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October 25, 2015

**Marcella Crane, Contracts Manager
Arizona Developmental Disabilities Planning Council
1740 West Adams, Suite 410
Phoenix, AZ 85007**

**Subject Clarification Response to Questions on Renewal of ADDPC-FFY14-GP-00
Comprehensive Education Projects to Promote Self-Advocacy and Information/
CarePRO Program**

Dear Ms. Crane:

Below are the responses to the questions that you indicated in the October 22, 2015 letter requesting further clarification. Attached you will also find our Budget Request and Budget Narrative.

1. What was the process used to arrive for the original target number of 44 participants that would participate in a CarePRO Workshop and what are your thoughts as to the reasons for not having the targeted number of participants ? How will this be addressed in Year 2?

The anticipated number of participants in the Year One proposal was based on providing four (4) workshops throughout the state. These workshops were to be held in Northern Arizona, Southern Arizona and 2 workshops in the Greater Phoenix area. We based the number of participants on our experience of providing CarePRO workshops throughout the Chapter during the past four years. Because we were offering limited numbers of workshop specific to the needs of caregivers for individuals with developmental disabilities we felt that the workshops would be slightly larger than our average of 8-10 participants. We over estimated the community response to our specialized workshops.

We believe that there are many reasons for not having the targeted number of participants. As stated in our renewal proposal they are:

- a. Alzheimer's Association staff members under-estimating the time needed to recruit participants
- b. Lack of Alzheimer's Association staff members being able to connect directly with family caregivers of individuals with I/DD and Alzheimer's disease
- c. Families and providers both seem to have a somewhat limited understanding of appropriate screening and assessments for aging-related conditions within the I/DD population. This lack of education and knowledge of aging-related conditions is a barrier to participation in CarePRO
- d. Lack of preparation families and caregivers of adults with Down syndrome have related to medical issues commonly encountered in adulthood especially Alzheimer's disease and related dementia
- e. Lack of caregiver knowledge about the prevalence of Alzheimer's disease and the need for education and support to provide care for individuals with the disease
- f. Lack of an established "baselines" for comparison as individuals with I/DD age within provider agencies and by families resulting in delayed awareness of disease progress
- g. Prevalence of myths and stereotypes about aging in persons with I/DD that still exist by both provider agencies and families
- h. Push back to change care focus for individuals with Alzheimer's from making gains to maintaining function and dealing with eventual loss and decline within provider agencies and families
- i. Lack of understanding that Alzheimer's is a progressive fatal disease and the importance of building a support network related to disease progression

During Year 2 we have revised our estimate of workshop size to eight (8) and the number of workshops to three (3). Before we expect that family members will participate in lengthy workshops with time commitments like CarePRO we must spend time working within the DD community to provide baseline information about why caregivers should learn about and participate in CarePRO. We believe that that can be accomplished through short educational workshops at existing support and advocacy groups that already work with the DD community. Providing this information in a shorter 30 – 45 minute format educational class/workshop will help them develop the knowledge about the prevalence of Alzheimer's disease and the need for additional education and support. In addition, working with local physicians/researchers, who are familiar with CarePRO and, provide care for their loved ones with Down syndrome who also have Alzheimer's will provide additional opportunities for referrals to our services.

2. Of the 10 participants in a CarePRO Workshop, provide a breakout of what region they represented (i.e. Phoenix, Tucson, Prescott)?

The participants were from Southern Arizona and the Greater Phoenix area.

3. Due to the difficulty in achieving the target number in Year 1, the expected number for Year 2 is 24. Do you feel this is a reasonable target number to achieve in Year 2, and how will that impact your budget?

Because we are revising the number of participants for each workshop series to 8 we feel that this number is a reasonable target. Our attached budget was revised to reflect three CarePRO workshops. Each workshop has fixed costs for staff time and it is hoped that the number of participants might increase but the cost still remains the same for each workshop series.

4. Specifically, what changes to the learning objectives and workshop materials are or will be made for the CarePRO curriculum?

The learning objectives will include more emphasis on basic Alzheimer's disease education and progression and more specific examples of behavior and communication changes in individuals who develop Alzheimer's disease and skill building to address those changes

5. Specifically describe the outreach methods that will be used in each community for participant recruitment?

Participant recruitment will be enhanced during this next year of funding by the following additions and changes:

- a. Provide a minimum of three (3) 10 week CarePRO sessions for a minimum of 24 caregivers caring for individuals with I/DD
- b. Provide additional a minimum of 6 basic Alzheimer's education workshops for families to help them better understand the disease and how it affects individuals with I/DD – these workshops would be offered to existing support groups, advocacy groups and other organizations that provide resources and services to the DD population.
- c. Ensure additional collaboration with ADDPC to find ways to reach out to individual families
- d. Provide additional Alzheimer's education workshops for support providers to help them better understand the need for "baseline screenings", the prevalence of Alzheimer's disease and related dementia, basic disease information and the importance of referring families caring for individuals with I/DD to CarePRO

- e. Work with local physicians and researchers to identify and refer families to participate in CarePRO.

6. By the end of each quarter period during the Year 2 contact, what benchmarks or output data will need to occur; and what analysis will be done to ensure target numbers and outreach methods are being met and successful?

Quarter 1:

- Research will be done identifying educational workshop opportunities at support and advocacy groups that provide resources to individuals with DD and their families. Outreach to schedule 4 workshops completed.
- Meet with ADDPC to collaborate on better ways to reach out to individual families
- Meet with physicians and researchers to set up identification of potential participants and develop referral process
- Identify and schedule Alzheimer's 3 education workshops for support providers, provide education on Alzheimer's disease and the purpose of CarePRO developing support for referrals to CarePRO

Quarter 2

- Continue outreach to existing community groups
- Schedule and hold 1 CarePRO workshop series in the Greater Phoenix Area.
- A minimum of 8 caregivers will participate in the workshop
- Evaluate the effectiveness and outcomes of CarePRO for this target population to verify we are adequately meeting needs.

Quarter 3

- Continue outreach to existing community groups
- Schedule and hold 2 CarePRO workshop series - 1 in the Greater Phoenix Area and 1 additional workshop series in either Southern or Northern Arizona.
- A minimum of 8 caregivers will participate in the workshop
- Evaluate the effectiveness and outcomes of CarePRO for this target population to verify we are adequately meeting needs.

Quarter 4

- Continue outreach to existing community groups
- Schedule and hold any additional CarePRO workshop series in areas of interest and need
- Evaluate the effectiveness and outcomes of CarePRO for this target population to verify we are adequately meeting needs.

7. Choose one Self-Advocacy Element that will be implemented in the contract period for Year 2.

Participation in diverse leadership coalitions:

People with disabilities should be able to take control of their own lives, including being in charge of their own care in the medical system whenever possible. The self-advocacy movement is about people with disabilities speaking up for themselves. It means that although a person with a disability may call upon the support of others, the individual is entitled to be in control of their own resources and how they are directed if possible. It is about having the right to make life decisions without undue influence or control by others.

As the effects of Alzheimer's disease progress, individuals are able to self-advocate less and less and it is often the caregiver who must become the advocate. They must learn how to speak for the individual who has intellectual disabilities and Alzheimer's disease. Caregivers do this by making decisions about their care and life, learning how to get information so that they can understand things that are of interest to the person they are caring for and finding out who will support them in the journey. They must understand and know the rights of the person with memory loss and do their problem solving by listening and learning, reaching out to others when they need help and friendship, and learning about self-determination for the individual with Alzheimer's disease.

CarePRO helps caregivers build political and community support for strong enforcement policies and activities that affect individuals with Developmental and Intellectual disabilities and Alzheimer's disease. Caregivers are the ones who work for changes in state and local laws, policies and procedures and insuring programs and services are research-based and are based on best practice principles. The Alzheimer's Association is the leading voice for Alzheimer's disease advocacy, fighting for Alzheimer's research, prevention and care initiatives and provides education and venues for caregivers to fight for the rights of those who have this disease.

8. Address how the following barriers are being addressed for the program to succeed in Year 2: Barrier A, B, E, F, and I.

A. Alzheimer's Association staff members under-estimating the time needed to recruit participants.

- As an organization that is known for providing services to seniors we needed to develop credibility and relationships with a whole new set of agencies that provide services to a different population. We have spent significant hours during the past year developing relationships with local agencies and organizations that provide programs and services to individuals with developmental disabilities. While that time impacted our ability to reach our goals in year one we would

anticipate that the hours spent and relationships developed will result in greater outcomes in year two.

B. Lack of Alzheimer's Association staff members being able to connect directly with family caregivers of individuals with I/DD and Alzheimer's disease.

- Because the Alzheimer's Association Desert Southwest Chapter is not a recognized provider of services to the developmental disabilities community we have a very small direct connection to family caregivers of individuals with I/DD. During the past year we have worked to develop a relationship with provider agencies and case managers. During this next year we would like to work more closely with the ADDPC in finding ways to reach out to individual families that might benefit from participation in CarePRO. In addition, the opportunity to work with local physicians and researchers will open up avenues of outreach and referral for families who already have loved ones with developmental disabilities and Alzheimer's.

E. Lack of caregiver knowledge about the prevalence of Alzheimer's disease and the need for education and support to provide care for individuals with the disease

- Working with support and advocacy groups throughout the state and providing shorter workshops about the prevalence of Alzheimer's and the basic disease information including the resource of CarePRO will help families who are currently affected and those that will be affected in the future understand the need for support and specialized resources.

F. Lack of an established "baselines" for comparison as individuals with I/DD age within provider agencies and by families resulting in delayed awareness of disease progress

- Continued work with community agencies and provider organizations about disease prevalence and emerging needs while providing them with resource information about baseline development will help reduce this lack of awareness. Our goal is to continue this education into Year Two.

I. Lack of understanding that Alzheimer's is a progressive fatal disease and the importance of building a support network related to disease progression

- This issue will be addressed in all trainings and education workshops that we provide to support and advocacy groups. Also as we provide education to provider agencies and case managers throughout the state awareness of this need will increase in future years.

9. Provide additional information on how this program will be sustained without ADDPC funding.

CarePRO is an ongoing program of the Alzheimer's Association Desert Southwest Chapter. As we develop specialized materials, community partnerships, collaborations and individuals from diverse communities begin participating in CarePRO, that specialized need will be folded into our ongoing program offering and become part of

our core programming. We have a diverse funding base and are constantly looking for new funding sources to sustain all of our ongoing program offerings.

10. Provide a signed and updated Budget Summary Page.

See Attached

Please let me know if any additional information is needed or you have any questions about our responses. Thank you for the opportunity to clarify our proposal.

Sincerely,

A handwritten signature in black ink, appearing to read "Cindy Vargo". The signature is fluid and cursive, with a large loop at the end.

Cindy Vargo
Central Region Director

CC: Deborah Shaus, Executive Director

BUDGET SUMMARY

Budget Request Form

Contractor Name Alzheimer's Association Desert Southwest Chapter

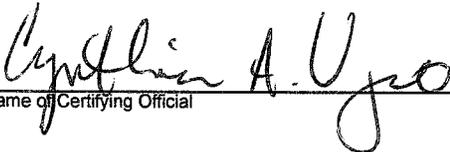
Contractor Address 1028 E McDowell Road, Phoenix, Arizona 85006
Street Address City State Zip

Project Name CarePRO for Family Caregivers of Individuals with Developmental Disabilities

Budget Category	Requested ADDPC Funds	Non-Federal Cash Match	Non-Federal In-Kind Match	Total Program Cost
Personnel / Salaries	25,182	6,296	0	31,478
Fringe Benefits	7,744	1,936	0	9,680
Supplies / Operating Expenses		810	0	850
Travel	0	445	0	280
Rent or Cost of Space	0	1,776	0	1,776
Contracted Services / Professional Services	0	0	0	0
Administrative / Indirect Costs	0	0	0	0
Total Costs	32,926	11,263	0	44,064

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 the match. The contractor agrees to submit additional background information to the ADDPC upon request.


 Name of Certifying Official

Central Region Director
 Title of Certifying Official

602-528-0545
 Phone

cvargo@alz.org
 e-mail

BUDGET NARRATIVE

Budget justifications detail is provided for each expense line item, both for funds requested and for match.

Personnel / Salaries/ ERE = \$31,478 total; \$25,182 Requested Funds; \$6,296 Match for Salaries
 \$9,680 Total; \$7,744 Requested Funds; \$1,936 Match for ERE

A total of 1,096 staff hours or 0.51 FTE (Full Time Equivalent) for direct project support is proposed, as follows:

Region	Position	Staff Name	# Project Hours	Project FTE	Hourly Wage	Project Wage	Pro-Rated Project ERE
Central AZ	Regional Director	Cindy Vargo	168	0.08	37.74	6,340	1,680
	Program Manager	Mindy Wakefield	130	0.06	27.19	3,535	1,155
	FCC	TBD	200	0.09	23.00	4,600	1,600
Northern AZ	Regional Director	Meg Fenzi	149	0.07	39.77	5,925	1,520
	FCC	Mary Novar	100	0.05	28.08	2,808	885
Southern AZ	Regional Director	Kelly Raach	84	0.04	32.08	2,695	660
	Program Manager	Morgen Hartford	65	0.03	21.15	1,375	535
	FCC	Elizabeth Kinder	200	0.10	21.00	4,200	1,645
TOTAL			1,096*	0.50		31,478	9,680

ERE (Employee Related Expenses) are pro-rated for both requested funds and match for the staff positions noted above. This includes employer paid health plan, 401k plan, payroll taxes, etc. The benefits package for all employees is approved by the Board of Directors annually.

Supplies / Operating Expenses = \$810 total; \$0 Requested Funds, \$810 Match

- Snacks/Water for workshop participants: 7 Basic and 3 CarePRO workshops @ \$10.00 = \$100.00
- Notebooks and materials for CarePRO workshop participants: 24 participants @ \$15. = \$360
- Handouts/materials for Basic Alzheimer’s Education Workshops:100 participants @ \$2. = \$200
- Office / program supplies: pens, flip charts, paper, etc. = \$150

Travel: = \$445 total; \$0 Requested Funds, \$445 Match

A total of 1,000 miles of travel from the Chapter’s offices to the workshop locations is included in the budget at the Arizona Accounting Manual personal vehicle mileage reimbursement rate of \$0.445 per mile (effective 11/15/06). This includes travel of all staff to workshops in Phoenix, Prescott and Tucson areas, as well as all four project staff driving to do any outreach in their respective regions.

Rent or Cost of Space = \$1,776 total; \$0 Requested Funds, \$1,776 Match

Projected cost of \$1,776 is projected for pro-rated office occupancy space for .50 FTE.