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

Marisa C. Brown MSN, RN
Kim A. Bullock, MD

Georgetown University Center for Excellence in Developmental Disabilities

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

Developmental Disability Definition, Cont.

- 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.**

The state of the science of Health and Wellness for adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 51(5), 385-398.

Anderson, Lynda Lahti, Humphries, Kathy, McDermott, Suzanne, Marks, Beth, Sisarak, Jasmina and Larson, Sheryl (2013).

• • •

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

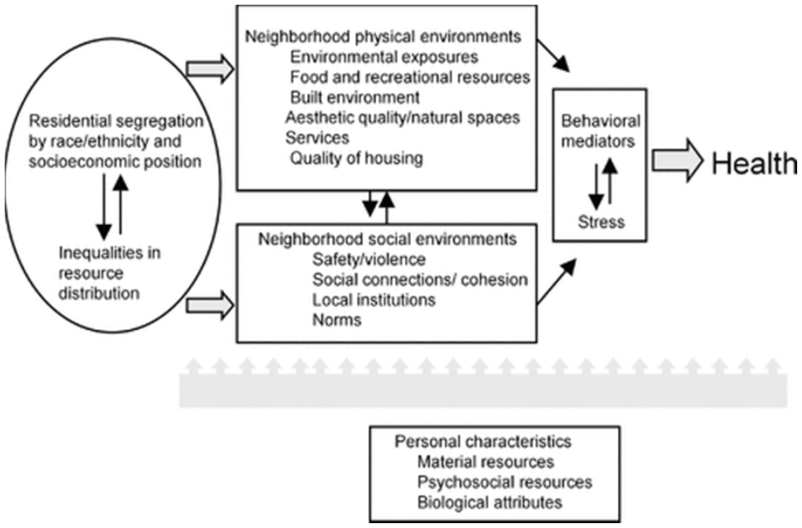
Obesity-Related Factors

- 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)
- BMIs 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 life styles
- 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 an diabetes

Neighborhoods and health



Annals of the New York Academy of Sciences
Volume 1186, Issue 1, pages 125-145, 16 FEB 2010 DOI: 10.1111/j.1749-6632.2009.05333.x
http://onlinelibrary.wiley.com/doi/10.1111/j.1749-6632.2009.05333.x/full#f1

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

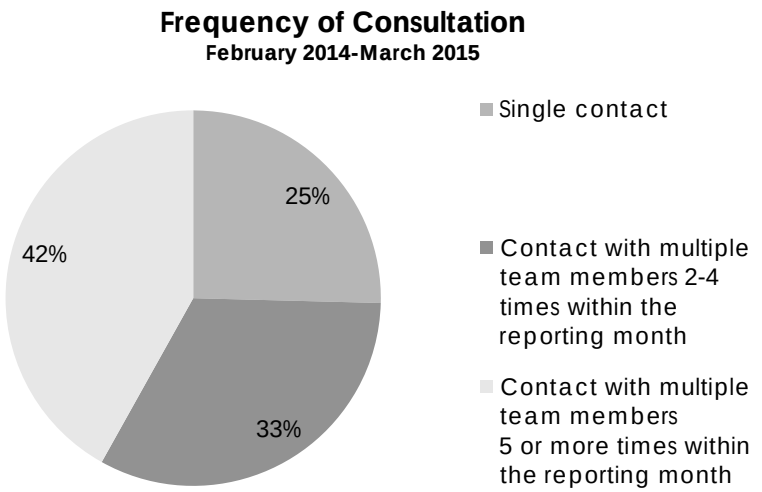
DDA Health Initiative

- 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

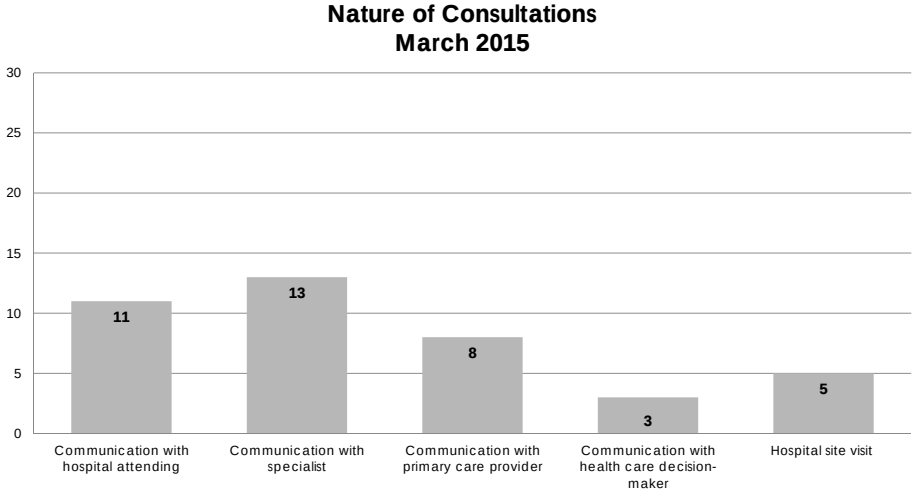
Medical Consultation

- 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.,* cardio-vascular, etc.
- Decline in function for which no cause has been determined following appropriate advanced testing.
- Unintentional weight loss f 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.*



Medical Consultation, *contd.*



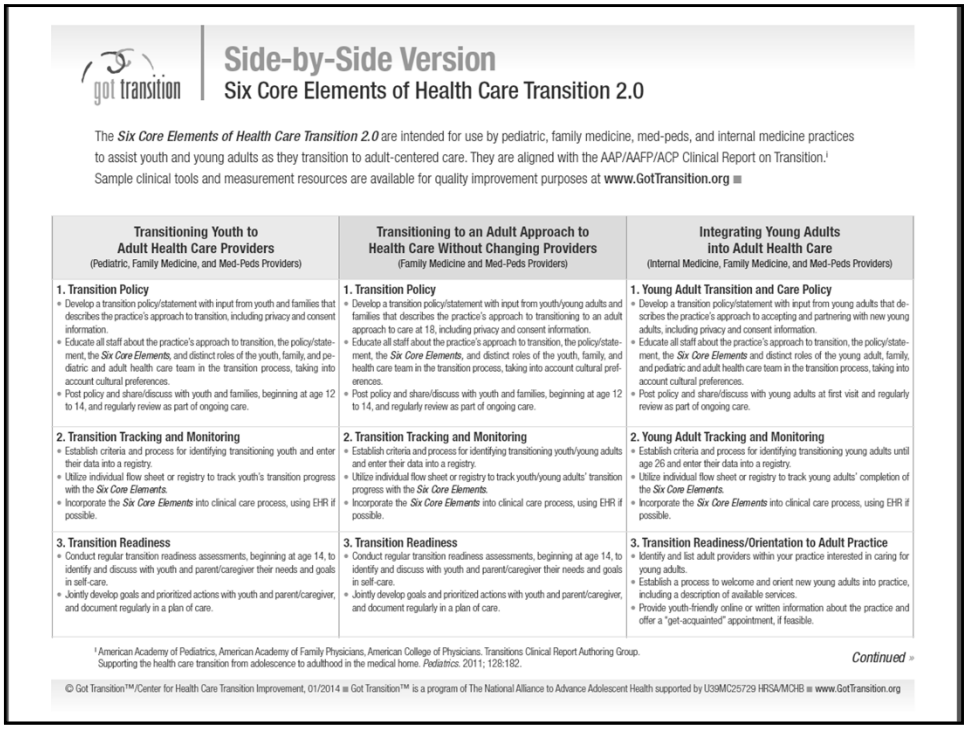
What is health care transition?

- 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.

http://gottransition.org/providers/index.cfm

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



got transition

Side-by-Side Version

Six Core Elements of Health Care Transition 2.0

The ***Six Core Elements of Health Care Transition 2.0*** are intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAFP/ACP Clinical Report on Transition.[1] Sample clinical tools and measurement resources are available for quality improvement purposes at **www.GotTransition.org** ■

Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)	Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers)	Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)
1. Transition Policy • Develop a transition policy/statement with input from youth and families that describes the practice's approach to transition, including privacy and consent information. • Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements*, and distinct roles of the youth, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences. • Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.	**1. Transition Policy** • Develop a transition policy/statement with input from youth/young adults and families that describes the practice's approach to transitioning to an adult approach to care at 18, including privacy and consent information. • Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements*, and distinct roles of the youth, family, and health care team in the transition process, taking into account cultural preferences. • Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.	**1. Young Adult Transition and Care Policy** • Develop a transition policy/statement with input from young adults that describes the practice's approach to accepting and partnering with new young adults, including privacy and consent information. • Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements* and distinct roles of the young adult, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences. • Post policy and share/discuss with young adults at first visit and regularly review as part of ongoing care.
2. Transition Tracking and Monitoring • Establish criteria and process for identifying transitioning youth and enter their data into a registry. • Utilize individual flow sheet or registry to track youth's transition progress with the *Six Core Elements*. • Incorporate the *Six Core Elements* into clinical care process, using EHR if possible.	**2. Transition Tracking and Monitoring** • Establish criteria and process for identifying transitioning youth/young adults and enter their data into a registry. • Utilize individual flow sheet or registry to track youth/young adults' transition progress with the *Six Core Elements*. • Incorporate the *Six Core Elements* into clinical care process, using EHR if possible.	**2. Young Adult Tracking and Monitoring** • Establish criteria and process for identifying transitioning young adults until age 26 and enter their data into a registry. • Utilize individual flow sheet or registry to track young adults' completion of the *Six Core Elements*. • Incorporate the *Six Core Elements* into clinical care process, using EHR if possible.
3. Transition Readiness • Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care. • Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.	**3. Transition Readiness** • Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care. • Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.	**3. Transition Readiness/Orientation to Adult Practice** • Identify and list adult providers within your practice interested in caring for young adults. • Establish a process to welcome and orient new young adults into practice, including a description of available services. • Provide youth-friendly online or written information about the practice and offer a "get-acquainted" appointment, if feasible.

[1] American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011; 126:182.

Continued »

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 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

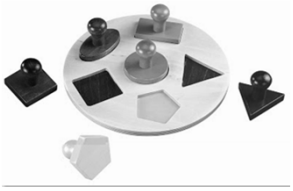
http://supporteddecisionmaking.org/

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/

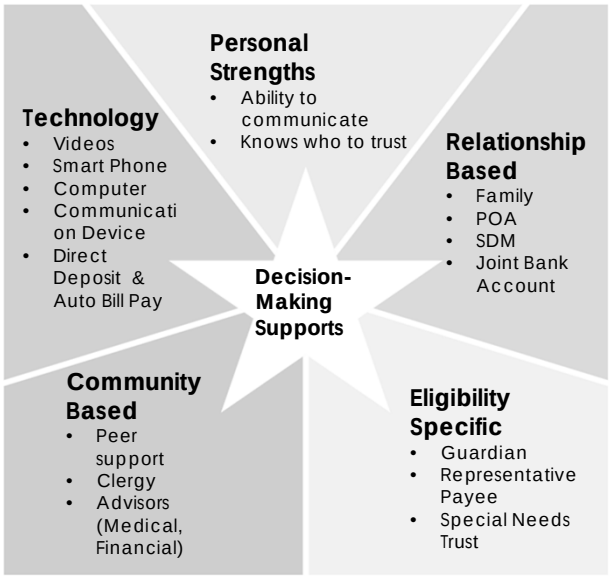
It's A Paradigm, Not A Process

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/



Erin Leveton, State Office of Disability Administration, Department on Disability Services

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 provided to assist community support providers, service coordinators, and health care decision makers in obtaining the information needed to promote safe 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 form.

Health Conditions

☐ 1. Do you understand the individual's health conditions?
- A. Reason for hospitalization
- B. Past health conditions
- C. New diagnoses

☐ 2. Do you understand signs of health problems to watch for after discharge?
- A. Specific signs of health problems
- B. Health problems requiring immediate medical evaluation

☐ 3. Do you have the names and contact information for the physician/health care provider to notify if problems occur?

☐ 4. Were there any cognitive or functional changes that occurred during hospitalization?

☐ 5. Does the individual have any open skin areas? If yes, have you:
- A. Inquired about the extent of the problem and ordered treatments
- B. Determined how long the open areas have been present
- C. Requested to see the affected areas
- D. Obtained measurements of wounds
- E. Obtained the results of wound cultures, if drainage is present

Notes: _____

Discharge Instructions

☐ 6. Do you understand the discharge instructions?
- A. Special treatments (i.e. dressing change, respiratory treatments)
  1. Identified who will perform the treatments
  2. Ensured the person has been informed of the treatment procedure
  3. Understand the frequency of the treatments
  4. Initiated the process to obtain treatment supplies/equipment
- B. Physical activity level
  1. Understand the mobility precautions and supervision level needed
  2. Understand the proper use of any assistive device/equipment (walker, cane, shower chair, etc.)
     - a. Obtained a physician order for new medical device/equipment needed for the home
     - b. Obtained a prior authorization if needed
     - c. Understand the type and purpose of equipment owned by/ordered for the individual
     - d. Planned for all necessary staff to be trained on the proper use of the equipment
     - e. Know who will order the equipment
     - f. Know the primary vendor name and number
     - g. Know who will deliver the equipment
  3. Inquired about any special positioning or transfer protocols

A Checklist for Coordinators & Supervisors

Psychiatric and Behavioral Problems in Individuals with Intellectual Disability

This checklist is based on ***Treatment of Psychiatric and Behavioral Problems in Individuals with Mental Retardation: An Update of the Expert Consensus Guidelines (2004)*** by M. C. Aman, M. L. Crismon, A. Frances, B. H. King, and J. Rojahn, which summarized the recommendations of a panel of national experts. The checklist was developed for Service Coordinators, Program Managers, QMRP's, 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–University Center for Excellence in Developmental Disabilities.

When to Use This Checklist

This checklist is intended to help you coordinate and supervise the care of individuals with co-occurring intellectual disability and psychiatric/behavioral problems. **For mandatory requirements, consult the Developmental Disability Administration's guidelines.**

Individuals with co-occurring intellectual disability (ID) and psychiatric/behavioral diagnosis have:*

☐ Significantly subaverage intellectual functioning (IQ of 70-75 or lower) evident before age 18 years.**

☐ Limitations in adaptive skills and functioning in at least two areas (such as communication, self-care, social skills, self-direction, health, and safety).

☐ Significant psychiatric or behavioral problems.

☐ Note that the diagnosis of ID requires that the impairment in IQ precedes and is unrelated to the psychiatric disorders.

ASSESSMENT

Key Principles in Diagnosis

☐ Effective treatment is most likely when there is an accurate and specific diagnosis

☐ As the level of ID becomes more severe, it is increasingly difficult to make psychiatric diagnoses other than autistic disorder, but it is still extremely important

☐ The two diagnostic manuals to be familiar with are the DSM-IV-TR (current *Diagnostic Style Manual of the American Psychiatric Association*) and the DSM-ID (*Diagnostic Style Manual for Intellectual Disability*) by NADD and the American Psychiatric Association

☐ Sometimes treatment is focused on improvement of target symptoms. Even when a specific diagnosis can be made with confidence, the clinician should also assess for behavioral symptoms that may be appropriate targets of treatment

**Based on criteria from the DSM-IV-TR and the American Association on Intellectual and Developmental Disorders.*
***Editor's note: Many of these guidelines are also applicable to individuals with cognitive limitations acquired in adulthood (as in traumatic brain injury).*

HEALTH PASSPORT

CONSUMER INFORMATION

First Name:	Last Name:
Address:	City, State, Zip:
Home Phone:	Agency Phone:

Birth Date:	Age:	Sex:	Race:	Height:	Weight:
Social Security #:		Hair Color:		Eyes:	

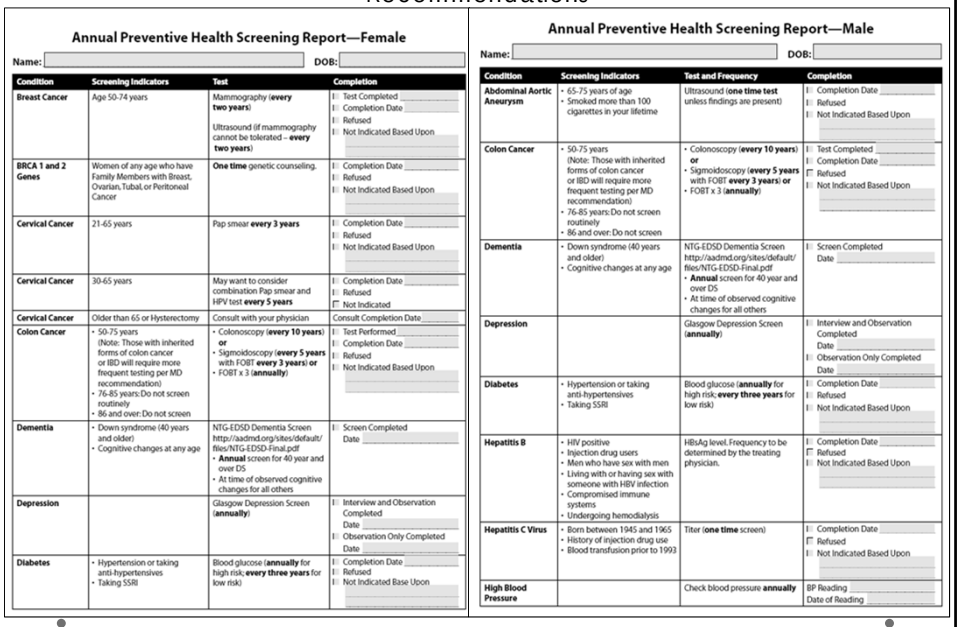
Medicaid #:	DNR / DNI? (If yes, please attach) Yes ☐ No ☐
Medicare #:	
Medical Insurance Provider and Number:	

CONTACT INFORMATION

Guardian:	Guardian Home Phone:
Guardian Address:	Guardian Work Phone:
Next of Kin (relationship):	Next of Kin Home Phone:
Next of Kin Address:	Next of Kin Work Phone:
Provider Agency:	Provider Office Phone:
Agency QMRP:	QMRP Phone :
Agency RN:	RN Phone :
DDA Service Coordinator:	DDA Service Coordinator Phone #:
Primary Physician:	Physician phone #:
Physician address:	
Primary Dentist:	Dentist phone #:
Dentist address:	
Primary Psychologist:	Psychologist phone #:
Psychologist address:	
OB GYN:	OB GYN phone #:
OB GYN address:	
Specialist:	Specialist phone #:
Specialist address:	
Specialist:	Specialist phone #:
Specialist address:	

Developmental Disability Administration, District of Columbia
Adapted by the DC Health Resources Partnership, Georgetown University from the Massachusetts Dept. of Mental Retardation
Revised November 2012

Preventive Health Screening: US Preventive Services Task Force Recommendations



Annual Preventive Health Screening Report—Female

Name: DOB:

Condition	Screening Indicators	Test	Completion
Breast Cancer	Age 50-74 years	Mammography (**every two years**) Ultrasound (if mammography cannot be tolerated – **every two years**)	☐ Test Completed ☐ Completion Date ☐ Refused ☐ Not Indicated Based Upon
BRCA 1 and 2 Genes	Women of any age who have Family Members with Breast, Ovarian, Tubal, or Peritoneal Cancer	**One time** genetic counseling.	☐ Completion Date ☐ Refused ☐ Not Indicated Based Upon
Cervical Cancer	21-65 years	Pap smear **every 3 years**	☐ Completion Date ☐ Refused ☐ Not Indicated Based Upon
Cervical Cancer	30-65 years	May want to consider combination Pap smear and HPV test **every 5 years**	☐ Completion Date ☐ Refused ☐ Not Indicated
Cervical Cancer	Older than 65 or Hysterectomy	Consult with your physician	Consult Completion Date
Colon Cancer	• 50-75 years (Note: Those with inherited forms of colon cancer or IBD will require more frequent testing per MD recommendation) • 76-85 years: Do not screen routinely • 86 and over: Do not screen	• Colonoscopy (**every 10 years**) **or** • Sigmoidoscopy (**every 5 years** with FOBT **every 3 years**) **or** • FOBT x 3 (**annually**)	☐ Test Performed ☐ Completion Date ☐ Refused ☐ Not Indicated Based Upon
Dementia	• Down syndrome (40 years and older) • Cognitive changes at any age	NTG-EDSD Dementia Screen http://aadmd.org/sites/default/files/NTG-EDSD-Final.pdf • **Annual** screen for 40 year and over DS • At time of observed cognitive changes for all others	☐ Screen Completed Date
Depression		Glasgow Depression Screen (**annually**)	☐ Interview and Observation Completed Date ☐ Observation Only Completed Date
Diabetes	• Hypertension or taking anti-hypertensives • Taking SSRI	Blood glucose (**annually** for high risk; **every three years** for low risk)	☐ Completion Date ☐ Refused ☐ Not Indicated Base Upon

Annual Preventive Health Screening Report—Male

Name: DOB:

Condition	Screening Indicators	Test and Frequency	Completion
Abdominal Aortic Aneurysm	• 65-75 years of age • Smoked more than 100 cigarettes in your lifetime	Ultrasound (**one time test** unless findings are present)	☐ Completion Date ☐ Refused ☐ Not Indicated Based Upon
Colon Cancer	• 50-75 years (Note: Those with inherited forms of colon cancer or IBD will require more frequent testing per MD recommendation) • 76-85 years: Do not screen routinely • 86 and over: Do not screen	• Colonoscopy (**every 10 years**) **or** • Sigmoidoscopy (**every 5 years** with FOBT **every 3 years**) **or** • FOBT x 3 (**annually**)	☐ Test Completed ☐ Completion Date ☐ Refused ☐ Not Indicated Based Upon
Dementia	• Down syndrome (40 years and older) • Cognitive changes at any age	NTG-EDSD Dementia Screen http://aadmd.org/sites/default/files/NTG-EDSD-Final.pdf • **Annual** screen for 40 year and over DS • At time of observed cognitive changes for all others	☐ Screen Completed Date
Depression		Glasgow Depression Screen (**annually**)	☐ Interview and Observation Completed Date ☐ Observation Only Completed Date
Diabetes	• Hypertension or taking anti-hypertensives • Taking SSRI	Blood glucose (**annually** for high risk; **every three years** for low risk)	☐ Completion Date ☐ Refused ☐ Not Indicated Based Upon
Hepatitis B	• HIV positive • Injection drug users • Men who have sex with men • Living with or having sex with someone with HBV infection • Compromised immune systems • Undergoing hemodialysis	HBsAg level. Frequency to be determined by the treating physician.	☐ Completion Date ☐ Refused ☐ Not Indicated Based Upon
Hepatitis C Virus	• Born between 1945 and 1965 • History of injection drug use • Blood transfusion prior to 1993	Titer (**one time** screen)	☐ Completion Date ☐ Refused ☐ Not Indicated Based Upon
High Blood Pressure		Check blood pressure **annually**	BP Reading Date of Reading

DOWN SYNDROME HEALTH CARE GUIDELINES

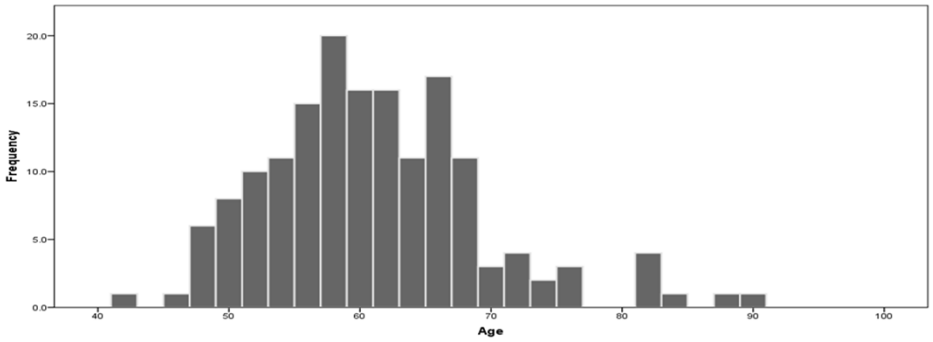
Down Syndrome Quarterly, Vol. 4, No. 3, Sept.1999, pp 1-16.

- 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.
- Opthalmologic 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

Adherence to Preventive Health Services Study

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

Adherence to Preventive Health Services Study

RESULTS

Breast & Cervical Cancer Screening Rates Compared to the General Population

	Study Sample	General Population (baseline)	p-value*	Healthy People 2020 Target Goal**	p-value*
Mammography (Women)	**95.6%**	73.7%	**<.001**	81.1%	**<.001**
Pap Smear (Women)	**89.2%**	84.5%	0.078	93.0%	0.056

Colorectal Cancer Screening Rates Compared to the General Population

	Study Sample [a]	General Population (baseline)	p-value*	Screening Goal**	p-value*
Colorectal Cancer Screening	**95.40%**	52.1%	**<.001**	70.5%	**<.001**

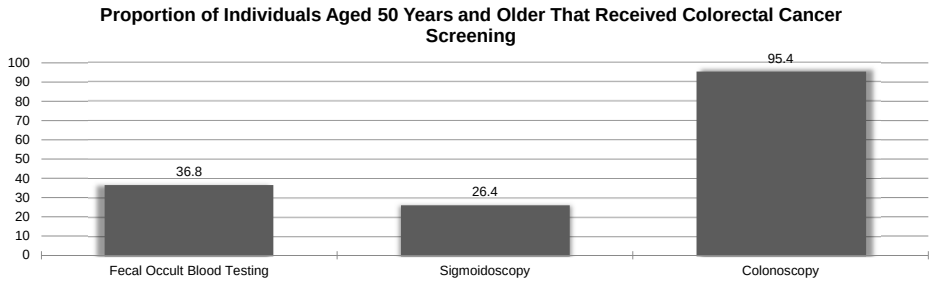
[a] Includes only those who received colonoscopy

*p-values derived from one-sample nonparametric binomial tests

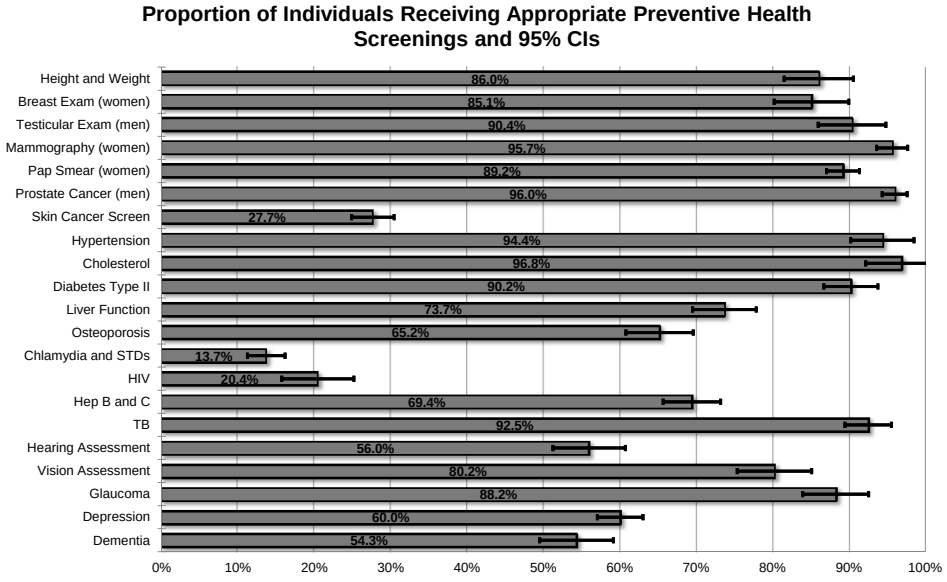
**Healthy People 2020 screening goals based on most recent guidelines

NOTE: All baseline percentages are 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

Adherence to Preventive Health Services Study



Adherence to Preventive Health Services Study



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

GLASGOW DEPRESSION SCALE
(SELF-REPORT)

Name: Date:

Name of Evaluator: Credentials (of Evaluator):

Instructions:

- Each question should be asked in two parts.
  First, the participant is asked to choose between a 'yes' and 'no' answer. If their answer is 'no', then the score in the "no" column should be recorded as ('0').
  If their answer is 'yes', they should be asked if that is 'sometimes' or 'always', and the score recorded as appropriate.
- Supplementary questions (italics) may be used if the primary question is not understood completely.
- If a response is unclear, ask for specific examples of what the participant means, or talk with them about their answer until you feel able to score their response.

Introduction:
To establish a frame of reference for "In the last week…", remind the person about a specific event that happened one week ago that can serve as a reference point.

Start the interview by saying:
"I am going to ask you about how you have been feeling in the last week or since [state specific event from one week ago].

	In the last week…	Never/ No	Sometimes	Always/ A lot
1.	**Have you felt sad?** *Have you felt upset?* *Have you felt miserable?* *Have you felt depressed?*	0 ☐	1 ☐	2 ☐
2.	**Have you felt as if you are in a bad mood?** *Have you lost your temper?* *Have you felt as if you want to shout at people?*	0 ☐	1 ☐	2 ☐
3.	**Have you enjoyed the things you've done?** *Have you had fun?* *Have you enjoyed yourself?*	2 ☐	1 ☐	0 ☐
4.	**Have you enjoyed talking to people and being with other people?** *Have you liked having people around you?* *Have you enjoyed other people's company?*	2 ☐	1 ☐	0 ☐
5.	**Have you made sure you have washed yourself, worn clean clothes, brushed your teeth and combed your hair?** *Have you taken care of the way you look?* *Have you looked after your appearance?*	2 ☐	1 ☐	0 ☐
6.	**Have you felt tired during the day?** *Have you gone to sleep during the day?* *Have you found it hard to stay awake during the day?*	0 ☐	1 ☐	2 ☐
7.	**Have you cried?**	0 ☐	1 ☐	2 ☐
8.	**Have you felt you are a horrible person?** *Have you felt others don't like you?*	0 ☐	1 ☐	2 ☐
	In the last week…	Never/	Sometimes	Always/

		No		A lot
9.	**Have you been able to pay attention to things like watching TV?** *Have you been able to concentrate on things (like TV shows?)*	2 ☐	1 ☐	0 ☐
10.	**Have you found it hard to make decisions?** *Have you found it hard to decide what to wear, or what to do?* *Have you found it hard to choose between two things?*	0 ☐	1 ☐	2 ☐
11.	**Have you found it hard to sit still?** *Have you fidgeted when you are sitting down?* *Have you been moving around a lot, like you can't help it?*	0 ☐	1 ☐	2 ☐
12.	**Have you been eating too little or eating too much?** *Do people say you should eat more or less?* *(positive response for eating too much or too little is scored)*	0 ☐	1 ☐	2 ☐
13.	**Have you found it hard to get a good night's sleep?** *Have you found it hard to fall asleep at night?* *Have you woken up in the middle of the night and found it hard to get back to sleep?* *Have you woken up too early in the morning?*	0 ☐	1 ☐	2 ☐
14.	**Have you felt that life is not worth living?** *Have you wished you could die?* *Have you felt you do not want to go on living?*	0 ☐	1 ☐	2 ☐
15.	**Have you felt as if everything is your fault?** *Have you felt as if people blame you for things?* *Have you felt that things happen because of you?*	0 ☐	1 ☐	2 ☐
16.	**Have you felt that other people are looking at you, talking about you, or laughing at you?** *Have you worried about what other people think of you?*	0 ☐	1 ☐	2 ☐
17.	**Have you become very upset if someone says you have done something wrong or you have made a mistake?** *Do you feel sad if someone disagrees with you or argues with you?* *Do you feel like crying if someone disagrees with you or argues with you?*	0 ☐	1 ☐	2 ☐
18.	**Have you felt worried?** *Have you felt nervous?* *Have you felt tense/wound up/on edge?*	0 ☐	1 ☐	2 ☐
19.	**Have you thought that bad things keep happening to you?** *Have you felt that nothing nice ever happens to you anymore?*	0 ☐	1 ☐	2 ☐
20.	**Have you felt happy when something good happened?** *If nothing good has happened in the last week then ask: If someone gave you a nice present, would that make you happy?*	2 ☐	1 ☐	0 ☐

SCORING INSTRUCTIONS
Note: At the conclusion of the interview, add up the scores. If you calculate a score of 13 or greater, please do one of the following:

1. Seek a referral for a mental health consultation from the primary care provider; or
2. Seek the consultation of the psychologist on the interdisciplinary team (if the person resides in an ICF-IDD setting).

Document your findings and actions in the progress notes and be sure to contact the DDA service coordinator and the QIDPP.

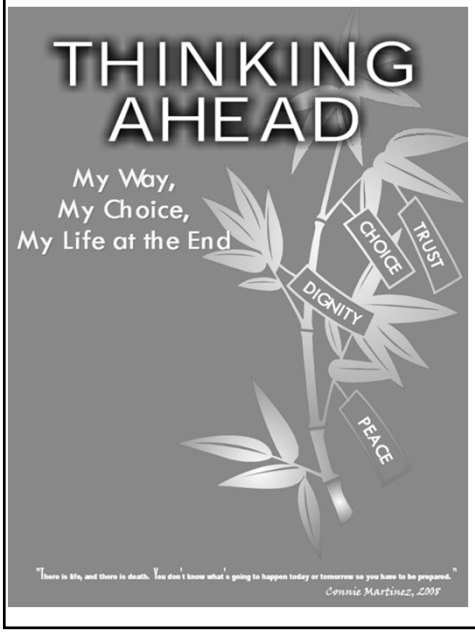
NTG Activities

- **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'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 **not** want medical treatments intended to keep them alive. These days, many treatments can keep people alive even if there is **no chance** that the treatment will reverse or improve their condition. Thinking about the person for whom you are making medical decisions, reflect on what would be in their best interest given the situations described below, if the treatment **would not reverse or improve** their condition.

Directions: Circle the number from 1 to 5 that best indicates the strength and direction of what you think is in the best interest for the person for whom you are making medical decisions.

1. **Definitely want** treatments that might keep the person alive.
2. **Probably would want** treatments that might keep the person alive.
3. **Unsure of what to do.**
4. **Probably would NOT want** treatments that might keep the person alive.
5. **Definitely do NOT want** treatments that might keep the person alive.

	Definitely Want Treatment ↔				Definitely Do Not Want Treatment
What if the person for whom you are making decisions…					
a. No longer can recognize or interact with family or friends.	1	2	3	4	5
b. No longer can think or talk clearly.	1	2	3	4	5
c. No longer can respond to commands or requests.	1	2	3	4	5
d. No longer can walk but gets around in a wheel chair.	1	2	3	4	5
e. No longer can get outside and must spend all day at home.	1	2	3	4	5
f. Requires continuous analgesia for the treatment of severe pain.	1	2	3	4	5

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.