Aging and the Intellectually Disabled Patient: Nuances of Treatment

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Learning Objectives

• Describe the process of normal aging for various organ systems
• Describe the aging process differences in the Intellectually Disabled population
• Describe nuances in treatment and services for the Intellectually Disabled Patient
“Aging is not lost youth, but a new stage of opportunity and strength.”

-Betty Frieden
February 4, 1921 – February 4, 2006
Betty Friedan

Aging and ID Roundtable 2013

A series of short papers addressing some or all of the following will help guide the Roundtable discussions:
I. Common experiences and challenges in health and aging
II. Bridging the aging and intellectual disability service systems
III. Changing profiles in family caregiving and caregiver supports
IV. Redesigning long term services and supports (and/or long term care)
V. Examples of cross-system learning
VI. Opportunities from collaboration

Statistics on Normal Aging

- After the age of 65 years, maladies include:
  - Arthritis 49%
  - HPTN 37%
  - Hearing Problems 32%
  - Cardiac Disease 30%
  - Sinusitis 17%

Statistics on Normal Aging

- Aging maladies continued..
- Orthopedic implants 16%
- Diabetes 9%
- Visual Impairments 9%
- Tinnitus 8%
- Varicose veins 8%
- Cataracts 17%

Normal Aging Process

• “Normal Aging” is a combination of genetics and lifestyle

• **Hair**: thins on head, pubis, & armpits, pigment cells decrease so grey hairs increase. **Skin**: becomes less elastic, drier, & wrinkles, fingernail growth slows

• **Touch**: Decreased sensation of touch and sensitivity

Normal Aging Process

- **Hearing**: high frequency sounds more difficult to hear, background noise, change in tone & speech are less clear > 55
- **Vision**: Presbyopia, lens of eye less flexible, decreased night vision, clarity of color, visual “sharpness” declines, glare increases, loss of depth perception & peripheral vision
- **Taste/Smell**: decreased tastebuds and saliva, decreased sense of smell

Normal Aging Process

- **Sleep**: circadian rhythm changes, less sleep, sleep onset can be delayed, early AM wakening
- **Height**: by 80 yrs., 2in (5cm) decrease in height (posture, discs, compression)
- **Bones**: decreased mineral content, osteoporosis (vitamin-D, calcium, smoking)
- **Metabolism**: slows, greater body fat, less muscle mass, (fat shifts)
Normal Aging Process

- **Brain & Nervous System**: by the 30’s, brain weight decreases, nerve networks decrease, blood flow decreases, (brain adapts), less recall of recent memories (names & details)

- **Genitourinary**: frequency, SE meds, mobility issues, decreased size, function, & clearing of waste & medications by the kidneys, prostate size increases, decreased sperm production & response time, ovulation ceases, hormones decline.
Normal Aging Process

• **Cardiovascular:** heart less efficient and larger, (gradual decline of endurance), arteries stiffen with age, atherosclerosis

• **Pulmonary:** breathing capacity declines each decade, lack of exercise leads to decreased lung efficiency.

• **Hepatic:** liver less able to metabolize ETOH and meds

• **Gastrointestinal:** digestive enzymes decrease
Intellectual vs. Developmental Disability

- Difference between an Intellectual Disability and Developmental Disability was delineated by DHS 11/15/11
- Intellectual Disability: significantly sub-average intellectual functioning; (2 std. deviations below the mean (IQ of 70 or below)
- Manifested before 18 years of age

Department of Human Services (DHS). Difference Between Intellectual Disability & Developmental Disability. N.p.: Mental Health and Disability Services, 15 Nov. 2011. PDF.
Intellectual vs. Developmental Disability

• Accompanied by significant limitations in adaptive functioning: (2 skill areas)
  • Communication
  • Self-care/ Health / Safety/ Self-direction
  • Home-living
  • Social/Interpersonal skills
  • Use of community resources/ Leisure
  • Academic/Work skills

Department of Human Services (DHS). Difference Between Intellectual Disability & Developmental Disability. N.p.: Mental Health and Disability Services, 15 Nov. 2011. PDF.
A Developmental Disability is defined as:

- A severe and chronic disability
- Is attributable to a mental or physical impairment or combination of both
- Manifests before age 22 years of age
- Results in substantial functional limitations in 3 or more areas of major life-activities
Intellectual vs. Developmental Disability

- Self-care/ Mobility
- Expressive & receptive language/ Learning
- Capacity for independent living
- Economic self-sufficiency / Self-direction
- Need for a combination & sequence of special inter-disciplinary or generic care which is life-long or of extended duration & are individually planned & coordinated

Department of Human Services (DHS). Difference Between Intellectual Disability & Developmental Disability. N.p.: Mental Health and Disability Services, 15 Nov. 2011. PDF.
From birth-5 yrs. Developmental Disability;
Substantial DD or specific congenital or acquired conditions with a high probability of resultant DD if services are not provided.
Examples: autism[ASD], FAS, cerebral palsy, Downs, spina-bifida, intellectual disability, behavior disorders, brain-injury

Department of Human Services (DHS). Difference Between Intellectual Disability & Developmental Disability. N.p.: Mental Health and Disability Services, 15 Nov. 2011. PDF.
History of Public Law 88-156

- Kennedy creates National Institute of Child Health & Human Development
- 10/24/63: Maternal & Child Health & Mental Retardation planning amendment to the Social Security Act
- 10/31/63: funding related to the prevention, care & treatment of people with Intellectual Disabilities (research institutions, treatment centers & community programs created)

Books on Aging and ID

Health of Women with Intellectual Disabilities
EDITED BY Patricia Noonan Walsh & Tamar Heller

Mental Health, Intellectual Disabilities and the Aging Process
EDITED BY Philip W. Davidson, Vee P. Prasher and Matthew P. Janicki

Physical Health of Adults with Intellectual Disabilities
EDITED BY Vee P. Prasher and Matthew P. Janicki

Books on Aging and ID

Health of Women with Intellectual Disabilities
EDITED BY Patricia Noonan Walsh & Tamar Heller

• The first in a series by IASSID
• The book addresses ID woman’s health issues throughout the lifespan
• Menopause issues etc.

Books on Aging and ID

• The second book in a series by AISSID

• This book addresses psychiatric & behavioral issues that people with intellectual disabilities face as they age

• Depression, medical, nursing, bereavement etc.

Books on Aging and ID

Physical Health of Adults with Intellectual Disabilities

• The third book in a series by IASSID
• This book addresses health issues specific to patients with Intellectual Disabilities broken down by organ systems
• Barriers to care etc.

Books on Aging and ID

• A comprehensive guide to various symptoms and causes of dementia in the Intellectually Disabled population

• The book also concentrates on services for the patient with dementia

Books on Aging and ID

- Another book sponsored by IASSID
- This book outlines various supports as well as various social service agencies involved in the care of the Intellectual Disabilities

Books on Aging and ID

- This publication is geared to professionals making policy decisions regarding the Intellectually Disabled population
- Includes vignettes regarding various scenarios

2005: Two issue series on aging (Vol. 109 #2&5)

- Aging, Downs, Alzheimer's, Fitness, and Nutrition
- Family and Service System Supports, Caregivers, Service Provision and Utilization (longer need for support)
American Journal on Intellectual and Developmental Disabilities (AJIDD)

- AJIDD 2012 contained 6 articles: on Intellectual Disabilities and Aging
  - Prevalence of Falls and Risk Factors in Adults with Intellectual Disabilities
  - A comparison of the Prevalence of Chronic Disease Among People With and Without Intellectual Disabilities
  - Self Directed Support: Impact of Hiring Practice on Adults with Intellectual and Developmental Disabilities and Families

American Journal on Intellectual and Developmental Disabilities (AJIDDD)

- AJIDDD 2012 contained 6 articles: on Intellectual Disabilities and Aging
  - Into the Unknown: Aging with Autism Spectrum Disorders
  - Active Aging for Individuals with Intellectual Disabilities: Meaningful Community Participation Through Employment, Retirement, Service and Volunteerism.
  - Unique and Universal Barriers: Hospice Care for Aging adults with Intellectual Disabilities

AJIDD : Falls

- 1,515 adults with and Intellectual Disability looking at falls and risk factors
- 25% had 1 or more falls in the past 12 months
- Prevalence increased with advancing age
- Other risk factors: ♀, arthritis, seizures, > 4 medications, walking aids, difficulty lifting or carrying ten or more pounds

AJIDDD: Health

• 791 people in Québec, Canada were compared with and without Intellectual Disabilities
• ID patients had greater heart/thyroid disease, but less arthritis, spinal pain, migraines and food allergies. (earlier age related illness)
• Significant differences noted when patients were stratified by etiology (i.e. Downs) & severity of the ID

AJIDD: Social

• The general and Intellectually Disabled population is living longer
• Maintain, reduce, or retire working
• Participating in Service and Volunteerism
• What other specific activities would be helpful for the ID patient to engage in?

AJIDD: Death and Dying

- Hospice & palliative care for ID patients
- ID patients are requiring end of life care
- There are multiple challenges to obtaining hospice
- Staff’s perceptions, family issues, etc.
- Hope for a more collaborative approach for palliative & hospice treatment of ID patients

AJIDD Death & Dying

- Loss of ability & decline seems the opposite of growth, development, inclusion & self-determination
- Little attention to how ID pts experience grief & loss (caregivers etc)
- Help ID patients see end of life as part of a journey
- Spiritual leaders identify strengths ID patient

• 60 million worldwide have an ID
• Severe difficulties with *lifelong* supports from family, charitable organizations, or state subsidies
• ID patients had shorter lifespans, lack of medical care, rehabilitation services, & poor living conditions
• Limited access to quality healthcare
• ID patients face ageism and handicap-ism
• Millions of ID adults live with their families
• ID adults are routinely excluded from planning aging services, & “age friendly” communities
• ID patients can benefit from services & supports provided for neurotypical elderly

IASSID

• Social needs: stigma & discrimination for access to recreation & leisure activities

• Housing needs: support to families, brokering co-living arrangements, GH, supervised apartments (>115,000 on national wait list for GH placement)

• Health needs: regular check-ups, preventive care

• Fewer financial resources

• Activity or Work: Intellectually Disabled patients need continued activity or work which prevents depression, social & community activities are important otherwise they become at risk for depression
• Special Care Needs: Alzheimer’s, fragility
• Higher rates of obesity & sedentary lifestyle
There are now models of consumer-directed supports, (personal assistants, supported living, and cash subsidies)

All increased as a result of the Real Choice Systems Change Grants of the 2000 New Freedom initiative & the Robert Wood Johnson Self-Determination Initiatives

Increased satisfaction, more needs met, assistive technologies, social interaction
• OASIS: national education organization for neurotypical adults; life-long learning and service
• Sharon Hales founder of “OASIS Friends”
• To address training re: classes outside of disability system
• Today 50 ID adults in OASIS (St. Louis)
• 30 volunteers keep community integration
Impact Newsletter

• 1995-2008 **Involving All Neighbors** comprehensive approach to including ID adults in the community (developed by the Dept. of Neighborhoods in Seattle)

• The Center on Aging & Community at Indiana Institute on Disability & Community published, **“The Guide to Building Community Membership for Older Adults with Disabilities”**

“Aging Adults with Intellectual Disabilities

• Older adults >70 million in 20yrs.
• Life expectancy for persons with mild ID now has parity with neurotypicals
• Moderate to severe ID live into the late 60’s and late 50’s
• ID patients have complex medical & mental health needs.

• 1.2 million ID adults over the next 20 years, (641,860 in 2000)
• literature searches consistently report higher rates of morbidity & mortality in adults with Intellectual Disabilities
• ID patients have unrecognized or poorly managed health problems; (vision, hearing, seizure, dental, psychiatric, GI and poly-pharmacy)


Report highlighted disparities in healthcare status, access to care, & healthcare quality

Lack of training of physicians & other health professionals to the needs of ID patients
More than 10 years after the conference, progress is slow

Still poor coverage/marketing of health promotion & preventive care for ID patients

Many physicians uncomfortable with this patient population as a whole
NIH Article

• 3 groups were compared as to attainment, social participation, psychological functioning, & health in mid-life & early old age

• In midlife, the ID parents were similar to neurotypical parents. (except for employment and social participation)

• By early old age, the ID parents had poorer physical & mental health
• Co-residence by adult ID pt & parent was prevalent during the pt’s midlife 51.4% & early years of old age 38.6%
• There were different parental outcomes depending on the residential status of the ID patient

NIH Article

- Midlife & Aging Parents of Adults with Intellectual & Developmental Disabilities
- Impacts of “lifelong” parenting
- Parents of ID adult n= 220
- Parents of neurotypical adults n= 1042
- Parents of ID adults further divided by living with their parents or elsewhere
- Study was of longer duration for follow-up

siblings of ID patients

• Market Research firm IPSOS (Easter Seals), released a national poll in Dec. 2012, about neurotypical siblings caring for ID siblings
• Received feedback from 351 siblings of ID patients across the country
• Control group of 1,400 siblings of neurotypicals were also polled

Siblings of ID Patients

• 50% of siblings from ID patients are or are planning to be the primary caregiver for their ID sibling
• 23% are primary caregivers
• 30% expect that role in the future
• If ID present, siblings were twice as likely to be involved in day to day issues regardless of weather the primary caregiver or not.

Siblings of ID Patients

• If the sibling is the primary caregiver, 75% said the role is “a full time job”
• 30% felt they had no emotional, physical or financial support
• 20% say having an ID sibling has negatively impacted their relationships with family members or quality of life
• Increased strain on the family *per se*

Siblings of ID Patients

• Greater than 50% of respondents said having a sibling with an ID had a positive impact on their quality of life.
• 80% reported being close with the ID sibling enhances their lives.
• The figure is much lower for adults with neurotypical siblings.

Aging and Intellectual Disability

MEET THE BLOGGER

Terri Lee Ryan

Chicago Career Coach Terri Lee Ryan is an expert on career issues. A former executive search recruiter and outplacement specialist, Terri uses her experience to prepare and repackage job seekers for a new job or new career.

Author of “My Sister’s Helper: Life With a Handicapped Sibling”

Raising Renee

QuickTime™ and a decompressor are needed to see this picture.

Dear God,
It's 12:01 am, Jan. 1, 2008. I am in my studio painting. What a great way to bring in the new year!! Happy Happy New Year!! May 2008 bring lots of painting days my way. I am happy to be in my new home in NC and ready for new and exciting adventures that await me in 2008. The sky is truly the limit. I love you God.
Future Planning for Adults with ID

• “Pour-over” will, (pour over into a special needs trust)

• A special needs/supplemental needs trust: {retirement funds, IRA’s, non-probate assets}

• Work with agencies within the community where the ID patient will be living

Future Planning for Adults with ID

• Confer with family members, friends, financial planner, attorney & social worker

• Consider Power of Attorney for healthcare & property for the parents (POA for property should include Medicare gifting powers)

• Assets go to the ID adult child with a disability as defined by the Social Security Act

Future Planning for Adults with ID

• There is NO 5yr. “look back”
• The parent will qualify for Medicaid for a NH & preserves the funds for their ID child
• If guardianship not needed, consider having patient sign durable POA for health care
• POA for advocacy: allows agencies, family, to advocate for the ID patient

Future Planning for Adults with ID

• Overcomes the confidentiality shield that prevents parents, friends, relatives and agencies from being effective advocates due to the restrictions of The Health Insurance Portability & Accountability Act

• Letter of Direction: (informal),

• Names, addresses, phone numbers & relationship of significant family members

Web site of the Institute on Community Integration, University of Minnesota
Future Planning for Adults with ID

- Letter of Direction: (continued)
- How to contact respite workers, job coach, neighbors
- Location of wills, trusts, birth certificate, guardianship, POA’s, burial plans, deeds, and titles to properties
- List of current doctors and therapists

Future Planning for Adults with ID

• Letter of Direction: (formal)
• Hopes, dreams and wishes for their child
• Guidance for the caregivers
• Finally: have all information about your assets together so they are not lost when you die. (pensions, benefits, insurance policies)
• Executor or Trustee should be aware of these

Resources for Intellectual Disabilities

• Formerly known as The Association for Retarded Citizens

• National Organization for people with ID

The ARC was established in 1950 in Columbus Ohio

Resources for Intellectual Disabilities

The Arc’s National Sibling Council

The Arc’s National Sibling Council welcomes all siblings and those who support siblings who are members of The Arc either at the local, state or national level. The Council will offer opportunities for:

- Support and resources for those needing guidance in situations unique to their family
- Supporting the advocacy and programmatic efforts of The Arc
- Networking – meet other siblings – face to face and online
- Celebrating the sibling relationship
- Leadership development and training through involvement in standing committees, ad hoc committees and task forces

Sibling Leadership Network

• Ohio SIBS is holding their 13th Annual Adult Siblings Conference on November 8-9, 2013

• A webinar on what professionals need to know about siblings with speakers from the SLN, and hosted by ANCOR on September 19, 2013

Aging and ID Resources

• National Academy of Elder Law Attorneys (www.NAELA.org, 703/942-5711)

• Academy of Special Needs Planners (www.specialneedsplanners.com, 866/296-5509) attorneys who specialize in ID

• MetLife Center for Special Needs Planning at www.metlife.com/specialneeds. (letter of intent)

Aging and ID Resources

- [www.uic.edu/orgs/rrtcamr/index](http://www.uic.edu/orgs/rrtcamr/index) (University of Illinois, Chicago)
- [www.iassid.org](http://www.iassid.org)
- [https://www.nichd.nih.gov/research/support/ed/eksiddrc.cfm](https://www.nichd.nih.gov/research/support/ed/eksiddrc.cfm) (Eunice Kennedy Shriver center for Intellectual & Developmental Disabilities)