

Matt's Interview

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SPEAKERS

Alex Schiwal, Jeff Sheen, Matt Wappett



Jeff Sheen 00:11

(Music) Welcome to the Mental Health Crossroads podcast where we explore the intersection of mental health and disability. This is your host, Jeff sheen. (Music)



Matt Wappett 00:27

Recent research on the University of Utah indicates that youth with Autism Spectrum Disorders are more at risk for suicide, although more research is needed to understand the warning signs and symptomology with this population. (Music)



Jeff Sheen 00:45

Joining us this week in our premiere episode is Dr. Matthew Wappett, who you just heard in the clip. Dr. Wappett is the executive director of the Center for Persons with Disabilities, at Utah State University, a University Center of Excellence in Developmental Disabilities. He is also one of the leaders of the Mental Health and Developmental Disabilities National Training Center. It is a partnership between the University of Kentucky, Utah State University, and the University of Alaska-Anchorage. And this project we'll be talking about today is a National Training Center for Mental Health and Developmental Disabilities. And I understand that it's a collaboration with a few other partners in Alaska, as well as Kentucky, can you tell us who these partners are?

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Matt Wappett 01:26

Well, this project is a collaboration between the University of Kentucky Institute for Human Development, the University of Alaska-Anchorage Center for Human Development, and the Utah State University Center for Persons with Disabilities. And we each bringing a certain, I think, strength and focus to the table. The one thing that this project has that's different, I think, from existing resources is that each of these centers has a focus on rural populations, and a need to really get this information out to folks who live in maybe some of the more underserved areas of the country. But we also are collaborating with NADD which is a national association that focuses on the mental health needs of people with intellectual and developmental disabilities. NADD has been a national leader in training in this area and our hope is to really leverage some of their expertise in their existing training and really expand upon that. Make it more accessible.

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Jeff Sheen 02:30

So Matt, maybe you can give us a little bit of an overview of the scope of that project.

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Matt Wappett 02:33

The Mental Health and Developmental Disabilities National Training Center is an initiative funded through the administration on community living. It's a three year grant to really build capacity and awareness around mental health issues among the population of people with intellectual and developmental disabilities. The primary focus is to provide specialized training that increases that capacity of professionals, parents, and people with disabilities, and the support staff who work with them, the direct support staff on the ground, to recognize and effectively address mental health aspects of IDD. Which IDD is a acronym I should introduce, intellectual and developmental disabilities.

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Jeff Sheen 03:21

Can you give us an idea of, when you refer to individuals with developmental disabilities, and/or intellectual disabilities, what, what are you referring to for those that may not be familiar?

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Matt Wappett 03:31

So, intellectual and developmental disabilities is a broad, is a broad category. Some people prefer to lump them together, some people like to break them out. Intellectual disabilities, would be what we, in the past, have referred to as mental retardation.

Individuals who would score with a lower IQ, typically that's IQ of 70 or below, qualifies having an intellectual impairment, or an intellectual disability. Developmental disability is a little bit of a broader category. It's a disability, or a physical phenomena, it can be an injury, that happens prior to the age of 18 that affects the development of a person. So it can be something from Cerebral Palsy, which in many cases is caused by birth trauma, to a traumatic brain injury, to an Autism Spectrum Disorder. So, and those and those are all things that affect, right, the development. There's, it's a very broad category. Down syndrome would fall into a developmental disability. But again, it's usually something that occurs prior to the age of 18, that affects the development, either physical or cognitive, of a person.

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Jeff Sheen 04:44

So, when you're talking about mental health issues and developmental disabilities, and intellectual disabilities. What are some of the most critical training needs in this area? This is a training grant. So, what are the most critical training needs, that you see, in this area?

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Matt Wappett 05:00

I think there's, there's existing trainings for clinicians, but where things are lacking right now are around training for direct support staff who work with adults with intellectual and developmental disabilities. Parents, really supports for parents to recognize and address the needs of their adult children with disabilities. And then there's really not a whole lot of training out there, directly for people with intellectual and developmental disabilities. So, you know, a big part of this project is going to be helping these groups, you know, who are dealing, probably, on a day to day basis more than clinicians, with this population, about how to sort of recognize and address and support the mental health needs of this specific population. Again, there is a portion of this that will help clinicians and other professionals you know really recognize and assess and diagnose mental health issues in the IDD population, but in general I think what this grant brings is that focus on the day to day staff. Those direct support staff, home and community based services, the parents and the people themselves.

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Alex Schiwal 06:17

To find out more about what's available for practitioners and clinicians to screen and identify mental health conditions in populations of people with intellectual and developmental disabilities, visit our website MHDDcenter.org, where we have a training and resources page for professionals, families and for self-advocates and follow us on Twitter, LinkedIn, Facebook and Instagram @MHDDcenter.



Jeff Sheen 06:43

So when you think about the impact you're hoping this project has on individuals with this lived experience and on their family members, what really is the impact, you're hoping to see at the end of these three years.



Matt Wappett 06:56

Well, so the first impact is really raising awareness, I think, of these issues. There's not a lot of folks who are aware of the extent and nature of mental health needs among the intellectually and developmentally disabled population. Their research indicates that this population seems to experience mental health issues at almost twice the rate of the general population. And so really raising awareness of that fact and then, increasing the tools and the capacity of our service systems to address those mental health needs. I think is the big impact that this grant will hopefully bring. It's, again, I think there's a burgeoning awareness among clinicians, but that hasn't really trickled down to the day to day folks who are working in various disability service systems. That, I think, is the big the big focus of this project.



Jeff Sheen 07:49

So you've talked about the direct service workers, there is an element, though, in this project, for clinicians. What is the impact, you're hoping to have with clinicians, mental health professionals, that are working in this area, or have maybe avoided working in this area because they don't have, they don't perceive that they have the background or skills to work with this population. What is the impact this project is hoping to have on that particular group.



Matt Wappett 08:16

I think that a big part of it is really helping clinicians recognize how mental health issues manifest in the population of people with intellectual and developmental disabilities, and really helping them be more effective and supportive in their diagnostic and treatment options. You know, the majority of mental health assessments and diagnostic protocols are not adapted, necessarily, for a population of, people with intellectual disabilities or more complex developmental disabilities. They're normed on a typically developing population, so a lot of the traditional tools in diagnostic protocols just don't work. And so really helping clinicians identify what are the, the signs, the warning signs, the behavior, things like that, that would indicate a mental health concern with a client with severe, you know, intellectual or developmental disabilities is a big part of what this project hopes,

hopes to accomplish, you know. And ideally, really, building the skill set among clinicians to, to recognize and diagnose, and effectively treat these mental health issues.



Jeff Sheen 09:30

So there are some other groups that have worked in this area, which is sometimes referred to as dual diagnosis, as far as having a mental health diagnosis along with a development of disability. Where do you see this project fitting into the bigger picture? It's, it is a National Training Center. How do you, what is it going to be adding to the conversation, or adding to the resources available to the folks that you are reaching out to?



Matt Wappett 09:57

The resources that are currently available, I think, are again when you look at what's out there there's a few things for parents, there's a few things for some direct support professionals, but they're not systematic, and they're not that, they're difficult hard to find. I would say that there's a growing awareness among clinicians, and there are some clinical training programs that are addressing this issue, but really what we're trying to do is bring, bring this content, make it more accessible. Really create clearinghouse for this information, to address, and to really, when people are looking for it they don't have to go to, you know, dig down into some State Department of Health to find it, or something else, you know. If they're looking for Mental Health and Developmental Disability hopefully we pop up and we're able to connect people with, you know, a lot of existing resources, some, some new resources that we, that we will be developing and disseminating. And again, sort of being that clearinghouse model.



Matt Wappett 10:58

I think the biggest impact though, going back to what I said before, is really the piece of direct support staff, parents and people with disabilities. There's just not a lot specifically targeted at those populations and really empowering them to understand how to, how to manage, and, in many cases, just live with a mental health diagnosis.



Jeff Sheen 11:21

I understand there are a lot of different parts to this project, there's going to be some online training modules, there are going to be some webinars, there's things like this podcast that we're launching a blog, other things on the website that will be launching. When you think about the big picture of this project and all the things that are involved with it, what are you most excited about? What components are you most excited for

other people that have access to?

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Matt Wappett 11:46

I think there's, well there's a lot of things to be excited about, you know, given my personal background I'm really excited about the opportunity to be providing information for parents and people with disabilities around mental health supports. The other thing that I think there's a real need is really developing a leadership capacity of people who are working in the field of intellectual and developmental disabilities. There's, if you look at the research that's being done on, say, mental health and developmental disability policy, there's a tremendous amount. If you go, if you just type in a basic search, mental health and developmental disabilities and policy, and you look in Google Scholar, there's a ton of work being done in Australia, Great Britain, all throughout the EU, but there's very little being done here in the United States.

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Matt Wappett 12:35

And, you know, although there are a few folks who, who are kind of basing their career on this area, in terms of leadership driving a national dialogue and really making the systems change we don't have a good cadre of leaders in that area. So one of the things that this grant brings is a leadership institute that will be hosted here at Utah State University. It's going to be a week long intensive training to really build systems change leadership capacity among people who are working in the field of intellectual and developmental disabilities. And I think that's probably one of the most exciting elements of this grant, is the opportunity to, to get a group of people thinking along the directions of, 'where can we go?', 'what needs to be done?', and 'how do we systematically address the needs at both the ground level, but then the bigger systems level to meet the needs of this population?'

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Jeff Sheen 13:32

So you mentioned the idea of policy related to this area. And you also mentioned national conversations and national, kind of, movement forward in this area. I'm curious how you see this project playing into some national conversations that we're having around mental health, around suicide prevention, around reducing stigma around mental health. And then, in light of that, what are the policy, what are the critical policy components you think need more attention?

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Matt Wappett 14:04

Well, I think that currently, right now, there's not, there's not a national conversation going on around policy priorities in this area. And I would say that the big policy issues really trickl down to more the state and the local level. Every state and locality has a different public health and mental health system. In most cases they're, they're separate, they don't work together. And so one of the big issues that we see with this population is really coordination of care. And in getting these two systems, the mental health system and the primary care system, to work together. You know, one of the reasons, one of the reasons that this hasn't made, been a big policy issue is that, number one, you know, we're struggling with just the basic epidemiology of this, and nobody is too clear. There's speculation, I think, about the prevalence of mental health, intellectual/developmental disabilities, the comorbidity of them, but there's not really good numbers on it because we don't have good diagnostic protocols. There's clearly, you know, when we look at the, some of the research is being done, there's an inability on the part of primary care providers to meet the needs of this population, and to diagnose the needs of this population.

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Matt Wappett 15:28

And then, there's, again, going back to the systemic issues, there's, they're two separate systems. The mental health system operates over here, the primary care system operates over here. Mental health practitioners are sort of trained to deal with mental health issues, primary care practitioners are trained to deal with primary care issues. And the two worlds very rarely cross, share information. And for us to effectively meet the needs, people with complex needs, especially intellectual and developmental disabilities, are already seeing multiple specialists. And to really provide holistic care and support for them, these systems, these providers, need to be talking together and, you know, simple things, like sharing an electronic health record, is really difficult between mental health systems and primary care systems. It goes both ways. And so, you know, these are the state, local, in some cases, federal policy issues around HIPAA and everything else. But these are things that we're starting to recognize are barriers to providing good, holistic care, for this population. You know, I think in terms of other more systemic issues, and again I'm not sure if this is policy really, but we're really lacking good assessment and diagnostic tools.

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Matt Wappett 16:48

A few years ago, NADD and the American Psychological Association came out with the DM-ID which is really a diagnostic manual for people with intellectual disabilities. It provides a starting point for diagnosing mental health concerns in people with intellectual disabilities, but it's just a starting point. And most assessment and diagnostic tools, right

now, are not accessible and don't take into account complex needs or communication preferences of somebody with a significant disability. And so, it's really hard to diagnose these and so, again, that goes probably to higher education and training, and, you know, more of these professional certification type of issues. But really, how do you effectively identify what is a manifestation of a disability, what is mental health manifestation because it's going to look different in that population.

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Matt Wappett 17:48

And given, kind of, building on that, given the lack of adequate diagnostic tools, what tends to happen is that people, primary care providers and folks who are, kind of, working on the front lines, tend to see behaviors as just a manifestation of the disability, because there's not a good tool to diagnose whether somebody's feeling anxious or depressed. Necessarily, there is a the tendency to medicate, medicate away the behaviors. Which, you know, addresses the symptom, but not the underlying cause. And so, what one other, I guess, and this is a policy issue, at some level, is this issue of polypharmacy in this population. This is a population who is already taking multiple medications because of the disability, and who then may need other medications on top of it, because of mental health issues, and really understanding the interaction of these medications on this. This is somewhere we're researching and policy, that there needs to be really almost clinical policy around how do you manage this. You can imagine somebody with epilepsy, who's taking anti-seizure medication, maybe several other medications to help manage their epilepsy, and then taking potentially an anti-psychotic or an antidepressant on top of it, and then looking at how all of those medications work in the brain is a huge research and policy issue.

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Jeff Sheen 19:15

What, if anything, do you think is working well in this area?

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Matt Wappett 19:19

I think people are starting to pay attention to it, so I think that's a bright spot. I mean, I think we're having the conversation now. People are starting to recognize this is an issue. And that's the first step to actually doing something about it. We still, but just recognizing the issue is just a starting point to actually doing the work that needs to be done. The systems are separate, the mental health system and healthcare system still kind of work on a separate but equal type basis. And to, really, and so, again, recognizing that they need to come together. We need to be providing integrated care. That we need to be communicating across these systems. It's a starting point. Again, I think that we're starting

with conversations. I think there are some model programs out there, I think. You have the University of New Hampshire whose doing, whose Center for Start Services is doing stuff around clinicians and really addressing more urgent scenarios. You have the Triad Program at Vanderbilt University. You have the research, the Rehabilitation, Research, and Training Center at Ohio State University that's doing research on health care and mental health in children with disabilities.

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Matt Wappett 20:33

So, I mean, I think there's a lot of initiatives that are currently underway, that are helping to advance the field and the conversation. You know, in terms of saying somebody has a good, model practice, I think that's difficult to point out and, you know, if I was to point out one really good bright spot I think that the Home Clinic that we have here in Utah, the University of Utah Medical School, where they're meeting the needs of adults and children who have dual diagnosis. And some of the clinicians who are working in that setting, are doing good work, and are really driving some of the conversation moving forward. But again, I think, it's not systemic, in any way shape or form. It's little bits and pieces here and there. You know, really, the hope of the center is that we can elevate the conversation. We can highlight the good work that's being done across the country, and provide that clearinghouse and that ability to get a more robust initiative moving forward in this country.

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Matt Wappett 21:40

One of your questions was around, 'how does it reduce stigma around mental health issues?', and what this does is it raises the awareness that mental health affects everybody. Mental health issues affect everybody. It's not just a typically developing population. It's not just women with postpartum depression and everything else. If you have Down syndrome, you can be anxious or depressed. If you have Prader-Willi, you can also have schizoaffective disorder. I mean, it's this recognition that mental health issues cut across the population, and we need to be aware of that. And be mindful of the fact that it probably manifests different in these, in these populations. I think the other one is that it needs to be a consideration, you know, when we're looking at behaviors when we're looking at the needs of people with disabilities. I think that, you know, one of the things we need to look at is not just managing the behavior, but looking at the root cause. What's causing that behavior and could it be a mental health concern. And do we need to get mental health professionals involved. A lot of times, again, just like with medication and medicating really behaviors, we tend to want to manage behavior instead of actually figuring out, and recognize that behavior is a form of communication and they're telling us that something deeper is wrong. And I think that's an important thing that this project

brings.

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Matt Wappett 23:02

I think the last one, you asked about suicide and some of the questions about suicide, and this is a place where we're just starting to see research. And actually, this is going back to the Home Clinic, Anne Kirby, who's an occupational therapist there, just this year, published, really, the first study in the US looking at suicide prevalence among adolescents with Autism Spectrum Disorders. And what they find is that, you know, going back quite a few years, she went back 20 years, I think, it looks pretty level, but again our Autism diagnostic ability back 20 years was still evolutionary, at best. But what they found in the last few years, is that there's, there's a much higher prevalence of suicide among adolescents with Autism Spectrum Disorders. And I think what this does is that, well, what her research shows is that we, the warning signs and the things that you look for in somebody who is, you know, who has suicidal ideation, who is wanting to commit suicide don't look the same in this population. And so, really, it raises an awareness that we need to, yes, this is a population that is at risk. Yes, they experienced similar issues and that the warning signs of what we need to be looking for, in terms of supporting this population, are something that, again, we need to spend a little more time understanding. (Music)

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Alex Schiwal 24:37

Thanks for tuning in for our premiere episode of the Mental Health Crossroads podcast. We hope you enjoyed it. I'm your co-host and producer Dr. Alex Schiwal. Each week I'll provide additional information beyond the interview, and sometimes I will host the episode. We'll be back next month with Dr. Elaine Eisenbaum from the University of Kentucky. Watch for updates on our social media channels. Bye.