Down syndrome and Alzheimer's disease: A retrospective medical records review

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Purpose

- The objective of this study is to identify training opportunities for caregivers of adults with Down syndrome and Alzheimer’s disease.
    - Information can be applied to subsequent projects with the goal of developing and evaluating a specific training program.

Why is training of caregivers important?

- Currently there is no cure for Alzheimer’s disease; therefore:
  - Available treatments (e.g. Aricept) and health and social supports are current provisions that can reduce the severity and progression of the disease.
- Due to the high prevalence of this disease among individuals with Down syndrome, it is imperative that these individuals are able to access resources that improve the overall quality of their care.

Are current health care practices sufficient?

- Burt and Alyward (2000) proposed a model of best practice for diagnosis of dementia among individuals with ID:
  - a) Establish baseline of premorbid functioning by age 35
  - b) If decline is present, conduct detailed diagnosis
  - c)Provide appropriate care to client and caregivers as well as adequate specialist/staff training
- Auty and Scior (2008) question whether these recommendations are implemented in practice:
  - They surveyed clinical psychologists and found noticeable variability in practice, assessment methods and explanations given to both patients and caregivers.
  - Furthermore, the clinicians themselves noted that <u>they felt there were many deficits in service provision</u> once aging individuals with ID began to show signs of dementia.

Current challenges

- Ability of caregivers to recognize and respond to early symptoms of the disease[5]
    - Intellectual disability often precludes the ability to distinguish noticeable cognitive changes
- Lack of provision of stimulating tasks reduces opportunity to observe change in function[6]
- Employee turnover and familiarity with baseline function

Study Design

- The study is a retrospective medical records review.
- At completion more than 100 medical records are expected to be reviewed.
  - Currently 30 records have been completely reviewed.
- Data collection was completed independently by LEND fellow.

Methods

- IRB approval was received from St. Raphael's Hospital, the University of Connecticut Health Center and the Department of Developmental Services.
- Medical records were retrieved from assessment clinic.
- Patients were matched with ID numbers for confidentiality.
  - ID list was kept locked with medical files.
- Information from initial patient visit was recorded in Microsoft Excel codebook.
  - All variables with the exception of 'recommendations' were coded quantitatively.

Examples of Information Collected

- Age
- Gender
- Respondent
- Score on DOWNS test
- Living arrangement
- Work or day program
- ADL
  - Independent, supervision, cuing, assistance, dependent
- Medical concerns
  - E.g. Thyroid, hypertension, cataract
- Number and type of medications
- Diagnosis of Alzheimer’s or Dementia NOS
- Recommendations (qualitative)

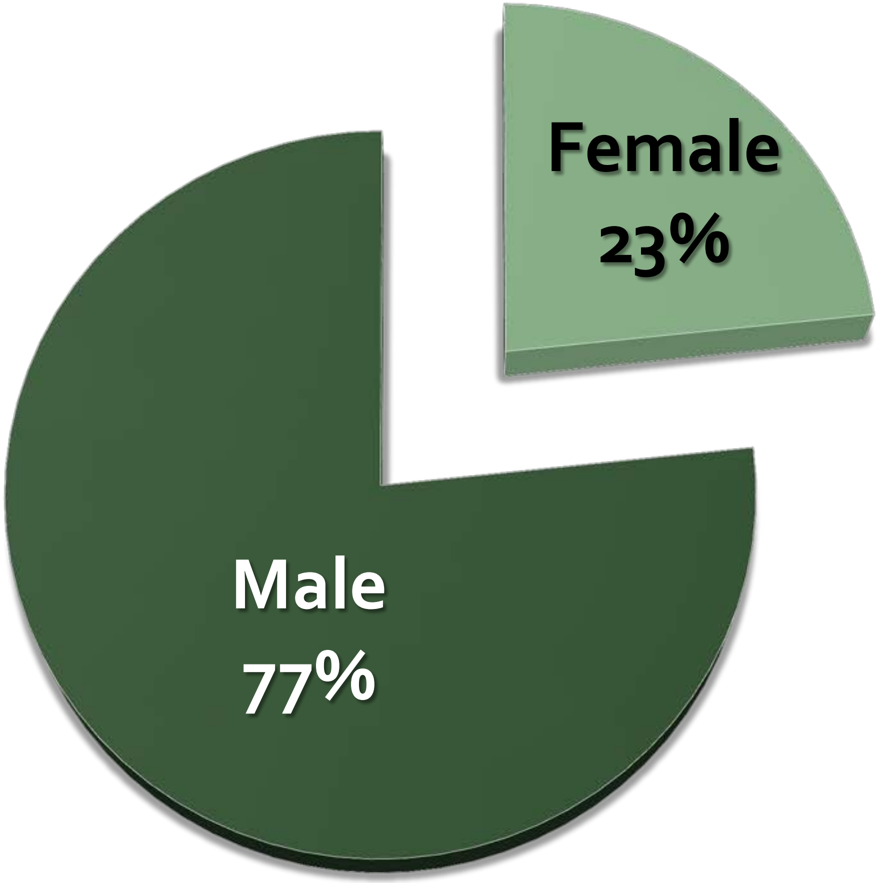
DOWNS Test

- Used to monitor progression of cognitive and memory-related ability.
- Score is relative to individual functioning but can be observed over time to note changes.
- Each section is scored separately and is recorded during each visit.
    - Total score is out of 69.

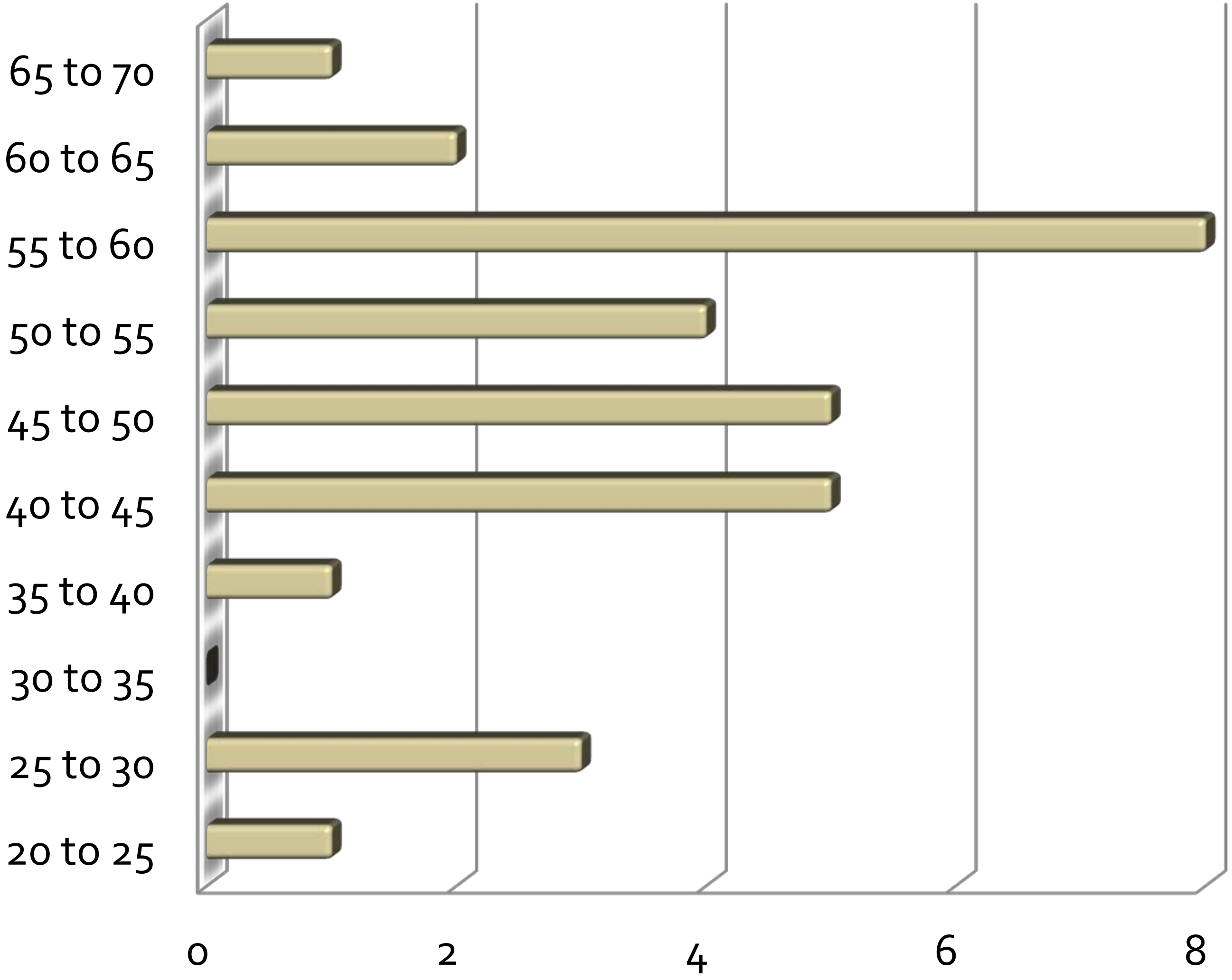
RESULTS

•Preliminary Analyses•

Gender

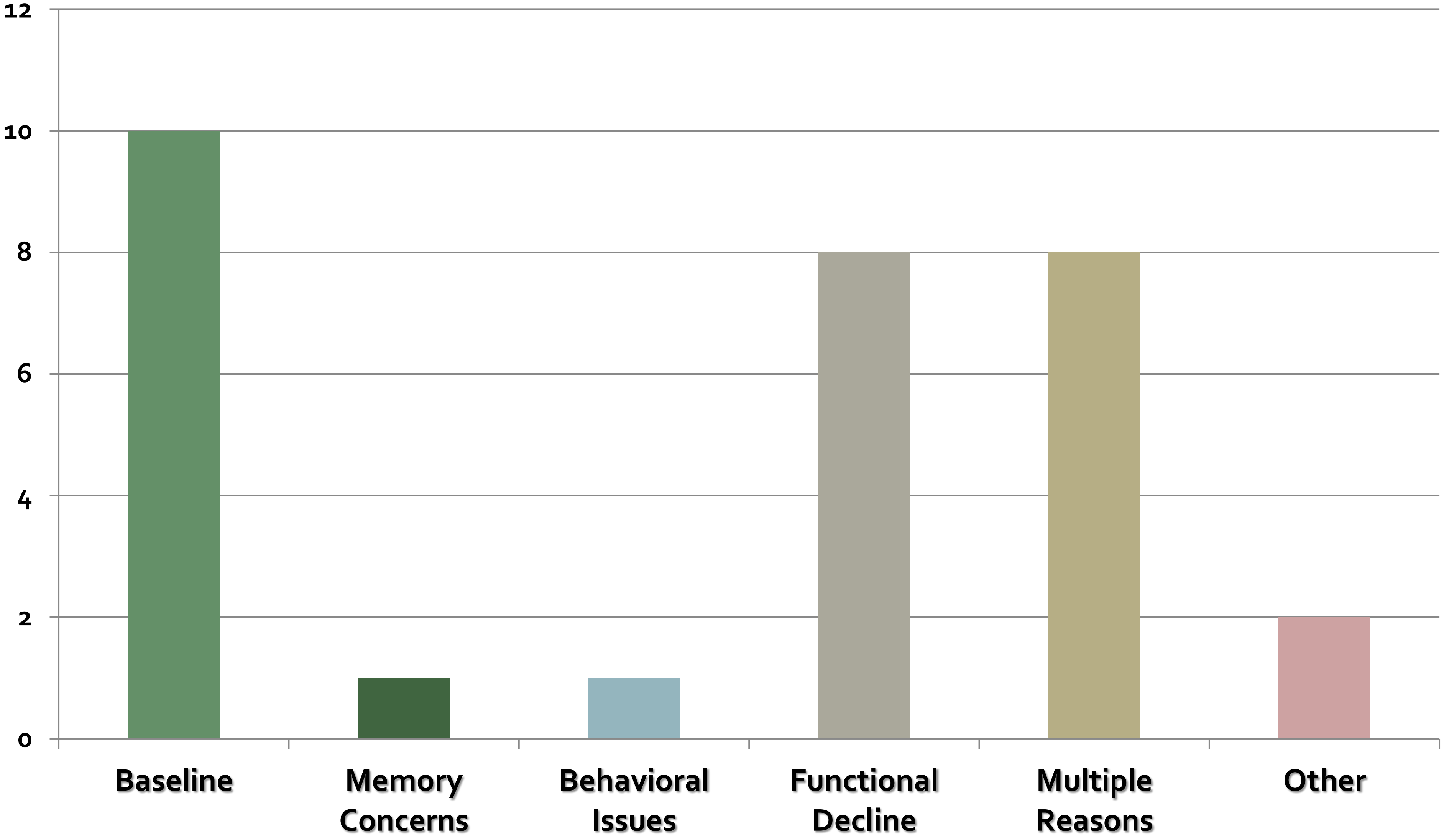


Age

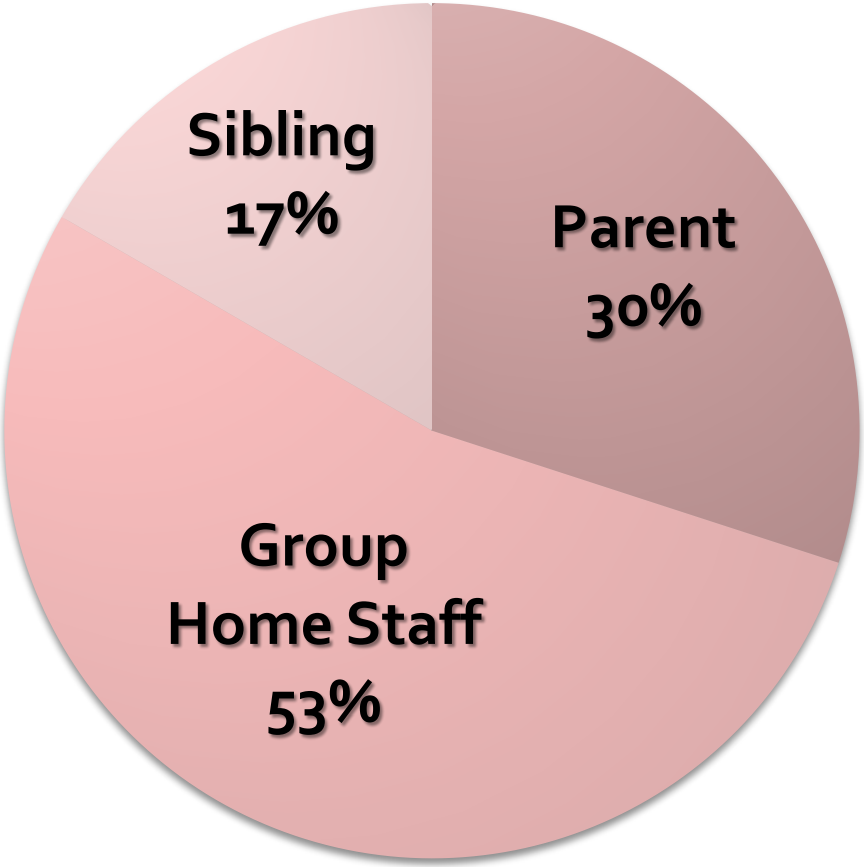


Statistics		
Age		
N	Valid	30
	Missing	0
Mean	**47.9**	
Range	**42**	

Reason for Visit



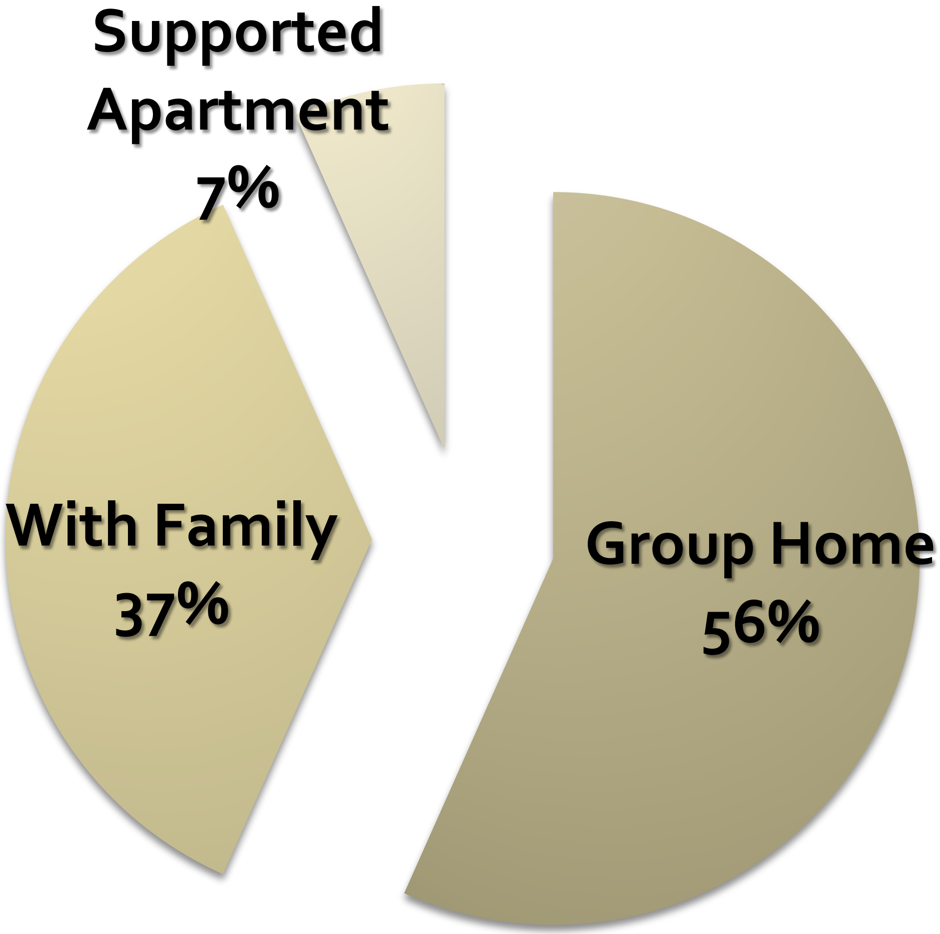
Respondent



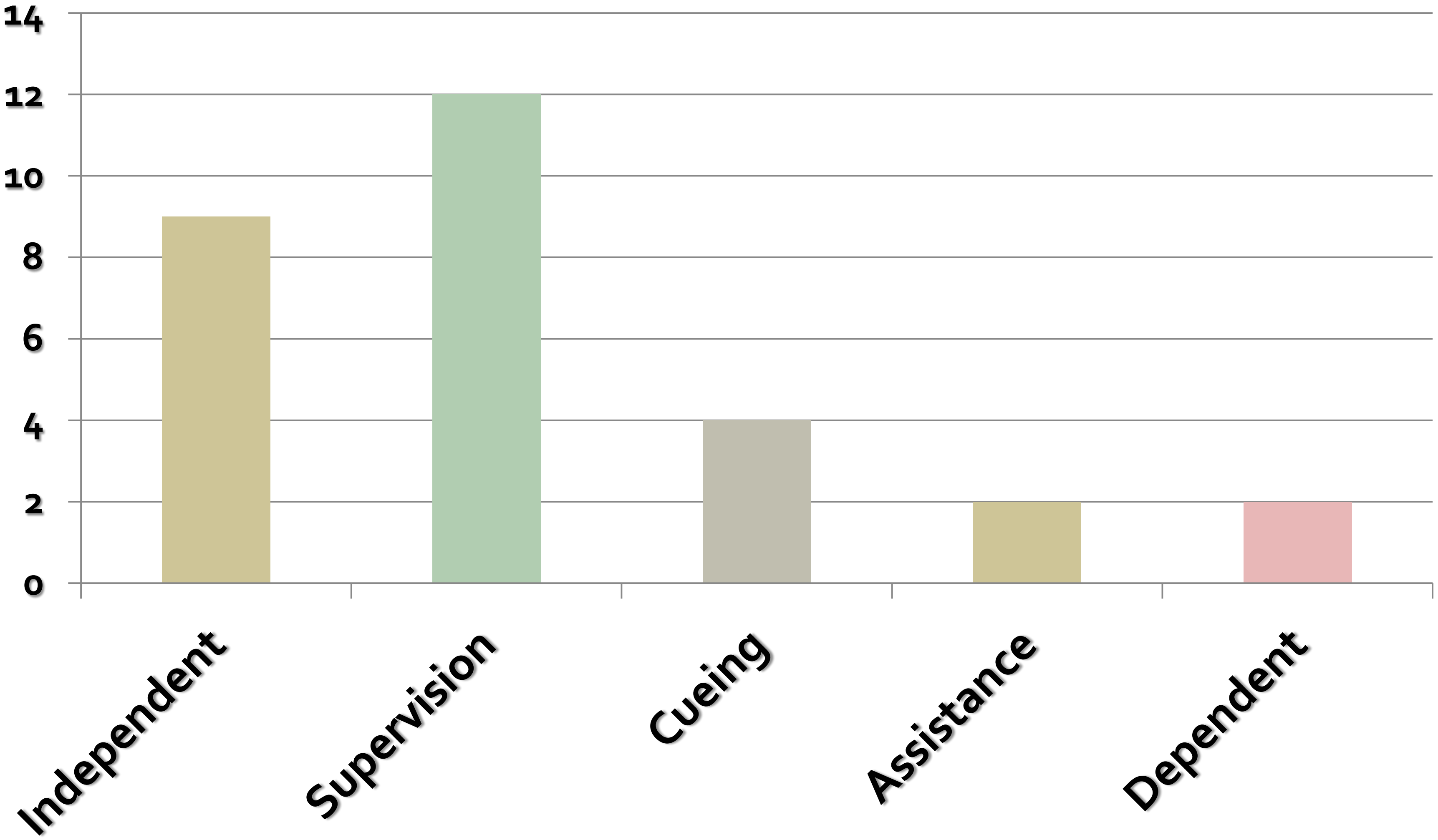
Down Syndrome Mental Status Testing Score

Valid Cases	**20**
Missing	*10*
PROPERTY	**SCORE (out of 69)**
Mean	**42.7**
Range	48
Minimum	14
Maximum	62

Living Arrangement



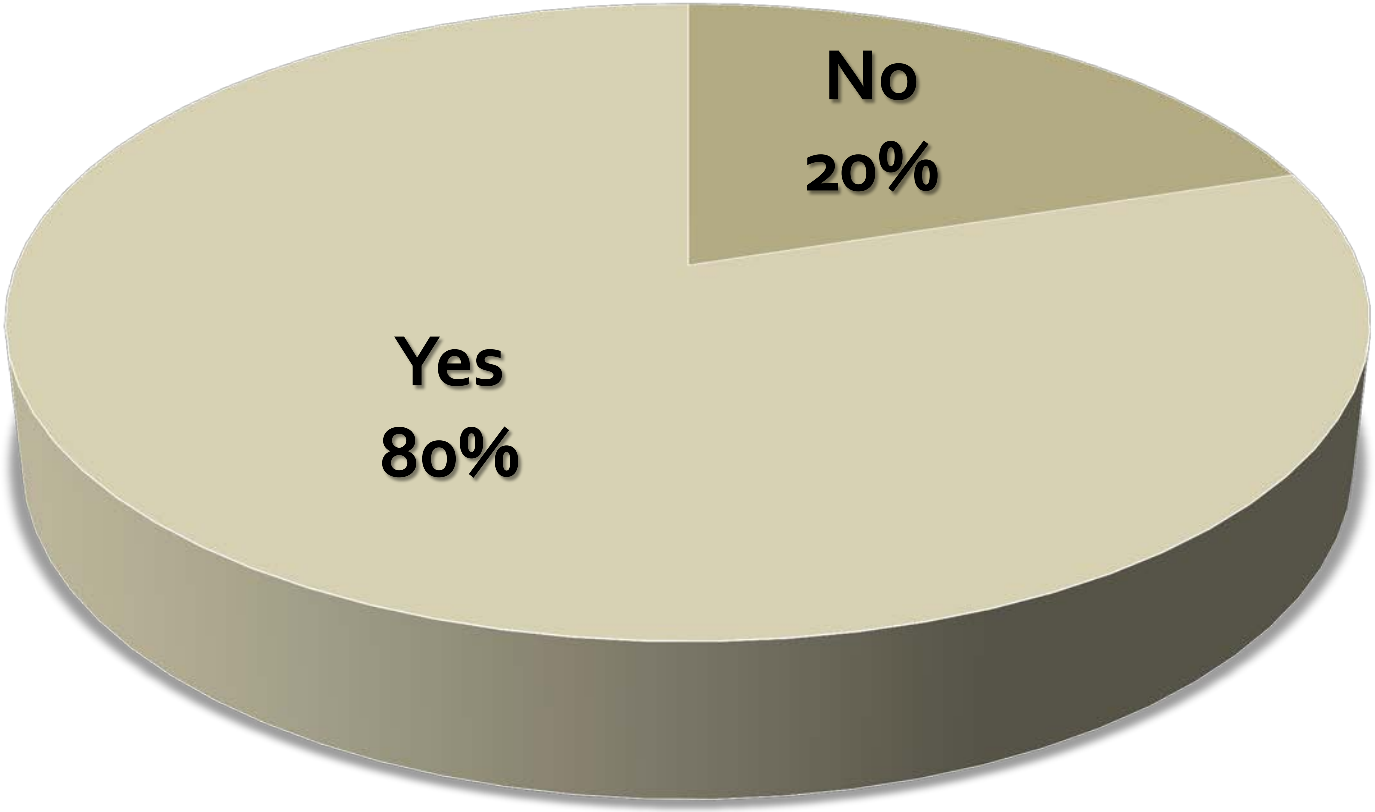
ADL


14
12
10
8
6
4
2
0
Independent
Supervision
Cueing
Assistance
Dependent

Number of Medications

Valid Cases	*30*
Missing	*0*
Mean	**2.93**
Range	7
Minimum	0
Maximum	7

Spends Time with Family



Implications and Conclusions

- There are a number of characteristics of individuals with Down syndrome and Alzheimer’s that merit consideration in development of a comprehensive training program.
  - In this study, the following have emerged as significant characteristics that warrant further exploration:
    - Dependence on group home staff and supports
    - Availability of support for individuals with no family contact
    - Development of person-centered recommendations that reflect level of functioning
    - Importance of follow-up testing to monitor progression

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Thank you!

Questions?