

Proposal to Arizona Developmental Disabilities Planning Council
Research to Practice: *Future Care Planning: A Roadmap for Individuals with Disabilities, Families, and Support Professionals*
Second Year Funding Request October 2016 – December 2017

INTRODUCTION

The Sonoran University Center for Excellence in Developmental Disabilities (UCEDD) is requesting a second year of funding. Year One funding will end on July 30, 2016. Year Two objectives and activities will begin on October 1, 2016 and end on December 30, 2017. The overall purpose of this project is to a) improve late-life transition planning for adults and older persons with developmental disabilities (DD) and b) to support family caregivers during the planning process. The primary goal of Year One was to engage family caregivers, individuals with developmental disabilities, and service providers through participation in a research project that informed the completion of the *Future Care Planning: A Roadmap for Individuals with Disabilities, Families, and Support Professionals*. The proposal for Year Two (2016-2017) focuses on dissemination and training: 1) dissemination and testing of the Roadmap through multiple outcome measures; 2) implementation and evaluation of a Train the Trainer model for service/support professionals (SSP); 3) implementation and evaluation of caregiver classes; 4) development of evidence based practice resources for SSPs; and 5) creation of a Spanish version of the Roadmap. The activities are designed to increase access, integration, utilization, and sustainability of Year One efforts. In order to accomplish this, a broad range of opportunities and resources will be created and made available to individuals involved in the planning process. The nine outcomes and 14 activities are presented in more detail below. In order to ensure the success of the training program, five individuals will be recruited and compensated to assist the project director in the development of training strategies and curriculum, recruitment of participants, and evaluation efforts. They will become part of the Leadership Training Team. Feedback from the trainings and classes may lead to minor revisions to the Roadmap.

The Sonoran UCEDD is requesting support in the amount of **\$90,414** for Year Two. We are requesting additional support, not included in the current budget, for the printing of the *Future Care Planning: A Roadmap for Individuals with DD, Families, and Support Professionals* by the Arizona Developmental Disabilities Planning Council. The Roadmap will also be available as a free download on the Sonoran UCEDD with a link to the ADDPC website. The ADDPC, Sonoran UCEDD Community Advisory Committee, DD Network, and disability organizations will be invited to provide input on dissemination and training efforts. Upon the successful completion of Year Two objectives, the projection for Year Three includes a broader statewide dissemination and training through community forums and additional SSP and caregiver trainings/classes that includes persons with disabilities. This will enhance the sustainability of the first two years of the project.

This proposal includes the following:

- Year One Accomplishments and Challenges
- Year Two Project Team
- Outcomes and Objectives for Year Two
- Timeline
- Appendix – Presentation at June 2016 AAIDD, Atlanta, GA

Year One Project Accomplishments and Challenges

In Year One, the following objectives were met:

1. Designed research methodology.
2. University of Arizona Human Subjects approval granted for research study.
3. Developed surveys for family caregivers and service/support providers.
4. Implemented online survey with a goal of 300 responses. Recruitment efforts focused on Arizona. To date, there are 165 responses, two-thirds from caregivers. Recruitment efforts are continuous and will be expanded nationally in Year Two.
5. Caregivers and individuals with disabilities were recruited for interviews through Arizona disability organizations, DD network, and the aging network. The project target is 60 participants: 40 caregivers and 20 individuals with disabilities. As of August 17, completed interviews include: 40 caregivers (100%) and 18 persons with disabilities (90%).
6. Several interviews have not been transcribed since the grant ended before staff was able to submit them for completion.
7. Coding and analysis continues.
8. Roadmap content is being developed with input from persons with disabilities, family members, and service providers. Personal stories are being included to enhance content.
9. Preliminary research data and practices were presented at the annual AAIDD 2016 conference in Atlanta, Georgia. There were approximately 50 participants at the session. Appendix A is the PowerPoint notes from the conference. This was not a budget item in Year One.

Challenges

The development of the online survey took much longer than anticipated. This was partly due to revisions based on feedback from families and professionals in the disability community. The goal was to create a meaningful and user-friendly questionnaire. Recruitment efforts for both the online survey and interviews require diligence and multiple attempts to solicit participation. The required Human Subjects approval required two revisions due to staff changes and modifications in recruitment materials and efforts. In order to meet the target numbers, recruitment efforts will continue through the end of the project and possibly beyond. Personal contacts and disability networks are being asked to re-distribute information. In order to encourage participation, interviews were scheduled in the evenings and weekends.

Staff change mid-project was a disruption. There were a couple of months where support staff was not available. Lynne Tomasa had sole responsibility for all tasks. Kim Kelly was hired in January 2016 (mid-project) and is leaving on June 30, one month prior to the end of the project. The draft outline of the content of the Roadmap was developed prior to the data collection. There have been several revisions during the interview process. Family caregivers and support providers, along with people with disabilities are active participants in content development. This process has taken longer than expected. It is anticipated that the final Roadmap will not be completed in Year One. The Roadmap will be completed during the first three months of Year Two.

Year Two Project Team

Lynne Tomasa, PhD, MSW, will continue to be the principal investigator on the project and is responsible for all project activities. Yumi Shirai, PhD, current Director of the Sonoran UCEDD Artworks program will provide consultation and writing support for the training materials and project manuscript. Dr. Shirai is qualified and appropriate to consult in all areas of the project. She is a necessary team member and was involved in an earlier research study on the same topic with Dr. Tomasa. Patricia Philbin and Miriam Barrientos have been chosen for this project because of their expertise and quality of work. Ms. Philbin is the graphic artist for the revised roadmap. She will be involved with the development and design of training materials, web modules, online webinar, and layout of the Spanish version of the roadmap. Ms. Barrientos, a native speaker from Mexico City was the Spanish translator for the DDPC supported housing manual (My House, My Home) and has extensive teaching and translation experience. A program coordinator who has skills in curriculum development and training will be hired. Based on the experience during Year One, it is clear that a program coordinator is needed so that Dr. Tomasa can focus on data analysis, dissemination of knowledge, community relations, and manuscript development.

Outcomes and Objectives for Year Two (October 2016 – December 2017):

Outcomes:

1. Leadership team that includes 5 Senior Trainers who will serve as champions and consultants
2. Train the Trainer curriculum for 45 participants
3. Family caregiver classes and curriculum for 30 caregivers
4. Interviews with 10 service/support professionals (SSPs) and 10 family caregivers
5. Two caregiver audio dialogues
6. Two training videos on how to use Roadmap
7. Two evidence based practice tools/resources for SSPs
8. Manuscript submission to a disability or practice journal about the two-year project.
9. Presentation or poster at a local and/or national conference.

Objectives

1. Develop and implement the Train the Trainer program and curriculum through various strategies. The purpose of this program is to train SSPs on how to use the Roadmap; how to implement strategies that encourage communication about planning; and how to support individuals and families through the planning process. (October 2016 – July 2017)
 - a. Recruit 5 SSPs who will serve as Senior Trainers. Their role is to assist in the development, revision, and recruitment of SSPs for the training sessions. They will be part of the Leadership Team that promotes the use of the Roadmap into practice.
 - b. Implement 3 SSP trainings for 45 participants statewide.
 - c. Follow-up interviews with 10 SSPs after the training to further understand the usefulness of the training and ways to improve future trainings. This will involve 5 trainers post-class and 5 trainers who worked directly with caregivers.
 - d. Lynne Tomasa will provide consultation on how to use the roadmap for 5 SSPs through co-facilitation and observation of their meeting with a caregiver.
 - e. All 45 SSPs will receive an evaluation on the day of their training and a follow up online survey 3 months after their training.

2. Implement 3 Roadmap classes for 30 family caregivers. The classes will be held in Pima County or neighboring communities in Southern Arizona. The purpose is to introduce the roadmap; teach strategies to facilitate engagement of persons with DD; and to share caregiver concerns and successes. The classes will be video taped with permission of participants and will be used as additional data for the caregiver manuscript to be submitted at the end of the project. (January 2016 – June 2017)
 - a. Conduct participant observation of classes to further enhance skills of SSPs
 - b. Interview with 5 caregivers post-class to evaluate the Roadmap and curriculum
 - c. Interview with 5 caregivers who used the Roadmap with 5 trained SSPs to identify the usefulness of the Roadmap
3. Follow up contact with individuals who downloaded roadmap from the Sonoran UCEDD website. Anticipated number is 5 individuals. Individuals who download the Roadmap from the website are not required to leave their contact information, making it difficult to recruit a large number of participants. (March 2017 – July 2017)
4. Transcribe interviews and analyze data from various sources that include surveys, interviews, and participant observation. (March 2017 – September 2017)
5. Develop 2 audio dialogues with caregivers who participated in interviews during Year One or classes in Year Two. The focus will be on sharing personal stories about future planning, use of the Roadmap, and the behavioral and emotional experiences with the planning process. Lynne Tomasa and Patricia Philbin will utilize audio equipment from the Sonoran UCEDD and will develop the audio dialogues. (June 2017 – September 2017)
6. Develop 2, 4-minute videos on how to use the roadmap. One will focus on individuals and families and one will focus on SSPs. (July 2017 – September 2017)
7. Develop 2 evidence based practice tools for SSPs. Tools will be disseminated through the Arizona DDD Network, DDD, and disability organizations. (July 2017 - September 2017)
8. Poster or presentation at the AAIDD national conference. (June 2017)
9. Write a manuscript about the two-year project for publication in a disability or practice journal. (February 2017 – December 2017)
10. Update roadmap as needed based on input and feedback provided at trainings and classes. (October 2016 – June 2017)
11. Complete the Spanish translation of the *Future Care Planning: A Roadmap for Individuals with Disabilities, Families, and Support Professionals*. (July 2017 – December 2017)
12. Complete final report of findings and final version of Roadmap. (August 2017 – December 2017)
13. Work closely with Area Agencies on Aging, the Arizona DD network, and other disability organizations to disseminate materials. (December 2017)
14. Submit reports to ADDPC on progress. (January, May, September, December)

After the final revision of the *Future Care Planning: A Roadmap for Individuals with Disabilities, Families, and Support Professionals*, it is anticipated that the roadmap will not need major revisions for five years. Resource links will be provided in the roadmap so users will be able to access updated information on legal topics. The Sonoran UCEDD is requesting that the Arizona Developmental Disabilities Planning Council be responsible for the printed hard copies of the roadmap.

PROPOSED Timeline of Activities for Year Two: October 2016 to December 2017																		
ACTIVITY	STAFF (PG = Program Coordinator)			MONTHS														
	LT	PG	YS	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	June	July	Aug	Sept	Oct	Nov	Dec
Year One – completion of Roadmap				X	X													
Year Two (2016 - 2017)	LT	PG	YS	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	June	July	Aug	Sept	Oct	Nov	Dec
Testing of the Roadmap																		
1. Develop Train the Trainer program and curriculum	*	*	*	X	X	X												
a) Identify 5 Senior Trainers to be part of leadership team	*	*		X	X	X												
b) Implement 3 service provider trainings (N=45)	*	*					X	X	X	X								
c) Interview trainees post training (N=10)	*	*						X	X	X	X							
d) Provide consultation to trainers through co-facilitation and observation of CG interaction using Roadmap (N=5)	*	*						X	X	X	X	X						
e) Follow-up survey with trainers: 3 months post training (N=45)	*	*								X	X	X	X					
2. Implement 3 Caregiver Roadmap Class (N=30)	*	*					X	X	X	X								
a) Conduct Participant Observation of Classes	*	*					X	X	X	X								
b) Interview CGs post class (N=5)	*								X	X	X	X						
c) Interview CGs who used Roadmap with trainers (N=5)	*							X	X	X	X							
3. Follow-up contact with people who downloaded CG Roadmap from website (3-months post download) (N=5)	*	*							X	X	X	X	X					

Year Two (2016 - 2017)	LT	PG	YS	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	June	July	Aug	Sept	Oct	Nov	Dec
4. Transcribe interviews and analyze data from various sources (survey, interviews, and participant observation)	*	*	*						X	X	X	X	X	X	X			
5. Develop 2 audio dialogues with caregivers	*	*										X	X	X	X			
6. Develop two 4-minute videos on how to use Roadmap (service providers & caregivers)	*	*											X	X	X			
7. Develop 2 evidence based practice tools for service providers	*	*	*										X	X	X			
8. Presentation/poster at a local and national conference	*	*										X						
9. Write manuscript for publication in journal	*	*	*					X	X	X	X	X	X	X	X	X	X	X
10. Update Roadmap as needed	*	*	*	X	X	X	X	X	X	X	X	X						
11. Complete Spanish translation and re-format Roadmap for Spanish version													X	X	X	X	X	X
12. Complete final report of findings and final version of Roadmap	*													X	X	X	X	X
13. Work with AAA, DD Network, and disability organizations to disseminate products	*	*																X
14. Reports	*	*					X				X				X			X