

Liz Lightfoot ([00:00:03](#)):

Hi, my name is Liz Lightfoot and I'm a professor at the School of Social Work at the University of Minnesota. I'm happy to welcome you to this podcast where I'll be talking with Sharyn Dezelar about a new practice model for working with parents with disabilities called Parent-Centered Planning. Um, before we talk with Sharyn, I'll tell you a little bit about parent, the parent centered planning model. Um, and then we'll go on and have a more in-depth discussion with Sharyn.

Liz Lightfoot ([00:00:30](#)):

Uh, as many of you might know, there's more and more people with all types of disabilities who are becoming parents. Unfortunately, there are few formal services or supports to assist them with parenting as our support and service system focuses on supporting people with disabilities as individuals, rather than as parents or caregivers. So our social service system just really isn't designed for providing supports for caretaking right now. Um, hopefully this is changing and this is what we're trying to do with this new model. There have been some promising interventions developed to assist people with disabilities with parenting, but these tend to focus on increasing parenting skills like individual parenting skills, and we actually have some good evidence supporting some of these interventions, which is great, but these interventions focus mainly on strengthening individual's skills focused just on the individual or the parent with a disability rather than developing supports or looking at their broader environment, which is what we often focus on from a social work perspective or a disability supports perspective.

Liz Lightfoot ([00:01:41](#)):

And there really has been less emphasis on developing family or community supports. And there's only a few studies showing how these types of supports can help parents with disabilities. When intuitively we know that they can. Uh, the more I personally have been doing research highlighting the barriers parents with disabilities have been facing, the more I've become interested in developing even a very simpler basic program for parents with disabilities to figure out how they could start building their own supports. And I was fortunate to receive funding to do this from the National Institute on Disability, Independent Living and Rehabilitation Research, which we know fondly as NIDILLR as part of a partnership I had with the National Research Center on Parents with Disabilities out of the Heller School at Brandeis University. So together with my research assistant at the time, Sharyn, who I'll be talking within a few minutes, we created this Parent-Centered Planning model, which we have developed.

Liz Lightfoot ([00:02:42](#)):

And now we have pilot tested. And this model is based on the Person-Centered Planning approach, which is really common in working with people with disabilities, particularly youth transition age, but really used with people at all life stages, um, and very the Person-Centered Planning, um, approach the main goal of it is to help a person with a disability plan for supports through a process that assists people and their broader social networks to plan by focusing on a person's strengths and preferences rather than on a formal assessment or a formal plan, or having an expert determine what a plan would be. So key parts of person-centered planning are that it's individualized with a person as a disability at the center of the planning and decision-making process and supportive people are invited to participate such as family and friends, but they are not to direct the nature of the goals or to be directed decision-making at all, uh, it's typically done using a series of structured exercises, focusing on strengths and preferences of the individual with the disability and is facilitated by a trained facilitator.

Liz Lightfoot ([00:04:00](#)):

And again, that facilitator's role is to facilitate decision-making, um, of the person with a disability and their supportive team rather than to provide input or make assessments or make recommendations. So our Parent-Centered Planning Model, which we'll talk about today, draws on this person-centered planning approach, but broadens the focus from the individual to the parent with an intellectual or developmental disability and his, or her children with a specific focus on the parent in his or her parenting role. So that's what parent-centered planning is it's really taking this person-centered planning model and broadening it to be parent-centered or family centered. And we will go into the details of this model through a discussion with Sharyn Dezelar. And I'm really happy to have Sharyn today with me to talk about her experiences with the Parent-Centered Planning Model, because she was the social worker who the social work researcher who is responsible for implementing the Parent-Centered Planning Model here in our pilot study at the University of Minnesota. Uh, she is now an assistant professor of social work at St. Catherine University, where she teaches a variety of master's level social work classes and continues her research interests related to disability services and supports. So now I will ask Sharyn to, to talk with me about the Parent-Centered Planning Model. I am happy to have Sharyn here today to talk about her experiences with the parent-centered planning model. So can you walk through what the parent's centered planning model looked like as the social work researcher implementing it, using an example? And of course, obviously we will use de-identified examples here. So we're not actually giving the personal information of anyone here.

Sharyn Dezelar ([00:05:54](#)):

Yeah, absolutely. Um, the participant That I'm gonna talk about today, I'll refer to as Jessica in this story, um, and as stated that's not her real name. And so all the names including of her other family members have been changed throughout as well.

Liz Lightfoot ([00:06:10](#)):

And the details too.

Sharyn Dezelar ([00:06:11](#)):

and the details have been edited a little bit to protect her privacy.

Liz Lightfoot ([00:06:16](#)):

Okay.

Sharyn Dezelar ([00:06:17](#)):

Um, the process starts with an intake meeting, um, at this meeting we gather information about, um, who are the key support people that are involved in the parent's life. I ask questions about the disability, how that might impact parenting and get a sense of what types of things this person might want to work on. So what are the things in their life that are challenges for them or barriers for them? Um, while we're not really starting on a full goal setting process at that point, we're starting to talk about that. So we can plan our intervention in a way that's the most helpful to the family. Um, at that intake meeting, we identify who those key support people are so that we can invite them to a meeting, which is the second step the parent gets to decide if you know, who gets to be there and also how we're going to invite those folks. So I often helped with that process in other cases, such as, uh Jessica's she said that she was comfortable reaching out to her friend on her own to invite that person to the meeting. And.

Liz Lightfoot ([00:07:25](#)):

Can you tell us a little bit more about Jessica?

Sharyn Dezelar ([00:07:28](#)):

Sure, yeah,

Liz Lightfoot ([00:07:29](#)):

What was her. What was her situation? What was her disability? What were her background information?

Sharyn Dezelar ([00:07:34](#)):

Um, yeah. Yeah. So um, when I show up to the intake meeting who is present, there is Jessica as well as her mom, whose name is Vicky and, uh, Jessica and her daughter Bea who's 13 years old, live with Vicky. And, um, this was not always the case. Um, they had, you know, lived on their own, had their own apartment. However, um, Jessica had a very, um, severe car accident that resulted in multiple injuries. Um, Bea her daughter was, uh, approximately three at the time that that happened. Um, so this is about 10 years ago. Okay. And she had a very severe accident, um, that resulted in a traumatic brain injury, as well as some visual impairment, several broken bones. She's had multiple surgeries, reconstructive surgeries to heal from this accident. And, but the biggest negative impact for Jessica and her independence is the traumatic brain injury. It's really resulted in a loss of her being able to work.

Sharyn Dezelar ([00:08:39](#)):

She'd previously been an independent gainfully employed, um, registered nurse. And while clearly, still very intelligent, she really struggles to be organized. And she really struggles with maintaining her emotions. A part of her brain that was damaged in the accident, um, had a lot, has a lot to do with emotional regulation. And so her skills for that appear very childlike and she's able to articulate this, she's aware of it. And it was also very aware to me as I met with her, I saw examples of this happening. And so because of that, they moved in with Vicky, which is, um, Jessica's childhood home. Um, Vicky really helps Jessica take care of Bea and acts as almost a primary parent in a way when Jessica is not able to, to function well.

Liz Lightfoot ([00:09:30](#)):

So did, does Jessica have any other support people that she identified at this initial intake meeting?

Sharyn Dezelar ([00:09:38](#)):

Yes, she, she did mention, um, that she had a group of friends. Most of whom were not really supportive for parenting. They were just more like a group of girlfriends that she had occasionally, you know, would get together with. Um, however, she did identify one best friend. Um, his name is Pedro and they've been best friends since high school really. And that he is like a father figure to Bea. And, um, since Bea's dad, isn't very involved in her life, so he is involved and does help her out a lot. And so she also identified Pedro as someone that, um, was a good support for her, for parenting that she'd really like to have be a part of this intervention process.

Liz Lightfoot ([00:10:22](#)):

Okay. Then Jessica invites, who did she invite to the meeting?

Sharyn Dezelar ([00:10:26](#)):

She invited Pedro and also Vicki to be a part of the meeting. And I met Vicky at the intake meeting and that was really helpful. We also do invite participants to have someone present with them at the intake meeting. It's their choice. If they feel like they would like someone to be there to help support them. And it was really helpful in this case, Vicki was able to fill in some of the gaps in the story when it was confusing for Jessica to share the story. As I had mentioned, she struggles with organization and it includes organization of her thoughts. She will tend to jump around from topic to topic. And so Vicki will help with that, you know? And so she was at the intake meeting as well.

Liz Lightfoot ([00:11:09](#)):

Okay. So then after you've invited people to the meeting, then what happens? What's the next step?

Sharyn Dezelar ([00:11:14](#)):

Yeah. Then we schedule a person centered planning meeting, and this is the main intervention, um, meeting that we have for the parent centered planning intervention. And at this meeting, we do a number of, um, things. We go through a goal planning process that is very strengths-based. And we start with asking the parent what their dreams are for the future. And, um, it's really important as in the title of the intervention that the parent is at the center. Their wishes, their goals are, what is centered. Support people are there to, you know, at times give suggestions, but more to discuss how they can be a part of supporting the parents goals.

Liz Lightfoot ([00:12:05](#)):

So it's really the person or persons centered planning philosophy, just addressing parenting, right.

Sharyn Dezelar ([00:12:12](#)):

Exactly, exactly. This intervention is modeled after person centered practices, um, which again puts the person at the center of the planning, the person with disabilities and strengths-based practices. Right. And we have altered this to focus specifically on parenting, on the parenting role. And so we started for Jessica's case, we started with her, her dreams for the future and which she, she struggled a little bit with this because with her challenges with organization, it's, it seemed a little abstract for her. I mean, she said very general, general things about, um, you know, would love to be living independent again with her daughter, but she also recognized her stated recognition that she didn't also really think that that was maybe a good idea, but she mentioned it as something that she thought about as in like a very dream-like sense. But when we broke it down from, um, dreams to, Hey, what are some really positive and possible goals for one year, that she was able to identify some specific goals.

Sharyn Dezelar ([00:13:22](#)):

Um, before we talked about those goals, however, we did talk about Jessica's strengths and she was able to identify that, you know, she was a very caring mother and when she was functioning, well, she was a very good attentive mother. And it's hard for people to talk about strengths without talking about their challenges. And so she did identify that it's day to day for her, how she's functioning. And there isn't really a way to predict it if she wakes up with like a really bad migraine or something that might last for two days. And she's basically in bed for two days and not able to function as a parent. And then in those cases, it's very necessary for Vicky to be there and to step in and be the parent. Jessica was fortunate in having the support of Vicky, her mother, because Vicky's retired. So she had the time to

give and she, and so Jessica fully recognized that this was a strength for her family, but also a privilege that not a lot of families have. She was in full recognition that they were okay because of Vicky. Um, So she.

Liz Lightfoot ([00:14:23](#)):

So that's a strength of hers too. Support

Sharyn Dezelar ([00:14:24](#)):

It is, It is, she did have that support of her mom.

Liz Lightfoot ([00:14:27](#)):

Right.

Sharyn Dezelar ([00:14:28](#)):

So that was definitely a strength. And, and then as I stated, when she was feeling well, she was a really good fun mom, liked to take her daughter to do things, um, very caring. This family has a ton of pets. And so, yeah. And so they were, um, and of which she is the primary caregiver, for the pets as well. And that, that's a very good thing for her to be doing.

Liz Lightfoot ([00:14:54](#)):

So, can I ask you, um, this takes place in their home, right?

Sharyn Dezelar ([00:14:59](#)):

Yes. Yes. So we're meeting, um, we're meeting with the participants really at the place that they feel comfortable. And of all of our participants everyone wanted to meet in their own home except for one preferred to meet at a coffee shop, but it's their choice. We prefer to do it in home because we want to help families in their natural environments. But if they're not comfortable with that, we certainly, they don't need to do that.

Liz Lightfoot ([00:15:21](#)):

Was the child there?

Sharyn Dezelar ([00:15:23](#)):

Um, she was there for part of the intervention meeting. Um, one thing that had happened as I had mentioned, how, um, Pedro was invited to this meeting and Pedro was present for the intervention meeting for about the first half of it. And then he brought Bea to urgent care due to a suspected sinus infection. And this was planned and discussed before I arrived. So the, um, he was planning to be there for the meeting. And then Jessica said, you know, Bea is really sick. Like instead of being at the meeting, can you actually take her to the clinic? Cause that's what I need .

Liz Lightfoot ([00:15:59](#)):

An example of support.

Sharyn Dezelar ([00:16:01](#)):

It is. And, and he was very willing to do that. And it seemed that he'd done that before, like he was comfortable with what insurance the child had. And so he was, he was okay filling in for that role. So, but he was there for the beginning of the meeting. Um, he didn't add a lot of input, but he was present and just, he just is, it was a very calm kind person that it appeared that his presence with just was helpful for Jessica.

Liz Lightfoot ([00:16:31](#)):

So in, in other, um, examples of when you did the parent centered planning meeting, where there larger groups present, in some cases?

Sharyn Dezelar ([00:16:39](#)):

In a couple of cases, there were, um, groups of up to six people present, which could include friends, family members, you know, immediate family members like parents, aunts ,partners. So in some cases the groups were larger. In other cases, some families really struggled with finding anyone to invite and maybe only one person would be there. We actually had one, um, example where a person had invited a couple of friends and then no one showed up or they had indicated shortly beforehand that they couldn't come. So I think that really speaks to the limited supports that some parents with disabilities have for parenting in that they really struggled to even find people to invite.

Liz Lightfoot ([00:17:29](#)):

And, and this was very different from our typical person centered planning, which we might do with a young person with a disability where they might be able to enlist a whole host of people, friends, family, caring, adults, teachers, people from church, people from other other organizations who can come in. And sometimes we see examples where there's a dozen people at a personal planning meeting. But for, for these parents in our project, we had a hard time. Some of them had very limited supports.

Sharyn Dezelar ([00:18:02](#)):

They did. And again, some of them really struggled and they were really isolated. Some parents like a different example. There is a parent who lives in a disability high rise with her child and her child is the only child in the entire building. And so to think of how isolating that is for, for the child to be in a large apartment building. And there's not a single other kid there, um, as far as playmates and how close are they to parks and schools and things where kids are, um, that also made it challenging for that parent to have friends that were parents. She had lots of friends, they were a lot of friends in her building that were great support for her, but those people were not parents. And so they didn't really know the ins and outs of parenting as a parent myself.

Liz Lightfoot ([00:18:56](#)):

Like the camaraderie.

Sharyn Dezelar ([00:18:57](#)):

Right, the being able to vent about challenges with toilet training children or children who don't stay in their own bed at night and to not have any friends to problem solve that with was really a challenge for her as well as then for social opportunities for both her and her child. So that, I mean, that was a different case, but I think it highlights how isolated this population might be and how it may differ from

a traditional person centered planning model. And just how, because of the so few supports that some of these families had.

Liz Lightfoot ([00:19:27](#)):

Okay. Yeah. That's very interesting. Um, so, so we've got this smaller group at this parent centered parent centered planning meeting, and in Jessica's case, you've identified the strengths and the dreams. What were some of the positive, and possible goals that she had?

Sharyn Dezelar ([00:19:47](#)):

Yeah, well, at the intervention meeting, we really identified three main goals of things that she wanted to work on. And again, these are all identified by Jessica with some support and input from Vicki, but they are Jessica's goals. The first being more of a, just an immediate, shorter term goal, but it was an important one. Um, Vicky was coming up in about a month from the meeting, was going to be out of the country for a couple of weeks and was very concerned about how Jessica and Bea were going to function without her there because of the primary role that she takes on. And, you know, without getting into too much detail, this is an annual trip for Vicki. And in previous years, sometimes it's been really awful. Um, in terms of things that have happened while they're gone, um, you know, not in the terms of like extreme abuse or neglect, but more in the sense of the impact on Jessica and her mental health and her physical health with being so overwhelmed and not having Vicky support.

Liz Lightfoot ([00:20:50](#)):

The stress,

Sharyn Dezelar ([00:20:50](#)):

Just the impact of the stress on her, of not having that person to rely on, to help with her daughter. So that was, uh, a goal was preparing and making sure that, um, they had some plans and supports in place so that Vicki could feel a little more comfortable, uh, going away and less concerned about what was happening at home while she wasn't there and making sure that Bea is safe during that time and well cared for. And also from Jessica's perspective, it was, she brought it up, but her concern was a little bit more of my mom needs to let me do this. And so she wanted the independence and she didn't want her mom to over plan it. So the goal was directed by her. She wanted to feel like she was trusted to do it. And, you know, she, she wanted her mom to relax and let her do it.

Liz Lightfoot ([00:21:47](#)):

Such a good goal.

Sharyn Dezelar ([00:21:48](#)):

So, um,

Liz Lightfoot ([00:21:49](#)):

That's a very short term immediate goal.

Sharyn Dezelar ([00:21:51](#)):

Yes. that was a shorter term goal. The other two goals were a little bit more, long-term one related to Bea's mental health as B is an adolescent. Um, Jessica is really noticing some signs of depression and

anxiety, and she thinks a lot of it has to do with their family situation. The fact that she doesn't get to have much of a relationship with her father, also just family history of depression and anxiety. And so she really wants to get that addressed and she really wants to make sure that Bea is okay and get, Bea connected with some mental health services.

Liz Lightfoot ([00:22:18](#)):

Well that's a really insightful goal for her.

Sharyn Dezelar ([00:22:21](#)):

Yeah, absolutely.

Liz Lightfoot ([00:22:23](#)):

That explains she's a caring mom.

Sharyn Dezelar ([00:22:24](#)):

Yeah, absolutely. The third goal area that Jessica brings up is that she really wants to make sure or she wants to work on her relationship with her mom with Vicky. There is a lot of tension between the two of them. They both stated it and it was really apparent being in the home. It appears to me that there are some unaddressed, resentment and tension about this change in roles, right. And Jessica at times, um, as I mentioned previously with her struggle with lack of emotional regulation and emotional control, and she can, at times act very immaturity will, um, sometimes really yell at Vicky or scream at Vicky about things. Um, she'll just be very angry. Um, she'll seem very demanding and like, well, I need you to do these things for us. Vicky basically just absorbs all of that. Um, I did not observe Vicky to be combative or to argue back, but you could just tell that she was in a sense taking a lot of almost verbal abuse. It would seem, you know, that way.

Sharyn Dezelar ([00:23:37](#)):

However, Vicky was recognizing that this was words that were coming out of her daughter's mouth, that her daughter couldn't control. So you could tell she was trying really hard to take it personally, but that is a very hard thing to live with. And so they wanted to work on their relationship.

Liz Lightfoot ([00:23:51](#)):

And they both wanted to work on it.

Sharyn Dezelar ([00:23:52](#)):

They both wanted to work on it. Jessica brought it up and Vicki said, you know, confirmed that this was an issue. And she expressed some sadness about the change in the role that she was a caregiver for Jessica again, almost like parenting another teenager in a way with some of the emotional reactions. Whereas, you know, they used to be able to do fun mother-daughter things together and that's gone. Like they used to be able to take trips together and now that is gone. And so she really had a lot of sadness and um, so they wanted to work on that relationship. So that was the third main goal that was identified.

Liz Lightfoot ([00:24:28](#)):

So then after you make these goals, then what's your, what do you do? How do you, how do you wrap up the meeting?

Sharyn Dezelar ([00:24:35](#)):

Yeah, Well, we start with the positive and possible goals for one year, and then we work backwards in a way to say, well, okay, so where are things at now? And identify the gaps in between now and what you want it to look like in a year and then really break down what are the supports, both informal supports as well as connections to services that you might need in order to achieve those goals. So we, we identify those resources that are needed that we need to build on. And we break down into more attainable action steps, like, well, what could we do in three months time that would be steps towards these goals, but are also very doable for three months. And then from the three month point, we identify one or two goal steps.

Liz Lightfoot ([00:25:24](#)):

Okay.

Sharyn Dezelar ([00:25:24](#)):

These would be things that we choose, something that we are pretty confident that are going to happen so that the person gets to build a very doable, but a bold step. And so really getting someone to make that commitment. And in this case, there were more than one bold step because they related to two different goal areas. One of the bold steps that the group came to was we scheduled a time to meet, to do a planning session about the Vicky's trip. So that was one of the thing was let's actually schedule a time to have a focused conversation about Vicky's trip versus just sort of like talking about it casually.

Liz Lightfoot ([00:26:07](#)):

Right. So it was, you made an actual appointment.

Sharyn Dezelar ([00:26:10](#)):

Yes. We made an appointment to plan Vicky's trip.

Liz Lightfoot ([00:26:14](#)):

And where you were involved in that.

Sharyn Dezelar ([00:26:15](#)):

And I helped facilitate and support that appointment.

Liz Lightfoot ([00:26:18](#)):

Okay.

Sharyn Dezelar ([00:26:18](#)):

So that was one of the goal steps. The other one was that Jessica was going to call, make a phone call to the County that they lived in a children's mental health services and ask about, um, how she could be connected. So basically, you know, contacting that, that initial front door services, which are what some counties call it, their front door services. So just to make that call and to ask. Like, she didn't need to get

appointments scheduled or anything. It was just this one doable thing. You'd make this initial call to ask about getting connected with services and, and just learn about what are her next steps. So those were the goal steps that she identified at that time.

Liz Lightfoot ([00:27:01](#)):

So then afterwards, um, so sometimes in other types of person centered planning, it sort of ends there, but for the parent centered planning, we have some follow-ups. So can you tell us what the follow-ups were like or are like?

Sharyn Dezelar ([00:27:15](#)):

Yeah. So there was a little bit of variation based on the family's needs and goals, but typically there was an additional one or two meetings that happened that were continuations in a way of that parent centered planning meeting. Um, in this case, one of those was that planned meeting about let's plan for Vicky's vacation. And so that was one of those. It was, it was very, um, it had a specific purpose. In some other cases, those meetings might have been, uh, an opportunity for me to bring back some resources. So for example, if we had discussed what independent living services are or what, um, adult rehabilitative mental health services are, if we had discussed those things in the intervention meeting, and I had presented those as options, some families didn't know what those things were and were not connected to those services. And so then we would schedule that follow-up meeting and then I would bring them information about that. I would bring them like the phone numbers to contact and, you know, sort of how to start to get connected.

Liz Lightfoot ([00:28:20](#)):

So they would have ideas about what kinds of support they might need, but they didn't know what, what services existed, is that right?

Sharyn Dezelar ([00:28:28](#)):

Right. So those things came out of that parent-centered planning process, right. When we kind of identified what the goals are and then break that down into, what supports and services do you need to help you to meet your goals? Um, some people weren't aware of what those were, and also because I don't know ahead of time what the parents' goals are going to be. I couldn't call them with that information and to do at that time. So we would schedule a future meeting that was usually done within one or two weeks, because that was often tied to their goal steps. So I tried to go back out pretty quickly so that people could then make the, make that bold step because now they'd have the information and sometimes they had already made the step. And so then that was the second step, right?

Sharyn Dezelar ([00:29:12](#)):

So I may meet with people one or two times, following that initial parent centered intervention meeting. Then with this intervention, we did have a planned three months meeting again, and now this three months later meeting brings the team back together. And so this, those one or two meetings that happen after might have been with just me and the parent, depending on the situation and the need, right. But this three month meeting then involved bringing those other support people, all the support, people back together and reviewing, where are we at now? And we would update the goals and set new goal steps, right. And new action steps, because within three months time, we would have hoped that some of those, you know, three months steps that we had identified would have been accomplished. So in this case at the three months meeting, both Vicki and, um, Pedro were there again.

Sharyn Dezelar ([00:30:09](#)):

So her support continued. Right. And so that was, um, how, how it worked for this family.

Liz Lightfoot ([00:30:16](#)):

Okay. And how were they doing it?

Sharyn Dezelar ([00:30:19](#)):

Right. Well, at the, at the three month point, it was, you know, reported that, um, the trip went fine. They didn't really, they kind of wanted to move on, didn't want to discuss it too much, which gave me the impression that perhaps there were a couple of challenges, but nothing so severe that it needed, they needed to rehash it to address it. And, and we were able to, um, I'll back up just for a moment when we did have that meeting, where we planned Vicky's trip, we were able to pull in additional supports for that time. Um, and in fact, we asked, had come up with the plan and then Jessica had asked Pedro to check in with her regularly on that trip. That was not normally something that he would have done. Um, and so they had planned, she had asked him to please call her and check in on them every day in case that way, if she was having a really, really bad day, he could come and, um, be there for Bea.

Liz Lightfoot ([00:31:15](#)):

Sounds like a reasonable plan.

Sharyn DeZelar ([00:31:16](#)):

Right, right. So that was what had happened. So at this three months meeting, we followed up on that a little bit, but not too extensively. Um, we did have some follow-up about the mental health goal for Bea. Um, there was really, uh, some challenges with that while Jessica would state, and I would certainly agree that she followed through, um, she made calls to the, um, get connected with chil children's mental health case management at the County. And she did have, um, an assigned worker who gave her a bunch of resources and referrals for getting some assessments done for Bea.

Sharyn DeZelar ([00:31:57](#)):

And I think also there was some insurance things that needed to be straightened out based on some complications with the health insurance. And so the worker was, you know, sort of giving her some things to, to follow up with on that so that they could get Bea involved in mental health services. From Jessica's perspective, the information was provided to her in a way that she was not able to follow through with, um, she would be given lists of potential clinics she could reach out to that were printed off. The internet font size was inconsistent, often, very small, pages weren't numbered. And so sometimes the phone number would be on the page after the page that listed who she was supposed to call. And that was really a challenge for Jessica because organization and paperwork is really something that she struggles with. And so the way that this stuff was provided to her was not done in a way that she could follow through with. And she indicates that she stated this, she said that she needed more help than that. She was very excited about the idea of case management, children's mental health case management. Cause she felt that's what she needed. She needed somebody to help her organize and manage it. And what she felt like she received were just like directives of what to do, versus any sort of support or skills. And she didn't feel like those was, were accommodated based on her disability based on her cognitive needs. Um,

Liz Lightfoot ([00:33:29](#)):

So the material or the resources she was giving given weren't in an accessible format to her. She wasn't asked what her accommodation needs were.

Sharyn DeZelar ([00:33:40](#)):

She was not, it was also not visually accessible as a result of this injury. She struggles with some visual impairments and she literally couldn't see some of the fine print. She could not read it.

New Speaker ([00:33:51](#)):

And yeah, and I mean, there have been guidances from the Department of Justice and the Department of Health and Human Services requiring child protection offices to make sure that their services are accessible under the Americans with Disabilities Act. But I think this information, somehow isn't reaching everyone at the street level the implementors of these policies. And this is a really great example of this. So someone who, who even asks for a comp, she might not have used the right terms.

Sharyn DeZelar ([00:34:24](#)):

She may not have

Liz Lightfoot ([00:34:25](#)):

Like I need accommodations, but this is something that it's the child protection agency's responsibility.

Sharyn DeZelar ([00:34:30](#)):

Right. So she's indicating that she, um,

New Speaker ([00:34:33](#)):

I guess this is children's mental health.

Sharyn DeZelar ([00:34:34](#)):

Yeah, this is children's mental health case management, but it's County, it's still County services that she saw it herself she's voluntarily seeking support and help. And so what she indicates to me is that she tells them I can't do this. I can't make these calls. I can't keep this straight. I'm not sure what I'm supposed to do. And her perspective is that the response she receives on this is very judgemental and, uh, including with a negative tone, indicating that she's not being compliant. She asked for these services and yet she's not following through. They also, you know, don't know that these words were used, but she's indicating that she felt like they were questioning her ability to be the parent because she couldn't follow through on this. And.

Liz Lightfoot ([00:35:20](#)):

That can be really scary for a parent where you think the County services are questioning your ability to parent.

Sharyn DeZelar ([00:35:26](#)):

Exactly. And Jessica being a previously very competent professional, who knows a lot about healthcare systems knows how to advocate for herself. And she asked to speak to a manager, um, and, and she did,

and she was explaining what had happened and how she wasn't, that the services weren't helpful that she reached out because she needed help. And she didn't feel like she was getting help. She felt like she was getting, um, more challenges rather than help. And so according to Jessica, this manager indicated that Jessica should be using her independent living services worker, ILS worker, to help her with this organization. So um an independent living skills worker is someone who does help with an individual with disabilities on a number of tasks. Um, it can include organization of paperwork and scheduling of appointments and keeping track of those things. However, the way that those services are well, the way that they're billed and the way that, the way that they're funded. And, um, the, the policies related to that is that it all has to do with the individual who has the disability. So they were for her own appointments,

Liz Lightfoot ([00:36:37](#)):

Not for, not for her parenting, her child.

Sharyn DeZelar ([00:36:40](#)):

Right, not for For her daughter's appointments. It's, it's very clear that the services are for the individual, with a disability. And so, and Jessica knew this, she knew that this worker was not supposed to help her with that. She had a really good relationship with her ILS worker. They had been working together for about five years and they had a good supportive relationship. And this worker would, you know, not to get anyone in trouble here, but at times go outside of that, just to say, well here, why don't you make this call first? Right. If it had something to do with the daughter, you know, just to, um, she wouldn't make those calls for her. She, because she needed to draw that boundary. Right. Whereas if it's about Jessica, she could take that advocacy role, but she did give some guidance as somebody who knows the system, at the same time, that's not in her role. And clearly this manager of the children's mental health services did not know that it was not aware that disability services do not look at parenting. They don't recognize parenting as one of those

Liz Lightfoot ([00:37:41](#)):

Major,

Sharyn DeZelar ([00:37:42](#)):

Major life functions that need support, um,

Liz Lightfoot ([00:37:46](#)):

Which is a big issue. You know, one of the largest issues in supporting parents with disabilities is that we don't have funding streams to support parents with disabilities.

Sharyn DeZelar ([00:37:57](#)):

We don't, the services are very siloed. There's the services for children and the services for parenting. And then in a, you know, completely separate policies, rules, and funding or services for disabilities. And the two just don't, and nor are they aware of each other, because again, here's what we're talking about. A County social services manager thought that the disability services should be helping her with this. When Jessica reached out to the County for help with that. Right. Because she knew her disability services could not do that. And so that's exactly the service she was seeking. And, and she was, she was terminated from the services. So because she was deemed non-compliant and so she just indicated just

how she was judged and treated was really a challenge. So this was one of her major goals and it was a big roadblock to getting those services. This is at the three month followup point

Liz Lightfoot ([00:38:51](#)):

So by the six month follow-up were there, were there any, any more steps towards her goals?

Sharyn DeZelar ([00:38:59](#)):

Yeah. Um, she, she was able to get, be connected with some mental health services. And what had happened is since the new school year started, so all of the, like roughly August, everything fell apart with the County services. And so because Bea, um, was in a traditional middle school, many middle schools have school-based mental health services and clinics. And so we all kind of discussed that. Well, now that we're almost to September anyways, but when the school year starts get her connected that way the insurance issue is still unresolved. So she still needed support with that. Because again, she didn't, you know, get that resolved. She needed to enroll, um, be in some county-based insurance because Jessica had insurance connected through her social security disability. And so she needed to get Bea, Bea was actually uninsured. And I didn't, we didn't know until I came, I came up through this, so that still needed to be resolved.

Sharyn DeZelar ([00:40:00](#)):

And so it became, well, let's just use the school-based services. And so when at the six month follow-up, it had been Bea had been receiving those services for a couple of months. And Jessica reported that the school social worker, which wasn't the person providing the services for Bea, but the school social worker was sort of overseeing it and organizing it and, and following up with Jessica and serving that role that Jessica needed. And she felt like that relationship was a positive relationship with that school social worker. She didn't feel that the school social worker judged her negatively for her needs, for support, which she did feel with the County. So it wasn't to a point to report a significant symptom reduction for Bea. At this point, she was really struggling with depression and staying focused in school. And, but she was, at least she was getting services. Somebody was, she was meeting with a therapist with a therapist regularly. The social worker was involved at the school and paying attention. So Jessica felt good.

Liz Lightfoot ([00:41:03](#)):

Good. And what about the relationship with her mother?

Sharyn DeZelar ([00:41:06](#)):

Yeah, so that was another thing that required a, uh, a meeting, a separate meeting. And so I, um, we scheduled a meeting to talk with just Jessica and Vicky about their relationship. And so I went and did a visit again with them, and we talked about that and in a way it was a, like a one time sort of lighter counseling session in a sense which I have experienced having been an outpatient mental therapist. So I felt comfortable doing that with them. But also recognizing that it wasn't my role to do that in an ongoing way, but it was sort of a, like a one time session where we got to talk about things. And if it would have seemed that ongoing family counseling would have been a good idea, we could have made those referrals, right? Like that would have been another service we would have tried to connect with.

Sharyn DeZelar ([00:42:00](#)):

So, as I had mentioned previously with the story, um, there was really a lot of resentment, a lot of sadness, and you could just feel the tension in the room or in the home, just anytime being there, you could tell that there was a lot of caring and they just really had not spoken directly to each other about those feelings and acknowledged those feelings. They did acknowledge some loss and some changes. I think it was really helpful for Vicky to hear from Jessica, just how much she does appreciate her. And also just that awareness that her emotions are completely dysregulated and that she acknowledges that she does, for example, yell at her mother or be very harsh with her and very demanding with her and that she feels terribly that she does that. And she recognizes that she can't control it. It was really helpful for Vicky to hear that, to hear that Jessica knows that she's doing this and that she wishes she wasn't doing it.

Sharyn DeZelar ([00:42:56](#)):

And so it really provided Vicky and opportunity. And I think she did in the first place, but it was even more so to recognize that as a disability-like symptom, rather than something that was part of Jessica's personality, right? Like this was a disability symptom. So this was something that happened around the time of the three-month follow-up that we had that conversation because it wasn't one of the two goals that were identified to work on immediately. So at the six month appointment, they talked about, you know, the level of support is really pretty much the same, but they did think that perhaps the arguments had been less intense because Vicky's walking away. And so Vicky is when Jessica is lashing out, Vicky's just leaving the room and she's recognizing it as, this isn't my daughter trying to argue with me, this is the emotional dysregulation.

Sharyn DeZelar ([00:43:47](#)):

That is a symptom of my daughter's traumatic brain injury. And so she just walked away. And then even at that six month appointment follow-up appointment, it was almost even another, a little bit of a mini counseling session again, where, um, Jessica acknowledges that Vicky is doing that. She thanks her for doing that. And she says that that's what it's going to take because she doesn't think she has the skills to not do it. She's like, it's going to take you just walking away. So even if I'm yelling at you for walking away at the time, which is, was happening, you know, this is what, um, Jessica's saying, you know, even if I'm yelling at you as you're leaving the room, like, why are you leaving? We need to talk about this. You're doing the right thing by leaving. And so that was really affirming, I think for Vicky.

New Speaker ([00:44:28](#)):

Yeah that sounds very insightful too.

Sharyn DeZelar ([00:44:29](#)):

Yeah, it is mean I was just so impressed with Jessica's insight and her skills. It was just really challenging and sad to just see the impact of that. Just such a significant traumatic injury and how that can really change someone and change someone's functioning when they're still a lot of who they always were there. And then there's just this complete loss of skills in some areas,

Liz Lightfoot ([00:44:58](#)):

But it seems like they're able to, they're, they're co coming up with a new normal for, for themselves and how they're gonna work together to raise that girl.

Sharyn DeZelar ([00:45:09](#)):

Right. To raise that girl. And I, and I think really, um, th the situation seems manageable and doable. I'm not sure how it's going to look for Jessica. Once Bea is no longer a child or no longer needs to live in the home, because right now they're sort of rallying around Bea and rallying together for Bea, which is good, right. Which isn't, which is great. Um, that's down the road, but I could see that being a transition that could be very challenging for this family. And if there were this type of service in the community, that would be another possible planning, planning, planning session, or planning time for this family to figure out, you know. It's a new transition.

Liz Lightfoot ([00:45:50](#)):

So like sort of taking a step back, um, in this project, we had 13 different families participate in this, and, you know, we can't talk about all of them, but what sort of strikes you as the person who did all these interventions, what were the greatest needs for the parents with disabilities who participated in this project?

Sharyn DeZelar ([00:46:13](#)):

Yeah, well, one, we mentioned earlier, which was the lack of support overall, and just how limited the support networks were for many of the families just limited in number and how isolated some people were. And related to that is a second area that I, that really struck me was those kind of fuzzy lines between formal and informal supports. So a lot of people identified like their paid staff as some of their primary support people for parenting. And as I mentioned, paid staff for disabilities, really, aren't supposed to be doing that. I mean, it's great that people are seeing the family unit. And some people had been like a direct support professional for someone for like three or four years. So they do become friends in a way, but it's still, um, there's still some recognition that the person is still paid to be there,

New Speaker ([00:47:06](#)):

Paid friends,

Sharyn DeZelar ([00:47:07](#)):

They're paid friends. So what if they leave that job? Are they still their friends or are they still that support person for parenting? And in some of our families, some of those relationships fell apart during the course of the intervention. So people who had identified, paid staff as support, and then those person left those jobs and there's, you know, then they lost that support for parenting. Another one that was really challenging to hear is one person, you know, indicated one of her paid support people as like her best friend, but then also felt like that she wasn't really doing her job. Like she was coming over and just sort of hanging out. And she actually needed things that needed to get done. And this person wasn't doing them because they were friends. So she was hanging out and watching soap operas with her. And it felt she felt stressed to push the person to help her with the duties because she didn't want to lose the friendship. Yeah. It was just really messy and fuzzy. And then how that played into supporting parenting as was really a challenge.

Liz Lightfoot ([00:48:10](#)):

Yeah. And that's one of the reasons people push for the natural supports because they are not, they're not paid supports, but can, it's easier said than done. And as we saw it in these families, most of them did have very few non-paid supports.

Sharyn DeZelar ([00:48:26](#)):

Right. Um, one of the things that was an interesting outcome overall, I know this is jumping ahead a little bit, but in a couple of families, we were able to support those informal support network people to become paid. So there was more than one example where an immediate family member was providing a lot of support and the perse. And we were able to get that person enrolled as like a personal care attendant for that person. So that then that improved those relationships because then they were compensated for all the work that they were doing. So,

New Speaker ([00:48:59](#)):

which is different,

Sharyn DeZelar ([00:49:00](#)):

it's still a fuzzy boundary, but it was different,

New Speaker ([00:49:03](#)):

a different type of fuzzy, boundary.

Sharyn DeZelar ([00:49:05](#)):

It was an intentional, okay. So another area that is a really great need that we found, uh, we were really surprised at the high percentage of co-occurring mental illness diagnoses. Um, in fact, it was over three-fourths of our participants had also had a diagnosis of a mental illness

Liz Lightfoot ([00:49:26](#)):

And the people were participants in the study. They qualified because they were either had a intellectual or developmental disability or,

Liz Lightfoot ([00:49:35](#)):

Or physical disability.

Sharyn DeZelar ([00:49:36](#)):

Right. So the mental illness, wasn't the qualifying reason while we certainly know some mental illness can be disabling. And some of, um, some of our participants did have diagnoses severe enough to be considered a mental health disability. However, that wasn't what qualified them for the study. So I think it just really speaks to this just significant mental illness within this population.

Liz Lightfoot ([00:49:58](#)):

And were most of the people receiving supports?

Sharyn DeZelar ([00:50:01](#)):

It was mixed. Um, some people were connected to services such as psychiatry, or we're seeing a regular outpatient therapist weekly, or an in-home therapist weekly, and some participants were not receiving any supports or services at all. Um, of a lot of those folks, they, they did mention having specific diagnoses, like they previously had been connected to services, they received the official diagnosis. And often when they took on the role of parenting, they lost those services.

Liz Lightfoot ([00:50:36](#)):

Why do you think they lost them? Like they were too busy or

Sharyn DeZelar ([00:50:39](#)):

Right. Well, some of it was focusing on the parenting role and putting more attention on their children than on themselves. And so they just sort of.

Liz Lightfoot ([00:50:46](#)):

A typical parent thing naturally.

Sharyn DeZelar ([00:50:47](#)):

Right, right. So they just sort of stopped going. But also some of it is that maybe those supports aren't accommodating if they have very few supports overall, and now they have a toddler, right. They'd have to bring their toddler with them to their therapy session. And that does not work.

New Speaker ([00:51:01](#)):

Right. Or have somebody to care for the toddler, which if they don't have a support network,

Sharyn DeZelar ([00:51:06](#)):

If they don't have a support network, they don't have anybody to care for the toddler. Right. So that was just an interesting example. And some people were connected to some services, but maybe not all of the services they could receive. For example, there was one participant that used to receive ARMS services, adult rehabilitative, mental health services. He did continue to receive psychiatry, but had fallen off with ARMS and he wanted to reconnect with ARMS. And then he did as part of the intervention. So that was one of our, you know, real successful outcomes was getting people reconnected to those services of which a lot of which were mental health services that they maybe had lost or had never participated in.

Liz Lightfoot ([00:51:46](#)):

So what about the other disability services? Did you find that people were receiving those types of services?

Sharyn DeZelar ([00:51:52](#)):

Yeah. Again, some people were connected to independent living services, that area outside of mental health services that we saw the biggest increase in service connection to was vocational rehabilitation services. So a lot of folks had identified when we talked about their dreams and their positive and possible goals for one year, a lot of people identified some sort of employment activity and it might have been even something along the lines of, I want to start volunteering or I want to find a training program. And so, um, they were very realistic goals, but that was again, outside of mental health services. That was the area, the biggest area where people had not been receiving those services. And then they got connected with them. And then at the six month point, were still working with them and had made progress, you know, perhaps conducted some assessments. One participant had completed a job shadowing that was sponsored by vocational rehab. And then right after the six month appointment, which he was about to start up a part-time supported employment position and that came out of the intervention and the goals.

Liz Lightfoot ([00:53:04](#)):

So how do you think participating? I mean, just from your impressions, how do you think participating in this process was helpful to the parents? I mean, I know that's sort of a broad question and you just gave one example, but

Sharyn DeZelar ([00:53:19](#)):

Right. Yeah. So definitely, um, taking action towards achieving goals, pretty much every family with the exception of one took action towards their goals. Okay. Um, right. And a variety of the goals. So that's pretty good. That's pretty good. And those goals may have been including connections to services like I've just been talking about, but some of those goals also included, um, reducing their isolation. They wanted to make friends, they wanted to have their children involved and, you know, they wanted to not have their isolation negatively impact their children so much. So for example, well, the example I gave of the child and the mom that live in the disability high rise, where there was no kids, she was able, she actually enrolled him in two regularly scheduled community activities because there was no children for him to play with. So he, um, became enrolled in Boy Scouts and he was participating in Boy Scouts every week.

Sharyn DeZelar ([00:54:13](#)):

And then she also, um, had him in a park and rec soccer program. So, right. And so up until that point, he hadn't been doing any community activities. And then she also saw this very insightfully as a way for her to make friends that are parents, because she had to bring, you know, like who are the other moms of the Boy Scouts, right. Like when the, you know, so this was a way for her to meet some, some parenting friends so that some parents,

Liz Lightfoot ([00:54:42](#)):

Good example.

Sharyn DeZelar ([00:54:43](#)):

Yeah. Yeah. So those are some of the examples of the action towards goals, as already mentioned, increasing connection to services, both mental health, as well as disability services. And then the other real area that we saw, the planning process was really helpful to the parents and their family was improving and clarifying those supportive relationships. This is really, um, highlighted in the case example we gave with Jessica and her mom, Vicky, and how the process really helped them have some clarifying of needs and where help is wanted.

Sharyn DeZelar ([00:55:17](#)):

Um, at times Jessica felt that Vicki took over and was helpful, like too helpful. Um, but sometimes she really needed the help, but on days that she was doing well, she wanted to do it. And so she was able to voice that to Vicky and Vicky was able to recognize when Jessica was doing well and just back off and consider it, Hey, I got a free day to myself. She doesn't need me today and she could go do something else. So that was good. And that really supported independence for Jessica as well as others. So there's other families where there was a similar pattern where if the parent with the disability had a lot of support from their parents. So from the grandparents, a lot of times they wanted more independence. Like they recognize they wanted the support, but they wanted more independence. And so by talking

about that, the grandparents were able to back off in some situations and everybody felt good about that.

Sharyn DeZelar ([00:56:08](#)):

Grandparents felt good about that too. They got to be grandparents again instead of primary caregivers. Right. So that was really helpful with those boundaries. We also did have a couple of families, you know, initially it seemed like a reduction in number of supportive relationships from people who were identified at the intake, like here's my group of friends. And then throughout the course of the intervention, um, they reported that they were no longer friends with certain people. So while that might seem like a reduction, part of the facilitated discussion about who your support network is and how those people support you kind of brought forward that some of these relationships were not supportive or helpful. And in fact, somewhere unhealthy and were draining, um, one participant realized that two of her friendships, she was always giving and they were never there for her. Um, she was taking care of their kids when they had appointments.

Sharyn DeZelar ([00:57:01](#)):

And then through this process, she specifically had reached out to someone to arrange childcare for a significant medical appointment that she had, and then it fell through and she had to cancel the appointment last minute because the person didn't show. And so she realized that these are actually not supportive and helpful people, and it felt very freeing and helpful for her to kind of eliminate those people as supports because she was giving so much including money. In some cases, some of the people it appeared almost were being taken advantage of financially. And so by cutting those people out, their situation was better.

Liz Lightfoot ([00:57:37](#)):

That's good. Yeah. That could be helpful, helpful to figure out these more healthy boundaries and determining who's, who's actually supportive and who isn't. So for, you know, when you were doing these, you're, you're obviously a really experienced social worker, you're a licensed clinical social worker. You have many years of social work practice, and personal experience with disability and variance in a wide range of types of social services. So you're really the ideal person for carrying for carrying this out because you can be helpful, you know, lots of community resources, but you also have clinical skills, like when you were talking about with Jessica. So how do you, I mean, I think you were the ideal person, but how do you think your social work experience helped you with doing the parent-centered planning intervention?

Sharyn DeZelar ([00:58:28](#)):

Yeah, well, um, you know, thank you for saying that about my skillset and my experience. At the same time, I think other social workers can do it too. It's really the social work skills. It's the social work skillset. So we're really meeting people where they are at. And I think, you know, using the story of Jessica and how, I mean, you know, I don't know if this manager of the children's mental health services was a social worker or not. She appeared very judgmental about the fact that Jessica had some challenges and that if that made her suitable to be a parent, right, right. And we know all parents need support to parent, right. Disability or not, all parents need support and help. And, um, that whole, it takes a village concept. And so being able to meet people where they're at and then see them in that strengths-based way, recognizing the strengths that they have for parenting the skill set they have towards meeting their goals.

Sharyn DeZelar ([00:59:23](#)):

This is sort of some of our, um, Social Work 101, like, I mean, this is how we approach working with people. And so that's a really important piece. I think, in working with this population and in doing this intervention specifically. Additionally knowledge of the resource system, how service systems work, how to help people get connected to resources, linking people, advocating for people. Again, these are some of these core social work functions, and that was really needed in many of these cases of which I explained with Jessica specifically how that came up, but that was pretty commonly the case that people needed some assistance with knowing what resources were out there, how do they get connected with the resources and then that follow up.

Liz Lightfoot ([01:00:06](#)):

So you, you function both as a facilitator because as a general person-centered planning model, the person running the group has a facilitator.

Sharyn DeZelar ([01:00:15](#)):

Correct.

Liz Lightfoot ([01:00:15](#)):

But in this version of it, you were the facilitator. You weren't doing social work assessments or making, helping them make goals or plans or giving them ideas for what they wanted to do. But when they came up with their ideas, then you could help with your knowledge of the system, and what types of supports.

Sharyn DeZelar ([01:00:35](#)):

Right. So it was very important to make sure that the goals were directed by the family, but then if they needed assistance breaking those down into steps or recognizing what resources might be needed to realize those goals, then it, it did take on a little bit of a case management role and families were aware from the start that it was time limited. Like they, they knew that it was all about going through this goal setting process and that I would help them through that process. But I'm not like a long-term case manager for parenting, right. I mean, because that's not the term, it's a short, it's a short term intervention, but there was a lot of case management, like tasks, referrals, um, researching resources, referrals following up. Um, I did very little advocacy with other social service systems. I really tried to put all of those skills onto the person to be, or their support people to be able to do that for themselves. But I did give people a lot of resources and help them break it down and told them, I told them how to do it. And sometimes sat there while they did it, but they, I didn't do it for them. I didn't call County workers for them.

Liz Lightfoot ([01:01:43](#)):

So do you think having a trained social worker is essential for facilitating this type of parent-centered planning intervention?

Sharyn DeZelar ([01:01:53](#)):

Absolutely. As mentioned previously, that social worker skillset was really important. And also as in the example of Jessica, there were times when the meetings almost turned into like a light counseling or like a brief counseling. So having those skills to be able to facilitate healthy discussion between family

members about challenges and expressing feelings and making sure multiple voices are heard, um, you know, is, is very much a counseling activity, a therapeutic activity in a sense, right.

Liz Lightfoot ([01:02:28](#)):

You know, this was a short-term intervention. It's not a long term intervention. So it's conceivable that some organizations that provide services to people with disabilities who might happen to be parents or organizations that do support parents with disabilities, specifically, there aren't that many of those, but that they could consider offering parent-centered planning for parents with disabilities. What advice would you have for an organization or a social service organization that was thinking of doing this?

Sharyn DeZelar ([01:02:59](#)):

Yeah, well, I definitely think that organizations should seriously consider taking this on as a role and it could fit within an existing staff or could fit within an existing case management type role, for example, or a disability services role. Because as social workers, like we're used to wearing lots of different hats as we work with folks. And so it could be discussed, you know, okay, now I'm going to facilitate, you know, like you said, using the facilitator role, we're going to facilitate this parent-centered planning model. And you can do that with, you know, kind of embedded within other case management services or other types of services. I think it's really important that some, uh, you know, some groups take this on because as you mentioned, there aren't services specifically for parents with disabilities. There's very few scattered across the country, you know, and within larger metropolitan areas, such as we're in, there's really nothing that's specific for that population.

Sharyn DeZelar ([01:03:57](#)):

And, you know, it's definitely something that is needed. Um, Jessica's example really highlights how siloed those services are. Services for disabilities and services for parents are just not interacting at all and working together and not even aware what the other is doing. So I think for, you know, disability services to really take that role on to me, seems like a really good fit, recognizing the individuals with disabilities that they're working with as whole people and as members of families and as caregivers themselves, not always as people receiving care giving, right. And that sometimes are caregivers themselves. And that's part of who they are as a whole person and that we can support. We can support that.

Liz Lightfoot ([01:04:38](#)):

Well, that seems like a really sort of good way to end our discussion here. Do you have any final words?

Sharyn DeZelar ([01:04:45](#)):

Well, I just really would like to, um, put the call out to our disability service system to begin to recognize people with disabilities as parents and their parenting role as part of who they are as a whole person. I think that's a growth area for disability services. I also think that services that work with families and services that are directed towards children need to have greater awareness of disability issues and recognizing the requirements to provide accommodations. I mean, the Americans with Disabilities Act requires this and that they need to be providing accommodations and that it's not a burden to do so. It should be done because these are people and these are parents and it's best for kids to be with their parents, right? Like research has shown it's best for kids to be with their parents. So we should be able to provide support to families, to be able to stay together, providing support to parents, to be able to be

the best parents they can. And it just really seems like some of our services have a long way to go in learning and understanding that.

Liz Lightfoot ([01:05:48](#)):

It also seems to me, you know, we're both social work professors that this is something that we might want to embed more in our social work education, where we're looking at parents as whole people.

Sharyn DeZelar ([01:06:01](#)):

Right. We're looking at parents as whole people. And we're looking at people with disabilities as whole people.

Liz Lightfoot ([01:06:06](#)):

and people with disabilities as possible parents,

Sharyn DeZelar ([01:06:07](#)):

not just as clients that need caregiving, but also people that might be in a caregiving role. Definitely.

Liz Lightfoot ([01:06:14](#)):

Right. Well, I want to thank you very much for coming and sharing your experiences in this project. And I hope that people listening will think of ways that they might be able to incorporate parts of this model or the entire model into their service system.

Sharyn DeZelar ([01:06:31](#)):

Yeah. You're welcome. Thanks. It's been a pleasure.

Liz Lightfoot ([01:06:33](#)):

Yes. Goodbye.

Speaker 4 ([01:06:36](#)):

This podcast was supported in part by a grant from the Minnesota department of human services, children and family services division.