

RFGA #ADDPC-FFY23-PRTSPT-0300
Pregnancy Support for People with Disabilities

Contractor Name: Sonoran Center for Excellence in Disabilities, UA

Contract Period: July 1, 2023 – June 30, 2024

Reporting Period: July 1, 2023 – September 30, 2023

Progress to Date

Project staff and partners convened bi-weekly to plan and provide updates on project activities. Key activities during this project period by major focus areas are shared below.

Data Collection

The first quarter of the project primarily focused on gathering data from persons with disabilities, their families and significant others, and professionals who support them on their experiences and perspectives as it relates to pregnancy and parenting for people with disabilities to determine gaps and needs for supports and professional practice. This included:

Pregnancy & Parenting Survey for People with Disabilities and Family Members

- Survey that was launched prior to the grant application remained open for on-going data collection.
- Sonoran Center staff (Nadine Chau) monitors, manages and summarizes survey responses.
- Vicki Copeland (DDD) facilitated approval from AHCCCS to disseminate recruitment flyer for the survey to DDD members to boost number of responses.
- Tracy Avant (UHC) sought approval from United Healthcare to recruit ALTCS members they serve to boost number of responses.

Focus Groups & Interviews

- Sonoran Center staff (Austin Duncan) developed the focus group and interview discussion guides which were submitted for determination as human subjects research to UA-IRB and received confirmation that they the qualitative data collection is not considered research requiring UA-IRB oversight.
- Two virtual focus groups were held with a total of 19 participants, of which 17 were parents with disabilities. Ability360 recruited 13 and the Arizona Spinal Cord Injury Association recruited 5 participants for the focus groups. Sonoran Center staff (Austin Duncan) facilitated the discussions.
- Ability360 staff created written transcripts of the video recordings from both focus groups and submitted to Sonoran Center staff.

- Five virtual interviews were conducted by Sonoran Center staff (Austin Duncan) with 2 parents living with disabilities and 3 service providers. Ability360 referred 3 professionals and 4 individuals with disabilities for individual interviews.
- A third focus group for service providers is being scheduled with coordination from Vicki Copeland to recruit from the DDD and Medical Education Collaborative (DAME) which involves providers and community leaders from UACOM-P, UACOM-T, Midwestern, AT Still, Mayo, Banner, PCH, First Place and many others.
- All project partners share contacts and referrals for potential interview participants. Janna Murrell (RSK) will connect Sonoran Center staff with parents of young adult children to potentially participate in interviews.

Health Care Provider Survey

- Shadie Toughie (March of Dimes) and Vicki Copeland (DDD) met bi-weekly to develop a provider survey that was adapted from a previous study's interview guide for providing reproductive health care to women with I/DD.
- Sonoran Center staff (Jacy Farkas, Nadine Chau, Austin Duncan) reviewed/revised the survey and transferred the instrument to REDCap for online data collection. The survey will be piloted by project partners and Dr. Tamsen Bassford, a primary care physician for adults with I/DD in October prior to dissemination.
- Project partners contributed to the recruitment plan by brainstorming potential outlets:
 - Shadie Toughie can help distribute recruitment flyer to providers and through AZ hospital healthcare association (newsletter)
 - Healthcare providers via DAME and partner networks
 - Alliance for Community Health Centers
 - Watching over Women and Babies program through Tucson Medical Center

Communication & Outreach

- All partners disseminated information to recruit participants for the Pregnancy & Parenting Survey through newsletters, listservs, email, and flyers at in-person events when hosting exhibitor tables.
- Sonoran Center staff (Drew Milne) developed a recruitment flyer for the health care provider survey on serving patients with I/DD as it relates to reproductive health.
- Raising Special Kids identified trainings they are offering in 2024 that could provide opportunity for education and information sharing from this project (i.e., Talking with Your Child About Sexuality, Abuse and Neglect).
- Janna Murrell (RSK) will contact health plans to find out if any listings of providers are available specific to this population.

Product Development

- Jocelyn Watson, Sonoran Center master in public health intern with an emphasis in maternal and child health is supporting the project. She has attended national webinars related to pregnancy and parenting for individuals with I/DD and has begun researching local and national resources to utilize in product development for the project.

Implementation Plan

The project's implementation plan for the first quarter is on track overall, however, there have been a couple of delays due to recruitment representative of key stakeholder groups. The following items will be completed during the next reporting period:

- Develop one additional video awareness and recruitment story as identified (April Reed, Ability360 lead) – seeking pregnant or parenting participant who identifies as neurodivergent or having a cognitive disability, as all other videos feature individuals with physical impairments. Project team has identified potential participants and intend to confirm participation in next quarter.
- We have nearly reached our target number of participants for qualitative data collection (24 out of 25). However, additional interviews and a focus group for service providers are being scheduled for early in the next quarter to have greater representation of perspectives across stakeholder groups. (Austin Duncan, Sonoran Center lead)
- Identify 10 content experts who have a disability to share their stories, experiences, and journey related to pregnancy decision-making, having a child, and parenting with a disability through interviews or mini focus group discussions. (Drew Milne, Sonoran Center lead) – project staff and partners are inviting those who participate in focus groups and interviews to share their stories through public dissemination vehicles (e.g., news article, social media posts, etc.).

Project Partners

Our partners play a key role in providing input and implementing this project. Below is a table of our partnering organizations and the representative supporting the project. Their contributions are outlined above in our Progress to Date.

Partner Organization	Representative/Primary Contact
Ability360 (formal subawardee)	April Reed, Vice President of Advocacy
Arizona Division of Developmental Disabilities	Vicki Copeland, Medical Director
Arizona Spinal Cord Injury Association	Sharon Malone, Peer Mentor Specialist

March of Dimes	Shadie Tofigh, Maternal Infant Health Director
Raising Special Kids	Janna Murrell, Assistant Executive Director
United Healthcare Community Plan	Tracy Avant, Healthy First Steps Program Manager

Financial Reporting

The project is on track to expend award funds for this reporting period. The formal subaward with Ability360 was executed with the University of Arizona’s sponsored programs office. A revised budget is attached for ADDPC’s review and approval to reflect the change in PI (see Potential Contract Amendment).

Potential Contract Amendment

We are in the process of transitioning the PI for this project to Jacy Farkas due to the departure of Wendy Parent-Johnson from the University of Arizona. Please let us know if ADDPC anticipates issuing a contract amendment to reflect the PI change.

Project Evaluation

Summary reports of data collected through focus groups, interviews and survey responses will be submitted to ADDPC. The findings will inform the development of project products and training.

The following data will be tracked by project staff through systems for training registration, surveys, dissemination vehicles, and web analytics:

- number of participants in focus groups, interviews, surveys with demographic data
- number and types of training sessions offered
- number of participants trained with demographic data
- training survey evaluation results
- number of products developed and disseminated (e.g., how/where disseminated, impressions, shares, downloads)
- self-reported satisfaction and useability of trainings and products

Summary of Responses to date from Pregnancy & Parenting Survey for People with Disabilities and Family Members

Drawing from the information from the REDCap project database retrieved on October 30, 2023, a total of 41 respondents completed the Pregnancy and Parenting Experiences of People with Disabilities survey. Respondents included 12 parents of individuals with disabilities, 9 individuals with disabilities, 4 guardians or healthcare decision makers, and 1 friend or other significant person. Of the total responses, 36 respondents identified as female and 5 identified as male, with the age of respondents ranging from 20 or younger to age 55 or older. Most respondents (78%) identified as being straight or heterosexual, and the majority (76%) also identified as white, with 15% identifying as more than one race. 46% of

respondents are married, with 43% currently single and never married. Many of the respondents (83%) live in Maricopa and 10% live in Pima County, with some respondents (64%) living with their spouse and children and some (14%) living by themselves.

Pregnancy Decisions and Supports

A total of 24 respondents (62%) have wanted to become pregnant or have a baby, and 19 (50%) have talked to someone about it. Of those who have talked to someone about becoming pregnant or having a baby, many talked to their spouse or partner (29%), friend (27%), or family (18%). For those who decided not to have a baby, some respondents were concerned about long-term problems with their health or body (14%) and being smart enough or capable to be a parent (14%). Many respondents also considered health risks to themselves (11%) and the baby (11%).

16 respondents reported they decided to become pregnant or have a baby, with age ranges of 20 or younger up to 41-45 years old when they first became pregnant. 12 respondents were married when they became pregnant for the first time, and 8 were single. Many respondents (41%) decided by themselves to get pregnant or have a baby, with 38% consulting with their spouse or partner as well. Many respondents (24%) decided to have a baby because they knew they could be a good parent, and they received a wide range of information regarding pregnancy and parenting with a disability. Of those who have children, 65% of respondents raised them with their spouse, and 18% are raising them by themselves. Respondents received information such as how their disability will affect their pregnancy (11%), changes in how they can do everyday things (10%), how their need for help from others could change (10%), and how pregnancy could affect their disability (9%). The most common sources of information included doctors and healthcare providers (34%), the internet (11%), and family (10%).