Preparing for the Aging of Population of People with ID/D. A Focus on Mobility and Vision

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• “Oldest old” (> 85 yrs) is fastest growing of many older populations
• Expected to be 19 million in 2050 (5 percent of all Americans)
• More older women than older men
The “Silver Tsunami”

United States of America: Old-age Dependency Ratio

Prevalence of chronic vision impairment in the U.S. is strongly age-related!

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Legal Blindness</th>
<th>Uncorrectable Low Vision</th>
<th>All Visually Impaired</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Persons</td>
<td>%</td>
<td>Persons</td>
</tr>
<tr>
<td>60-69</td>
<td>59,000</td>
<td>0.3</td>
<td>176,000</td>
</tr>
<tr>
<td>70-79</td>
<td>134,000</td>
<td>0.8</td>
<td>471,000</td>
</tr>
<tr>
<td>&gt;80</td>
<td>648,000</td>
<td>7.0</td>
<td>1,532,000</td>
</tr>
</tbody>
</table>

Data from National Health Interview Survey Lee DJ et al., *Arch Ophthalmol.* April 2004;122(4):506-509
The Ultimate Geriatric Syndrome: Multiple Chronic Conditions (MCC)

- MCC is Common
  - 2/3 of Medicare population has 2 or more chronic conditions
  - 23% have 5 or more chronic conditions

- Patients with MCC are at increased risk for
  - Hospitalization
  - Complications
  - Disability
  - Institutionalization
  - Death

Medical Expenditure Panel Survey 1998 (N=24,072)
Comorbidities that are especially common in seniors with vision impairment!

- Depression
- Hearing Impairment
- Cognitive Impairment
- Balance Impairment/Falls

Brody et al. Ophthalmology 2001
Lin et al., J Am Geriatr Soc 2004
Klaver CC et al., Am J Epidemiol 1999
Whitson HE et al., Arch Gerontol Geriatr 2010
Lord SR et al., Clin Geriatr Med 2010
Patients with Multiple Chronic Conditions Still Really Value Vision

• 390 patients with ocular disease (ages 27 to 89)
  - 250 with “serious” comorbid illness (DM, heart disease, ESRD, cancer, or stroke)

• Time trade-off utility questions
  - E.g., how many years of remaining life would you trade for good vision?

**No significant difference** in response in those with vs. without the serious comorbid conditions

• **Conclusion**: Vision loss is a MAJOR detractor from patient-perceived quality of life, whether or not the patient has serious systemic comorbid disease

Physical Health: Mortality

Life expectancy differs between individuals with intellectual disability (ID) and individuals in the general population.

![Bar chart showing life expectancy differences between general population and individuals with ID]
Co-morbidities in older individuals with ID

- 1047 individuals 50 years of age and older with ID
- Levels of ID varied from mild (24.3%), moderate (48.2%) to severe/profound (24.9%)
- Prevalence of ≥ 2 conditions – 79.8% (95% CI: 77.3-82.2)
- 47% had ≥ 4 conditions


- 1023 individuals 16 years and older with ID (16-83 yrs.)
- 98.7% had co-morbidities
- 5 most prevalent conditions: visual impairment, obesity, epilepsy, constipation, ataxic/gait disorders

What Vision Problems Do We Expect To See in the Aging Population With ID
• Cataracts
• Glaucoma
• Refractive Errors (not different, just not corrected)
• Age-Related Macular Degeneration (AMD)
• Diabetic Retinopathy
• Dry Eye
• Low Vision
A cataract is a clouding of the lens in the eye that affects vision. Most are related to aging. By age 80, more than half of all Americans either have a cataract or have had surgery.

What causes cataracts?

- The lens lies behind the iris and the pupil. It focuses light onto the retina. The lens also adjusts the eye's focus, letting us see things clearly both up close and far away.
- As we age, some of the protein clumps together and start to cloud in the lens. Over time, the cataract may grow larger and cloud more of the lens, making it harder to see.
- Smoking and diabetes contribute to the development of cataract. Or, it may be that the protein in the lens just changes from the wear and tear it takes over the years.
Glaucoma

- Glaucoma is a group of diseases that damage the eye’s optic nerve and can result in vision loss and blindness. However, with early detection and treatment, you can often protect your eyes against serious vision loss.

- Anyone can develop glaucoma. Some people, listed below, are at higher risk than others:
  - African Americans over age 40
  - Everyone over age 60, especially Mexican Americans
  - People with a family history of glaucoma
Refractive Errors

When the shape of the eye prevents light from focusing directly on the retina due to the length of the eyeball (longer or shorter), the shape of the cornea, or aging of the lens.

Myopia (nearsightedness) is where objects up close appear clearly, while objects far away appear blurry.

Hyperopia (farsightedness) where distant objects may be seen more clearly than objects that are near. Some people may not notice any problems with their vision, especially when they are young. For people with significant hyperopia, vision can be blurry for objects at any distance, near or far.

Astigmatism is where light does not focus light evenly onto the retina. This can cause images to appear blurry.

Presbyopia is age-related condition, the ability to focus up close is more difficult. As the eye ages, the lens can no longer change shape enough to allow the eye to focus close objects clearly.
Age-Related Macular Degeneration (AMD)

AMD causes damage to the macula - the part of the eye needed for sharp, central vision.

• AMD can advance slowly or progress fast and may lead to a loss of vision in one or both eyes.

• The loss of central vision in AMD can interfere with simple everyday activities, such as the ability to see faces, drive, read, write, or do close work, such as cooking or fixing things around the house.
• There are a group of eye problems that people with diabetes may develop including cataract, diabetic retinopathy, and glaucoma.

• Diabetic retinopathy is the most common diabetic eye disease and is the leading cause of vision loss and blindness in adults 20–74 years of age.

• The longer a person has diabetes, the greater the risk is of developing diabetic eye disease.
Dry Eye

• When the quantity and/or quality of tears fails to keep the surface of the eye adequately lubricated. The risk of dry eye increases with advancing age. Women have a higher prevalence of dry eye compared with men.

Symptoms of dry eye:
• Scratchy sensation or the feeling that something is in the eye.
• Stinging, pain or burning
• Excess tearing that follow periods of dryness
• Discharge and redness in the eye
• Blurred vision.
Low Vision/Vision Rehabilitation

• Vision that cannot be corrected with standard eyeglasses, contact lenses, medication, or surgery.
• Activities of daily life become more challenging!

**Signs of low vision:**

• Signs of vision loss may include difficulty:
  • Recognizing faces
  • Getting around the neighborhood
  • Doing activities around the house

• The sooner vision loss or eye disease is detected, diagnosed and treated, the greater a person’s chance of keeping his or her remaining vision.
• Systemic structural and institutional factors contribute significantly to disparities in health¹

• Age, ethnicity, sex, and chronic health conditions contribute to disparities in vision impairment and age related eye diseases²

Why do disparities exist?

Barriers to good health for people with ID include:

• Insufficient provider training
• Diagnostic overshadowing
• Limited prevention education
• Limited self-advocacy
• Attitudes/Discrimination/Discomfort/Lack of Awareness
• Cultural Beliefs
• Increased poverty
• Poor enforcement of laws/acts
Secondary Conditions

- Adults with ID are more likely to develop chronic health conditions at younger ages:
  - Biological factors related to syndromes and developmental disorders
  - Limited access to healthcare
  - Lifestyle and behavioral issues
  - Longer lifespan

- Secondary Condition is a preventable health problem occurring as a result of or related to a primary disability, that can limit health, functional capacity, participation in life activities, and independence.
  - Can be physiological or psychological
  - Can be environmental
Secondary Conditions

Examples of Secondary Conditions (similar to ANY aging adult)

- Poor physical fitness
- Inadequate dietary patterns
- High blood pressure
- Type 2 Diabetes and/or Metabolic syndrome
- Heart Disease
- Arthritis
- Flu-related complications, like pneumonia
- Oral health diseases (peritonitis, decay, abscess)
- Consequences of violence, abuse or neglect  *(However, these issues are 4-10 times more frequent in adults with ID)*
Secondary Conditions

Examples of Secondary Conditions (more unique to aging adults with IDD)

- Bowel, bladder, and gastrointestinal problems
- Pain
- Pressure sores or ulcerations
- Depression
- Injuries
- Overweight and obesity
- Fatigue
- Osteoporosis
- Contractures

UNDERLINED conditions can be ameliorated by physical therapy
Compared to general population, persons with ID:

- Have 4 times more preventable mortality.
- Receive less care
  - 2.7 visits yearly compared to 3 for men,
  - 5 for women and 6 for children or elderly.
- Receive less care from specialists
  - Only 30 - 47% see specialists
  - 92% have needs requiring specialty care.
- Experience poor access to mental health services - only 1 in 4 receive needed treatment.
### Physical Health - Secondary Conditions

Individuals with Down Syndrome are more likely to have diabetes, and at a younger age.

• May be related to increased levels of obesity in persons with Down Syndrome

*Leading cause of death in the World Health Organization member states.

<table>
<thead>
<tr>
<th>Disease</th>
<th>Gen Population Death Rate</th>
<th>ID population Death Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular Disease*</td>
<td>31%</td>
<td>10 % to 50%</td>
</tr>
<tr>
<td>Chronic Obstructive Pulmonary Disease</td>
<td>5%</td>
<td>33% (severe) to 50% (individuals in residential facilities)</td>
</tr>
<tr>
<td>Other lung conditions (pneumonia &amp; influenza)</td>
<td>4%</td>
<td></td>
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<tr>
<td>Diabetes Mellitus</td>
<td>6% (US), 3% (UK)</td>
<td>1.6% to 9.1%</td>
</tr>
<tr>
<td></td>
<td>Global</td>
<td>Africa</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>n</td>
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<tr>
<td><strong>Health Promotion total</strong></td>
<td>26</td>
<td>84622</td>
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<tr>
<td><strong>Low Bone Density</strong>*</td>
<td>24.7</td>
<td>3823</td>
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<tr>
<td><em><em>Obese</em> (youth)</em>*</td>
<td>14.8</td>
<td>5553</td>
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<tr>
<td><em><em>Overweight</em> (youth)</em>*</td>
<td>14.9</td>
<td>5599</td>
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<tr>
<td><em><em>Obese</em> (adults)</em>*</td>
<td>31.8</td>
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<tr>
<td><em><em>Overweight</em> (adults)</em>*</td>
<td>28.4</td>
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<tr>
<td><em><em>Underweight</em> (adults)</em>*</td>
<td>15.95</td>
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<td><strong>Use Tobacco Products</strong>*</td>
<td>6.5</td>
<td>4747</td>
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<tr>
<td><strong>Exposure to Second Hand Smoke</strong>*</td>
<td>36.4</td>
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## Healthy Athletes Data 2007-2014

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<th>Africa</th>
<th>Asia Pacific</th>
<th>East Asia</th>
<th>Europe/Eurasia</th>
<th>Latin America</th>
<th>Middle East North Africa</th>
<th>North America</th>
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<tbody>
<tr>
<td></td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
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<tr>
<td><strong>Fun Fitness total</strong></td>
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<td>34189</td>
<td>10.7</td>
<td>199</td>
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<td>27.3</td>
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<td><strong>Exercise Program</strong></td>
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<td>52.3</td>
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<td>59.6</td>
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<td>38.8</td>
<td>934</td>
<td>33.8</td>
<td>1620</td>
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<tr>
<td></td>
<td>5.2</td>
<td>3079</td>
<td>8.8</td>
<td>128</td>
<td>8.9</td>
<td>213</td>
<td>6.7</td>
<td>321</td>
</tr>
</tbody>
</table>

**Latin America**

|                              |          |        |              |           |               |               |                           |               |
|                              | 27%      | n      |              |           |               |               |                           |               |

**Middle East North Africa**

|                              |          |        |              |           |               |               |                           |               |
|                              | 27%      | n      |              |           |               |               |                           |               |

**North America**

|                              |          |        |              |           |               |               |                           |               |
|                              | 27%      | n      |              |           |               |               |                           |               |
A MESSAGE ABOUT FALLS

FALLS AMONG OLDER ADULTS ARE

COSTLY

$50 Billion Annually

$29 Billion Medicare
$12 Billion Private/Out-of-Pocket
$9 Billion Medicaid

COMMON

1 in 4
Older adults (65+) falls each year

PREVENTABLE

Clinicians can use STEADI to prevent falls & reduce costs

A MESSAGE ABOUT FALLS

Fall Death Rates in the U.S.
INCREASED 30%
FROM 2007 TO 2016 FOR OLDER ADULTS

If rates continue to rise, we can anticipate
7 FALL DEATHS
EVERY HOUR
BY 2030

Learn more at www.cdc.gov/HomeandRecreationalSafety
Persons with ID/DD face a significant and diverse range of health challenges.

Despite the high prevalence of physical and mental health problems among individuals with ID/DD, little is known about the quantity and quality of services received.

What data are available suggest that these individuals do not receive the health services that their conditions require.
Summary

• Individuals with I/DD:
  • Are susceptible to the same health conditions as individuals in the general population.
  • Have many special health care needs which increase as they age.
  • Experience more barriers to receiving quality care than individuals without I/DD.
  • Are therefore in greater need of appropriate prevention services.
Special Olympics Athletes

- Special Olympics athletes have a significant and diverse range of health challenges.
- Special Olympics athletes have a significant unmet need for care.
- Too much of the care is crisis oriented.
- There is underinvestment by society, health systems, health professions in care for people with intellectual disabilities.

- Special Olympics Healthy Athletes addresses and fills unaddressed needs for prevention and care.
The Aging Athlete and Health

The degree of health and functional capacity normally declines with age including an impact upon: vision, hearing, balance, stamina, memory, and strength.

Aging increases the risk of illness including osteoporosis, heart disease, hypertension, depression, cancer, stroke, lung disease, and spinal disease.
Individuals with IDD are living longer and experience age-related functional decline.

Participation in sports may become more difficult as one gets older.

Competitive sports may become more difficult for the senior athlete.

Adults with IDD drop out of Special Olympics as they get older.
**NEEDS** – equitable and knowledgeable health care for all people with IDD in all communities.

**BARRIERS** – in many communities around the globe, significant disparities exist in access to and payment for health services.

- Lack of knowledge of best practices to work with those with IDD
- Lack of awareness of the health issues to those with IDD
- Amplification of these problems in rural areas

**STAKEHOLDERS** – healthcare professionals, health systems, universities, families
HEALTHY ATHLETES

MISSION:
• Improve each athlete’s ability to:
  • Train
  • Compete in sports and in life activities

GOAL:
• Enlist health care professionals as volunteers.
• Provide health care professionals with experience and insight to use when caring for people with intellectual disabilities in their own communities.
IMMEDIATE OBJECTIVES

• Improve the health of the athlete.

• Improve health care for people with intellectual disabilities.

• Increase access to health care.

• Train health care professionals.

• Advocate for improved and equitable health care.
BE A FAN OF ACCEPTANCE, DIGNITY, AND THE HUMAN RACE.
WHAT ARE HEALTHY COMMUNITIES?

• A health care delivery approach that focuses on the whole person with IDD
• A model to provide integrated health care, health promotion and wellness services to people with IDD in their communities
• A flexible model that can be tailored to the specific needs of each community.
• A partnership model that encourages local resources and organizations to engage with Special Olympics.

WHAT ARE THE GOALS?

■ To extend the principles of HA to a steady presence in the lives of those with IDD
■ To build healthy inclusive communities
■ To develop and foster accessible follow-up care
■ To develop health promotion and wellness education and opportunities for those with IDD
■ To engage partnerships and collaborations for these programs
Benefits of Exercise!

• Control/manage weight
• Manage chronic diseases
• Lower blood pressure
• Prevent falls
• Reduce/prevent depression
• Reduce pain
• Improve Connections between brain cells
Exercise- the basics!

- **Endurance:**
  - 150 minutes/week

- **Strength**
  - 1-3 times/week with resistance

- **Flexibility**

- **Balance**

- **Recommendations remain the same as we age!!!!!!**
Community Resources

• Resources in Community
  • Referrals to appropriate providers
    • Vision Specialists
    • Physical Therapists/Occupational Therapists
  • Local Aging Resources
    • Senior Centers
    • Evidence Based Prevention Programs
    • Special Olympics
    • Others
• Deaths from Falls Among Persons Aged ≥65 Years — United States, 2007–2016
  • https://www.cdc.gov/mmwr/index.html

• SUPPLEMENTARY TABLE. Age-standardized fall death rates and annual percentage change by state, adults aged ≥65 years — United States, 2007–2016
  • https://stacks.cdc.gov/view/cdc/53652

• Estimating the Economic Burden Related to Older Adult Falls by State
  • https://journals.lww.com/jphmp/Abstract/publishahead/Estimating_the_Economic_Burden_Related_to_Older.99483.aspx