

Down Syndrome Association of Minnesota- The Family Connector Program

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SPEAKERS

Ashley Olthoff, Narrator, Priscilla W.

Narrator 00:02

Welcome to Inclusion Matters, a podcast about children's development from the Center for Inclusive Child Care .

Priscilla W. 00:08

Welcome to Inclusion Matters a podcast from the Center for Inclusive Child Care. I'm Priscilla Weigel, the Executive Director. And I'm so happy to be here today to record part two of a series, really highlighting the wonderful organization, the Minnesota Down Syndrome Association. And this is a follow up to part one, which we had the CEO and resident Sarah Curfman on and she talked about just Down Syndrome and the history of the organization and what you all do. And today, I'm really excited to have Ashley Olthoff, Director of the Family Connector Program, which is part of the Down Syndrome Association of Minnesota. And Ashley, I'm so glad to talk with you today.

Ashley Olthoff 01:02

Thanks for having me. I'm excited to be here.

Priscilla W. 01:05

Great! So you're going to tell us today all about the wonderful supports that the Family Connector Promote Program provides within the Down Syndrome Association. And so why don't you just jump right in and talk a little bit about the mission of the program? And what are your hopes and then the great services that you offer.

Ashley Olthoff 01:26

Thanks. Yeah, so our Family Connector Program started in the fall of 2020, in large part from a grant from DHS to help families better navigate the complex systems that they need to support their loved one with Down Syndrome. So our family connectors, we work with families from diagnosis all the way through adulthood, and we help them navigate county services, finding medical providers, finding mental health providers, financial assistance, resources,

grants, waivers, medical assistance, Social Security application, and special education.

Priscilla W. 02:11

Wow, wow, what a gift for families to have all that housed within that your organization for support.

Ashley Olthoff 02:20

Yeah, it's just one of the many programs we have. But there's six of us on staff, we all work part time, the majority of us are mothers of either children or young adults with Down Syndrome, or have a background in social work, we have a really diverse group. I like to say the six of us our brain, are all of our brains working together like one super brain. So that team approach is really important. There's rarely a question where we can't come up with some sort of action plan of how to better support the family or how to find answers for the family.

Priscilla W. 03:01

Yeah, and to really complex questions, truly, I mean, when you think about all the services that are available for families, but then understanding how to navigate and how to fill out the forms, and where do I go for that? And how do I connect there. And so folks can really just come to you and the team that you have to just like you're saying, you all can work together for that I love the fact that you all, most of you, you said have walked this road of being a parent of a child with Down Syndrome, which is, I'm sure a lovely gift to those who come to you because you can share your personal experiences, and also really have that listening heart to them and their needs as well.

Ashley Olthoff 03:47

Yeah, I think there is a big difference between how the system or how the program is supposed to work and how it actually works, or how it, how that process actually goes. And so for all of us having that lived experience on top of the training and the research that we've done, allows us to provide families a much more comprehensive approach to support. We, also because there's six of us, we never just say like call the county, we are able to find what is the number for you to call and we're able to prompt with what's the language to use. The biggest barrier to access is understanding what are those key terms to use mean access to the support that you need? And so we'll find the number for you will tell you exactly how to ask for the support that you need. And then because there's six of us we can work or walk alongside the family as they navigate the system. So it's not just a one and done. Good luck with the process. It's such a complicated process. That and oftentimes, these programs are very segment mentored. And so we will walk alongside and we'll check in every couple of weeks. Hey, did you get that application? And did you hear anything back? And we know timelines, we know when to be that squeaky wheel and check back in again. And questions come up. So throughout that entire process, having a family connector, who is your person your go to, is just such an incredible support for our families.

Priscilla W. 05:29

Oh, definitely. That's so beautiful, too, that you check up and follow up and know the system well enough and deeply enough to know when to give the reminders to the folks going through the process to say, follow up because oh, that seems like a little bit of a long wait. Because when you're in the process yourself, and you've never experienced that, you try to be patient and you think, Is this normal? is this how long is something like this takes? And there's so many different services with different expiration times and different deadlines. And I'm sure that families really take advantage of the opportunity to stay connected with the Family Connect.

Ashley Olthoff 06:10

Yeah, I have families who I work with for maybe six months, I have a couple of families I've worked with for over a year, just as we go through each step in the process. And just having that go to person who knows the system. I know it from my personal experience navigating systems for my own child who has Down Syndrome. But I also know it from all of the trainings we've done. We've done trainings with DHS, we've been trained by Disability Hub, we have so many different contacts within at least the metro for sure. But our goal is to have contacts within every county in Minnesota so that we can help all of our families. If they're we're seeing or hearing something that we know isn't how that's supposed to work, we have somebody we can go to who we've built a relationship with. And we can say, hey, can you help with this? Having that personal connection helps a lot as well.

Priscilla W. 07:05

Oh, that's fantastic. So when you think about all these, we keep talking about these complex services and systems. What are some ones that you find families really need the help with? I mean, just a listing site, I mean, there's so many that you mentioned earlier in the intro, but just jump in wherever you feel you sense the weightiness and the challenge from families.

Ashley Olthoff 07:29

Definitely. So almost 40% of our requests are about disability services. And there are so many different disability services, I think the biggest question we get is, how do I get a waiver? How do I get respite care? I hear, you know, another family's getting paid to help care for their child with a disability, how do I get that, and that is a very long process to get there. That is about we see, especially right now, with long waitlists, or backlogs, we see about a year from starting to apply to having actually the waiver set up with the services being provided. With many different departments that have their own application and have their own application system. And they're all segmented, they don't work together. I think 10-15 years ago, you could call the county and say I have a child with Down Syndrome, you are connected instantly with a case manager, that case manager walked you through every process of getting

services setup, that isn't the process anymore. Now, suddenly, you know, you need a MN Choice assessment. But there's a lot of steps that happen before the MN Choice assessment that there is no support with. And so our Family Connectors, we can help families, you know, the first step applying for medical assistance for your child. A lot of families get the denial because of financial need, they don't need medical assistance, they get a denial and they say we are denied anything, we can't get anything, they don't understand that then there's a separate application separate process for MA TEFRA. Okay. And so helping them with the tough road piece, part of the tougher pieces, the SMRT process, getting a State Medical Review Team Disability Certificate, then the MN Choice and then looking at the programs that your child or loved one is eligible for because of their disability. So it's a it's a lot of steps to get there. And it's not. It's so segmented and those departments don't work together don't talk to each other. So having a team of people who understand how each of those steps is supposed to work and knowing how to navigate it and knowing, like you said, when to reach out for additional support or when to reach out to be that squeaky wheel is really important.

Priscilla W. 10:07

And not to be discouraged when one bug happens, because there may be further opportunities to access along the way.

Ashley Olthoff 10:15

Yeah, definitely. And it's it is a really exciting time in Minnesota, for families who have a child with a disability, you used to have to pay into MA TEFRA, based on your household income and size. And that parental fee was oftentimes a barrier for families to access these grants and waivers. The state legislation just passed a law, the governor signed it in May 2023. It went into effect July 1 2023. There's no longer a parental fee with MA TEFRA. So that means any child with a disability really should be looking into these services looking into these supports.

Priscilla W. 10:56

Yeah. Another piece that I think families look at and go what is that is, you know, SSI, Supplemental Security, you know, that whole process and how that looks and what families need to know. And I know you provide support around that as well.

Ashley Olthoff 11:08

Yeah, we can talk to families about the, the eligibility requirements. I oftentimes hear from hospital staff, oh, every kiddo with Down syndrome needs to get on SSI. And that's not true. Maybe that was true 20 ish years ago, but it's based off of the household income and size. And so until our child with Down Syndrome turns 18, oftentimes, the household income and size doesn't meet that eligibility requirement. But we are able to provide the information

from the SSA website to say, here's the eligibility chart, you can check your household if you would qualify, we can either connect you with an SSA advocate, or we can help explain the process of applying.

Priscilla W. 12:02

Okay, and you know, what about navigating the road of special education and and you know, like, because, of course, your child is going to qualify for services because they have a diagnosed disability. So that whole process can be very daunting. I think for families.

Ashley Olthoff 12:19

Definetly. I think for Down Syndrome specific there's, there's not this worry about if they're going to qualify, right, we know they're going to qualify because of their diagnosis. It's more of understanding what are your rights as the parent and how does the process even work? Yeah, I'm multiple of our Family Connect Mirrors, myself included, were educators in a former life. Before my child with Down Syndrome was born, I taught elementary school for many years, we have another family connector, who also was an educator. And then we also work really closely with a Special Education Consultant. She herself is a special educator. She's taught for 15 years, and she started her own company to help families navigate the IEP process and to help explain to families what their rights are, and how to have productive conversations around what your goals for your child are, what your needs for support are. So we work really, really closely with her. And she works directly with families, she can read through an IEP, and in really tough situations, she can join an IEP meeting virtually. But just having her perspective, and her understanding is so key to our program.

Priscilla W. 13:42

Sure, oh, that's fabulous. And then, you know, thinking about medical rand other things like that, I mean, there, I'm sure you have resources to support families with those questions.

Ashley Olthoff 13:54

A lot of families want to know, like, who does everybody go to, who is the Endocrinologist, everybody in the community is going to , and so the Down Syndrome Association, Minnesota, we have a lot of virtual support groups, through Facebook. And so our Family Connectors, we keep our eye on that we make sure we're tracking who are those endocrinologist that everybody's going to, but also even, you know, more complex of sometimes parents are going through grief with the diagnosis or cyclical grief, every transition brings up this grief again, and so we have therapists who we would recommend that we know work with parents of children with disabilities and medical needs. And also mental health providers for people with intellectual disabilities. In this post COVID, if I can say that world we've noticed a lot of our loved ones especially teens and adults with Down Syndrome are struggling From this

collective trauma we all just went through in, people with disabilities were hit harder than other populations and really losing all of our support. So we have small lists, not a huge list, but small list of mental health providers who have experience working with people with IDD, and communication needs. And it's amazing to be able to provide those referrals to families as well.

Priscilla W. 15:26

Oh definitely. What a wonderful thing. And also, and I know, Ashley, we've talked about this, but you know, our coaching when there is a childcare situation and involved, you know, having that, that support for families to feel that there's someone that's really trying to help anyone working with their child understand what their child's needs are, in a setting, whether it's child care at the doctor's, at the, you know, IEP, having advocates who can help you understand about your rights. I think that because so often those, I'll just use an IEP meeting for an example is, it's a lot of people at a table. And you know, well it used to be I mean, now, it's probably there's a lot of virtual ones options. But that's, that's overwhelming for families be just sitting there and knowing from the beginning of that meeting to the end, all the things that they can ask for and expect and know and especially if they're new to it with the, you know, brand new child in the system. So that's such a fabulous support. I also know that you all provide help with that transition to adulthood, that can be really daunting, because you just think you've navigated the whole education system and all of that. And then oh, boy, now they're on the verge of being a grown up. Now what?

Ashley Olthoff 16:48

Exactly I hear from a lot of families, and then it felt like the cliff dropped off. . Yeah. And so our Family Connector program started in 2020. The first year was just what are all these systems, we need to learn? How do we best help families through these processes? Our second grant cycle was how do we help families so that it's not a cliff, it's more of a gentle decline off of those supports? Because everything will be ok, until it's not. And so how do we help families, create community, create structure, create routine, when they've just lost all of that through the school based program. So that we did a year's worth of research a year's worth of connecting with people learning about systems learning about what are those needs within our community. And today we have over 100 parents in transition to adulthood, parent group, and they meet once a month, and they have speakers, and they connect with each other. I think learning from each other and supporting each other is such a key piece in having a child with a disability. And, yeah, it's it's an amazing support to families we created. We call it the checklist to turning 18. What are all of those pieces? What are all of those legal, medical, financial things I need to think about as my loved one becomes an adult.

Priscilla W. 18:16

Yeah, oh, my goodness, what a gift to families. Because I know that speaking with friends who have had that

situation with their adult, their young adult children with Down Syndrome. That has been truly and you the way you describe it a cliff, and just now what I'm wondering too, as I'm listening to your supports, and this, you may not be able to answer this. But um, you know, other disability focused supports within the nation, you know, other disabilities, I know, have associations, I would hope that there would be similar connectors or those types of things within those organizations as well. Because I feel like you all are doing such a fabulous job of really looking at the whole picture, and making sure that you're giving families what they really need. And I do you do know, just from being out and about in the world and different connections, what other organizations are doing similarly or not

Ashley Olthoff 19:18

Yeah, we are supported a lot by the National Down Syndrome Society, they do a fantastic job of mapping out kind of what are all of these services, and kind of the umbrella of what it can look like, and they are a fantastic resource for us to tap into. And I oftentimes reach out to them with questions or concerns. The issue is they're national, they're not state, so every state provides these systems and these programs a little bit differently. And so having people who understand this is how this works in Minnesota for a person with Down Syndrome right my lens is very, very on what specific to Down Syndrome. How does this work for a person with Down Syndrome in Minnesota. Other DSA's have social workers on staff have people who can help navigate on staff. But we think that our program is the only one running like this with this, like partial employment team approach. And the walking alongside families through the process, not just answering a question, and okay, good luck, but really walking alongside them helping every step of the way. I don't see anybody else offering that type of program.

Priscilla W. 20:43

Beautiful. Well, I mean, you said the Department of Human Services for the state of Minnesota as it provides the funding for the Family Connector piece, correct?

Ashley Olthoff 20:51

They did the the first two years, we did a grant cycle to get started and then to get transition started. And now we've tripled the number of families that we've connected with, compared to 2018. And our fundraising is able to support this program and other grants have helped. But mostly our fundraising is what's keeping this program going. Our families are so grateful and appreciative for the support we provide.

Priscilla W. 21:21

That's fabulous. Well, and for our listeners out there, you heard it, fundraising keeps the program afloat. So let's give the help where it's really being used well. That's so I'm just, you know, every time I talk with you, Ashley, I just am amazed at all the work that your organization is doing for families and children. And I'm super excited to have these

two podcasts that we can put on our website. And we'll certainly share with you to to disperse them out. And we will make sure that our listeners take a listen and be sure to share with families that they come in contact with. You know, we have a lot of early educators who are listening to our podcast. So thank you for the good work you do the way that you truly, compassionately support and carry families through their lifelong process. Thank you for being a guest. And I look forward to other podcasts in the future. If you have updates that come up for your organization, reach out and we can do a new episode and just really, let's stay in contact.

Ashley Olthoff 22:23

That sounds so great. Thank you for having me. I really appreciate you helping us spread the word because it is really important for families who we might not have connected with in the beginning. Those early educators are key and making sure we're connected with families. We also have interpreter services and are able to work with families who are not English speaking and families who might have fallen through the cracks. We need those educators to help us get connected with them.

Priscilla W. 22:51

Yes, that's for sure. And we will all help to do that. Thank you, Ashley. Take care.

Narrator 23:06

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