Institute for Community Inclusion-UMass Boston

Expanding the Dialogue on Autism: Reflections on Research.

March 7th, 2018

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>> Hi, everybody. Thank you for being here early and filling out this poll so we can see who is attending. We are excited to see everyone on the call. We will get started in a couple minutes. While we are waiting, I will also include the link for the closed captioning. Anyone who needs to access closed captioning... now, I am having trouble sharing my screen. Sorry. Hello, Allen, from Reno. Hopefully people are getting ready here. I am having trouble sharing my screen. Anyone want to help me do that? Alvero or Katie?

>> You want to select your zoom application.

>> Are you in full screen? If you are in full screen, move your mouse all the way to the top ‑‑

[Presenters preparing for meeting]

>> Rebecca: Thanks for your patience, everybody. I can see others are seeing and hearing us and that is awesome. Here we go!

Here we go. I don't know how we are doing on the poll. Do you think we can close that? How many people have answered? People are still answering. Why don't I talk for a minute.

>> Hi again all, and thanks for   
joining us for the first webinar   
in our new autism speaker   
series. We’re really looking   
forward to some wonderful   
discussions.

We will have five Webinars and today we are talking about education. We have advocates for people with disability, agency staff, teachers and researchers on the line, so welcome to everyone.  
I’m Rebecca Lazo from the   
Institute for Community   
Inclusion, or ICI. We’re hosting   
these discussions as part of our   
50th anniversary celebration,   
and because we’re committed to   
expanding the discussion around   
autism and developmental   
disabilities.  
Before we get started, I want to   
run through some quick   
housekeeping items.  
I am going to end this poll. I am not sure if it is in the middle of everyone's screen or not, but there we go.

For anyone new to zoom, or has questions about how to get around, I made this little diagram for you. We want to make sure this black bar is available and you can navigate, whether you are seeing a chat box, and mute it, and I think everyone is muted. You want to make sure if you are putting in a question for our staff here at ICI that you include all attendees and panelists so the question goes to the whole group and not just one individual. Make sure that blue pull down Dropbox is all panelists and attendees. If you have questions about how to use zoom, or questions for the panelist, we invite you to put them in the chat box. We have people monitoring who will answer about technology issues as we go. Questions for panelists or presenters, we will hold until the end. The panelists will be ready to answer those questions.

Also, I want to note that in the   
disability community, there’s   
disagreement around the best   
terms for talking about people   
on the autism spectrum. So   
during today’s talk, you might   
hear folks say “autistic   
people,” “people with autism,”   
or “people on the spectrum.” For   
this series, it’s fine to use   
whichever of those terms you   
prefer. That goes for our   
presenters and also for anyone   
posting in the chat pod.   
Now I’d like to introduce Tom   
Sannicandro, the director of the   
ICI, who’ll be moderating   
today’s discussion. Since this   
is our first event in this   
series, I’d like for him to   
share some context and   
background about the purpose of   
the series and why the ICI   
decided to launch it. Tom?

>> You are muted, Tom.

>> Tom: There we go. Thank you, Rebecca, and thank my panelists and everyone who is on the line today for coming out and being with us today to talk about these very important subjects especially I want to thank the team at ICI and Rebecca for heading this up. There is a lot of work that goes into this process that you can imagine, and we are all spread across the country as we do this which is kind of an exciting thing that is happening.

First off, this is a series that is part of our 50th anniversary celebration of the Institute for Community Inclusion. We thought a good way to celebrate would be to have an educational speaker series that would be informative as well as to showcase the expertise we have at the ICI. This series will be a chance for us to get beyond common stereotypes around autism and to open up to a much richer conversation.

Today our panelists will be discussing issues around education and autism. Now, back to Rebecca to introduce today's panelists.

>> Rebecca: Thanks, Tom. With us today we have Stephen Shore is a clinical   
assistant professor at Adelphi   
University. He has an EdD in   
special education and is a   
nationally regarded scholar   
around autism, as well as being   
on the spectrum himself.

Julia Landau is a senior program   
director at Massachusetts   
Advocates for Children. She’s a   
specialist in special education   
law and provides workshops for   
parents and professionals.

Ned Pavlak is a student at   
Holyoke Community College.

Ned is also on the autism spectrum and he will be sharing some of this experiences and thoughts about education disability. We also have  
Maria Paiewonsky is a transition   
specialist here at the ICI.   
She’s an expert on involving   
young people with intellectual   
and developmental disabilities   
in research about their college   
experiences.

Welcome, everyone. Thank you for being here. Julia, we need to make sure you are on camera. Tom, are you ready?

>> I am ready. Panelists, glad you are here. What I am going to do is ask questions and ask each of you to weigh in. What I will do initially, at least, is to call on you directly just to keep things flowing more smoothly since sometimes it can be a challenge to figure out who should and shouldn't be talking at this point.

The other thing is don't feel obligated to answer or to respond to any of these. On the other hand, you may feel like you really want to get pretty involved with some of these questions as they come out. Feel free to do that. We will try to keep on a reasonably tight schedule. We will continue with this question and answer period until 2:50 and then open it up to questions from the audience.

The first question I want you to think about is: Let’s talk a bit about some   
myths and facts regarding   
students on the spectrum. What’s   
an example of a common belief   
about students on the spectrum   
that’s just not accurate, and   
what is the reality?

Steven, would you like to start out on that? You have to unmute, Steven.

>> Steven: There we go. As an autistic individual who was a student, and also who has students with autism in my classes, there are so many myths out there.

One of them is that all students are ‑‑ all people on the autism spectrum are visually oriented. I think the best way to look at learning styles is that why we know us autistic individuals are probably visually oriented it isn't necessarily so. What we can say is whatever that learning style is, it is probably going to be to an extreme.

>> Tom: Great. Julia? Everyone has to unmute, I guess, since we are ‑‑ maybe we can unmute all the panelists at this point.

>> Julia: Sorry about that. I think one of the most largest overarching myth is just these assumptions that get created about the lower competency of people with autism. You know, when people see the different modes of communication, or different behaviors, there is assumptions made about the lack of competency all together.

I want to give a couple example of what we see time and time again where we have to represent students and families in legal cases because of these assumptions.

We have a lot of families who want to focus on more inclusive options for their kids who have autism, and sometimes the district will believe that a child needs to be segregated in a pullout setting because the child is too distracted. This is based on the myth because the child isn't looking at the teacher and establishing eye contact that the child isn't paying attention and learning. Then we have had to get experts and argue and demonstrate through the legal process that even though the child may not be looking at the teacher, it doesn't mean that there is a lack of attention, and show that the child, you know, in many cases, is listening and learning as you can see in the academic progress.

That is one example. Another example that we see time and time again is these lowered expectations if the individual is non‑verbal or limited oral speech. There can be assumptions made because the child isn't communicating verbally that they don't have the potential to learn or be successful and so, often the parents might see even though the school believes the child can't learn to read, the parent might see the child at home sitting with their siblings, picking up books, and really then advocating for different kinds of augmented communication devices so that the child can really learn, you know, to their potential. Those are some few examples.

>> Tom: Great. Thank you. Matt, would you like to weigh in ‑‑ Ned.

>> I have two common myths. Some kids use their disability as an excuse for something they are not doing well, and in reality they may not have all the supports, or maybe they have strung each support out to the point where something maybe isn't clicking.

For second myth, I have heard some people say autistic kids shouldn't be in school, you know, maybe because of their disability it is hard for them to concentrate or be able to do things just like a normal kid, which I feel like that is kind of not true. In reality, if they find the right support, and maybe find friends that can relate to them, to what they are going through, they can go to school just like anybody else.

>> Tom: Maria?

>> Yeah, I will just tap into what Ned was saying. I am going to move myself over. Ned and I were talking about this yesterday. Ned and I do a lot of work around college access and I said do you mean people have doubted that young people on the autism spectrum can go to college and he said, yes, but I have always experienced that in high school, too, so I guess you mean, both, Ned?

>> Right.

>> I would say a myth I think, because I do a lot of work around training people to do transition work, is that individuals with autism need a lot of specialized support and I hear that from the college end, and I hear that from the high school end. I think really that is a myth because although they might need some specialized support what they really benefit from is what all young adults and adolescents need and that is early and ongoing support and planning and the ability to change your mind and start over again and that they have a team of people supporting them, no matter who they are. That would be the myth I would contribute.

>> Tom: Great. Thank you, everyone.

The next question is:   
People on the spectrum, and   
their friends and allies, often   
do a lot of powerful advocacy.   
I’d like you to describe a time   
when you advocated for yourself,   
or for someone on the spectrum,   
or when you observed someone on   
the spectrum advocating for   
themselves. What was the   
situation, how did it play out,   
and what was the result?

Who would like to start on that one? Julia, are you ready to weigh in on that one?

>> Are you hearing me? At the autism center, we do advocacy for individuals and legislative advocacy. We see the strength and efficacy of having people involved in all different legal advocacy and legal workshops and training. When we are advocating with policy and lawmakers, when we have young adults with autism testify on their own experience it is unbelievable powerful and when we have fellow autism members be present when we co‑educate parents and educators it is very impactful.

Also, years ago, we were getting more and more calls from parents who were concerned about the bullying that their kids were experiencing in the public

Schools. So, we mobilized with a lot of our sister organizations to try document the extent of bullying occurring. We knew antidotally students with autism were being bullied at higher rates but wanted to get a sense of what the breadth of the problem was. We conducted a state‑wide survey and individuals from around the state documented what their experience was, and that mobilized self-advocates and parents to mobilize at the Statehouse and had legislature enacted an anti‑bullying law that had very specific protections for students with autism. There is a long way to go until that law is fully and effectively implemented so having self‑advocates it is really important to have individuals with autism involved as much as possible.

>> Ned, would you like to weigh in?

>> Due to my life circumstances, I have had to move a lot of times, and because of, you know, living with families and different environments that were ‑‑ my family kept arguing and stuff like that, where I had to advocate and find different people who would, you know, at least be a temporary place until I am currently where I am at now, where I don't have to worry about being in a different or bad environment. That is basically where my advocating has been.

>> Great. Thank you. Maria?

>> I guess I am going to share a story. This is a story that comes from this part of the state in western Massachusetts. I do a lot of inclusive research, so I am doing research with young people with autism, and also individuals with intellectual disabilities. I was working with a young woman who had autism and I heard this great story about how she was going to college because she wanted to be a better writer. She was accustomed to writing fairy tales and knew in college she might be able to learn to write better and was interested in mythology so her advisor selected the class and said you will have to talk to the professor about getting into the class. She told the professor she was interested in the class and he made assumptions about her ability to read and understand mythology. And he said this is the textbook we use in the class and she said yes, I have it at home and I have read it all and I think I belong in this class. So I see that as an example of someone advocating and per severing when she could see the low expectations.

>> Steven?

>> I have a story coming from western Massachusetts as well. I was helping a friend on the autism spectrum to advocate for herself to the student's support office at one of the community colleges in western Massachusetts.

We went in there with a plan to describe what challenges my friend faced in education in terms of what needs she needed for accommodations. I was very pleased because she did very well. She described what her needs were and the response from the counselor at the disabilities office was even more encouraging. The response was, well, you know, I don't know that much about autism so please teach me.

I think that was very, very encouraging on all sides.

>> Right? Thank you.

>> Sure.

>> The next question is:   
What’s the biggest change you’ve   
seen happen in terms of   
including students on the   
spectrum in classrooms, and what   
other changes need to occur?

We will start with Maria.

>> Maria: Okay.

Well, one of the things I do an awful lot of work with transition and inclusive dual moment.

>> Can you describe to folks that may not have heard the term dual inclusive enrollment. What that is?

>> Yes, sorry. That is an opportunity for transition age students, 18‑22, and absolutely are still eligible for transition services but have already completed four years of school. There is a new trend here in Massachusetts for quite a while, but also through the higher ED ‑‑

[Audio quality poor]

>> It is so exciting.

[Audio quality poor]

>> I think you are breaking up. I am not sure if the other panelists can confirm?

>> Julia is breaking up from this end, too.

>> Hold on. It is great story we need to hear. Why don't we transition to Steven, if you want to weigh in, since your connection is clearer at this point?

>> Stephen: Sure. ‑‑

>> Stephen: Sure. They are learning more and more about what needs to be done and that is encouraging. What I think we need more of is more support for educators in the schools both in grade school education, and higher education, because what I find is that teachers at all levels are thirsting for information on how to support their students on the autism‑spectrum and what they are finding, and I find as well, is that an educator who can teach a student with autism and come up with strategies is often a better educator all around.

>> Tom: Julia?

>> Julia: Sure, I will pick up where Maria was headed. I would say the inclusion of those with autism and intellectual disabilities in higher ED is the biggest change. In Massachusetts, and other parts of the country, there are new initiatives, so the students in special ED and that have IEPs and in the 18‑22 year old age range, are now fully included in college courses and in the life of the campus, and really demonstrating that untapped potential we talked about before how these students are learning the ‑‑ they are automating classes for most part, they are learning to their potential, they are learning to take public transportation, they are learning to navigate the campus, they are really learning the skills they need to live and work as independently as possible in the community and it is a partnership, that is the dual enrollment piece, between the school district and special ED department as well as the higher ED system. As Stephen has talked about, it is really important, especially when these initiatives are being launched, to make sure that the educators really have to kind of support they need to know how to address the needs of individuals with autism, but a lot of the strategies are really strategies that make the faculty, the professors, the special ED educators better educators for everybody. And that is really what a lot of professors talk about in higher ED after having the experience of including individuals who may not be awarded a regular high school diploma at the end of their special ED involvement in the school district, but can greatly benefit from the benefits of higher ED.

And in terms of other changes that need to occur, what we see kind of at the same time is that as school districts are struggling in some cases to meet the complex communication, and behavioral and social needs of kids with autism, there could be a tendency to provide specialized services a kid needs whether it is behavioral therapy or speech and language in pull‑out separate settings. Sometimes that is what kids need, but a lot of times we have seen when the service are infused in the general setting the kids can continue to learn with their non‑disabled peers and get the kind of specialized instruction they need. Like with everything, there is still more changes that need to occur, and a lot of progress at the same time.

>> Tom: Let's see if we can go back to Maria?

>> I turned off my camera with the suggestion that might help me and Ned with our connections. Can you hear me better?

>> Tom: Very clearly.

>> Maria: Julia, thank you for picking up. There is a question for some of us talking about autism and intellectual disability and we are not meaning to connect those two. In Massachusetts, we have an initiative where these two populations are getting this incredible opportunity so that is why you are hearing us talking about these two different populations.

But great question. I am glad you pointed that out. One of the things I would say is that we have learned so much about how much students are learning in college that it makes us want to go back and, I think a lot of transition specialists, say we have to do more to prepare students for this incredible opportunity. More opportunities for inclusive secondary ED which we are still working on and more access to career and vocational occupational classes. I think that is a path we are still really working on. Thank you for the opportunity to finish that up.

>> Tom: And then Ned, would you like to weigh in on this?

>> Ned: Yeah, a big change that I learned is being a part of the inclusive enrollment program, being a part of that, and just being able to be enrolled through my West Field public schools and getting a chance to learn about college, learn what it is like, learn what I can do, and get a feel of it before I pick a major and go from there, and you know, be able to go to a couple of the speeches along the way. I have learned a lot. Now I am ready, hopefully by the fall, ready to take those skills elsewhere.

>> Tom: Great. Great. This is getting to a more technical part of education and autism. It is a specific question.  
What’s the most challenging   
regulation or piece of   
legislation for students with   
autism, and how would you change   
it?

Stephen, do yeah want to you want start out on that one? ‑‑ do you want to.

>> I can't tell if I am muted or not.

>> Tom: Nope, you are fine.

>> Stephen: In general, what I see the biggest challenge is the support that occurs after graduation from high school. Be it the standard age of 17‑18 or all the way up to the edge of the 22nd birthday, if there was legislation in which to continue some of those supports so that that person can engage in higher education, should they be able to, so that that person can find fulfilling and productive employment and also residential. Right‑sizing the support. Some of us on the spectrum may need a lot of support in our adult living, and others of us just need an hour a day or a few hours a week of support. If there were ways to provide these, you know, to provide these provisions for support, I think that would be great.

>> Tom: Okay. Ned, do you want to weigh in on this one?

>> Ned: Yes, I would like to. In regard to what Stephen was saying, in our program, some of the supports only last until the age 22. What I have noticed is certain kids need, certain students not kids ‑‑ certain students need a lot more support depending on how strong their autism disability is. But the hard part is some of that is we don't know where to look, or the families don't know where to look, or they are not available. For example, I am finishing with an internship and I was hoping to, you know, get more job assistance, but because I turned 22, my internship will not let me join in the summer, so I have to look for another way to get a part‑time job because I am not ready for what, you know, I want to do in my career‑job. It would be great to see resources available after the age of 22. I would love to see.

>> Tom: Great. Maria?

>> Maria: Sorry.

I totally agree with what Ned and Stephen are saying ‑‑ it would be nice to have more supports.

Also, I guess what I am just learning so much about the opportunities that students are getting and it has led me to get much more interested in how IEPs and IDDA could be more integrated.

>> Tom: Maria, you have continued to break the rules here. You just gave us a lot of alphabet and now you are going to be required to tell the audience on what it is you are talking about.

>> Maria: Charging buster. I am so sorry. I am very interested in how the individualized education program could be adjusted now to better reflect these great opportunities that students are getting because I still see schools using traditional forms. I think when the individuals with disabilities and education act is reauthorized it would be great to see more opportunities reflected in directing teachers, and teams, to be looking in this direction and, also to throw in more community‑based transition services. I apologize for the jargon. Tom, thank you for busting it!

>> Tom: All right. Julia?

>> Julia: We have all a similar theme in terms of this question. I think the clip Stephen and others talked about is one all individuals of autism face whether it is at 18 or 22 and it can be a really dramatic cliff without a safety net under it. ‑‑ cliff.

I think in terms of the existing laws, I think one of the most exciting, and really challenging parts of existing legislation are what Maria was talking about, the federal special law, the individuals with disabilities act, was strengthen to add a lot more services and planning for transition‑age youth. Age 16 to who they graduate or turn 22 or in some states like Massachusetts the services start at the age of 14.

The law is so strong and innovative, but I think around the country school districts are struggling with fully implementing its promise in terms of helping special ED departments and schools providing this on the community, in the college campus, in the recreational setting so kids with autism can generalize and learn the skills they will need to succeed to live independently and have jobs.

The kind of partnership Maria is talking about are envisioned in the law. Partnering with rehab, with the developmental disability service agencies, but I think the implementation of the law still needs a lot more work, and a lot more collaboration. It has huge potential.

Tom: Great. One of the things that ‑‑ I am going to be off‑script because I have run out of questions. But, you know, you folks here on the panel are the experts. At this point, I mind ‑‑ I would say ‑‑ there is a lot of people, and I think the number one group of people in this seminar now, are advocates and looked like agencies was, I think the way it was described. What advice would you have for them as they go forward in working with people on the spectrum or, you know, advocating for people on the spectrum, or even sort of in the public realm? What advice or what would be the best advice that you could give these people? I know I am taking you off guard.

>> Stephen: I guess I will start.

>> That is good, Stephen. Thank you.

>> Stephen: Many, many things come to mind. One thing that comes to mind is to presume competence and that the autistic individual understand more than they are able to express, or at least express in a way you are looking for. We may need to look for alternative means of that expression and that is usually assisted communication devices. I see that happen so often when people report they are talking about a person on the autism spectrum at a team meeting, they are in the room, they are saying negative thing and suddenly there are challenging behaviors coming from that person and that means that they are picking up, they are understanding the situation. One is presume competence.

Two, the autism spectrum is incredibly wide and what that suggests is if you have met one person on the autism spectrum you have met one person on the autism spectrum. There is huge diversity.

And I guess finally, the potential of autistic individuals ‑‑

>> I think those are captions we should put on as we advertise this reporting. Maria, are you ready to weigh in on advice?

>> Tom ,would you mind in one sentence, I want to make sure I am answering this correctly.

>> That is a challenge to remember what I asked. The question is we really have a lot of advocates and folks who work, I believe, it was phrased with agencies so I presume they work a lot with folks with autism. What would be the advice you give them? Or the advice you would give, sort of the broader world, about autism.

>> I guess what is kind of popping into my head is really from both the education perspective and also from the adult services perspective is that I would suggest that we really are imploding and reconstructing what we mean by services and support. We definitely still have, I hate to say it, but there is a medical model that is out there, and I think we need ‑‑

>> Tom: You have to describe the medical model.

>> I am sorry. Why am I on this panel? I don't know. A more clinical approach to disability. I really love a lot of the comments that I am seeing in the chat about presuming ability and concepts of universal design and I think that is really, right now, we have an opportunity to really just deconstruct the way we were doing disability services and reconstruct in a way we were are not looking at disability, but more ability. I apologize, to everybody, for my jargon.

>> Tom: No, you are getting into the technical piece and it is an opportunity to give more information out in the process. I appreciate you digging into the weeds. I think it is important that we are there. But I want everybody to be clear what we are talking about.

Ned, would you have advice for advocates and people that work for agencies when talking about education and people with autism?

>> Ned: For me, it would be education is important either way. You know, people on the autism spectrum should be allowed to get as much support as they need to be able to become their dreams. It is just like, I mean gee, it is like what I learned at the current job I work. You know? A lot of PBS station shows teach us about how to make a dream even if we are different than other people, you know? I am in college. I have got to take classes that most of the people would think oh, I wouldn't do. I took a photographer class and a lot of people thought you will not be able to learn all the ins and out. I struggled through it, but I got through it.

In regards, anything is possible. It doesn't have to be a normal ‑‑ I think with autism, they can get there if they have and use the right supports. That is my suggestion.

>> Tom: And another question off‑script at this point, but maybe need to be brief and maybe you don't want to be brief when I ask this question, but when you are talking about education, and you are talking about people on the spectrum, what advice would you give to people on the spectrum as they are, maybe in high school at this point, or in college, what advice would you give to them as they move forward in their educational process?

>> Ned has a suggestion.

>> Ned: My suggestion for anybody in high school or college, just, you know, don't stop for anything, you know? You will have people that want to tell you you can't do things, but we are the only ones that make our dreams, you know? Other people may give suggestions, but it is only up to us to prove it to ourselves, not anybody else. We are not here to prove things to people only to ourselves.

>> That is the next quote we will use in advertising this seminar. Thank you.

Julia, looked like you were ready to jump in there.

>> Julia: I think building on what Stephen and Ned said, I think the recognizing of the potential, presume competence, and what I would say to people in the service agencies, or to the youth with autism still in school, is to recognize these are laws that are civil rights laws. The reason these civil rights laws that create educational opportunities were created is because lawmakers recognized that barriers have to be removed so that the potential of people with autism, as well as other disabilities, can be untapped. When the barriers are removed, that is when people are really able to live their dreams and learn to their potential. The other thing I would say to the young adults, and youth themselves, is that the law really emphasizing having to build on the strength of students with autism, having to build on their own preferences of what they want to focus on, and do, and learn, and I think maybe I don't want to put words in Maria's mouth but part of what she meant by medical model is all too often we focus on the so‑called deficits of somebody with autism instead of figuring out how to remove the barriers so individuals can learn to their potential and build on their strengths and interests.

>> Great. Thank you. Stephen?

>> Stephen. Yeah, I think the best thing for us individuals on the autism spectrum to do is to identify our abilities, to identify our strengths, to turn away and this goes for everybody, to turn away from what I call a model of deficit disorder and disability in how we look at autism, to an abilities‑based model. We need to be asking the questions what can we do. That said, certainly, there are challenges to being on the autism spectrum, if there were not we would not be here trying to figure it out. We need to look toward the strengths. Nobody I knew has built a career out of mediated inferences. Everyone successful on the autism spectrum has found a way to pile their interest and strengths into successful employment.

>> Thank you. I think we are ready to go to audience questions. I have one here from Nancy that is a philosophical question that says: If education could be totally redesigned, do the panelists think that autism would still be a disability?

>> Ned: Autism is a disability, but it doesn't have to define us. It doesn't have to define any person. It is just like ‑‑ my autism has come because of the life I went through with family and dealing with arguments and certain circumstances, but that doesn't mean, you know, I have to use that as, you know, not being able to go to work, not being able to do anything. I can still make a dream even if I had an autism disability, you know? I think that is something that some people have, you know, a lot of people our age and we have to work with, have to look into it. Like what Stephen said about strengths, you know? We can make a dream, or anything, if we know our strengths. It is that simple.

>> Tom: Anyone else?

>> Stephen: Pretty much echoing what Ned said. Autism is a disability because it significantly impacts your life. But what we also ‑‑ also, as part of autism, is what I call a really spiky profile. What that means is the things we are good at we tend to be incredibly good at, the things we are not‑so‑good at are big challenges and there is not so much in the middle. If we can catch those spikes to help promote success and accommodate for those real significant challenges, then we can make fulfilling and productive lives for people on the autism spectrum the rule rather than the exception.

>> You ready for another question? Does anybody else want to weigh in on that one?

>> Go ahead with another question.

>> It says how much do you think our educational constructs, structure, delivery methods, learning materials, and activities contribute to obstacles for learning with these individuals? Might a society be able to create an educational experience that would render autism as a set of individual learning traits rather than a disability? I believe that may be part of the same question, but does anybody want to weigh in on that?

>> The term universal design comes to mind. That is, if we design curriculum from the get‑go to accommodate people with differences, and maybe in how we perceive or take in information, be it visually, auditory, and so on and provide diversity in how we can process this information, and demonstrate mastery of material, then we will be moving towards having one curriculum, you might say, to reach more people.

>> Tom: Anyone else? Here is a maybe more specific question. It says: What will be the advice that the panelists, as experts on autism, give to the general public, service providers, and educators about individuals with autism who communicates with an AAC device which I am not sure ‑‑ I don't know what that stands for? Augmented communication?

>> Augmented and assisted communication device.

>> The question goes on it says in my experience, many AAC‑users on the spectrum are considered dumb, not knowing anything, and often not receiving much support that they need to be successful. So I guess it is the question resolves around what advice would you give to professionals and educators about individuals who are using an AAC device?

>> Julia: I don't mind starting here, others can jump in. The federal laws, the special ED laws and the American with disabilities act itself are very clear and strong about the obligation to provide not just the devices that might be needed for people with autism, the students with autism who are either non‑verbal or have limited oral speech, and as that question points out, it is what we were talking about at the beginning, there can be a lot of myths and stereotypes about the lack of competency and lack of potential about somebody because they communicate using some kind of assisted technology rather than communicating orally.

I think the advice I would give is that it is important that an individual have access to the kind of alternative communication that would enable them to really communicate what they are thinking, help them to learn in a classroom because they have a way to communicate, but the law also talks about the need to provide support and training for the educators and for the non‑disabled peers, and for the family, because what we find in our experiences is that family might be successful in obtaining a communication device that could sit gathering dust in the classroom if the educators don't have the support they need to effectively teach the students to use the device and to know how to teach someone who does use alternative means of communication. What is important is to make sure whether it is employers, people in the community, teachers, family members, everybody in addition to the person with autism, has what they fully need so they can learn and contribute. When people are able to communicate they can contribute to the whole classroom and community they are participating in.

>> Tom: Anyone else interested in weighing in on that one?

>> This is Maria. I would add what we try to do from the training perspective, especially with transition specialist, is to remind people to include questions about assistive technology, augmented devices and general technology in everything you are thinking about; a plan for employment, in assessing the technology ‑‑ how technology might enhance that experience, or that opportunity. Same with college, same with travel training, same with any kind of community work, and same with education.

I think just always taking that into consideration is a good first step in making sure that you are always thinking about how technology of one kind or another could be assisting or enhancing an opportunity.

>> Anyone else interested in that? Weighing in on that question?

The next question is from Kathy. It says why would you have a curriculum for students with autism in an inclusive setting? I think there is a lot in that very simple question. I am not sure who is interested in jumping in on that one... I can repeat it if you need it.

>> Stephen: There is a lot in that one.

>> Tom: There is!

>> Stephen: I go back to my idea of universal design and that is if a curriculum is designed for a person with autism, for people with diverse learning styles, and that includes people are other conditions, as well, in addition to autism, then we are going to have greater reach with one curriculum, and we will also be addressing the learning styles of those students who don't have a documented disability and wouldn't be considered to have a disability, but they will be helped, too, because people tend to have preferred styles and methods of learning. I just saw Glen type into the chat box ‑‑ won't they live in an integrated society as an adult and that is a very good point; integration begins with education, in grade school, even preschool.

>> Tom: I just want to get another part of that question that I was, you know, sort of the unspoken part of that question, was what about the question of including students with autism in general education settings. And I am not sure if that was part of the question or not? Do you want to weigh in?

>> Stephen: Yeah, I mean inclusion in general education settings wherever possible because the world is not, you might say a special education school, but for lack of better terminology, it is the world, it is where we live, and the more exposure the person with autism, and by extension people with other differences, can have to the general population in school, the better they will be able to integrate into society and flipping it around the more exposure students who don't have disabilities have to those who have differences, that will make it easier for those individuals to accept people with differences in their community later on as an adult.

>> Julia: I could jump in. I agree completely with what Stephen is emphasizing. I think with the special ED laws and the disability discrimination laws give us tools on how to make it work so that inclusion is really effective and appropriate for the student with autism, as well as for the whole educational community.

I think what we see in our law offices is that all too frequently students and families are faced with a, kind of, choice, neither of which is a viable option, that if a student needs focus on their social skills, or they need some focus on some of their behavioral issues, then the way to provide that kind of instruction is in a pullout setting and then it is hard to access the academic curriculum that is based on those higher ed expectations. Preach there are models around the country where students are successfully across all included. They still get their learning needs met, but they are learning to be included with non‑disabled peers, and their non‑disabled peers are benefiting from everything they have to contribute, and that is with really what the law contemplates.

It takes some advocacy to make it work correctly in my experience.

>> Tom: Anyone else want to weigh in? I have another interesting and challenging question that is another very simple question. Let me just move to that one. Kathy is asking what the panelist thing about and put in quotations disclosure. "Disclosure". Anyone want to address that one?

>> Stephen: Well there is much to say about that too. Disclosure has two parts. One is the autistic individual and how do you tell the autistic individual they have autism and it should be done in a way that emphasizes the abilities, but at the same time you have to be realistic about the very real challenges or why would they have the diagnosis. I think first is the disclosure to the person on the autism spectrum. I was very lucky in this regard. My parents used the word autism in the house just like any other word so I don't remember any time when I didn't know that I was autistic. That certainly helped explain a lot of differences. However, I find that many people don't learn about having autism that way, so I have developed a four‑step approach which is helpful in telling people and helping them understand what it means to them to be on the autism spectrum.

Then there is the other side. When do you tell somebody else you are on the autism spectrum? One rubric you might say I use is that if the effect of being on the autism spectrum significantly impacts a relationship or a situation then you may need to consider disclosure. With disclosure comes advocacy. Here is a very, very simple example that I often use in, say, an office or restaurant situation, and that is you may think that my hat here is a fashion statement. And I guess in some ways it is. It is always good to support my university. Adelphi university. But one thing autism means to me is sitting under down lights is like looking into a spotlight for many other people. So what that may mean is that say I am going into an restaurant, or a business office situation, say a supervisor is showing me my desk, I may have to say to that supervisor, I wonder if it is okay if I wear this hat and the reason why is because these lights hurt my eyes, I have very sensitive eyes. What I did there was known as a partial disclosure and only talked about the aspect of autism that significantly impacts the situation and often a partial disclosure is another.

But for other situations like teaching a class on diagnosis and intervention in autism, it seems to make a lot more sense to do a full disclosure because that does have a meaningful impact on my relationship with my students. In a nutshell, those are my ideas about disclosure.

>> Go ahead, Julia.

>> Julia: That was very well said, Stephen. The person with autism comes to head because it is said the students are supposed to participate in their IEP meetings and become self‑advocates depending on the age of 14 or 16.

What we have seen educators and family wrestle with how can they be self‑advocates when nobody has talked to them about the fact they are autism, what that means, and how to address that has a positive part of their identity. We have a lot of folks struggling with having to make disclosure appropriate and positive around those ages.

>> Tom: Anyone else on the panel interested in weighing in on the issue of disclosure?

>> Hello, Tom, this is Ned. In regards to disclosure. I think it depends on the person that person is talking to or in regards of like ‑‑ it is good to talk about your autism so people can understand how to help or assist them. I think that is where there is a fine line between if I told someone about my autism, are they going to be able to assist me or make fun of me? I think it depends on the situation who the person is you are talking to in terms of disclosing.

>> Tom: I now have a simple question. What age should a child be tested for autism? I don't know if any of you folks have the expertise on that. But anyone want to weigh in on that question?

>> My immediate response is as soon as possible. As soon as you notice a departure from typical development. So, say you have a child who has a lot of difficulty in engaging in association reciprocity at age 18 months, you may not be able to diagnose autism at that point, but maybe you could see if the child was at‑risk of being on the autism spectrum.

From what I know it is possible to get a reasonably reliable diagnosis from about age 24 months.

>> Julia: And I think increasingly, pediatricians and other kinds of professionals are training themselves to provide support, as well as information for parents, so they can know what might or might not be a sign of autism. The children are diagnosed as soon as possible because we do know that when children get the kinds of support and accommodations and services they need, early on, then that really improves their overall learning to their potential.

>> Ned or Maria?

>> You said me, but he actually had something to say.

>> In regards to knowing what age. That was one of the things my parents didn't do, why it led to took so long to get an understanding ‑‑ I had a lot of history and some things I have did with my family and my family didn't treat it like they were supposed to it. That is what led to some of the stuff I went through and finally having to leave my family and getting an understanding of what I had. I had to get more supports.

>> You thought they would have benefited from having you tested earlier, you said, yeah. I think we will leave it at that. Ned wanted to say that.

>> Tom: At this point we are running out of time. Rebecca, who was our MC is in Pennsylvania and I guess the storm got a little rough there, and she lost power during this process. So, I am going to do the wrap‑up here. Katie Allen is assisting me and jumped in to put on the screen who today's presenters were. It was a great discussion today. I learned a whole lot. I think we have got a lot of important information that came out today. I want to thank today's presenters. Stephen  
Stephen Shore is a clinical   
assistant professor at Adelphi   
University.   
Julia Landau is a senior program   
director at Massachusetts   
Advocates for Children. She’s a   
specialist in special education   
law and provides workshops for   
parents and professionals.”  
Maria Paiewonsky is a transition   
specialist here at the ICI.   
Ned Pavlak is a student at   
Holyoke Community College.  
and I am the director of ICI and we are celebrating our 50th anniversary and why we are having this seminar series.  
I’d also like to remind you to   
follow the ICI on Facebook and   
Twitter. That’s a great way to   
stay up to speed and know when   
events like this are coming up.   
You can see our Facebook and   
Twitter URLs on this slide.  
The next event in this series   
will focus on employment. It’s   
coming up on DATE. Watch our   
website, communityinclusion.org,   
and our social media channels.  
That’s it for today’s event.   
Thanks again for coming. Before   
you leave today, please navigate   
to the link on the screen that   
says “Give Feedback,” and let us   
know what you thought of today’s   
presentation. Thanks again and   
have a wonderful day.

Special thanks to Rebecca Lazo and the crew at ICI who made this rather challenging event happen. It was a tremendous event and thank you all for being part of it.

>> Katie: I just want to add the give feedback button changed. You will get a follow up e‑mail and in the e‑mail will be a link for an evaluation for today's webinar and after completing that, if you are eligible to receive certified education credit, you will receive those after taking the evaluation.

>> Thank you, Katie, and thank you, everybody. It was a great presentation today.

>> CART PROVIDER: Thank you!