

Interview with Rylin Rodgers: Disability & Mental Health Policy

30 minutes 25 seconds

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Speakers: Alex Schiwal, Rylin Rodgers, Matt Wappett

Alex Schiwal 00:00

Music Hello and welcome to the MHDD Crossroads podcast, where we explore the intersection of mental health and developmental disabilities. In this episode, Matt Wappett interviews Rylin Rodgers from AUCD. We hope you enjoy this episode. Make sure to look at the show notes for more resources.
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Matt Wappett 00:25

Welcome, everybody. I'm Matt Wappett. I'm the Executive Director of the Center for Persons with Disabilities here at Utah State University. I'm also one of the project staff on the Mental Health and Developmental Disabilities National Training Center. It's my privilege to host this version of the podcast and we're here today with Rylin Rodgers. Rylin is the Director of Public Policy at the Association of University Centers on Disability, or AUCD for those of you in the know, where she works on federal policy and legislative issues that affect people with developmental disabilities and their families. Prior to working at AUCD, Rylin served as the Training Director and Family Leadership Coordinator for the Riley Child Development Center in Indiana, and was a founding board member of the Family Voices program in Indiana. Both as a parent and a professional, Rylin has extensive experience on topics including special education regulations, public and private health care, financing, and family professional partnerships. We're really glad to have you with us today, Rylin. Thanks for being here.

Rylin Rodgers 01:30

It's great to be here.

Matt Wappett 01:33

To kick it off, can you tell us a little bit about yourself and your background, in addition to what we just read, and your connection to disability and mental health?

Rylin Rodgers 01:41

Yeah. My children, who are now young adults, always called this the origin story question, 'why are you doing this and why are you here?' I think that references superheroes. My reasons for being connected

to disability policy and making it my life's work are really personal. I identify as a person with a disability. I'm dyslexic. But it was when I became a parent of two children, who are now young adults, and both of them had visible disabilities, medical complexities, that I really started to be very aware of how policy impacts the lives of families and individuals, and how in many cases policy isn't working well for people with disabilities and their families. In the course of raising our family, my husband acquired a traumatic brain injury so we like to say that in terms of disability, we are all-in in our household. It's become our life's work.

Rylin Rodgers 02:45

Through those personal experiences, I started to engage in policy at the grassroots level of building relationships with legislators. I felt like I had some skills and was able to build some skills in translating lived experience to legislators, but then, also important, in helping individuals understand what policy proposals might mean to their lives. That started me down this journey, about two and a half years ago, around the same time that my kids became young adults and were no longer in the full-time being-raised-stage. I, too, was ready to graduate and looking for new opportunities.

Rylin Rodgers 03:27

I had done my previous work in the state of Indiana, and there was an opportunity to go to Washington, DC and work full-time on policy. I was really drawn to coming to AUCD for a couple of reasons. One is really reflected in this conversation, I think it's critically important to have voices from every state and territory at the table. And the AUCD network has that and they have it in really important ways. We have researchers. We have folks that are experts in best practice and emerging practice. We also have a network that includes people with disabilities and their families in every state and territory. So whenever I'm working on a policy issue, I can check-in and see what's happening and be able to share that back and forth. That's what brought me to Washington, and brought me to working on this full-time. It's been an unusual American moment to dive in full-time on policy, but in a lot of ways it's been very grounding. I think that there are lots of opportunities, for all of us, to learn about what is our individual role in policy. And how can we, when we're seeing things not work in our lives and our communities, what's the way to advocate and make a policy change. That's really what got me here and the work that I get to do every day now.

Matt Wappett 04:58

Yeah, you're kind of moving full-time into this space right now and clearly in the news media it's all about how dysfunctional it is. And yet, I sense that voice of optimism and what you just said that there's opportunity to be had here and the chance to maybe make a difference. That's actually refreshing to hear. *Laughter*

Rylin Rodgers 05:24

I'm trying super hard. I also believe that if I could do it in the really hard times, then when the pendulum swings a little bit in a more functional direction, which I think we all hope it will, then maybe I'll actually be good at it. At that point, it will look really great.

Matt Wappett 05:41

Yeah, yeah. One of the problems that has historically faced the field of developmental disabilities and mental health is they've been seen and perceived as two separate issues. And the policies in both arenas have kind of pursued two separate tracks. Why do you think disability and mental health are often thought of as separate and distinct issues?

Rylin Rodgers 06:08

I think it's really important how you framed that question, because you talked about the history and this is not a new challenge. I also think when you're talking about disability, particularly developmental disabilities, and mental health as being separate there's a third piece to the challenge. And the reality is that the way systems have evolved in our country, developmental disabilities are sort of one silo and mental health services are another silo. And then healthcare is often seen as a third and distinct silo. Some of the tension around each of those pots have continued to perpetuate this challenge of what fix? Where? And how do you address an issue? In some ways, it's an outcome of advocacy and history.

Rylin Rodgers 07:01

We really came into a developmental disability system that through the DD Act, which was the last piece of legislation that President Kennedy signed. He came to that effort as a sibling of a person with an intellectual and developmental disability. That created an amazing foundation that we all get to benefit from today in terms of the developmental disability system. But it took a giant leap forward in ways that weren't accessible and readily available to other types of disabilities, so it created a silo. And we've seen other things and issues sort of lurch over time. We've seen the AIDS epidemic create a push on blood disorders and other issues. We've seen advocacy and research in the cancer space move things forward. We've seen the evolution of health science and how it's changed the life course and life expectancy for individuals that are born with conditions of childhood, that did not use to survive to adulthood who now do.

Rylin Rodgers 08:06

All of those things have created change over time in terms of what's gotten the attention. It's only recently that people have started to take a step back and say that doesn't work. It turns out that each of us doesn't fit neatly into one system and not another. And having an intellectual disability does not mean you will not have a mental health need. And having a mental health need doesn't mean that you benefit from some of the systems and services that have worked well for people with intellectual and developmental disabilities. The other giant in the room is how do you pay for it all? And where you get a lot of that oxygen is the larger healthcare system, which tend to think of disability issues and mental health issues as farther down on the priority ladder. It's a little bit of a perfect storm that's created this separation. I think it's been individuals who have been starting to do the work, to show the data of the fact that the silos aren't real. That's not how lives work, and that the needs cross.

Rylin Rodgers 09:23

I think the other piece that's been a particular challenge, is sort of the world of diagnostic codes and whether something is seen as a mental health issue or developmental disability issue. We saw, I don't

really like the word war, but almost a battle in the space around autism. Whether it should be considered a developmental disability, or a behavioral mental health disability. That back history of how we diagnose things has created another layer of challenge. That's a lot. I think it speaks to how there's a lot of challenges there.

Matt Wappett 10:03

That is a ton. I appreciate you bringing up the autism example. I think it is one that we frequently overlook. But I think it's a current and recent issue, with the new DSM that came out a few years ago and the recontextualization of that. Yeah, that's a really good example nobody's brought up before. I also appreciate that idea of health care as a separate silo. We do sometimes get the blinders on, right? When we're in our own little worlds. You're exactly right, these are very interdisciplinary issues. They overlap and intersect and that creates some unique challenges of actually trying to address them, especially since the funding pots tend to be completely separate too. *Laughter*

Rylin Rodgers 10:53

I think the term that is frequently used is a braided and blended funding. I think that sounds better than it has actually ever been executed. So whenever I hear braided and blended funding, I always look for budget cuts that are coming next. So it's a worry term in my world.

Matt Wappett 11:14

Yup, absolutely. You're there in Washington and you're kind of engaged in this every single day. You've talked a bit about the autism thing, but right now, on the hill, what are some of the most pressing issues in disability and mental health policy?

Rylin Rodgers 11:31

Wow. Today, we're recording this on September 30, and it's been one seriously wild day. You know, we are living in an ongoing pandemic and the way that pandemic impacts all lives and all systems continues to be an American challenge. It has been true since last March that every policy decision under consideration in Washington is seen through the lens of COVID. That has created the need, as my friends in social work and psychology will say, to reframe some existing problems that we've known or need to make them resonate in a COVID environment. I think that piece is very pressing in Washington. We are getting ready to have a new session of the Supreme Court. And we have been in a multi-year process, for many states have been suing to end the Affordable Care Act. And that case will actually be heard in front of the Supreme Court on November 10, with the potential to repeal the Affordable Care Act. That's created a very different conversation about what's happening and what comes next.

Rylin Rodgers 13:02

We're talking on September 30, everybody knows there's gonna be an election in many states. The election's underway. And that tension of what will the condition be and will there be a transition has created a little bit of a stuckness, in terms of moving something forward. I think the other piece that's really important for us all to remember and be aware of, for the immediate term and the long term, is

that COVID has created an economic recession in our country. And that is going to have a multi-year impact on federal spending. When we're thinking about policy and we're thinking about the tension of the recession and what decisions will be made, I think we always have to be mindful of that balance when we're sharing ideas that are investments, and that we believe strongly in that. There's definitely a reality check that the economic situation is different than it was a year ago.

Matt Wappett 14:11

There's a lot to grab there. There's a lot. *Laughter*

Rylin Rodgers 14:15

Yeah, welcome to my day.

Matt Wappett 14:20

You're right, the challenges seem absolutely overwhelming. When we started working in this area of dual diagnosis, a couple of years ago they felt big, and they seem to have gotten bigger as we continue to try to move down this track.

Rylin Rodgers 14:41

You mentioned at the beginning that I seem to have maybe a twinge of optimism and awareness of the possibilities. I think that comes from the reality that we've made progress, in awareness of the issues. I think the reality is that we're going to tackle these hard changes, these policy changes, that need to be made to break down those silos, to see individuals as who they are. As people in terms of their complicated needs and where they're living and families and communities, and really create a system that allows them to get the services they need and not have to fit right into a box related to a certain diagnosis.

Rylin Rodgers 15:35

If we're going to make that kind of progress, we have to have champions, and we have to have policymakers, and their staff that understand the need and understand the issue. I've been encouraged by the way that staffers have more knowledge about these challenges than they would have 10 years ago. I think there's a lot of things to credit that to. We have made significant progress as a country around the stigma of mental health issues. There is greater awareness on an individual level, that many of us have family members who have mental health needs. We are more transparent and aware of our family members' disability status, so there's that personal connection. But also there's a growing awareness of how systems are not working well, and how there's a need to modernize those systems.

Rylin Rodgers 16:35

Our current executive director at AUCD, John Tschida, has a great phrase, 'never waste a good crisis'. I think there's some realities of our current crisis that really help us to continue moving the progress. An economic crisis really is a chance to rethink our spending. You're less likely to do something that way, because you've always done it that way. You need to really take a look at it so that's always a positive. I think the reality that COVID has shined a light on service systems that support individuals with

intellectual and developmental disabilities, and service systems that support individuals with mental health needs and mental health disabilities has really created an opportunity to have a big conversation about what's working. What are some things that are positive that we can build on? And what are some of the things that have gotten laid bare in this crisis that are priorities to fix. I think there's some chances in the current transition. And there's always an opportunity during an election to raise issues in a way that you don't get to otherwise. Every member of the House is running for office, and they're willing to talk to anybody now. They might be willing to talk to you for the first time about an issue that they previously didn't have an interest in. And it could be one of those conversations that creates a new legislative champion.

Matt Wappett 18:15

Yeah. I think that idea of champions is really interesting and going back to what you said earlier about blended and braided funding. It frequently takes a champion who is willing to do the problem solving to figure out how to make those interdisciplinary-cross-silo programs actually work. I mean, in your experience, what are some of the attributes of those champions? Or what are some of the things that we do to ensure that interdisciplinary-cross-silo programs continue to happen?

Rylin Rodgers 18:55

I think that's such an interesting question, because it makes me think about the need to always be thoughtful about at what level a policy and government and system is the sticking point or the need for advocacy? We've been talking really big picture about the issues in mental health and developmental disabilities. The sort of joy of all of those systems is that there is both a federal side and a state side. And very frequently there are additional community policy lovers, and then institutional lovers. Sometimes we're thinking about what does it take to make a great idea real? It's all of the above, and you need to have champions at all of those levels. You can have Medicaid at the federal level agree to pay for some great services. But if the state government hasn't bought in on that option, or if your local hospital or healthcare system isn't willing to turn on the codes, you're stuck. Thinking through all of those different levels is important. I think there's opportunity to develop anyone into a champion. We know that as humans, our instinct is to try to solve problems and make things better. So when we can share both a need and a solution to a need, that's a chance to get somebody to engage in a partnership with you and resolve that issue. So it's a great way to think about it.

Rylin Rodgers 20:37

A lot of times, we may rule out somebody as a potential champion, because we haven't had a lot of success in the past and they haven't seen or been open to it. There's a couple of things about that. Sometimes it's a long and slow moving process. It's just about sharing information over time and being persistent. The other reality is that individuals' lived experience changes. So somebody may not have a background in this, it may not be a priority issue. Then they become a grandparent, and their grandchild has an intellectual and developmental disability, and some complicated behavior health needs. Then, you're starting with a very new conversation. The reality is, there's lots of chances to think about shared priorities and build those relationships. Sometimes it's going to be really successful instantly. Sometimes, it's going to be a longer process.

Matt Wappett 21:39

Yeah, yeah. That's a good point. Going back to the idea of silos, we sometimes just look at the national picture and we forget that depending on the system we're working in, states and communities have huge influence over what those systems look like. I know that the mental health system here in Utah looks very different than most other states. I think we'd see tremendous variability across the United States. Being familiar with all the different levels, and that idea of a sticking point, and identifying where is the problem, we could work on this important takeaway from this conversation. How can people be more effective advocates for mental health supports in the developmental disabilities field?

Rylin Rodgers 22:32

I think a couple of things, a willingness to continue to do the education, and to be able to clearly say what it is we're talking about and share for whom this is important. Sometimes that's data sharing that there are numbers of individuals, in every community in every state, and families that need these types of services. Sometimes it's sharing a personal story or profile, but being very intentional about continuing to raise the issues and do that education piece.

Rylin Rodgers 23:10

I think it's also a little bit about being strategic, looking for when there are opportunities where things may move, or when there's a chance to make progress on an issue. In Washington, there is definitely a flow or a cycle to the work here. Congress has a two year session. Every January, we start with the budget and appropriations process. Every September, they miss their deadline and they get a continuing resolution and we push it further down the road. But knowing what the cycle is, when would be a good time to have a conversation, and then looking for opportunities.

Rylin Rodgers 23:53

I mentioned that right now COVID is framing everything. That doesn't mean we shouldn't be actively talking about mental health needs of those with intellectual and developmental disabilities. But we should be talking about how those needs have continued during this pandemic, how the need to shelter in-place has created barriers to services, how we're seeing increased issues around isolation and what that means. And we should be sharing those pieces and whatever the frame is. It's likely that once we get past the COVID surge, whether that happens through effective treatment or vaccine, that our country's attention will shift to recovery and those economic recovery issues. So how can we tell the story of intellectual and developmental disabilities and mental health needs in the lens of economic recovery? How does this help us move forward? Really thinking about what's happening around you. You're framing messages. And then it's that long term relationship, always being willing to go back and have the conversation again, and be a resource and share what the work is that you're doing and what your lived experience is.

Matt Wappett 25:15

Yeah, that idea of lived experience is really important and I've found it to be extremely important in making policy actually change. Lived experience speaks louder than anything else, even data in many cases. *Laughter*

Rylin Rodgers 25:31

But if you can have the two together, that's how we get stuff done. *Laugh*

Matt Wappett 25:34

Even better, right? You talked about personal lived experience. One of the things that we like to do here is ask people, what strategies have they found effective to support their own mental health? Especially during COVID. I know there's been some unique challenges around that. What have you found to be effective in supporting your own mental health?

Rylin Rodgers 25:55

We have an have had, for a number of years, a family theme word. We really like the word resilience. We've raised kids with complicated health care needs, and lots of emergencies and crisis. Resilience. I don't have a tattoo, but if I did have a tattoo that would probably be mine. I feel like that background was really helpful as we entered COVID to sort of think about that. I also think about the need to embrace flexibility, which is not actually my area of strength, I would like to be in charge of everything and make it go the way I want it to. But I, famously, pre-COVID wasn't super outdoorsy. Like I preferred my nature through class. But then the gyms shut down, and the need to be socially distanced was very apparent. I am now a three-mile-a-day outdoor nature path jogger. I found some flexibility because I needed to do something. And I knew that in order to keep being able to function and have that balance, I had to find a new path. So yeah, I even know about birds, and all sorts of things at this point. I think that that flexibility and that resilience, and I am one of those people in this world that is lucky to have an amazing partner, my husband, and having that partnership has been key to my success over time, in balancing all the things that we have to balance as humans.

Matt Wappett 27:36

Yeah. You're not the only person who said they've had to completely step outside of their comfort zone as a result of COVID and rediscover what it means to take care of themselves. I appreciate you sharing that. What's one key idea or action item that you would like our listeners to take away from this conversation?

Rylin Rodgers 27:59

I hope that everybody that's listening is thinking and can reflect about their expertise. They really are experts in their lived experience and in the work that they do in the systems, that they see either working or not working. And policymakers desperately need to hear from them. In order for policy to work, we need their expert experience guiding that policy. I often say to trainees or emerging leaders, you need to just own your greatness, and realize that you have a lot to offer to these conversations. And if your voice isn't at the table, the conversations aren't going to move forward in the way that they need to. I think sometimes we have assumptions about you have to have X, Y, or Z before you can engage in policy. And those assumptions prevent us from bringing the full and rich experience, that so many of us have, to the conversation. I would just encourage everybody to see themselves as experts, and to bring that expertise to policymakers.

Matt Wappett 29:14

Great. How can people get in touch with you if they'd like more information about anything you've talked about in this episode?

Rylin Rodgers 29:20

Yeah, so I'm super easy. I have a weird name. So if you Google my name, you get all the ways to find me. The easiest is via email. So my email is RRodgers, and it's Rodgers with a D, rrodgers@aucd.org. I'm also on Twitter and Facebook and Instagram and LinkedIn. I take it any way people want to reach out. I'm happy to continue the conversation.

Matt Wappett 29:49

Great. Thank you, Rylin. We appreciate your insights and the expertise and the thoughtfulness you brought to this conversation. Thank you.

Rylin Rodgers 29:58

Thank you!

Alex Schiwal 29:58

Music Thanks for listening to this episode of the MHDD Crossroads podcast. We hope you enjoyed it. Make sure to visit our website mhddcenter.org or follow us on social media at MHDD center. You can also look in the show notes for our speaker bio, transcripts in English and Spanish, and other resources mentioned in the episode. Thanks for listening. *Music*