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Good afternoon, everyone. My name is Lisa Zimmerman from the rehabilitation research and training Institute in Albany, New York. Thank you for joining us for today's webinar, Alzheimer's disease and other dimensions, functional and behavior changes. These professional development webinars presented in conjunction with RRTI and the Lewin Group for social workers, counselors, registered nurses and other healthcare professionals are supported through the Medicare Medicaid coordination office or MMCO and the Centers for Medicare and Medicaid Services or CMS to ensure beneficiaries enrolled in Medicare and Medicaid have access to seamless high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated coordinate care, the Medicare Medicaid enrollees, MMCO is developing technical assistance and actual tools based on successful innovation and care models such as the webinar series. To learn more about current -- resources, please visit www.resourcesforintegratedcare.com for more details. A little housekeeping before we get started. Your microphones will be muted throughout the presentation. However, there will be a question and answer portion during this webinar. If you have a question, please click the raise hand feature on your control panel at the designated time and you will be unmuted by an administrator. You can also type your questions into the chat window and an administrator will ask the question out loud during that designated time. There will also be poll questions throughout this presentation. A window will appear with the question and you can submit your answers at that time. At the conclusion, a tab will appear in your browser prompting you to complete the evaluation survey. It is required that you complete this evaluation survey in order to receive three contact hours each from the Michigan social work continuing education collaborative, New Hampshire nurses Association, national Association of social workers, and the national Board for certified counselors. Please note that these are not CEUs but rather contact hours, which can be translated to CEUs. You will need to verify with the appropriate credentialing organization as to what would apply for your particular state license agreement requirement. It should be noted that contact hours with the national Association of social workers are not recognized in the states of California, Michigan, North Carolina, and West Virginia. If you are unable to complete the survey at the end of the webinar, you will receive an e-mail tomorrow with a link to complete the survey at that time if you have not already done so. Everyone will receive that e-mail, so if you did complete the survey, at the end of today's presentation, you do not need to complete it again. You can just disregard the e-mail. At this time I'd like to introduce our instructors to you. Jill Dorsi is a licensed clinical social worker for the -- with over 30 years' experience working with individuals with mental illness and developmental disabilities including individuals above age 60 and community-based family residences. She is also a trainer and person centered planning, cultural competence and recovery focused practices. Linda Anderson is a registered nurse for health quest Thompson where she meets and reviews patients in all area hospitals and potential rehab candidates and subacute rehab and is PRI and screen certified. She was previously employed as a CMH as the DDS over 20 years in the family care unit and 15 years at Helen Hayes hospital in acute r ehab. Ms. Anderson is also a member of the bereavement committee at the DDSO and a Prader Willie educator as well as a participant in IVR study on Fragile X and Down syndrome and Alzheimer's disease. Jill and Linda?

Hello. It's good to be here with you. I'm Jill Dorsi. I'm here with Linda Anderson. We're going to be talking about Alzheimer's disease and other dimensions and how they impact people with intellectual and developmental disabilities. We're going to look at the challenges that individuals face as well as the challenges that their caretakers face in helping individuals understand the process and to provide supports for people with dementia. We've sent you some PDFs and we encourage you to download these and look at them as we will be referring to them during the presentation. If you have a question as we go, please type it in. Your questions will be collected and we will answer them at the end of each section. Our learning objective for this session includes identify the scope and cognitive changes associated with the progression of dementia for people with intellectual disabilities. Become familiar with the ways that Alzheimer's disease and other dimensions affect individuals with intellectual and developmental disabilities. Learn about early evaluation and assessment strategies for identifying and managing dementias to facilitate better support. RO identify syndrome specific concerns for individuals with Down syndrome. Differentiate between behavioral changes that may signal the onset of dementia and those that may indicate other, often treatable, mental or physical conditions. The intellectual and developmental definition is it's an intellectual limitation that hinders independent functioning and daily activities such as healthcare, communication or education. It's a limitation that occurs before the age of 22. It's expected to continue indefinitely and result in the need for long-term of active and functional supports. For people with developmental disabilities, some people do not have -- they face other challenges such as behavior disorder, communication disorders, Prader-Willi syndrome, which is an eating disorder. So as Linda was saying, not everybody with a developmental disability has an intellectual disability. And we also need to distinguish between the intellectual disabilities or developmental disabilities and dementia. It's important to recognize that people with ID/DD often times lack particular skills or cognitive abilities. These may be underdeveloped or absent across the lifetime. So the person has worked very hard at developing this skill that he or she has. And the progress is slow but measurable. Someone with dementia is going to begin to lose existing skills and abilities. As we talked about dementia with people with ID/DD, we're going to be focusing on distinguishing between the skills and abilities that they have developed or have lacked across a lifetime and the skills that they're going to be losing as a result of dementia. And this is sometimes very complex, a complex station to make. So one of the reasons this has become an issue that's very important is that people with ID/DD are living longer. As a result of living longer, they are experiencing more of the risks associated with aging, particularly Alzheimer's disease and other dimensions. Right now it's estimated that about 6% of the people who have ID/DD will be affected by some form of dementia by the time that they are 60. People with Down syndrome in particular have both increased lifespan and increased risk of developing dementia, 25% of people with Down syndrome are likely to experience dementia after the age of 40. That goes up significantly to 60% to 70% after the age of 60.

Right now, this is a very relevant issue. There is ongoing research across the world, which is looking at aging and the process in general and how it impacts individuals with intellectual and developmental disabilities. One of the issues being looked at is developing person centered planning and self determination so that who do experience dementia associated with aging are able to continue to live in this community. Assessment and evaluation tools are being designed specifically for people with ID/DD. As I said earlier, people who have intellectual and developmental disabilities may lack the skills that most tools screen for dementia are testing for. It's important to be able to be aware of what skills the person lacks on a lifelong basis. And screening is important for early identification so that planning and supports can be developed in a timely way. So we're going to begin by looking at what dementia is an the various causes of dementia. In particular, who is at risk for dementia?

What is dementia? It's a term that describes a generic assess characterized by cognitive decline that impairs ability to function socially, personally, and productively. It's persistent and progressive and is associated with chronic brain disorders. A disease process not part of the normal aging process may be caused by various factors such as stroke, CVA, head injury, heart disease. It's important to make a differential diagnosis. Normal pressure hydrocephalus may be preventable and reversible if caught early. Some with early diagnosis and treatment process be slowed. I mean, the progression of the disease disorder can be slowed by early treatment.

So the first step in working with someone with a intellectual and developmental disabilities is to get a really lopmental disabilities is to get a really good baseline. Identifying dementia in people with ID/DD can be really complicated because diagnosis of dementia is typically based on the impairment and communication in daily functioning that individuals with ID/DD often have as a lifelong disability, part of their developmental disability. So the standard assessment tools used for the general population and are not designed for people who have ID/DD -- because they are based on the person being functionally independent throughout their lifetime. And then focusing on the loss of these skills. So people with ID/DD, when you think about it, they often struggle with things like activities of daily living, self-care skills, dressing themselves. These are exactly the areas that are most frequently impacted when someone develops dementia. By developing a baseline early for an individual, it can be used as a tool in assessing the loss of skills and diagnosing a dementia at the early-onset. The best way to develop a baseline is to use a video recording of the individual. Because it documents the person's abilities very comprehensively. It's beyond just making a list of what the person can or can't do. It captures who the person is, what the personality is like, what his style of communication is. And it's recommended that video recordings of the individual be repeated on an ongoing basis, usually starting from the age -- for someone with Down syndrome -- about 30 to 35.

Some groups are at higher risk for developing Alzheimer's disease. People with Down syndrome over the age of 40, are more likely to develop -- have an increased incidence of Alzheimer's developing and beyond the age of 60, that rate was even higher. People with a history of Alzheimer's disease, people who have suffered a serious head i njury, or a series of head injuries during their lifetime, for example people with seizure disorders, people with Down syndrome and longer lifespan, it puts them more at risk for d ementia. So you need to be proactive in getting family histories, and sharing that with health professionals and contacting families to get health histories.

As Linda was mentioning, there are many different types of dementia. The treatment outcomes are different depending on the type of dementia. The differential diagnosis becomes very important in planning for future care. The causes and progressions of some are different. They may not progress. A person may actually have some reversal of dementia if there's treatment or can avoid further progression with treatment. Symptoms, functioning deficits and presentation varies significantly, depending on the type of dementia. We're going to be reviewing the kinds of dementia.

This graphic depicts the most common types of dementia. We're going to look at each of these in greater detail as we go o n. Just to give you a general idea, we're looking at some of the things like vascular dementia, mixed dementia, frontotemporal dementia, dementia with Lewy Body, mph, normal pressure hydrocephalus, mild cognitive impairment, Parkinson's disease, and Alzheimer's. All of which have different ways of dementia progressing.

So Alzheimer's disease is considered the most common form of dementia. When we hear about the most -- it accounts for about 60 to 80% of all cases and that's right across the board including individuals with ID/DD. Alzheimer's disease is characterized by abnormal deposits of fragment beta-amyloid, a brain is basically made up of proteins. And one type of protein that sees the brain is beta-amyloid. In dementia or Alzheimer's disease, abnormal deposits of beta-amyloid occur. This can be diagnosed through a PET scan. And through CAT scan, which would show atrophy. The PET scan will show the deposits of amyloid. And we have a great graphic that's going to be coming up that will show you what that looks like. Vascular dementia is caused by many small little strokes or changes in a brain blood supply. The damage may occur anywhere in the brain. Where that damage occurs will determine what kind of functioning is affected. Diagnosis is not -- is complicated because vascular dementias are a common feature of Alzheimer's disease. No treatment is available although causes of stroke such as high blood pressure can be addressed. To try and prevent the problem from occurring. Vascular changes are seen in vascular dementia, like those seen is called -- seen in Alzheimer's but are not progressive.

There is also a mixed dementia which is a combination of Alzheimer's disease and vascular dementia. As a result of Alzheimer's disease, vascular function is compromised if this puts the person at greater risk for stroke. It's necessary to make a differential tie doses between the type of dementia, is it purely vascular or is it a combination of Alzheimer's and vascular dementia? As Linda said if it is a purely vascular dementia, or treatment can be provided to decrease the risk of stroke and the progression of that dementia can be stopped or slowed significantly.

Frontotemporal dementia involves damage to brain cells in the front and side regions of the brain. Symptoms may include personality and behavior changes or difficulties with communication, the areas of the brain that are impacted. Example is Pick's Disease characterized by bodies in the frontotemporal lobe. There are no distinguishing microscopic abnormalities. Pick's Disease is like Alzheimer's it but it's much more rapid. It's not reversible. Pics bodies makes tiny holes in the frontotemporal rontotemporal lobe. It's a very rapid progression unlike Alzheimer's, which may progress over 10 to 15 years. Pick's Disease progresses as quickly as a few months, you'll see significant changes. Personality changes. A sense of personal self identity. They a flat affect. Wandering is a very common problem. They require intensive oversight and often have to be in an environment where they are protected from wondering either by a device that warns staff that that person is getting up and looking to exit to exit the door, or having door alarms so that the staff are aware that that person might be trying to n might be trying to wander.

Another type of dementia is dementia with Lewy Body's. This is an irreversible brain disease associated with protein deposits called Lewy Body's. These appear in deteriorating nerve cells. Often found in damaged regions of the brain. Such as people with Parkinson's disease are particularly at risk for dementia with Lewy Bodies. Symptoms are very similar to Alzheimer's. And it is often confused with Alzheimer's disease. Differential diagnosis is complicated but important to get. And dementia with Lewy Bodies has some very unusual features. It's characterized by fluctuation in cognitive symptoms so that a certain time, the individual with this type of dementia may be functioning just about the way they always function. They may seem very alert, able to problem solve, able to get dressed and take care of themselves. And then even the next day, they lose those skills again. This becomes particularly stressful for caregivers and family members because it's difficult to understand what's going on. It also makes it difficult to diagnose if the person goes for an evaluation at a time when they are functioning well, the screen is not going to show a love of symptoms with dementia. Another thing that's very common with dementia with Lewy Bodies is a sensitivity to psychotropic medications. As well as visual hallucinations, muscle rigidity and some tremors.

Normal pressure hydrocephalus is another type of dementia caused by a buildup of fluid been the brain. Symptoms include difficulty w alking, memory loss, possibly inability to control urine. And NPH can sometimes be corrected with surgical installation of shunt to drain excessive fluid. That's why early diagnosis is so essential. Then that person can be shunted and preserved the brain activity.

Shunts will have to be monitored because they sometimes clogged or block. You may see a reappearance of the symptoms, it's not that the problem has not resolved, that the shunt needs to be corrected.

Mild cognitive impairment is a problem with memory and cognitive skills severe enough to be noticeable but not severe enough to interfere with daily life. Our concerns disease, many people go on to develop dementias in later stages of the disease. Recent studies have indicated that the presence of Lewy Bodies is also discovered in people with Parkinson's disease. MCI or mild cognitive impairment is not a part of normal aging. It is an actual condition. You need to monitor to see if anything else is happening to evaluate. This may not lead to anything.

We're going to be talking about the distinction between normal memory loss and cognitive impairment later on.

Just to summarize, there are multiple causes of dementia. Including illnesses that actually attacked brain cells. These include Lyme disease, Alzheimer's disease, Parkinson's disease, Huntington's disease, high fever and systemic lupus.

Some other causes of dementia can be disruption of oxygen flow to the brain due to heart disease, C BA, stroke, or smoking. Chronic poor nutrition and dehydration can contribute. Metabolic disorders such as liver or kidney diseases, drug or alcohol abuse, traumatic rain injuries, STDs including AIDS also can contribute to dementia. And exposure to environmental industrial toxins.

So we're going to talk about Alzheimer's disease in greater detail. Alzheimer's disease progresses over a period of time. And it has very distinct -- somewhat distinct phases. It does go through each of these. Stage one is where there's no visible impairment. Although there may be changes in the brain with the amyloid -- the beta-amyloid deposits. Stage two, mild cognitive decline. Stage three, mild -- very mild cognitive decline and then mild cognitive decline. Stage four, which is where early Alzheimer's disease would most likely be diagnosed is a moderate cognitive decline. These progress right up until the end stage, severe cognitive decline which is late stage Alzheimer's. We're going to be looking at each of these stages in greater detail. As we go through. This is a graphic that depicts the stages of Alzheimer's. It demonstrates that Alzheimer's is a progressive, irreversible, and it moves through life. Usually takes about 10 to 15 years of decline. And early diagnosis is important because you can prepare for care needs and so forth as time goes on.

Possibly slow the process but not going to cure it.

This is a PET scan like we talked about before, showing the brain changes with Alzheimer's. The red on the -- on my left -- I don't know how this is -- you can -- the brain that you see on the left with the red deposits, that indicates amyloid. Amyloid is the protein deposits that occur with Alzheimer's. And on the other side, the more blue picture depicts a typical brain. Where the dark blue indicates no amyloid. The other colors in order like the colors of the rainbow, also -- also show progressively increasing levels of amyloid.

So now the brain with the amyloid seems like early-stage Alzheimer's.

As you get more and more red areas, as Alzheimer's advances. And of course more damage.

Okay. As stage one we talked about, no impairment noticed. Apparent normal functioning, not evident in testing by a healthcare professional. So no impairment is noticed by the person, friends or family during this stage. Changes could be very subtle if at all.

If you went to the doctor, what a doctor be able to diagnose?

Not in stage one.

Would they be able to diagnose it with a PET scan?

Still not in stage one. Too early.

Stage two, very mild cognitive decline. There may be some memory loss, forgetting familiar names, what we laughingly call senior moments may become very common. Like little glitches in the p erson's memory. The person might forget where he left some common objects like keys or glasses. As with the early stage, stage one, often not noted. In our culture we think it is normal to be forgetful as you get older. At this point however, a brain scan would show some changes particularly atrophy. That would be as a PET scan.

Yeah. You would see some shrinkage. Shrinkage also comes with age.

Definitively diagnosed.

Even with a CAT scan, it wouldn't be a definitive diagnosis.

Stage three is a mild cognitive decline. Friends and family start to notice a difference. The person experiences decreased ability to remember names. The persistent -- the person has impaired retention when reading but they are not noticing it. They may read the same book over and over but they can't -- people will frequently you lose objects. The person experiences diminished ability to plan. Medical diagnosis is possible with PET scans. There is a memory loss that obvious to outside world, not so much to the person that it is occurring.

There's also a lack of insight associated with the person is not aware.

Stage four, it's very common to have your first diagnosis of early Alzheimer's disease. A healthcare practitioner who knows the person will be able to detect the reduced memory based on the person's history. The person is going to have difficulty remembering recent events. They may forget that they saw somebody a few hours earlier. You also lose the ability to do complex math and perform complex tasks. Again, with someone with an intellectual disability, they may never have been able to do these things. So that may not be obvious but you are going to see a decline in their ability to do something like get dressed independently. And there's also a change in behavior. People will frequently become withdrawn.

Stage five is the mid-stage of Alzheimer's disease. The person experiences major memory gaps. The person needs assistance with their ADL skills, activities of daily living. Bathing, feeding, picking out clothes, dressing themselves. The person is disoriented around time and place but not to their own name. They know their name, the names of close family members. They can -- this is a time when you might start to need some assistance at home. Look at hiring an eight to come in. If you need to get to work, family members -- their time would be impacted. The person is not going to be able to deal with it by themselves.

At this point, does the person have any insight into something changing? Are they aware that they're losing skills or losing memory?

There may be frustration but they are not really aware. Not aware. They know their own name and close family members names, but they are disoriented to and place. They may wander. So it's not someone that you can like leaves by themselves.

So stage six, we're going to see severe cognitive decline. There may be some personality changes. Someone who was very social and friendly may become aggressive. The person is no longer able to recall personal history, when things have happened. They are going to forget the names of familiar people even people who were really close to them. People they see every day. And again, like the level of care that the person needs is going to begin to increase significantly. Someone who used to have ability to dress themselves and brush their teeth and do all of the self-care things may no longer be able to do that. And they are going to need hands-on personal assistance at this point. This is not only for people with intellectual disabilities, this is something you would see with someone who has functions in the normal range of cognitive a bilities. Sleep disruptions become particularly significant. You may have heard of the sundowner syndrome where as early evening progresses, the person becomes more agitated and more anxious. And may vocalize frequently and become very, very fearful. People also may become incontinent of urine and feces when they used to be independent in that area. And wondering becomes a huge issue. When you are planning community supports for this individual, you are going to want to be able to be aware of where the person in this at all times because they could wander out a dork or wander away from you if you are in the community and got lost. So stage seven is a very severe cognitive decline. This is what we call late stage or end-stage Alzheimer's disease. The person has lost the ability to respond to his or her environment. He or she is no longer able to generate, recognizable speech. They may become incontinent, both bowel and bladder. The person may no longer be able to walk without assistance. He may lose the ability to smile. They have a very flat affect. The person may display abnormal reflexes and muscle rigidity. Impaired swallowing and they may also experience seizures. [Indiscernible] New York is willing -- at this point in time where there is on recognizable speech or how they're going to judge that the time for that to step in because this is fairly late stage Alzheimer's. The risk is aspiration pneumonia. It may also aspiration -- aspiration may be through primary use for a cause of death at this stage, because of choking.

And they lose the ability to swallow because of deteriorating nerve functions.

Yes. That muscle rigidity, abnormal rigid -- reflexes, swallowing is a normal reflects.

So deterioration skill is one of the tools that is used to identify the stage of Alzheimer's disease. It was developed by Dr. Drug -- Dr. Doug Drummond. It's important to notice here that this is developed for people in the general population. It wasn't developed for someone with a pre-existing intellectual or developmental disability. Stay aware of -- if you were going to use this to work with somebody with ID/DD, you would need to be screening out the skills that the person never had.

Like know their baseline.

Know their baseline. We are doing -- thanks for reminding me. We're going to be stressing baseline over and over throughout this presentation because particularly with someone with an intellectual disability, it's essential to have a good baseline so that when you start to evaluate them for the possibility of dementia, you know what you're looking for.

I think also we had some questions that have been sent him.

I'd like to go over -- the global deterioration scale, if we look at that, Alzheimer's in stage one or two, those are the times when you are beginning to see some mild memory loss. So testing is generally normal. That person is probably able to live independently. There's no change in your care setting at that point. When you hit stage three, with a mild cognitive impairment, you're still able to live independently. You might seem -- need someone looking over your shoulder because of some mild memory losses. But you're basically still capable of functioning. Stage four is early dementia, clear-cut emphasis on careful clinical interview. You are already needing to be diagnosed with all timers at this stage. At the beginning stages as such. Denial is common. Withdrawal from challenging situations is common. This person might be able to live independently, or perhaps with some family assistance or caregiver that is hired coming to assist on a part-time basis. But they are still able to have some level of independence. In stage five under moderate dementia, the person is no longer able to survive without home care assistance. This is when the person either has to live at home with a family member or a hired caregiver or in a senior residents where they have assisted living supervision. Maybe not a Skilled Nursing Facility but they may be able to survive in an assisted-living facility where there is some protective oversight. They do get some disorientation. They do have some trouble recalling major events. And some self-care skills deficits. In stage six, and also stage seven, this is when you're going to -- someone is going to need in -- live in a more complex scarce -- care situation such as a Skilled Nursing Facility or have 24 hour home care because this person can't take care of themselves. Not aware of their environment and not able to self advocate. Not able to complete the activities of daily living. At that point any longer.

So just to review the questions, Linda, I'll ask -- I think a lot of these fall under your area of expertise. These are from Camille in Arkansas. At what stage what a high functioning educated person with Alzheimer's typically start needing 24 hour care?

As we said, this is where stage six and seven Alzheimer's -- according to the global deterioration scale, that's where you're going to see someone needing that more complex level of care, the Skilled Nursing Facility or 24 hour home care. Other questions?

In the advanced stages of Alzheimer's, do they usually end up going into a facility? You were talking about how they would need complex care in either a nursing home or something.

Right.

And I think from what I understand about working with people with Alzheimer's and what I've experienced myself, it's really difficult for one person to care for the individual at that point because it's really 24 hours around the clock.

That's right. Stage six and seven of Alzheimer's is where we would see someone needing that 24 hour care. As far as sports in the community, there are some assistance through aging care, programs, grant programs where they will help with some financial assistance but we're not talking about large amounts of funding. So this is where you're going to need to make a Medicaid application unless you have the financial resources to pay for nursing home care. So that person is either in a nursing home environment or they're going to need 24 hour care at home, which means rotating levels ting levels of caregivers coming in, to -- or hired through an agency. Moneywise, you're looking at in New York, I'm not sure about -- a Skilled Nursing Facility is approximately $12,000 a month. If you are paying out-of-pocket. For a nursing home. So financial resources go very quickly. And Medicaid has to be started so that person can be cared for in a nursing home setting. There's varying degrees of nursing homes. There are nursing homes that are -- have a locked facility where someone who has a tendency to wander is not going to be able to get that that unit by themselves. And at this stage of Alzheimer's, that may be a necessary thing. Or like we talked about before, b ed, chair, door alarms. These would have to be in place in the facility that you choose. It has to be someone from the facility that is geared for dementia, taking care of someone with Alzheimer's or severe d ementia. It's more than just the same level of care that a typical nursing home that would offer -- you need a facility that is specifically for dementia at this stage.

And again, I'm not sure what's available in all -- in Arkansas. Some states will pay family members through the HCBS waiver. They will pay family members to care for an individual so that if you did want to keep a person at home and you had more than one individual, more than one c aregiver, it would be possible and depending on what your state has approved, you might be able to access HCBS waiver funds to reimburse your caregivers. And I see that you do work for the Arkansas State Government. You're probably aware of -- I know that Mexico has a program that does that. There was also a pilot program a few years ago through Medicaid called passion counseling that did reimburse family members to care for their loved ones at home.

Hospice tends to be willing to come in in stage seven when that person -- they judge the criteria of when they will start to pick someone up through hospice support. When they have lost their verbal capabilities, that's the judgment call. Then they can get that person in need of their services where they -- where there is some funding for those services through Medicare. Again, that's not 24 hour a day assistance. So there has to be a plan on how to get that assistance -- if they are going to try to keep someone at home rather than in a Skilled Nursing Facility.

We do have a couple more questions.

Okay.

Actually, Camille? Two more questions. At what stage do caregivers usually decide that a person with Alzheimer's needs to go into a facility? If they've the decide that is necessary, what are the usual determining factors?

From my experience, that's a determination based on the family and what they're capable of doing and every family has a different cutoff time of what they consider they are able to do. Later stages of Alzheimer's, it's not unusual for the person with Alzheimer's to start striking out at the person taking care of them. So that determination starts during level six and seven, when you start seeing that aggressive behavior. That's the time I see most people coming in and saying, I can't do this anymore unless they had adequate help at home and caregivers. And a funding source to have those caregivers there unfortunately.

And again, as Linda says, it's a very individual decision. But it really will become impossible for a single individual to care for someone with Alzheimer's, because the needs are relentless. They are ongoing and they are complex. And for example, husband and wife or elderly parents caring for an individual with an intellectual disability, the caregiver begins to have health concerns themselves, they really cannot keep up the pace of no sleep, no rest, not being out to do grocery shopping. So it really becomes quite the challenge. It's really important for counselors or social workers to be very upfront when talking to the family members about how it's g oing. And what challenges are facing. How are they sleeping? What are they doing to get some recreation and downtime for themselves?

Do they have a support system built-in that allows them breaks so if they go to the grocery store, they can take care of their own needs as well? Lack of sleep creates tremendous problems for caregivers. That's usually when I start to see someone come in and they say, I can't do this anymore. I can't walk out the door. I'm concerned about what's going to happen to my relatives. As soon as I turn my back, something can happen. Or the person is getting assaulting or aggressive, I've heard many times someone come in and say, I don't know what happened. My husband was always so loving and kind. I know he has Alzheimer's but now he doesn't know who I am. He pushed me out of bed in the middle of the night because he didn't recognize who I was. Those of the kinds of things you start to see.

-- those are the kinds of t hings.

You currently have an individual who is forgetting that she has eaten. What stage would she be in?

That's in your early stage where forgetfulness start coming. If you look at the global determination scale, deterioration scale, sorry, that's around stage four or five, you start to see forgetfulness starting in already.

You've probably seen some other issues coming up with the person may be forgetting that she has seen somebody or had a conversation with somebody. Eating maybe the thing that she's not verbal about, but there are probably other Mable -- maybe subtle changes that you're noticing.

Speech ends up being a lot of it going to forgetting names of objects and calling them -- a thing you can look for -- did ask for a pencil or for the thing that you write with? Do they ask for a fork or the things that they eat with? Those of the starts of -- the things you will start see. Loss of words. They can still carry on a conversation, but they are describing things in a different manner than they would typically describe.

And Dallas says, my mom has dementia. First thought she was a 4 but she has some characteristics of stage five. She has 24-hour care. Is it possible to have or show some things and not all of the different stages?

The brain is a funny organ. Things come in gaps and pieces. And each stage is a generic suggestion of what is to come but there's overlap in those stages. Or how you are viewing something maybe a little different as time goes on.

I think also coming from the social work perspective, when you're very close to somebody, you have a strong sense of who that person is as an individual. You have a sense of her as a p erson. So you may be seeing more of who she is then a caregiver who isn't as familiar with her, may not be in touch with her pronounced look -- personality as much as you are. So you're seeing the retention of certain skills because you know who she is and you know what she can d o.

Okay. We're going to move onto the next section. As with this, please type your questions in as we go. And we will answer them at the end of the next section. What we're going to talk about now is dementia and Down syndrome in particular. As people with Down syndrome have particular risks and vulnerabilities associated with the syndrome. And this makes them much more horrible to experiencing dementia.

Okay. So the risk factors for Alzheimer's disease in people with Down syndrome, first off, someone with Down syndrome is living longer. So that puts them at increased r isk. We talked to this earlier. After age 40, there's a possibility of developing an Alzheimer's disease. After age 60, that percentage of how many are at risk increases. There's a pre-existing genetics accessibility with -- susceptibility with down syndrome. Women have increased risk of Alzheimer's disease due to estrogen deficiencies and earlier menopause, which were protecting them but being there at such early menopause alone with Down syndrome, that puts their risk a little bit higher.

So also another problem is that there's a syndrome specific brain development, decreased brain waves and size, reduced frontal lobe volume and decreased dendrite branching during fetal development with someone with Down syndrome. Of a POE gene located on chromosome 19 and is link to lipid metabolism -- the Institute of IDR did a research project on Down syndrome and Alzheimer's. There was significant evidence that lowering cholesterol level may reduce the risk of early development of Alzheimer's. It doesn't prevent someone with Down syndrome from getting Alzheimer's if that was what was going to occur, but it does delay by treating the cholesterol levels.

So there's a particular neuropathology.

As we go on, people with Alzheimer's disease and adults with Down syndrome display similar brain deposits and characteristics of Alzheimer's disease. No pathologic changes consist of Alzheimer's disease appeared very early in Down syndrome at that age, 35 to 40. Already starting to see an indication of Alzheimer's in someone who is heading in that direction. Not everyone with Down syndrome ends up with Alzheimer's disease. Just a higher incidence. Measurable symptoms of dementia may not become evident until age 50. But the possibility and the brain changes are already occurring at 35 to 40 in someone with Down s yndrome. Pet scan could reveal some of those protein protein deposits.

So when you're working with somebody who has Down syndrome, you want to keep in mind that they are at extreme risk for developing dementia. With the caveat that not all people with Down syndrome get dementia but they all are vulnerable to it because of their syndrome specific issues. They have a tendency to age very quickly and at an earlier age. And this increases their risk of dementia as a result of A lzheimer's. Some people with Down syndrome are going to begin to see some of the symptoms as early as in their 40s. I've actually worked with people with Down syndrome who have showed symptoms between 35 and 40. And it seems that often times once you see the early symptoms, the progression seems to be a little more rapid with somebody with Down syndrome. It's very important that we develop at some point standardized tests for people who have Down syndrome. And ID/DD. Because the tests that are currently available are designed for people who do not have an intellectual or developmental disabilities. We are going to be looking at some tests that are just in the pilot stage that have been designed for people with ID/DD. We're going to talk about how these are distinct from those that have been developed for the general population. When you're working with someone with a intellectual disabilities or Down syndrome, their cognitive Miller -- abilities very individually. As you know, some of them are going to be able to do a lot more. They're going to have better s kills, they're going to have better cognitive abilities. They may be able to read better. Somebody else may not be able to beat, mainly more assistance with ADL. These needs to be documented in the baseline so that if you are screening for dementia, you're looking for skills that the person has lost and you have to distinguish these from skills that the person may never have d eveloped.

So dementia and Down syndrome requires a change in status over a period of six months. So it's not a day-to-day change, but you want to see a consistent change, a consistent decline over a period of time. You're going to probably sutured juice in both cognitive functioning and behavior functioning. With individuals with Down s yndrome, and also often with people with any kind of intellectual and developmental disabilities, your first clue is going to be a change in behavior and a change in personality. You're going to see a person who is very social begin to isolate or somebody who got along very well with people, may suddenly become argument did or even aggressive. When you're trying to screen somebody for dementia when they have Down syndrome, it's going to involve reporting from both a caregiver or the family member as well as looking at what the person can do. It's going to be two people providing input. And that is why again that baseline is so important and it's very important for the person who goes to the doctor with the individual to help with that dementia screen, knowing the individual very well and is aware of what the person can do and what the person is no longer able to do.

Some specific tests that were developed for someone with Down syndrome to determine dementia, there's the Down syndrome mental status exam. It's a test that includes vaccination of simple designs, Word object matching, serial naming of objects developed by Dr. HAC Sam Silverman. It's also based on baseline. You have to have that baseline on that person, prior to development of Alzheimer's. Baselines is determined things like does the person know their net -- how to write their name? What kinds of things are they able to name? Do they work and what kinds of skills do they demonstrate at that job? Do they tell time by different means than using a clock? Can the person right his or her actually -- can the person read -- Down syndrome is so many varying to what that functioning is. You want to know, what were they able to do before? And the mental exam is going to use those things that were common to that person -- a person on our caseload, Michael, who had Down syndrome and also developed Alzheimer's. And legacy was really in his 40s when he started seeing the signs of that. But what we knew about Michael was that he could write his first name. He had learned how to write just Mike. So that was something we recorded before we saw those Alzheimer's changes. He could tell time but he didn't tell time by a clock. He told time by mealtime. He knew if it was breakfast, lunch or dinner, that's how you determined time. He knew that Monday to Friday were work days. He went to a workshop. We don't even have workshops now. We have people in the community jobs. At that time, we did. He knew his weekdays by whether it was a day he could -- he was at home or at work.

Friday, he got pizza.

He always knew Friday was pizza night. He had himself at the table because he knew exactly when it was going to be delivered.

It was also the last day of work wake and that the weekend was coming.

He knew the names of his caregivers. But he didn't know his family -- his natural family members names because he didn't live with them. He lived in a state appointed foster family home care set up. So he knew all the people that were his siblings that were the children of the caretakers that he lived with. And those are names he could name. When you take a standard test and you say, what are the names of your family? He couldn't name is family but he could name is caretakers. If you asked him to write his -- a sentence, he couldn't write a sentence but he did know how to write million Mike. And how he judged changes in Mike was when he also all of a sudden was no longer able to write his name or could only make the first letter of his name. He didn't know the order anymore. Those are all indications of changes happening with him. Not having a more flat affect and not being a threat -- interested in pizza day or socializing with the people in his home. Those were the skills we started seeing him lose. When you say the test asks you for -- to recognize several objects, we picked objects that were objects Michael could relate to, like a picture of pizza or a picture of a favorite truck he liked to carry around with him. Those were things he would be able to pick out as something he understood. When you add them -- ask them to name three objects, you picked objects that were important to him based on his baseline. So that's a lots of how the Down syndrome mental status exam came to be. They started to figure out that you couldn't take the standard mental exam and expect someone with a cognitive impairment that was pre-existing to be able to fly through that kind of a test unless it it was geared specifically to their baseline. Another test is the TSI, which tests for severe impairment of cognitive function in people with severe impairments. There was a criteria you followed that was set up by Doctors Albert and Cohen. Also a way to test for Alzheimer's and Down syndrome is with questionnaires, with caretakers. That's a big piece of how you can make that determination. They are the people who know what that person is capable of doing, what's typical of that person's abilities and then they are the ones who are going to be the first people to know. Not the doctor that you take that person to, but the caretaker coming in its -- saying, I noticed he is no longer brushing his teeth unless someone stands over him. Or he used to be able to take a shower and now he does not remember what part of the body to wash first. That's how you're going to do those assessments in someone with down specific testing. So we're going to look at some of the assessment tools. In particular the standard assessment tools. Those are the ones designed for people who don't have a pre-existing intellectual or developmental disability.

Or only in a mild one.

As Linda was saying, these can be adapted or used with somebody with an intellectual or developmental disability as long as they -- there are adaptations made. The caregiver or family member reporting alongside of individual is able to report on what that person's baseline is. Did you want to go over what the standard assessment is like?

Diagnostic criteria that specifies decline in memory in at least one of the following cognitive abilities. What we are looking for is that decline in memory but also ability to generate coherent speech, understands vocal and written language, ability to identify objects, ability to execute motor functions, ability to think abstractly, carry out complex t asks, these are the criteria you're going to be looking at. Are there changes in that criteria?

It's important to remember that dementia is often experienced differently for people who have ID/DD than people who have -- who don't have a pre-existing intellectual and developmental disabilities. People with Down syndrome are much more likely to experience dementia at an earlier age. And it's often progresses much more rapidly. There's a briefer duration between the diagnosis and end-stage that ultimately in individual gets. So you want to be alert for behavior changes in particular. These are often the first changes you're going to see. They may be other changes that are going on, but does the person already has that pre-existing intellectual or developmental disability, those may not be immediately evident. But the behavior changes, particularly if you know the person well, are going to become evident. Diagnosis is going to be complicated. Caregivers are going to also need to be very strong advocates if you are seeing changes. They are going to want to bring that to the attention of the healthcare professional to be evaluating the individual. They want to be able to speak very clearly to what the individual's baseline was and what they are seeing as a change in how they are noticing over that period of six months. That the individual is beginning to lose some skills. Another piece that makes it really difficult or challenging to diagnose an individual is that the person has a lifelong need for caregiving in many situations it they've been in situations where people have cared for them. They're used to having supports around them. So it makes it hard to tease out what the intellectual disability and what is the dementia? You want to be aware of it so that you can begin to develop supports so that the person is able to age in place if that's what his or her wish is. And what we're talking about is I want to refer you to like a workbook called my finger's not working, prepared by the national task force on intellectual disabilities. You can get it at the website listed below. I think you can also access that through resources for integrated care. It's just a wealth of information on working with somebody who does have Down syndrome and its beginning to -- and is beginning to experience dementia. A lot of statistics and recommendations for resources. It's a really helpful tool as you are working with somebody.

So standard assessment tools for people who have dementia, really may not be valid for assessing a person with intellectual or developmental disabilities. We've been talking about this, but there's some very specific reasons why they may -- maybe you should also be aware of. People with intellectual and developmental disabilities I'm not generally good self reporters. If they are experiencing dementia, they're going to start to lose that insight. They may not be aware that things are changing. They may be aware they don't feel the way they used to or that they are uncomfortable or that they are agitated, but they are not going to necessarily report a loss of m emory. Again, this is somebody who doesn't have an intellectual disability, may also not be aware of cognitive decline but is going to be particularly true with somebody who has ID/DD. They already may have limited functional or expressive and receptive language skills. It may be hard for them to communicate even if they are noticing changes or things that are concerning them, they may not have the words to let somebody know, to say that they are worried. They may not even know the names of common objects. If somebody has a developmental disability or intellectual disability, their language is frequently impacted. They may have a communication deficits to begin with. People with ID/DD also do not typically have good abstract reasoning skills. It's a function of the disability. It's often part of that lifelong disability. Those are things that are typical declines with someone with d ementia. The baseline is important because you want to be able to tease out what the change in the person is. What did the person used to be able to do? And what is he or she no longer able to do? That's true also with the functional skills and independent living. Somebody who does not have a pre-existing intellectual and developmental disabilities already has skills in independent living and it's obvious when they begin to lose them. Somebody who has ID/DD may have already need a lot of help in those areas. So it's going to take a caregiver who is very alert and aware or a family member. And it's also important to have that baseline in place. I know I keep repeating the baseline, the baseline, the baseline but that's because it's really essential. And once the person has begun a decline, you can't get that baseline anymore. So the earlier you get it, the better. I really encourage people to develop a baseline for someone with Down syndrome as early as possible.

As Jill just discussed, pre-existing impairment must be considered for dementia diagnosis in someone with ID/DD. Most of the standardized screening tools have limited value or have to be geared towards what that p erson's baseline is. A diagnosis of dementia for people in the general population is based on the assessment of memory loss or cognition decline. You have someone who already has a cognition decline, that's pre-existing, then you have to have that baseline to know where the change is really occurring. There are many efforts underway to develop assessment and screening tools specific for someone with ID/DD. And again, everything is going to be going back to that baseline. You need that baseline to be able to determine when something is changing.

So when we're trying to recognize people with dementia and people with intellectual and developmental disabilities, you're going to use the baseline. Because caregivers can refer back to that when they are speaking with healthcare provider and pinpoint the areas where the person used to be able to function independently or used to have a much higher degree of functionality. And they can refer back to the baseline. It gets you a concrete and more scientific tool to use in that dementia diagnosis. As caregivers, you want to be alert to changes in the person's b ehavior. Behavior is typically the first sign that you're going to see. Changes in memory and cognition may not be the most obvious symptom in the beginning. But if you're seeing somebody becoming very agitated or isolating themselves, or even becoming aggressive when the person used to be very easy-going and getting along with other people, those may be important signs that there's some dementia going on. If a person is living in a congregate care situation, you want to be paying particular attention to those individuals who could be at risk for developing dementia. That would be people with Down syndrome, people who have a history of high blood pressure, vascular dementia, somebody with Parkinson's disease. So you want to be very person centered and individualized in looking at the individual in that congregate care setting. And you want to make sure that you get frequent and early screening that the person's healthcare provider is aware of the baseline and that you have good lines of communication so that you're able to bring any concerns to a healthcare provider as soon as possible.

As Jill has been discussing, there's many reasons why standard screening tools are inconclusive for adults with ID/DD or Down syndrome. There's varied levels of cognitive function due to the syndrome, the Down syndrome or the intellectual impairment. There's decline in individuals with ID or Down syndrome can occur in different ways than in the general population. Sometimes you are seeing more behavior changes rather than cognitive decline as the first indicator. It's difficult to establish a cutoff score of when you are doing a standard test, there's cutoff scores for what the indication of Alzheimer's or dementia is developing. That cutoff score may be very different for someone who already has an intellectual impairment. Aging caregivers also sometimes contribute to poor level of information because they are also aging along with the person they are taking care of and is there information always reliable? Or affected by how they are seeing changes?

They see the person every day, subtle changes are not going to be as obvious.

That's another issue. So they're working on developing more specific tests, but it isn't there just yet.

So what can you do? We recommend that you are very proactive. The most proactive thing you can do is to get a baseline of the p erson's functioning. And people who are doing research on dementia and individuals with Down syndrome recommend that a baseline is obtained at the age of 30 for someone with Down syndrome. They highly recommend that that be a video, that it be beyond just checking off what the person can or can't do. You really want to be able to capture what that personality is like. You want to know who the person is. You want to provide regular and ongoing evaluations of the individual. That should go on like maybe every six months for someone who has Down syndrome. And you should use a variety of tools. As we've mentioned, right now there are tools specifically designed for people with Down syndrome and ID/DD but they are in the pilot stage. You want to be aware of these tools as they become more widely used. But if you do end up working with a tool that's developed for somebody who does not have an intellectual disability, you want to be an advocate for the individual. You want to come to that evaluation very prepared to discuss what the person has been able to do in the past and what changes you are seeing and what skills you are noticing the person is may be struggling with and is no longer as competent at. And this is all part of doing like a real person centered focus with the individual. You want to support the individual as he or she ages. You also want to be considering what kind of care the individual is going to me given fact he or she does have Alzheimer's. We've talked about how Alzheimer's is irreversible. And it is progressive. If someone has Alzheimer's diagnosis, we know that in 10 to 15 years, individual is going to need a much higher level of care than he or she needs right now. And you want to be thinking about how you're going to provide that, what kind of supports are going to need to be developed for the individual. And the way you can do that is having that support. Work very closely with your healthcare providers, the office of aging in your community and so forth. And we will talk about that more later as we go forward in this presentation.

As we've been talking about all along, you need to document that baseline, whether by charging or by video. Because staff changes. If you don't have a good track record of information, on what that person was like who has Down syndrome or an intellectual disability, it's very hard to assess a change going forward. Because you need that information to keep going and like I said, staff changes. Living in group homes settings, foster home settings, the person -- the people taking care of that person can change over time and then how do you know what's typical and normal for that individual?

Even people living with family caregivers, that parents or brothers or sisters who used to provide care for them may no longer be able to be -- be able to provide care and you want to know who the person was if the caregiver gets the information.

Also typical of along with ID/DD or downs, they are not like Jill said, they are not good self reporters. So a lot of the assessment tools that we have for someone with Alzheimer's and dementia are based on what you're getting your information and self reporting. Is this a person that never was very good at self reporting? Your information is very inconsistent or not available at all unless you have documented baselines through their caregiving years.

So video recordings are a great assessment.

As we keep saying, and I said, I promise that we are going to be stressing the baseline. It is so invaluable. The baseline can be used to identify any new changes in behavior. As we were saying, caregivers may not be objective reporters. They see the individual every day or they've known the individual across his or her lifespan, they may not, they may be subjective, not able to identify subtle c hanges. You want to be able to backup any cognitive tests that are being given to the individual with a review of what that person's functional abilities were. How did that person do with getting dressed in the morning? Choosing appropriate clothing for the weather? How did the person do with social relationships? With a interested in everybody's business? Where they like, very interactive and friendly? Did they like to go out to movies and go shopping? Go to yard sales? How did they engage in their daily routine? You want to look at this and then you want to consider, how is it different? What has changed recently? Does the person seem confused? Are they -- with the gentleman that Linda was talking about, Michael, he always knew that the week ended and that was the night he got pizza. That meant he didn't have to go to work the next day. Is that still happening? Is he still excited about the p izza? Or has that become something that he's really not aware of any l onger? Did the person used to be very cooperative and now they are resisting when there's direction, when it's time to get up in the morning, they don't want to get up or go to work? When they used to love to go to work? Those are the things that you really want to be alert to and to fine-tune your own powers of observation so that you are capturing them. And that will prompt you to look further and do some further screening with the individual.

Additional supports for reliable assessment. You need to train your caregivers to ensure they understand risks and process of dementia and elements of reliable diagnosis. Teach them what you are looking f or. What's changed? What's the change you should be reporting? What's normal behavior? What's not normal behavior? Facilitate regular ongoing screening for dementia. Use healthcare professionals trained in dementia. So that they are able to make the assessments you need. And that they are aware of the limitations of ID/DD Down syndrome so that they know when doing an assessment, they are able to get a different way of looking at things. And you need that baseline to be able to make those determinations of change. These conversations ensure continuous collaboration between all parties. Use as many tools as you can to make the reliable assessment.

So one of the early screens that's specifically for individuals with ID/DD is the early detection screen for dementia. This is developed by the national task group, which I mentioned earlier. And I believe we included a PDF in the package so that you can look at it. I'm going to review it with you in a few minutes. This can be used as part of an annual wellness visit. And it's not necessarily a diagnostic tool. It's more of a screen. But it makes something easily accessible for caregivers and family members to use. It's perhaps -- what's most important when you are using this it's going to start the conversation between you, a family caregiver, and the doctor so that you are beginning to look at the individual and consider that there's a possibility of some early signs of dementia. If we look at this, in particular, what you'll see is that the screen is based on what's always been the case, what was always there but is no longer available, no longer happening, a new symptom, or something just doesn't apply. So it begins by capturing what the individual was able to do initially. What their baseline is. And then it goes on to evaluate what skills the person may not be able to use as readily as before. For example, does the person need help with washing or bathing? Maybe they always used -- needed help. If they never needed help and now they need a little bit and that's something that has been occurring in the past year, the screen is going to capture it. Language and communication. Does the person initiate conversation? Maybe the person has always initiated conversation. You are going to be able to mark that but then evaluate it further to see if the person is no longer initiating conversation. It really walks you through a baseline of what the person's skills used to be at baseline, and what skills are being lost, what new symptoms are being developed.

So another tool that's been available online is the Down syndrome dementia questionnaire. This is something developed by a support group in Kansas City. The Down syndrome Guild of Kansas City. It's specifically for family members or caregivers who work very closely with the person. Again, this is something that is a screen. It's not designed to diagnose dementia, but it will start a conversation between the caregiver and the healthcare provider so that you can begin to be aware and take your diagnosis to the next level. Again, this questionnaire is based on what the person used to be able to do and what the person may no longer be able to do. It begins with what kinds of things can the person remember? Does the person remember an impressive events that took place during the last week? Has the person always been able to talk about something that happened? Or is that something that the person probably never did? Or is the person -- if the person used to be able to do it, that's going to be a signal that there are some cognitive changes taking p lace. And it goes on, through all of the abilities that individuals may h ave. And the person report personal history? Do they remember events that happened many years ago or when they were a child? It compares it to what the baseline is and what the person is able to do now. And --

Hang on. Talks about is the person able to wash themselves? Again, there's a comparison between the skill that the person may never have had or is it a skill that the person had and is now beginning to lose? So not always dementia.

Before you jump to the conclusion that a change in behavior is related to dementia, you need to rule out other illnesses and conditions that can affect memory and behavior of a person with ID or Down syndrome. There's acute or chronic illness, pain, seizure disorders. All things that need to be ruled out. Those can be contributing to the change. Life changes such as separation or bereavement, moving to a new residence, losing a best friend, making someone depressed. It can be misinterpreted as dementia. Mental illness, particularly depression. Nutritional deficits. That's why someone with Down syndrome -- we supplement with B12 and folate because the deficiencies are fairly common. And they can contribute to what seemed to be dementia but it's really a treatable nutritional deficiency. Urinary tract infections, change behavior. People don't feel well. Upper respiratory infection, ammonia, UTI, their behavior changes as well. So you need to roll those things out. Does the person have a vision or hearing loss? That's substantially changes behavior to all of a sudden you can't see or hear well. You're behavior changes. Hypothyroidism is another thing that could be ruled out by a simple lab test. A behavior differences can be connected to that as well. If someone isn't getting adequate sleep or have a sleep apnea, is there another reason why you may see it -- a behavior change but it's because of a sleep d eprivation? Reactions to medication side effects. Look at the meds. Always look at the meds someone is on. They may be the contributing factor to the change in behavior. It's not a dementia at all, it's simply a medication reaction and can be corrected.

Would things like a urinary tract infection or pneumonia contribute to a cognitive symptom shift?

Yes. They have. And we see it quite often. How many times have you taken someone to the emergency room where they would -- that were behaving completely different and what did it turn out to be? Pneumonia or UTI, they felt that are, they could get back to feeling like their normal selves. And the problem was resolved. If you look at all things first. Always look at your labs and meds.

I think it's important to keep in mind that frequently, people with ID/DD are not good self reporters. They may be feeling ill and maybe having a sore throat or they may be using the bathroom a lot and having some pain on urination but they may not report it that way. Their reaction may become agitated or passive.

We had an incident where someone had broken their ankle and they were walking on the fracture. And all of a sudden they were like walking differently and everyone was like, it must be something -- some dementia developing. They are not walking normally. They had a fractured ankle. When that was diagnosed, we corrected the problem, and they were their usual selves. This is someone that was not telling anyone, she was in pain. She was continuing to try to do what she normally did and it turned out to be a fracture.

So that's all to say that caregivers need to be very alert for any kind of changes when they're working with someone who is elderly. And in particular in this situation for someone with Down syndrome because dementia may be possible or there could be some other health concern going on. When you see somebody every day, subtle changes are very easy to miss. You want to look for subtle personality changes. Someone who used to be in everyone's business was like always like asking questions and like wanted to know what people did and did they have a boyfriend and so forth? Suddenly begin to spend more time alone, they may want to be in the room by themselves, they may get into arguments with people they used to get along with really well. People who used to take great pride in their appearance may certainly not be as careful. They may not look as well groomed they may not be brushing their teeth or combing their hair the way they once did. Another clue that there may be some dementia beginning is the onset of seizures for someone who doesn't have a history of a seizure disorder. This isn't really a particular -- particularly subtle sign, but a caregiver needs to be aware of the individual's history so that they know that this is something new. And again, that speaks to good documentation and making sure you have a good history of the individual, particularly for someone who has moved a lot or has had a change in caregivers r ecently. We also want to be watching for gradual but increasing confusion. Somebody who suddenly seems to be more disoriented. If the person -- if the caregiver is not close to the person, if they don't know the person well, this is something they might miss. They might dismiss it as part of the intellectual disabilities, and again it's really important -- what this person's baseline was. It's important to have that baseline available for sharing. It's important to remember that caregivers may not always be objective. Even people who know the person very well may not notice changes over time. Sometimes we have a blindness with people we're very close to. We don't want to see those changes. Or sometimes the changes are so subtle that we don't pick them up because they happened so gradually. Family members who are caring for individuals with ID/DD may also be experiencing health and cognition issues themselves. So their own abilities to notice or document changes may be impaired. That's something that is a significant issue now. 75% of individuals with intellectual and developmental disabilities live with family members. And those family members are also aging. It's like kind of a graying of the caregiver population. It's creating some challenges in providing supports for individuals. And denial can play a real roll particularly with family members or as I said, people who are very close. You've watched an individual struggle to gain the skills that they don't have because of their developmental disabilities. And now for a caregiver to watch somebody lose those skills that have been so difficult to obtain is really painful. It's difficult to see. That's where I think denial sometimes clicks in. You don't want to see it. Because it is so tragic. And you have this attitude, may be if I don't admit that I'm seeing i t, maybe it will go away or maybe I'm imagining it. Maybe the symptom really isn't there. Environmental factors play a huge role in diagnosing dementia. Individuals who are living in congregate care may experience multiple caregivers over the course of weeks or months. Even over days sometimes. So you want to ensure that caregivers who are providing information know the person as well as possible so that they are more reliable in reporting any changes in memory or skills. The natural flow in a congregate care setting is to respond almost automatically to the needs of individuals by providing more and more support, so you want to really try to tease out if a person is gradually using more support, because caregivers often times instinctively provide support, they may not be aware that somebody is gradually needing more support. So that's a place where reporting may not be as accurate as we would like. You want to avoid missing a diagnosis of dementia and not diagnosing it as the person is really experiencing advanced symptoms. You want to remember that not all dementias are aggressive. Some of them are treatable. They may not be reversible, but you can stop the increased progression. So you want to be alert to any changes at all so that if it is a treatable dementia, it can be treated and further decline can be avoided.

As Joe was saying, cognitive care situations may limit a p erson's ability to exercise judgment independently. A lack of opportunity can mask decline in cognitive abilities. Individuals with ID/DD and have lived in sheltered environments with few intellectual demands, subtle memory impairments and times are more difficult to detect. Risk of advanced stage of dementia before diagnosis is possible. So remember that many dementias can be treated such as NPH, or can be delayed with early intervention. So you really want to make the diagnosis as early as possible.

Memory problems are not always the first symptom of dementia for people with Down syndrome.

Right. Personality changes or what you're going to see uncooperative behaviors, irritability, aggressive behaviors or inappropriate actions, maybe even giddiness. So be alert to any change in the way a person interacts with the world. Memory loss is not usually the initial symptom for someone with Down syndrome. So do we have any questions?

We do. A cyst on the thyroid gland being a cause of MCI?

I don't know the answer to that question. And our medical expert here, Linda Anderson, doesn't know either.

If it's a thyroid problem, thyroid problems sometimes can be misinterpreted as a dementia, when left untreated, but I'm not so sure how a cyst on a thyroid -- what that would do.

But I think if the person does have the cyst, they are probably -- it's been diagnosed by a physician and usage -- should certainly open that conversation with the physician if you are seeing cognitive decline with the individual. And that whole conversation, that interaction is really important because if there is some decline being noted and it persists after the cyst is treated, you're going to want to pursue that further and to some dementia screening for the individual.

Where can one obtain the Down syndrome mental status exam or test for severe impairment?

They're online. I think that they've been embedded in the slides for this presentation. So the slides will be available on the Resources for Integrated Care website. And they're hotlinks. So I -- if you just click on them, you should be able to get to the website. We've also included suggested readings and resources. And all of those handouts are cited in the suggested readings and resources. And again, links in that bibliography are also hotlinks. So you would be able -- they're hyperlinks. He would be able to click on those and access the information that you're looking for and it should come up. You can also do copy and paste.

Do you think that aging individuals with ASD are more likely to develop Alzheimer's and/or other forms of dementia?

Actually, people with autism spectrum disorders are not at an increased risk for dementias. Their risk is about equal to what it is for the general population. But that being said, some of the risk factors for dementias are head injuries and individuals with autism spectrum disorders frequently have poor judgment. They may end up in situations that result in a hit injury. So it's not the spectrum disorder. The spectrum disorder that puts them at risk. But some of the associated issues around that may constitute a risk for dementia. But in general, statistics show that they are at a risk level that is equal to what the general population is. However, there are not a lot of studies for people with autism spectrum disorders. It's a fairly new area of d iagnosis. And most of the studies are based on the needs of young adults with autism spectrum disorders. So I would watch the research that's ongoing, because as time goes on, more may show up. But at this time, there is no additional risk.

And last question. Are videos kept as part of a p erson's medical record? If not, who keeps them?

Those should be kept as part of the person's record. As we move to more electronic health records, I think you can probably speak to the company that provides your electronic medical record and see if you can embed those videos in the healthcare record. I think if you are keeping a paper record and your video is on a DVD, you would keep that in the record with the other evaluations for the individual. And you should also be observing all of the HIPAA regulations around protecting private healthcare information. Because that baseline video is part of the person's personal health information.

Good question.

We'll be taking a 10 minute break. So it is to 31:00 right now. So we'll be back at around 2:40. We'll see you soon. Thank you.

[Event is on break until 2:40.]

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Okay, everybody. Welcome back. In the next section, we're going to look at some of the standard assessment tools that are frequently used to assess people with dementia in the general population with aging individuals. These tests may not be measures for people who has a intellectual and developmental disabilities or someone with Down syndrome, and they may not -- they may need to be modified to take into account that person's baseline ability.

The reason why we're going to go over the self-administered general cognitive exam used in the general population or useful in someone with a mild intellectual disability that has some reading and writing skills, to give you an idea of what these tests are like in comparison to how we have to adapt them for someone with an ID or Down syndrome diagnosis. The stage is a reliable tool for evaluating memory and cognitive ability again like I said in more of the normal for mild ID population. A 15 minutes and written exam useful in the earlier -- early detection of Alzheimer's disease. And as I said before, it would have to be adapted for someone with ID/DD to be able to be connected to their baseline. It can be achieved from the w ebsite, there's many different versions of the test. We put in the slide, one version of the test just to give you a sense of what it looks like. Sagetest.osu.edu. So as you go through, you'll see that they are evaluating cognitive changes. Someone could fill this out for someone who has limited writing or reading skills, but they would have to be able to have the history and some ability to self report to answer the question. As you can see what these questions are, you're going to check memory by things like asking for what today's date is. You're going to ask someone to name the pictures. Like I said with Michael before, we took and tested him. We took pictures of things that he understood, like he loved his trucks and ate pizza. Those are pictures he would recognize. These may not be pictures that he would recognize at all. So you can view these tests for the level of the person. You are asking questions about function of objects, what -- how are these similar? You are testing math skills. In Alzheimer's, math skills are one of the things you're going to see changes in as you progress further along the stages of the disease. So could you make changes? Again, in someone in the ID population with a severe range of developmental disabilities, or higher, may not have ever been able to make change. Or are they someone that work in the community and is capable of making that kind of an answer? So you're giving them simple math tests. You're giving them a simple memory test. At the bottom of the last page, you're going to say, right I am done. And on the last page, did they remember to do that? The last page is page five. We going to look and see if they have spatial skills, like to copy a picture. You have to have some sense of space in the environment. Some concept to deal with the repeat of that picture. Again, these are tests geared for someone that probably is in a more normal for mild developmental r ange. Drawing test is you draw the face of a clock and tell them what position to put the hands of the clock in. If they never could tell time, they're not going to be able to do it.

But if they could tell time and they are no longer able to do that --

Them that would be an i ndication. Right down the name of 12 different fruits or vegetables. It could be done verbally with someone else writing it down. As you go on in this test, this is a test that is geared for someone with a higher intellectual development than what we tend to see in our population. Connect the dots. Can they do that? How to put it in the right sequence order. Could they do that at all? Could they count to 12? Could they recite the alphabet if they never did before? They're not going to be able to do this test. Go onto the next page. You're doing a lot of move the triangle in the order of what that's set up on the page. It's something they may not be able to do. The last thing, are you done, you're supposed to be able to r ight, I am done -- done -- to write. And there's a scoring for this. If someone has Down syndrome for more than a mild intellectual disability, they're not going to be able to do this. It's useful to see what kinds of testing you do within the normal population.

This can also give you an idea of you can kind of extrapolate out what kinds of losses are typically evaluated for in the general population. It will help you to be more alert in working with people with intellectual and developmental disabilities. You can kind of be on the lookout for issues that may be coming up in their daily functioning. Another test or another tool that can be used is the Mini-COG. This can be administered by someone for a mild indicator of cognitive changes. And this test based on research has at least 83% rate of accuracy. I think a lot of that is contributing to the fact that it is seen by someone who knows the individual very well. The first part is listening to three words. Completing a clock drawing. And then recalling the words from part one. In terms of the clock drawing, as with the sage, if the individual was never able to tell time or to draw a picture of a clock, that's not going ing to be reliable, because it's only reliable if they could do it. And now they can no longer do it. It's a loss of a pre-existing skill that we're going to be evaluating four. So when you're going to administer that, you ask the person to listen carefully to three words. For example ocean, book, desk. And very simple, clear words. Ask them to repeat them back. Then you ask the person to do the clock drawing. And you can tell them to show the time as a specified time, 10:30, 1:00, whatever. After the person has completed the -- the clock drawing, you can ask them to repeat back the words that were originally said. And when you score that, there's the word we crawl score -- recall score. They get one point for each word they recall for a maximum of three points. For the clock drawing, the clock test is considered normal if all the numbers are present and they are in the correct word you and then you've asked them to represent a specific time. If the hands represent that correct time, you can get a maximum of two points. If they get between zero and two points, it's an indication that some dementia may be present. If you're going to want to do some additional assessments. Take it a step further and talk to their healthcare provider. And look further if -- if they score between three and five, it's negative for any symptoms of dementia. If the individual was never able to tell time and never have the ability to count from one one to the 12, that clock drawing is not going to be possible to do.ible to do. But they actually pass the test. So as a memory test, it's useful as you are dealing with numbers. It may -- in someone who didn't have those abilities, it's not going to be useful. But it at least has some use in the population you're working with.

I think for people in a congregate care setting, if some of you are in the position of t raining, direct support professionals, this is something you might want to review with them so that they are alert and looking for these types of changes in individuals with functional abilities.

The Alzheimer's clock test with Alzheimer's as you are advancing in stages of Alzheimer's, math skills, ability to put numbers in the correct order will become things that you are no longer able to do. That's why the test is such a common test given in Alzheimer's. In someone with more than a mild I D, they may never have been able to work in the face of a clock to begin with. The test is used to differentiate in a possible dementia. What would be abnormal is that you couldn't put the numbers on the clock in the correct order. If you were told 8:00 a.m., you couldn't put the clock hands in the right direction, that would would indicate a need for further t esting.

This is just a sample of the clock drawing test.

Just filling in the blanks. Some of our ID Down syndrome patients that we've had, they can copy and they lose the ability to copy as an indication of dementia. So in some cases, we would draw that clock for them and put hands on the clock and ask them to copy what they just saw. And if they were able to copy, all along as part of their baseline, that would be a way of indicating change. It might be a way of visualizing that we've done that in the past. Because they didn't have the ability to put those numbers in order but they were able to copy. Knowing that was their baseline, able to differentiate a change by suddenly not being able to copy what they saw accurately.

So again, it's really important to be proactive in providing these screens for individuals to think outside of the standard boxes. And these are not diagnostic tools. They're screening tools. And they're going to help you to capture some changes that you will then bring along further to a healthcare professional who can do more conclusive testing. But you are really kind of the first -- think of yourself as the first responder in capturing a change that may be very subtle. So another screen for Alzheimer's is a simple balance test. And caregivers may initially notice that a person is having difficulty performing tasks that require balance. A very common one would be getting dressed in the morning. Are they having trouble standing on one leg? Just to put on slacks or underwear? Dr. Yves Roland did a test suggesting a link between physical performance and cognitive decline. Kind of a warning signal that there may be some dementia processes going on. The one leg balance test is linked to a brain decline in function, a decline in brain function over two years. And individuals within normal one leg balance test are less likely to do -- to be developing Alzheimer's disease. As you do notice this again, it's an indication of it's not a diagnosis -- but it is a warning. It's something you are going to want to bring up want to bring upon the persons wellness visit, bring to the attention of the nurse or that person's primary care physician.

Change in balance maybe not only dementia as we said before. There are other reasons why people have changes that are chronic disease, hypothyroidism. Other things that need to be assessed out that also could be an indication. Not a diagnostic tool per se to allow dementia. It's an indication for testing needed.

The many mental State exam -- Mini Mental State Exam. Geared towards someone who has cognitive decline pre-existing. This is the mental status exam that's a useful tool in someone with higher intellectual functioning or people -- to do this test you must have functional communication and orientation as a baseline, which means it's not useful for someone with a pre-existing moderate to severe range of intellectual disabilities. It tests an individual's orientation, attention, c alculation, recall, language and motor skills. Again, it's completed -- this is a test completed by a healthcare professional, not a self-administered test or family administered test. You can receive a sample of it at this website, www.health.gov/DC. We include the full steam version, but there's many different versions of the mental State exam. And as you can see, the scoring you get and the kinds of questions you are asking are testing recall calculation, the ability to have cognitive skill changes or not. And as you go to the tests, you get a scoring. As you can tell as you are oriented to time, place, person, the year, season, day of the week, those are things you gain points for. If you know where you are, what state, what County, what town, are you in a hospital or are you home? Those of the things you are asking to get a score for getting them correctly. Examined and name three unrelated objects, saying all three of them, testing a patient's recall. I would like to count backward from 100 by seven. Can they do that? Can they count backwards and deduct seven each time? Spell the word world backwards. Are they able to recall the letters and in backwards and front word order? You gain points for each task. Can you name three things? Can you tell me what those things -- what those three things are? Can then name the actual items? Not say, instead of pencil, the thing you write with.e with. Show the patient two simple objects such as a wristwatch and a pencil. And ask the person to name them. You want to hear the name of the item, not the function of it. Name just function of an item is an indication of an early dementia. Repeat the phrase, no ifs, ands, or buts. Can they repeat back in order what you just said? That's how they are gaining important on the test. Folded -- that's a multi-step t asks. That's what you're testing to see. Can they do a multi-step task? Please read this and do what it says, written instruction and close your eyes. So again, you have to have reading capabilities to take that test. And they do what it says? Can they follow directions of the written word? And they gain a point for that? It goes on. There's a picture -- make up a sentence about anything. It must be a complete sentence with a noun and a verb. And then you total the scores and based on -- there's a way of interpreting based on the amount of points you got up to a maximum of 30 points. So if you have less than 24 points on the test, that's an indication that there is a level change, dementia possibility. Okay.

These are more screening and comprehensive tests.

And you go on and we're going to be also like we said, you're not -- you've got to roulette other t hings, just because there's a change on the Mini Mental State Exam or on one of the cognitive tests, maybe there's a reason other than dementia, so you have to rule out medical and medication. Side effects. So early screening for warning signs, followed by a complete exam. So if you see a change on one of the dementia screens, you want a complete physical exam to determine if there's anything else. And a complete physical exam should include a family or personal history and medication history. Full physical and neurological, psychological exam, vision and hearing screening, again, it may not be dementia. It may be that your vision or hearing has changed. And that's making the change. By requiring sleep and weight monitoring, sleeps -- sleep pattern changes can be indications of something else going on. Or depression, other things besides dementia. You want to run a complete lab testing that includes a CPC, fasting blood count, liver function tests, thyroid function test, folate and B12 levels, drug levels, EKG test -- chest x-ray, MRI of something one of the previous tests indicated the need. And determine dementia or alternative diagnosis based on the test results. So using a multidisciplinary approach to try and rule out what you're dealing with. As a dementia or a health problem? Or medication problem?

I think this approach is pretty standard for the general population as well. Many times elderly individuals will seem like maybe there is some cognitive decline and it will turn out that there's something else going on there, B12 levels may be low or urinary tract infection. They may have forgotten to drink and just be dehydrated. So it's a really important -- keep in mind, don't jump to that immediate conclusion that there's a dementia that's beginning. There could be other issues. It's not always dementia. And that being said, it's important to keep up-to-date on annual screenings, just to make sure that your baselines are as comprehensive as possible. And to ensure that the person's health is being maintained. It's important to assess for mobility and balance disorders. Especially for people who already have gait and balance issues. Somebody with cerebral palsy or Fragile X or new news, they may result just like a pre-existing condition -- they have difficulty walking, difficulty maintaining balance. And in thinking about this, remember that some dementias are the result of head injuries. And that being said, some of the issues associated with challenging outcomes in aging are associated with falls, earlier in life. So people on top of in interventional mobility and orthopedic screening -- so that you can provide a safe environment and allow any kind of gate or balance disorder in addition to ruling out dementia. You want to do a full risk assessment. On a regular basis -- fall risk assessment. If you go to the CDC website, CDC.gov and type in fall assessment or fall risk, there are a number of tools that are provided that you can download so that you are able to assess the people that you are caring for for their likelihood of falling. It also has recommendations for supports that can be put into play. A few other screening tests you would want to do that would indicate problems other than dementia, axial and stability screening is necessary in Down syndrome. It's a common problem in Down syndrome baseline. It is done as an adult with a spine x-ray and needs to be repeated annually if that person is symptomatic. Osteoporosis screening can be done with bone density scans. Medication receive your review for potential interactions or contraindications should be done at least every six months or if a problem is noticed. Remember, if there's a problem, you want to rule out med reactions, particularly when you are working with the elderly. So we're going to talk in greater depth about dementia versus depression. Some of the symptoms of depression are very similar to those of dementia. And we want to be alert to what those are so that we can treat appropriately, if it is a depression. We want to treat that depression. At this dementia, we want to be aware of that so that we can provide appropriate support. So depression and dementia are linked to a number of -- both depression and dementia may be present with similar symptomology. And as a very high risk for misdiagnosing dementia and depression. Part of what contribute to that is the increase in pain, individuals with ID/DD are frequently not good self reporters. They lack the communication skills or because of life circumstances and life experiences, they are not forthcoming in talking about their feelings and what they are experiencing. Dementia sometimes will occur as secondary to depression. This happens even in the general population as high as 10 10 to 20% of the time. Those of you who have worked very closely with people who experience depression are aware that frequently, depression has changes as part of the symptomatology. People aren't able to read. They may not do as well as intellectual tests because of the depression. And it's important to make that differential diagnosis as someone ages. It is a depression or dementia? Sometimes depression is actually a prodromal to the development of dementia. So somebody may become depressed. That may be a neurological change that is signaling the onset of a dementia. And some of the neurological symptoms in adults with depression may also indicate underlying organic process. There may be something else going on physiologically with the individual. And it is resulting in neurological changes that are experiencing depression. So if we look at this chart, this demonstrates some of the similarities between symptoms of Alzheimer's disease and depression in people, particularly people with intellectual and developmental disabilities. People who are depressed often times don't have the energy to take care of themselves. One of the things we assessed when we were working with somebody who is possibly depressed is what is their hygiene like? How are they groom themselves? Do they continue to dress nicely? Depression also results in change in sleep habits. People who are depressed may have trouble falling asleep or maybe wake up in the middle of the night at 3:00 in the morning and not be able to get back to sleep. Appetite changes. You people may eat more or less. This is also something common with Alzheimer's disease. Increased agitation and irritability, many, many times people who have depression present with agitation. They going to the doctor and say, I'm really nervous. They really have like an anxiety that's secondary to that d epression. As we've talked about with people with ID/DD, oftentimes one of the first changes that we see in dementia with someone with ID/DD is a change in behavior and increase in agitation or. Ability or an increase in apathy and isolation. That's also very common with depression, people -- one of the symptoms of depression is a lack of interest in things that the person really used to enjoy. Of course moodiness is a symptom of both depression and early-stage dementia. So when you're working with individuals, particularly older individuals, you want to be able to tease these out and you want to be able to look at some of the likelihood. Is the person really experiencing a cognitive decline or has something happened in that individual's life that is prompting him or her to develop depression?

There are some challenges to a differential diagnosis of depression versus dementia. Individuals with ID/DD may not be able to consistently and effectively describe experiences and may lack the ability for self-assessment. So you have a good report -- a good self reporters to give you the criteria, you need to make that determination. Reports by caregivers may be imposed by a caregiver's tolerance level or what they are able to recognize as difference in the person they are caring for. Symptoms of weight loss or gain and sleep changes may re-result of psychotropic medications. You may have nothing to do with a depression versus dementia. It may simply be related to the medications they are taking. Cup you causing weight loss or weight gain. And some symptoms of depression such as self injury maybe part of the individuals physical behavior pattern. You can't use that as a criteria. So why is it important to get a differential diagnosis? It affects the way you are going to treat things. It affects the outcomes. Depression is often treatable. And reversible. There's also -- it's important to remember that depression may signal the onset of dementia. If a person has developed dementia, if they have Alzheimer's, you're going to want to know about it so that you can begin to prepare for future care. They are going to need enhanced care. So the differential diagnosis in this regard becomes extremely important so that you can provide person centered planning and development of future supports. Part of making a differential diagnosis, consider some of the recent changes that may be having an impact on this person's ability to cope. Think about somebody has passed away in the person's life -- have they had to move or have their parents died, have they no longer -- do they no longer have contact with someone who is a long-term caregiver? Has there been a change in something they do on an everyday basis? Did their work environment change? Did they get a new boss or did somebody who was a close work colleague go to a different work location? Did they pass away? Has the routine changed? Have relationships changed? All of these are triggers for depression. For someone who has an intellectual or developmental disability, sometimes they are more challenging than they are for other people. Because it takes them longer to understand what has happened. Again, individuals with intellectual and developmental disabilities may be reluctant or unable to talk about what's going on. Because they are not used to talking about their feelings. They may have grown up in situations where they were listened to on a regular basis. So it's very important to work patiently and carefully with the individual. And the person may feel that something is wrong but they really may be struggling with what is that's wrong. They know something is off, but they can't identify it as feeling sad. They can't identify it as I missed my boss at work or I've been given a job that's too hard for me. There are ways to improve outcomes. By using a standard classification system for dementia and Down syndrome. Educate caregivers on how to recognize changes. Early diagnosis affects outcomes. So again, you want to be observant and note those changes early because there may be treatments that can prevent or delay the onset of dementia. Long-term follow-up should begin at the age of 35. You're going to see dementia in an earlier age. You want to start early. Assess cognition and ADL skills and monitor for changes at leased annually. Recognize the need for an intellectually stimulating environment. People fade away or if there's no stimulation where they live. They have no cause -- if there's nothing stimulating in the environment, they want to keep that environment. Remember, memory loss is not the first sign. You will see behavioral and skill changes first in someone with ID.

I think the need for that intellectually stimulating environment is true for the general population as well. People who are very actively involved with their lives who learn -- learn new things are much less likely to lose cognitive skills as they age.

That brings us to the end of this section. Are there any questions? As we move forward into the last part of this presentation, if you do have questions, that come up or from earlier sections, just type them in and we can answer them at the end. So we're going to talk about supporting autonomy and community life for aging individuals with ID/DD. Down syndrome and dementia, we want to discuss some generations and resources for helping these people to remain independent as long as possible and also consider ways that people can be helped to make informed decisions about their c are, even as their cognitive abilities are declining. And that person centered focus will provide sports for them as they age so that they are able to age in place and maintain their choices as long as possible. The Edinburgh principles often proactive and person centered practices for identifying and developing and implementing supports for individuals who are experiencing dementia. These were developed through collaboration and professionals through the University of Stirling in Scotland, University of Albany in Albany, New York and the University of Illinois in Chicago. And what the University of Albany in New York and the University of Illinois Chicago have ongoing research -- both have ongoing research and we've included some of those websites in our bibliography. I encourage you to look at them because they are full of information that's really valuable. The Edinburgh principles are designed to be internationally relevant. This is an issue that goes beyond our national borders. It's a testimony to the global concerns for managing dementia and individuals with intellectual and developmental disabilities. You can get a copy of the Edinburgh principals at the website listed below. And you will find them referenced frequently when you -- whenever you are finding sports for people who have intellectual and developmental disabilities. I've included a copy of the Edinburgh principles in this slide so that you also have them available. I'm going to go over them because they are so relevant to what we're talking about. You want to adopt an operational philosophy that promotes quality of life. Really essential in providing supports for somebody who is aging and in particular for somebody who is experiencing dementia. You want to affirm that i ndividual's strengths and decision-making. This part of self determination and person centered planning is making informed choices, that something you want to include as you are making -- working with individuals to make plans for the future care. You want to involve the individual in his or her family -- in planning and services. You want to ensure availability of appropriate diagnostic and service resources. That's why we've talked about the tools that are available, the tools that are currently being piloted so that you are aware of what's out there. So that you can be knowledgeable on what you're doing. You want to plan and provide sports to optimize remaining in the community. People do better is familiar situations. They rely on familiar routines. Once in the community, just by virtue of what is, more s timulating. It will help individuals preferred help individuals prefer their skills -- preserve their skills. Ensure they have access to s ervices. And by the Americans with Disabilities Act, people with intellectual disabilities are covered under that act. They have the right to these same services. Many times individuals with ID/DD have the same level of needs that other individuals who don't have ID/DD in the community may have. It may be appropriate in regular programs for the aging in your community. Ensure the community dementia services planet also involves a focus on adults with ID/DD as part of networking so that your community, your out there advocating for the people that you are serving. You want to ensure generic cooperative and proactive strategic planning across relevant policy provider and advocacy groups. This involves consideration of the current and future needs of adults with ID/DD that are affected by dementia. So how do we begin to implement these pencils? It's important to recognize that the Edinburgh principles are designed using a person centered and strength-based approach. You want to work with individual as a collaborator. You want to learn about what his or her wishes, concerns and goals are. You want to focus on the skills that the person has developed and the skills that he or she retains. But what we don't want to do is be working with the person to develop new skills. So the focus is no longer on developing new skills but rather on retaining current abilities. You want to be very open in talking with the person, with his or her caregivers, family members, what do people think about what's going on? What other person's wishes? Does that person wants to age in place? What's important to his or her? What are the persons fears? What is he or she afraid of? What do they worry about? You want to continue to do regular and ongoing assessments. And you want to provide education to caregivers and family members so that they have a better understanding of what's happening. Dementia can be very frightening for caregivers. It can be very mysterious. And you want to allay their fears and clarify things as much as possible.

You want to try to develop a network of qualified professionals who are skilled in assessing people with intellectual and developmental disabilities so that you can have ongoing conversations and you can implement a more comprehensive screening for the individual that you are caring for. And you want to learn about the community resources, what people with -- and you want to advocate for developing more if you think that more are necessary. Advocacy is very essential. You want to ensure that people working with the individual with ID/DD and healthcare settings understand who that person is and how do they communicate? What are their capabilities? Are they able to address -- to dress themselves, feed themselves, are they ambulatory? Can they self toilet? All of these things are important to know what that person is capable of doing. Do they have any special diet needs or preferences? And what does he or she needed to make them feel safe and what needs to be in place so they feel safe and confident in their environment? These are all questions you should be asking and looking at and aware of to be able to advocate effectively. Should have conversations with your caregivers. As caregivers age, they may no longer able to be able to provide a previous level of support. Encourage caregivers to identify their own personal goals for retirement and healthcare and what their needs are so -- are they still effective caregivers? Can they handle taking care of the person in their home or do they need additional support? Discuss the plans for their family members care, who will care for this person in their absence? Do they have a sibling? Do they have a brother or sister that is willing to come in and take over for a parent? Or is there someone you assigned to being a caregiver for this person in your absence? Help family caregivers develop a wish list for their family members and help them to prioritize and actualize those wishes. Keep asking questions all along the way. What's the plan? What you want to do? What does the person you're taking care of want and collaborates to identify community resources to make the plans and issues a reality. And there are caregiver assistance suggestions on that Albany .edu website on aging.

That's kind of like a treasure trove of sports for people who are carrying for individuals with ID/D D. It tends to be somewhat specifically oriented to family members who are caring for individuals, but it's also relevant for paid caregivers as well.

You want to optimize quality of life. Support and enable the person's existing abilities. Try to teach new skills as someone has dementia, they will lose us -- new skills they are not able to obtain. But you want to try and maintain what they are able to do. You want to know what is normal routines to maintain them. Predictability and familiarity help a person feel more secure. So you want to know what's normal in the routine. Safety is always first. You need to increase staff or have monitored nutrition and intake. Review environments regularly for more lighting because someone with dementia -- aging as well, vision changes occur. Lighting needs to be in place. If someone needs to get up in the middle of the night and use the toilet, they are still able to do that without assistance. You want to ensure the pathway to the bathroom is safe. Encourage exercise if the person's condition permits it. It can help maintain physical and mental abilities. Important socialization. Plan the activities that the person is able to participate in. Geared towards what that capabilities are, not try to develop a new skill or talent. Support what they can do. With familiar people.

And a big part of optimizing quality of life is really being prepared for somebody who's going to be having increased needs. Many residential situations actually offer a progressive level of care. So as the persons skills decline, that level of care and the amount of support around them increases. And this is also a way to optimize quality of life.

And Alzheimer's dementia is progressive and irreversible but the process can be slowed and the person's quality of life can be maintained.

So there are a lot of efforts going on now for learning more about dementia. It's a very hot topic, a lot of research is currently being done. The national test group of intellectuals with developmental disabilities and dementia p ractices. We've included the website. Where you can access information and some of their handouts. There is a wealth of information available with a focus on assessment and evaluation. Developing assessment tools designed for people with ID/DD, that's going to be a place where you're going to learn about tools that are currently being piloted for assessing dementia in individuals with ID/DD. There's a lot of information about developing supports. Advance directives, which can be crucial with -- when somebody has dementia. While that person still has the ability to talk about what he or she wants, you want to get some sense of what that person would like going forward. There's a lot of information about how to facilitate aging in place. Many individuals would prefer to live at home as long as possible. Where their home is with family members or in a congregate care setting. So really encourage you to make use of those resources. The American Association on intellectual and developmental disabilities is a collaborative effort between the American Academy of medicine dentistry and the rehabilitation training center on aging and DD at the University of Chicago. This has many, many resources.

So the national task group was developed specifically to look at issues around dementia for people with intellectual and developmental disabilities. And the tasks they were charged with was to develop early detection screens for dementia related changes in people with ID/DD. We did discuss the screen that they developed earlier in this presentation. They also developed practice guidelines for healthcare and supports around dementia in adults with ID/DD. These are really good resources, particularly when you're working with developing a community network of healthcare professionals so that they are aware of the idiosyncratic needs around having an intellectual or developmental disability. Many healthcare providers may not be aware of issues that are very specific to Down syndrome or two ID/DD. And the practice guidelines that are provided through the -- they are very useful in providing that kind of information for your healthcare providers. It also helps to identify models of community-based support and long-term care for people with ID/DD. The publications that so far the NTG has produced our my thinker is not working, a handbook that's easy to download. It's quite long. So we have not included it. But we do have a link to it in the bibliography that's included with the presentation. There's also guidelines for structuring care and support for people with intellectual disabilities and how they are affected by dementia. That can also be downloaded as a PDF and is also very useful. So all that being said, you want to learn as much as you can. These are some resources that are worth looking at. Vermont has a developmental services resource guide on aging and dementia published in 2008. You can download that from the Vermont website, which is provided there. It's accessible, easy to read. There are frequently asked questions. And links to additional resources including the Edinburgh principles. It's a really good handbook to share with caregivers or family members. It explains a lot about dementia in a very clear language. It's good for somebody who may not be a healthcare professional. It's also good to use as a training tool if you are working with support professionals. Aging older caregivers of people with intellectual and developmental disabilities. This is an excellent resource for supporting people who are aging themselves and yet continuing to provide supports for family m embers. It has like good suggestions for initiating a dialogue with caregivers. It has good ideas for accessing community resources so that that caregiver has some time to themselves and they can pursue their own health care needs, their own recreational interest and their own support. As you can download a PDF of that at the website given there. And aging and Down syndrome is a very useful handbook for professionals and family members. It provides information on developing a person centered approach to aging in place and providing supports for people who have Down syndrome and are at risk for dementia. And again you can get that PDF. Very easy to download at the web address provided. These are some useful websites that provide additional information on protocol and assessment tools. Rehabilitation research trading sent -- training center with developmental disabilities dev is out of the -- bibliography on a care. It also includes fact sheets and background materials. There's links to other dementia reports and guidelines. And then also update information on conferences and workshops that may be going on. We've provided the web address for that. And then in addition to that, there's the social welfare school at the University of Albany in Albany, New York. And this is dedicated to providing resources for individuals who are caregivers, particularly family members and direct support professionals that have a lot of articles that are very interesting. It has links to assessment tools. It has tips to initiating conversations with caregivers. If you want to help them to make plans or to recognize needs that may be emerging for individuals. So that also has a wealth of information. There's also the Institute on aging at the University of Wisconsin. I strongly encourage you to visit that and make use of the resources available. Assuring that you are informed and aware of recent research, resources and development will support your practice and assure that the individuals served can receive optimal care. Another useful website is the Institute on community integration, which is University center of excellence out of the University of Minnesota. Again, a lot of resources. Information, training o pportunities, for people with intellectual disabilities and also for the families and caregivers. And I've included the website. So we will move on -- before we move onto questions, I think we have a test. Are there any questions that we want to answer first?

No questions.

So these are true and false questions. I'll begin -- Linda, you will do number two.

Okay. Number one, dementia is a process characterized by cognitive decline and impaired ability to function. Is that true or false?

That is true. It's a progressive loss of functional and cognitive skills. Standard assessment -- standard assessment tools for dementia are reliable tools to assess dementia in the ID/DD population. True or false? That's false. As we talked about earlier, there are some specific tests that would be more useful, because unless someone is in the mild range of intellectual disabilities, and has some reading, writing capabilities, the standardized assessment tools for dementia are not going to be very accurate. You need to know a person's baseline. The test that would be more useful is the Down syndrome Mini Mental State Exam, the TSI, the caretaker assessment questionnaires, some more specific to someone with ID and downs. That would be more useful than a standard assessment tool.

Alzheimer's disease is a rare form of dementia unlikely to affect in the visuals with Down syndrome. Is that true or false?

Okay. That's false. Alzheimer's disease is the most common form of dementia. Individuals who have Down syndrome are very prone to developing Alzheimer's disease. Many of them show early symptoms of Alzheimer's disease as early as age 35. And as we've been stressing throughout the presentation, it's very important to get a baseline for someone with Down syndrome as early as age 30, because the decline does happen so early. And people who are -- with Down syndrome as old as 60 are about 70% more likely to develop Alzheimer's as a form of dementia. People with Down syndrome are dying at younger ages than previously. True or false. Today, at one time, people with Down syndrome were dying -- had life expectancy of -- but today life expectancy is in the 60s. Due to medical interventions, more awareness of how to manage someone with Down syndrome. And the various medical dementias that come along with Down syndrome.

Okay. The DSM, the TSI and the caretaker questionnaire are useful tools in diagnosis of dementia in the intellectually disabled Down syndrome population. Is that true or false?

Okay. That's true. As Linda was saying earlier, these are tools that can be modified so that you get a more accurate picture of what the individual -- how the individual is functioning. You always want to be comparing the skills that the person had at baseline to skills he or she may be losing. You don't want to be testing the person on skill that he or she never acquired. Okay? Baseline of capabilities prior to dementia is an effective tool for diagnosing and recognizing symptoms of dementia in the ID population. True or false? Okay. Baselines are the most useful tool in diagnosing dementia and Down's or ID. And should be done like Jill said, as early as age 30 in someone with Down syndrome so you have an accurate baseline prior to any indication of Alzheimer's.

Okay. Symptoms of depression and Alzheimer's can be similar in individuals with intellectual and developmental disabilities. Is that true or false? Okay. That is true. Many times, the symptoms of depression and Alzheimer's are very similar for somebody with intellectual or developmental disabilities. It's important to get a differential diagnosis so that appropriate treatment can be provided. If it is a depression, that's something that is often times very easy to treat. And there can be a good outcome. But it's important to get that differential diagnosis, because oftentimes depression is a sign that there is going to be an onset of dementia.

Okay. The Edinburgh principles recommend is to do so utilization of individuals with ID/DD who have mild to moderate dementia. True or false? -- recommend institutionalization of individuals with ID/DD who have mild to moderate dementia? True or false? That's false, as we talked about earlier. The Edinburgh principles are all about maintaining people in their homes, maintaining people's ability and encouraging -- preserving the person's autonomy.

The first sign that a person with Down syndrome makes -- maybe experiencing dementia is usually a change in behavior. True or false? That is true. Oftentimes we are going to notice a cognitive change in individuals with Down syndrome as quickly as we're going to notice a change of behavior. Individuals who are very social may begin to isolate themselves and not be as interested in relationships that they once had. Used to get along well with other people, may begin to be argumentative or even aggressive. And those are all signs that they may not necessarily mean that the person is developing Alzheimer's disease, but there's certainly something that you would want to look into further and do some screening.

Okay. Planning future supports for an individual with ID/DD should not include individuals -- should not include the individual, since it would be upsetting for him. True or false. Okay. Person centered planning is always the most comforting why -- way of planning a person's care. They should have autonomy in decision-making and they should be encouraged to express what their wishes are so that they can be maintained comfortably in the environment that they're in. We do have a raised hand. Catherine, you had your hand r aised. I sent you the audio PIN. So you should be able to unmute. Or you can -- if you like, you can type your question into the question box or the chat box. What is the average time span of the seven stage of dementia?

There's no actual time span, but it is progressive. And at the end stage, it's going to move more rapidly. But as far as a specific time span, it could be months, it could be years. End-stage is the seven stage, end-stage dementia. In Alzheimer's.

With people with Down syndrome, the progression is more rapid than somebody who doesn't have Down syndrome. So I think you need to be prepared that that person with a diagnosis of Alzheimer's is going to progress into a stage where they're going to need very intensive ongoing 24 hour support. But how long that will last is not something that will be clearly defined. But it's also a stage where the risk of swallowing disorders, aspiration pneumonia, seizures, that's all becoming prevalent. So what usually ends up tumbling a person is that -- aspiration pneumonia or a seizure with a severe injury following it.

That's it? Okay. Thank you very much, and have a good afternoon.

Remember, once I end of the webinar, you'll see a tab appear in your browser for the survey. If you weren't able to get to answer the test questions, that's okay. Don't worry about it at all. And if you can't finish the survey today, as I mentioned earlier, you will be receiving an e-mail tomorrow, and you can finish that. And if you have any questions, that you can think of after, the w ebinar, please feel free to e-mail me, lisa@nyrehab.org. Thanks, everybody. We'll see you next time.

Goodbye.

[event concluded]Actions