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Specialized Aging Support for Individuals with Intellectual and Developmental Differences

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OBJECTIVES



Participants will be able to describe the characteristics and challenges associated with intellectual and developmental differences (IDD) and how these intersect with Alzheimer's disease and related dementias (ADRD).



Participants will explore strategies to design and implement inclusive and supportive programs that cater to the unique needs of individuals with IDD and ADRD.



Our Mission

The Arc Jacksonville serves and advocates for individuals with intellectual and developmental differences to achieve their full potential and to participate in community life.

Our Vision

Individuals of all abilities enrich their communities and have quality options on how they live, learn, work, and play.

SPECIALIZED AGING SUPPORT

1

Create a dementia capable workforce

2

Provide services to those living with or at high-risk of dementia

3

Increase support and education for caregivers

ADPI
Program





WHAT IS IDD?

Intellectual or developmental difference

- Down syndrome
 - Cerebral palsy
 - Autism
 - Spina bifida
 - Prader-Willi
 - Phelan-McDermid
 - Developmental disability
-

DEMENTIA= OVERARCHING TERM FOR OTHER DIAGNOSES

TYPES OF DEMENTIA

Dementia is an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

- Alzheimer's
- Vascular
- Lewy body
- Frontotemporal
- Other, including Huntington's
- * **Mixed dementia:** Dementia from more than one cause



INEVITABLE RISK FACTORS FOR DEMENTIA



Age (although this is not a normal part of aging)



Family history



Down Syndrome

DOWN SYNDROME & DEMENTIA

90% risk of
developing ADRD
by age 65

Increasing rate as
they age through
each decade of
life after age 40

McCarron M., et al. (2017).

Alzheimer's is
the #1 leading
cause of death
in people with
Down Syndrome

Krinsky-McHale, et al. (2023).

The 21st
chromosome
carries a gene
that contains a
genetic risk
factor of
Alzheimer's

National Institute on Aging

IDD & DEMENTIA

ADRD develops
at an
accelerated
rate in those
with IDD (earlier
& more rapid)

Nelson, L. D., et al. (2023).

Those with IDD
have a 50%
higher rate of
developing
ADRD than the
typical
population

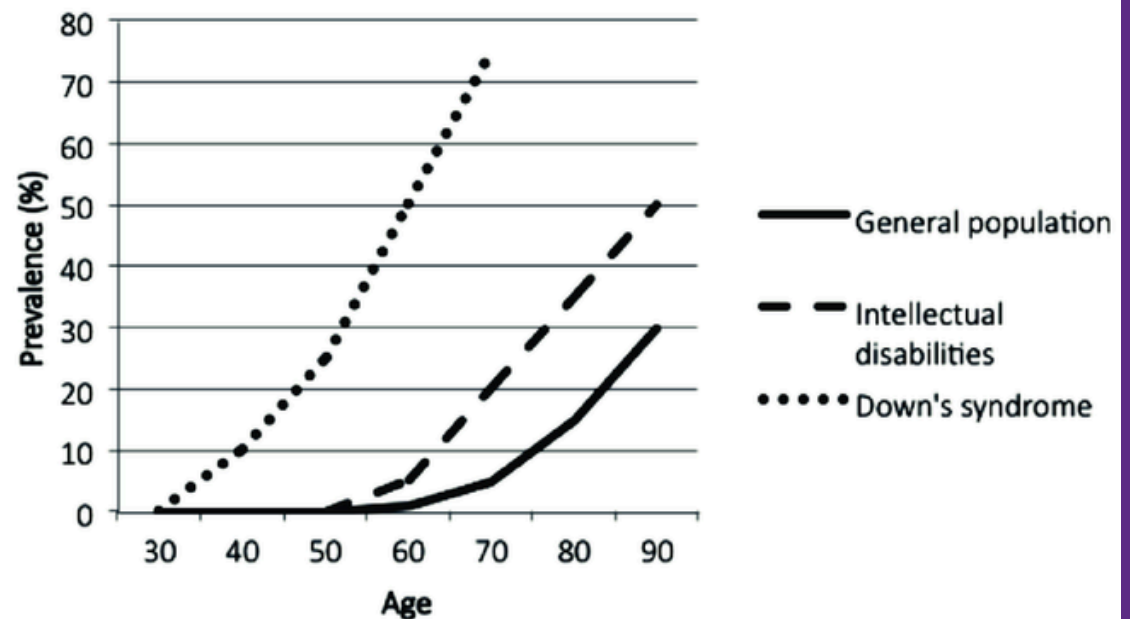
National Institute on Aging



DEMENTIA BY THE NUMBERS

Most adults with IDD are at a *slightly* higher risk with an earlier onset than the general population

Down Syndrome is at a significantly higher risk with an earlier onset



(Scheepers, M.)

KEY DIFFERENCE

“ —
The KEY DIFFERENCE between dementia and IDD is the loss of a person's typical level of functioning, or baseline.
— ”



(Informing Families.)

KEY DIFFERENCE

Needs help loading a dishwasher:

- Always been the case
- **Always been the case but worse**
- **New symptom in the next year**
- Does not apply



NTG-EDSD

(National Task Group on Intellectual
Disabilities and Dementia Practices)

BEHAVIORS & WHAT TO DO...

- Identify what is causing the behavior
- Redirection
- Validation: Accepting their reality
- "Therapeutic fibbing"
- Communication
- Meaningful engagement



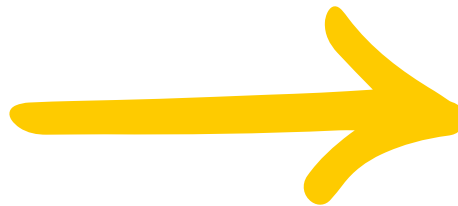
Why did The Arc Jacksonville see this need?

Age requirements for senior-based services and programs



Excludes those with IDD who have an earlier onset of symptoms

Limited education and training on the IDD population



Leads to resistance in accepting those into senior-based programs

Difference in age within certain programs integrating those with IDD



Limited social engagement between older adults and those with IDD



Eligibility & Intake

Eligibility

- High risk
 - Down Syndrome 30+ years of age
 - Obesity (BMI)
 - Lack of exercise
 - History of poor nutrition
 - All other IDD diagnosis 50+ years of age
- Living with
 - 3 or more signs of cognitive decline including memory loss

Intake:

- Category placement
 - Living alone
 - Living w/ caregiver
 - Living w/ dementia
 - Living at high-risk
- Tour of day program center
- Service Agreement signed
- Early Detection Screen for Dementia (NTG-EDSD)
- Enrolled in program
- Functional OT assessment
- Environmental OT assessment



Developing Curriculum

Modifiable Risk Factors:







- Cardiovascular health
- Physical inactivity
- Limited education
- Decreased social engagement
- Depression
- Diabetes
- Hearing impairments

Curriculum Components:

- Cognitive stimulation
- Exercise
- Music
- Life skills
- Nutrition
- Creative expression
- Reminiscence & recollection

WEEK: _____

MONDAY

TIME	SCHEDULE
8:30–9:00	Welcome
9:00–9:30	 Coffee & Brain Game Warm Up: _____
9:30–10:00	Movement: _____ 
10:00–10:30	 Music: _____
10:30–11:00	Nutrition: _____ 
11:00–12:00	 Creative Expression: _____
12:00–12:30	Reminiscence and Recollection: 

Example of Life Skills Curriculum



Specialized Aging Support

Hygiene Matching

Description

Participants will engage in a matching activity where they pair common hygiene items (ex: toothbrush, shampoo, deodorant) with the corresponding body parts they are typically used for. This hands-on, interactive session is designed to promote body awareness, reinforce hygiene routines, and support cognitive functioning while building on practical life skills.

Materials

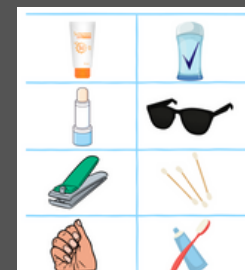
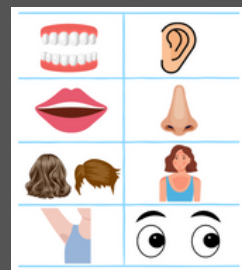
- Hygiene matching cards (cut out boxes) OR
- Physical items to match hygiene photos
 - Hairbrush
 - Toothbrush
 - Toothpaste
 - Chapstick
 - Fingernail clippers
 - Q tip
 - Shampoo/ conditioner bottle (empty if possible)
 - Tissues
 - Soap
 - Deodorant
 - Facewash
 - Sunglasses

Instructions

1. **Welcome clients and explain** the importance of personal hygiene and taking care of our bodies to stay healthy.
 - Ask questions related to hygiene:
 - **What is included in your morning/ evening hygiene routines?** (brushing teeth, showering, washing face, etc.).
 - **What can happen if we don't complete our hygiene routines?** (cavities, smell bad, get skin irritation)
 - **How would you remember to do these tasks every day?** (daily chart, phone reminders, checklist, someone reminding you)
2. **Gather all materials.**
3. **Pass out sets of hygiene matching cards or physical hygiene materials.**

4. Explain step-by-step instructions.

1. Identify different body parts with the group (mouth, fingers, ears, armpits, etc).
2. Have client take items out of a bag and place them with the appropriate body part (or take turns taking one item and passing it around and have volunteers tell what the object does)
 - a. Teeth- tooth brush, toothpaste
 - b. Lips- chap stick
 - c. Finger- fingernail clippers
 - d. Ear- q tip
 - e. Eyes-sunglasses
 - f. Hair- comb, shampoo, conditioner
 - g. Nose- tissues
 - h. Hands- soap
 - i. Armpit- deodorant
 - j. Face- facewash
3. **Encourage clients to try to figure out what the item is used for**, discuss what each item does and why it's important (ex. sunglasses protect our eyes from the sun while we are outside).
 - a. Toothbrush, toothpaste: keep our teeth clean and help prevent cavities
 - b. Chap stick keeps our lips from drying out
 - c. Fingernail clippers: help keep our fingertips to a length to avoid bacteria
 - d. Q tip: help keep our ears clean
 - e. Sunglasses: keeps sun out of our eyes and protects our eyes from the sun
 - f. Comb, shampoo, conditioner- keeps our hair clean and presentable
 - g. Tissues- prevents us from getting others sick and getting foreign bacteria from our nose
 - h. Soap- keeps our hands clean to prevent the spread of bacteria
 - i. Deodorant- prevents us from smelling stinky
 - j. Facewash- keeps our face from getting filled with bacteria







**Group
Fitness
Room**



Kitchen



Sensory Room



Functional Living Room

Caregiver Education Nights

- Every-other month
- Community for caregivers
- Expert in the field
- Hands on activity to take home
- Resources provided
- Dinner and snacks served

VOLUNTEER & STUDENT TRAINING

- Living with IDD and Dementia: Meeting a Person Where They Are (Riverside Center for Excellence in Aging and Lifelong Health)
- IDD & Dementia 101 Training (The Arc Jacksonville)
- Alzheimer's Association courses
 - essentiALZ (Florida grant ended)
 - 10 Warning Signs
 - Effective Communication Strategies
 - Understanding and Responding to Dementia Related Behaviors

Staff Training

**NTG- 3 day training
OR Positive
Approach to Care**

**Behavior Symptom
Management**

NTG-EDSD Training

**IDD & Dementia 101 &
Alzheimer's Association Trainings**

Living with IDD and Dementia

BARRIERS

1 Transportation to the center

2 Caregiver challenges

3 Targeting those living with dementia
who are living alone

4 Home based interventions

Outcomes

- Lifestyle Change Tool Improvements
 - Exercising at least 30 min/ day improved from 2 days/week to 5 days/week
 - Overall socialization from 5.16 days/ week to 6.75 days/ week
 - Engaging in cognitive stimulation activities from 3.2 days/week to 5.3 days/week
- IDD & Dementia 101 Training
 - Pre-training: Only **75%** understood the importance of accepting reality when communicating with someone with dementia
 - Post-training: Understanding increased to **90%**
- Sensory Room
 - 85% of clients who use the room are in the “Living with Dementia” group
 - 52% of the people who enter are agitated/anxious
 - 95% of clients leave calm/regulated
- Caregivers report overall improved mood and increased engagement after attending the SAS program

Outputs

- **4** full 12-week curricula developed
- **14** “high-risk” individuals currently enrolled
- **18** individuals living with dementia
- **612** individuals trained on IDD & Dementia 101
- **40** individuals trained Early Detection Screening for Dementia
- **207** individuals Behavior Symptom Management
- **2,726.44** volunteer hours (2024)
- **52** total volunteers
- **10** affiliation agreements signed

Expansion & Sustainability

- Transitioned from being open 4 days/week to 5 days
 - Collaboration with other day programs within The Arc Jacksonville
 - Increasing training across different schools & medical professionals
- MedWaiver Funding
 - Continued opportunities seeking grants and funding through hospital systems and local foundations
 - Medicare funding through OT services



Please take post- training survey

Your score does
not matter, just
give it your best
guest!



<https://www.surveymonkey.com/r/101Post>

QUESTIONS?



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Thank
you!