

Aging and Disability: Systems of care, research, and clinical issues

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Key topics: Aging, systems of care, and policy

Dr. Christopher Smith

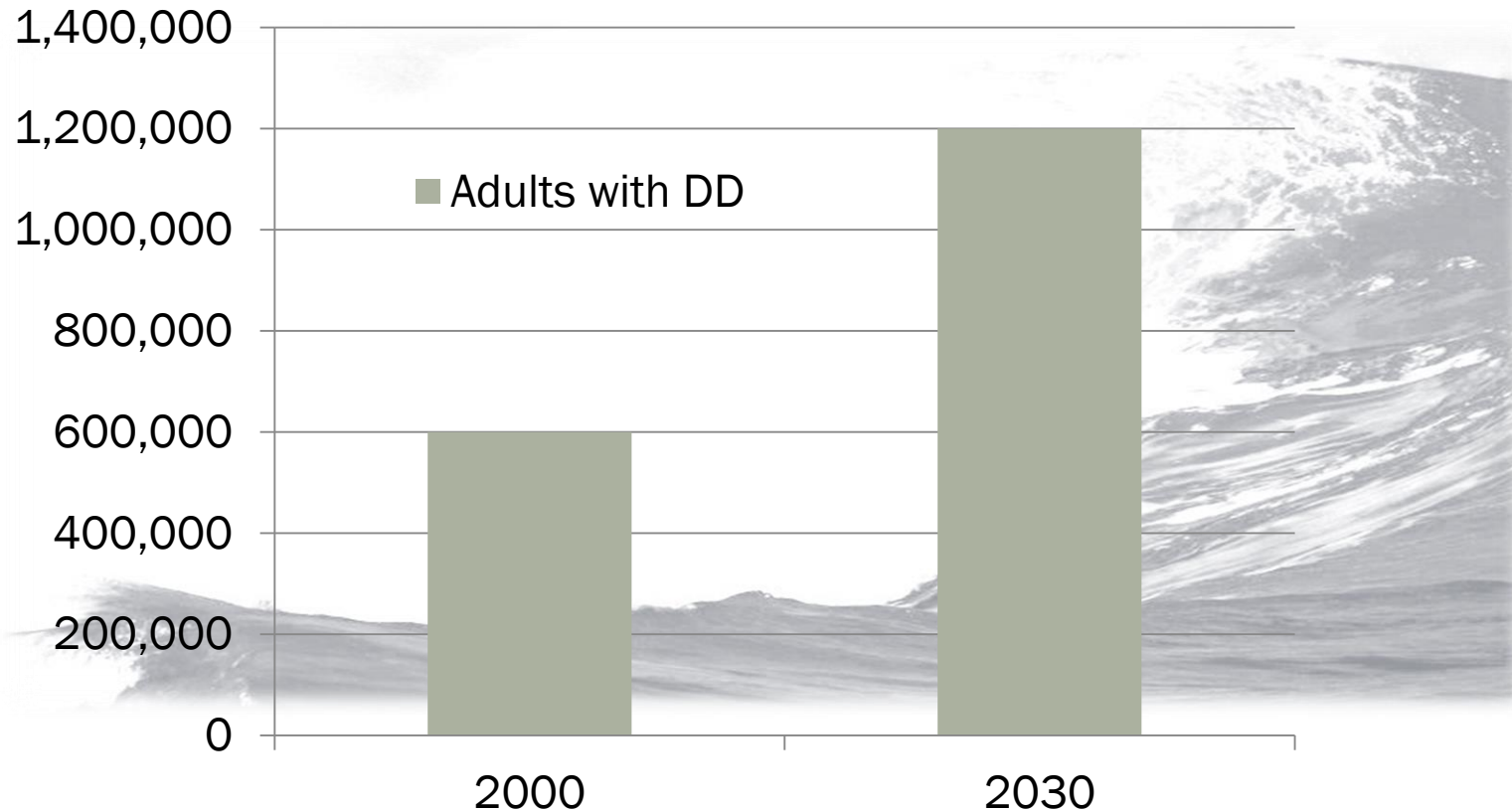
1. Who are the “aging” and “disabled”?
2. What systems of care impact their lives?
3. Current and future policy and other issues impacting lives.

Who Are the Aging and Disabled?



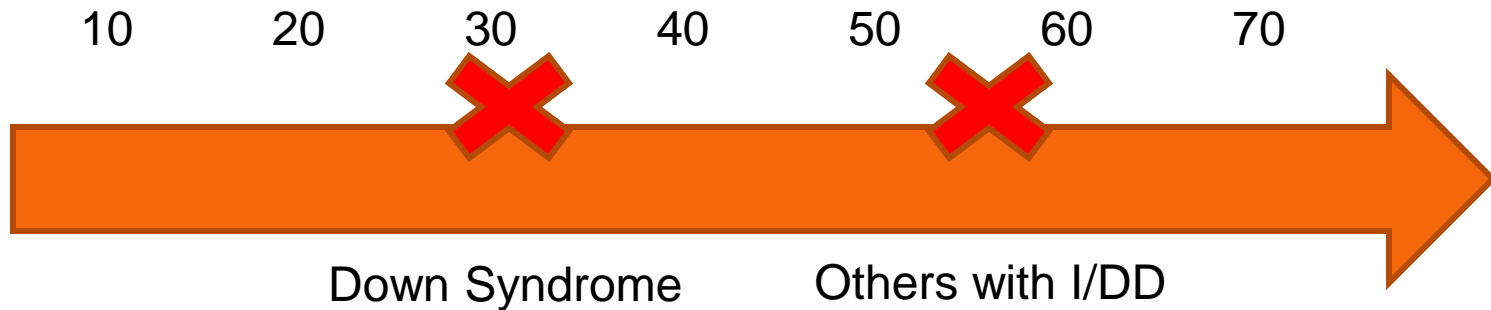
Keeping the Promise: Self Advocates Defining the Meaning of Community Living

Aging and Disability: An Age wave!



Number of adults w/ I/DD aged 60 years and older projected to double from 641,860 in 2000 to 1.2 million by 2030

Who are the “aging”?



∞ Aging: Remember this is only a trend

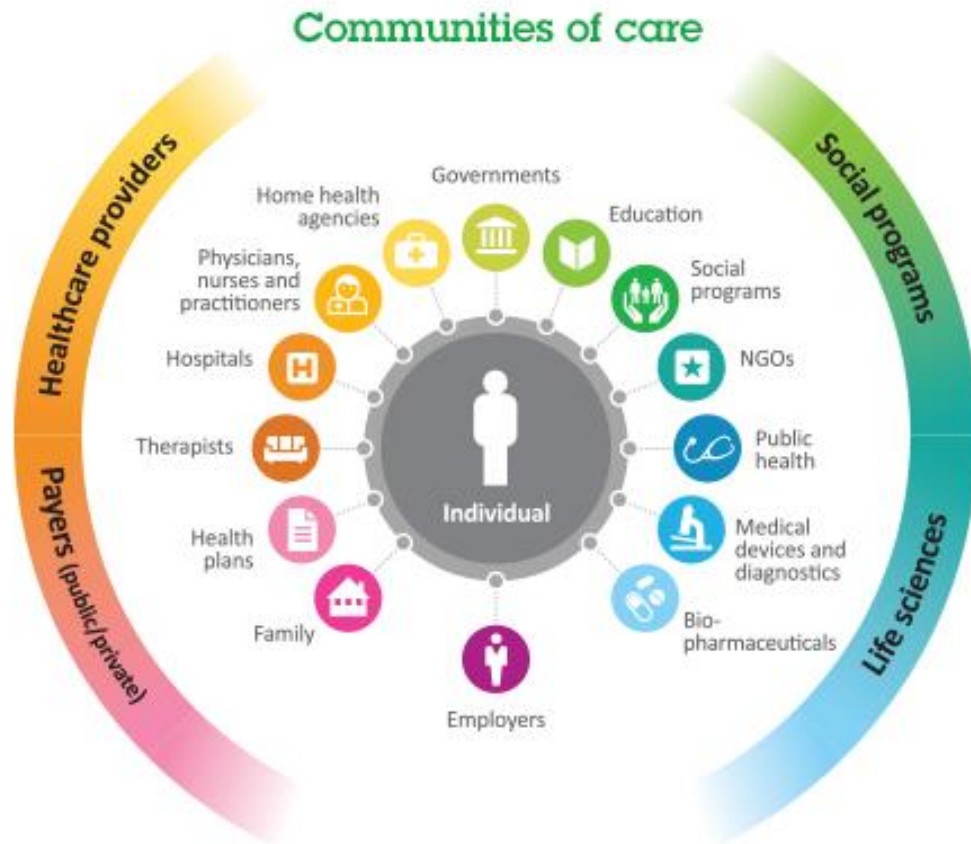
∞ I/DD: Intellectual/Developmental Disability 1, 2

Our Understanding Changes Over Time

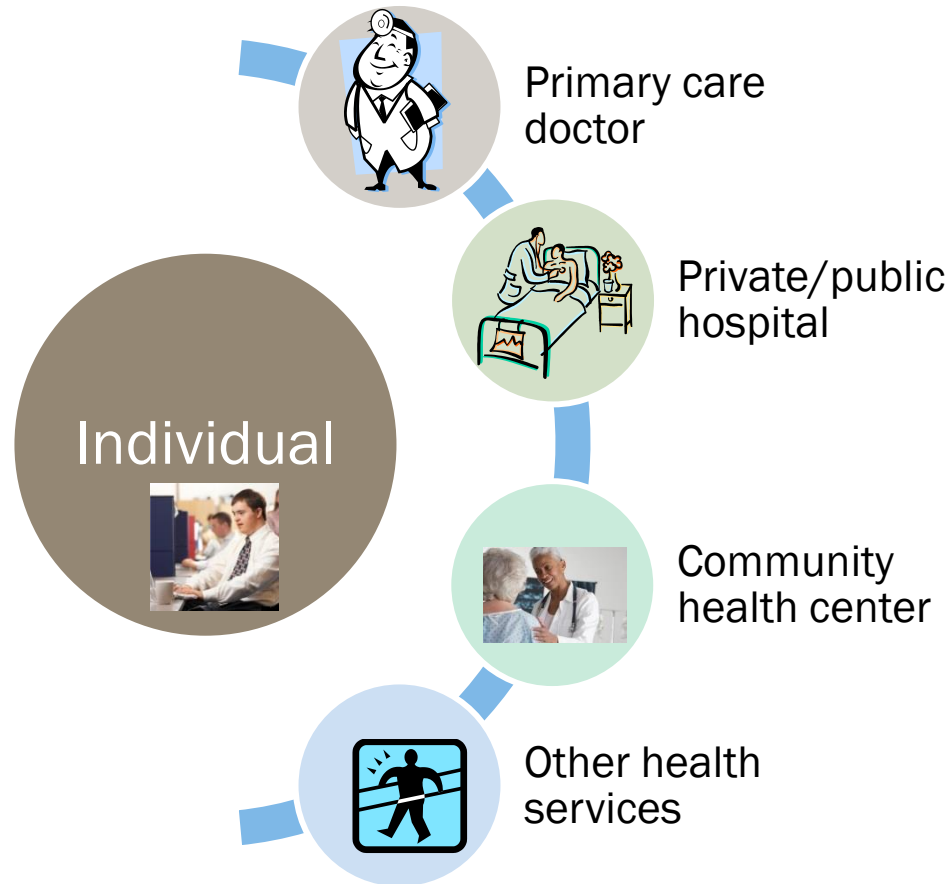
- ∞ Prior to 1975 poor health status blamed on institutionalization
 - lack of good nutrition
 - living conditions
 - medication, ₃
- ∞ 25% family care providers >60 yrs. old
- ∞ Care-givers 40 yrs. old may have more health problems than general population ₃
- ∞ Individual/Families and Communities NOW carry the Responsibility
- ∞ State and federal policies and priorities are shifting



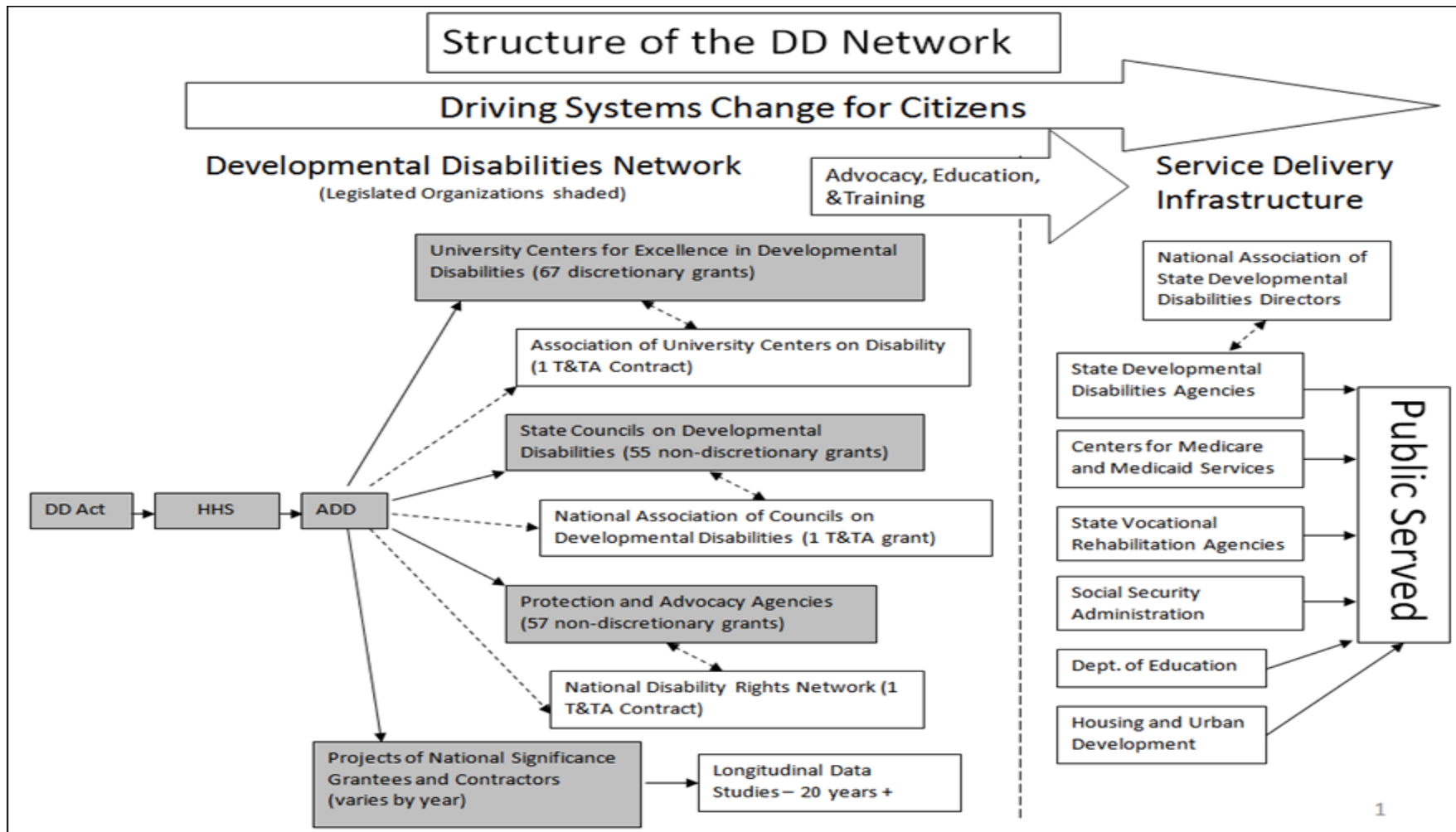
What Systems of Care Impact Their Lives



Medical Care Systems



State and Federal Systems of Support



Current and future policy and other issues impacting lives.

☞ Community inclusion

- Medical
- Housing
- Recreation
- Work
- Education



☞ Rebalancing public funds

- Move toward community inclusion and self-direction
- Less funding for segregated care

Are we prepared?

Proper identification and management of disease related to aging remains an unmet need

Increase in new population of aging adults with medical and disability needs



Addressing challenging behavior is a huge and unmet training need for senior, disability systems

Inadequate knowledge



Key topics: Health, aging, disability and research

Dr. Joan Jasien

1. Why is field exciting?
2. What is known ?
3. Research in the field



Exciting field because need unmet !

- ∞ Individuals with DD >18 and family interviewed about experience in adult ED
- ∞ 39% able to get to toilet, 22% med on time, 18% enough to drink.

- ∞ Staff

- Impatient

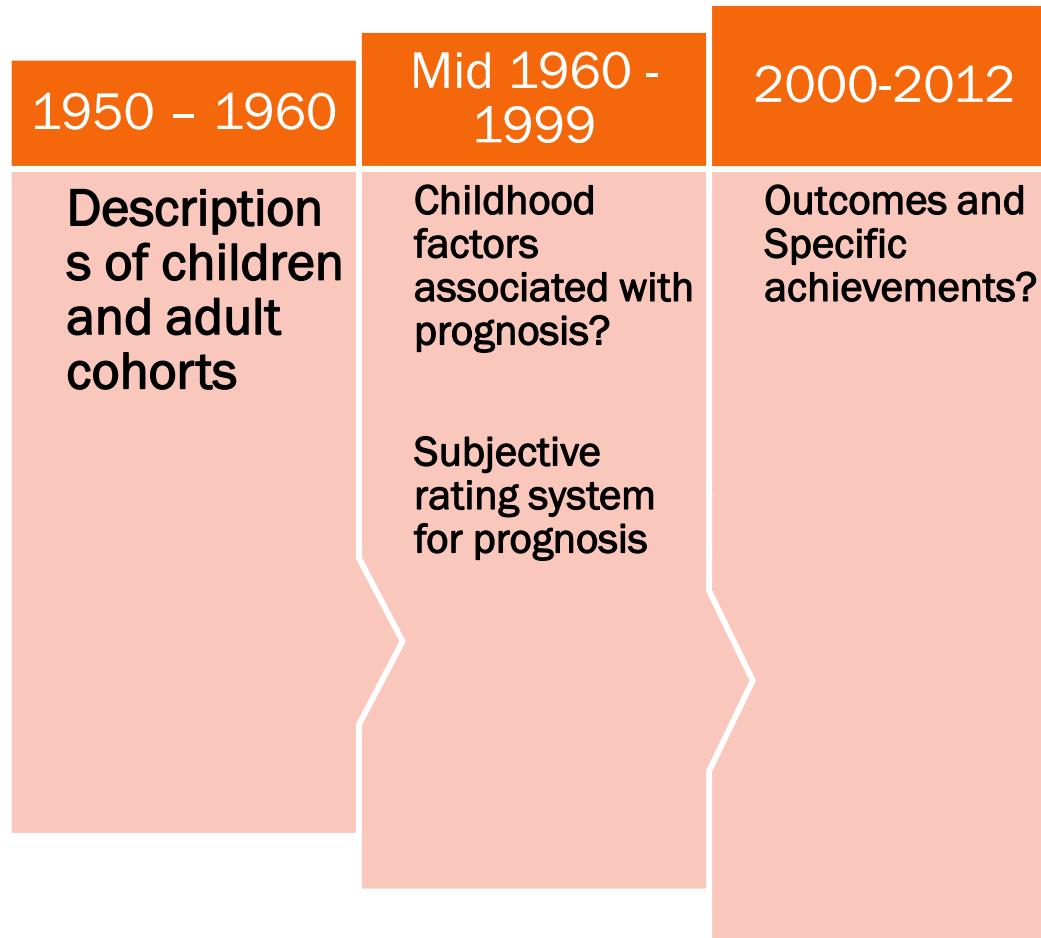


- ***Lack skills and knowledge in DD***

What is known about aging issues and DD?

- ☞ Autism
- ☞ Down Syndrome
- ☞ Cerebral palsy
- ☞ General intellectual disability

What is the history of autism and aging research?



What does the literature say about autism and aging?

IQ /language development predicts outcome

Inconsistent results on core deficits improving

Core deficits persist

Most individuals remain disadvantaged even if normal IQ.

Limitations of autism and aging literature



Follow-up age is 20-30 years

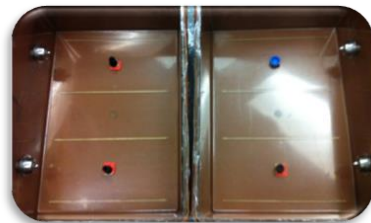
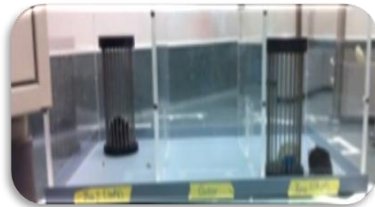
Small sample sizes

Definition of “autism” has changed over time

No/handful of females included

Aging in ASD-like mice

Behavior Analysis



Quantitative Proteomics

- Identify significantly altered proteins.
- Identify post-translational modifications.
- Quantify proteins of interest.
- Do bioinformatics analyses to get further information on protein:
 - Functional groups
 - Functional pathways

Down syndrome and aging

- ☞ Visual and hearing impairments
 - 50% over age 50 had cataracts
 - Age related hearing loss by age 50
- ☞ Obesity
 - Social intervention?
- ☞ Hypothyroidism, Sleep Apnea
- ☞ Low bone mass density, Dementia



Aging and bone health-review

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Int J Endocrinol. 2012;2012:469235. Epub 2012 Jul 22.

Aging and bone health in individuals with developmental disabilities.

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Abstract

Low bone mass density (BMD), a classical age-related health issue and a known health concern for fair skinned, thin, postmenopausal Caucasian women, is found to be common among individuals with developmental/intellectual disabilities (D/IDs). It is the consensus that BMD is decreased in both men and women with D/ID. Maintaining good bone health is important for this population as fractures could potentially go undetected in nonverbal individuals, leading to increased morbidity and a further loss of independence. This paper provides a comprehensive overview of bone health of adults with D/ID, their risk of fractures, and how this compares to the general aging population. We will specifically focus on the bone health of two common developmental disabilities, Down syndrome (DS) and cerebral palsy (CP), and will discuss BMD and fracture rates in these complex populations. Gaining a greater understanding of how bone health is affected in individuals with D/ID could lead to better customized treatments for these specific populations.

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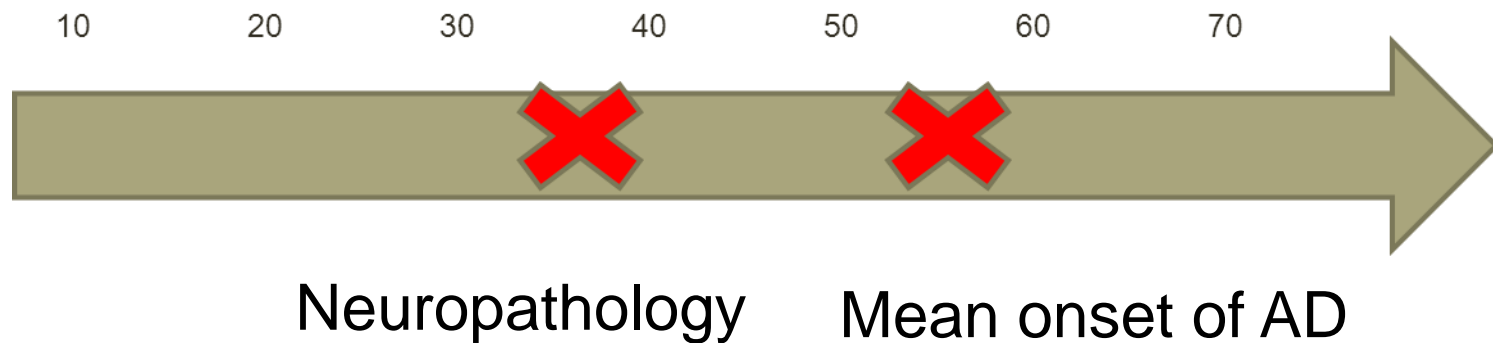
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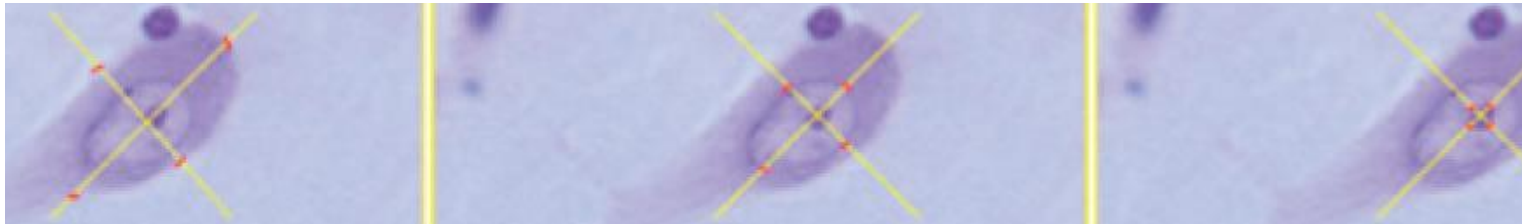
Down syndrome and dementia

- ∞ Dementia affects 70 to 80% of adults with DS



Asymptomatic Alzheimer Disease (ASYMAD)

- ∞ Hypertrophy of neurons in CA1 of hippocampus neurons in ASYMAD subjects compared with control.



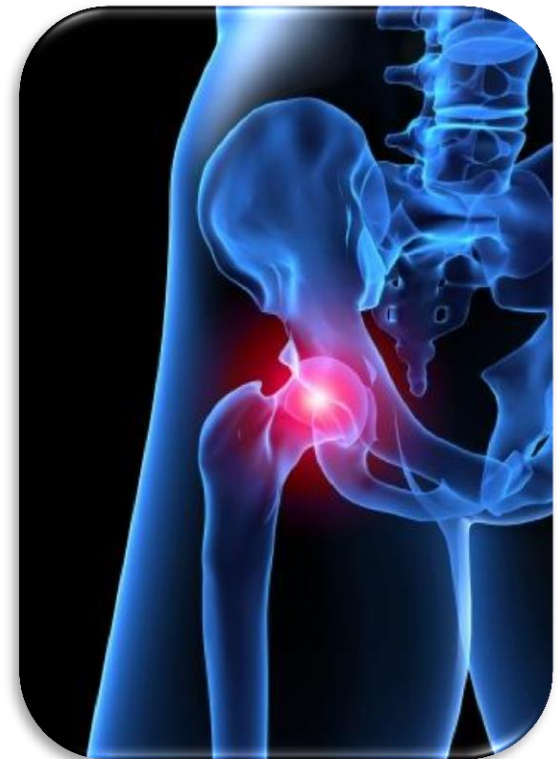
- ∞ Is hypertrophy a reaction to neurotoxins or a compensatory mechanism ?



- ∞ Pilot study

Adults with Cerebral palsy often have pain

- ☞ 67-82% of adults w/ Cerebral palsy report pain and fatigue
 - ☞ Patella alta
 - ☞ Hip pain/displacement
 - ☞ Neuromuscular scoliosis
- ☞ Obesity
- ☞ Low bone mass density



General ID and aging

∞ Vision and hearing loss

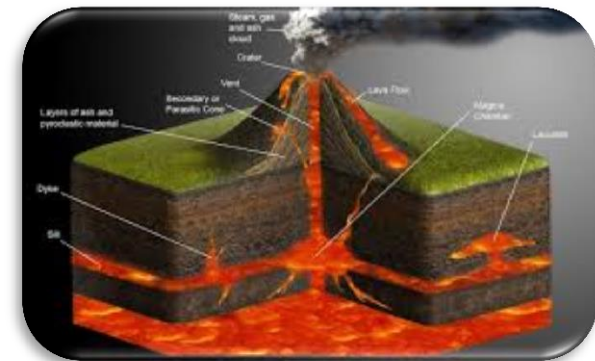
- 50% of sensory impairments previously undetected

∞ Women's Health

- Cancer screening limited for breast, cervical, and uterine disease
- Seizure patterns change around menopause
- Increased risk of Cardiovascular Disease?

∞ Behavioral Issues

∞ Low bone mass density (AED)



Wang et al, 2007; Merrick, 2004

Mortality and DD

∞ Adults with DD compared to general population are more likely to die of a Respiratory Infection

- In DS population
 - 47% had pneumonia listed as cause of death.
 - Most bacterial pneumonias are due to aspiration of pharyngeal contents.
- Pilot study



Take back to the clinic points

- ✎ Most adults with ASD remain disadvantaged even if normal IQ
- ✎ Adults with CP frequently have pain in LE
- ✎ Be creative about weight interventions
- ✎ Consider sensory impairments/changes in communication devices
- ✎ Don't forget about possible swallowing and bone health issues

We have more ? than answers



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