

# Living Better with I/DD, Alzheimer's, and Related Dementia

Thomas Buckley Ed.D.  
YAI Director of Population health

Annual Manhattan Family and Provider Resource Fair  
December 17, 2019, 10:30-11:45

**Dr. Margaret Chan, Director-General of the World Health Organization, opening remarks at Global Action Against dementia Summit, Geneva.**

“I can think of no other disease that has such a profound effect on loss of function, loss of independence, and the need for care.

I can think of no other disease so deeply dreaded by anyone who wants to age gracefully and with dignity.

I can think of no other disease that places such a heavy burden on families, communities, and societies.

I can think of no other disease where innovation, including breakthrough discoveries to develop a cure, is so badly needed.”

**This statue is called “Emptiness” and was created by a grieving parent. It strives to describe how a parent feels after losing a child.**



# Key Message

People with I/DD, including Down syndrome, **typically** have:

- different early signs of Alzheimer's disease or a related dementia (ADRD)
- may be at greater risk
- have onset at a younger age (during young or middle-age adult years)
- decline at a faster rate
- experience higher numbers of health conditions (comorbidity)
- benefit greatly from YAI's specialized dementia services and supports for people with I/DD and dementia and their families

People with Down syndrome require highly specialized YAI early-onset dementia services

# Quality of Life Outcomes

## As a person with I/DD living with dementia

- I feel empowered, independent, valued, and enabled to exercise rights and choice, maintain my identity and to be treated with dignity and equity.
- I maintain my optimal level of physical, spiritual, mental, social, and emotional wellbeing.
- I have access to YAI staff that can support my spiritual, cultural, ethnic, or personal beliefs and reflect my wishes
- I feel safe, comfortable, secure and can be as independent as possible in an environment that is familiar.
- I cherish my valued relationships and social networks and have the opportunity to develop new ones.
- My family members, friends, and support staff have access to information, education, and support that enhances my wellbeing.

**February 3, 2014 the YAI Director of Population health traveled to Washington DC and Testified to the National Alzheimer's Advisory Committee Supporting Resolution 13**

**Resolution 13**

**“Some populations are unequally burdened by Alzheimer’s disease... People with Down syndrome almost always develop Alzheimer's disease as they age. In addition, because Alzheimer’s disease primarily affects older adults, the population with younger-onset Alzheimer's disease faces unique challenges with diagnosis, care, and stigma. HHS will undertake the actions below to better understand the unique challenges faced by these groups and create a plan for improving the care that they receive, which will be integrated into the broader efforts to improve care for all people with Alzheimer's disease.”**



**In 1999, Tom Buckley and Dr. Matthew Janicki of the National Task Group on Intellectual Disabilities and Dementia Practices created the nation's first I/DD specialized dementia group homes.**

Today, YAI is implementing I/DD specialized early-onset Alzheimer's disease services and supports in existing residential programs, enabling residents to age in place.

YAI day services are in the process of redesigning smaller dementia-friendly environments for people with I/DD and early onset Alzheimer's disease.

The YAI Director of Population Health is writing individually tailored dementia care plans conforming to federal dementia care plan guidelines



# State of New York 2017 Report of the New York Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias

- "Individuals with Down syndrome are **at increased risk for developing Alzheimer's Disease**, particularly the early onset form of the disease, **due to the accelerated aging process** experienced by this population. These individuals have a partial or full third copy of the 21st chromosome. The 21st chromosome carries genes that are involved in the aging process and in producing the proteins that contribute to the development of AD. The properties of this chromosome set make Alzheimer's Disease a more acute concern for this population"
- "For this population, **cognitive decline occurs more rapidly and can be aggressive**, making early diagnosis crucial to providing better support. Individuals with Down syndrome are more prone to co-occurring conditions such as sensory loss; hypothyroidism; obstructive sleep apnea; osteoarthritis; atlantoaxial instability; osteoporosis; and celiac disease. The presence of multiple co-occurring conditions makes diagnosis of and treatment for this population difficult because many dementia symptoms are associated with other conditions"
- "Due to the unique presentation of Alzheimer's Disease in individuals with Down syndrome, **this population requires specialized care from formal and informal caregivers**. The National Task Group on Intellectual Disabilities and Dementia Practices recommends specific caregiver training, the use of respite services, environmental modifications, and collaboration with service agencies."

**“OF ALL THE FORMS OF INEQUALITY, INJUSTICE IN HEALTH IS THE MOST SHOCKING AND INHUMANE.”**

DR. MARTIN LUTHER KING



# Our Shared Dementia Vision

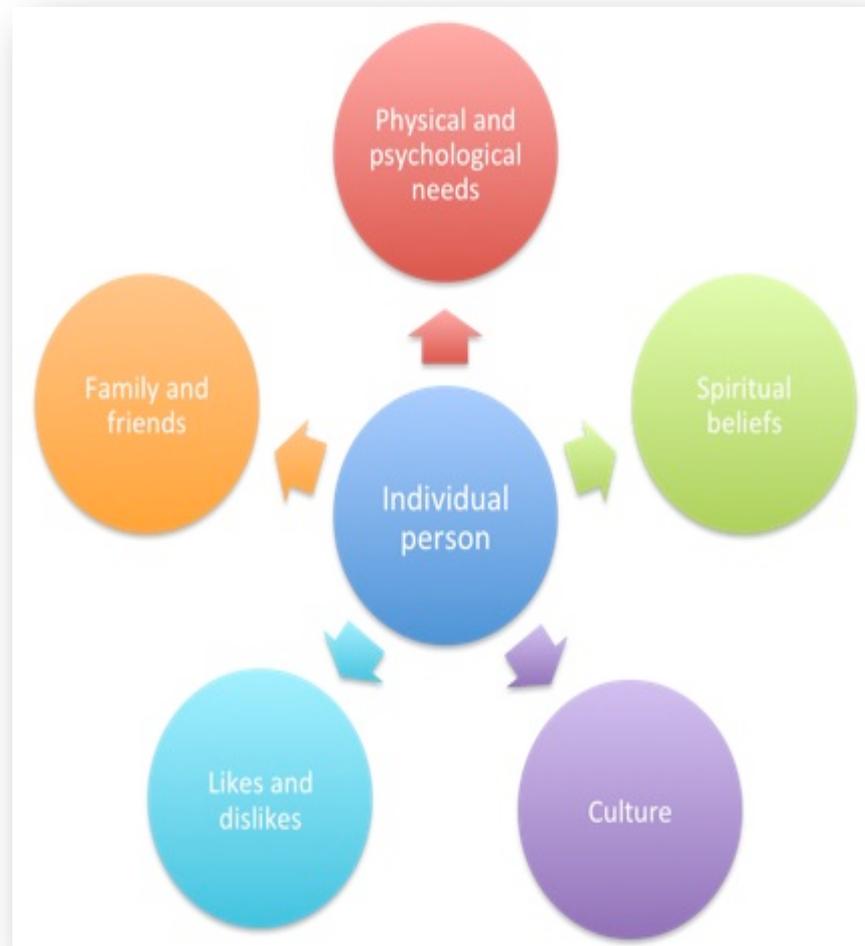
Caregivers, family members, friends, and YAI staff have the knowledge, skills, and empathy to support people with I/DD and early-onset dementia **to ensure they live the most independent, meaningful, and fully engaged lives possible.**

# The Truth About Alzheimer's Disease

- It is progressive, and **ultimately fatal**.
- \*\*\*\*Between 2000 and 2017, **Alzheimer's disease deaths rose by 145%, while those caused by heart disease dropped by 9%**.
- Alzheimer's disease **disproportionately affects** people with I/DD (especially Down syndrome), African Americans, and Latinos.
- 3 African Americans with Alzheimer's disease die to every 1 white American with Alzheimer's disease; 2 Latino Americans with Alzheimer's disease die to every 1 white American with Alzheimer's disease.
- There is no cure for Alzheimer's disease, but it is possible for caregivers to maximize the independence and quality of life for people with Alzheimer's and Down syndrome.
- Living through this experience requires tremendous support. Build a team by recruiting, accepting, and using whatever resources are available.
- One of the key features of Alzheimer's disease is a loss of short-term memory and inability to learn and recall new information. Expectations must be readjusted to accept that the goal is no longer to teach new skills or increase independence.
- People diagnosed with Alzheimer's typically live only 4-8 years following diagnosis—though some can live up to 20 years depending on their situation, severity of symptoms, and their response to medication.
- More than half of the 5.8 million American's living with Alzheimer's disease may not realize they have it.

## Our results desired by different YAI stakeholders include:

- Safety and security.
- Slowing or mitigating of declines associated with normal aging.
- Ongoing assessment of person's functioning.
- Maintenance of self-care skills.
- Health and wellness promoted.
- Medical advocacy.
- Physical health promoted.
- Positive mental health status.
- "Aging in place"
- Social functioning.
- Active New York community involvement.
- Social inclusion.
- Happiness and maintaining quality of life.
- Retirement.
- Mediating issues between family choice and person-served choice.
- Grief counseling.
- YAI support with end-of-life issues.
- YAI education of people with I/DD, families, and staff about options for end-of-life supports.
- Transition planning.
- Preparation for hospice.
- Access to palliative care.

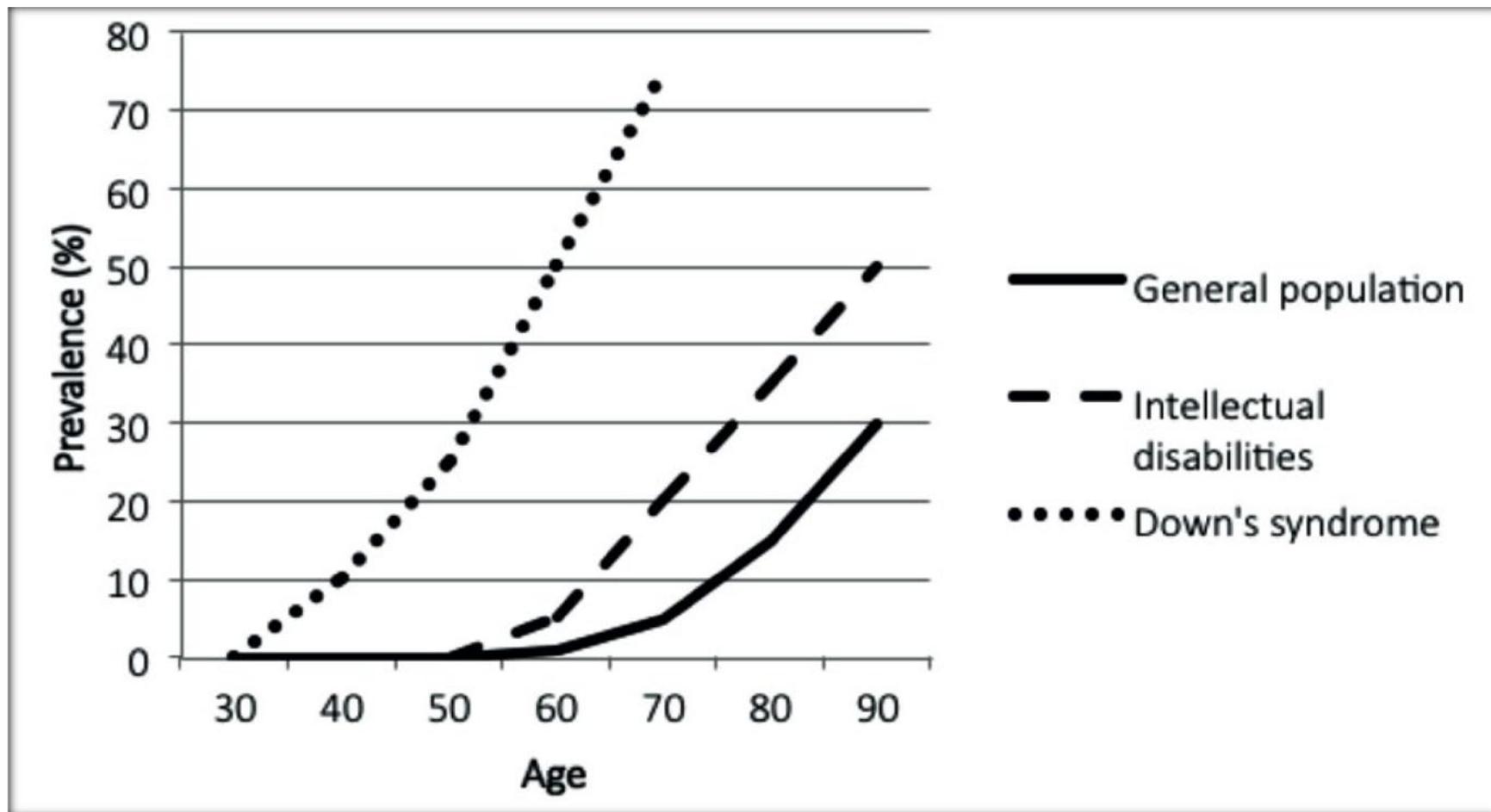


## YAI's Lifelong, Fully-Integrated, Specialized I/DD Dementia Capable System-first in the United States

- Early-Onset Alzheimer's Caregiver Support Groups and Training
- Dementia Care Coordinators
- Individually Tailored Dementia Care Plans
- Dementia Day Services
- Stage-Based I/DD Specialized Dementia Residence
- YAI Staff Dementia Trained
- YAI Dementia Assessments
- Home Dementia Safety Reviews
- Falls Prevention
- Polypharmacy Reviews
- Premier HealthCare I/DD and Dementia Specialized Doctors
- Nonpharmacological Interventions
- End-of-Life-Planning

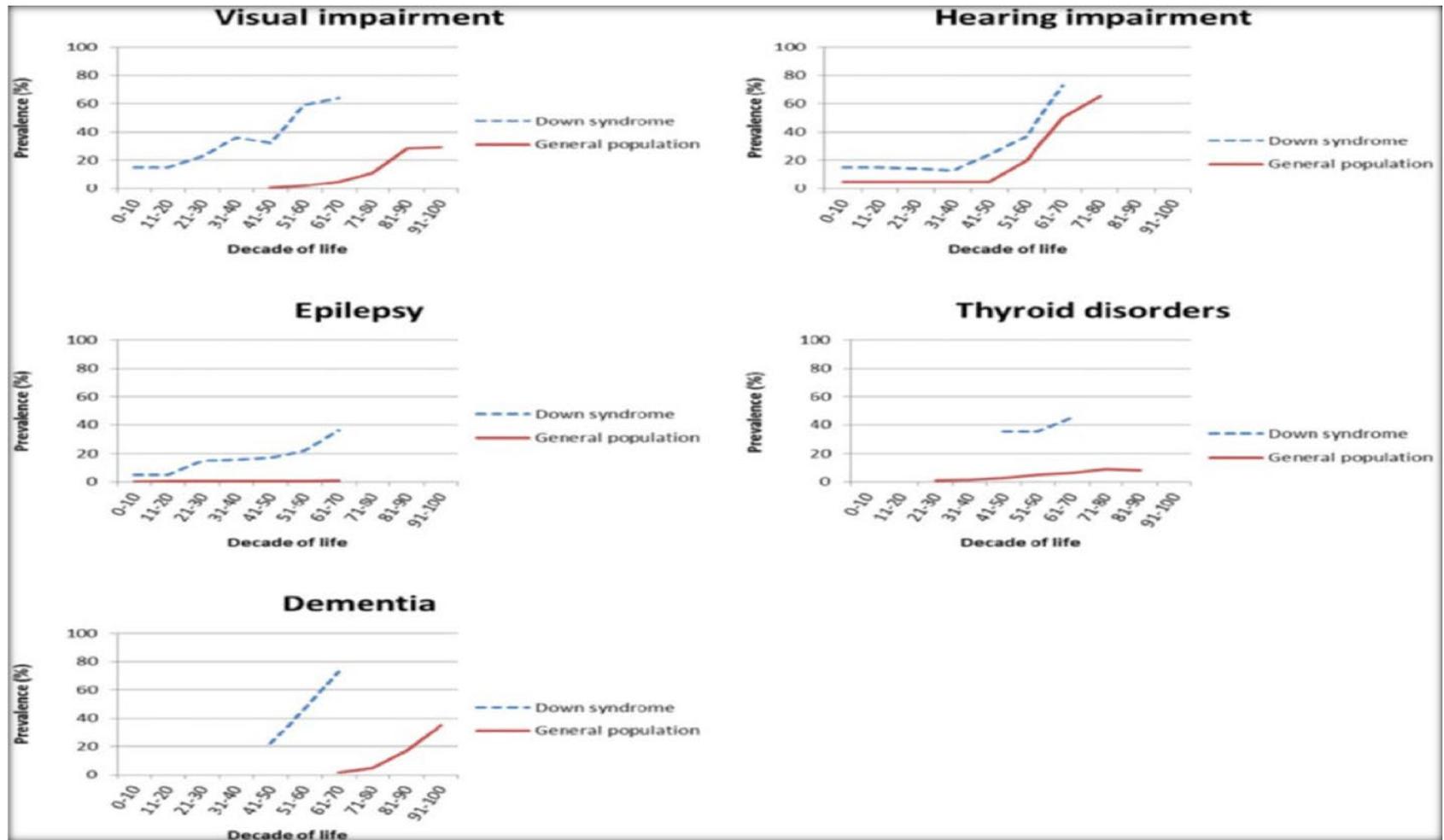


The figure below summarizes the age-related prevalence rates of dementia in people with Down syndrome, those with intellectual disabilities without Down syndrome, and in the general population.



People with Down syndrome experience accelerated aging versus the general population.

At 40 years old, people with Down syndrome typically present with 5.2 health conditions.



# Accelerated Aging for People with Down Syndrome “Epigenetic clock”

## Down syndrome. *Aging Cell*. 2015 February 9

- Researchers at UCLA’s David Geffen School of Medicine published the first study that provides definitive evidence that people with Down syndrome age at a faster rate. In the Feb. 9, 2015, online issue of *Aging Cell*, researchers led by Dr. Steve Horvath reported that they have applied an “epigenetic clock” developed for normal aging to tissues from people with Down syndrome.
- Down syndrome is not only associated with intellectual disability, but also with a group of clinical symptoms of accelerated aging. These include premature wrinkling and gray hair, early menopause, reduced immune function, and Alzheimer’s disease.
- They found that Down syndrome did accelerate aging, but different types of tissue age at different rates. For example, brain tissue shows a greater age acceleration effect (11 years) than blood (about 4 years).
- **Display a mild form of progeria.**

# Below are two YAI resident's co-morbid health conditions

## Resident 1

- Down syndrome
- Alzheimer's disease
- Impulse Control
- Unspecified astigmatism
- Eczema
- Cheilitis
- Gastroparesis
- Esophageal reflux
- Hypothyroidism
- Osteoporosis
- Expressive language disorder

## Resident 2

- Dementia with behavioral disturbance
- Parkinson's disease
- Impacted cerumen
- Diverticulitis of colon
- Benign neoplasm of prostate
- Unspecified blepharitis eye
- Conductive hearing loss
- Anxiety disorder
- Right bundle branch block
- Memory loss NOS
- Unspecified psychosis

# Comparing early signs of Alzheimer's disease for people with I/DD (Down syndrome) and the general population

## For people with I/DD and Down syndrome

### Early changes in the following

- Personality, such as being more aggressive or more withdrawn and passive
- Handling interactions
- Doing (or not completing) task
- Mood (such as acting sad, no longer interested in previously enjoyed activities, decline in appetite or sleep)

### Late changes/Decline may appear in the following:

- Short-term memory
- Language
- Decision-making and other thinking functions

## General Population

### Early changes in the following:

- Short-term memory
- Recalling specific words while talking
- Losing or misplacing objects; getting lost
- Difficulty making decisions involving many choices

### Late changes/Decline may appear in the following:

- Completing task
- Personal care
- Personality
- Becoming more irritable, or the opposite, more passive

# Several critical health care considerations for people with Down syndrome

- average age of onset of Alzheimer's disease is 20 years earlier than the general New York population
- incontinence occurs in 87 percent of people with Down syndrome and Alzheimer's disease and related dementia
- gait changes occur in 97 percent of people with Down syndrome and Alzheimer's disease and related dementia
- dysphasia (difficulty swallowing) occurs in 58 percent of people with Down syndrome and Alzheimer's disease and related dementia
- hypothyroidism (low thyroid): though the thyroid develops normally in children with Down syndrome, it stops working in 50 percent of people with Down syndrome, which may increase the risk for progressive dementia
- obstructive sleep apnea is common in people with Down syndrome and may increase the risk for progressive dementia
- late onset seizures are much more common (79 percent) in people with Down syndrome than for the general population (2 percent)
- Rapid-decline forms of Alzheimer's disease can lead to death less than two years after onset in people with Down syndrome

# NTG Three Stages of Alzheimer's Disease-Recommended Actions

## Early Stage

- Engage the person receiving services and their family, and/or other caregivers in advance care planning (and prepare advance directives) consistent with New York requirements.
- Identify and plan to remediate the environmental challenges to help maintain YAI and community-based living with family members.
- Establish a daily regime that provides for purposeful engagement based on individual needs and preferences yet is organized so as not to cause anxiety and confusion.
- Provide ongoing clinical supports to address behavioral and psychological symptoms associated with dementia.
- Redesign YAI residential, day, and respite activities and programs so that participation in valued activities and opportunities for interaction with others continues.

# NTG Three Stages of Alzheimer's Disease-Recommended Actions

## Mid-Stage Recommendations

- Provide increased assistance with personal care and hygiene when needed.
- Secure appropriate YAI residential supports and consider housing options to accommodate increasing losses in independent functioning.
- Continue surveillance and periodic YAI and Premier HealthCare assessments to determine extent of change and progressive dysfunction as well as the possible development of co-morbid conditions.
- Monitor any medications being taken to prevent adverse drug reactions.
- Enhance training of YAI and Premier HealthCare clinicians, staff, and family, as well as consultation of caregivers around coping with behaviors and adapting routines.
- Institute planning for long-term YAI residential and day specialized dementia services and supports.
- Ensure protections are in place to preclude abuse or harm in both YAI and Premier HealthCare formal and informal settings.

# NTG Three Stages of Alzheimer's Disease-Recommended Actions

## Late and End-Stage Recommendations

- Reorganize YAI and Premier HealthCare management toward non-ambulatory care.
- Reassign YAI residential and day staff to activities more structured around nursing and personal care including the support of family caregivers who wish to maintain the person being supported at home.
- Obtain support from palliative care or hospice specialists.
- Institute YAI and Premier HealthCare procedures to maintain dignity, comfort, and address pain and symptom management.
- Organize YAI and Premier HealthCare end-of-life supports and post-death arrangements.
- Ensure end-of-life celebration per the person with I/DD and dementia's wishes.
- Involve family members and friends
- Involve participants of YAI residential and day services in memorial services and grief counseling.

# Physical Environment and Behavioral Changes

- Behavioral changes and decline in functioning always need to be considered within the context of the YAI residential and day physical environment.
- Physical environments can be a barrier to functioning.
- Rule out problems with the YAI residential and day physical environment as the cause of decline and behavioral change.
- The person being supported may see their reflection in a window and thinks it is a prowler.
- A curtain blowing in the wind may look like someone is hiding behind it.
- A black rug may look like a huge hole in the floor.
- The person receiving services may urinate in corner of the bathroom because there is insufficient color contrast to recognize toilet.

## Seeing the world through the eyes of a person with I/DD living with dementia.

A highly buffed floor may appear to a person with Alzheimer's disease as a wet floor. They will not enter the bathroom and resist stepping on the floor. The behavior will be inappropriately recorded as, "refusal to use bathroom." Avoid high gloss wax or paint.



**Many people with I/DD and dementia lose 25%-50% of their body weight during the dementia journey.**

**On many occasions, someone will not eat their food because they cannot identify where the food is located. Many people indicate, “I am starving. Where is my food?” The food was in front of them on a tray the entire time. As soon as staff identifies the food, the person will eat.**



***White food on a white plate may be difficult to see.  
A coloured plate can make a big difference.***

**A person with I/DD and dementia may have used the front door of the YAI group home to access the van for years. Suddenly, they view the bright sunshine differently. The person may resist exiting the front door with bright sunshine. Staff may indicate, “Refused to load on the van.” Use a side door or garage with no direct, bright sun. Sunglasses can also diminish resistance.**



**The person with I/DD and dementia may urinate in the bathroom on the floor. It is crucial that YAI staff not write a behavioral plan and recognize the person cannot identify the toilet.**



***A toilet or bath may not be seen or used appropriately if the bathroom is white. Adding colour as shown here makes the toilet easier to see.***

**A person with I/DD and dementia might sit in a residence room for hours because they cannot locate the white door to exit the room. Use contrasting colors to differentiate the door from the wall.**

**If the door enters the resident's bedroom, a gentle reminder (picture, memorabilia, baseball hat) will remind the person that the door is for their room.**



***A white door may become lost against white walls. This may be useful if you do not want the person to use this particular door. By painting the door and/or walls in different colours access becomes much clearer and easier to identify.***

**Although mirrors can make small residential bedroom appear larger, a person with I/DD and dementia might be confused and can try to lay down against the mirror thinking it is their bed. Shadows will appear as objects on the floor, so reduce shadows cast from lamps.**



# Antipsychotics in dementia: Beyond 'black-box' warnings

The FDA in 2005 issued a black-box warning of increased mortality risk with atypical antipsychotics when prescribed to people with Alzheimer's disease.

Psychosis affects approximately 40% of people with AD, whereas  $\geq 80\%$  of people with dementia experience agitation at some point in the illness. These symptoms can lead to:

- caregiver morbidity
- poor patient quality of life
- early patient institutionalization

# YAI will actively present I/DD specialized dementia trainings

## Trainings will be focused for:

- Direct Support Professionals
- Managers, supervisors, administrators
- Doctors, neurologists, dentists, therapists
- Family members, caregivers, friends
- Those wishing to become “I/DD Specialized Dementia Train-the-Trainers”