GROWING OLD WITH A DEVELOPMENTAL DISABILITY

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And
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Outline

* Understanding the Context of our Practice
* Knowing we were not prepared!
  * What we first learned related to life expectancy
* Questions
* Method
* Findings
* Discussion of Findings
* Recommendations
Violet Franks is 61 years old and has Down Syndrome, some hearing loss, and early stage dementia. All of her life, she lived with her parents; however, last year, her mother died.

Her father, Harry, 86 years old and with a history of cardiac troubles, was concerned that he can not provide the necessary care for Violet. He reluctantly moved his daughter into a long-term care facility.
Knowing we were NOT prepared!

* Developmental disabilities (DDs) defined as conditions originating before the age of 18 that result in significant limitations in intellectual functioning, and conceptual, social and practical adaptive skills. (Luckasson et al. 2002)

* People, including those with developmental disabilities, are living longer than ever before, and with increased life expectancy comes increased challenges in addressing age-related issues.
Due to their pre-existing neurological, functional, and physical impairments, individuals with developmental disabilities demonstrate signs of aging in their 40s and 50s that the general population traditionally may not experience until 20 to 30 years later.

Adults with Down syndrome are likely to experience premature aging with marked biological age-related changes occurring from about 40 years. Some people with developmental disabilities began to experience degenerative changes of the spine as early as their twenties.

Bittles, et al., 2002; Hemming, Hutton & Pharoah, 2006; Maaskant, Gevers & Wierda, 2002; Olive & Holland, 1986; Seltzer & Luchterhand, 1994; Thomas, Strax, Luciani, Dunn & Quevedo, 2010
# Life Expectancy

## Life expectancy

<table>
<thead>
<tr>
<th>Year</th>
<th>male</th>
<th>female</th>
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<tbody>
<tr>
<td>1921</td>
<td>58.8</td>
<td>60.6</td>
</tr>
<tr>
<td>1951</td>
<td>66.4</td>
<td>66.3</td>
</tr>
<tr>
<td>1981</td>
<td>71.9</td>
<td>76.5</td>
</tr>
<tr>
<td>2001</td>
<td>77.1</td>
<td>82.2</td>
</tr>
<tr>
<td>2011</td>
<td>78.8</td>
<td>84.1</td>
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## Down syndrome children

<table>
<thead>
<tr>
<th>Year</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1929</td>
<td>9</td>
</tr>
<tr>
<td>1947</td>
<td>12-14</td>
</tr>
<tr>
<td>1961</td>
<td>~ 18</td>
</tr>
<tr>
<td>2000</td>
<td>58 +</td>
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The following QUESTIONS were asked:

* What is unique about individuals who are aging with a developmental disability?
* Are there health challenges that this unique group of adults face?
* Are there interventions that might have enhanced benefit for this group, specific to identified health challenges? and
* How does our practice need to change?
Method

* Searched for the time period between 1990 and the present.
* Search terms included: aging, older adults, disability, developmental disability, intellectual disability, mental retardation, and health.
* Words were used in combination so that most articles specific to young children and adolescents were eliminated.
* Articles were obtained via electronic library sources and interlibrary loan.
* A hand search was completed of the reference lists of obtained articles to supplement the initial literature base.
* The majority of research articles located and obtained were quantitative in design.
Most studies are prevalence based because of limited financial resources / resource timelines;
Most studies used different definitions of older adult;
Measurement tools differed; and
Small numbers and small sample size were used.
Findings

1. A / DD

- A disease lens to A/ DD
- Subpopulation lens to A /DD
- Impediments to aging well with a DD
- Promising
Aging with a Developmental Disability: Key points

Physical health

- Older adults with developmental disabilities show age-related changes in health, cognitive, and functional capacities indicative of accelerated aging.
- The earlier age of onset suggests that women with developmental disabilities are at increased risk for post menopausal health disorders, such as heart disease, depression, breast cancer, and osteoporosis as a result of the cessation of estrogen production.
- Obesity levels and related lack of exercise should be a concern because of their strong association with higher rates of morbidity and mortality.
Mental health

* Psychiatric problems are more prevalent among people with DD (Esbensen et al., 2006)
* ~ about 50% of PDD have a diagnosis of a psychiatric or behavioural disorder (Santos et al., 2002)
* Higher levels of stress (Olsson et al., 2003)
A Subpopulation Lens to Aging with a Developmental Disability: Key points

- Adults aging with Cerebral palsy
  - Studies indicate that older adults have the highest rates of periodontal disease and need to do more to maintain good oral health.

- Adults aging with Down syndrome
  - Prevalence of Alzheimer disease, E.g.:
    - Janiciki & Dalton, 2000
    - Coppus, Evenhuis, Verberne, Visser, Van Gool, Eikelenboom & Van Duijin, 2006
The course of Alzheimer’s disease for people with Down syndrome is atypical, onset is earlier, and its course is more rapid.

Symptoms of dementia may often be caused by other conditions that are treatable such as hyper/hypothyroidism, depression, and sensory impairments, for persons with Down syndrome.

Diagnosis and management of dementia is complicated by the high rates of co-morbid physical and mental health problems.
CVD
- Elevated disease presence complicated by age changes to cardiovascular physiology

Respiratory disorders
- COPD

Hypothyroidism
- If left untreated – wrongly attributed

Cancer
- Breast cancer
Impediments to Aging Well with a Developmental Disability: Key points

- Identification and Diagnosis of Health Challenges
  - Identification is complicated by lack of knowledge of health care providers

- The lived experience of pain in individuals who are aging with a developmental disability is not clearly understood.

- Lack of uptake of health promotion / disease prevention activities.
Promising Practices: Key points

- Individuals who are aging with disabilities have the ability to be active participants in their own aging and health care.
- Elements of good practice in working with adults who are aging with developmental disability are similar across the life course.
Discussion of Findings

- The forgotten
- The presence of pain
- Grief, loss, and death
- Adequate assessment / intervention

Recommendations:
- Health care practitioners
Grief, Loss, and Death
Adequate assessment / intervention

* Documenting base line functioning
  * a standardized test
  * Administer periodically prior to emergence of problems
  * Compare changes over time
* Get medical assessment
  * Rule out all possible causes / process of elimination
  * Document a progressive decline from baseline
* Service delivery models
  * Community / aging in place – adaptations as client needs
  * Dementia specific environment
  * Placement
Recommendations for health care practitioners

* Basic professional education for health care professionals e.g. registered nurses must include content / skills specific to aging and developmental disabilities
* Regular monitoring for aging changes should begin by 40 yrs of age
* Monitor use of prescription and over the counter medications
Recommendations con’t

- Dialogue with adults who are aging with a developmental disability how to best empower them to participate in their own health care.
- Consider the development of a health promotion policy / program specific to aging with a developmental disability for adults who are aging with a developmental disability.
- Establish a task force of health care professionals, practitioners, and policy makers to create curricula to improve knowledge and clinical practice skills.
- Expand the current research base by including qualitative studies.
BUILDING BRIDGES

AGING

DEVELOPMENTAL AGING

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