PROMOTING SUCCESSFUL AGING IN ADULTS WITH INTELLECTUAL DISABILITIES AND THEIR CAREGIVERS

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Overview

• What is good health/successful aging?
• Why are people with disabilities at risk for poorer health/less successful aging?
• Key abilities and concepts to promote self-determination and self-advocacy in health
• Useful resources
• Tips for promoting good relationships with healthcare providers
What is Good Health?

Health is a state of complete **physical**, **mental** and **social** well-being and not merely the absence of disease or infirmity.
Successful Aging

Rowe & Kahn defined successful aging as multidimensional:

Avoidance of disease and (aging-related) disability

Maintaining high physical and cognitive function

Sustained engagement in social and productive activities

Why are people with disabilities at risk for poorer health?

The presence of disability ≠ illness.

However, some disabilities lead to secondary conditions that can increase risk of poor health and reduce quality of life.

– **87%** of persons with a disability report at least one secondary condition vs. **49%** of those people without a disability

– People with disabilities report more secondary conditions than persons without disabilities (**4.02 vs 1.28**)

Common Secondary Conditions

- Chronic pain in muscles/joints
- Sleep problems
- Extreme fatigue
- Weight gain/eating problems
- Skin problems
- Respiratory infections
- Falls and other injuries
- Bowel/bladder problems
- Muscle spasms
- Asthma
- Depression
- Anxiety
- Social isolation
- Lack of romantic relationships
- Lack of friendships
- Lack of community engagement

(Kinne et al., 2004).

Remember: Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.
People with Disabilities Report Poorer Health.

<table>
<thead>
<tr>
<th>Self-reported Health Status</th>
<th>With Disability</th>
<th>Without Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent/Very Good</td>
<td>27.2%</td>
<td>60.2%</td>
</tr>
<tr>
<td>Good</td>
<td>32.5%</td>
<td>29.9%</td>
</tr>
<tr>
<td>Fair/Poor</td>
<td>40.3%</td>
<td>9.9%</td>
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</tbody>
</table>

*Aged 18 years or older

(Self-Rated Health Status Among Adults With and Without Disabilities - United States, 2004 - 2006; CDC, 2008).
Poor Health Status Results in Poor Health Outcomes


**People with ID** are a particularly vulnerable population.

More likely to...............

- Live with complex health conditions
- Have limited access to quality healthcare/health prevention programs
- Miss cancer screenings
- Have poorly managed chronic conditions, eg. epilepsy
- Be overweight
- Have undetected poor vision
- Have mental health problems
<table>
<thead>
<tr>
<th>Health Indicator</th>
<th>People With Disabilities (%)</th>
<th>People Without Disabilities (%)</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health care access</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In past year, needed to see doctor but did not because of cost&lt;sup&gt;a&lt;/sup&gt;</td>
<td>27.0</td>
<td>12.1</td>
<td>BRFSS 2010</td>
</tr>
<tr>
<td>Women current with mammogram&lt;sup&gt;a&lt;/sup&gt;</td>
<td>70.7</td>
<td>76.6</td>
<td>BRFSS 2010</td>
</tr>
<tr>
<td>Women current with Pap test&lt;sup&gt;a&lt;/sup&gt;</td>
<td>78.3</td>
<td>82.3</td>
<td>BRFSS 2010</td>
</tr>
<tr>
<td><strong>Health behaviors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults who engage in no leisure-time physical activity&lt;sup&gt;a&lt;/sup&gt;</td>
<td>54.2</td>
<td>32.2</td>
<td>NHIS 2008</td>
</tr>
<tr>
<td>Children and adolescents considered obese (aged 2-17 y)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>21.1</td>
<td>15.2</td>
<td>NHANES 1999-2010</td>
</tr>
<tr>
<td>Adults who are obese&lt;sup&gt;a,b&lt;/sup&gt;</td>
<td>44.6</td>
<td>34.2</td>
<td>NHANES 2009-2010</td>
</tr>
<tr>
<td>Adults who smoke (100 cigarettes in lifetime and currently smoke)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>28.8</td>
<td>18.0</td>
<td>NHIS 2010</td>
</tr>
<tr>
<td>Annual no. of new cases of diagnosed diabetes (per 1000 persons)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>19.1</td>
<td>6.8</td>
<td>NHIS 2008-2010</td>
</tr>
<tr>
<td>Adults with cardiovascular disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-44 y</td>
<td>12.4</td>
<td>3.4</td>
<td>NHIS 2009-2011</td>
</tr>
<tr>
<td>45-64 y</td>
<td>27.7</td>
<td>9.7</td>
<td>NHIS 2009-2011</td>
</tr>
<tr>
<td>Victim of violent crime (per 1000 persons)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>32.4</td>
<td>21.3</td>
<td>NCVS 2007</td>
</tr>
<tr>
<td>Adults reporting sufficient social and emotional support&lt;sup&gt;a&lt;/sup&gt;</td>
<td>70.0</td>
<td>83.1</td>
<td>BRFSS 2010</td>
</tr>
<tr>
<td><strong>Social determinants of health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult (&gt;16 y) unemployment</td>
<td>15.0</td>
<td>8.7</td>
<td>CPS 2011</td>
</tr>
<tr>
<td>Adult (&gt;16 y) employment</td>
<td>17.8</td>
<td>63.6</td>
<td>CPS 2011</td>
</tr>
<tr>
<td>Adults with &lt; high school education</td>
<td>13</td>
<td>9.5</td>
<td>BRFSS 2010</td>
</tr>
<tr>
<td>Internet access</td>
<td>54</td>
<td>85</td>
<td>NOD 2010</td>
</tr>
<tr>
<td>Household income &lt; $15 000</td>
<td>34</td>
<td>15</td>
<td>NOD 2010</td>
</tr>
<tr>
<td>Inadequate transportation</td>
<td>34</td>
<td>16</td>
<td>NOD 2010</td>
</tr>
</tbody>
</table>

Note. BRFSS = Behavior Risk Factor Surveillance System; CPS = Current Population Survey; NCVS = National Crime Victimization Survey; NHANES = National Health and Nutrition Examination Survey; NHIS = National Health Interview Survey; NOD = National Organization on Disabilities Survey of Americans with Disabilities; Pap test = Papanicolaou test. All differences reported are statistically significant. Most of these data were drawn from the HP2020 Data Indicators Warehouse<sup>40</sup> additional sources used for mammograms and Pap tests<sup>41</sup> and violence<sup>42</sup>

<sup>a</sup>Age-adjusted.

<sup>b</sup>Obesity defined as a body mass index of ≥ 30 kg/m².

The Diversity of the Aging Process

Individual Aging Process

- Susceptibility to disease
- Universal physical changes (sensory, reduced efficiency/capacity of organ systems, loss of muscle/bone mass)
- Compensatory behaviors + access to Resources (e.g. healthcare)
- Gender

Genetic profile

Lifestyle

Social and cultural factors (e.g. quality of social network, family cohesiveness)

Aging with lifelong disability & comorbidity

Florida Center for Inclusive Communities
Data from CDC http://www.cdc.gov/ncbddd/cp/data.html
Epilepsy, Glaucoma, High-Cholesterol, Frailty, Cataracts, Hypertension, Stroke, Lung-Disease, Vision-Loss, Hearing-Loss, Depression, Heart-Disease, Dementia, Anxiety, Osteoporosis, Cancer, Diabetes, Osteoarthritis
Modifiable Factors for Successful Aging Apply to All Populations

- Eat a balanced and healthy diet (and supplements)
- Maintain a healthy weight
- Exercise on a regular basis (include weight bearing exercises)
- Manage stress / allow time for relaxation
- Don’t smoke / alcohol in moderation (and avoid secondary smoking!)
- Education (promote lifelong learning)
- Occupation/Productivity (esp. promotes curiosity, or working with people)
- Enjoyable Leisure activities (mental, social, physical)
- Enriching relationships (evolving)
- Living in a nurturing/clean physical environment
Self-determination and Self-advocacy in Health Care Across the Lifespan

It is important:

A) To know and carefully describe what your health concerns are

B) To understand your disability and conditions that may arise

C) To know your options for treatment

D) To make decisions about your treatment based on the advice of the doctor

E) To be able to take medications/follow care plans – and let your doctor know what might be difficult for you to do
Self-determination and Self-advocacy in Health Care Across the Lifespan

It is important:

F) To be aware of when you are not feeling well and that some medications have different side effects

G) To continue to seek treatment, and have regular physical check-ups

H) Always ask if you don’t understand, you have a right to know!

I) Have a circle of support, family members who participate in your health care
Health Advocacy

It’s all about good communication!

1) Communicating needs in a way that healthcare providers can understand and act upon!

2) Communicating information about aging and health to individuals and caregivers.
Resources: My Health Passport

• Not just another form....
• Designed to be eye-catching, provide information that is useful
• Needed to be comprehensively concise 😊
• Provide health care providers with strategies to modify the environment, or their own behavior
• Appropriate for all ages
My Health Passport

• Versatility
  - relevant to a wide range of healthcare settings
  - alternative uses – emergency/disaster management preparedness, quick “cheat” sheet for new staff members in residential settings, respite care providers
  - format can be adapted to suit different agencies

• User-friendly

• It’s free!!
My Health Passport

- After the demographic information

...notice that the first thing that is emphasized is how does the person **communicate**

Does the person avoid eye-contact but attends to everything that is said?

- Do they make idiosyncratic sounds that have a consistent meaning – e.g. Are they able to verbalize yes and no clearly – “e.g. do they make “eee” sound for yes?”
Brief history, medications, allergies: all important to document.

How a person prefers to take medications: established routines to be adhered to, food / drink preferences

Pain/Distress:
- health care professionals might be particularly apprehensive when presented with an individual in pain/distress with intellectual disability.
- we all experience pain differently, does an individual understands a numeric or picture pain scale.
- when distressed, is there an effective way comfort them?
Coping with medical procedures:

-Taking a blood pressure can be a relatively novel experience.

Mobility/personal care needs: helps people from “over-assisting”, from lack of knowledge.

Eating/drinking:

-individuals may have needs that are easily accommodated if only they are shared.
..e.g. only drinks from a particular cup, only likes to eat from a bowl, does not use a knife!
Food/drink: Food/drink refusal may occur from restricted range of drinks/foods that are tolerated. Certain textures (e.g. jello), odors from certain foods, presentation of unfamiliar food, may contribute to difficulties at meal-times. Food/fluid intake is crucial, so availability of alternative choices is critical.

Hypersensitivities can also be problematic, given clinical environments (e.g. the odor from alcohol swabs), tv’s/music if in a shared room/open ward.

Follow-up appointments: Request early/late times, pre-examination orientation visits to new clinics/offices. Pictures of the medical/nursing staff that will be seeing the person.
My Health Passport

Print and/or save file directly from FCIC’s website:

http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf
http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_Spanish.pdf
There’s an App for that!
http://healthcarecommunicationapp.com/
What You Should Know About Good Health and Hygiene!

Why is being healthy so important?

Maximizes the possibility of successfully aging!

Need to consider **physical, mental and social** health.

Free factsheet - Good Health and Hygiene!
FCIC Resource: Education for Lifelong Health Series

http://flfcic.fmhi.usf.edu/docs/FCIC_EFLH_Complete_Series.pdf
Education for Lifelong Mental Health

What I should know about ANXIETY

What is anxiety?
Anxiety is when you worry too much about typical everyday things that you do or happen around you. There are different types of anxiety. Some anxiety can be normal. For example, when you go to a new place, you may feel anxious. Anxiety can also be a problem. Anxiety can help you deal with tough situations and help you work harder.

You might have an anxiety disorder if you feel so worried that it gets in the way of your daily activities and work. They are very common. About 1 out of 6 adults has some type of anxiety disorder. The good news is that there are many helpful treatments.

Why do people get anxiety disorders?
- Sometimes anxiety is in their brain and not working.
- Sometimes anxiety is in their body and not working.
- Sometimes anxiety is in their family and not working.
- Sometimes anxiety is in the world and not working.
- Sometimes anxiety is in their mind and not working.

How do I know if I have an anxiety disorder?

Thoughts and Feelings:
- Feeling scared or nervous
- Not able to focus
- Thinking the worst will happen
- Feeling anxious
- Feeling stressed for no reason
- Feeling worried all of the time

If you think you might have anxiety, you should let your caregiver and/or doctor know. They can make sure you get the help that you need.

http://flfcic.fmhi.usf.edu/program-areas/health.html available for free - under the materials and resources tab
Promoting Mental Health!

Florida Developmental Disabilities Council Website: http://www.fddc.org/publications/order-online
Caregiver Mental Health!

An informative and user-friendly booklet that describes how to manage stress.

Caregivers learn how the mind-body connection affects response to stress.

Caregivers are given practical guidance on how to ease their stress.

Hard copies may be ordered online through the FDDC website.
Promoting good relationships with healthcare providers

1) Be prepared!
   Bring all medications
   Describe the condition
   What makes it better? What makes it worse?
   Bring a health passport/health summary

2) Always record the advice of the healthcare provider
   Ask if you can use a voice recorder (you can use your phone)
   Ask them to explain any words/terms that you don’t understand
   Make notes or ask someone else to take notes for you

3) Always communicate any concerns and ask questions
   You know yourself best – share everything you know, and ask about anything you want to know.
Contact Information:

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http://flfcic.fmhi.usf.edu/projects/health.htm

Member-At-Large, Board of Directors, American Association on Intellectual and Developmental Disabilities
FCIC Representative, Florida Developmental Disabilities Council
Advisory Board - Disability and Health Program, Florida Department of Health
This newly updated 500+ page book provides a comprehensive overview of the aging process, describes common aging-related conditions/diseases and also includes chapters on caregiving, aging with lifelong disabilities, death and dying, complimentary medicine.