Vanderbilt SLP Journal Club: Neurodiversity and Speech-Language Pathology - Thinking Differently

Recorded July 18, 2019

Presenter: Mary Alice Keller, MA, CCC-SLP
SpeechPathology.com Course #8964

- - [Amy] And at this time, it is a pleasure to introduce Mary Alice Keller, who-- Presenting Neurodiversity and Speech Pathology, Thinking Differently. Mary Alice Keller is a PhD student at Vanderbilt University in Nashville, Tennessee. She has practiced as a speech-language pathologist for four years, focusing on autism and AAC. Her research interests include the evaluation and treatment of autism and language disorders as well as disability studies and its impact on speech pathology. So thank you so much for joining us, Mary Alice. You can go ahead and turn on your mic.

- [Mary Alice] Okay, thanks, Amy. Hello, everyone. I'm so glad to be able to present on this topic today. And so, like Amy said, today we're talking about neurodiversity and speech pathology. And so I first wanna go over my learning outcomes. So after this course, participants will be able to define the term neurodiversity and what it means, describe the relationship of neurodiversity to the disability movement, and then also identify strategies to improve their clinical practice using the concept of neurodiversity. So just an outline of what we're gonna be talking about today. I have a little introduction. We're gonna talk about some terminology, then kind of dive into neurodiversity and what it means, how it relates to autism and the history of autism, and then the important part, clinical strategies and how we can apply neurodiversity to practicing as a speech pathologist. And we have a case study at the end, and then we'll have time for questions. So just jumping right into it, a little bit about my background, as Amy said, I've been a practicing speech pathologist. But I've also been involved in the disability community for much longer than I've been practicing. So I really love being a speech pathologist. And most of my background is in pediatrics. But prior to that, I worked at several recreational camps for children and adults with disabilities and have volunteered at Respite Nights for children with disabilities and just been involved in that community. So I've always been really interested not only in the clinical aspect of speech pathology but also the impact that speech pathology and other treatments can have on children and families and adults who have disabilities, and kind of what that looks like from a bigger picture, more holistic perspective. And so that's kinda gonna weave into all of this today. So I just wanted to give a little bit of background there. And so next we're gonna talk about terminology. And I know at the beginning this can be a little bit dry and seem a little theoretical. But I think it's really important to discuss it at the outset so we all are working off shared definitions when we're discussing these things. So even though it'll be a little, sometimes, theoretical at the beginning, I promise you we're getting to the clinical piece.

So it will all tie together. But I wanna first talk about disability and what that means. And as speech pathologists, we all work with people with disabilities, for the most part. And so I think it's easy to kind of breeze past this word and think, oh, yeah, so-and-so has a disability, or this diagnosis is a disability. But I think it's really important to sort of take a step back, especially when we're talking about this topic, and think about, what does disability really mean? What does it mean to clients who may have a disability? What does it mean to people who do not have a disability? And there are a lot of different definitions out there, and I think it means different things to different people. But the definition I have here is from the World Health Organization. And they consider disability to be an umbrella term that covers impairments, activity limitations, and participation restrictions.

And then they really nicely break each of those pieces down. So they consider an impairment to be a problem in body function or structure. So I like to think that as thinking about maybe a child who has an articulation impairment. The impairment would be the difficulty with the function of the articulators. And then an activity limitation is a difficulty encountered by an individual in executing a task or action. So in that example, maybe a difficulty pronouncing a word or using a sound correctly in a sentence. And then participation restriction is the problem experienced by an individual in involvement in life situations. So in this same example, thinking about a difficulty communicating to a peer or in class, or some kind of social restriction related to embarrassment of a mispronunciation. And so that's a simple and speech-related example of what that can look like. So we're gonna talk about that a lot more. But I just wanted to have kind of a standard definition from the outset. And so next we're gonna talk about models of disability. So we defined what disability means, at least according to the World Health Organization. And so these models of disability are really different ways of thinking about disability. And so there are a lot of models of disability. If you look in the disability studies literature, there are 10 out there. But the two that are talked about most and apply most to our purposes in speech pathology are the medical model and the social model.

And so I wanna start at the outset by saying this can be controversial. And not everybody agrees with either model, or a specific one. But I think it's really important as healthcare providers and as speech pathologists to be aware that they both exist, just to inform your interactions with people with disabilities, who may have different views. So just to say that from the beginning. But so the medical model considers that any difficulties that a person experiences related to their disability are the result of the impairment itself. So thinking about someone who may be paralyzed and uses a wheelchair, any difficulties that they experience navigating their world because they're in a wheelchair would be considered the result of that paralysis or that difficulty walking. And so in order to become less disabled, the problem would be to fix that paralysis in some way or provide some other mode of transportation. And so that's kind of where the medical model is coming from.

And I think, not always explicitly, but this is kind of the perspective that healthcare providers are often trained in, because we are, especially if you are a speech pathologist working in a healthcare setting, your job is to evaluate and identify a problem, and then treat it. So it makes sense that often the medical model is the one that people are more familiar with and makes the most sense to people who are kind of steeped in this medical environment. And I think it often applies to school settings, too, just because of the way speech pathologists are often trained. And so switching gears, the other one we're gonna be talking about today is the social model. And so this holds that difficulties that a person with a disability may experience are the result of society's reaction to the impairment. So using the example of a person who uses a wheelchair, any difficulty they experience navigating their world would be, for example, the result of society's failure to provide an accessible community, or provide ramps or other ways for that individual to navigate things safely and easily.

So the challenge here, as the social model holds, is not necessarily the disability itself but how society reacts to it or fails to react to it, and so that society should accommodate and accept the disability. And so this one can be controversial to some people. Some people who really believe strongly in a social model will even go so far as to say that disability is created by society. So everyone is different and has different strengths and weaknesses, and that disability is really the result of society's reaction to that. And so I think, personally, I fall somewhere in between these two. And so I think it's, as a speech pathologist, especially, who's practicing, it's important to be aware that they both exist. And I find, in my practice, I end up borrowing from both of them. But I think it is important to realize that there are people who are firmly in both camps. So that's a little bit about the social model.

And so next, moving into neurodiversity. And so a lot of what neurodiversity is kind of pulls from this social model in some ways. So that's why I wanted to address that first. But so first, we're gonna talk about, what is neurodiversity? So this term was coined in the late '90s by a sociologist from Australia named Judy Singer. And she herself is on the autism spectrum. And so she, I believe, published a dissertation that was partly on the topic, but it was really popularized by this journalist named Harvey Bloom, who published some things on the topic. And so the first time this was kind of appearing in popular press was from Harvey Bloom in "The Atlantic" in 1998. And he stated that, "Neurodiversity may be every bit as crucial "for the human race as biodiversity is for life in general. "Who can say what form of wiring will prove best "at any given moment?" And this is some more language kind of from that time, but, "Cybernetics and computer culture, for example, "may favor a somewhat autistic cast of mind." So even though that's not necessarily the way we would phrase that now, and we have a different view of the internet and computer culture as it's developed, what he's really saying is that there's not necessarily one correct or right way to think, not one right way to be. And that really captures what neurodiversity is. It's the view that everyone has differences, and those are to all be accepted. It's not necessarily that there is something normal and then others that are abnormal.

And so that kind of plays into the idea of, okay, well, what is a disorder and what is a difference, especially when we're thinking about speech pathology in a field where we are most often required to diagnose people. And I think often in training in speech pathology, it comes up, this disorder versus difference piece, in terms of language delays or differences, in terms of articulation. But it's also good to think about it in terms of other diagnoses, like autism, which we're gonna get into some more. And then this also relates to universal design, so kind of in the same vein as the social model. The idea of universal design holds that we can design workplaces and schools and communities to be accessible to all people.

So it doesn't, in this kind of theory, or this ideal world, we wouldn't need accommodation specifically for people with disabilities, but the world would be accessible to them. There's an organization called the Centre for Excellence in Universal Design in Ireland, and they have a really nice website that defines a lot of this really clearly. So I'm just gonna read a little bit from their site. But they say that, "Universal design is a design "and composition of an environment "so that it can be accessed, understood, "and used to the greatest extent possible by all people "regardless of their age, size, or disability. "Environment should be designed to meet the needs "of all people who wish to use it. "This is not a social requirement "for the benefit of only a minority of the population. "It is a fundamental condition of good design. "If environment is accessible, usable, convenient, "and a pleasure to use, everyone benefits. "By considering the diverse needs and abilities of all "throughout the design process, "universal design creates products, services, "environments that meet people's needs." So that's kind of just something to keep in the back of your mind. So of course, not all of that relates directly to speech pathology, but when we're working with these people who may consider themselves neurodiverse, it's important to understand that there is an idea out there that we can kind of make strides to make everything accessible to people, whether they have a disability or not. So that is just kind of an overview of neurodiversity.

So next, I wanna talk about how this applies more directly to speech pathology. So one of the reasons I think it's really important for speech pathologists to be aware of neurodiversity and to know more about disability in general is because we still commonly treat diagnoses that are relevant in neurodiversity, and so thinking about autism, which will be the main focus of this presentation. Neurodiversity can also apply to people with learning disabilities, people who stutter, hearing loss, language disorders, so kind of across the spectrum of diagnoses that are treated by speech pathologists. So because we're so often seeing children and adults as our clients who kind of fall into these categories, I think it's really important that we're aware of this.

And that kind of falls in, again, to this disorder versus difference piece. How do we treat these people who consider themselves neurodiverse, or who are kind of aware of this movement, or who may not be necessarily aware that it is a movement in itself but who, on their own, have kind of developed some of these theories or opinions. And so of course that applies directly to diagnosis and treatment. So how and when should we treat and evaluate children and adults? There is a podcast called "StutterTalk." If you haven't checked it out, I highly recommend it. I have not, as a clinician, specialized in stuttering, but I still think it's really interesting to hear the thoughts that are shared on this website. And they have a podcast. And they have a series of podcasts that are entitled "Should SLPs Treat Stuttering?" And there are several podcast episodes where there are licensed SLPs, some of them who stutter, some of them who don't, talking about the speech pathologist's role in stuttering and whether or not stuttering should be treated. And so that's kind of an example of how this can sometimes be controversial. 'Cause you can imagine that some speech pathologists feel strongly that it should be treated, and some people who stutter feel strongly that it should not. So I would recommend, if you're interested, to kind of check that out as an example of a different way of thinking about speech pathology as it relates to this neurodiversity movement and the social model.

And of course, it's important to remember, and I wanna just state that I know, that we all have constraints in our work settings. So some of this, we can take into account when we're treating and practicing, but I know that every work setting has its own constraints and requirements in terms of of diagnosing and treating, and what that looks like. So kind of just putting that out there. And so the reason I'm gonna be talking in so much about autism today is because the autism community has kind of really owned this term, neurodiversity. Like I said, Judy Singer, who was a person on the spectrum herself, coined the term. And a lot of people who have autism have identified really strongly with this term.

But it can apply to others. And we'll talk about that, though less so. And I do think it's important, too, when we're talking about autism as it relates to neurodiversity, I just wanna say that I understand, and I think it's important to remember that autism is such a spectrum. And it can present so differently in different people. So there have but some criticisms of neurodiversity from people who say, well, that's really easy and all well, fine, and good to say that everyone's different, and we should accept everyone when you're talking about maybe an adult with autism who is really considered high-functioning or has a lot of language and cognitive skills and is able to live independently or function well day to day. But it may not be as applicable for someone who has really severe impairments or is considered nonverbal. And so I just wanted to throw that out there that I think that that distinction is important. And I'm not saying that neurodiversity does not apply to people on the spectrum who have more challenges as a result of their diagnosis. I think it can apply to everyone. But I think it's also important to be realistic about the fact that people with autism sometimes can have really different skills and different functioning levels.

So I just wanted to put that out there. But related to all of this, I'm just gonna breeze through some of the history of autism. Because I think it's just important to understand all of this in the context, especially because the autism community has been so active. In terms of the neurodiversity movement, I think it's good to know kind of where we're all coming from in terms of this history. So in 1943, there was a paper published by Kanner, who sort of pioneered the way in terms of identifying children who were considered to be on the autism spectrum. So prior to this, we did not have a word for it. There were people who were presenting in this manner, but there was no consistent diagnosis or awareness that this was a consistent group of people who were presenting in a similar fashion.

And then directly after that in 1944, Hans Asperger published a similar paper that was identifying similar types of people who had more language and cognitive skills. And that's where the term Asperger's came from, because that was his last name. So this was kind of the beginning of some awareness of autism. Of course, it looked really different from what we have now, but this is the beginning. And then in 1949, a theory came about called the refrigerator mother, sometimes called frigid mother. And this was the idea that autism was caused by something in the environment, specifically how the mother of a child with autism was treating the child. And so this was posing the idea that a mother was withholding intimacy or affection or emotional connection in some way, and that was causing the autism. And so you can imagine how that could be really damaging to families, specifically mothers, who were concerned that they were causing autism in some way. But then in 1952, we started to move towards having a more consistent diagnosis of autism. At that time, it was called childhood schizophrenia. And it was officially listed in the first edition of the Diagnostic and Statistical Manual, the DSM, which is used to diagnose autism still today, and other psychological disorders. In 1964, Lovaas started to develop behavioral therapy targeted towards children with autism, which is today applied behavior analysis, ABA, so obviously, something that is still really prevalent in autism treatments.

And then in 1980, in the third edition of the DSM, the term was changed to infantile autism. So at that time, there was still this huge focus on children with autism that we're starting to move away from now. And then in 1991, autism was entered as a special education category in the school so you could qualify as having a disability through that category. And then in 1999, Judy Singer coined the term neurodiversity. And then in 2009, the incidence of autism really started to take off. At that time, it was published by the CDC that incidence was one in 110, which was up from one in 150 in 2007. And then in 2012, again, a increase to one in 88. And then in 2013, what was previously autism subcategories in the DSM-4 were combined into the DSM-5, and so this was a big deal in the autism community for some people, specifically those who formerly had a diagnosis of Asperger's.

There were a lot of people who really strongly identified as having Asperger's or being an Aspie and being part of that group. And so when the DSM changed, Asperger's was absorbed into the term autism, and there was no longer that distinction. And there was kind of some uproar about that in some communities. So some people will continue to refer to themselves as an Aspie or having Asperger's, even though that diagnosis no longer technically exists in the DSM. So that's just something to be aware of. And then in 2016, the autism incidence increased again to one in 68 children. And that is where it's holding today. So that is just a brief history of autism. And I think I'm gonna have some ideas for further reading at the end. And there's a book that goes into all this in a lot of detail, if you're interested in more detail. And so as I mentioned on and off, there are some communities where I think this directly applies, the neurodiversity piece, specifically the stuttering community. Like I mentioned, StutterTalk is a great website to get started on if you're interested in knowing more about how neurodiversity can apply to the stuttering community. There's also a great research article that I've read recently. It was published by Chris Constantino in 2018. It's called "What Can Stutterers Learn "from the Neurodiversity Movement?"

And again, even though I don't specialize in stuttering, I really enjoyed that article. And I think he did a really nice job of talking about both autism and stuttering, and what the neurodiversity movement means for speech pathologists. And he is a speech pathologist, his license. So I would really recommend that article. And then the deaf community is another community where you often kind of see some of these ideas, so specifically thinking about the big D Deaf community, who sometimes may believe that hearing loss, and specifically their deafness, I'd just a natural variation in humanity and is not something that needs to be fixed through a cochlear implant or amplification. And so in both of these communities, not for everyone, certainly, but for some people who are in these communities, speech pathologists might not always be necessarily celebrated.

Again, I'm not in the stuttering community, but I have heard that at some conferences that speech pathologists are not always welcome, because they're considered trying to kind of cure something that some people believe should not be cured. So that's just, again, something to be aware of when you are treating children and adults with communication disorders. So next we're gonna talk about clinical strategies and how all of this can be applied directly into clinical practice, which is really important. So how does this affect speech pathology? I wanna talk about how this can affect patient quality of life, talk a little bit about identity versus person-first language, goal writing, and then recommendations and referrals. So first, quality of life. I think that this is something that it can be easy to forget about in the day-to-day kind of hustle and bustle of practicing, especially with a large caseload, and you're running from client to client. But I think it is important to step back and remember, okay, well, how is my treatment and practice as a speech pathologist going to affect the quality of life for this child or adult? So I think it can really affect, I think incorporating some ideas from neurodiversity and the social model can impact an individual's understanding of a diagnosis.

So especially if you are someone who is often evaluating or starting to treat a client at the very kind of outset of their diagnosis, whether it be autism or something else, I think being ready and able to counsel them a little bit on what that looks like for them, it can be really helpful in having them understand the diagnosis. Kind of an example I have is, a few years ago, I was treating a child for an articulation disorder. He was about four, I think, and he had started to stutter. So I was doing some counseling with the family about that and about whether or how they wanted to pursue treatment for that. And when I was explaining the diagnosis to the dad after I had evaluated him, I was explaining that he could grow out of this, potentially, or that it may not be something that the child would grow out of.

And so the dad asked me, "Well, what happens if he doesn't grow out of it?" And I said, "Well, he will continue to stutter." And the dad said, "Oh, that's it? "He just stutters?" And I really loved that reaction of that father. I think it was a really good example of, you know, for some people, that would be a really concerning diagnosis. Or that might be upsetting to them. But for this parent, he just kind of accepted that as something that might be a characteristic of his child. And so I think being able to kind of support a family no matter how they're reacting can be important. And that goes along with acceptance of the client's own self and of others. So thinking about autism, if a child or a family or an adult gets an autism diagnosis, and they view this as something that is really negative and tragic, heartbreaking, I think it can be harder, perhaps, for them to accept themselves and to accept others who have autism or a disability. So I'm not saying that people should not be upset with an autism diagnosis. I certainly understand that. But I think it is good to also help a family accept it in the way that's best for them when they're ready. So I think it's good to be able to at least feel comfortable kind of supporting a family in that way. And that kind of goes along with identity, how a person views themselves. And then clinician's rapport with a client or family, I think this is so important. I know this is sometimes talked about in practice, but I think this is something we can forget, too, especially if you're working in a setting where you have regular interactions with, like if you're working with children, with a child's family. I think it can be so important to show that you are on board with however they are viewing things.

So maybe they really do have a problem with the diagnosis, or they're very upset about it, and that's fine. You can meet them there. Or this is something that they wanna treat but are less concerned about. Then you can meet them there as well. So I think really being able to meet the family or the patient/client where they are can do wonders for the rapport that you have. And of course, that can lead to better outcomes in therapy. And so all of this just kind of ties into supporting the whole person, so just remembering that even though we need to be focused and write goals and treat the patient or the client who's in front of us, I think it's important to make sure that you don't have blinders on, and to remember that what you're doing is so important, because it can really impact the life of a client, and how that looks in the big picture. So next, talking about language and how to use language specifically around autism or other diagnoses with a client. And so when I was trained in graduate school, I was trained very strictly to use person-first language. So that would be calling someone a person with autism as opposed to an autistic person. And so for a long time, I thought that was the only respectful way to talk about a person who had a diagnosis. And I felt really strongly about that. But then as I've continued to be involved with the disability community and learn more, I've learned that some people with disabilities do not prefer person-first language. And they actually prefer identity language. So they would prefer to say, "I'm an autism person." And some people's reasoning behind that is they say that, "Well, you cannot separate autism from me. "That is part of my identity. "It is part of who I am." And so they prefer to have someone refer to them as an autistic person. And so that was really eye-opening for me, because I use down to think that that was very offensive, and some people may continue to find offense to it. So I think it's important to be able to follow the lead of your client. So for example, when I meet a new client, I usually use person-first language at the beginning, because I kind of feel like that's safer for me and is just a good foot to start out on.

But then if I notice that they are consistently using identity-first language like autistic, I will follow their lead and kind of match their language. And I think often it's just okay to ask directly, if you feel comfortable doing that, asking a client or a family, how do you prefer to be referred to in terms of your diagnosis? Or how do you identify with this? So I think that is good to know. And that also helps you, if you're kind of aware that some people prefer this identity language, it helps you kind of not be shocked when you hear someone use it or not feel like you need to correct a family if they're using that identity language. And so next, thinking about goal writing and how this can incorporate into our day-to-day practice of goal writing. So I think, thinking about all of this, it's really important to keep in mind the strengths of the client that you're working with. So one thing that I like to ask in an evaluation or when I'm starting therapy with a client is to ask the client or the family, what do you do best, or what does your child do best? And what is your favorite thing about yourself, or what is your favorite thing about your child? And I love that for two reasons. One, I think that often in evaluations, or when someone is starting treatment, they have just finished answering a ton of questions about what they or their child does not do well and struggles with. And I can imagine that that would be really challenging for some people to kind of, especially if they're at the beginning stages of the diagnosis and this is something that's new for them. And then the second reason I really like this is because it helps me to remain kind of strengths-focused and remembering that, although in goals we are addressing the weaknesses, there are things that we can build off of and strengths and preferences that we can kind of expand on to address the goals that will target those weaknesses. We can also use the ideas of neurodiversity to think about greater areas of concern. So I mean this in terms of sort of the big picture. Like for this client who's sitting in front of me, what are their or their family's areas of concern in terms of addressing goals. So this is kind of making sure that you're not just, okay, well, this is a child with autism, and this is their score on the PLS, so these are the goals I'm gonna focus on, but really thinking about the person as a whole.

So thinking about a goal that's really common for children with autism is to address eye contact. And so I think it's important. I don't think it's a bad goal. But I think it's important to think about, okay, well, why am I writing this goal? Is my end goal really to focus on eye contact? Is that what I want for this child? Or am I focusing on, really, on engagement? And is there a way to write the goal perhaps more broadly that could include eye contact as a correct response that is really targeting engagement, so really kind of trying to focus on what the target really needs to be for that client. And so as a part of this, parent and patient input can be really important. And I know that this can really vary across settings. If you're treating people in a school setting, you may not consistent access to the parent. And that can make things more challenging. So again, we're just working within the constraints of our own unique settings. But I think getting the parent or the patient input on goals can be really important for carryover, for that rapport piece, and just have a better impact on the outcome of treatment. Because if you are just kind of grabbing from your goal bank and plugging goals in without ever asking the parent or the patient what they wanna focus on within your scope of practice, I think sometimes it can result in a lot less buy-in. So I think that's good to try and get that input when it's possible. And then also, remaining transition-focused, so thinking about what this client is going to be experiencing after therapy. So of course, we wanna make therapy as best and most effective as we can. But I think it's good to kind of always keep your eye on the prize, which is, what is this gonna look like? What do we need to have accomplished when this child or adult finishes therapy? When they're done with therapy, are they going to be in a public school setting full time without any supports? Are they going to be going to try and get a job, going to college? What does that look like? And what do we need to have accomplished or done before that happens? And that kind of feeds into this idea of solution-focused therapy. So again, we're not just writing goals to write goals, but we really wanna focus on solving difficulties or problems for the client in front of us. And then sort of the same goes for recommendations. So when you're making a recommendation outside of speech pathology, or a referral of some kind, considering, why are you making the recommendation?

So what is the goal? So again, not just referring every child with autism to ABA, because that's what you do, but really thinking about, is this a recommendation that's appropriate for this child? And is the client and the family on the same page? So an example I have of this is, a few years ago, I was seeing a child who, I believe he was about four and was going to be transitioning to kindergarten in the fall. And he did not have a diagnosis of autism, but based on what I was seeing in therapy, he was definitely going to qualify for one. And so that was a difficult conversation to have with the family. And I recommended that they seek an autism evaluation and that they also seek some kind of behavioral intervention. Because I had been seeing him for several weeks, maybe a couple of months, and we were just making really slow, minimal progress in therapy because of his challenging behaviors. And he was really limited in his ability to participate in treatment, and then to do carryover activities at home. So I made those recommendations to the family, and they were not ready to follow through on either of those. I think they were not quite there yet in terms of pursuing an autism diagnosis, though we did kind of talk through some of that. And then they were not interested in pursuing behavioral services at that time. And so thinking about the priority level of the recommendation, both of those recommendations were not a priority for the client, for the family. But one of them was a priority for me. So as the treating therapist, I was okay without the diagnosis. I was kind of trying, again, to meet them where they were. And they were letting me know that they were not ready for a diagnosis. But what I really needed is for him to be able to participate in therapy. And so that behavioral recommendation was a really high priority for me. And they continued not to pursue it.

So eventually I got to the point in treatment, with the backing of my supervisors in my clinic, that I was not able to treat him any longer until he pursued behavioral services and could participate more fully in therapy. And so he ended up discharging from therapy, because we were just not able to come to an agreement on that. But the next steps were, of course, seek behavioral therapy and come back when he's able to more fully participate. So I think that's just a good example of, some things may be really important in terms of recommendations. Some things may be less important, and just being really open with the client, the family, the adult, as much as you can, and letting them know how following through or not following through may affect treatment in terms of your speech therapy treatment.

And so kind of tying all this together, using the models of disability in your clinical practice, I think first and most importantly, just be aware that they exist. I think it's great to, as a speech pathologist, learn more about disability, disability studies, neurodiversity, just so as you continue to treat these people who may consider themselves to have disabilities that you can be more educated and kind of meet them where they are, even if it doesn't align exactly with your training or your personally opinions. Again, adjusting treatment where possible and necessary, when it's appropriate. And then discussing things with clients, counseling them when appropriate about their diagnosis or about their treatment. And then above all, just remaining client-focused. And I think it's, again, so great to remember that what we do is really important, as a speech pathologist. And it can really have a great effect on clients' lives. And so to remember that and own it, and think about how it can affect the client in all sorts of aspects, not just kind of in the narrow-focused way that we sometimes can get stuck in when we're thinking about goals or billing, and our progress notes and that kind of thing. Okay, so now I have a couple case studies that I wanna walk through. And so before I do that, though, I wanna talk about the World Health Organization's ICF. You may be familiar with this. ICF stands for the International Classification of Functioning.

And it's a guide that's published by the World Health Organization that is really just a nice framework of how to think about disability, especially if you're practicing in the healthcare space. So this is pulled from the World Health Organization's website. And the ICF model, again, breaks disability into these different, multiple-dimensional concepts. So like we talked about before, the body functions and structures are something important to think about, the activities of people who have disabilities, the participation or involvement of people in all their areas of life. And then what this kind of adds, which is different from the disability definition that we saw at the very beginning, is the environmental factors that affect these experiences.

So this is doing a nice job of, again, pulling in aspects of the whole person and thinking about how their day-to-day environment may affect their participation or success in treatment. So the ICF conceptualizes a person's level of function as a dynamic interaction between all of these things, the health condition, the environmental factors, and personal factors. So we're gonna use this to kind of frame how we're thinking about the case studies that we're gonna be talking about. So again, this is just a different way of showing how the ICF is organized. So they've kind of got it here, broken into two parts, functioning and disability, and then contextual factors. And then this is a really nice graphic that I like that shows, at the top, you can see health condition, which is the disorder or the disease. And then the arrow shows that the health condition affects body functions and structures. It can affect activities. And it can affect participation. But then on the bottom, you can see that environmental factors and personal factors also feed into those three things: body functions and structures, activities, and participation. So all of these things are not operating in a vacuum. A health condition especially is not operating in a vacuum. But this person's day-to-day life is impacted by health condition, like a communication disorder, and then all of these other things that are going on in their day-to-day life. So the first example that we have for this case study, keeping this ICF, International Classification of Functioning framework, in mind is Patient S. He is a five-year-old with autism who has a language disorder.

So here I have things kind of set up in a way that applies to the ICF. So looking in the first column, you can see the body functions and structures. Here, it would be the diagnosis of autism. For this child, his cognition ability is unknown at this point because of his difficulty participating in standardized tests, like an IQ test. In terms of the speech and language, he has a profound receptive and expressive language disorder. He uses physical proximity, reaching, leading by hand, signs, and visual symbols, and is trialing an AAC device to communicate. He attends to vocalizations and signs, and he inconsistently responds to his name and follows directions. So those are kind of just the objective facts about how this child is functioning in terms of his diagnosis.

And then in the middle column, you can see activities and participation. He relies on caregivers to anticipate his needs most often because of his communication disorder. He participates in therapy by facial expressions, vocalizations, physical activity, gestures, signs, and high-tech AAC. He plays near peers but does not engage with them. And he does not use objects functionally. So you can see that for a five-year-old, this is really not age-appropriate. But we're just listing, we're not necessarily making judgments in that way, but just listing what he is able and not able to do. And then in terms of environmental and personal factors, he's five years and two months. He's motivated by toys and objects, like cars and trains, and preferred foods, he really loves Goldfish. He is motivated to communicate, especially requesting those preferred items. He has a really supportive family, including siblings and grandparents who are active participants in therapy. And the family's very involved in their church. And then something fun about this family is that etiquette is really important to them. So yes, ma'am and no, ma'am are very important and something mom talked about a lot with me. And then they go to an etiquette camp every summer. And so this is just something kind of different that I thought was important to think about and include during treatment. So that is just a summary of this patient, and so thinking next about the clinical piece.

So for body functions and structures, what impairments most affect the function in the current setting or at discharge based on the clinician assessment and the individual self-report? So because this child had a lot of impairments in terms of language, I think, and I think the family would agree, that the impairments that were most affecting him at that time was just his inability to communicate verbally. And often he had difficulty communicating nonverbally as well. So that receptive, expressive language impairment was really affecting his functioning the most at that time, in terms of what was in our scope of practice. And then what activities are most important to the individual in the current or discharge setting? So the family really wanted him to be able to participate in family and community activities, because they were really active in their community, but also, this child was transitioning to kindergarten in the fall, and so they were really focused on kind of getting him kindergarten-ready, whatever that meant for him and for their family. And then what environmental and personal characteristics help or hinder participation in activities or situations? So this family was so involved and supportive, which was great, and most of the time a good thing. But it also meant, their family was large and they were really busy, so sometimes carryover activities at home were challenging for them, because he was kind of indifferent either with his grandmother or his parents, moving around a lot, and being consistent about kind of homework activities was often a challenge. So I think that's good to remember that some personal or environmental characteristics can be both a help and a hindrance, just depending on the situation. So that's a little bit about him. So a long-term goal that I thought about for him would be that he would use a total communication system to communicate functionally and participate in social activities with family, peers, and familiar adults, 80% of the time in the home, school, and church settings by a certain time after receiving therapy and caregiver training. And so again, I know that long-term goals, or goals in general, will look different based on your setting, but this is just kind of one that I created in making sure it was a smart goal. So it's a little bit longer. But thinking about short-term goals that would be appropriate, this is something you can work through on your own at home. But I think that learning a new AAC skill would be really important for him, and then because carryover was a challenge, making it a goal for carryover of, again, a seen skill at home or another preferred location, like church for this family.

And then I think, third, having a parent education goal would be really important, because he was trialing a new device, and carryover was sometimes challenging, so making really sure that the parent or some other caregiver was activity involved in the device. And so for him, he had an older sister. She was maybe like 12. And she was really interested in therapy and was really helpful for him. And so I ended up training her partly on the device. And she loved it, because she could be involved and felt like she was contributing to his treatment. And then it was also great 'cause I kind of had a go-to in terms of who knows a lot about this device. And that was of course cleared by mom and by her. So that was a choice for her, and she was really excited about that. So that's kind of an example of how to use this ICF framework, thinking about a child who has autism, and specifically, as it relates to goals. And so next I wanna run through a case study with an adult, well, an almost-adult, an adolescent, thinking about recommendations as opposed to goals. So this is Patient P. He is a 17-year-old patient with ASD. Thinking about his body functions and structures, his diagnosis, again, is autism. But his cognition it typical. In terms of speech and language, he has normal articulation and receptive, expressive language abilities. His academic performance is average. But he has deficits in pragmatic language based on standardized testing and clinical observations. In terms of activity and participation, he lives at home with mom and dad. He has had two jobs but lost them due to difficulty with social skills. And he has difficulty making and retaining friendships but is interested in dating. And then environmental, personal factors, again, he's an adolescent. He's interested in history and video games. Those are preferred topics for him. He's motivated to communicate about those preferred topics. He has a supportive family. And he attends a large public high school.

So in terms of the impairments that are affecting him most, again, for him, this would be mainly this pragmatic social skill challenge. The activities that are most important to him would be, from this, we would think holding a job of some kind and developing and maintaining relationships, whether that be friendships or some kind of romantic or dating relationship. And then personal environmental characteristics, it's good to know that he has a supportive family. The fact that he goes to a large public high school means that he may have a lot of opportunities for social communication and making friendships. And so it's good to know that. And then he has had some work experience, so there's something that we can kind of work from. So thinking about recommendations, first I wanted to think about the areas to address. So one would be employment, then friendships and dating. So these are kind of the things that we know about this patient that seem important to him and his family. So recommendations I might make based on that goal would be if it was appropriate, and family and him were on board, some kind of social skills training to get at that relational piece. Both friendships and dating can be addressed that way. If they were interested, I think some kind of parent support group might be beneficial, just to know how to continue to support this young man as he transitions from adolescent to adult. That can be a really challenging time for everyone but especially for people on the spectrum. And then also, some kind of transition support, so whether or not he wants to pursue college or some kind of job, helping him identify, finding someone who can help him identify what his preferences are in terms of that and what the next steps are, which could include some kind of workplace training, perhaps. So those are some recommendations that I would make, keeping this ICF framework in mind. So those are kind of the case studies that I wanted to talk about and how to apply those directly. And so next I just have some further ideas for reading on this topic. The first is a really recent article by Simon Baron-Cohen.

And he is a really prominent author in the world of autism. And he has an article out in "Scientic American" called "The Concept of Neurodiversity "Is Dividing the Autism Community." It talks a lot about how neurodiversity can be really controversial and how it is affecting the autism community recently. He's talking a lot about the INSAR conference, which is an international conference for autism researchers and people with autism, and some things that happened at that conference that were controversial. A book that I really like and would highly recommend is by Barry Prizant. It's called "Uniquely Human." And if you're not familiar with Barry Prizant, he is a speech pathologist. I believe he is at Emory, I think, the Marcus Center for autism. And he does, I think, a really nice job of writing a book about autism that sort of bridges the gap between the medical model and the social model. So I really liked it for that reason. Because he's very aware, and I think, believes in neurodiversity but also is a practicing speech pathologist.

So he kind of has that unique view. The next book is called "Look Me in the Eye: My Life with Asperger's." It's written by John Elder Robison. And so this author is actually the brother of the author who wrote "Running with Scissors," which I just thought was really interesting, the memoir, and he talks about growing up with Asperger's and getting the diagnosis, and how that kind of changed things for him. And then the last one listed here is "NeuroTribes: The Legacy of Autism "and the Future of Neurodiversity." This has been a really popular book. And this is the one that I was referring to that gets more into the history of autism. And it also talks a lot about neurodiversity. And then a couple articles from ASHA, one is "A Strengths-Based Approach to Autism: "Neurodiversity and Partnering With the Autism Community." That's in the "Perspectives" journal. And then I also have an article from last year that was published just in "ASHA Leader" called "Is This Normal?" And it's talking a lot about what we talked about today in terms of how neurodiversity and viewing disability can apply to practice in speech pathology. So those are two that apply directly to speech pathology. And then as I mentioned before, that research article by Chris Constantino, "What Can Stutterers Learn "from the Neurodiversity Movement?" I think is another really great one. So those are just some ideas for further study if you're interested in thinking more about this, and more about how it can apply to speech pathology. And that is all I have in terms of content. So if there are any questions, I'm happy to answer them at this time.

- [Amy] All right, great. Excuse me. Thank you so much. Let's see if we can address some of the questions. Victoria is asking, "How are these various movements "of disability awareness and neurodiversity," oops, I'm sorry, "impacted by cultural differences "and understanding the nature, etiology, and ramifications," let me open this a little bit more, "of differences that are viewed either positively "or negatively as disability "or, quote, unquote, 'problematic'?"

- [Mary Alice] Mm-hmm, that's a really good question. And I think that's something important to remember, that, if I'm understanding the question correctly, that not all cultures view disability the same. So in my clinical practice, I had a really diverse caseload. And so there were several families that I had that were from other countries, who viewed disability as something that was really not talked about and was really,

really negative. And in their home country, I mean, it would not be treated or acknowledged. And so of course, with those families or those clients, you may wanna tread lightly. And what I would do when I had those clients is just directly ask them, "Okay, what does this look like in your country?" Or, "How are you doing with this?" Or sometimes grandparents would be closely involved with the family, and they were just not on board with the diagnosis. And so I think supporting them as much as you can, even though that may not be your culture, trying to learn more about it, showing that you're open, I think, is good, and was always really fun for me. Because I got to learn more about a different culture or a different country, and then trying to weave some of this into that. And so again, I definitely don't think that you need to force any view on anyone, especially if they're coming from a totally different culture. But I think just being able to support them where they and lend as much help to them as you can, whatever that looks like, is a really good way to start.

- [Amy] Okay, great, thank you. That's very helpful. And then the terms neurotypical versus neuro-atypical are often used in our field. When thinking about neurodiversity, how should we approach the use of such terminology, especially when discussing diagnosis and treatment with clients and their families?

- [Mary Alice] Yeah, I'm glad you brought that up. And neurotypical is something that I hear a lot, too. I think that it can totally be, I think that's great terminology to use if you kind of have that already established with a family. I think there are some families that seem, at least in my experience, that seem really keyed into this kind of thing and are super aware of the neurodiversity movement and kind of use that language. But I think perhaps for a family, for whatever reason, may not be as aware of this kind of thing, I little throwing out neurotypical can be a little bit confusing, and they may not know what you're talking about. So I think if you feel strongly about using that terminology, I think, at least personally, I think it's totally fine. You just may need to do some backtracking or explain to a family what you mean by that. And again, I think just asking families what they prefer, what language they prefer to use, so there may be some families that really identify with that terminology, and maybe some families who don't. So I think just making sure that you're always explaining the terminology that you're using, and then honoring the family's preferences, personally, I think that that is a good way to handle it.

- [Amy] Absolutely. All right, so let's move on to the next one. Janice is saying, "I continue to have parents tell me "that they don't want a diagnosis "as they don't want their kids to be stigmatized. "What articles are out there to educate these parents? "I myself have a six-year-old son with moderate autism."

- [Mary Alice] That is such a good question. And that is something I ran into a lot, too, in clinical practice, and it's a toughie. Off the top of my head, I'm sure what articles necessarily would help directly with this challenge. I think what I always try to do is walk the family through different options that they had in terms of disclosing the diagnosis. So I had some families, because I was working in a medical setting, who said, "That's fine that I have this medical diagnosis, "but I never, every, every want the school to know." And of course, I would honor that, because those are the rules of HIPAA. But what I always would make sure to do no matter what the family chose was just to educate them on their rights in the education system and let them know what it might look like for them if they were to accept a diagnosis of autism or share that with the school system. I think some families, especially at the beginning, can have so much fear around the diagnosis, which is totally understandable, because it's all new, and what does that look? And it can be different for different children or different schools or environments. So I think just kind of walking the family through that can be good sometimes. If you have access to a social worker, that can be a great resource to just help the family process this difficult diagnosis. Or if you don't have one, making that recommendation to someone whose full-time job is counseling and can walk them through this really challenging thing for them. Again, off the top of my head, I'm not sure what articles may help them. Because it is just such, I think, an individual thing, like every family's different. But I think really supporting them, whether that's through you or a referral in terms of counseling and just making sure that they're really educated in terms of accepting a diagnosis or sharing it with the school system could be good.

- [Amy] Okay, great, thank you. And then the last question is, "It is possible that those "who consider themselves to be neurodiverse "are less likely to participate in therapy?"

- [Mary Alice] That's a great question. I think it could. And I think that that is sometimes why this can be controversial for some people, especially those who may have milder impairments or who don't consider autism or other diagnoses to be a disorder or a disability. Yeah, they may not wanna participate in therapy. And that is what some of that podcast that I was talking about from StutterTalk, some of it talks about that, about whether we should even be treating stuttering. Again, I'm not saying one way or the other what I think about that, but I think, but yeah, for some people, you may have more resistance to therapy when they're coming from that mindset. And that's one of the reasons I think this is so important. Because if you have someone walk into your practice and is like, "Well, I don't want therapy," it can be really challenging to understand if you're not aware of this perspective or this movement. So yeah, I think that's totally a possibility. And I think it's really important for us to be ready to honor as speech pathologists and to understand that it's just a different way of thinking. And especially for an adult, that's their choice. I think for children, it can be a little bit stickier in terms of what's best for them. But for an adult, I think it really could result in that. Yep.

- [Amy] Okay, so that does bring us to the end of the questions. Thank you to the participants for submitting those. And I'd like to thank you, Mary Alice, for joining us today. Really great information to be thinking about and considering as we work with families and clients. And so I wanna thank you for that. And with that, we can go ahead and wrap it up there for today. And thank you to all of our participants for joining us. We do appreciate your time and look forward to seeing you again soon. Have a great rest of the day.

- [Mary Alice] Thank you so much, everybody.