

# Caregiver Perspectives on Transition Services For Individuals with IDD and ADRD

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## Introduction

- Individuals with Intellectual and Developmental Disabilities (IDD) are at risk for early onset of Alzheimer's Disease and related dementia (ADRD)<sup>1</sup>
- Few families are making transition plans<sup>3</sup>
- 60% of parents expect siblings to assume care<sup>2</sup>
- Transitioning in crisis related to negative outcomes for individuals with IDD<sup>4</sup>
- Few studies examined caregiver needs during transition process

**Research Aim: To explore what services sibling caregivers of individuals with IDD and ADRD feel that they need to make effective transition plans**

## Methods

**Design:** Qualitative descriptive study  
**Participants:** Two female sibling caregivers from suburban Pennsylvania; convenience sampling  
**Data collection:** 2 semi-structured phone interviews  
**Data Analysis:** Thematic Coding

## Results

Impact of Alzheimer's on available services

*"Its not really because she has Down syndrome anymore because the Alzheimer's is what is making her mind not be able to do things for herself"*

"Caring for one"

*"if you know a familiar face when you are going into a strange setting, it makes that strange setting a little bit better"*

"Finding the right thing"

*"I think you just need someone to say to you that it is the right thing even though it may not be the perfect thing"*

## Discussion

- Data supported literature that transition services are difficult to navigate
- Service options not always compatible with ADRD symptoms
- Caregivers want loved one to maintain routines & meaningful occupations post transition
- Caregivers want support from health professionals and other transition families
- More research needed on comorbid population in diverse geographic locations

## Implications for OS/OT

- Advise formal care providers on routines
- Caregiver education on ADRD
- Community mental health for caregivers
- Patient advocacy and caregiver collaboration during transition process

## References

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4. Knox, M., & Bigby, C. (2007). Moving towards Midlife Care as Negotiated Family Business: Accounts of people with intellectual disabilities and their families "Just getting along with their lives together". *International Journal of Disability, Development and Education*, 54(3), 287-304.