Taina Karru-Olsen – We Just Kind of Run Our Family on Rage

Carrie Basas: [00:00:00] Welcome to Rooted in Washington, a podcast from Roots of Inclusion. I'm your host, Carrie Basas, and my guest is Taina Karru-Olsen, and I'm gonna work on rolling my Rs more, but there we go.. Thanks for joining me today.

Taina Karru-Olsen: Thank you for having me. This is great. I'm excited to talk about some serious things.

Carrie Basas: You're always up for talking about serious things. I don't think you shy away-- that's what I like about you, one of the many things. I've met your lovely family, but it is podcast about family engagement, so tell me what you'd like to share about them.

Taina Karru-Olsen: First and foremost, I'm a parent to a really wonderful, multiply disabled middle schooler called Aune .

And we're just a family of three. So it's me, her dad, and her. And we are an immigrant family, a [00:01:00] privileged one, but an immigrant family. We've been in the US now for 12 years, and I am originally from Finland and Anna's dad Ken is from Denmark. So we're representing Scandinavia here.

Carrie Basas: The place where we're all hoping to immigrate next according to social media.

Taina Karru-Olsen: No we can change things for the better here.

Carrie Basas: Excellent.

Taina Karru-Olsen: This is where we are. Yeah. While my main thing is parenting because that for sure is real labor, I dabble a little bit in advocacy and stuff like that, and we just kinda run our family on rage.

Carrie Basas: Run your family on rage. That's definitely t-shirts, sweatshirts, bumper stickers. You could put 'em on some Teslas.

Taina Karru-Olsen: Yeah. Outrage for breakfast.

Carrie Basas: Outrage for breakfast. A big bowl of that. Yeah. With some lactose- free milk. I don't know.

Taina Karru-Olsen: Always nice.

Carrie Basas: Run your family on rage. So do you all agree to that?

Taina Karru-Olsen: Yes. We're a very outraged bunch. Just genetically, [00:02:00] I think.

Carrie Basas: Genetically outraged.

Taina Karru-Olsen: And Aune is really coming to her own as an advocate for herself and some of her friends. And that's interesting to see that budding.

Carrie Basas: Yeah. I have n't seen her in a few years. I'd love to see that.

Taina Karru-Olsen: Yeah. Middle schoolers are brutal and she has taken it on with gusto.

Carrie Basas: I love when somebody will break it down for someone else.

Taina Karru-Olsen: Inclusion for all is this sort of grassroots group without centralized leadership. So while I am a co-founder and I often call myself director when I need to be a little bit more official, we are just like a wildly freewheeling bunch of people.

Why we really came to found Inclusion for All was that I was hanging out with-- 'cause sometimes people will be friends with me.

Carrie Basas: You have many friends.

Taina Karru-Olsen: I was hanging out [00:03:00] with a lot of other parents with disabled kids. Then you quickly realize when you're thrust into those environments is that a lot of those more structured ways of hanging out that organizations will have and that doctors and hospitals and schools will try to push you into are those groups really quickly, can become very toxic about disability and about services and everything. So we found out that it was really best to be hanging out with others if you're focused and congregating around an actual issue and not just commiserating around parenting, because quickly that goes beyond, you're just talking about the joys and stresses of parenting people

will start quickly making about disability and that is not a great thing to happen and that is not a good environment to be in.

So we all found out that we all wanted our kids [00:04:00] included in school obviously 'cause we'd all done our research and knew that was the best thing that could happen for them. And we realized that's not gonna be easy. So that seemed like a really good thing to start working on. We also realized that it's never a great thing just to advocate for your own kid and try to get them things-- that we always will need to start talking about the system and try to change the system.

So that's how Inclusion for All came to be-- just a bunch of parents. And then we also soon realized that we shouldn't just be a bunch of parents and that we needed to take some guidance from folks who'd been through the system. So that's how we also decided that we're just gonna stay like a grassroots more mutual aid type of movement rather than become, officially, we're a nonprofit, but we're barely a nonprofit 'cause we're not good at paperwork. When you are decentralized, it's hard to do paperwork. [00:05:00]

Carrie Basas: It's true. A friend and I are doing a workshop on governance and just governance for nonprofits next month and we're trying to figure out the tips we want to offer about how do you preserve that spirit while checking off the things for paperwork should someone come and visit you? But a few things that you said about the parent groups and going in, and then if it is just a parent group-- I realized that when we first adopted Dasa, it'd be connected through disability organizations focused on parents and go and meet people and realize that their biggest desire was to have not had a child with a disability. And there I am as a person with a disability, so I never want to see those people again. I feel very awkward and I can understand their stress and grief, but I just thought: hi, I'm also here with you. And then there was a lot about individual resolution. What can I get for my child? And things are set up to wear you down in [00:06:00] that way so that you barely have enough energy to get the thing for your child or to keep asking for it. And you know that it might be off the table if you ask for others, but I didn't always find people in the group that were thinking about others or the system like you mentioned. And then many of those groups didn't have connections with adults with disabilities who had their own sense of identity. So coming together around a common need and set of values is really important, and it's often hard to find those kinds of communities.

Taina Karru-Olsen: Yeah. It helps to be like a really vocal Finn who puts it all out there. So people are not attracted to me who are not gonna align with things that I say and do. So that is helpful, just being really open about everything that

you believe or don't believe. It doesn't make you a lot of friends, but it makes you the important friends.

Carrie Basas: [00:07:00] Yeah. People I think often feel like they need to be in community with other parents, especially parents of kids with disabilities when their kids are young. And I had a few experiences where I liked the other parents, but it seemed like I liked them enough. We didn't go deep and that's probably why we continued to stay at that level.

But then they wanted my child to be almost part of their child's socialization experience. So I realized I was the cheap form of ABA therapy and I said, no, thank you to this. And it's good to have community, but I am not a therapeutic intervention either. And I haven't really signed up for this strategy with regard to your child or any other children.

Taina Karru-Olsen: Yeah. I think that's it is really hard to be a parent in that space, especially when your kid is young, because everybody and their mothers will tell you that this is your short window in time where you can do all the things for your child so they can have a good life.

When Aune was [00:08:00] young, it used to be so that you can make her more normal, and now they're still doing the same thing, but then now they're just calling it reaching full potential or something else like that. There's still imposing the same things on you. I often talk to parents who are telling me that they're having a really hard time with schools because they wanna bring in their own service providers because they have this quote unquote, very short time to intervene. And that is coming from the therapy industrial complex.

Carrie Basas: I wonder when it is that we give up on people. If we could just state that age, that would be helpful because we're compressing a lot. Sometimes we give up on people before birth. This is kind of tongue in cheek, but then as your child gets older, people say we don't really do that anymore in this context --like we don't teach reading anymore In high school, for example. Wait, but you still have kids who have reading related disabilities and you have adults who are dyslexic, so you have to be able to do that. When [00:09:00] did we give up? I didn't sign off on that. And then is it every swim lesson you can get in before the age of four that will make your child a better person and then you skip ahead and hope you get them in mock trial In high school, what we're really supposed to focus?

Taina Karru-Olsen: I know we're just joking around here, but if you look at who funds what and when, there is time for what, I can understand where that

very short window comes in from because it comes in during the time prior to public education, that takes a lot of your child's time. So it's really beneficial for people who wanna sell their services to believe that they can intervene most beneficially during the time where nothing's like school is gonna intervene. Into that.

Carrie Basas: And often I think it's to prepare young people for school too to make them easier to deal with in the system that's about to come up.

Taina Karru-Olsen: Oh, that is definitely part of the marketing for sure.

Carrie Basas: [00:10:00] There's so much someone needs to do before a child gets into school. Who knew it was so critical and then

Taina Karru-Olsen: Exactly.

Carrie Basas: And then we stop?

Taina Karru-Olsen: Yeah, because when you didn't use that window of time, then they're just gonna go into that other wing of the school building or that, little cottage at the back of the, portable, the behind the football field or whatever, where the special needs kids go.

Carrie Basas: Yeah. With a lovely portable ramp on it that rattles or falls off the building. Yeah, because we physically separate them. Gosh, I don't think anybody would wanna have a child if those were the parameters.

Taina Karru-Olsen: Yeah. And that's when, that's what most people grew up with, it's easy to see where some of that desperation comes from in those parent groups because folks just don't know any better.

Carrie Basas: Yeah, it's pouring everything in. Then people are exhausted and then people are told their task for the next set of years is [00:11:00] to fight back, or I guess. That's on the, that's on the rage side. So a lot of people would be told just to go along. Defer to the professionals. Go along.

Taina Karru-Olsen: Because I find that a lot of sort of family engagement narrative that prevails is that you either fight the system, navigate it for your own kid, or you go along. There isn't a lot about how do we change large systems. Like we keep using a lot of resources on how do we make parents better advocates for their kids and then I talked to a bunch of families who are just exhausted and they feel guilty because they're not doing all the things and

they're not taking all the trainings and they missed some webinar about the perfect IEP, and that's built in that if we just train [00:12:00] families more than they can navigate the system and there isn't an option for you to go, hang on, how do we, let's all get together and start changing these parts.

Like we don't want families to have to fight. We don't want families, we for sure don't want them to go along but what are we really doing if we're just teaching them to navigate a system that isn't serving anybody well?

Carrie Basas: Yeah, so many people don't feel good about the system that they're participating in as students, as parents, as employees.

Some do. It stays there, but some people really don't, and that brings out behavior that is not aligned with burning the system down or critiquing the system. Sometimes it brings out rage in other people that you would point out the thing that's on their minds all the time but they participate in daily, so it's not telling-- it's always helpful to tell people who are experiencing oppression, if you try [00:13:00] harder, then it will work better for you. And then you bring out someone for whom it's worked or a paid commercial break and look, it works well for this person. I don't know what's going on with you. I think we call that gaslighting.

Taina Karru-Olsen: Yeah. Yeah. Lots of that going on.

Carrie Basas: Lots of gaslighting. What is meaningful family engagement then in the context of thinking about disability justice and inclusion and the positive identity? What is that? What does that look like?

Taina Karru-Olsen: Yeah, so that is the thing. It really is, I'm coming to believe that it really has to be like this sort of very loosely structured groundswell.

And if there is structure, it's more like a mutual aid structure and it cannot be this expectation of like very eloquent advocacy, and it has to include, we really have to focus on solidarity so that it's not just focused on disability, it is not just focused on inclusive practices [00:14:00] because we can get only so far with inclusive practices because we have to realize that inclusive practices can still be ableist practices and they can still be racist practices.

So moving away from the kind of family advocacy that invites families in. And rather letting families participate in as their full selves, because that's what we want for kids, which means that you don't have to participate in the official

ways and be on advisories and be the check mark or understand all the things in order to participate.

Like it's really hard to participate in some of the opportunities. Because you enter into some calls and then you're in this big meeting with 30 people and there are three parents there, and then one disabled person-- the token person there to advise on some of these rules and things and the system that's gonna happen.

And then it's always the same parents because they know what's going on. [00:15:00] It's not possible to come into these situations and have family engagement that's authentic if it's structured from the system side. So it really has to, family engagement has to be like, the system has to come to where the family engagement is happening.

Carrie Basas: And I guess ask questions. What would you like to participate in? What would be meaningful?

Taina Karru-Olsen: We can start creating IEP goals. You and I think, have talked about this before a couple of times, we can start creating IEP goals that really enable students to be more vocal about how they would like to access things and how they could access things as opposed to somebody else deciding what that's gonna look like.

That's something that sort of getting back to family advocacy, that's something that family advocacy can do really powerfully is start leveraging the existing structures in more, like not just in one individual IEP, [00:16:00] but more across the board. So that we can create authentic student participation and student leadership and not just I'm always looking forward to a time where it isn't disability specific or participation in a disability specific group.

Like we want that kind of grace and that kind of curiosity for access to exist in things. The school district that I live in has a couple of student representatives on the school board, and although they're lovely, they're also like super eloquent and knowledgeable sort of future politicians and that's great, but they're certainly not the students most impacted by the system that they're in.

So trying to think of like the work that you're doing right now with your youth group is how can we take some of that? And make it so that exists in youth groups [00:17:00] where not everybody is disabled.

Carrie Basas: A lot of the young people that I heard from that expressed interest in the project shared they didn't have anything else going on.

They had incredibly thoughtful responses to questions. I did show some bias against people who were on student council, I have to say. Yeah, sorry, your resume is full enough, but then you'll survive. But that part nags at me because I don't have a ready slate of ideas, or there aren't many existing structures to connect people with, especially with thinking about older students who are 15 to 22 or beyond. We have poured a lot of time into early learning. Let's do everything we can until they're three or four.

Taina Karru-Olsen: It's that window.

Carrie Basas: It's that window. And then what I would love for people to have [00:18:00] community and authentic community and be seen and be engaged and for it to be across disability and beyond disability, but we don't set up many opportunities for people, disabled young people to connect with others and develop a sense of identity and community. And then we haven't really looked at the work of quote mainstream organizations in how they reach out to and sustain every student.

Taina Karru-Olsen: This is really where I think the battle line currently is with the existing documentation and how we do specialty design instruction is that if we start creating IEPs where where goals are built around participation and self-advocacy, it doesn't have to be self-advocacy. We can just do an advocacy goal.

Somebody has a pet cause. So we can leverage those things and [00:19:00] that really would be changing the system. Of how we do things. And I think that would be something I would love to see. Way more IEPs that really take on what the student's role is in the community and how they can participate. So the IEP can create access, and I know I'm shifting away from family advocacy a little bit, but I'm not, because this really is what family advocacy could be about.

So creating the kind of growing space for the student to be a fully participating member of the community in not in ways that the community would be least bothered by or would most accept because of biases, but would really leverage disability as a source of power and knowledge that not everybody else has in the community.

Carrie Basas: That would shift how schools relate to community organizations too, and it doesn't have [00:20:00] to be an organization that has a nonprofit

status. But Their expectations that, okay, if we have a student that wants to do animal rights advocacy, for example, because a lot of these self-advocacy goals, let's just admit they are a number of times student raised hand with a question in a class.

But let's say you have a student who's really interested in animal rights or animal welfare, and then the school says we have a student. And then part of their goal is really how they can have an impact on the stray cat population in our town or something like that. And then the school then has an expectation of the community partner.-- You won't blink twice when we reach out and say, this is one of our students who would like to get involved with this advocacy. And you will look at your own house about how you address racism, ableism, gender identity, all the things that are coming with the student [00:21:00] coming into the world, and we will have a partnership here.

And that self-advocacy won't be something that we use to blame a student or family for not getting a better outcome from school for themselves.

Taina Karru-Olsen: Yeah, exactly. A lot of those goals that we now call self-advocacy goals-- they are goals to, we just slap on the word self-advocacy, but really they are goals to make student participate in normative ways or make student behave in normative ways.

That's really what they most often are, they're not about being a full-fledged member of the school community or a community outside of school in a way that is natural to the student that enhances the ways that they already navigate the environment and 'cause we can use goals to legitimize that.

We can take kids who have serious passions about projects like you were talking about, animal rights. [00:22:00] If a kid has that and you make a goal about that, that would be awesome. That would make the IEP a meaningful document that it's supposed to be.

Carrie Basas: That part is really interesting. Even this morning I had an email from a teacher asking me how to use liberatory design tools and what she is doing with a student who's in a transition program, and I don't really know the teacher. We've intersected through some other work. I would love to talk to her because I think maybe the emails will probably get longer and not make a ton of sense back and forth. But I'm trying to understand the context and because it is a transition program, it does involve community partners, and so what she really wants is a meaningful engagement for the student that she's supporting, and then something that is useful to the community partner, which is I believe like a

quasi nonprofit, or city/ county agency partnership situation. She wants to make sure she's not doing [00:23:00] anything that's infantilizing. She wants the student to be connected with community, to use their skills, and she wants whatever they're doing to be useful to their partner because that also will build into all of this. Because who was just wants to send older students with disabilities in the community and say, go do an inspirational speech, or take a photo with our executive director, whatever?

It's not that, and that's not something I feel can easily answer with just a few lines of an email. But I was thinking today, what are the resources out there for educators and others who are having these moments where they want to do better too and are intrigued by something and they know there's a space in which they can try? I'm happy to support her in that journey.

But people don't often get a chance to slow down or [00:24:00] problem solve or think creatively through that because they're not really set up with something where a student is interfacing with an outside community. And then you want them to have a positive experience. There's so much there that's great and should be supported.

Now I just wanna go meet with a community partner and figure out what would be helpful and I realize that's not necessarily a business model on my end, but I want to encourage more work like that because students and their families end up being so isolated-- physically, socially, emotionally, from everyone else.

Taina Karru-Olsen: And I think that is because traditionally family advocacy has been, you're always stopped when you start talking about other kids besides your own, you're always stopped when you start poking at the elements of the system rather than what's happening for your individual child. And that's really the shift that we need in family advocacy, family engagement, is to understand that [00:25:00] none of us can be doing this just for our own kids and that it actually may be harmful just to do it for our own kids.

Carrie Basas: I have my own theories about why we're stopped, but it would be good to get yours too. I realized that a lot of my advocacy as a parent for my child, and now she just turned 16 last week, so not a whole lot of time left in this k to 12 system. Yes, it can start from something individual, but when I get really worked up, it is about seeing the systems issues. And that's where I think I am most seen as a parent from hell, because I can't stop if it's happening. I can stop, but I'm viewed as someone who can't stop. I think at times, like you were joking early on about a limited number of friends, there are people who live in fear of me and I'm actually like this five foot four woman with a cane.

I am not that scary. Probably telling people I'm not that scary doesn't help those who would like to find me scary. Please go ahead [00:26:00] because I'll get to you eventually. And there are other people I wish would find me really scary, but I get in the space where if I am saying to a school or an institution organization-- I'm not just pointing out what's happening to my child. My child actually has it better. It's still a crap situation, but I know better and I know that she's not the only one who's experiencing this, and this is what is making me really upset because she's going to get the best treatment possible. We are here, I navigate systems. Most days, you like me, so you know you're not getting a restraining order against me. We're having a conversation. I've helped other people work these systems, so if this is as good as it gets, and we'll say this is as good as it gets. I am not okay with what's happening for everyone else, and that is where people just would like to avoid me for the rest of time on Earth.

But sometimes I think they do that because there's shame. Even [00:27:00] if you don't mean to elicit shame in someone else, they have it and. They too know something is broken. And if you're gonna point out that it's happening for more than one person , they do the math and say we can't really change all of that. Or people deal with their cognitive dissonance by becoming more black and white about things and just saying, this is what it is.

But where I do think it elicits more of a negative reaction, whether it's escalating emotions or people just totally withdrawing-- when you go beyond your individual child, those aren't the rules of the game. That's not how you're supposed to interact, but what else is behind that?

Taina Karru-Olsen: Yeah. Yeah, that is such an interesting question because I like you have your theories.

I have my theories. I'm often in conversations where when I start talking about more changes across the board. Like let's say with district administration, I'm being told well, you're on this end, you want these things. And then I have these other [00:28:00] parents who are at this other end.

Carrie Basas: Oh, the mythical other parents. And then you imagine , you're in the other conversation and you are the other parents to that parent. We can't please everyone.

Taina Karru-Olsen: I think that is just because systems don't like to change. They just don't. It is very hard. I did this exercise with a high level district admin a couple months back where we talked about, okay, so let's look at the continuum of alternative placements.

What would it look like if you did not have a single IEP that required a self-contained environment? What would that look like? Implementing the law? And then he's kinda: it's, like getting rid of all of that. And then one IEP comes in and it requires it like spinning that back up? That would be just-- we couldn't ever do that!

And I think that the root of that is just fear because we could have no [00:29:00] IEPs that require a self-contained environment and they would still be evidence-based, data-driven, and measurable IEPs because we know from tons and tons of research that there aren't students who require a self-contained environment, that they don't need to have a special classroom where they do their learning as opposed to other spaces. We know that's a reality, but we have this continuum of alternative placements that the law says it has to be there because somebody might need it. So it is, and I could see like the wheels turning in his head around like staffing and scheduling and locations and finances and it was very interesting to see because I could feel, and also based on when we talk through it is that it is just not a place where districts wanna be like, they don't even wanna be thinking about it 'cause it's so complicated. So I think that's where it comes in. Like [00:30:00] Taina , you're at this end of the continuum. You want a hundred percent inclusion for everybody. And you're not even just asking for inclusion, you're saying use anti- ableist practices and we're not exactly sure what that means.

And then you have these other parents who really want their kids segregated. So that's when we end up having those conversations instead. So being played against other parents instead of we do not understand what our system would look like if we did this sort of evidence-based research-based solution that works best for everybody's education and actually builds community rather than fragmenting it and builds the kind of skills in our students that would be pivotal skills for the world of the future and not buttoning or counting coins in, I don't know, the 1950s.

Carrie Basas: The buttoning. Yeah. Aw. It takes me way back. My daughter played one of her teachers for over a year. We went to the IEP meeting and they said we [00:31:00] have to keep the donning of the jacket on as a goal.

And I said, what are you talking about? And she said every day, Dasha asks me to put her jacket on for her. I said, she's been putting it on for a year. I don't know what you're talking about. She just likes you as her personal service in this mix. That is not a goal. She's been doing that, but congrats, she decided she would rather you do it for her, and stop what you're doing and come put her jacket on for her. I think we can move past that. But you've been suckered by a

child. She was in first or second grade at the time. I'm like that's great you, she didn't wanna put on her jacket. It was much nicer to have the whole, putting on the ceremonial robe or something.

I have a hard time , I know that there are people who exist who don't want to get rid of environments that are secluded, that are segregated. Part of me wonders if they would think differently if their child had a [00:32:00] positive experience in an inclusive environment.

There's so much faulty reasoning in if we dismantle the thing, what if somebody comes along and we dismantle the thing and it works? I Think that's the part where people aren't willing to believe that it will work well. But if you dismantled the thing, it worked well and someone came down the road that had an IEP maybe from somewhere else, not from your lovely school in which it's been working well, and said that they needed to be in the segregated environment, that you'd have to pop up a segregated environment again.

You would say, that's not what we do at this school. The students are served well, they're engaged. These are what our numbers look like or experiences, and it's to me, and I don't want to minimize the strong history of racial justice and civil rights, so much of disability rights and justice comes out of that--

I was thinking about how inconvenient it [00:33:00] was to board up a second door at a school when we were looking at racial segregation. How very inconvenient! And I have this physical memory of going through the Brown versus Board of Education museum in Topeka. And I just thought, it's, to me it's a lot like that saying I'm sorry but we made two doors and I'm gonna have to have the contractor come out and board that up.

We know though, that there is value sometimes for people in community in separation education when they can be with others who have a shared identity or similar access needs to share ideas. In terms of cultural racial identity, like HBCUs, that's not what we mean by segregation in This context. Yeah. And there's a lot of value for people being able to opt into the kinds of learning environments where they can celebrate who they are fully. But I just thought, it's like saying, if you make me put a board over the second [00:34:00] door, I am gonna going to have to pay for a contractor to come and take it off later.

That's not a valuable argument. Years ago I was arguing, not arguing, with maybe some court administrators about how school absenteeism isn't best addressed by their juvenile justice system. And I said what about programs in

community for engagement-- not all that rebrand ed truancy boards, those community engagement boards or whatever.

That's just confusing. Nobody knows who they're visiting then. And they said we could do that if we had more money, because then we could hire those other people. And I said no, your jobs would go away. That's where the money savings is. Your jobs in their current form, unless you have these other skills, which you haven't demonstrated by locking up kids, go away. Cool. You actually, this could be a money savings for you. And this is what we're spending money on now. They're like but we need more money. I'm like, Nope, you actually. Nope, you don't.

Taina Karru-Olsen: Yeah. That is a big [00:35:00] part of the explanation. One of the explanations is that, we have this other group of families who want segregation.

Another one is inclusion is so expensive and somebody. Someone Pretty high up in one of the school districts just said that it does cost more money if you're doing it right. And I wanted to scream because it doesn't. Running two parallel systems, one of segregation and one of inclusion in pockets that's really expensive.

Sure. 'cause you're funding two separate systems. And I think that's where, that's another explanation that we get when really if you go to the source, it's all about fear and it is just the system's inability to reenvision itself. And I think ideally that's where I see meaningful family engagement come in, is as the resistance because the system will not change itself. So you do need, and that's why I'm like, I'm always [00:36:00] so angry when we're driven to believe that family engagement is about, like civil conversations and navigating a broken system, or not even broken, the system is functioning exactly like it was designed to function.

But navigating that system instead of resisting these things because it's, if I could pull away all of the like, or pull in that energy that some of the family groups have where there's a lot of frustration, if we could channel that into this resistance to these things that were decided in like pre- 1970 of how education works for disabled kids, if we could pull in that energy into resisting. And that would be family engagement instead of the resistance being located in, oh, you can file due process or you can file a community complaint and that's how you can resist. 'cause those two things are not gonna change the system.

Carrie Basas: But it is so weird because you've got two [00:37:00] sides who are supposed to be focused on a child, and then that it becomes focused on the adults so often.

Taina Karru-Olsen: Yeah. And the institution itself, that has been created by the adults, not the children who are passing through. Yeah.

And that is one of the arguments. That you often also hear is that once you start talking about the system, is that no, you have to center the student that we're no longer talking about the student.

Even though if you change those things about the system, it would be better for that student and for a number of other students as well. So it really is, it is a devious cycle that happens where all of these arguments come in that aren't, it all just goes back to fear and the system not wanting to change itself.

So it's, that's just part of it.

Carrie Basas: There's so much fear, replication, sense of overwhelm. People's comfort and doing the same things, [00:38:00] even if they're things that they don't enjoy necessarily. Being part of it is part of their routine, and in that way, it can be comforting to them and predictable. It offers some stability, however perverse that can be too.

And yet schools are a place where a lot of parents and students learn what it means to be disabled. How did you learn about disability identity? Because you were among a group of parents that had a different idea about it than the moms, dads, caregivers I got lumped with when I first came into town that were just based on the fact that you could be a parent of a child that had an intellectual or a developmental disability, and their values were so far off.

So where did your idea of disability identity and disability justice come from? You didn't get it from [00:39:00] school somewhere?

Taina Karru-Olsen: Potentially maybe from Finland. I don't know.

Finland was ahead of the curve in just not necessarily like inclusive practices. I don't think they really talk about inclusion more about sort of community values. And everybody has membership in a community. And it's ridiculous to say that about Finland because Finland is like the most homogenous country on earth where everybody looks the same and does all the same things. But that does lead to a place where like you enter a school and you can go into a school

building in a big urban city, or you can go into a rural school and kids will be learning the same things and the level of teaching the practices will be the same or similar.

So I think just coming from a background where we think about community a lot more as opposed to individuals and we [00:40:00] look at achievement and we look at participation from a community perspective rather than from an individual achievement perspective. I think that was certainly helpful to begin with.

And then also I think just like having lived in so many different countries where people do things very differently and understanding that this is not the center of the world here. The US certainly has a footprint, but there are many assumptions that are built into the national psyche almost that don't always sit right with me. So I think just that as a background and then getting Aune's diagnosis while I was still pregnant. I mean we got it at week 13 of pregnancy, so had a lot of time just to read up on things and come into everything prepared. And 'cause I was reading about inclusive education when I was still pregnant and I was reading about like positive [00:41:00] disability identity while I was still pregnant with her.

So it almost like I was able to come into it without knowing her specifically. So I got to have all of this background information and then she was born and then I was able to okay, this is my kid to have that layered in later I think was helpful.

Carrie Basas: It seems like you would have to look for that because if you were to just type a diagnosis into a search engine that would not come up high.

Taina Karru-Olsen: Yeah, and I think that's where like my general background as thinking about what makes a person have value and different ways of being in the world, that all still our ways of being in community with others. I think that's where that sort of comes in, so that then I would be able to look at and read stuff about disability and be like, this sounds really off. This sounds really bad. And I think it started with something like, I remember reading something about Down Syndrome specifically, [00:42:00] and it said the risk of Down syndrome. And I was like, what about the chance of Down syndrome? Like risk doesn't-- and that was even before we had the diagnosis. We knew that something was going on, but we didn't have the specific diagnosis.

I was like risk doesn't sound right like that. I would use something like chance or probability and just it didn't. I was like, because having Down Syndrome is

just another way of being in the world. And those are specific to me, but I think we're getting closer to it when we start talking about belonging as opposed to inclusion or being included in, and I think belonging is where it has a stronger connection to disability justice, because disability justice, all of the different elements are nobody's asking to be included in something that somebody else built.

All of us are looking for a belonging in the communities of our own [00:43:00] choosing.

Carrie Basas: I think that we set up parents and students sometimes to ask to be included in the thing that someone else built, because that hasn't happened as, just an entry. But then when you go into the place, practice, program that someone else built, it doesn't feel good if you've had to ask to be there and you were never in mind, you were never intended to be there, and your experience of that thing, eh, no one really cares about. Just being in a space doesn't mean that you belong. It can mean that you are sitting there suffering silently or not.

I've had work groups, for example, when we were talking about race and I had colleagues later come and say: we all got along before we had this [00:44:00] conversation. We all got along.

Taina Karru-Olsen: You mean some people were quiet about the things that were bugging them?

Carrie Basas: Yeah, and then I had talked to another colleague who said because I just didn't even bother with that person. That's why we got along. That wasn't genuine. I still had my thoughts, but I just didn't say it. It doesn't mean that we were in harmony or we all belonged. I suck that up. I lived with that because I just thought, they're not gonna get it. It's not worth it. Maybe now's not the time. They are not that important to me. I do this all the time, not now.

All kinds of reasons why, or they didn't feel empowered by the rest of the community of the group to say it because we often go along to get along. To have somebody for whom the environment was always constructed to come and say, is their complaint to someone in management: we used to get along before we had this conversation, and I have to say in the [00:45:00] most empathetic way, yeah, people are doing that for you and now they aren't. And that is growth, my friend, but people want it. They want we got along.

We had the award for the kid with a disability-- most inspirational. We did something. How did that make someone feel? So yeah, the idea of belonging

means that we get outside of ourselves and we would ask people, not only observe them, but ask them if they felt like they did belong, what would it take to get there? It's a continuous work, mental work in, work in progress towards this idea and kids are growing and changing, so it can't be a stagnant approach. Or we do this one thing for kids with Down syndrome to make them belong. It's in our spreadsheet.

We only have a couple minutes left together. I know. And there's so many things.

Taina Karru-Olsen: I really beered away from.

Carrie Basas: I did too. I was right there along with you. We were adaptive. How about that? You're [00:46:00] responsive. What does disability justice and family engagement look like for your family moving forward for the rest of the years of school?

Taina Karru-Olsen: I think growing the idea that Inclusion for All should be about mutual aid. I really think that we need more thinking around mutual aid and what that looks like, so that we're not like stuck in this cycle of nonprofits coming in and getting funding from wherever funding's gonna be available anymore.

Who knows? And then being beholden to a certain, some expectations that maybe not are really beneficial. So I think looking at it through the lens of mutual aid and then really digging in to all of the different principles of disability justice, like what does it look like? Because we still have a lot of work to [00:47:00] do around, currently now I see a lot of advocacy around how the government's coming for disabled kids, but I'm like, no, they've been coming for multiply minoritized kids all the time, for a long time, and we cannot let go of that. Like they're not mistakenly targeting disabled kids now. Like we have to be in solidarity with many more communities and understand what the work can look like.

So for our family, I'm now a citizen so I can get arrested without being deported. Hopefully.

Carrie Basas: In theory. In theory, we've seen that happen a lot this week. You can end up somewhere fun for a while.

Taina Karru-Olsen: Yeah.

Carrie Basas: That's how the law is supposed to work.

Taina Karru-Olsen: So I think I can have an even bigger impact now potentially, but also really Aune is growing as somebody who cares about-- she's always been super [00:48:00] into disability and having that positive disability identity and I think she is now growing into starting to understand what it looks like in her community. She's had a great identifying able a structures goal in her IEP for years, and it's growing that for her so that she can start figuring out when stuff is not designed for her. She now, she already, she can figure that out now, but then starting to say what it should look like. That's the step that she's now taking. So really we're supporting that 'cause she knows when stuff is not great for her and she will leave and she will, be very vocal about things that are not working for her, but getting her to, to a point where like she could say, okay, what would work then?

And then having people have to listen to her and not dismiss her. And I want that for all the kids whose needs are never respected. [00:49:00]

Carrie Basas: Yeah. To listen and do something with it. Or be honest about what they can and will do with it, instead of just sitting there uncomfortably or saying something patronizing in response: " Oh, that's such a special idea, Aune. Thank you!"

Because I would love--, I was seeing in my mind stickers that say " ableist structure" and just sticking them on people, places, documents , just tagging everything.

Then that second part that you highlighted about what would it look like to be different, and then what are the people that gate- keep that thing, lead that thing, get paid to run that thing. Or even peers. In what ways are they going to be responsive and accountable, and how do we learn together?

Taina Karru-Olsen: So that really is what it's gonna look like for us going forward, and then making sure that it's not just happening for her, but that [00:50:00] this is something that is happening across the board in our schools where kids, they know themselves, they know what would work, and we should just listen.

Carrie Basas: Yeah. We should just listen. And some of them haven't been asked in the past. Yeah.

And sometimes can be a little shy to name that thing. Or just haven't had practice doing that. But when they're genuinely invited, they can do it.

Taina Karru-Olsen: Yeah, and I'm seriously on a campaign to get this ableism goal into as many IEPs as I can.

Carrie Basas: That would be a good professional development on the other side when it's in there, what does someone do with it? Thank you so much for joining me today. It's always good to see you . It; s been too long.

Taina Karru-Olsen: Thanks for having me.

Carrie Basas: Awesome.