B. Executive Summary

Alzheimer's Disease and Developmental Disabilities: Practical Information for Families and Support Professionals w/ Emphasis on Urban and Rural American Indian Communities

The number of older adults with a developmental disability affected by Alzheimer's disease and related dementia (ADRD) is growing. This growth is posing a significant challenge to families and friends, provider agencies, and federal and state agencies concerned with the provision of supports and services to individuals living with an intellectual disability. Although the research community is making strides to better understand the causal and evolutionary factors leading to the onset of ADRD in general, the social care system still remains challenged with the 'here and now' of offering the best, most effective and useful means of identification, daily supports, and long-term care.

Many adults with a developmental disability live in community settings, either independently or with support from families, friends and service providers; with advanced age, they experience age-related conditions and diseases, including. ADRD has a devastating impact on adults with developmental disabilities as well as their families, friends and service provider staff who often provide essential long-term support and care. Community service providers are facing a 'graying' of their service population, many of whom are affected by dementia. Most often these support providers are challenged to provide effective and financially viable daily supports and long-term care. This challenge is even greater in Native American communities, urban and rural, where medical care and knowledge about ADRD can often be outdated or non-existent.

Alzheimer's Association Desert Southwest Chapter is requesting $10,000 to provide a series of ten (10), three hour workshops throughout Arizona targeting individuals who are aging with developmental disabilities, family members and support professionals with a special emphasis on Native Americans.

Workshops will be led by Alzheimer's Association staff experienced in working with individuals with developmental disabilities, have extensive knowledge of ADRD and the cultural competence to work with diverse populations. They will be designed to help participants better understand aging issues, the effect on persons with I/DD, ADRD warning signs, stages of ADRD, diagnosis processes and accommodations for the changes ADRD brings for individuals with I/DD. Educational workshops for family members, case managers and other support staff will improve their understanding of dementia and potentially lead to earlier identification and acquisition of timely supportive services. Also, our hope is that workshop participants will be able to better support the creation of dementia friendly communities and help identify and support intervention best practices for adults with a developmental disability affected by ADRD.

Workshops will be held in the Phoenix, Prescott and Tucson areas and will be designed and delivered in collaboration with the Arizona Department of Economic Security – Division of Developmental Disabilities, local nonprofit organizations providing support for individuals with developmental disabilities, and specific organizations that provide support services for the Native American communities both urban and rural. Workshops will ensure that those who participate in self-directed services and support, adult day programs and site and community-based programs are included in the invitation to participate.

EXECUTIVE SUMMARY

S.E.E.K. Arizona appreciates the opportunity to submit this grant application to the Arizona Developmental Disabilities Planning Council. We are excited to be considered a recipient as we value educating families on Positive Behavior Change. For over ten years, S.E.E.K. Arizona has been supporting families with children/adults on the autism spectrum and with other developmental disabilities.

We are hopeful that we will be awarded grant dollars to teach, share and explore options for Positive Behavior Change for up to 40 families members. Our expected outcome is that families are empowered and educated with additional information and tools that will effect positive behavior changes for their family member with a disability.

In our efforts to empower and educate, each participant will receive a three ring binder of all printed materials and the PowerPoint presentation. The information will be available to each participant (at no cost) on a CD and a free t-shirt will be distributed to each participant after they complete the required surveys for this workshop. The goal is to offer the families every opportunity to succeed with the Tools for Parenting Positive Behavior Change.

The Board Certified Behavior Analyst (BCBA) and the Bachelor and Masters level behavior coaches are motivated to collect data in our efforts to create positive change. This will directly apply their data collecting skills to ensuring that the required surveys are distributed, collected, analyzed, and submitted in a timely manner. Preparing graphs of the survey data collected will be the responsibility of the BCBA to submit to the ADDPC.

We are thrilled for the chance to offer this specialized training directly to families. The expertise of Dusty Jones, BCBA Co-Presenter and Consultant and Travis Heth, BCBA and Co-Presenter will offer specific training for individuals with challenging behaviors. The Bachelor and Masters level behavior coaches are excited to be part of this training as small group facilitators. Being part of this grant is also a part of their continuing professional development. Travis Heth will provide two hours of training in advance of the workshops to prepare the behavior coaches to be effective small group facilitators throughout the workshop.

Thank you again for the opportunity to apply for this funding source.

"**Do You MIND?** ***Perspectives on Behaviors and Management in the Home***" is a conference designed to improve independence of individuals with physical and developmental delays and disabilities by strengthening the influence of healthy caregiver interactions. By bringing together information for parents and caregivers of the physically and developmentally disabled to assist with managing challenging behaviors in the home, this information will increase the potential for highest quality of life by facilitating empathy and relationship structure while encouraging the team approach to decision-making and conflict resolution. "**Do You MIND?** ***Perspectives on Behaviors and Management in the Home***" is a conference designed for parents/caregivers/guardians to encourage and equip them with additional tools to best fill their role as facilitator and guide through the independence process and daily life. *This conference will be held in two locations: Phoenix and Tucson.

The topics will offer information and action steps and involve:
1) assessment of motives & goals of the caregiver 2) understanding the mind of the differently abled 3) considering age 12 and under boundaries 4) negotiating the 13 and up boundaries. Each of the four segments will contain a brief testimonial from an individual who has cared for someone with Spina Bifida and has implemented necessary practices to speak on the topic.

Day of event collaboration in Phoenix is proposed with the Arizona Spinal Cord Injury Association, Hydrocephalus Association, Children's Rehabilitative Services, Arizona Disabled Sports, ABIL, and Spo-Fit. Tucson collaboration consists of DIRECT, Pilot Parents, and JAWS with the University of Arizona.

Key staffing to develop and facilitate the conference are three Program Assistants of the Spina Bifida Association of Arizona who will assume the roles of Support Staff, the Executive Director who will be the Conference Coordinator, and a Conference Planning Committee. The committee will consist of the Sharri Runnels, Exec Director & Coordinator; Heather Bieber of the Board of Directors, Angela Chaput, Support Staff; Caryn Paye of Southern Arizona; and Dr Susan Wolf, speaker and consultant.

To best conduct this conference and implement the objectives, the Spina Bifida Association of Arizona is requesting funding in the amount of $10,000.00 of the Arizona Developmental Disabilities Planning Council.

B. EXECUTIVE SUMMARY

Arizona Autism United's purpose is to provide support and services to children and families affected by autism. Rates of autism continue to rise; autism now affects 1 in 64 children in the state of Arizona.

Arizona Autism United has held an Annual Conference for the past four years for the English-speaking Community. On May 18, 2013, we hosted our first conference for the Spanish-speaking Community. It was held in the building where Arizona Autism United is located – in the Disability Empowerment Center in Phoenix. The meeting space has a capacity of 200, which we filled at the 2013 Spanish Conference.

The Spanish-speaking community is underserved with regards to autism information and support. To further provide this population with support, we would like to grow the Spanish Conference for March 2015, with the goal of 300 attendees, including as parents, caregivers and educators. Outreach efforts to the Spanish-speaking community will be made throughout the state of Arizona.

Because of the increased goal of 300 attendees, we require a larger venue than the Disability Empowerment Center. Funds from the Council Sponsorship for Conferences Grant would be used to help offset rental costs for a larger venue. Additionally, we will have increased food, beverage and audio visual expenses for the 2015 Conference. **Therefore, Arizona Autism United is requesting a grant in the amount of $10,000, to help support a larger number of participants for this Conference.**

The 2015 Spanish Conference will follow a similar format to previous, successful AZA United Conferences. Speakers will provide information to parents and caregivers on evidenced-based practices such as Applied Behavior Analysis, which can be used to help support positive behavior for children with autism.

As we have for past conferences, we will collaborate with other non-profit organizations such as Raising Special Kids, the Southwest Autism Research and Resource Center, and Southwest Human Development for outreach and conference presentations. Additional outreach efforts will be made with Spanish media partners such as Univision, Telemundo, and La Voz Newspaper, some of whom have, in the past, provided media coverage for Arizona Autism United Conferences. Key staffing will include Arizona Autism United Directors, Managers, and clinicians, as well as volunteers.

We look forward to the 2015 Arizona Autism United Spanish Conference. This conference will provide further support to the underserved Spanish-speaking community by providing information on evidence-based practices for their families and children affected by autism.