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- HELEN GENOVA 00:10 [music] What we do is we really have a few themes that we try to incorporate into our research. One is positive psychology, where we try to incorporate well-studied concepts in the field of positive psychology into our study of individuals with autism.
- BANKS-SMITH 00:28 That was Dr. Helen Genova, and I'm your host, Joan Banks-Smith. Welcome to another special edition Fast Takes podcast. Recently, I had the opportunity to interview Dr. Helen Genova, associate director of our new center for autism research here at the foundation. We spoke about various ongoing studies, what this center means to the autistic community, and what the future might look like for this new center. Can you tell me about the center and how this research can impact those on the spectrum and those caregivers of individuals on the spectrum?
- GENOVA 01:04 What we're planning to accomplish is we are hoping to explore different outcomes and to develop interventions for individuals on the autism spectrum and their families. One of the areas that we want to focus on is the transition from adolescence to adulthood. We want to really help people across the entire lifespan, not just young children with autism. And we are going to start using a broad range of techniques such as principles of positive psychology, virtual reality, web-based interventions, neuroimaging, eye tracking, because really, we want to address the complex issues facing individuals on the spectrum. And we also want to directly engage the autistic community. So we want to have a direct conversation with caregivers and stakeholders and individuals on the spectrum to make sure that the research we're doing is meaningful to the community, that it's accessible, and then also that it's evidence based.
- JOAN BANKS-SMITH 02:08 You mentioned that you'll be looking across the lifespan. Why is that?
- GENOVA 02:13 The reason that is is because historically, research on the autistic community has been done in very young children. So there's a lot of research about how to support them almost as soon as they get diagnosed, when they're young, and how to improve outcomes as they grow. And so there's been just a huge emphasis on that particular stage of life. And so what happens is is that then there's this drop off of research for adolescents, for example, teenagers, kids who are in high school and looking to start college or to try to gain employment. There's not a lot of research on how to support that particular population. And so what I want to do is I want to help that particular age group because we know that that's the age when these young adults are going to be trying to become financially independent, trying to gain jobs, trying to become independent from their families. And so they really need a lot of support.
- BANKS-SMITH 03:18 What type of studies are you doing now in case there are people in the autism community listening that would like to participate?
- GENOVA 03:26 We are doing quite a few studies right now. So for example, one of the studies that we're looking at is looking at the science behind job interviews. So how the job interviews affect people's ability to obtain employment, for example, how

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performance on job interviews, that initial conversation between you and a potential employer, how that impacts your ability to get a job, and how we can help people improve those job interview skills. So we have a couple of studies actually focused on the job interview, and those studies are completely virtual. So if someone would like to participate, they can just let us know. We'll meet with them online. They do not have to come into the center. So it can literally be anybody in the country. It does not have to be in the state of New Jersey. We have actually a study for residents of the state of New Jersey if they would like to come to our center in East Hanover or in West Orange, New Jersey, and that involves an MRI scan where we're really looking at brain networks involved in how individuals with autism or on the autism spectrum, how they see themselves. So that involves an MRI scan. And then we also have a completely online study where people just answer survey questions and we find out more about them and what their needs are. So that's another study, and we're always looking for focus group participants. So if somebody is listening right now and they would like to be a part of a focus group and give us their opinion on different interventions that we're developing, we would love to talk to you and have you be a part of that study as well. So if anybody wants to participate, they can always reach out and contact us at [autismresearch@kesslerfoundation.org](mailto:autismresearch@kesslerfoundation.org).

BANKS-SMITH 05:15

And we'll make sure we have all of this information in the program notes for our listeners. They can check the studies out online, and also they can just reach out to you and contact you. So we'll have all of that. Can you describe your overall approach to research in the autistic population?

GENOVA 05:35

What we do is we really have a few themes that we try to incorporate into our research. One is positive psychology, where we try to incorporate well-studied concepts in the field of positive psychology into our study of individuals with autism. And we also really focus on intervention development and implementation. And then finally, we have a strong focus on community engagement.

BANKS-SMITH 06:03

You've mentioned a few things here. Let's try to break this down one by one. Can you tell us more about the positive psychology?

GENOVA 06:11

Absolutely. So positive psychology is a field of psychology that focuses on things that are positive. So what that means is historically, we have had, in the field of psychology, an emphasis on trying to fix what's wrong with a person. So when you're feeling sad, when you're feeling depressed, when you're feeling hard on yourself, you go to a psychologist for them to sort of fix that aspect of your life. I don't want to be depressed. I don't want to be sad. And so psychology is all about trying to remove those negative things out of your life. Positive psychology actually does the opposite. There's not a focus on negative. Rather, it looks at what is going right for an individual. So it says something like, "Well, forget about the negative. What is going well in your life and how do we cultivate that and how do we bring those factors out?" And there's a really beautiful analogy that's sort of a garden. And if in typical psychology, where you focus on fixing what's wrong, would be like weeding your garden. Taking out all the weeds, trying to get it to the level. So kind of fixing what's wrong with the garden. Whereas positive psychology says, "Well, if you do all that, all you're left with is dirt, really." So positive psychologist really asks, "What can we

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cultivate to make that garden look beautiful? So can we put in flowers? Can we water it? What do we do to enhance the positive?" So that's really what positive psychology is. And so what we're trying to do in the autism community is to say, for many of these young adults on the spectrum, their entire lives, therapy has been focused on teaching them what's wrong about you. And what we're trying to do in the center for autism is like, "Okay, let's put a pause button on that and let's try to focus on what's right with you, and then how you can cultivate that moving forward to help you achieve your life goals."

BANKS-SMITH 08:08

Why is that important in autism?

GENOVA 08:10

I think that there's just been this huge emphasis on deficits throughout their life. So if you have a young child with autism, a lot of what therapy is aimed at doing is to stop problematic behaviors. So stop stimming, stop acting out, stop getting overwhelmed. But if you're hearing my language, it's all very negative. Stop doing this, stop doing that. And what we're trying to do is kind of say, "Let's reverse that pattern. Rather than focusing so much on telling them to stop doing things, let's figure out what they're doing right and then increase those behaviors."

BANKS-SMITH 08:52

And you also mentioned community engagement. What do you mean by that?

GENOVA 08:57

Historically, again, in science, I think that scientists have taken the approach of studying what needs to be done in a certain population and then doing it. And I think that that's wonderful. But I think one step has been sort of missed, and that is to engage the community and the population that you're attempting to help. So in other words, if you're studying somebody or if you're studying a treatment for multiple sclerosis, one crucial step in the research is to go ask people with multiple sclerosis, "When you think of this treatment, is this a treatment that you want to have happen?" And so I think that this is something that the autism community has really been advocating for, which is ask us which treatments we want, ask us what we think of the treatments, and then to really take those opinions and perceptions of the autism community into consideration. And so what we're trying to do is increase the amount of times we engage directly with the community, where we're holding focus groups, as I said, direct conversations, where we're asking them, "How are we getting this right? How are we getting it wrong? What can we change? And what research do you think needs to be done?" So that we can do the research that's really meaningful to them.

BANKS-SMITH 10:21

You talked about intervention development. What types of interventions are you focusing on?

GENOVA 10:27

Right now, because we're focusing on young adults on the spectrum, we're really focusing on interventions that help them improve their chances of obtaining meaningful employment. So if somebody on the autism spectrum wants to work, if that's a goal of theirs, how do we get them to achieve that goal, whether that means helping them on the job interview, giving them skills that they can use on the job in order to maintain their employment. And so we focus a lot on employment. We also focus on social functioning. So for example, if somebody really wants to make meaningful relationships with others, with friends, with their employer, etc, how do

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we help them achieve that goal of maintaining meaningful social relationships? And then all the other things that come with becoming an adult. So getting into college, doing well in college in terms of managing your schedule, regulating your emotions, all of those things that they may need support with, those are really the interventions that we're focusing on right now.

BANKS-SMITH 11:36

If somebody was a member of the autism community, how would they be able to contribute to this work?

GENOVA 11:42

They can always contact us at [autismresearch@kesslerfoundation.org](mailto:autismresearch@kesslerfoundation.org). They can contact me directly if they, for example, wanted to just speak to me about my research. So [hgenova@kesslerfoundation.org](mailto:hgenova@kesslerfoundation.org). H-G-E-N-O-V-A. And just reach out and tell us whether you'd like to help, how you'd like to help, even if it's just giving us your opinion. We would love to hear from anybody in the autism community.

BANKS-SMITH 12:08

Let's switch gears a little here. As you know, Kessler Foundation is known as a leading research facility in the country. How are you going to use Kessler Foundation's already existing resources to help you with your research on autism?

GENOVA 12:24

That's what's really so exciting about this new center, is that Kessler Foundation has really been building its research center for years and years. And we have such amazing tools at our fingertips because of the innovative work done by other scientists. So for example, we have a neuroimaging center, it's research-dedicated, specifically for research. And so we can use that to look at neural networks in the autism community and to find out what is different and special about their brains compared to their peers. So the neuroimaging center, for one. We have a MOC scanner that was purchased specifically for the use in the autistic population. And a MOC scanner is basically a fake scanner. It's something that looks like an MRI machine. It sounds like an MRI machine, but what it does is if somebody is concerned that they would not be able to go through with a study in the MRI, the real MRI, they can come and practice in the MOC scanner, and they can spend as much time as they want to feel comfortable. And that way, when the actual scanner session happens, they don't need to feel anxious because they've already done their session in a MOC scanner. And like I said, that was a resource specifically purchased for the use of individuals on the autism spectrum. And then we have other really amazing tools. Like I said, we've done so much groundbreaking work with virtual reality in different populations. And so what we're doing is we're trying those virtual reality tools in the population that we're studying, in the autistic population, to see if we can either develop interventions or to look at different challenges they may be having, to put them in a situation where it appears to be real life, but they're just wearing virtual reality goggles, etc. So there's a whole host of really great things that we have access to.

GENOVA 14:23

And so I'm really excited about being able to use everything that Kessler Foundation has to offer in this really wonderful population of the autism community.

BANKS-SMITH 14:32

I've actually had the opportunity to see some of this equipment, and it really is amazing being able to use this for research and getting outcomes from this and also helping the community.

- GENOVA 14:46                      Absolutely.
- BANKS-SMITH 14:47                About a year ago, you did a podcast with Dr. Regina Peter of The Newmark School on how the pandemic might affect the autism community. And now you recently have had an article published on that topic. Can you summarize that for us?
- GENOVA 15:03                      This was an article that was recently published in Frontiers in Education, and our goal was to look at how the pandemic affected school-age children on the autism spectrum compared to their peers. And we really wanted to do this because I was hearing from the autism community, either on social media or just in my town, about how much the shutdown of our schools and the virtual learning was having an impact on the autism community. And so I really wanted to look at that scientifically and say, "How can we publish this and make other people aware of what school-age kids on the spectrum were going through at that time so that we're prepared in future pandemics to make sure that these kids don't fall through the cracks?" And what we found was that their challenges during the pandemic were very different from their peers. So a lot of parents and families were concerned about social isolation, for example, and having kids having to stay home and missing their friends. And what we found was that was really a very large stressor for the neurotypical kids, the kids who do not have an autism diagnosis, where they were really missing their friends and having significant social isolation. And in the autism group, it's not that they weren't missing their friends and it's not that they weren't socially isolated. It just wasn't as big of a stressor to that community as it was for their peers. What was a huge stressor for them was the disruption in their routine, was staying home, having to get on virtual learning, having to only interact with their teachers through a computer screen, not knowing what to expect.
- GENOVA 17:00                      In March of 2020, we all went home thinking this would last for two weeks and everything will be back to normal in two weeks or in a month. And here it's stretched out for as long as it has. And so I think with autism, one of the biggest challenges is not doing well when life is very unpredictable, and individuals on the spectrum really thrive when they know what to expect. That sort of reduces their anxiety levels. So to have every day be, "Am I going to go to school today? Is school going to open at all? Do I have to log in? Is there going to be technical difficulties?" All of that really took a toll on families where there was an autistic child in the house and parents were very stressed as well, because they became the teachers, the lunch ladies, the the rapists, etc, to these kids. And I think that everybody really suffered at that time.
- BANKS-SMITH 18:01                Do you think the effects of the pandemic on the autism community are ongoing?
- GENOVA 18:06                      Absolutely. One thing that I worry about was I would talk to moms in the autism community who would say that their child wasn't getting anything out of virtual learning. So if you had a child without an autism diagnosis whose academic and educational goals were not being met, it was tenfold for a child with autism. So you might have, let's say, everybody should be learning at 100%, and a child without an autism diagnosis was only learning 75% because of virtual learning. So 25% of their attention span, let's say, wasn't there. A kid with autism, might have been 10% that they were learning. There's no way to scientifically capture what they lost in terms of education, in terms of academics. However, I really believe that they lost a lot, and

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that I hope that there's a plan in place to gain back what was lost. And that's really one of the major reasons we published this article, was that people could read it and say, "Wow, this is a population that definitely is going to need help moving forward. They need additional resources that their peers may not need, but they really desperately need to have special attention to them to catch up on what they lost during the pandemic."

BANKS-SMITH 19:32

What can parents do related to the effects of the pandemic?

GENOVA 19:36

I would think that the number one thing that they should do is to-- if you have a child on the spectrum and you feel that there were significant academic losses last year, I would absolutely bring it up to the IEP team, the Individualized Education Plan team. Make sure that they are aware of your concerns. Make sure that they don't say something like, "Oh, everybody missed out on so much. It's no big deal." Because we have the scientific evidence that kids with autism, their parents feel that they missed out more than their neurotypical peers. And so I think it's the kind of thing where you really have to advocate for your child and say, "Listen, okay, everybody lost something, but I think that my child lost a significant amount, and we have to address it in order for them to continue to make their goals of this year and moving forward." So I think bring it up to the schools, the IEP team, anybody you can, and then also to rope in therapists. If you have a private therapy that goes on for your child, talk to them. Make sure that everyone on your team is aware of your concerns and that they are being addressed, and not to feel bad about that. You are your child's biggest advocate.

BANKS-SMITH 20:51

Absolutely. Before we wrap this up, can you just recap what studies you're doing in the center right now in case anybody wants to participate, and then remind us how people can participate?

GENOVA 21:04

We have a number of studies. We have our survey study, where it takes about an hour of your time. You're answering questions. That, we are looking for individuals on the autism spectrum. We're looking at individuals without a diagnosis of autism. That's a completely virtual study. We have an in-person MRI study, where someone can come to our facility and participate in an MRI scan. That's another study for New Jersey residents. We have a few virtual studies that are focused on job interviews. They're all virtual, and those are for young adults on the autism spectrum. And so if anybody wants to participate in any of those, they can contact us at [autismresearch@kesslerfoundation.org](mailto:autismresearch@kesslerfoundation.org).

BANKS-SMITH 21:53

Thank you, Dr. Genova, for taking the time to speak with us today and for sharing about the new, exciting center for autism and what the future looks like in autism research.

GENOVA 22:05

Thank you. And thank you for giving me the opportunity to explain it all. That's great.

BANKS-SMITH 22:10

To learn more about Dr. Genova and the center for autism research, links are in the program notes. Tuned into our podcast series lately? Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. Be sure to subscribe to our SoundCloud channel, Kessler Foundation, for more research updates. Follow us on Facebook, Twitter and Instagram. Listen to us on Apple Podcast, Spotify, SoundCloud,

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