

# Dementia Resource Guide Book

*for individuals with developmental  
disabilities and their caregivers*



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NTG Education & Training Curriculum on Dementia and ID. Copyright 2014. [www.aadmd.org/ntg/curriculum](http://www.aadmd.org/ntg/curriculum)

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## **What is the purpose of this guide book?**

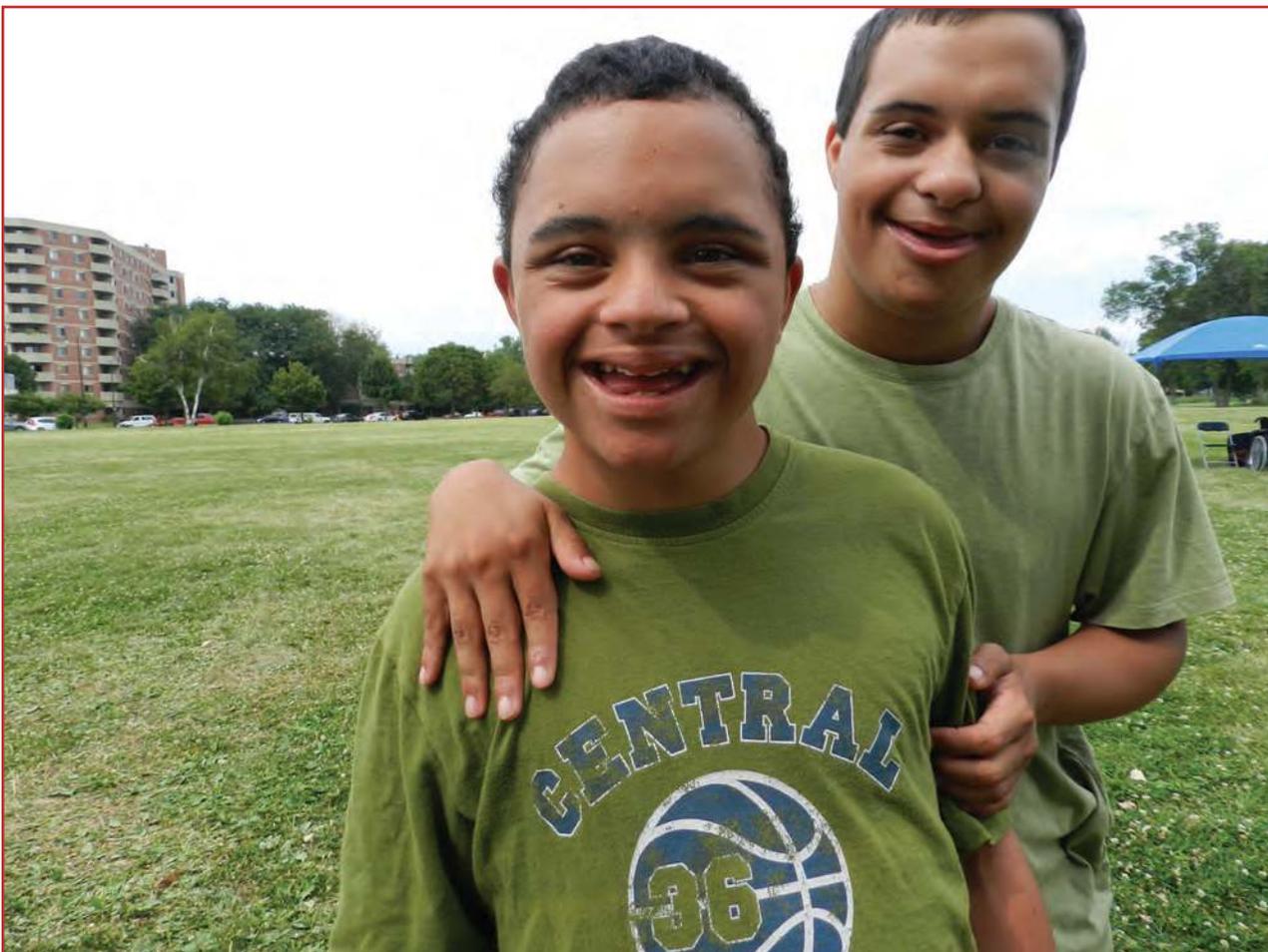
This guide book has been designed for individuals with intellectual/developmental disabilities (I/DD) and dementia, their family members, and caregivers to help increase the quality of care and life for the individual with I/DD and dementia. It is intended to help individuals navigate and advocate for their own health care. It is also intended to help family and caregivers understand changes in condition, document and monitor those changes, communicate to providers and advocate for the individual’s health care. Each section addresses critical areas of a person’s health care. Also included in the guide book are videos of individuals and/or their families who have been on and/or have experienced the journey of dementia.

## **What is Mind & Memory Matters?**

Mind & Memory Matters is a project supported by the 2014 Alzheimer’s Disease Initiative - Specialized Supportive Services (ADI-SSS) Grant awarded to the WI Board for People with Developmental Disabilities (BPDD) by the Wisconsin Department of Health Services (DHS) and the Administration for Community Living (ACL). The project’s purpose is to help increase awareness about the connection between dementia and those with intellectual/developmental disabilities (I/DD) while helping increase the quality of life for the individual. The team provided outreach and training to professionals, caregivers, families and individuals with I/DD. As part of the project’s sustainability plan, staff within Wisconsin’s Long-Term Care system, including Dementia Care Specialists and Dementia Care Leads, were trained by the National Task Group on the subject of I/DD and dementia. As a result, individuals with I/DD enrolled in a long-term care program in Wisconsin will now have access to the information and the National Task Group – Early Detection Screen for Dementia (NTG-EDSD) tool (Section 4). This guide book is also part of the project’s sustainability plan.

## Why is this project important?

- People are living longer including those with I/DD. Studies show that 6 out of 10 people with Down syndrome, over the age of 60, are affected by dementia.
- 25% of individuals with Down syndrome, over the age of 40, will show clinical signs or symptoms of dementia, with 50-70% being affected by age 60.
- There are several forms of dementia with Alzheimer's disease being the most prevalent. Alzheimer's disease is the 6<sup>th</sup> leading cause of death – more than prostate and breast cancer combined.
- Symptoms of dementia may “appear” differently in people with I/DD and specifically Down syndrome.
- Health care disparities for individuals with I/DD can begin to show up 20 years earlier than the general population.
- Common testing may not be appropriate for individuals who have a cognitive impairment. The NTG-EDSD (Section 4) was created specifically to monitor changes in individuals with I/DD, help provide critical information to a physician, keep the individual's health care information in one place, and be used as a resource to refer to as the individuals health changes.
- Early detection can lead to early diagnosis and referral for services and supports. There is a potential to proactively address signs, delay symptoms, and identify potentially treatable conditions that are causing symptoms. The overall outcome is to increase the quality of life for people with dementia and their caregivers.



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10/19/16



# I am still me.

My behaviors may change. I may begin wandering, repeating questions, have verbal and/or physical outbursts. I may resist personal care and begin hoarding. I may have sleep disorders and/or hallucinations or paranoia. Something may be bothering me. I am trying to communicate it to you in a different way now. **But I am still me.**

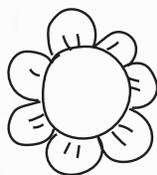
Try to stay calm and resist arguing or reasoning with me. Do not correct me but try to re-direct me. Stay calm, empathize and understand rather than raising your voice and trying to reason with me. I can hear your smile. It helps me feel safe and secure. **I am still me.**

Remember that I am unique. Activities and conversations that successfully redirect one person may not work with someone else. My truth is the truth. **I am still me.**

Keep my routines consistent. It will reduce my anxiety and help decrease your stress. **I am still me.**

Adapt my activities to what I can do now not what I used to do. Limit my choices, provide gentle guidance, break tasks down into single step directions, and remain positive physically and verbally. I may have changes, but **I will still be me.**

Please don't say "no" or "don't do that". I am not a child. Treat me as an adult. Step away for a few minutes. Maybe we both need some time. **I am still me.**



Give me choices or suggestions instead of open-ended questions. Instead of "Where would you like to go today?" Ask "Do you want to go to the park or the beach today?"

I still like most of the same things. I just may not know how to tell you. **But I am still me.**

I may still like hugs, be a part of the conversation, and attend gatherings and events. But I may forget names and places. Keep me involved. **I am still me.**

Please advocate for me when I cannot. Exercise, diet, and a positive environment can help me. Monitor and report my health changes. **I want to still be me.**

My memory is short-term. Rewarding me or offering incentives for better behavior now and in the future will no longer work. Negotiating with logic or reason will no longer work. You may become frustrated. I don't mean to frustrate you. I learn differently now. Most of the time it is beyond my control. I can be frustrating but **I am still me.**

Everyone has a life story. Please document mine. Scrapbooks, videos, hobbies, likes/dislikes, and my routines. When I can no longer tell my story, it will be helpful to my family, friends, loved ones, caregivers, and my care plan. So that **I can still be me.**





# { Section 1 } Healthy Aging

**F**rom the moment we are born we are all aging. There are similarities to how people age, but aging will affect everyone differently as an individual. Therefore, aging throughout life should be planned for and tracked on an individual basis. This section will define aging and look at different ways that people will age throughout their life and some ways to stay healthy. There is also information on some of the challenges people with disabilities face when it comes to healthcare and healthy aging.

## Topics covered in this section:

- **Aging Across the Lifespan**
- **Annual Screenings Throughout Life**
- **Challenges to Healthy Aging for People with Disabilities**





# Ageing Across the Lifespan

## What is aging?<sup>1</sup>

- Aging is generally defined as the progressing changes to the physiology (normal functioning) of the body and mental processes.
- Aging is an active process that occurs over an individual's entire life, from birth to death.
- Patterns in aging are unique to each individual, although some traits can be similar to other people depending on your genes. *For example, Race and gender can have an effect.*

## Ageing across the lifespan<sup>2</sup>

There are similar patterns of aging for all adults regardless of pre-existing disability. Genetics, lifestyle, environment and attitude all influence health and well-being in old age. All adults need proper nutrition, hydration and exercise across the lifespan. The lifespan approach to advocacy and healthy aging connects all phases of life to the health and well-being of people with intellectual/developmental disabilities. The approach is based on the premise that what happens in childhood and young adulthood affects the quality of life in old age. To maintain health and well-being in later years, healthy practices across the lifespan can make a very positive difference.



## Categories of aging<sup>1</sup>

- Chronological aging
- Psychological aging
- Social aging
- Physical/biological aging

## Changes as we age<sup>1</sup>

- Normal aging leads to some typical and expected changes in our function and capacities.
- Pathological aging is when certain age-related diseases or conditions become evident.

Decreased Motor Skills	Impaired Senses	Slower Reaction Time
Decreased strength and coordination	Vision problems	Decreased processing of information
Decreased flexibility	Hearing problems	Pain and stiffness in muscle and joints

<sup>1</sup> Janicki, M., (NTG 2014) National Task Group on Intellectual Disabilities and Dementia Practices. Module 2: Introduction to Aging and ID. Retrieved from NTG Regional Trainer Curriculum

<sup>2</sup> Janicki, M., (NTG 2014) National Task Group on Intellectual Disabilities and Dementia Practices. Module 3: Introduction to Healthy Aging. Retrieved from NTG Regional Trainer Curriculum

<sup>3</sup>National Down Syndrome Society (2018). Alzheimer's Disease and Down Syndrome: A Practical Guidebook to Caregivers. Retrieved from [https://www.ndss.org/wp-content/uploads/2018/04/NDSS\\_Guidebook\\_FINAL.pdf](https://www.ndss.org/wp-content/uploads/2018/04/NDSS_Guidebook_FINAL.pdf)

## Factors that affect aging<sup>2</sup>

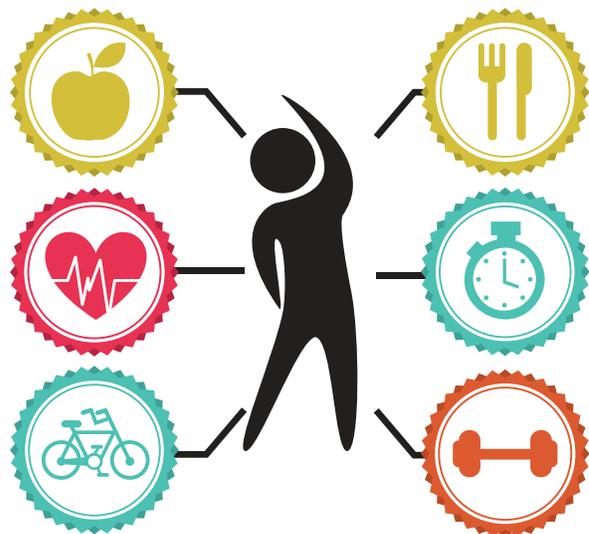
- Poor lifespan health practices (excessive eating/drinking, smoking)
- Long term consequences of early life therapeutic interventions
- Prolonged usage of medications adding to chronic conditions in older age (adverse drug reactions)
- Problems accessing health services
  - Not having medical personnel familiar with I/DD
  - Not tracking risk conditions
- Age-associated pathologies
  - Dementia, cardiovascular disease, etc
- Lack of exercise
- Poor nutrition and bad eating habits

## The effects of stress on your body

- Raises blood pressure
- Causes your heart to beat faster
- Acid productions goes up
- A decline in sensory will cause stress

## Healthy Lifestyle Recommendations<sup>3</sup>

- Don't smoke
- Keep your blood pressure, cholesterol and blood sugar within recommended limits
- Regular cardiovascular exercise
- Maintain a healthy weight
- Limit alcohol consumption
- Avoid preventable head trauma
- Stay well-rested
- Take care of mental health
- Stay mentally and socially engaged



<sup>1</sup> Janicki, M., (NTG 2014) National Task Group on Intellectual Disabilities and Dementia Practices. Module 2: Introduction to Aging and ID. Retrieved from NTG Regional Trainer Curriculum

<sup>2</sup> Janicki, M., (NTG 2014) National Task Group on Intellectual Disabilities and Dementia Practices. Module 3: Introduction to Healthy Aging. Retrieved from NTG Regional Trainer Curriculum

<sup>3</sup>National Down Syndrome Society (2018). Alzheimer's Disease and Down Syndrome: A Practical Guidebook to Caregivers. Retrieved from [https://www.ndss.org/wp-content/uploads/2018/04/NDSS\\_Guidebook\\_FINAL.pdf](https://www.ndss.org/wp-content/uploads/2018/04/NDSS_Guidebook_FINAL.pdf)

## Annual Screenings Throughout Life

### Health Care Guidelines for Individuals with Down Syndrome

The American Academy of Pediatrics (AAP) has put together a guide for healthcare test and things to monitor for people with Down syndrome. The timeline is from pregnancy to age 21. For this guide book, we will only highlight ages 13-21. You can find the whole list on the National Down Syndrome Society's (NDSS) website. Below is a list of common medical conditions in aging adults with Down syndrome and the AAP recommended frequency of testing.

COMMON MEDICAL CONDITIONS <sup>2</sup>	RECOMMENDATIONS <sup>1</sup>
<b>Vision Loss/Impairment:</b> due to early cataracts (clouding of the lens in the eye) and keratoconus (distortion of the shape of the eye).	Have an exam by an eye doctor at least every 3 years unless there is a known problem—then more frequent depending on what your eye doctor recommends.
<b>Hearing Loss:</b> is common for individuals with Down syndrome who have narrow ear canals. There is a higher chance of having ear wax impaction which can cause some hearing loss.	Hearing tests are recommended at least every year. If there is a known issue with an individual's ears, consult your doctor on how often to have tests done.
<b>Hypothyroidism:</b> is a condition that causes your thyroid gland to be underactive which can cause symptoms of fatigue and mental sluggishness.	The Thyroid gland is usually normal in babies with Down syndrome, but it can stop working normally for about half of people with Down syndrome by the time they reach adulthood. A blood test is recommended at least once a year, unless there are known issues. Treatment is safe, and your primary doctor should be able to start treatment.
<b>Obstructive Sleep Apnea:</b> is a sleep disorder that leads to poor quality of sleep and makes people feel sleep-deprived even after a full night of sleep.	<p>Since this is a very common problem for people with Down syndrome, it is recommended that every child with down syndrome have a sleep study by the age of four. If you notice the following symptoms consult your doctor about a sleep study to test for Obstructive Sleep Apnea.</p> <ul style="list-style-type: none"> <li>• Loud Breathing</li> <li>• Snoring</li> <li>• Waking up often at night</li> <li>• Daytime sleepiness</li> <li>• Restless sleep</li> <li>• Uncommon sleep positions (sitting up to sleep)</li> <li>• Pauses in breathing during sleep</li> <li>• Behavior problems</li> </ul>

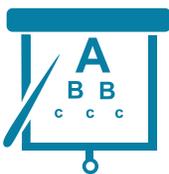


<sup>1</sup> Bull, M.J., Capone, G., Cooley, W.C., Mattheis, P., Robison, R., Saul, R., Stanley, M., Spire, P. (2013, July) Health Care information for Families of Children with Down Syndrome. Retrieved from <https://www.ndss.org/resources/healthcare-guidelines/>

<sup>2</sup>National Down Syndrome Society (2018). Alzheimer's Disease and Down Syndrome: A Practical Guidebook to Caregivers. Retrieved from [https://www.ndss.org/wp-content/uploads/2018/04/NDSS\\_Guidebook\\_FINAL.pdf](https://www.ndss.org/wp-content/uploads/2018/04/NDSS_Guidebook_FINAL.pdf)

COMMON MEDICAL CONDITIONS <sup>2</sup>	RECOMMENDATION <sup>1</sup>
<p><b>Atlantoaxial instability and cervical spine disease:</b> caused by congenital and/or degenerative changes around the spine at the base of the skull and neck. This can cause pain and effect movement, strength and function.</p>	<p>There are usually signs if an individual is experiencing pain or a lack of movement in the neck. X-rays are not needed unless you notice the following: stiff or sore neck, change in stooling or urination, change in use of arms or legs, head tilt, change in walking, numbness or tingling in arms or legs. If X-rays show an abnormality your doctor may refer you to a spine or neck specialist.</p>
<p><b>Osteoporosis:</b> is a condition that causes thinning and weakness in bones that can cause fractures. Many anti-seizure medications cause osteoporosis so if an individual with Down syndrome is taking anti-seizure medication it should be watched much closer.</p>	<p>Sometimes people with Down syndrome have issues communicating pain. If there are changes in behavior or movement, it is suggested to have a pain assessment completed to rule out other causes. Your doctor may recommend a Bone Mineral Density (BMD) test.</p>
<p><b>Celiac disease:</b> is an autoimmune disease that causes an inability to digest wheat and gluten. This can cause stomach distress, vitamin deficiencies, weight loss, and overall irritability.</p>	<p>It is good practice to discuss toilet patterns with a doctor throughout the lifespan, at each doctor visit. Testing can be done to confirm Celiac disease, but it can usually be managed through changes in diet. Let your doctor know if an individual is experiencing the following: very loose stools, hard to treat constipation, slow growth/weight loss, belly pain or stomach swelling, new or challenging behavior problems.</p>

### Health screens to be considered when an individual is having issues with loss of function or memory:



**Blood Work:** Complete Blood Count (CBC) to rule out infection or anemia, Thyroid-Stimulating Hormone (TSH) test for hypothyroidism, Basic Metabolic Panel (BMP) to check for kidney function and electrolyte balance, A1C test to check for blood sugar problems, Check on B12 levels because a deficiency can cause dementia-like symptoms



**Eye Exam:** to check for loss of vision or depth perception

**Ear Exam:** to check for hearing loss, wax impaction, and balance issues



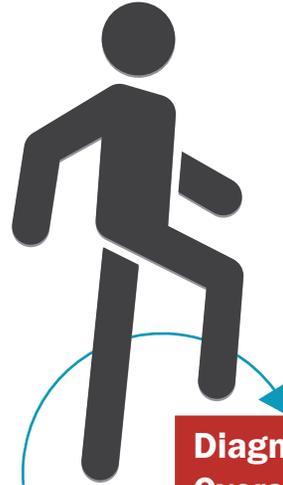
**Heart Monitoring:** to rule out cardiac arrhythmias or congestive heart failure, either of which can cause fatigue, confusion and refusal to be active.

**Pain assessment:** to rule out loss of function related to arthritis in joints or fracture from osteoporosis (high risk for individuals taking anti-seizure meds).

<sup>1</sup> Bull, M.L., Capone, G., Cooley, W.C., Mattheis, P., Robison, R., Saul, R., Stanley, M., Spire, P. (2013, July) Health Care information for Families of Children with Down Syndrome. Retrieved from <https://www.ndss.org/resources/healthcare-guidelines/>

<sup>2</sup>National Down Syndrome Society (2018). Alzheimer's Disease and Down Syndrome: A Practical Guidebook to Caregivers. Retrieved from [https://www.ndss.org/wp-content/uploads/2018/04/NDSS\\_Guidebook\\_FINAL.pdf](https://www.ndss.org/wp-content/uploads/2018/04/NDSS_Guidebook_FINAL.pdf)

# Challenges to Healthy Aging for People with Disabilities



## Diagnostic Overshadowing:<sup>2</sup>

- The tendency for physicians to attribute symptoms or a change in behavior of a person with I/DD to their underlying cognitive deficits and therefore underdiagnose the presence of co-occurring disease such as dementia.
- With the rise of information about the connection between Down syndrome and Alzheimer's disease, there has been a rise of diagnostic overshadowing in the opposite way. Meaning physicians will attribute any new behavior or symptoms of a person with Down syndrome to Alzheimer's disease.
- Both are examples of why health care advocacy is so important and why the differential diagnosis needs to be completed.

## Lack of systems for advocacy in agencies and families:<sup>1</sup>

- Information provided for the appointment may not include all of the important information.
- Staff/family attending health care appointments may not be the most knowledgeable about the symptoms.

## Lack of knowledge of medical history due to the following:<sup>1</sup>

- Staff turnover
- Family not available for information, historical documentation unavailable
- Health care provider turnover
- Providers not understanding baseline functioning of the older adult with I/DD

- No required training on ID in medical schools
- No required training on aging unless you are going into the field of geriatrics
- No medical textbooks on aging and ID
- No references in most textbooks on ID
- Little available research
- Few practitioners with expertise
- Few patients in health care providers caseload with ID diagnosis

# { Section 2 } Types of Dementia

**T**his section is meant to provide a base of information about what Dementia is, the most common causes of dementia, and an insight into common behaviors. Many people use Alzheimer's and dementia interchangeably, but they are not the same thing. Dementia is a group of symptoms that can be caused by many different things. There are certain causes of dementia that are treatable and there are causes that are not treatable. The hope is that after going through this section, you will have enough information for informed conversations with a care team.

## Topics covered in this section:

- **Dementia Defined**
- **Treatable and Non-Treatable Causes of Dementia**
- **The Five Most Common Causes of Dementia**
- **Common Causes of Dementia**
- **Dementia and Intellectual/Developmental Disabilities (I/DD) Dementia Defined**
- **Treatable and Non-Treatable Causes of Dementia**
- **The Five Most Common Causes of Dementia**
- **Common Causes of Dementia**
- **Dementia and Intellectual/Developmental Disabilities (I/DD)**





# Dementia Defined

## What is dementia?<sup>1</sup>

- Dementia is a group of behavior and function change symptoms caused by different conditions or diseases.
- Dementia causes a loss of cognitive function severe enough to interfere with daily functioning.
- Dementia is not a disease.
- Dementia describes clinical/behavioral symptoms associated with certain diseases or conditions.
- Dementia is NOT a part of normal aging.

## Types of dementia<sup>2</sup>

### Reversible

- Some things can cause the symptoms of dementia but are not a permanent change and can be reversed.
- Treatable means, it can be reversed or cured and is a temporary condition. The brain will regain lost functions when treated.

### Non-reversible

- These causes of dementia will result in permanent brain damage and cannot be reversed or cured.



<sup>1</sup> Janicki, M., (NTG 2014) National Task Group on Intellectual Disabilities and Dementia Practices. Module 5: Dementia Characteristics and Types. Retrieved from NTG Regional Trainer Curriculum

<sup>2</sup> Tripathi, M., & Vibha, D. (2009). Reversible dementias. Indian Journal of Psychiatry, 51 (Suppl1), S52–S55. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3038529/>

## Treatable and Non-Treatable Causes of Dementia

### TREATABLE

#### Depression

**Medication:** • negative drug interactions • drug/alcohol overdose

#### Heart Disease

**Malnutrition:** • especially Vitamin B-12 deficiencies • Iron deficiency

**Trauma:** • concussions or contusions

**Metabolic disorders:** • thyroid disease • hypo/hyperglycemia • dehydration

**Infections:** • fevers can affect the brain's cognitive abilities

#### Visual/hearing loss

**Heavy Metal Poisoning:** • gas leaks • exhaust fumes • other toxins

### NON-TREATABLE

#### Alzheimer's disease

#### Vascular dementia or Multi-infarct dementia

#### Parkinson's disease

#### Huntington's disease

#### Creutzfeldt-Jakob (mad cow) disease

#### Fronto-temporal dementia

#### Dementia with Lewy bodies

## The Five Most Common Causes of Dementia<sup>1</sup>

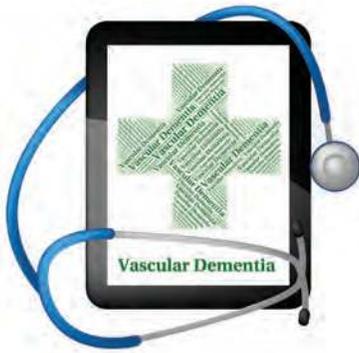
### 1. Alzheimer's disease

**Symptoms:** Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include: impaired communication, poor judgement, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.



### 2. Vascular dementia

Previously known as multi-infarct or post-stroke dementia, vascular dementia is less common as a sole cause of dementia than Alzheimer's, accounting for about 10 percent of dementia cases. Lack of blood flow can damage and kill cells anywhere in the body. The brain has one of the body's richest networks of blood vessels and is especially vulnerable.

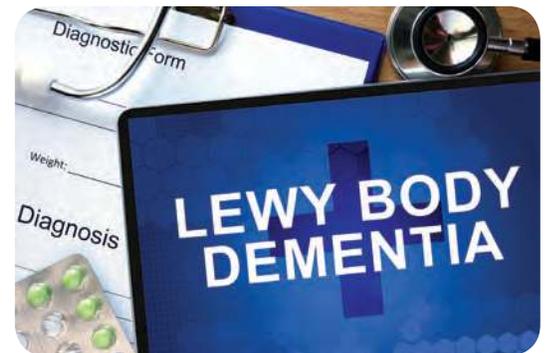


**Symptoms:** Impaired Judgement or ability to make decisions, plan or organize is more likely to be the first symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's. Occurs from blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain. The location, number and size of the brain injury determines how the individuals thinking and physical functioning are affected.

- Confusion
- Disorientation
- Trouble Speaking or understanding speech
- Vision loss

### 3. Dementia with Lewy bodies

Dementia with Lewy bodies is the third most common cause of dementia, accounting for 10-25 percent of cases. The Hallmark brain abnormalities linked to DLB are named after Frederick H. Lewy, M.D., the neurologist who discovered them while working in Dr Alois Alzheimer's laboratory during the early 1900s. Alpha-synuclein protein, the chief component of Lewy bodies, is found widely in the brain, but it's normal function isn't yet known.



**Symptoms:** People with dementia with Lewy bodies often have memory loss and thinking problems common in Alzheimer's but are more likely than people with Alzheimer's to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and slowness, gait imbalance or other parkinsonian movement features.

- Changes in thinking and reasoning
- Confusion and alertness that varies significantly from one time of day to another or from one day to the next
- Parkinson's symptoms such as hunched posture, balance problems and rigid muscles
- Visual hallucinations
- Delusions
- Trouble interpreting visual information
- Acting out dreams, sometimes violently, a problem known as rapid eye movement (REM) sleep disorder
- Malfunctions of the "automatic" (autonomic) nervous system
- Memory loss that may be significant but less prominent than in Alzheimer's

## 4. Parkinson's disease

As Parkinson's disease progresses, it often results in a progressive dementia like dementia with Lewy bodies or Alzheimer's. The brain changes caused by Parkinson's disease begin in a region that plays a key role in movement. As Parkinson's brain changes gradually spread, they often begin to affect mental functions, including memory and the ability to pay attention, make sound judgements and plan the steps needed to complete a task.



**Symptoms:** Problems with movement are common symptoms of the disease. If dementia develops, symptoms are often like dementia with Lewy bodies.

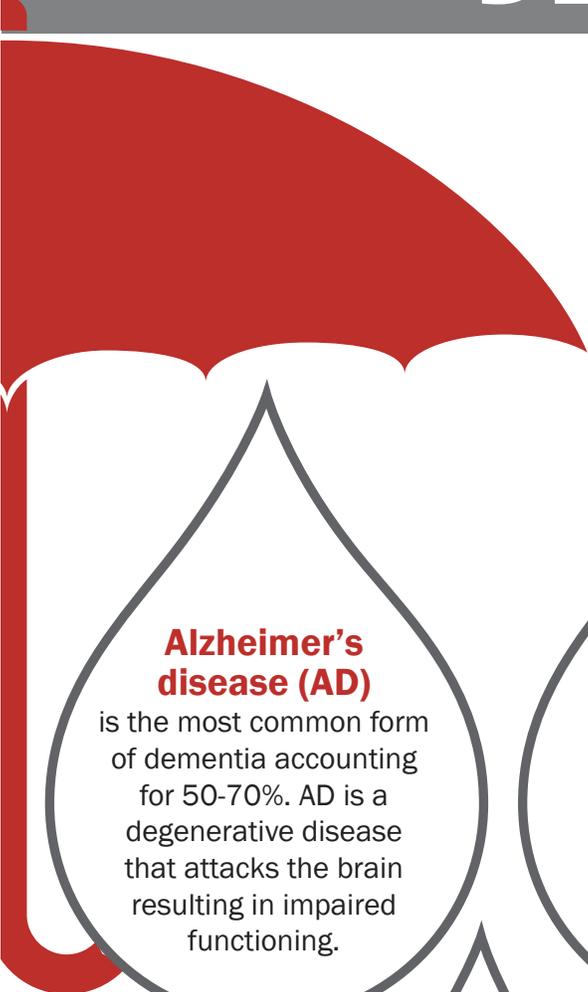
- Changes in memory, concentration and judgement
- Trouble interpreting visual information
- Muffled speech
- Visual hallucinations
- Delusions, especially paranoid ideas
- Depression
- Irritability and anxiety
- Sleep disturbances, including excessive daytime drowsiness and rapid eye movement (REM) sleep disorder

## 5. Frontotemporal dementia

The nerve cell damage caused by frontotemporal dementia leads to loss of function in these brain regions, which variably cause deterioration in behavior and personality, language disturbances or alterations in muscle or motor functions. There are several different diseases that cause frontotemporal degenerations. The two most prominent are: 1) a group of brain disorders involving the protein tau and 2) a group of brain disorders involving the protein called TDP43. For reasons that are not yet known, these two groups prefer the frontal and temporal lobes that cause dementia.

**Symptoms:** Typical symptoms include changes in personality and behavior and difficulty with language. Nerve cells in the front and side regions of the brain are especially affected.

# DEMENTIA



**Defined:** An umbrella term used to describe the symptoms of a group of more than 100 conditions that impair memory behaviors and thinking. The most common causes of dementia are outlined below.

## **Alzheimer's disease (AD)**

is the most common form of dementia accounting for 50-70%. AD is a degenerative disease that attacks the brain resulting in impaired functioning.

## **Fronto-temporal dementia (FTD)**

accounts for 5% of dementia cases. FTD is associated with rounded and tangled bundles of protein in brain nerve cells.

## **Parkinson's disease (PD)**

accounts for 5% of dementia cases. PD is a degenerative disorder of the central nervous system.

## **Vascular dementia (VaD)**

is the second most common form of dementia accounting for 20% cases. VaD occurs through a reduced blood supply to the brain usually due to a stroke.

## **Dementia with Lewy bodies (DLB)**

accounts for 15% of dementia cases. DLB is associated with Lewy bodies which are abnormal brain cells.

The symptoms we call "dementia" can have many different causes. Alzheimer's disease is the most common.

# CLINICAL FEATURES OF VARIOUS DEMENTIAS

## Alzheimer's disease (AD)

**Memory, visual-spatial and language disturbances**

Indifference • Delusions  
Agitation • Behavioral changes

## Dementia with Lewy bodies (DLB)

**Visual hallucinations**

Delusions • Falls  
Syncope • Parkinsonism  
Fluctuating memory  
Sensitivity to anti-psychotic medications

## Fronto-temporal dementia (FTD)

**Personality changes**

Executive dysfunction  
Disinhibition • Impulsivity  
Progressive loss of speech

## Vascular dementia (VaD)

**Abrupt onset**

Stepwise deterioration  
Prominent aphasia • Motor dysfunction  
Mood or behavior changes  
Severe depression symptoms

Although the brain neuropathy will differ, caregivers need to note the nature of the behaviors exhibited.

Healthy  
Brain



Alzheimer's  
Brain



## WHY IS IT IMPORTANT OR USEFUL TO KNOW TYPES OF DEMENTIA?

Different types of dementia have different characteristics. It can be helpful to know that particular behaviors are part of the disease process and not bad behavior.

- Lewy body - visual hallucinations
- Fronto-temporal - profound personality change, disinhibition

The type of dementia may impact what medications are used:

- Lewy body - sensitivity to certain anti-psychotics
- Fronto-temporal - does not respond to common Alzheimer's medications such as Aricept

Ensure that treatable causes of symptoms have been ruled out.



[www.MindandMemory.org](http://www.MindandMemory.org)

11/29/16



## Dementia and Intellectual/Developmental Disabilities (I/DD)<sup>1</sup>

Most adults with intellectual/developmental disabilities are typically at no more risk than the general population. The exceptions are for people with Down syndrome who have a much higher risk due to a genetic link between Down syndrome and Alzheimer's disease.

### Intellectual/Developmental Disability

Age	Percentage
40+	3%
60+	6%
80+	12%

### Down Syndrome

Age	Percentage
40+	22%
60+	56%
?	?



## Alzheimer's Disease and Down Syndrome<sup>2</sup>

Down syndrome is caused by a genetic abnormality- an extra full or partial copy of Chromosome 21 (Trisomy 21). This extra copy of genetic material alters the course of development and causes the characteristics associated with Down syndrome. Chromosome 21 carries the gene- Amyloid Precursor Protein (APP). The APP gene makes the protein plaques that are indicative of Alzheimer's (beta-amyloid). It is because of this extra copy of chromosome 21 that individuals with Down syndrome have an overproduction of this protein and puts them at a higher risk for Alzheimer's disease. This does not mean that every person with Down Syndrome will develop the disease.

<sup>1</sup> NTG Education & Training Curriculum on Dementia and I/DD. Copyright NTG 2014. All rights reserved

<sup>2</sup>National Down Syndrome Society (2018). Alzheimer's Disease and Down Syndrome: A Practical Guidebook to Caregivers. Retrieved from [https://www.ndss.org/wp-content/uploads/2018/04/NDSS\\_Guidebook\\_FINAL.pdf](https://www.ndss.org/wp-content/uploads/2018/04/NDSS_Guidebook_FINAL.pdf)

People with Down syndrome are also at risk of developing treatable causes of dementia which is why it is so important to rule these causes out through the Differential Diagnosis. Below is a list of common medical conditions in aging adults with Down syndrome.

- **Vision Loss/impairment** due to early cataracts (clouding of the lens of the eye) and keratoconus (a distortion of the shape of the eye).
- **Hearing loss**, which may occur more commonly with age and is often made worse by wax impactions, especially in small and narrow ear canals.
- **Hypothyroidism**, a condition that causes an underactive thyroid gland, which contributes to symptoms of fatigue and mental sluggishness.
- **Obstructive sleep apnea**, a sleep disorder that leads to poor quality, non-restorative sleep that makes people feel sleep-deprived even if they appeared to have a full night of sleep.
- **Osteoarthritis**, which can cause pain and stiffness that can make tasks more difficult to perform or can contribute to overall irritability.
- **Atlantoaxial instability and cervical spine disease**, caused by congenital and/or degenerative changes in the region of the spine located at the base of the skull and neck, which can have a variety of effects on normal movements, strength and function.
- **Osteoporosis**, a condition that causes thinning and weakening bones that can lead to fractures which cause pain and impaired mobility.
- **Celiac Disease**, an autoimmune disease that causes an inability to digest wheat and gluten, which can lead to stomach distress, vitamin deficiencies, weight loss and overall irritability.

## Alzheimer's disease often presents differently in people with Down syndrome<sup>2</sup>

1. Abrupt onset of seizure activity when there had been none in the past.
2. Incontinence when an individual has always been independent in toileting.
3. Short-term memory loss may depend upon the previous level of memory demands and reliance on memory in everyday life.
4. Sleep/wake cycle disruptions.

## Indicators of Onset of dementia in Adults with I/DD<sup>1</sup>

1. Notable memory loss
2. Personality changes, irritability or apathy
3. Change in language skills
4. Confusion
5. Changes in self-care skills
6. Outward behavior changing



<sup>1</sup> NTG Education & Training Curriculum on Dementia and I/DD. Copyright NTG 2014. All rights reserved

<sup>2</sup>National Down Syndrome Society (2018). Alzheimer's Disease and Down Syndrome: A Practical Guidebook to Caregivers. Retrieved from [https://www.ndss.org/wp-content/uploads/2018/04/NDSS\\_Guidebook\\_FINAL.pdf](https://www.ndss.org/wp-content/uploads/2018/04/NDSS_Guidebook_FINAL.pdf)

# { Section 3 } Stages

**T**here are a number of dementia staging systems used by professionals to classify the progression of dementia. The simplest way to categorize the progression, as the National Task Group has done, is to think of it as early stage, middle stage, and late stage. Providing proper care through each stage of dementia can be confusing for the caregiver but is critical for the individual. If the caregiver can help manage the individual's behaviors and ensure that the individual is receiving proper services and supports throughout each stage, it not only is extremely beneficial for the individual, but can create less stress and anxiety for the caregiver. **Keep in mind everyone is an individual and symptoms may vary throughout the stages.**

## **Goals for caring for an individual with dementia during each stage are:<sup>1</sup>**

- **Advocate** for the best possible health care services and supports
- **Help** maintain the person's independence for as long as possible
- **Protect** the person from physical injury
- **Focus** on what the person can still do
- **Provide** physical and mental activities that the person can and want to do (at that moment in time)
- **Maintain** the essence of the person
- **Support** the person's dignity and self-esteem at all times

## **Topics covered in this section:**

- **Early, Mid, and Late/Advanced Stages**
- **Common Behaviors in Dementia**
- **End of life care visit: <https://www.nia.nih.gov/health/end-of-life>**



***If you want your loved one with dementia to change, then you are the one that has to change.***

– Dr Natali Edmonds, Careblazers

<sup>1</sup> National Task Group on Intellectual Disabilities and Dementia Practices. Module 14 a-c: Stage-Based Strategies. NTG 2014. [www.aadmd.org/ntg/curriculum](http://www.aadmd.org/ntg/curriculum)



## Is it symptoms of dementia or just aging?

### Early symptom recognition

- Recurrent memory problems... not just forgetting
- Confusion and loss of focus
- Disorientation
- Changes in habits

### SIGNS OF ALZHEIMER'S DISEASE/DEMENTIA

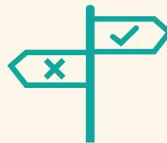
**Poor judgment  
and decision  
making**



**Inability to  
manage a  
budget**



**Losing track of  
the date or the  
season**



**Difficulty having  
a conversation**



**Misplacing  
things  
and being  
unable to  
retrace  
steps to  
find them**



### SIGNS OF AGING

- Making a bad decision once in a while
- Missing a monthly payment
- Forgetting which day it is and remembering later
- Sometimes forgetting which word to use
- Losing things from time to time



# STAGES OF DEMENTIA

## Early Stage

- Mild memory problems for recent events
- Mild problems with word and name retrieval
- Starting to have difficulty with complex tasks
- Repeat questions
- Mood and personality changes
- Increased supervision



## Mid Stage

- Increased memory loss and confusion
- Trouble completing multi-stage tasks
- Sleep-wake cycle disrupted
- Disorientated to time and place
- Poor judgment
- Difficulty with ADL's
- Wandering
- Impulsive behavior
- Safety issues emerge
- Unsafe to be left unsupervised



## Late Stage



- Inability to communicate
- Swallowing problems
- Incontinence
- Increased sleeping
- Weight loss
- May be bedridden
- Total assistance with ADL's

# Early Stage

## Important tips:

Changes are often subtle

Increased supervision may be needed for the individual

There is no definite point when the early stage ends and a new stage begins

## BEHAVIORAL CHANGES

- Apathy
- Lack of pleasure
- Withdrawal from activities previously enjoyed and/or social withdrawal
- Mood and personality changes. Irritable, easily upset, volatile, emotional, suspicious, paranoid
- Decreased verbalization, loss of language skills – difficulty finding right words



## MEMORY CHANGES

- Mild memory problems. Short term memory loss – sometimes day to day, hour to hour. Examples include balancing checkbook, following a recipe, writing a letter. May have difficulties learning new information or retrieving new things. Trouble recalling recent events or recognizing people and places. Repeating questions and conversations. Challenges with complex tasks
- Beginning of disorientation takes place including time and difficulty navigating familiar areas
- Riding in bus or van may become challenging. Individual may be disoriented, miss stops, overly sensitive with their personal space, irritated by noises, environment may seem too dark, uncomfortable seat, and/or having difficulty getting in and out of vehicle

## PHYSICAL CHANGES

- Physical Changes
- Difficulty performing common tasks
- Problems with gait/walking
- Not keeping up with personal care
- Changes in activities in daily living (ADLs) such as eating, toileting, bathing/grooming, safety, structure



## SUGGESTED TREATMENTS/SOLUTIONS

- Offer support for the person to function as best as possible. Maintain written and verbal communication between caregivers - including other family members, drivers, and clinical staff. Include phone calls. Note lack of sleep, increased fatigue, agitation. Document what works, what doesn't work. Note the surroundings that may cause behaviors. Team needs to work together in supportive caregiving manner.
- Keep moving – regular activity
- Sudden change in behavior – check for constipation, UTI, pneumonia or other possible health issues
- Bathing -Provide good lighting, warm room, assistance, may now occur less per week
- Dressing-Offer 1 or 2 choices, choose clothes for comfort - textures and material are important
- Eating and drinking – allow extra time, may choose one food at a time, red plate, keep hydrated

## PLAN FOR FUTURE

- Document using videos, photos, scrapbooks and journals. These will serve not only as “great storytellers” of the person's life, but also, helpful resources for caregivers to understand the changes the person may have experienced. May also help with future planning of cares. Also see Section 4 Screening Tool and Section 8 Caregiving.
- Prioritize health and wellness

# Mid Stage

## Important tips:

Behaviors in mid-stage become more notable for they are representing significant changes in function. Some behaviors may be caused by pain/discomfort, effects from medications, depression, environment and/or

Unsafe for individual to be left unsupervised. Additional supports and more personalized structure will be necessary

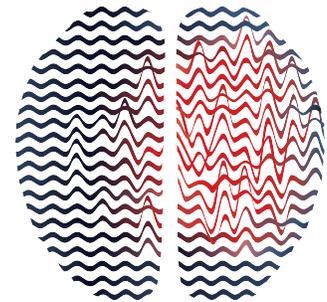
Be creative in how to provide aid. Also keep in mind, what may work one time may not work for another time

## OVERALL CHANGES

- Functional loss and profound memory impairment
- Difficulty understanding language
- Disorientation to time and place
- Confusion and frustration
- Severe changes in personality
- Refusal to participate in previously enjoyed activities, transportation
- Safety issues emerge. Decline in judgment and decision making
- Speech difficulties – hard to understand – difficulty expressing

## PHYSICAL CHANGES

- Incontinence
- Swallowing
- Mobility changes/frequent falls
- Weight loss
- Seizures
- Sleep disturbances



## TREATMENTS/SOLUTIONS FOR OVERALL CHANGES

- Increase in need for one on one care and assistance with ADLs
- Validate person's feelings and emotions
- Modify routine and environment as needs change
- Minimize stimulation
- Minimize choices
- Give reassurance
- Continue to advocate for proper health care
- Plan for future – what supports will be needed? Placement? Advance directives, guardianship, etc.
- Watch for caregiver burn out – plan ahead

## PLAN FOR FUTURE

- What supports will be needed? Placement? Advance directives, guardianship, etc.
- Watch for caregiver burn out – plan ahead

what's next?

# Late Stage

## Important tips:

Capture the **ESSENCE** of the person! What do they respond to now?

Knowing who the person has been over a lifetime can give clues for the best comfort care during the late stage

Care for the caregiver is crucial. Bringing in an agency to provide hospice care may be considered.

## OVERALL CHANGES

- Increasing frailty – weight loss
- Communication severely impaired
- Dependent on others for all care
- Chewing and swallowing difficulties develop
- Severe memory loss – unable to recognize those close to them or even their own reflection
- May no longer be able to find their way around familiar surroundings or identify everyday objects
- May believe that he/she is living in a time from their past, and may search for someone or something from that time
- Increasing difficulty walking. May be lying in bed or sitting in chair most of day. Possibly bedridden
- Loss of most previously learned skills and interests
- Still able to appreciate or respond to stimuli such as music, scent, and touch
- Continue to talk to the person, even if he/she can't respond
- Increased sleeping



## BEHAVIORAL CHANGES

- Rock backwards and forwards, repetitive movements or calling out the same sound or word. Is the person otherwise calm? This may be a useful coping mechanism. Is the person tense? He/she may be distressed.
- Hallucinations, delusions, distorted ideas – don't argue, instead distract and divert to a pleasant activity.
- Restlessness, pacing, wandering – may need more physical activity. Help to walk at different times throughout the day, do gentle exercises, rock themselves in a rocking chair (if able)
- Excessive hand activity – wringing hands, fidgeting. Create a rummage box that includes pictures from person's past, textural items, "safe" tools

## TREATMENTS/SOLUTIONS

- If individual seems distressed, check physical needs and provide care and comfort. Feelings of pain, constipation, hunger and dehydration are key triggers for changes in behavior
- Will need total assistance with Activities of Daily Living (ADLs) including appropriate food consistency
- Care shifts focus on comfort and dignity.
- Sensory activities such as favorite music, aromatherapy, massage therapy, bird watching and sitting in the sun. Provide warm blankets and often reminisce
- Do not talk about individual as though he or she is not present. Assume he or she understands your presence and voice even if not responding. Maintain calm and relaxed body language and tone of voice
- Caregivers dealing with grief and bereavement issues should seek support





## COMMON BEHAVIORS IN DEMENTIA

**Behaviors are communication  
All behaviors have meaning**



# HELPFUL TIPS FOR CHALLENGING BEHAVIORS



## Change your communication

### **Difficult behaviors cannot be changed with words**

Change your approach to the person, reaction to their behavior, and/or change their environment. • Individuals with dementia often times have impairments in short term memory as well as an inability to learn new information. • They cannot be told to do, or not do something and be expected to remember. • But it is important to make sure you have their attention. • Use short sentences with yes/no answers. • If necessary, distract and redirect.

### **Don't say "No" and never argue**

You cannot reason with a person who has lost the intellectual ability to process thoughts in a logical and rational manner. • Arguing will encourage frustration, fear, and anger. • Your goal is not to be "correct" or "right". • The person is experiencing a decline in their reasoning skills at the same time they are experiencing an increase in their emotional reactions. • Feelings are more important than facts. • Loud voice can be interpreted as angry. • Stay calm. • Step away and try again in a few minutes. • Allow time.

### **It's their reality and you must enter it**

- ✓ Validation – builds empathy and creates a sense of trust and security that reduces anxiety. Enter their reality and reminisce with them. Match their emotions. Loud voice can be interpreted as angry.

### **Reduce fear by acknowledging underlying emotions**

- ✓ Empathize – as the disease progresses the person loses their ability to express and cope with their fears. A person with dementia cannot "self soothe" if their fears become overwhelming. Reassure the person and respond to their emotion.

**Repetitive Questions** – Answer but maybe answer differently each time and/or redirect them to a different subject. • Make it fun! "Are we going?" Give them 5 cards or 5 objects. Each time they ask take away the card or object. Remind them when they have no cards/objects it will be time to go.

**Verbal Outbursts/Physical** - Behaviors do not come out of the blue. Stay calm, do not shout or initiate physical contact, reassure, make eye contact and identify the trigger. Document behaviors and triggers.

**Inappropriate sexual expression/resistance to personal care** – What is the trigger? Clothing issue? Pain? UTI? Vaginitis? Constipated? Some people are not used to others being in the bathroom with them.

**Paranoia/Hallucinations/Delusions**- Audio or vision issues? Impact in ear canal? Cataracts? Make sure to rule out treatable issues. Live in their world. Help them look. Distract if necessary. "There's a fireman outside my window". "Let's go see if we can help him". Or possibly close the curtain.

**Sleep-Wake Disorders** - Is this treatable? Is it sleep apnea?



## Change the environment

**Sundowning** – Increase full-spectrum lighting especially between 3-6pm (before dark). Reduce stimuli and confusion. Close curtains to reduce shadows and reflections. Try to increase supports during transition times. Stick to routines. Minimize stress with quiet music. Provide light meal for dinner. Also, offer regular breaks/naps throughout the day. The #1 reason for behaviors happening is fatigue.

**Wandering** – Assume the environment is always new to the person. Keep landmarks the same as much as possible. Do not prevent movement. Create safe spaces with snack and drinks. Disguise doorknobs and locks. Have meaningful activities including dancing, music, and exercise.

**Rummaging/Hoarding** – Organize but don't remove. These are often items the person cherishes. Create rummage boxes.

### **Dementia alters visual perception – can't shut out other stimuli:**

- Adults with I/DD may already have been compromised
- "lost in space" – help with cues like placemats on the table or pictures on door
- Bathrooms often white on white – need contrasting colors
- Keep landmarks the same – arrows to the bathroom
- Colors may appear differently, glare sensitivity, black & white tiles or "busy" carpet
- Visual field about 3' from floor
- Food – one food at a time – don't load plate with all and use contrasting colors and easy to use utensils

# { Section 4 } Screening Tool

## The National Task Group-Early Detection Screen for Dementia (NTG-EDSD) and the NTG-EDSD Manual

Often, families and caregivers start to notice changes with the individual with intellectual/developmental disabilities (I/DD) and may assume it is because the person is cognitively challenged. Sometimes they notice memory changes, but often recognize behavioral changes. For example, an individual who was once comfortable taking public transportation may lose interest or possibly refuse to take it. A person who usually makes their breakfast or their lunch starts to make the meals differently or not at all. The individual may refuse to get dressed in the morning, take a bath or shower, or have other changes in their usual tasks and/or Activities of Daily Living (referred to as ADLs). These are all signs of behavioral changes. It is important to rule out health issues as the cause of these changes - such as hearing/visual impairments, side effects of medications, hypothyroidism, dehydration, urinary tract infection (UTI), sleep apnea, depression, and other conditions that may be treatable - before determining the person is showing symptoms of dementia. The NTG-EDSD tracks changes and can be helpful in ruling out those conditions.

### Topics covered in this section:

- What is the NTG-EDSD?
- Explanation and Purpose of the NTG-EDSD
  - NTG-EDSD: Do I Need to Take It?
  - NTG-EDSD Screen and Manual
  - Next Steps: From Screening to Diagnosis



“

***We all use tools in our lives. This is a tool to help another that you care about.*** ”

- Marcia Stickel



## What is the National Task Group–Early Detection Screen for Dementia (NTG-EDSD)?

- The NTG-EDSD is an early detection screen for adults with intellectual/developmental disabilities (I/DD) who may be showing early signs of dementia and/or a change in health condition. It does not create a diagnosis but can be helpful to note functional decline and health problems and record useful information for a further assessment. It can also be used to record a person's baseline abilities and function as a reference for later when abilities and memory may change.
- Commonly used memory testing tools may not be appropriate for individuals who already have a cognitive impairment.
- The NTG-EDSD can help provide critical information for a physician, and keep the individual's health care information in one place.
- Early detection can lead to early diagnosis and referral for services and supports. There is a potential to proactively address signs, delay symptoms, and identify potentially treatable conditions that are causing symptoms. The overall outcome is to increase the quality of life for people with dementia and their caregivers.



## Who can assist with the NTG-EDSD?

- Anyone familiar with the person for at least 6 months can provide the screening tool.
- It is helpful to have more than one person complete the screen for the individual. Often people's perception is different, and it would be helpful to have more than one point of view. Who spends a lot of time with this person? A family member? A caregiver? An employer? These are people who know the individual best and can provide the best perspective.

## When do we use the NTG-EDSD?

- It is suggested by the National Task Group to start using the tool by age 40 for a person with Down syndrome, age 50 for a person with I/DD in general.
- It would be most beneficial to complete the initial screening as early as possible preferably when the individual is at their best of health – usually between the ages of 18-21. This will create a baseline of reference to compare to in the future when changes are suspected. It can also be helpful as a record to refer to when there is a change in caregivers.
- Once there is a good baseline screen, the individual may not need to be screened again until there is suspicion of a change in condition. Continued screening is recommended as changes are suspected.



### What else can be incorporated with this tool?

- Video-taping the individual doing usual routines and/or tasks can be extremely helpful when monitoring for changes. For example, if “Ronnie” makes eggs and toast every morning - video tape his routine. Over time, you may begin to see changes. Is he having difficulty remember ingredients? Cracking an egg? Buttering his toast? Things that were once simple and regular tasks for “Ronnie” may now seem difficult and confusing.
- Combining video and the completed screen can provide a more thorough picture of changes in the individual. These items can help providers generate a better assessment and, along with other tests such as lab, MRI and/or CT scan, can help with a diagnosis while looking at other diseases or conditions that may be present.

### Where can I find more information about the NTG-EDSD?

- Included in this section is the NTG-EDSD Manual that provides detailed information pertaining to each section of the screen
- The screen is available in an electronic fillable form along with multiple languages. Look for these and many other resources at: [www.aadmd.org/ntg/products](http://www.aadmd.org/ntg/products)

**Sharing the NTG-EDSD is strongly encouraged and can benefit other individuals with I/DD and their family/caregivers.**



## Early Identification of Dementia in Individuals with Intellectual or Developmental Disabilities

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In the United States, 6% of adults with I/DD will be affected by some form of dementia after the age of 60. For adults with Down syndrome, studies show that 50-70% will be affected by dementia by the age of 60. The NTG-EDSD was created because the typical screening and evaluation tools used with the general population, involving complicated memory tests may not be feasible for people with I/DD. With early identification, there is potential to proactively address signs, delay symptoms and identify potentially treatable conditions that are causing symptoms.

### **National Task Group-Early Detection Screen for Dementia (NTG-EDSD)**

The NTG-EDSD is used by caregivers and providers in any setting for adults with I/DD who may be experiencing changes in thinking, behavior, and adaptive skills that could be related to dementia.

This tool is meant as a first pass screening to identify individuals who might need a more complete assessment.

The NTG-EDSD was not designed to diagnose dementia, but to help in the early identification and screening process, as well as to provide information to begin the conversation with health care providers.

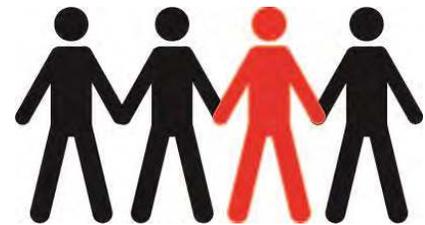
### **When should the screening tool be used?**



This instrument can be used annually or as needed with adults with Down syndrome beginning at age 40, and with other at-risk persons with I/DD when suspected of experiencing cognitive change.

### **Who should fill out the NTG-EDSD?**

The form can be completed by anyone who is familiar with the adult (has known them for more than six months) such as a family member, support worker, or a behavioral/health specialist using information gathered through observation or from the adult's personal record.





# MIND & MEMORY MATTERS

## How to use the information you get from filling out the NTG-EDSD

The tool is a living document and can continue to be referenced over time.

- 1 If no signs or concerns are observed, then the form should be filled out and saved as a baseline for future reference.
- 2 If changes are observed, then the form can be used to start a conversation with your healthcare provider to determine next steps.
- 3 The information on the form can be shared with healthcare providers during any health visit, your annual wellness visit (provided under the Affordable Care Act) or as part of eligibility determination.
- 4 The form should be shared with all healthcare specialists who are part of the healthcare team to provide proactive treatment and appropriate support for the caregiver.

### Early Signs of Dementia:

**These problems must be notable and usually occur in a cluster**

**\*Dementia is a group of behavior and function change symptoms caused by different conditions or diseases**

**Unexpected Memory Loss**

**Onset of New Seizures**

**Problems with Gait or Walking**

**Difficulty Doing Usual Tasks**

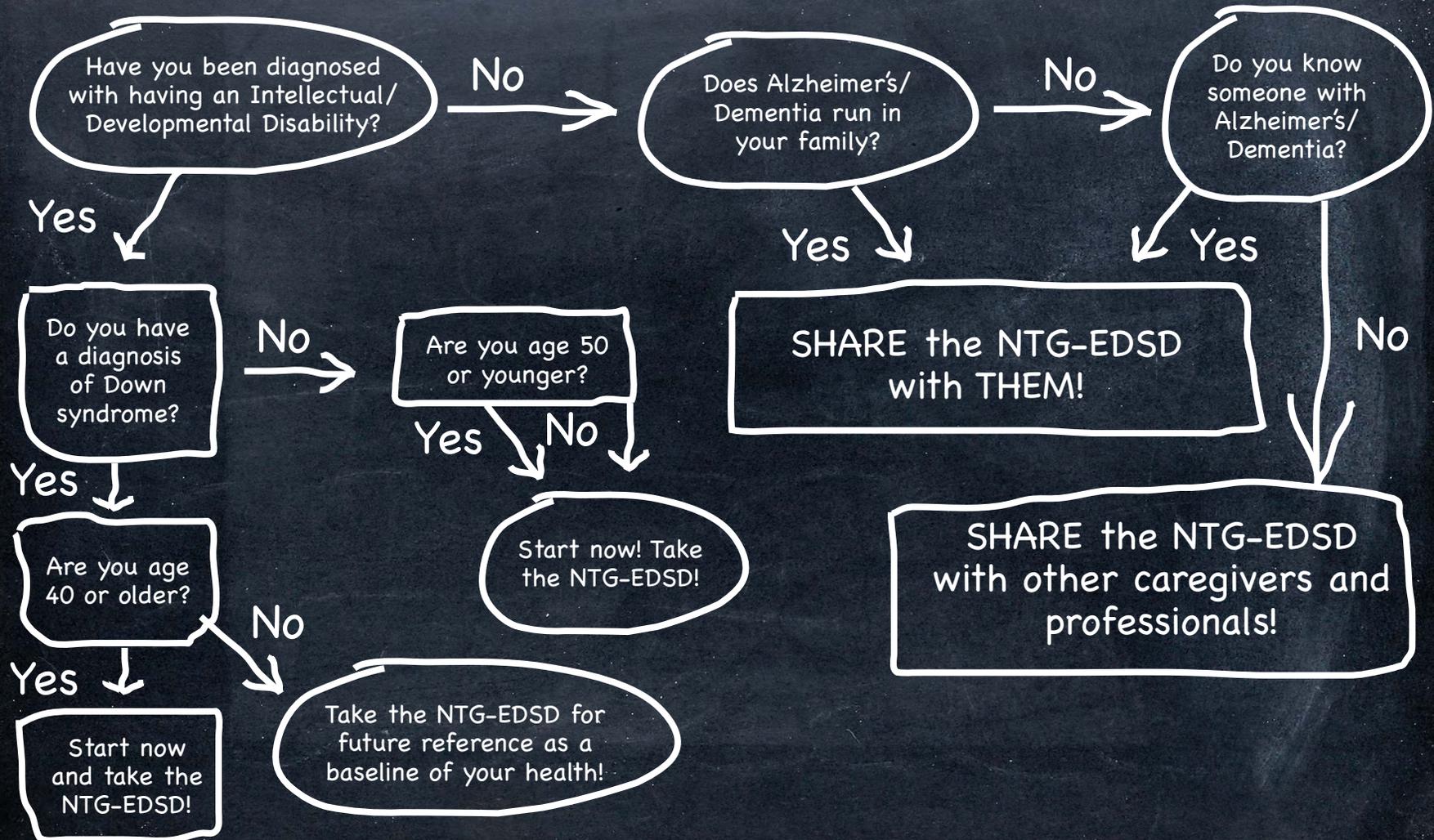
**Getting Lost or Misdirected**

**Confusion in Familiar Situations**

**Personality or Behavior Changes**

**For more information go to: [www.MindandMemory.org](http://www.MindandMemory.org)**

## DO I NEED TO TAKE THE NATIONAL TASK GROUP-EARLY DETECTION SCREEN FOR DEMENTIA (NTG EDSD)?





# NTG-EDSD

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](http://www.aadmd.org/ntg/screening)).

(1) File #: \_\_\_\_\_ (2) Date: \_\_\_\_\_

Name of person: (3) First \_\_\_\_\_ (4) Last: \_\_\_\_\_

(5) Date of birth: \_\_\_\_\_ (6) Age: \_\_\_\_\_

(7) Sex:

<input type="checkbox"/>	Female
<input type="checkbox"/>	Male

(8) Best description of level of intellectual disability

<input type="checkbox"/>	No discernible intellectual disability
<input type="checkbox"/>	Borderline (IQ 70-75)
<input type="checkbox"/>	Mild ID (IQ 55-69)
<input type="checkbox"/>	Moderate ID (IQ 40-54)
<input type="checkbox"/>	Severe ID (IQ 25-39)
<input type="checkbox"/>	Profound ID (IQ 24 and below)
<input type="checkbox"/>	Unknown

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

<input type="checkbox"/>	Autism
<input type="checkbox"/>	Cerebral palsy
<input type="checkbox"/>	Down syndrome
<input type="checkbox"/>	Fragile X syndrome
<input type="checkbox"/>	Intellectual disability
<input type="checkbox"/>	Prader-Willi syndrome
<input type="checkbox"/>	Other: _____

**Instructions:**  
For each question block, check the item that best applies to the individual or situation.

**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: \_\_\_\_\_

<sup>(10)</sup> General characterization of current physical health:

	Excellent
	Very good
	Good
	Fair
	Poor

<sup>(15)</sup> Seizures

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

<sup>(11)</sup> Compared to one year ago, current physical health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

<sup>(12)</sup> Compared to one year ago, current mental health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

<sup>(13)</sup> 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

<sup>(14)</sup> 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:

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

<sup>(16)</sup> **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:

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

<sup>(18)</sup> **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
<b><sup>(19)</sup> Activities of Daily Living</b>				
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)				
<b><sup>(20)</sup> Language &amp; Communication</b>				
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)				
<b><sup>(21)</sup> Sleep-Wake Change Patterns</b>				
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				
<b><sup>(22)</sup> Ambulation</b>				
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
<b><sup>(23)</sup> Memory</b>				
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				
<b><sup>(24)</sup> Behavior and Affect</b>				
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				
<b><sup>(25)</sup> Adult's Self-reported Problems</b>				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
<b><sup>(26)</sup> Notable Significant Changes Observed by Others</b>				
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]

	<sup>(27)</sup> Chronic Health Conditions*	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
	<b>Bone, Joint and Muscle</b>				
1	Arthritis				
2	Osteoporosis				
	<b>Heart and Circulation</b>				
3	Heart condition				
4	High cholesterol				
5	High blood pressure				
6	Low blood pressure				
7	Stroke				
	<b>Hormonal</b>				
8	Diabetes (type 1 or 2)				
9	Thyroid disorder				
	<b>Lungs/breathing</b>				
10	Asthma				
11	Chronic bronchitis, emphysema				
12	Sleep disorder				
	<b>Mental health</b>				
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:				
	<b>Pain / Discomfort</b>				
23	Back pain				
24	Constipation				
25	Foot pain				
26	Gastrointestinal pain or discomfort				
27	Headaches				
28	Hip/knee pain				
29	Neck/shoulder pain				
	<b>Sensory</b>				
30	Dizziness / vertigo				
31	Impaired hearing				
32	Impaired vision				
	<b>Other</b>				
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)





National Task Group on Intellectual  
Disabilities and Dementia Practices

# **National Task Group Early Detection Screen for Dementia**

## **NTG-EDSD**

## **Manual**

Version 1 May 2013-e

Available at [www.aadmd.org/ntg/screening](http://www.aadmd.org/ntg/screening)

For suggestions, comments, or more information,  
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Version 1 May 2013-e

## BACKGROUND

The National Task Group Early Detection Screen for Dementia (NTG-EDSD) is an informant-based rating tool for use with adults with intellectual and developmental disability who are suspected of having changes in thinking, behavior, and adaptive skills suggestive of mild cognitive impairment or dementia. It is considered an administrative, and not a clinical assessment, tool. The use of the NTG-EDSD provides an opportunity to review relevant information that can be used by the team and healthcare practitioner to aid in shared decision-making, and planning training, services, and supports. The NTG-EDSD was not designed to diagnose dementia, but to be a help in the early identification and screening process, as well as to provide information to begin the dialogue with health care professionals. Persons who complete this instrument are asked to indicate whether they have observed the occurrence of new problems or a worsening of problems that have previously been observed. The items are associated with changes in cognition, behavior, mood, and activities of daily living.

### *Why Early Detection?*

Early detection is one of the aspects stressed by the *National Plan to Address Alzheimer's Disease*. With early detection, assessment and diagnosis can be carried out to determine whether cognitive changes are the result of a neuropathological process related to disease or trauma to the brain, or attributable to other causes, often treatable and reversible. However, early detection among persons with lifelong cognitive impairments can often be difficult and problematic (Prasher, 2005). Specialized measures are needed that help take in account lifelong impairment and assist in picking up on subtleties in dysfunction. The NTG-EDSD was developed to address these issues, capturing early changes in function and specializing in accounting for subtleties in these changes.

In general, dementia is not a condition that can be solely determined on the basis of one laboratory or medical test. The diagnosis of dementia is based on a combination of data, including the confirmed observations of changes in cognition, mood, behavior, and adaptive functioning with a rule-out of other known conditions and factors that might mimic dementia, but which are not related to dementia (such as sensory loss, delirium, depression, or environmental stressors). Recent evidence indicates that signal biological markers may be present some twenty years prior to the observation of behavioral changes. However, by the time these observable changes occur, significant neurological changes have already begun to occur. . Therefore, the earlier that change in cognition, behavior and functioning is recognized in adults with intellectual disabilities, the greater the opportunity for families and staff to allocate necessary resources, access available treatment, and plan for future programming, services and supports.

Early detection is necessary in cases where functional changes are suspected or observed so as to pick up areas of concern that may require immediate or prolonged attention. The early

detection of functional change can signal the need for a more comprehensive evaluation and help in identifying the cause of the functional decline. Early detection can result in treatments or interventions that reverse functional change or introduce a period of greater surveillance to check for other areas of decline or change. For instance, early recognition of change in cognition might lead to recognition of unaddressed sensory impairments, untreated depression or difficulties adjusting to a new life situation (such as a new roommate or new living arrangement).

Early detection can be an outcome of individual screening (Borson et al., 2013). There is an important distinction between *screening*, involving the use of the NTG-EDSD and *evaluation or assessment* which is conducted using formal instruments designed to diagnose dementia. The function of screening is the identification of current atypical functioning indicative of decline or cognitive impairment. A screening tool does not help establish the origins of change; but, it is useful in substantiating change. On the basis of this observation, the person with suspected dementia can be referred for an assessment using a standard dementia assessment instrument and other medical measures. Screening tools generally are quick, easy to administer, can be completed by a family member or staff caregiver, and can be used at intervals to ascertain changes. Such screening results in a determination that the adult meets a clinical, behavioral, or functional threshold to be referred for assessment and / or to initiate dementia-related services and supports.

Conversely, the function of an assessment is to comprehensively evaluate the health and functioning of the person when changes are suspected. The assessment is conducted by a qualified individual with the appropriate credentials; the focus is on those areas of functioning that are most relevant in confirming a diagnosis of dementia. In the case of individuals with intellectual disabilities, instruments must be selected that are appropriate to the level of the individual's known cognitive abilities. Assessment instruments that have been developed for the non-IDD population will not be informative. Usually assessments result in a preliminary diagnosis of possible or probable dementia or determination of underlying causes of atypical functioning or progressive cognitive impairment. Assessment may also be used to determine that the individual does not meet criteria for dementia and observed functional changes may be attributed to other, potentially reversible, causes (e.g., medication interaction, depression, nutrition or hydration problems, etc.)

The NTG recommends conducting a screening either on a prophylactic basis or when caregiver suspicions are raised. The early identification of signs and symptoms of cognitive impairment and dementia is an important first step in managing the course of the disease and providing quality care.

### ***Why the need for an administrative tool?***

The NTG-EDSD is considered an administrative tool. Such a tool is meant as a first pass screening to identify individuals who might need more comprehensive assessment. Each service

setting may develop its own protocol regarding how information from this assessment can best be utilized on behalf of the consumer. However, it is conceivable that care paths might include sharing the information with the consumer's physician, deciding if there needs to be a change in programmatic or personal care supports, a reallocation of resources, or provide an implication for the residential setting. The team may want to adopt a "watchful waiting" approach in which certain areas of identified change are further monitored through additional data collection. As many agencies indicated that they did not have access to professionals who could provide a cognitive screening, the NTG wanted to make a tool available that was accessible to caregivers who were not necessarily trained to do assessment, but had valuable information regarding day-to-day changes in functioning. The tool needed to be easy to administer, cannot be time consuming, and should be sufficiently robust to yield information that could be used as an aid in shared decision making.

The items that make up the NTG-EDSD are associated with the changes typically observed in dementia. Via the use of this screening tool caregivers or staff can substantiate if a person with and intellectual disability manifests these changes and can then share the information with health care providers.

The NTG-EDSD can also be helpful in training caregivers or staff in being good observers and reporters of information which will be valuable in making decisions to advance the care, supports, and services of persons with intellectual disability. This can provide an opportunity for family and provider data to support initial suspicions, to provide preliminary data for an initial assessment interview, and to provide longitudinal information. The tool can be used by caregivers to record observed behavior and can be used by providers to have a running record of health and function that can complement any in-depth personal and clinical records. An administrative tool can also serve as addition to the permanent record and augment any other periodic assessment information kept on the individual.

## **DEVELOPMENT OF THE NTG-EDSD**

### **Historical basis**

The NTG-EDSD has its roots in a meeting held in the mid-1990s, which was the first time a collection of researchers interested in dementia and intellectual disabilities came together. In 1994, a conference support grant from the National Institute for Health helped support a meeting held in Minneapolis, Minnesota, held in association with an international Alzheimer's conference, which was one of the early iterations of the international Alzheimer's conference now known as the ICAD [International Conference on Alzheimer's disease]. The outcomes and products of this meeting included a number of reports and publications as well as the formation of an informal network of the researchers in the field of intellectual disabilities and dementia. One of the papers that resulted from the meeting was co-authored by a team lead by Drs.

Elizabeth Alyward and Diana Burt (see Alyward et al., 1996) and published in the *Journal of Intellectual Disability Research*. The paper addressed the rationale for and reviewed assessment and diagnostic tools relevant to conducting research on individuals with intellectual disabilities affected by dementia. These tools were for direct assessment of adults with intellectual disabilities suspected as having cognitive changes associated with dementia and were in use for various purposes (some purely clinical and some research based). The interested reader is directed to the work of Alyward and Burt (Alyward et al., 1996; Burt et al., 2000). See also Jokinen et al. (2013) for a listing of prevalent assessment instruments currently in use and their applications.

The work accomplished by these reviewers put in play an analysis of the utility of the various instruments for both research and clinical purposes, but also spoke to their limitations with respect to how to best assess cognitive change associated with dementia in persons with diverse intellectual capacities. While the work of this group was useful to researchers, it left open what might be applicable for use by lay workers and family caregivers. Over the years, there evolved a growing interest in the early recognition of cognitive, behavior, and adaptive changes that could be substantiated by family and staff caregivers. Provider agency staff indicated that they needed an instrument for early detection and initial screening that could be used by direct support workers and families. The original instruments cited in Alyward et al. (1996) were direct assessments requiring professional level administration and were tied to full diagnostic workups. Many agency staff and families did not have access to psychologists and other practitioners who had the expertise to conduct such assessments; however, there was a need for something that could serve as an early detection measure. Furthermore, there was increasing demand for a rating instrument that could help capture information about changes that could then be shared with health care practitioners to advance service planning, supports and decision-making.

Given the increasing number of adults with intellectual disabilities who were growing older and the uptick in the prevalence of adults affected by age-related cognitive and functional decline, there was a general call for some type of screening or instrumentation that could help families and agencies better prepare and become aware when changes were occurring. For this and for other reasons, there was a need for some type of national conversation on ways to identify early and address suspected dementia among adults with such lifelong disabilities.

When the National Task Group on Intellectual Disabilities and Dementia Practices was organized in late 2010, among its first tasks was to identify a screening tool that could be widely used as a first pass screen for early detection of changes that would identify individuals who needed additional, more comprehensive assessment. Group S (for ‘screening’), one of the NTG’s three original working groups, was tasked to look at extant instruments and see which, based upon the literature and professional judgment, would be best suited to be adapted for more general usage as a screen. During this process Group S had input and involvement from some of

the original members of the 1994 workgroup on diagnosis and assessment. Group S members elicited feedback from the other NTG members regarding tools that were in current use and which have proved helpful in identification of individuals who might have dementia.

### **Development process**

In preparation for the inaugural June 2011 NTG meeting in St. Paul, Minnesota, Group S had been charged with determining whether individuals could be identified for possible or probable signs of dementia. Members of Group S submitted 11 screens for review. Most of the respondents favored an informant based instrument. The instruments reviewed represented a delimited sample of instruments in use in the US and elsewhere. Criteria were that a first instance instrument should be tied to behavioral indicators of dementia or warning signs and still capture newly presented and successive changes in function. It should also be constructed in a manner so it could be completed by direct support staff or family caregivers with minimal training or orientation. Further, the screen could be used to confirm suspicions or changes in function to support decisions to refer individuals for further assessment. One of the instruments that was favorably rated by Group S was an adaptation of the Dementia Screening Questionnaire and Interview for Intellectual Disabilities (DSQIID), originally developed in the United Kingdom by Professor Shoumitro Deb of the University of Birmingham in the United Kingdom, and adapted for use by the Philadelphia PMHCC [Philadelphia Mental Health Care Corporation] for use with the Pennhurst class. The resulting adaptation was an easily administered screen that could help family and direct care providers open up a dialogue around declining function.

The members of Group S then reviewed the instruments on a variety of indicators. On the basis of this review, the members endorsed the use of the DSQIID (Deb, 2007). This recommendation was reviewed when the full NTG convened at its June 2011 meeting in St. Paul in conjunction with the AAIDD's annual conference. At this meeting, Group S was further tasked to come up with an early detection screen that included an augmentation and adaptation of the DSQIID and which could be used by family and staff caregivers. It was decided also to include ancillary information so as to broaden its content and usefulness for clinicians. Thus, items gathering information on individual demographics, co-incident medical conditions and impairments, and significant life factors were added.

Coincident, with the working group's efforts, the Philadelphia PMHCC also undertook a secondary adaptation of the DSQIID with the assistance of Dr. Karl Tyler of the Cleveland Clinic (Philadelphia Coordinated Health Care Group, 2011). This version was further adapted by the working group to include items felt to be pertinent to early detection. The draft composite instrument went through several revisions and then was field tested over the summer of 2012 in eight sites, including agencies in the continental U.S., Canada, and Austria. The Austrian field test used a German language translation.

## **Field Testing of the NTG-EDSD**

The field test was designed to elicit feedback on items and the process of completing the instrument. Each participating site was asked to rate at least five adults suspected of having dementia using the instrument and to provide feedback in the utility of the tool. The feedback provided included comments on wording of items, formatting, content, and utility. The eight field test sites all indicated that the NTG-EDSD was helpful in relevant data collection and was user friendly. Comments were also received from agency reviewers who, while not ‘officially’ applying the draft instrument, scrutinized it and offered suggestions. Specific comments and suggestions on wording and structure were assessed and final changes were made to the instrument at a working group meeting in December 2012.

Unlike the DSQIID, the tool upon which the NTG-EDSD was based, the instrument was not intended to provide a definitive diagnosis of dementia. The instrument was designed as a way of collecting seminal information, and recording indicators and signal behavioral markers of significant change. The purpose was to give family and professional caregivers a tool that would enable them to capture objective data on changes in function when suspicions arose and prior to making a referral for a comprehensive assessment. As such, the NTG-EDSD is regarded as an administrative rating tool and not an assessment instrument. The NTG-EDSD can also present helpful data which can be shared during the annual wellness visit under the Affordable Care Act as many agencies are looking forward to that process to help them with identifying any significant potentially neuropathologic functional and cognitive changes among the individuals whom they support. See Cordell et al. (2013) for a discussion of instruments in use with the general population for this function.

## **THE NTG-EDSD**

### **Description of the NTG-EDSD**

The NTG-EDSD is composed of four primary sections containing some 40 questions or question groupings about relevant demographics, ratings of health, mental health and life stressors, a review of multiple domains associated with adult functioning, and a review of chronic medical conditions. It also provides for a notation on the number and nature of medications being taken, and permits comments on observations to be entered. Specifically, the NTG-EDSD contains ten basic demographic items (such as identification data, personal characteristics, diagnostic, and residential setting information, eight health and function items, and the adaptation of the DSQIID (including queries as to Activities of Daily Living, Language and Communication, Sleep-Wake Change Patterns, Ambulation, Memory, Behavior and Affect, the Adult’s Self-Reported Problems, and Notable Significant Changes Observed by Others. The NTG-EDSD also contains an adapted form of the University of Illinois at Chicago’s Longitudinal Health and Intellectual Disability Survey (Rimmer & Hsieh, 2010) which is used to

note co-incident conditions (these include the following categories: Bone, Joint and Muscle; Heart and Circulation; Hormonal; Mental Health; Pain-Discomfort; Sensory; and Other). The last section of the NTG-EDSD contains an item on current medications, a place to note comments related to other notable changes or concerns, and next steps and recommendations, as well information on the form completion.

### ***Uses of the instrument***

The NTG-EDSD can be completed at any point in time on an adult with an intellectual disability. Minimally it can 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 NTG-EDSD can also be used in preparation for the annual wellness visit under the Affordable Care Act. Having concise information available for the examining physician can help instigate queries and any follow-up assessments. For recommendations on its use as part of any physician visit, see Moran et al. (2013).

The initial review using the NTG-EDSD can be accompanied by notes indicating onset of conditions. Following the initial review which would serve as a baseline, the caregiver completing the form can indicate whether there has been a change within the last year since the last review. At the point that the individual is determined to need more comprehensive assessment, a referral should be made for more comprehensive work-up that would include medical and psychological testing.

The interdisciplinary team can share ratings of “new symptoms” or “always but worse” with the health practitioner and discuss among members of the team implications for programming, personal assistance, residential placement, services and supports. With the advent of the Diagnostic Statistical Manual-5<sup>th</sup> edition (DSM-V), the health care practitioner can link documentation of change with updated criteria for the diagnosis of dementia. .

### ***Who can complete the NTG-EDSD?***

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.

### ***Useful information to have available to aid completion***

Sources such as the individual's medical record, information on living arrangement and personal functioning, as well as consensus information on functioning from other staff or family members would be highly beneficial to have on hand. A list of laboratory tests that can be useful in determining if there are medical conditions that may contribute to cognitive or adaptive changes are found in Appendix B.

### ***How to complete the form***

See Appendix A for a 'pull-out sheet' on how to respond to the items on the NTG-EDSD.

### ***How to use the information obtained from this review***

The information may be used in various ways: (1) if no signal items pop up as warranting further attention, then the form should be retained for comparison against any future administrations; (2) if select signal items begin to show, then the form can be used to begin a conversation with available clinicians to determine their relevance and immediacy for concern; (3) the information on the form can be shared with the examining physician during any health visit (and in particular during the annual wellness visit as provided for under the Affordable Care Act); and (4) the form may be shared with the agency's consulting psychologist as part of any follow-up procedures put in place specific observations for noted change areas

### ***What are some signal items?***

Signal items are those items throughout the *NTG-EDSD* that are linked to the general warning signs of MCI or early dementia, and include:

- Unexpected memory problems
- Getting lost or misdirected
- Problems with gait or walking
- New seizures
- Confusion in familiar situations
- Changes in personality

### ***Limitations***

It is important to understand that the *NTG-EDSD* is NOT a diagnostic instrument and should not be solely used to determine the presence or for the diagnosis of dementia.

### ***Areas for further development***

There is no scoring system currently associated with the use of the NTG-EDSD. This instrument provides the opportunity for a qualitative, not a quantitative review of changes that

may be associated with the types of changes in cognition and adaptive functioning observed in dementia. As the instrument gains more widespread use there would be value in collecting data linking confirmed diagnoses with results of screening. This may result in a scoring system or allow for identification of signal items most likely indicative of dementia.

### ***Versions of the NTG-EDSD***

The NTG-EDSD is currently available in English, German, Greek, and Italian language versions. Versions in Dutch, French, and Spanish are in development. See [www.aadmd.org/ntg/screening](http://www.aadmd.org/ntg/screening) for copies of available language versions.

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## **ACKNOWLEDGEMENTS**

This screening tool has had multiple permutations since development of the DSQIID by Dr. Shoumitro Deb in 2007. Thanks to Dr. Deb for his hard work in developing the DSQIID, which is still in use to assess dementia, worldwide. Thanks to Melissa DiSipio, Dr. Karl Tyler, and the team at PMHCC [Philadelphia Mental Health Care Corporation] who adapted the DSQIID in order to monitor individuals of the Pennhurst class, who were originally residents of an institution in the Philadelphia, Pennsylvania area and who now reside within the community. The work of that team in monitoring health status is still on-going and has resulted in three years of data collection. Special appreciation is extended to members of the NTG who offered input into the process and the NTG steering committee who provided input, suggestions and encouragement.

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For suggestions, comments, or more information, contact Dr. Lucille Esralew at [drlucyesralew@gmail.com](mailto:drlucyesralew@gmail.com)



**APPENDIX A: Instructions for the completion of the NTG-EDSD.**

Item #	Item Title	Comment
1	File#	For agency use
2	Date	Date form completed
3/4	Name of person	Fill in first and last name of person being screened
5	Date of birth	Provide day, month, year
6	Age	Age when form was completed
7	Sex	Indicate male or female
8	Best description of level of intellectual disability	Draw from any previously completed assessments or estimate if none ever done
9	Diagnosed condition	Draw from any previously completed assessments or estimate if none ever done
-	Current living arrangement of person	Pick most appropriate item
10	General characterization of current physical health	Pick most appropriate item
11	Compared to one year ago, current physical health is:	Pick most appropriate item
12	Compared to one year ago, current mental health is:	Pick most appropriate item
13	Conditions present	Indicate those diagnosed as well as observed
14	Significant recent [in past year] life event	Indicate those that occurred
15	Seizures	Pick most appropriate item
16	Diagnostic history	Complete this item only if the person has been formally assessed and diagnosed; use information provided in diagnostic report
17	Reported date of onset of MCI/dementia	Indicate month/year when first symptoms were noticed
18	Comments/explanation about dementia suspicions	Indicate any behaviors that triggered suspicions or referral for assessment
19	Activities of daily living	Pick most appropriate column item for each <b>'Always been the case'</b> means the need, problem or behavior has been present for a very long time <b>'Always but worse'</b> means the existing need, problem or behavior has further declined requiring more personal assistance <b>'New symptom in past year'</b> means this need, problem or behavior was not present until recently <b>'Does not apply'</b> means these needs, problems or behaviors are not present
20	Language & communication	Pick most appropriate column item for each

21	Sleep-wake change patterns	Pick most appropriate column item for each
22	Ambulation	Pick most appropriate column item for each
23	Memory	Pick most appropriate column item for each
24	Behavior and affect	Pick most appropriate column item for each
25	Adult's self-reported problems	Pick most appropriate column item for each 'Self-reported' means the adult has expressed one or more of these things
26	Notable significant changes observed by others	Pick most appropriate column item for each Assume that these are new behaviors
27	Chronic health conditions	Pick most appropriate column item for each Draw from any previously completed medical evaluations or current health notes in record
28	Current medications	This item is to help the physician or other clinician assess whether current medications may be the cause of behavioral or functional changes. Best to include a listing of current medication, with dosages, when sending or bringing form to assessment.
29	Comments related to other notable changes or concerns	Use this item to make comments of use related to behavior, function, or any events that may influence behavior
30	Next steps/recommendations	Check most relevant item
31	Date completed	Date form completed
32	Organization/agency	Name of organization providing services to the adult
-	Name of person completing form	Indicate your name
-	Relationship to individual	Indicate whether you are staff, a relative or someone else
-	Date(s) form previously completed	If the <b>NTG-EDSD</b> has been completed before, indicate when

[www.aadmd.org/ntg/screening](http://www.aadmd.org/ntg/screening)

## **APPENDIX B: Some of the laboratory and medical tests that might be used to rule out other sources of cognitive change among persons with intellectual or developmental disabilities**

1. Recent Primary Care Physician appointment/review
  - Review of existing lab results and follow up on out of range values
  - DD Diagnosis
    - Recent Blood work (within 3 months) that includes
      - Liver panel (especially if on psychotropic medications)
      - Kidney function (GFR)
      - Complete Blood Count (CBC)- to account for some causes of potential delirium) Complete Blood Count
      - Comprehensive Metabolic Panel
      - Hepatic testing
      - Renal Function Test
      - Thyroid Studies(including TSH)
      - Vitamin B 12
      - Folic Acid
      - Hormone levels in women over 30
  - Sleep Apnea ruled out
    - If sleep apnea then investigate possibility of vascular dementia
  - Specifically for people with Down Syndrome, celiac screening (total serum IgA if not done previously, and tTg)
2. Hearing/Audiology Testing
3. Electroencephalogram
4. Urinalysis
5. Chest X-Ray
6. Computerized Tomographic Scan
7. Magnetic Resonance Imaging
8. Vision Testing

Explore conditions which are likely to involve pain/discomfort (including dental pain) and put in place a pain management protocol

Explore medication side effects or interactions (pharmacist and or PCP are most likely resources)

Special thanks to Isabelle Grenon, Ph.D. and Melissa DiSipio, MSA for their assistance in compiling this list.



## I HAVE TAKEN THE NTG-EDSD....WHAT ARE THE NEXT STEPS? FROM SCREENING TO DIAGNOSIS

### Step 1: Screening

NTG-EDSD and discussion  
with primary provider

### Step 2: Assessment

Dementia Assessment Scale,  
Neuro-psych evaluation,  
CT-MRI

### Step 3: Diagnosis

Possible. Probable.  
Definitive

# { Section 5 } Medical Visits

It is important for people who have intellectual/developmental disabilities (I/DD) to have regular medical check-ups and consistent care. The Self-Directed Health Care Kit is designed to help individuals and their caregiver/support person to advocate for the best care possible while keeping thorough documentation of the person's health records. The NTG-EDSD, discussed in Section 4, is included in this health care kit.

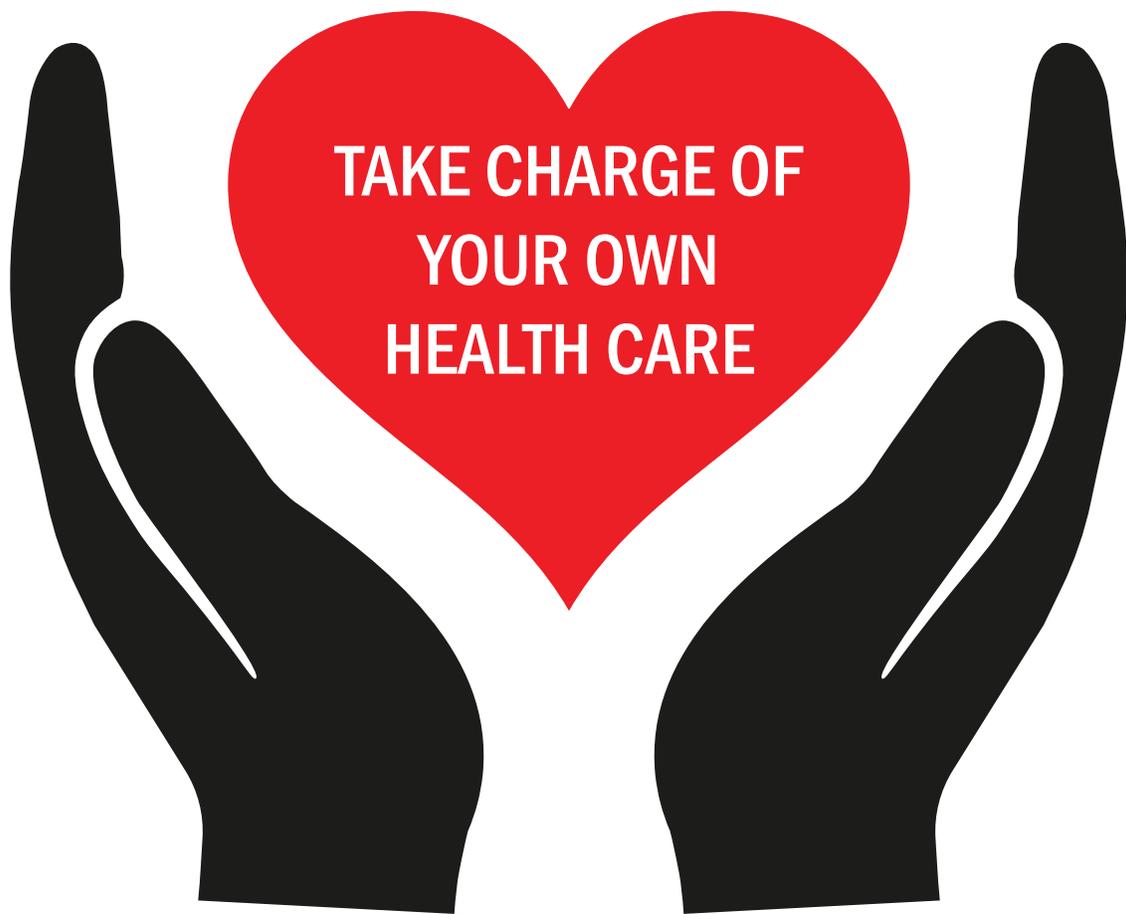
## Topics covered in this section:

- **WI Board for People with Developmental Disabilities (BPDD)**  
**Self-Directed Health Care Kit –**
- [wi-bpdd.org/index.php/bpdd-publications](http://wi-bpdd.org/index.php/bpdd-publications)





# SELF-DIRECTED HEALTH CARE KIT



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



# Self-directed Health Care Kit



**Marcia Stickel BA, BSN, RN**

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.

# 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.





# 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 \_\_\_\_\_





# 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		

### 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.*



# TODAY'S VISIT

**Complete this form and take to the health care practitioner**

Location of today's visit \_\_\_\_\_ Name of care practitioner \_\_\_\_\_

Address \_\_\_\_\_ Phone # \_\_\_\_\_

Purpose of visit \_\_\_\_\_

## Checklist of items to bring with you on appointment:

- |   |   |
|---|---|
| <input type="checkbox"/> This form completed  | <input type="checkbox"/> Health insurance card (if needed)  |
| <input type="checkbox"/> Updated medication list  | <input type="checkbox"/> Residential forms (CBRF, AFH, etc.)                                      |
| <input type="checkbox"/> Monitoring forms/charts (i.e. sleep, behavior, NTG-EDSD Tool/Screen, etc.) | <input type="checkbox"/> Something fun to do (if you have to wait i.e. book, puzzle, games, etc.) |
| <input type="checkbox"/> Summary of your medical history and medical records (if needed)            | <input type="checkbox"/> 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 I need a checkup

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.)

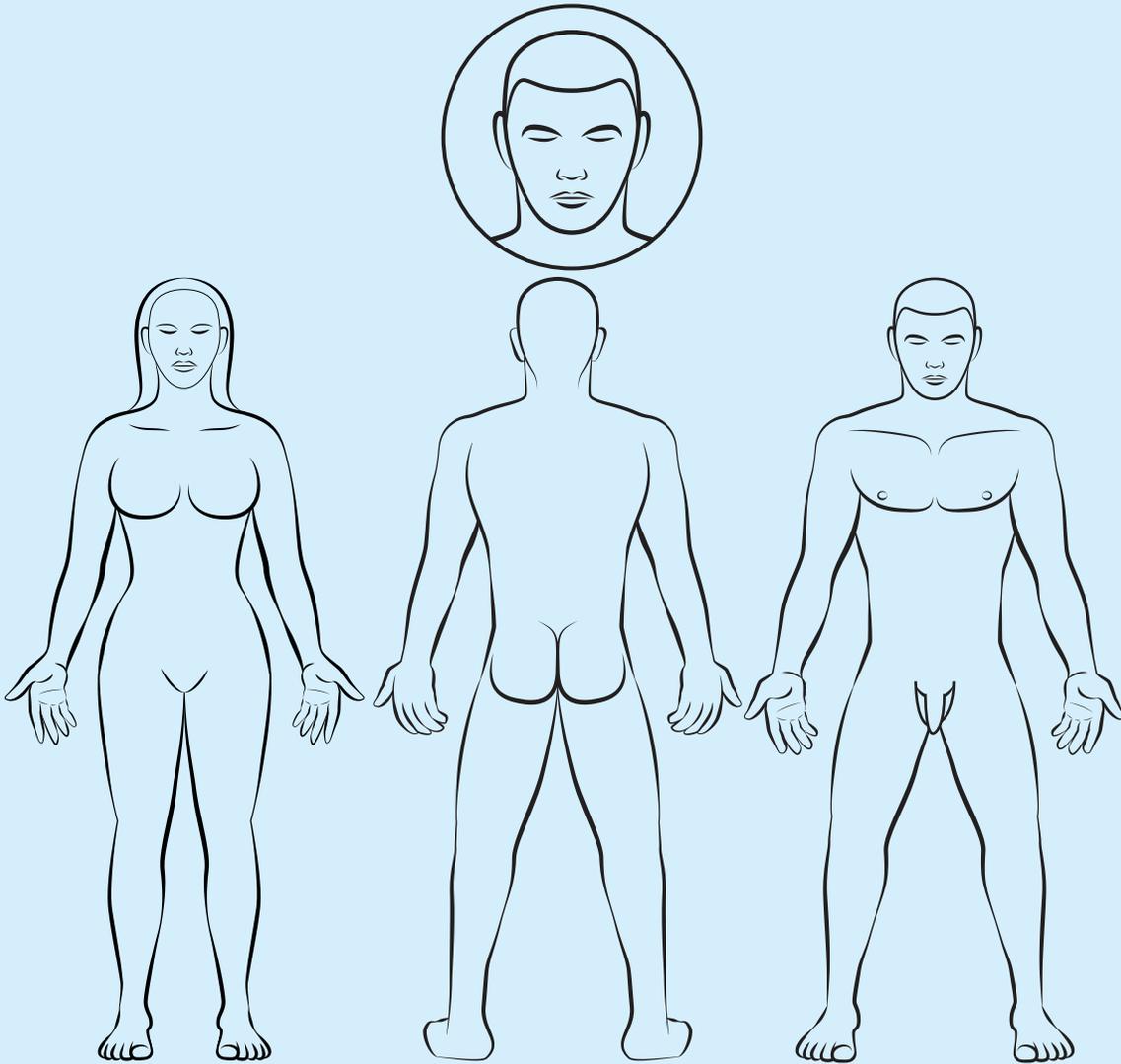
I had some recent medication changes: Yes  No

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

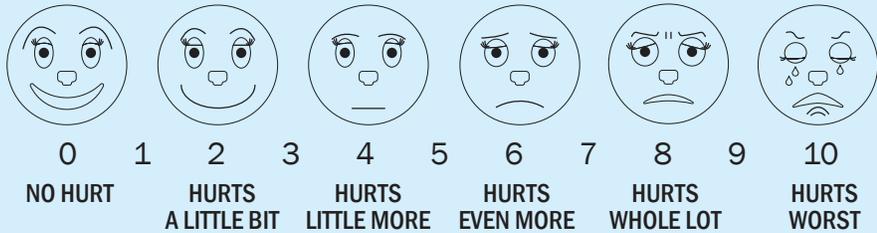
Activity level  Mobility  Sleeping habits  Bladder changes  Eating patterns  Weight change

Swallowing  Bowel changes  Other \_\_\_\_\_

**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)**



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 in the past two years (doctor, dentist, care providers, etc.):

Name \_\_\_\_\_ Location \_\_\_\_\_

Name \_\_\_\_\_ Location \_\_\_\_\_

# SUMMARY OF VISIT



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

Date \_\_\_\_\_

## 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 referrals) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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 \_\_\_\_\_





# 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 will help you understand what's going on with me, and she/he can help me do the things you want me to do when I 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		Interpreter	
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: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_





# 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 \_\_\_\_\_ Their contact is \_\_\_\_\_

Person making my medical decisions today is \_\_\_\_\_ Their contact is \_\_\_\_\_

My regular Dr is \_\_\_\_\_ Contact: \_\_\_\_\_

I have these allergies: \_\_\_\_\_ My triggers/sensitivities are: \_\_\_\_\_

### I am here because:

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

### I am currently being treated for:

<input type="checkbox"/> High blood pressure	<input type="checkbox"/> Heart problems	<input type="checkbox"/> Diabetes	<input type="checkbox"/> Cancer
<input type="checkbox"/> Bladder infection	<input type="checkbox"/> Lung/breathing problem	<input type="checkbox"/> Stomach	<input type="checkbox"/> Arthritis
<input type="checkbox"/> Seizure disorder	<input type="checkbox"/> Thyroid	Other _____	

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



#### Physically:

<input type="checkbox"/> I can push the call button	<input type="checkbox"/> I cannot push the call button		
<input type="checkbox"/> I walk unaided	<input type="checkbox"/> I walk slowly	<input type="checkbox"/> I use a walker	<input type="checkbox"/> I use a wheelchair
Other _____			



**With help I can:**

<input type="checkbox"/> Do my personal care	<input type="checkbox"/> Get in and out of bed	<input type="checkbox"/> Go to the bathroom
<input type="checkbox"/> Feed myself	<input type="checkbox"/> Take medication	

**I will need to be:**

<input type="checkbox"/> Lifted in and out of bed	<input type="checkbox"/> Fed	<input type="checkbox"/> Bathed	<input type="checkbox"/> Toileted
<input type="checkbox"/> Take medication			
Other			

**Communication:**

<input type="checkbox"/> I can speak for myself, please try to listen	<input type="checkbox"/> I cannot speak for myself			
<input type="checkbox"/> I am deaf/hard of hearing	<input type="checkbox"/> I have an interpreter			
<b>I can communicate through:</b>				
<input type="checkbox"/> Computer	<input type="checkbox"/> Gestures/facial expressions	<input type="checkbox"/> Sign language	<input type="checkbox"/> Pictures	<input type="checkbox"/> I can write things down

**Understanding:**

<input type="checkbox"/> I can understand what you say to me
<input type="checkbox"/> I like simple terms and step by step directions
<input type="checkbox"/> I may not understand what you say to me

**Special concerns and/or fears: Please tell me before you do any of these things.**

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

<input type="checkbox"/> It is hard for me to sit still
<input type="checkbox"/> I am fearful of: <input type="checkbox"/> Medical exams <input type="checkbox"/> Being touched <input type="checkbox"/> Shots
Other

**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:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# { Section 6 } Services & Supports

**Everyone can benefit from long-term health care planning.**

**F**or an individual with intellectual/developmental disabilities (I/DD), long-term health care planning is critical for quality of life. Health disparities are already a concern and, in addition, individuals with Down syndrome can begin experiencing premature aging and are at risk for diseases often 20 years earlier than the general population. Section 1 Healthy Aging addresses those disparities. The onset of Alzheimer's/dementia can also bring on a whole new set of health issues. Sudden seizures and incontinence may be just a couple of the new complications that are introduced. Advocating for the individual's care and having a plan can help ensure that the proper services and supports are in place. It may also help alleviate some of the frustrations and fear that can arise as some of the symptoms of dementia emerge. Most importantly, honoring a person's final wishes is critical to supporting the individual in their end of life stages.

## Topics covered in this section:

- **Making Important Health Care Decisions (including end of life)**
- **Choosing a Primary Support Person**
- **Service and Support Options**

**Important WI Documents:** [www.dhs.wisconsin.gov/forms/advdirectives/index.htm](http://www.dhs.wisconsin.gov/forms/advdirectives/index.htm)

- **Wisconsin Living Will:** [www.dhs.wisconsin.gov/forms/advdirectives/f00060.pdf](http://www.dhs.wisconsin.gov/forms/advdirectives/f00060.pdf)
- **Wisconsin Power of Attorney – Health Care:**  
[www.dhs.wisconsin.gov/forms/advdirectives/f00085.pdf](http://www.dhs.wisconsin.gov/forms/advdirectives/f00085.pdf)
- **Wisconsin Power of Attorney – Finance and Property:**  
[www.dhs.wisconsin.gov/forms/advdirectives/f00036.pdf](http://www.dhs.wisconsin.gov/forms/advdirectives/f00036.pdf)
- **Wisconsin Final Disposition, Funeral:**  
[www.dhs.wisconsin.gov/forms/advdirectives/f00086.pdf](http://www.dhs.wisconsin.gov/forms/advdirectives/f00086.pdf)
- **Supported Decision Making booklet:**  
[www.wi-bpdd.org/wp-content/uploads/2017/10/Supported\\_decision\\_making\\_booklet.pdf](http://www.wi-bpdd.org/wp-content/uploads/2017/10/Supported_decision_making_booklet.pdf)

<sup>1</sup> National Task Group on Intellectual Disabilities and Dementia Practices. Module 14 a-c: Stage-Based Strategies. NTG 2014. [www.aadmd.org/ntg/curriculum](http://www.aadmd.org/ntg/curriculum)

<sup>2</sup> Information and guidance provided by Marcia Stickel, Clinical Nurse Specialist – University of WI Waisman Center. See Appendix/References

<sup>3</sup> Information and guidance provided by Marcia Stickel, Clinical Nurse Specialist – University of WI Waisman Center. See Appendix/References



# Making Important Health Care Decisions

## Things to consider:



- ✓ How do I want to live out my life?
- ✓ What's important to me?
- ✓ Is it important to me to be able to communicate with others?
- ✓ Is it important to me that I still be able to take care of myself including bathing and eating?
- ✓ Do I care if I am alive by machines? Do I want life support? If yes, which ones are ok?

### Life support – medical care that can help you live longer:

- CPR/Defibrillator - cardiopulmonary resuscitation/setting up a DNR – Do Not Resuscitate - This can include: forcing air into your lungs, pressure on your chest, electrical shocks to your body (defibrillator), medicines administered into your veins
- Dialysis - when your kidneys are no longer working a machine will help replace your kidneys and clean your blood.
- Feeding Tube - A tube used to feed you that is inserted when you cannot swallow.
- Blood Transfusions - when there is a loss of blood and it is then added in your veins
- Breathing Machine/ Ventilator – A machine that pumps air into your lungs so that you can breathe. Used when a person cannot breath on their own.
- Life-saving medicines

- ✓ Is it important to me to be pain-free?
- ✓ Do I want to be kept alive with the use of medications?
- ✓ Is my religion/spirituality important to me?
- ✓ Where do I want to be when I am terminally ill?
- ✓ What happens once you pass away?

(see Wisconsin Final Disposition, Funeral document at

[www.dhs.wisconsin.gov/forms/advdirectives/f00086.pdf](http://www.dhs.wisconsin.gov/forms/advdirectives/f00086.pdf))

- Location of your last moments of life – home, nursing home, hospital, etc.
- Final disposition
- Funeral/spiritual arrangements

- ✓ When I pass away, do I want my organs donated? Which organs?
- ✓ Am I ok with having an autopsy?
- ✓ Do I want my Primary Support Person to make these decisions for me?



## Choosing a Primary Support Person

### Why does someone need a primary support person?

A primary support person can help assist with a variety of decisions including medical and financial decisions. If designated as a legal guardian, POA – Health Care and/or POA- Finance and Property, this person is especially needed and legally able to make those decisions when an individual is unable to make those decisions themselves.

### Who can be a primary support person?

- A family member
- A friend
- Someone at least 18
- Someone who can be trusted
- Someone who understands the individual well and can communicate their needs to others

### What decisions can they make?

- Decisions related to health
- Health-related care providers including: doctors, nurses, social workers, etc.
- Locations of health-related concerns including: hospitals, clinics, etc.
- Types of medical tests
- Care plan information
- Types of medications, if any
- Types of skilled care, if needed
- Decisions related to finances and estate/property



### Types of Support:

- **Natural Supports:** People that can assist an individual “naturally” with no fee. Family members, friends, and neighbors are all examples of natural supports. They can assist by: checking in on an individual, helping with supportive care (like cleaning, cooking and laundry), taking an individual to an appointment, and/or providing transportation to a place of employment. These are just a few examples. This person is not able to make decisions for an individual’s health or financial concerns.
- **Guardianship:** A legal guardian is a person who has the legal authority and duty to care for another person. Guardians are typically used in three situations: guardianship for an incapacitated senior (due to old age or infirmity), guardianship for a minor, and guardianship for developmentally disabled adults. Guardianship information for Wisconsin: <https://www.dhs.wisconsin.gov/publications/p2/p20460.pdf>



## MIND & MEMORY MATTERS

- **Power of Attorney – Health Care:** A person that is at least 18 years of age, and is considered competent, may assign someone to make health care decisions for the individual when he or she can no longer make those important decisions. Once the individual is designated as incompetent (usually by a physician) the assigned person is able to exercise the power of attorney to make those health-related, including end of life decisions.(see Wisconsin Power of Attorney – Health Care document at : [www.dhs.wisconsin.gov/forms/advdirectives/f00085.pdf](http://www.dhs.wisconsin.gov/forms/advdirectives/f00085.pdf))
- **Power of Attorney – Finance and Property:** A person that is at least 18 years of age, and is considered competent, may assign someone to make financial decisions for the individual when he or she can no longer make those important decisions. Once the individual is designated as incompetent (usually by a physician) the assigned person is able to exercise the power of attorney to make their critical financial decisions including estate/property. (see Wisconsin Power of Attorney – Finance and Property document at: [www.dhs.wisconsin.gov/forms/advdirectives/f00036.pdf](http://www.dhs.wisconsin.gov/forms/advdirectives/f00036.pdf))”



## Service and Support Options

### **Aging and Disability Resource Center (ADRC): [www.dhs.wisconsin.gov/adrc](http://www.dhs.wisconsin.gov/adrc)**

The ADRCs of Wisconsin provide a variety of resource information about services and supports for older adults and/or adults with disabilities. Staff can assist in helping people understand the long-term care options that are available, along with helping people apply for programs and benefits. Information can be provided via a visit to the local ADRC, a home visit from a staff member, or by telephone.

### **ADRCs can provide information on the following:**

- In-home personal care and nursing
- Housekeeping and chore services
- Adaptive equipment
- Health, nutrition, and home-delivered meal programs
- Medicare, Medicaid, and Social Security
- Housing options
- Home modifications
- Transportation
- Caregiver supports and respite

### **Click here to find an ADRC in your area:**

<https://www.dhs.wisconsin.gov/adrc/consumer/index.htm>

**Health Care and Coverage:** [.dhs.wisconsin.gov/health-care-coverage/index.htm](https://www.dhs.wisconsin.gov/health-care-coverage/index.htm)

**Disability Benefit Programs:** Social Security Disability Insurance (SSDI), Medicaid (MA), Medicaid Purchase Plan (MAPP)

**Medicaid Waiver programs** - most common options are Family Care and Include, Respect, I Self-direct (IRIS).

**For information about the Family Care program:** <https://www.dhs.wisconsin.gov/familycare>

**For information about the IRIS program:** <https://www.dhs.wisconsin.gov/iris>

**How to apply:** <https://www.dhs.wisconsin.gov/ddb/apply> Also see above ADRC.

**Long Term Care and Support:** For a complete list of long-term care and support options go to [www.dhs.wisconsin.gov/long-term-care-support](http://www.dhs.wisconsin.gov/long-term-care-support)

### **Memory Clinics**

The Wisconsin Alzheimer's Institute (WAI) offers a network of Memory Clinics throughout the state of WI that provide services and supports for people with symptoms of dementia. There are over 200 physicians, nurse practitioners, psychologists, social workers, and various clinical staff that provide information and care to thousands of individuals of all ethnicities and areas of the state. For more information visit the WAI website at: <http://www.wai.wisc.edu/clinics/overview>

*Other resources: See Section 10 Resources*





# { Section 7 } Safe Environment

**H** health and safety are the biggest concerns for someone caring for an individual with intellectual/developmental disabilities (I/DD) and dementia. Ensuring their environment is comfortable and safe is imperative. It can alleviate health hazards such as falls/tripping, kitchen burns, food/liquid burns, improper use of medications, and panic attacks, just to name a few. Keeping the environment comfortable should be a priority. Remember, as the individual's condition changes, his or her environment may need changing as well.

## Dementia affects:<sup>1</sup>

- **Judgment** – forgetting how to use household appliances – leaving stove on
- **Sense of time and place** – such as getting lost on one's own street
- **Behavior** – becoming easily confused, suspicious or fearful
- **Physical ability** – incontinence, having trouble with balance, walking
- **Senses** – experiencing changes in vision, hearing, sensitivity to temps or depth perception

## Topics covered in this section:

- **Safe Environment**







## Safe Environment

Safety is a top priority when caring for individuals with or without dementia. However, people with dementia will be affected by changes in behavior during different stages. Often times, their environment can be something that has created those behaviors. Dementia alters visual perception. It affects the ability to process, interpret, and respond. A lot of over-stimulation can produce emotional distress. Remember what works today may not work tomorrow. Be flexible.



**Example: An individual may no longer want to go into a room they often visited.**

- **Observe the lighting**, the level of noise (the television for example), the color of the floor/carpeting, the curtains/blinds.
- **Take a photo of the room**. Does the light from outside create stripes on the floor as it comes through the blinds?
- **If it is dark outside, it may be helpful to close the curtains/blinds**. Often times the reflections on windows can be disturbing. Sometimes people believe they see someone outside looking in. Having the curtains/blinds closed can minimize behaviors and reduce issues.
- **Mirrors may create confusion for the individual and also create the impression of an intruder**.
- **If it is the bathroom, observe the colors in the room**. Is there a lot of white? Is the toilet, sink, floors and/or walls white? It may be difficult to distinguish what is the toilet, the bath/shower, sink. Try to use contrasting colors. Coloring the toilet water may also be helpful to the person in order to identify the depth of the water. If person is beginning to refuse a shower offer a bath instead.
- **Remove loose rugs when possible**. Their visual representation can be confusing and can be a tripping hazard especially if the person is struggling with visual impairments.
- **Colors are critical throughout the home**. A white door can get lost against white walls. Using bright colors are easier to distinguish. Often pastel colors can be seen as grey.
- **Soft lighting, lighting with sensors, signs pointing to the person's bedroom/restroom can all be helpful tools**.
- **Keep all rooms calm and clutter free**.



The following are some home safety issues suggested by the National Task Group to consider:

**Evaluate your environment.** A person with dementia may be at risk in certain areas of the home or outdoors. Pay special attention to garages, work rooms, basements and outside areas where there are more likely to be tools, chemicals, cleaning supplies and other items that may require supervision.

**Avoid safety hazards in the kitchen.** Install a hidden gas valve or circuit breaker on the stove so a person with dementia cannot turn it on. Consider removing the knobs. Use appliances that have an auto shut-off feature. Keep them away from water sources such as sinks. Remove decorative fruits, sugar substitutes and seasonings from the table and counters.

**Be prepared for emergencies.** Keep a list of emergency phone numbers and addresses for local police and fire departments, hospitals and poison control helplines.

**Make sure safety devices are in working order.** Have working fire extinguishers, smoke detectors and carbon monoxide detectors.

**Install locks out of sight.** Place deadbolts either high or low on exterior doors to make it difficult for the person to wander out of the house. Keep an extra set of keys hidden near the door for easy access. Remove locks in bathrooms or bedrooms so the person cannot get locked inside.



**Keep walkways well-lit.** Add extra lights to entries, doorways, stairways, areas between rooms, and bathrooms. Use night lights in hallways, bedrooms and bathrooms to prevent accidents and reduce disorientation.

**Remove and disable guns or other weapons.** The presence of a weapon in the home of a person with dementia may lead to unexpected danger. Dementia can cause a person to mistakenly believe that a familiar caregiver is an intruder.



**Place medications in a locked drawer or cabinet.** To help ensure that medications are taken safely, use a pill box organizer or keep a daily list and check off each medication as it is taken.

**Remove tripping hazards.** Keep floors and other surfaces clutter-free. Remove objects such as magazine racks, coffee tables and floor lamps.

**Watch the temperature of water and food.** It may be difficult for the person with dementia to tell the difference between hot and cold. Consider installing an automatic thermometer for water temperature.



**Avoid injury in the bathroom. Install walk-in showers.** Add grab bars to the shower or tub and at the edge of the vanity to allow for independent, safe movement. Add textured stickers to slippery surfaces. Apply adhesives to keep throw rugs and carpeting in place or remove rugs completely.

**Improve laundry room safety.** Secure and lock all cleaning products such as detergent, liquid laundry “pods” and bleach. Prevent access to the washer and dryer. Keep emergency number for poison control posted. If possible, keep the door to this room locked.

**Assess safety hazards in the garage and/or basement.** Secure hand and power tools including equipment such as lawn mowers and weed trimmers. Keep poisonous chemicals such as gasoline, spray paint and paint thinner out of reach. Install a garage door safety sensor.

**Support the person’s needs.** Try not to create a home that feels too restrictive. The home should encourage independence and social interaction. Clear areas for activities.

# { Section 8 } Caregiving

**We cannot forget the importance of caregivers and their critical role. Caring for an older person with dementia may take an average of 4.5 years.<sup>1</sup> Caring for an individual with I/DD can take a lifetime.**

Caregiving can be provided by a close family member, a spouse, significant other, friends, or professional providers. It can come in many forms. This section covers an array of helpful caregiving tips to consider, including caregiving tips for the caregiver. Caregiver burnout and chronic health conditions are common concerns for a person who provides regular caregiving – especially when caring for a loved one. Often times, a caregiver’s own needs are no longer a priority. Feelings of frustration and added stress can, and will eventually, affect the caregiver’s health. It is imperative that the caregiver’s own health take precedence when possible.

Included in this section is a Caregiver Self-Assessment Questionnaire along with helpful handouts that provide suggestions for the caregiver. Section 3 Stages and Section 10 Resources incorporate additional caregiving information specific to the stages of dementia and links to other available resources. There are also many useful resources and guidebooks available online or at your local library.

## Topics covered in this section:

- **Caregiving**
- **Cultural Diversity and Care**
- **Caring for the Caregiver**
  - **Caregiver Self-Assessment Questionnaire**
  - **Respite**
  - **Holiday Caregiving**
  - **In-Home Health Care**



***The person with dementia is not trying to give you a hard time. They are having a hard time.***

– Dr Natali Edmonds, Careblazers



***There are only four kinds of people in the world. Those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.***

– Rosalynn Carter

<sup>1</sup> National Alliance for Caregiving & AARP, 1997



## Caregiving

It is important to understand that everyone is an individual. What the person may need or require for cares may be different than what others need or require. Also keep in mind, that what they may need for cares now will most likely change over time. Eventually, there will be a different direction in the caregiving process that will require a shift of thinking for the caregiver. Initially, we all are part of a caregiving process of encouraging growth and goal achievements such as skill building, increasing knowledge, increasing independence and being part of the community. However, when providing cares for an individual with dementia, the caregiver will eventually need to adjust their thinking of how to simply maintain a person's current functioning abilities. The focus will be on monitoring behaviors, creating a safe environment and adjusting to the person's current abilities and health concerns as they continue to change.

***Always remember to embrace the person as who they are in the moment.***

**The National Task Group (NTG) has developed extremely helpful tips for caregivers including these 5 Key Concepts to take into consideration when providing cares:<sup>1</sup>**

- 1. Maintenance Support** – This type of support refers to focusing on remaining abilities of the person while trying to reduce or eliminate difficult behaviors during all potential stages of their maintenance Support takes into consideration physical, social, communication, functional and behavioral aspects.

### Physical

- Reducing potential for fear and disorientation by modifying/adapting environment.  
*Ex. Reduce clutter, increase lighting, limit choices.*

### Social

- Use of structured, failure-free activities that avoid frustration.  
*Ex. Reminiscence, music, gardening.*

### Communication

- Increased use of body language, gestures, cueing, signs to compensate for decreased verbal skills.
- Never say “no” or argue, use redirection, enter their reality, respond to the emotion.

### Functional

- Excess disability arises due to the person's emotional reaction to disease.
- Avoid open ended questions, “chunking” – a series of short, simple commands.

### Behavioral

- Behavior is a form of communication. To change a behavior we must change our approach.
- Analyze the behavior to find underlying trigger: pain, frustration, environment, confusion.

**2. Life Story** – Everyone has a life story. Embrace the essence of the person and document their story as they continue to change over their lifespan. When the person can no longer tell their own story, the information can be shared and incorporated with their activities and care. The individual’s documented story can be especially useful when there is a change in caregivers. Types of story recordings include scrapbooks and videos of the person’s interests, hobbies, likes/dislikes and routines. *\*Note: video taping their typical tasks and routines can be helpful when monitoring changes as mentioned in Section 4 Screening Tool.*



**3. Redirection** – Redirecting a person can help avoid or delay behaviors and/or outbursts. Changing the conversation topic, providing food, drink, or rest can be all be forms of redirection. Always use a reassuring tone when offering suggestions for new activities or conversation topics. Keep in mind, activities and conversations that successfully redirect one person may not work with someone else. For example, “I need to catch the bus and get to work!” The individual is no longer employed but thinks they are. Reverting to past experiences is very common in stages of dementia. Suggested response: “Ok but first let’s have breakfast.” “It’s important to have a good meal to help you start your day.” This response can help redirect the person’s attention to eating breakfast instead of trying to leave.



- People with dementia easily pick up on body language. Relax and smile when re-directing the individual. People with dementia often experience “emotional mirroring” - picking up on other people’s emotions. Staying calm will help them stay calm.
- What works in one moment, may not work the next time - or for another person. **Everyone is an individual!**

**4. Validation** – Validation is about focusing on empathy and understanding. It is important to accept the reality and personal truth of the individual no matter how confused he or she may seem. All behavior has meaning and is an attempt to communicate. Validating someone’s feelings can help reduce stress, agitation, and need for challenging behavioral medications. Forcing a person with dementia to accept aspects of reality that he or she cannot comprehend is inappropriate and unkind to the individual. Their emotions supersede logic. For example, “Where are my glasses?” “Someone took my glasses!” Suggested response: “I can see why you are upset.” “Let’s see if they are in your drawer.” “Here they are.” “The staff probably put them in your nightstand drawer so that your glasses don’t get lost or break.”



- Telling someone not to be upset may cause them and the caregiver to be more frustrated and escalate the situation.

**5. Reorientation** – Do not try to correct or reorient the person. Remember it is their reality that they are living in – not what may actually exist. Imagine if the individual’s mother has passed away yet he or she believes that their mother is still alive. An example of their comments may be “What time is mother coming?” Suggested response: “She’ll be here in a little while.” “Let’s get a dish of ice cream while we wait.”



- Stay in their reality. Don’t argue. A person with dementia can no longer make sense of the present, and as recent memories are lost, memories of years past will become their new reality. They may even re-live past events. This is not lying – it is living in and respecting their reality. Wouldn’t you be upset if someone told you your mother was no longer alive (if you believed she was still alive)?

## Cultural Diversity and Care

Ethnically diverse communities define intellectual/developmental disabilities (I/DD) and dementia differently depending on the culture and the cultural belief system's definition of disability and disease. Some signs, symptoms and behavioral changes may be seen as normal depending on the culture. Myths and attitudes about aging can delay or prevent diagnosis and treatment. Dementia may be seen as mental illness or "craziness in the family" and the stigmas that come with it. Few still believe it is a curse or punishment for bad behavior. Those with less education are less likely to seek out services or resources on dementia. The more isolated from the regional mainstream culture, the increased likelihood the ethnic community will maintain its own beliefs and practices.



Respect for elders may also result in a tendency to not mention the functioning loss or bring the symptoms to provider's attention. Some cultures believe in "taking care of their own" and their lack of trust results in reluctance to seek outside help.

Language can be a challenge when there is not an exact term to translate the type of dementia to and from English. It may not be recognized by a specific culture because there is no term to refer to the specific disability.

For some, the concept of supportive services is not understood or used. Often, people of diverse communities have difficulty finding service providers that speak the same language. Many supportive services do not understand diverse cultures.

### Ten steps to providing culturally sensitive dementia care (NTG):<sup>1</sup>

1. Consider each person as an individual, as well as a product of their country, religion, ethnic background, language, and family system.
2. Understand the linguistic, economic and social barriers that individuals from different cultures face, preventing access to healthcare and social services. Try to provide services in a family's native language.
3. Understand that families from different cultures consider and use alternatives to Western healthcare philosophy and practice.
4. Do not place everyone in a particular ethnic group into the same category, assuming that there is one approach for every person in the group.
5. Respect cultural differences regarding physical distance and contact, appropriate eye contact, and rate and volume of voice.
6. Cultivate relationships with families over time, not expecting immediate trust in and understanding of resources such as the Alzheimer's Association.
7. Consider the family's background and experience in determining what services are appropriate.
8. Consider the culture's typical perceptions of aging, caring for elderly family members and memory impairment.
9. Understand that a family's culture impacts their choices regarding ethical issues, such as artificial nutrition, life support and autopsies.
10. Regard the faith community for various cultures as a critical support system.

<sup>1</sup> National Task Group on Intellectual Disabilities and Dementia Practices. Module 14 a-c: Stage-Based Strategies. NTG 2014. [www.aadmd.org/ntg/curriculum](http://www.aadmd.org/ntg/curriculum)

## Caring for The Caregiver

Caregivers play a critical role in our society. Those who care for an adult child with intellectual/developmental disabilities (I/DD) have unique challenges versus those who care for an older family member. While caring for an older family member may average 4.5 years, it is a life time commitment – possibly 60 or more years – for a parent with a child with I/DD<sup>1</sup>. Individuals with I/DD are living longer and enjoying a similar life expectancy as the general population. As this population ages, they are now routinely outliving their parents. Individuals with moderate to severe I/DD can expect to live into their late 60s. Keep in mind, as mentioned in Section 1 Healthy Aging, individuals with Down syndrome, as they age, can show health disparities 20 years earlier than the general public.<sup>2</sup>

Caregivers often show concerns about: inadequate help, being stressed, tired, and putting their own priorities and personal interests on hold. Often caregivers are also managing cares for an additional family member and are known as “compound caregivers”.<sup>3</sup> This can create an additional heavy toll on the well-being and health of the caregiver themselves. In 2010, Brent Fulton from the University of California – Berkeley discovered that caregivers are spending approximately 8 percent more on health care than non-caregivers.<sup>4</sup> The Alzheimer’s Association recently announced that the physical and emotional impact of caregiving has resulted in over \$10 billion in health care costs in the U.S. alone. Therefore, it is important for caregivers to take care of themselves and avoid caregiver burnout along with short-term and/or long-term chronic health conditions.



Included in this section is a **Caregiver Self-Assessment Questionnaire**. Results from the assessment can help caregivers look at their own vulnerabilities and possible risks. This tool is available electronically, in a downloadable form, and in multiple languages. Like the NTG-EDSD, it can be a helpful tool for a healthcare provider. As a team, the caregiver and their provider can work together to create a healthy plan in order to help avoid stress and burnout and potential chronic health conditions.

The **Caregiver Self-Assessment Questionnaire** along with additional resources and tools for caregivers can be found at: [www.healthinaging.org/news/tip-sheets](http://www.healthinaging.org/news/tip-sheets)

<sup>1</sup> National Alliance for Caregiving & AARP, 1997.

<sup>2</sup> National Task Group on Intellectual Disabilities and Dementia Practices. Module 14 a-c: Stage-Based Strategies. NTG 2014. [www.aadmd.org/ntg/curriculum](http://www.aadmd.org/ntg/curriculum)

<sup>3</sup> Perkins, E. A. (2011). Compound caregivers: overlooked and overburdened [White paper]. Tampa, Florida: University of South Florida, Florida Center for Inclusive Communities.

<sup>4</sup> Schreiber, M.J., Breitenbucher, C. (2017). My Two Elaines: Learning, Coping, and Surviving as an Alzheimer’s Caregiver. Bothell, WA. Book Publishers Newark.

# Caregiver Self-Assessment Questionnaire

## How are YOU?

Caregivers are often so concerned with caring for the relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have ...

- |  |  |   |  |
|--|--|---|--|
| 1. Had trouble keeping my mind on what I was doing....                           | <input type="checkbox"/> Yes <input type="checkbox"/> No | 13. Had back pain.....  | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2. Felt that I couldn't leave my relative alone.....                             | <input type="checkbox"/> Yes <input type="checkbox"/> No | 14. Felt ill ( <i>headaches, stomach problems or common cold</i> ).....   | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3. Had difficulty making decisions.....  | <input type="checkbox"/> Yes <input type="checkbox"/> No | 15. Been satisfied with the support my family has given me.....   | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 4. Felt completely overwhelmed.....  | <input type="checkbox"/> Yes <input type="checkbox"/> No | 16. Found my relative's living situation to be inconvenient or a barrier to care.....   | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 5. Felt useful and needed .....  | <input type="checkbox"/> Yes <input type="checkbox"/> No | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress.                        | _____  |
| 6. Felt lonely.....  | <input type="checkbox"/> Yes <input type="checkbox"/> No | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. | _____  |
| 7. Been upset that my relative has changed so much from his/her former self..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |   |  |
| 8. Felt a loss of privacy and/or personal time.....                              | <input type="checkbox"/> Yes <input type="checkbox"/> No |   |  |
| 9. Been edgy or irritable.....   | <input type="checkbox"/> Yes <input type="checkbox"/> No |   |  |
| 10. Had sleep disturbed because of caring for my relative.....                   | <input type="checkbox"/> Yes <input type="checkbox"/> No |   |  |
| 11. Had a crying spell(s).....   | <input type="checkbox"/> Yes <input type="checkbox"/> No |   |  |
| 12. Felt strained between work and family responsibilities...                    | <input type="checkbox"/> Yes <input type="checkbox"/> No |   |  |

### Comments:

*(Please feel free to comment or provide feedback.)*

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## Plan Ahead to Make the Most of Your Respite Time

Respite is a short period of time that helps you, as a caregiver, take a break from the stress that can come along with providing care to a loved one. It is a temporary relief that allows you to “recharge your battery” while avoiding burnout. These suggestions below are to help you plan to get the most out of respite time. This is your time - use your imagination, relax and have fun!

### Take a day trip

If you are comfortable with your loved one’s caregiver – spend the day away!

- Dig your toes in the sand and relax at the beach
- Travel to another city and explore the area
- Visit family or reminisce with old friends
- Take in a concert, museum, art gallery, or Broadway show and enjoy a nice lunch
- Seek some thrills by checking into an amusement or water park with friends or other family members
- Escape to another world by listening to an audio book on a long drive

### Go out on the town

For a few hours while a caregiver looks after your loved one at home, consider:

- Catching the latest movie that’s just been released
- Enjoying some peace and quiet while spending an afternoon at the library
- Pampering yourself with a relaxing massage and/or a manicure and pedicure
- A lovely dinner at a restaurant with your spouse, friends, or family
- Going shopping! Browse around your favorite store or treasure hunt a local garage sale
- Taking a long walk - breathing in the fresh air, observing all the sounds and surroundings
- A school play or concert and delight in your family members’ talents and performances
- Attending a church service, a meditation center, synagogue or other spiritual space
- Taking a seat at a local baseball game. Don’t forget the peanuts and Cracker Jacks!



### Staying home

You can get temporary relief even if you stay home. A caregiver can spend time with your loved one in another room while you:

- Relax with a favorite movie and/or video and enjoy with some hot buttered popcorn
- Take a long bath by candlelight or a long, soothing, hot shower and a nap
- Spend time in the garden and/or tinker with a favorite hobby
- Giggle and play with your children/grandchildren outside in the summer’s green grass or the fresh fallen snow
- Create a favorite recipe with your spouse or a friend and enjoy a cozy dinner for two
- Snuggle up with a blanket and a warm cup of coffee or tea. Dive into a book, complete a crossword/puzzle, or catch up on the latest in your favorite newspaper or magazine



## Caregiving Through the Holidays

Holidays can be meaningful, enriching times for both the person with dementia and his or her family. Maintaining or adapting family rituals and traditions helps all family members feel a sense of belonging and family identity. For a person with dementia, this link with a familiar past is reassuring. The tips below can help you and the person with dementia visit and reconnect with family, friends, and neighbors during holidays.

### Finding the Right Balance

Many caregivers have mixed feelings about holidays. They may have happy memories of the past, but they also may worry about the extra demands that holidays make on their time and energy.

Here are some ways to balance many holiday-related activities while taking care of your own needs and those of the person with dementia:

- Celebrate holidays that are important to you. Include the person with dementia as much as possible. Also find time for holiday activities you like to do. Accept invitations to celebrations even if the person with dementia is unable to attend. Ask a friend or family member to spend time with the person while you're out.
- Set your own limits, and be clear about them with others. You do not have to live up to the expectations of friends or relatives. Your situation is different now.
- Involve the person with dementia in simple holiday preparations, or have him or her observe your preparations. Observing you will familiarize him or her with the upcoming festivities. Participating with you may give the person the pleasure of helping and the fun of anticipating and reminiscing.
- Encourage friends and family to visit even if it's difficult. Limit the number of visitors at any one time, or have a few people visit quietly with the person in a separate room.
- Photos are an excellent connection to the past and to your guests. Help make that connection by reviewing photos with the guests the day they are visiting. Also, if the person with dementia becomes upset or overstimulated, the family photo albums can help as a quiet distraction for the individual.
- Try to avoid situations that may confuse or frustrate the person, such as crowds, changes in routine, and strange places. Also try to stay away from noise, loud conversations, loud music, lighting that is too bright or too dark, and having too much rich food or drink.



## Preparing Guests

Explain to guests that the person with dementia does not always remember what is expected and acceptable. Give examples of unusual behaviors that may take place such as incontinence, eating food with fingers, wandering, or hallucinations.

- If this is the first visit since the person has become severely impaired as a result of dementia, tell guests that the visit may be painful. The memory-impaired person may not remember guests' names or relationships but can still enjoy their company.
- Explain that memory loss is the result of the disease and is not intentional.
- Stress that the meaningfulness of the moment together matters more than what the person remembers. Focus on the essence of who the person is now and what chapter they are now living in their life.
- Some key communication tips to consider:
  - Keep questions simple – possibly to yes or no answers
  - Do not try to reason or argue
  - Loud voices can be interpreted as angry
  - Stay calm – body language is important

## Preparing the Person with Dementia

Here are some tips to help the person with dementia get ready for visitors:

- Keep the memory-impaired person's routine as close to normal as possible. Structure and routine is important.
- During the hustle and bustle of the holiday season, guard against fatigue and find time for adequate rest.
- Provide physical and mental activities the person can do.
- Support the person's dignity and self-esteem at all times.



## Hiring an In-Home Caregiver

Hiring an in-home caregiver can provide many benefits for both your loved one and for you, as a family caregiver. It can allow you to maintain your relationship with the person as a family member while your loved one receives the proper care that he or she needs. It may also free up your time to have a job, complete tasks or run errands, explore hobbies, or even enjoy some rest and relaxation. Having an in-home caregiver not only frees up some of your time for your own needs, it also minimizes your risk for injury and stress-related illnesses.

### Assess what is needed for everyone

Prior to hiring, think about what type of help is needed. Here are some examples to consider:

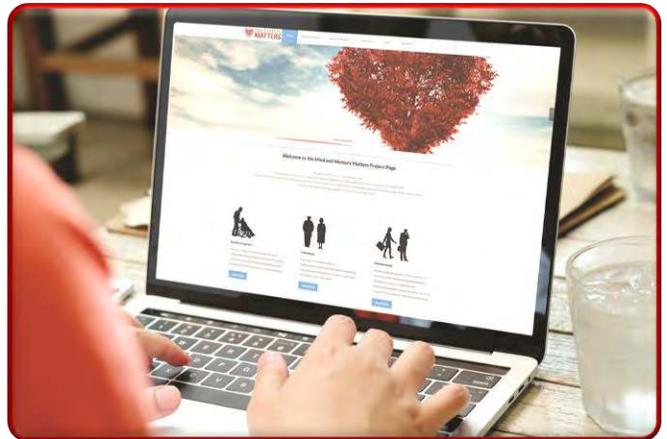
- **Supportive care:** Assistance with laundry, cooking, cleaning or other household tasks
- **Personal care:** Assistance with medications, bathing, dressing and toileting
- **Companionship and miscellaneous activities:** Car rides, visits to places of interest for the loved one, appointments, run errands

### Directly hiring an in-home caregiver

Do you want to directly hire an in-home caregiver? Maybe you know a family member, friend, acquaintance, or someone that was referred to you and has experience in the type of in-home cares that are needed.

**Here are some questions you may want to consider:**

- Why are you interested in this position?
- Where have you worked before? What were your duties?
- Do you provide cares for others?
- Describe your experience making meals for other people.
- How do you handle working with someone living with memory problems? Give an example.
- How do you handle people who are angry, stubborn and/or fearful?
- What is your experience transferring someone out of bed or chair and into a wheelchair?
- Do you have a car? Would you prefer to drive your own car or our car in transporting? (Ask for proof of insurance and a current driver's license.)
- Is there anything in the job description that you are uncomfortable doing?
- What is your availability? Days? Hours? Do you have any upcoming vacations planned?
- Can you give me two work-related and one personal reference I can contact? (Also ask for ID that verifies the individual can work in this country – make a copy)



## Hiring From an In-Home Health Care Agency

There are benefits to hiring from an in-home health care agency. Some things to consider:

- An agency can handle the responsibilities of hiring including background checks, payroll, training, staff replacement (staff no-show, illness, time off), and Medicaid billing
- Agencies will pay a different rate depending on the type of care needed, number of hours, type of shift (day, night), certification/education
- Do you have a long-term care insurance policy? Do they accept long-term care insurance?
- Consult with your accountant - fees you've paid for caregiving may be tax deductible
- Is your loved one eligible for a long-term care program such as Medicaid? Often services can be paid for by one of Wisconsin's programs. Check with your county ADRC (see below).

## Looking for an agency?

- Check with friends, family, your physician, and/or other clinical staff
- Ask your county Aging and Disability Resource Center(ADRC) staff: [www.dhs.wisconsin.gov/adrc](http://www.dhs.wisconsin.gov/adrc)
- The Wisconsin Department of Health Services provides well-rounded specifics on in-home health care agencies: [www.dhs.wisconsin.gov/regulations/hha/introduction](http://www.dhs.wisconsin.gov/regulations/hha/introduction)

## Questions you may want to consider when hiring from an in-home health agency:

- How long has the agency been in business? Is it part of a larger corporation?
- What qualifications, certifications, and/or experience do the agency's caregivers have?
- Are the caregivers insured and bonded and is workers' compensation in place?
- How does the agency supervise the care and visits of caregivers?
- Will there be consistency with the caregivers who provide the care? Is there backup coverage?
- Does the agency conduct a home visit before starting the case?
- Does the agency offer the opportunity to meet potential caregivers prior to receiving the service?
- Does the agency conduct national and local criminal background checks and driving records of all employees? How often?
- Does the agency provide personal cares, supportive cares, and/or companionship services?
- Does the agency provide on-going training for their caregivers? If so what kind and how often?
- What is their rate for services and billing practices? Do they accept Medicare, Medicaid and/or other long-term care insurance?
- Consider other questions you may have specific to your needs and your loved one's needs

Keep in mind you may need to start slow with someone new coming into the house. Your loved one may not like the idea of a stranger assisting. Sometimes it helps if you tell your loved one that the person is there to help you, the caregiver. They are often more willing to accept caregiving if it is for someone they care about and not specifically for their own needs. The agency may also have suggestions on how to help with this transition.

# { Section 9 } Research

**R**esearch is helpful in finding solutions. In health care, it can be the fastest way to discover useful information and contribute to improving people's lives. We all can play a role in helping improve healthcare for everyone. As mentioned earlier in this guide book, there is little training and education on intellectual/developmental disabilities (I/DD), along with the lack of research.<sup>1</sup> According to the Banner Alzheimer's Institute (BAI), 80% of Alzheimer's disease research studies are delayed because of too few participants.<sup>2</sup> While there is no cure for Alzheimer's disease, there are organizations that provide continual opportunities to participate in research in hopes of finding a cure including: the Alzheimer's Association, Johns Hopkins University, the Mayo Clinic, Cleveland Clinic and the Banner Alzheimer's Institute (BAI). To find out more information or to participate in any of these studies go to: [www.endalznow.org](http://www.endalznow.org).

## Topics covered in this section:

### Research participation opportunities:

- The Waisman Center
- Wisconsin Registry for Alzheimer Prevention (WRAP)
- Other Research



<sup>1</sup> National Task Group on Intellectual Disabilities and Dementia Practices. Module 14 a-c: Stage- Based Strategies. NTG 2014. [www.aadmd.org/ntg/curriculum](http://www.aadmd.org/ntg/curriculum)

<sup>2</sup> The Banner Alzheimer's Institute (BAI). Alzheimer's Prevention Registry. [www.endalznow.org](http://www.endalznow.org). 2018



## The Waisman Center Research

The Waisman Center at the University of Wisconsin-Madison and the University of Pittsburgh Medical Center are seeking adults (ages 30 and above) with Down syndrome to participate in a research study involving an MRI and a PET scan.

The study will consist of two visits which can be completed during a single, two-day stay in Madison. The first visit will take at least 4 hours and includes describing the study, reviewing the procedures of the MRI and PET scan via video and pictures. The second visit will take around 4 hours and includes an MRI which will take approximately 30 minutes, and a PET scan which will take approximately 1 hour. In addition, a blood sample will be drawn.

Participants will be compensated for their time and expenses. Funds are available for participants and caregivers to stay overnight. This will allow the two study visits to be completed over two consecutive days.

**For the Madison site please call  
Renee Makuch at the Waisman Center,  
University of Wisconsin-Madison  
(608-262-4717 or toll-free at 1-877-558-7595)  
if you would like additional information.**

<http://www.waisman.wisc.edu/amyloid/>

<http://www.waisman.wisc.edu/PIR-studies-ds.htm>



# Wisconsin Registry for Alzheimer's Prevention (WRAP)

The main goal of WRAP is to understand the factors (biological, medical, environmental, and lifestyle choices) that increase a person's risk of developing Alzheimer's disease. This is a first step in developing interventions that may protect against developing Alzheimer's disease.

**WRAP** is an observational study that is tracking the characteristics and habits of two important groups of volunteers

- people who have one or both parents with Alzheimer's disease (the family history group), and;
- people whose parents lived to old age with no signs of Alzheimer's disease or other serious memory problems (the control group).

**Participation in WRAP includes** an initial study visit and follow-up visits every 2 to 4 years. At each visit, study volunteers are asked to:

- Complete questionnaires about their background, medical history, and lifestyle habits such as exercise or diet.
- Have height, weight and vital signs such as blood pressure measured.
- Complete cognitive tests to check memory, attention and other cognitive skills.
- Give a blood sample for laboratory testing.
- Provide stored blood samples for use in future analyses, including genetic analyses.

Participants in WRAP are eligible to participate in research studies at the Wisconsin Alzheimer's Disease Research Center.

**For more information:**

**<https://www.wai.wisc.edu/research/wrap.html>**

**Toll-free: 1-800-417-4169**

Frequently Asked Questions: [http://www.wai.wisc.edu/research/wrap\\_faq.html](http://www.wai.wisc.edu/research/wrap_faq.html)

## OTHER RESEARCH

### Wisconsin Alzheimer's Institute (WAI)

The Wisconsin Alzheimer's Institute (WAI) is an academic center within the University of Wisconsin School of Medicine and Public Health. WAI promotes education, training, program development and research directed at improving our understanding of how to treat and prevent Alzheimer's disease.

WAI is currently recruiting for the Wisconsin Registry for Alzheimer's Prevention (WRAP), which will consist of 700 adult children of persons diagnosed with Alzheimer's disease and 150 people whose parents did not have Alzheimer's disease. WRAP will support genetic, epidemiological and clinical studies designed to identify those factors which may delay or prevent the onset of Alzheimer's disease. To find out more about the program or eligibility requirements, contact the WAI at **800.417.4169** or **608.263.2862**, or email them at **waimail@mailplus.wisc.edu**



### National Institutes of Health

In November 2015, the National Institutes of Health launched a \$37 million initiative to identify biomarkers in the blood and brain that can help identify and track Alzheimer's in people with Down syndrome. The Alzheimer's Association, the Linda Crnic Institute for Down Syndrome and the nonprofit Global Down Syndrome Foundation convened scientific workshops addressing Alzheimer's and Down syndrome, and are funding efforts to develop a blood test able to detect who is at high risk for developing Alzheimer's.



National Institutes of Health

You can find a complete list of Alzheimer's trials involving people with Down syndrome at <https://www.nia.nih.gov/alzheimers/clinical-trials>.

### About Alzheimer's Association TrialMatch®

Alzheimer's Association TrialMatch is a free, easy-to-use clinical studies matching service that connects individuals with Alzheimer's, caregivers, healthy volunteers and physicians with current studies. Our continuously updated database of Alzheimer's clinical trials includes more than 250 promising clinical studies being conducted at over 700 trials sites across the country.



### The Wisconsin Alzheimer's Disease Research Center (W-ADRC)

of the University of Wisconsin School of Medicine and the Geriatric Research, Education and Clinic Center (GRECC) of the Madison VA Medical Center, works on identifying new treatment strategies for Alzheimer's disease, investigates the processes which occur in the brain compared to normal aging, and looks for effective prevention strategies.



Wisconsin Alzheimer's  
Disease Research Center  
UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH

Multiple research studies are being conducted that examine potential treatments for Alzheimer's disease and other types of memory problems as well as how to prevent memory decline and dementia. If you or someone you know might be interested in participating, call **866.636.7764** or contact them by email at **adrc@medicine.wisc.edu**.

## Dean Foundation

The Dean Foundation often conducts clinical research studies for those with Alzheimer's disease. For a list of current research studies go to <http://www.deancare.com/patients/clinical-trials/clinical-trials-search-results/?termId=b727e823-23e1-df11-9c3f-001d0934ebc8> or contact them at **608.827.2333** or **800.844.6015**.



## Children's Hospital of Wisconsin

Doctors and researchers at Children's Hospital of Wisconsin are working hard to further research on these conditions and others, and your family's participation in research could help us improve outcomes for other children with Down syndrome. Every study is reviewed by the hospital's Institutional Review Board to make sure that it is safe and ethical. Current research studies include Down Syndrome and Alzheimer's Disease (adults 30 and older). **Contact Renee Makuch at (608) 262-4717** or by **email [makuch@waisman.wisc.edu](mailto:makuch@waisman.wisc.edu)** <http://www.chw.org/medical-care/down-syndrome-clinic/research-in-down-syndrome/>



# { Section 10 } Resources

Throughout this guide book, a variety of worthwhile resources have been mentioned. This section includes a list of additional resources that may be useful for individuals with intellectual/developmental disabilities (I/DD) and their caregivers. The internet and local libraries can also provide information at no cost. The Community Conversation Tool Kit can be particularly beneficial when establishing an I/DD and dementia support and/or coalition group. These supportive groups are popping up locally, nationally, and internationally. Families (and professionals) have found these groups to be an exceptional way to gain information, network, and receive unique support and reassurance. Most importantly, included in this section, are stories of families, caregivers and professionals whose lives have been touched by I/DD and dementia. These intimate conversations are relatable to some, informative to others, and can be beneficial to all.

## Topics covered in this section:

- **Additional Resources**
- **Community Conversation Tool Kit**
- **Videos of individual, family, and caregiver stories**



**Click for Anne's video**  
<https://youtu.be/jcJ79QxsYCE>

**Click for Carol's video**

<https://youtu.be/TGwFrwNZ7rw>



**Click for Ronnie's video**  
[https://youtu.be/2B6Sr\\_y0878](https://youtu.be/2B6Sr_y0878)



**Marcia Stickel,**  
Clinical Nurse Specialist –  
University of WI Waisman Center  
with Andrea Gehling, Support Broker –  
Avenues to Community

**Click for Marcia and Andrea's video**  
<https://youtu.be/dhvcnozSvUs>



**Click for Cindy's video**  
<https://youtu.be/UG7tBLOAEsY>



## Additional Resources

 <p>MIND &amp; MEMORY <b>MATTERS</b></p>	<p><a href="http://www.MindandMemory.org">www.MindandMemory.org</a></p>
	<p>WI Board for People with Developmental Disabilities (BPDD) – <a href="http://www.wi-bpdd.org">www.wi-bpdd.org</a></p>
 <p>Wisconsin Department of Health Services</p>	<p>WI Department of Health Services <a href="http://www.dhs.wisconsin.gov">www.dhs.wisconsin.gov</a></p>

## Alzheimer’s Disease Initiative – Specialized Supportive Services (ADI-SSS) grant partners:

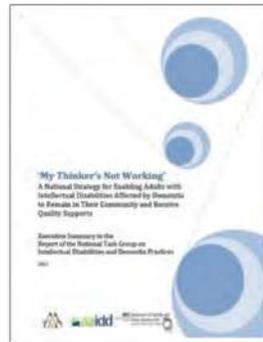
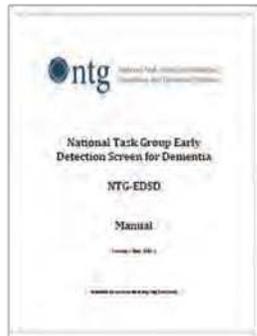
	<p>Wisconsin Alzheimer’s Institute - <a href="http://www.wai.wisc.edu">www.wai.wisc.edu</a></p>
	<p>The Waisman Center - <a href="http://www.waisman.wisc.edu">www.waisman.wisc.edu</a></p>
	<p>The Greater Wisconsin Agency on Aging Resources, Inc. - <a href="http://www.gwaar.org">www.gwaar.org</a></p>
	<p>University of WI – Oshkosh - <a href="http://www.uwosh.edu">www.uwosh.edu</a></p>
	<p>Alzheimer’s Association Greater Wisconsin Chapter - <a href="http://www.alz.org/gwwi">www.alz.org/gwwi</a></p>

# Additional Support and Information

	<p>Local/County Aging and Disability Resource Center (ADRC) - <a href="https://www.dhs.wisconsin.gov/adrc/index.htm">https://www.dhs.wisconsin.gov/adrc/index.htm</a></p>
	<ul style="list-style-type: none"> <li>• Bad River Band of the Lake Superior Tribe of Chippewa Indians</li> <li>• Forest County Potawatomi Community</li> <li>• Ho-Chunk Nation</li> <li>• Lac Courte Oreilles Band of Lake Superior Chippewa Indians of Wisconsin</li> <li>• Lac du Flambeau Band of Lake Superior Chippewa Indians</li> <li>• Menominee Indian Tribe of Wisconsin</li> <li>• Oneida Nation</li> <li>• Red Cliff Band of Lake Superior Chippewa Indians</li> <li>• St. Croix Chippewa Indians of Wisconsin</li> <li>• Sokaogon Chippewa Community</li> <li>• Stockbridge-Munsee Community</li> </ul>
	<p>NTG Tool &amp; Guidelines <a href="http://www.aadmd.org/ntg">www.aadmd.org/ntg</a></p>
<p>Special Olympics Wisconsin - healthy athletes - <a href="http://www.SpecialOlympicsWisconsin.org">www.SpecialOlympicsWisconsin.org</a></p>	
<p>Epilepsy Foundation Heart of WI - <a href="http://www.epilepsywisconsin.org">www.epilepsywisconsin.org</a></p>	
<p>Alzheimer's and Dementia Alliance of WI - <a href="http://www.alzwisc.org">www.alzwisc.org</a></p>	
<p>Down Syndrome Association of WI, Inc - <a href="http://www.dsawfamilyservices.org">www.dsawfamilyservices.org</a></p>	
<p>Autism Society of WI - <a href="http://www.asw4autism.org">www.asw4autism.org</a></p>	
<p>Autism Society of Wisconsin Resource Guide - <a href="http://www.asw4autism.org/resource_directory.html">http://www.asw4autism.org/resource_directory.html</a></p>	
<p>Traumatic Brain Injury of WI - <a href="http://www.traumaticbraininjury.com/injury-resources/state-resources-for-tbi/wisconsin/">www.traumaticbraininjury.com/injury-resources/state-resources-for-tbi/wisconsin/</a></p>	
<p>Alzheimer's Association - <a href="http://www.alz.org">www.alz.org</a></p>	
<p>Global Down Syndrome Foundation - <a href="http://www.globaldownsyndrome.org">http://www.globaldownsyndrome.org</a></p>	
<p>National Down Syndrome Congress - <a href="http://www.ndscenter.org">www.ndscenter.org</a></p>	
<p>National Autism Society - <a href="http://www.autism-society.org">www.autism-society.org</a></p>	
	<p>The National Alzheimer's and Dementia Resource Center <a href="https://nadrc.acl.gov/">https://nadrc.acl.gov/</a> The National Alzheimer's and Dementia Resource Center Guides <a href="https://nadrc.acl.gov/node/96">https://nadrc.acl.gov/node/96</a> <b>Guides include:</b></p> <ul style="list-style-type: none"> <li>• Financial planning (user-friendly and written for people with dementia);</li> <li>• Health care planning (user-friendly and written for people with dementia);</li> <li>• Planning for daily care needs (user-friendly and written for people with dementia); and</li> <li>• Making financial and health care decisions for someone with dementia (written for family members).</li> </ul>

## Tools and guidebooks

WI Board for People with Developmental Disabilities (BPDD) Supported Decision Making booklet and Self-Directed Health Care Kit along with other resources – [www.wi-bpdd.org/index.php/bpdd-publications](http://www.wi-bpdd.org/index.php/bpdd-publications)



National Task Group-Early Detection Screening Device (NTG-EDSD) and manual - [www.aadmd.org/ntg/products](http://www.aadmd.org/ntg/products)

“My Thinker’s Not Working” [www.aadmd.org/ntg/thinker](http://www.aadmd.org/ntg/thinker)

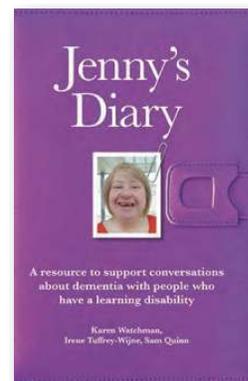
“Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia” [www.aadmd.org/ntg/practiceguidelines](http://www.aadmd.org/ntg/practiceguidelines)



Down’s Syndrome Scotland <https://www.dsscotland.org.uk/resources/publications/for-parents-of-adults/> Resources including: “Let’s Talk about Diet, Weight & Exercise”, “Let’s Talk about getting older”, “Living with Dementia” (environment, eating, nighttime challenges), “Let’s Talk about Dementia”, “Let’s Talk about Death”.



National Down Syndrome Society - [www.ndss.org](http://www.ndss.org) Resource “Aging and Down Syndrome Health and Well-Being Guidebook”



Jenny’s Diary [www.uws.ac.uk/jennysdiary](http://www.uws.ac.uk/jennysdiary)



## Eunice Kennedy Shriver Center

UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL

Eunice Kennedy Shriver Center –

University of Massachusetts Medical School

Aging with Intellectual and Developmental Disability Trainings: Aging and End of Life

- [http://shriver.umassmed.edu/cdder/aging\\_idd\\_education](http://shriver.umassmed.edu/cdder/aging_idd_education)
- Dementia and IDD: [http://shriver.umassmed.edu/cdder/aging\\_idd\\_education/dementia-and-idd](http://shriver.umassmed.edu/cdder/aging_idd_education/dementia-and-idd)
- Launching a Memory Café: [http://shriver.umassmed.edu/cdder/aging\\_idd\\_education/launching-a-memory-cafe](http://shriver.umassmed.edu/cdder/aging_idd_education/launching-a-memory-cafe)
- Memory Café Toolkit: <http://www.jfcsboston.org/Our-Services/Older-Adults/Alzheimers-Related-Disorders-Family-Support/Memory-Caf%C3%A9-Toolkit>



U.S. Department of Health & Human Services - <https://www.nia.nih.gov/health/end-of-life>



# COMMUNITY CONVERSATION TOOLKIT





# MIND & MEMORY MATTERS

## Community Conversation

### PERMISSION TO PARTICIPATE, PRODUCE AND USE AUDIOVISUAL MATERIALS

From time to time Mind & Memory Matters and/or the Board for People with Developmental Disabilities may wish to write about, photograph, videotape, audiotape, etc. Community Conversation participants, representatives and other associates as a means of promoting the Mind & Memory Matters Project. These articles, photos, videos, audios, etc. may appear in publications, newsletters, brochures, websites, local, state or national news and other print, visual, or audio materials. I understand there is no time limit term in regards to this consent.

As a part of our record requirements we ask that you read and complete the following form, sign, date, and return it to your Facilitator. Thank you.

I, \_\_\_\_\_, am willing to participate in Mind & Memory Matters Community Conversations and give my consent to the use of my name, photographs and/or other means mentioned above for publicity and promotional purposes of the Mind & Memory Matters Project.

Signature: \_\_\_\_\_ Date: \_\_\_ / \_\_\_ / \_\_\_

Legal Guardian: \_\_\_\_\_ Date: \_\_\_ / \_\_\_ / \_\_\_

**IF THE PARTICIPANT SIGNING THIS DOCUMENT IS UNDER THE AGE OF 18 THEY  
MUST HAVE AN ACCOMPANYING SIGNATURE OF A PARENT OR LEGAL GUARDIAN.**

**ADDITIONAL RELEASE INFORMATION ON REVERSE SIDE OF THIS PAGE**



PERMISSION TO PARTICIPATE, PRODUCE AND USE AUDIOVISUAL  
MATERIALS pg.2

I hereby give my consent to be included in video or audio tapes, photographs, still or motion pictures, television or other audiovisual materials which are produced by the Mind & Memory Matters Project and/or the Board for People with Developmental Disabilities (101 East Wilson Street, Suite 219, Madison, WI 53703).

I authorize the use of these materials for general educational and/or promotional purposes for a term of which there is no time limit. My name, likeness, and biography may be used for publicity and promotion of these materials.

I hereby release the Mind & Memory Matters Project and the Board for People with Developmental Disabilities from showing or distributing the above-names materials or portions thereof, from any claim by me or damage to my person, property, reputation, or for invasion of privacy.

I further affirm that the Mind & Memory Matters Project and/or the Board for People with Developmental Disabilities is the owner of all rights in and to said materials and that no monetary consideration is due and owing myself.

Date: \_\_\_ / \_\_\_ / \_\_\_

Signature: \_\_\_\_\_

Printed Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

If Under the Age of 18 a legal guardian's signature is required:

Legal Guardian: \_\_\_\_\_ Date: \_\_\_ / \_\_\_ / \_\_\_

Printed Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_



# MIND & MEMORY MATTERS

## COMMUNITY CONVERSATIONS QUESTIONS & GUIDELINES

### Who We Are

Mind and Memory Matters is a joint effort between the Wisconsin Department of Health Services (DHS) and the Wisconsin Board for People with Developmental Disabilities (BPDD) to provide education and training to families, individuals with intellectual and developmental disabilities (I/DD), and care providers on the prevalence of Alzheimer's Disease/Dementia in the developmental disabilities community. Critical goals of the project include: addressing the importance of early detection, obtaining a diagnosis, caregiver stress and more. For more information go to: [www.MindandMemory.org](http://www.MindandMemory.org).

### Why Community Conversations?

We need to find out what information communities are lacking and what people want to learn so that we can improve education and awareness regarding I/DD and Alzheimer's/Dementia. To help get that information, please incorporate the following questions into your meeting(s).

### Questions for meeting(s):

- 1) What do you want to know more about dementia and how it affects people with I/DD?
- 2) What can this project do to develop information and resources to support people with both I/DD and dementia and their caregivers?
- 3) What are the best ways to get people to participate in screening for early detection?
- 4) As a caregiver, what is your biggest challenge? Best success?
- 5) What supports/resources would you find most useful?
- 6) With the information we've discussed today, what next steps should Mind and Memory Matters take?

### Your group's input will be extremely helpful!

Be sure to complete the Notes form for each meeting and return (along with Participants list and Consent forms) to Jeremy Gundlach or Brenda Bauer. If scanning and emailing (preferred method) send to: [jeremy.gundlach@wisconsin.gov](mailto:jeremy.gundlach@wisconsin.gov) or [brenda2.bauer@wisconsin.gov](mailto:brenda2.bauer@wisconsin.gov).

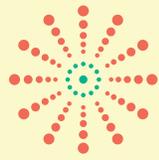
If mailing, send to: BPDD, 101 E. Wilson St. Room 219, Madison, WI 53703.



# MIND & MEMORY MATTERS

## Guidelines

- We recommend using the “Launching Inclusive Efforts Through Community Conversations” booklet enclosed in the packet for ideas. This is a very handy guide!
- Everyone attending should sign in on Participants form.
- Be sure that all attending have signed a Consent form.
- Turn cell phones to silent or off.
- Everyone has an opinion and it counts!
- Raise hands to speak during the large group discussion portion of the conversation.
- No interruptions - Let each person speaking finish their thoughts before speaking.
- Casual, calm setting with plenty of seating, comfortable temperature.
- Be creative and accommodating – keep in mind people attending may have dementia (less stimulation, time of day, etc.)

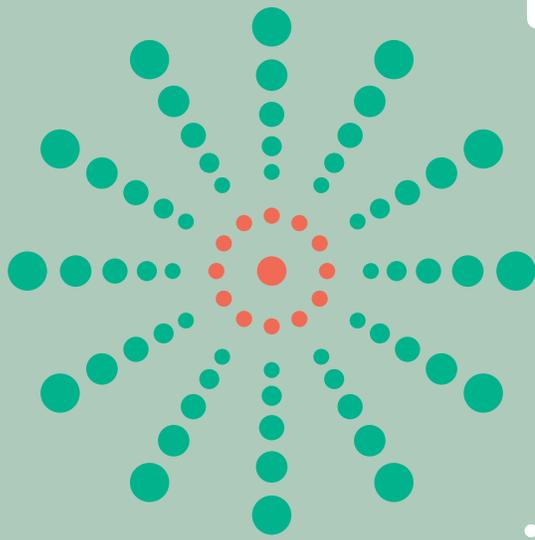


# Launching Inclusive Efforts Through Community Conversations

A practical guide  
for families, services  
providers, and communities

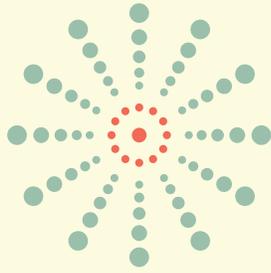


• Beth Swedeen  
• Molly Cooney  
• Colleen Moss  
• Erik W. Carter



We can create  
the future we  
want to see  
by starting  
with the power  
and connections  
we have.

The staff from the Natural Supports Project wants to extend its heartfelt appreciation to and respect for the parents who dedicated more than a year of their “discretionary time” toward developing, implementing, and reflecting on the impacts of community conversations. The creativity, generosity, and dedication demonstrated by these parents truly reflect the power all of us have as individuals in creating real community change. Their extreme patience as a crew of Natural Supports staff followed and documented their every move was an additional act of graciousness. This guide is dedicated to these parent organizers in recognition of the significant changes they made and still make in creating more inclusive and welcoming communities.

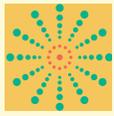


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# Introduction



Sarah had been advocating for years within her school district for more inclusive educational experiences. Because each of her four children had a different “label” that determined the program they would receive, they were attending four different schools. Despite many years of discussions with school staff, little prospect for change seemed evident—either for her own children or other students with disabilities in the district. A different approach was needed. She proposed to her local parent support group the idea of having a “community conversation” on inclusion.

Together, they sent invitations to and personally invited a broad range of community members to come together for an evening discussion focused on how they could work together to make the local schools more inclusive. More than 50 people came! Almost half of these attendees might not usually be thought of as people who would be willing to take part in an initiative addressing special education, including a county executive, a grocery store manager, school board members, and town alders. But they sure had much to contribute. The two-hour conversation—held over soda and snacks—generated

several dozen compelling ideas for how schools and the community could be more inclusive. Numerous new community partners were identified who could help. Shortly after the conversation, several “work groups” emerged to launch specific projects, including a transition “weekend camp” at the local university pairing high school students with disabilities with college student mentors, new inclusive extracurricular clubs at the high school, and a series of discussions with the school board and school services director focused on eliminating self-contained programs and creating more co-taught classrooms.

Imagine living in a place where all residents have meaningful opportunities to fully participate in their schools, on the job, and in recreational and civic pursuits that strengthen their connection to each other and the vitality of their community. Communities in Wisconsin and across the country are discovering their own ability and power to create change and improve the lives of all residents through a community organizing strategy that involves hosting community-wide conversations to elicit ideas, solve problems, create new connections, and share resources.

Drawing upon a model of intentional dialogue called the “World Café,”<sup>1</sup> these community conversations can focus on any issue of interest to a community, such as how to be more eco-friendly, how to engage marginalized groups in community life, or how to respond to economic challenges. This guide addresses how this approach is being used to create more welcoming, inclusive communities for individuals with significant disabilities.

“We can create the future we want to see by starting with the power and connections we have.”

Despite more than 35 years since the passage of the Individuals with Disabilities Education Act (IDEA) and 20 years since the Americans with Disabilities Act, we still often struggle to fully support people with significant disabilities, as well as to foster lasting and supportive relationships for and with these individuals in our schools,



communities, and workplaces. Nationwide, fewer than 10 percent of students with significant disabilities spend the majority of their school day in inclusive settings.<sup>2</sup> Adults with disabilities are only about a third as

likely to be gainfully employed as their peers.<sup>3</sup> Perhaps one reason for the limited progress in creating inclusive opportunities has been that the full range of potential resources and supports within a community often has not been engaged in finding or offering solutions.

### The World Café

 The framework in this guide has been sourced from The World Café.

The World Café has been used in a number of contexts. Businesses and civic groups use it for strategic planning, while communities use it to address local matters like budget cuts or public school concerns. Government and non-governmental organizations use the strategy to address local, statewide, national, and international concerns like environmental issues and public health concerns. For more information about the World Café and to access numerous resources, visit their website at [www.theworldcafe.com](http://www.theworldcafe.com).



<sup>1</sup>Brown and Isaacs (2005)

<sup>2</sup>U.S. Department of Education (2009)

<sup>3</sup>National Organization on Disability (2010)

## Core principles

Community conversations using the World Café approach offer a promising way to engage the broader community in discussion and action around an issue of shared concern. This approach starts with the premise that every community is already rich in opportunities

for people with significant disabilities to develop relationships, share their gifts, learn and practice new skills, and enjoy activities. Instead of dwelling entirely on barriers to participation, community conversations are designed to explore

the often-untapped resources, creative ideas, and effective problem-solving strategies that can result when new and diverse perspectives come together around a shared challenge or concern. This community organizing approach—as it was used in our project—relies on several core principles:

- All communities possess unique opportunities, connections, resources, and relationships.
- Members within each community are the experts on the challenges that are most pressing, the solutions that are most viable, the strategies that will work best, and the most effective ways to enlist others in support of change.
- Any group of community members who come together—no matter how well-connected each individual already is—will learn about new resources, connections, and ideas by interacting with others who share different viewpoints and have different life experiences.
- Real change that lasts is most likely to come when ideas are based on locally-feasible strategies and approaches.

## What is a community conversation?

A “community conversation” is a way to bring a diverse set of community members together to collectively brainstorm strategies and resources that can be used to address a challenge facing the community (see Figure 1). In short, it provides a fun and creative way to find local solutions and new partners to address issues that matter most in a community.

These two-hour events revolve around small-group discussions and are held at a familiar and inviting community location, such as a local coffee shop, restaurant, library, or community center. After arriving, participants sit together at small tables to encourage conversations and new connections among attendees.

“[The community conversation] was something different. It was something new and...it was going to make a big change in these kids’ lives, and...I’m all for that.”





**FIGURE 1:**  
What might a community conversation look like?

### 6:00-6:15 Welcome

- Attendees settle into seats (perhaps after getting food and/or drinks).
- The facilitator/host introduces purpose of event and outlines the conversation process.



### 6:15-6:35 Round 1: Conversation about question #1

- The facilitator poses question to group and encourages attendees to participate in discussion with others at the table.
- This question is designed in advance by the facilitators to elicit solutions, strategies, and resources that address the topic.
- The designated “table host” initiates the conversation and writes down key points made during the discussion.
- This discussion lasts 15-20 minutes.



### 6:35-6:55 Round 2: Conversation about question #1

- After 15-20 minutes of discussion, everyone except the table host moves to a different table and continues the discussion about the same question for another 15-20 minutes.



### 6:55-7:15 Round 3: Conversation about question #2

- The facilitator poses a new question that encourages attendees to consider what they might do to resolve the issue, or what the group can do to create change in their communities.

After the three rounds of discussion, each participant will have personally met and shared ideas with as many as 12-18 other people.



### 7:15-8:00 Harvest

- A large-group discussion of the best ideas, resources, and strategies is held. Ideas are posted on a large poster-sized piece of paper for the group to see.
- In most situations, the facilitator or another organizer shares the key points of the conversation via e-mail with the attendees at a later date.



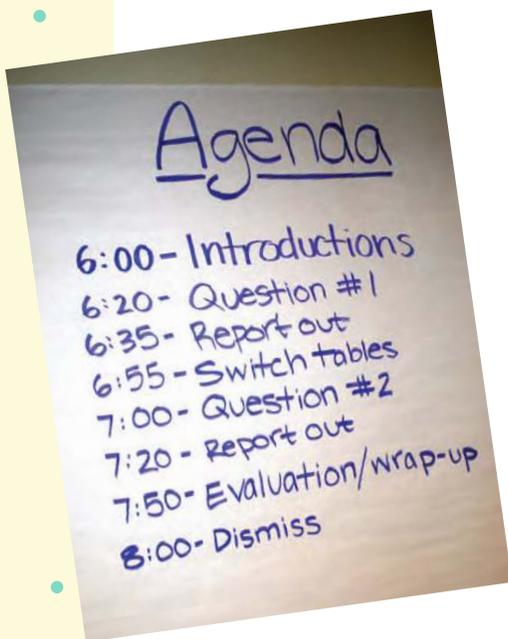
A facilitator or host welcomes the group and introduces the event by explaining the purpose for the meeting and outlining the conversation process. This introduction lasts about 10-15 minutes. To begin

“[Community conversations are] like a huge brainstorming—people walk away with ideas that they can literally use.”

the small-group discussions, the facilitator poses a question to the group (e.g., “What can we do as a community to improve employment outcomes for youth with disabilities?”) and asks everyone to discuss the question with the 4-6 participants

seated at their table. These questions are designed in advance by organizers to elicit solutions, strategies, and resources that address the topic. One person at each table is designated a “table host” who facilitates introductions and takes notes. After 15-20 minutes of discussion about the question, everyone except the host at each table disperses to different tables and continues discussion around

the same question for another 15-20 minutes. After this round of conversation, participants disperse to new tables one last time. During this final discussion, a new question may be posed that demands more specific action. For example, the question may encourage participants to consider what they personally can do to resolve the issue, or what the group might do in the next six months or year to change their communities. After the three rounds of discussion, each participant will have personally met and shared ideas with as many 12-18 other people. After this final discussion, the facilitator reconvenes everyone for a large-group “harvest” of the best ideas, resources, and strategies generated to address the topic, which are then posted for the group to consider. Most conversation organizers share the results back via email with participants and other interested community members at a later date.



## Learning alongside parents

Community conversations are one strategy the *Waisman Center's Youth Transition Area of Emphasis* has used to discover, support, and disseminate creative and promising approaches for supporting individuals with disabilities to participate more fully and naturally in school, work, and community activities, including the same relationships, work- and volunteer-related experiences, and community opportunities as their peers. We have sought to draw out the very best ideas and approaches for enhancing full participation of individuals with disabilities, based on the premise that most communities are full of opportunities for all residents to develop supportive relationships, explore their strengths and interests, learn important life skills, and make valuable connections. Too often, however, participation by individuals with disabilities in work experiences, school, extracurricular and community activities, social groups, and other opportunities is restricted to "special" programs that depend wholly on the presence and support of paid supports. When invited to think about the issue,

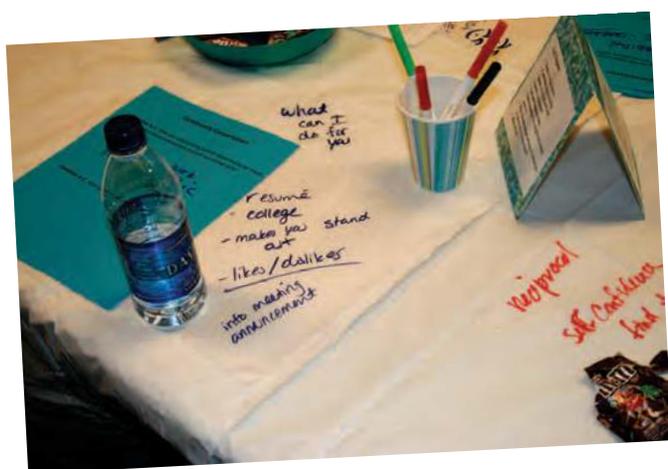
communities increasingly are discovering that it often doesn't require special services and paid supports to meaningfully include people with disabilities. Indeed, classmates, neighbors, co-workers, and other individuals who are already involved in school activities, places of business, and community programs can readily be drawn upon to more naturally support the inclusion of people with disabilities.

Typically, these individuals just need some basic information and a little guidance to effectively offer supports in existing school classes and activities, jobs, and other community opportunities. Quite often, they simply need to be asked.

Upon completion of a project that used community conversations to increase employment opportunities for youth with disabilities in high school, we organized an effort in which ten parents throughout Wisconsin received training and

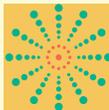


resources to host their own community conversation. We focused on parent leaders as organizers, drawing upon their connections, advocacy skills, and passion for improving the lives of people with disabilities. We observed and learned from their experiences as they planned and held their events, documenting their lessons learned for this guide. In the pages that follow, we include their stories and the lessons we learned from implementing their conversations. We also outline steps for organizing your own community conversation. For more information on our project and to access our resources, guides, and videos, please visit our website at [www.waisman.wisc.edu/naturalsupports/resources.php](http://www.waisman.wisc.edu/naturalsupports/resources.php). For more information about findings from our studies of community conversations,<sup>4</sup> see the Reference section at the end of this guide.



<sup>4</sup>Carter, Swedeem, Cooney, Walter, and Moss, *in press*; Carter, Owens, Swedeem, Trainor, Thompson, Ditchman, and Cole, 2009; Trainor, Carter, Swedeem, and Pickett, *in press*.

# Getting started

 Jennifer wanted to find ways that her daughter, Kelly, could become more involved in the community, as well as the ways the community could become more involved with Kelly. She wanted Kelly to be welcomed into social events and clubs happening both during and after middle school hours. Jennifer was convinced that if community members developed personal connections to people with disabilities, they would more easily see the obstacles that get in the way of full participation and would be more willing to help remove these barriers.

In addition to wanting inclusive opportunities for her own child, Jennifer also wanted other children at Kelly's school to have these experiences as well. To begin working toward her vision of an inclusive community for all children, Jennifer decided to organize a community conversation.

She decided to focus her event on increasing the number and quality of inclusive recreational activities available to children and youth with significant disabilities, especially those happening after school, on weekends, and during the summer months.



## Choosing a focus

The first step in organizing a community conversation is to decide on its focus.

Each conversation in our project focused on expanding inclusive opportunities for students with and without disabilities. A starting point involves considering what you specifically want to address using this approach. For example, you might be interested in increasing:

- Access to general education classes and coursework
- Inclusion in extracurricular clubs and after-school programs
- Involvement in social events and relationship-building opportunities
- Meaningful work opportunities for youth or adults with disabilities
- Recreational and leisure activities
- Postsecondary learning opportunities
- Civic involvement and leadership opportunities

Perhaps you already have a focus in mind. If not, here are some questions to consider. First, if you have a disability, a child with a disability, or someone else in your life with a disability, what experiences are they having right now? What types of opportunities are they experiencing that you would like to expand or deepen? What barriers are they encountering?

As a middle school student, numerous in- and after-school activities were potentially available to Kelly. Jennifer wanted her daughter to be actively involved in the life of her school and to have meaningful opportunities to interact and develop friendships with her peers, just as other students at the school did. However, if Jennifer didn't make arrangements far in advance for someone to accompany her daughter to an after-school or community event, Kelly couldn't participate. Kelly's

support needs meant that Jennifer couldn't just drop her off and plan to pick her up a couple of hours later. Jennifer wanted to increase community awareness about this challenge and to brainstorm possible solutions and strategies to overcome the problem.

Second, think about your "ideal" community. What would it look like? What experiences and opportunities would all people have?

For Jennifer, her ideal community was one that offered opportunities for all children with disabilities to participate in activities of their choice with their peers.

Third, with these ideas in mind, list areas that need to change for this vision to come to fruition. For example, what needs to happen within schools, businesses, community recreation programs, or faith communities for this vision to take shape?

Jennifer wanted to use natural supports available in her community, but felt that the community members needed encouragement to offer their support.

Jennifer believed that in order for her daughter to have the same in- and after-school opportunities, school staff needed to be aware of the challenge and problem solve ways to provide needed support. Jennifer did not expect the school system to carry all of the

responsibility for addressing this challenge, but she wanted them to be aware that students with disabilities may want to participate in the same opportunities as their peers. In addition, Jennifer thought students and community members needed to feel more comfortable interacting with and offering assistance to her daughter without needing permission. Jennifer wanted to use natural supports available in her community, but felt that the community members needed encouragement to offer their support.

Finally, from the ideas you generate, which one area, if addressed, would have the greatest impact on the lives of individuals with disabilities and their families?

Jennifer wanted to focus on increasing inclusive community and school activities, but she realized this topic might be too broad for a community conversation. While making her list, she realized that social inclusion often becomes more challenging in middle and high school than during elementary school, when children are sometimes more accepting and their parents more involved in their social and academic lives. Jennifer observed that as students age, they become more independent and interested in being around peers who have things in common. For this reason, and because her daughter was in middle school, Jennifer decided to focus her event on increasing inclusive community and school activities for middle school and high school youth.

After you have selected the focus of your conversation, share it with a few people (e.g., family members, friends, co-workers) to get their impressions and feedback. Does your topic also seem relevant to them? Is it important? For additional examples of focus areas, see the sidebar on this page listing the topics parents in our project addressed.



## Parent-selected community conversation topics

- Expanding opportunities for all youth in volunteer and career development activities
- Expanding local community-based employment
- Exploring ways to ensure persons with differences in ability can more effectively participate in and contribute to all aspects of life in the community
- Increasing employment, higher education, and other opportunities for young adults with disabilities
- Determining the status and direction inclusive youth programming is headed in the community
- Informing an anti-bullying and autism awareness campaign at the middle school level
- Exploring what the community and school district can do to make sure all children are and feel included



## Is a community conversation always the best approach?

Community conversations are just one organizing tool used to create energy and direction around local change. Other community organizing strategies to consider might include:

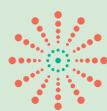
- **Community asset-mapping:** Based on work from the Asset-Based Community Development (ABCD) Institute at Northwestern University, this approach is designed to identify the existing resources, opportunities, and organizations in a community with a goal of more effectively connecting with existing resources.<sup>5</sup>
- **Futures planning tools** such as PATH<sup>6</sup> and MAPS<sup>7</sup>: These approaches from the Inclusion Network in Toronto, Canada, use individualized planning strategies that any local group or organization could adopt to do strategic planning.
- **Learning circles or communities of practice**<sup>8</sup> allow an established group that is committed to meeting regularly to explore a topic or goal in-depth by applying their own experiences and learning from each other.

<sup>5</sup> Kretzmann, McKnight, Dobrowolski, and Puntenney, 2005

<sup>6</sup> Pearpoint, O'Brien, and Forest, 2001

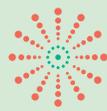
<sup>7</sup> O'Brien, Pearpoint, and Kahn, 2010

<sup>8</sup> Wenger, McDermott, and Snyder, 2002



## A community conversation may not be the appropriate method to use when:

- A group has already identified promising solutions to the challenge. In this case, a learning circle or community of practice to keep momentum and connections going may be more appropriate.
- The goal is to share information with a group of people, rather than soliciting their insights and ideas.
- Less than 90 minutes is available.
- Fewer than 12 people are gathered. In this situation, a futures-planning approach in which the group works together may be more appropriate.



## The various roles in a community conversation

There are four main roles people take during a community conversation:

- **Organizer:** The organizer(s) is the person or group (referred to as the planning team) who decides to hold a community conversation. This person or planning group plans the event by choosing the venue, inviting participants, and finding table hosts.
- **Facilitator:** The facilitator is the person who facilitates or runs the actual event. This person welcomes the group, explains the process, keeps track of time, asks people to switch tables, and facilitates the harvest at the end of the event. During the harvest, the facilitator may record all the ideas shared by writing on poster paper or the facilitator may ask someone else to do this writing. The organizer frequently plays the role of the facilitator.
- **Table hosts:** The table hosts are people who are asked to sit and stay at one table. These people facilitate the small-group discussions by taking notes of the conversation, encouraging everyone to share, and keeping the conversation on topic and focused on solutions.
- **Participants:** The participants are the individuals who attend the event and participate in the small-group discussions.

## Choosing questions

Friends Tanya and Emily worked together to organize and host their community conversation. At first, they were somewhat hesitant about the community conversation format. After all, they were tired of people talking and not doing anything. They wanted action! How could a series of guided conversations lead people to action? As they learned more about the World Café process, they realized that asking the right questions really could make all the difference.

If your community conversation event is going to culminate in practical ideas and doable strategies for expanding inclusive opportunities in your community, the event has to be solution focused. Solution-focused conversations enable participants to focus primarily on generating strategies, gaining insights, making connections, and planning next steps instead of spending valuable time discussing the obstacles. Conversations that only focus on challenges and barriers to inclusion can reinforce inaction and result in hopelessness and stagnation. Most people are already well aware of the existing obstacles. Community conversations should instead focus time and energy on generating solutions and possibilities.

**FIGURE 2: Checking your questions**

**1. Think about your questions as you consider the following ideas:**

- Do your questions simultaneously address the topic *and* encourage solutions?
- Are the questions phrased broadly enough to encourage responses from everyone who will be coming to the conversation?
- Are the questions relevant to your participant?

**2. Pose your questions to others (e.g., family members, friends) to get feedback.**

This is a great way to receive input and to see if you get the types of responses you were anticipating. It may take some tweaking to get the question just the way you want it.

The World Café model uses two strategies to keep conversations positively framed. First, organizers are encouraged to structure their events around 1-2 questions that move people toward solutions and action (see page 13, Possible community conversation questions). The World Café model uses questions to approach a topic instead of simply asking participants to discuss an idea. Meaningful questions lead people to think creatively and innovatively. Ideas that had not yet been thought of emerge when people think about and engage in conversations about important questions. Second, the table hosts seated at each table facilitate the conversations to keep them positive. We will talk about the role and responsibilities of the table host in the Organizing the Event and Art of Facilitating sections (see page 15). Right now, we address how to frame your questions.

**1. Pose only one or two questions for an event.** You may think of many questions that could be asked, but to fully explore and discuss the topic and generate solutions, we suggest posing only two questions.

**2. Ask questions that push people to think about what they can do to elicit change.** Starting your questions with “*what*” and “*how*” helps facilitate conversations about possibilities. Consider the difference between these two questions: “How can we make after-school activities more inclusive of all students?” and “Why are there barriers to including youth with disabilities in after-school activities at our school?” The first question specifically asks for strategies and ideas. The second question dwells on reasons inclusion is challenging, focusing on difficulties without uncovering solutions. Avoid questions that keep people focused on problems.

**3. Avoid questions that explore the value behind your topic,** such as “Why is inclusion essential for all people?” Although this type of question may raise awareness, it does not help people see their role in finding solutions and committing to action. Because people chose to come to your event, you can assume they already recognize the importance of inclusion. Help them take the next step by posing questions that tap into participants’ personal experiences and connections, such as “What can our community do to meaningfully employ more people with disabilities?” or “What resources do we have to support children with disabilities in summer recreation programs?”



4. Make a list of several questions about inclusion that are important to and will resonate with the community.
5. Pick one or two questions from the list that stand out because they could be answered by a broad range of community members or they could uncover valuable resources or connections.
6. Write these questions in a way that encourages action and commitment.

While looking over the questions posed by parents as part of our project, we noticed two elements that seemed to be effective at encouraging action and commitment. First, consider using the words “we” and “I” in your questions. These pronouns make people consider their personal role, rather than focusing on what *other* people should be doing to increase inclusion. For example, “What can *we* as a community do to increase inclusive recreational opportunities in our town?” Second, consider adding a second, more specific, time-limited question to encourage participants to think about and plan next steps. For example, “What can I do in the next *six months* to increase the inclusive recreational opportunities in my community?”

## Possible community conversation questions



Below is a list of possible questions that could be used for a community conversation. Adapt any that would be applicable for your event.

### Topic: Employment

**Question 1:** How can we as a community increase employment opportunities for all youth?

**Question 2:** What can I do to increase employment opportunities for all youth?

### Topic: Inclusion of high school students

**Question 1:** What can we do to ensure that all high school students are and feel included in the extracurricular activities and classes available in the district?

**Question 2:** What can I do in the next 6 months to ensure that all high school students are and feel included?

### Topic: Post-secondary preparation and options

**Question 1:** How can we better prepare our youth for life after high school?

**Question 2:** How can I help prepare youth for post-school life?

### Topic: Collaboration between community, schools, and families

**Question 1:** What can we do as a community to better support collaboration between the community, schools, and families?

**Question 2:** What can I do in the next 3 months to improve collaboration between my community, schools, and families?

### Topic: Community engagement

**Question 1:** How can we better engage individuals with disabilities in our community and civic opportunities?

**Question 2:** How can I engage individuals with disabilities in our community?

### Topic: Community inclusion

**Question 1:** How do we build upon the strength of our communities to ensure that all citizens are included?

**Question 2:** What can I personally do in the next 6 months?

**7. Think about the questions you have drafted and consider the following issues:**

**Do your questions simultaneously address the topic and encourage solutions?**

For example, if your topic is related to increasing inclusive recreation opportunities, a question that asks for definition, such as “What is inclusion?” or “How does it feel to be excluded?” may not result in ideas, resources, and connections that change the community. If you pose your questions to two or three other people and they do not generate action-oriented responses, consider revising your questions.

**Are the questions phrased broadly enough to encourage responses from everyone who will be coming to the conversation?**

Consider the following example: “What can we do as a community to help include your child in activities of his/her choosing?” Some participants will not have children or may not have a child who feels excluded. Simply changing the wording from “your child” to “all children” makes it appropriate for all participants. Or, consider this question: “How can we as a school community be more inclusive for all students?” This question is appropriate if all participants are members of the school community—staff, families, and administration. If you will be inviting a broad cross-section of your community to the event, some people will not consider themselves members of your school community and may not have many ideas on what can be done to initiate change. Changing the wording—such as “How can we as a community increase inclusive school opportunities for all students?” or “How can we as a community make our schools more inclusive for all students?”—reframes the question and helps participants consider what their role could be as a community member for making schools more inclusive.

**Are the questions relevant to your participants?**

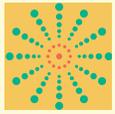
You want participants to see how inclusion benefits everyone and contributes to a stronger community. A few parents took particular care in developing wording that made the questions more universally relevant. For example, one parent focused her conversation on inclusive employment. Her initial questions were: “How can we get employers to consider hiring people with disabilities?” and “What can schools and families do to better prepare young adults for the work force?” However, she realized that many participants would be employers and she wanted to appeal to their particular needs and interests. She wondered what employers would have to gain by hiring people with disabilities and altered one of her questions to read: “What can I do to diversify my workplace?” She felt this question would resonate with most event participants, especially to employers. Another parent decided to focus on inclusion more generally, recognizing that many people without disabilities also feel excluded from or on the margins of their community. By asking a more general question—not specific to the inclusion of people with disabilities—more participants would see the topic as relevant and important to address. She reworded her question to state: “How do we build upon the strength of our communities to ensure that all citizens are included?”

**8. Pose your questions to others (e.g., family members, friends).**

This is a great way to receive feedback and to get the types of responses you anticipated. It may take some tweaking to get the questions just the way you want them.



# Organizing the event



When Maureen decided she wanted to do a community conversation on increasing employment opportunities for youth with disabilities, she first sought some partners to help her. She approached her local Arc and an adult service agency in her town, both of which were happy to help her organize the event. They met as a “planning team” three or four times before the event. They realized that to get employers to come to their event, they would need to host it early in the morning before local businesses opened. Having their conversation at 7:30 in the morning over coffee, fruit,

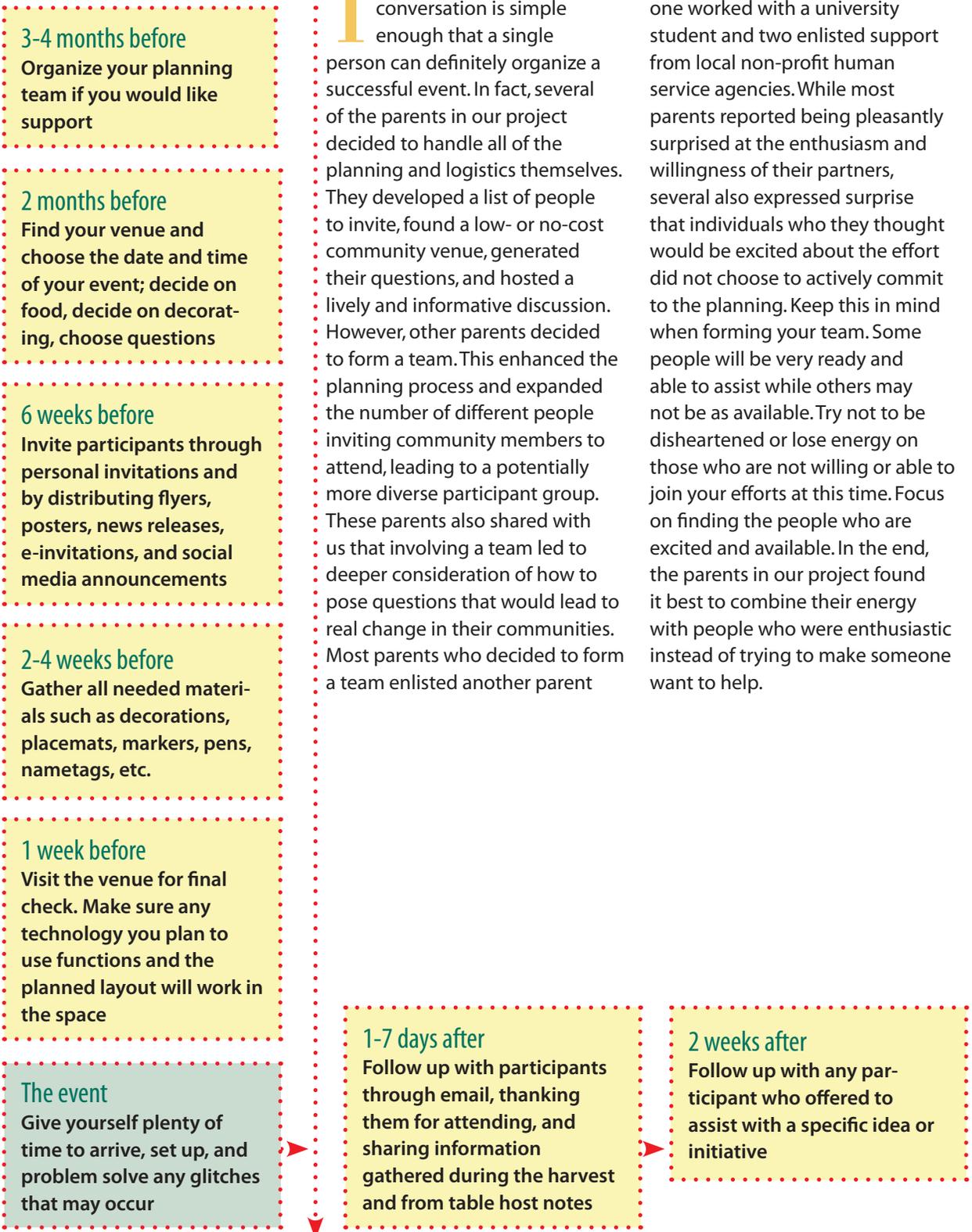
and pastries at a local café meant a greater likelihood that employers could attend. The partnering agencies had connections with employers and were integral in inviting and getting business leaders to attend. The team invited a local professional with facilitation experience to introduce the event, conduct the large-group harvest discussion at the end, and float among tables to spur conversation.



Conversely, Kristen decided to coordinate her community conversation with an established parent leadership group. Their event focused on expanding community recreation options

for children and youth with disabilities. She asked a friend who owned a local brewery if he would be willing to let her use his space for free. Because the brewery was typically closed on Mondays, her event would not compete with business. Parents in the group brought potluck dishes, limiting the expense. The publicity was also free as Kristen emailed most of the invitations. She and a friend co-facilitated the evening, which further minimized costs.

**FIGURE 3:** Sample timeline for organizing a community conversation



## Finding support

The scope of a community conversation is simple enough that a single person can definitely organize a successful event. In fact, several of the parents in our project decided to handle all of the planning and logistics themselves. They developed a list of people to invite, found a low- or no-cost community venue, generated their questions, and hosted a lively and informative discussion. However, other parents decided to form a team. This enhanced the planning process and expanded the number of different people inviting community members to attend, leading to a potentially more diverse participant group. These parents also shared with us that involving a team led to deeper consideration of how to pose questions that would lead to real change in their communities. Most parents who decided to form a team enlisted another parent

or group of parents, although one worked with a university student and two enlisted support from local non-profit human service agencies. While most parents reported being pleasantly surprised at the enthusiasm and willingness of their partners, several also expressed surprise that individuals who they thought would be excited about the effort did not choose to actively commit to the planning. Keep this in mind when forming your team. Some people will be very ready and able to assist while others may not be as available. Try not to be disheartened or lose energy on those who are not willing or able to join your efforts at this time. Focus on finding the people who are excited and available. In the end, the parents in our project found it best to combine their energy with people who were enthusiastic instead of trying to make someone want to help.

## Choosing a venue

The most important factors in choosing a location for the event are that the space is well known in the community, comfortable for participants, and conducive to creative thinking. The term “World Café” was developed because the events sought to create the intimate, pleasant atmosphere of a café where people come to relax, sip coffee, and share ideas with others. Try to avoid typical agency locations like schools or human service centers because they may be associated with a specific perspective and may not seem as conducive to informal conversations.

Many parents chose free space, such as a community center, public room at a library, or space donated by a local business. For example, one group chose a well-known museum with windows looking out over a large lake. They emphasized the value of having beautiful space to inspire participants. Most public spaces must be reserved 6-8 weeks or even more in advance.

## Creating a comfortable space

Conversations tend to be more lively when the location and set up are both inviting and functional. Make sure your room is easy to locate. If it will not be clear where people should go when they arrive at the venue, post signs that give directions to the room or have a greeter present to welcome and direct people. Participants should arrive to a welcoming space that is accessible, comfortable, and relaxing, but they also need to be able to hear one another and easily move when it is time to rotate tables. Creating a comfortable and useable space, though, does not need to cost a lot of money. Consider the following when setting up your space:

**TABLE SIZE.** Most venues will come with tables and chairs. Ideally, tables will have seating for at least four, but no more than eight individuals. We have found that having four to six people per table means there are enough people to keep the conversation going, but not so many that people have little time to share or feel intimidated to speak.

Depending on the venue, you may not have a choice of table size. Be creative and consider alternatives. If the tables are too small, push two tables together. If the tables are too big, limit the number of chairs set at the table. If a venue only offers chairs, borrow card tables from friends and neighbors. Or, go without tables by placing the chairs in a circle and leaving a pen and pad of paper on each seat for notes and doodling. If possible, avoid the large, circular conference tables that seat eight to ten people. It is sometimes hard to hear people sitting across from each other.

**LAYOUT.** Finding the right balance is important. Place tables close enough together to make the space feel cozy and intimate, but not so close that participants cannot easily move around or hear each other speak over other conversations. Everyone should be able to leave their table with ease when it is time to switch tables, get more food, or use the restroom. They also should be able to speak without competing with voices from surrounding tables. At one parent’s event, the room was quite large for the small gathering she had planned so she used a registration table to partition off part of the room for the tables. This change made the room feel smaller and more intimate.



**DECORATING.** To make the room look more like a café and less like a conference room, cover the tables with tablecloths. Although linen tablecloths are fine, easel or chart paper taped to the top works well. Scatter markers and pens that people can use to take notes, doodle, or draw. Participants can write directly on paper tablecloths or paper placemats can be included in front of each chair. At most events, parents scattered candy or confetti on the center of each table. Use flowers or plants as table centerpieces, or place them on the registration table or in other easy-to-see locations. Include a table tent that describes “café etiquette” and/or the responsibilities of the table host at the center of each table (see Figure 4). At one event, the parent organizers decorated the room by writing quotes about the importance of inclusion on chart paper and posted them on a wall (see page 29). This was very effective—it set the mood and tone for the event, cost very little, and many attendees asked for a copy of the quotes.

FIGURE 4: Café etiquette table tents

### Café etiquette

- **Focus** on what matters
- **Contribute** your thinking
- **Speak** your mind and heart
- **Listen** to understand
- **Link and Connect** ideas
- **Listen together** for insights and deeper questions
- **Play, Doodle, Draw**—writing on placemats & tablecloths is encouraged!!
- **Have FUN!!**

### Possible pitfalls:

- If you plan to hang items on the walls, make sure your venue will allow this.
- Some participants may want to keep their notes and the drawings they make on the placemats. Ideally, you will collect these items after the conversation to compile the breadth of ideas that were shared by everyone at the event.

**FOOD.** Food always seems to bring people together. Offering snacks and coffee can help you create a café-like environment. The food you provide does not need to be elaborate or expensive. Some of the parent organizers were actually surprised by how little the participants ate. When trying to decide what food to serve, consider the time of day at which your event will take place and who will be attending. If you meet in the morning, offer muffins, fruit, and coffee; if you meet later in the evening, offer coffee and simple desserts. If your conversation will include students, ordering pizza can be a great way to get more youth to attend. If you choose a potluck, ask members of your planning team or attendees to each bring a dish.



### Foods provided by parents

- Cinnamon rolls, croissants, muffins
- Snack foods like cheese and crackers, relish trays, chips and salsa, fruit
- Coffee, juice, soda, water; one event was held at a brewery with a cash bar available
- Pizza and salad delivered by a local pizza company
- Desserts, ice cream floats, cookies, candy



### How the food was provided

- Catered by the venue, such as a restaurant, café, hotel conference room
- Members of planning group all brought an item for a potluck
- Volunteer parent group made food at home ahead of time
- High school cooking class prepared food
- Ordered/bought cheese and meat tray from grocery store

## Possible pitfalls:

- Make sure to deliver on what you advertise. If you state on your invitation that a light meal will be served, offer a light meal.
- Some venues may not allow outside food or will require you to use their catering services. Before booking your venue, make sure you can work within their parameters.
- Be sure food is set up before the first attendees arrive.

## Organizing on a budget

Organizing a community conversation does not need to be a costly endeavor. An event can cost less than \$250 and, with some creativity, it can be almost free. The venue, food, decorations, and printing of invitations typically cost money, but there are ways to keep expenses to a minimum. First, consider options that are less expensive. Second, explore sources of free or donated elements.

**VENUES.** When choosing a venue, libraries or community centers are often free or available for a very reasonable rate. These locations usually have tables, chairs, and some technology (e.g., LCD projectors, screens, wi-fi, etc.) available free of charge. Ask around to learn about other low-cost venue options. For example, one parent in our project used a beautiful community room at a local furniture store for free. Few people know this resource even existed.

**FOOD.** Depending on the number of people you anticipate attending, consider buying beverages and snacks in bulk at a warehouse retailer. If you have a planning group, ask that each member bring one or two items

to share. This divides the cost and shares responsibility.

**DECORATIONS.** Go minimal. For the tables, use chart paper for table cloths and make confetti by shredding colorful paper or using a decorative hole puncher. Bring a couple of plants from home (or borrow some from friends) to add a little green to the venue.

### PRINTING COSTS.

Depending on how large your event will be, there may be some printing costs. As we will explain in the “Inviting and Marketing” section (see page 21), it is most effective to use a number of different invitation strategies. An electronic

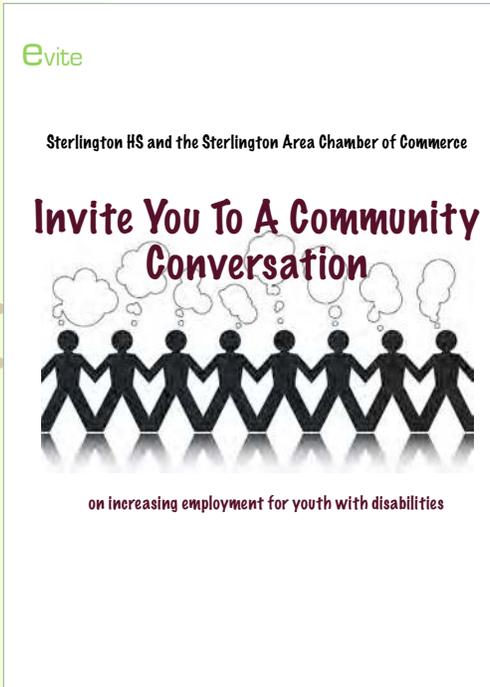
Evite ([www.evite.com](http://www.evite.com)) is an excellent way to reach a large number of people for free (see Figure 6 for an example). Invitations delivered in person or over the phone cost nothing and are usually the most effective way to draw a large crowd. Posting flyers and following up personal invitations with a flyer are good ideas. Other approaches include asking organizations to include the event in their existing newsletters or to distribute the announcement through their electronic listservs. To reduce costs, print in black and white or print on colored paper instead of with colored ink.

FIGURE 5

## Venue planning checklist

- Parking.** If your venue has limited parking available, be sure to include in your invitation directions on where to park.
- Equipment and electrical outlets.** Some conversations started with a video or slideshow that required use of LCD, laptop, and screen. If you will need electricity for any aspect of your conversation, check the venue ahead of time to locate electrical outlets. You may need to bring extension cords or a power strip.
- Childcare.** Depending on who will participate at your conversation, you may want to offer childcare. This can ease the burden for some families and result in a higher turnout. One parent organizer held her event at a hotel with a water park. While the parents attended the community conversations, their children received free childcare at the small, indoor water park.
- Registration table.** When participants arrive at the event, have a prominent space for registration. Participants can sign in (see sample sign-in sheet on page 32) and get a name tag. Someone should be at the table to welcome people, encourage them to sign in, and direct them to food, beverages, and a seat.

**FIGURE 6:**  
Example electronic invitation



**Host:** Sterlington High School and Sterlington Area Chamber of Commerce

**Location:** Steelpine Golf Course  
5555 W Foliage Street  
Valley Wood, WI, 55332  
[\(view map\)](#)

**When:** Thursday, January 24, 6:30PM-8:30PM

Please join us for an evening of conversation about how our community can increase employment opportunities for youth and young adults with disabilities. We will have an informal discussion about increasing employment for youth with disabilities and explore ways to create new opportunities over coffee and great desserts!

**DONATIONS.** Think about who you already know. Does someone connected with your planning team own a restaurant or coffee shop? Does anyone work at one and have a good relationship with the manager or owner? Two parents in our project had space donated because they or someone they knew had a relationship with a local business. Many businesses will also donate food to support a community function. This allows them to give back to the community, and it provides free advertising for their business. Depending on the size of business, you may need to plan ahead. Larger businesses frequently have an established process for responding to requests for donations. Do not be afraid to ask.

## Deciding on a date and time

People who have lots of connections and relationships in their communities are already very busy. No date or time will fit the schedules of everyone you may want to invite. Parents in our project sought to avoid conflicts with school sports and arts programs, school board and city government meetings, and religious observations. Some chose to host their event just before a key decision-making time in the community, like several weeks before a school board budget was passed or an agency budget was due. Most chose an early weekday evening (Monday through Thursday starting at 6:30 or 7 p.m.), and some started even earlier by including a potluck dinner. As noted earlier, one parent scheduled a morning conversation to make it easier for some local businesses to attend. Another group met on a Sunday, but that time frame did not attract many community participants outside of the existing parent group sponsoring the event.



## Inviting and marketing

Events had the highest attendance when members of the planning team personally invited participants to come. Invitations and other publicity such as news releases, flyers, and posters were distributed six weeks in advance. All communication about the event listed sponsoring agencies and groups. Parents in our project had a sample list of potential agencies and organizations in each community that they might want to consider inviting (see Figure 7). Importantly, most deliberately extended invitations to people who might not initially realize their connection to disability or inclusion issues, but who were active community members, such as leaders from business groups, individual employers, city leaders, volunteer and civic groups, local policymakers, faith communities, community activists, and many others. Including a wide cross-section of participants increases the likelihood that fresh perspectives, new ideas, and unexplored resources will emerge and that new partnerships and initiatives can take shape. The e-invitation, press release, flyers, and word-of-mouth strategies also keep costs down.

FIGURE 7

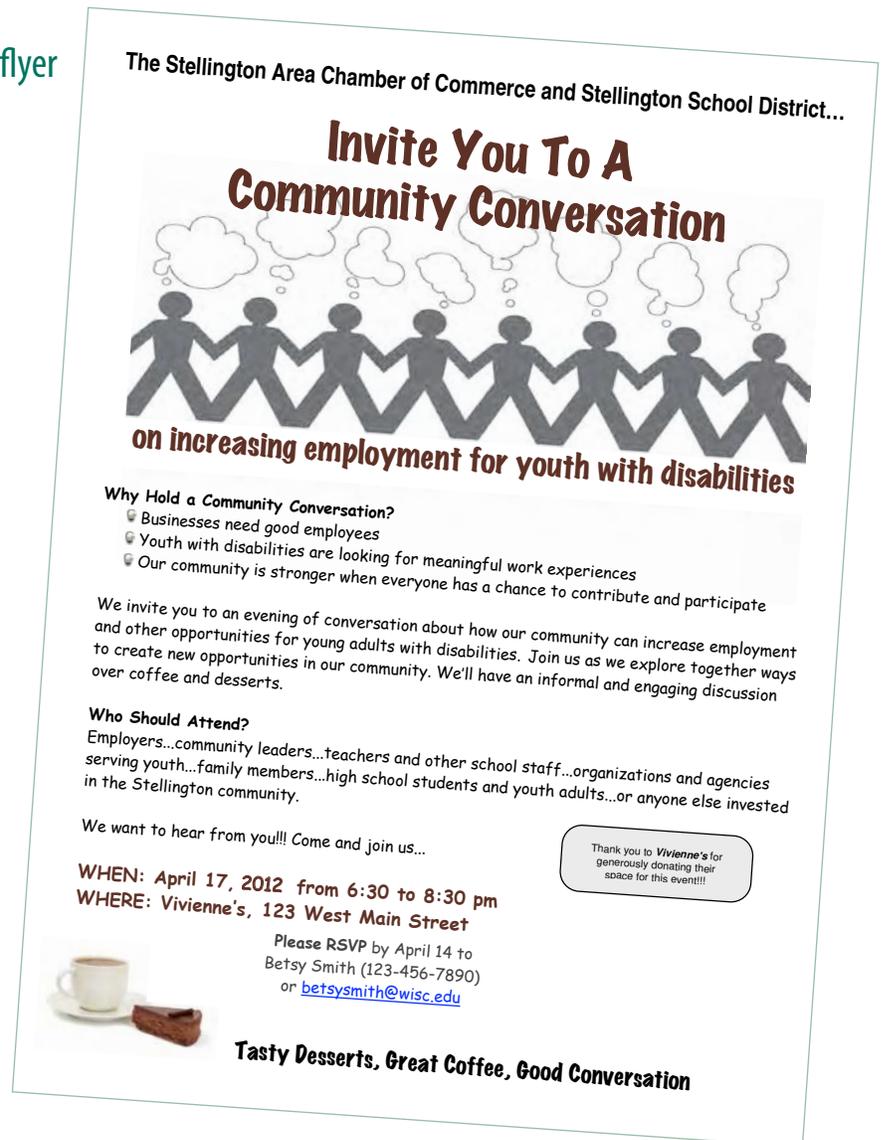
### Possible participants for a community conversation

- Neighbors
- Friends
- Family
- Youth
- Parents
- Teachers and school staff
- Local business owners
- School and community recreation programs
- Clergy
- Church members
- Chambers of Commerce (Director & Members)
- Boys and Girls Club
- Directors of pupil services
- Job coaches and employment specialists
- Arc
- Residential support providers
- County social services departments
- Division of Vocational Rehabilitation (DVR)
- Habitat for Humanity
- State assembly representatives
- Transitional living facilities
- State employment representatives
- Center for Career Development and Employability Training
- Youth services programs
- School administrators
- Community Access Program
- Social workers
- Mental health centers (Hospital)
- Department of Human Services (county)
- Community non-profits
- Deans for student services (university system)
- Social Security Administration
- Supported employment providers
- School board members
- Newspaper reporters
- Superintendents of curriculum and instruction
- Community art centers
- YMCA
- Director of special education services
- State Representatives
- School district parent liaisons
- County fine arts/adaptive programs
- Mayors
- Assistant to the mayor
- University Extension staff
- State Rehabilitation Council
- Job developers
- High school transition coordinators
- Civic organizations (e.g. Kiwanis, Lions, Rotary)
- Family support centers
- University graduate students
- County Time Banks
- University Centers for Excellence in Developmental Disabilities
- Disability services at universities
- United Cerebral Palsy
- Autism Society Madison
- Epilepsy Foundation
- Down Syndrome Association



All used some sort of flyer that they could attach to an email and send out, reducing postage costs (see Figure 8). However, most also personally invited people they especially wanted to participate. Several also used a press release template (see Figure 9 for an example) to encourage media coverage of their event, and many used social media such as Facebook and Twitter announcements to further advertise the event. Prior publicity (newspaper articles, radio public service announcements) also increased participation.

**FIGURE 8:** Example community conversation flyer



**FIGURE 9:** Example community conversation press release

FOR IMMEDIATE RELEASE

Feb. 27, 2012

HIGH SCHOOL, BUSINESS COMMUNITY WORK TOGETHER TO IMPROVE EMPLOYMENT  
FOR YOUTH WITH DISABILITIES

Contact: Betsy Smith, (123) 456-7890, betsystemith@wisc.edu

(STELLINGTON) — Four out of five high school students with disabilities say they plan to work during summer break. Yet fewer than half that number actually landed a job this past summer.

In fact, fewer than 15% of students with the most significant disabilities worked, according to preliminary findings from a research study following students with disabilities in 34 Wisconsin high schools.

Staff from Stellington High School are teaming up with the Stellington Area Chamber of Commerce in hopes of changing those statistics by connecting students with disabilities with jobs for this upcoming summer.

One of their first efforts will be to invite the community to an evening of conversation and free desserts in hopes of gathering great ideas, untapped resources, and better connections between schools, local businesses, and the greater Stellington community.

“We have students at our school who want to work and would be very successful if they could connect with the right job,” says Emily Bowers, Stellington High School special education/transition teacher (INSERT SIMILAR QUOTE AND NAME OF SPEAKER HERE).

“We also know this is a community that really cares about its young people. We hope that by gathering the community together well before summer starts and working together, we can find the connections and supports ahead of time to increase the likelihood our students can get and keep a job, and ultimately be more successful as employees and community members,” says Mayor Richards (INSERT SIMILAR QUOTE AND NAME OF SPEAKER HERE).

The “Community Conversation” is scheduled for April 17 from 6:30 to 8:30 p.m. at Vivienne’s on West Main Street. The event is open to anyone interested in improving employment and community involvement for youth with disabilities. Business and community leaders, local policymakers, faith communities, youth agencies, families, and young people are especially encouraged to attend.

Coffee and free desserts will be provided.

For more information or to RSVP, contact Betsy Smith at (123) 456-7890 or betsystemith@wisc.edu (INSERT ORGANIZER’S INFORMATION HERE).

###

## Choosing a facilitator

Anyone who feels comfortable in front of a group and understands the purpose of the conversation can act as a facilitator. Individuals are especially successful conversation facilitators if they can:

- Succinctly frame an issue,
- Relinquish control to the group,
- Redirect conversations that go off-topic while honoring participants' perspectives, and
- Identify connections and themes among the diverse conversations.

The most important facilitator responsibilities are to:

1. Frame the event so people understand why they were invited;
2. Overview expectations and etiquette to ensure everyone will feel comfortable contributing;
3. Float between tables as participants discuss the questions, redirecting the conversation when necessary to keep it solution-focused; and

4. Facilitate the "harvest" large-group discussion at the end, which connects participant ideas and leads toward proposed solutions.

Most parents in our project facilitated their own events and indicated the task was not overwhelming. One important feature of community conversations is that most of the ideas should come from the participants, not the facilitator. If you are interested in using a professional facilitator, many communities have trained professionals who can be called upon to facilitate a community conversation. You might consider contacting your county Cooperative Extension Service, local university continuing/adult education program, or inquire about private consultants trained in community organizing strategies from the ABCD Institute ([www.abcd.org](http://www.abcd.org)). For more training tips and supports for facilitators, visit the World Café website at [www.theworldcafe.com](http://www.theworldcafe.com).

"I felt it was important to identify people ahead of time and I think it worked out well, because we had some control then, versus the conversation going completely off topic."

FIGURE 10

### Table host responsibilities

Thank you for serving as a Table Host for our community conversation tonight! Here are some ideas to help you as the Table Host:

- Facilitate introductions at your table
- Remind people to jot down on the table cloth and placemats key connections, ideas, discoveries and deeper questions as they emerge
- Remain at the table when others leave and welcome people from other tables
- Briefly share key insights from the prior conversation so others can link and build using ideas from their respective tables

## Choosing and preparing table hosts

The role of table hosts is to make initial introductions among people sitting at their table, take notes during each round of conversation, and help participants connect ideas and solutions from earlier conversations at the event. A list of table host responsibilities is usually placed on each table before the conversation (see Figure 10 on page 24 for an example).

While some organizers just ask someone they know at each table to take this role at the beginning of the conversation, many parents in our project asked individuals they knew in advance to act in this role. Choosing table hosts in advance enables you to select and ask friends or colleagues who you

know would feel comfortable and successful in this role. It also allows you to share with them information about what their responsibilities will be during the event. Ideally, table hosts should be comfortable redirecting conversations and keeping the conversations solution-focused. In general, people who tend to dominate conversations do not make effective table hosts. Instead, choose people who have the skills to draw out ideas and feedback from all participants. Because there should be a host at each table, you can determine the number of needed table hosts based on the number

of people you anticipate will attend your event and the size of your tables. We recommend having one or two extra volunteers in case the attendance is greater than expected or a table host unexpectedly cannot come.

### A few other tips...

- Meet with your table hosts before the event to explain the community conversation

approach, their roles within the process, and strategies they can use if participants stray from the topic or focus on problems instead of solutions. Consider sharing the example table host reference sheet as it includes responsibilities, sample agenda, and facilitation

strategies (see Figure 11). If a personal meeting is not feasible, send the group an email outlining these points and encourage them to ask any questions. One planning team that made arrangements to meet with their table hosts a couple of weeks before the event emphasized that having this time to discuss the conversation's purpose and the table hosts' roles led to richer discussions and more focused set of solutions at their conversation.

- Ask your hosts to arrive about 15 minutes before the start of the event to get settled, review their roles, and welcome others.
- Have pens and paper available for table hosts to record key ideas and strategies generated during the conversations.

**"We could not have done it without our table hosts. It would not have gone as successfully as it did... without having trained them and explaining their role."**



FIGURE 11

## Table host reference sheet

Thanks again for your involvement in this hopeful and purposeful event. These details and tips will help you through the evening. It is probably best to review them ahead of time, rather than to flip through as you are facilitating discussion.

### Responsibilities

- Facilitate brief introductions at your table—just names, so that people can address each other. No need for delving deep into explaining perspectives as that will come out with the ideas through the conversations.
- Encourage and ensure that people are jotting down key connections, ideas, discoveries and deeper questions on to the placemats as they come up. We will be using this to augment our notes that go into the action plan.
- Remain at the table when it is time for the participants to switch. Welcome your next group of participants with the same brief introductions.
- Jot down the key ideas for yourself, as you'll be sharing briefly with the next group what the previous group came up with.
- If necessary during the whole-group wrap up, get the ball rolling with a comment you heard at your table. We'd prefer for the participants to all take part in this, but if there is hesitance at the beginning, we will look to the table hosts to kick things off.

### Café etiquette

This is from the World Café website. Participants may or may not need reminders of this:

- Focus on what matters
- Contribute your thinking
- Speak your mind and heart
- Listen to understand
- Link and connect ideas
- Listen for insights to deeper questions
- Doodle and draw on the placemats and tablecloths
- Have fun!

### Facilitation tips

Here are some possible statements you might use when during the conversations:

**Tangents:** when there are long stories, personal struggles, or comments about topics other than the current question, here are a few ideas for getting back on track...

- "Let me read the question once more."
- "I see how that gives background on your perspective, but let's talk about how to progress from there."
- "Maybe that's something the 2 (3, 4) of you could discuss after the time allotted for this conversation."
- "That's interesting, but let's get back to inclusive thinking."

**Silence:** when there is a prolonged lull or when there are certain individuals not offering their thoughts...

- "Joe, we're interested in your take on that."
- "You may not have direct personal or professional impact on this question, but sometimes that's just the fresh perspective called for."

- "Think of what you enjoy about living/working in our community. Where do you go in your free time, what do you do, who do you see? What adjustments might have to be made to some of those assets so that people with physical, social, medical or intellectual differences might also partake alongside you?"
- "Let me get us started, one idea I had was... Can I get your thoughts on that or hear some of your ideas?"
- "Anything that comes to mind, we're not ruling out here and now, were compiling possibilities."

**Negativity, listing obstacles:** people who are eager to tell you that something won't work because of personal bad experience or because they can quickly list difficulties or obstacles...

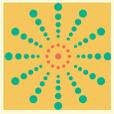
- "We're going to focus on what should happen, not so much on feasibility at this point yet."
- "I understand you had a struggle in this area, thus illustrating the need to get creative about how to go about it. What are your ideas for progress here?"
- "If you must list obstacles, for each, you have to offer a possible way around it."

**Dominance:** when one person takes over the entire conversation and may even inhibit others from partaking...

- "Those are good thoughts. Let's see what other people have to say, Mary?"
- "You have a lot of experience here. Let's see what other new ideas there might be."

Overall—the goal is to keep all conversation constructive, positive, and focused on solutions, action toward progress, and gathering perspectives and ideas from all participants. Don't be afraid to use these exact straightforward words as a reminder when needed.

# The art of facilitation



Emily and Tanya spent weeks

focused on the details of their community conversation, including reserving a beautiful space, ordering special food, and brainstorming who to invite. They chose their fifteen table hosts well in advance and met with them two weeks before the event to explain their responsibilities and to share facilitation strategies they had compiled on a tip sheet.

At first, they felt they should hire a “professional” facilitator to ensure that their event was a success. However, after attending several other community conversations, they realized that no one would be more invested in the discussion than themselves.

They knew exactly how they wanted to frame the evening to create an atmosphere that elicits creative conversations that result in action and change. Ultimately, they decided to co-facilitate their conversation together.



## The facilitator and table hosts

**B**oth the facilitator and table hosts play a critical role in the facilitation of a community conversation. While both are responsible for welcoming participants and keeping the conversations on track, the facilitator is also charged with (a) framing the importance and intent of the event and (b) “harvesting” the best ideas, solutions, and connections at the end of the evening. The table hosts have additional responsibilities, including (a) facilitating introductions among people at their table, (b) taking notes of key ideas and encouraging participants to write down or draw out ideas on the paper placemats, and (c) briefly summarizing the main points from previous conversations after people rotate to new tables. When facilitators and table hosts pay careful attention to each of these components, community members are more likely to leave the conversation feeling it was both a good use of their time and an effective springboard for personal and collective action on the topic. Although effective facilitation is pivotal to a conversation’s success, most parent organizers did not solicit a professional or trained facilitator. Instead, they successfully performed these roles themselves or in partnership with one other person.



## Welcoming participants

**A**n important element of community conversations that sets them apart from typical meetings is the informal and hospitable atmosphere. Facilitators can contribute to such a context by arriving early and greeting participants as they arrive. For those participants who are unfamiliar with the format and topic of inclusion, facilitators can be especially helpful in offering a personal welcome and even taking a minute to explain the intent of the evening and the importance of their perspective to the event’s success. Some organizers set up an attractive sign-in table and asked volunteers to greet and welcome participants while they personally floated around the room welcoming participants. As participants find a place to sit, the table hosts welcome them to their table and facilitate introductions.

## Framing the event

**Emily and Tanya wanted to create an atmosphere that welcomed participants the moment they arrived. Throughout the room, they posted inspirational quotes highlighting the value of inclusion. They began the evening with a slide show underscoring the difference between “being present and tolerated” versus “being welcomed and valued.” Their brief overview of the evening’s conversation challenged participants to think about the importance of being a contributing, included, and appreciated member of society. Then they invited people to discuss how their own communities could move toward realizing this vision.**

The event needs to be carefully framed by the facilitator so all participants understand the conversation process and their roles and potential for meaningful contributions to the issue. The most successful conversations include a broad range of community members, including people who are unaffiliated with disability or inclusion issues. However, without adequate explanation, they may

## Example inclusive quotes

“Inclusion is not just a matter of putting in wheelchair ramps and accommodating disabled kids in public schools. Real inclusion must occur in all aspects of daily life.”  
—SHANNON FLORA

“We are less when we don’t include everyone.”  
—STUART MILK

“What takes real skill, intelligence, and determination and results in a better place for everyone to live in is the ability to lead by inclusion, to involve everyone, and to harness the benefits of diversity.”  
—SUE MORONEY

“One of the greatest things you have in life is that no one has the authority to tell you what you want to be.”  
—J. ESCALANTE

“Interdependence is and ought to be as much the ideal of man as self-sufficiency. Man is a social being.”  
—MOHANDAS GANDHI

“Lasting change is a series of compromises. And compromise is all right, as long as your values don’t change.”  
—JANE GOODALL

“Every single person has capabilities, abilities and gifts. Living the good life depends on whether those capabilities can be used, abilities expressed and gifts given. If they are, the person will be valued, feel powerful and well-connected to the people around them. And the community around the person will be more powerful because of the contribution the person is making.”  
—JODY KRETZMANN & JOHN MCKNIGHT

“The good we secure for ourselves is precarious and uncertain until it is secured for all of us and incorporated into our common life.”  
—JANE ADDAMS

“Every great dream begins with a dreamer. Always remember, you have within you the strength, the patience, and the passion to reach for the stars to change the world.” —HARRIET TUBMAN

“If you don’t like the way the world is, you change it. You have an obligation to change it. You just do it one step at a time.”  
—MARIAN WRIGHT EDELMAN

“Without leaps of imagination, or dreaming, we lose the excitement of possibilities. Dreaming, after all, is a form of planning.” —GLORIA STEINEM

“The people who get on in this world are the people who get up and look for circumstances they want, and, if they can’t find them, they make them.”  
—GEORGE BERNARD SHAW

“We are all born included. Inclusion is the natural state, everything else is an artificial environment.”  
—KATHIE SNOW

“Look into the face of a person with a disability and acknowledge that he or she was born included, then question how segregation and second-class citizenship of that person...can be justified. Keep looking and imagine the awesome possibilities when inclusion is your highest operating principle.” —KATHIE SNOW



not understand why they have been invited. For example, a facilitator's introduction that welcomes the participants, explains the event, and connects the issue to every participant in the room helps participants understand

"We thought we needed a facilitator, and then we realized we knew how we wanted it to go, so no one could facilitate it but us—we knew where we wanted to take it."

their involvement and role. To make this connection, a facilitator can explain how the event will unfold and say, "This matters to all of us because this is our community, these are our neighbors [individuals with disabilities], these are our employers, these are our employees. We need everyone in our community to be a contributing member. This will make our community stronger."

In contrast, a facilitator who does not explain the process nor connect participants to the topic, risks having less engaged participants who do not understand their role or how they could contribute to the issue.

Framing begins with the invitation (see Figure 8 in the previous section). Notice how this event was publicized as jointly sponsored by two diverse stakeholder groups: a school district and a chamber of commerce. The rationale outlined in this invitation also underscores the mutual benefits to both individuals with disabilities and the broader community when more inclusive employment opportunities are available. Likewise, the facilitator's introduction at the

beginning of a conversation sets both the tone and direction for the conversation. At Emily and Tanya's conversation highlighted on page 28, the quotes posted around the room and the opening slideshow that contrasted the differences between being tolerated, acknowledged, and included made the case that inclusion is important and relevant to all people. By setting this tone, participants understood the relevance of the topic to their experience. Another organizer who hosted a conversation on youth employment, asked her facilitator to point to local data showing that businesses with entry-level positions needed reliable employees, and youth with disabilities needed early work experiences. The facilitator then called on the collected group to think of ways to meet both groups' needs simultaneously.

## Facilitating introductions & summarizing key points

After the facilitator has welcomed the group and framed the event, the first question is posed and the small-group discussions begin. The table hosts start by asking everyone to share their name and why they came. Extended introductions could easily take all of the time, so keep them very brief so there is plenty of time to discuss the question.

Each time participants switch tables, the table hosts facilitate introductions before the round of conversation begins so that everyone knows each other's

name. The table hosts also very briefly summarize the previous round of conversation and asks each person to briefly share one key idea or insight from the conversation at their previous table. This enables everyone to hear, connect, and build upon ideas that have been discussed, thereby deepening the discussion on the current question.

## Keeping the conversation on track

Strong facilitation ensures that community conversations lead to new solutions, connections, and resources, rather than yet another list of barriers and seemingly insurmountable problems. Both facilitators and table hosts play a key role in keeping the conversations on track. Certainly, facilitators and table hosts should honor participants' experiences and challenges, but they also should encourage and guide participants to build upon those experiences to consider how their community can change and improve.

After framing the event at its opening, the facilitator floats among tables to assist the table hosts as they guide discussions toward local solutions. An example of how a facilitator or table host can both validate individuals' experiences and guide discussion toward community change might be to say, "It sounds like you have encountered a lot of barriers. What are one or two things we could begin to do differently in our community that might move us beyond these challenges?" Other phrases that redirect the conver-

sation back to the topic include, “I’m going to pull you back to the question...” or “So what’s going to help?” If an individual does not have ideas of their own, a facilitator can turn to the entire table to ask for ideas. For example, one facilitator frequently used this approach: “John has not had a lot of success in advocating for inclusive school experiences for his son. From your experience, what could we do as a community to work on this issue together? Who do we know who could help us in this effort?”

Besides keeping the conversation on topic, the table hosts also invite everyone at their table to share their responses to the questions raised by the facilitator. While some participants will readily share their views, others may need some encouragement to voice their thoughts. A table host may try comments like:

- “Sarah, we’re interested in what you think about this.”
- “How about you, Joe? What is your perspective?”

Conversely, there may be a person who tends to dominate the conversation. Recognize their contributions and ask another participant to speak by saying:

- “Those are good ideas. Let’s see what Marta has to say about this.”
- “Who else can build on Nathan’s idea?”

During these conversations the table hosts should write down key points or thought-provoking ideas shared at their table. The table host can use this information to summarize the conversation and to share back with the organizer. Otherwise, many of the creative and compelling ideas that were discussed at individual tables may get lost. Table hosts should also encourage everyone at their table to write and draw on the paper placemats their ideas and insights. These placemats can remain at the table when everyone switches seats for others to add to, or people can bring their placemats to the next table to continue adding new ideas.

## Harvesting the best ideas and solutions

Conversations that yielded the most concrete ideas for change and personal commitments from participants tended to provide sufficient time for a large-group discussion after the series of small-group conversations at individual tables. Sometimes called “the harvest,” this final 30 to 40 minutes of the evening invites all participants to discuss together the ideas they heard during the evening that resonated most strongly with them or seemed to be the most promising. Although table hosts will have taken notes of the ideas that were shared at each table and participants will have switched tables two or three times, a time of large-group discussion allows the very best ideas to be voiced and discussed by everyone together. A good facilitator will encourage all participants to share their ideas for change, identify themes emerging across the series of small-group

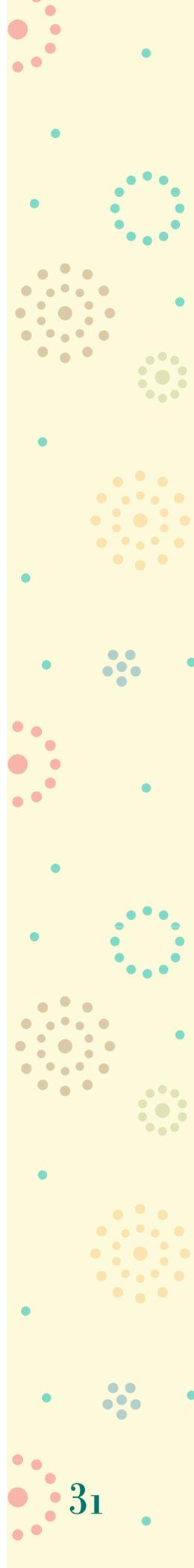
discussions, and gently push the gathered community members toward a commitment to action.

Facilitators can begin the harvest by making connections with statements like:

- “It sounds like there was a lot of great discussion. It’s time to pull it all together and think about next steps we can take as a community.”
- “It sounds like this group had a great idea. Did anyone else talk about ways to accomplish this goal?”
- “Your table had some great ideas about employment. I know other tables talked about that as well. What were other potential ideas people came up with?”

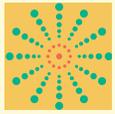
Sometimes, they can elicit a specific example that they heard at a table. If an individual does not feel comfortable sharing their idea in the large group, the facilitator can summarize the example. For example, some youth and young adults with disabilities were quite active in small-group discussions, but were reluctant to speak in front of a large group.

The facilitator also is responsible for bringing the conversation to a close at the end of the harvest, thanking people for their contributions and sharing potential next steps for the community. At most of the events in our project, participants were asked to sign in and include their email and mailing address (see Figure 12 for an example sign-in sheet). This allowed the organizers to share a summary of the conversation and one or two next steps with participants within a few days of the conversation. At two events, facilitators asked someone to type up a





# After the conversation



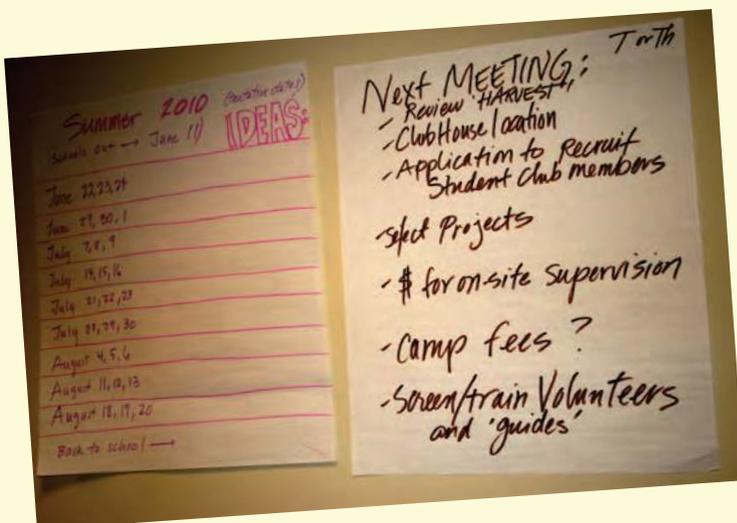
Organizing a conversation is a

significant endeavor, but it is really just a springboard to gain long-term community momentum around inclusion. Hopefully, you are reading this section as you organize your event to keep in mind a few ideas about what you would like to do to build that momentum after your conversation has occurred.

**FIRST**, have realistic expectations. Community conversations are a wonderful vehicle for creating excitement around an issue of importance in the lives of people with disabilities and their families. The organizers, planning team, and participants usually walk away from the conversation feeling energized and hopeful about what can happen next. So it can feel disappointing when a couple of weeks go by and it seems like nothing has happened. You and other members of the planning team may be busy catching up on responsibilities that were put on hold while you prepared for your event. Keep in mind that this one event will probably not “change the world” and result in a more inclusive community overnight. Try to be patient and realistic. The outcomes associated with a community conversation may not be visible for a long time and they may be subtle.

**SECOND**, consider the role you personally anticipate having in carrying out the ideas raised at the community conversation. Your own willingness to continue involvement varies greatly depending on the desired outcomes. For some parents in our project, the main goal was to organize and hold the conversation. They knew that an event would increase awareness and help participants see ways they could help make their community a more inclusive society. But, they did not necessarily see themselves playing a prominent role after the conversation was over. However, other parents desired tangible action from the event and they wanted to help new ideas take shape. This attempt to keep the energy alive can be challenging and frustrating. Our parents found it disappointing when they realized that if they personally did not work hard to sustain the energy, it would likely wane.

**THIRD**, keep in mind that one person cannot be responsible for everything. One of the main points of a community conversation is to share responsibility for change. It may be helpful before the conversation to consider what and how much you can realistically do after the event. To keep the momentum going, it is important to find other partners who can help carry out the next steps. These partners may be participants who showed strong enthusiasm for the cause and expressed interest in remaining involved. Some of our parents



are realizing that after the event, their role of organizer continued. They discovered that other people—their new partners—were motivated to put forth energy and time to complete initiatives and take action but they needed someone to lead them.

**FOURTH**, think about the kind of change you would like the community conversation to spur. For example, you might anticipate:

- Greater awareness in the larger community about inclusion and disability issues
- More opportunities for children and youth with disabilities to participate in school programs and community activities
- Creation of new work groups that focus on specific projects
- Organizing another community conversation on a more specific topic

Having an idea of what you would like to see happen as a result of your conversation may clarify what steps can come next after the event is over. It may also help you direct others to action.

**FIFTH**, during the harvest, consider issuing a “call to action” to invite people to commit to any of the ideas or projects that have been raised during the conversation. There are different ways to do this. Pass out commitment cards that ask people to list one thing they are going to do after the event to increase inclusive opportunities (see Figure 13 for an example). Pick these cards up and mail them back to participants at a later date as a reminder. Consider listing people’s names next to their ideas during the harvest. Or, at the end of the event, ask any one who is interested in assisting on a specific initiative to write their name next to the initiative or let you know of their interest.

Once you have conducted your conversation, here are some next steps to consider.

- Make sure to celebrate after the event is completed. You have taken an important first step to launching new conversations in your community. Make sure to give yourself this pat on the back.
- Contact all the participants and planning members to thank them for making the event a success.
- If you collected participants’ written notes and placemats, read through this information to see if any additional ideas emerge. Look for interesting quotes, insights, or comments that you could share with others. Keep in mind that these notes can be difficult to decipher if you were not directly involved in that particular conversation.

**FIGURE 13:** Example commitment card

**Commitment card**

Name \_\_\_\_\_

Return address \_\_\_\_\_

**What will you commit to after this conversation?**

\_\_\_\_\_

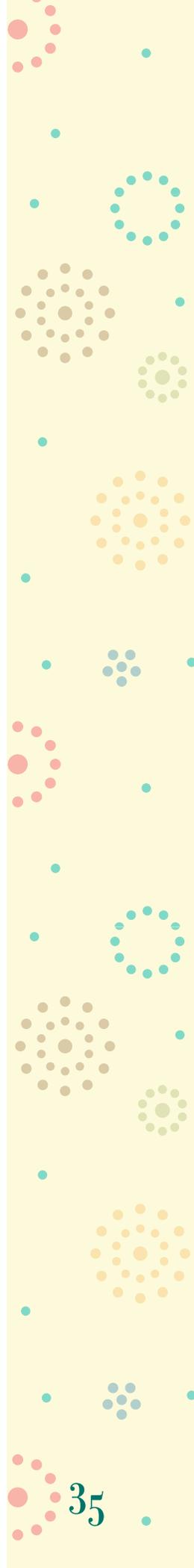
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\_\_\_\_\_

\_\_\_\_\_

- Share the information and ideas generated at the event back with participants, planning members, and others who expressed interest, but were unable to personally attend. This is done most efficiently through email, but you can call people or meet face-to-face with key stakeholders, such as a mayor or school board member.
- When you share this information with people, invite them to act on any idea that interested them. They do not need to wait for you to initiate action. Posing a question like, "How could we get started on this?" invites people to offer next steps. This shares the ownership of the event and its results with all the people in attendance.
- Pass a summary of your conversation on to any other person or group who would be interested in it. For example, if a number of your participants were teachers who voiced ideas and strategies they would like to see their school implement, share this information with the school's administrator.
- Pass a summary of ideas from your conversation to any stakeholder or stakeholder group who needs to become aware of the community's position and perspective on inclusion and disability issues. Examples of groups you could share results with include school boards, school administrators, parks and recreation, city council, chamber of commerce, and others. This summary does not need to include specific names or contact information as it is important to protect the confidentiality of participants.
- Follow up with anyone from the conversation who expressed interest in assisting with a project or discussing ideas further.
- Create a list of participants who seemed especially interested and engaged. These people could be called upon to assist with a future project or initiative.

Other next steps after the event may come to you from participants or others in the community who heard about your conversation. You may be asked to assist with an organization's related initiative or to facilitate another community conversation for a particular group or around another topic. These opportunities are some of the surprising outcomes that can emerge after holding a community conversation.



# Conclusion

Community conversations offer a fun and well-received approach to engaging more people in an important cause, finding possible solutions, and being a catalyst for change. We have shared numerous suggestions, based on our experiences, those of the parents in our project, and World Café resources ([www.worldcafe.com](http://www.worldcafe.com)) to help you organize and host a conversation in your own community about issues that matter to you. Please do not let the many details and recommendations offered in the previous pages deter you from organizing and holding an event. The conversation process offers great flexibility—be creative and make it your own. At the end of our parents' conversations, participants completed an evaluation. Regardless of venue decorations, how well the questions were worded, or whether the table hosts were thoroughly prepared, nearly all participants (96%) across the 10 conversations felt the event was a good use of their time. Even if glitches arise on the evening of the event, participants will enjoy and gain from it, as will you. As one parent said, "The only failure is not holding a conversation." We encourage you to go for it!



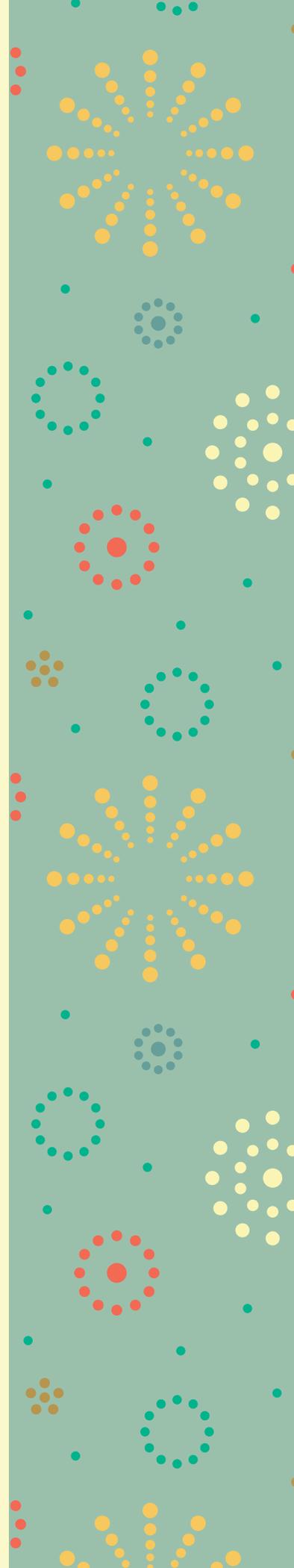
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## Who We Are

Mind and Memory Matters is an initiative between the WI Department of Health and WBPDD to provide education and training to families and care providers on the prevalence of Alzheimer's in the developmental disabilities community, early detection, obtaining a diagnosis, caregiver stress and more.

If you would like more information or would like to request a training please contact us or visit our website  
[www.MindandMemory.org](http://www.MindandMemory.org)

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Dementia Awareness Outreach Specialist  
608-266-5565  
[Brenda2.Bauer@wisconsin.gov](mailto:Brenda2.Bauer@wisconsin.gov)

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Communications Specialist  
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[Jeremy.Gundlach@wisconsin.gov](mailto:Jeremy.Gundlach@wisconsin.gov)



# Mind and Memory Matters Social

## Menu

Join us for a night of community and conversation in a relaxed setting!



### *Social Etiquette*

- Focus** on what matters
- Contribute** your thoughts
- Speak** your mind and heart
- Listen** to understand
- Link and Connect** ideas
- Listen together** for insights and deeper questions

*Doodle, Connect,  
Have Fun!*

## *Project Goals*



Increase awareness of the connection between Intellectual/Developmental Disabilities and Alzheimer's/Dementia.

Provide outreach, screening, training, consultation and support for families and individuals with Intellectual/Developmental Disabilities.

Provide Training/Outreach to Professionals who support people with Intellectual/Developmental Disabilities.

## *Daily Specials:*

**1.**

What do you want to know more about dementia and how it affects people with I/DD?

**2.**

What can this project do to develop information and resources to support people with both I/DD and dementia and their caregivers?

**3.**

What are the best ways to get people to participate in screening for early detection?

**4.**

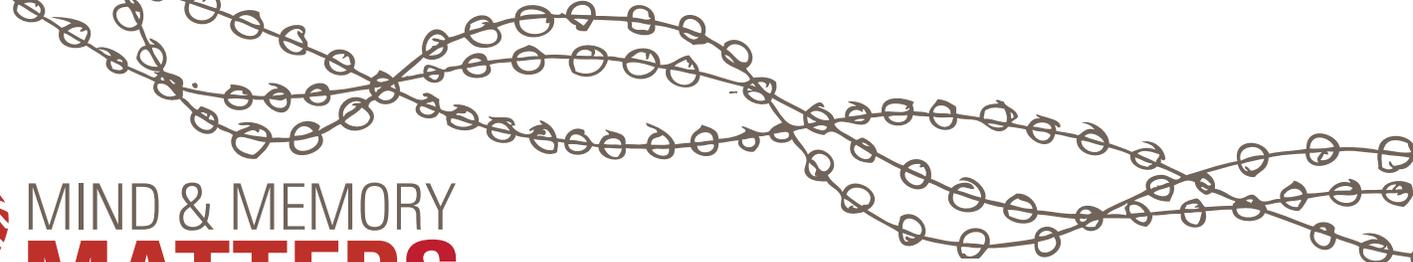
As a caregiver, what is your biggest challenge? Biggest Success?

**5.**

What supports/resources would you find most useful?

**6.**

With the information we've discussed today what should Mind and Memory Matters next steps be?



# MIND & MEMORY MATTERS

## Community Conversation Notes

Date \_\_\_/\_\_\_/\_\_\_ Group Reporter \_\_\_\_\_ Group Location \_\_\_\_\_

Our conversation started with...

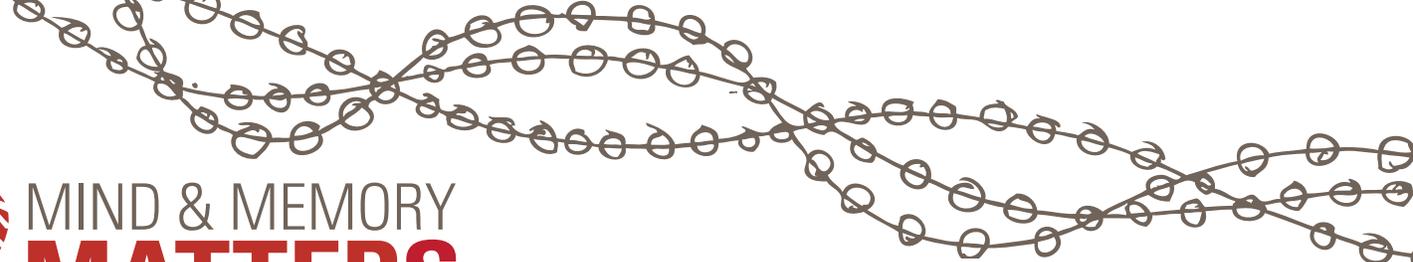
Four horizontal grey bars for writing notes.

Our issues and concerns regarding I/DD and Dementia...

Eight horizontal grey bars for writing notes.



\*Please email completed form to:  
[Brenda2.Bauer@wisconsin.gov](mailto:Brenda2.Bauer@wisconsin.gov) or  
[Jeremy.Gundlach@wisconsin.gov](mailto:Jeremy.Gundlach@wisconsin.gov)



# MIND & MEMORY **MATTERS**

## Community Conversation Notes

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Our recommendations and information we need are...

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Area for writing recommendations and information needed, consisting of 18 horizontal grey bars.



\*Please email completed form to:  
[Brenda2.Bauer@wisconsin.gov](mailto:Brenda2.Bauer@wisconsin.gov) or  
[Jeremy.Gundlach@wisconsin.gov](mailto:Jeremy.Gundlach@wisconsin.gov)



# MIND & MEMORY MATTERS

## Community Conversation Notes

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Caregiver biggest challenge? Best success?

Challenge

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Success

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Best ways to get people to participate in screening?

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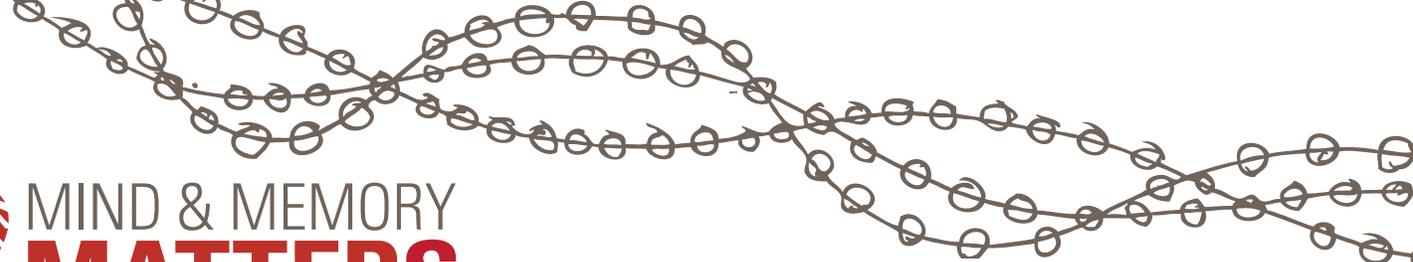
What should Mind & Memory Matters do next?

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# MIND & MEMORY **MATTERS**

## Community Conversation Notes

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### Additional Notes

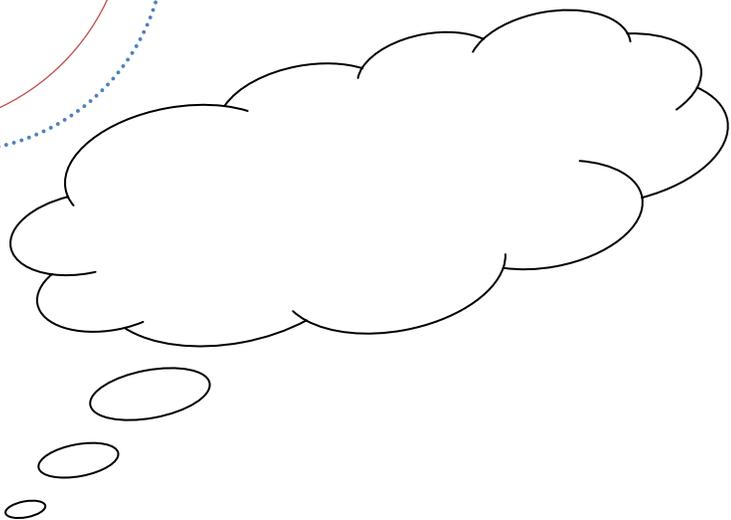
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A series of 18 horizontal grey bars provided for taking additional notes.









**Today is going to be AWESOME**

# { The Appendix }

Caregiving can be overwhelming, confusing and frustrating. Trying to understand the terms and acronyms of health care can add to an already stressful situation. The Glossary is meant to help define some of the vocabulary and acronyms of health care and alleviate some of that anxiety. Of course, this guide book would not exist if it weren't for the information, training, and support provided by those listed in the reference section.

## Topics covered in this section:

- **Glossary**
- **References**





# Glossary<sup>1</sup>

**ACL** – Administration for Community Living – [www.acl.gov](http://www.acl.gov)

**AD** – Alzheimer’s Disease – See Section 2

**ADI-SSS Grant** – Alzheimer’s Disease Initiative – Specialized Supportive Services Grant – funding providing to BPDD for Mind & Memory Matters Project focused on IDD and the prevalence of dementia provide by the ACL.

**ADRC** – Aging and Disability Resource Centers are available in every county in Wisconsin. They offer non-biased information and assistance for older people and people with disabilities. The ADRC is also the gateway to obtaining publicly funded long term care.

**AFH** – Adult Family Home is certified by county social services or human services department in which a limited number of adults that are unrelated to the operator, receive care, treatment and services. Certified or Licensed under ch.HSS 82 rules.

**Aging Network** - Refers to Department’s Bureau of Aging and Disability Resources, Area Agencies on Aging (AAAs), county and tribal aging units (C-TAUs), nutrition projects for the elderly, senior centers, and all other public and nonprofit organizations in Wisconsin that plan for, develop, and provide services for older adults.

**AOA** – Administration on Aging is part of Health and Human Services and is responsible at federal level for Older Americans Act programs.

**Assisted Living Facility (also CBRF)** - Popular name for a place where 5 or more adults reside which consists of independent apartments and which provides each tenant with up to 28 hours of supportive, personal and nursing services per week; 1997 Wisconsin Act 13 amended statutes to change official name to residential care apartment complex. Community Based Residential Facility

**BadgerCare** - Wisconsin’s program to implement a child health plan block grant under Title XXI of the Federal Social Security Act and to expand Medicaid eligibility to ensure that all children and parents in families with income below 185 percent of the Federal Poverty Level who do not have health insurance have access to health care.

**BADR** - Bureau of Aging and Disability Resources.

**BPDD** – Wisconsin Board for People with Developmental Disabilities – formerly WCDD Wisconsin Council on Developmental Disabilities

**CBRF** - Community-based residential facility; a place in which 5 or more unrelated adults live and where they receive care, treatment, or services, but not nursing care on any permanent basis, in addition to board and room. CBRFs are licensed by DHS under ch. HFS 83 rules.

**CIP** - Community Integration Program: CIP-IA is for persons relocated or diverted from DD centers; CIP-IB is for developmentally disabled persons relocated or diverted from nursing homes; CIP II is for elderly and physically disabled persons diverted or relocated from nursing homes to appropriate community settings with the assistance of home and community

**COP** - Community Options Program; a Department-financed, county-administered program to reduce the number of persons admitted to and resident in nursing homes; involves assessing the need of MA

**CMO** – Care Management Organization

**CWC** – Central Wisconsin Center – a short-term DHS residential facility in Madison for developmentally disabled persons which includes a Short Term Assessment Plan (STAP).

**DBS** – Disability Benefits Specialist A person in each Aging and Disability Resource Center who helps adults under age 60 years obtain and keep Medicare, Medical Assistance and other human services program benefits.

**DD** – Developmentally Disabled/Developmental Disability A disability of a person manifested before the age of 22, and expected to continue indefinitely, attributable to mental retardation, cerebral palsy, epilepsy, autism, brain injury or another neurological condition closely related to mental retardation or requiring treatment similar to that required for mental retardation, and that results in substantial functional limitations in three or more major areas of life activity.

**Dementia** – a group of symptoms - a usually progressive condition (such as Alzheimer’s disease) marked by the development of multiple cognitive deficits (such as memory impairment, aphasia, and the inability to plan and initiate complex behavior) ... *dementia is diagnosed only when both memory and another cognitive function are each affected severely enough to interfere with a person’s ability to carry out routine daily activities.* — *The Journal of the American Medical Association*

**DHS** – Department of Health Services formerly DHFS – Department of Health and Family Services (State) [www.dhs.wisconsin.gov](http://www.dhs.wisconsin.gov) and HHS - U.S. Department of Health and Human Services (Federal) [www.hhs.gov](http://www.hhs.gov)

**DRW** – Disability Rights Wisconsin - A Madison-based organization doing legal and other advocacy to protect and promote the interests of persons with a developmental disability or a mental illness. <http://www.disabilityrightswi.org/>

**DNR** – Do Not Resuscitate - orders of physicians to withhold restorative treatment, usually limited to cardiopulmonary resuscitation, from patients who suffer cardiac or respiratory arrest.

**DQA** - Division of Quality Assurance; responsible for licensing nursing homes, home health agencies CBRFs and hospices, approving hospitals, certifying health care providers for Medicare, certifying programs that train and test nurse assistants and aides and operating a registry of qualified nurse assistants and aides.

**EBS** – Elderly Benefit Specialist - A person in each county, usually in the county aging office, who helps elderly persons obtain and keep Medicare, Medical Assistance and other human services program benefits.

**FDD** – Facility for Developmentally Disabled – a nursing home primarily for developmentally disabled persons.

**Frontotemporal Dementia** - See Section 2

**Guardianship** – See Section 6

**GLITC** – Great Lakes Inter-Tribal Council – a coalition of 12 Indian tribes of Wisconsin and Upper Michigan.

**Health Care Agent** - An individual who has been designated by a patient, pursuant to ch. 155, Stats., Power of Attorney for Health Care, to make health care decisions on behalf of the patient.

**HHA** – Home Health Agency

**HIPPA** – Health Insurance Portability and Accountability Act of 1996 signed by President Clinton. Title I protects health insurance coverage for workers and their families if they change and/or lose their jobs. Title II requires national standards for electronic health care transactions and national identifiers for providers, health insurance plans, and employers

**HOS** – Hospice - A residential or nonresidential program that provides care to persons who are dying,

with the care provided not being directed at a cure of the individual but rather at lessening pain and other physical symptoms, with the provision of various kinds of support to the individual and the individual's family. Hospices are licensed by DHS under ch. HSS 131 Adm. Codes.

**ILC** – Independent Living Center – an agency that provides or arranges services to help severely disabled individuals live as independently as possible

**Lewy Body** - See Section 2

**LGBT** – Lesbian, Gay, Bisexual, and Transgender community

**Living Will** - Also referred to by the public as the “Living Will,” a form which enables a person to declare his or her wishes in advance concerning the use of life-sustaining procedures in the event of a terminal illness or injury when the person has become incompetent. Forms distributed by the Department's Division of Public Health.

**LTC** – Long Term Care

**LTS** – Long Term Support

**MA** – Medical Assistance also known as Medicaid (Title XIX) program which pays for necessary health care services for those that are eligible. Financial resources are not adequate to provide for their health care needs. Medical care for low-income persons.

**MCO** – Managed Care Organization as part of the MA Waiver program Family Care

**Medicare** - Title XVIII of the federal Social Security Act and 42 CFR 405 to 424; insurance-like payments for medical care of persons aged 65 and over; administered by federal Social Security Administration.

**MRI** – Magnetic Resonance Imaging used in health care as a diagnostic tool to produce images of body structure and organs

**NH** – Nursing Home - A place which provides 24 hour services including board and room to 3 or more unrelated residents who because of their mental or physical condition require nursing care. Nursing homes are licensed by DHS under ch. HFS 132 Adm. Codes

**NIA** – National Institute on Aging [www.nia.nih.gov](http://www.nia.nih.gov)

**NIH** - National Institute of Health [www.nia.nih.gov](http://www.nia.nih.gov)

**NTG** - National Task Group - See Appendix/References

**NTG-EDSD** - National Task Group - Early Detection Screen for Dementia - See Appendix/References

**OBVI** - Office for the Blind and Visually Impaired in the Division of Long Term Care  
[www.dhs.wisconsin.gov/blind/index.htm](http://www.dhs.wisconsin.gov/blind/index.htm)

**ODHH** - Office for the Deaf and Hard of Hearing in the Division of Long Term Care [www.dhs.wisconsin.gov/odhh/index.htm](http://www.dhs.wisconsin.gov/odhh/index.htm)

**PACE** - Program of All-Inclusive Care for the Elderly that is out of Milwaukee and Waukesha counties under Community Care and DHS

**Parkinson's disease** - See Section 2

**PCS** - Personal Care Services - Mainly refers to assistance with activities of daily living such as eating, dressing, bathing and walking

**POA** - Power of Attorney - for Health Care and Property and Finance - See Section 6

**PPO** - Preferred Provider Organization - A limited or preferred group of physicians and hospitals (providers) that offer a discount on their normal charges for services provided to members of an organization which contracts with it.

**PT** - Physical Therapy - using mechanical force and movements to help correct and promote mobility, function, and quality of life. May be provided with other medical services.

**RCAC** - Residential Care Apartment Complex (assisted living)

**Respite Care** - Temporary, intermittent relief for the family member or other person taking care of an elderly or disabled adult or a child at risk.

**SNF** - Skilled nursing facility; a federal Titles XVIII and XIX certification term and state licensing term for long-

term care facilities that provide care to residents who no longer need the type of care and treatment provided in a hospital but do require some medical attention and continuous skilled nursing observation.

**SSA** - Social Security Administration

**SSDI** - Social Security Disability Insurance

**SSI** - Supplemental Security Income - federal government income support program for aged, blind and disabled persons; checks are distributed by the federal government; monthly grant includes a state supplement amounting to over 20%.

**SSI - E** - The state's extra supplement to SSI payments made in recognition of exceptional expenses and available to persons who live in licensed or certified residential care settings or who live at home but receive a high level of supportive services.

**Supportive Home Care** - Care provided to elderly and disabled persons residing in their own homes; consists of assistance with daily living needs, including household care and personal care.

**SWC** - Southern Wisconsin Center - a DHS residential facility for developmentally disabled person in Union Grove, WI

**TBI** - Traumatic Brain Injury - a physical trauma to the brain caused by falls, vehicle accidents, violence or other external force that injure the brain. TBI can result in physical, cognitive, social, emotional, and behavioral symptoms, and outcome can range from complete recovery to permanent disability or death. In addition to the damage caused at the moment of injury, a variety of events in the minutes to days following the injury may result in *secondary injury*.

**Vascular dementia** - See Section 2

**WDC** - Wisconsin Disability Coalition



## References



The Mind and Memory Matters training materials, including presentations, handouts and this guide book, are based on information provided by the National Task Group.

For more information about NTG go to their website:  
<http://aadmd.org/ntg>

Resources provided by NTG including the NTG-EDSD:  
<http://aadmd.org/ntg/products>

### **Marcia Stickel, Clinical Nurse Specialist – University of WI Waisman Center**

Information and guidance also provided by Marcia Stickel, a community nurse in Dane county. Marcia directs the Wellness Inclusion Nursing (WIN) program which assists with cares for individuals with intellectual/developmental disabilities (I/DD) including those with symptoms of dementia.

