



RUTGERS HEALTH

**The Boggs Center
on Disability and Human Development**
Robert Wood Johnson Medical School

An Overview: How to Support People with I/DD Age Well



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for The Arc of New Jersey
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Official Obituary of

Kathleen M. Graham

May 9, 1961 ~ February 16, 2025 (age 63)

Kathleen Graham Obituary

No one had a greater influence on my life and career than Kathleen and her parents, Ann and Jack. She and I met in the nursery (we were born hours apart, delivered by the same doctor). We were inseparable in early life and close buds until I left home for college. Stories of Kathleen have always been woven into my teaching around disability rights and inclusion and particularly on the power of the words we use to describe people. No one loved harder, better, truer, or more loyally than Kathleen.

—Margaret Gilbride

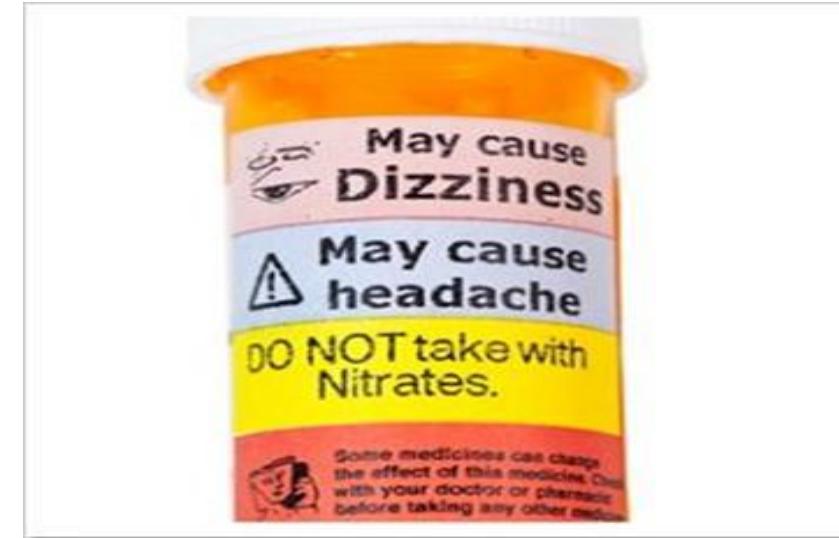
AGENDA

- Understand age-related changes
- ID home and community modifications
- Implement support strategies



Causes of Age-Related Changes

- Aging itself
- Life-long choices
- Environment
- Relationships
- Genetics
- Health



Early Onset of Aging DOES Occur

Those with Down syndrome,
cerebral palsy, spinal cord injury
and other significant disabilities
experience

- Same age-related changes but
earlier onset
- rate of change compressed



Physical Health and Wellness

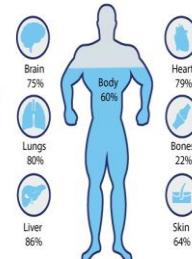
- Vision/hearing
- Oral health
- Skin changes
- Gastrointestinal issues
- Taste/smell
- Sleep
- Musculoskeletal



Water & Hydration



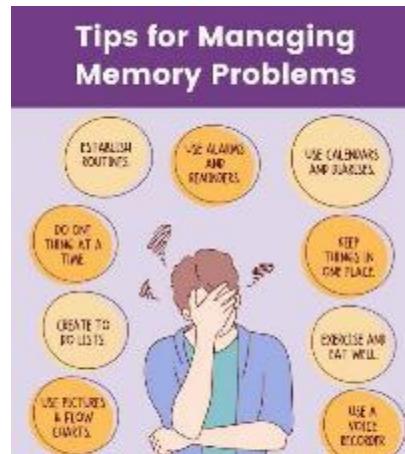
SOMA TECHNOLOGY, INC.
Smart, Dose & Retracted Medical Aspirator



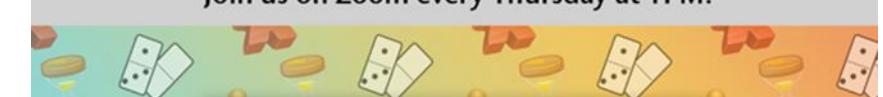
Jimmy Jenson,
48.
Picture credit:
Best Buddies

Cognitive, Mental and Emotional Wellness

- Memory
- Following directions
- Executive functioning
- Details
- Concentration
- Processing a/v
- Loneliness
- Isolation

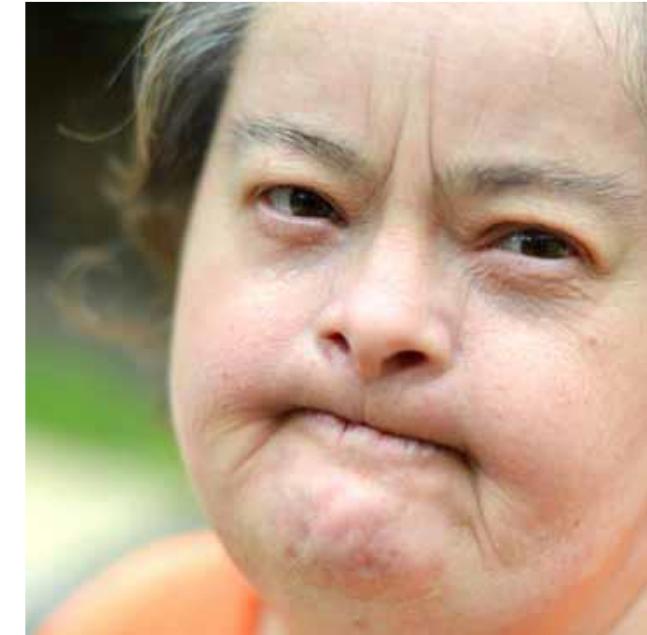


NJSAP Brain Games on Zoom!
Live, interactive board games with the NJSAP Team for you to test your creativity and knowledge and to have fun!
Join us on Zoom every Thursday at 1PM!



Alzheimer's Disease and PWDS

- All people with DS develop the neuropathological lesions associated with AD
- Amyloid plaques, neurofibrillary tangles, are present by age 40, ***though not all people with DS will develop AD***



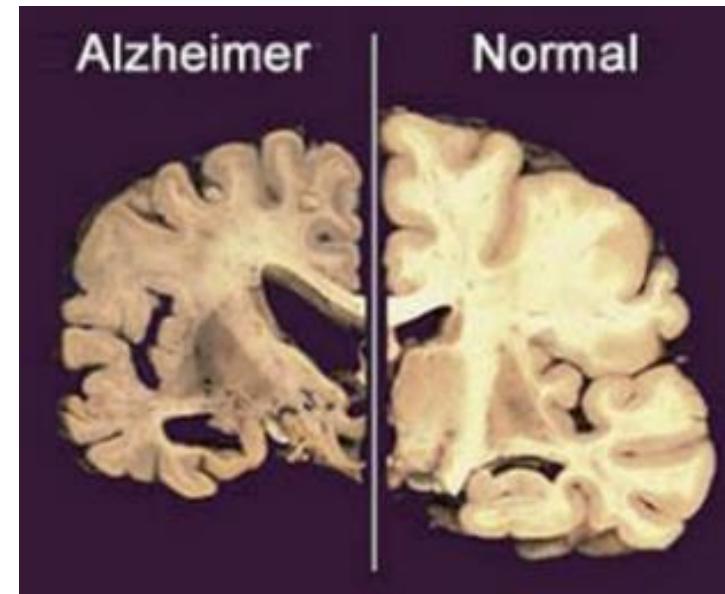
Alzheimer's Disease (AD)

General Population

- >65: 10.3% have AD
- >85: 47.2% have AD
- Average age of onset = 72
- Course: ~15 years; up to 25

People with Down syndrome

- >60: 56% have AD
- Average age of onset = 52
- Course: often 5 years usually 7-10



NTG-EDSD

v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQID™, can be used for the early detection screening of older adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be completed by staff and family caregivers to the person with an intellectual or developmental disability. Care Act's dementia assessment as well as to screen for dementia. This instrument comes with an annual or bi-annual cognitive assessment review. It is recommended that this instrument be used on an annual or bi-annual basis with adults with Down syndrome or cognitive change. The NTG-EDSD can be completed by anyone who is familiar with the adult's personal record, such as a family member, agency support worker, or a behavioral or health specialist using information derived from six months or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.asadm.org/ntg/).

File #: _____ Date: _____

Name of person: (1) First: _____ (2) Last: _____

(1) Date of birth: _____

(1) Age: _____

(1) Sex: Female _____ Male _____

Best description of level of intellectual disability:

- No discernible intellectual disability
- Borderline (IQ 70-75)
- Mild ID (IQ 50-59)
- Moderate ID (IQ 25-39)
- Severe ID (IQ 20 and below)
- Profound ID (IQ 10 and below)
- Unknown

Diagnosed condition (check all that apply):

- Autism
- Cerebral palsy
- Down syndrome
- Fragile X syndrome
- Intellectual disability
- Prader-Willi syndrome
- Other: _____

Instructions: For each question block, check the item that best applies to the individual or situation.

Current living arrangement of person:

- Lives alone
- Lives with spouse or friends
- Lives with parents or other family members
- Lives with paid caregiver
- Lives in community group home, apartment, supervised housing, etc.
- Lives in senior housing
- Lives in congregate residential setting
- Lives in long term care facility
- Lives in other: _____



National Task Group on Intellectual Disabilities and Dementia Practices

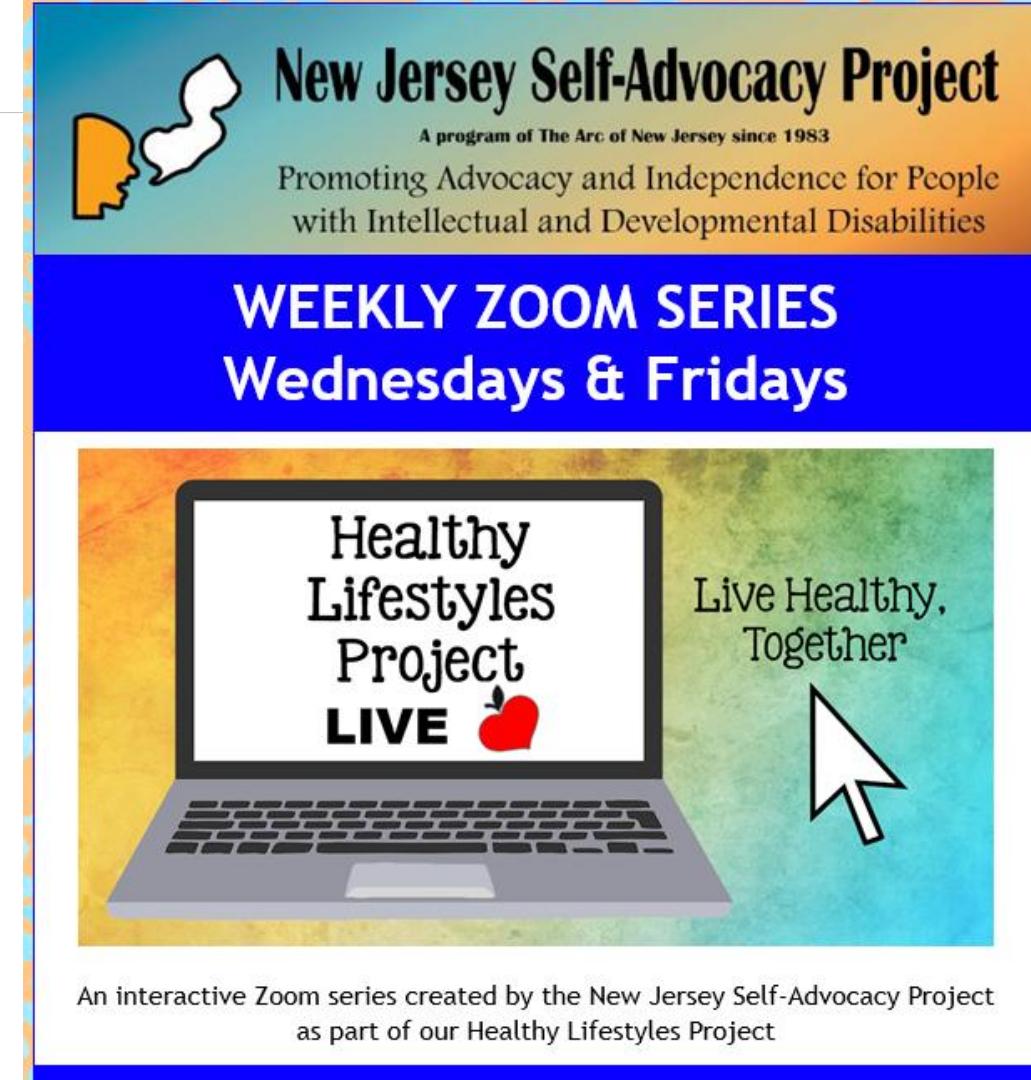
<https://www.the-ntg.org/family-caregivers>

Early Detection Screen for Dementia in People with IDD

<https://www.the-ntg.org/ntg-edsd>

These are live, interactive events to promote healthy living for adults and students with intellectual and developmental disabilities. We will be holding events on Zoom every Wednesday at 11 AM and Fridays at 1 PM on a variety of topics relating to healthy living!

Healthy Lifestyles Project (HLP)



The graphic features a blue header with the text "New Jersey Self-Advocacy Project" and "A program of The Arc of New Jersey since 1983". Below the header is a white banner with the text "Promoting Advocacy and Independence for People with Intellectual and Developmental Disabilities". The main body is a blue box with the text "WEEKLY ZOOM SERIES" and "Wednesdays & Fridays". Below this is a white box containing a laptop screen with the text "Healthy Lifestyles Project LIVE" and a red heart icon. To the right of the laptop is the text "Live Healthy, Together" and a white cursor icon pointing towards the laptop. The background of the graphic is a colorful gradient from orange to green.

New Jersey Self-Advocacy Project
A program of The Arc of New Jersey since 1983

Promoting Advocacy and Independence for People with Intellectual and Developmental Disabilities

WEEKLY ZOOM SERIES
Wednesdays & Fridays

Healthy Lifestyles Project **LIVE** 

Live Healthy, Together

An interactive Zoom series created by the New Jersey Self-Advocacy Project as part of our Healthy Lifestyles Project

Enhancing Accessibility in the Home

- Structural changes
- Environmental Adjustments
- Assistive technology



Day Programs

- Adapting activities to accommodate changing physical and cognitive abilities
- Arts, music, social
- Focus on wellness
- *Staff training



Thanks to Supported Living staff, clients can participate in activities like the Special Olympics. Gregory Maxwell, an experienced skier and racer, competed in the advanced slalom and advanced giant slalom at the 2024 Special Olympics Games in Indiana.



Support Activity

Aerobic Exercise 3-4 times/week

- Walking
 - Inside or Outside
- Dancing
 - Chair dancing counts
 - Add props/movements
 - Intersperse with other activities
- Cycling
 - Stationary/trails

Support Musculoskeletal System



- Have “strength training” 2-3 times/week
 - Light weights more often (plastic bottles filled with sand, soup cans, inner tubes, person’s own body weight, walls)
 - Include Weight-bearing exercises

Fitness Centers

- Ensure physical accessibility-routes, space, bathrooms, showers, pool
- Inclusive and adaptive activities
- Inclusive machines/equipment
- *Staff training



Places of Worship

- Physical accessibility
- Sensory accommodations
- Social connections
- Valued roles



The Arc's Center for Future Planning

- Daily routines, needs, supports
- Living arrangements
- Finances
- Doctors' contact information
- Medical history
- Decision-making support
- Details about employment, hobbies, religious beliefs, music, interests, and important relationships.

<https://futureplanning.thearc.org/pages/learn/future-planning-101>



Use our
free tool
to build
your plan.

GET STARTED

Future Planning: It's Possible

Future planning is possible regardless of income.

Welcome to our Community of Learning

Charting the LifeCourse is designed to be used for your own life, for your family members, or in the work you do. The framework and tools will help you organize your ideas, vision, and goals, as well as problem-solve, navigate, and advocate for supports.



You can use LifeCourse with your family or for yourself

- Learn more about yourself or your family
- Organize your thoughts and speak out for what you or your family wants and needs
- Problem-solve and plan for taking action in your life or on behalf of a family member
- Direct services and supports
- Advocate for change

Professionals use LifeCourse in the work that they do every day

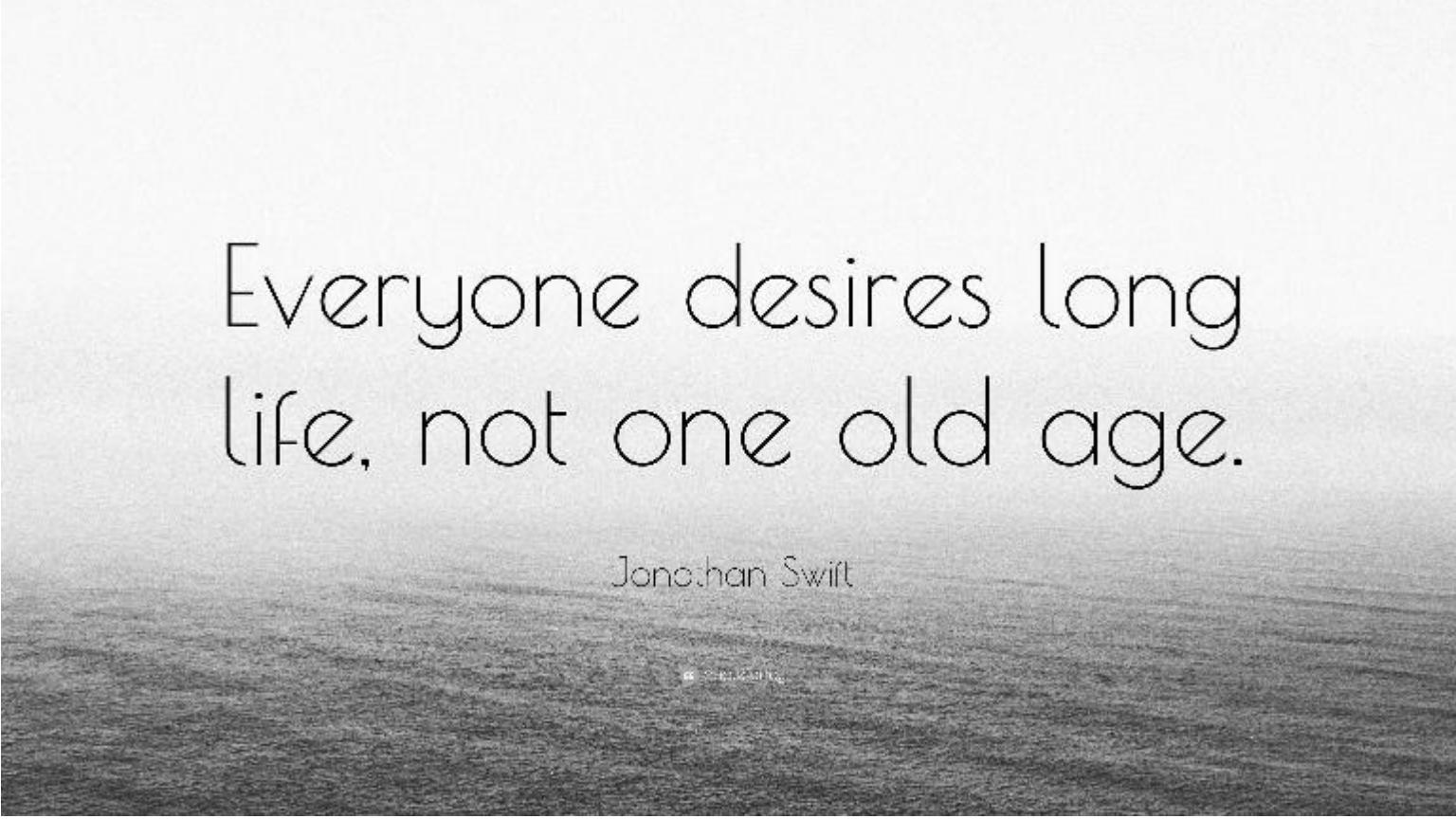
- Educating others on possibilities
- Facilitating planning for now and the future
- Problem-Solving
- Coordinating Integrated Services and Supports
- Conflict Resolution and Advocacy

Website [here](#)

Leaders use LifeCourse to drive policy, practice, and cultural change

- Reframing Expectations at All Levels
- Training and Coaching Staff
- Education and Outreach Activities
- Driving Policy, Practice and Cultural Change
- Transforming organizations and communities

Focus on Aging [here](#)



Everyone desires long
life, not one old age.

Jonathan Swift

