

**Project Number:** 1005505

**Date:** October 31<sup>st</sup>, 2023

Please find the attached report for the project, “**PATHS (Providing Accessible Training and Home Support) for Parents with IDD**” with the reporting time frame of 7/1/2023-9/30/2023.

Thank you,

*Ronda Jensen*

Ronda Jensen, PhD

Professor, Research Director

Institute for Human Development

Northern Arizona University

## **RFGA# ADDPC-FFY23-PRTSPT-0300-02**

### **Quarterly Report**

#### **Quarter 1: July 1, 2023-September 30, 2023**

The purpose of the PATHS for Parents with IDD project is to improve access to high-quality parenting support for Arizona parents with intellectual or developmental disabilities (IDD) who have infants or young children. The populations of interest are (a) parents with IDD who have children ages 0-3 and (b) home visitors who provide parenting information and support through evidence-based home visiting (EBHV) programs in Arizona. Through this project, home visiting programs and home visitors will receive materials and training that enhance the curricula (information and resources) and the delivery (relationship-based support) to address the needs of parents with IDD.

In future quarterly reports, the second section of this report will contain participant demographic data. For this first quarter, only the first section elements are included in the report.

#### **Section 1**

The first section of this report is organized into the following parts.

1. Project summary
2. Implementation challenges and project adjustments
3. Collaborative partners
4. Success stories
5. Expenditure update
6. Need for a contract amendment
7. Evaluation

#### **1. Project summary**

This section summarizes the activities associated with launching the project and the activities planned for the first quarter.

##### ***Project launch***

Important steps for launching this project included reviewing the proposed scope of work, engaging in clarifying conversations to ensure all team members clearly understand the details of activities necessary to accomplish the scope of work, and deciding on the communication strategies that will be used for promoting the project and engaging partners. The project team was able to update Jon Meyers and Marcy Crane from ADDPC on these decisions on August 16, 2023 and obtain their input.

##### **Project name and communication**

To promote the project and invite participation, the team wanted a name that represented the focus of the project. The team decided on **PATHS for Parents with IDD**, with PATHS being an

acronym for **Providing Accessible Training and Home Support**. Accompanying the project name, the team developed a logo that graphically represents the socioecological framework of the project as well as the beginning years of parenthood and childhood with an infant/toddler in the family. In addition to the project name and design of a graphic, templates to be used for recruitment materials as well as training and program enhancement materials were developed. The project webpage hosted on the NAU Institute for Human Development website includes the flyers used to date for announcing the program and recruiting participants. See the web page at <https://nau.edu/ihd/paths>.

### Target populations

This project has two target populations: parents with IDD and home-visiting professionals. The team discussed interpretations of developmental disability and/or intellectual disability and how these disabilities would be communicated when inviting participation and in project materials. Often, when discussing the needs of parents with disabilities, it is presumed that the parents have a physical disability. While aspects of this project may be relevant to parents with physical disabilities, the team decided that our target population is parents with an intellectual disability. When communicating about the project to home visiting program leaders and home visitors, parents with intellectual disabilities will be described as parents who experience cognitive limitations that may affect communication, reading, learning, and problem-solving.

The team also reviewed the proposed list of Arizona home-visiting programs and has taken steps to announce the project to each of them and hold initial conversations with program leaders.

### Preparation for data collection

Two types of data collection are included in this project. One source of data is published home visiting program information, research, and curricula. A description of the process of obtaining and analyzing this data is described later in this report. The second source of data is the program information gathered through interviews with home visiting program leaders and home visitors. Because this project is an important first step toward further work on improving home visiting programs to be more accessible for parents with IDD, the team decided to seek approval for the interviews through the NAU Institutional Research Review Board (IRB). By obtaining IRB approval for the interview portion of this project, the project team will have important background data for seeking further funding for continued research and training.

### ***Quarter 1 key activities***

The key activities for the first quarter included gathering published information about the Arizona home visiting programs, announcing the program to Arizona home visiting program leaders, preparing for home visiting program leader and home visitor interviews, and recruiting participants for the advisory board.

### Announcing project

The project team sent emails to the leaders of the five Arizona home-visiting programs announcing the project. With all of the project leaders, except for Early Head Start, there has been ongoing communication which has helped with recruiting advisory board members and interview participants. Two members of the project team also attended the Strong Families Arizona Home Visiting Conference in September 2023 and were able to make connections with home visitors at the conference as well as gather information about the home visiting programs available in Arizona. The project team will continue to try to engage Early Head Start throughout the second quarter.

### Project board oversight

During the first quarter, the team recruited three home-visiting supervisors as members of the Advisory Board. These Advisory Board members include a home visiting supervisor with Nurse-Family Partnership located in Tucson, a supervisor with Parents as Teachers in Tucson, and a statewide supervisor for Healthy Families located in Maricopa County. Other planned members of the Advisory Board include parents with intellectual disabilities. Recruitment of parents is ongoing and has been challenging. See the description of implementation challenges for more details.

### Research

**Gathering home visiting program information.** Program model data has been collected on five evidence-based home visiting programs in Arizona: Healthy Families, Health Start, Early Head Start, Parents as Teachers, and Nurse Family Partnership. Key information collected on each program includes eligibility criteria, intended population, locations served, target outcomes, model services, duration, adaptations and enhancements, and research outcomes that provide the evidence base for the program.

The team is also examining published literature about parenting programs that are either designed for parents with disabilities or include components for parents with disabilities. The team began by gathering a collection of 312 articles sourced from two different databases: Web of Science and Academic Search Complete. The team has outlined the protocol for screening abstracts for relevance for our project and then screening the full text of the article for relevance. The full text of the articles that are relevant to this project will be synthesized and the findings will be used to inform the development of the training materials. Screening and initial synthesis are underway and results will be included in the next quarterly report.

**Interviews.** The protocol for conducting interviews was approved by the NAU Institutional Review Board (IRB). In summary, the interviews ask home visiting leaders and home visitors about their experiences working with parents with intellectual disabilities, current methods of adapting the curricula for parents with disabilities, and their questions or concerns about how well the home visiting curriculum meets the needs of parents with intellectual disabilities. The next quarterly report will include a description of who was interviewed, a synthesis of the results, and feedback gathered from the Advisory Board.

## Training

The development of the training materials will be described in the second quarter report.

## Resource development

As mentioned, preparation for training resources to be developed and shared occurred in the first quarter. This preparation entailed the development of a project logo, accessible formatting style, and a project landing page on the IHD website.

## **2. Implementation timeline, challenges, and adjustments**

The project encountered three challenges in the first quarter. First, as mentioned earlier in this report, engaging with Early Head Start has been a slow process. The project team will continue efforts to connect with the program leaders through the fifth month of the project. If we are unable to engage with Early Head Start, we will focus on the other four Arizona home visiting programs that have already engaged with the project.

The second challenge has been the recruitment of parents with intellectual disabilities for the Advisory Board. The team has contacted the five home visiting programs planned for participation in the project as well as other programs across Arizona to recruit parents with intellectual disabilities for the Advisory Board. The programs contacted to date include Special Care Nursery at Flagstaff Medical Center, Northland Rural Therapy Associates, Raising Special Kids, University of Arizona Medical School, AzLEND, Supporting Inclusive Practices in College (SIP-C), and Care for the Caregivers Flagstaff. The team will continue to recruit parent representatives for the Advisory Board by including recruitment information in the home visitor interviews and utilizing other IHD connections through the IHD Community/Consumer Advisory Committee.

The third challenge has been obtaining full curriculum materials from the home visiting programs. The extent to which the curriculum will be shared with us varies by program and their concerns for the distribution of intellectual property. The programs' concerns regarding intellectual property are not surprising and this challenge was accounted for in the design of this project. Because the programs are evidence-based, substantive information about the programs is publicly available. Additionally, the interviews included in this project will provide essential detailed information about how the programs are implemented. Both the interview results and the review of publicly available information will be used when developing the training.

The following table lists the activities projected to occur in the first quarter and the status of completion. As shown in Table 1, some activities planned for the first quarter are underway or will show substantial progress in the second quarter.

**Table 1. Status of proposed quarter 1 activities**

<b>Activities</b>	<b>Quarter 1 Status</b>
<b>Project preparation</b>	
Develop a statewide list of home visiting program contacts	Met
Announce project to home visit programs and follow up with phone calls	Met
Recruit Advisory Board members	In progress
Convene project orientation meeting with Advisory Board members	Not met. The Advisory Board member orientation will be described in the second quarterly report.
<b>Aim 1: Literature review</b>	
Gather curricula from home visiting programs	In progress
Analyze curricula	In progress
Conduct literature review	In progress
Present analysis to the Advisory Board and gather input	Not met. The Advisory Board member input will be described in the second quarter report.
<b>Aim 2: Gather and analyze program information</b>	
Analyze program information from home visiting programs	In progress
Conduct interviews	Not met. Interview processes, participants, and results will be described in the second quarter report.
Analyze interview results describing home visiting services	
<b>Aim 3: Training</b>	
Develop draft training materials	Not met. A description of the draft elements of the training will be described in the second quarter report.

### **3. Collaborative partners**

As mentioned, the project team has made contact with four evidence-based home visiting programs: Healthy Families, Health Start, Parents as Teachers, and Nurse Family Partnership. The Healthy Families statewide program manager was also able to connect us with a representative from the Baby Talk Curriculum, which is used by the Healthy Families Program. Home visiting supervisors with Parents as Teachers and Nurse Family Partnership (both in Tucson) as well as the statewide supervisor for Healthy Families have agreed to be Advisory Board members and to assist with recruiting parents with disabilities for the Advisory Board and interview participants.

### **4. Success stories**

In this first quarter, interactions with project participants had not yet begun. However, it is promising that during initial conversations with home visiting program leaders, the project team

heard that this project is greatly needed and individuals were enthusiastic about assisting with the project.

#### **5. Expenditures update**

All financial aspects of the project are on track for the completion of the first quarter.

#### **6. Need for contract amendment**

There is no need for a contract amendment.

#### **7. Evaluation**

As this project involves community members, this project will take a participatory approach to evaluation. The evaluator will examine the degree to which the perspectives of community members are integrated into training and materials.

There are two components to the evaluation. The first component addresses the degree to which feedback from the advisory board is integrated into the training. The evaluator will attend and observe all advisory research team meetings and take detailed notes on the recommendations made by community members and how the PATHS team responds by integrating these recommendations into the training. The second component is the evaluation of the training sessions. Two surveys will be used to evaluate the knowledge gained through the training and participant feedback on the training. One survey will be an immediate post-knowledge check/training feedback and the other survey will be a cumulative knowledge check/training feedback home visitors take after completing the training series. The evaluator will synthesize the results from the training surveys, which will inform improvements made to the training content and delivery of training.

### **Section 2**

No participant data was gathered in the first quarter.