The SUCEDD Medical Director leads the annual Interprofessional Education Disability event in UA Health Sciences with more than 400 students from Public Health, Pharmacy, Medicine, Occupational Therapy, Nutritional Sciences, and Nursing.

SUCEDD faculty engage in other partnership activities with programs, departments, and colleges across campus. The Assistant Director participates in the multi-discipline disabilities study initiative offering seminars and topical discussion groups for students as well as exploring the development of a new degree program. The Executive Director is a member of the Center for Excellence in Attention Deficit Hyperactive Disorder (ADHD) workgroup focused on establishing a university-wide comprehensive, coordinated system of educational and social supports for students with ADHD. Affiliated faculty are leading members of an Autism group on campus with multi-discipline representation designed to address issues experienced by students on campus, encourage greater enrollment, offer seminar trainings, and serve as a support resource for other faculty. The SUCEDD co-sponsors educational events together with the UA Disability Cultural Center, Disability Resource Center, and other entities on campus. Staff and affiliated faculty are represented on other committees, workgroups, and educational events in the department, college, and school that bring the perspective of disability to the table when planning and decision-making occurs.

### Community Services Program

The SUCEDD provides direct services focused on model development and capacity building to enhance current service delivery practices and outcomes. These are designed and implemented in collaboration with other state agencies, school districts, providers, community partners, families, and people with disabilities. Our current services and how we plan to expand them over the next five years include: 1) Project SEARCH, a youth training and internship model leading to competitive employment currently with sites in Tucson and Phoenix with plans to grow to support rural and Tribal community sites across the state; 2) Pre-Employment Transition Services, a work-based learning and school transformation model focused on providing youth with real work experiences and paid summer work currently in Tucson and Phoenix focused in the upcoming years on expanding to schools statewide, determining effective approaches for supporting foster youth, training and technical assistance for developing school implementation capacity, enhancing opportunities for Tribal members and youth in rural areas other than reservations, and working with companies to provide internship support for Autistic college students enrolled in Engineering programs; 3) Transition AHEAD Roundtable, an innovative service modality designed to engage the young adult and their family in collaborative activities that address employment, healthcare, education, independent living, and relationships to find and support the kinds of actions and decision-making that will help them achieve greater levels of independence and become the "leader" of their own lives. Scaling up our current pilot activities will focus on broadening the population group, establishing fidelity of implementation, and testing a telehealth model with replication sites around the state; 4) ArtWorks, a community art studio and training program focused on promoting mutual learning through creative and expressive art interactions between adults with DD and university students will expand their program to offer classes in different mediums and artistic expression for all members of the community including those with disabilities; 5) Native American Disability Center, a new center that will be designed together with Tribal communities to build a central point of connection, resources, and support for Native Americans across the state to access inclusive of services that promote culturally and linguistically competent practices for Tribal members with disabilities on the twenty-two Tribal Nations and high population centers in urban areas.

Our community services are designed to respond to community needs with new strategies developed in partnership with the users and deliverers of those services to improve outcomes and impact change in AZ systems. By testing new ways of doing things, collecting data to evaluate their effectiveness, and assisting providers and agencies with the essential policy and practice changes they need to implement, we can ensure the methods are sustained over time. The SUCEDD is committed to universal design across services, materials, and products inclusive of plain and Spanish language, and both language and ASL interpreters.

**Community Services Innovative Designs and Methods:** The SUCEDD's work plan brings creative ideas and approaches to address new and long-standing problems. We plan to engage people with disabilities, families, and community stakeholders to participate with us in strategic thinking and idea generation to

identify and test new approaches. Areas to be addressed include specific services such as transportation, employment, and interventions, as well as how services are delivered such as accessibility, plain and multilanguages, and technology use. We plan to develop new models around supported decision-making in practice, intergenerational approaches across all age groups, virtual work and supports for competition in the global employment market, and volunteer connections as builders of social capital, all contributing to individual life outcomes. The SUCEDD proposes intervention development and testing related to transition, health care transition, healthy living, peer support, and dual diagnoses with the intent to translate findings into service modalities that can be scaled up and put into practice.

## Training and Technical Assistance Programs

The SUCEDD is well-known for its frequent and varied trainings across topical areas, such as employment, health, aging, person-entered approaches, and transition. These are often tied to projects and offer new information, practical strategies, and tools to promote skill development, capacity building, and improved service delivery practices. Our satisfaction data indicates participants' positive feedback regarding the training formats and content presented. During the next five years, we plan to expand our training program through adding a registration cost that can then be used to re-invest in increasing our trainings and continuing them after the funded project ends. We receive requests for many of the previous trainings and will respond to this interest by offering them again, as well as adding new trainings to attend. There are a few additional components to our proposed training activities. The SUCEDD will establish formal Centers within the Sonoran Center including the Employment First Center, Native American Disability Center, and FASD Resource Center all of which will offer training as a central component. We will be developing and conducting trainings in partnership with people with disabilities on topics they have asked for, such as healthy relationships, using technology, getting a job, serving on boards, how to vote, and becoming a leader. The PTI Raising Special Kids and the SUCEDD are planning a parent series on topics frequently requested with number one being transition, employment, and health care transition. It

is important to note that we have purposefully targeted trainings to be inclusive of nontraditional families with relevant information for grandparents raising children, foster and adoptive families, LGBTQ families, and people with disabilities who are parents. We have arranged with a plain language expert to conduct trainings for our staff and multiple events for the state to address the long-standing need and lack of capacity for translation in our state. Our approach to engaging volunteer opportunities and community groups as ways for people to connect with others, provide a service to their communities, build relationships and social networks, and immerse in like-minded passionate areas of interest, will open many new opportunities for people with disabilities and training avenues for the SUCEDD to assist organizations with establishing an inclusive environment (e.g., our work with the zoo).

Interestingly, as the SUCEDD was preparing their work plan and meeting with our CAC members, we had synthesized the feedback into an objective around establishing a technical assistance center. It was rewarding to hear the response "that is what you already do" and have acknowledgement for our extensive technical assistance that we provide to agencies, organizations, community members, and individuals. We plan to build on our rich history of continuing to provide assistance at no cost, and also to build a fee-for-service program that will allow us to have a greater reach and extensive impact. One area of intensive technical assistance will be around provider transformation and assisting interested organizations with changing their service delivery model from center-based and group employment models to integrated competitive employment. Other model development is centered on school transformation and providing intensive technical assistance to build capacity for providing work experiences and transition services that result in post-school outcomes. Our efforts in assisting nursing homes and the aging community with responding to the challenges presented by COVID and moving to more integrated living and community engagement models through intergenerational connections and supports will be done in collaboration with staff who will provide assistance contributing to the identification of effective strategies that we can bring to others. Our model care coordination clinic will

be expanding through the development and implementation of a train-the-trainer approach followed by intensive technical assistance to support other medical clinics with adopting the comprehensive, coordinated health services.

**Community Services Address Emerging Problems:** Our community service program is forward thinking in responding to current needs while preparing for anticipated challenges and opportunities in the future. For example, the post-COVID world necessitates that we do business differently and in order to ensure that people with disabilities are not left behind, we plan to expand services to include virtual work, remote supports, telehealth approaches, and technology use. The isolation and loneliness of this past year has exacerbated the already existing problems people with disabilities experience in establishing friends and social networks. We are focusing on services that increase opportunities for people to develop relationships through the provision of intergenerational supports and engagement in volunteer activities, hobbies and social groups, and peer-to-peer connections. Concerns over news of "long haulers" and secondary disabilities from COVID has resulted in initial stages of planning with our clinical services to provide training for other clinicians in response to these anticipated needs. Our mechanisms in place for on-going feedback from our CAC members, people with disabilities and families, and community partners allows us to gain insights on emerging issues and be planful in modifying or expanding our community services in anticipatory response.

# Research Program

The SUCEDD's research program is designed to gather data for purposes of evaluation, program improvement, model development, and data-informed decision-making regarding specific projects, the overall UCEDD, and important questions addressing needs and issues across topical areas. Our research program concentrates on development of new knowledge and strategies in areas where people with IDD often experience barriers and poor outcomes. For example, transition from school for youth and transition for those who are aging; health care transition from pediatric to adult care; and physical, mental, and social healthy living promotion. Additional studies are focused on informing service delivery such as access to supported decision-making, intergenerational supports across cultures and living/ engaging in one's community, and social networks contributing to social capital and community connections. Studies will be designed to promote equitable access and reduce disparities, increase civic engagement and support civil rights, and enhance participation in a tech world and post-COVID future.

The SUCEDD has a robust team of affiliated faculty and staff who are engaging in research and evaluation in areas such as employment, foster care, sleep, aging, trauma-informed care, transition, care coordination, physical therapy, and cancer prevention. We have recently hired two post-docs, two research consultants, and a research methodologist/statistical analyst, two of whom have a disability, to work across many of our projects in moving beyond pilot studies and evaluation to designing and conducting research investigations that add to the evidence-base and contribute new knowledge to the field. Our talented team of trainers, practitioners, clinicians, and people with lived experience are engaging in model development and creative innovations that lead to new and better ways for service delivery and support. Being able to quantify their work and share to promote policies and practice will be an important addition to our next five-year plan.

**People with Disabilities as Active Participants in Research:** Data is collected using a variety of approaches including needs assessments, pilot studies, systematic review, focus groups, interviews, surveys, Talking Circles, and design studies. People with disabilities participate in helping us decide research topics and participate on research teams where members work together to plan and conduct the research. Several staff with disabilities participate in data collection, conducting interviews and focus group discussions. We also hire people with disabilities for project specific studies and pay them a stipend or hourly wage for their work as data collectors and subject matter experts. The SUCEDD is a participating Collaborative Research Entity on the AUCD AIR-P project funded by Health Resources and Services Administration and awarded to University of California Los Angeles focused on building an infrastructure that supports

Autistic individuals in research and recently submitted two proposals together with an Autistic PhD research colleague. Another grant was just submitted that would assist us with improving involvement of people with IDD in SUCEDD research activities and engage in new research focused on patients with IDD being active participants in their own healthcare management and decision-making. Efforts are underway to expand our research program as outlined in our workplan and to ensure people with disabilities are partners in the design and execution of research activities.

#### Information Dissemination Program

The SUCEDD produces and disseminates information resources that fall into the following three categories: Communication, Products, and Project-Specific Resources. Communication includes our newsletter, social media posts including Facebook, Twitter, YouTube, and LinkedIn pages; and website highlighting upcoming events and the work of staff and faculty. Products address areas of interest and need, such as sharing stories of employment successes, infographics, videos, and topical information briefs. Third is project-specific resources such as brochures, curricula, guides, and toolkits. Some examples include sharing information through webinars and virtual forums that focus on transitions across the lifespan, such as healthy relationships, physical changes, and employment. The modes of dissemination include listserv, webinars, website, social media, event tables, mailings, and conferences.

Our work plan will build on our existing dissemination activities with an emphasis on knowledge translation and innovative ways to share information and resources for use by a variety of audiences. A reoccurring theme throughout our needs assessment was "to go beyond the toolkit" and design other approaches for people to access the best practice strategies and knowledge findings resulting from our many project activities. We plan to develop translation products that highlight our intervention development studies, healthcare intervention tools, a personal project analysis technology platform for supporting life goals, and community organization guides for inclusive engagement. The SUCEDD will produce research and policy briefs that will highlight our work and be produced in universal and plain language formats for use to advocate and promote systemic change. We will explore online products, infographics, digital storytelling, videos, and other visual illustrations for communicating information. Our budget supports plain and multi-language translation, and language and ASL interpreters to increase access, meaningfulness, and use of our communications, resources, and products.

Universal Design and Accessibility: Products are designed to reflect best practices utilizing person-first language, person-centered thinking, and universal design elements. In light of the COVID-19 pandemic, our work has focused on ensuring community members with DD have what they need to fully participate. This means ensuring CART/captioning and ASL interpretation are available for virtual workshops and webinars. We also make an effort to ensure Spanish interpretation is available if requested. The impact of the pandemic on how we all connect with one another has made our team even more sensitive to the needs of our community. People with DD are consulted to ensure our virtual meetings and sessions are accessible. Additionally, our work in American Indian communities has provided additional insight into how we create our products. An ongoing work-based learning experience in the Tribal community has given us the opportunity to discuss marketing/communication techniques with an individual with personal, lived experience. We also have a staff person with a disability whose expertise is graphic design and contributes to video editing and accessible formats. This staff person also offers insight into how we conduct our webinars and virtual sessions to the community and what techniques/approaches should be taken. We propose to expand on these efforts to produce integral information in multiple formats so the SUCEDD's entire constituency can assimilate content for use in daily life, program development, policy and advocacy initiatives. The SUCEDD plans to expand the use of positive images and portrayals of families and people with DD who are representative of different cultures in products and publications. Products are accessible with close captioning and low reading level. Pictures are used to illustrate content for our meeting agendas, materials, schedules, and other supplemental information. Not only does this increase use and participation by people with DD but has been praised to be the preference of those without

disabilities as everyone receives the same pictured information and sets a model of universal design and inclusivity.

## **SECTION 3: BUDGET**

A detailed line-item budget is presented outlining how funds will be used to implement the activities described in our five-year workplan. The budget forms, detailed budgets, and budget narrative for the five years can be found in the face pages of this proposal. Arizona is a Tier 1 state with a poverty rate of 14.4%, greater than the national average of 11.5% and therefore, qualifies for a reduced match requirement. Our robust workplan is supported by internal and external resources contributing to its fiscal efficiency and overall impact. Funds requested through this grant will supplement and not supplant those funds that would otherwise be made available for activities conducted by the SUCEDD. Our continued growth as evident by the number of external projects and strong collaborations with state partners who committed to sharing their resources to implement our workplan in line with their priorities, enhances the influence of these grant dollars ensuring achievement of our goals and objectives while increasing potential for leveraging additional funds to further advance our work.

### **SECTION 4: PROJECT IMPACT**

The SUCEDD will evaluate its five-year plan using both qualitative and quantitative methods to determine if we are meeting our goals and objectives. The evaluation plan is based on the logic model, which is organized according to SUCEDD priorities (goals) as identified by SUCEDD staff, faculty, and CAC members. The model outlines the inputs into those goals, activities under each goal, our benchmarks (outputs) and the initial, intermediate, and ultimate outcomes. The **Logic Model** will serve as our guide for the overall evaluation of the five-year plan, linking to our other evaluation methods including the National Information and Recording System (NIRS) and AIDD Annual Report; Project Specific Evaluations; and CAC and DD Network Review. (See Logic Model in Appendix B).

#### Quantitative and Qualitative Evaluation Methodology

The SUCEDD will evaluate its five-year plan on an on-going basis through a variety of reporting mechanisms, including regular project meetings, progress reports, and the utilization of a wide range of program evaluation tools (surveys, focus groups, key informant interviews, and changes in policies and practices). SUCEDD evaluation leads, Julie Armin, PhD and Jennifer Schultz De La Rosa, PhD, will work with individual projects and initiatives to develop appropriate evaluation measures, as needed (see logic model), and to collect data for our focused evaluation of program impact on access to disability programming, especially for historically marginalized communities. All model programs and interventions to be implemented in this five-year plan will document procedures and best practices, including "lessons learned," using a process evaluation approach, that will facilitate future program development, pilot initiatives, replication, and scaling up.

In this five-year plan, we have identified two major focus areas: 1) increasing access to inclusive programming across the life course, and 2) engagement of self-advocates in individual and community advocacy and leadership for increasing access to and inclusiveness in disability-focused services, social programs, and civic activities. Data points will include outputs from activities, such as program and training participant counts (institutional, community, and individual), products developed (e.g. curricula, models, solutions), and dissemination activities (e.g. presentations, briefs). In addition to evaluating outputs from activities in our workplan, we will **engage people with disabilities and communities in identifying, developing, and implementing evaluation metrics** to measure the SUCEDD's impact. Using a participatory action research approach (PAR) with communities and individuals with DD will provide a social justice framework, promoting research, action, and reflection (Baum et al 2006).

Our evaluation approach for focus area #1 (increasing access to inclusive programming across the lifespan) includes: Using lifecourse theory to guide the evaluation, we will examine the elements that influence access to disability programming across major lifecourse phases, with a special focus on adults. A life course approach enables an evaluation of the life trajectories of people with disabilities, providing

a framework for interpreting longitudinal data. Further, the proposed projects in the five-year plan will facilitate data collection from stakeholders engaged in early intervention, K-12 education, and young adult, adult, and senior services, as well as individuals with IDD. In this evaluation goal, the team will examine social/support network structures for people with disabilities (e.g. Special Education staff in K-12, Support Professionals) to describe how the social/support network structures facilitate or hinder key activities related to education, employment, and health care during transition stages. These data will enable the SUCEDD to characterize the "typical trajectories" at important life transitions, identify strengths and weaknesses, and model ideal social/support network structures.

Our evaluation of focus area #2 (engagement of self-advocates in individual and community advocacy) includes: Using a framework of self-determination (Wehmeyer, 1998) that acknowledges interdependence, as well as individual autonomy, enables a social justice-focused approach to evaluation. This approach is inclusive of an anti-racist and anti-colonial self-determination (Carlson, 2017) that invites and is inclusive of perspectives that favor collectivism over individual choice, and supports empowerment and the awakening of self-determination especially for communities and individuals influenced by historical marginalization based on race, social class, gender, language use, and sexuality. The proposed projects in the five-year plan will facilitate data collection regarding the development and implementation of programming that supports people with disabilities in leadership positions, as peer supporters, and as civically engaged citizens. Further, this focus will assess the degree of meaningful collaboration with people with disabilities as participants in program development and research through descriptive (qualitative) data. Potential data collection may involve Photovoice, a qualitative approach that highlights individuals' stories (Williamson et al., 2020), surveys, observations, meeting notes, focus groups, and in-depth interviews.

Across these two focus areas, and with an eye to inclusiveness of historically marginalized populations, the evaluation team will assess the following at a program level: proportional representation

of participants who identify as Black, Indigenous, or People of Color, and proportional representation of participants who report speaking a language other than English at home. Further, using a PAR approach to evaluation, we will share process data and activity outputs related to focus areas #1 and #2 with stakeholders (e.g. CAC, self-advocates) and elicit emerging questions and ideas for collecting data to answer those questions.

# **CAC and DD Network Review**

The CAC meets at least three times per year and at each meeting reviews the progress on the fiveyear plan. At each meeting, evaluation and progress data are shared and three or four objectives are discussed in greater length in order to utilize the CAC's input where needed most. Other areas of the plan are the subject of brief updates and problem-solving, as needed. CAC meetings are an opportunity to discuss emergent issues or changes we would like to make to our activities in response to changing needs. CAC members bring their diverse experiences and perspectives to these discussions, leading to revised or enhanced approaches to program delivery. We also engage the DD Network in a review of our five-year plan through both their participation in our CAC, as well as regular director meetings. Together we discuss emergent issues, current work, and obtain input on factors that may affect our work.

# SECTION 5: ORGANIZATIONAL CAPACITY

# <u>Programs Reflect a Lifespan and Interdisciplinary Approach and Active Participation of Individuals with</u>

The SUCEDD's mission is to learn from and support people living with developmental and other disabilities through all stages of life (see vision, mission, and values statement in Appendix G). The mission is accomplished through interdisciplinary education, direct and model services, research, dissemination of information, and policy development and advocacy carried out in partnership with people with DD and their families. Our services, activities, and programs are diverse and responsive to identified needs ranging from early childhood through aging. Examples illustrating our interdisciplinary work across the lifespan

include: 1) Early childhood – Statewide Professional Development Leadership team, Intense Physical Therapies to Improve Function in Young Children with Cerebral Palsy intervention research; 2) Youth and Young Adults – Pre-Employment Transition Services model development, Tohono O'odham Community College Tribal high school/community college/university transition and mentoring program, Transition AHEAD Roundtable healthcare transition model service development; 3) Adulthood – Provider Transformation from center-based services to competitive employment training and technical assistance, TBI person-centered planning systems change, Cancer Screening Education among Native American women with disabilities; 4) Aging – I-AADAPT Dementia Capable Care for people with IDD, My Life and My Wishes end of life planning tool, Coolidge Institution to Community Transition planning; and 5) All Ages – ARSOBO wheelchair and prosthetic community empowerment border initiative, Sleep and Memory intervention research, Community Health Collaboration with Special Olympics AZ Healthy Athletes Med Fest Health Leadership, and Sexual Abuse and Prevention research and evaluation.

**Independence of the Sonoran UCEDD:** Documentation is provided by a Memorandum of Understanding with the University of Arizona Health Sciences (Appendix D) and demonstrates that the SUCEDD is an independent entity within the UA College of Medicine with the authority and support to carry out the core functions of a UCEDD.

# **Organizational Structure of the UCEDD**

The SUCEDD is part of the Department of Family and Community Medicine (DFCM) in the College of Medicine (COM), UA Health Sciences (UAHS). The UA in Tucson, Arizona is a land-grant university with more than 46,000 students. It is ranked 19<sup>th</sup> among public research universities and 34<sup>th</sup> among all public and private universities and colleges in research expenditures. UA serves as the state's major academic research institution. The UAHS consists of the Colleges of Medicine, Nursing, Pharmacy, and Public Health and has the state's only Colleges of Medicine and Public Health, both of which have established campuses in Phoenix, Arizona as well. The UA College of Medicine also is home to the Arizona Leadership Education in Neurodevelopmental Disabilities (AZ LEND) located in the Department of Pediatrics. Together, the AZ LEND and the SUCEDD provide opportunities for trainees, sponsor joint events, and teach in each other's curriculum. Pediatrics, LEND, and the SUCEDD collaborate on projects, support trainee practicum and research hours, and share funding for a full time post-doctoral Research Associate who bridges their work and enhances innovative developments and collaborative funding initiatives.

# **Organizational Chart and Management Structure**

The SUCEDD organizational chart (located in Appendix G) illustrates the location of the SUCEDD within DFCM and its relationship to the College of Medicine and UA Health Sciences. Dr. Wendy Parent-Johnson, the Executive Director, reports to Dr. Myra Muramoto, DFCM Department Chair, and has monthly meetings with the Chair and each individual member of the Executive Leadership Team including Outreach and Research, as well as attends monthly departmental faculty meetings. The SUCEDD Director and faculty/staff serve on DFCM committees, teach classes, mentor resident research, and collaborate on scholarly work.

Oversight and leadership of the SUCEDD is conducted by the Executive Director, Dr. Wendy Parent-Johnson, and the Assistant Director, Jacy Farkas, MA, ABD in collaboration with the leadership team, which includes Kim Rogan, BS, Office Manager and Executive Assistant, Jeff Javier, MBA, Communications Director, and Justin Archer, MBA, Business Manager. An organizational chart highlighting all staff roles and positions is located in Appendix G. The leadership team meets monthly to discuss, plan, and strategize regarding organizational activities, issues, development, and growth. A monthly staff meeting is held for all members associated with the SUCEDD including staff, affiliated faculty, student workers, fellows, and consultants where new and current events are shared, accomplishments celebrated, updates and opportunities presented, and identified content areas discussed and explored. All staff report to a lead staff person who provides supervision, support, and guidance on completion of five-year work plan responsibilities, specific project tasks, and other SUCEDD activities. Dr. Parent-Johnson provides supervision and mentoring for all leadership team members, senior staff, affiliated faculty, researchers, and project managers across multiple grants. Overall administration of operations and team support is provided by our office manager, business manager, administrative assistant, program aide, and a student office assistant. Dr. Parent-Johnson and Ms. Farkas will oversee and monitor progress on goals, objectives, and activities of the five-year plan, as well as data collection and reporting. A talented team of SUCEDD personnel have designated responsibility for leading our core functions and ensuring we are completing our proposed workplan activities, maintaining a robust and responsive agenda, reporting data, and collaborating on the integration of lessons learned, translation to practice, inclusion of diverse participants, and universal/language access across core functions. Our core function leaders include Jacy Farkas, MA, ABD, interdisciplinary pre-service preparation/continuing education; Justin Archer, MBA, community training and technical assistance; Heather Wolff, BA, community and model services; Jennifer de la Rosa, PhD, research; and Jeff Javier, MBA, information dissemination. The core function team will meet monthly for the first six months of start-up with the new workplan and scope of work, followed by quarterly meetings for the duration of the five years. In addition, they will provide updates and discussion with the Executive Director at monthly one-on-one meetings. Each will also provide updates at monthly staff meetings and arrange trainings and in-service opportunities in their areas for staff, faculty, and students as needed.

# **Employ individuals with Disabilities and Family Members**

The SUCEDD is staffed with 44 individuals, 6 of whom have an identified disability including 4 with a developmental disability, and 4 who have a family member with a disability. Of the 44 staff, faculty, and consultants affiliated with the SUCEDD, 43% are representative of diverse race and ethnicities including 7 who are Hispanic, 7 who are Asian, 4 who are Native American, and 1 who reports more than one. The remaining 57% identify as Caucasian. We are working to enhance the diversity of our applicant pool and hires including people with disabilities and family members through careful examination and modification

of position descriptions and requirements, recruitment strategies, and search committee member training. The SUCEDD was selected as the UCEDD pilot site for expansion of the U.S. Office of Disability Employment Policy's successful Workforce Recruitment Program focused on recruitment and employment of college students and graduates with disabilities. The UA Human Resources and multiple departments participated in planning meetings to pilot and determine how best this federal program could be implemented in a university setting. Unfortunately, COVID necessitated stopping activities and they have not been revisited at the time of this proposal. Additionally, the Executive Director is one of the department's Diversity Champions serving on the College of Medicine's Diversity, Equity, and Inclusion initiative to improve diversity of the workforce, patients, and students to be representative of the state of AZ.

**Qualifications of UCEDD Director:** Wendy Parent-Johnson, Ph.D.is the Executive Director of the SUCEDD and Professor in the DFCM. She has been in this position since November 2018. Previously, Dr. Parent-Johnson was the Executive Director of the South Dakota (SD) UCEDD and LEND program. She is the chair of the AUCD Employment SIG, serves on the UCEDD Resource Center Project Advisory Committee, and is an AUCD Professional Fellows mentor and Outbound Fellow recipient. Dr. Parent-Johnson has a long history of leadership in the disability field most notably related to her scholarly work and advocacy in the areas of transition and employment. She has over 35 years of experience in model development, grantsmanship, research and evaluation, personnel and resource management, and collaboration with diverse community partners. Currently, Dr. Parent-Johnson is the Principle Investigator on 14 state, federal, and foundation grants and contracts totaling \$4,067,332. Her last year as the SD UCEDD Director, she was the Principle Investigator on 20 grants and contracts and fee for service accounts totaling approximately \$6 million. Her passion is evident in translating research to practice impacting service delivery, policy, and outcomes. Dr. Parent-Johnson's biosketch highlighting her qualifications and experiences is located in Appendix E. **Qualifications of Faculty and Staff:** Time commitments of faculty and staff by core function and areas of emphasis/workplan responsibility are outlined in the budget narrative located in the face pages of this proposal. A biosketch for our key personnel, Jacy Farkas, MA, ABD, Assistant Director, and bio descriptions of our core function leads are located in Appendix E.

#### Role of the Community Advisory Council (CAC)

The SUCEDD CAC is a vibrant, cohesive group with a strong voice providing input and assistance in developing, implementing, and evaluating our five-year plan. The CAC currently has 44 members and includes 61% of members who are people with disabilities (36%) and family members (30%) (see listing of CAC members in Appendix F). Our CAC includes individuals who represent key agencies, organizations, stakeholder groups, and people with lived experience who bring their perspectives, ideas, suggestions, and feedback to inform and guide our work. We reached out to groups representing diverse communities in selecting members to enhance our CAC's composition and cultural representation that approximates the ethnic diversity of our state. We are always adding new members, as most recently a parent who reached out to us for assistance with her child with Fetal Alcohol Syndrome Disorder and afterwards asked if she could be a part of the work we do. All DD Network members serve on the CAC, as well as membership from self-advocacy groups, the parent information and training center, and relevant state agencies and organizations. The CAC meets three times a year, providing input and feedback on our ongoing projects, sharing emerging issues as they arise, guiding changes to our five-year work plan, and assisting with problem solving challenges that are encountered. With COVID, CAC meetings were held virtually, however, we would prefer and are planning in-person meetings as soon as possible with remote access provided for those who cannot attend. Travel expenses and supports/accommodations are provided for CAC members. In response to our members' suggestion, we will rotate and hold meetings in different areas of the state throughout each year. Gabe Martinez, self-advocate and peer mentor, is responsible for coordinating our CAC (see bio description in Appendix E).

#### **Collaborative Relationships with DD Network**

All DD Network members have active representatives on both UCEDD CACs and ADDPC. The SUCEDD also has a staff member representative bringing a disability perspective to the AZ Center for Disability Law's advisory group. The AZ DD Network directors meet regularly to discuss and plan collaborations in specific areas, as well as respond in real time to an urgent issue requiring advocacy and attention. The DD Network works collaboratively on a variety of efforts such as our combined response and advocacy on issues related to COVID and the DD community. As a result, we collectively advocated with the executive office to allow family members to be in the hospital with their family member with a disability when no visitors were allowed; facilitated family and agency discussion sessions and assisted with addressing information requests, support coordinator virtual visits, clear masks, and plain/multilanguage/interpreter resources; and provided guest speaker topical webinars to share information on strategies and practices helpful for the areas of need people were requesting. AZ is a participating state on the Georgetown Cultural and Linguistic Competency Community of Practice whose members include the DD Network, Developmental Disability Services, and the Parent Training Information Center. Together we are focusing on increasing availability and access to services and supports that are culturally and linguistically responsive to users with disabilities and families. A provider and agency training and leadership strategic planning meeting are scheduled during the summer of 2021. DD Network staff collaborate on projects and activities across multiple content areas and core functions. Our dissemination counterparts develop and share communications together, co-conduct virtual events, such as the Native American Disability Summit and African American Conference, and produce products for distribution by each organization. Currently, the two UCEDD's in the state have two shared grants together focused on transition and cancer prevention and are in discussion regarding collaborative research efforts. It is not uncommon for one or more of the four partners to assist another with conducting a training, providing a guest lecture, sharing a resource or contact, trouble shooting a problem, or responding to a request.

Informal and formal meetings occur frequently among the network partners, often weekly. Additionally, each director informs the others of important information and news releases shared among their own affiliated networks. The three DD network partners were instrumental in developing our five-year plan and shared their current and future priority areas to further strengthen our collective efforts building on and supporting each other's work. Letters indicating commitment to our continued partnership and support of our workplan are in Appendix F.

**Collaborating Partners:** As highlighted throughout the work plan, the SUCEDD will conduct its work in collaboration with other entities in the state. Specific partnerships and their commitment to collaborate with us are demonstrated by letters of support located in Appendix F. These include Arizona RSA, Department of Education, Division of DD, AHCCCS (Medicaid agency), Arc, Raising Special Kids, Diverse Ability, Tohono O'odham Community College, Statewide Independent Living Council, ARSOBO, Self-Advocacy Solutions, Tribal leader, and LEND program. The SUCEDD engages in collaborative partnerships with a variety of other agencies and organizations in the state as indicated by the listing located in Appendix G. It is important to note many of these stakeholders are represented on our CAC and contributed to the development of our workplan, as well as oversee its implementation, suggesting and facilitating intersections and opportunities for partnership along the way. Staff are actively involved in university and statewide work groups, task forces, committees, and strategic planning sessions as leaders and participants representing the SUCEDD.