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

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1. Who are the “aging” and “disabled”?  
2. What systems of care impact their lives?  
Who Are the Aging and Disabled?
Number of adults with 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
Prior to 1975 poor health status blamed on institutionalization
- lack of good nutrition
- living conditions
- medication

25% family care providers >60 yrs. old
Care-givers 40 yrs. old may have more health problems than general population
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

Individual

Primary care doctor

Private/public hospital

Community health center

Other health services
State and Federal Systems of Support

Structure of the DD Network

Driving Systems Change for Citizens

Developmental Disabilities Network (Legislated Organizations shaded)

- University Centers for Excellence in Developmental Disabilities (67 discretionary grants)
- Association of University Centers on Disability (1 T&TA Contract)
- State Councils on Developmental Disabilities (55 non-discretionary grants)
- National Association of Councils on Developmental Disabilities (1 T&TA grant)
- Protection and Advocacy Agencies (57 non-discretionary grants)
- National Disability Rights Network (1 T&TA Contract)
- Projects of National Significance: Grantees and Contractors (varies by year)
- Longitudinal Data Studies – 20 years +

Advocacy, Education, & Training

Service Delivery Infrastructure

- National Association of State Developmental Disabilities Directors
- State Developmental Disabilities Agencies
- Centers for Medicare and Medicaid Services
- State Vocational Rehabilitation Agencies
- Social Security Administration
- Dept. of Education
- Housing and Urban Development

Public Served
Community inclusion
- Medical
- Housing
- Recreation
- Work
- Education

Rebalancing public funds
- Move toward community inclusion and self-direction
- Less funding for segregated care
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
1. Why is field exciting?
2. What is known?
3. Research in the field
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*

Lakin et al, 2008
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?

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<tr>
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<tbody>
<tr>
<td>Description of children and adult cohorts</td>
<td>Childhood factors associated with prognosis?</td>
<td>Outcomes and Specific achievements?</td>
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<tr>
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<td>Subjective rating system for prognosis</td>
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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

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

Merrick et al, 2004
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 (DADs). It is the consensus that BMD is decreased in both men and women with DAD. Maintaining good bone health is important for this population as fractures could potentially go undetected in neurological individuals, leading to increased morbidity and a further loss of independence. This paper provides a comprehensive overview of bone health of adults with DAD, 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 DAD could lead to better customized treatments for these specific populations.

PMID: 22030344 [PubMed]  PMCID: PMC3408858  Free PMC Article
Dementia affects 70 to 80% of adults with DS

Neuropathology  Mean onset of AD

Zigman, 2013
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

Ianco et al, 2008
Adults with Cerebral palsy often have pain

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

Overeynder et al, 1992
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
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

Zigman, 2013
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

You are invited
References

• **Background**
  4. Lakin et. al, Institute on Community Integration, 2009

• **Morbidity**
  10. Janicki & Jacobson
  12. Piner et al., 2001-impact
References

- Morbidity continued
- 17. Veraart, Mul, Bierman, 1998-article in Dutch
Demographics of adults with ID

- Impact. Volume 23 Number 1, Winter 2010