Dementia Action Collaborative
Washington State

Introduction to Dementia and Intellectual/Developmental Disabilities

Facilitator Guide

Developmental Disabilities Administration

Washington State Department of Social & Health Services

Transforming lives

Welcome to Introduction to Dementia and Intellectual and Developmental Disabilities (I/DD) Training. This training is meant to introduce direct support professionals to the fundamentals of how to understand, empathize and care for an individual with I/DD and dementia.

Trainer's Manual for Instructor-led Courses (Virtual and Classroom)
Course Title: *Introduction to Dementia and Intellectual and Developmental*

Disabilities (I/DD)
Course Code: TBD

# of CE hours: ?

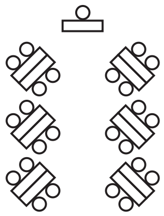
Class Size Recommendation: Min?- Max? (4-12 people)

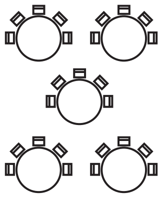
****Piloting**

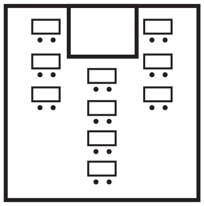
Intended Audience: Direct support professionals.

Before the event:

1. **Virtual:** Book the webinar room and send out links to all participants with log in information.
2. **In-person:** Reserve the room, invite attendees, and determine if you will provide light refreshments.
3. Along with the event, schedule time on your calendar to practice in advance. No matter how well you know the material, you should go through it before you stand to deliver. (Virtual: It is a good idea to do a "run through" a day or two before the training to make sure everything is working well. Have all presenters/trainers attend the run through.)
4. **Virtual:** make sure everyone has an electronic or printed copy of the material BEFORE the training. Have electronic copies handy and ready to email if participants show up without materials.
5. **In-person:** Prepare certificates. Print one for each person with their name, instructor number (if needed) and the training information. The certificate for this course is available in the master's section of this guide.
6. **Virtual:** Send certificates via email with a copy of the electronic evaluation form.
7. Practice using the activities. Ensure that you have included written instructions in the participant toolkit so they can follow along – including time each activity takes.
8. Gather all materials you will need to facilitate the training ahead of time. Do not count on materials that are saved in file folders on your computer (make sure these files are open and ready—any videos cued up). Be prepared and organized.
9. **In-person:** Arrange the room.







Each example arrangement allows for safe evacuation, small group discussions and easy access to the front of the room so participants can focus on the presenter and visuals.

Place a large table at the front of the room for training materials, laptop, anything you need for your presentation.

10. **Virtual:** start by NOT sharing your screen and request participants turn on their video. This will help participants (and facilitator) greet each other. Welcome them and review class expectations this way. Then share your screen and review the course material.
11. **In-person:** Provide stress-reliever objects for kinesthetic learners such as squishy balls, tangle toys, or pipe cleaners. Also have markers, post-it notes, 3x5 cards, and pens.

12. Greet participants as they enter.
13. **In-person:** Provide instructions on the dry erase board or easel regarding name tags, table tents or what to do to fill their time. (Table challenges or puzzles are a great way to fill time for early guests.)
14. **In-person:** Create a sign-in sheet including the course name, date and location. Participants may print names and sign in or pre-print participants' names and have them initial or sign for each day present. Participants must complete to receive a certificate. Archive the sign-in sheet or an electronic form for six years.
15. **Virtual:** You will want to find a way to track participants. You can screenshot the "Participants screen" in your webinar platform (be sure to teach people how to rename themselves so you see their first and last name). You can also use an online tool like Survey Monkey to take attendance.

Materials for this course:

Virtual:

- Computer
- Wi-Fi
- Materials for activities (if applicable)

In-person:

- Computer
- Wi-Fi
- Sign-in sheet/Participant Toolkit
- Items you will need to facilitate (Facilitator Guide)
- Blank paper
- Pens, markers
- Easel and paper
- Sticky notes/writing pads
- Name plate/name tags
- Fidget toys
- Monitor / projector and speakers
- Screen or blank white wall
- Long extension cord
- Materials for activities (if applicable)

In-person Easel sheets to prepare before class:

- Welcome
- Instructions for completing sign-in sheet, name tags, table tents, where to sit

Trainer Tips:

Your tone of voice needs to vary throughout the training. A visual learner likes it to be fast and funny, an auditory learner likes it medium speed and a kinesthetic learner likes it slow and calm. Avoid a monotone voice.

Be intentional in your movement. Stay in one location and if you have to move, be intentional! Some facilitators are also successful with slowly moving around the room.

Use normal hand gestures and arm movements.

Connect with people. Look at faces for no longer than 5 seconds or for a full thought. Looking people in the eye for longer than can make them uncomfortable. Looking over their heads breaks your connection with them. Make brief eye contact with everyone at some point during the training.

Focus on the group. What do they need? Are they getting tired? Give them a break, or do some movement. Are they hungry? Are they bored? Do not let your need to cover content make you forget that people cannot learn if they are anxious, bored, tired, hungry, or stressed.

Start training by reviewing the Purpose Statement and Learning Objectives.

Developed by:

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Index: Training

This training is intended to take_____hours and is presented by trainers approved by Dementia Action Collaborative. This training's intended audience is paid caregivers and direct support professionals, however much of the information would benefit a wider audience (Course Code: _______________).

Module 1: Fundamentals of dementia and intellectual/developmental disabilities (I/DD)

- What is dementia?
- Common type, signs and symptoms of dementia in individuals with intellectual/developmental disabilities (I/DD)
- Ways that individuals with dementia and I/DD change over time
- Building empathy and compassion

Module 2: How to care of individuals with dementia and I/DD

- Social justice, dementia and I/DD
- Meeting the challenges of dementia and I/DD
- Mapping strengths and the importance of interdisciplinary teams
- Family-centered approach to care
- Communication

Module 3: How to take care of yourself

- Self-care Tools for direct support professionals
- Helpful resources for direct support professionals

Icon Map

All visuals in this Facilitator's Guide are used with permission under a Creative Commons License or were free.

🚶	Activity
🧰	Participant toolkit/ handouts
💡	Trainer idea or note
?	Discussion / Questions to ask
💬	What to say, answers to questions
🎥	Video clips

This course was originally designed by members of the Dementia Action Collaborative for Direct Support Professionals.

Developmental Disabilities Administration

Dementia Action Collaborative
Washington State

Module 1:

Fundamentals of Dementia and Intellectual / Developmental Disabilities (I/DD)

- *Why it is important to understand both dementia and I/DD*
- *Signs of dementia*
- *Ways individuals with dementia and I/DD change over time*

Review the Introduction, Purpose of this course and the Learning Objectives carefully. Answer any questions participants may have about this course. Emphasize the importance of all Direct Support Professionals having a basic understanding of dementia and how it affects our community with I/DD.

Remember: individuals with intellectual and developmental disabilities are often marginalized and forgotten when supports and services are developed. Often symptoms of dementia are hidden by stigma, similar features of certain developmental disabilities and because of the lack of effective screening tools adapted to serve our individuals with I/DD.

Introduction

Providing direct care and supports to individuals with intellectual and/or developmental disabilities can be life-changing and meaningful work. When an individual with I/DD develops dementia, new dimensions are added to the care provided by direct support professionals. It can also be challenging to fill in gaps in services and care. This training will focus on the complexities of caring for an individual with I/DD and dementia.

Purpose statement

This training provides direct support professionals with insights to the uniqueness individuals with intellectual and developmental disabilities and dementia live with. This training offers tools and strategies DSPs can use to provide better supports to these individuals.

Learning objectives

1. **Fundamentals:** As a result of this training, DSPs will be able to articulate the fundamentals of caring for an individual with I/DD and dementia, including:
    - The impact of dementia on those with I/DD
    - How signs and symptoms of dementia affect the person with I/DD, caregivers and family
    - How dementia affects the individual's specialized care
2. **Caring for the individual:** As a result of this training, DSPs will use compassion, empathy, social justice and enhanced communication to support individuals with I/DD and dementia.

Understanding Dementia and I/DD

Introduction to dementia

Dementia is a condition caused by damage to or loss of nerve cells and their connections in the brain.

When brain cells cannot communicate normally, thinking, behavior, and feelings can be affected. Depending what area of the brain is affected, dementia can impact people differently and cause different signs and symptoms.

Some of the most common signs and symptoms of dementia include:
- Memory problems, particularly remembering recent events
- Increased confusion
- Reduced concentration
- Personality or behavior changes
- Apathy and withdrawal or depression
- Loss of ability to do everyday tasks

What is dementia?

Dementia is a general term for a decline in mental ability that is severe enough to interfere with daily life. To be considered dementia, two or more of the following functions of the brain must be affected:
- Memory
- Communication and language
- Ability to focus and pay attention
- Reasoning and judgement
- Visual perception

? Give each participant some time to contemplate and jot down some ideas on the discussion question below and then debrief with the group. The highlights are:

– Signs of dementia are often missed when caring for individuals with developmental and intellectual disabilities.

– There is a cognitive bias in how individuals are screened for dementia (high expressing, reading, writing and comprehension ability).

Discussion questions:

Why is understanding the intersection between dementia and I/DD so Important?

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Dementia and I/DD

There are a few reasons why it's important to understand I/DD and dementia. The occurrence of IDD and dementia is relatively new. People with I/DD are living longer, just like the larger population. Given that age is the biggest risk factor for dementia, living longer puts people with I/DD at greater risk for dementia.

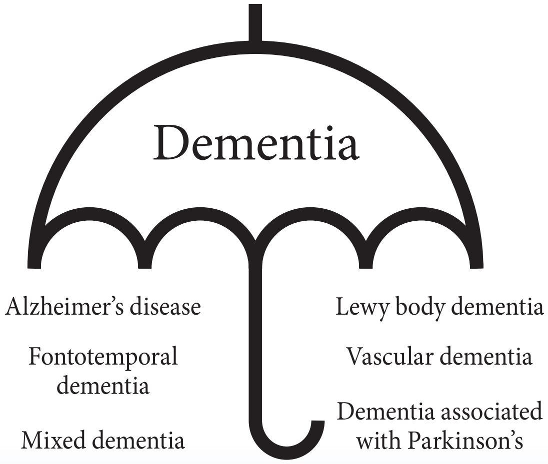
Another reason it is important to understand I/DD and dementia is that life for an individual changes dramatically. This means that life changes for their family, friends and direct support caregivers, too.

TEACH-BACK ACTIVITY: You will be divided into small groups. Each group will be assigned a different type of dementia. Below are descriptions of each type. For virtual trainings there is a link below, please click on the link and research the type of dementia you were assigned. For in-person groups, your trainer will give you a handout with information about each type of dementia.

Prepare to teach the class about this type of dementia. You can use graphics, summaries, discussions, and role-playing to teach this source material back. Please be creative!

Types of dementia

The diagram below shows dementia is an "umbrella" for the many kinds or causes of this condition.



Alzheimer's disease: the most common type of dementia accounting for approximately 40-70% of all cases. https://www.nia.nih.gov/health/what-alzheimers-disease

Vascular dementia: second most common type of dementia accounting for approximately 15-25% of all cases. https://www.mayoclinic.org/diseases-conditions/vascular-dementia/symptoms-causes/syc-20378793

Lewy body dementia: accounting for approximately 2-20% of all cases. https://www.nia.nih.gov/health/what-lewy-body-dementia#:~:text=Lewy%20body%20dementia%20(LBD)%20is,movement%2C%20behavior%2C%20and%20mood

Frontotemporal dementias: the most common type of dementia accounting for approximately 2-4% of all cases. https://www.nia.nih.gov/health/what-are-frontotemporal-disorders

Mixed and other dementias: Parkinson's disease, Huntington's disease, HIV or alcohol-related dementia and others have a rare occurrence. https://www.nia.nih.gov/health/what-mixed-dementia-causes-and-diagnosis

Activity Teach-Back Format Below

TEACH-BACK ACTIVITY: Have small groups type or write directly onto the template below. This will help them organize their thoughts and keep their ideas brief and succinct.

Once they complete that in the small groups, debrief with the larger class and ask small groups to summarize their work or display the template to the class. This will help spark large group discussions on this topic.

Looks Like (Signs)

- Short term memory loss

Feels Like (Symptoms)

Type of Dementia

____

Resources / Supports

Risk / Challenges

Now your class is aware that there are different types of dementia. Remember, this may be a new concept to some or many participants in your class. This transition is to help individuals start to recognize some of the different symptoms of dementia. Remind them that different types of dementia can share similar symptoms and only a professional can accurately offer a dementia diagnosis, but it helps all of us to begin to recognize the symptoms and some of the differences.

Have the class read the chart below and ask them the following questions:

– Does any of the information on the chart surprise you?

– Why do think it would be important to recognize differences in symptoms?

– Symptoms of dementia are often missed (in the early stages) for individual with I/DD, why do you think this is?

– Individuals with I/DD and dementia may already have a cognitive difference that mask the dementia symptoms (examples—challenges with short term memory, challenges with attention span, etc.).

What's the difference between these types of Dementia?

	Alzheimer's	Vascular demenia	Dementia with Lewy bodies	Frontotemporal dementia
Prevalence	**60-80%**	**15-30%**	**12-20%**	**10-15%**
Early Symptoms	• Memory loss • Executive dysfunction • Aphasia • Apraxia • Apathy/ depression • Poor insight	• Slow processing speed • Poor attention • Less memory impairment • Poor acquisition/ learning • Apathy/ depression	• Visual hallucinations • Muscle rigidity • Parkinsonism • Tremors • Fluctuating cognition • Visuospatial problems • Memory loss	• Behavioral issues • Personality change • Attention problems • Executive dysfunction • Language problems
Course	**Progressive, gradual**	**Progressive, gradual or step-wise**	**Progressive, fluctuations**	**Progressive, rapid**

Intersection of dementia and I/DD

In the United States today, people with intellectual and developmental disabilities, mostly individuals living with Down syndrome, develop dementia (30%-70% over age 60 with Down syndrome have dementia.

People living with other developmental disabilities also develop dementia (10% over age 65 living with ID/D besides Down syndrome develop dementia). [Knowles et. al, 2019]

After you have the discussion above have your class look at the discussion question below and independently write down their answers. Give them about 5 minutes to contemplate this and write down and answers. You can invite them then to share with a small group or with the whole class. Then be sure to review the ideas below of how Direct Support Professionals (DSPs) can make a difference.

Discussion questions:

How can direct support professionals make a difference in the lives of individual who have dementia and I/DD?

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Direct Support Professionals can make a difference!

1. **DSPs providing direct care:** are most likely to notice changes (even subtle) in the individual. If you know signs and symptoms of dementia you can proivde early detection and intervention before signs are severe. Early intervention increases supports to improve the individual's quality of life, provides more time for decision making before the individual is no longer able to, and ensuring supports for direct service professionals are in place.
2. **Recognizing signs and symptoms of dementia early:** most changes indicating dementia relate to behavior, mood, inability to complete tasks done for years, inability to learn new tasks and loss of interest in socializing. These changes likely mean the direct support professionals will continue to provide more assistance and support with daily living activities, behavior management, and health issues.
3. **Recognizing memory loss:** allows the individual and DSP to plan for the future, for example preparing for home modifications that make it easier and safer for the individual to navigate their residence.
4. **Prolonging independence:** There is no cure for dementia and memory loss. Early support and service interventions when signs and symptoms of dementia arise promote a longer period of independence, but no amount of support will slow the ultimate progression of dementia or stop the loss of skills, functioning and neurological impacts. It is important to practice person- and/or family-centered care. Each individual and family system are different and require unique supports.

This activity can be completed individually or with a small group. You can also turn this into a whole class trivia activity. The point is to both engage and check for knowledge retention from this section of the training.

Common dementia types for individuals with I/DD

For individuals with intellectual and developmental disabilities, those with Down syndrome can develop Alzheimer's (*50% of those over age 60 with Down syndrome may develop Alzheimer's), but typically, not other types of dementia. Individuals with IDD that is not Down syndrome may develop any kind of dementia. (*citation: Aging and Down syndrome, National Down Syndrome Society (NDSS), Moran,J et al, 2013, p.19)

Activity: review the matching activity below. Common signs and symptoms of dementia are listed. Some are not symptoms of dementia. Match common signs and symptoms of dementia to the brain image.

Learning checkpoint: Symptom Matching Activity

Below is a list of symptoms. Draw an arrow to the the human brain image if the word onthe list is a dementia symptom.

- Memory loss (Example)
- Increased confusion
- Nausea
- Reduced concentration
- Congestion
- Changes in behavior and/or personality
- Changes in personality
- Loss of skills (activities of daily living)
- Apathy, withdrawal, depression

Memory loss

One of the most common signs of Alzheimer's dementia is forgetting information recently learned, such as dates or events, or new information. An individual may find it difficult to rely on others and memory aids for keeping track of life. Most people forget things more frequently as they age. They can usually recall them later if their memory loss is age-related and not due to dementia.

Increased confusion

Dementia can make it hard to judge the passing of time. People may also forget where they are at any time. They may find it hard to understand events in the future or the past and may struggle with dates.

Reduced concentration

Some people living with dementia may experience changes in their ability to develop and follow a plan, or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things they did before.

Personality or behavior changes

Dementia can change a person's personality and behavior. They may act differently than before, and say or do things they would not have previously done. Family and friends may feel uncomfortable and be confused about why the person is behaving this way. As brain neurons are lost, behaviors often reflect parts of the brain losing neurons. For example, the brain's frontal lobe controls humor, initiation, motivation and impulse control. When damage occurs, a person may have trouble concentrating or may become impulsive and act out sexually or aggressively.

Apathy and withdrawal or depression

People with dementia can lose interest in or concern about emotional, social, spiritual or physical life. They may become depressed and no longer care about activities they used to enjoy. A person with dementia and depression may feel desperate, yet unable to express sadness in words. They may develop delusional fears, agitation and withdrawal, or aggressive or suicidal behavior.

Loss of ability to do everyday tasks

A person with dementia may find it difficult to complete tasks they used to regularly do, such as changing television settings, using a phone, making a cup of tea, or getting to a familiar location. They may also find it hard to engage in conversations. They may forget what they are saying or what somebody else has said. It can be difficult to enter a conversation.

Below are some scenarios about individuals who have a particular symptom of dementia arising. Ask the class to name/identify the symptoms that is being illustrated in the scenario below. You can do this together as a small class or break people into smaller groups and assign each group a scenario to read and identify.

Maria: lives with her adult daughter and her three grandsons. Maria has autism. She is very close with her family. She has taken care of her grandsons since they were babies while her daughter went to work full time. Her grandsons are all in high school now. Recently Maria's daughter sought support from their family doctor because she noticed that Maria is not acting like herself. She accuses her grandsons of stealing her things that later the family finds in odd places. Maria's daughter says her mother was once happy, easy going and the jokester of the family. Now Maria seems angry, withdrawn and paranoid. Maria's team thinks she may be showing symptoms of dementia. Can you identify a symptom?

There are few different symptoms that can be identified but the one we are looking for is: ***Personality or Behavior Changes***.

John: lives with his wife of 50 years. John and his wife have Down syndrome. They live in a retirement community. Lately John's wife has been noticing that he is more forgetful. John has always had challenges with short term memory and has learned to create a visual schedule for himself and a routine he follows every day. Common memory lapses for John (and many other adults) are that he often forgets where his keys are. Recently, however, John's wife received a call from their local Safeway, indicating that John was in their parking lot and could not find where he parked his car and could not remember his home phone number. Luckily a neighbor worked as a clerk at the store and had John's home phone number. John's team believes his is showing signs of dementia. Can you identify a symptom?

There are few different symptoms that can be identified but the one we are looking for is: ***Memory Loss***.

Malcolm: lives in his own apartment with a roommate he has known for 10 years. He moved there after his sister, who was his guardian for most of his life, died. He is close with his nieces and nephews and visits with his family every week. Malcolm has autism spectrum disorder and follows a strict daily routine. He receives support from a Supported Living Program for activities involving dressing, bathing, running errands around town to pay bills, shopping and participating in his self-advocate activities with Developmental Disabilities Administration. His direct support professionals have noticed he needs more support with tasks he was normally able to complete on his own. He is nervous about bathing and has resisted his typical bath days and his bath aide is trying more and more creative activities to help ease his worry and anxiety around bathing. His Direct Support Professionals have noticed that he forgets to turn the burner off after he makes his oatmeal, and needs more support in activities he used to perform with ease. When offered help, he often becomes frustrated and verbally snaps at Direct Support Professionals around him. Luckily, his team has been with him for a long time, so they know how to joke with him, play his favorite music and generally ease his upset. He team believes he is showing signs of dementia. Can you identify a symptom?

There are few different symptoms that can be identified but the one we are looking for is: ***Loss of ability to do everyday tasks***.

Janice: lives with her adult daughter in a small home in a rural community. Janice loves to garden, go on hikes in the woods and adores the animals on their farm. She normally rises early to feed the chickens and can often be found laughing with the baby goats in the goat pen. From sunrise to sunset, Janice can be found outside tending to various chores and enjoyment at the farm. Her sister called her DDA Case Manager because she was concerned about Janice. Lately Janice has not been wanting to come out of her room or leave the house. Last week they found her at a neighbor's property, apparently lost and when the neighbors (who she has known most of her life) approached her, Janice ran into the woods. Her sister found her and took her home. Since then, she has not wanted to leave her home. Her sisters said she is not her normal active and happy self. Janice's team believes she is showing signs of dementia. Can you identify a symptom?

There are few different symptoms that can be identified but the one we are looking for is: ***Apathy, withdrawal or depression***.

Summary

The early signs and symptoms of dementia can be very subtle and vague and may not be immediately obvious. By learning some of the most symptoms of dementia, those living with someone experiencing the onset of dementia may be more aware of these changes earlier and be able to seek support and resources.

Ways to care and support people with dementia and I/DD may change over time

Research and anecdotal information indicate that an individual with ID/D changes in significant ways once dementia is present in their lives. These changes may create a substantial difference in how an individual lives their life and may create significant changes in how support should be provided to this individual.

Direct support professionals and case managers may face challenges supporting clients developing dementia. This training addresses five ways care and support can be provided when dementia is present for an individual with IDD.

1. **Dementia has a broad impact:** Once an individual begins experiencing dementia, it may affect every aspect of their lives.
2. **Increased care needs:** More and higher levels of care may be needed over time for an individual with dementia.

Have attendees pair up and write down all of the ways dementia may impact activities of daily living. Have the groups share to the class an idea of how broad the impact of dementia can be.

Rank the levels of care

(1 being the lowest level of care and 7 being the highest level of care)

______ Living independently (own home)

______ Memory care facility

______ Living at home with a full-time family caregiver or with full-time 24-hour care and support (example-supported living)

______ Living in a group home, group training home or adult family home

______ Assisted living facility (non-memory care)

______ Living independently with part time care/supports (example—supported living)

______ Nursing home (non-memory care wing)

Answers

1 Living independently (own home)

7 Memory care facility

4 Living at home with a full-time family caregiver or with full time 24 hr. care and support (example-supported living)

5 Living in a group home, group training home or adult family home

3 Assisted living facility (non-memory care)

2 Living independently with part time care/supports (example—supported living)

6 Nursing home (non-memory care wing)

3. **Risk factors around medication management needs:** Because of memory loss, an individual with dementia may no longer be able to remember which medications they take, the dosage, or frequency. This loss of skill can be life threatening and direct support staff must be vigilant in increasing supports as necessary.

? Pause here, this is an important discussion. Highlight that dementia often co-occurs with other acute medical conditions such as diabetes and hypertension. Ask the class what might happen if an individual with dementia injects too much insulin or doubles their heart medication? This can be a fatal mistake. This is why good personal care is vital to support individuals with dementia and increasing that care when the need arises is so important.

4. **Impacts on decision-making:** Because dementia attacks the executive functioning brain areas (where we process risks and make critical decisions) an individual with dementia may experience a loss of inhibitions, and their ability to emotionally regulate may be compromised. Direct support professionals may experience an individual's angry behavior. Conversely, an individual may become anxious at certain times of the day, particularly the transition from day to night. It is important to learn what soothes that individual. Use environmental interventions, such as calming activities, familiar surroundings, limiting activity or changes in environment whenever possible. The person will likely not benefit from skill-building interventions (learning coping skills, new routine, etc.). DSPs and CMs should (also) not argue or try to "talk sense" into a person experiencing distressing behaviors. Good questions to ask yourself when the person you are supporting becomes dysregulated: Are they H.A.L.T-P (hungry, angry, tired, lonely or in pain)?

Hungry
Angry
Tired
Lonely (or sad)

Pain

It is important to add P to HALT-P because individuals who are in pain may not benefit from skill building and their behaviors may mask as symptoms of dementia. For example, individuals who are experiencing pain have trouble concentrating, may experience memory loss and personality changes. Conversely, individuals with dementia may have trouble telling direct support professionals that they are in pain. Pay attention to indicators of pain and work with medical professionals to adequately manage pain.

Some of the individuals you will work with who have I/DD and dementia may not be able to verbally communicate their needs with you. It is important to identify non-verbal cues for each of the following.

Hungry (***example*** *– holding stomach*): ____

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____

Angry (***example*** *– yelling*):____

____

____

Tired (***example*** *– falling asleep in public*): ____

____

____

Lonely (***example*** *– following caregiver from room to room*):______________________________

____

____

Pain (***example*** *– wincing, whimpering*):____

____

____

The important part of the activity above is that your class start to think about how an individual would communicate these conditions when they are not able to verbally speak to their caregiver. It is important for direct support professionals to get to know how to recognize these signs and intervene early.

5. **Social impacts of dementia:** Dementia's progression may result in a loss of skills. This includes social skills. An individual with dementia may not want to socialize the way they used to. Individuals with dementia may also be comforted by routine and may have strong reactions to changes in their environment. DSPs and CMs may want to suggest one-to-one socialization. This will be less overwhelming for the individual living with dementia.

Below are some creative activities direct support professionals can engage in with someone who has I/DD and dementia:

Listen to music and sing: Music can awaken the brain and is stored in another part of the brain than language. It is not uncommon for individuals with dementia to be able to sing long after they are unable to speak. Choosing songs from childhood or songs familiar to the person will be the most comforting and engaging.

Experiment with sound: introduce simple instruments (rattle, bells, etc.) or sing-alongs. Sometimes humming can be calming and enable them to participate without having to remember lyrics.

Encourage visual expression: painting and drawing can be a way to express feelings and unlock creativity. This can also help with physical coordination. Use bright and bold colors on big surfaces, avoid small instruments that will frustrate those with declining coordination.

Create tactile and sensory crafts: clay, play dough, cotton balls, pipe cleaners – all of these can exercise the brain and stimulate creativity. Having objects of various sizes can also help stimulate the brain.

Fold warm laundry in the company of others: the warmth can be soothing and folding can stimulate the brain. Offer things that are easy to fold like towels or wash cloths. Make room for varying skill with folding, simply manipulating the fabric is enough.

Walks and being in nature: being outside and taking walks while in the company of someone familiar can be very adventurous to individuals with dementia. Keep the pace slow and stop to smell the flowers, watch the birds, etc.

Think of one more activity to add to this list:

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____

____

6. **Managing grief/loss:** Families of those with I/DD and dementia may feel overwhelmed by the changes in their loved one. DSPs and CMs may recognize this and notice additional care is needed. Remember the stages of grief, you may see family members moving in and out of these different stages of grief:

? Lead the class in a discussion about the stages of grief. Have them think of examples of how an individual with dementia may express their grief and then have them think of examples of how a family member or a loved one of a person with dementia might express their grief. Normalizing these feelings and experiences is important as individuals, their families and support systems navigate life with dementia.

? Allow participants in this training course to fill out the following questions independently. Once they have jotted down some of their thoughts, either divide them up into small groups to discuss their answers or host a large group discussion. Be prepared to name three local supports and services you are aware of in your community that supports individuals with dementia.

Discussion questions:

Name three supports or services an individual living with I/DD and dementia may need that they didn't need prior to developing dementia?

1. ______________________________

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2. ______________________________

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3. ______________________________

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Describe two ways to support an individual with IDD and dementia who is becoming angry or anxious?

1. ____

____

2. ____

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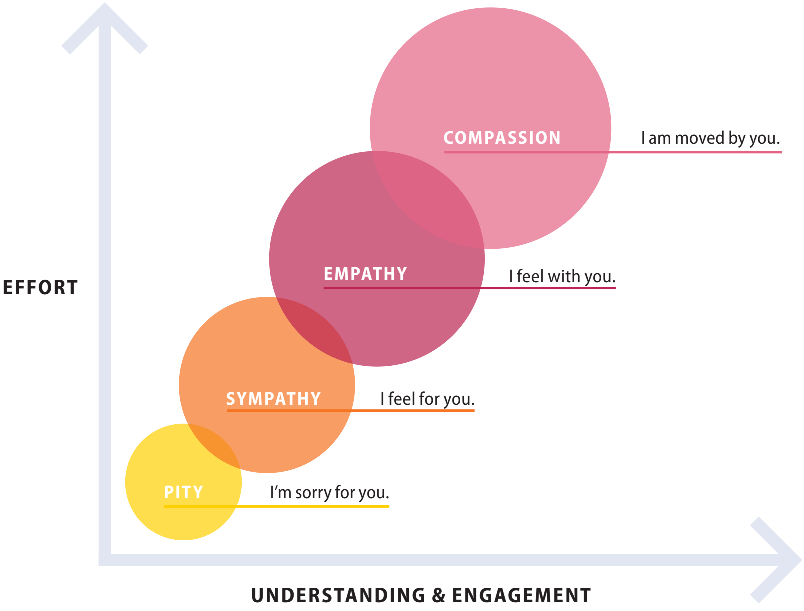
Summary

Individuals with I/DD and dementia may suddenly experience a change in their abilities and behavior, or slowly over time. It is important to identify the changes so care can be modified, increased or added to best sustain individuals and their families. Adapting to these changes will enhance quality of life.

Building Empathy

Start this section by asking the class to take out a blank piece of paper or open a blank word document. Ask them to write a letter or a poem from the perspective of someone who has I/DD and dementia. Ask them to describe their life, their relationships, how they feel and what they think. This first activity is how we will introduce the importance of empathy for individuals with I/DD and dementia

SPECTRUM OF EMPATHY[1]



Have the class read and discuss the following. Highlight that being a direct support professional adheres to a code of ethics that guides our practice and decisions around how to care for those with I/DD and dementia.

Your core mission and values

Our "purpose" is often linked to inspiring vision, clear mission, and strong values. You buy in, align with your agency's values and code of ethics because you believe client success is intrinsically linked to your success and goals.

Though the code of ethics and competencies do not call out empathy specifically, they do call out elements of empathy, understanding and compassion. You can view the language from the National Alliance for Direct Support Professionals: https://nadsp.org/ethics-competency/.

Integrity and responsibility: As a DSP, I will support the **mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support**, other professionals, and the community.

Why developing empathy is vital to providing high quality direct care

With great power and privilege, comes greater responsibility. As DSPs, you understand how many challenges and barriers impact clients and families every day.

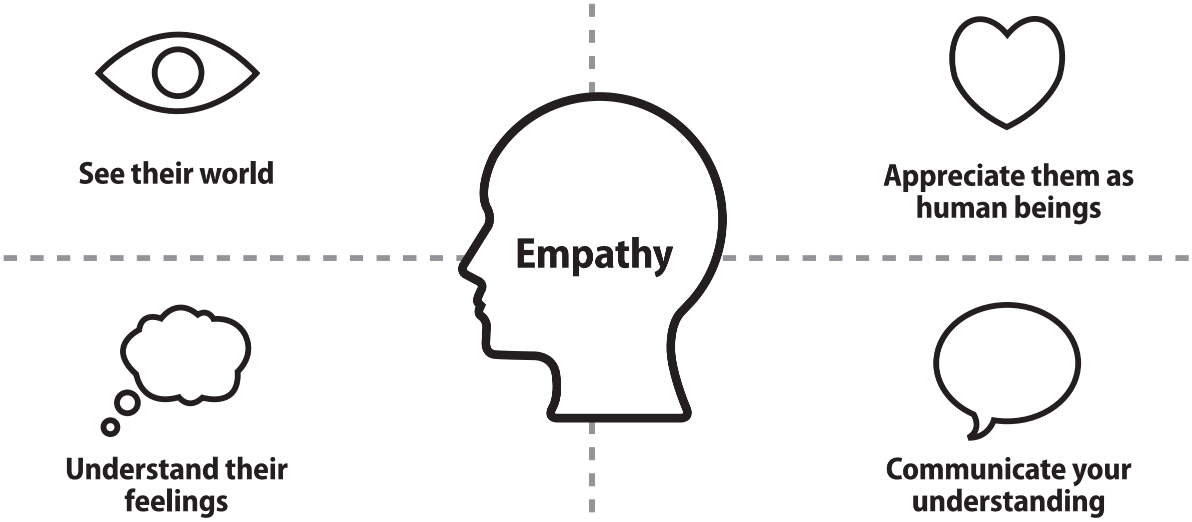
Parents of children with I/DD are at increased risk of experiencing stress compared to other parents.[2] Families may experience stress associated with increased caregiving demands and coordination of care (e.g., communicating with multiple professionals, attending meetings, transporting child to various services). Beyond the day-to-day care and coordination, stress may skyrocket when co-occurring behavioral or medical conditions are present.

With dementia, co-occurring behavior and challenges are common and affect many families. These stressors, in addition to financial strains for costly services, feelings of isolation and lack of social support; may place families at risk for higher distress.

Families may feel overwhelmed and helpless meeting these needs. These feelings may be associated with heightened levels of depression.[3]

Skills and Approaches

Building compassion and empathy is a long journey with many different elements.[4]



Pair the class up and have them read the following scenarios. Then have each pair fill out the empathy chart below.

Scenarios

Jacqueline: lives in a group training program. She does not like to leave the house because people often stare at her because of her stimming behaviors (rocking back and forth helps her self-soothe and stimulate her senses so she can cope with everyday life). Jacqueline uses adapted sign language and some verbal words to communicate. The DSPs who work with her, have known her for years and she is close to her family. These are the people she trusts. Lately the DSPs that work with her notice that she is struggling to speak the verbal words she knows and her adapted signs are becoming harder to recognize. She is more resistant to leave her house and will refuse to bathe or get dressed 2-4 days per week. This is unusual since Jacqueline has always loved sweet smelling soaps and fashionable clothing. She also seems withdrawn, and last week had her DSPs cancel her family movie night (which she looks forward to all week). She was recently diagnosed with vascular dementia.

Ming: lives with her husband of 30 years and they share an apartment. Ming is enrolled in services with a supported living program. They provide 24-hour support to Ming and her husband. Ming has Prader Willi syndrome and experiences unstable hunger and a compulsion to eat non-edible items. Her staff are specially trained to make sure that Ming's environment is safe. Ming is on a special diet because she has developed diabetes. Her staff and husband have noticed she is more confused and forgetful than normal. In the evenings she becomes really distressed and agitated. Her husband now retreats to another bedroom at night and they increased staffing in the evenings to help support Ming. She was recently diagnosed with Alzheimer's disease.

Their world view? 	**Strengths of this individual??**
Their feelings?	**How would you convey your empathy? Provide compassion and care??**

Below are skills each DSP can practice to increase their emotional intelligence, and ability to manage themselves and relationships effectively across four fundamental, emotional intelligence capabilities[5]:

Have your participants read the list below and circle the two attributes they feel are their strongest attributes when working with individuals who have dementia. Have them discuss why they are strong in those areas.

Part 2: have each participant circle their greatest weaknesses and then have them discuss in small groups or pairs why this is their greatest weakness and strategies they will use to improve these areas.

Self-awareness

- **Emotional self-awareness:** ability to read and understand your emotions as well as recognize the impact on work performance, relationships, etc.
- **Accurate self-assessment:** a realistic evaluation of your strengths and limitations.
- **Self-confidence:** a strong, positive sense of self-worth.

Self-management

- **Self-control:** the ability to keep disruptive emotions and impulses inside.
- **Trustworthiness:** a consistent display of honesty and integrity.
- **Conscientiousness:** the ability to manage yourself and your responsibilities.
- **Adaptability/Initiative:** adjusting well to changing situations, overcoming obstacles and a readiness to seize opportunities.

Social awareness

- **Empathy:** able to sense others; emotions, understand their perspective, and take an active interest in their concerns.
- **Service orientation:** ability to recognize and meet clients' needs.

Social skill

- **Influence:** ability to wield a range of persuasive tactics.
- **Communication:** able to listen and send clear, convincing, and well-tuned messages.
- **Conflict management:** ability to de-escalate disagreements and find creative solutions.
- **Building bonds:** proficient at nurturing relationships and building a strong support network.

My top 3 strengths are:

1. ______________________________

2. ______________________________

3. ______________________________

My top 3 challenges/weaknesses are:

1. ______________________________

2. ______________________________

3. ______________________________

Summary

Effectively caring for an individual with I/DD and dementia starts with our mindset and the skills we develop. Building empathy changes how we respond to clients and families in a way that anticipates their emotions, builds trust and initiates rapport. Displaying a natural ease in forming relationships, getting to know the family and cultivating a deep bond, require empathy.

Discussion questions:

Discuss moments you felt empathy and compassion were missing or present? How and why?

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How do you sense others' emotions, understand their perspective, and take an active interest in their concerns?

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Developmental Disabilities Administration

Dementia
Action
Collaborative
Washington State

Module 2:

How to care for individuals with dementia and I/DD

- *Social justice, and dementia and I/DD*
- *Meeting the challenges of dementia and I/DD*
- *Mapping strengths and the importance of interdisciplinary teams*
- *Family centered approach to care*

Social Justice as a tool for direct care

Have the class read the following section and discuss their reactions. What do they think about social justice as a tool for caregiving? What are their initial thoughts about this?

When we think of Social Justice, we often think of the Disability Rights movement that brought us the services and supports that exist today. We think of the hard-fought battle individuals with disabilities, their loved ones and families waged to make sure power and choice exist for individuals we support.

But how can Social Justice be used as a tool for caregiving? In this section you will learn how Justice, Fairness and Equity is an ideal to strive for and is part of the National Association of Direct Support Professionals code of ethics.

Have the class break up into small groups and discuss the NADSP code of ethics. Why is it important to have a code of ethics? Why would justice, fairness and equity be a key part of NADSPs' ethical code?

NADSP

Making a world of difference
in people's lives

National Alliance for Direct Support Professionals and social justice

The National Alliance for Direct Support Professionals has an ethical calling toward justice, fairness and equity. This means DSPs will affirm the human and civil rights and responsibilities of the people they support. DSPs will promote and practice justice, fairness, and equity for the people they support, and the community as a whole.

DSPs have an ethical obligation to promote the rights of an individual with I/DD and dementia, and promote their dignity throughout their life. Learn more at https://nadsp.org/code-of-ethics-text/.

The focus on social justice has resonated with the dementia care community. Many organizations and dementia care programs are adopting a dementia bill of rights to guide ethics and guidelines for care.

Learning checkpoint: Individual rights matching activity

Instructions: Some items below are part of the dementia bill of rights and others are not. Use an arrow to match items you believe are connected to an individual's rights.

- Informed about your diagnosis (Example)
- Receive appropriate and ongoing medical care
- To advocate for yourself
- Be part of your community (local, global, online, etc.)
- Have care professionals trained in dementia care
- Be treated as an adult, listened to and afforded respect for one's feelings and point of view
- Be with individuals who know your life story, including cultural and spiritual traditions
- Engage in meaningful activities daily
- Live in a safe and stimulating environment
- Regular access to outdoors
- To welcome physical contact (hugging, hand holding, etc)

How to honor individual rights through meaningful daily activities

DSPs have an ethical calling to facilitate the expression and understanding of one's rights and responsibilities with the people being supported.

What does it mean to promote justice, fairness and equity? It is a DSP's responsibility to facilitate expression and understanding of an individual's rights.

Break participants into small groups to read and work through one of the 3 scenarios. Have each group report out to the whole class.

Consider the following scenarios and discuss which right is being violated and how a DSP might respond or advocate in the following situations.

Rick: lives in an adult family home and the owner directs you to lock Rick in his room on the 2nd floor when he goes to sleep at night because he exit-seeks in the middle of the night and gets confused. The owner of the AFH is worried he will wander away at night and get hit by a car. You notice (as a DSP) that other residents are allowed to walk to the park and go in the large backyard but Rick is confined to the house and either discouraged or stopped from leaving the house.

Susan: lives with her aunt. You are her DSP that comes in 5 times per week to support Susan with activities of daily living. Susan is not able to speak, but you notice that she is losing key skills. She used to be able to dress herself but can no longer do this. This week, she can no longer feed herself. You mention to her aunt (and guardian) that you suspect she might be experiencing symptoms of dementia.

Susan's aunt shrugs her shoulders and tells you that Susan is "special" and these things are part of her disability. You have known Susan for 5 years now and you know this is not typical. You ask if you can make an appointment with Susan's doctor, her aunt tells you that you are "being dramatic" and to leave the healthcare decisions to Susan's family.

Jose: lives with his older brother. He has Down syndrome and early onset Alzheimer's disease. He was recently diagnosed and his brother, who is also his guardian, has decided not to share his diagnosis with him or others outside their immediate family. Jose's friends have noticed that he fails to show up for planned activities and many of his friends have stopped calling or coming around. Jose is distressed by this and asks his brother for help. His brother shrugs off his worries and blames his friends for being "fake friends" and changes the subject. You are Jose's DSP and he asks you for help and advice.

Break participants up into small groups to have the following discussion and bring the groups back to share and compare ideas

Discussion questions:

Do places in the community exist where individuals with I/DD and dementia may face stigma or may not have access?

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How can I empower individuals I support to advocate for themselves in the community so persons with I/DD and dementia can have a higher quality of life?

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In the United States, individuals are living longer and this positively correlates with the rise in dementia diagnoses. The rise occurs in the I/DD community as well. Individuals with dementia thrive on routine and predictability in their environment, but they also need activities that bring life meaning. These activities can be soothing, decrease challenging behaviors and offer a high quality-of-life for those with dementia and I/DD.

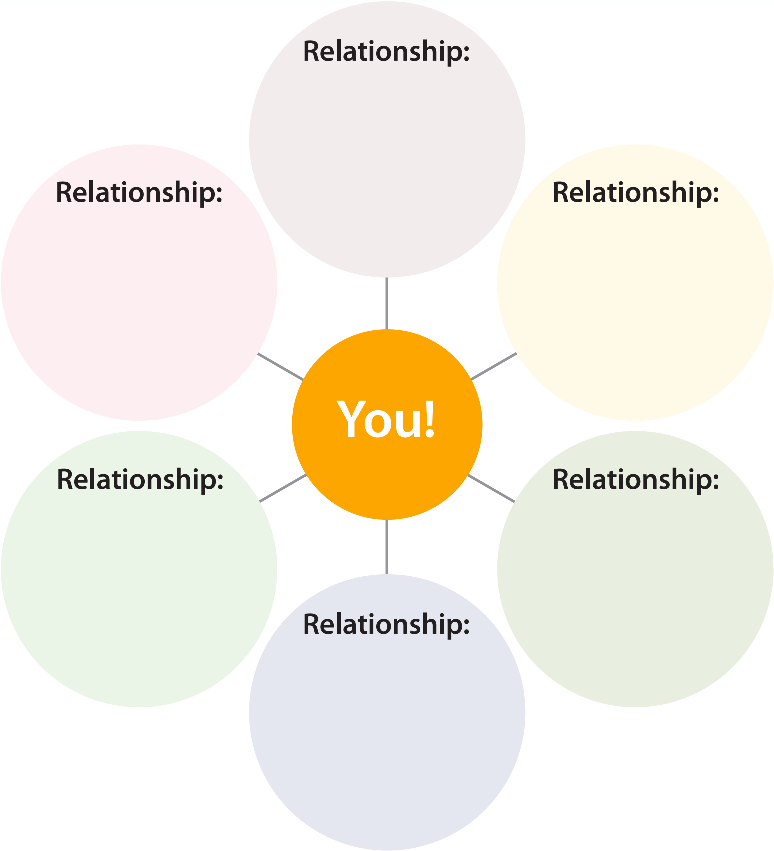
Direct support professionals are our best source for creating meaningful activities. But before we can assist the people we support, we need to define what makes our life meaningful right now.

Have each participant fill this out independently for themselves and then have them work in small groups to share what activities make their lives meaningful.

Activity: Look at the graphic below and fill in activities you are doing at home to give your days meaning and/or cope with this changing time.

Have participants independently fill out the chart, writing down their closest relationships. Have them work in the same small groups and share

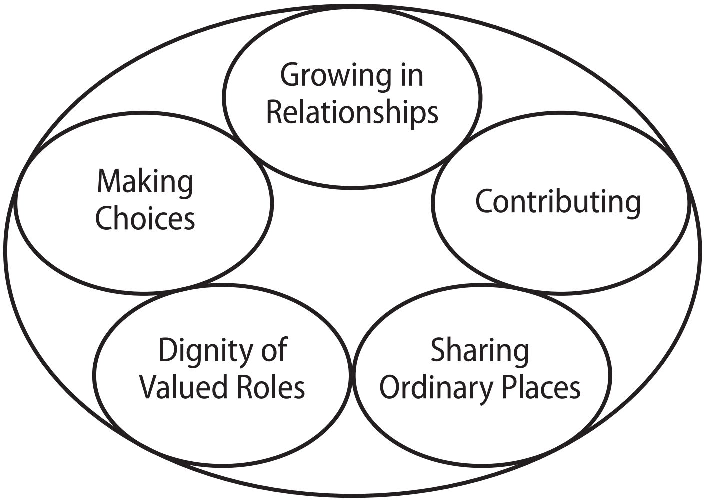
Write down relationships you have outside of work. Also fill in the meaningful relationships outside of work that are helping you cope. Some have many and some have a few.



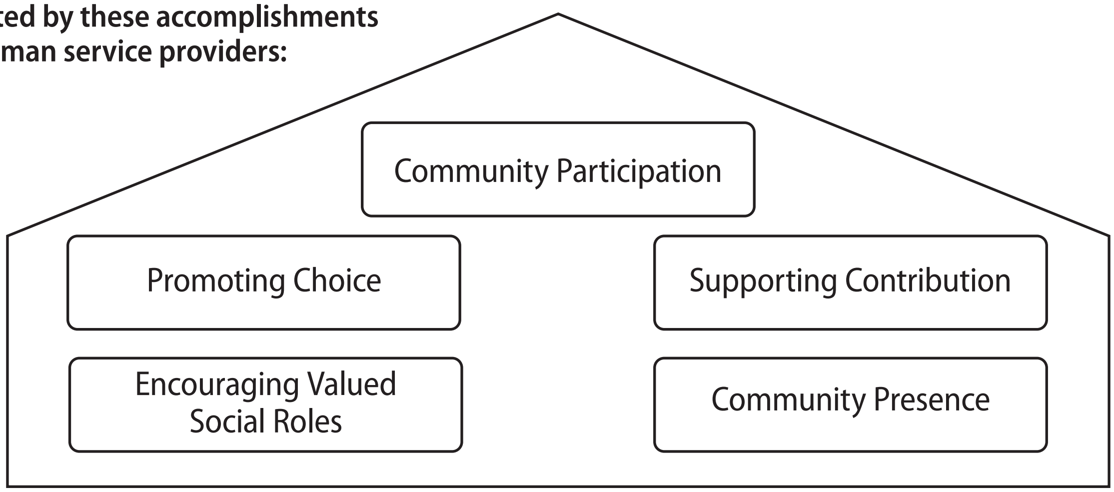
Keep participants in their small groups and assign them 1 of the 5 core human experiences. Have them teach back to the class what each of these core human experiences are, examples on how we help the individuals we support attain these human experiences and why they are important.

John O'Brian, a lifelong advocate for person-centered planning and advocate for individuals with developmental disabilities, outlines five core human experiences that shape a meaningful life.

Valued experiences for people...



Are created by peoples own efforts and the efforts of friends, family and community members, and are assisted by these accomplishments of human service providers:



5 Core human experiences

Looking at this graphic we are challenged to incorporate these five core human experiences into an individuals with dementia's diminishing skills. Write down an idea to support someone with each of these core human experiences:

Promoting choice: It is important for individuals with dementia (at every phase) to have voice and choice in their lives. This can be an increasing challenge as skills and cognition decrease. However, offering individuals to make choices daily will decrease power struggles, increase security and add some autonomy to the individual experiencing the changes dementia brings.

One dementia care facility was built as a circle and all the residents could walk the loop with an exit that led to a contained garden area where they could safely go outside and enjoy the flowers and birds. In this loop were fish tanks, clothing racks, games and a sitting/kitchen area. Caregivers never left anything out that was dangerous, but as individuals walked the loop, they were able to make choices about what they picked up, if they wanted to watch fish, stand or sit in the garden, etc. Offering choices does not have to be complex or include high-level decision-making.

Encouraging contribution: each of us needs to contribute to our household and life. This need does not diminish with dementia, but it does ask DSPs to be creative. Contributions include putting the forks on the table for dinner, folding laundry, greeting visitors, serving snacks, deciding where to put items in the house, even if DSPs do not think those items should be placed in that location.

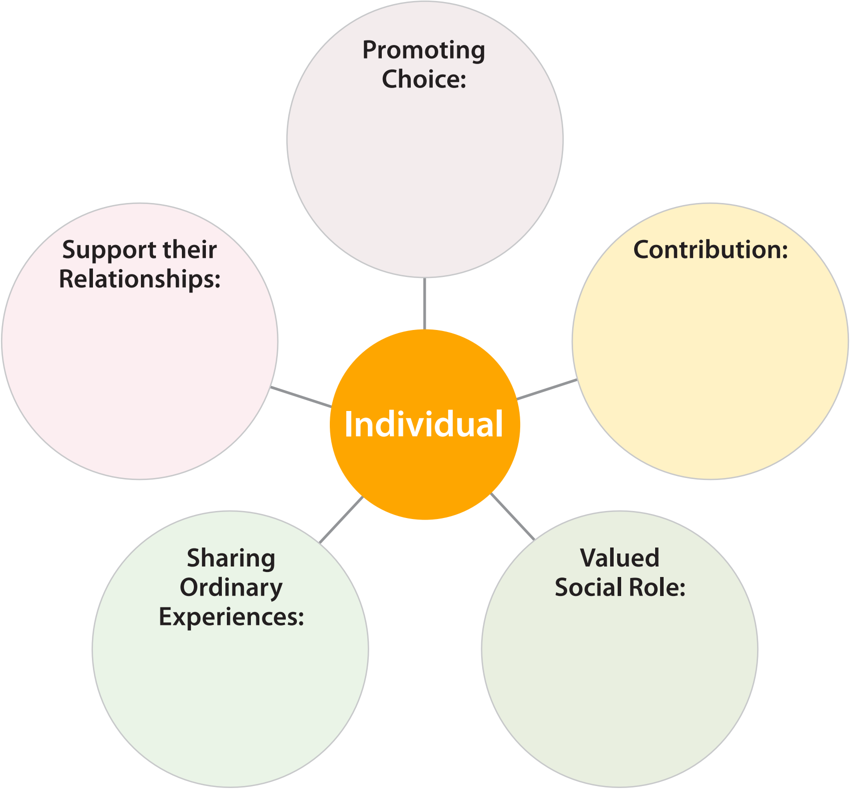
Valued social role/supporting relationships: this is especially important for individuals with Dementia. Even if they cannot remember their family members, they still deserve to have people present who know their history. Having dementia does not make them any less of a sister, wife, brother or friend, even if they don't remember. We need to encourage and support these relationships.

Sharing ordinary experiences: this is where DSPs have incredible power. As humans we are social creatures. We need and thrive from human connection. Even when skills and memories are eclipsed, it is still important to follow a routine. Share dinner, share favorite TV programs, play their favorite music, continue daily chores. As much as you can create some sense of normalcy and familiarity, it will be a comfort to an individual, even in advanced stages of dementia.

Have participants independently fill out the learn checkpoint activity and share in pairs.

Learning checkpoint/activity:

Look at the graphic below, think about how you would support an individual with dementia and I/DD in the five core human experiences. Write down at least one idea for each experience.



Facing the challenges of dementia and I/DD

As a direct support professional for someone who has I/DD and dementia, it can be challenging to care for ourselves in addition to meeting the needs of the individual we are supporting.

In this section we cover the challenges you may be facing by caring for this population and some of the resources you can use to overcome the challenges.

We will also map out the strengths of our DD system-of-care and the unique perspectives we have that provide a set of strengths when caring for someone with I/DD and dementia.

Changing abilities, behavior and communication

Often signs of dementia are noticeable to those closest to the person experiencing symptoms of dementia and changes in behavior and communication. This is especially true for individuals with I/DD. Sometimes those closest to them notice changes in their abilities, behaviors and communications.

Early challenges may include increased anger and aggression, loss of language or communications skills that once were easy for the individual. It is common for those experiencing early symptoms to socially isolate, and feel anxious about situations they used to enjoy. You may also notice their daily living activities are intermittently interrupted; some days they may lose focus or be unable to perform hygiene tasks they could perform previously, they may need more support.

Give the class the example below to illustrate how to use this tool to identify challenges in different quadrants. Then break them into small groups to use the tool to identify challenges associated with a specific changing ability or behavior.

After you review the example below break the class into small groups and ask them to identify a change to an ability or challenging behavior related to dementia. The group can identify their own example or you can use the examples below and assign 1 changing ability/behavior below:

Confusion/memory Loss

Wandering (no exit seeking)

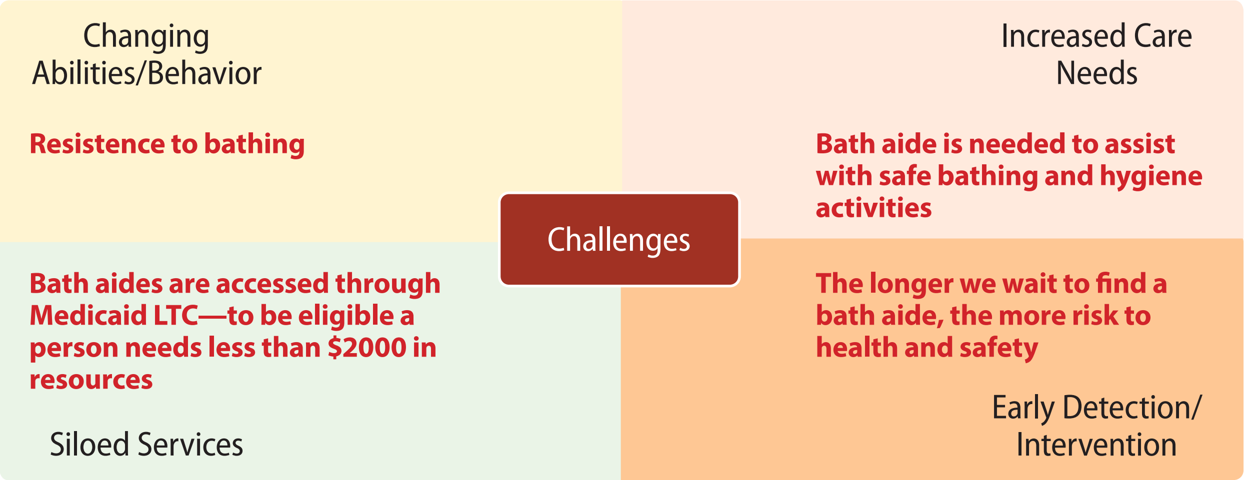
Exit seeking

Resistance to personal care

Agitation and aggression in the evenings

Paranoia (feeling like people are stealing their personal items)

Challenges:



Changing Abilities/Behavior

Resistence to bathing

Increased Care Needs

Bath aide is needed to assist with safe bathing and hygiene activities

Challenges

Bath aides are accessed through Medicaid LTC—to be eligible a person needs less than $2000 in resources

Siloed Services

The longer we wait to find a bath aide, the more risk to health and safety

Early Detection/ Intervention

Increased caregiving needs

Many individuals with dementia face increasing challenges with activities of daily living that require increased caregiver support. This increased need for support can be disruptive and an individual who used to live independently or need minimal support may need more and more support over time. However, tracking when to increase supports can be complicated because early warning signs are easy to miss. This is especially true for individuals who have I/DD and dementia who are already receiving a higher level of support and care. Early warning signs for those with I/DD and dementia are:

- Behavior changes or personality changes
    - Example: an individual may resist bathing and become combative with their bath aide or have increased sensory sensitivities
- Disruptions to routine
    - Example: an individual may have a strict routine and all of sudden they will stop engaging in these activities or become fearful of leaving their home or familiar environment
- Loss of skills
    - Example: an individual may have been able to navigate the bus/public transportation system on their own with minimal support and they are no longer able to navigate their way around.

- Changes in communication
  - Example: an individual who uses a Dynavox to communicate may have trouble finding basic sentences or utilizing this communication device like they used to. They may be slower to respond to prompts or appear more confused.

Early detection and intervention

One of the biggest challenges individuals with I/DD and dementia face is a lack of early detection and intervention. Often individuals with I/DD do not fit into the neuro-typical developmental stages. The tests for detecting dementia may not be accessible to a spectrum of individuals with I/DD. Even primary care physicians can miss early signs of dementia. Often individuals with I/DD are stigmatized for having deficits in cognition, memory and communication, so when their abilities decline, they need those closest to them to sound the alarm and help them have a voice so they get the best care possible.

Siloed services and navigating a new system of care

The developmental disabilities system of care is becoming savvier with recognizing symptoms of dementia and supporting those who are aging. However, aging and disability services are often a front door for many dementia care facilities and services. It can be challenging for individuals with I/DD, as well as caregivers to navigate a new system of care. Many services are siloed and not interconnected. Sometimes the best hub for these is our medical system and that can sometimes have trouble connecting individuals to the necessary services.

Strength mapping is a way to overcome challenges. There is an activity in this section that will illustrate how to do this. In this section you will want to lead the class in a discussion about the importance of strengths and a strength-based approach. Often individuals with dementia are measured by their deficits and their decline and their resilience and strengths are ignored. Instead, we can use strengths to create strong case plans, create more individualized and person-centered supports and services. NOTE: there is more coming up about person-centered supports so you can look this over briefly and cover this more in-depth in Part 2 of this activity.

Mapping strengths

The good news is that there is hope. Just as there are challenges for those facing I/DD and dementia, there are also many strengths those with I/DD and dementia can use to tap into their own resilience.

Ask for volunteers to pull up these apps on their phones and break them up into small groups to discuss individual apps. Have the group report back to the larger class about what they discovered.

DD system of care has unique understanding of neurodiversity, communication differences and personal care needs

The developmental disabilities community has been innovating communication challenges for many years. The DD system of care and support network has a lot of innovative options to take advantage of as individuals with dementia experience communication challenges. The DD system of care also has many technologies to help increase communication when expressive or receptive challenges are present. The DD system can also use technologies to maximize independence using automatic door locks, retina recognition systems, sensors that turn off stoves left burning, etc. Below are a few apps that can be downloaded on smartphones and tablets to assist with expressive and receptive communication challenges:

TALKITT

WHO IT HELPS: People with motor, speech and language disorders

WHAT IT DOES:

- the Talkitt app translates difficult to understand verbal speech
- allows people to communicate using their own voice.
- the app is program to recognize an individual user's vocal patterns
- program works in many different languages

AVAZ

WHO IT HELPS: individuals with Social and/or speech disabilities.

WHAT IT DOES:

- app enables user to "speak" using pictures and symbols
- uses high-quality voice synthesis to help non-verbal users create messages for verbal communicators

STEPPING STONES

WHO IT HELPS: Children and adults who benefit from visual support

WHAT IT DOES:

- allows users to create visual guides - or 'paths' - using their own photos to create daily routines, schedules and/or social stories.

Person-centered approach

Signs of dementia present differently in each person. This is also true for individuals with I/DD and dementia. A person-centered approach is a vital tool when caring for an individual with I/DD and dementia. A person-centered approach recognizes the uniqueness of each individual. This enables the caregiver to both cultivate a deeper understanding of dementia and I/DD while treating each person as an individual and creating individualized plans to address all support needs. The person-centered approach normalizes a spectrum of abilities and supports that will enable each person to live their best life.

Strength mapping

One tool you can use to adapt services and supports for individuals with increasing support needs is to first look at their strengths. Looking at interpersonal strengths will serve all future planning or decision-making. Everyone has a different experience with dementia and how dementia impacts on their daily life can vary widely.

STRENGTH MAPPING ACTVITY (PART 1): Break the class up into small groups and have them read the scenario below and identify strengths. Have them also fill out the discussion questions below. Have each group debrief with the class and see how many strengths you can come up with collectively. Then lead the class through the discussion questions so the groups can hear the justifications for the strengths they selected.

Activity: consider the following scenario and practice mapping Abby's strengths. Use the strength list below the scenario to identify some of Abby's interpersonal strengths.

Activity scenario: Abby is a 67 year-old woman who has Down syndrome and was diagnosed with Alzheimer's disease two years ago. Abby lives in her own apartment with a roommate of 10 years, Morgan, who also has Down syndrome. Abby is retired, but worked at a local office as an administrative assistant for 20 years and still has close connections with former co-workers (two visits weekly). Abby loves to paint pictures of cats and doing yoga. Abby is a great neighbor and enjoys bringing gifts to her neighbors. Many of Abby's neighbors like her and often come to visit or invite her to BBQs and holiday events. Abby loves music and spends many hours listening to classical and choir music. Abby sang in her church choir for years, but decided to leave her church 10 years ago because she did not agree with their stance on LGBTQ rights. Abby is close with her younger sister, Monique (64 years old), who is also her guardian. Abby's parents passed away 10 years ago and they left Abby a trust that supplements her income and allows her supports to increase as needed. Monique is Abby's only family along with Monique's wife (of 30 years) and Abby's three adult nieces (Monique's children). Abby and Monique are close and talk nearly every day. Abby's diagnosis of Alzheimer's disease is distressing to Monique and lately Abby has been forgetting to contact her sister and does not recognize her voice on the phone. Recently Abby did not recognize her sister when she arrived for a visit. Lately, in the early evening, Abby becomes really confused, she yells and becomes physically combative with her caregivers when they enter her room to offer her medication or invite her to dinner. Two caregivers have quit as a result of this combative behavior and the team needs to meet to decide next steps.

Personal strengths

Below is a list of interpersonal strengths. Based on the scenario above, what interpersonal strengths does Abby have? Circle/highlight all that apply:

Achiever
Artistic
Charming
Confident
Curious
Empathetic
Fast
Ideation
Leadership
Open-Minded
Positivity
Speaking
Team-Oriented
Willpower
Action-Oriented
Athletic
Clever
Connectedness
Determined
Emotional Intelligent
Flexible
Individualization
Learning
Organized
Precise
Spontaneous
Thoughtful
Wisdom
Adventurous
Authentic
Compassionate
Courageous
Disciplined
Energetic
Focused
Inspiring
Motivated
Outgoing
Responsible
Social/People Skills
Visionary
Analytical
Caring
Communicative
Creative
Educated
Entertaining
Helping
Intelligent
Optimistic
Patient
Self-Controlled
Strategic Thinking
Warm

Discussion Questions:

Why did you choose these strengths?

How can these strengths be used to help Abby adjust to her progressing dementia?

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Environmental strengths

In addition to personal strengths, Abby also has several environmental strengths that can help her navigate the progression of her dementia. Environmental strengths are wealth, resources, natural supports (family and friends), cultural factors (spiritual community, access to community resources others do not have), etc.

Discussion questions:

Name at least three environmental strengths Abby has:

1. ______________________________

____

2. ______________________________

____

3. ______________________________

____

How can these strengths be used to help Abby adjust to her progressing dementia?

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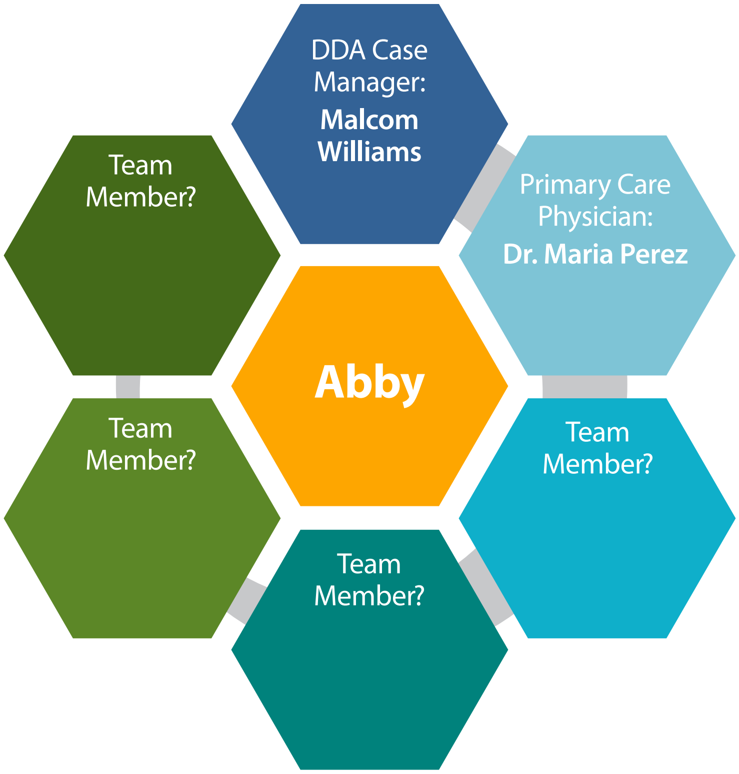
Interdisciplinary team model

Another strength of the DD Care Community is adeptness working in interdisciplinary teams. These teams can support an individual with I/DD and dementia and caregivers who stress when increasing services. These teams can also leverage person-centered supports to find the best balance between interventions and independence.

STRENGTH MAPPING (PART 2): Have the class remain in their original small groups from part 1. During this part of the activity they will be tasked with creating a multidisciplinary team, or a team with a mix of natural supports (family, friends, etc.) and different service organizations. Asks the groups to be prepared to justify each member of the team and what they hope each team member will bring that will support the individual being supported.

Activity instructions: Based on the scenario above, who should be on Abby's team? We filled in a few roles that should be invited, you fill in the rest.



Be sure, as you debrief, you talk about how important it is that the individual being supported be a big part of selecting who is on their team. This is also a time to talk about cultural considerations. In some families a family-centered approach is even more important than a person-centered approach. Direct Support Professionals will need to build a relationship with the person they are supporting and their natural supports to adapt services accordingly. Have participants read the following and fill out their discussion questions individually. Then you can debrief their answers with the group.

Strengths of family-centered approach to caregiving

People with I/DD and dementia and their caregivers are not in a homogeneous group. This diversity impacts caregiving and service access. Caregiving for people with I/DD and dementia affects people of all ethnicities, languages, and socioeconomic classes, as well as people living in a variety of geographic locations with different resources. For example, research indicates most adults with I/DD and dementia live at home with their families who provide much of the care and support. For racially, ethnically, and linguistically diverse groups, this may be even more common.

In the U.S., there is a push for person-centered care which promotes greater autonomy and self-direction. Often person-centered approaches to care include a mix of natural and paid supports. This is the basis for many state supportive care policies. However, this may not fit with the cultural norms of certain groups, or be feasible for some members. Based on this information, it might be conducive to look at a family-centered care model.

While person-centered care is a philosophy built around individual needs and contingent on knowing the person through an interpersonal relationship, family-centered care is defined as “mutually beneficial partnerships between health care providers, patients, and families in health-care planning, delivery, and evaluation.”

Discussion questions:

How can a family-centered approach offer a culturally sensitive way to provide care and support to an individual with dementia and I/DD?

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Do situations exist where a family-centered approach may not be appropriate or would not be feasible?

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Overcoming the caregiver stress in a family-centered approach

When systems adopt a family-centered care model and offer external support and resources to families, this better facilitates communication and information exchange among family members, direct service workers, clients and health care providers.

Family-centered care contributes to culturally-sensitive care plans by discussing specific cultural needs, as well as strengths related to personal values, preferences and ideas (i.e. religious preference).

In instances where clients’ cognitive ability gets impaired and they are unable to participate in decision-making, family caregivers ***can become active contributors to care-plan development and implementation***.

Summary

Most adults with I/DD, including those with dementia, live with parents — many of whom provide lifelong caregiving. These caregivers do not typically have experience accessing long-term services, including family supports and various residential supports (e.g., group homes, supported living). Health care policies are needed that emphasize family-centered care for individuals with I/DD and dementia.

Communication as a Tool for Direct Care

Why communication matters

Often people with dementia cannot put their thoughts into words. We have to understand them, both verbal and non-verbal behavior, to know what they are trying to say.

It is important NOT to give too much explanation about this activity. Have each person do this independently then break them in to small groups to compare their answers. The point is that there are likely many different interpretations of the same facial expression. The point is that we interpret nonverbal cues instantly and sometimes the information is incorrect. The way to accurately interpret non-verbal cues is to build a strong relationship with the person the direct support professional is supporting.

Activity

Look at the facial expressions below. Choose three to four expressions and label what the person might be feeling. Answer the following questions:

- If you were this person's direct support worker, how might you react to that emotion?
- How do you know what they are feeling?
- What if you are wrong?

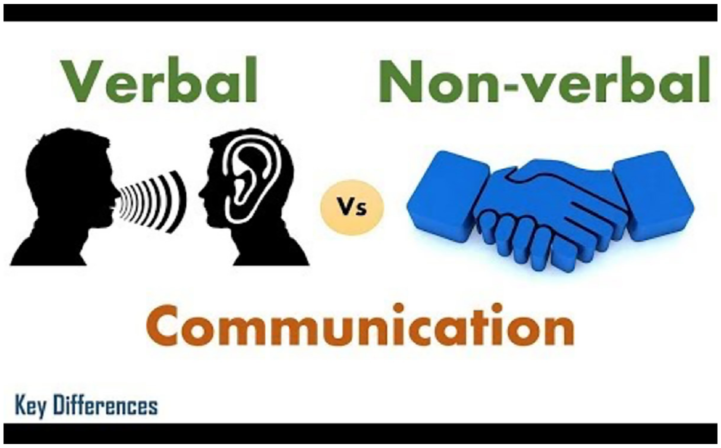
Interaction between a client and caregivers is crucial. One of the pillars to good communication is building a strong relationship with the individual you are supporting, especially as their ability to communicate begins to decline. Poor communication can compromise care, leading to undue client anxiety and frustration. It is vital that caregivers be skilled communicators to connect and engage with clients.

How they act sends a message about what they are thinking and feeling as much as the words they use.

Sometimes what our words say, and what our non-verbal behaviors communicate, are two different messages.

The words may be, "Don't worry about knocking that glass over," but the manner and tone may say, "I'm really angry you spilled your drink and I have to clean it up right now."

To which message, the words or the non-verbal, is the person with dementia likely to respond?



TEACH-BACK ACTIVITY: this next section has a lot of information. Break the class into small groups and have them create a poem, a role play, or a creative graphic to teach back the information to the class. Assign the following to the groups:

- Defining verbal communication vs. nonverbal communication
- Verbal communication tips (including paralinguistic tips)
- Non-verbal communication tips (including SOLER - *see below for explanation of SOLAR*)
- Helpful tips

Have each participant fill out the discussion questions independently.

What is verbal and non-verbal communication

People communicate with and without words. The words, statements and questions we express let others know what we think and sometimes what we want.

Communication also includes non-verbal behaviors, such as sounds, sign language, gestures, facial expressions, body postures, and the rhythm and tone of our voices.

Verbal communication: is the use of words to express oneself and is regarded as the key component in delivering a message. Words are symbols used to convey a message. Communication allows individuals to share their perceptions of the world and express their feelings. The choice of words is influenced by the person's sociocultural background and the environment in which the interaction takes place.

For message accuracy, the receiver needs to share similar words. This promotes mutual understanding and allows the communication process to flow. It is vital to make sure the receiver understands the message by evaluating feedback.

Research suggests the majority of communication is non-verbal. Only 7% of the message is communicated verbally by the words used during an interaction while the remaining 93% is communicated non-verbally. Of the non-verbal communication, 38% involves the use of vocal tones and 55% is attributed to body language.

	Verbal Communication	Nonverbal Communication
Oral	Spoken Language	Laughing, Crying, Coughing, etc.
Non Oral	Written Language/ Sign Language	Gestures, Body Language, etc.

Non-verbal communication: includes facial expressions, eye contact, posture, appearance, gestures, personal space and bodily contact. It plays a central role in human social interaction. It is culture-specific and contextually bound. What is accepted in a given sociocultural context might be inappropriate in another. When communicating with a client from a different culture, be aware of and acknowledge the unique way non-verbal communication can have different connotations. Expressions of pain or discomfort such as crying are different in various cultures.

Some cultures may value a more apathetic attitude while others may encourage a more emotional state.

Non-verbal communication conveys powerful messages and should be given special attention in all interactions. It should complement and reinforce verbal communication.

Most nonverbal communication helps regulate how the communication process evolves. For example, eye contact and close proximity may indicate interest, concern and warmth.

General verbal communication tips:

- Use short, simple words and sentences
- Give one-step directions and ask one question at a time
- Patiently wait for a response
- Avoid open-ended questions. Provide choices or suggestions
  - For example, instead of "What do you want for breakfast?" say, "Do you want oatmeal or toast?"
- Expect to repeat information or questions
- Turn negative statements into positive statements. For example, instead of "Don't go into the kitchen," say, "Come with me, I need your help with something."
- Make statements rather than asking questions. For example, instead of: "Do you want to go?" say, "Let's go!"

SOLER is helpful when engaging in non-verbal communication:

S – Sit facing the patient Squarely.
O – Maintain an Open posture.
L – Lean slightly forward.
E – establish and maintain Eye contact.
R – adopt a Relaxed posture.

When approaching communication, consider paralinguistic features of communication. This refers to how we speak or the individual characteristics of a person's voice. These include:

- **Volume –** soft or loud. A change of volume can express how the person is feeling. Volume can be changed to suit different situations.
- **Intonation and pitch –** range of frequencies (low to high) used to suit meaning.
- **Rate of speech –** slow or fast delivery can be used to express different emotions and attitudes.
- **Tone of voice –** combination of volume, intonation and rate of speech to convey different messages.

- **Conversational cues such as ‘mmm’, ‘hmm’, ‘I see’, ‘right’, ‘really’ –** indicate the degree of interest by the listener and whether or not they are agreeing. These are known as social reinforces.
- **Choice of words** and how they are emphasized – this may indicate the degree of interest.

Helpful tips:

Emphasize a positive approach: Non-verbal communication is critical. As dementia progresses, individuals rely more heavily on emotional cues to interpret communication, tuning into the tone of voice, facial expressions and body language.

- Pay attention to non-verbal communication and create an atmosphere that conveys a sense of safety and nurturing.
- Smile and avoid negative tones to your voice, as the individual may feel threatened or scared by this and react negatively.
- Avoid negative words like “no,” “stop” or “don’t.” Use positive or neutral language to redirect the conversation.
- Listen for the emotion and connect on that level. What is it that he or she is trying to say? I’m anxious? Confused? Depressed? Scared? Frustrated? Angry?

First steps to improved communication: Always look for opportunities to offer comfort and reassurance.

- Join in the person’s reality; begin where they are. Don’t correct them.
- Look for emotions behind the words.
- Try to avoid common problems:
  - Trying to convince, negotiate or appeal to logic.
  - Expecting an individual to follow new rules.
  - Engaging in an argument.
  - Correcting their speech, spelling or processes.

Intervening in problem behaviors: Behavior is a form of communication, although it’s not always clear what the behaviors mean. Problem behaviors can pose a safety risk to self or others.

- Problem behaviors include physical and verbal aggressiveness, self-injury, inappropriate sexual behavior, wandering or getting lost.
- Nuisance behaviors increase frustration and anxiety for self and others, but are generally not a safety risk. These include pacing, hiding, hoarding, rummaging or clinging.

Behaviors are sometimes expressed as a reaction to something specific and is commonly referred to as a behavioral “trigger.” Common triggers include:

- Communication problems (misunderstanding what is being said).
- Frustration with tasks that are too difficult or overwhelming.
- Environmental stressors (loud sounds, including loud voices, poor lighting, disruptive housemate).
- Personal upheaval (family illness, death of loved one, change in staff member).
- Medical status (physical pain, discomfort, illness).
- Stress of the caregiver or environment.

Paid caregivers and DSPs can attempt to modify the trigger by intervening before, or at the onset of agitation in the following ways:

- Provide reassurance and, if appropriate, a gentle touch.
- Use redirection techniques or distraction to something pleasurable.
- Keep in mind that different approaches work at different times.
- Be patient and flexible.

Compensating for sensory loss:

- Speak slowly and clearly in a normal tone.
- Face participants directly at eye level, so that they can lip-read or pick up visual clues.
- Keep your hands away from your face while talking as this can hinder lip-reading ability.
- Be aware that background noises, such fans or street noise, can mask what is being said.
- Make sure the room is adequately lit and sufficient light is on your face.
- Try to minimize glare.
- Encourage participants to bring and wear their glasses and/or hearing aides.
- Provide large-print versions of handouts if needed and/or helpful.

Discussion questions:

Think about and describe nonverbal behaviors you have observed with a client?

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What messages (words or non-verbal cues) is a person with dementia likely to respond to? Why?

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Developmental Disabilities Administration

Dementia Action Collaborative
Washington State

Module 3:

How to take care of yourself (finding your inner resiliance)

- *Self-care tools for DSPs*
- *Helpful resources for DSPs*

SELF-CARE

SELF-CARE

Providing direct support to those who are experiencing dementia can be extremely challenging. Finding a good work/life balance and practicing a strong routine of self-care will stave off burnout. Having consistent supports and a strong routine is important for individuals with dementia making it very important for us as DSPs to take care of ourselves. This section is about caring for ourselves so we can care for others.

Self-care definition:

"the practice of taking action to preserve or improve one's own health"
(Oxford Dictionary 2020)

For those who care for others, self-care is very important. Self-care is critical otherwise you cannot devote yourself to the duties of caring for someone else. When you find yourself caring for someone with dementia, care needs and demands on direct service and support individuals will increase. This can happen quickly or slowly, over time and these increased needs can take a toll on the support system (you).

Stress vs. toxic stress

Stress can permeate every part of your life, including your work life. Stress itself is not harmful. We experience stress when we wake up in the morning, when we anticipate new plans, when we adjust to new routines and take on new tasks. However, stress can become toxic if there is no relief, it is sustained and long-lasting. It is important to do what you can to minimize your stress because it makes you healthier.

POSITIVE	**Brief increases in heart rate, mild elevations in stress hormone levels.**
TOLERABLE	**Serious, temporary stress responses, buffered by supportive relationships.**
TOXIC	**Prolonged activation of stress response systems in absence of protective relationships.**

As a person who assists others with daily activities, it is important to manage daily stress. This will help keep stress from the "Toxic Zone." This also enables you to be present with the person you are supporting, and better listen and collaborate with them to offer power and choice. You are an extension of someone's ability to do things themselves and have a huge impact on their stress.

This activity will introduce a new tool. Have each person fill out the perceived stress scale independently. Then put participants in pairs to talk about the experience of filling this out. What surprised them? If they were to fill this tool out for someone they support with dementia what might the results be?

Activity: The first tool to help you manage stress is a test of your stress level. Humans have the capacity for predictive stress, which means stress is not limited to what is currently happening, but what we anticipate happening or perceive is happening. Let's test your current level of predictive stress. Complete the questionnaire below, score yourself and take a moment to discussion your results.

Perceived Stress Scale

A more precise measure of personal stress can be determined by using a variety of instruments. The first is called the Perceived Stress Scale.

The questions in this scale ask about your feelings and thoughts during the last month. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question.

The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way; just make a reasonable estimate.

For each question, choose from the following alternatives:

0 – never   1 - almost never   2 - sometimes   3 - fairly often   4 - very often

*****Put your score next to the questions***

___________ 1. In the last month, how often have you been upset because of something that happened unexpectedly?

___________ 2. In the last month, how often have you felt that you were unable to control the important things in your life?

___________ 3. In the last month, how often have you felt nervous and stressed?

___________ 4. In the last month, how often have you felt insecure about your ability to handle your personal problems?

___________ 5. In the last month, how often have you felt that things were not going your way?

___________ 6. In the last month, how often have you found that you could not cope with all the things that you had to do?

___________ 7. In the last month, how often have your irritations with your life felt acute or beyond your control?

___________ 8. In the last month, how often have you felt overwhelmed by all that you have to do or achieve in your life?

__________ 9. In the last month, how often have you been angered because of things that happened that were outside of your control?

__________ 10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

SCORING: Totaling Your PSS Score

Add up your scores for each item to get a total. My total score is________________ .

Individual scores on the PSS can range from 0 to 40 with higher scores indicating higher perceived stress.

- Scores ranging from 0-13 would be considered low stress.
- Scores ranging from 14-26 would be considered moderate stress.
- Scores ranging from 27-40 would be considered high-perceived stress.

The Perceived Stress Scale is interesting and important because your perception of what is happening in your life is most important. Consider the idea that two individuals could have the exact same events and experiences in their lives for the past month. Depending on their perception, total score could put one of those individuals in the low stress category and the total score could put the second person in the high stress category.

Disclaimer: *The scores on the following self-assessment do not reflect any particular diagnosis or course of treatment. They are meant as a tool to help assess your level of stress.*

Break the class into small groups and assign them a self-care activity and have them practice this together. Then have them lead the class in this activity.

Five ways to care for yourself if you are a caregiver

Once you have an idea of your stress level, you can make decisions that will help you focus on self-care. In this next section we will consider some self-care activities and create a plan that will manage our stress and prevent toxic stress build-up.

The Harvard Medical School Clinical Team recommends the following tools for self-care:

1. Self-compassion is essential to self-care.

Being kind to yourself builds the foundation to self-care. Self-compassion means giving yourself credit for the tough, complex work of caregiving, stepping away from the self-critical, harsh inner voice, and allowing yourself time — even if it's just a few minutes a day — to take care of yourself.

Lack of time or energy can make getting that time away particularly challenging. You may even feel guilty or selfish for paying attention to your own needs. What you need to know is this: *in fact, practicing self-care allows the caregiver to remain more balanced, focused, and effective, which helps everyone involved.*

2. Practice simple breath awareness for 10 minutes a day.

One of the simplest deep relaxation techniques is breath awareness. We go over breath awareness, paced breathing, and other breath techniques in ***The Harvard Medical School Guide to Yoga***. Here is one you can try:

- Find a comfortable seated position on a chair or cushion.
- Close your eyes and begin to notice your breath.

- It is common to have distracting thoughts come and go, but just let them pass, and gently bring your attention back to your breath.
- Breathe in slowly through your nose for five counts, hold and pause for five counts,* and exhale for five counts.
- Continue for 10 minutes. You may substitute phrases for the counts such as:
    - I breathe in calm and relaxing energy.
    - I pause to let the quiet energy relax my body.
    - I breathe out and release any anxious or tense energy.
- For deeper relaxation, gradually extend your exhalation, until you reach an exhalation twice the length of the inhalation (10 counts).

*Breathing exercises should not be painful or uncomfortable; if holding your breath is uncomfortable, just eliminate the pause between the inhalation and exhalation.

3. Try a mind-body practice like yoga, tai chi, meditation, and deep relaxation techniques.

Mind-body practices build physical health and deepen the awareness and connection between the mind and body. Yoga has been shown to reduce stress in caregiving groups. We describe yoga breathing, poses, and meditation techniques in *The Harvard Medical School Guide to Yoga*.

Mindfulness meditation and deep relaxation techniques can reduce stress. Guided audio meditations are available online:

- UCLA Mindfulness Awareness Research Center
- Smartphone apps like Headspace, Meditation Oasis, or Insight Timer.

4. Make eating well and getting quality sleep priorities.

It's easy to forget about your own needs when trying to help others. Maintaining adequate sleep and nutrition are key to preventing caregiver burnout. Build a daily 10-minute nighttime routine to achieve more restful sleep. Your nighttime routine can include your breathing exercises, meditation, or **yoga poses**. Missing meals can lead to irritability and fatigue, so it is important to eat regularly scheduled meals throughout the day.

Nutrition can also be an important factor to prevent burnout. Chronic stress has been linked to increased inflammation in the body, so it is helpful to avoid foods that are processed or high in refined sugars, which increase inflammation in the body. Avoid or reduce alcohol, since alcohol both increases inflammation in the body and disrupts quality of sleep.

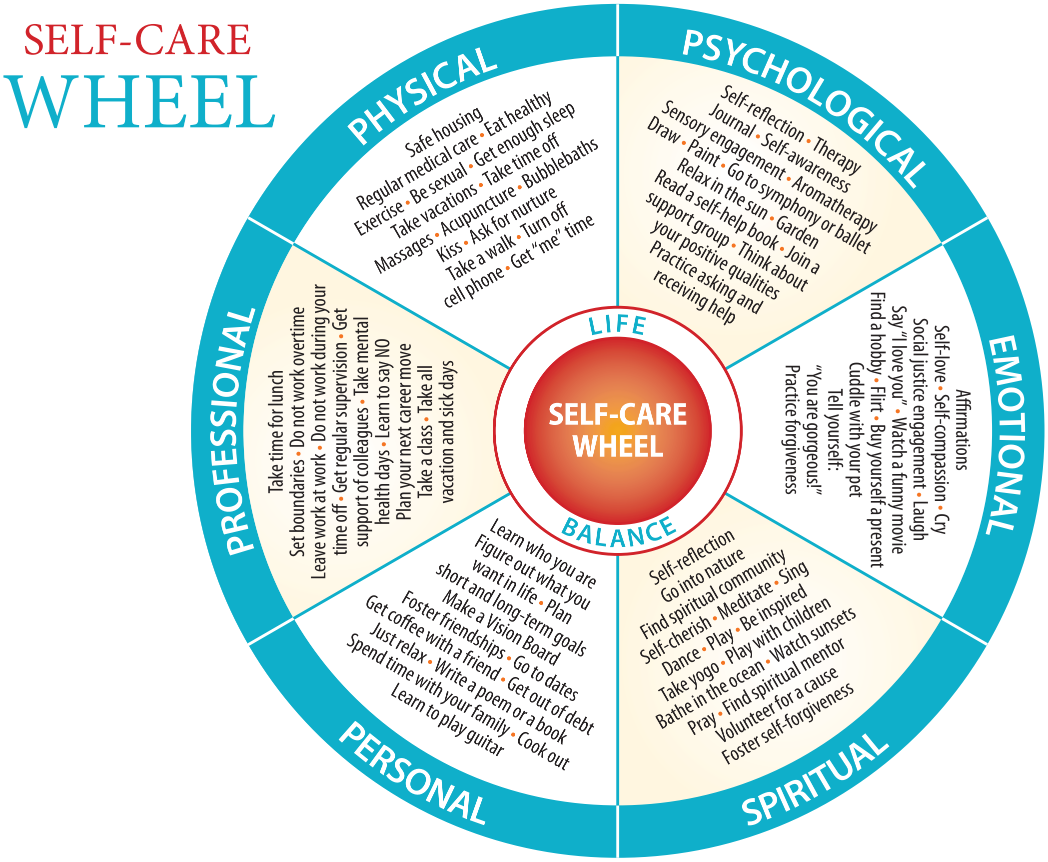
5. Remain socially connected. Find support through local caregiver support groups.

While it can be difficult to keep social appointments with friends and family in the face of medical caretaking, it is important to maintain social connections to feel less isolated and prevent burnout.

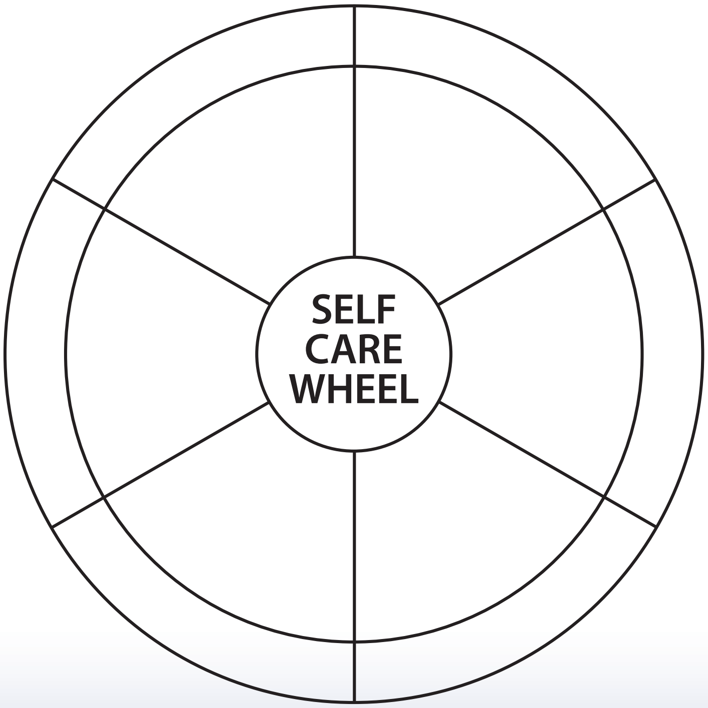
Realizing that you're not alone and that others are going through similar experiences nurtures your ability to be self-compassionate. Hospitals and local organizations often offer caregiver support groups for family and caregivers.

Each participant will fill out the self-care wheel for themselves. Then break them into small groups and share their self-care wheel. What areas are strong? What areas on the wheel need more support? What is an action plan to improve your self-care plan?

Activity: Review the self-care wheel below and notice that self-care is broken into different categories: physical, psychological, emotional, spiritual, personal and professional. You may think of more categories that apply. The important part of this activity is to create a self-care wheel that applies to your specific situation. Good self-care plans are routines and cover many different parts of your life. The plans are a holistic approach to self-care, not just focused on mental or physical health, but an integrated way to care for yourself as you care for others.



Activity: Take some time to complete a self-care wheel for yourself. Select your own categories and activities that will truly meet your self-care needs.



Summary

To effectively continue to care for people with developmental disabilities and dementia, taking care of yourself is critical. Caring for people can be challenging. It is important to practice self-care to lower stress and respond appropriately over the long term.

OPTIONAL ACTIVITY: Break them into small groups and have them visit a website or watch a video to expand their knowledge. You can have small groups do this and write a summary to share with the class. As an instructor, you can select a video to watch with your class.

Have each person fill out the discussion questions independently.

Resources for caring for individuals with dementia and I/DD

Caring for people with intellectual/developmental disabilities and dementia can be challenging. Individuals with disabilities may exhibit changes in behavior that are difficult to understand and address. It is critical that DSPs have access to resources to help them understand the interplay between I/DD and dementia, and to gain ideas for providing support to individuals who experience both. Resources empower DSPs with information, enhancing their ability to be successful in maintaining relationships with the people in their care.

Interactive resources

Interactive resources are a great way for DSPs to connect with and learn from each other. Online support groups allow caregivers to problem-solve, share ideas, and provide moral support. Some caregivers also find blogs useful, both reading and writing. Blogs can provide anecdotal information that allows caregivers to feel understood and know they are not alone in the challenges they face.

- **Websites**
  - www.dsrf.org – *Down Syndrome Resource Foundation, includes blog*
  - www.dsaw.org – *Down Syndrome Association of Wisconsin, includes online support group*
  - https://informingfamilies.org/dementia/ – *Informing Families, Washington State Developmental Disabilities Council*
  - www.ndss.org/resources/alzheimers/ – *National Down Syndrome Society*
  - https://www.the-ntg.org/ – *National Task Group on Intellectual Disabilities and Dementia Practices*

Written materials

Several written materials that describe I/DD and dementia exist. Books and articles can provide in depth information that describes the way disability and dementia intersect, the causes, and therapeutic interventions.

- **Books**
  - *Aging and Down Syndrome: A Health and Well-Being Guidebook* – National Down Syndrome Society
  - *Mental Wellness in Adults with Down Syndrome* – McGuire & Chicoine
  - *Intellectual Disabilities and Dementia: A Guide for Families* – Karen Watchmen
- **Articles**
  - www.ncbi.nlm.nih.gov/pmc/articles/PMC4878319/ – *Why Do We Need Guidelines, Alzheimer's Association*
  - https://pubmed.ncbi.nlm.nih.gov/29106536/ – *Intersection of Intellectual Disability and Dementia, International Summit on Intellectual Disability and Dementia*

- https://pubmed.ncbi.nlm.nih.gov/29583104/ – *Perspectives on Family Caregiving, Gerontology Social Work*
- https://pubmed.ncbi.nlm.nih.gov/29781149/ – *Supporting Advanced Dementia in People with Down Syndrome, Journal of International Disability Resources*
- https://portal.ct.gov/-/media/DDS/psychology/Aging_Dementia_Intellectual_Developmental_Disabilties.pdf?la=en – *Aging, Dementia, and I/DD, Development Disability Services of Connecticut*
- https://www.sevenhills.org/programs/idd-adrd?hsLang=en – *National Task Group on ID and Dementia, Rhode Island*

Videos

Allowing caregivers to see what dementia may look like in individuals with I/DD can be helpful. Videos can also help caregivers better understand how to manage difficult behaviors, how to talk to individuals with I/DD and dementia, and how to provide respectful care.

- **Videos**
  - Supporting People with Intellectual Disabilities and Dementia, Aging and Disability Resource Connection of Oregon
  - Dementia in People with Down Syndrome and ID, UCLA
  - Structuring Care and Community Supports for People with ID and Dementia, Part 1, National Task Group on ID and Dementia Practices

Discussion questions:

What is one interactive resource you are interested in exploring?

What are two written materials you are interested in reviewing and bringing back to your team?

Which video resource captures your interest?

Summary

Solid information is a form of self-care for DSPs. Knowing what individuals with I/DD and dementia are experiencing and how you can respond to them enhances the understanding between DSP and individual with I/DD and dementia. That relationship of understanding enables meaningful and effective interactions to take place, helping both DSP and individuals with I/DD and dementia to experience success.

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