

# Older Adults with Intellectual & Developmental Disabilities

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Region 2

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## Who we Serve in DDA?

1. Intellectual Disability (ID)
2. Autism
3. Cerebral Palsy
4. Epilepsy
5. Other Neurological Conditions (often Genetic Syndromes)

Note: 2-5 not always associated with ID

### **Who we don't serve?**

- ❖ There are at least twice as many more people who would qualify if they applied
- ❖ King County: About 900 of 5350 adult DDA clients are 55+ (17%)  
245 of those 900 get no services from DDA
- ❖ DDA clients can choose HCS COPES Waiver to access ADH

## Where do our elderly clients live?

68 % of all DDA clients in Washington live with their parents/relatives, or are supported by parents/relatives to live on their own

KC: 120 clients over age 40 live with parents/relative

US: 63% of caregivers over age 40; 25% over age 60

### **King County:**

< 1% overall live in Group Homes, but over 50% of those in group homes 55+

Adult Family homes:

300 AFH's have DD specialization (20 in Bellevue)

520 clients overall live in AFH's; 134 are 55+

# Where do our elderly clients live?

## **King County:**

Assisted Living: 13 total

Skilled Nursing: 25 of 30 clients are 55+

Supported Living: 287 of 906 are 55+ (32%)

Fircrest RHC: Average age of resident = 51 (130 clients)

About 90 in a Skilled Nursing Facility at Fircrest

(data from October 2014)

Life expectancy for those with IDD has significantly improved over the past 50 years

The number of adults with IDD age 60+ expected to double between 2000 and 2030

Longevity correlated to level of impairment:

Those with Mild to Moderate ID, similar longevity to the typical population

LE = ~70 vs 78 for general population

Those with Profound ID, avg. age at death Mid-50's

Those with Down Syndrome, avg. age at death 56 years

## Factors in lowered life expectancy for IDD:

- Comorbid medical/ biological problems associated with cause of disability
- Poorer Health Care and overall hygiene
- Lifestyle of inactivity/little exercise
- Poorer diet
- Higher rates of Obesity, Osteoporosis
- Medication side effects

People with IDD have higher rates of mental illness and challenging behaviors than general population

- Interacts with and adds to health problems above

## Dementia's and ID

Those with ID have similar rate of developing Dementia as general population, *except*:

- Age of onset earlier/ course compressed vis a vis lower life expectancy
  - For those with ID 60+, rate approx. = 6%
  - Those with ID 65+ rate aprox. = 20%
  - Mean age of onset in IDD 67.2 years
- If they have Down Syndrome!
  - Mean age onset of Alzheimer's type is 53 years
  - Mid to late 40's when symptoms apparent
    - Rates of 9-22 % have dementia by age 40
    - Rates of 32-56% have dementia by age 60
    - Onset to Death averages about 8 years, but can be less

# Edinburg Principles for People with IDD affected by Dementia

1. Adopt philosophy that promotes goal of utmost quality of life... and a person-centered approach
2. The individuals strengths, abilities, ... and wishes considered in all decision-making
3. Involve the individual, his/her family... in all phases of assessment and service planning
4. Ensure appropriate assessment and intervention services are available... to support healthy aging
5. Supports/Services optimize the person's ability to remain in their home/community
6. Ensure same access to services as any other citizen...
7. Include Current/Future needs of those with IDD in strategic planning of aging services policy and procedures



## Issues/Needs:

- No specialized services for seniors w/IDD in DD service world; so start contacting the Aging services
- People with IDD develop chronic health conditions at an earlier ages > need more medical Care
- Caregiver stresses magnified by fewer family and financial resources; Lifelong, not just last years
- Caregivers more likely to need skills to deal with behavioral and mental health concerns
- Doctors, etc./ Nursing Homes feel untrained to care for

## **Needs:**

- Bridge gaps between Aging and IDD service systems
- Cross training for Medical/Mental Health professionals
- Support for Family Caregivers
  - Respite/ transportation/ personal care/ etc.
- Training for Adult Day Health, Adult Family Homes

## **The Future?**

- Continue to involve IDD system and expertise in planning for Aging services

# Resources

## RRTC on Developmental Disabilities and Health

[www.rrtcadd.org/](http://www.rrtcadd.org/)



### Downloadable Materials:

- Health Matters Curriculum
- Guidelines for Dementia-Related Health Advocacy for adults with intellectual disability and dementia (Bishop et al., 2015)
- My Thinker is not working (on Down Syndrome Dementia)
- Edinburgh Principles, And more.....