Proposal to Arizona Developmental Disabilities Planning Council
Research to Practice: *Future Care Planning, A Roadmap for Family CaregiversV2*

INTRODUCTION

The Sonoran University Center for Excellence in Developmental Disabilities (UCEDD) is proposing a two-year project (January 2015 – December 2016). The overall purpose of this project is to improve transition planning for persons with developmental disabilities (DD) and to support family caregivers during the planning process. The primary goal of Year One (Jan-Dec) is to engage family caregivers, individuals with developmental disabilities, and service providers through participation in a research project that will inform the completion of the *Future Care Planning: A Roadmap for Family CaregiversV2.* Year Two (Jan-Dec 2016) will focus on three primary goals: 1) testing of the Caregiver RoadmapV2 through multiple outcome measures; 2) implementation of Train the Trainer model for service providers; and 3) development of evidence based practice resources for service providers. The end result of the two-year project will be a revised and expanded caregiver roadmap with chapters for individuals with DD utilizing plain language and family caregivers. In order to sustain the continued utilization of the caregiver roadmap, evidence based practice tools for service providers and teaching videos will be created.

The Sonoran UCEDD is requesting support in the amount of $70,029 for Year One. Upon successful completion of Year One project objectives, support for Year Two is estimated to be $65,000. We are requesting additional support, not included in current budgets, for the printing of the *Future Care Planning: A Roadmap for Family Caregivers*V2 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 websites. The goal is to disseminate the products statewide and nationally through collaborative efforts among the ADDPC, Sonoran UCEDD, DD Network, disability organizations and national disability networks. The projection for Year Three of the project includes a broader statewide dissemination and training through community forums and service provider and caregiver trainings/classes. This will enhance the sustainability of the first two years of the project.

This proposal includes the following:

- Capacity of the Sonoran UCEDD to meet the goals and objective
- Background of the *Future Care Planning: A Roadmap for Family Caregivers*
- Importance of the current project
- Goals and Objectives for Year One (2015) and Year Two (2016)
- Roles of stakeholders and collaborators
- Timeline
- Appendix

CAPACITY

The Sonoran UCEDD, established in July 2006 is located at the University of Arizona within the Department of Family and Community Medicine. The vision of the Sonoran UCEDD is to ensure that people with developmental disabilities (DD) and their families reach their goals, have accessible information and opportunities, feel empowered, exercise choices, and are integrated in our communities. The core functions of the Sonoran UCEDD include education and training, research and analysis, program development, and information sharing. The staff come from diverse backgrounds and has extensive experience in all of the core functions. The Sonoran UCEDD continues to work closely with individuals with DD, families, support and service providers, ADDPC, and the DD network to create successful programs in person centered planning, employment, creative expression and the arts, health care delivery, and transition planning. Technical assistance is provided in the areas of research, policy, data analysis, and program evaluation.

Project members who will carry out the activities of the proposed grant are well qualified to do so. Lynne Tomasa, PhD and principal investigator on the project has over twenty-five years experience in the field of aging, education, program development and evaluation, and data analysis. Lauren Penney, PhD and medical anthropologist has experience in research design, data collection and analysis, and project management. Both Drs. Tomasa and Penney have worked closely with diverse communities in designing projects that have a practical application. Patricia Philbin and Miriam Barrientos have been chosen for this project because of their expertise and quality of work. Ms. Philbin worked closely with Dr. Tomasa on several projects, most recently the creation of the ADDPC supported *My House My Home: Real Homes for Real People.* Ms. Barrientos, a native speaker from Mexico City was the Spanish translator for this housing manual and has extensive teaching and translation experience.

BACKGROUND

In 2007, the Sonoran UCEDD conducted a research study that explored the barriers to effective late-life transitions for older family caregivers who were the primary support for a family member with a developmental disability (DD). The aim was to develop effective interventions for these families. Thirty caregivers participated in individual interviews and focus groups in Coconino, Maricopa, and Pima County. Caregivers ranged in age from 47 to 84 and provided care for a period of 9 to 56 years. The study addressed the following questions:

- What are the concerns of aging family caregivers when he/she is no longer able to take as active a role or any role in the daily activities and care of their family member with a disability?
- How do parents and families start to plan for that future as they begin to age?
- What may hinder or promote the process of making future care plans?

The interviews and focus groups were transcribed, analyzed, and grouped into five themes: 1) components, timing, and triggers; 2) psychological and emotional responses of caregivers; 3) concerns, challenges, and successes; 4) resources and systems of care; and 5) health access and health care delivery. The results identified that families continue to struggle with formalizing a

plan that is communicated clearly with the individual with DD and his or her networks of support. Families often find it easier to complete a concrete task such as financial planning but have great difficulty with conversations that trigger emotions such as loss, fear, apprehension, and grief. The Aging and Transitions Project: Technical Report and White Paper (2008) is available at http://sonoranucedd.fcm.arizona.edu/publications/169.

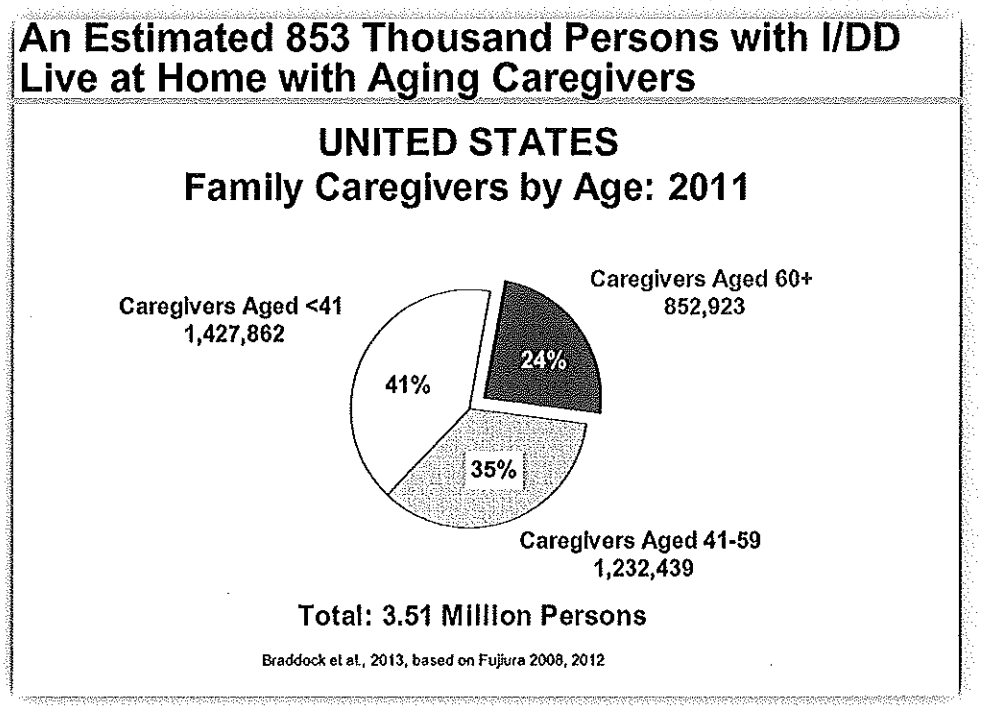
The outcome of this project was the development of the *Future Care Planning: A Roadmap for Family Caregivers,* available for download at: http://sonoranucedd.fcm.arizona.edu/ocat. The Caregiver Roadmap was available for free download on the Sonoran UCEDD website in 2010. In a Google search using terms "future planning for persons with disabilities," the roadmap is the first item identified (accessed 10/15 by author and 10/23 by two other individuals). When search terms "planning for persons with disabilities" are used, resources about emergency preparedness are identified. The caregiver roadmap was also nominated to be included in the QualityMall website that includes person-centered resources that support people with DD (http://www.qualitymall.org/products/results1.asp).

In addition to the caregiver interviews, a follow-up survey for the Arizona Division of Developmental Disabilities (DDD) support coordinators was conducted. This study identified the important role support coordinators play in future planning. Families and service providers need education and evidence based tools that address how to facilitate planning, include strategies that facilitate communication, and how to support caregivers who are experiencing difficult emotions.

IMPORTANCE OF CURRENT PROJECT

Aging Demographics and Impact for Persons with Disabilities and Their Families

In the report *A Profile of Older Americans 2013,* the older population (persons 65 years and older) in 2012 represented one in every seven Americans or 13.7% of the population. In Arizona, the older population represented 14.8% of the overall population and the percent increase from 2002 to 2012 was close to 40% (AoA ACL, 2014). Braddock et al. published an important document, *State of the States in Developmental Disabilities 2013: the Great Recession and Its Aftermath in 2013.* This report identified the important role family caregivers play and the critical service they provide to persons with disabilities and state programs (pg. 56-61). In 2011, 21,776 persons with DD lived with aging caregivers in Arizona. The chart below (Braddock & Rizzolo AAIDD webinar, February 27, 2013) identifies the estimated number of individuals with intellectual and developmental disabilities by age group living with family caregivers in the United States.



Future planning is a process filled with complex emotions and decisions that require several conversations over time. It is never too early to start this discussion. The lack of planning can result in unexpected or bad outcomes for the individual with DD and their family. If thoughtful planning does not occur with input from the individual, their life can be disrupted; he/she may be moved to a location that is not their choice; other people who do not know the individual may make uninformed decisions; friendships and supports are disrupted; and adjustment to new situations can be traumatic. For both the individual with DD and their family, sudden unplanned changes can be difficult.

Support professionals and staff play a key role in the planning process and must be knowledgeable about resources and strategies to support individuals and families through the planning process. Evidence based practices are needed. The *Future Care Planning: A Roadmap for Family CaregiversV2* will not only emphasize the tasks and decisions that need to be made but will also include expanded sections on how to address the emotional aspects of planning. Research shows that the avoidance and lack of guidance were two obstacles that were compounded by the emotional upset experienced by caregivers (Taggart, Truesdale-Kennedy, Ryan and McConkey, 2012). Although the roadmap continues to be a useful tool, it would also benefit from revised and additional sections (for example: special needs trust, end of life care, dementia care, grief, loss).

GOALS AND OBJECTIVES

This proposal outlines a two-year project. The primary goal of Year One (Jan-Dec) is to engage family caregivers, individuals with developmental disabilities, and service providers through participation in a research project that will inform the next edition of the *Future Care Planning: A Roadmap for Family CaregiversV2.* It will be accomplished by the following objectives.

Year One Objectives (January 2015 - December 2015):
There are two primary outcomes for Year One.

A. Completion of the *Future Care Planning: A Roadmap for Family CaregiversV2,* also referred to as the roadmap in this document.
B. Data collection from 300 online surveys, in-person or phone/Skype interviews with 20 caregivers, and in-person interviews with10 persons with DD.

Objectives

1. Design methodology for project and conduct a systematic review of the literature. This step is necessary to identify gaps in knowledge/practice and to develop appropriate data collection methods. This includes appropriate approval from the University of Arizona Human Subjects and Protection Program (January-February).
2. Design and implement an online survey for family caregivers and service providers. The survey will be created with input from the DDD network and key stakeholders in the disability community. This survey will be available online with a target goal of 300 participants statewide. The survey will be disseminated through the DDD network, the Division of Developmental Disabilities, disability organizations, and service providers. Multiple announcements will be made through newsletters, websites, existing community events, and personal communications. (January-July)
3. Recruit 20 family caregivers and 10 persons with DD for interviews.
    a. Outreach will be made to the caregivers who participated in the original 2007-2008 project in order to identify successful or unsuccessful strategies to future planning. It is anticipated that out of the 25 family caregivers, 5 individuals will agree to a follow-up interview. This will be a phone interview or remotely done through Skype. (March-April)
    b. In Pima County, 15 additional caregivers will be identified for in-person interviews. (March-August)
    c. In Pima County, 10 persons with DD will be identified for in-person interviews. Efforts will be made to recruit individuals from the same family where a parent or guardian is also a participant. (March-August)
4. Interviews will be transcribed and analyzed to inform the content of the roadmapV2. (March-October). Survey responses will also be analyzed during this time frame.
5. Develop content for caregiver roadmap simultaneously while survey and interview data are being analyzed. (May-October)
6. Complete report on project findings. This data will inform the development of the roadmap and assist in the planning for Year Two of the project. (October-December)
7. Develop a web tool to track roadmap downloads from the Sonoran UCEDD website. This is necessary to track the number of people accessing the roadmap. The web tool will ask for the following information: name of person accessing roadmap, contact

information, reason for download, and how information about the roadmap was obtained. An explanation for the requested information will be provided – "In order to assure that the roadmap is a useful tool, we would like to contact you. Your feedback will be helpful to the Sonoran UCEDD and the ADDPC as we understand how the roadmap is being used." Individuals may decline the request for information and will still be able to download the roadmap. All download attempts will be counted. (October)

8. Distribute a hard copy of the roadmap to all participating families and individuals. Follow-up with the families will be an objective in Year Two. (December)
9. Announce the availability of the roadmap. (December).
10. Quarterly reports of the project's progress and potential barriers will be completed every three months or as designated by ADDPC. (March, June, September, December)

This project's research questions will include but are not limited to:

- How do family caregivers and service providers frame future planning?
- What role does grief, loss, unfinished business, and end of life issues play in the future planning process?
- What strategies can service providers utilize to support families during the planning process?

Year Two Objectives (January 2016 - December2016):

There are six outcomes for Year Two (Jan-Dec 2016).

A. Development of 2 evidence based practice resources for service providers.
B. Testing of the Caregiver RoadmapV2 through multiple strategies:
    a. Train the Trainer program for 45 service providers
    b. Caregiver class for 30 caregivers
    c. Post training follow up with 45 service providers, interviews with 10 trainers, and interviews with10 caregivers
C. Follow up contact with individuals who downloaded the roadmap from the Sonoran UCEDD website. Anticipated number is 25 individuals.
D. Development of 2 caregiver audio dialogues.
E. Development of 2 training videos on how to use the roadmap.
F. Manuscript submission to a disability or practice journal about the two year project.

Objectives

1. Develop 2 evidence based practice tools for service providers based on Year One efforts. Tools will be disseminated through DDD Network, DDD, and disability organizations. (January-March)
2. Design testing instruments that involve several strategies (January-February)
    a. Develop a Train the Trainer program and curriculum and conduct 3 sessions for a total of 45 service providers. The purpose of this program is to train service providers on how to use the roadmap; how to implement strategies that encourage communication about planning; and provide knowledge about emotional barriers that exist to planning. (March-May)

b. Follow-up interviews will be completed with 5 trainers after the training to further understand the usefulness of the training and ways to improve future trainings. (April-June)
c. Drs. Tomasa and Penney will provide consultation on how to use the roadmap for 5 trainers through co-facilitation and observation of their meeting with a caregiver. (May-July)
d. All 45 trainers will receive a survey on the day of their training and a follow up online survey 3 months after their training. (3-month follow up June-August)

3. Implementation of 3 Caregiver 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. (March-May)
4. Follow-up interviews with 5 caregivers post-class and 5 caregivers who used the roadmap with 5 trainers to identify how the roadmap is used and its helpfulness. (May-July)
5. Follow up contact with individuals who downloaded roadmap from the Sonoran UCEDD website. Anticipated number is 25 individuals. (June-September)
6. Transcribe interviews and analyze data collected. (May-September)
7. Develop 2 audio dialogues with caregivers who participated in interviews during Year One. The focus will be on sharing personal stories about future planning, how they used the roadmap, and how they addressed the emotional aspects of planning. Lynne Tomasa and Patricia Philbin will utilize audio equipment from the Sonoran UCEDD and will develop the audio dialogues.
8. Develop 2, 4-minute videos on how to use the roadmap. (October-November).
9. Write a manuscript about the two-year project for publication in a disability or practice journal. (July-October)
10. Update roadmap as needed based on input and feedback provided at trainings and classes. (January-October).
11. Finalize and complete Spanish translation of the *Future Care Planning: A Roadmap for Family CaregiversV2.*

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.

ROLE OF STAKEHOLDERS AND COLLABORATORS

Throughout the two year project, the Sonoran UCEDD will request input from a variety of stakeholders in order to a) design and implement a study that is respectful and inclusive, b) recruit participants, and c) to disseminate the *Future Care Planning: A Roadmap for Family CaregiverV2.* Outreach will be made to the following:

- Developmental Disabilities Network.
- Community Organizations such as:
    - Disability and advocacy groups
    - Autism, Down Syndrome, and Cerebral Palsy organizations
    - Area Agencies on Aging
    - Alzheimer organizations
    - Caregiving organizations

Sustainability will be addressed through the Train the Trainer curriculum, development of resource materials like training videos, and can be enhanced through additional collaborations such as:

- The Arc in Washington, D.C. that initiated contact in June 2013. Robin L. Shaffert, Senior Executive Officer became aware of the first edition of the roadmap and shared information about the Arc's launching of a new National Resource Center for Future Planning. They are interested in having a continued discussion with the Sonoran UCEDD about future planning projects. Their announcement is available at: http://blog.thearc.org/2014/03/12/arc-launch-new-national-resource-center-future-planning/?utm_source=rss&utm_medium=rss&utm_campaign=arc-launch-new-national-resource-center-future-planning. (Email in Appendix).
- Arizona Caregiver Coalition provides help to find information, assistance, and answers to meet caregiver needs. Elizabeth Harris, Respite Project Coordinator/Volunteer Coordinator, is interested in providing guidance and assistance during the development and dissemination of the caregiver roadmap. Their website is located at http://www.azcaregiver.org/.

SUMMARY

During the two-year project, there will be multiple efforts to increase the community's understanding of the importance of future planning for persons with DD. These efforts will target family caregivers and service providers who are the support network for individuals with DD. The goal is to support family caregivers in the planning process in hopes that it will lead to earlier planning, more thoughtful planning, inclusion of the person with DD, and improved communication and collaboration among all parties. The project outcomes include several products: 1) a revised and updated *Future Care Planning: A Roadmap for Family CaregiversV2*; 2) Train the Trainer curriculum for service providers; 3) evidence based tools for service providers with training videos; and 4) audio recordings that share the caregiver's journey. In order to accomplish these outcomes, the project includes a research component that drives and informs the development of the products.

REFERENCES

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Timeline of Activities (2015)														
ACTIVITY	**STAFF**		**MONTHS**											
Year One (2015)	LT	LP	Jan	Feb	Mar	Apr	May	June	July	Aug	Sept	Oct	Nov	Dec
1. Design research methodology and conduct literature review	*	*	X											
2. Develop surveys for caregivers (CGs) and service providers, and protocols for interviews with CGs and persons with IDD	*	*	X											
3. Prepare and gain approval from UA Human Subjects			X	X										
4. Implement survey for CGs and service providers (N=75)	*	*		X	X	X	X	X	X					
5. Conduct Interviews (N=30)														
a) CGs from original study: 2007-2008 (N=5)	*				X	X								
b) New CGs (N=15)	*	*			X	X	X	X	X	X				
c) Persons with IDD (N=10)	*	*			X	X	X	X	X	X				
6. Transcribe interviews	*	*			X	X	X	X	X	X	X			
7. Analyze data from surveys and interviews	*	*					X	X	X	X	X	X		
8. Revise CG Roadmap v2	*	*					X	X	X	X	X	X		
9. Complete report on findings	*	*										X	X	X
10. Develop web tool to track Roadmap downloads	*												X	
11. Distribute Roadmap v2 to study participants		*												X
12. Market Roadmap v2		*												X
13. Quarterly Reports	*				X			X			X			X

PROPOSED Timeline of Activities 2016 – subject to change														
ACTIVITY	**STAFF**		**MONTHS**											
Year Two (2016)	LT	LP	Jan	Feb	Mar	Apr	May	June	July	Aug	Sept	Oct	Nov	Dec
1. Develop 2 evidence based practice tools for service providers	*	*	X	X	X									
Design TESTING instruments:	*	*	X	X										
2. Develop **Train the Trainer** program and curriculum	*	*	X	X										
a) Implement 3 service provider trainings (N=45)	*	*			X	X	X							
b) Interview trainers post training (N=5)	*	*				X	X	X						
c) Provide consultation to trainers through co-facilitation and observation of CG interaction using Roadmapv2 (N=5)	*	*					X	X	X					
d) Follow-up survey with trainers: 3 months post training (N=45)	*	*						X	X	X				
3. Implement 3 **Caregiver** Roadmapv2 Class (N=30)					X	X	X							
a) Conduct Participant Observation of Classes					X	X	X							
b) Interview CGs post class (N=5)	*	*					X	X	X					
c) Interview CGs who used Roadmap with trainers (N=5)	*	*					X	X	X					
4. Follow-up contact with	*	*						X	X	X	X			

people who downloaded CG Roadmap v2 from website (3-months post download) (N=25)														
5. Transcribe interviews	*	*					X	X	X	X	X			
6. Analyze survey, interview, and participant observation data	*	*						X	X	X	X			
7. Develop 2 audio dialogues with caregivers	*	*									X	X		
8. Develop two 4-minute videos on how to use Roadmap (service providers & caregivers)	*	*										X	X	
9. Write manuscript for publication in journal	*	*							X	X	X	X		
10. Update Roadmap v2 as needed	*	*	X	X	X	X	X	X	X	X	X	X		
11. Create final report of findings and final version of Roadmap v2.	*	*											X	X
12. Quarterly Reports	*				X			X			X			X

APPENDIX

From: Ira Barnett <iraleeb@gmail.com>
Subject: RE: Caregiver Roadmap possible Edition 2!
Date: March 20, 2014 at 10:39:13 AM MST
To: "'Tomasa, Lynne T - (ltomasa)'" <ltomasa@email.arizona.edu>

Hi Lynne,

You and I had chatted a few times over the last couple of years when I 'discovered' you and A Roadmap for Family Caregivers.

As you know, my professional focus is working with financial advisors to help them integrate LTC planning into their respective practices. In addition, I'm Program Chair for an LTC networking group here in Orange County.

Lastly, over the years, I've put together a 200+ persons e-mail distribution list comprised of a variety of professionals who have some significant part of their practice focused on LTC and/or LTC insurance and/or LTC planning – attorneys, financial planners, care coordinators, professional fiduciaries, etc. Most months, I'll forward some 'interesting articles' I've found in various print and electronic media addressing some facet of LTC.

I've used a PDF of your 'Roadmap' as a topic for my distribution list twice during the past couple of years. In addition, I'd posted it on LinkedIn and distributed a PDF to all the members of the networking group.

My wife and I have a special needs granddaughter (that's why we're in California rather than back in Illinois). We've observed and experienced the challenges to family and finances created by her life-long need for care. My own personal family experiences caring for my ailing mother in the 1990's, and the past 10 years in California have made me passionate about helping people prepare for an extended healthcare event.

As I find someone who, I believe, would find the 'Roadmap' beneficial, I provide them also with a copy. Those 'someones' have included consumers undergoing/about to undergo an LTC experience with a loved one, some psychologists with family and/or elder care practices, a couple of care coordinators and some LTC residential facility owners and managers.

The 'Roadmap', in my opinion, is extensive and comprehensive and has received nothing but positive responses from those to whom I've made it available.

I'm looking forward to completion of 'Roadmap 2.0' and hope I'll be able to receive a copy or two, when completed.

Thank you for all your hard work and great work product – keep up the good work.

All the best,

Ira

Ira L. Barnett, LUTCF
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From: Robin Shaffert <Shaffert@TheArc.org>
Subject: Introducing myself and requesting a time to talk about The Arc's new Center for Future Planning
Date: June 25, 2014 at 12:25:55 PM MST
To: "ltomasa@email.arizona.edu" <ltomasa@email.arizona.edu>

Dear Lynne,

I recently came on board in a new role at The Arc to lead the launch of our Center for Future Planning. The Center is focused on supporting planning by families with adults with I/DD who are living at home with aging family members. Here is a link to our press release announcing the Center: http://blog.thearc.org/2014/03/12/arc-launch-new-national-resource-center-future-planning/?utm_source=rss&utm_medium=rss&utm_campaign=arc-launch-new-national-resource-center-future-planning

In getting up to speed, I have come across the great work you are doing at the Sonoran UCEDD, and I am writing to ask if we could find a time to talk so that I can tell you more about the Center for Future Planning. Do you happen to have any time available on Thursday of this week (other than between 10-11 and 1:30-3:30 EDT)? If not, are there times that would work for you during the week of July 7?

I look forward to meeting you by phone.

Best regards,
Robin Shaffert

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Budget Request Form

Contractor Name: Arizona Board of Regents, University of Arizona

Contractor Address: 888 N. Euclid Room 510, P.O. Box 3308 (Street Address) | Tucson (City) | AZ (State) | 85722-3308 (Zip)

Project Name: Research to Practice: Future Planning, A Roadmap for Family Caregivers

Budget Category	Requested ADDPC Funds	Non-Federal Cash Match	Non-Federal In-Kind Match	Total Program Cost
Personnel/Salaries	43,657			43,657
Fringe Benefits	15,396			15,396
Supplies / Operating Expenses	4,610			4,610
Travel				-
Rent or Cost of Space				-
Contracted Services / Professional Services				-
Administrative / Indirect Costs	6,366		27,057	33,423
Total Costs	70,029	-	27,057	97,086

It is understood that Non-Federal Funds identified in this budget will be used to match only ADDPC Federal Funds, and will not be used to match any other Federal Funds during the period of the ADDPC funded Project.

Additional description and background information shall be included as a budget narrative, including for match. The contractor agrees to submit additional background information to the ADDPC upon request.

Name of Certifying Official

Title of Certifying Official

Phone Email

ADDPC Proposed Budget Narrative and Justification
Year One: January –December 2015
Sonoran UCEDD *Future Planning: A Roadmap for Family Caregivers 2nd Edition*

PERSONNEL ($43,657)
Lynne T. Tomasa, PhD, MSW (.027 FTE/3.24 person months funded) will serve as Principal Investigator/Project Director and will assume overall responsibility for the project. Dr. Tomasa will provide direction on the research design, data collection, community outreach activities, and the development of the Caregiver Roadmap in Year Two.

Lauren Penney, PhD (.25 FTE/ 3.0 person months funded), Research Specialist Sr. and Project Manager, is a medical anthropologist and will be responsible for the day-to-day activities of the project. She will provide overall coordination and management of community forums and interviews with family caregivers and persons with IDD. Dr. Penney will assist in the development of the surveys and the Caregiver Roadmap, 2nd edition.

Patricia Philbin, Graphic Designer (.06 FTE/.72 person months funded) in the Department of Family and Community Medicine will design and format the *Future Care Planning: A Roadmap for Family CaregiversV2.* Ms. Philbin will also create the web tool that tracks download of the roadmap from the Sonoran UCEDD website.

FRINGE BENEFITS ($15,396)
Personnel salaries are based on university schedules and ranges for the positions. All percentages are based on a 12-month contract for the project.

University fringe benefits rates are based on employee classification:

Appointed and Faculty-Regular	28.6%
Classified-Regular	47.8%

SUPPLIES ($400)
Purchase of paper folders, and pens.

OPERATING EXPENSES ($4210)

Printing and mailing of roadmaps for interview participants ($12 each for up to 30 roadmaps $360)

Caregiver and Individuals with DD Stipends ($1600)
All interview participants will receive stipends of $50 each as an incentive to participate (gift cards) in interviews that may last from one to two hours. This includes 20 caregivers ($1000) and 10 individuals with DD ($500). Two of the participating caregivers will share their personal stories that will be audio taped and posted on the web. They will receive an additional $50 each for their participation ($50 X 2 = $100).

Transcription on 15 of the 30 Interviews ($2250)
An interview that lasts 1.5 to 2 hours may take up to six hours to transcribe for a less experienced person. Estimated cost for each interview is $25 X 6 hours= $150 per interview ($150 X 15 = $2250). The researchers will transcribe the remaining 15 interviews.

CONTRACTED/PROFESSIONAL SERVICES (None)

Indirect Charges
We request 10% in indirect costs to support management of the contract, telephone and computer line support, housekeeping and maintenance.

Match
The match required by DDPC is being met through foregone in-direct costs (difference between 10% indirect rate and university rate of 52.5% for this type of project)