

Final / June 10 2024

New

Conference Sponsorship Summary of Proposed Projects

Contracts will be one year, July 1, 2024 – June 30, 2025. Each contractor will provide a survey and demographic information at the end of the contract period.

1. Care for the Caregiver requesting: \$7,500.

The applicant will provide a parent advocacy training series (every other week) for twenty parents, covering five topics. Each training session will be two hours long, in-person and held in Phoenix. The intention of the training series is to equip parents with the skills and knowledge they need to advocate effectively for their children and others in the disability community. This project will be done in conjunction with Raising Voices Coalition and Brenda Walsh as a consultant. All materials will be created in plain language, in Spanish, and each training will provide accommodations if requested. There is no cost to register, each training will be recorded. The budget supports the costs of the training, including four speakers, accommodation requests by the participants, development of training materials, and the venue.

The specific five-week training courses include the following:

- Past and Present: An overview of the disability advocacy movement, historical progress and the ongoing need for advocacy.
- Independent Living Movement: A review of the principles and objectives of the independent living movement.
- Education Law: Understanding key concepts such as Free Appropriate Public Education (FAPE), 504 plans, and Individualized Education Plans (IEPs).
- Policy and Legislation: Differentiating between policy making and legislative processes and understanding how each can impact advocacy efforts.
- Putting it into Action: Parents will break into groups to focus on either school advocacy or policy and legislation advocacy. They will work on practical activities, such as improving IEPs or advocating for specific legislative or policy changes.

2. Mary Gloria Foundation requesting \$7,489.

The applicant will partner with Southwest Institute for Families and Children to host the Inclusive Connections for People of Diverse Abilities: Family Resource and Career Exploration Conference in April 2025 for people with I/DD and their families and caregivers in Queen Creek and San Tan Valley communities. The half-day conference will focus on self-determination and meaningful careers for people with I/DD. They plan on reaching up to 75 participants to learn about the importance of self-advocacy, different career paths, and opportunities for personal and professional growth. Vendors will be able to engage with participants to share their information. The event will take place at Arizona Central

Community College. All materials will be created in plain language, in Spanish, and the conference will provide CART and ASL accommodations. There is no cost to register for the conference. Speakers will be identified to discuss the topics of the history of the self-advocacy movement, post-secondary education and transition planning, employment rights and responsibilities. Outreach to the Gila River Indian Tribe, the Gila River Youth Council and Tribal Health Department will occur to invite them to participate in the Conference and as a vendor. The budget supports the costs of the half day Conference, including SWI as consultants, accommodation requests by the participants, supplies and printing of materials and personnel. The Conference will not be recorded.

3. Southwest Institute for Families requesting \$7,495.

SWI will host an online self-advocacy conference to bring 50 self-advocates around the state to learn and share their lived experiences on various topics that are important to them. Five presentations/themes will be covered, self-advocacy, education, healthcare, employment, and independent living. The Conference will be held in May 2025 and there is no registration fee. The Sonoran Center will partner with SWI to create the online registration form and will host the conference on their Zoom platform. They will also participate in SWI's conference committee. Conference materials will be in plain language and available in electronic format, but SWI will provide the documents in any alternative format as requested. Spanish translation of materials will also be available. The budget supports the costs of the conference, including personnel costs and any conference accommodation. The Conference will be recorded, and videos created to upload to SWI's YouTube page and on their website.

Renewals/Year 2 Grantees

Self-Advocacy Leadership Project

The Arc of AZ is requesting \$60,000. The Arc of Arizona, with The Arc of Tempe will continue to meet the Self-Advocacy mandate. The budget for year 2 supports the work of the project undertaken by The Arc of Arizona and The Arc of Tempe. During this past year, they have initiated the following activities:

- The Arc of Tempe launched Arizona Achieve, the statewide coalition of self-advocates, which serves as the central hub for all information, programming, resources, events and outreach via their newsletter. Social media is a large part of their outreach efforts, including FB, and in the next year will expand to using Instagram and TikTok.
- Outreach to expand the number of self-advocates increased this past year. 87% of their members are self-advocates and are from across Arizona. Also, part of their membership includes family members and professionals. Targeted ads on FB will continue to expand into other rural areas.
- Arizona Achieve coalition meetings have been a strong foundation for their growing base of members and they meet monthly. It is driven by and for self-advocates leading the

discussion to address what is important to them. One area they would like to address is the lack of transportation.

- Self-Advocacy training is a large component of the work The Arc of Tempe conducts. They successfully delivered leadership training at three Arc chapters across Arizona. This included the chapters Y.E.S., Pinal County Arc and Mohave County Arc. Two more sessions will be completed by June 30 at Santa Cruz County Arc and one training at Tuba City. Feedback provided refinement of the training materials and comments have been positive, such as members stated, “I learned how to use my voice and put my story together”, “I would encourage my customers that their voice does matter in any situation”, and “I used this training to talk to legislators”.
- Peer-mentoring program debuted in October and through the year, 6 pairs were matched (3 self-advocates with adults). These matches allowed self-advocates to improve their self-determination skills and helped achieve their personal goals.
- Created a transportation video in Tuba City. This idea came about through the monthly meetings where self-advocates focused on the lack of transportation. The Northern Arizona Tribal Disability Coalition (NATDC) shared their personal stories and their advocacy around the lack of public transportation on the Navajo Nation. In response to this, Arizona Achieve undertook a special project related to the goal of transportation accessibility. Coalition members decided that Arizona Achieve should create a video to spread awareness about this transportation issue. In February, the Project Director spent two days in Tuba City, filming the surrounding area and interviewing members of NATDC on the lack of transportation and accessibility. They continue to conduct more interviews for the video and once completed, it will be shared widely.
- Disability Policy Seminar - Capitol Hill Day. Members from The Arc of Arizona and The Arc of Tempe attended the Disability Policy Seminar and were able to meet with various Arizona’s congressional legislators & staff to share their personal stories and advocate for key disability issues, such as the lack of transportation, disability benefits and other topics. As a result of these meetings, Ryan Barry with The Arc of Tempe, is in communication with Representative Staton’s office to lay the groundwork for a dialogue aimed at addressing the rural transportation issue. Rep. Staton serves as Vice-Chair of the House Transportation Committee.

Activities for Year 2 will focus on the following:

- The Arc of Tempe and self-advocates to attend more statewide conferences to share their work and to encourage new members to join.
- Creating awareness videos and videos featuring self-advocates. Further promotion using FB, Instagram and TikTok.
- Continuation of the Peer mentoring program; currently is on-line for the matches that meet twice a month for 30-45 minutes and they meet in person to work on projects. A graduation is held at the end of the mentoring partnership.
- Continuation of the monthly Coalition meetings, held on the first Friday of every month in the afternoon for self-advocates to express and share their stories and collaboration of projects.

- Creating curriculum videos and having a library of online courses for self-advocates. These videos will be no longer than 10 minutes in length and each video will cover various topics. This collection of videos will be critical for Arizona Achieves online leadership training course. Although the framework of this course is already in place, the introduction of video content will elevate the overall quality of the course. Members will be guided through the curriculum, starting with basic self-advocacy topics and graduating to more complex topics. Members will be able to navigate through each course chapter at their own pace based on their needs. This course not only facilitates more engagement with the material but allows us to monitor their progress to ensure they benefit from the course. By creating these videos, they will broaden the accessibility of these educational resources.
- The Arc of Tempe will closely work with state legislators to create impactful legislation and work collaboratively with other partners, non-profits, and government agencies, such as Maricopa County of Governments (MAG) and NACOG – Northern AZ Council of Governments. Having a dialogue with key stakeholders around problems helps to find solutions to these issues people with I/DD face.
- Continue to conduct in-person training on self-Advocacy Leadership. In Year 2, they will implement a hybrid approach, with four basic in-person trainings and two advanced Zoom training sessions for more advanced topics. They will conduct basic self-advocacy training at in-person locations for those unfamiliar with self-advocacy. Meanwhile, advanced topics will be offered separately via Zoom. This approach will retain engagement of the participants and effectiveness. And if needed, they will adjust the training based on different needs and topics.

Supported Decision-Making (SDM)

The Arc of Arizona is requesting \$80,000. The Arc of Arizona, in collaboration with Disability Rights of Arizona (DRAZ), is requesting second year funding to expand and sustain the supported decision-making initiative. SDM overall goal is to reduce guardianship and shift towards a more inclusive and empowering approaches for individuals with I/DD to retain their rights to make their own choices.

In Year 1, The Arc of Arizona with DRAZ completed the following activities to support SDM:

- Established a working advisory committee of 20 members that provides valuable feedback on tools and planning resources, and other insights throughout the project.
- Developed and adjusted, as needed, training materials based on feedback from the advisory committee, and from participants who attended the training sessions.
- Conducted 14 training sessions around the state of Arizona, both in-person and virtual, reaching an approximately total of over 1400 individuals.

- Developed various resource materials that include videos featuring self-advocates and parents; a one-page flyer explaining SDM and ensuring all resource materials are in plain-language and accessible.
- Expanded outreach efforts through social media platforms, newsletters, direct emails, and partnerships with other disability organizations.

In year 2, The Arc of Arizona will maintain many of the same activities and expand to new ones.

a. Conduct a minimum of 12 training sessions in Year 2, of which 6 of the training sessions are conducted outside of Maricopa County in the communities of Lake Havasu, Flagstaff, Page, Show low, Wickenburg and Yuma. The remaining training sessions will be virtual. The minimum number of participants per training is 8, however The Arc of Arizona has seen larger number of participants at each of their training sessions.

b. Focus of training may include any of the following groups: Individuals with I/DD and their families/caregivers; Service providers; Financial professionals, including trust managers, Healthcare professionals, including, clinics, hospitals, administrators, clinicians, physicians. Judicial and Legal professionals; Educational agencies, including public and charter schools, school districts, community colleges, universities, teachers, transition specialists.

c. The Arc of Arizona and DRAZ will participate and provide training and share resources at a minimum of two (2) statewide conferences where SDM would be relevant.

d. The Arc of Arizona will maintain and work with the SDM board; meet with them on a quarterly basis. Feedback from the board will be incorporated on SDM training and resources.

e. Maintain and expand the Communication Plan created in Year 1. These include stories to present in traditional media (newspaper, TV, radio), blogs, videos, and use of digital and social media marketing efforts, and more targeted approaches to communities, and certain groups who would benefit from learning about SDM.

f. New this year, The Arc of Arizona will develop a train-the-trainer component to broaden statewide reach and create a path for future sustainability. To begin to put the model together, The Arc of Arizona will first focus on developing a pilot of specialized training for potential future trainers. Then they will establish standardized requirements for successful completion of SDM training and create a process for tracking and supporting approved trainers. The official train-the-trainer model will fully start in year three.

g. The Arc of Arizona will seek alternative sources of funding to sustain SDM, post ADDPC grant funding.

Renewals/Year 2 Pregnancy-Parenting Education Grantees

ASU is requesting \$35,604. In year 1, ASU's project is to help raise awareness of best practices, policies, and support models for parents and prospective parents with disabilities amongst social services providers in Arizona, including social workers and other social service professionals. During this past year, ASU completed an extensive literature review, convened an expert panel of 12 individuals with diverse backgrounds who provided detailed input into the guide and researched existing models supporting parents with disabilities. In this last quarter, they completed the user-friendly guide, and they are currently in the process of finalizing their four training sessions (Tucson, Yuma, and Flagstaff each in person), and a hybrid training in Phoenix so that social workers and other social service professionals from across the state can participate.

Additional information on the user-friendly guide. The guide succinctly introduces eight underlying concepts helpful for working with parents with disabilities and prospective parents with disabilities (i.e. parental supports; parental risk factors do not cause child endangerment; the good enough parenting standard; presumption of unfitness bias; universal design, disability rights framework, social model of disability, and disability justice framework) and explaining these concepts as they relate to working with parents and prospective parents with disabilities.

The guide includes best practice tips for social workers and social service providers when working with parents with disabilities that align with practice concepts common in social work, such as the strengths-perspective and self-determination. It also introduces six promising models that social workers, other social service workers, and community advocates could use as models for establishing services or supports in their own agencies or communities, or as aspirations for state-level policy change. These six promising models complement the individual-based, behavioral approaches that have been developed and tested that focus on training and educating parents, as well as informal family and peer support.

The user-friendly guide includes a brief historical overview of treatment of parents with disabilities, a brief overview of relevant federal and state policies, links to state and national resources for more information, links to model programs, and seminal readings about services and support for parents with disabilities. English and Spanish language versions of the user-friendly guide are currently in production with the user-design consultant, and will be available and disseminated by June 30, 2024.

ASU has proposed the following activities in Year 2 if funded:

- Expand the outreach and training sessions to eight new audiences that may include paraprofessionals, psychology students, two tribal colleges and the LEND program at UA. The project director will also conduct a minimum of four training sessions to larger conferences, such as the Arizona Rural Health Conference, the Summer Institute for Behavior Health in Flagstaff, The National Association of Social Workers AZ Chapter's Annual Conference in Phoenix, and the Conference for Behavioral Health Providers in Tucson.
- Enhance or maintain materials, such as creating simple videos of their training, making them available on ASU School of Social Work YouTube Channel. Feedback from the

training participants will be used to share with their expert panel and to update their training materials.

- ASU will enhance their communication plan to draw more attention to the user-friendly guide and to the training videos that are created. The project director will work with ASU News to create at least one media story on this project that will be published online at ASU and shared with other media sources. Also, the project director will conduct media outreach in Tucson, Yuma, and Phoenix for potential stories to share, and to publish an article in *The Conversation* which is aimed for lay audiences.
- Their evaluation process will capture who attends training, feedback on the satisfaction/usefulness and effectiveness of the user-friendly guide and training, demographics of participants, metrics such tracking the number of downloads of the user-friendly guide, including number of downloads of the guide in English and Spanish, and analytics of any video posted on YouTube and ASU media sources.

NAU is requesting \$75,046. NAU's PATHS project or Providing Accessible Training and Home Support for Parents with Intellectual Disabilities (ID) is a comprehensive project that aims to improve access to high-quality parenting supports for parents with ID by increasing the capacity of home visitors to meet the needs of families. Evidence-based home visiting programs (EBHVP) such as Healthy Families, Parents as Teachers, Nurse-Family Partnership, and Health Start are national programs that utilize specific curricula to provide parenting support to families with children ages 0-5. PATHS will continue to provide training to home visitors (HVs) with these programs operating in Arizona to further increase their capacity to meet the needs of parents with ID while offering universal enhancements to the curricula used by each HV.

The project completed the following activities:

- Literature review, interviews with home visitors (a total of 15 will be completed) and feedback from training sessions was gathered. Information was gathered about the EBHVPs and curricula currently being used to serve families in Arizona.
- They designed and provided training sessions to home visitors from Arizona on how to best serve and meet the needs of parents with ID. A total of 3 training sessions will be completed by June 30th (April 22, May 6, May 20).
- PATHS is guided by a participatory approach supported by two advisory research teams (ARTs), one comprising parents with ID and one comprising representatives of home visiting programs. Each ART (a) provides input to inform project activities, (b) assists in the interpretation of research findings, and (c) provides feedback on the trainings and the materials associated with the enhancement to each EBHVP and its curriculum.

With continued funding, PATHS will continue to focus on delivering training to and sharing research findings from the first year of the project with Arizona home visitors to better serve parents with ID.

Collaborators include multiple home visiting programs in Arizona. These programs include those that are funded through the (a) Maternal Infant and Early Childhood Home Visiting (MIECHV) grants, (b) First Things First grants, and (c) Department of Child Safety (DCS) grants. Specific programs and

curricula include Arizona Health Start, Early Head Start, Healthy Families Arizona, Nurse-Family Partnership, Parents as Teachers, and Baby Talk: Family Engagement Model.

The first training on April 22, 2024, had 26 participants. This served as an introduction to intellectual disability by describing common myths related to parents with ID, identifying common challenges for parents with ID, and providing considerations for home visitors when working with parents with ID. The second and third training sessions took place on May 6 and May 20, 2024. These trainings built upon the information shared in the first training and are meant to enhance the content of the EBHVP curricula used by the training participants. The second training will offer information about individualized care for parents with ID. The third will share formal resources and tools to improve home visiting services for parents with ID. The trainings will be available to view free of charge on the NAU/IHD webpage for PATHS (<https://nau.edu/ihd/paths>).

NAU has proposed the following activities in Year 2 if funded:

- Finalize the analysis of the home interviews with HV's that occurred in the last quarter of Year 1 and submit the findings for publication.
- Enhance the training by developing 3 additional trainings. These include the following subjects, Co-Regulating your Child; Developmental Milestone, and Child Welfare Services. The original training sessions will still be offered to home visitor supervisors.
- The PATHs team will connect with home visiting programs on the Navajo Nation to discuss PATHs and the trainings that currently offered. The programs will include Parents as Teachers, Family Spirit, and Navajo Head Start. Representatives from the Navajo tribe will be invited to participate on the home visitor advisory research team (ART).
- The PATHs team will work with each ART team to create materials and infographics and other resources that will help home visitors better understand and meet the needs of parents with ID.

Evaluation methods include conducting and monitoring evaluation activities on a regular (at least monthly) basis. Process evaluation will track the project's progress to ensure that the project activities are being implemented as intended. Data involved in the evaluation will include meeting agendas, literature review and interview findings, ART participation in project team meetings, post-training survey results, and ART post-meeting wrap-up questions. ART wrap-up questions will provide advisory group member perceptions of whether their voices are being valued and incorporated into the project processes. Evaluation outputs that will be tracked include number of participants in trainings, schedule and number of meetings held, meeting artifacts, number of interviews held, and number of post-training survey responses. The evaluator will also assess open-ended feedback from the post-training surveys. Evaluation outcomes will include validation of ART perspectives being acknowledged, alignment of reported results with data sources, and verification that research bias is not present.

UA is requesting \$68,319. The Sonoran Center's project is funded to 1) better understand and increase awareness about the experiences and needs of disabled Arizonans related to pregnancy and parenting, 2) develop training and educational/resource materials to address needs of this

population for multiple stakeholders, and 3) develop peer-support groups for disabled Arizonans who are pregnant and parenting. Prior to this ADDPC award, the Sonoran Center and six other community organizations began collaborating around the needs and support available to people with disabilities who are pregnant, parenting or wish to become so. The other organizations collaborating with the Sonoran Center are Ability 360, DDD, AZ Spinal Cord Injury Association, March of Dimes, Raising Special Kids, and United Healthcare Community plan.

In Year 1, the Sonoran Center completed the following activities:

- Data Collection & Analysis which consisted of Surveys for people with disabilities and family members (n=45), and health care providers (n=6); Focus Groups and Interviews: Two virtual focus groups were held with a total of 19 participants, of which 17 were parents with disabilities, and 8 virtual interviews were held with 4 parents living with disabilities, 2 support specialists and 2 clinicians. By June 30, transcripts of these interviews will be analyzed. Information gathered during the focus groups related to treatment, services and supports throughout pregnancy and children's lives from disabled parents. Data and findings will be utilized to identify gaps and needs to inform product and curriculum development in Year 2.
- Training and Community Programming. The project team held an in-person event, Pregnancy & Parenting Forum, at Ability360 on February 21 to share what we have learned so far from the project, host a panel with individuals with lived experience to grow awareness of issues, and gather any additional input from community members for product and training development. Ability360 and Arizona Spinal Cord Injury Association (ASCIA) planned fun events for parents with disabilities and their families at the at the Ability360 Sports and Fitness Center to build community and share information. This included a "Parents with Disabilities Night Out!" They also developed and hosted a virtual class on self-care for disabled parents through their peer mentoring and support model.
- Resource & Product Development & Information Dissemination. The Sonoran Center and project partners engaged in resource information development and dissemination:
 - Sonoran Center public health interns and trainees in other disciplines researched local and national resources on family planning and adaptive equipment for parents of newborns that would be feasible for people with I/DD to utilize. This included attending national webinars on the topic and conducting a literature review in this area.
 - Sonoran Center student trainees developed an English/Spanish bilingual factsheet on vaccinations during pregnancy which was disseminated at the Feb 21 Pregnancy and Parenting Forum and Feb24 Disability Resource Fair & Vaccine Clinic at Mariposa Community Health Center in Nogales, AZ. A recording of Pregnancy & Parenting Forum is available on the Sonora Center YouTube Channel.
 - Representatives from all three ADDPC Pregnancy and Parenting Support grantees met to discuss the development of a track for the 2024 IHD Evidence for Success Conference (June 3-4). Each submitted a proposal about their respective projects and invited ADDPC to lead a panel session to set the stage and importance for this

work. All proposals were accepted, and a new track was added to the agenda for June 4th. Sonoran Center staff and project partners will present on this project.

The Sonoran Center will complete the following tasks by June 30th: Complete data analysis and report findings from qualitative data; develop 3 infographics and plain language summaries based on the research findings. Finalize post Pregnancy & Parenting Forum video. Interview a neurodivergent parent to create a video about their experiences. And compile all evaluation data for a report to the collaboration team and the ADDPC.

A few highlights for Year 2 activities include:

1. The Health Care Survey will remain open to capture more responses.
2. Host 2 webinars that will be recorded and archived on the Sonoran Center YouTube channel. One will be a collaboration with Circle for Indigenous Empowerment staff to offer a webinar as part of monthly Native disability webinar series related to pregnancy and parenting with disabilities. The other will focus on targeting health professionals leading up to the launch of the CEU/CME course.
3. Complete two additional infographics based on health care provider and evaluation data.
4. Present at the UArizona College of Medicine – Tucson Grand Rounds and ADHS Maternal and Infant Health Committee meeting.
5. Launch an online resource hub on the Sonoran Center website.
6. Continue to distribute the English/Spanish bilingual factsheet on vaccinations during pregnancy for the disability community.
7. Develop and offer 2 peer support modules, collaborating with the Centers for Independent Living and Care 4 the Caregivers organizations.
8. Develop, pilot and launch the self-paced online CEM/CEU course for health care professionals in English and Spanish at the Western Regional Public Health Training Center.
9. Host five in-person family events and training in the communities Tucson, Phoenix, Tuba City, Prescott, and Yuma.
10. Expand the family peer-to-peer informational events, by offering additional in-person parent/family social and informational events through the Centers for Independent Living and Care 4 the Caregivers organizations.
11. Their communication/outreach and dissemination plan include, developing stories, newsletter articles, videos, blog posts and infographic, fact sheets and use of social media campaigns. Materials will be in plain language, electronically accessible and translated into Spanish when possible.
12. New partners that will be collaborating with the Sonoran Center include Western Region Public Health Training Center, UA College of Public Health; ASSIST to Independence in Tuba City, Navajo Nation; Direct Advocacy & Resource Center, Tucson and serving S. Arizona; New Horizons Disability Empowerment Center in Prescott; Services Maximizing Independent Living and Empowerment in Yuma, and Care 4 the Caregivers.

The evaluation process includes gathering training/event satisfaction and knowledge gains, feedback data from participants and the collaborative team on how information is being shared, received and used.