

Renewal Proposals – Pregnancy & Parenting Supports, 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.