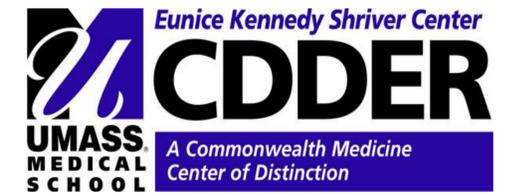




# What do I Really Need? Assessment of Caregiver Support for People with IDD and Dementia

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## Introduction

The increased needs of people with an intellectual and developmental disability (IDD) and a dementia related disorder can strain caregivers and existing community support systems. The project team, comprised of IDD and Aging experts and funded, in part, through a federal grant, conducted a needs assessment on the awareness and use of typical community-based resources such as senior centers. The assessment consisted of both telephone interviews and home visits with group home, shared living, and family caregivers.

## Methods

Nurse Practitioner (NP) conducted a total of 95 interviews with 54 site visits, and the evaluator completed 40 interviews with caregivers of people with IDD and dementia diagnosis. Analysis included both qualitative and quantitative data. Caregivers were asked:

- functional and health status of person with IDD since dementia diagnosis,
- receipt of dementia specific caregiving training,
- care confidence levels,
- perceived barriers to care,
- access to community-based aging resources.

## Results

Caregiver Respondents	%	Living Arrangement of Person with IDD	%
Paid Staff	93	Group Home	77
Sibling	5	Shared Living	17
NH, Independent	2	Family, NH, Independent	6

### Dementia Capable Training

- 76% Trained At time of NP Interview
- 53% Sought Training After NP Interview

### Caregivers Need:

- Dementia capable training
- Flexible respite, personal care assistance, day supports
- Assistance with resource navigation
- Plans to preserve quality of life
- Direction on medical care as dementia progresses
- End-of-Life Plan
- Collaboration between the IDD and Aging Human Service Support Systems

*Before she agreed to have John come live with me, his Auntie wanted to talk to me. She really couldn't walk well so I sat with her in her car. She asked me to promise her that John would not have to move again. "Yes", I said, "I care so much about him and he's always going to stay with me." So I pray to God to help me with this promise.*

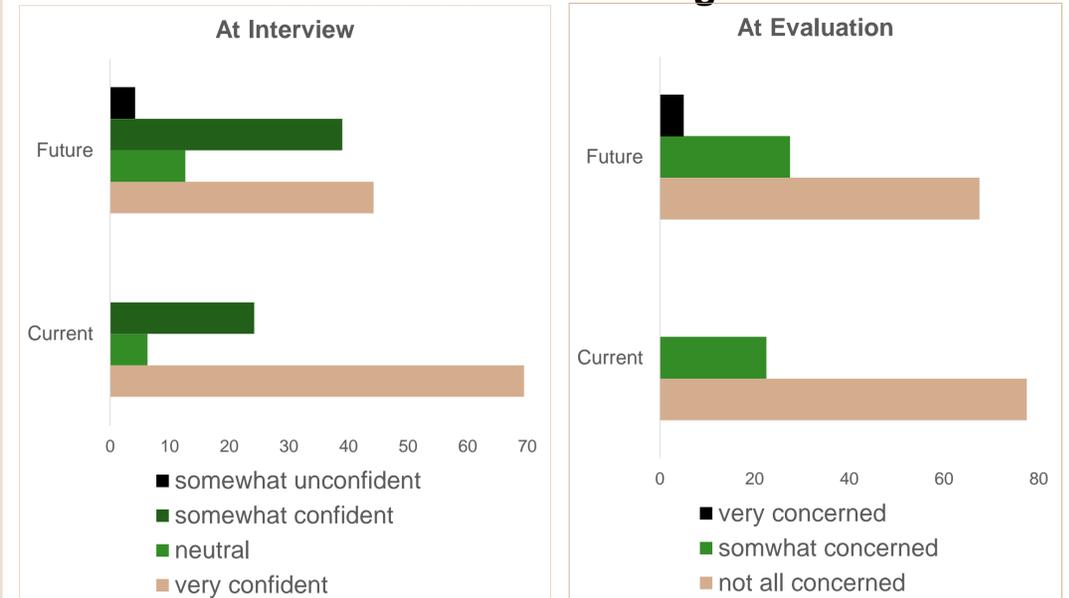


*Our other sister is insistent that Rose (our sister with Down syndrome and Alzheimer's) continues to go to all the family events. It takes a lot for me to do this (with my back and all) and no matter what, Rose often gets upset. Then she blames me for not taking care of Rose and ruining the party.*

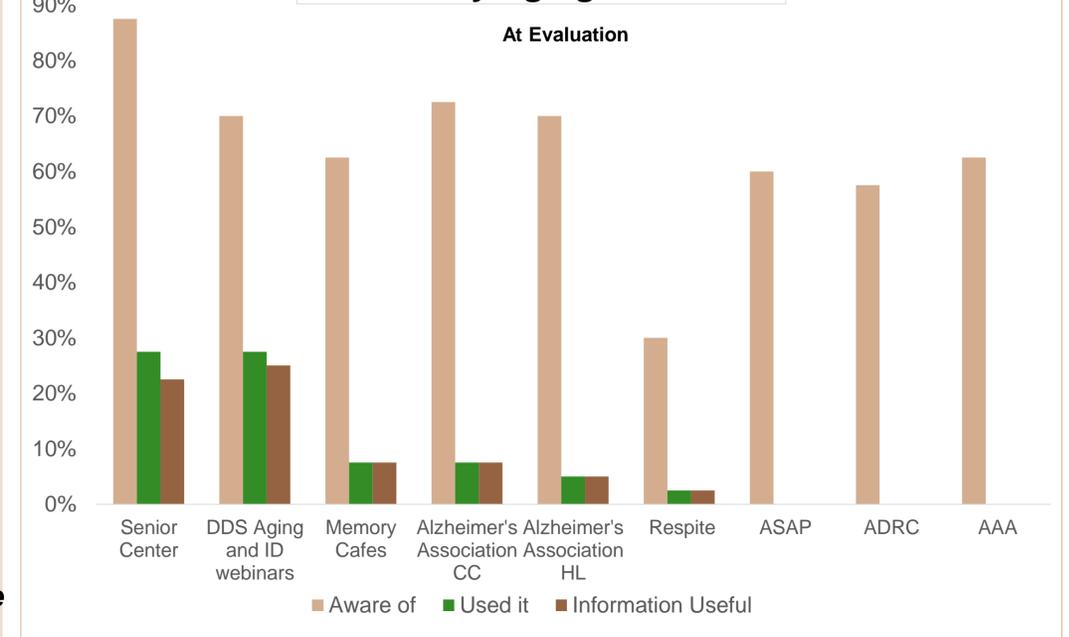
U.S. Administration on Community Living grant, # 90ALGG0018

## Results, Continued

### Confidence in Providing Care



### Community Aging Resources



Resources for People with IDD and Dementia:  
<https://shriver.umassmed.edu/programs/cdder/aging-intellectual-and-developmental-disability-trainings/dementia-and-idd/resources-individuals-idd-and-alzheimer-s-disease-and-related-dementias>