That’s Inclusive!

Episode 11 Transcript

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In this episode Pat interviews Sarah Sadowski, parent of a child with a disability and DD Council Member. Pat and Sarah discuss taking on the role of family caregiving and the effects of the paid caregiver crisis.

Vanessa Blais (VB): Welcome to That's Inclusive! Where we talk about disability and what it means to live a full life, engaging in our communities.
What does that look like? And how can we work together to make our world a more inclusive place?

Patricia Vincent-Piet (PVP): Hello and welcome to another episode of That’s Inclusive! from the NH Council on Developmental Disabilities. I am your host today, Pat Vincent-Piet. And before we get started, I’d like to make an announcement about the New Hampshire Caregivers Conference that’s coming up in November, on the 8th from 8 to 4, that’s a Wednesday. It will be at the Grappone Center in Concord, New Hampshire. They’re having a great keynote speaker this year. Her name is Becky Rule, she’s a comedic storyteller. Her presentation is called ‘We cried so hard we laughed: stories from New Hampshire caregivers’. I’ve been to the conferences before. It’s such a great opportunity to meet other caregivers and share ideas, commiserate a little bit and spend time around people who just get it. So if you are a caregiver and you have the opportunity, please join us November 8th, from 8 to 4 at the Grappone Conference Center in Concord, New Hampshire.

And today, I am fortunate to have with me, Sarah Sadowski. She’s a member of the New Hampshire Council on Developmental Disabilities. She’s the project director for New Hampshire Leadership which is an entity under NH Disabilities. She’s a caregiver for her daughter who has a disability. And as most of you know, I am also a caregiver. So, we’re going to spent some time talking about family caregiving and the ups and downs and the sweet surprises and all that great stuff. So, welcome Sarah.

Sarah Sadowski (SS): Thanks for having me, Pat. I'm happy to be here.

PVP: I'm taking off my headset right now because I hate hearing my own voice. So, why don't we start off with you telling us a little bit about yourself and your role.

SS: Sure thing. So, my name is Sarah Sadowski as Pat said. I live here in Concord New Hampshire with my husband and our four kids. They're ages 8 to 14 and our oldest has cerebal palsy and epilepsy and we're really thankful that her health is currently pretty stable, which is wonderful. She'll actually be a freshman here at Concord High next year, which is wonderful to be in the Concord High recording space. She's at camp with a friend today. We're really fortunate to have a great team around her. But, I know that's not the case for every family. But being her mom has really opened my eyes to the caregiving crisis here in our state. So thanks for having me.

PVP: We're really glad to have you. So a lot of the questions I have, you've already shared. When we had met before, the big thing that stuck with me was when you told me about the story of her hospitalization and your experience with other families at the hospital. Can you tell me a little more about that?

SS: Sure. Well, my daughter is very susceptible to respiratory infections, and unfortunately sadly when we land in the hospital, that's often what lands us there. So we've had several NicU, PicU stays. That's the intensive care unit at Dartmouth and also at Children's. She's been a frequent flier in both those places, sadly. One of the things that I'm so struck by when I am overnight at the hospital with her is how few children are actually accompanied by their caregiver. And so it just breaks my heart wide open that in this state we often have kids going through medical experiences alone. That's just really sad. Parents come in when they can but often we know the majority of children in New Hampshire have both earners in the workforce. If they're in a two person household, they have all possible earners are in the workforce, I should say. And yet, the paid leave is lagging behind. A civic strategy groups says Leave it to Beaver policies in a modern family era. Right? And to live that experience being in the hospital with Angelina and to feel my own family struggle with who goes back to work, who works luckily we're sometimes able to work bedside. But then you're torn because you have deadlines at work that don't just pause and you want to get your job done but you also want to be there and care for your child. I'm all about the cultural changes that we need to have happen so that more children especially can be supported by their loved ones. But, that's something that everyone deserves. In our moments of sickness and vulnerability, we depend on those around us. We all will. So making sure those systems are really robust is important.

PVP: As a caregiver of an adult, our experience has been, if someone goes into the hospital, Medicaid can no longer pay for the hours for a caregiver. And it's not like the staff at the hospital, I mean like we were just talking about, you were saying Dartmouth is down 1200 employees, 1200 staffers. Even if they knew how to care for someone who needed help with activities of daily living which they don't because that's not part of their training, there's not nearly enough people to do it. Hospital stays for people with disabilities is not good. You were saying that you have a good team around your daughter right now. Can you tell us a little bit about the team?

SS: Sure. It's been years in the making. We are very fortunate in that we met an incredible nurse, gosh it's been seven years that she's been with our family. Without her support, I simply could not work. Part of the way that epilepsy manifests in our family is a lot of sleepless nights. A lot of nights where it can be hard. Thankfully it's less so at this point. But our nurse is still there to make sure there's any kind of care that needs to happen in the middle of the night, particularly if there's something like vomiting or being sick to your stomach. You should not be alone when that stuff happens. It's really important that we have someone there who can take care of the medications that she needs and be there is something goes wrong. So we're really fortunate that we met a real unicorn of a nurse and she's the one who makes it all possible. That being said, we have night nursing 5 nights a week at our place and then, in addition to that, we do have folks who support our daughter in the community. I actually testified about this with my personal hat on at the state budget hearings this year. This workforce issue is something we have to get our arms around. Because this is just not a tenable situation where the workforce shortage is such that if we want to support our community members, being out and about, as they should be, as they have a right to live in their community like anyone else, we need to invest in our workforce. I'm very grateful there's a program right now where some caregivers can get compensated for a portion of the care they provide. But at the end of the day, my daughter's 14. She doesn't want my husband or I hanging out with her while she's going out with her friends to the movies or doing things that, she went to a middle school dance, for example. She doesn't want my husband hanging in the shadows. No matter how much we ask to chaperone, she politely declines.

PVP: You get politely?! I don't remember politely!

SS: But, she went with a friend. And we were able to have someone there who was a chaperone who was able to be responsible if anything went south. Because in our family we always plan for, what the worse case scenario that could happen? And we need to center personal safety. Because our child uses a wheelchair and uses an eye gaze to communicate, and because the eye gaze is very fatiguing at this point. She doesn't always have it with her. At this point she prefers blinks and she'll blink the affirmative instead of using her Tobii for example. So the caregiver issue – I hadn't heard that stat about Dartmouth but I'm sadly not surprised. This trend of workforce issues just seems to be – you and I were both at the family support conference this weekend. And hearing there's not a wait list but there's a caregiver crisis. The hours that you get don't matter if you can't fill them.

PVP: One thing I was thinking about this morning as I was thinking about this is the emotional intelligence it requires for someone to be a caregiver. To walk those lines between making sure someone is safe and that they have control over their own lives. Even if the person doesn't have or going to have family members who want to be involved in one way or another. And so we're asking people to take on this really delicate balance that requires a lot of emotional intelligence for $11 an hour? This is a hard job. It takes a lot. And we need to recognize that DSP and other paid caregivers as true professionals who are skilled. It's a skilled position. I think we look at it as regular labor like working in a factory. But it's not. It's a skilled position and we need to pay accordingly. I really appreciate right now all the people who have these amazing skills and are not being paid but are staying anyway. We can't continue to ask that indefinitely. Not if you want quality care.

SS: I completely agree with you. One of the things that you said that really struck me is the importance of the professionalization of the field. Centering consent –

making sure we have care providers who understand the importance of individual autonomy. Our daughter will be a really good candidate for the shared decision making agreement which is an alternative to guardianship which will really put her in the driver's seat for most of her decision making with us serving in an advisory role. And we really want to have that be the philosophical norm around our child as she hits this really important transitional age. But, you're right. It comes down to this is a hard job and people need to be compensated accordingly. And that it saves us money in the long run. When you think about the return on investment for preventative care, for being proactive about managing health conditions. In our case, making sure we mitigate the risk of aspiration to the best of our abilities. Well then you don't get a pneumonia that lands you in the hospital for days on end. If we can be proactive it's actually much more cost affective and it frees my husband and I up to be full earners – you know, we pay property taxes and we pay our health insurance, and we do all of the things you can do when you're able to be a part of the workforce. I want my kid to be able to be part of the workforce too and that happens with supports.

PVP: It doesn't happen in congregate living situations. It doesn't happen in group homes and nursing homes. It only happens when you have control over your schedule, over your space, over the people who are helping you, who work for you. It can be such a delicate balance. Because caregivers, when we don't pay very well. Some of them try to make it up in an emotional connection and then that ends up being very problematic. They want to be part of the family. And, I get that but you've only got some much band way. In fact Jim had one kid who, because I was also caregiving, was a little upset that he was treating me differently than he was treating her. He's married to me and so it's going to be different.

SS: Those are not comparable situations.

PVP: But that's where the emotional intelligence comes in. If you're not paying enough to hire people with that level of understanding, then you're going to get what you get.

SS: That's absolutely true. And I hadn't thought about that angle about folks looking for that deep emotional connection in a professional role. That's not something you see in other professions necessarily.

PVP: Because people don't see it as a professional role. They see it as they're giving up that this particular person minded up and she could get more elsewhere. And she was totally right. It would have been nice to have been paying her enough to say, no, you can't really—this is a job like any other job and you need to act like an employee.

SS: Your boss is not your source of emotional validation. Hopefully! If you have a healthy work place.

PVP: So, as you look toward her future, you talked a little about the alternative to guardianship. What are some other things that she's looking at doing that you're wondering how it's going to work out. You're wondering how the care's going to work out and do you have any ideas on where to get the care that she's going to need?

SS: Oh, that's a fabulous question, Pat. And it's really one that our family is talking and thinking a lot about right now. Going through NH Leadership Series, I graduated in 2017, like really opened my eyes to the importance of person-centered planning, and really centering the needs of an individual in that plan. We're in a situation where I think sometimes at 14 the future feels really far away and yet her father and I are already talking about, well, if it's college, how are we going to do—like so many families—how are we going to do college? I draw a lot of hope from the movement in post-secondary ed. I know it's not for everyone, but for some, there are programs like 'UNH For You'. Or, I know Syracuse has some really great options for individuals with disabilities to be supported in the university setting. I know that, I just have a feeling like my kid could really thrive in a situation like that and I definitely feel firmly that she should have the choice. Just like any of her other siblings, she should choose if she wants to go to college or not. That being said, I also recognize the constraints of working with a disability at the moment. It's so difficult, particularly the sticky situation with benefits and if you earn too much you get disqualified and if you get married you can get disqualified. There's a marriage penalty that's not right at all. And I feel like, this is really something that as my child plans her future, I want to keep the maximum number of options available. And when I think about what she might do for work, like so many families before us, could we pull off a small business. If college isn't in the cards, what can we do to explore those options? That being said, I think figuring out the caregiving situation will be a piece of that. It will be a piece for my daughter, it will be a piece for either my in-laws or my own parents. Figuring out how we address caregiving as a culture. I think is so important. I do draw a lot of inspiration from the way some of our older Americans are aging and the way that they're insisting on universal design housing, for example. Finding a place to live that's maybe not a house on an acre, that's not a single family home, but something that's closer to downtown and that is more integrated more into the community than maybe some of our more rural locations in the state. Yah, it's all tied together, though. But at the end of the day, she's got to be at the center of it and driving that decision making process.

PVP: It must be tricky. Because Jim works for VR. He's still working for VR and he's always talking about starting in the end of middle school, the beginning of high school starting with transition planning. I remember being a freshman in high school and all I cared about was what I was going to wear that day and how I was going to fix my hair. Just hanging on for the weekend when I could hang out with my friends. What 14 year old is thinking about—only very oddly, highly achieving one. They shouldn't have to. They should be able to enjoy that crazy, stressful time of being a teenager.

SS: Right. It's hard enough to be a kid today.

PVP: And we expect them to plan out their future at 14 years old, it just seems like an overreach.

SS: That pre-frontal cortex is not fully online. We know this.

PVP: Even when they graduate high school. I mean, I remember sending kids on to college, going with a list of rules and have fun, but do this, this, this and this to stay safe because… So, was there anything else that you'd specifically wanted to talk about? I want to make sure that you get all…

SS: Sure. I know when we first met we were connecting about the joys and the complexity of caregiving. And, I was thinking in preparation for today, there is a lot of joy, too, in being able to do this work. I was thinking about how fortunate we are to have the time. I heard your episode about inspiration porn with the Stella Young's clip which I just absolutely, I think that is so key to not put people on a pedestal and to be realistic about – being a human is hard. We're not all getting it right all the time. I just love that you all referenced that. And I do feel really fortunate that I have more time with my kid than a lot folks. And at 14, we still spend a lot of time together. And I feel very fortunate in that respect. And I can be my best self as a caregiver because I have a network of support around me. And that's so key I think in supporting her as she reaches her full potential. There's such a temptation [ ]--every now and then I'll run into people and they say, I could never do that, and that's such a cliché, it just sets my teeth on edge. Yes, you can. You would. We're all just a negative health incident away from this kind of thing. And we should be looking to each other for support. All of us. So, I was thinking about the joys. Are there any joys about caregiving that bubbled up for you as you were thinking about today?

PVP: Mostly to our daughter. She's really connected with her father. When she was little, we didn't think that that was going to happen because they had their…But now she comes and she cares for him. She worries about both of us which I kind of wish she wouldn't do. But, with her fiancé, we have gone on a couple of trips together the four of us. It's an incredible feeling, to be together with them and to watch them mature and take on the mantle of care giving and to enjoy it actually. I think about – this is my responsibility, not wanting to put it on other people. But then, people love to do it. They love to help out. They love to be connected with someone. It gives them a chance to connect with somebody in a special way that you don't connect with others on that level. She had a really great relationship with her father but one thing that drives her nuts, we go out and inevitably somebody comes and wants to pat Jim on the head and say, it's so great to see you out and Katelin is like…… because that's her father! When do you say that to someone's father?

SS: Well you never should. Not treating people in a paternalistic kind of way should be a standard. But Katelin has developed good instincts I bet about the kind of people that she wants to surround herself with too.

PVP: She has.

SS: There's a lot of beauty in opening ourselves up to help and support. And I'm saying that as me as a caregiver. It's so tempting to be like, I'm juggling it all but that actually does a disservice to the overall needs of our family because I benefit just as much if not more from a network that supports me and my kid. And so, I have found it challenging at times. We live in such an independent culture where it's you and your bootstraps. But you actually can have much more rich relationships when you open yourself up to the fact that we all need support. Being able to lean on my friends in a different way. That's been a gift. It deepens relationships and connections which we're all craving, especially right now.

PVP: Well, I think you and I could talk for hours. Unfortunately, I don't think people necessarily want to listen to us for hours.

SS: I would talk to you anytime Pat!

PVP: Same here. This has been great.

SS: Thank you so much for having me.

PVP: Well, thank you for coming. Maybe we can do it again sometime. Maybe talk a little bit about our professional role.

SS: Oh, that's right. We wear so many hats. I'd love to come in and talk about the benefits of the NH Leadership Series and if folks are looking for ways to grow their support network, I'd highly recommend checking out NH Leadership. We are a program that does training for individuals and families who experience disabilities. It's a great time. We're going into an excellent cohort for the year ahead.

PVP: We look forward to that in the future. Thank you all.

VB: Thank you for joining us today. I'm Vanessa Blais and this was a production of the New Hampshire Council on Developmental Disabilities produced by Isadora Rodriguez, Legendre, and Vanessa Blais with many thanks to Josh Hardy and rest of the crew here at Concord TV.
We love to have guests with differing perspectives. These are personal, and do not necessarily represent those of the DD Council.