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Good afternoon. My name is Lisa Zimmerman. I'm from the rehabilitation research and training Institute. Thank you for joining us for today's webinar: Growing Older: Implications for People with Intellectual and Developmental Disabilities. These webinars presented in conjunction with our OTI and the Lewin group for social workers, or disturbed nurses, and other healthcare professionals are supported to the Medicare Medicaid coordination office or e-MMC zero and the centers for Medicaid and MS -- CMS to ensure beneficiaries enrolled in Medicare and Medicaid have access to seamless and high-quality health care that includes the full range of covered services and programs. To support providers to deliver more integrated coordinate care to enrollees and MMCO is developing technical assistance and actual tools based on successful innovation for care models such as this webinar series. To learn more about current efforts and resources, please visit resources for integrated care atwww.resourcesforintegratedcare.com. Your microphones will be muted. There will be a question and answer portion. If you do 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. There will also be poll questions throughout the presentation. A window will appear with the questions. You can submit your answers at that time. At the conclusion, a tab will appear in your browser prompting you can -- to complete the evaluation. It is required you complete this evaluation survey in order to receive three contact hours from the mission -- from the Michigan, New Hampshire nurses Association, national Association of social workers. If you are unable to complete the survey, you will receive an e-mail tomorrow with the link to complete the survey at that time if you have not already done so. At this time I'd like to introduce our instructors to you. Jill Dorsi is a licensed clinical social worker who is the mental health program specialist for New York State Office of Mental Health. Ms. Dorsi has over 30 years’ experience working with individuals with mental illness and developmental disabilities including supervision of five nurses providing care to over 200 individuals above age 60 and community-based family residences. She is also trained in 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 as potential rehab candidates in subacute rehab and is PRI and screen certified. She is previously employed as the DDS so for 20 in family care unit and 15 years at Helen Hayes Hospital in rehab. Ms. Anderson is also a member of the bereavement committee and a Willie educator as well as a participant in IVR study on fragile and Down syndrome and Alzheimer's disease. Let's begin.

Hello, everybody. I'm Jill Dorsi. It's really exciting to be here today and to have this opportunity to present with Linda Anderson. As you just heard, Linda and I both have probably about 50 years’ experience between us. And we did spend a lot of that time working together in a program called family care, in which people with developmental disabilities lived with family caregivers, most of them were over 60, some of them were as old as 90. It was very challenging, very exciting. What was really good about it was that I as a social worker had the opportunity to work with Linda, a nurse. We learned ways to collaborate and blend our two actresses. So the learning objectives for today -- you are going to become familiar with the common physical cognitive and behavior changes of aging across all populations. So that would be not just people with developmental disabilities, we're also going to talk a little bit about how aging affects people in general. Examine how aging processes may manifest differently, in people with intellectual and developmental disabilities, and we are going to be using that acronym ID/DD. The use of psychotropic medications can contribute to behavioral issues for people with ID/DD. We're also going to be become familiar with the aging challenges that are specifically relevant to people with various syndromes, Down syndrome, seizure disorders, fragile ex-syndrome and the autism spectrum disorders. We're also going to consider aging supports and services within the contact of -- context of person centeredness and personal autonomy. We are not advancing, Lisa.

[Silence]

We'll be right with you.

A little glitch here? I think as Lisa mentioned earlier, you can also be putting in questions as we go. Lisa will be picking them up. At the end of each section, we're going to take the time to answer those.

Okay. So aging happens to everyone. It's a natural process. It can't be avoided or reversed. As my dad used to say, getting older is really difficult, but when I consider the alternative, it’s okay. We don't think of aging has something that we can cure or avoided. But we do think about how we can manage it in a constructive way. If we want to age well, we know this will be to some extent related to how we live our lives, if we have good health practices. Our lifestyle can affect how our bodies go forward in life. And how they respond to aging. Aging is a great equalizer. What Linda and I discovered is that many times people with developmental disabilities as they age really develop the same needs as people in the normal population did. Even so, people with lifelong disabilities often have age-related issues that are the result of the syndromes that they have, lifelong disabilities, also medical treatments that they may have experienced. Aging can be classified in many different ways. Primary aging is normal aging, a disease free life across the lifespan. Good health practices that contribute to having a disease free life across your lifespan. Secondary aging changes for health habits, disease processes affect your lifespan in not so positive ways. Tertiary aging is a rapid loss of function and end-of-life aging. How does aging change us?

We look different. Changes are subtle at first and we can conceal them with makeup, hair dresser becomes our best friend, but even so it becomes harder to lose weight, it's easier to gain it, we lose muscle mass, cognitively we start to think more slowly. It takes longer to lose new things. -- learn new things. People often make jokes about senior moments. The upside is of course we have the benefits of lived experience and we are getting older and wiser. Socially, we may lose friends. They may move away, they may retire and move to the South. People may pass on. That creates [Indiscernible] and depression. This contributes to many health issues. We become more to -- prone to injuries. Vision declines, hearing are limited. These can be addressed and managed but they can't be changed. We can however age gracefully. We can minimize the effects by being proactive. With good health practices, get enough exercise, eat well, work at staying fit, these are things that are helpful. It's important to try to learn new things, try to learn to play a new instrument, learn a new language, these stimulate your mind and they keep you bright and alert and engaged at staying socially involved, very important. Being in relationships that are nurturing and helpful. Here are some tools to help you age gracefully. Things like eat a balanced diet, take vitamin supplements, maintain a healthy weight, exercise regularly, take that walk down the driveway every day after work, use your exercise bike you have at home, join a gym. Routine and regular. Manage the stress, have time for yourself, time to take a breather at the end of the workday. No smoking, avoid alcohol in excess, continue your education, continue learning, and continue looking at new things, exploring new things. Don't get stagnant. Maintain your social context and nurturing relationships. There is some factors that can't be changed in aging. Your age, going to happen. No matter what. We all age. Gender can affect your aging process. Genetics have an impact on how we age. Ethnicity also has an impact on how we age. Individuals with ID/DD encounter additional factors that can't be changed. Complications of disability.

We are going to be talking about those in much greater depth in a little while. For people with developmental disabilities, the concerns associated with aging become more complex for a number of reasons. Perhaps most significantly because of other people's preconceived ideas about people with ID/DD. In particular, aging in general. We've all heard about ageism. We've also experienced many times people discount the abilities of somebody with ID/DD. And they dismiss what they are seeing as being related completely to the developmental or intellectual disability. So when we consider providing supports to people with ID/DD, it becomes important to focus on these broad areas, assuring that the activities available to them are able -- that they are able to sustain their level of function without increasing risk. We want to ensure continued community connections. That's important to health. Physical as well as mental health. We want to help preserve their autonomy and ability to make informed choices for themselves. We want to preserve their personhood. Linda, do you want to give an idea of the definition of intellectual and developmental disability?

Intellectual limitation that hinders independent functioning and daily activities such as healthcare, communications, work, education. It's a disability that developed before the age of 22 that was documented in your health assessment. Results in a need for long-term care and adaptive and functional supports.

This particular definition as you can see from the slide came from my thinker's not working, which is put out by the task group on dementia practices. It's provided in the resources for this PowerPoint. And it's really a helpful and very, very rich source of information on people with developmental disabilities who are aging and have a specific focus on Down syndrome, but I think it's applicable to many other people with developmental disabilities and IDA as well. So why is this so important for us right now to be considering people who are aging and who also have intellectual and developmental disabilities? Right now, there are people who have -- living much longer than they used to. In 2000 there were 641,000 people with ID and DD above the age of 60. That was 14 years ago. The life expectancy for people with developmental disabilities and intellectual disabilities has increased significantly. In 1930, a person who had Down syndrome was expected to live about nine years. Now an average life expectancy is 68. People with ID and DD are also living longer. At one time they would live about 20 years. Now they are living -- average age is now 72.As a result of increased life expectancy, we are encountering new needs for people with intellectual and developmental disabilities. As people with ID and DD age, they're going to need more sophisticated enhance supports than they do currently. We have to ask ourselves, are we prepared for these? Another issue is that their caretakers are growing older. 75% of people with intellectual disabilities live at home with family members. As the baby boomers age, the children that they are caring for who are now adults are also aging. So that creates a greater need for residential support. Also increased issue of dementia, particularly for people with Down syndrome. Estimated that 54,000 people will be affected with mild cognitive impairment, the early stage of dementia by 2010. As a result of this we are going to need to be looking at residential supports that are barrier free, that provide more nursing oversight, more access to community services with physicians, occupational therapists and physical therapists. So are there any questions?

Okay. Lisa is going to be reading those to us in a moment.

Any other questions?

No questions.

We'll go on. So the way people with ID and DD experience aging is often associated with the genetics and pre-existing challenges that are related to the lifelong disability. We're going to consider these issues so that we are aware of specific risk issues that are associated with these so that we can identify and develop sports. -- supports. Linda had talked earlier about things that could not be changed. Genetics, in particular. These are some of the situations that cannot be changed in aging. Down syndrome, seizure disorders, autism spectrum disorders, Fragile X Syndrome, Prader Willi syndrome. There are additional syndromes that are often affecting people, but these are the most common and the ones we're going to be focusing on for the purposes of this presentation. So Down syndrome is the most common chromosomal abnormality that leads to intellectual disability. For example, people with Prader Willi often do not have intellectual disability at all. People with fragile ex--- Fragile X -- people with Down syndrome almost always have an intellectual disability. This is related to chromosomal abnormality.

These are three different genotypes. It's an important thing to know which genotype in Down syndrome -- trisomy means there are three copies of the 21st chromosome. Trisomy also seems to be connected to more cardiac anomalies. Valve disorders at birth. It's a good thing to know because then you are aware that there could be cardiac anomalies connected to that particular genotype. The other genotype that you look at is Mosaic. Mosaic Down syndrome means there are some cells that have the abnormality. And some cells do not have the abnormality. And translocation Down syndrome is a duplication of the 21st chromosome. People with Down syndrome tend to have a typical lifespan in development because of an atomic disabilities, cardiac related immunologic disorders, neurological disorders, and endocrine and metabolic disorders. That's why we are monitoring for thyroid function, monitoring for B12 levels, folate levels, things that you are going to see changes in it -- in someone with Down syndrome. Not consistently across everyone. There are things we need to test for. Another anomaly that we test for in Down syndrome is cervical subluxation. We are -- if you screen for that, you can prevent or be aware that someone needs to watch their activity levels with that particular disability or they could have sub blocks in of the cervical spine which can lead to paralysis. So it's recommended we do an and jewel -- annual cervical screen. Mortality risks for people with Down syndrome are higher and at younger ages. Dementia occurs as early as 35 and 40. You could see if someone is prone to dementia, slows -- so we know what this person was like before dementia developed.

As Linda said, people with Down syndrome have multiple physical and neurological disabilities as a result of their genetic abnormality. So it's important for us to be aware of these so that we can make healthcare providers in the community also where of the intricacies of working with someone with Down syndrome. I think a good example Linda had mentioned Atlanta -- axial Atlanta supplicate -- subluxation. Still learning from her as the nurse, but in our practice together we often had to bring that to the attention of regular general practitioners and internists and request that they be evaluated for this because it was not generally known. Another issue to be aware of when you're working with someone with Down syndrome is that dementia may start with someone at an early age as Linda said, as early as 35 or 40 and it may be very subtle but what you may see is that the person is not communicating as well or the person is withdrawing or there may be behavioral issues where there didn't used to be any. It's important to screen for dementia beginning when the person is between 30 and 35. As Linda mentioned, we want to get a really good baseline. Which means we want to know who the person was before they started experiencing some of the deficits associated with dementia or with aging. And that baseline needs to be documented and past down from caretaker to care -- to caretaker. So that you have something to compare to pick what you're going to see in someone with Down syndrome before you see memory loss, you are going to see if your changes. Unless you have documentation showing what that person was like, you're not going to notice those behavior changes quickly enough. If you recall, we mentioned earlier that one of the issues with coping -- with the ID/DD population is that their caregivers are also aging. It's very likely that you will be working with someone who is in a completely new residential situation. Having that baseline is going to be particularly useful for the caregiver beginning to know who that person is. So other complications of aging and people with Down syndrome are incontinence, maybe related to renal involvement, may be related to ADL change because of developing dementia. You need to assess what is causing that problem. If this person was never incontinent before, is it a renal change? Is it because this person is developing dementia? We also screen for hypothyroidism, B12 deficiencies, and those are very treatable things with medication. But you need to know about them. Sleep disturbances can be an indication of depression. They can also be an indication of sensory losses or changes that this person doesn't understand. As you age, vision changes, hearing changes, are you seeing ADL skill changes because of that or ADL skill changes because of dementia?

I think what you're saying is that when you're working with someone with Down syndrome, I think to a greater extent and with the other disabilities as well, it's almost like you are on a detective story, really having to look at the person as a whole entity. And you need to tease out where the disabilities are, where that person may be beginning to age and experiencing some deficits. And you need to rule out, is it renal involvement? Is it dementia? Is this person withdrawing because they are depressed because they changed their home or is there really something going on where they are feeling they can't cope with the daily challenges of life?

So Fragile X Syndrome. This is a genetic condition which affects the X chromosome. Much more frequent in boys. Males have one X chromosome and one Y chromosome. Women have two X's. So if the X chromosome is damaged, you are going to see the results of that much more readily than you would if a woman had a damage on one X because the other X would function normally. As a result, women are carriers frequently, without even knowing it. So as a result of that deficits on the X-chromosome, people with Fragile X frequently have different protein levels for brain growth. This may result in some intellectual disabilities. Their behaviors are often effective. They may be impulsive, hyperactive. Some pot -- sometimes people with Fragile X Syndrome are misdiagnosed as being autistic or having an autism spectrum disorder because there's some behaviors that are very similar to what we see in someone with autism. Handclapping, poor eye contact, again, hyperactivity. There may be some delay with motor skills. Very usually large people, poor muscle tone as well. Long face. So as people with Fragile X Syndrome age, what are some things we would be looking for, Linda?

Balance problems. Due to attacks via, those balance problems can become more pronounced. Poor muscle tone also contributes to balance problems. Increased neurological problems such as seizures are common in ID and DD of -- in Fragile X. Obesity problems, cardiac issues, hypertension, medications play a huge role in how the person ages. Because of the medications or behavior and seizures that are used with someone with Fragile X, those medications have risks and benefits to them. Some of the side effects may change and poorly impact aging.

Another disability that's common with people with ID and DD is cerebral palsy. This is a nonprogressive neurodevelopmental disorder. What that means is it's not going to get worse over time. Usually, the neurodevelopmental disorder or damage occurs very early in life, at birth, commonly a birth injury. Or lack of oxygen at birth. You could also be related to an injury if a child falls, baby rolls up -- rolls off the changing table, that may also result in an injury that could lead to cerebral palsy. It persists through adulthood. We're seeing more and more people with cerebral palsy now. Because infants with low birth weight and infants who do have low oxygen at birth are surviving longer because we have better medical techniques now. People with cerebral palsy may not have any intellectual disability at all. They are often very bright and often able to live very productive lives. However, they do suffer from aging issues related to the fact that they are frequently in mobile. Linda is going to talk about that on the next slide.

Cromlech -- chronic inability results in increased musculoskeletal problems. Increased fracture rate. You have an increased incidence of arthritis. Ambulation challenges follow throughout these lives. And as you age, your muscle tone is changing, you are fatigued more easily. So those ambulation difficulties become more difficult because you don't have that stamina and ability to handle the difficulties in date. You also have spouses -- spasticity and movement disorders. Muscle function, body is deteriorating. Some people with cerebral palsy not only are prone to gate changes and fracture rates -- gait changes, they may end up in a wheelchair whereas prior to that they were able to ambulate. But now they are muscle function has diminished. So ambulation becomes a bigger problem. So people with autism spectrum disorders generally struggle socially. It's a disorder that usually appears in the first three years of life. Typically when a child would normally be socializing more, developing language and so forth, they often have communication deficits. On the other hand, they have a wide range of abilities. Many people on the autism spectrum have no intellectual disability at all. But they do as I said struggle with normal social and communication skills. They are also very hypersensitive to neurological input. They may become very hyperactive. If they are in a room with a lot of florescent lights for example, or a lot of ambient noise, maybe something that they hear much more profoundly than somebody who does not have autism. We don't really know what the causes of autism is. There's a great deal of research going on. It is noted that there is an increase in autism with people who have Fragile X.

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Aging with autism -- skills with age and are in someone with autism. Many age as anyone else and others do not. There's an increased risk of seizures in autism. There's also an increased risk of aspiration pneumonia. Or injuries, accidental death, drowning, suffocation because these are people with poor self-preservation skills, poor communication skills, so they would be more prone to recently -- there was a young boy in an elementary school that wandered out of the school. He had autism. He was nonverbal. He was unable to self-preserve. And he was found several weeks later in the River. He had drowned. These are things that can happen. Someone needs to have enough supervision so things don't happen. They have ritualistic behaviors. Maybe less frequent with age but sometimes they don't. It varies. People with autism that have the higher communication skills tend to -- as compared to someone who has poor community -- communication or self-preservation skills. Early interventions with someone with autism and speech therapy, occupational therapy, physical therapy, all can help improve the lifespan and success of aging. So in general as Linda was saying, there are no specific aging issues associated with people with autism at this time. I say at this time because most of the research that's been done on people with autism has been done on young children and young adults. I will note that people with autism tend to have a difficult time adjusting to changes. A certain inflexibility in the way they approach life. The ritualistic behaviors that Linda was speaking about are a way of comforting themselves, making them feel that the environment is safe and secure for them. If they have to change their living situations, if a caregiver retires, or passes away, it may be more difficult than before someone struggling with the effects of autism.

Seizure disorders is another area we're going to look at. Occurs when the electrical system of the same -- of the brain malfunctions. Uncontrolled discharge can result in unconsciousness or muscle contraction. The type depends on part and how much of the brain is involved in the electrical disturbance. Some of the seizures we look at are absent seizures, petit mall seizures, it's a brief loss of consciousness. Stare into space constantly. Is how you would do. Chronic seizures is what we reused -- used to refer to as a grand mal seizure, being the rigidity, tightening or stiffening of the muscles and chronic phase is a rhythmic muscle movements. There are also partial, simple and complex seizures. Partial seizures are for one focal point or one hemisphere of the brain, whereas a complex seizure could be multifocal. You can have a loss of function with a seizure, possibly even incontinence with the seizure. We had a patient in our care, Terry Jean, and we had a very difficult time getting seizures managed. She either had too many side effects from the meds or very poor seizure control. Our greatest wish in life is to not have to wear the helmet that was protecting her from falling because she had no aura and all of a sudden she would be on the ground. And to avoid a head injury, we had to use a helmet to protect her. This was like her greatest wish. So we did try -- set her up as a candidate for a vagal nerve stimulator, similar to a pacemaker, implanted device that when a seizure starts to occur, it sends out an electrical impulse that interrupts it and in theory would stop those seizures. We also didn't have tremendous success with the VNS device with Terry Jean because her seizures were so multifocal, so many different areas of the brain. It was very difficult to control her. So unfortunately we were never able to get her greatest wish to be able to look pretty and not have a helmet.

I think what I always liked about what you did with Terry Jean is that Linda really took it person centered approach to working with Terry Jean. This was a young woman, very attractive, she felt very stigmatized by the helmet. And Linda did a lot of research. She contacted a doctor who was actually doing some of the cutting-edge work with the VNS stimulators. And had a conversation with him, had her meet, and she really involved Terry Jean in this process. Of course, Terry Jean was thrilled at the thought that her seizures may be so well-controlled that she would not have to wear the helmet. This would have made a big difference in her life because she would have had a lot more independence. She had to live a very protected life because as Linda said, she could drop down on a sidewalk and begin seizing and need immediate emergency room intervention because her seizures also didn't stop on their own. She was often --

Yes. She was.

Just a little foreshadowing for when we are going to talk more about -- about person centered planning and taking a very individualized approach to working with each one of the people in your care. So seizure activity over the years does take its toll on people. That has an effect on aging. Each time a person has a seizure, it causes some brain damage. Not always a lot but it does cause some. If somebody has uncontrolled seizure as Terry Jean did, frequently season, as they age, it's going to affect their cognitive abilities. The other thing that becomes a real problem for people with seizures is that if they fall during a seizure, they often have fractures, and again as people age, repeated fractures, repeated injuries to the skeletal system, begins to have an effect over all. The other thing that's a huge problem with people with seizure disorders is that there are long-term side effects with the use of anti-epileptic medication. In working with somebody with a seizure disorder -- Linda, this is part of why you were so proactive with Terry Jean is you have to weigh the risks associated with that medication against the benefits. Of course, you want to prevent seizures and manage seizures as much as possible but you have to also consider the serious implications that go along with taking an antiepileptic medication for the long-term. Many years. So some of the things that the antiepileptic medications can affect our absorption, and metabolism, it affects absorption of cholesterol, folate, glucose, some of you glucose, some of you are already working with people with seizure disorders, may notice that people using antiepileptic medication have application with oral health, it affects their gums, very prone to gum disease. It also -- another effect is that people with seizure disorders are often -- they need to be in active and there's a risk of vascular disease associated with inactivity. Again as I mentioned earlier, the frequent falls will really impact the person's skeletal system as he or she ages. Another syndrome we're going to look at is Prader Willi, which is an abnormality on 15th chromosome. Most common life-threatening genetic cause of obesity if the obesity is not controlled. PWS typically causes should -- cottages short stature, incomplete sexual development, chronic hunger, and slow metabolism leading to obesity. Intellect range tends to be in the borderline range. To my old like mild level of ID. As a motor development delays, small hands and feet, many have behavior and psychiatric disorders in combination with Prader-Willi. We had a young woman that we were considering to take into one of our homes that was hospitalized prior to our accepting her. And what she -- what people in hospital failed to realize is she had Prader-Willi syndrome. They had her in a room right across from the nurses station, quite a number of cases of insurer were there. With Prader-Willi syndrome, not only do you have hyper aphasia, you don't have trigger to say I'm full, you have excessive hunger that doesn't seem to get satisfied. She also had no gag reflex and she was able to get there yourself into the nurses station and consume all of the cases of ensure until she ruptured her abdomen and duodenum and in essence they could not save her.

So she passed away?

Before we even got her into our program. After that time, we started doing a lot more community training on Prader-Willi syndrome and the kinds of things you would see with Prader-Willi syndrome to ensure that those kinds of episodes don't happen. That hospitals are aware of what's involved in the syndrome and the fact they can be manipulative, they can pursue -- they see that food sitting there and she was going to pursue that because it was there to pursue. And she had that desire, not just being satisfied.

I think that also really speaks to one of the points that we want to be making. Is that if you are working specifically with a group who have Prader-Willi or one of the other developmental disabilities, you're going to be aware of these things. Community healthcare providers may not be aware of them because they are so specific and unique. And I know Linda; you've done a lot of education around Prader-Willi. It's really important in developing your system of healthcare providers to include that educational component about specific individuals and what they are struggling with because of the genetics.

Some of the aging things that you would look at in Prader-Willi syndrome are not that different than the general public. The biggest factors -- if morbid obesity existed throughout their lifetime, they become at risk for diabetes, hypertension, joint and lung problems. If you are able to maintain someone in a controlled environment where they don't have the morbid obesity problems, then you can prevent a lot of those things from happening. Premature aging is related to physical morbidity and functional decline and absolute morbidity leak -- morbid obesity. If that is controlled, you are limiting the possibility of so many other medical problems occurring. Weight poorly controlled also can contribute to knee and hip problems. Many end up requiring joint replacement because they've had uncontrolled obesity for such a long time until they got into a program and it was recognized and -- the other part with Prader-Willi syndrome is it contributes -- parents will see this child that looks in the beginning, like they are failing to thrive, not eating well. All of a sudden, change happens and they start to have this huge appetite and eating well and it is initially viewed as my child has gotten better. They are now able to eat and doing well and they don't realize that what they have not been diagnosed with is Prader-Willi syndrome. And morbid obesity starts to become a problem until they are in a more controlled setting. There is also a higher incidence of cardiac problems, connected to the weight, also specifically heart disabilities. Higher incidence of skin disorders, rashes, dry skin. And a lot of your problems if they are controlled early in life with obesity, a lot of normal aging will occur, otherwise you're going to be dealing with the excessive problems of aging. Are there any questions so far?

No questions.

I think we're going to take a break at this point. About five minutes? 10 minutes? So we're going to start again at 2:00. And we'll see you then. I think Lisa, is it possible for people to type in questions at this point during the break? If you have questions, please go ahead and type them in. We're happy to answer them to the best of our ability. Thank you.

[Event is on break and will resume at approximately 2:00 Eastern.]

Okay, everyone. We are back. We did have a question from Jackie that Linda and Jill will try to answer now.

The question is -- what they are referring to is the Atlanta will axial subluxation which is a problem in some people with Down's. Not everybody has that subluxation. That's why there's a prescreening done for it. Yes you would have to prescreen before Special Olympics to make sure that that person did not have the subluxation problem. Because if they did, their activities would be more limited. Hiking would not be okay. Walking, yes.

Horseback riding?

Definitely no. Basically anything where the person has a risk of falling would not be good. If they don't have subluxation, by all means, they are appropriate for the Special Olympics. But you want to know that. You want to have a documented cervical x-ray to note that there is no subluxation before the Olympic activity. And once you have a documented x-ray, if it is negative, then that person does not have that. Then they are going through their normal regular exams. If the beginnings of subluxation are noted, then you are doing an annual exam to make that a little clearer. And even though some people don't have it, some people do. In our experience, it has gone undiagnosed. Linda and I established a protocol at the agency where we work so that everybody with Down syndrome needed to be evaluated for that Atlanta will axial -- subluxation. In -- one of the people I worked with had it. It was undiagnosed. She had a virus or a urinary tract infection and she sat down really hard on the floor and two days later she was paralyzed. It was like the subluxing was there. Like you were saying, a tunneling into the spinal column. The other thing I wanted to say as we go forward, please go ahead and type in questions if you have any. They can be on what we are currently talking about, they can be about earlier things that we've covered. Lisa is recording them as you go. So don't hesitate to ask questions. We are happy to answer them to the best of our ability. We don't know everything but we will try our best to give you the right answer. We're going to talk now about the long-term effects of medications and side effects.So as I was mentioning before the break, when somebody is prescribed a medication, you need to consider if that medication is appropriate. You do that by considering the risks versus the benefits. It's important to be aware that when you are treating a lifelong disability or the effects of a lifelong disability, a person may be on the medication for a long time. That is going to lead to side effects over the long haul. So it's not like getting antibiotics for 10 days. Sometimes people are on the same medication for many years. And the side effects begin to have a cumulative effect on their health. And particularly as they age, it may lead to deterioration of physical status, cognitive status. So you need to be as healthcare providers yourselves, be aware of what the person is on and work together, social workers with nurses, to really make the best choices for the people that you are working with. We are going to go over some of the medications that are commonly prescribed for people who have intellectual and developmental disabilities. You are probably very familiar with these. Antipsychotic medications, antiepileptic medications which it -- we are calling a ED's. Anti-anxiety medications, axial lytic -- this is why I work with Linda -- and hypnotic.

First thing I'd like to say, what are antipsychotics? They are a class of meds used to treat psychosis. They block the release of dopamine in the brain. They are several categories. Typically being conventional or older generation psychotropics. Atypical being new generation psychotropics. Typical are not selective and also block receptors in other areas of the brain which may produce unwanted side effects. Atypical, fewer acute or chronic symptoms. Atypical anti--- antipsychotics result in improvement in cognition compared to typical antipsychotics. Antipsychotics became more prevalent in the 1950s and have evolved since. And we are going to look at some of the complications of them. Typical antipsychotic side effects. First let's explain what the extra parameter symptoms are, which is referred to as EPS. Acute dystonia, muscle spasms of the eyes, the neck and the time. Inability to remain motionless or inability to initiate movement. Tardive Dyskinesia is involuntary movements of the face, lips, torso and legs. Additional side effects are Parkinson's lights -- like symptoms, depressed mood, low white blood counts, high prolactin, seizures, impotence may be a side effect, weight gain, dry mouth, rapid heart rate, or very life-threatening problem is known as neuroleptic malignant syndrome which is an autonomic system instability. It is a -- you start to lose levels of consciousness leading to coma and death.

With somebody with intellectual or just -- developmental disability be likened -- be likely to report these to someone?

Very likely they are going to realize that they are -- unless they are on the upper end of intellectual disability where they would know to some the symptoms or at least the G.I. symptoms would be a complaint. But we as professionals have to be aware of what we're looking at in symptoms, what is this person normally like and what are we seeing in symptoms? You need to recognize the difference between induced movement disorders. Extrapyramidal system is the voluntary movement system of the central nervous system. It regulates body movement, extrapyramidal systems side effects would include tremors, dystonia, muscle contractions, reduced muscle movement, and Russ -- restlessness. Not just a pacing restlessness, it's a restlessness where the person feels like they need to crawl out of their skin or they are excessively moving -- they've got to rip up paper or pace rapidly back-and-forth because they have this excessive restlessness, not a normal pacing or walking. Also result in dopamine blockage from the typical antipsychotics. That particular group -- treatment with anti-cholinergic juror -- drugs such as Benadryl.

In other words, if somebody has that feeling that they were clawing at themselves or they had to rip up paper, you might think it was a behavior issue.

But it is actually a side effect of the meds. When you see a symptom, always assume it is the medicine. Don't assume it's anything but the medicine. First check the medicine. If it's not, go on to look for another medical reason.

So if somebody -- say a counselor noticed this behavior in someone, would they refer to their regular physician or psychiatrist, how would you go about that?

At least start with the nurse. And then have that nurse refer to a physician. Probably a visit to the psychiatrist ordering the psychotropic would be the next choice -- the next best choice. I'm going to explain about Tardive Dyskinesia. This syndrome of symptoms characterized by bizarre facial and tongue movements, stiff neck, difficulty swallowing. It's a result of a dopamine blockage of a typical antipsychotic. The treatment is to discontinue that antipsychotic and Tardive Dyskinesia usually is not reversible.

I think this is something we see a lot -- probably 15, 20 years ago when you were mood -- using more of the older generation psychotropic meds. I've been told to move over. Another -- what we do to monitor for Tardive Dyskinesia or extrapyramidal symptoms is Ames scale. Aims scale should be done every three months. When you are going for that visits to the psychiatrist ordering the psychotropic meds, he's going to do a test called Ames scale. I believe -- has everybody cut a copy of this? If you pull up the AIMS scale, abnormal involuntary movement scale, the record -- it records the occurrence of possible Tardive Dyskinesia in people receiving psychotropic meds or neuroleptic meds. The test is used to detect BT and monitor severity over time. It's a global rating method used to observe and rate movements disturbances. If you look at the handout, you will see exactly what we would be looking for, facial oral movement scale. If this is done every three months you have that track record of his very change occur in? Looking at facial movements, lip movements, tongue movements, jaw clenching. Extremity movements, upper arm, legs, going to look to see if there's purposeless movements or you would see what they call -- someone would be -- can they see me? It would be -- person sitting there repeatedly doing the same action. That's a sign of Tardive Dyskinesia, called the pill role syndrome. These are things you're going to note on that scale. Going to look for trunk movements, neck, shoulder and hip, rocking or twisting or squirming. Global judgment, going to look for the severity of abnormal movements overall and you're going to rate each thing, whether it is minimal, mild, moderate, severe. You're also going to look at dental status. Does the person -- person have dentures? Are they moving all around in their mouth? Could be an indication that there's something wrong. Besides the dentures are not fitting properly, it the excessive mouth movements making them move. Movements disappear when the person is sleeping? That would be another thing you would ask. If that person is able to give you that information or their caretaker. Then you would score, total score of items one to seven. Represent observed movements. Item eight can be used as an overall severity index. Item nine, incapacitation. 10, awareness is what you're looking at. Item number 11 is your dental status.

Who would normally [Indiscernible]

The psychiatrist is going to complete the AIMS scale done on a three-month basis.

So for somebody who wasn't a psychiatrist, but maybe saw them every week or day, it would be important to be aware of the areas evaluated so that you could bring those maybe to the attention of the psychiatrist during the visit that you have observed during your time with individual?

Right. Going to examine that individual prior to going for the psych consult. You are going to have all that documented. Because if you have a person you are taking for a psychiatric consultation for psychotropic meds medication, they -- you are there advocate. You are the one that's going to be helping that person be treated in the way they need to be if that meant needs to be withdrawn, this is how you would assess that.

Again, these are symptoms that the person themselves may not recognize as being something important. They may not bring that to your attention. It may be something --

They may not be capable of telling you something's not right. The symptom is just simply they are not comfortable. That's all they are recognizing, not comfortable. But all these little things you can observe should be recorded and brought to the attention of the psychiatrist prescribing the medication. The next movement disorder we're going to look at is neuroleptic malignant syndrome, a very serious syndrome referred to as an MS. It can be fatal. It is very rare, but it is extremely life-threatening if the symptoms would be fever, Parkinsonian muscle rigidity, fluctuating blood pressure, diaphoresis, rapid deterioration of mental status. Very rapid deterioration all the way to. Like typical antipsychotics. And the only treatment for it to is -- is to immediately discontinue the psychotropic med.

Just looking at this, looks like this could also be the symptoms of the flu. Goes back to what you were saying that you always need to be aware of the medications people are on. And consider ruling goes out.

Right. Okay. Additional movement disorders. The other symptom we look for is anti-cholinergic side effects, which is dry mouth, blurred vision, possible constipation, urine retention, any confusion, tachycardia, rapid pulse. These are caused by acetylcholine blockage. The treatment is to discontinue any anti-cholinergic med, Benadryl, whatever you are using as an anti-cholinergic med. Some people can't tolerate them.

So the typical older generation psychotropic medication, which I guess are the ones that typically cause these movement disorders that you were talking about, are Haldol, Thorazine, --

A lot of these are not prescribed anymore. There may be things that people have been on for a long period of time before the atypical psychotropics came into existence.

Now, there's a newer generation of antipsychotic medications. These will probably seem more familiar to. -- more familiar to you. Clozaril, Zyprexa, ceric well, Abilify, Geodon and Risperdal. You -- much fewer side effects --

Everything still has side effects. Nothing has come a long that's going to be totally side effect free. The atypical -- demands that you are going to see more of now. Tendency not to use the typical as much.Side effects, tend to be more cardiac issues. Arrhythmia, predisposition to arrhythmias. Benefit of them is less likely to get EPS or TD but now you are monitoring for arrhythmias. Deep vein thrombosis, increase risk -- concurrent with age meds and ID and DD. What is it from? Elevated blood sugar levels. You need to monitor your blood sugar levels. You may have to back up on the atypical side -- psychotropic or you may end up needing to treat with diabetic meds. To control the blood sugar level. There's an increased risk of stroke or pulmonary elbow -- pulmonary embolism and increased fall risk because of sedation because of the atypical. Okay. Monitoring for atypical antipsychotics. We are going to also still do the AIMS scale because you still have that possibility of EPS or TD. Definitely still doing AIMS scale even though it is less likely, still possible. You want to know that. You are going to do EKGs. Cardiac arrhythmia is a big problem. EKG is where you're going to pick that up. CBC for any changes in white cell counts, lipid and liver function tests, monitor that person's w eight, we generally like to take a blood pressure and weight prior to the psych visit when we are monitoring meds. At least we know where we stand if we -- if this person is making a lot of weight gain, maybe you want to back off on the meds to some degree. Fasting glucose to monitor for those glucose levels may be in order. Monitor for NMS. Still a possibility. Seizures are still a possibility.

As people age, the way they tolerate these medications is going to change. Some of the age-related changes are that they absorb them differently. Particularly a change in liver metabolism. So you are going to need to monitor for a changed liver function test. They may be less able to excrete the medications through skip -- through the kidneys. So reduced renal excretion. Other risks include orthostatic hypotension, where the person stands up, they may get a little woozy as their blood pressure does not come up as quickly as it should. That's going to contribute to possibility of falls, which in turn increases risks of fractures. Also affects calcium absorption. Increased risk of osteoporosis associated with it. The combination of poly so -- polypharmacy, trying to treat a number of different conditions has the effect of piling on the side effects. So as people get older, the side effects be -- become more dramatic and they may be taking more meds. They have more conditions. So it's something to remain aware of and to really always keep in your -- in the topmost part of your mind when you are working with someone. So this is the medication I can't say. I call them anti-anxiety medications. Just saying it makes me anxious, anxiolytics. They often used before a meds appointment. Xanax, Ativan, Valium, Klonopin, and Restoril.

Some of the risks of anti-anxiety meds in older adults, benzodiazepines, the drug category we are referring to, anxiolytics, typically poor choices for elderly because absorption excretion problems as you age, you may need smaller doses. That's a problem that we always seem to have trouble getting across to physicians because you look in the PDR, this is the right dose to get to this particular -- but what they are not looking at is the age of the person and the absorption excretion issues that go with it. Sometimes much smaller doses have the effect you want them to have and that's what you should be aiming for, the smallest dose possible. Increased magnitude of side effects, particularly sedation, memory and psychomotor impairments. You may have -- due to a reduced rate of drug clearance in older adults. Some people experience a paradoxical effect like if you were prescribing to help someone get sleep or relax, they may end up with inability to sleep as a side effect of the medicine that's a paradoxical effect of the medicine. Oversedation can result in falls and fractures. You don't want to go beyond -- you need to observe and report what you are seeing. Is this person getting too sedated from this medicine? Time to back off a little. Long-term use may contribute to cognitive decline or possibly even addiction. Then you have to gradually take someone off of the med.

The next group of medications are the hypnotic medications. These are often used for insomnia. Probably familiar to you. Ambien, Lunesta, and Sonata. Some choices.

There's quite a few. Just giving you some of the names of some of the common ones we see prescribed. Risks of hypnotics, not recommended for long-term use. What do we do with them? We use them long-term. Someone can't sleep, they end up on that Ambien forever, never intended to be used in that way but it somehow gets used in that way. You also may see that paradoxical reaction instead of getting sleep that you want to, they may end up awake all night. They can be associated with a delirium or anti-cholinergic side effect which we talked about earlier. Additional potential side effects include excessive sedation, morning hangover from the medication, not getting a normal sleep, getting over-sedated sleep and then you have residuals of the meds you are waking up with and increased risk of fractures and falls.

We've talked a little bit about the antiepileptic medications already but we are going to go over those as well. Dilantin, Tegretol, lamentable, Neurontin are some of the most commonly prescribed a ED's.

Like any other medicine they also have benefits and risks. The newer AED's are better tolerated, often causing less sedation. AED's are known to increase the risk of suicidal thoughts and we need to monitor for signs of depression. They need to be.

-- be prescribed for a specific seizure type. Each AED you are looking at has different benefits to different types of seizures. You want to know that you are prescribing in a way that's effective.

Talking about efforts types of seizure, would that be what you talked about before?

Some of the seizure types we are looking at. Is it multifocal? Is it one area of the brain that decisions are -- that the seizures are coming from? Taking into consideration what meds you want to prescribe. There's also potential adverse effects of AED's. Some of the adverse unwanted side effects are drowsiness, tremors, impaired cognitive skills, hyponatremia, low sodium count, especially Tegretol has a great impact on lowering sodium levels. Coordination problems sometimes come along with prescribing AED's. They may inhibit or stimulate liver metabolism. That's why you are doing liver profiles. Liver function blood tests. You are going to have gum disease, particularly with Dilantin. Kind of an older school AED but also seems to be the only one that works for some people. And when you are using Dilantin in long-term, you have to watch for gingivitis and gum overgrowth. Bone loss for long-term therapy is a problem. Serious kindreds actions such as epidermal necrolysis, low white blood count, agitation, unwanted effects of AED's.

What would epidermal necrolysis be?

A black discoloration on the skin.

Is that something that is common?

Not common.

Still something you would --

If you saw a skin the cat -- discoloration, you want to report it. And that drug may have to be withdrawn.

You want to be observing and monitoring people for any unusual signs and symptoms when they are working with or taking AED's. You want to bring it to the attention of the medical professional, probably the first person you would talk to about it -- would be the nurse. It's important to realize that not only do people with ID/DD have physical problems associated with developmental disabilities but as they grow older, they are going to have additional issues on top of them. And they may absorb the medication differently. It may be slowed, they may be excreted differently. You want to also pay attention to the interactions with other medications that they are on. As I said earlier, somebody who is older may have a variety of different conditions, maybe taking a variety of different meds. So you could be piling on these medications and side effects. You want to pay attention to changes. As Linda has been saying throughout this presentation, when you see a change, you want to immediately consider it could be the result of a medication. Does not mean you are supposed to stop, it means you need to refer to one of the medical professionals that you are working with. Other interactions, if a person is taking antacids, it might decrease the absorption of Dilantin. Dilantin and Tegretol, which are also commonly used AED's may reduce the level of Coumadin which is an anticoagulant. So I was really surprised when we were doing the research for this presentation to find out that 41% of hospitalizations for people over 65 are related -- drug related, related to their medications. , medications that people over 65 take our digoxin and warfarin.

Warfarin is Coumadin.

That's the generic?

Yeah.

These issues are also frequently related to emergency room visits. So side effects associated with medications are things that become much more prominent as somebody ages. And they result in hospital use that might be unnecessary if medications were managed more effectively.

The other thing we wanted to point out is when you bring to -- bring someone to the emergency r oom, you want to bring the medication list with you because the doctor you are visiting may not be the one who prescribed the other meds and may not be aware of them. You can't evaluate drug interactions unless you know what all the drugs are. You want to bring a current list of what's medications and what imbalance -- what amounts that person is taking, on any visit, because it may not be known from one to the other. Communication always seems to get in the way.

Of course people that you are working with, people with intellectual and developmental disabilities may not remember all of the medications they are on. They may have a communication deficits and be able -- unable to report the medications they are on. If they are ill, that's going to increase anxiety and that's also going to complicate your ability to self report. So really relying on you to provide the information that can really be a difference between life and death in situations. So just to review what we've been talking about, aging makes everyone more prone to side effects. And we can't say this enough. Any symptom in any elderly person should be considered a side effect until proven otherwise. And I remember this gentleman who had some kind of event at his home, his family caregiver was not a native English speaker. And in his broken English, he described what had happened is an apparent seizure. He did not -- the person was admitted to the hospital. He didn't have another seizure but that was probably because he was prescribed Tegretol at a level that was really much too high. And within a couple of days, he went from being this very charming and delightful elderly man, very verbal, someone who was flirtatious and a good joke teller to someone who was really just lying in bed in the fetal position. And it was not that he was aging. Turned out he was having a very bad side effects from the Tegretol. As soon as the Tegretol was withdrawn, his seizure disorder was managed within of the medication he improved amazingly. So medications not used appropriately, effectively and safety can have devastating consequences. We need to keep that in mind. As we keep reiterating, you need to know your people's baseline. You need to know that that guy, Alfred, was funny, social, highly communicative man. And what we were seeing was just completely the opposite of what we were used to knowing with him.

I'm going to talk about prevention of medication related problems. Reiterating some of what we already discussed. Just again, medication side effects, directly impact daily functioning of disabled. Monitor for symptoms such as lethargy, confusion, depression, insomnia, incontinence, loss of appetite, fractures, memory changes, monitor a need for new meds, pain and oppression often go untreated, leading to declines in functioning and participation in social activities. You have to know the baselines of who that person is. They may not be able to communicate for themselves. But chart, person to person, family member to family member, someone needs to share who this person really was, what that person's baseline is. If you are having a medication side effect, you can pick it up.

I think another important piece of this is to always remember that the people you are working with, because of their disability may not experience pain in a typical way. They may not report pain in a typical way. Same with depression. They may feel really sad and they may not say, I'm feeling sad, a lone. What they may do is become more angry, more agitated, or they may isolate themselves, spend more time alone and avoid things that used to interest them. So you need to be aware of the changes that you see in the people you are working with. And you need to be very proactive in teasing out from them what's going on so that you can get a complete picture of what that person is experiencing.

A few more points on prevention and med related problems. Monitor for the unnecessary meds as medical problems change. People sometimes end up stuck on a meds because they always got that. We should continue it. Maybe they don't need it anymore. Those are things that need to be reassessed on a regular basis. Avoid problems from wrong med choices or inappropriate dose or condition not responsive to the meds or a more effective med may become available. It's a constant reevaluation process. Are we using the right thing for this person? Are they things they need or things that interact with other meds you are taking and you need to reevaluate what you're doing? Elderly individuals are more sensitive to CMS side effects of many medications. You need to be alert for oversedation, agitation, sudden change in mental status. So with all that being said about medication, you can understand why it would be important to consider other ways to work with people that don't involve a medication. If it's a seizure disorder, or something that needs to be managed with a medication, you are going to use that medication, but for some of the other issues that people confront as they age, you may be able to manage it without using a medication. If somebody for example has trouble getting to sleep at night and spent a lot of time being agitated and restless in the evening, consider decreasing the afternoon caffeine, maybe serving herbal tea instead of a cup of coffee or decaf. Might be important for the person to get fresh air, take a walk, instead of taking an afternoon nap. You also want to be aware of people getting up at night to use the bathroom. You would limit fluids. That's also getting up in the middle of the night, also is an increase in fall risk. Many people get up at night and they don't see well, so they may trip and you have another issue. Another issue to consider is nighttime pain. As people age, they may have aches and pains and sore joints they have not raised to the level of a diagnosis of arthritis but still something that impacts their ability to sleep. Again, people may not be good self-reporters. Aging comes on gradually and subtly for most of us. You may think, today my knee hurts, probably going to be better tomorrow. When it isn't, you keep going on. If you notice somebody is not sleeping well, pursue that with them, find out what is that's keeping them awake. Could be something as simple as roommate snoring. You could change the room and avoid prescribing a medication. So has anybody got any questions?

We did have a hand raised from Deb Lyons. Deb, I'm going to unmute you now. So you can go ahead and ask your question. Go ahead, Deb.

Hello, Deb? Deb Lyons? Deb, we were not able to hear you. If you want to type it in, we can answer it the next time we have questions. Again, I encourage all of you if you have questions or you want more information about something that we were covering more you have an idea you want to bring to our attention, please go ahead and type it in or raise your hand.

Absolutely. Looks like you have muted yourself, Deb. Unfortunately, I cannot unmute you. So like Joe just said, if you have questions, please type it in.

Okay. The next thing we want to talk about is dementia. As I mentioned earlier, has people with intellectual and developmental disabilities live longer, particularly people with Down syndrome, we're seeing a huge increase in the incidence of cognitive impairment or dementia. Creates a lot of complications for managing in the community and the caregivers and for the individuals themselves.

So what is dementia? Dementia is a group of symptoms that accompany certain diseases and physical conditions. Loss of intellectual function, severe enough to interfere with activities of daily living. It affect your memory, it affects thinking, language skills, judgment, capabilities, and behavior. The cause and rate of progression of dementia varies depending on multiple factors. We're going to gradually look at them on the next few slides.

How do you know when somebody is experiencing changes that may indicate the beginning of dementia? One of the things is that they may complain about memory loss but they are not really able to recall occasional forgetfulness. Sometimes that might search for a word or a name. They might just not remember. Somebody's name, even though somebody that they know really w ell, a familiar person, they may get lost a lot. They may have to think about directions, but these are normal memory changes. But they don't get lost in familiar places. They remember important events. Maybe they have to take notes in their calendar more frequently but they are able to carry on a conversation, remain socially aware and pursue relationships that have been important to them.

So take a look at what is a normal memory change. We all are aging and it's not uncommon -- I can't say I'm not guilty of it. I have to use the beeper on my car to find my car because I forgot where I put it in the parking lot. Things that happen. I'm aware of how to find my car. So some things are normal memory changes. If some things -- you forgot to do something, you have to write yourself notes because you are working, you have a busy day, a lot on your plate. So it's very common to just forget something. That does not mean you have dementia. Memory changes in dementia? Going to talk about next.

So these are the person may complain of memory loss if asked but they don't recognize they have a memory loss. If you say, seems like you are getting more forgetful, the person might say, I guess so. They would not bring it to your attention. They would not say I had a senior moment and I don't remember where I put my keys. As it's really out of their awareness. They have trouble finding words. One of the things that's really remarkable when somebody is beginning a cognitive decline is they will ask for something by the function, not by the name. If they want a drink of water, and they're looking for a class, they will say drink. They want say, where's the glass? They get lost in a familiar place. They may need extra time to get home, may become confused when outside of their home environment, they don't converse as well. They lose words. They can't really remain active in a conversation. And they may begin to behave inappropriately. Acting out, even some greater -- aggressiveness and someone who used to be very easy to get along with and very -- social and fun. You will notice at the bottom of these slides, we've given you a resource to help guide -- the help guide.org/Alzheimer's. What we found for the presentation is available there as well as some of the information we are going to use. It's full of resources. I highly recommend looking at it.

Some of the common issues associated with dementia -- just a reiteration of some of what Jill touched on, memory loss, difficulty completing multi-step tasks is common. All of a sudden if it's not a simple task you're doing and it needs several actions to complete, they get mixed up part way through. Unable to navigate previously familiar places, all of a sudden this person that always took themselves to the bathroom now can't remember where the bathroom is. They want to go to bed at night and they somehow managed to get into someone else's bedroom by mistake because they really are just not able to remember where their own room is. When you start to see things like that, that something that would be a clue. Reduced judgment skills, personality changes, loss of social skills like Jill was discussing. Taking longer to do more difficult mental tasks. Like I was saying multi-step tasks and language problems, difficulties with names of familiar objects. What you would see more of.

One of the things to point out is that if you are working with someone who has Down syndrome, you may begin seeing these things when the person is very young. They can start as early as 35. It can be very accelerated. You may see early symptoms. Within a very short time, you could see somebody really advancing rapidly to the stages of dementia. So it's important as we've been saying to have a baseline of who the person is and to be really alert for these changes. I think also to do some differential diagnosis to rule out that it could be a reaction to medication or could be depression over the loss of a loved one.

Or a medical problem. You want to look at all the varying possibilities. The other thing we had that we took from the help guide, the website that Jill just mentioned, is a little self-test. Give an idea of what kinds of things you start to look at. You can download that test yourselves at some other point. I don't believe that was one of the things we did as a PDF. So the questionnaire is not a definitive guide. It's just an indication that there might be a problem. It's a test that you can run on yourself on a relative or one of the people on your caseload. Based on what their skill levels are. Some of these things are things you'll notice. Some of these are things you can ask. The kinds of things you look at are the same things we were discussing, memory, in the self-test, a section on memories and the kind of thing you would look at, and does this person have a memory loss? Yes or no answer. Does -- has this person's memory worsened over time? That's why you need the baseline so you can judge that. Are they not remembering things that they commonly remembered? Are they forgetting that it is 11:00 and they always watch the news and all of a sudden they don't remember it's 11:00 or the news time to watch? Does the person repeat questions, statements, stories over and over again, you give them the answer but they don't remember you gave them the answer? They just repeat -- keep repeating that question? Have you had to take over tracking events and times and appointments for that person? Does the person misplaced items often? How often? Things like if they need their keys, they put the keys to their house in an uncommon place like normally they always had it in a little dish next to the bedside so they knew where they were but all of a sudden now they can't figure out where they put it order on -- or in unusual places like the freeware -- like the refrigerator. Does this person start hiding or stealing items and stashing them away? All of a sudden they need -- start to think paranoid thoughts like someone might steal my favorite tees so I'm going to hide -- but then they can't remember where they put them. Orientation questions, some of the questions on here. Is this person unable to find their way around familiar places? Yes or no? Is this person getting confused when outside of their home and they are having to to somewhere else? They mix up the destination they are heading to. Functional ability declines. Do they have trouble -- if they were able to handle money at one point in time, are they now suddenly not able to make simple change? Was it someone that had the capability to do those things and now that capability is gone? Do they have trouble taking their meds, able to do their own medications? Do they suspect you of giving them poison because now you are giving the medicine and they are not remembering that used to take it? And they get suspicious? Other kinds of things you're going to look at is visual spatial ability. On this little self-test, are they lost in familiar surroundings? Another kind of question. Do they lose their sense of direction? Are they suddenly unable to visualize going down the steps? Maybe you have to have better lighting because they are not able to visualize that there is a step. They lost their depth perception. And language, as their language skills changed? Is a little scoring to this? Take the self-test, see what it's like. See how it fits into your caseload on who you are taking care of. As ways of evaluating someone -- before you head to a doctor. As you do that kind of self-test with yourself or someone, it's an indicator that yes, it's time to go see a doctor and do further testing or is this just simple aging, normal memory loss? And I think just being familiar with this test, it will help you to start thinking about those things. I know as we were working on this and I started reading this, I began noticing among the people I was with, I began thinking about, did this person always need reminders around this issue? Is this something that is new? So it puts it into your awareness as a practitioner so you can be thinking about it, if you see a lot of issues that are concerned, you might want to complete this on a person you are working with even if that person is 38, 39 years old, if they have Down syndrome, you could be seeing the beginning of Alzheimer's disease.

Let's look at the chart.

So this is a comparison of what would be considered a normal memory change. You can't find your keys, Linda can't find her car in the parking lot, I can't ever find my keys so I just keep them on a hook and it solves a lot of panic in the morning. But as we mentioned before, someone with early Alzheimer's might put their keys in a strange place instead of on that hook, which is next to the refrigerator, I might put it into cheese drawer or I might put my wallet in the dishwasher. Again, a normal memory loss is associated with aging, you forget a few names, you haven't seen somebody for a while, you can't remember their name, somebody with early Alzheimer is going to forget the names of people they know really well. Going to forget the names of common objects. And going to change the way they use words. They may want a spoon and they may say, eat. Another one is forgetting conversational details. We all live in a routine that is very demanding, we have a lot of things we have to remember. It's common to forget something that you heard in a conversation that you had with somebody. May have been very casual, even a serious conversation. You may forget some of the details but you don't forget the entire conversation. Somebody with early Alzheimer's may forget ever seeing the person, ever discussing something with the person.

Again, getting lost is a big indicator. Somebody with mild normal age-related memory loss may take an occasional wrong turn, they may have to think before they drive to a place they haven't gone to for a while. Somebody who has early Alzheimer's is going to forget how to get home from the supermarket if they -- that they go to every day. It's going to become a big issue for them. Again, this is from the help guide for Alzheimer's disease. It's a very helpful website with a lot of information and a lot of resources.

I would go over a few other things. It's normal to feel cold as we age, we are more sensitive to cold, but someone with Alzheimer's, what you would see is they have seasons wrong. Like they want to wear shorts in the winter and look into where an overcoat in the summer. Those are indications of Alzheimer's. They're not recognizing the difference in seasons. And feeling occasionally sad is a normal aging change. But big mood swings, going from tears to rage, is an indication of Alzheimer's.

This is again we're going to reiterate the same things we just discussed. Functional capabilities in dementia. The person loses skills in areas where he or she used to function well. The person may no longer -- maybe a longer period of time to respond to a conversation or situation to focus on and assess what you just said. Personality changes may occur and can lead to depression. The person may not be able to find favorite objects or clothing item that they would like to wear, the person can become easily upset, confused or short tempered.

Again with somebody who has a disability, this -- a loss of skill that the person previously had. It's important to make that distinction when you are working with the person. This is somebody who used to be able to speak very well, used to be able to carry on a conversation and then you are seeing a decline in that ability. Or somebody who used to be able to dress themselves independently is suddenly having difficulty figuring out what part of his body his pants go on. So it's a change in the current level of function. A change in the baseline. Again, with people changing caregivers, it's important. We cannot stress this enough. Would keep going over it and over it again. You need to document what the person can do, what the person has typically been able to do, what skills they have learned and achieved. As they age, they may begin to lose those skills and you are going to want to be aware of that.

More changes. Some of these changes can become severe. A person may become paranoid or distressed with familiar activities. Sudden mood changes leading to explosive emotion or aggressive behavior. As Alzheimer's progresses, these are the kinds of things you would see. Disorganized and frustrated, unable to find a favorite object, person losing language skills.

I think one of the things that's probably the most tragic about watching somebody with Down syndrome or ID/DD experience dementia is many times they have struggled for their entire lives to achieve these skills. And then to the extent that they are aware, there watching those skills disintegrate. And I think a lot of them become very depressed. And it is very, very frustrating. And it's frustrating for caregivers as well. When you're working with somebody like that, it's important to keep that in mind. They may be very difficult and frustrated to work with somebody who repeats the same question over and over again. Or somebody who has very aggressive behaviors when they used to be very easy-going. But that is that person's expression of the loss that they are experiencing. And it is their tragedy that you are watching and that you need to support. So what can you do? How can you support this question you want to learn about the differences encountered when working with people with ID/DD and dementia? Help them maintain their connections to others and in the community. When we talked about graceful aging and preventing a lot of the onset of aging, we talked about how important social connections and relationships are and how important it is to continue to stimulate your memory and your mind. So you want to provide ongoing opportunities for that person to continue to be engaged and active. The person is working or has daily activities that he goes to outside of his home, you want to encourage and provide the supports to enable the person to continue to do that because the more the person is stimulated, the more the person is engaged, the longer that person is going to be able to maintain his or her ability to function within his home and within his community. By community, not just his neighborhood and the town he lives in but that community of people who are his friends and family. You also want to seek out resources that will help you design activities for people who have dementia, things that are going to take into consideration declining skills, but that are going to continue to stimulate them and encourage them to keep the abilities that they have. Any questions?

No questions at this time.

No questions. Should we give a few seconds for people --

Sure. Give a chance.

Again, if anybody has any questions, please feel free to type them into the chat window. Or you can use the raise hand feature on your control panel. And then I can unmute you. And you can ask your questions.

Is anybody typing in questions?

I'm going to go ahead and go on. If things do come up that you have questions about, please go ahead and type them in and Lisa will pick them up and we will have one more discussion period at the end of the presentation. What we're going to talk about now is supporting the person's choices. And this is something that you are doing throughout the person's life, but that support should not diminish as the person ages. So you still want to work with the elderly people to help preserve their autonomy and self-determination. One thing that aging doesn't change, it doesn't change who the person is. It's important to develop supports that are going to have the person continue to be who he is and who he wants to be. Some of the valued outcomes in aging are you want to maintain your physical and mental health, somebody with an intellectual disability wants that same thing. They may have difficulty expressing it but if you work with them, you will find in most cases that the person wants to continue to be active, they want to continue to feel good. They want to be rude -- be able to remain engaged, be able to see their friends, they want to be able to work when they have jobs. They want to be able to pursue interests, hobbies, whatever. And they want to continue to be part of their community. They want to go to church, they want to go to the library if that's something they've been doing. They want to continue to see their families. Participating birthday parties, holiday celebrations, in other words, they want a real life. And a valued outcome is to preserve those aspects of life that are most enjoyable for the person even as he ages and experiences disabilities. Something we hear a lot about is aging in place. What that means is people have the environmental and care support that makes it possible for them to remain in their homes and involved in daily work and recreational activities. Safely, as long as possible. Safety is a huge concern. Particularly when we're talking about people who may be in wheelchairs, who may have seizure disorders, safety becomes a huge issue as those individuals age. You want to consider how to make this possible by looking at the supports across the board, taking a very holistic view of what you are providing, both at home and in the community. You want to consider the person and his or her lifestyle from this perspective of looking at the entire team -- at looking at the entirety. Is it possible to modify the residents that person is currently living in to minimize risk? Is there a downstairs bedroom that would be more safe for that person family upstairs bedroom? Do you need to change lighting in the evening? What other support can be provided to help the person stay in that particular home? Is the person's work environment safe? If not, what kind of accommodations can you advocate to be put into place for the person? A lot of times in my experience -- Linda would agree, people may not realize that the person is aging, particularly if you are working with a person very, very frequently, seeing them maybe once a week or once every other week, somebody who doesn't see the person as often or doesn't see the person at home may not be aware of changes that are going on. If you bring them to the attention of somebody at a workplace, they are more than happy to work with providing environmental accommodations. Travel. If the person is used to traveling, they have the ability to take it as or in some cases even to drive, make sure that the supports are available so they can continue to access transportation. Is it possible to obtain a van that would accommodate a wheelchair? Somebody has recently become non-ambulatory, many buses provide sports for people who are using walkers or wheelchairs. The biggest piece of this is training. You want to make sure that the individual and caregivers understand the implications of new needs that are emerging and how to support these. So you want to help them to be alert to new needs. Possible meds reactions and side effects. You want to be observant and aware of how the person is coping today. You want to be aware of what's happening today so that tomorrow you are more likely to notice if there's a change. It's a kind of a constant vigilance when you're working with someone who is aging. And you also want to provide information to people and caregivers about what dementia is like, what the implications are and what kinds of signs and symptoms they should be aware of. You may want to share that aims or dementia test with people, hands-on providers of care so that they are alert to those tiny subtleties. And not that those can be used for nonprofessional diagnosed -- diagnosis, but a source of information and they can bring what they see to the attention of the nurse or the physician so that further tests and evaluations can be done. So self-determination is something we've heard a lot about. And in general, we hear about it with young people and young adults. This is also something that applies to people who are aging. They still want to be who they are. They want to have a real life. They want to be able to exercise the same rights that all citizens exercise. They want to be able to vote. They want to be able to grout to their community and enjoy a movie, go out to eat. So they want freedom. They want to have some authority over their resources. If somebody is experiencing dementia they may not be able to actually manage their funds but they want to be able to have some choice over where they live, over the kinds of things they do. They want to have the supports they need to exercise that authority. So they want you to interact with them in a way that you are listening to what they're saying, you are hearing what their needs are, what their dreams are, what their personal goals are. Even if those goals are for a abbreviated amount of time, they're still important to the portion. And they want to be responsible. They may not be able to manage their funds anymore. But they still want to be an important part of their community. They still want to be able to contribute money in their church on Sunday. Or they still may want to volunteer if they've been volunteering with children or at a nursing home. And when somebody is self-determined, what that means is when they talk about what they w ant, it's listened to and supported so that they are able to go ahead and put things into place that make their goals really achievable and attainable.

I have one thing I wanted to add on self-determination. People -- sometimes we forget that everybody has like these -- their own ideas of what life should be like. And circumstances sometimes change. It's important that we know routines for that person. I was just thinking of a young man with Down syndrome that -- he had a routine set with his dad about when was breakfast, what time you go to bed, he went to bed at 11:00, after the news was finished. Then he knew that was bedtime. He could not tell time, he couldn't read but he had some clear self-determined ideas of how his day should run. Dad got sick. Dad had to go have surgery and his sister ended up being the person that he temporarily stayed with. While that was in the hospital. And their routine in that house, they never thought about what -- they thought about their routine at 10:00, bedtime, everybody goes to bed. He was a quite determined young man and he looked at the clock -- ELLIPTA the television and he said the 11:00 news is not on so I'm not going to bed. My time to go to bed is 11:00. And she had to eventually concede and allow him to stay up until the 11:00 news was finished. Because he was so self-determined that this is what he wanted, he was going to exercise his right to make that decision. And go to bed after 11:00 news. And it was useful for her to actually know those things prior to taking her brother in with her because it made a little dissent initially, and she finally had to accept the fact that this was his routine and he was not going to change his routine because his life suddenly changed temporarily.

Sounds like he was also a really good self-advocate.

Yes he was.

I think what you bring to mind, Linda, when we are trying to provide support to somebody with ID and DD, we may have our own ideas of what that person needs or wants. But we don't really know unless we ask them what they need or want. I think looking back to the dark ages when I was initially writing goals for people, a common goal was something like John will be compliant with taking his meds. If you think about it, that really wasn't John's goal. John may have been willing to take his medication if it made him feel better, he may have wanted to take an analgesic for a headache but his goal in life was not to take the medications that somebody else gave him. I think it's important to support not just what a practitioner may identify as being useful or important, but what that person is identifying for himself. And I think by doing this, you are also supporting a healthy aging process because the person will be happier. So how do you assure person centeredness and self-determination? As I was saying, you want to support individuals to talk about what they want. And as somebody ages, it's a good idea to talk to them about what their thoughts are about aging before it becomes a crisis, before they have to move out of their parents’ home and into a different living situation or before they become very ill. You want to really know what that person has had in mind for himself. And you want to document it. Some of the things you want to talk about is where would they like to live? Do they want to try to live in their own apartment if they are capable? Physically capable as they age? Who would they like to live with? Do they have a best friend? Are they happier living with somebody who is a roommate or would they prefer to live in a situation where they have their own room? Don't be afraid to talk to them about the realities of what they are confronting. People who have intellectual and developmental disabilities have a lot of ability to understand what's going on around them. They have a lot of ability to understand their situation. It may take longer for them to get a sense of what the implications are, but that's where your role comes in. Talk to them about the barriers. Talk to them about what it means to have parents who are aging and can't provide care to them. Explore their sadness over that loss. It's not a secret that things are changes. You know it and the person knows i t. And it's really important to get it out there and look at it. Help the person to identify alternatives. They always wanted to live in an apartment, on the top floor, but they are not able to walk upstairs anymore, what would a good second choice be? What would help them to feel comfortable in their living situation? So where would you begin by doing this?

First we have to demystify the aging process through conversations with the person and caregivers. Talk about how aging is affecting individuals, changes in appearance, health, stamina, thought process, initiate discussions around individual's wishes for developing new supports or living arrangements to manage age-related needs. Like this young man that ended up temporarily staying with his sister, it was not his ideal choice, but we had to sit down with him, had to explain to him that dad needed to surgery and eventually we also had to find him an alternative placement because his sister was not able to keep him in her home. And it was not going to work between their routines. So we had to look at alternatives for him. And they were not his choices but they were alternatives we had to sit down and work out with him. Initiate discussions around the individual's wishes and living arrangements and needs. Encourage caregivers to discuss their concerns and plans honestly and openly which is something that we did with Jeff's dad. He knew he was aging, he knew he needed to have a plan for Jeff. So that he could go on with life beyond his dad. And that was a possibility that eventually came around. Some of the topics you want to discuss, where do you want to live? In a small house with family? With friends? What things are most important to you where you live? Do you want your own room? Do you want to have familiar people around you? Do you want to have access to shopping? Do you want to have TV available? Do you want to be able to get out to the movies once in a while? What do they do for trips in the residence you're living in? Who are your -- who are your closest friends? Where are they located? Can be near them? It's a big loss to lose the friends and family that you've always had around you if suddenly you're living circumstances change and you are no longer to able stay in the home you are used to living in. How important is it for you to have people visit you to keep in touch with you? Ask questions about what other kinds of things do they like? Music, crafts, video games? Concerts, movies? So what do they want to do? What do they want to be kept into their lifestyle? What do you want to do during the day? Do you want to continue to work? Do you need supportive employment? Do you need to go to a day program of some kind? Do you want to have a retirement plan and go to senior citizen center?

And those are all things to bring up. The other conversations that we want to bring up is with caregivers. As caregivers age and they may no longer be able to provide a previous level of support, what's the plan? What are you going to do? Sometimes just not thought about until too late, especially someone living in a community with an aging parent, all of a sudden that parent is no longer able to provide the care, what happens to that person? Where do they end up going? I have one person that comes to mind, her mother lived -- she was in a mild range of intellectual disability. The mother's plan was that she had an account set up for her so she could stay living in the home she had always lived in. But she never really worked with her on how to manage money, how to manage paying for electric bills and food. Those are things that were never planned on or discussed. Ultimately that person ended up not being able to stay living in that house. And it created a long period of depression for her because she wanted to have her home. She wanted to stay in what was familiar. There was no one there to take care of her anymore. Just setting aside a money account to manage things was inadequate because she did not have the life skills to manage that money. Or that household. Encourage family caregivers to identify their personal goals for retirement and healthcare. You need to discuss their plans for a family member care, who will care for that person in their absence? Like the father that just assumed his daughter would have no problem taking on her brother's care, but she did. She had young children of her own, she worked part-time, she had a household to run. And Jeff took more time than she had to give, but they never really had that conversation while dad was still alive and ultimately Jeff ended up going off to a place that ended up upsetting him until he adapted finally. Those are things that could have been avoided. You could have taken him to the home that he was possible -- and look at other choices besides living with his sister, who didn't know how to say to her dad that this is not something I want to take on as my job. Those are things you should be discussing. Maybe someday it's going to look like it became your job and you can't do it, what's the alternative? Is there a group home? Is there a caregiver somewhere in the community that's going to take on that job? He did not have the skills to live by himself or on his own.

He may not have wanted to live by himself either. Loneliness and isolation are huge issues as well.

Help caregivers develop a wish list for their family member and help them to prioritize and actualize those wishes. It has to be a practical plan. Can this really work? It may be what you wish for someone but can it really work? Is it feasible for that person to live in a home on their own? Is it feasible for Jeff to live with his sister? Those conversations should have been happening, not when dad passed away. Collaborates to identify community resources to make their plans and wishes a reality. By including the person in those discussions, you are supporting that person's autonomy and helping him to take on -- take ownership of his own life. This is something that for people with ID/DD historically has not happened. Where they traditionally have been discounted when they really are capable of learning to advocate for themselves, learning to make very good decisions for themselves if they have the tools and the supports to consider those decisions from a variety of different perspectives. So how can you do that? You want to become as knowledgeable as possible about the aging process for people with ID/DD. So that you are aware of the changes that you are seeing in people. And you want to be able to have the time to really explore and discover what it is that is affecting the person at a given time. Is the person beginning to show signs of dementia or is this a drug reaction? Is this something that can be changed or is part of the aging process that's going to go forward on its own inertia? You want to be aware of the supports for aging in your community. There are many, many supports being provided through state and federal programs right now. I'm sure you are all aware of the Medicaid waivers, the home and community-based waivers. There are contingencies built into those that support aging in place for the elderly in the community. You want to become knowledgeable about those. There may be opportunities provided in your state that you're not aware of but that would be really useful and would make a huge difference in the life of somebody you are working with. You want to develop partnerships with community health care providers. And I think that's something that in our experience, Linda and I have found to be tremendously important. People with ID/DD may not be known to healthcare providers. Healthcare providers may not have an area of expertise within their practice that's going to give them the knowledge to really address very specific issues around somebody with Down syndrome, somebody with Fragile X. There's that tragic story that Linda shared about the woman with Prader-Willi who ate herself to death in a hospital surrounded by medical professionals because they weren't aware of that whole issue around food that people with Prader-Willi experience. So partner with healthcare providers. Develop a network of providers who are dedicated to working with people with ID/DD and who want to learn more, who want to consider new and important ways to support them and to help enhance their quality of life. You want to include the individuals and caregivers in conversations around aging. Aging isn't something that we look forward to. My dad said as I said earlier in this presentation, aging isn't great, but if you consider the alternative, it's not that bad. So talk about aging. Talk about what's happening. It's fine to bring a little humor into it. Because it's something that everybody experiences. We all age, whether we have an intellectual disability or not. Aging is something that happens. By including individuals in those conversations, you take away the fear and mystery that surround it. You say, this is what we're dealing with. How can we make it work for you? How can we think about what you want and help you to achieve that as you grow older? In those conversations, you want to find out what the person's wishes are, what that person is open for as he grows older. What things are important to him right now that he wants to p reserve? It may be really important for him to take a daily walk to the pond near by and feed the ducks. How can you keep that in place as he grows older? Was in a wheelchair, to be able to get a ride because he can no longer negotiate uneven pavement? All those things are important as part of your person centered planning process. And what you're doing when you're working with a person from this perspective is you are really protecting their autonomy, protecting their personhood. You are going to do this by documenting what the person identifies as most important. And again, this is a baseline but it's not just a few words. You want to make this a very comprehensive description of who the person is, what the person wants, and you want to be able to share this information with the people who work with that person in addition to yourself. So you want the person's doctors to know about it, if he goes to a particular medical practice, you want the nurses to know about it, caseworkers, even his family members. Sometimes when people live outside the home and they only see their family members once a week or once a month, the family member may not be aware of what the person's hopes and dreams and personal goals are. Again, consent is an issue. You want to make sure that the person is comfortable with you sharing these things with other people. If you can get the person to participate in talking about what he wants with his doctor, with his day program providers, that's even better. By doing that, you are empowering the person, saying what you want is important. And we're listening to you and we're going to work with you to achieve it as much as possible. You can't -- none of us can have all of our hopes and dreams fulfilled. But if we have people who hear them and who help us on our journey through life, that in and of itself is of tremendous value. So you want to develop partnerships and alliances wherever and whenever possible. Share that information. Talk about what resources there a re. If you are talking with people from a day program, they may know things you are not aware of. They may know about resources in the community that have worked for somebody who is struggling with a similar issue. You and the person can go and get -- can go investigate that. Maybe it's a day program for senior citizens that has a lot of music and the person loves to sing. That may be more enjoyable than what is currently doing. You want to make a person continued autonomy a continued priority. You want to protect the person's personhood. Even though the person is getting older and experiencing age-related changes, these are things that are happening to the person, not changing with the person is. In doing this advocacy is essential. We've tried to talk a lot about how people with intellectual and developmental disabilities may struggle with communicating. Maybe just out of habit, out of a historical basis of never being asked, what do you think about this? What you want to do? You want to be aware of how the person communicates. You want to know if that person has a certain facial expression maybe that means they are in pain or maybe they do not understand what's being said. Sometimes it's helpful if you are talking with a doctor and that person is in the room, doctors may sometimes not talk directly to the person. They may not talk directly to a patient even if that person doesn't have an intellectual disability. They may just talk to the caregiver. Tell me what you understood from that conversation? Is there something about that that you don't understand? By advocating with that person, you are encouraging them, saying it's okay to say what you think. Let's hear what you say. And you are supporting them to communicate the way they are most capable of communicating, even if it is slow speech or hand gestures or facial expressions. You want to be aware of what the person can do. What are his capabilities? Can this person see it -- feed himself or does he need an assistive device to be able to scoop food from a did -- dish into his mouth? Is this person able to stays -- able to say I need to use the toilet or is this something he may need a device to do? Is the person able to dress himself? Do they need help with zippers or buttons? Does he need to be fed? If the person is hospitalized, this is something you want to bring to the attention of the people caring for him. The person -- does the person have a special diet need? We are going to talk in a few minutes about some of the people we worked with. Somebody who may not have teeth may still be able to eat food that is not completely puréed. Do they like their feud puréed? What do they prefer? Are they a vegetarian? Do they not want to eat any meat? These are things that a person with ID/DD may not be used to advocating for four themselves. They may sit with something, they don't want to eat in front of them and not eat. What does that person need to sit -- to feel safe and confident? Do they like a light on in the room at night? Do they like to go to sleep with the TV turned low? By knowing these things, when the person is in a new situation or the person is experiencing a health need, if you can provide these things, you are going to make the person feel better and promote that person's recovery and continued health. Also important to be aware of public initiatives and resources for aging individuals. We have the Affordable Care Act. You can go online and look at some of the accommodations provided in there. Specifically for people with intellectual and developmental disabilities or lifelong disabilities as well as supports for the aging. The Affordable Care Act includes sports for people who need application support -- habilitation support. Get them information about that. Be aware of what your state's Olmstead plan is. The Olmstead Decision supports progressive indication -- integration, people should be living in the most integrated setting and as promoted throughout this country, the closing of a large institution and also promoted supports for people to remain in the community. Find out what aging supports are available for senior citizens in your community. Just because a person has intellectual and developmental disabilities does not mean they can't benefit from those services. And May continue to be eligible for them as well. It does not preclude the ability to be part of them. Aging and disability resources centers are a collaborative effort. And they are available in different locations. They will provide you with additional resources and support for developing services for certain people you are supporting. Keep yourself informed. When Linda and I first started practicing, there was hardly in for -- hardly any information out there about people with intellectual and developmental disabilities. And just about none for people who were aging with these lifelong disabilities. Now there is just like a wealth of information that you can find. So look at state and federal websites for information on resources and funding. You can also look at University centers of excellence for developmental disabilities. And you will discover more information than you could have even imagined. Is available. So at this point we get to the fun part where we talk about people we've worked with, Linda. We're going to start with Daisy. I will give a little background and I will let Linda fill you in on the medical complications. So I do the social work part, which is the story. Daisy was a black woman. She was tall and thin and really very attractive. She was in her early 80s. And she was very bright, probably in today's climate, Daisy never would have been put in an institution but unfortunately, she was at an early age. Linda and I got to know her; she was living with a family caregiver. And Daisy was experiencing pneumonia. She had recently been treated and hospitalized for pneumonia. All of a sudden she stopped eating and she became disoriented, not like her usual self. What's going on with her? I know I spent a few hours in the emergency room with her. What happened is Daisy was having a reaction. And when we sent her back to the hospital, basically she ended up in admissions. The hospital staff prejudged, they assumed that she was always like this. Behaving inappropriately, with hospital staff, shouting out, throwing things, none of this was normal behavior for Daisy. It was all related to the medication. And it took some convincing with the physician and the staff to relook at what antibiotic they have given her. She wasn't on any site -- psychotropic meds. She had nothing but vitamin supplements. And they were looking at her as this is normal behavior. And making that assumption. Took some convincing.

I was -- Linda had spent one night, the night before in the hospital with Daisy or someone else. I was supporting Daisy in the emergency room. In talking on the phone to Linda like every half-hour saying, now what should I say? But what Linda kept saying to me was, make sure they look at that piece of paper that has her med list and her functioning ability on it. I would go over to the nurses station and that piece of paper -- they were doing tests on Daisy, that piece of paper kept going lower and lower on the chart. As shifts changed, I would have to keep finding it for them and saying, this is not to Daisy is. This is not how she typically behaves. Something else is going on. She has had an acute change of mental status. What has finally happened is the shift changes and a doctor came on new Daisy, he had taken care of when she was hospitalized for pneumonia. And he was the one who said, there's something that has changed with her. He admitted her and that's when they discovered it was the Levaquin.

What we learned from that is although the paperwork we sent to the hospital -- someone to advocate for them, every time a shift changed, someone had to come in and read discuss the case -- discussed the case again. Otherwise they were getting buried at the back of the chart and one shift to the next shift, never bothered to tell what the real person was. So it was a good learning lesson for us as well.

It was really enlightening. The next person we want to talk about is Robert. Robert was a very quiet man, very bright. He had good skills. He went into the hospital for pneumonia. Once again that magic sheet, the baseline we keep talking about that talked about everything Robert could do ended up at the back of the chart and nobody was looking at it. And --

The problem with Robert was he was a very timid man. And he did not self-advocate well. Even though he was verbal, he was in a new environment, he was not verbalizing. And what we knew from past experience with Robert is you had to make it clear that he had permission to do something and then he was able to carry through that activity. What the hospital was doing was bringing him his dinner tray and dropping it in front of him but no one bothered to tell him that you are allowed to eat this. Evidently that's what he needed to hear. Said he was not eating. They were saying, something must be really wrong with him because he is -- we cannot get in the intake in him and we are getting concerned. I said -- I went in to visit him and saw what they were doing and I said, did you tell him he was allowed to eat this? You need to tell him, this is his and its okay. You can have this. Then Robert ate.

I also think when people who have intellectual or developmental disability are hospitalized, they're in such an unfamiliar situation, everything that is familiar to them and known is different. And they due process things more slowly. They are not used to self-advocating. It becomes really overwhelming for them. And you have to really maintain an awareness of that. DJ has cerebral palsy. And he was almost a quadriplegic. He had very -- the only thing -- he was nonverbal first of all. He was a young man, ended up with scoliosis, wheelchair-bound with cerebral palsy. And his means of communicating, index finger and thumb were the only two things he could move. He could manipulate an electric wheelchair. He could use a chapter board. Checkerboard, there's an half of that in the middle, keywords on each side for basic tasks, and he can choose to spell out a word or you could choose, need the bathroom, need a drink, point to different categories. It was a simple device. Eventually we progressed him into a computer assisted voice, but when he went to the hospital for scoliosis surgery, this was a man with no intellectual impairments, he was quite bright. He actually was mistakenly institutionalized at first. He was a twin and was assumed at that time that because he had cerebral palsy, therefore he will never be able to learn, so institutionalized and forgetting. A very clever staff realized that he was reacting appropriately at their jokes. And started putting two and two together and connected DJ to educational services and in five days, this very bright man learned the entire alphabet and could spell basic needs. On a checkerboard. And then he came into an educational program, placed in a different setting and unfortunately, with scoliosis, have to go to the hospital for surgery. We had to convince a doctor that he was entitled to the surgery because they said he does not walk, what does he need scoliosis surgery?

He's not going to be able to sit up in a wheelchair without the surgery. When we got to the hospital in New York City, where nobody was familiar with him, he was nonverbal, he could not tell anybody unless he used his checkerboard, which evidently the hospital did not consider a very important piece of equipment so they put in the corner facing the wall and he was nonambulatory, nonverbal, he couldn't get access to it. They gave him a call bell that you needed an entire hand to use to press the button instead of something that was geared for someone that could lean against it. He could not even call for help. The assumption was made because he was nonverbal, that he had no capability of comprehending what was going on around him and because he was cerebral palsy, they assumed he should have a baby food diet, which was nothing he ever ate, nor wanted to eat. So when we came in to visit him, that was what we needed to explain to the hospital staff, that he can talk through a checkerboard, he can communicate his needs if you put the board next to him so that he can point to what he wants, and he is -- you have to give him a urinal when he calls for it, by giving him a buzzer he can actually use. And eventually we resolve some of those problems. Had got him back home after surgery. But it was quite an awakening for everybody there because they just made an assumption because he was nonverbal that he must also be intellectually impaired and because he had cerebral palsy he would not be able to swallow a regular diet, which he could.

I think what this all indicates is that many times because people are not educated about people with intellectual and developmental disabilities, they're not aware of the really broad scope of skills and abilities that many of them do have. And they're also not aware of how really very small supports you can change the whole quality of that person's experience in a given situation. That's why we recommend baseline, but almost equal to baseline is establishing partnerships and communication networks with caregivers who are going to be providing supports to individuals.

Aging does not change waitperson is. We've talked about this before. As a person who is aging still has hopes, dreams, connections to families and friends that they want to keep established, sure that that person is included in developing and considering new and enhanced sports as they need them and person centered planning and principles of self-determination are the foundations of the plan.

I think at this point, we're going to do a test.

Want to talk about the website?

Right. I jumped ahead. I think we also send you a PDF that lists articles and handbooks and useful websites. I wanted to highlight these in particular. The rehabilitation research and training center on aging with developmental disabilities is maintained at the University of Illinois. There is an enormous amount of research going on there right now. And there's also a lot of resources available to you just by going on the website. There are assessment tools, there are links to dementia reports and guidelines. And also information on conferences occurring where you can get even more information. The school of social welfare at the University of Albany -- a state University, has a website that's dedicated to intellectual disabilities, aging and dementia. A particular focus on working with caregivers and providing support in the community. The focus -- there is information on people with disabilities who are aging but there's an equal amount on how to provide environmental support and how to work with caregivers around developing resources for people as they age and also as caregivers age. One of the things that you might find very helpful there is there's a whole article on how to talk to caregivers about their plans for providing supports going forward for a family member who has intellectual or developmental disability. Institute on aging at the University of Wisconsin in Madison. This provides a lot of resources and articles and information on policies and practices in healthcare for people who are aging. There is some good PDFs for downloading. They also have a nice person centered focus that I think is very useful. There's also the University center for excellence at the University of Minnesota. It's the Institute on community integration. It also offers resources and information and training opportunities, not just for people who are caregivers but also for people who have intellectual disabilities. The focus is on providing support for people who want to be more involved in their lives, more autonomous and to be very active in their communities. And just by going to these links, I don't know if they are hot links and you can link to them, but if you go to these, you are going to be amazed at the resources that are available. So I think Lisa is going to be explaining how we do the test.

The posttest, Joe and Linda will go through each question individually. And as each question comes up, you will see something appear on your screen as a poll. We would you question by question. And you will have to answer true or false. So click either one on your screen. And once the question is done, we will go onto the next and get to the 10. After that we will take questions. I know some people have their hands raised and we will be getting to you. So just bear with us. But let's get through the posttest right now.

Okay. First question is aging is classified in different ways. Primary, secondary, tertiary. Is that true or false? Okay.

Number 2. Gender and genetics are on modifiable factors in aging -- are unmodifiable factors in aging. True or false?

 Number 3, a normal memory change is characterized by acknowledging memory loss when asked about it but not being aware of any loss of memory in daily life.

Are we ready to go to number 4? Down syndrome is the most common chromosomal abnormality leading to an intellectual disability. True or false?

Number 5, aging makes us less prone to medication side effects. True or false?

Number 6. Chronic immobility increases musculoskeletal problems. True or false?

 Number 7. Individuals with ID/DD maintain the same level of need for residential supports across their lifetimes.

People with ID/DD are usually good self-reporters? True or false?

Excessive use of psychotropic and ADD meds in the ID/DD population creates additional vulnerabilities as people age.

10. Life expectancy of people with ID/DD is declining.

 So we're all on the honor system here. The answer to the first question, which was aging is classified in different ways, primary, secondary, tertiary is true. Answer to the second question which was, gender and genetics are unmodifiable factors in aging, also true. The answer to the third question which was normal memory change is characterized by acknowledging memory loss when asked about it but not being aware of any loss in daily life is false. Number 4, Down syndrome is the most common chromosomal abnormality leading to ID. And that is true. Number 5, aging makes us less prone to medication side effects. False. Okay. Number 6, chronic immobility increases musculoskeletal problems. And that is true. Individuals with ID/DD maintain the same level of need for residential supports across their lifetimes. And that is false. Number 8, people with ID/DD are usually good self-reporters. And that is false. Number 9, excessive use of psychotropic and AED meds in the ID/DD population creates additional vulnerabilities as people age. And that is true. Life expectancy of people with ID/DD is declining. And that is false. So we still have some time if people have questions or if you have things you would like to raise for further discussion, this is a good time to do it.

We do have some hands raised. Going to start with deadlines. Deb, I'm going to unmute you now so you can go ahead and ask your question. Deb? Should we unmute the next one?

Jack? Or Jackie? You need to enter your PIN in order to be unmuted. Jackie typed it into our chat window. What if the person's choice includes something that cannot be done? As if I ever have to live without a pet? Not many pet friendly settings for ID/DD, even those without ID/DD, it isn't much to ask for, but if it is out of reach, how to make it okay? Second choices and good enough.

That's really a tough one. Many times in my experience, we have had situations where people were able to keep their pets and their home. I would really encourage you to explore every possible option for that person being able to keep his or her pet. Another thing that sometimes is helpful is if the pet can be adopted by someone who is very close to the person, family member or good friend, so that the person continues to be able to have contact with the pet. I know in one particular situation a person wasn't able to keep his dog. And he was devoted to the dog. Sounds like the person you are thinking of is also quite devoted to the pet. One of the staff at his house took the dog and was able to spend a lot of quality time with his dog several times a week. And he could take the dog for a walk. And of course not the same as having the pet with you on a daily basis, but it is a second-best. And I know as -- working with people with disabilities, we always want to make things work out the best possible way. And sometimes we just can't. And it's important to realize that that is part of life. Life isn't fair. Not fair that people have lifelong disabilities. It's not fair that they can't always have what they want. But it is the reality of it. I would encourage you to explore every possibility that you can.

We also had someone that I had worked with that could not keep their own pet, because living circumstances changed, but what we were able to do for them to satisfy that need to be near animals was reconnected them to the Humane Society in the town they lived in. They would go there every Saturday as a volunteer and they would get to work with the cats and dogs and it gave them some satisfaction. And it was a helpful suggestion at the time.

That sounds like it was a great idea. There's a lot of research that supports therapy animals. And if you maybe could bring that information to the landlord -- I'm not sure what kind of situation you're working with, but if you could make that information known, maybe you would be able to negotiate and advocate on that person's behalf so that something could be worked out? Is there any other questions, Lisa?

Only one more?[Indiscernible -- low volume] Deb and Jackie. No one else seems to have any questions.

Okay. We want to thank you for your time. It's been very enjoyable presenting to you. I hope you found the information useful. We're going to be presenting two additional modules. The next one we will deal specifically with dementia. And issues associated with dementia including arranging community supports and residential situations. And then our third one is going to be specifically focusing on aging in place. So I hope that you will join us again. We would search -- we have certainly enjoyed our time with you. Thank you.

If anybody has any questions or comments or concerns, after today, please as always, do not hesitate to get in contact with me.Lisa@nyrehab.org. If you -- even if you think of something that wakes you up at 2:00 in the morning should have asked this question, by all means, please ask it. Jill and Linda will definitely answer it. We'd be delighted to respond. We think about this stuff all the time. So it's a pleasure to be able to talk about it. Thank you very much.

Thank you.

The evaluation survey will pop up as a tab in your browser once I and this webinar. If you don't have a chance to do it today, no worries. You will receive an e-mail, I believe sent out at 12 midnight tonight, just a reminder. So you can complete the survey t hen. Thank you so much.

 [event concluded]