Spectrum: Hi everyone, we're just going to wait a couple of seconds to let everybody sign on and get in the room. Okay, great we're going to get started hi everybody Thank you so much for joining our webinar today. Unfortunately, as you can see, one of our speakers is having some technical issues, but she has an audio so we're just missing the video, but it should be okay. Thank you so much for joining us. Welcome to today's webinar, we will be talking about the Lancet Commission. And this is featuring Tony Charman and Catherine Lord. I am Laura Dattaro, one of Spectrum's news writers I will be hosting a webinar today. So, we will have a question-and-answer session in the last 15 minutes of today's presentation, you can feel free to ask your questions at any point. Our speakers today are Tony Charman, Chair of Clinical Child Psychology at King's College London and Catherine Lord, distinguished professor of psychiatry and education at the University of California Los Angeles Tony and Cathy co-chaired the Lancet Commission that we will be discussing today. So, let us jump in. Tony, Cathy, thank you so much for being here with us today, we really appreciate it.

Catherine Lord: Alright, sorry about this, but I'm here.

Spectrum: Okay, as long as we can hear your lovely voice that was good. So, I guess, for the first time to get started, can you give us up kind of an overview about what the lens that Commission is, and you know what its goals were as a group, and how the group puts them together.

Tony Charman: I'll start and then I'm going to jump in. So, I was approached by Lancet who identifies issues that they want addressed and that they think are worth a whole commission, which is like a supplement to Lancet.

CL: And so, they asked me, and I asked Tony to join me as Co-chair and then, together with the Lancet editors we identified an international group of authors and I could share the screen, if you want me to largest to list. Sorry, it falls so that is better then. Reading off a list I think what's different about this and other things is that we really did try to get people who represent. A range of both providers stakeholders' parents and people from different countries, so we actually covered six different continents and I think 13 different disciplines, including autistic stakeholders and parents, as well as various kinds of providers and researchers.

CL: Great and we are there.

Spectrum: Were people with autism and their families on the Commission as well?
CL: Yes, there were so there were three autistic stakeholders, and I think about for parents, as well as a couple of clinicians and then a couple of more basic researchers and then a lot of clinical researchers.

Spectrum: Excellent.

CL: And this just summarizes the process.

Spectrum: Can you tell us a little bit more about that, and how did, how did you bring all these different perspectives together, especially during the pandemic.

CL: So we, I mean we were lucky because we finished in person meetings right literally the end of February in 2019 so we had three in person meetings we I just raised money for these from not for profit family foundations, as well as I see Jessica and autism speaks and several in next for autism all gave us relatively small sums, but it added up to being able to pay to bring the group together three times so we met in person, three times and then after each of these meetings we divided into committees and the committee's wrote different sections, we tried to group and agree upon recommendations than everybody reviewed what everybody wrote and in the very last meeting we presented this to three formal reviewers who also wrote long reviews. We went back again revised it and then, if anyone is dealt with Atlanta before you know you then revise it now multiple times again for grammar and all kinds of things and in the end, it was finished last December.

Spectrum: Quite a process.

TC: What it is, I would just kind of add Cathy that I see, and it was it was February 2020 it was it was two years ago next month that we have. All the files in person meeting in in London, so it was literally just as things were beginning to close down, you know so we were lucky didn't mean that we could have a mixture of the in person, meetings and all the electronic communication that you know. That also sort of goes along with that, so I think that was that was an important part of the process, so we can have some open discussions with the whole group there you know, in person, as well as to electronic communication, so we were looking back you know we look back to those meetings in that pre pandemic gear with gratefulness.

Spectrum: That is good timing um, and so what we're when you set out sort of were there any goals are like guiding principles that you used as you begin this process and who, in your mind was the audience for this report.

CL: I think that we, one of the things we decided to do because you know there's been a huge increase in research, you know autism, in the last 20 years was focused on what could research what information could research provide that would change the lives of people who are here now, so people who have autism now and their families, so I think that was a big push I think we also decided we wanted to use research that was from the higher income countries, so we didn't want to throw out anything even if it was very specific to countries that have a lot of resources, but we also wanted to constantly keep in mind both countries that have less income and less
resources and also segments of all of our populations that are under-represented in research and under-represented in services Tony you want to add anything.

TC: I think you know, one of the other things that's a challenge with the way that the editor at the Lancet the senior editor, who is dealing with us, looked after us sort of you know very well, right from this from the staff and the discussions, she initially had with Cathy and then with the rest of the group and myself and, in some ways, you know Lancet commissions are supposed to be speaking to a wide range of audiences that you're supposed to keep in mind you know we certainly had that in mind all the time to try and speak, which is a challenge, globally, that not just speaking about high income countries, or you know, North America, Europe where Cathy and I happened to come from, which is why we had to sort of global sort of representation from six of the continents and then you're also sort of thinking about speaking to the clinical community, the research community policymakers family members advocates and sort of broader sort of influences so on and that's a challenge because I'm trying to write something that can communicate to that wide range of audiences, you know is never sort of easy, but in some ways, you know we were asked to be very broad in scope and that's what we've tried to deliver.

Spectrum: Mm hmm that makes sense, so what I know there is a lot in this report, the final report is 667 pages so there is quite a lot there, but what I guess in your mind are some of the key recommendations of the key ideas that came out of this groups work.

CL: Tony, do you want to start?

TC: Why don’t you start because that is very much your baby Cathy.

CL: So I think what we wanted to do a one of the things we wanted to do was there been a lot of evaluations of what research we have on evidence for the effectiveness of treatment and I think there's there is a lot of research about effective treatments, but we wanted to figure out how you actually implement that or use that in a new healthcare model, so what we came up with was the idea of stepped care, which is not our idea, but the idea of trying to help people think about what are we trying to accomplish when we have intervention or support for a person with autism. And we wanted to be focused on that, as opposed to, for example, basic research or even assessment in the sense of what do we do when we meet a person with autism. What are we, what are we trying to accomplish and we then developed a step care or personalized health model, which was the idea that you can include not just cost to the system like How much is it cost your healthcare system to provide this service but also cost to the person and cost to the family and preferences, because we know that if interventions are what if people do things that they are interested in doing they are going to be more successful. So that that was that was an idea and I think one of the reasons it is so important is because autism is so header and unique genius it's you know it affects people who can't talk for themselves to people who are very, very articulate and need very specific kinds of supports we're also conscious it's a developmental disorder and so that it really changes. From when someone is identified two or three or four to the needs of a four-year-old and how do you incorporate that so that we have a better understanding of what's going to work with WHO.

Spectrum: Tony do you want to add anything there?
TC: One of the other slides that we've prepared but, but one of the important things about this about this sort of process is this is something, and this sort of individualized sort of step care approach is something that can take what we know we can do and what we know in many communities can be done well. But it makes the process sort of better, so this can apply to thinking about what are the, how do you do assessments, who does assessments in what context, what you know what are the steps that you take to do assessments and what are you looking for from doing an assessment in fact what we did, which too many may seem a small sort of changed but we started talking about how this applies to intervention and support and treatments, rather than sort of about how it applies to assessment so Cathy you probably can walk through this where these are just schematics that show how this way of thinking which can be applied in different healthcare settings in different contexts in different communities that will have different personnel that will have different resources, where the individuals. Who are who are coming for the for the assessment or requiring supporter intervention will be different their family in their community will be different. But this is a process that can be applied within a broad range of context, so we hope we hope that it's what will help many communities to develop sort of models of care is not call them here in the UK or pathways that can be applied in in a wide range of settings in many communities.

CL: So, Laura can I show a couple slides. Sure, so I think just to just exemplify what Tony just said. Part of the issue is that we do with very young kids often we are treating core features of autism so, for example, we're trying to help a child, with social communication, but often we're also treating other things, so this is just an example, I think, Tony said. Where if you are, if you had a minimally verbal child in a lower to middle class country that does not have a lot of resources, you would start on the left with what are the priorities for this family. And what are you trying to accomplish with treatment and one of the first issues that you might see if you're as you're moving to the right is safety, I mean a family might be worried about this child eloping, but we also need to consider how old is this child if the child is to down the whole they're not going to be left alone very much, but it also may be that the child might be, I mean a five year old it might be that families were thinking they're going to be able to go to school, but at school, if they're going to elope, we need to have safety. We also might consider how severe this child's functioning is the child is functioning at a two-year-old level than we need to. Have goals that are appropriate for a two-year-old and to consider where at home, everyone is happy with this child. And are moving forward with basic skills, but trying to incorporate this child into a school is difficult. And is the child socially motivated It may be that this child loves to be around people, it also might be that the child gets easily overwhelmed so then we move to the very right box. Which is considered again, not just for the hospital system or the medical system, but what makes the most sense for this family, and it may be. That, for example, home based support for the family, makes a lot of sense but of the family, for example, thinking about people in New York who have tiny apartments It may be that sending someone into the home to try to do intervention is much less appropriate than finding this child at preschool and working in there. You know, a reason example is that CMS, which is the U.S. governing body that controls Medicaid and social security said that you cannot use Telehealth they have retracted that. But it often we have found that makes a lot of sense to have a first visit via zoom where families can tell you about their child without bringing them all the way to a clinic and parking them somewhere, while you are talking to the parent. They can also show you their home they can
show you that child and then bring them in. And so, trying to say to healthcare systems really think about this and how it makes the most sense for the family, the second case would be a 15-year-old, who is very verbal, and it was very socially anxious. And here you're not going to be treating so much the autism per se, but we want to reduce that anxiety and it may be, for example, that if you can move from the Left. That this family is really looking for medication and if that's what they want, we need to figure out. What medication would be helpful if any and also help them understand if there are other strategies other families may not want medication at all. We also need to know from the 15-year-old, what do they want in terms of motivation and then consider you know with this with this young teenager benefit from being in a group. And would they enjoy that, or would that be harder so trying to incorporate in this model not just is it cheaper for the system, but also what are the, what are the preferences of the individual and the family. And also, what are the needs of the individual and family, because they are so different across different people with autism.

Spectrum: That's I think that example of how the insurance companies in the U.S., are you know waffling on Telehealth is such a so illustrative of how you must work within different systems and different countries and to try to try to make things work the way, like we can't necessarily do exactly what you would like, depending on what different countries policies and setups are. And so let's talk a little bit about some of the research recommendations that were in in the report, because I know, there was a lot on how we can have a better understanding of you know which therapies are more effective, for which children are which people with autism, can you tell me more just about what kind of recommendations, you made there, I mean how you see that affecting the research community.

TC: So um, let me start off with sort of that, I mean it was Kathy's already said, one of the you know, one of the things which is on you know. Which is positive in many ways, but also a limitation is it is not like there has not been plenty of research, at least in high income countries, you know into interventions of one sort or another in the past 20 years. In fact, you know, there are a lot of studies and a lot of trials, including randomized control trials which we know which provide at least. For some sorts of you know interventions can provide the least bias sort of sources of evidence. But it's also true the panel felt that the group felt that the research that hasn't been done hasn't provided the ounce the answers that we need, in a way that we need them and sort of this partly speaks back to the sort of personalized sort of step care approach but also is thinking about autism is a spectrum where there's great variability or heterogeneity between individuals, you know who have the diagnosis and the way that we've sort of already described and also between individuals at different points in their life. And some of those other questions that we need most urgent answers to you know, have not been as well addressed as they need to be so what we've tried to call for both to researchers, but also to research funders is to be a bit smarter about the kind of studies and trials that are set up, you know some of the basic questions that would be useful thinking, for example for many young children with autism about early intervention often focused around improving social communication abilities that are important for the young child and for those who care for them that you know some of the basics, are the questions around what works best for whom how long intervention should be how intensive you know intervention submit, and should, be they have not been sort of well answered and that we have a lot of evidence from randomized control trials that test one intervention against a sort of what we call a waitlist control or care as usual treatment, as usual, control and that that design is
helpful to identify interventions or treatments that may be initially beneficial, but they don't necessarily answer those questions about, for whom it works better how it's going to work in particular community contexts and the different sorts of design, for example, the compare different interventions against each other or designs that are much more targeted at Community effectiveness and community into implementation you know, are the things that need to be funded and researchers, need to be interested in answering those questions and that that needs some coordination both between research groups. In many communities and across the globe and between certainly national funders of research and then there's another sort of set of questions which are probably things that we just haven't got. We haven't done enough research on which is most of the intervention research in autism has been focused on children quite a lot of it, but not all of it on younger children and understanding more about interventions that are appropriate for the whole spectrum of individual autistic individuals in adolescence and adulthood, and indeed even older adults are going to be important and then work is just beginning is how interventions can work, how they can be used in low resource and lower middle-income countries and some of the group on the Commission were involved in some of that and we know that is going to be important for the scaling up that's needed to do for intervention and support evidence to translate globally.

Spectrum: Cathy, would you like to add anything?

CL: I think, just to do what Tony said, I think, part of it is we need studies that are more organized from the top that involve larger samples because we're current investigators have a particular intervention that they're very you know committed to, which is a huge job. They tend to look for a sample that is going to show the biggest difference from their intervention and to restrict who comes into this study. So that they will have the most likely effect, but then we don't know who this is going to work for and even a smart design, which is very clever. Where you start with one intervention and then you randomize people, depending on how they do in that intervention into another intervention has the potential to look at when did the event intervention, who did the intervention work for but people haven't done that, because they don't have large enough samples. So, instead, what they've done is compare intervention one to intervention to instead of well who did this work for and who did not. And so, somehow we need funding mechanisms that encourage people to have large samples and to compare across treatments and that's just not the way at least the US funding works. You know we're really most people are looking for the biggest bang for the buck, and what we want to know is not, you know how much this intervention works, but does it work better for. Child X or adult why and do we need 20 hours a week, do we need once every two weeks, I mean. So very practical often boring questions that really do have very direct implications for what families need, I think the other thing which Tony alluded to, is that if we knew this better we could provide more information to people around the globe who are trying to adapt interventions to be appropriate to their cultures. And not that they have to do exactly the same thing, but if you have no idea if 20 hours a week or 30 hours a week or two hours a week is appropriate, you don't even know where to start. And I think that that is really important, and we could do a better job like it cancer centers in the US, where you do have coordination I don't know about the UK Tony back there you do have coordination across multiple centers that allow you to get sufficient sample sizes decisions about who does this work for you.
TC: Let me just sort of add one other sort of point and it's you know it is and there's a panel in the Commission report in The Lancet and which is just talking about it's talking about the vulnerability of parents or caregivers to non-evidence based treatment so. Partly again, you know, in a global context, but we see this certainly you know I know from you know from Cathy and others in North America, we see it here in the UK and in Europe that also it's true, and this is no true many sort of parts around the world that parents and careers can be vulnerable to miss information about things which are presented, sometimes as possible cures or treatments for autism, for which there's no evidence base, and in fact often some of these either maybe potentially dangerous or, indeed, some could be literally sort of dangerous and just thinking about educating on communities and parents and providing information for practitioners in all communities around things that should not be recommended around things that parents need better information on and sort of I suppose one of the things that we, you know that we're very conscious of throughout the whole sort of Commission and we'll come on to this because I know we'll be talking about profound autism which we've also talked about in this sort of condition, that is, and to think about underserved and vulnerable sort of communities and thinking about interventions, alongside the need for. For better and smarter and as Cathy said more coordinated, probably top-down sort of programs to be developed and sort of funded it's also important with the knowledge that we have now to guard against sort of potential exploitation and disadvantage to vulnerable careers and parents.

Spectrum: Yeah, that makes a lot of sense.: And what um what are some of the I guess like a lot of these ideas of having sort of bigger studies multinationals and that sort of thing. Are there sort of like practical steps to go from there or is our you know, like it, it seems like a difficult thing to make into a reality, do you guys have thoughts about what might happen to make that become more realistic in the future.

CL: We're not in charge of funding, but I think I think encouraging you know funding agencies to consider this that this is, you know it mean very much of funding.

CL: At least in the US, and I think in the UK an investigator is initiated like I have an intervention, I want to prove it works. And so I go to and I ah or herself and I propose it, and I think what we're saying is, we need to move beyond that we need to you know take something like that Nice guidelines are some of the and say what do we need to know about interventions and who they're going to work with and where they might not and what are the practical questions, I mean, for example, just dose. You know how much do you, you know, can you do a parent mediated treatment that is every two weeks versus a parent mediated treatment that is twice a week and when do you need one and when do you need the other. And can you do it by Tele health in you do it in person, what are the components, but how does that relate to, for example, the child. As opposed to the investigator, as opposed to like my treatment versus Tony's treatment, what we really want to know is how does it work for a nonverbal three-year-old versus a very verbal three-year-old or an eight-year-old or 12-year-old or an adult, so I think I mean I’m floored well I don't know if it's unfortunately we're not in control of that. But I think it is going to require moving beyond the typical way that we fund research which is, there are studies like this, but they tend to be underfunded small studies and not considered on the degree of, for example, like the cancer centers in the U.S., where you can propose a new intervention or
new treatment and say I want this across you know 50 centers and we need to see if people who have X or y benefit from this.

Spectrum: Great um so let's talk about the report also introduced this term of profound autism, which Cathy you talked about, probably in the past but it's sort of was I guess more formally introduced here. Can you, I know you thought about this for a long time Cathy, can you tell me sort of your thought process behind this and what the term is intended to me and how you know I guess you know who would use this term, and what sort of intended for, I mean, I think we're proposing a new term we are not proposing a new diagnosis, housing and administrative term and the primary goal.

CL: I think that we still feel like there is an autism spectrum, that is huge and that the important things about this spectrum are both the range of people that in effects, but also, then the Co-occurring disorders, or lack of co-occurring disorders so we're not changing that, but what we want to do, and I think where we're moving toward, at least in the US is we're beginning to have discussions for DSM five about not having a new diagnosis, but having a different way of organizing severity or severity of functioning so to distinguish that but between the severe yet functioning as opposed to severity of the individual symptoms but I think the concern arose because much of the media attention and have high proportion of certain kinds of research, not all research is really focused on people with autism, who can speak for themselves which might include even five year-olds. And part of it is simply hard to do, for example, imaging somebody who can't speak and you can't explain to them what they're doing being stuck in an MRI. So we worry that there is not sufficient attention to the fact that there is a significant and I think it's typically a minority of significant minority of people with autism who need considerable support so really need 24 hour support they don't need someone telling them what to do for 24 hours but they really can't be, for example, left alone at all. And that is very, very different than you know, for example, the images of autism that you see on TV where you have very verbal articulate people who have problems in living. What we wanted to do was try to figure out a way to identify this subgroup who needs more support and the particular relevance for systems is there have been arguments are in the US, for example, that say that, for example, additional funding in the build back better but bill from Biden, which is not happening, but was going to go to home base caregivers but not to caregivers in congregate settings so, for example, we have I have patients who live on a wonderful farm. That is for people with autism and developmental disabilities, but that would not be eligible, because it's considered an institution. We are not recognized for recommending institutionalization, but we realized that some people are going to be better off in a farm that has 24-hour staff, then they will be living. In they can't live, for example in a supervised apartment where somebody just POPs in you know, once a day to see if they're all right. And so we want to be sure, and these people cannot speak for themselves, and I've tested self-advocates can speak for them, but sometimes they do, and sometimes they don't. And so we also are trying to just push the self-advocates a little bit to be aware, there are other people that are not as articulate and not as smart, as they are, and these people were talking about mostly do not use, for example, facilitated communication or supported communication they're really need, we need to be able to listen to their parents and their caregivers and I do have a slide here. If you want to show it, which just shows we looked at three very different samples and one is an epidemiological study of people with autism and other disabilities in Norway one was a snap study, which is a basically population-based study in the UK and one is my own early
diagnosis study, which is people referred for autism at 230 years ago and This just shows the proportion, you see, in the blue who meet these criteria for profound autism. For criteria we picked an IQ under 50 or minimally verbal status and one of the things we were able to show is that this is really quite stable. After ages about eight to 12, so we are not recommending using this term with very young kids you can't tell who is going to fall in this category, with a three-year-old. But by the time kids are in older elementary school, you can and families can begin to make decisions about the fact that these are kids that are going to be needing more support, it also turns out that there are proportionally more females in this group, then you might expect, and there's a proportion of a variety of other things, for example, epilepsy and genetic disorders, so we want to be again aware that this is just a group that needs different services, I don't know Tony what did I forget?

TC: Well, I you know, and I think one of the other sort of considerations, you know, and we know so emphasizes that have before, but if it is you know we were we will wanting to sort of promote on an inclusive a broad sort of set of recommendations that would that would address some of the heterogeneity that comes with how variable autism as a conditional sort of can be in different autistic individuals. And, in some ways as Cathy says, this is not proposes a new diagnostic term we know we've used the terminology we're posing as an administrative term. Partly as Cathy said, because these individuals who fit the criteria that we've that we've used to define and the samples that you can see, on the slide in front of you that you know that's and those individuals, you know are autistic individuals who are going to need know you from later on in childhood you almost always to adult life very high levels of care and indeed a very vulnerable and often very underserved sort of communities yeah, certainly in the UK people you know the audience and UK will be very familiar with various scandals over the past 10 years and still be replicated in countries right across the globe of individuals with intellectual disability and who also have autism, who have been abused and, in some cases, resulting in you know not just significant injury and death in care home settings and other sorts of settings and that we thought it was important to give this a name and not everyone is going to agree with the name the group discussed this at considerable length and this was the best that we were able to do and that it's a it's a way to say communities should be counting individuals who have this presentation, you have this level of need, because they're vulnerable because there's no because they're underserved we care about social justice, and these are individuals who societies and governments and institutions systems and institutions should be looking out for, and in fact we're also wanting and put a call in the published paper that researchers need to specifically focus particular questions on addressing the underserved needs of this very large group of individuals on the autism spectrum.

Spectrum: Excellent um and Cathy, you can go out and screen share mode here. And then, thank you, and so we have a lot more questions on the preferred autism and various other things, but in the last couple minutes here before we go into que, I just wanted to ask sort of what feedback, or what responsive even seeing what has been happening, since the report female and are there any next steps for you, with this work.

CL: Like one next step is we've had a request to try to translate the document into plain language. And so I think I am going to try to do this and then pass it on to Tony and then everybody else as soon as I get to run and to try to produce something that is not written quite so
technically, so I think that's a request we've had a request for hard copies, and Lancet is going to make hard copies available not millions, but I think thousands and so we're hoping in this spring, those were will be available for people that want them. I think, for me, I don't know Tony you can speak for in the UK, but I think I have had a number of requests like to talk to NIH and talk to various agencies, and we hope this will stimulate some discussion, for example, about research funding about again what works for whom when and how to answer those practical questions and then we've had a lot of feedback about profound autism I think both from predominantly from parents who are very appreciative of the fact that we are trying to recognize their children or adults children and then also some concerns from self-advocates that we are that you know that this may confuse the issue. And we are working with DSM-5, which is a very common I mean APA is a very complex organization, but we're beginning to work with them to see what we can do there.

TC: Well, I you know I mean just from the electronic communication with the other Commissioners from different parts of the globe, you know, we know that people are you know, on because it was only published. Early in the beginning of sort of December, and then there was the holiday sort of season so it's still know it's still recently still live, and you know we are know that many of the Commissioners are presenting it to national bodies, and you know we. We always saw this as a as a document and a set of you know lots of sets of recommendations aimed at different audiences we search funders policymakers practitioner groups and the broader sort of community. And that that we are hopeful that some of the messages will continue to have an influence and affect them and be part of the conversation that happens in you know within many national communities, you know, certainly that's that that's work that many of the Commissioners are undertaking, now the beginning of 2022 after the reports being published so we think this is the beginning of a process, and we hope it's going to be ongoing, you know we and we will be working on a more accessible sort of salary, because we accept that the 63 page slanted articles quite dense even for those of us who spend too much time reading those sorts of things.

Spectrum: I'm great well, thank you, I'm this isn't my interesting discussion and I just wanted to address because I've been a couple questions about this. This webinar is being recorded and will be put on our website, along with the transcript um I usually just takes us a couple days to get it up there, but it will be there on spectrum news.org so this can be re watched and you can read the transcript once it is available. Great so I'm going to go through, I we've got a lot of questions so we won't be able to get to all of them, but I will try to touch on a lot of the themes that are coming up here. There was a question here, I guess, about this recent discussion can you say more about what you're working with the ap APA on with regard to the next edition of the DSM I guess would be the DSM six now right will be the next one.

CL: Well, there's going to be five point I guess 5.1 is coming out.

Spectrum: Right, some of these like some edition.

CL: The APA is a very is the American Psychiatric Association, it is a very complex body of people and so like I am not in charge of that. But we did approach that committee on ABA about changing things and in discussions there, it seemed like the immediate possibility was we might
be able to introduce new ways of looking at severity levels, because nobody is happy there, there are currently severity levels of function. In the in the DSM-5 autism section which I don't think anybody is happy about, and so it might be that we would be able to change this and have something the equivalent of profound autism in this severity levels, but it is it, this is a multi-layer bureaucracy, and we are the bottom layer, but I think we're trying to figure out how we can make this more palatable to everybody, but also again make sure that we try to represent.

CL: The people that cannot necessarily speak for themselves.

Spectrum: Mm hmm that makes sense um and can you clarify this is an interesting question can you I guess I just read out loud, to what extent is profound autism kind of independent from co-occurring neurodevelopmental neurological conditions such as intellectual disability or epilepsy. How do you sort of distinguish the two or is there not really a distinction in your mind.

CL: Why not go ahead, Tony.

TC: Well, let me say, and then and then Cathy, you may will disagree, but actually I was just looking up early this morning UK time and I'm just reminding myself, because I remember when we were writing this sort of section that because DSM five the APA diagnostic castigation, does have these clinical specifies that we speak about an intellectual ability and communication ability has a very complicated sort of substructure under the under the autism spectrum disorder sort of condition, but one of the one of the classifications that certainly you know.

Spectrum: No one that I know, yes.

TC: Yes, it's the international Classification of Diseases so called that's the WHO medical classification system that's used in many other parts of the world, and it has autism spectrum disorder with disorder of intellectual development and absence of functional language well you know. It's a little bit you know I'm sort of similar to that and I think we were thinking about the profoundness being based. In a sense, on people's intellectual ability and functional communication skills, but also on the care levels that they you know. The big that they are likely to require and the vulnerability to those individuals have, and you know, so I think there's a way in which you know overlaps with some individuals found autism would have epilepsy, but many individuals with autism would not some would have associated neurological conditions, some would not the presence of co-occurring conditions in India across the whole spectrum is very high, the presence of co-occurring conditions across the board is probably higher in individuals with what we've described as who meet our criteria for potential profound autism, then, and then in those who don't but it's not defined by those is defined by our criteria around the functional sort of capacity that the individuals have.

CL: I think the two things I'd add is one is, I think that there's something called zips laws, the IPF, which is that people need short terms, so, even though we have autism with a company's you know severe intellectual disability people don't use that and so we need something that's easier for people to say and I wouldn't defend to the death for term profound but we tried to come up with something that left available severe so that there could be somebody who has very severe autism but doesn't have what we're talking about doesn't need 24 hours support.
t I think the second thing I would say is, although we are talking about the overlap between autism intellectual disability were very severe communication delays or disorders, though those are not apparent often when kids get diagnosis, so when kids get diagnosed in preschool. We don't know who's going to have severe intellectual disability we don't know if they're going to learn to speak necessarily. Until kid people do get autism diagnoses first in certain cases, and we want to be, we want to acknowledge that and many families are really wed to the concept of autism, although their kids also have intellectual disability which becomes apparent later or severe communication disorders, so that was the logic for trying to say, this is a subgroup of people with autism, or at least I shouldn't even say a subgroup it says it's a severity level in terms of needing help and then why we came back to IQ and language level is just because those are dark those are numbers that are documented in medical records and in epidemiological studies so you can find people that way, but we really are talking about people who need 24 hours support which just isn't in a in a that isn't accessible through medical records.

Spectrum: That makes sense and there's a question here about why the you cited, you know, three different data sets kind of trying to measure the prevalence of this. Why do you think the number was so diverse there was quite a wide range and um Does that mean anything about how it might be used in clinical practice, perhaps and consistently or you know what, what do you make of that wide range?

CL: I think it's really important to realize, there was a huge range and one of the things we are conscious of was also for people from lower middle-class countries. The people with profound autism are the people that need are getting diagnosed, I mean that's not necessarily good because it does mean that we're missing a lot of other people, but when people. Are people from South Asia and from Latin America and from Africa they're saying, these are the artistic people that we see. And so we want to recognize that that's quite different than from in the US, where the latest CDC reports much smaller numbers. And you know the high proportion in our study is because we are talking about people who were referred for autism at each to 30 years ago and that's who is referred, I mean about half of our sample is people who are minimally verbal the other half are a huge range, whereas that's not true today, I think the other thing we learned from the study was that they are using nor registries of autism that are predominantly, I think. People go into registries predominantly by a psychiatrist entering people, so they had much smaller numbers and because there was a study testing preschool kids. We found out that many of the kids that would have had profound autism diagnoses aren't even making it into the registries and so those registries are not necessarily representing the full range of autism so and then snap is sort of in the middle Tony you can talk about it.

TC: I you know I've you know you know snap as a do I mean you know each of the studies have it as a different sampling design and none of them were set up to measure this concept, which we know which we as a group sort of you know constructed they've given us sort of name to you know for the clinical reasons, you know, and I think for the social justice reasons that we've you know that we've sort of outlined. And you know I would be sort of you know I’m on this point, which is rare for me, I would be optimistic that actually the term is out there, at least for researchers and I think for. You know, for service providers in many communities, they can start doing something about this and I think it will be good if many other research groups start looking into their own data sets and start thinking about these issues, you know. In more sort of detail,
we did that initial piece of analysis, because it happened to be that three of the Commissioners had access to the you know, to the research data sets that we had from different studies that were collected for different purposes, but they did help us speak to this sort of question and we felt it was helpful to at least present some data to indicate that this was not a very, very rare small sort of subset of the whole autistic spectrum that we were talking about. But was actually as Cathy said, you know, probably different in different communities for different reasons, but a significant sort of group of individuals who you know who are both vulnerable and he's needs a currently in most communities badly underserved so, so I would see that as a positive and I think you know and it's the first publication, to mention profound autism in this way into present some data. But we all hope that it won't be the last and the many groups would be looking at their own data to understand what it may mean for them.

Spectrum: And a few people are asking, can you just remind us what those three data sets are again like what those acronym stands for.

CL: Their mobile is mothers and babies so it's a study of 100,000 consecutive pranks pregnancies in Norway, where they followed the pregnancies, all the way up to I think some of the kids might even actually be 20 now they're like between 10 and 20 but there that's everybody. And then they went back and counted how many of those kids ended up in registries as being labeled autistic um I actually I forget.

TC: SNAP is a cohort for myself and colleagues in the UK, many Simons often others, he was on the Commission, you know, have been studying so, and this is the special needs autism project and in South in the south of England we were the first group anywhere to report. As many as one in 100 children had autism in 2006, and this is the population that we studied, then in mid chartered who are now in their mid 20s so we followed them through to middle of their 20’s to young adulthood and we've looked at their outcomes to define the group who, who have the level of need, which we've used to define the profound autism so that's a different epidemiological population sample of initially children with autism, who are now in adulthood and then, our earth ED access for early diagnosis and this is not an epidemiological sample it's consecutive referrals at age 230 years ago for possible autism.

CL: And we have followed up this group of people who are from Chicago North Carolina and Michigan into their early 30s so it's a very different group than either of the samples and is not representative of the population at all it's just who got referrals at 230 years ago that makes us.

Spectrum: And we just Oh, we don't have much time here at all, but there was just one quick question I guess about when we talked a lot about interventions earlier what kind of interventions are you talking about are the specific examples of things that are being studied.

CL: I think we're talking about both early intervention so naturalistic behavioral interventions that could be a host of different things, but we're also talking about things like CB CT or peers or social groups or psychotherapy so really any kind of thing and again trying to figure out when does it work for when, for whom how much do you need.
Spectrum: Mm hmm that makes sense. Great and in our last minute here my favorite journalism question is there anything else you would like to add.

CL: I mean we one of the things that we wanted to emphasize was just the importance of neuro diversity and the importance of recognizing. That people with autism do have strings and that we want to be sure that we remember that and hope you know that we know a lot. We know a lot about what we can do, and often we're just not doing it well, and so I think that's a good way that if we use the information we had we could help people.

TC: I think I think that's absolutely right so you know we have a set of nine key messages on the front page of the landed Article one of those you know is that valuing autism and neuro-diversity benefits society as a whole and that's something as the group felt very strongly about, and we wanted that to be. In that very first page of the key things so you know the other thing we haven't mentioned, is that you know this is urgent, 78 million people around the globe have autism most do not have access to the services they need, and you know we hope this is going to be part of a wake-up call that we can as societies across the world do better.

Spectrum: I think that's a great note to end on, and I really appreciate you both joining us and all of our attendees and I just want to remind everyone.

Spectrum: A complete replay and recording of this webinar will be available on the spectrum site in a few days. We also have this webinars part of an ongoing series, we have webinars regularly on a variety of different topics, so please check our site for upcoming webinars and we also have a video archive of past discussions. So, thank you again everyone for joining us, and thank you, Tony and Cathy for being here.

CL: Thanks Laura.

Spectrum: Have a great day.