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Moderator: Amy Wiatr-Rodriguez
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Coordinator: Welcome and thank you all for standing by. At this time I would like to remind parties that your lines are in a listen-only mode until the question-and-answer session at which time you may press star 1 to ask a question. Today's call is being recorded. If you have any objectives you may disconnect at this time.

I will now turn the meeting over to Amy Wiatr-Rodriguez. Thank you, you may begin.

Amy Wiatr-Rodriguez: Wonderful, thank you so much. Thank you, everybody, for joining us on today's webinar. I am Amy Wiatr-Rodriguez with the Administration on Aging within the Administration for Community Living. And I'll be moderating today's webinar, People with Intellectual or Development Disabilities and Dementia, which is the second in a five-part series.

Before I introduce our speakers, we have a few housekeeping announcements. First, if you have not done so, please use the link included in your email confirmation to get on to WebEx so that you can not only follow along with

the slides as we go through them, but also ask your questions when you have them through the Chat feature.

If you don't have access to the link we emailed you, you can also go to www.webex.com, click on the Attend a Meeting button at the top of the page and then enter the meeting number which is 669 430 412.

If you have any problems with getting into WebEx, please call WebEx technical support at 1-866-569-3239, that's 866-569-3239. Unfortunately sometimes there are certain settings on your individual computers and I can't help you with those types of things but the folks at WebEx hopefully can.

As the operator mentioned, all participants are in listen-only mode. However, we welcome your questions throughout the course of this webinar. There's two ways that you can ask your question. The first is through the Web using the Chat function in WebEx. You can enter your questions and we'll sort through them and answer them as best as we can when we take breaks for questions after each presenter.

And secondly, after the presenters wrap up, we will offer a chance to ask questions through the audio line. When that time comes, the operator will give you instructions as to how to queue up to ask your questions. If there are any questions we can't answer during the course of this webinar, we'll follow up to be sure that we get them answered.

And if you think of any questions after the webinar, please email them to us at my email address which is amy.wiatr@acl.hhs.gov, or you can send them to any of the email addresses that are included in the PowerPoint slides that are the basis for today's webinar.

As the operator mentioned, we are recording this webinar and we will post the recording, the slides and the transcript to the AOA Web site at www.aoa.gov as soon as possible.

Our speakers today include Laurie Ryan, PhD, Program Director with Alzheimer's Clinical Trials at the National Institute on Aging, Seth Keller, M.D., Co-Chair of the National Task Group on Intellectual Disabilities and Dementia Practices and Immediate Past-President of the American Academy of Developmental Medicine and Dentistry.

Ira T. Lott, M.D., Emeritus Professor of Pediatrics and Neurology with the University of California at Irvine School of Medicine and Andrew Morris, Administration on Intellectual and Developmental Disabilities within the Administration for Community Living.

At this point, I'd like to turn it over to Laurie Ryan with the National Institute on Aging to kick off today's webinar. Laurie?

Laurie Ryan: Hi, well thank you very much, Amy, I have the privilege of welcoming everyone to this webinar, another in a series that we've been doing and I think on a very important topic. I'm going to keep it very brief because I think the information that's coming from the rest of our speakers is going to be terrific.

So let me just say a couple of words. As everyone may know, Alzheimer's disease is a progressive, degenerative disorder of the central nervous system. It's characterized typically by changes in cognitive functioning decline, memory impairment and other cognitive things like problem-solving, planning as well as a decline in activities of daily living, behavior and personality.

And it's the most common cause of dementia in people aged 65 and older. From the Alzheimer's Association 2013 Facts and Figures, we can see their estimates of about 5 million people currently in the U.S. living with Alzheimer's. It's the sixth leading cause of death overall and the 2013 cost of AD and other dementias is roughly \$203 billion, so it's an extremely costly illness.

And unfortunately with the rapidly aging population that we have, those expenses are only going to get worse and, of course, that's not even including the actual burden to the patients and their family members themselves. So, we are really looking at a significant increase in individuals with dementia. And that, of course, is assuming that we do not have available treatments and right now, we have very limited treatments only for the symptoms.

Alzheimer's disease - age is the number one risk factor but I think you are going to hear with the next speaker that there are some other risk factors, as well, for example, individuals with Down syndrome are at one of the highest risks for developing dementia. And actually traumatic brain injury, head injury, can also put you at increased risk.

So, I do want to say a couple of words, too, before I end about the National Institute on Aging. We are the lead Federal agency funding Alzheimer's research and as well as other dementias. We do research on understanding the disease, diagnosis and interventions to both prevent and treat the disease. So we're interested in people across the Alzheimer's disease spectrum intervening at all points.

And there are a number of resources that we have that are available for clinicians, researchers, patients and families and you're going to hear about

that in one of our later speakers. So with that, I'm going to turn it over to where the real meat of the presentations are happening.

Amy Wiatr-Rodriguez: Great, thank you so much, Laurie. And we'll get right into it. So next we're going to hear from Dr. Seth Keller who is going to give us an overview of the scale and scope of how dementia affects people with intellectual and developmental disabilities. Dr. Keller?

Seth Keller: Yes hi. Thank you very much. This is Seth Keller. Just wanted to give just a quick word about myself and my perspective. As mentioned in the introduction, I am the Co-Chair of the National Task Group on Intellectual Disabilities and Dementia Practices as well as the Immediate Past-President of the AADMD.

And really what all that means is I'm a - basically I'm a community-based developmental neurologist treating adults with developmental disabilities as my main practice. And we focus on advocacy for individuals with developmental disabilities and as a neurologist, I focus on aging issues.

And we've learned quite early on that folks with - who are aging with developmental disabilities and years ago who may not have lived that long that some of the concerns of decline of the aging population weren't really known about or prevalent.

And because of the fact that folks are living longer, we realized that these issues were really becoming more troublesome obviously for the individual, their families, the support structure. And I work for a number of organizations including the Arc of New Jersey, as well as the Developmental Centers in my state. Next slide.

And really the - to kind of sum up of how the next 30 minutes of my presentation is kind of a summary of how I'm going to kind of lay the land here is really just get a sense of understanding what dementia is in terms of this population.

I'm going to use the word early-squirrelly onset dementia Down syndrome. And I'm going to be talking about that on several slides, no doubt. And the issues of challenges to the diagnosis and care is going to be a huge issue which I'll talk about.

Assessment, how do we assess decline in someone that already has some type of cognitive impairment as a baseline because of their developmental disability? How do we know that there's a change from their baseline and I'm going to talk a lot about that.

And then the care guidelines, I'm going to spend a slide or two talking about care practices. And certainly tips for advocates that folks that are there both by families and support organizations and direct support, how best can they do to try to help improve care.

One thing that we've learned quite well in helping adults with developmental disabilities and children, of course, is the team approach that for those that are needing support, it really takes a whole group of efforts to do the best thing for them.

And that really is the framework for we in the National Task Group that had been formed several years ago on how we all join together realizing that the issue of aging in developmental disabilities and dementia were becoming huge issues.

So we really on the private sector with the National Task Group (is) kind of all came together in unison from all across the spectrum of families, advocacies, various community-based organizations that support developmental disabled individuals, both Federal, state and county organizations.

So I'll point to some of the issues of the National Task Group multiple times through the presentation. Next slide.

One thing that's very key and there's a lot of bullet points. I'm not looking to belabor some of these issues. I'm going to kind of go through them and I know that some of this will be archived for people to kind of look at later.

There's a lot of things we certainly do know about dementia. People with intellectual developmental disabilities have rates of dementia which are very similar to general population. However, the key is you'll hear or know about from which was already implied is that the much higher rates within Down Syndrome is head injury so, again just mentioning that.

The percent of any adult client pool may certainly be affected in any different way. The effects of dementia will be progressive and eventually lead to death. Unfortunately, which is very sad obviously all around.

Early intervention, we'll talk a little bit about early intervention and early diagnosis - why that's also very important, but there's also many things we don't know. Who really will be affected? Do we really predict in someone with developmental disability with Down Syndrome to be that predicted with that individual real as time goes on, their life definitely be affected.

We don't know and we'll talk about that. I know in the research angle that Dr. Mott will talk about. There's also discussion in some respect too. How pronounced will some of these changes be?

Will they be very manifest early and what will those changes be? And what about the nature of the change in function? How dramatic will they really be and do we know in everyone how that will turn out to be? And I'm going to talk more about that.

How long will a person live after the diagnosis of dementia is made and what other diseases or medical conditions may coexist and that's really what's caused the differential diagnosis. Not everyone with Down Syndrome who has aging issues and change is definitely saying that they actually have dementia.

There are other causes or reasons why that change may have happened and it's important to appreciate that and I'll talk about that too. And what are some of the particular dementia related behaviors that are very evident more than other ones? And I'll talk about that in some respect, next slide.

Well these two points on the slide really talk about to the far left in blue the percentage of people with Down Syndrome who developed dementia at different ages. And as an individual with developmental disability with Down Syndrome ages from the 30 decades all the way up to 40, 50s, and 60s.

As you can see by the percentages from the research that's been out there, in following people with Down Syndrome, as you can see from the 40s to the 50s, it really starts really generally going up quite dramatically.

And by the 60s, it's estimated that perhaps 50 to 70% of all individuals may at some point develop a clinical sign of dementia. And certainly one thing that's

also you'll see is it's not 100% and there's nothing saying for sure that someone with Down Syndrome that they would absolutely all develop Alzheimer's Disease or dementia.

To the next point right next to that on the right is really more of an issue within the pathology within the brain. And I know that Dr. Mott will be talking in some respect about some of these changes as well also and that is with the percentages of what are termed neurofibrillary tangles and plaques at autopsy as you might appreciate on this slide is the bars, the yellow bars.

As the age group also ages is a extremely high percentage of individuals much higher than actually that's clinically present with Down Syndrome and dementia that actually have these changes. So there's some mismatch.

There's actually a mismatch between what is seen within the autopsy of those that have died prematurely for other reasons and what is actually manifest. So there's some issues that has to be explained as that as well. Next slide.

Issues that arise with respect to Dementia Down's Syndrome. Well, as mentioned, there's much higher prevalence and I mentioned that the neuropathology with Down Syndrome. Generally dementia of Alzheimer's type is really the most common variety that's seen in the form of dementia as compared to other forms of dementia that are seen in other populations such as front temporal dementia or subcortical dementia.

And I already showed that the average age is anywhere or early onset around the 50s and perhaps a little bit later for other ones. Most Alzheimer's diagnosed within three years of onset is it really does take some time from when it's really clear that the change is very relevant and it might be then take some time.

And I'm going to talk about why there might be a delay of the diagnosis. I'm going to talk about it a little bit. I'm going to talk in the next one about personality changes as compared to memory loss is one of the early changes and some of the signs.

And as a neurologist, one of the things that I do - get a lot, is rate seizures. When an individual is living their life and all of a sudden they begin having seizures as an adult, that's actually a sign that something's happening within the brain and in some respect in somewhat Down Syndrome that might be a sign or one of the earlier signs that they actually might be developing dementia.

The duration of the disease, unfortunately can be very quick. And I'll talk about some of the aggressive forms too that that can occur. But the duration of the illness from the early signs until death can be anywhere as short as really within less than even a year that can even be out to seven years or longer.

So it's actually a shorter duration of (sentimentology) from beginning to end, unfortunately with people with Down's Syndrome and Alzheimer's. Next slide.

Many issues arrive in people with respect to Dementia Down Syndrome. Older adults with Down Syndrome are obviously at risk and I mentioned also that not every person who's an (unintelligible) with Down's Syndrome will show signs of dementia.

So it's definitely not a guarantee whatsoever. And I want to surely emphasis that because I think certainly with a lot of education training, there might be a

like a bias in someone who is evaluating, treating, or caring someone with Down Syndrome that there's a change.

They may label them and be quick to judge them, they must be developing Down Syndrome with Alzheimer's. And I think that's something that we as care provider practitioners, researchers and providers have to really appreciate about being very careful not to judge too quick.

One thing that's very important is understand what the baseline is. And for folks like myself who practice medicine and developmental medicine, it's really understanding when treating and evaluating someone with a developmental disability, it's really understanding is really what is their baseline?

What have they been functioning at, at a functional level, a cognitive level because once I see them for a consultation on a change, if I don't really have a sense of where they started, it's going to be really challenging to know how they really are at this point and comparative to.

One thing that also is useful to know is the signs of mild cognitive impairment which is MCI and dementia. And really keep track as mentioned about capabilities and that's really the issue of functionality and active daily living.

I'm going to talk on several slides about early detection screening. What are the best ways to really understand about in someone who has an intellectual disability or developmental disability - about how can you really know and what testing can be done early on and assess them?

Early referral for assessment is actually very important. But the other issue about early referral assessment for diagnosis is who are they going to go to?

Who are they going to be referred to and what kind of level of training, education does this referral base have?

Are they experienced? Do they have the knowledge? Do they have the ability to give accurate and appropriate information? Next slide.

What this slide really talks about with the line, the very colored line is really what's called the trajectory. And really the trajectory unfortunately has to do with progression. How quick will someone from the time of diagnosis charge into the issue of getting worse?

And this really just shows several - a lot of really possibilities. But one thing that you can see in many respect and the trajectory over time once the symptoms start is really it's downward. It's actually a downward projection. People's functionality, cognitive skills, lifestyle, health status, all dramatically drop off after time.

And certainly this slide is actually talking about more general populations. People with developmental disabilities who in some respect have already a baseline disability of functioning and I'll share that in the next slide or so. What we'll see how that might have more of a dramatic effect upon them. Next slide.

And this is the slide I just alluded to. And one thing that is certainly important is appreciate that these are live. These are actually people who have lives, who have families, who have personalities, who have jobs, who have everything in their lives about trying to do the best they can and their functionality.

And in some respect even trying to be as independent as they can. And what this slide is really implying is that in people who have a developmental

disability, who are basically able to support themselves or have some ability to live on themselves with perhaps some lesser degrees of additional support from either family or direct support or agencies.

If they begin to have some slight decline in their functionality cognitive, specifically what that may lead is all of a sudden for them to be independent or semi-independent to require within a relative short amount of time with some degrees of loss of functions to become more dependent.

So this might be different as compared to a non-developmental impaired individual who might be able to compensate and have more support and be able to maintain their independence longer than someone with a cognitive impairment with a developmental disability.

Smaller degrees of a drop off of functions in some respect may have very dramatic effect in every respect to where they're living their lives and their quality of life, so this is not a small issue, it's actually quite huge, next slide.

The challenge of diagnosis and this is what I live - this is basically what I live with in terms of myself as a neurologist, is the challenges (consequence), recommend someone with say Down Syndrome or another form of developmental disability who's aging and there's changes.

So the individual may not - who has developmental disability they, themselves, may not be able to explain or speak or tell me exactly what is going on and how they feel. So the reliability or the ability for me to get information in itself is different in itself.

So there's really some of these are going to be key issues would make someone with a developmental disability, Down Syndrome or not, a different from a normative population with that developmental disabilities.

Subtle changes in some of their habits or behavior, personality or functioning may not be really appreciated. They may not be noticed in any way. Commonly used dementia tools and I'm going to talk about that, are really not as relevant.

As a neurologist we used in many middle statuses as a very basic example, clock draw, verbal testing. Unfortunately people with developmental disabilities those types of typical tools that I might use in my general neurology practice, unfortunately not very relevant with the thing that we're relying on other means.

Difficulty measuring change and I mentioned this earlier is the key in many respect is to know what is the person - a normative baseline. So then what level of functionality in every respect - active daily living, their language skills, their gait skills, their ability to dress, hygiene, work - everything has to be really appreciated because that's where you're starting from.

And trying to get appreciation of where that was and where it's going and the changes and how it does change is really the key to making the diagnosis and following them surely over time. And I'm going to talk more about that.

Conditions associated with and intellect and developmental disabilities may be mistaken for symptoms of dementia and what is really called diagnostic overshadowing. I'm going to talk in some perspective more about that. And this really goes with the differential diagnosis.

Not everyone with developmental disability who ages and changes and loses functions - no means is that implied that should mean it's all dementia. It could be due to a number of factors. It could be due to a thyroid dysfunction. It could be due to medication. It could be due to depression. It could be due to many changes that also could also be mistaken.

So when someone is presenting to someone with a developmental disability, who's aging and changing, it's really prudent upon the provider who's servicing them to make the appropriate diagnosis, their understanding and knowledgeable enough to not to jump to conclusions.

The changes of hearing, the changes of vision, all these kinds of things can be very dramatic and have some great implication upon the person's functionality which may mask and may look like someone who has dementia but that actually may not be true.

Environmental influence may be very important to people with intellectual developmental disabilities. People that might live at home and then change over to group home or institutional settings. They, themselves, may have dramatic effects upon their behavior or how they act.

And one thing that's very clear in people with - who are aging with developmental disabilities specifically Down Syndrome, is they might in fact be living in their respects with their parents. And their parents may be in their 70s, 80s, and above, and what about folks as their parents and what kind of health are they experiencing.

What kind of level of cognitive function are the parents dealing with? What kind of ability for them to be able to support their loved one who's changing?

So the key thing also is not only the issue of diagnosis but long term care, and I may have talked a lot about that.

What do we know about research and I know Dr. Mott will talk about. What do we have in terms of education and training? It's lacking. It's really lacking and one thing that was very important is all the work that our government has been doing, AOA, Administration of Acute Living, AIDD, and NAPA, about trying to get to help our country in terms of getting our arms and minds wrapped around this enlarging Alzheimer's issue, not only within developmental population, but all issues.

And we in the National Task Group take this to heart, which is kind of why we're very ardent in our ability to talk about these issues and try to get the word out and find partnerships and work in private and sectors and also partner with federal agencies. Next slide.

Assessing the problem and I make it a problem. It's really appreciating that there is a problem or not. Knowing that a change in function is a concern. When is a change in a function really just part of normal aging?

Here I am, I'm 51 years old and I certainly know that I can't run as fast, I can't (unintelligible) as fast and I just don't look like I used to, but that's certainly normal for me. And what do we know about some of the normative changes aging in developmental population.

Century pathways, hearing, vision, muscular, skeletal changes all are very normal decline. And the one thing that's very relevant is in someone with a developmental disability who already has a baseline of altered functions just based on the nature of them having a developmental disability is also initially impaired.

So as they age, will not that change that they've already been experiencing their whole life become even more dramatically affected when they just normative change anyway? And that's absolutely true.

But what's the boundary between normal aging and not and that really raises a lot of questions and what we're trying to deal with. The diagnostic overshadow and I wanted to come back to this is the issue of really coming to a not blame everything on the fact that they have a developmental disability.

And that happens a lot and someone with a developmental disability Down Syndrome saying, "Oh, they're changing," their behavior is a certain kind of way. Of course that's - they act that way because they got a developmental disability.

So really what is diagnostic overshadowing is really a quick judgment of a bias or a stereotype and it changes some of the developmental disability and that's a term diagnostic overshadowing. And that type of bias can be given by families and agencies, by physicians and colleagues and everybody.

So it's really something that everyone has to be very careful about when someone's changing and not to be too quick to judge about why and blame it on their underlying disability that they have. The benefits of early diagnosis, well, early intervention.

Trying to get them the right resources, trying to get them to right practitioner, trying to make sure that the change that they're experiencing is not due to other difficulties or other challenges of physical, mental or other issues that can be corrected or rectified.

The one thing I'm going to talk about also is the issue of assessment - documenting a change in function has occurred. We in the National Task Group over time over the past few years in collaboration with a number of our partners, both overseas, internationally and the United States, have created - which I'll show you, is the early detection screen for dementia.

And that is a early - in essence it is an early warning sign that's what's called informant base, provided a written out by direct support or families that talk about a noticeable change in function and I'm going to show that in some respect too.

I'm going to talk about what are some of the important diagnostic assessment tools that have been used and helpful to people with developmental disability and Down Syndrome to helping make more accurate diagnosis. And also I'm going to have a slide on change of care perspective, next slide.

The early detection screening is called the - is what I just mentioned and really what is - and this is all available in the National Task Group Website. And it's probably not a lot of time for me. I don't want to steal the thunder from everyone else.

But really what it is it really talks a lot about a person's baseline health and it's several pages and it takes about 15 minutes that is written out by support staff and we recommend that this particular tool be performed at least probably beginning at age 40.

And so with Down Syndrome, and later in someone who might notice some changes in someone with a developmental disability who's also showing some decline. And really what it talks about it picks up health status, ADLs,

behavior, function, memory, and also some self-reported problems by the individual and really looks at it as an early warning sign.

So in essence when someone reports a change from their prior function level, this would be more of an objective piece of information which would then be written out and then taken to the next step.

And the next step after a change is noted would probably be either person within the agency, a family member or nurse or then maybe to the healthcare practitioner, nurse practitioner or physician who would then say, "Oh, look at these changes that have occurred in their functionality, now we really realize objectively speaking things are not the same, let's go to the next step."

So again this is available on our Web site and it's also available in multiple languages because we realize that of course not everyone speaks English. We had this in multiple languages, in Danish and French. We have it in Greek and we are looking for more languages because of the population of people that are going to need fill this out. And again it's on our Web site, next page - next slide.

This is really a slide which is a busy slide that talks about some of the what - I'll use the word neurocognitive scales or neuropsychiatric testing. Which really is various scales and measurements and tools that have been used over time by a number of different psychologist and neuropsychiatric clinicians who really help to define more about what might help lead towards an accurate diagnosis of dementia in the developmental or Down Syndrome population.

So are a lot. There might be somewhat informant based but a lot of them in some respect are done by neuropsychologist or specialist. I, myself, as a

community based physician, in essence do use these. I have another assessment tool that I can talk about at another situation or time, but this is really used. These tools are used more by higher level folks that I, myself don't use sometimes. Next slide.

One thing that's actually very key in someone who works in developmental medicine is really appreciate when someone has - is coming to my office who again has a developmental disability.

They've been living alive. The support and families who've been working, helping, loving them. Have been really focusing on making gains. To ensure that their level of functionality that they have in their lives is really trying to make sure that they can get as much out of life as possible.

And the saddest reality is in that someone who is developing dementia, Alzheimer's is the opposite. Is that the change of focus, instead of making gains is really looking - is the issues of dealing with eventual loss and decline. That is a very, very difficult thing for families and caregivers to understand and appreciate, or to really appreciate. There are some levels of denial. Like a lot of psycho-social issues that really go into this.

We definitely have to appreciate the caregivers themselves. Recognizing the challenges of a caregiver. If it's a family member who's already in their 80's as a mom or dad who is aging with their own physical difficulties. The agencies themselves who might have a burnout or lack of experience on the aging DD population, what it really means to them.

So the care perspective is huge and it's not all about just an accurate diagnosis or medication. It's really appreciating the backstory, the background, the

information about the individual and their lives and who supports them. Next Slide.

In the national task group God bless, we've done a lot of amazing things. This is one slide that relay's on our website, that talks about the guidelines for structure and community care and supports for people with ID affected by dementia.

And I'm going to give a call out and shout to a number of my individuals whose names are there, (Nancy Yoken) and Dr. Matt Janicki, my co-chair as well, (Phil McKinley), and (Lawrence Forest) who basically have been really the lead in helping with this wonderful document. I have a slide next that's going to show you what's inside.

This is a how to. This specific guideline has been designed specifically for families and those that support people, and agencies that support people in the community and such. Who basically are really there to help them along the route as they develop early signs? Can you go to the next Slide? I'm going to show you an example what's inside.

Some of the key features of the guidelines, is it really gives you a background about what the national task group is, the ongoing principle. It gives some baseline information about dementia. But one thing it also talks about, which is very key, is a staging approach.

It talks about the early stages. It talks about the middle stages, the late stages. It talks about the expectations of what families and caregivers and such are going to need to appreciate. How they are going to learn. Because a lot of this is there's what's called anticipatory guidance.

Once a diagnosis is made, because it's a progressive course of disease, sadly enough, we know basically what's going to happen next, which is a downhill course of their functionality. We know what will happen to their language. We know what may happen to their swallow. We may know what will happen to them in their environment. We may know all of these things.

So really what it is, is predicting, expecting and planning. Rather than the typical putting out fires at every spot, which often happens in many cases. It talks about early detection. And it certainly talks a lot about program and support options, the critical concerns of various circumstances.

And even certainly the non-pharmacologic approaches, which may be useful and helpful in supporting folks who have certain behavioral issues or other challenges in their difficulty with dementia.

We can't not talk about abuse and financial issues and neglect. Liability issues and nutrition are also very important that are built into this guideline principle. The one thing I already mentioned on my first slide in the beginning, is the issue of collaboration. I could go on and on and just talk all day about the importance and need of collaboration amongst all of us.

Certainly, I had looked at the list of people coming on the phone today and it's just wonderful that everyone who really was interested and knows this important issue came on to hear this and it's important to have the details.
Next Slide.

What could I say about healthcare advocacy, but a lot? I do have a lot of training. Train the trainers. I do a lot of work with people who really are my right-hand people to really help them. I can sit in my office, but folks that are supporting folks with developmental disabilities go back day-to-day, live their

lives, supporting them. I do a lot of training. They themselves without some kind of education training may not always know.

So this really talks about a number of bullet points that talk a lot about that. This is really built in to a lot of our guidelines. But the other guidelines that also the national task group is going to be putting out, is really guidelines that is built all around healthcare advocacy and support. These are going to be coming out to be published in the very near future.

One that is being published right now is one that was just accepted for publication within the Mayo Clinic proceedings, which is something that is something that is talking specifically about healthcare practitioner guidelines, diagnosis, treatment and assessment and long-term planning. Next Slide.

Additional tips. And one thing that I say to folks who are the advocates, is be empowered. I mean, forming alliances and partnerships and really realizing that they're the advocate. They are the people with the strong voice who have to really appreciate and speak their mind. And really come in to the appointment and when they are seen and really support them. Really tell them exactly what the issues are and concerns.

We definitely have to appreciate, as I've mentioned several times already, aging issues and how that's really appreciated, and what the other folks are going through on the parental side. How challenging it must be for them. And what is it I can say? What is it that I can provide? What kind of advice might we be able to provide to them in the challenges that they are facing in helping and support and watch your loved one go through this terrible situation.

Understand and create a support structure. This is also a guided in a lot of our guidelines that we've talked about. The one thing also is the expectations and

goals. When I'm assessing, treating and evaluating someone over time, to be honest and truthful about what is it that they're going to get over time with treatments and various valuations for them. Next Slide.

Just a few more slides and I believe I'm kind of going to be done. What kind of services? Well that's huge. Services are key. Support for continued living with family, if that's available or appropriate. Certainly that's - if someone's been living with their family , or in a group home or other kind of setting, community - we can use the concept of what's called an Aging in Place model if that's really appropriate.

Trying to maintain the person and enable them with certain levels of support as they progress through their stages of dementia. To try to see if they can actually stay there and live there. As compared to moving out into a long term care facility that might be cold and barren and not be able to provide them the comfort or sensitivity or such that they need, that they often get. But that's not always appropriate.

Engaging in activities. Well certainly, folks like ourselves on the phone, we live in a world, we live in a community, we want to be engaged. It's the same thing with someone with developmental disability who ages and changes, is trying to ensure they are connected. Having a connectedness is very important in some respect.

We talk a lot about, when we talk about services, is health reviews and surveillance about, from the clinicians. Understanding and education in ID aging and what the various neuro-pathologies are. I did talk a lot about screening and assessing for aging related conditions, as well as issues which are very important, about regular nutrition.

Regular physical exercise because unfortunately, if someone is aging with decline, their ability to get good nutrition or access for regular physical fitness, exercise and training may not be the same.

So if someone who's heart is getting weaker, or their weight is increasing and they're not getting regular nutrition, that may perhaps affect the course of their disease or not. That's not sure, but that's really one thing that we talk about.

Support for dementia capable care. We talk a lot about in the national task group, in our training guidelines about the importance of dementia capable care. I kind of emphasis actually what it is, that these are specialty services that not only are for developmental disabilities, but other ones on how they can watch and care for them as the disease progresses. That does involve a fair amount of staff education training for everyone. Next Slide.

Well, to finish up in the next few slides, is really the key is the team approach. In the middle of this circular is Tom and Mary. I use Tom and Mary as a prototypical folk with a developmental disability, Down Syndrome or not and it's really about folks around them. The color is a little dark, you might not be able to see it.

But these are really the folks around them who are part of the support structure. How everyone around them or with them interacts and how they help and participate, those are yet to be determined. At different degrees, there's different bonds, and there's different relationships.

We in the national task group, what we've done, is we've preformed various work groups. We've been around to different cities around the country as well as in Canada. Where we do training. We talk a lot about the support model

and the training model. About bringing in different advocacy groups, both with the aging side and DD side.

And we realize how important it is to try to bring everyone together. It's wonderful that within the administration community living, now is bringing together the aging and the AIDD together and realizing that we all can work together. It is extremely helpful because it leads to better outcomes.

One thing that is very important, is appreciate all that we can do. I, as a physician, can only do what I can do. But I expect a lot from my direct support. I expect a lot from the aging services and the ID agencies and my mental health colleagues. I expect a lot from my primary physician care providers.

It's really each other appreciating what each other can provide and realizing that we're all respecting each other and needing each other to lean on. To help support and care for an individual. Not everyone knows the team. It's always important I think, in many respects in someone who has IDD and dementia to really go through these over time and remind ourselves about the importance of a team. Next Slide.

Really finally, and this is kind of and what I just talked about is really people are vulnerable. People with developmental disabilities are a vulnerable population. They need special help when the dementia symptoms arise.

Comorbidity and the fact that they already had a developmental disability and I didn't really get a lot into discussion of behavioral issues which is really a huge issue unto itself and many people with development disabilities have a comorbidity of behavior and how the behavior may be part of the problem or

become more dramatic as they age and change and how that might need importance for a perspective.

Specialized housing, careful settings to try to avoid or preclude from being institutionalized as they age. Could - folks could be residing with older parents or siblings who they themselves need additional help and being able to assess due to life-long cognitive impairments or abilities as self-report is a challenge and I mentioned about the National Task Group's ability to perform the EDSC and other assessment tools.

The benefits of partnerships and I talked a lot about just recently on the last slide about the importance of the aging agencies and developmental disability agencies working together with providers. Next slide.

Resources. Well we all can't do it ourselves and this is just a really busy slide that talks about some of the online resources that are out there.

We in the National Task Group - I keep alluding to the National Task Group because I'm kind of proud of the work we do. We actually have a wonderful collaboration with quite a number of various organizations.

I am a member of the American Academy of Developmental Medicine and Dentistry but we also have and supported organizations for the National Task Group, the Arc and DSS. All service associations, AUCD and EDD, (DDNA) and a number of other organizations which I didn't mention who are really supportive.

We've become knowledgeable that, you know, God bless our government and federal agencies, but we are basically running with the issue. We are basically

taking full front and trying to work on guidelines and assessments and so we're really trying to do what we can to support people.

Others - there are people out in the community and we mentioned about going to the development agencies or your local ID agency, aging agencies, perhaps the Arc, the (USED)s or state developmental disability planning councils, Alzheimer's Association, and other dementia assessment clinics or centers and caregiver support programs.

That is basically - I didn't - I usually don't want to go through so quick but that's - I wanted to leave time for the other folks. Can you have the next slide?

And I really just want to thank everyone for coming on because certainly without the generous support and realizing the IDD and dementia is a huge issue and important to talk about, this type of presentation and moving forward wouldn't happen. And just one thing that we hope and appreciate is that now that the National Alzheimer Project Act and the task force reports have been put out there, is action steps.

What - where will we go from here and that's a whole discussion into itself? We certainly are trying to be very proactive with a lot of these issues but there're a lot of other issues that partners which we have lot of room to move to improve the situation.

So again I want to thank you very much and also give a call out to my co-chair and partner, Matthew Janicki at the University of Chicago who has been hugely key in helping to work with me in this respect as was my other National Task Group colleagues. Thank you very much.

Amy Wiatr-Rodriguez: Okay, thank you so much Dr. Keller. That was just a great amount of information for everyone. I know we had several questions coming in from the chat feature. I know in the interest of time we want to make sure we get to all our presenters so I'm going to take just one now and we'll get to others as we go on.

So there's one question from (Tiffany). She was asking about the Ruocco Tool and I'll spell that, it's R-u-o-c-c-o, for assessment in this population. She says it was created by a geriatric nurse and advocate and she was wondering if you had any feedback.

Seth Keller: Lou Ellen Ruocco is actually on the National Task Group and I believe that she is the one who is actually involved with it. To be honest with you I can't say I know a lot about it but I know that what we've done is that when we actually created and helped put together the current tool that we recommend for very early signs, the EDSC.

We actually had taken a lot of people, and I know Lou Ellen had been involved in some capacity in helping to frame some of these discussions and try to come with a different framework.

So even in my ability to promote some of these tools, there are other tools out there including this one in particular but in terms of all the details some of them were in a formal base and other ones - some are trying to be more towards diagnostic than other tools. So they all have different levels and what kind of information is important but I don't have actually a lot of or more any specifics than that.

Amy Wiatr-Rodriguez: All right, great. Well we in the interest of time like I said, we're going try to move on hear about some of the important research that's going

on to improve the understanding and response to many of the points that were just mentioned so now I'm pleased to have Dr. Ira Lott from the University of California at Irvine talk about some of the research that's going on, so Dr. Lott.

Ira Lott: Good morning, it's a great pleasure to be here this morning and I appreciate Dr. Keller's comprehensive overview. So I'm going to talk a little about research opportunities and challenges.

So how much research is there in Down syndrome? One of the yardsticks I like to use is how many publications, peer-reviewed research publications, are there in the National Library of Medicine? And as we sit here today there are about 28,000 publications on Down syndrome.

By comparison there are about 23,500 on autism and 6,000 on fragile X. So you can see that Down syndrome has been a very emphasized area of research. Next slide. And so the four topics are listed here that I'd like to cover. Now the mouse models, what does a mouse have in common with people with Down syndrome?

A mouse brain weighs about 0.02 ounces and a human brain weighs three pounds so there's an enormous difference in terms of the weight but 90% of the genes that are present in the human condition are present in the mouse so 90% of the genes that are needed to structure and create function in the mouse are represented in the human.

So on this basis Down syndrome is due to an extra chromosome 21 and there is a chromosome 16 in the mouse that contains most of the genes on human chromosome 21, so the mouse models have afforded an opportunity to

manipulate an experimental situation to see if we could understand and possibly come up with treatments for Down syndrome. Next slide.

Coordinator: Okay, and Dr. Lott, we are hearing from some people that the audio is a little bit difficult to hear so as much as you can speak up. I know we've had some problems with your line earlier too but as much as you can speak up that would be helpful.

Ira Lott: Okay, I'm going to bring this closer. Is this better?

Coordinator: A little bit. Yes, as much as you can do, would be helpful.

Ira Lott: Okay. Here is a picture of the brain of Down syndrome and you can see the different parts of the brain and how cell alignment in the brain is different in Down syndrome than it is in the typically developing brain. And this has been the target of a great deal of research interaction over the last 20 years. Next slide.

So here is what we have been able to learn from mouse models for Down syndrome. Compared to the human brain there's over expression of the SIM genes. There's an opportunity to study individual genes. You can experimentally manipulate the model and then there is a platform for translational research. Next slide.

And here is a depiction from a recent review article by Haydar and Roger Reeves. On the left side you see the mouse cartoon and on the right you see the human brain and below that you see all of the functions that are conserved between the mouse and the human and some of those functions have already led to some early clinical trials. Next slide.

Now in terms of cognitive functioning in Down syndrome we do know that people with Down syndrome have a characteristic cognitive profile. They tend to have a disruption in keeping incoming information on line and so the information that involves mental computation and storage is not working quite properly. There seems to be an uneven working memory.

There is this interesting difference between visual short-term memory which appears worse in people with Down syndrome than visual spatial memory. Now what's the result of all this? This may impair down field cognitive performance in language, vocabulary and problem solving. Next slide.

One of the conundrums of Down syndrome is that amyloid which is one of the major constituents of the plaques and tangles that Dr. Keller referred to. This amyloid is laid down very early in Down syndrome so you can see in the brain from an infant four months of age who died of another cause that there is already this accumulation of amyloid.

And we think this is related to three copies of a gene on chromosome 21 which is called amyloid precursor protein and so it just makes more amyloid than the brain can handle and this amyloid starts to accumulate. You can see the hole there where it says intact neurons. The neurons are still intact but already from infancy the amyloids accumulate. Next slide.

Now here is a so-called benign plaque from a young adult with Down syndrome so you see there is more amyloid around but the holes are still there and the holes represent intact neurons. But are these neurons really intact?

If you look carefully in the holes you'll see little red dots and these red dots represent certain chemicals which contribute to what is called apoptosis or cell suicide. So even in the healthy appearing neuron there are chemicals related to

an enzyme called caspase which really make the neurons vulnerable to early cell death.

Now as a pediatric neurologist this is very interesting to me because it suggests that we found a therapy that was safe, efficacious and tolerable in adults with Down syndrome. Here is an example where we can step back to earlier age epochs and possibly improve the functioning of these cells at an early age and they have a beneficial effect on cognition.

And several of the clinical trials which are now being developed or actually in use from some pharmaceutical houses are targeting young adults with Down syndrome prior to the onset of the age of dementia and this is a window on Alzheimer's disease that is not present in the general community, the typical Alzheimer's disease. This is something quite specific for Down syndrome and I think you can see its potential importance. Next slide.

So what is the effect of this amyloid on what we call executive functioning? What is executive functioning? Executive functions are first the cognitive operations that regulate processes such as attention, planning and working memory. It's kind of the executive part of the office if you will.

Adolescents with Down syndrome show impairments to executive functioning. They take the form of problems with past assessment, shed shifting working memory and this becomes more marked with age and dementia. So we think we have narrowed down the part of cognitive functioning that is first affected in the dementia process and then one that becomes more affected as dementia proceeds. Next slide.

One of the characteristic early changes of dementia in Down syndrome is an emotional change. So their health and caretakers will report that this person

with Down syndrome say at 45 years of age has lost interest in their environment. They've taken to bed.

They no longer want to go to the workshop. They no longer want to go to the socials. They appear "depressed" when in fact they do respond transiently to an antidepressant but this appears to be one of the earliest signs of dementia in Down syndrome and there are a number of ways to measure this cognitively.

I will just mention one other symptom on the list and that is a problem with gait. We have found almost universally in the adults we've seen with Down syndrome over age 40. If they're developing dementia they get a problem with gait. They're not paralyzed. They're not weak. They're not spastic. They just don't know what to do with their feet in space so they come to a step and they hesitate.

They come to a crack in the sidewalk and they hesitate. They try to get out of the van and it takes them much longer. Now not a lot is known about this but neurologists would call this probably a frontal gait dyspraxia and it's the same part of the brain that we think contributes to the changes in executive functioning. So the next slide.

Well there have been a number of standardized procedures, research procedures, that have been used to look at cognitive functioning in Down syndrome and Dr. Keller mentioned a few and here are some recent ones as well. Next slide.

We just completed a couple of years ago a clinical trial I'll tell you about in a moment and we had a whole bunch of neuropsychological outcome measures and we found that they correlated very well with each other across the spectrum of dementia and out of this whole group has come a new test in our

group which we have worked on which is a short sensitive measure of cognitive functioning.

It's called the Rapid Assessment for Developmental Disabilities and it was developed by David Walsh and our group. And it has been shown to be valid and reliable and correlates better with these other measures than any of the other standard tests so we're hoping going forward that we have a short, efficient, reliable way to look at cognitive function.

Now this won't tell you if someone's demented but they will give you a point in time to what they're - it would be just an overall view of what their cognitive function is like. Next slide.

I'm going to talk for just a moment about a clinical trial and, you know, here is an issue where we have animal data but we have different data in regard to a human trial but if you look at the mice and compare to the human, although there are similarities in a large number of genes there are differences.

There're differences in gene expression from the mouse to the man. There're differences in molecular signature and there's a difference in the parts of the brain that are affected, obviously the cortex. It's much more developed in man than it is in the mouse. So there are differences.

Anyway this is how this trial developed. Their oxidative stress is one of the major biochemical changes in Down syndrome and oxidative stress is due to what are called reactive oxygen species.

These are chemicals containing oxygen and reactive oxygen species can be very deleterious to DNA, to cell membranes, to RNA, to the function of the

neurons, to cellular signaling. And it is a pathological process which is well described in Alzheimer's disease and also in Down syndrome.

Now here is a slide showing the accumulation of oxidized amyloid. We call this oxidized abeta and A, B, C and D represent the accumulation of oxidized abeta in a beagle dog which is a model for Alzheimer's in the general population and you can see that the brain from an individual with Down syndrome at age 31, 40 and 54 years shows this oxidized abeta.

So this led Alzheimer researchers in our group and in other groups around the country to give a trial in high potency antioxidants to these dogs and over a course of two years there was a sustained and highly noted improvement in cognitive functioning in the dogs as well as a result of a diet that contained the high potency antioxidants. These happened to be vitamin E, vitamin C and alkaline folic acid. So we thought, oh boy, next slide.

We know in Down syndrome that the mitochondrial which are the energy parts of the cell are affected by oxidative stress and oxidative stress is associated with mutations in the control region of the mitochondrial. Next slide.

And this is just some technical data from our group but if you look at the control groups, the Down syndrome groups with Alzheimer's, Alzheimer's disease and various body tissues, there is an increase in - with age, in mutations in the control region of the mitochondrial. So here we have two lines of evidence, the mitochondrial abnormalities reflecting oxidative stress and the beagle dog showing oxidative stress and a sustained response to an antioxidant diet.

Next slide. So this is a polygraph from the National Institute of Aging in which we looked at a population of individuals with Down syndrome and dementia and treated them with a high potency antioxidant supplement similar to what was done in the dogs and we followed them over a two-year period.

I'm not going to go into details about this trial except that it was a successful trial but there was no therapeutic effect once the dementia had set in and this is I think a very clear signal about clinical trials and Down syndrome.

If we're going to be successful you have to start before the dementia sets in and Dr. Keller outlined some of the reasons for this. And people with Down syndrome do not have a lot of brain reserve so once they start having the neuronal deterioration there's very little we're going to be able to do to reverse that.

So there is an increasing interest in looking at the pre-demented population, young adults or possibly children as targets for therapeutic trials. And I think this is the way we're going to need to go.

Now as far as oxidative stress is concerned, probably just giving oral vitamin E, vitamin C and alkaline folic acid isn't going to do it. There's just not enough to get them to the - that gets into the brain so there're going to have to be new ways to package antioxidants to target the mitochondrial and there's quite a bit of research on these new vehicles.

One of them is called a (lysosome) and there're also drugs that now target directly the mitochondrial so I would predict in the next several years oxidative stress is going to be re-visited by some of these new approaches.
Next slide.

We have to be sure if you give them medication that it's taken and these are actual vitamin E levels during our trial and you see that people actually took the drug. Now this involves a lot of work on our part. We did pill counts, we called the home.

We've carried out another study in a large population of people with congenital intellectual disability and we have charted how they take their drugs. We were able to do this in a closed pharmacy system and we found overwhelmingly if people live in a group home they generally receive medications 90% of the time.

If they live semi-independently or they live in their family home, they miss their medications a third of the time, a third of the time. Doesn't matter which medicine, hard medicine, diabetes medicine, anticonvulsants, psychoactive medications.

So I think all of us who are concerned with the welfare of people with intellectual disability living in a community need to realize that medication compliance is a real issue in those two specific settings and it really reflects what goes on in the general population.

There are many studies that show a third of the people don't take the drugs that they are prescribed and that one of the officers that I met, he said many years ago drugs generally can't work if people don't take them. So we have this issue with compliance and I would suggest that those living arrangements are key to future research. Next slide.

So my final topic is telemedicine. Telemedicine has been a particular interest of mine for the last ten years. Telemedicine is the use of healthcare technology to provide medical care when distance separates the doctor and the patient.

And I've done now about 1500 consults in telemedicine and I'm convinced of its utility in health disparity populations and people with Down syndrome are one of those health disparity populations. Not everyone with Down syndrome lives within 50 miles of an academic medical center and so they can't come in for clinical trials.

In California there are vast areas of the state that are under populated and telemedicine is a vehicle for reaching these people. The previous Governor of California was very active in establishing telemedicine sites up and down California so there are now 1300 sites in rural clinics, some urban clinics, that are considered health disparity, that are reachable by telemedicine.

And so it's called the California Center for Connected Health and so the technology is there and now the operation needs to be made efficient and probably you're going to be hearing a lot more about this. Next slide.

So this is our screening for dementia and Down syndrome by telemedicine. This slide is a couple of years old but this represents a part of California and you can see that we identified subjects, screened them, there are positive screens, and at least got a diagnosis of dementia. What we ultimately hope to do is to have people participate in clinical trials by vehicles like telemedicine.

I would finally add that telemedicine is simply a communication vehicle and one of the big exciting areas I think for healthcare in general would be the use of these remote technologies in the home to, for example, measure medication compliance, to help families carry out behavioral programs, to monitor the status of dementia, and many of the other functions that Dr. Keller has pointed to that become a problem in people with Down syndrome.

So I think we're going to be hearing a lot about, you know, there are a lot of gadgets out there to do this and what is required is to have uniform, easy to use, inexpensive technologies like wireless, Wi-Fi, Bluetooth that people can turn on and off and use comfortably within homes. So I would suggest that telemedicine is going to be a major area for clinical trials and research and for care in health disparity populations. Next slide.

So I'd like to acknowledge our working group. We have been part of the Alzheimer's Disease Research Center at UC Irvine now for about 25 years. This is a center funded by the National Institute on Aging and we are still one of the only ADRCs in the country that has had a sustained and robust program with Down syndrome and we're very much trying to interest our colleagues in Alzheimer's research in this area.

NICHD, and they funded a current grant that we have trying to predict who is at the most risk for developing dementia and Down syndrome, NICHD and NIA have been very helpful working with Alzheimer's Association in bringing together scientists from the Alzheimer's community and the Down syndrome community, basic and clinical, so that we can have a more integrated approach to people who have with Down syndrome with a particular window on this disease. So I thank you very much for your attention.

Amy Wiatr-Rodriguez: Great. Thank you so much Dr. Lott. We'll take just one question that came in from the web chat. It was a question from (Cathy) and I think you kind of touched on this already but it was a question regarding dementia drugs like Aricept being effective with people with Down syndrome and what you...

Ira Lott:

Yes, yes. Just to give you an idea. The first - we published the first open trial of treating dementia and Down syndrome in 2002 so you can see that clinical

trials of any type for dementia and Down syndrome are very recent. Aricept works. Memantine works. They work about as well as they do in the general population which is to say they work for a period of time. They're not a cure. They're not a major treatment.

I like the analogy of having a tired horse, if you whipped the horse it'll run quicker for a while and then it poops out. So these drugs do have a role and when we see people in our clinic we do use them but just like in the general population, we do need other much more direct approaches for this disease.

Amy Wiatr-Rodriguez: Great. Thank you so much. Well as all - everybody who's listening in on today's webinar can hear, there's so much going on in both practice considerations, research considerations and we've also heard as well the critical aspect of supporting people and those, the different support resources out there for people with dementia and intellectual and developmental disabilities.

So next up to review some of the federally supported resources is Andrew Morris with the Administration on Intellectual and Developmental Disabilities within the Administration for Community Living. So Andrew?

Andrew Morris: Good afternoon. I'm Andrew Morris from AIDD and the Administration on Community Living as Amy had mentioned. And I just wanted to spend some time today to give from federal resources that can be of assistance to people. Next slide.

So here the Administration on Intellectual and Developmental Disabilities we have four different program areas that we work with people with disabilities. We have the University Centers for Excellence on Developmental Disabilities, those are in every state. Some states do have two centers.

And then a number that are known as USAIDS. The USAIDS do have a number of dementia related grants and they are conducting research on early onset Alzheimer's and other dementia for people with disabilities.

Also, we have the Protection Advocacy Systems in each state and territory. They provide legal and advocacy services for people with disabilities, especially around helping people live in the community successfully and to be moved out of institutions.

And also they do legal services for people who are in institutions and when there's suspected abuse or other problems happening. Also we have Developmental Disability Councils in each state and territory.

They do a lot of policy and advocacy for people with disabilities. The Councils are made up of people with disabilities, family members, professionals, etc. And then also we have a grant program which is our Project for National Significance.

We do different - we have some projects such as family support and what-not through that grant program. Next slide.

And then now I just wanted to go over real quickly some resources that we have here. We have the Alzheimer's Disease Support of Services Program which is part of ACL and it's really designed for people in the HCBS system and to help people with dementia. Next slide.

I just wanted to talk real quickly about the National Alzheimer's call center, also known as the National Alzheimer's Contact Center, which is available in the states and territories 24 hours a day, 7 days a week, all year long.

And on the next slide is a Web site for the Contact Center. Just some notes on that, since 2003 over 2 million people have been served on that - through that call center. The National Alzheimer's Association is the grantee for this program and you can find it at alz.org. Next slide.

We do have the National Family Caregiver Support Program. The program has - supports five different services. Information to caregivers about available services, assistance to caregivers in gaining access to services, individual counseling, organizational support groups, and career training, respite care, and supplemental services.

And that's through the Administration for Community Living. Next slide. Also, ACL does have the Lifespan Respite Program, and this is for everyone in the Lifespan.

Just one comment I forgot on the previous slide is that in 2006 for the Family's Caregiver Support Program, when the Older Americans Act was reauthorized, it was opened up to people of all ages and not just the elderly. Next slide.

And then again the Lifespan Respite Care Program that we are grants done through - as grants through ACL. Next slide.

Also I wanted to bring up here the alzhiemers.gov Web site and the highlights of Down's syndrome on that. Next slide.

The Alzheimer's Web site through the ACL Web site does have links to prior webinars and also upcoming webinars that we will be presenting on dementia and Alzheimer's. And then also - next slide - we wanted to mention the

National Institute on Aging and NIH Alzheimer's Disease Education Referral Center.

This is another service that people can call and it's through phone and web. Next slide. This is another example of just the NIA funded Alzheimer's Disease Centers that can be found on the Internet. Next slide.

Also there's been - we've had questions in the past about clinical trial availability for people that have Down's syndrome and other intellectual disabilities and this is a NIH website that does have - does help people to locate drug trials if you're interested. Next slide.

And then also, the Alzheimer's Association does have on their Web site a link to trials that are happening and the phone number that you can call if you're interested. Next slide.

And then we just wanted to say that registration for our next webinars 3 and 4 is open and the slides and audio from our webinar series is available on the AOA Web site. And I think that concludes my presentation.

Amy Wiatr-Rodriguez: Great, thank you so much Andrew and thank you for sharing all of these resources. I just wanted to make a clarification on the one about the National Family Caregiver Support Program, it is available for people who are caring for a person with dementia of any age.

And so that is something that definitely is important for this audience in particular to be aware of. So thank you again for sharing all of those different resources and opportunities for collaboration and referral around all the resources out there.

So at this time, I just want to again thank all of our speakers and thank everybody who's attending. We're going to now move on to the Q&A portion of the webinar.

So I'm going to ask the operator to come on and give instructions for how people who have questions that they'd like to ask on the phone, how they can do that.

Coordinator: Thank you. At this time if you'd like to ask a question, please press star 1 on your touch tone phone. Please record your name clearly when prompted and I will announce you when I'm ready for your question.

Again, press star 1 and record your name. One moment please as we wait for the first question.

Amy Wiatr-Rodriguez: Okay, and while we're waiting for that I'll take some questions that came in over chat and email. So one of the questions that we got through chat was dementia occurrence rates and those with schizophrenia. I'm not sure if any of our presenters on the line have information regarding that?

Seth Keller: This is Dr. Keller, do you hear me?

Amy Wiatr-Rodriguez: Yes. Go ahead.

Seth Keller: I mean, the one correlate to that, that I can actually make note of, and it may not answer the question, is really dual diagnosis is that in - and I kind of mentioned this in one of my discussions - is that in quite a number of people with developmental disabilities, Down's syndrome and not do have a lot of co-occurring behavioral issues.

And some of the behavioral issues may be manifest as psychoses and I don't know specifically of any information about the likelihood or changes or such that occur with dementia in folks with a dual diagnosis and Down's syndrome and how that changes.

It is a very prevalent problem, is very significant in some respects about behavioral issues. But I don't know specifically about the diagnosis.

And I just think it's a little challenging also with the diagnoses themselves, working the field for many years in developmental disabilities and the labels and things that are often given for people with developmental disabilities, behavioral issues, whether it's bi-polar disorder, mood dysfunction, psychoses.

I think some of the challenges are labels and how any amount of data can be looked at to try to differentiate between some of the information and make some sense of it. But, it's somewhat of a gray area I think and I'm not sure if - Ira, if you have any comments about behavioral issues and schizophrenia.

Ira Mott: Yes there's just one. Self-talk is pretty common in adults with Down's syndrome and every year we see referrals as the patient's schizophrenic and usually not. I mean, self-talk seems to be a common Psychological manifestation of adults with Down's syndrome.

Sometimes it's attendant to the loss of a parent or a change in their environment. But I would agree with Seth Keller that, you know, schizophrenia does not emerge as a major co-morbidity and sometimes can be over diagnosed in Down's syndrome.

Amy Wiatr-Rodriguez: Okay, great. Let me check in with the operator and see if we have any questions coming in on the phone.

Coordinator: I do have one question from Mary Hogan. Your line is open.

Mary Hogan: Hello there. Thank you for taking my question. Mr. Morris gave us a list of possible resources that one could access. Can somebody please elaborate on the National Family Caregiver Support Program?

And how people in communities, families with a family member who has a diagnosis of Down's syndrome and Alzheimer's diseases, how they can access these kinds of services because I can see from experience that across the nation (unintelligible) to have a lack of information about how-to in regards to funded services from the Federal Government.

Amy Wiatr-Rodriguez: This is Amy Wiatr-Rodriguez. I can just mention very quickly, and then certainly Andrew can add anything he'd like to, that the National Family Caregiver Support Program is funded through the Older Americans Act and those funds go through state units on aging and then out to local area agencies on aging.

And so you can find your local area agency on aging by going to the Elder Care Locator. And that's something that maybe we can try to add whenever we post the materials from today's session afterwards.

But, I believe if you go to www.eldercare.gov that is the Web site there. You certainly also could contact the National Alzheimer's Contact Center. That number and information was listed there and I'll try to pull up real quickly the Elder Care Locator phone number because I don't know that off the top of my head.

But the National Alzheimer's Contact Center could certainly provide referrals to local community programs and your local area agency on aging. Because those are grant dollars they are limited and so the exact types of, and quantity and locations of services will vary from area agency to area agency.

So, you know, the best bet is, kind of, contacting those local area agencies on aging and finding out the specifics. And the phone number for the Elder Care Locator is 1-800-677-1116. And, I don't know, Andrew? Is there anything else that you'd like to add?

Andrew Morris: Just that, although it's the Elder Care Locator, I think for Alzheimer's and dementia it's for people of all ages under the Family Support Program.

Amy Wiatr-Rodriguez: Great, thank you. So hopefully that answers your question.

Ira Mott: This is Ira Mott. I'd just like to make a comment. I believe this is the Mary Hogan who has been such an advocate for people with Down's syndrome. I do think, Mary, that there is a problem in, as Amy alluded, to resources within communities for Down's syndrome.

And this may be an area where the local Down's syndrome organizations can work with the elder care organizations, with the Alzheimer's organizations, to help to provide some resources that can be specifically targeted for Down's syndrome.

Mary Hogan: Well I do know Dr. Mott - can you hear me?

Seth Keller: Yes Mary, you're on. We can hear you.

Mary Hogan: I just know that across the United States there is a major problem in terms of supporting families once the diagnosis has been made.

And I also know that there are a growing number of aging parents who are care givers or aging siblings who are care givers and there is a major obstacle that people are encountering in terms of accessing support services.

So I think that there isn't the kind of open dialogue that there needs to be around how agencies network with one-another to support families who face this challenge on a day-to-day basis.

Seth Keller: This is Seth Keller. Mary, thank you very much for bringing that up. I think one thing that's going to be very important now that we have time to look at the national Alzheimer's plan and the taskforce report that came out is really the actions steps.

Looking at some of the inadequacies or need for change or improvement and I think we're really touching on one that's going to be very important of resources and information. And I think this is something that we're going to be talking a lot about more to come in the near future.

Amy Wiatr-Rodriguez: Great. This is Amy and I think that's a great - I mean there is obviously so much work to be done and hopefully some of the information that we talked about in this webinar can be helpful to people in their local communities as they continue to work toward improving the resources and the supports that are available for individuals and families.

So I see that we're almost at the end of our allotted time. We did have, like I said, other questions that have come in. Let me see if we have any others on the phone?

Coordinator: I'm showing no other questions at this time.

Amy Wiatr-Rodriguez: Okay. And I'll just get to one real quick then that came in via email. So there was a question that came in from Sandra regarding risk and prevalence of Alzheimer's in mothers or siblings of those with Down's syndrome as well as average age of onset.

So, I don't know if maybe Dr. Laurie Ryan or (Jane Telly), if you guys are on, if you'd like to talk about that?

(Jane Telly): Amy, this is (Jane). I'm on but I don't know anything definitive about that topic. But that's certainly something we can look into and get back.

Ira Mott: Hey, yes, this is Ira Mott.

Amy Wiatr-Rodriguez: Yes.

Ira Mott: (Nichole) Schpux has, S-C-H-P-U-X, I think that's the right spelling, at Columbia has published a great deal on this topic about age of onset of mothers of people, you know, where there's Down's syndrome in the family.

And I don't have her data right here but there is any relationship, then I would probably start with Dr. Schpux's papers on the subject.

Amy Wiatr-Rodriguez: All right. And, Dr. Ryan, is there anything you'd like to add?

Laurie Ryan: No I don't think I can add anything to that.

Amy Wiatr-Rodriquez: Okay. Wonderful. Well I guess at this point in time, we will go ahead and wrap things up. Again thank you all of our wonderful speakers. Thank you everybody who took the time out of your busy schedules today to be on our webinar.

As we mentioned, we absolutely will be looking forward to posting the slides, transcript, and audio from today's session on our Web site. Give us about a week or so to get that all together and get it up.

But we will send out an email to everybody who registered today letting you know when those materials have been posted. If you do have any other questions for us, as well as if you have feedback for us on was this webinar helpful?

Was it - did we cover the right information? Is there anything else you'd like us to know? Please do email us. You can email me at my address, amy.wiatr@acl.hhs.gov. We definitely want to hear your feedback so that we can make these webinars as useful as possible to you.

Thank you again for joining us. We look forward to having you join us on our future webinars. This concludes today's webinar. Thank you.

Ira Mott: Thank you.

Coordinator: Thank you for joining. You may disconnect at this time.

END