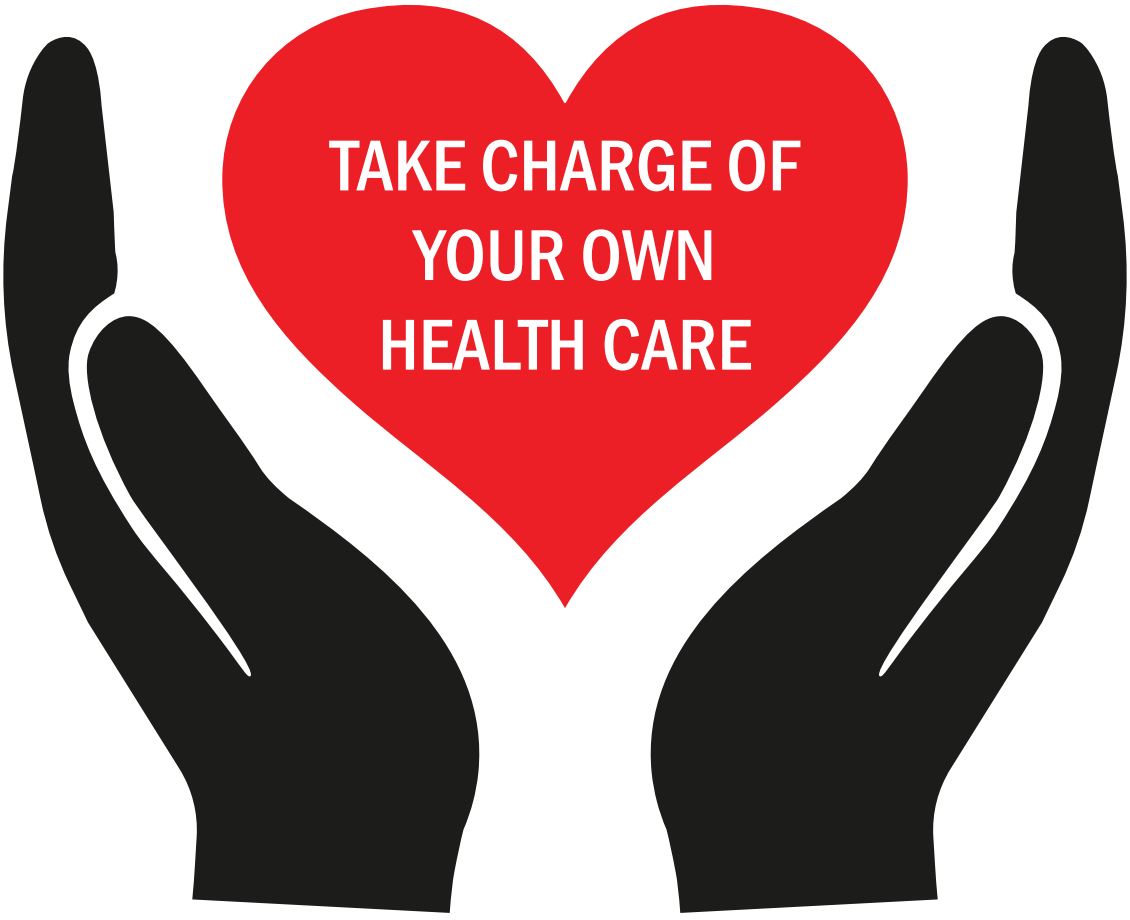
SELF-DIRECTED HEALTH CARE KIT



A Project of
Wisconsin BPDD
Wisconsin Board for People with Developmental Disabilities

Designed for individuals with disabilities and the people who support them.

Self-directed Health Care Kit

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As a community nurse who works in and around Madison, Wisconsin, I direct a program called Wellness Inclusion Nursing (WIN) - a Waisman Center outreach program. I assist and advocate for the proper care for individuals who have intellectual and developmental disabilities (I/DD) along with challenging health issues. This includes attending doctors' appointments with people or helping them to prepare for doctors' appointments and also helping as they try to follow instructions and doctor's orders. As a result of my extensive knowledge and experience, I have been collaborating with the Wisconsin Board for People with Developmental Disabilities (BPDD) on their projects.

Regular medical appointments and care are important for people who have intellectual and developmental disabilities (I/DD). In addition to the standard tests and assessments, individuals with certain types of disabilities may be at higher risk for some chronic illnesses that should be monitored more closely. Proactive health care can prevent chronic illness and treat other conditions before they worsen into a health crisis and/or hospitalization.

Individuals who have I/DD may not attend appointments regularly if it is difficult because of mobility obstacles, behavioral challenges, transportation issues and/or difficulty arranging for a support person to attend the appointment. Sometimes, too, lab tests and other screening tests are not considered necessary by health professionals when a person has I/DD. Additionally, doctors may not thoroughly assess a person who is unable to get on the exam table without use of a Hoyer lift. Advocacy to remove these barriers to care is essential to ensure each individual with I/DD has quality health care.

Individuals and their families or other caregivers often are stressed and are unsure of what to share at an appointment. High turnover of caregivers can also add to this complicated matter, causing lack of and/or improper documentation. Doctors may miss diagnosing a problem because of unclear, missing or limited information. Medical professionals may also assume that a person with I/DD whom they see is always nonverbal or unable to walk because of his or her disability rather than probing to see if these limitations are indications of an illness.

This Self-directed Health Care Kit is a practical way to help you and your supports set up and prepare for appointments by gathering the needed information ahead of time. It gives you the necessary tools to be prepared and to receive the quality care you deserve at every medical appointment or hospital visit. We hope this kit is useful to you and becomes a part of your health and wellness routine.

PURPOSE

This Self-directed Health Care Kit is designed to help individuals with developmental and intellectual disabilities (I/DD) advocate for their own health care and support clear communication between the individual and their health care practitioners. The kit includes a set of forms for tracking health care concerns and interventions. It has also been designed to help the person in a supportive role to help advocate for the individual and enhance the interaction between the individual and the health care practitioner.

EXPECTATIONS OF SUPPORT PERSON

This process is built on the presumption that a support person would help prepare the individual for a medical appointment to which the individual would go alone or be accompanied by the support person who assisted.

The preparation begins with the support person reviewing the kit with the individual and completing the medical history form. This would include the individual's health concerns and current medication. A completed National Task Group-Early Detection Screen for Dementia (NTG-EDSD) form may also be helpful for the visit and should be completed by someone who is familiar with the individual for at least 6 months.

**See the NTG-EDSD form for more information*

Where and when possible, there should be an agreement to the support person's role during the visit. This may include completing the **TODAY'S VISIT** and **SUMMARY OF VISIT (both Light Blue)** forms.

This kit provides VALUE:

For the individual – he or she will go into a health care visit prepared and more confident that they will be listened to and that their concerns will be addressed.

For the support person – he or she will have a better sense of the individual's concerns and a plan for presenting those concerns. Time taken in preparation will save time and stress during the visit.

For the health care practitioner – he or she will have a better understanding of the individual's current concerns, abilities and disabilities. The supportive person's role will be defined for them and they will have information they need in writing. Putting their instructions on the form should provide more assurance to them that those instructions will be carried out.

Overall – Keeping the forms in the individual's file will build an ongoing medical history for people supporting the individual in the future. It will be a beginning point for preparing for future health care visits. Successive use will foster better communication and interaction between patients and providers.

What is included in the Self-directed Health Care Kit?

LEFT SIDE OF PACKET
(WHITE PAPER):

Introduction

Helpful Tips and Suggested Questions – This is additional information that may help you be better informed about your health.

Setting up Your Health Care Appointment – This is a helpful tool to help you prepare and advocate for an appointment that is best for you.

Health History – Completing this form and keeping it in the packet will help establish a medical history and help you prepare for future health care visits. As a completed form in the kit, it can be helpful as a reference for completing the TODAY'S VISIT form. This information will be useful for support people and health care practitioners in your life.

The National Task Group – Early Detection Screen for Dementia (NTG-EDSD) – This form should be completed every 6 months, after the age of 40, by a person who has known the individual for at least 6 months. It should be updated as needed and brought to the person's physician appointments. *See the NTG-EDSD form for more information

RIGHT SIDE OF PACKET
(THIS INFORMATION MAY BE GIVEN TO HEALTH CARE PRACTITIONER VERBALLY INSTEAD OF PROVIDING FORM):

TODAY'S VISIT (Light Blue) – Complete this form and take to the health care practitioner.

SUMMARY OF TODAY'S VISIT (Light Blue) – This form is to be completed by the health care practitioner, if possible, at the visit. Once completed, it should be filed into the Self-directed Health Care Kit.

ABOUT ME (Yellow) – This form can be an additional aid for information about you. This form would be especially helpful for a first time visit with a health care practitioner. As a completed form filed in the kit, it can be helpful as a reference when completing the TODAY'S VISIT form.

URGENT CARE OR HOSPITAL VISIT (Pink)- This form should be partially filled out and filed in the kit. It should be fully completed when preparing for a visit to urgent care/emergency visit and/or hospital stay.

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ABOUT ME

Complete this form and use as an additional aid for information about you.
Take this form to a first-time visit with a health care practitioner.

Hello _____ My name is_____ I like to be called _____

I want you to be able to help me get the most out of this appointment and I want us to be able to communicate. It is important that you see me as a person first and that you treat me like all of your other patients. I am an individual with a disability and I would like to use this paper to help you understand how my disability affects me and how I communicate. Together we can understand what's going on with me. My support person can help me do the things you want me to do after we leave today.

Insurance	
MA#	

The person with me is:_____

My primary support person is _____

My support group is:

Family member(s)		Personal Care Attendant	
Job coach		Neighbor	
Guardian		Interpretor	
Case Manager		Other	

I am working:

My job is:_____

Hours a week: _____

My allergies include:

Food _____

Medicine _____

Other (latex, etc.) _____

What I want you to know about how my disability affects me:

My triggers and/or sensitivity issues are: _____

_____

_____

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Physically:

I walk unaided	
I walk slowly or with a walker	
I use a wheelchair	
I need help to get on the exam table	
I need to be lifted onto the exam table	
I would like to be examined in my chair	
Other	

Communication:

I can speak for myself. Please, try to listen	
I cannot speak	
I am deaf/hard of hearing	
My companion can help you understand	

I can communicate through:

Computer/ other communication device	
Pictures	
I have information written down	
Sign language	

Understanding:

I can understand what you say to me	
I like simple terms and step by step directions	
I rely on the person with me to understand the details of what you tell me	

My living Situation:

My own home/ apartment	
Supported living environment	
My family home	
In a group home	
Other	

Things I rely on others to help me with are:

Personal cares	
Filling prescriptions	
Taking medications	
Preparing meals	
Transportation	
Other	

MEDICATIONS I AM CURRENTLY TAKING:

Medicine	Directions/ dosage	Purpose	Prescribed by	Date Started

HEALTH HISTORY

HELPFUL TIP **Complete this form and file in the kit. This will help establish a medical history and help you prepare for future health care visits.**

Name	Age/Birth Date
Address	City/State/Zip
Phone	Primary Support Person's phone number
Primary Care Physician	Clinic
MA/Insurance numbers	

Doctors I have seen in the last two years:

Name	Reason

I am being or have been treated for:

Condition	Check box if current condition	Date diagnosed
High/Low Blood Pressure		
Diabetes		
Seizures		
Arthritis		
Depression/Anxiety		
Bladder infection		
Constipation/Diarrhea		
Stomach problems		
Heart problems		
Breathing problems		
Cancer		
Other		

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My allergies:		
Foods	Medications	Other

My immunization records:			
Immunization	Date	Immunization	Date

My family health history:			
Family member	Diagnosis and date	Diagnosis and date	Diagnosis and date
Mother			
Father			
Brother			
Sister			

My medication history:					
Medicine	Directions/dosage	Purpose	Prescribed by	Date started	Date stopped

Memory tests I have completed:		
Test name	Completed by	Date completed

**If you have not taken a memory test, this kit includes the NTG-EDSD form that can be used as an initial baseline for the individual and then updated every 6 months. See the NTG-EDSD form for more information.*

HELPFUL TIPS

Patients who ask questions and take an active role:

- **are happier with their care**
- **make better decisions about their own health care**
- **see more improvement with their health than those that don't**

Preparing for your appointment:

- **Ask someone to go to your appointment with you to help you understand and remember answers to your questions.**
- **Create a health history that includes your current conditions and past surgeries or illnesses and bring to your appointment.** Include your family's medical history and your current medication list. This may also include a completed National Task Group-Early Detection Screen for Dementia (NTG-EDSD). ****Use the Health History form and NTG-EDSD form (both White)***
- **Bring questions regarding your appointment. Ask the important ones first.** Let the nurse and staff know that you have brought questions. ****Bring Today's Visit form (Light Blue)***
- **Being able to understand the answers is important.** Take notes and/or have the person with you take notes. If you don't understand an answer tell the health care practitioner and ask him or her to re-explain.
- **When you are given the plan and/or next steps that your health care practitioner recommends, ask him or her to complete form.** Ask questions if you don't understand what the health care practitioner is suggesting. ****Use the Summary of Visit form (Light Blue)***
- **Often clinics offer a summary of your visit.** Be sure to ask for a copy of the clinic's visit summary before leaving your appointment.

You also may need to follow-up with your health care practitioner:

- If you are experiencing any side effects from treatment, test, surgery and/or medication
- If your symptoms get worse
- To get results of the tests and/or questions about the test results.

Answers to these questions may help you make better decisions, receive better care, avoid medical harm, and overall, feel better about your health care which could also lead to better results for your health.

→

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SUGGESTED QUESTIONS

The health care practitioner may give you a diagnosis, recommend a treatment, give you a prescription for medication, suggest a medical test, or suggest surgery. Here are some suggested questions pertaining to those areas:

RESULTS/DIAGNOSIS GIVEN:

What is my diagnosis?

Will I need more tests?

How soon do I need to make a decision?

What is the future outlook of my condition?

What may have caused this?

What are my treatment options?

How much will the treatment cost?

What if I don't have the treatment?

Will I need additional special help for this?

MEDICATION:

What is the name of the medication?

Is there a generic version that I can take?

How much should I take?

Are there any side effects that I should be concerned about?

What if I forget to take it?

What else should I know about this medication?

What is it for?

When should I take it?

How long to I need to take the medication?

Do I need to avoid any food, drinks, or activities?

Are there side effects?

What if I take too much?

Will it be set up for a refill?

MEDICAL TESTS:

What is the test for?

How accurate is it?

Is this the only way to find out the information that is needed about my condition?

When will I get the results?

How will the results be explained to me?

How is it done?

What do I need to do to prepare for the test?

When will I get the results?

What would be the next steps after the results?

SURGERY/HOSPITAL:

Why do I need surgery?

What type of surgery is it?

Will I need any type of anesthesia?

Is this a day surgery or will I stay overnight?

What if I wait or don't have the surgery?

Is there another way to treat my condition?

Have you done this type of surgery before? How many?

What happens after surgery?

How long will it take me to recover?

When will I receive care instructions?

SETTING UP YOUR HEALTH CARE APPOINTMENT

A useful tool to help you prepare for an appointment that is best for you

THINGS TO HAVE READY:

- **Calendar**
- **Your insurance card**
- **Health Care Practitioner's name**
- **Health Care Practitioner's phone number**
- **Your phone number**
- **Your Date of Birth (DOB)**

CALL (SCRIPT):

Hello my name is _____

I would like to schedule an appointment with _____

The reason I am calling is because _____

What dates and times are available? _____

How long is my appointment for? _____

Can I get extra time for my appointment?

I need extra time because:_____

_____

REPEAT BACK:

Ok, so my appointment is with _____ on_____

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TODAY'S VISIT

Complete this form and take to the health care practitioner

Location of today's visit _____ Name of health care practitioner _____

Address _____ Phone # _____

Purpose of visit _____

_____

Checklist of items to bring with you on appointment:

- ❑ This form completed
- ❑ Updated medication list
- ❑ Monitoring forms/charts (i.e. sleep, behavior, NTG-EDSD Tool/Screen, etc.)
- ❑ Summary of your medical history and medical records (For 1st time appointments and/or if needed)
- ❑ Health insurance card (if needed)
- ❑ Residential forms (CBRF, AFH, etc.)
- ❑ Something fun to do (if you have to wait i.e. book, puzzle, games, etc.)
- ❑ Other items requested by health care practitioner

Hello, My name is _____ I like to be called _____

I have an appointment with _____today.

I am a new patient: Yes ❑ No ❑ Phone _____ Address _____

Date of Birth _____/_____/_____ Gender: Male ❑ Female ❑

The person with me is: _____ and is my _____ (caregiver, family member, etc.)

He/She's contact info: _____ My pharmacy is: _____

I have these allergies: _____

❑ I am here because this is a follow-up appointment

You treated me for _____

I did ❑ did not ❑ take the medicine

I didn't take it because _____

I did ❑ did not ❑ do what you told me

I didn't do it because _____

_____

❑ I am here because I am having problems

I'm having problems with _____

I have pain ____ I feel sick _____ *(See back of form)*

It started and/or I noticed it _____

It occurs (how often) _____

I have treated myself at home by _____

_____

Possible causes/contributing factors could be: _____

I had changes in my living or social environment: Yes ❑ No ❑ (family illness/loss, move, etc.)

I had some recent medication changes: Yes ❑ No ❑

I had some recent physical changes (may also refer to the NTG-EDSD form): Yes ❑ No ❑

❑ Activity level ❑ Mobility ❑ Bladder ❑ Bowel ❑ Weight ❑ Swallowing ❑ Eating patterns ❑ Sleeping

Other _____

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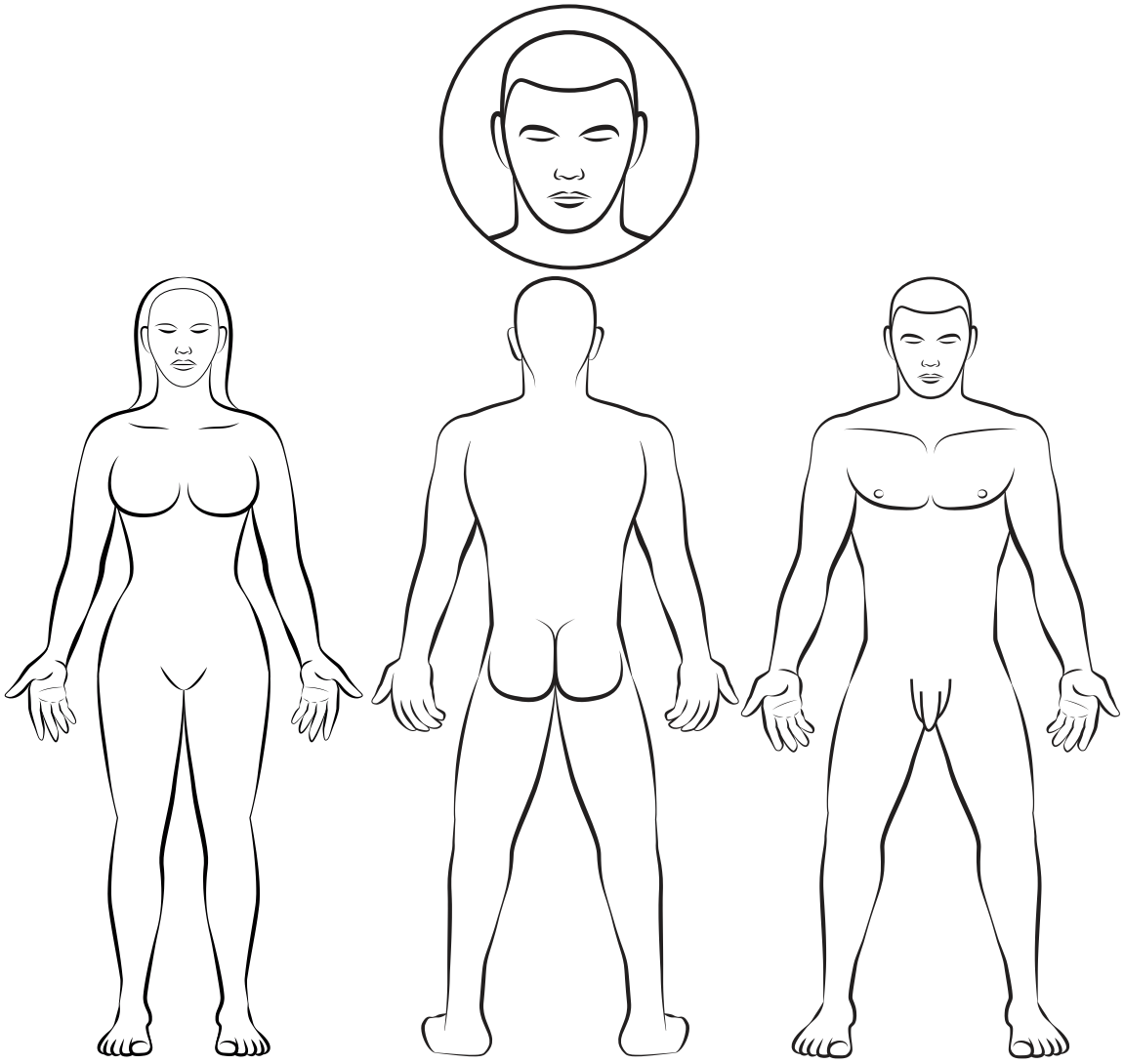
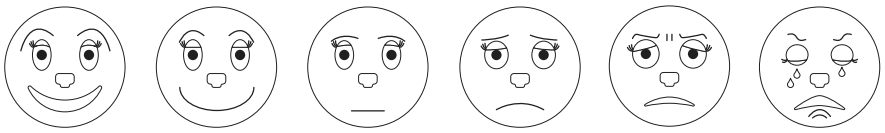
Location of symptoms:
USE THE FOLLOWING PICTURES OF THE BODY TO HELP YOU SAY WHERE YOU HURT OR FEEL SICK.



Severity of symptoms (circle one) →



0	1	2	3	4	5	6	7	8	9	10
NO HURT		HURTS A LITTLE BIT		HURTS LITTLE MORE		HURTS EVEN MORE		HURTS WHOLE LOT		HURTS WORST

It's worse when:_____ It's better when: _____

Conditions I am being treated for now: _____

Serious illnesses I have had in the past: _____

My sensitivities/triggers are:_____

Health care practitioners I have seen since my last visit (doctor, dentist, care providers, etc.):

Name _____ Location _____

Name _____ Location _____

Name _____ Location _____

SUMMARY OF VISIT

Date_____

Take to today's visit.
To be completed by Health Care Practitioner.

Checklist of items to leave with today:

- ❑ This form completed
- ❑ Completed Residential forms (may be requested for Adult Family Home, Assisted Living, etc.)
- ❑ Clinic's visit summary

Name of Health Care Practitioner _____

Location _____ Phone # _____

Next appointment: _____

Schedule at least 30 minutes and the best time of day for the individual

Purpose of next appointment: _____

_____

What did you find during today's visit?

_____

Treatment plan/Recommendations (including any needed referals)_____

_____

_____

Who else may be involved (physical therapy, occupational therapy, speech therapy, etc.)?

_____

Suggestions for my general good health: _____

_____

Medication:

Any change in medication? ❑ Yes ❑ No

New Medication	Dose	Purpose	Special instructions

Care provider signature: _____ Date _____

Copy this on Light Blue paper

URGENT CARE OR HOSPITAL VISIT

Take to Urgent Care or Hospital Visits

I have a developmental disability. I think it will help you care for me if you know a little bit about how my disability affects me when I am well. It means there are things I can do, things I need help with, and things I cannot do. Please place this information in my chart so that it may help everyone who will care for me while I am here. Thank you.

Date_____ My name is _____I like to be called_____ Room #_____

Person with me is _____ Contact: _____

Person making my medical decisions today is _____ Contact: _____

My regular Dr. is _____ Contact: _____

I have these allergies:_____My triggers/sensitivities are: _____

I am here because:

❑ I hurt myself	How?	When?
❑ I am in pain ❑ Sharp ❑ Ache Where?		
❑ I am sick	How long?	
❑ I am short of breath	❑ I have chest pains	❑ I passed out
❑ I keep throwing up	❑ I have diarrhea/cramps	
❑ I have a bad ❑ cough ❑ sore throat ❑ earache		
❑ I had a seizure It lasted____ minutes Other		
I usually treat the issue by		

I am currently being treated for:

❑ High blood pressure	❑ Heart problems	❑ Diabetes	❑ Cancer
❑ Bladder infection	❑ Lung/breathing problem	❑ Stomach	❑ Arthritis
❑ Seizure disorder	❑ Thyroid	Other	

What you should know about me and how my disability affects me:

Physically:

❑ I can push the call button	❑ I cannot push the call button		
❑ I walk unaided	❑ I walk slowly	❑ I use a walker	❑ I use a wheelchair
Other			

Copy this on Pink paper

With help I can:

❑ Do my personal cares	❑ Get in and out of bed	❑ Go to the bathroom
❑ Feed myself	❑ Take medication	

I will need to be:

❑ Lifted in and out of bed	❑ Fed	❑ Bathed	❑ Toileted
❑ Given medication			
Other			

Communication:

❑ I can speak for myself, please try to listen	❑ I cannot speak for myself
❑ I am deaf/hard of hearing	❑ I have an interpreter

I can communicate through:				
❑ Computer	❑ Gestures/facial expressions	❑ Sign language	❑ Pictures	❑ I can write things down

Understanding:

❑ I can understand what you say to me
❑ I like simple terms and step by step directions
❑ I may not understand what you say to me

Special concerns and/or fears:

When I am anxious or frustrated it helps me feel better if I have:_____

❑ It is hard for me to sit still
❑ I am fearful of: ❑ Medical exams ❑ Being touched ❑ Shots Other _____
Please tell me before you do any of these things (list):

People in my life:		
Relationship	**Name**	**Phone number**
Family Member:		
Guardian:		
Attendant:		
Support Person:		
Home Health:		

Medical decisions, Advanced Directive, and/or Power of Attorney information:

_____

_____

_____

NTG-EDSD

v.1/2013.2

The **NTG-Early Detection Screen for Dementia**, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/ screening).

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(1) File #: _____ (2) Date: _____

Name of person: (3) First_____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex:

	Female
	Male

Instructions:
For each question block, <u>check the item that best applies</u> to the individual or situation.

(8) Best description of level of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

(9) Diagnosed condition (*check all that apply*)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:

- □ Lives alone
- □ Lives with spouse or friends
- □ Lives with parents or other family members
- □ Lives with paid caregiver
- □ Lives in community group home, apartment, supervised housing, etc.
- □ Lives in senior housing
- □ Lives in congregate residential setting
- □ Lives in long term care facility
- □ Lives in other: _____

(10) General characterization of current physical health:

	Excellent
	Very good
	Good
	Fair
	Poor

(11) Compared to one year ago, current physical health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(12) Compared to one year ago, current mental health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(13) Conditions present (*check all that apply*)

	Vision impairment
	Blind (very limited or no vision)
	Vision corrected by glasses
	Hearing impairment
	Deaf (very limited or no hearing)
	Hearing corrected by hearing aids
	Mobility impairment
	Not mobile – uses wheelchair
	Not mobile – is moved about in wheelchair

(14) Significant recent [in past year] life event (*check all that apply*)

	Death of someone close
	Changes in living arrangement, work, or day program
	Changes in staff close to the person
	New roommate/housemates
	Illness or impairment due to accident
	Adverse reaction to medication or over-medication
	Interpersonal conflicts
	Victimization / abuse
	Other:

(15) Seizures

	Recent onset seizures
	Long term occurrence of seizures
	Seizures in childhood, not occurring in adulthood
	No history of seizures

If MCI or dementia is documented complete 16, 17, &18

(16) **Diagnostic History**

Mild cognitive impairment [MCI] or dementia previously diagnosed (Dx)?:

[ ] No

[ ] Yes, MCI

Date of Dx:

[ ] Yes, dementia

Date of Dx:

Type of dementia:

Diagnosed by:
□ Geriatrician
□ Neurologist
□ Physician
□ Psychiatrist
□ Psychologist
□ Other:

(17) Reported date of onset of MCI/dementia
[When suspicion of dementia first arose]
Note approximate year and month:

(18) Comments / explanations about dementia suspicions:

[Check column option as appropriate]

	Always been the case	Always but worse	New symptom in past year	Does not apply
[19] **Activities of Daily Living**				
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
[20] **Language & Communication**				
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
[21] **Sleep-Wake Change Patterns**				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
[22] **Ambulation**				
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				

	Always been the case	Always but worse	New symptom in past year	Does not apply
[23] **Memory**				
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				
Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
[24] **Behavior and Affect**				
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
[25] **Adult's Self-reported Problems**				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
[26] **Notable Significant Changes Observed by Others**				
In gait (e.g., stumbling, falling, unsteadiness)				
In personality (e.g., subdued when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

[Check column option as appropriate]

	[27]Chronic Health Conditions*	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
	Bone, Joint and Muscle				
1	Arthritis				
2	Osteoporosis				
	Heart and Circulation				
3	Heart condition				
4	High cholesterol				
5	High blood pressure				
6	Low blood pressure				
7	Stroke				
	Hormonal				
8	Diabetes (type 1 or 2)				
9	Thyroid disorder				
	Lungs/breathing				
10	Asthma				
11	Chronic bronchitis, emphysema				
12	Sleep disorder				
	Mental health				
13	Alcohol or substance abuse				
14	Anxiety disorder				
15	Attention deficit disorder				
16	Bipolar disorder				
17	Dementia/Alzheimer's disease				
18	Depression				
19	Eating disorder (anorexia, bulimia)				
20	Obsessive-compulsive disorder				
21	Schizophrenia				
22	Other:				
	Pain / Discomfort				
23	Back pain				
24	Constipation				
25	Foot pain				
26	Gastrointestinal pain or discomfort				
27	Headaches				
28	Hip/knee pain				
29	Neck/shoulder pain				
	Sensory				
30	Dizziness / vertigo				
31	Impaired hearing				
32	Impaired vision				
	Other				
33	Cancer – type:				
34	Chronic fatigue				
35	Epilepsy / seizure disorder				
36	Heartburn / acid reflux				
37	Urinary incontinence				
38	Sleep apnea				
39	Tics/movement disorder/spasticity				
40	Dental pain				

*Items drawn from the Longitudinal Health and Intellectual Disability Survey (University of Illinois at Chicago)

(28) **Current Medications**

Yes	No	Indicate type
□	□	Treatment of chronic conditions
□	□	Treatment of mental health disorders or behavior problems
□	□	Treatment of pain

For reviews, attach list of current medications, dosage, and when prescribed

□ List is attached for reviews

(29) **Comments related to other notable changes or concerns:**

(30) **Next Steps / Recommendations**

□ Refer to treating physician for assessment

□ Review internally by clinical personnel

□ Include in annual review / annual wellness visit

□ Repeat in _____ months

Form completion information

(31) Date completed	(32) Organization / Agency
Name of person completing form	
Relationship to individual (staff, relative, assessor, etc.)	
Date(s) form previously completed	

Acknowledgement: Derived from the DSQIID (*Dementia Screening Questionnaire for Individuals with Intellectual Disabilities; Deb, S., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LHIDS (Longitudinal Health and Intellectual Disability Survey; Rimmer & Hsieh, 2010) and as further adapted by the National Task Group on Intellectual Disabilities and Dementia Practices as the NTG Early Detection Screen for Dementia for use in the USA.