

## **Autism Spectrum Disorders Advisory Board Quarterly Meeting**

**Thursday, October 8, 2021**

**1pm to 3pm**

**WebEx Meeting**

### **Welcome and Introductions: Courtney Burke**

Welcome everybody. I hope you had a nice conclusion to your summer. I think the last time we met was late July. And at that meeting we spent a good deal of our time talking about the report and the progress that is being made in the various areas that are in the report. I have the report here in front of me. I don't know how many other people do. But, last time we talked through the recommendations that we as a taskforce had made. We were able to get through numbers 1-6 and number 8. And just as a refresher, number 1 focus area was enhancing communications to raise awareness and combat discrimination. Number 2 was supporting people with autism spectrum disorders living in the community. Three, was increasing collaboration between state agencies, we spent a lot of time on that. Four was establishing family support groups. And five is focus on wellness by supporting exercise and nutrition. And six, was better support telehealth services which we all know there was a real explosion of telehealth services during the pandemic. So today's meeting is going to focus on report outs for recommendations 7 through 10 minus number 8 since we really covered that last time. And look at those recommendations and see if there is any way that we as board want to sign off in some way on asking the state to continue working on previous recommendations and then possibly amending number 8. And maybe one of the other ones based on how our discussion goes today. At this point I'm going to turn it back over to staff at OPWDD to help guide us through 7 through 10. And, I would ask that members of the advisory board feel free to jump in if you have a question but I think what we'll do is pause after each recommendation to allow some time for discussion if that sounds good and we have a good amount of time today so I think we can get

through everything. Greg, I don't know if there is anything that I missed or should cover in terms of logistics.

**Greg Roberts:**

No Courtney I think you hit the nail on the head regarding on what we would like to accomplish today. However, I think before we go into discussion with the board we'd like to hear from our guest speaker to give a presentation regarding family support organizations. We're excited to have her here with us today.

**Courtney Burke:**

Great. Yes. Janine sorry about that.

**Janine Kruiswijk:**

How are you Courtney?

**Courtney Burke:**

Good. So happy that you could join us today.

**Janine Kruiswijk:**

Well thank you for inviting me.

**Courtney Burke:**

Welcome.

**Janine Kruiswijk:**

Thank you. So are we ready to go Greg?

**Greg Roberts:**

Alright Janine. Thank you very much. As a way of introduction to the board, Janine and I had some very good discussions this summer about family support organizations that was spurred on by the board's recommendation to help support these family organizations and to get links out there so families that need families that are looking for information can find organizations such as the Autism Society of the Greater Capital Region, New York. And Janine just had so many great things to say, important things to say I thought it would be helpful and informative to the board on their recommendation as well as to the public at large that's always looking for information so with that Janine I'd like to turn it over to you. Thank you.

### **Presentation and Discussion Regarding Family Support Groups:**

#### **Janine Kruiswijk:**

Thank you so much Greg for the mutual helpful conversations that we've been having in this unprecedented time of COVID. But, I'm the executive director of the Autism Society of the Greater Capital Region. I am also the parent to a now 33-year old young woman with autism and co-occurring mental health and physical health needs. So I've had quite a few years of experience in working through cross systems and trying to figure out the best ways to support families and adults who are on the spectrum with different types of programs and really looking in the niches to see where we can provide support and out of the box programming that will support our families and adults where the system is unable to provide that support. So we are not Medicaid billers. We are fee for service, donation, grants and that is the status of many of the non-profits today. General statement on non-profits, it's going to be a very messy upcoming year or two. I think we are going to be in this for the long haul. Traditional financial streams are reduced for us, so our walks, our galas, all of these are going virtual in an effort to protect our communities, to keep everybody safe and that's going to impact non-profits in a very large way. So we're concerned about the status of the few remaining family systems that are providing advocacy across the state.

Now, the Autism Society is part of the larger national network of the Autism Society of America. They have representation in almost all states. We're called affiliates. We used to be called chapters. And we provide boots on the ground services to our family members as soon as an individual is diagnosed we are with them through their lifespans so we really are a cradle to grave service. Many individuals who are diagnosed with autism may come to that diagnosis quite late and despite the fact that autism can be diagnosed as early as eighteen months the average age is around 4 or 5 years old. So there is a large gap in services. So we support families the minute they contact us. We support the community at large and where these individuals are living with their families or independently. And then we try to support the professionals that are serving them.

Can you go to the next slide please?

So right now our current statistics are 1 in 54 who are being diagnosed with an autism spectrum disorder. Every two to four years the CDC releases new prevalence statistics and so in my thirty plus years of providing advocacy I've seen this number continuing to increase in terms of the amount of people who are being diagnosed or recognized as being on the autism spectrum. Next slide please.

So here just some facts. There's a lot of misconceptions about autism. Some stigmas that are left over. Right now, and we're still waiting for statistics to catch up, but there are more than 3.5 million Americans living with an autism spectrum disorder. That number is probably higher now. You can see these statistics came from 2014. There is a lag from when they are surveilling the community to when that information is available to us.

Right now we're looking at about 1 in 34 boys and 1 in 44 girls. So they're estimating that it's a 4.5 times incidence in boys but here is one of the issues that we have. Most of the testing is normed on males. So we're seeing more and more females coming through our doors. The testing is starting to change. People are starting to see what it looks like in women. Often times we will have a little girl come in with a new diagnosis

and mom is looking at us going I was just like that. And so we are watching families who are being co-diagnosed at the same time, both child and then parent.

We know that Caucasian children are diagnosed earlier with ASD. Both Black and Hispanic families, Hispanics in particular, have a lower incidence of being diagnosed early and recognized as autism versus purposeful behavioral disorders. They're catching up, but there's still a lag in disparity in terms of racial and ethnic diagnosing of children.

Thirty one percent of children with autism have an intellectual disability and that is generally characterized as 70 IQ or below. Twenty-five percent is considered the borderline range which means they're right at the cutoff for OPWDD services, 71 to 85. So that leaves many families and individuals who have a hard time with eligibility through OPWDD.

And then there is approximately 44 percent who have IQ scores in the average to above average range. Now, my daughter will often say to me she is an autism level 2 what would formerly have been known as Asperger's syndrome, Asperger's falls somewhere between autism level 1 and level 2. And when she hears the term high functioning autism she is very clear with me to say to me that isn't the way you experienced my autism, that is not the way that I experienced my autism. She's very clear that IQ does not necessarily indicate the severity of the autism. And that is important for us to keep in mind as we are crafting programs and trying to support this community.

Most children still being diagnosed after age 2, excuse me age 4, but they can be reliably found at age 2 so there is still a disparity on diagnostic age. We still have half of those with autism who wander and bolt from safety. This leads to drowning and other tragic incidents.

Nearly two-thirds of children with autism between ages of 6 and 15 have been bullied. That continues into adult years. We don't have good statistics on that but we are starting to see a lot of bullying reports in the workplace. It is of great concern to us.

Over the next decade, an estimated 707,000 to over a million teens are going to be entering adulthood. We do not have great statistics on the adult autism community. We are not preparing enough both in New York state and nationally for this wave of adults that is going to be coming through. Some of our services that I'm going to be describing are really targeted towards this age group. There's a huge gap. You'll hear terms like they are off the cliff, buses no longer coming, and families and adults are really struggling in entering the adult world and figuring out the appropriate services to support them.

I'm so sorry I'm working from home. I have my dogs in the background so I'm sorry for the barking.

So about 2.21% of adults in the United States have ASD. This is a loose number. We don't require any registry or counting of our autistic numbers beyond the CDC. And those statistics are geared on eight year olds with autism. We're really lacking information about our adult population.

Thirty-five percent of young adults and again these numbers are getting a little bit better. 35 percent of young adults ages 19 to 23 with autism have not had a job or received postgraduate education after leaving high school. Now, this is back in 2012. Dr. Shattuck does great research in this population. Still a great disparity between our kids who are aging out of traditional high schools and where they're going to and the lack of opportunity for them.

More than half, fifty-four percent, of adults with ASD are also diagnosed with a psychiatric condition. Nearly all major medical chronic conditions are significantly more common in adults with ASD. So we really need to take a look at blending our services and accommodating what the medical needs are for our adult population as well as the child and pediatric population. You see seizures, gastrointestinal, epilepsy, diabetes, autoimmune, sleep, GERD, and many many others.

Again, not enough work. There was one major adult study that was done on the health conditions and they were looking at the average life span somewhere in the fifties in

terms of age and that's very concerning for us. We are not meeting the medical needs of our autism population.

The rate of suicide completion and suicide actions and ideation is much higher and harder to detect. And so many of our kids are completing suicide so their cross system needs are really significant. There's been some new programs that are coming up but they're still in many cases in pilot best practices program mode and so we're really still looking for the best way to accommodate this population and make sure that we can keep their mental health moving forward and their physical health moving forward.

ASD is a lifelong condition. There are still some younger families who think that with enough services they can cure autism. At this time we do not have a cure for autism. There are many in our adult population who will very emphatically say they do not want to be cured of their autism. They see it as a natural part of the neurological biodiversity of human kind. And they have pride in the fact that they have an autism spectrum disorder so there's still a lot of conflict within our community about cure versus research that is related to treatment and supports. So there's some friction going on.

Next slide please.

Our autism affiliate, we serve 14 counties right now. We are on the edge of moving down through Westchester county. So they're very large areas. It's not unusual for an autism society affiliate to be serving large geographical areas which means we are crossing border lines of regions, OPWDD regions, state ed regions, OMH regions, many of our kids are in foster care so it's a very complex and very difficult system to figure out.

I've also sat on the commissioner's cross systems committee work. So for years we've been working on blending funding, taking a look at how we can best use the siloed funding in New York state to our best ability to support our community. Next slide please.

So, lifespan services. We are -- our board members are primarily professional family members along with adults who are on the spectrum. And we started to frame our services in terms of lifespan services. Once a family or individual walks in our door we really do walk this journey with them through their entire life. And so we have to look depending on the age group and the needs of the individual recreation, respite, post secondary education, health and wellbeing, all of the factors that are here. We have to look at the whole life of the individual and we are very devoted and passionate about making sure that there is quality of life in all of the natural life areas not just in can we get them through the school door. We really want to build community around them. Make sure they have access and equitable access to healthcare and all support services. Next slide please.

We moved just a few years ago. We had our own office spaces over in Schenectady. We joined Urban Coworks so we're a shared coworking space which has been very interesting. In that space, we have a variety of meeting, offices and so forth. Great on site support. Right now we are still out of our offices as many non-profits are. And we don't know when we'll return to the office. Everything is virtual right now. One of the main reasons we walked into a coworking space is that we are very determined to be an integrated part of our community. So in Urban Coworks there are probably about fifty different businesses and it was really important to introduce our emerging young adults and adult populations to business owners because we really wanted to change how employment looks and how people are comfortable meeting somebody who is neurodiverse and making sure that we can guide better relationships and understanding. But, hopefully we'll be back in our offices. I'm hoping by spring.

One of the reasons that we are out, and we're going to see this with non-profits and other businesses, is we just received our general liability insurance renewal with a very clear exclusion clause for any bacterial or viral related incidences which means we're going to have to think hard about how we are going to bring people back together. Is it going to be safe? And what is the mitigated risk that we are going to be facing as a non-profit if somebody decides to sue us if they become ill at an event? And so, we cannot



take that risk right now, as many small non-profits cannot. And so we are still working virtually. Next slide please.

One of the main services that we offer and this is the same for many non-profits is information and referral for families, adults, professionals. They can call the autism society anywhere in the country and they are going to get information about connecting to community, social and health services, we have trained staff. Most of our autism affiliates have the same across the country. We often use graduate level social work interns for training. So, we do it twofold, we're providing services to the community but we are also informing the field by making sure that social workers are informed about the autism community.

This service is available to any community member. Hospital. Physician. Service provider. Anybody who needs it has access to information and referral lines. Next slide please.

The support that we give to our families and community, it is a flexible and responsive system. There are times when we are meeting individually, there are times when we are bringing together groups. We serve both families and adults with autism. Right now we've got a very strong autism, adult autism group that meets. And, they are all virtual. We just had one of our meetings last night. We bring that community together. We do not take the stand of curing autism. We stand side by side with individuals with autism. And we help them to grow into their autism or grow into their lives in the way that is most important to them.

And so there is no shame in having autism. We don't ever want somebody to feel shame for having autism or displaying autistic behaviors. We want to strengthen them, teach them how to survive in their communities while validating the fact that they indeed do have autism and that is perfectly fine. Next slide please.

We do a lot of service navigation and facilitated enrollment. Many families come to us. Could be we're working with an eighteen year old who nowhere in their school history has anybody talked to them ever about OPWDD. So we're first educating them then

we're hopefully bringing them through the process. We partner with our CCOs, our care coordination organizations, we connect families directly to them and then we follow the process to make sure that their eligibility activity remains on a nice path forward and that they don't get dropped through the cracks.

Many don't understand Medicaid or how it relates to people who have private insurance. Yet they need to understand that their children may be also eligible for Medicaid, food stamps, SSI, SSDI, ACCESS-VR. There are – you know it's a million different doors that these families need to walk through and we try to be a no wrong door. If they come to us we can get them to any other door that they need to go through. And we don't just hand them a phone number. We make sure that we are navigating with them and making sure that process goes well.

And we sit on the lifeplan meetings and circles of support of many of the individuals that we serve. And part of the reason that we do that, there's still a great deal of turnover in the care system and often times they may have a care manager who is brand new to their role and so we've got to helm them through including the care management organizations and staff to understand what the needs of the individual are and how they can appropriately service them through self-direction plan or agency supported plans. Next slide please.

Education and training. Again, everything is somewhat on hold in terms of in person meetings. We will do small skills shops where we are talking about feeding, sleeping, toileting, behavioral solutions. When we were in person, these were very small groups giving families opportunities to really talk about their personal needs with a professional. We will probably start running those again virtual as things start to quiet down a little.

We do workshops on education, behavior, communication, transitions, employment. We do that for families. We do that for communities at large. And we're starting to take a much larger role in talking to employers about neurodiversity and onboarding a neurodiverse employee into their talent pool.

Professional symposiums. We may have conferences, half day full day. We work with the Department of Labor under their DEI grants, their disability employment initiatives. We are working with them to understand the needs of the IDD community in particular. We do go beyond autism. Autism is our main community of concern but we find that many of the programs that are designed for individuals with autism are globally accessible for other disabilities and so we started to offer our services beyond the autism community to great effect. Next slide please.

We provide technical assistance. We get many many calls from care managers. Berkshire farms is on the foster care side. They have children that they are supporting in foster care who come in with families. Foster families may not be trained in autism they don't know how to make those connections. So we provide that.

We really talk a lot with our medical system making sure that families and adults get the right services. We get calls from Ellis Hospital and other psychiatric centers who have an individual with autism who may or may not be able to communicate verbally walking them through the process of how to communicate with their patient.

We also, again, I sit on the cross systems committee, we look at New York state as a service. Although, they are siloed, we really try to look at it as a single service and try to figure out how to blend those funds together.

And the Office for the Aging, we have an aging population of individuals with autism and so we've got a very clear picture of kids with autism, we have a cloudy picture of adults with autism, and we have a very obscure picture of what the aging process looks like for our community. So wherever we can insert ourselves to try to help with that. And we really don't know what the long term health implications are for people with autism. We know in down syndrome there's a higher risk of dementia in that population. We don't have that same information available to us yet for the autism population. So its of great concern to us to make sure that people age in a supported way, age in place if they want to stay there, and that these agencies are informed about how to better care for that population.

We go and talk to libraries, parks and recreation, scouting, YMCAs and we introduce them to autism and then we'll take a step further and you know try to help them best serve that population.

And again, corporations and businesses are becoming a much larger crowd for us. There's a big call for neurodiversity for diversity in general and businesses don't always understand what that means. Its not enough to just hire somebody who is neurodiverse, you really have to invest in changing your supervision structure, providing enough supports, and getting a foot in the door is not satisfactory for our adult population. Many of them are highly educated and they want a career path and a career ladder that is available to them. So we talk to businesses not only about the talent pipeline but the retention and the career pathways for our adults so that they are working at the level that their education and abilities most likely align with. Next slide please.

We do a lot of advocacy. We do it both in our local government, especially during COVID-19, there was of course you know a million families that were in distress. Families who were being required to work remotely while caring for their children who have significant autism who are not in school. We had to make some calls on behalf of one family because she was unable to fulfill remote work. She was told that they had taken that as her voluntary resignation. And so that was calls to legislators and the head of the program in order to be able to get her unemployment insurance during that time. Her child is still only in program two days a week. And again a child with very high needs and pika so she's got to really be monitored.

And its important for us that, you know we understand what families and adults want and that we can represent their voice on a policy level and a legislative issue level as needed. And we really do defend and safeguard their rights. This is very important to us. We hear terrible stories about adults who you know really are languishing in their parents' basements. They are languishing you know with no employment no opportunity for proper support and college.

And, families are aging. I can't tell you how many calls we get from an older sibling or older parent who is going into a nursing home or who recently passed away. And they are still disconnected from any service system. They may have had earlier OPWDD engagement but somewhere along the line that's been dropped. And they have no programs. They've just been living with their parents, going on vacations, doing day to day things. But now that those families are no longer available now we've got a sixty year old with autism and who you know we've got to really scramble and get those services and supports in place.

And, we really stand by our adults with autism. And want them to have the life that they feel is of value and importance to them. We don't want a service system who is going to dictate what quality of life is. We listen to what the individual wants for quality of life and then we ask the system to be responsive. And that is the philosophy, the overarching philosophy of the autism society of America and all affiliates as well. So we'll step in and do what we can to change systems, policies and interact where we can. Next slide please.

Some of our programs that we've come up with. SenseAble programs. We were going out into communities training staff of these different venues. And they are typically venues that families would go to with their other children and maybe were locked out of them because they have a child with autism that wasn't being accommodated. And, not by purpose but they you know lack of education lack of understanding. Right now all of our in person programs are on hold and we will see a virtual set of SenseAble programming coming in. You know, whatever we can do to provide that recreation and socialization for those families. Next slide please.

Our college success program. We're in partnership with SUNY Schenectady and Schenectady ARC. We support students who are on the spectrum who have been accepted to the college and who would like a greater level of support than the typical disability office can offer. And this program was really crafted based on many young adults coming to us saying I tried college, I couldn't do it and so while they got their foot in the door their retention rate was really poor. This offers daily support to them, helps

them with their online classes, and classes through navigation and social supports. And hopefully as we see how the colleges are working we'll continue and expand this program as well. Next slide please.

Structured life coaching is a new program for us. Again, based on what we were watching occur with young adults into adulthood. And despite the fact that they may have had OPWDD services and ACCESS-VR they just weren't progressing. So we started putting a life coaching model together and it is a very structured approach to personal growth and development. We do deliver this service it was crafted for individuals with autism but very effective for other individuals ADHD, we have some with learning disabilities, we have some who are not even diagnosed but they struggle with structure in their life.

The areas that we help with our independence, maintaining their environment, community connections, physical wellbeing, emotional wellbeing, and education and employment. And we pair them. It's a one to one program. They are paired with a coach who is knowledgeable in the area that they would like help with. And we make sure that they are moving forward and that they have a successful launch into adulthood. Next slide please.

Gig works is another new program that we opened up. We were watching some of the traditional service providers really looking for full time employment for our community. There's a lot in our community that are willing to work but they may not want to work full time. And so we started to look around into the corners and niches to see what was the industry looking for and what could we do to provide employment opportunities that were a better fit for many in our community.

And so, with Gig works we started connecting with businesses who were looking for temp staff. Who were looking for project based staff. Who were looking for somebody to come in two or three days per week. And the way this program is funded is we are more of a placement agency so it is the business partners who are providing the financial

support for this. So its completely outside of the traditional Medicaid or ACCESS-VR system.

Then we pair them. If they don't come with job coaches we do that facilitated navigation again to make sure they are connected to the proper support services. And, this has been a great opportunity to get kids into the workforce. Our partnership became very strong with NYSID the New York State Industries for the Disabled. We've got several individuals who are placed currently at the Department of Health providing a variety of administrative and clerical support, e-biz docs that is a document imaging center, and so its been highly effective and its been a great way to support a non-profit because we purposefully choose not to pursue Medicaid funding.

We want more flexibility and we want more opportunity to work from the point of need of the consumer and not the point that the service system can afford to provide for them. So it's a growing program. We expect to serve more and we're really a think tank in this area. We will continue to flex and mold this program and make sure that more of our adults have that employment opportunity. Next slide please.

And that's the end of what we offer at the autism society. I always end with a slide reminder that April is National Autism Awareness Month with the caveat that individuals with autism need support every single day. And always remembering what my daughter says to me that because my IQ may be intact, please don't presume that my autism does not have a significant impact on my life. We provide year long, everyday support wherever we're needed. And we'll continue to that and we'll continue to talk to our community to figure out out of the box solutions about how we can support the community. And this next year we're concerned. We're looking at what we believe will be a one to two year disruption in all services. We still have families that can't access not all of the day programming and schooling opportunities are still somewhat remote. We're seeing some schools closing for two weeks, reopening, only do in person for two days. Many of our children and adults cannot access services in that way. And so we're trying to support as much as we can philosophically, policy wise and also with simple

things. Our refrigerator broke. We don't have the money to buy a new one. How can we support them in those day to day needs.

I'll be happy to answer any questions that anybody has.

**Courtney Burke:**

That was really great Janine. Thank you. Great overview of a wide variety of issues and services. Employment, transitions, aging issues. Very impressive. I'll open it up to members of the taskforce if they have any questions.

**Charles Massimo:**

Hi Courtney its Charlie Massimo. Janine. That was a phenomenal presentation. Thank you so much. And I applaud all the work you're doing and one hopefully those slides will be shared with us because I'd like to review them even further.

**Janine Kruiswijk:**

Yeah. I'd just like to point out one second Charlie. I just realized our old email address is on there. Its no longer [info@albanyautism.org](mailto:info@albanyautism.org). But if you go to our website which is correct on there. There is a contact us form that you can use and it will send us the message directly.

**Charles Massimo:**

Great. As to data to autistic young men I'm not surprised by all the statistics its very frustrating that none of the statistics are improving they just seem to get worse. But I do have a question on health and what you're doing with your families in helping them not only pick but monitoring the psychiatrists that you may refer to.

And the reason I ask, is my experience over the past 21 years raising my boys is you know we go back and forth with many psychiatrists with very little training or understanding of autism and their first go to is very potent antipsychotics which lead to



even further issues with our young men and women including things now like catatonia which is always misdiagnosed or not understood. And I wonder if you're doing anything with families or helping families you know refer and monitor psychiatrists that are really on – not cutting edge – but doing good work in this field and understanding that maybe antipsychotics are not a fit for all and there may be other alternatives. I just want to get your feedback on that.

**Janine Kruiswijk:**

Yeah Charlie. You know that's a huge issue. Number one we don't have enough psychiatrists period and then we really don't have enough in terms of the pediatric and adolescent psychiatrists. And so what we're watching is the phenomenon of nurse practitioners who are prescribing, pediatrics who are prescribing, and so through our information and referral and community outreach we are in constant conversation with both providers and families. One of the new players in town is Albany Med who came up with the Autism Medical Home and they are, I think, probably one of the leading models about how they are approaching autism and its developmental needs alongside its medical needs.

Families can go there, they can get a diagnosis. They can get pediatric services for their children and then they can get the ancillary supportive services such as gastroenterology, psychiatry, social work, and it really is a medical home model. And that is a model that we are supporting greatly.

We also inform families and individuals that they have a right to question and to be educated on any medication issues but they also have a right to say no. That there are other alternatives. We won't take a stance in any particular way but we educate individuals to the best of our ability on all of the options that are out there and we try to give them as much scientifically and statistical facts that might help them make the best decisions.

We want to be very careful not to dictate to families you know what choice they should make. But we want them to be aware of any pitfalls and psychiatry medication

management this is a huge issue. Particularly in the adult population you know where they don't have a correct diagnosis of autism to begin with and so the medications everything is presumed to be of psychiatric nature they don't look at the developmental issues. I'm not saying that some psychiatric medications don't have efficacy they definitely do. The science and statistical information is there. But families are really lacking in terms of information and adults they may struggle to navigate all of the choices. And they are over medicated or under medicated. Or don't have access at all. It's a messy system and we do our best to educate on both ends where we can.

**Charles Massimo:**

Thank you very much.

**Courtney Burke:**

Thank you Charlie. I thought I heard somebody else trying to pipe in with a question.

**Michael Gilberg:**

Thank you Janine. I hope you got my email. Its good to hear from you.

**Janine Kruiswijk:**

Hi Michael. I figured we would catch up today.

**Michael Gilberg:**

Thank you. I'm glad to hear things are moving with the Hudson Valley you know I've been talking to national about that. I actually just got appointed to their panel of spectrum advisors for national ASA.

**Janine Kruiswijk:**

Oh congratulations.

**Michael Gilberg:**

Yeah so I'm looking forward to working with you on that. I think one of the issues I find as a special ed attorney is so many parents the further north you go from the city don't know what to do when their child is having trouble in school. And often they find attorneys like myself and others either via google or via other sources and I think one of the big things we need to deal with as a community is getting word out to parents when their children because obviously addressing needs as a child versus an adult is a lot easier. And one of the things I've seen in Connecticut and I don't know how this would work in New York is there's a group that is started because parents – legal services are expensive. I charge less than other special ed attorneys but I still charge a decent amount because I have a living to make. And I think that part of the problem is parents hear 5,6,7 thousand for legal fees and it scares them. And one of the groups in Connecticut started a grants program for parents who could not otherwise afford a special education attorney. I'm not sure how that would look in New York but I think it would be worth considering the idea of how to make legal services more affordable so that attorneys like myself and others can get hired and parents don't have to worry about breaking the bank. I think if you give services when people are kids you know it's a lot easier to serve a kid than an adult and change behavior. And I think – so I think that's something to consider. A grant program for people to hire special ed attorneys but also to get the information out because what I'm finding is, again, the further north you go, once you get north of Westchester, there's a lack of attorneys out there. That's why I get calls from people very far upstate. In the virtual world I can do it. In a non-virtual world it gets costly if I'm driving 2 hours each way to a CAC meeting. Something to consider.

**Janine Kruiswijk:**

Yeah. I would agree with you. Our philosophy is we try to help early on. It is far less expensive to try to keep a family out of a hearing situation and needing an attorney if that is at all possible. So we do rely on partners such as Parent to Parent are funded for direct advocacy and or are doing training. We also do it. We are not directly funded for that but we do help wherever we can and give that advice. And sometimes its just

simple practical advice that we give to families such as documenting everything the school is sending home, all conversations, and when they have finally gotten to a point that all other routes have been explored we do make those referrals to attorneys but you know its very stressful for families not only financially but also emotionally. They are, you know, we try to keep them in good relationships with their districts but also with the high expectation that district's are providing high quality services that are within the regulatory expectations on both IDEA and the part 200 regulations.

**Michael Gilberg:**

The problem is too many districts don't follow you know the IDEA requirements. And you know I find my job as an attorney is often not to necessarily go to litigation but to try to resolve the issue. Just having an attorney as I say to people doesn't mean its got to get contentious. I think there is an important piece there that so many parents, especially now with COVID, so many parents are struggling with the distance learning. This is a recurring theme especially with the younger kids on the spectrum. They're having a real difficulty accessing the distance learning.

**Janine Kruiswijk:**

Yeah and I think we're going to see some court cases hearing cases that will go through where families are going to start pushing now that the panic is starting to reduce a little bit to concentrate on lack of access to services. I think we will see some court cases moving through with some significant decisions. You know right now families who may have a valid reason to go into a hearing they don't because they're trying to work from home, they're trying to manage their child with autism or other disabilities and under tremendous tremendous stress.

**Michael Gilberg:**

Exactly. And I always tell families let me worry about part of it so you don't have to. Like I said though I'm looking forward to working with you on the panel of spectrum advisors. From the self advocacy perspective I think the autism society is a unique space

because on the one side you have Autism Speaks who most self advocates hate because of the history as I'm sure you know "inaudible" and on the other side you have some self advocates who are very militant at the other extreme. I think autism society the ASA has found a nice balance between the Autism Speaks and the "inaudible" lets make society conform for who we are.

**Janine Kruiswijk:**

Right. We're working on it Michael. Definitely working on it.

**Michael Gilberg:**

I'm just saying you know. And I think the mask wearing is actually a good example of conforming to society rules even if we don't necessarily like them.

**Janine Kruiswijk:**

Yes. Yes. And that's a good example.

**Michael Gilberg:**

Good to speak with you Janine.

**Janine Kruiswijk:**

You as well Michael.

**Courtney Burke:**

Thanks Michael. Any more questions from advisory board members? Well thank you again Janine. That was an awesome presentation. Really appreciate you taking the time.

**Janine Kruiswijk:**

It was nice to be able to do that Courtney.

## **Continuation of Discussion Regarding Progress on Board Recommendations and New Recommendations:**

### **Courtney Burke:**

Yeah. Be well and hope to see you soon. So we're going to move on to the next item of the agenda which is going through our report recommendations numbers 7 through 10. As I mentioned at the start of the meeting we did discuss number 8 in pretty significant detail back in the summer when we met. And so I'd like to turn it over to Greg to walk us through 7, 9, and 10.

### **Greg Roberts:**

So, thank you very much chairperson Burke. Number seven from the board was to study how assistive technology can be utilized more fully. One of the recommendations that the board had put forward is for the state to hold a tech summit so that we can get out better ideas, receive ideas from all the wonderful companies out there and other people who are designing apps and technology that's useful to people.

One of the things that the board has done is on November of last year the autism spectrum disorder advisory board of self advocates convened and they had a lot of good information that they put forward on what helps them. What technology is useful to them. Helps them in their daily lives. And be within the community as much as possible. And to be self reliant. There was also a presentation to the board that Kristin Thatcher who is one of the board members helped guide through about the outcomes of that meeting. And that will be included in the final report along with more details of what had been discussed.

But a tech summit has not yet been held. That might be something that the board members should keep on the agenda. COVID probably put a big damper on gatherings but it might be something the state could help facilitate in the future.

But one thing I do want to point out in this area is OPWDD had been doing a lot of outreach to families regarding what might have worked or what might not have worked so well in response to COVID. And this is in relation to some of the telehealth services that we had discussed last time. And one of the issues that we have been hearing from our focus groups as well as our from family advocates that something that perhaps should be included in this number seven going forward in the future – I mean I don't think the wording necessarily needs to be changed – but something we can focus on is that there are many people who just didn't have the right technology at home as well as some of the organizations out there trying to support people to help people take advantage of some of these telehealth options. Some of it is broadband in rural areas but certainly a lot of it is just technology access and finding ways that individuals can access that technology. So I think that that's something the final report or the next report will have to mention. Because I think that the if infrastructure is there and the laws and rules have been changed then we still have that barrier of some people who may not be able to access either through lack of ability to get a computer or network but also perhaps some physical things that might have to be adapted so that they can use the technology better.

So I think the COVID has really put a highlight on the issue as well as the assistive technology. Would anyone like to comment on that?

**Unidentified Speaker:**

Comment on that if I may. And I wanted to let you finish. But there may be an interim solution. As you pointed out, COVID has made in person meetings difficult for the near future. But I don't know how widely viewed if OPWDD were to do a webinar and post it on YouTube where you could feature some of these assistive technologies that are being used by individuals or families. That might be a nice interim step to have a handful of those.

**Greg Roberts:**

That's an excellent idea.

**Unidentified Speaker:**

I'm sure you can find willing vendors. And perhaps families as well or individuals that are users.

**Greg Roberts:**

Ok. That sounds like a good to do list for the agenda going forward. Any more comments from members of the board?

**Vicky Hiffa:**

Greg? Can you hear me?

**Greg Roberts:**

Yes I can.

**Vicky Hiffa:**

Its Vicky Hiffa from the DDPC. So the ARC of Westchester, I don't know if you know, they've done a technology conference for the last couple years. The one in 2020 was canceled. But you may want to reach out to them in terms of getting you know some resources. I don't know if they're doing something in the interim around technology.

**Greg Roberts:**

Thank you.

So as Chairperson Burke mentioned we touched on 8 last time however I thought we might want to touch on it again today. We had a long discussion last time on ABA and the board had recommended that the state embark upon a communication strategy to try and get the public so they are more aware and perhaps get some people interested in ABA and it may lead to people choosing that as a career. In the long run that could result in better supply of ABA people to meet the needs of New York. Which I think, you



know, are not necessarily being met because of the shortage of professionals. And the presentation at the last board meeting was provided by the ABA association and they had some thoughts that there may be some scope of practice issues or some other structural issues that may be dissuading people from pursuing ABA in New York. So even if a public service campaign or something along those lines got someone's attention and they did a lot of work and research into it and it intrigued them and they wanted to do it as a profession that they might look elsewhere to perform or to work.

And so I wanted to see if the board had any thoughts on maintaining this recommendation as it is or tweaking it a little bit in response to those concerns. But I wanted to throw that out there to the group.

**Courtney Burke:**

This is Courtney. I'm deferring to others and I know Jill Pettinger is on the line. She's always been helpful on this issue.

**Jill Pettinger:**

And certainly this is you know we continue to hear the challenges in the field of the availability of appropriately trained professionals who do this kind of work in New York and there continues to be challenges with modalities for reimbursement and having people to supervise practitioners who need to work under supervision in order to get their own licensure and certification so I think there's just a whole series of challenges and I think Dr. Napal kind of pointed some of those out in her presentation last month. So again I'm not sure if others have thought more about this. I know there's been. I don't know if. I think there are wages on. Connie I know there's also discussions happening around with the Department of Health around the topic of the ABA and you know reimbursements. So again I know there's more discussions happening trying to look at some solutions to address the concerns about you know the pipeline of professionals to do the work and have ways to get reimbursed for doing this work. I'm not sure if other folks have ideas or thoughts. Again I think Dr. Napal Tunnel kind of laid everything, a number of issues out there for us last time. It's a matter of getting traction

on some you know possible solutions. Other states are struggling with these areas as well its not just New York.

**Greg Roberts:**

And board members feel free to follow up with me later on offline if you wish to further discuss or put some input in. I'm happy to hear input anytime even outside of these official meetings.

**Constance Donahue:**

I think I may have been on double mute. It's Connie. Can you hear me ok?

**Courtney Burke:**

Yes.

**Constance Donahue:**

Ok great. So I was going to say is the early intervention program is still working towards being able to have licensed ABA practitioners and also the certified behavior analysts assistants working in the early intervention program. We have Medicaid spa approval we might have talked about that last time. We've made the regulatory change we need to make and now we're just working on kind of a big project which is the new system for early intervention. When that launches in April 2021 or May but right in the spring we will be able to then have applicants who are certified or licensed behavior analysts and certified behavior analysts assistants working in the early intervention program. And the hope is that will be helpful. I hadn't understood the limitations that were discussed at the last meeting and I think that's a whole other discussion and probably one worth having. I happen to be in the American Speech Language Hearing Association the trade journal called the ASHA Leader that has an interesting article about the differences if you will between speech language pathology and ABA practitioners. But also another interesting topic that we might want to have a little more discussion about in the future at a future meeting.

**Courtney Burke:**

Great idea Connie. Yep. Well as Greg said if there are any thoughts or ideas on this particular recommendation we know how to find Greg for input.

**Greg Roberts:**

Ok. Thank you Chairperson Burke.

**Unidentified Speaker:**

Greg.

**Greg Roberts:**

Yes?

**Unidentified Speaker:**

This is Josie. Not to interrupt you but Steve has his hand up.

**Greg Roberts:**

Oh ok. Steve. Go ahead.

**Steve Katz:**

Can you hear me? Hello?

**Greg Roberts:**

Yes sir.

**Steve Katz:**

Ok good. I just wanted to. When we had this discussion before. There are a number of people who have been experienced with people who are not actually doing ABA but

claiming they are. And there's a lot of negative energy about ABA out on social media. Part of any kind of outreach we need to kind of make a correction to let people know that its not offering since "inaudible" a lot of people think it's the same thing. There are a lot of people who really felt tortured by this free trial training. Other practitioners who were doing all sorts of other things that were very negative, using a lot of negative reinforcement. So I think its important when we do the outreach to practitioners we also need to do outreach to the public to let them know what ABA is and what it is isn't.

**Greg Roberts:**

It's a great point. Thank you.

**Courtney Burke:**

Ok. I guess we'll go ahead and include that one Greg and I guess we'll keep going.

**Greg Roberts:**

Yes. So. Number 9. Recommendation number 9 last year was the board had directed the state to engage in some cutting edge research around autism spectrum disorders and to perhaps to try and get a research bank together. So families and practitioners will have maybe a one stop place to go to for the latest information that may be around but isn't being used practically. Get this in people's hands and how can we make people more aware of it.

And so what staff have done to this point is try and collect a large list of places where this research is located, where research can be found with the intention of putting that into the report so that anyone who is looking at the report might be, find these research centers. And that would enable the families and anyone who is interested to go to those locations and look and make their judgments as to whether they found it useful or not.

So a lot of this work and initial research that was done for this report was done by Dr. Yoo who is one of OPWDD's great researchers and she's a member of the board so Dr. Yoo I apologize for not flagging you in advance that you would be called on but did you

want to comment at all on this topic? And the work that's gone into the document that you've been preparing and we shared a draft with the board members about all the places that research can be found out there.

**Helen Yoo:**

Sure. Its been a while since I prepared that document so I may be a little hazy on what's exactly on that document but I do want to direct everyone's attention to a federal research registry called [clinicaltrials.gov](https://clinicaltrials.gov) and if you search by topic such as autism social skills training or any of the subcategories that you are interested in you can find studies by just going to that website. And that may be the place to look for current research that's undergoing.

**Greg Roberts:**

Ok. We'll be sure that's included in the report so that the public has access to it. Thank you very much Dr. Yoo.

**Helen Yoo:**

Sure.

**Greg Roberts:**

Are there any other comments or thoughts from the board? I think that this is a wonderful recommendation and as these reports are annual perhaps we can keep this in there and update it every year you know as new universities come on line or offline or their creating new programs or new research comes out there you know this might be a very good place to have a breathing living document so to speak for families and individuals and other researchers to look at so I think this is where again once again the board hit the nail on the head regarding recommendations. So the list so far has been distributed to the board members as a draft. So I encourage you to look at it. If there are things you want to be added, as the one that Dr. Yoo just recommended, more than

happy to do so. I also do plan on reaching out to some others in the field and trying to get as much input as is possible. So thank you very much.

**Courtney Burke:**

Alright. Doesn't sound like any more comments on this recommendation. So I think we'll move on.

**Greg Roberts:**

Ok. So number ten. The tenth board recommendation was to review the impact of New York's systemic therapeutic assessment resources and treatment or New York's START program that does in home supports for individuals with autism spectrum disorder.

So I do have a little bit of news on that front. So OPWDD is currently changing that program a little bit. In the budget that was adopted on April 1<sup>st</sup>, it included language that enables OPWDD to receive federal participation and federal financing to help assist us with this program. Which we think is going to be able to enable us to expand it to more people. There has been some review going on of its efficacy and so hopefully, what we found might be people to work better and be put into the new program moving forward and the new program will be called Crisis Services for Individuals with Developmental Disability, CSIDD, to throw another acronym out there. I know it doesn't roll off the tongue as easily START but that program will be renamed and perhaps retooled a little bit. And I know Dr. Pettinger is leading the charge on that from the state's perspective. And Dr. Pettinger is there anything else that I, we should add at this point. That the board should know as we move forward on this recommendation?

**Jill Pettinger:**

I can give some additional information Greg. And I can also give just a little bit on the work that we did on looking at what has been, what started out under our New York START program really originated as a pilot project and we had rolled the program out to four regions of the state. And I was able to pull some of our data in looking at who were

the individuals being served under that project under the New York START program. And as Greg referenced we did submit a state plan amendment. We did get federal approval for essentially a service that is modeled after the START program in that its intended to be a short term rehabilitative service targeted to individuals with intellectual and or developmental disabilities which would include autism spectrum disorder who have significant behavioral and or mental health needs. And, again the service would be delivered by multi disciplinary teams that would personalize intensive and time limited crisis intervention, pro active engagement with a system, as a system of support types of services which is again what we've been doing under the START program model. And again to put a better framing around it, it is more focused on, that this is intended to be a time limited service. Its intended to really improve the capacity within the broader service system across multiple partners if you will. So that we're not sort of recreating specific crisis services that are unique and only contained within the developmental disabilities service but rather if a person has a developmental disability with comorbid mental health conditions like major depressive disorder and they really need treatment for their major depressive disorder that we would be seeking and working within that system of care with mental health service system to access what may become necessary support such as for example an in person admission for 5 or 7 days for review and stabilization of that individual. That we're not creating sort of a different parallel system because the person has a developmental disability. We're trying to streamline a system of care so that the mental health services have the resources and knowledge and training to effectively support individuals with a developmental disability.

So again that's very. That is how the start model was developed and implemented. So again we have a platform that has been established over the past several years. With the implementation of that model to now leverage basically the capacity for that type of service to be for us to receive some reimbursement for the delivery of that service so that we can bring it to a larger scale and hopefully meet the needs of more individuals who have support needs and behavioral health and or mental health needs in addition to their developmental disability support needs.

So I think that. This is going to move us in a very positive direction. I was able to look at some of our data of our START program just to see how were we in fact serving or how many individuals were we in fact supporting through the START program that had autism spectrum disorders because obviously a program serving individuals who are OPWDD eligible so that's a broad array of developmental disabilities and intellectual disabilities. But I really wanted to understand who were they serving among the population of individuals who have autism spectrum disorders.

So in looking at our data we served. Lets see. Let me just find my notes here. I did work with the Center for START Services. Back in the spring or summer of last year. We were able to identify some data parameters to pull out of that. The Center for START Services has START information reporting system that START teams nationally use to enter information about deidentified information about individuals that are being served by their START programs and so New York participates in that.

We were able to learn from that review based on data pull that was done in November that we had about 55% of the individuals that were served in our New York START program that did have a diagnosis of autism spectrum disorder. And I was able to look at those individuals average ages. For example for adults it was 26 years of age, average age for children receiving START services was 13 years of age. Not surprisingly, there were more males with ASD that were served as compared to females with ASD through the START service at 53% were males and 24% were females.

Also I was pleased to see that it the majority of the children and adults with ASD receiving New York Start services were living at home with their families. Seventy six percent of children and fifty six percent of adults. I say that because I was also able to look at data from other states and that trend wasn't necessarily the same when I looked across individuals with ASD who were being provided START services in other states. So that tells me that there's the family support services and other home and community based waiver services that are available to individuals. I interpreted that to be a positive indicator that those services and supports are helping families and individuals to remain in their family environment for longer periods and to not end up in what I'll call



institutional type of setting which may be what is happening in other places across the country.

So there were some other. And again I didn't have a full analysis prepared for today but again there were some other interesting details again just as we were able to look at what are the types of data collected through the START information reporting system and what I was able to pull out. Again, its sort of broad based aggregate types of data which I can't get into a lot of details about individual specific situations because that's not how the database is set up. Its very much as a I said deidentified and more sort of big picture kinds of data. But again I think there was some interesting information in there and again importantly our New York START program were serving many individuals with ASD who had cooccurring challenges around behavioral or mental health needs. We were able as I dug into with the START team looking into some individual specific cases I was able to see some very positive outcomes as a result of individuals being able to receive the START services.

I'm very optimistic again as we're going forward with CSIDD, which as Greg said we have to introduce a new acronym, that's what we do here. But I do think now that we'll be able to bring that to a larger scale because we'll have a mechanism for funding the service more effectively to sustain it. I think again there's the potential for very positive outcomes. So that's. I hope that's helpful Greg.

**Courtney Burke:**

Very helpful for me.

**Greg Roberts:**

Yeah that's. And as much information as we can will be included in the report.

**Courtney Burke:**

That was really helpful Dr. Pettinger. So Greg are we ready to move on to next steps?

**Greg Roberts:**

Well I. You know we've covered the ten recommendations that the board had put forth for the last report over the course of the last two meetings. I think there's many of the recommendations New York's going to be able to report that some progress has been made. I wanted to see if the board. You know we've had a lot. Certainly the world's been upended with COVID in this last year. And it's kind of highlighted some problems or concerns and even opportunities that haven't existed before or people may not have been aware of before. So I thought this might be a good time to see if the board members have any recommendations they might want to make to the state so that policymakers can be you know focusing on what's changing in front of us. So perhaps we can open it up for some board input. You know is there anything new? Are there recommendations that we should add? Doesn't seem like any of the ten were completely accomplished so the state perhaps should keep working on those. But are there any new things we should look into and work on? And I open it up to the board if your ok with that Chairperson Burke.

**Courtney Burke:**

Yeah absolutely. And maybe I'll get us kicked off in case anybody has anything else. I think that one of the big changes during the pandemic obviously was the use of remote technology and I'm going back to our recommendation of assistive technology to see if it's broad enough to encompass. I think there are mixed opinions about the use of technology. Obviously, more people got a lot more comfortable using it. So ours was study how assistive technology can be utilized more fully and there's the recommendation about the tech summit. Maybe part of that could be tweaked to talk about the adoption of remote use of technology so that there's more of an emphasis on that. Because I think it grew and I think it was successful.

**Greg Roberts:**

Actually I think recommendation number six speaks to that so removing the regulatory barriers.

**Courtney Burke:**

Right. Forgot about that.

**Greg Roberts:**

And community supports.

**Courtney Burke:**

Yeah yeah. You're right. Definitely the better place for it. I think actually looking through that a lot of its already in there I think.

**Greg Roberts:**

I suspect the report will have a lot of information on all the changes that's been happening through the Department of Health, through OPWDD as well as the other state agencies. There have been submissions to the federal government to expand some of the opportunities. You know the governor had issued some executive orders expanding the opportunities. And so right now OPWDD has been busy engaging their stakeholders in order to see what worked what didn't work in hopes of making some of the things permanent that have been effective. We're certainly at least extending them for a while so that more research can be done. I think we find it's a mixed bag. Some individuals have really adapted well its really worked well for them particularly in some of the getting medical assistance or seeing a physician or clinician that's really helped. Other people it has not worked at all for various reasons its been very ineffective so I think one thing the state is state leaders are looking at is what works but also keeping in mind it doesn't work for everybody. And so we have to be careful that its not a panacea and it has to be used appropriately and effectively just like any other interventions. And I think. And modalities. And I think its going to be slow going to get that but I think we're heading in the right direction.

**Constance Donohue:**

This is Connie again. I wonder if any of the other state agencies are conducting any surveys of stakeholders. We're working with an early intervention coordinating council taskforce that started off on workforce the past meeting now they have added to their mission teletherapy. And what we're working on is coming up with some surveys that will go to parents and professionals and maybe agencies are working on actual audiences but to find out about people's experiences so that when we do as you said Greg go forward and I think deliberately and systematically we'll have that information to help us with decision making and how we would incorporate it in our various programs. So if any of the other agencies are doing something similar it might be good for us down the road to combine what we learn and talk about it.

**Courtney Burke:**

Great idea. Any other ideas from the board members regarding the question of how the world has changed and ways we may want to update our recommendations.

**Sean Culkin:**

Well. This is Sean speaking by the way. This isn't related to the pandemic but its something I think a lot of people have been thinking about. I've been hearing about cases across the United States of people with – autistic individuals or other people with developmental disabilities being on the wrong side of the law in a sense. And I was wondering if we have an estimate on the amount of people incarcerated right now in New York state that have autism or a similar condition. Can we get any information on something like that. I think it might be eye opening and it may change discourse as we talk about making laws and advising in the future if we had an idea of the people that have fallen through the cracks most of all. The ones that have ended up in on the wrong side of the law in a sense. Do we have any information concerning that?

**Courtney Burke:**

Greg I defer to you.

**Greg Roberts:**

Yeah. I do not. I.

**Jill Pettinger:**

This is Jill.

**Greg Roberts:**

Yeah thank you.

**Jill Pettinger:**

Yeah. We don't have any information on this in the aggregate. Its certainly something that I can talk to my staff here in the Bureau of Intensive Treatment Services because we have discussions regularly with department of correctional services and many other folks in the legal and forensic arena. And see if there is anything that would allow us to gather some information on that topic. Right now I can tell you that other than you know individuals that we may serve in some of our own settings that we wouldn't have any ability to look at that data from sort of a big picture perspective. Not at this point.

**Sean Culkin:**

Absolutely. I fully understand that. The cases that I've heard about have all been out of state. So I was just simply curious and I'd like to see if we can get some of that information in the future.

**Kristin Thatcher:**

This is Kristin here. I think we should have for a recommendation. I think we should have cops like trained police officers about autism spectrum. Because sometimes we don't follow commands very well and sometimes we it looks like we're not listening but we really are listening but we don't follow that the orders very well. You know what I mean? So I think there should be trainings.

**Greg Roberts:**

Thank you Kristin. And Mike Tripodi has his hand up and I think Mike is in a pretty good position to perhaps respond to that a little bit and I can follow up as well. Mike, did you want to comment?

**Michael Tripodi:**

Yeah well my comment was going to be more around the preparedness programs. But we definitely do need to work on the first responders. I know we've talked about first responders training and police, fire, and EMS. And, I think we just really need to make sure those move forward and it needs to be involved and delivered by individuals who are autistic. It really has a much different impact like just even like the people like today. I'm currently deployed to the California wildfires as a deputy assistant director of response covering four of the fires in northern California with the red cross. And just like my daily interactions and you know the trainings that I'm providing on the ground are a lot more impactful for the responders the fact that I'm like yes I'm an autistic adult. Here's the deal around autism and working. You know these are what the needs are these are what my needs are. And really have a much higher impact and really shows. You know other than having somebody who is quote unquote supposed expert who just really got it from a book. It really does show effect when it comes to the retention, the understanding and also being able to ask questions. You have to create that safe space where some of the questions can get pretty personal. It helps build a better understanding and I think we really need to focus any of this especially around police interactions. You know one of the best examples was with Sheriff Craig Apple up in Albany where we did traffic stop training. Where we actually got pulled over by the sheriff.

**Greg Roberts:**

Mike I think we lost you. There we go. But I do want to mention that the New York legislature recently passed a law that is being implemented where state police and the local sheriffs departments are required to have training. And I know that those programs

are being implemented in the academy stage as well as you know I believe ongoing trainings with the deputies across the state.

**Michael Tripodi:**

My comment. My original comment was going to be more around the pandemic, especially that came out of the pandemic and also to the constant barrage of disasters this year. Is, we need to. We have the state citizen preparedness corps trainings about citizen preparedness, preparing your family, how to prepare yourself. There's no flexibility. Inaudible. Right now they have no power, no internet. You know, how do I be prepared for this? Like I couldn't use my stove because there's no power. I really think that is something and we could do a little bit about pandemic preparedness. I think that's a topic we need to that should be brought up too. Because a lot of times the discussions around first responder training but I think we also need to look at that personal preparedness, family preparedness, you know like what kind of you know what things you should have in your emergency kit? What do you need to have on hand? Like what records? Like you know do you need to have copies of your medical records? Do you need to have like for example extra fidget toys and sensory items? Like I always have at least two sets of noise cancelling headphones because that's one of the things that I need. I think that should probably be added to the list too is that personal preparedness piece. And so that's kind of my thoughts on it on things to add to the list. And I'll be more than happy to help. I'll be back in New York in a week and I'm more than happy to help. I actually have some programs that were kind of developed in kind of prototype with my position at the Red Cross as one of the national part of the national response team that would be more than happy to work with New York state to develop. Yeah.

**Greg Roberts:**

Are you putting forth a recommendation that New York state work on a disaster preparedness program or information that could be distributed ahead of time to help families prepare for events before they happen? Inaudible. Ok. Wonderful.

**Mike Tripodi:**

Yeah in conjunction with the already existing citizen preparedness corps. The problem with that presentation its very inflexible. And it doesn't allow for modification. You know it doesn't cover some of the topics that need to be covered. Not all audiences need those topics. But it'd be great to have like a module or if we presented to -- a modification that we could present to the autism community. Right. Adults. Families. Children. Community leaders.

**Greg Roberts:**

Excellent. And I think Patrick Paul had his hand up as well. So if people wanted to comment on that or anything else. That would be wonderful. Mr. Paul?

**Patrick Paul:**

When you were talking about ABA professionals and just to let you know that actually SUNY Empire, we collaborated with SUNY Empire and they opened up a new center which would really support individuals with autism who want to go to college and help them put supports in line to support them while they're trying to get their degree.

In addition, we're going to be working with them also to work with professionals who are looking in to focus on becoming BCBAs and LBAs and actually we're going to be opening up a site there where those students would be going and receiving hands on supervision. And other organizations can also join in and have their staff also be part of that student body to also receive that same training and support. It sort of touched on the issues that we have been talking to as an advisory board.

Also, the center for autism inclusivity is also now having some townhall meetings where they're looking for input on to what's actually needed. So it's a good opportunity. If you want to go to their website for us for Empire State College they do have some information for the townhall meetings to get input from the community to see what



needs to be met. So, just wanted to throw that out there so people know what's going on out there.

**Greg Roberts:**

You've got your hand up again. Steve? You're on mute Steve.

**Steve Katz:**

Can you hear me?

**Greg Roberts:**

Yes we can now thank you.

**Steve Katz:**

Ok. In terms of the COVID lockdown, you know I run weekly support groups here in New York City and I hear a lot of people complaining they don't know what OPWDD services are available or what's not. I know that I have some services available to me. I was in the middle of applying for soft interaction and that's now going forward. But I know that for example the education department but I haven't heard from my ACCESS VR person in six months. So, there's not a lot of information about what's available online. It would be great for people to at some point broadcast what's available and what's not.

**Greg Roberts:**

Thank you.

**Courtney Burke:**

Alright any other ideas from the taskforce? You guys are good? So it seems like you've got a fair number of things to add Greg.

**Greg Roberts:**

Yes.

**Next Steps:**

**Courtney Burke:**

Lots of good ideas. For sure. So I think in terms of next steps I know that you'll be adding these to the report and I don't know if the board wants to consider asking someone from the advisory board to potentially present to the DDPC, what's been going on with the report and the updates. I think. I know that because the DDPC has in terms of getting the word out of what we're doing and the recommendations that might be a great thing for us to do in the coming months.

**Greg Roberts:**

And the DDAC as well from OPWDD.

**Courtney Burke:**

Yes. Yep. Another great resource. Yep. Yeah and remind me Greg how often does the DDAC meet?

**Greg Roberts:**

The DDAC is meeting quarterly and so you know that might be a good opportunity and if the board wishes I can try and work with OPWDD so that when the report is published and out that the board or members of the board select members however you want to do it could provide OPWDD – the DDAC is developmental disability advisory council that advises the OPWDD commissioner and so that's an excellent way to get I believe the information in your report out publicly as well as get it into the OPWDD workstream so to speak. And as Chairperson Burke had mentioned to the DDPC might be another

opportunity might be another place that the board members of the board can help present their final recommendations to help get the word out.

**Courtney Burke:**

That would be great.

**Vicki Hiffa:**

Hi this is Vicki Hiffa. That would be oh. Sorry I don't know if you can hear me. This is Vicki Hiffa from DDPC. We meet three times a year. Our next meeting is at the end of October. But then our next meeting is in February. We also have an extensive listserv so I'm sure there's a number of ways we can get the word out as well in our agency.

**Courtney Burke:**

That would be great. I think that both the DDAC and the DDPC would be good ways to continue to spread the word. And I know that Greg your taking some of the recommendations from this meeting and the last meeting and updating the report. And I think the plan was also to note the steps that the state has taken to address some of the recommendations. Because I know you've been very active on using the report as a template for action steps which is great. So I think it would be important to note where some of those improvements adjustments and recommendations have been implemented.

**Greg Roberts:**

Yeah that's correct. I've been working over the past year or so with all the state agencies and many other actors to tell them these things are in the report what can we do? What can the state do to meet some of these goals? And I think there's a number of good things we're going to be able to put down that the state has done. And I think by listing what the state has done it helps sort of hold everyone's feet to the fire so to speak. About, you know, this has been the board's recommendation. How do we get these actually implemented so its not just a document that sits on a shelf and collects

dust. That there's actually outcomes and results from your work. So I really think that's a good way to go forward and it can also perhaps give a roadmap for other states and other people that are looking at things. You know this is how New York may have tackled this issue. So yeah that is the idea to go forward to list what's been happening with the scoresheet so to speak. So that the board can see what successes have been happening and maybe haven't been happening. So that perhaps more attention can be focused in those areas. But I know a number of board members have spoken to and wanted to ensure that the state is taking steps and that your hard work isn't just gathering dust somewhere. So I think its important that we make sure the word gets out there as well as the state response whenever possible.

**Courtney Burke:**

Agreed. So I don't think there is anything else on our agenda today. I know that we want to get the 2021 meetings established so you can get the date out for the January meeting. So weird to be talking about January already. But we wanted to make sure people can get those meetings on their calendars. So I think you're working on those now so let us know so we can make note.

**Greg Roberts:**

We will. And I think that some of our some participants the public members had a hand up and wanted to weigh in and comment. I think we are still running with a little bit of technical difficulties trying to figure out how exactly we do these zoom meetings, excuse me this is not a zoom a Web Ex meeting with broad public participation. But I want to give my email address out there. I know there is an autism board email address but I'd like to give my email address out there if the people of the public wanted to comment to please get those to me and I can get those forwarded to the board. So, my email address is Gregory g-r-e-g-o-r-y dot F as in Frank dot Roberts r-o-b-e-r-t-s at OPWDD dot NY dot gov. And I'll be taking that information that you get and I'll be forwarding things to the board as they come in. I know that – its my understanding that the OPWDD website did have a link prior so that families could reach out there and connect

directly with us. The OPWDD website was restructured a number of months ago so that link may have been down for a little bit. But its my understanding that it should be back up soon. But I wanted to make sure that my email address was out there so people could connect so that we can be sure we are hearing from the public. And that the information gets to the board members who are leading this charge and thank you very much for your knowledge and expertise. Its been great hearing from everybody and hopefully we can continue to make advances.

**Courtney Burke:**

Yeah this has been great. And I too thank the members of the advisory board but I also want to say thank you Greg and all the staff at OPWDD and the other agencies who are working to actually implement these recommendations. So thank you. And we'll look forward.

**Greg Roberts:**

Someone did want me to just. I'm sorry. I apologize. Someone did ask me to repeat that email address. So I'd like to do it again. It's Gregory g-r-e-g-o-r-y dot F dot Roberts at OPWDD dot NY dot gov. And I see Josie has wonderfully put it in the chat room. So that people can read visually – pick up things better visually rather than audibly and can see it there.

**Courtney Burke:**

Great idea Josie. Ok. If there is no other business. I hope everybody has a great holiday. And keep our fingers crossed about COVID staying low case wise in New York state and we're aiming for January so we'll get those meeting the 2021 meeting dates out soon. Anything else Greg?

**Greg Roberts:**

No I think that'll do it. You know we're going to be working hard over the next few weeks and months to get the information together. As I said I will be also reaching out to some

other experts in the field to run by some of these lists. And if any of the public has ideas about family groups locally that you are aware are doing great things we'd love to hear that. So we can make sure that everybody can connect.

**Courtney Burke:**

Great. Alright. Good to hear everybody. Good to see some of you. Thanks so much for the input today and the hard work. Be well. Thank you. Good bye.

Bye everyone.