

National Resources for Aging Individuals with IDD and Dementia

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Research Question

What resources exist nationally to address the needs of individuals with IDD who are aging with Alzheimer's and dementia?

Research Goal

- Identify national programs for aging individuals with IDD and dementia
- Showcase the lack of programming and resources available for this population
- Showcase a need for further programming and resources

What is IDD?

- A difference present at birth that impacts an individual's physical, mental, or emotional health (NIH, 2021)
- Characterized by performance differences in both intellectual function and adaptive behaviors
- More likely to have health complications (Havercamp et al., 2015)

Alzheimer's, Dementia, and Other Related Conditions

- **Dementia** - Condition in which an individual loses their memory, language, problem-solving abilities, and other higher-level thinking tasks
- **Alzheimer's** - Most common type of dementia that impacts memory, thinking and behavior
- Increasing prevalence of dementia in individuals with IDD as life span improves

Aging with a Disability

- Operationally defined as 60+
- Average lifespan for individuals with a disability has increased
 - 20 years less than non-disabled peers (O'Leary, 2018)
- WHO predicts that ~46% of adults 60+ will have some form of disability (WHO, 2015)
- Appropriate care for aging individuals with a disability is limited

Healthcare Access Barriers

- 1 in 4 adults with a disability ages 18-44 do not have a regular healthcare provider
- 1 in 5 adults with a disability ages 45-64 have not had a physical in the past year
- Factors that limit access with age
 - Transportation
 - Mobility
 - Income
 - Social isolation
 - Digital medical documentation

(CDC, 2023)

Procedure

- Extensive website review
 - Centers on Aging
 - *Centers for Independent Living*
- Every program and service was evaluated
 - Had to mention one of the following terms:
 - Memory
 - Dementia
 - Alzheimer's
 - Parkinsons

Procedure

- Further evaluated if the program was general or specific to IDD
- Included Programs
 - Include one or more keywords
- Excluded program
 - Those that did not include a keyword

Results

- Centers on Aging
- 79 programs or services nationwide met criteria
 - Wisconsin had the highest amount with 12
 - Followed by Nebraska with 10
 - 16 states contained 0 programs or services

Majority are only referencing the state aging and disability resource page, not a true service

Results

- Centers for Independent Living
 - 42 states have no CIL program that has services that meet criteria
 - 9 states have a CIL that meets criteria
 - **Total of 11 services combined nationwide**
 - CT contains 1 of these services

Limitations

- Data collection was constrained by what was published on each website
- Limited time frame for data collection
 - March → April
 - Unable to further evaluate organizations

Conclusion

- Confirmed lack of resources nationally
- State resources across the country need to be improved!

References

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