Providing High Quality Health Care Experiences for Individuals With Intellectual and Developmental Disabilities

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With collaboration from
Project Action! Washington, DC
self advocacy organization

Intellectual Disability Definition

- Disability characterized by significant limitations in intellectual functioning and in adaptive behavior
  - Consider limitation within context of community environments
  - Valid assessments
  - Limitations coexist with strengths
  - Use limitations to develop profile of needed supports
  - Over time, and with appropriate supports, functioning will generally improve

Slide Source: D.C. Health Resources Partnership, 2006
Intellectual Disability Definition, Cont.

- **Significantly sub-average intellectual functioning:** An IQ of approximately 70 or below on an IQ test:
  - Mild = approx. 50 – 70
  - Moderate = approx. 35 – 50
  - Severe = approx. 20 – 35
  - Profound = below 20

- **Concurrent deficits in adaptive functioning in at least 2 areas:**
  - Receptive communication
  - Expressive communication
  - Self care,
  - Social skills
  - Motor skills
  - Community use
  - Health
  - Safety
  - Occupational skills
  - Functional academic skills

- **The onset is before the age of 18 years.**

Developmental Disability Definition
as specified in federal Public Law 100-146

- A severe, chronic disability of a person that:
  - Is attributable to a mental or physical impairment or combination of mental and physical impairments that is likely to continue indefinitely.
Developmental Disability Definition, Cont.

- Results in substantial functional limitations in three or more of the following areas of major life activity:
  - self-care
  - receptive and expressive language
  - learning
  - mobility
  - self-direction
  - capacity of independent living and
  - economic self-sufficiency; and

- Reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong extended duration and are individually planned and coordinated. [42 U.S.C. 6001(5)]
DISABILITY SPENDING IN THE STATES

State of the States in Developmental Disability
Report developed by the University of Colorado, Anschutz Medical Campus

- Spending by federal, state, and local units of government constitutes a large proportion of the resources available to assist people with disabilities in the United States.

- These public funds pay for health care, income maintenance, special education, vocational rehabilitation and training, and long-term care including housing and related residential support services. Funds are allocated directly to individuals as well as to schools, health care organizations, and tens of thousands of nonprofit and proprietary disability services organizations.

- The findings of this study illustrate the increasing size and growth rate of disability spending as well as a strong, continuing shift away from the use of institutional and nursing facility care toward more individualized community residential and personal support services.


A review of 91 research articles on health and health promotion for people with intellectual and developmental disabilities.
Health Disparities’ Impact on People with IDD

- Decreased life expectancy
- Greater rates of co-occurring conditions
  - Sensory impairment, epilepsy
  - Psychiatric disorders
  - Limited mobility
  - GI disorders
- More likely to develop common health conditions
  - High cholesterol
  - Hypertension
  - Cardiovascular disease
- More likely to experience multiple chronic conditions

Oral Health

High rates of periodontal disease and caries
- Resulting in decay, missing molars and restorations
- Insufficient preventive dental care including sealants
Aging

- Elevated rates of dementia, particularly people with Down syndrome
  - More than half of the people with DS over the age of 50 will experience dementia
- Women with DS appear to enter menopause earlier than their peers (dementia and early mortality)
- People with cerebral palsy
  - Increased pain levels
  - Sarcopenia
  - Osteoporosis
  - Arthritis
- Exacerbation of osteoporosis by medications frequently prescribed (e.g. phenytoin and SSRIs)
- Bone loss exacerbated by sedentary lifestyle and poor nutrition

End of Life Care

- Under-utilization of hospice and palliative care
- Late diagnosis of a terminal illness
- Challenges related to informed consent
- Lack of knowledge about people with IDD by palliative care professionals
- Lack of models by service agencies to provide effective end of life care
Obesity-Related Factors

- Mixed results from the research
- Some show higher prevalence of obesity among people with IDD than the general population (21% - 33.6%)
- Other studies suggest that in the absence of a known genetic condition, the prevalence is less than or similar to that of people living in the same communities and receiving similar health care (70.7% for people with DS)
- BMI is not accurate for some sub-populations
- People living in the home of a family member or their own have highest rates of unhealthy weight gain, obesity, CVD and CVD-related mortality

Obesity-Related Factors, cont.

- Access to and participation in physical activity
- Sedentary lifestyles
- Immobility
- Highest rates of obesity risk include people with DS, Prader-Willi syndrome and spina bifida
- Polypharmacy (6.5 medications for people in community-based settings) may lead to increased rates of obesity and diabetes
Surgeon General’s Report: Closing the Gap

- Health Promotion and Community Environments
- Knowledge and Understanding
- Quality of Health Care
- Training of Health Care Providers
- Health Care Financing
- Sources of Health Care
DDA Health Initiative

- Implementation of the use of health passports that accurately convey essential health information to hospitals, specialists, and dentists
- Preventive health screening policy that has resulted in the elimination of health disparities for the screening of certain adult health conditions
- Development of products related to safe transitions, mental health guidelines, exercise, and sensory stimulation
- Strong Medicaid program for dental care reimbursement

Medical Consultation

- Direct admission to intensive care services, or requiring emergency surgery
- Change in status as an in-patient and requiring transfer to a higher intensity of service, i.e., to the Critical Care Unit or Intensive Care Unit (“CCU/ICU”)
- In-patient hospital stay with a length over two weeks
- New cancer diagnosis
- Decline in function which impacts critical organ system, e.g., cardiovascular, etc.
- Decline in function for which no cause has been determined following appropriate advanced testing.
- Unintentional weight loss more than 5% of body weight
- Admission to hospice or being considered for hospice admission
- Conflicting recommendations from two or more specialists
Medical Consultation, contd.

Frequency of Consultation
February 2014-March 2015

- Single contact: 25%
- Contact with multiple team members 2-4 times within the reporting month: 33%
- Contact with multiple team members 5 or more times within the reporting month: 42%

Medical Consultation, contd.

Nature of Consultations
March 2015

- Communication with hospital attending: 11
- Communication with specialist: 13
- Communication with primary care provider: 8
- Communication with health care decision-maker: 3
- Hospital site visit: 5
What is health care transition?

- Health care transition is the process of changing from a pediatric to an adult model of health care. The goal of transition is to optimize health and assist youth in reaching their full potential. To achieve this goal requires an organized transition process to support youth in acquiring independent health care skills, preparing for an adult model of care, and transferring to new providers without disruption in care.

Six Core Elements of Healthcare Transition

- Establish a policy
- Track progress
- Administer transition readiness assessments
- Plan for adult care
- Transfer
- Integrate into an adult practice
First Office Visit

- John is a 33-year-old man who presents for a new patient appointment. He is accompanied by an unrelated adult. He is smiling and nicely dressed, but instead of answering your questions, he repeats the last word or two of your question. The person accompanying him says that John lives in a group home and he was only told to get him to your appointment on time (which he did!). How should you proceed?
Supported Decision-Making

Think About It

How do you make decisions?
What do you do if you’re not familiar with the issue?
- Taxes?
- Medical Care?
- Auto Repairs?

What Do You Do?

http://supporteddecisionmaking.org/

Supported Decision-Making

- Emphasis on legal capacity as a “right”
- Provides for Meaningful Involvement by the Person needing support in Decision-Making
- Discusses the needs for self-advocacy support and new strategies for safeguards
- Identifies Guardianship as the Most Restrictive Intervention

http://supporteddecisionmaking.org/
Three Core Elements of Supported Decision-Making Methods

- They recognize the person’s right to make decisions on an equal basis with others;
- They recognize that people can create a decision-making process that does NOT result in the removal of their decision-making rights; and
- They recognize that people will often need assistance in decision-making through various means

(Dinerstein, 2012)

Common Supports

- Help people to understand relevant information, issues, and available choices
- Focus attention in making decisions
- Assist people to weigh options
- Base decisions on preferences and expressed desires
- Facilitate interpretation and communicate decisions

http://supporteddecisionmaking.org/
One Size Does NOT Fit All

There are many ways to support people to make decisions.

Guardianship AND SDM are both “tools” to be used to assist people.

Goal = right tool, in the right amount, at the right time for each person.

http://supporteddecisionmaking.org/

It’s A Paradigm, Not A Process

There is no one method to implement Supported Decision-Making.

Strategies can include, as needed and appropriate:

- Informal support
- Interpretation based on knowledge of person
- Written agreements, like Powers of Attorney, identifying the support needed
- Micro-Boards, Circles of Support and Natural Support Networks

http://supporteddecisionmaking.org/
Tools at Your Disposal

- Transition of Care Guide
- Checklist of Psychiatric and Behavioral Problems in People with Intellectual Disabilities
- Health Passport
- Preventive Health Screening: US Preventive Services Task Force Recommendations
- End of Life Planning
**Transition of Care Guide**

A Guide for Community Support Providers to Facilitate Safe Transitions from the Hospital or Long Term Care Facility to Home

The following questions are important to assist community support providers, service coordinators, and health care decision makers in obtaining the information needed to proceed with health care transitions from the hospital or long term care facility to the home setting for individuals with developmental disabilities.

This document is not meant to replace the discharge summary or medication reconciliation forms.

**Health Conditions**

- Do you understand the individual's health conditions?
- Do you understand the individual's treatment plan?
- Do you understand the medication regimen?
- Do you understand the follow-up care?
- Do you understand the patient's rights?

**Discharge Instructions**

- Do you understand the discharge instructions?
- Do you understand the patient's responsibilities?
- Do you understand the follow-up care?
- Do you understand the patient's rights?

**Notes**

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**A Checklist for Coordinators & Supervisors**

Psychiatric and Behavioral Problems in Individuals with Intellectual Disability

The checklist is based on the Treatment of Psychiatric and Behavioral Problems in Individuals with Intellectual Disability: An Update of the Expert Consensus Guidelines (2006) by M. A. Asarnow, M. L. Carr, L. R. Crenshaw, S. E. Cooper, and J. Rosen. This document contains the recommendations of a panel of national experts. The checklist was developed for Service Coordinators, Program Managers, CASES, and others who coordinate and supervise care for individuals with intellectual disability. It was adapted from the expert consensus guidelines, with permission of the publisher, by the DC Health Resources Partnership at Georgetown University Center for Excellence in Developmental Disabilities.

**ASSESSMENT**

- Key Principles in Diagnosis
  - Effective treatments typically require that there is a clear diagnosis of the problem.
  - A clear diagnosis of the problem is more important for making treatment decisions than for making treatment decisions when there is a clear diagnosis of the problem.
  - A clear diagnosis of the problem is more important for making treatment decisions than for making treatment decisions when there is a clear diagnosis of the problem.

**When to Use This Checklist**

This checklist is intended to help the care coordinator and supervisee in the care of individuals with co-occurring intellectual disability and persistent behavioral problems. However, it is not intended to substitute for the expert consensus guidelines or the developmental disabilities administration guidelines.

**Notes**

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**HEALTH PASSPORT**

**CONSUMER INFORMATION**

- First Name: [Name]
- Last Name: [Surname]
- Address: [Address]
- City, State, Zip: [City, State, Zip]
- Phone: [Phone Number]
- Email: [Email]
- Medication: [Medication]
- Diagnosis: [Diagnosis]
- Other Information: [Other Information]

**CONTACT INFORMATION**

- Phone: [Phone Number]
- Email: [Email]
- Gender: [Gender]
- Employment: [Employment]
- Education: [Education]
- Marital Status: [Marital Status]
- Additional Information: [Additional Information]

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Adapted by the DC Health Resources Partnership, Georgetown University Center for Excellence in Developmental Disabilities. Published in [Year].
Preventive Health Screening: US Preventive Services Task Force Recommendations

### Annual Preventive Health Screening Report—Female

<table>
<thead>
<tr>
<th>Condition</th>
<th>Screening Indications</th>
<th>Test and Frequency</th>
<th>Completion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Down Syndrome</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mental Retardation</strong></td>
<td>Age 0-10 years: Special needs; ages 11-20 years: General</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hearing</strong></td>
<td>Adult: 20 Hz max. Bone conduction audiometry; ages 11-20 years: Otoscopy</td>
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<td></td>
</tr>
<tr>
<td><strong>Cervical spine x-rays</strong></td>
<td>Adult: 17-25 years; Special needs: Imaging special needs reasons</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cervical</strong></td>
<td>Age 14 years; Special needs: Imaging special needs reasons</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cardiovascular</strong></td>
<td>Adult: 16-18 years; Special needs: Imaging special needs reasons</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ophthalmologic</strong></td>
<td>Adult: 16-18 years; Special needs: Imaging special needs reasons</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Clinical evaluation for sleep apnea</strong></td>
<td>Adult: 16-18 years; Special needs: Imaging special needs reasons</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Dementia screen</strong></td>
<td>Adult: 40 years; Special needs: Imaging special needs reasons</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Annual Preventive Health Screening Report—Male

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DOWN SYNDROME HEALTH CARE GUIDELINES


- TSH and T4-Thyroid Function Test (annual).
- Auditory testing (every 2 years).
- Cervical spine x-rays (as needed for sports); check for atlanto-axial dislocation.
- Ophthalmologic exam, looking especially for keratoconus & cataracts (every 2 years).
- Clinical evaluation of the heart to rule out mitral/aortic valve problems. Echocardiogram-ECHO (as indicated). Reinforce the need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adults with cardiac disease.
- Clinical evaluation for sleep apnea.
- Dementia screen beginning at age 40
RESULTS

Of the 511 participants in the original sample, 10 were dropped from the study (e.g., transferred, discharged, deceased). The Health Form 1 was collected for 444 of 501 Evans class members, yielding a response rate of 88.6%. The majority of Evans class members were male (63.5% vs 36.5%) and fell into the 50-59 years and 60-69 years age groupings.

Adherence to Preventive Health Services Study

Three screens performed most frequently:
- Cholesterol screening
- Prostate screening (men)
- Mammography (women)

Three screenings performed least frequently:
- Chlamydia and STDs
- HIV
- Skin cancer
### Breast & Cervical Cancer Screening Rates Compared to the General Population

<table>
<thead>
<tr>
<th></th>
<th>Study Sample</th>
<th>General Population (baseline)</th>
<th>( p )-value*</th>
<th>Healthy People 2020 Target Goal(**)</th>
<th>( p )-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mammography (Women)</td>
<td>95.6%</td>
<td>73.7%</td>
<td>&lt;.001</td>
<td>81.1%</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Pap Smear (Women)</td>
<td>89.2%</td>
<td>84.5%</td>
<td>0.078</td>
<td>93.0%</td>
<td>0.058</td>
</tr>
</tbody>
</table>

\(^*\, p\)-values derived from one-sample nonparametric binomial tests

\(^\text{**}\) Healthy People 2020 screening goals based on most recent guidelines

**NOTE:** All baseline percentages come from the National Health Interview Survey (NHIS); Centers for Disease Control and Prevention, National Center for Health Statistics (CDC/NCHS). For the year 2008. Baseline estimate for adults aged 50-75 years.

### Colorectal Cancer Screening Rates Compared to the General Population

<table>
<thead>
<tr>
<th></th>
<th>Study Sample *</th>
<th>General Population (baseline)</th>
<th>( p )-value*</th>
<th>Screening Goal(**)</th>
<th>( p )-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colorectal Cancer Screening</td>
<td>95.40%</td>
<td>52.1%</td>
<td>&lt;.001</td>
<td>70.5%</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

\(^*\) Includes only those who received colonoscopy

\(^\text{**}\) Healthy People 2020 screening goals based on most recent guidelines

### Proportion of Individuals Aged 50 Years and Older That Received Colorectal Cancer Screening

<table>
<thead>
<tr>
<th>Screening Method</th>
<th>Proportion</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Fecal Occult Blood Testing</td>
<td>36.8</td>
<td></td>
</tr>
<tr>
<td>Sigmoidoscopy</td>
<td>26.4</td>
<td></td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>95.4</td>
<td></td>
</tr>
</tbody>
</table>
Adherence to Preventive Health Services Study

Proportion of Individuals Receiving Appropriate Preventive Health Screenings and 95% CIs

Height and Weight 88.0%
Breast Exam (woman) 85.1%
Testicular Exam (man) 90.4%
Mammography (woman) 95.7%
Pap Smear (woman) 92.2%
Prostate Cancer (men) 96.8%
Skin Cancer Screen 76.0%
Hypertension 94.4%
Cholesterol 92.2%
Diabetes Type II 90.2%
Liver Function 72.7%
Osteoporosis 86.2%
Chlamydia and STDs 13.7%
HIV 90.4%
Hep B and C 59.4%
TB 97.3%
Hearing Assessment 86.3%
Vision Assessment 80.2%
Glaucoma 88.2%
Depression 96.0%
Dementia 89.2%

Health Screening Study Recommendations

- Continue the requirement that providers use the Health Form 1 to guide decision-making for participation in age and gender-based recommendations for preventive health screening.

- Annually convene a group of health care experts to review current recommendations of the U.S. Preventive Services Task Force and other health policy groups to determine if changes need to be made to the Health Form 1.

- Provide education to health practitioners about how to assess for sexual activity either during the annual medical exam or the annual nursing assessment.

- Provide education on how to conduct depression screening for people with intellectual disabilities.

- Provide education on dementia screening requirements and the appropriate screening tool to use.
Depression Screening

NTG Activities

- An early detection-screening instrument (NTG-EDSD) & manual
  - Various language versions available
  - Access at www.aadmd.org/ntg

- Practice guidelines
  - Community supports guidelines
  - Health practitioner assessment guidelines
  - Health advocacy guidelines
  - Community dementia care setting guidelines

NTG Education & Training Curriculum on Dementia and ID. Copyright 2014. All rights reserved.
NTG’s ‘Thinker Document Recommendations

- Early screening, health and wellness across the lifespan, and quality lifespan diagnostic services
- Formal (paid) and informal caregivers (family) also at risk with the intersection of the aging needs occurring
- Community and health care provider education
- Caregiver supports and services
- Increased research
- Health care advocacy
- Need for dementia capable services, supports, and advocacy
- Long term planning process needed that includes ID at the agency, regional, state, and federal level.
- Collaboration across networks

End of Life Planning

Quality of Life Considerations

These questions will help you think about situations in which you believe the person for whom you are making decisions would seek or refuse treatments intended to keep them alive at the end of life. If you think about the person for whom you are making medical decisions, reflect on what you believe is their best interest given the situations described below. If the treatment would not improve or improve their condition...

1. Reluctantly would the person agree to do the treatment?
2. Reluctantly would you want to do the treatment that might keep the person alive?
3. How much would you want to do the treatment that might keep the person alive?
4. If you were the person, would you want to do the treatment that might keep the person alive?
5. If you were the person, would you do the treatment that might keep the person alive?

What to do if the person for whom you are making decisions...

<table>
<thead>
<tr>
<th>Reluctantly Would the Person Agree to Treatment?</th>
<th>Reluctantly Would You Want to Do Treatment?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No longer can recognize or interact with family or friends.</td>
<td>2. No longer can think or talk clearly.</td>
</tr>
<tr>
<td>3. No longer can respond to commands or requests.</td>
<td>4. No longer can take part in activities of daily living.</td>
</tr>
<tr>
<td>5. No longer can talk to family or friends.</td>
<td>6. Requires continuous analgesia for the treatment of severe pain.</td>
</tr>
</tbody>
</table>

Options: 1. Reluctantly would the person agree to treatment? 2. Reluctantly would you want to do the treatment that might keep the person alive? 3. How much would you want to do the treatment that might keep the person alive? 4. If you were the person, would you want to do the treatment that might keep the person alive? 5. If you were the person, would you do the treatment that might keep the person alive?
People with developmental disabilities continue to experience health disparities.

Two Surgeons General reports have documented these disparities and have made recommendations to address their decline.

It is imperative that health disparities be addressed, and as this panel demonstrates, it requires a coordinated and complex set of strategies that engage the greater community, legislatures and state agencies.