



Episode 1: Kids Across the Spectrums

There is incredible diversity in children's relationships with digital technologies, which introduce a range of opportunities and challenges for their rights, learning, and wellbeing. Kids on the spectrum, however, must also contend with popular stereotypes and misinformation about autism and technology, which impact them in complex ways. In this episode, Dr. Sara Grimes chats with Dr. Meryl Alper, about her ongoing research on the role of media and digital technologies in the lives of disabled children and their families.

Dr. Sara Grimes 0:00

Have you ever heard the term digital native? What about cyber child? Marketers, academics, journalists, and policymakers alike have been using these terms for over two decades to describe the perceived affinity and ease with which children engage with digital technologies. Such terms, and the assumptions they emerge out of are celebratory and optimistic. They evoke an image of the child as empowered and innately skilled, ready to meet the challenges of the information age, the very opposite of the child at risk. But the idealization of children as inherently and universally superior at using digital technology is also incredibly problematic. It effaces the stark inequities in access to technological devices and infrastructures that exist among children living in different countries or different parts of a country or even different neighborhoods in the very same city. It also ignores important differences in familiarity, skill, and literacy among kids of different ages and abilities, as well as the persistence of systematic disparities along class, race, and gender lines.

The idea of the digital native is based on overgeneralizations and misconceptions, and it works to perpetuate them. Children on the spectrum are impacted in especially complex ways by the myth of the digital native. It intersects with other stereotypes and flat out misinformation about autism and technology that kids on the spectrum are forced to confront at school, in popular culture, and across their everyday lives. This includes the stereotype of the autistic savant, which is found in media representations of all people

on the spectrum as geniuses with exceptional skills or brilliance in particular field. The compounding of these myths means that there's often a lot that is assumed about how kids on the spectrum do or should use technologies. It obscures the diverse needs and experiences of children with different forms of autism, the different types or levels of support they might need, and the impact of intersectionality on their technology access and use.

Dr. Meryl Alper, Associate Professor in the Department of Communication Studies at Northeastern University is determined to bring these issues to light. Her forthcoming book, *Kids Across the Spectrums: Growing Up Autistic in the Digital Age*, to be published by the MIT Press, shares insights and findings from the latest study in her ongoing research on the various and at times conflicting opportunities and challenges that media technologies provide to young people with disabilities and their families.

This larger work has been published in numerous articles, including *Digital Technology and Rights in the Lives of Children with Disabilities*, which was co-authored with Gerard Goggin and published in *New Media & Society* in 2017. It's also the subject of two previous books that Dr. Alper has published with the MIT Press. *Digital Youth With Disabilities*, which came out in 2014, and *Giving Voice: Mobile Communication, Disability and Inequality*, which was published in 2017. Dr. Alper is a leading scholar at the intersection of children's studies and disability studies. Her last book, *Giving Voice* won the 2018 Outstanding Publication in the Sociology of Disability Award given by the American Sociological Association. And she's frequently invited to share her expertise with children's media and technology producers, including Sesame Workshop, PBS Kids and Disney.

I'm Sara Grimes, Director of the Knowledge Media Design Institute at the University of Toronto and host of the Critical Technology Podcast. Today, I'll be talking to Dr. Meryl Alper about her upcoming book, *Kids Across the Spectrums* and her thoughts on the rule of digital and media technologies in the everyday lives of autistic kids and their families. Please note that in order to protect their identities, Dr. Alper uses pseudonyms in our interview when discussing her research participants. Your forthcoming book is called *Kids Across the Spectrums*, who are the kids described in this book and why did you focus on these particular children in your research?

Dr. Meryl Alpher 4:24

So in my last book, *Giving Voice*, I focused on kids who were non-speaking, who due to a variety of developmental disabilities, so that might have been down syndrome that might have been cerebral palsy, but most of them actually turned out to be on the autism spectrum. And I was really focused on the ways that they were using iPads, these ubiquitous mobile devices as assistive tools. But at the end of all of that massive amounts of data collection, I had all this stuff that had to do with everything else they were doing with the iPad that wasn't just this one prescriptive use. Their YouTube usage, and not just the iPad, but all the other technology, all the other devices, all the other platforms in their lives. So there was sort of this... I had this data, I was ready to do something with it and build on it, but also from a more theoretical or conceptual level, I had focused on this idea of what does voice even mean?

I had thought a lot about how in the mass media, in the press, in the language, around these tools, as it relate to people with speech disabilities, this idea that technology gives them a voice. And we can talk about that on a lot of levels, a lot of different marginalized groups, the idea of them being themselves inherently in some manner disempowered and the technology as this equalizer, as this liberator, all these other things.

So I had been playing around with voice and in thinking about kids on the spectrum, and again, some of them do have significant speech disabilities, but many, many do not that the core theme that seemed to come out of that was that the way that these kids use technology also plays upon this idea of what does it even mean to be social? Considering that you're talking about this idea, non-speaking people don't have a voice, well clinically autistic people are characterized as having deficits or a lack in social communication as an absence or a kind of deviance of sociality.

So in the same way that I was thinking about voice from this more grounded perspective, how is voice enacted? How is it made? How is it contested around and through technology in these different contexts? I thought that there was something here to hone into as that related to being social as well. I should also note that I am not on the autism spectrum myself, neither am I a clinician or a family member of a person on the autism spectrum, but I am a curious person.

And I had read in terms of what has been written about autistic kids and their technology use, I'd seen some like parent memoirs, I'd read blog posts, or even kind of individual academic studies, but it wasn't a topic that I'd seen a real academic book length attention paid towards in the way that... In the field of youth and media and technology, that there had been many books written about. And I thought that this topic deserved that kind of critical attention.

Dr. Sara Grimes 7:49

An important goal of your work is to dispel the various myths that exist about young people on the spectrum, which emerge as assumptions and stereotypes that are often heavily focused on technology use. Would you mind telling us a little more about these myths and the impact they have on autistic kids' lives?

Dr. Meryl Alpher 8:06

So I'd say that there's two main myths that circulate around autism technology and youth. One is this idea that they're just all technologically savvy, technological savants. This idea of the autistic savant in general is a kind of archetype that exists. And when it comes to technology, you see it repeated in TV shows like Silicon Valley, just kind of popular discourse in general, the idea that, oh, the halls of, pick your tech company are filled with kind of people on the spectrum, whether they are diagnosed or undiagnosed.

Speaker 3 8:48

I guess I just don't understand why anyone would use space over tabs.

Speaker 4 8:52

I do not get why anyone would use-

Speaker 3 8:53

If it's all the same why not just use tabs?

Speaker 4 8:54

Spaces over tabs. I mean, why not just use-

Speaker 3 8:54

There is no way-

Speaker 4 8:55

Vim over Emacs.

Speaker 3 8:56

I'm going to be with someone who uses spaces over tabs.

Dr. Meryl Alpher 9:02

So there's this inherent, this idea of this being this natural relationship. There's also this myth of an inherently unnatural relationship in this idea of, oh, technology isolates kids on the autism spectrum to the point at which they prefer technology over people, and that they don't have empathy for others. And this kind of narrative, you find it tracing through rhetorics around video games and autism and school shootings. So the idea of either it's a very natural relationship where they're so good at it, or this kind of pathologized in a different way, framing of it kind of sours their ability to be human in a way. So A, those myths are, they are myths. They serve a kind of cultural purpose in a way, but their relationship to reality is a totally separate thing. But the impact of these myths, I think there are direct and indirect impacts on autistic kids' lives.

So one is just, they are dehumanizing and they make it easier for people to treat autistic people as less than human. They're based on, I think at the very core based on these longstanding ideas from kind of mid 20th century onward about autistic kids not just preferring technology, but being robotic themselves and products of, or kind of victims of post-war industrialization. So there's this already sort of stripping away of the nuance of humanity. And then I think in an indirect way, at least like as a researcher, those presumption of, oh, we already know what their relationship is between kids on the spectrum and technology then limits the kinds of questions we might ask about their technology use from a more grounded perspective.

Dr. Sara Grimes 11:09

The theoretical framework applied in the book is something you call the socio-technical shaping of sociality or STSS. It draws on science and technology studies, especially feminist STS, anthropology, communications, and media studies in a really innovative way. Can you tell us more about STSS and why this approach is useful for examining the relationships kids on the spectrum have with technology?

Dr. Meryl Alpher 11:36

I started thinking about really that what I was interested in wasn't just about society and institutions and the kind of macro level. Thinking about how autism, the way that it is kind of imagined, has so much to do with sociality and both the individual person and their relationship to others, their relationship to themselves, their bodies, their environment, and from the side of cultural anthropology and critical autism studies, there's this notion of autistic sociality and the notion of possibility was something that I thought was really interesting in that concept.

It's this idea that there are many different types of ways to be social and for autistic people, again, not everybody uniformly in the same way, but for autistic people that might be different, but it's not all together lesser. So thinking about kids on the spectrum and thinking about possibility that kids aren't just acted upon by the world, they act on the world, they are the selves actors in both individual and collective and structural ways. So to me then, STSS, it is about kids on the autism spectrum, but it's about understanding this dynamic relationship between social norms, which, and I should say, largely neurotypical social norms, societal frameworks, and then technologies that enable and disable sociality in different ways and to different ends.

Dr. Sara Grimes 13:23

Your response just now is reminiscent of one of the key arguments you make in the introduction of your book, which is that the experiences of kids on the spectrum are not so much defined by their diagnosis as they are shaped by how their disability intersects with other dimensions of their identities, including race, ethnicity, class, and gender. How did this finding emerge over the course of your study and what are its implications?

Dr. Meryl Alpher 13:48

So for this project I went in looking to recruit a diverse sample of kids. But when I talk about diversity, I meant both in terms of their autism, so different degrees or different... Some people, some kids who do have intellectual disabilities, some who don't, some who do have complex communication needs, some who don't, some who have other kind of co-occurring conditions like OCD or anxiety. So in that respect, but also really especially demographically, because so much of autism is just so very white and so very male, and it traces through everything. It traces through the actual development of the diagnostic category itself. It traces through who is researched, for whom services are funded. It traces through who is represented in mass media as the face of autism.

So what emerged in doing the ethnographic work that I was doing, which, and part of that data was from the work that I had done in LA prior to 2015 and in the greater Boston area, which has significant income inequality, as well as massive racial segregation. You don't have to go very far in Boston to hit economic extremes. And to also just have large areas where there's just not a lot of racial or ethnic diversity. So the landscape of the actual city itself was something that I very much took into account in doing this work, as it relates to what kind of services are available, kinds of neighborhoods, what does it mean to grow up as a kid in a place?

So what emerged was that just because two kids were on the autism spectrum or even had a similar profile in terms of their cognition or their behavior or communication didn't mean that much of their life looked the same at all. For example, the physical space that they inhabit on a daily basis, whether they're in a house or an apartment, the communities that they were in, whether that was a safe neighborhood or not, that all of those things shaped their leisure time and the role of media within it. And the extent to which they felt a sense of safety and security through media. So you can't take a one size fits all approach to autism and technology, but that's not just because autism as a diagnostic category is so complex, but because autistic people are too.

Dr. Sara Grimes 16:38

The book is divided into three main themes, cultural belonging, social relationships, and physical embodiment. I'd like to delve a little deeper into each theme, starting with cultural belonging. How do questions of cultural belonging and children's desires for

cultural belonging come into play as kids on the spectrum engage with technology.

Dr. Meryl Alpher 16:58

So whenever qualitative researchers kind of come up with categories, there's always this caveat of I had to separate them out, but of course they're interwoven. So of course, cultural belonging is shaped and related by social relationships and physical embodiment, they shape each other. But the chapters related to cultural belonging, one is related to identity and one is related to learning. So essentially how do kids on the spectrum get a sense of where they belong in the world and specifically through institutions like media and education. Kids on the spectrum in terms of identity, make space for themselves through the media that they use, the technology that they engage with, to get a sense and understand what it is to be autistic. I kind of hone in on autistic identity in the context of media and technology for these kids.

And I should say I'm focused on kids ages three to 13. So before you hit high school, before you hit puberty, the ways in which kids are able to articulate feelings of difference or kinship or recognition happens in these really interesting and diverse ways through the Minecraft characters that they make, or through the ways that they do or do not identify with certain representations of disability in media. So that chapter sort of illustrates those layers. And then in terms of belonging on a daily basis, where do children learn is a very complicated question, but thinking at least about the institution of formal education that there's on many levels, kids who do not find themselves belonging in their schools, in their classrooms because of the conditions around them. So where does learning take place?

A lot of learning happens informally with media for kids on the spectrum, but what came out through the work is that a lot of that has to be contextualized against the backdrop of being excluded from or receiving a subpar education in these formal learning spaces. So one example that I start the chapter with is a young girl named Sophia. A Latino, a five year old, and how she had been spending really much of her summer at home, not really going anywhere and just consuming massive amounts of the show Clifford the Big Red Dog on YouTube. All this field work was conducted prior... A little bit of it edged into the pandemic and so I had some remote interviews, but the ways in which, understanding why she was just all of the time had this iPad and was watching publicly funded

educational media was because she... She was supposed to have summer school that summer, but when her mom dropped her off the paraprofessional that was assigned to her child said that basically she just sat in a room all day with crayons and did nothing. So that wasn't really education.

They didn't have a lot of space. They were living in a gentrified neighborhood where they had to move in with Sophia's mom's family. And so there wasn't an extra playroom or exercise space or something to move around in. She also had really significant sensory sensitivities. So getting on the bus to go get somewhere or even local playgrounds, in the neighborhood they were in there wasn't much green space. To understand the sheer number, the sheer amount of what she was watching had to really understand the ways in which Sophia had been failed by institutions and infrastructures all around her.

Dr. Sara Grimes 21:08

The second theme is social relationships. What rules do technologies play in the social relationships and resources or repertoires of your child participants, for example, in terms of making and maintaining friendships with other kids.

Dr. Meryl Alpher 21:22

The literature says that most kids on the autism spectrum do desire friends. The question is what do those friendships look like? Are they the same kinds of friendships that neurotypical kids desire and what are the challenges that can on the spectrum have in developing those bonds? Because the challenges that kids have, they aren't just related yes to their own skills and abilities. So that might be challenges with... And again, it's not a uniform thing, but some are highly, highly empathetic and maybe are really, pick up very easily emotions of others. And some have difficulty with emotional reciprocity. Some may be very direct or have very... Play with repetitive speech patterns in a way that maybe neurotypical kids don't necessarily understand, or so kids themselves have these differences. But there's also this really powerful way that stigma and discrimination works in terms of how kids do or do not become part of the communities in which they spend their days, in their classrooms, in their schools.

So the kids that I spend time with, some had very close friends, some kids were very admittedly introverts, explicitly said that they were. But technology became part of their social repertoires in these four main ways. So one as kind of a form of social scaffolding,

something that would challenge their sense of social safety and security, something that enabled them to exert agency over their social lives. And then also something that was shaped by these broader societal and contextual factors. So when I say scaffolding one way in which that worked is using language and speech from media to practice social interactions. There were a number of kids who, that they didn't speak a lot when they were a kid or had difficulties with what's known as social pragmatics. So in particular social situations, using particular social terminology and language.

So just memorizing lines from TV shows and being able to say them to other kids in a new situation that was like the thing they'd seen in a TV show. Or even practicing conversation. One kid who I watched really talked to the YouTuber, Markiplier, a gamer YouTube in a way where he was enacting a pseudo interactivity purposefully by turning on the captions on Markiplier's videos and seeing also what Markiplier was saying, and filling in the blanks and having a conversation. To me, these are kinds of, these are scaffolds for, it's not to say that there's some then higher, more ideal version of being social, but they're tools that kids use to find their rounding in a way. In terms of agency and making clear choices, video games were a really active choice, not exclusively for boys, but a lot of boys in the study of having a clear structure and purpose, especially during something like a play date where games give you a social activity with a shared goal.

And that being something that facilitated interactions that would not have been possible, or would've been maybe more frustrating and a lot more tears and a lot more anger. And that's not to say that video games didn't also lead to interpersonal conflict, but they created a way for kids to make choices. But there's also a third thing as it relates to safety is the games are increasingly networked. And there's lots of other opportunities for kids to be socially networked and autistic kids are also exist as we all do in a culture of personal likability where putting yourself out there is rewarded. But those risks can be very high to kids on the spectrum, especially if they don't necessarily understand all of the many layers of social complexity that come along with that. So there are risks that are opened up, and there are kids that I talked to who saw the scary end of things.

And thankfully have come out the other side, but it's stuff that's really hard to prevent, but stuff that I think in part, because it's not talked about enough, what bullying can look like for in these complex ways and these nuanced ways that aren't necessarily obvious

for kids on the spectrum, especially I should say in the context of social media girls. And I think that's in part because girls on the spectrum are just understudied in general.

And then lastly, race is something that I think is really central to talk about for kids. Thinking of one kid that I studied, who was a black child in a somewhat diverse neighborhood. But mostly his peers were other white kids and building friendships wasn't just about the technology that they played together, but also the culture around this child who understands a black child or a black autistic child as a threat. As somebody who maybe is no longer a child once they reach a certain age. So the understanding of building bonds of friendship and openness and bonding that occurs in these after school, out of school spaces around technology have to be understood against that backdrop as well.

Dr. Sara Grimes 27:42

The third theme of is physical embodiment, this section of the book includes a chapter on census, which is adapted from a previously published article you wrote entitled Inclusive Sensory Ethnography. In that article, you refocus the discussion on autistic kids' sensory experience and embodied engagement with technology. This brings such an important and often overlooked dimension of technology use to the forefront. How does looking at senses help us to better understand how kids on the spectrum use and experience technologies?

Dr. Meryl Alpher 28:13

So my initial learning in the context of assistive technologies was actually through one therapeutic field, the field of occupational therapy, which has to do with what occupies you on a daily basis and how do you work to improve that activity? And a lot of when it comes to occupational therapy and autism is related to sensory integration, how do you make the sensory environment around you more amenable to your functioning so that you can sit in class, so that you can go to the dentist and be able to sit there? How do you better balance your own sense of sensory regulation or dysregulation which is something

that a lot of kids on the autism spectrum experience and the world around you, which you may or may not have much control of sensory wise.

I had absorbed that literature and thought about that in relation to talking about media and the sensory. There was one moment when I was in a kid's house, where to me, I was like, oh, there's a lot going on here sensory wise that I don't know if the literature on media and the senses really gets at, and it was a kid who had this thing called a Gorilla Gym, which is like in your door frame, you can stick up a chin-up bar or like a pull-up bar for home exercise. But this was something in this kid's apartment that in order to get his vestibular sense of movement, the mom had set up a swing. And that's something that lot of kids on the spectrum either have a higher or lower threshold for movement.

So this kid had a swing. To the left of the swing in the family dining room, there was an iMac set up with a bunch of DVDs scattered all around, and the kid would watch DVDs on this bigger screen, this iMac, but would watch it from the side while he swang forward and backwards. The multidimensionality of this space and the different layers of the senses in media here, it's not just how does looking at the senses I think help us understand how kids on the spectrum use and experience technologies, but how their experiences of technology helps us think more complexly about the senses. Whether that's the fact that we don't... It's not just five senses, it's also this proprioceptive sense of your sense of gravity, of where you are positioned, of the vestibular sense of your sense of motion. Because when these things go off, they can be really disruptive.

Dr. Sara Grimes 31:08

I'm going to shift gears a bit and ask you the question that I'm asking all my guests this season, the United Nations recently adopted a new general comment, confirming and outlining, how children's rights apply in the digital environment. Do you think this will have any impact on the kids issues and relationships described in your book?

Dr. Meryl Alpher 31:28

So I think that it can have an impact, but it really depends, especially if we're thinking on a global scale, not just about children's rights and about the digital environment, but specifically about autism. So autism, there is so much stigma globally about the

causes of autism, the treatments of autism, and even just being able to count who, what, how many kids globally are on the autism spectrum. There's a lot of that counting that happens in countries like the United States or the UK or Australia but globally, you have these massive gaps in information just about who are these kids, how many are there? Let alone then what are their needs? So something that we talked about in the New Media & Society piece that I wrote with Gerard Goggin, that sets out to understand where the UN Convention on the Rights of Persons with Disabilities does, or doesn't align with the UN Convention on the Rights of the Child.

That there's all these areas that we could talk about the ways in which autistic kids' rights are really pressing in the digital environment, whether that relates to sexual health and their understanding both of sexual information and exposure to sexual information, to online safety, to education. But there's just this real gap of baseline data. And so I think to even assess the rights of these kids, they have to be counted in the first place, but that requires better research methods. That requires these wider global teams. And I think that that's going to be important for this general comment to really fully have the weight behind it that it needs.

Dr. Sara Grimes 33:30

A big thanks to Professor Alper for joining us today. Please follow the links in the podcast description to find out more about Dr. Alper's research, her upcoming book, Kids Across the Spectrums, and the other publications mentioned in today's episode, as well as information on where to send your questions or comments. The Critical Technology Podcast is produced by me, Sara Grimes, with support from the KMDI. Audio mix and sound design by Mika Sustar, music by Nicholas Manalo. Theme song by Taekun Park. Our logo was designed by JP King and the artwork for today's episode was created by Kenji Toyoka. Please subscribe to stay up to date on new episodes and posts as they become available and thank you for listening.