

Hey, everybody! My name is Vanessa Blais, and I am the director of policy and planning here at the NH Council on developmental disabilities.

And I'm here today with Nicole Sheaff. She is a parent of children who have disabilities, and she is also a graduate to the 2022 NH Leadership Series. And she is here today to talk a little bit about her experiences being a parent and also inviting others to share their experiences and to be support for each other when they are navigating the systems, especially in the school systems.

So, Go ahead Nicole.

So, Thank you, Vanessa for inviting me to do this. So, I am a mother of 4 children that are all diagnosed with developmental, learning and mental health needs. I have a professional background in health care and also in special ed settings, so when I became involved in the special ed process I felt like I had a step up in that in that I had a medical background, and I knew how to write goals and it was still all new to me. And I had to do a lot of research, so I have felt for 17 years, cuz my oldest is 21. I have 18-year-old, a 14-year-old, and a 9-year-old. That having children diagnosed with various disabilities has really isolated our family.

We really felt isolated in the community, within the schools, just because my kids were never successful with sports or extra-curricular activities. Many of them had one on ones. So that made it very difficult for them to be successful in a lot of areas both school and within the community.

That isolation, I would say was our biggest challenge over these past 17 years. Both of my sons were identified for IEPs at early ages like right when they were 3 so coming out of early intervention and being identified for an IEP and during that time event though they qualified for a developmental preschools a developmental pre school was not a full-time placement. It was a couple days a week for a few hours, so we did require because both my husband and I worked full time private preschools and both unfortunately both my boys at different times were asked to leave their private preschool.

So, in turn my husband had to quit his job and stay home with my kids, my boys because there wasn't anything to fill the gap.

They needed the services from the school, yet there wasn't anything the private schools didn't feel like they had the support or the ability to provide what my boys needed at that time.

So, my husband stayed home, and we did do some neuro-psych testing on both of our boys. We brought them down to Boston. When my second son was about kindergarten, first grade and my oldest one was about first grade, second grade. And they did receive diagnosis but one thing that really impacted kind of us over the years was that my second son, although he had a lot of symptoms and met a lot of criteria of a developmental disorder such as like autism, the doctors felt that he was almost too social. So, he didn't get that diagnosis. And you know sometimes your happy that you don't get a diagnosis and sometimes you're not happy and I think parents struggle with the importance of a diagnosis. What does it really mean? So instead of a formal diagnosis he just received a multitude of language disorder, sensory processing disorder, ADHD, cognitive delays, learning disabilities, all independently.

And what kind of came of that was over the years we found that because he never had a formal diagnosis of a developmental disorder, he didn't qualify for any services. So that really impacted my second son's progress I think through school and now he's 18 so he is an adult.

So, we found out quickly that private insurance would not cover a language disorder for speech therapy. Because it was a disorder, it was not considered an acute condition. So, it was not covered. So, we really had to rely on school-based services for most of his his supports. 5:15

And a lot of insurances wouldn't cover services so we had to privately pay out of pocket for short terms because due to financial need, you can't pay you know \$260 a session for very long. So that was another thing that got in our way. So, eventually, over the years of working with the school and my childrens' disabilities, I ended taking them off of my private insurance and actually putting them on state insurance because I found that I was able to access more services that way. However, at the same time, not a lot of private takes more of a state-based insurance.

So, my son my second son does qualify for medical based Medicaid, so I was able to get him access for that. But it was interesting to see kind of that struggle

between private insurance and then Medicaid. And being a professional and a working parent, kind of, struggling internally with taking state assistance that way too. It was difficult.

So, he really, the boys didn't receive any outside services. When my second son started kindergarten, he did qualify for full day kindergarten through the school to receive all of his services, but the staff really felt like he wasn't ready. And that is kind of where my advocacy really kicked in high gear. I had to prove why he needed the services. I needed to prove why he needed a full day. I had to prove everything.

So that is when I discovered the **Parent Information Center**. And received my handbook on all the special ed rules and regulations. And started reading and tagging. And I sat at every single meeting and started quoting off laws and rules and hired an advocate for a short term. And really kind of became my boys' case manager and advocate. Very strongly because no one else was going to do it. No one else had that intensity. And because I think I am a provider too, I felt like I needed to look in every area to get my children the support and the resources that they needed, and they deserved. **8:07**

So, I had mentioned that I have four kids. I do have two daughters. And they didn't receive their IEPs until about first grade. And through all of their experiences I have been the one, along with my husband, reading the IEP goals, reading over the evaluations, lining things, underlining things, marking things, putting comments, questions, doing research on various techniques that are out there. Just so I can make sure my kids are getting the best services they need. And like I said, because we have to solely depend on school services based on insurance, we didn't have that ability to do that a lot of outpatient work. And also, on a one income salary because my husband had left his job to stay home with my children.

So, just really experiencing finding things and finding resources on my own. We did, like I mentioned access Parent Information Center. I have needed to contact the Department of Education to find out kind of the rules for what due process is, what mediation is, how I need to find information about seclusion and restraint. To contact the **Disability Rights Center**. We had access to a lot of community health agencies and area agencies.

And these are things that I just found. I had to research on my own. I had to find on my own. We've had many case managers over the years, but I feel like because everybody's understaffed and underfunded, I really feel like parents, for me at least, need to do a lot on their own. 10:03

And It's very overwhelming, so I think we found as a family that we were in desperate need for respite, desperate need for home supports. We could never find babysitters that had the skill, that would take the amount of money that we could afford to pay. So, we did have access to respite money but never actually used it because of the pay and the skill level we needed. We were just never able to find somebody.

And my children were sometimes in constant states of crisis at school. So, I would be at work, and I would be getting phone calls and you know my husband started his own business at home, but because I was the medical provider and that expert and that case manager, like I was the one that was contacted. I needed to go. I needed to pick them up. I needed to have a meeting. I needed to be there for everything.

It impacted my reliability with work, how often I could get to work and do what, I kind of put myself in my career.

So, again that lack of diagnosis really impeded my children's ability to access services. They had the level of need there but because the diagnosis wasn't there, they didn't, they would qualify for conditional involvement with the area agencies. And even my daughter as she became older, I had applied several times to our area agency for her and she was declined because it was perceived that it was her needs were more mental health related and I eventually spoke to supervisors, and they sent her for a clinical review, and she did qualify. So, again, it's required me to be the push and be that squeaky wheel to get my children what they needed. And that was pretty exhausting for me.

My daughter eventually required residential, and the school was adamant they were not going to provide that. I had to really do my research, contact various state departments legislators, and was able to get a placement for her. But I think the school immediately was like well this was at that time was CHINS, so a child in need of services and I think that they thought that would be helpful, however and

the time, CHINS was related to them losing parent rights, so we didn't want to go that way.

So, I really had to work hard talking to all these departments to get her placed because we weren't able to keep her safe at home. She needed something. And she was there for a year and she's home and she is amazing now. So, like I am so glad that that is where we were able to get her.

And so, it's just been a lot like I said it wasn't till about five years ago that I found kind of my tribe. So, after doing this for about 17 years on my own really finding support groups on Facebook, within the community, and really understanding that there isn't something wrong with our parenting. This is our children have disabilities. We are learning how to manage them. They are great children. And just to have that support from others and to have that outlet to be like I really had a tough day and have people understand. That was huge, and I wish I had that from the start because that made me feel more, our experiences more normalized, I guess.

So, you know we are still plugging away, but I do a lot of research on finding trainings. Myself, when my second son was going through transition, I researched every transition zoom and in service that might be out there just so I could be on top of what I needed to lay out with the school, with services, what I needed to pursue for voc rehab, all of those things. So, it's been a long and very busy road. I eventually decided to stop working because the caregiver burnout was just so intense that it was affecting my physical and mental health and because I project manage four children that's kind of was my second job but now is my full-time job. So, there is always an ebb and flow and a loss and a gain with everything.

15:23

I'd say that now, now I have a good idea of what resources are out there and what I need to and they're in good spots. I am kind of taking this advocacy to help other families know what is available and you're not alone and that you'll get through this as hard as it is but just really relying on the support of others and learning from others, so.

Can you share a little bit about what you think the school system can be doing that would be more supporting of parents?

I think, you know I, the school like I had mentioned before, I think everybody is short staffed and I think they are underfunded. And the teachers have a lot on their plate. I really feel that understanding and empathizing with families and knowing that families are doing the best they can and if they are struggling, they need more support and more help. So instead of making families a, not necessarily an enemy, but I think when you have parents like me who are very intense and when they come to the table with a list of demands, and saying I need this, I need this, I want this, I want this, I want this, I think it's automatically, it's kind of antagonizing, I think. And having schools and places understand that this is a defensive reaction, and families are really trying their best for their kids. It's not necessarily a parenting issue. It is that they need more. They need more help. They need respite. And really connecting with other families I think is helpful, I think outside of school to make you feel more normal. If that is a thing.

I think also having information. Cuz I, I again, I have a background in some of that special ed and healthcare and so I knew the rules and so I a lot of families coming into this don't know the rules, that those goals need to be measurable. That those goals need to have specifics in there and what the services are going to look like and when the services are going to be provided. And I feel like educating some families more about the process would be really good for the school to do and make them, it more of a team feeling because families are the expert in their children. So, the school is the expert in school but at the same time the parent is the expert of their child. So, really making parents feel important and valued and heard I think will change the dynamic a lot with the school system. And helping find outside resources. It might not be funded by the school but looking at community-based supports and really building in a sense of community.

My children really were either isolated by their either by their ability or their behavior or were placed out of district for several years and what we discovered in that from those experiences is that they didn't really have friends. They were kind of seen as oh don't play with this child or they were taken out of class or the class was moved or they were sent out of district an hour away so they weren't in their home community.

They didn't have the peers; they didn't have the resources and the connections and that really impacted them. Their mental health. That feeling of inadequacy

and their self esteem and really kind of developed mental health needs because of their lack of friendships.

So, I think that making the school and the community be accountable for making those safe and integrated placements is crucial. I could never find a baseball league that my son could play with play in. Or a camp even because all the camps required a one on one and we couldn't pay for a one on one or find a one on one. So, then they miss out on the camp experience. So, it is just all of those things that make kids kids that they really it was hard to find they really relied on each other for friendships.

So that but also I think not necessarily in the school but really looking at children based on their need and not necessarily their diagnosis. I had mentioned this before, but my son did not qualify for a lot of services because he did not have a neuro developmental diagnosis. The interesting thing is that when he was 18, he received a neuro developmental diagnosis because I pushed it and pushed it and pushed it. So, he lost a lot of time yet had the need. Same with my daughter. There was a need. Our family had a need. There was a level of intensity that was there. Yet because one word wasn't there, there were no services and supports that could be provided. So, I think that is something else to look at.

For us, respite supports, having lists of providers, financial assistance. And even when I quit my job, I am still working but I'm not being paid to be there case manager. So, I think, I think that families that have the financial resources may be able to access more. But working middle class families are staying afloat and there's not that extra money there to pay those thousands of dollars of a specific treatment.

So just having those resources, having those financial resources, community resources. Lists of providers. We have had to do research ourselves to find specific providers that might be skilled in a certain area, and we've had hospitals tell us okay you need to find a provider that's skilled in x, y, and z. Go ahead. Gofind somebody. And that is really difficult, so.

Parents and families that may not be as outgoing or understand the system as well like I struggle. Like, I am struggling, and I feel like I know it. So, families that are just starting or don't know what is they should expect. You know, that's kind of where I really where I am trying to help right now, too but. I would say for us,

we did eventually get home supports through the Fast Forward program and that changed our lives. Because we had always been to different providers for all our kids working as individuals and we have been given you know, hundreds of suggestions and use this task board and this behavior chart and do this and that and we tried it all and we could never quite get it to work for our family because we have four kids who are all different personalities and all different intellectual abilities, all different interests. So how can you manage four children and survive?

We need something that works. So, having Fast Forward come in and they you know outsourced a provider to come into our house and work with our kids and provided a respite so my husband and I could actually go and have a date. So that was something that was really helpful. Had I wished that had happened ten years ago? Yes. So eventually we got to what we needed yet, we lived in kind of a state of crises, and I would say fear because we were constantly did we do enough, have we found the right thing, do we need more? What is there? So, constantly just feeling like we needed to do more. And once we felt like we were supported, and we had the services we needed then we could take a breath. 24:50

And then, like I said the being a squeaky wheel. I don't mind being a squeaky wheel. I think sometimes I do come off as fairly aggressive when I am in my school meeting because I have my list of things and over time I have been really explaining to the school where we are as a family and the struggles that we are having and being completely honest and being very vulnerable and saying hey, I need your help. I am not an enemy. I don't want you to be the enemy. We need to work on these kids together and you need to help me, and I need to help you has made our connections with the school have been better.

And not so stressful and understanding that and really balancing my self-care. Like I am in a career where I am supposed to be telling everybody to balance their lives? And I was terrible at it. And so, I think really having that breath and taking that moment I needed and I needed people to help me do that. Because I was so overwhelmed. My family was so overwhelmed. We were just living in a state of kind of fight fight or flight at all times basically. So having people help you to make a phone call, help you to fill out an application, um, do that research, that gives you time to then breathe. And I feel like every family and caregiver that is

whether you have one child who experiences disability or ten that experience disabilities, you need help. You can't do it by yourself. 26:53

So just really having those supports I think is crucial and to me if I had as soon as I found out my children had, were, as soon as I kind of went through this process of even from a young age and going through that loss of ok what's my life going to be and not knowing and having a support system then, and having a community then, and having a support group or knowing that you are not alone, then, I think would have made my experience a lot different.

So, starting there and then and building those, and then working on the services I think would have been really helpful for me and feeling like I was a valued member of the school team. And not having to fight so hard, I think, would have mind things and then insurance and it the difficulties with the insurance companies and what they will pay and what they won't pay and what provider they will cover and what they won't and having to and even providers not taking insurance. I think a lot of our struggles so kind of understanding that and would have been helpful. I could speak on this for hours. But, I just think that parents need a voice. They need to be understood and they need help and support. So.

I want to thank you so much for taking the time to share your story with us and I'd like to wrap up with just asking you if a parent who is just starting this journey came to you what would you say is the first thing that they should do?

The first thing that they should do is find time in their day to rest and to find a support network like I had just mentioned. And also, to connect themselves with a tribe of people that have those resources. That can get them started with alright you don't have to start researching alone. Here are some places you can start. And that's a good starting place. But I feel the need for having a community and having a support and having that respite built into your day, is where people need to start. And then once you have those things start tackling the advocacy part. Because it is very easy to go one hundred percent into advocacy because you love your children so much and you want everything for them that you forget about yourself. So, yes. Connect. Connect and support.

That's great. Connect and support. Thank you so much.

You are very welcome. Take care.