

Genia: Welcome to the Good Things In Life Podcast. I'm your host, Genia Stephen. The Good Things in Life podcast helps parents of children with intellectual disabilities support their kids to build good lives in community - inclusive education, friendships, and belonging. In this episode of the podcast I am speaking with Ben Drew from Open Future Learning. Open Future Learning is an online education platform for support workers. If you haven't seen Open Future Learning's social media posts, you should definitely check them out. The link is in the show notes. The posts and educational opportunities are thought provoking and often really funny.

Genia: Ok. Before we dive into this episode, which is part one of a two-part interview, I'm going to ask a multiple choice question. I want you to write down your answer.

Genia: When hiring support workers for people with significant disabilities it is important that:

- A. They have a lot of experience and training in the field.
- B. They are knowledgeable about the disability the person has.
- C. They have a background in social work.
- D. They have a background in social work.

Genia: Do you have your answer? Ok. Let's dive in.

Genia: Ben, thank you so much for joining me today on the Good Things in Life Podcast. I'm thrilled that you are here to talk about, um, support workers, supporters, um, and uh, and just, you know, thinking about how we provide support to people with intellectual disabilities in a way that is really about the person and about supporting the person to have, um, you know, a good life and access to the good things in life and, um, to be living their life in community. It's a really important, um, topic and I know it's one that many, many families and organizations struggle with. So thank you for being here today.

Ben: Thank you, Genia. Thank you for having me. And before we get started, thank you for everything that you do and I'm sure, and this is a really valuable resource and thank you for making it available to people.

Genia: Yeah, I appreciate that. So I wonder if you could start by talking about your background, your experience with people with disabilities and their families and then, um, you know, how that evolved into the work that you're doing now.

Ben: So, um, when I was at school, I, I struggled quite a bit and I think if I went, if I was at school now, I probably would have some labels or diagnosis maybe. And um, that, that was, uh, one element that I think probably subconsciously got me interested in the work that we do. And then what happened beyond that was I grew up in a small village in the UK and there was a, um, on the outskirts of that village, there was a, a home or community actually a little bit like compare without the farm, a community for people with learning disabilities in the US. You, what kind of do you say developmental intellectual disabilities, in the UK we say learning disabilities or learning difficulties.

Ben: Um, and so there was this community of people on the outskirts of the village where I lived. And as it happened, my best friend at school, uh, he was living in that village. His parents help too, manage and run the community I guess. Um, so just through knowing him,

I was spending a lot of time around people with, with developmental disabilities and getting to know them without really ever thinking or really knowing that I had a disability. I knew, I guess I didn't at some stage I must have figured it out, you know, but it wasn't ever, um, it was never really a big deal. In fact, there was just a great thing that there was all these guys that you could play soccer where then we are automatically a soccer team at the drop of a hat.

Ben: And that was always fun, you know. And then what I would see was, you know, as I got older I'd see those occasionally they would come into the village to do their shopping. And um, I would see that my other friends who didn't know them reacted to them in a way, you're not going to see that. The way that I spoke about them and interacted with them was different. And sometimes, yeah, really disrespectful. Um, and I think not stayed with me as well. And then I ended up doing different things, you know, voluntary work and in the field. And working on a summer camp over here in the US.

Ben: And then eventually just really lucky too, then my first job, um, as a support worker after finishing school at, um, at 18 was, um, working for this incredible guy in the UK who was a real lead, is a real leader in our work. And he, from that point, he really mentored me. Um, and for that, you know, I'm eternally grateful because I think that gave me this incredible start. And subsequently in a, since that time I, I went and trained as a learning disability nurse and I saw terrible things. But I think because I always had that initial grounding and perspective, I could see everything in a different light.

Ben: And you know, managed to get through some really difficult experiences of working in places that weren't doing the right thing. And then eventually I ended up setting up my own organization in UK called Options where we help people to buy or rent their own homes, manage and control the support, some pay for their own support. Um, and, um, and then now, so about 11 years ago, I moved back to New York with my wife that was on a long term plan and seven years ago I established Open Future Learning. So that's, that's what I do now.

Genia: And can you tell us a little bit about Open Future Learning?

Ben: Sure. So we're an online learning resource, 100% dedicated to the field of developmental disabilities. Um, we, we try to actually help people to think beyond online learning, just being one person sat in front of a computer. Uh, that's definitely one way that you can digest our materials, whether you're on your phone or your tablet or your computer. But, um, we're also facilitating people to be able to learn in groups alongside the people that are supporting. Um, uh, and what we, what we're doing is we're collaborating with leading thinkers and advocates and families from all over the world and really helping to share their knowledge, their experiences, their stories, um, in a way that's financially efficient for learners and for organizations.

Genia: And so Open Future Learning, um, the, there seems to be in the materials that I have seen both on social media and, um, on the website and the presentations, um, or the videos that I have seen, seems to have a particular philosophical, um, approach. You know, like this is, uh, these videos are not about like how to take care of somebody well. There's definitely, um, a different approach to supporting people with disabilities to live good lives in community. And I wonder if you could talk a little bit about, about kind of where the, um, where you're coming from. Of course you've cover many, many, many different topics in the different videos, um, but there's, there's clearly a, um, perspective that ties them all together.

Ben: Yeah. I mean, we could probably talk for several days about this if we wanted to. Like, there's so much to it. Um, and I'm going to try not in this podcast. I'm going to try not to say the words person-centered and community too many times because I know that's like the, um, but yeah, I mean it's, there's so many pieces to what we do and to good support for people and the, the value, in a way we're a values-based resource. I think there's a little, well maybe you can think about. Um, what that means to people, I think it's quite hard sometimes to put your, your finger on and there's, you know, we can all use these, there's words that everybody uses, but the, the application of those words and what they really mean, that can change from person to person and from provider to provider.

Ben: Um, and I do sometimes feel it's a little bit like fridge magnets, you know, you can kind of arrange them in a different order. Um, and that's kind of what you see in our industry. Everybody saying the same words in a different order and it kind of loses its effectiveness half to fall because you know, everybody's executing on them in the same way. But, um, I mean, yeah, when we think about good support, there's, it's a, it's like a jigsaw puzzle. There's, there's a thousand pieces to it. What makes a good life for somebody? And that's what we're trying to, um, extricate, I'm thinking that word. Um, that's what we're trying to refine and um, communicate with it through our other source. Um, um, you know, we can go into that if you would like.

Genia: Yeah, I, yeah, I would like to, um, I just wanted to mention when you're talking about the avoiding the, uh, using words community and person-centered, there's one particular Open Future Learning social media posts that I really loved and it, there are several, but pertaining to this, it said something along the lines of if only, um, if only people's lives improved every time somebody said person-centered, you know, organizations use the term person-centered cause it really does get, um, everybody talks about it but not necessarily, you know, that doesn't necessarily translate into, um, effective supports for people, uh, or any actual person-centered kinds of approaches to supporting people to have good lives.

Genia: One of the things that I think is sort of a thread that I see running through the resources that Open Future Learning provides is, um, is sort of this idea that, um, we just shouldn't get weirded out and confused and take a different approach and track when thinking about the lives of people with disabilities compared to thinking about the lives of people without disabilities. Like basically just don't mess it up in the first place by getting all weird about it, right? Like the kinds of things, the kinds of things that are, make a good life for people with disabilities are not different than the kinds of things that make a good life for anybody else.

Ben: I was just thinking about this this morning, knowing I'm going to be talking to you and figuring that you would probably want to be talking about great support and what that means to people and it's kind of interesting when you muddle over these words and concepts and ideas in your head and then you think about what makes sense. You know, I was thinking about the two things, like what do people want in a support person? Um, and then how do we think about the people we support?

Ben: And how do families and providers need to be working with those support staff? And how do they need to be supporting that kid and the people that are supporting? I mean, these concepts, they're not, it's not like some kind of magical formula. Um, it's like what makes sense to you and your life, you know? Um, if we all the same words and theories and approaches that we use about the people we support, if we also applied those to the people

who are doing the work, we would really be doing a fantastic job of supporting those people and facilitate what they do.

Genia: Can you tell me a little bit more about that? I'm not sure I understand what you mean.

Ben: Well, you know, we want to be person-centered [inaudible]. That's a little counter for how many times we want to be person-centered with, um, the people that we're supporting. We spend a lot of time. Yeah, I'm thinking about the approaches and ways to think and plan. Well, same with families. We should be thinking about every person in that family in a person-centered way. I mean we have person-centered planning for the people we support. Um, but for support staff we should be helping to think about the support staff person in a person-centered way as well. What's going, you know, what are their needs and wishes? And what's going on in their life? And are we accommodating them in the right way?

Ben: I've seen it before, you get support staff person who's burnt out and they're struggling to make it through the week and nobody's sat down with them to say, um, you know, what could we do to make your life easier? And I remember when I was chatting to David Pitonyak, he was telling me this story about a lady who, I think she was consistently late to her, to her, the shift that she was supposed to be doing in a home and she'd been written up for, um, she was kind of begrudged by the other staff members who had to wait until she got there, until she could leave. It turned out and that she's trying to drop her kid off at daycare and then she's using public transport to rush through the city to get to the job.

Ben: And if all that she needed was a slightly different schedule and she just needed an understanding that she was, couldn't start the shift at the time that they wanted to have to start that shift. And um, and on Thursday nights, her son had soccer practice and that was really important to her that she was able to help us some to be able to go to soccer practice. And if we can kind of learn and understand the needs of the support person as well as we do the person who's receiving the support, everybody's going to win. We're going to have, I think they're just going to be happier and more satisfied in their lives. It's, um, in the same way that we, we talk a lot about listening to, um, the people that we're supporting. We need to be listening to everybody. I would suppose that.

Genia: Yeah. Yeah, that makes sense.

Ben: Um, in the same way that we need to be present when we're supporting people, we need to be present when we're interacting with families. And so all of these approaches, um, in a device to fail, dignity of risk, same for support staff, great organizations that support staff, be vulnerable, make mistakes, mess things up, you know. Um, they let that staff have that dignity, that and understand that they will, they're human and nothing's ever going to be perfect. Organizations that are doing the opposite of that gives a staff for the mornings when they make a matter, um, bring them in for supervision when something goes wrong in the community. Supervision in a good way. Um, so all of these concepts and approaches, they, it's just, it's interesting. Like very often when we film and record with leading thinkers in the field and I have, uh, film makers, they with me and audio people who had know nothing about our work that come out and go, "You know what, that's just incredible advice for life."

Genia: Right. Yeah.

Ben: [inaudible] so much from this in terms of just how I interact with my family, how I engage with my children, how I support my friends. So it's, I think sometimes we get a little bit lost in our kind of service line bubble and think that this is, it's all about the people we support and it doesn't, it's just, it's good for life. A lot of what we talk about, it doesn't matter who you're interacting with.

Genia: Right. Yeah. I think that's, I think that makes a lot of sense. And I, um, I think the good advice for life is a really great filter as well for figuring out are we, are we doing something that's weird service line bubble stuff ?or is this probably, you know, a solid core idea or principle, you know?

Ben: The stuff we get hung up on when I talked to my friends about it, who know nothing about our work, they just can't wrap their heads around it. Like, why is this so complicated? It doesn't makes common sense to anybody who's not involved in our work. Um, you know, we, we talk about, you know, see the gifts. Well, we've got to see the gifts in everybody, like that was great organizations and families see the gifts in the people who are coming in to do the job as well as the people that are supporting.

Genia: Yeah. Yeah. And what you're saying about, you know, seeing the gifts and about um, being person-centered, both those things really I think contribute to helping to, to an understanding of sort of interest-based supports. So the, what I see a lot of, so most of my audience is younger families, right? So there are probably, um, few, fewer people in my audience are going to be, um, have a lot of experience with like group homes or agency related kinds of, of issues. They're, um, you know, experiencing medical, um, model issues, school system issues.

Genia: Like those are the major systems that are um, involved. And one of the things that happens an awful lot is that when people are looking for supporters, they are often recruiting through a disability lens or a medical model lens for people who have, um, some background or knowledge with some sort of like service, kind of. Like what they have to offer is the servicey stuff. But you might get, you know, some middle-aged woman, um, who is a lovely, you know, a lovely human with um, you know, an education background, um, hired to support a kid whose primary interest is like basketball.

Ben: [inaudible] I mean when I was running, uh, Options in Bristol, from the very beginning and we had an incredible opportunity to start an organization with nobody. It was just me. So if I say we, that's me. I had incredible opportunity to start one person at a time. And I know this is kind of service line stuff because it's, this isn't the world that families are living in, they're not running organizations and then maybe not even interacting with service providers yet. But this applies to, you know, when they think about how they involve people in the crowd that the children. So how does some kind of opportunity to start from scratch? And one thing I knew I could not do and wasn't going to work, and I, I did try a couple of times and it really didn't work, was to recruit people who had any kind of experience in a field from the very beginning, really, purposely set out to recruit people with no experience because it's, I'm not going to say it's impossible, but it's very difficult to separate yourself from that experience and that perspective that you have once you've developed it.

Ben: And so, and that is a frightening concept for a lot of people. Um, social services when they were commissioning our services and we what supported some quite complex people. I mean in terms of their behavior and other things, um, the social services, they would say,

right, we have a referral for you and we just want to make sure that people that are going to be supporting this place and they're going to have experience, right. And I, we need people do your team here. They need to be, people have to wrap around this person. They need to have a lot of experience in doing this kind of work or supporting people with these kinds of needs. And I would just kind of nod my head then recruit, work on helping that person to recruit people who I had no experience because it always worked. But, and then we could.

Ben: And then what happened is you create this culture, the, initially we're providing a lot [inaudible] a lot of input and really intensive training. And, um, spending a lot of time with people about how they thought about their work and how they can think about the lives of the people that are supporting and the work that they do. And then an interesting thing happened was I noticed at some point, um, we still did that. But then at some point you develop this culture and everybody just starts, you have people join your organization and within a matter of days they're using all of the same words that everybody else uses. Because as humans, we're social. We're like sheep. You know, it just, you become the around you. And that was, that was an incredible thing to see people be like that. So I think for families, you want to try and replicate that and be what you want to see in the people who are supporting their kids. And it's your job to be that, like the culture that you, as it were. They're still, culture is still relevant I think even though you're not a support provider, I think it's still kind of develop.

Genia: Absolutely. Yup.

Ben: So in terms of how you think about your son and your daughter and how you want other people to think about them and you communicate that just in everything you say and do [inaudible] you find out the people assuming they don't have the preconceived ideas about how they're supposed to do the job and what it means to be supporting people, I think they just, they just would develop that, you know. But sometimes without even needing to physically kind of tell them, this is who I want and how I want you to support our son.

Genia: Yeah. Yeah. I think that that, I think you're absolutely right that families do need to be, um, conscious of, of the culture that they're creating. And one was small example of that is, um, you know, how you talk about the position, like the support position and how you talk about what it is that the person who requires support needs. So, you know, for example, you can talk about what the person needs in the way of like custodial care or in the, you know, interventions or the, the therapies or in what they can't do. Or you can talk about the need in, um, in the context of, you know, the person's, um, roles, you know.

Genia: So for example, um, you know, my son, Will, need some help in order to be able to connect with his friends at the skate park is very different than, you know, the kinds of, like if we talked about all the steps that were required in, in assertive, like micro custodial kind of way. And it frames also, I think, um, not just how people see their position and how they see what it means to be good support, but it also just frames whether or not they see the person as primarily a person or as primarily a service recipient.

Ben: And it's, but it's tough though. I mean, it's so tough because I'm in the life of a family who live in our community here and they, their son has autism and he's just started self-directing some of his own services. He's, he's 10 years old, I think. Um, and I'm, so I'm in his circle of support and we, I went to his folks meeting. Um, there's, you know, a number of other professionals there and bear in mind these people have already spent some considerable

amount of time into acting with the family and uh, that's on prior to this. And they have their own, they come with their own cultures at way. When they come into your home and they're using all these terms and um, already just the way that they think and refer to this family's son pushes in the opposite direction.

Ben: It's very easy, I think as a family, even if you already kind of have in your mind that those values and what you would want to see for your son in terms of gifts and capacities. And you could be quite strong on that, but it'd be quite easy to be pushed into the other direction. Even when we're talking about self-direction and a circle of support, um, on a circle meeting and they, I'm going to say like they came to the circle meeting. This is, we've got a broker, we've got the [inaudible], I don't even know what half these in at the service coordinator and it's called people and things like that. And but they'll, but different time. Really. This is now things are changing in the disability landscape, but these people are 40, 50, 60 years old and they're still using even though they're working now in a different framework.

Ben: And what it seems quite exciting, 11 year old kid who's directing his own support and [inaudible] life in a circle of support seems like an incredibly progressive thing. And then you have these people, they come in and we spend a great deal of time talking about what this young man wanted in his life and how people, maybe paid support people could help him to facilitate and achieve those things and his dreams and his goals. And at the second meeting, and I already noticed that the first meeting, that language was not in keeping with some of the things they were communicating, while in keeping with the progressive nature of the meeting. And then at the second meeting they arrived with what we've written out the, we've got all the paperwork here that the state needs and we just want to go through what we've got and just everybody agree on where we are with this.

Ben: And they were using words like, uh, habilitation and community integration. Um, you know, you just go through the, the fridge magnet list of, um, words [inaudible] and use in our field. And you know, I had to stop them at some point and say, "Hold on. You know, the person we are meeting with is 11 years old and regardless of his age, first of all, you're using words that I don't even entirely know what they mean. And I've been working this [inaudible] for like over 20 years and know, if you know, the expectation that families, you know, you could see how companies would start taking on this. It's not using these words. And just, um, you know, rather than just saying, um, this person, what it helped to be able to get together with, with his friends and pursue his interests in music or whatever it might be, not talking about, um, the language. It's just, it's just atrocious, you know? And they're stuck in that. And I actually say, well, I did, as I said, "How about we rewrite this and we use plain language and words that this boy is going to understand and the family's going to understand that everybody can use." And they said, "Well, hold on. But that's just not how we do it. I had to stay right and understand what you mean." And I said, if an 11 year old can get that, I think the state is going to be [inaudible]

Genia: Surely, yeah. Surely we can. Yeah. Yeah.

Ben: But that's not [inaudible].

Genia: And if we're going to influence change, if we're going to influence change by making somebody adapt to a different language that comes from a different culture, best to make the state stretch to adapt to a different framework and a different uh, direction.

Ben: [inaudible], you know, then they're going to work on finding people who can support him or that kind of, it was all, um, that's fantastic that you could see how quite easily, if you didn't continually, uh, recenter yourself, you could end up communicating the needs of your son in a different way to those people who come in the door and using a different form of language that is system-based, that is medical, that isn't focused on [inaudible] capacities, that looks, and then well, that ultimately is going to affect the kind of support that that person gets.

Genia: Yeah.

Ben: And it's back to that, like the thousand piece puzzle. I think we've got to try and get like every piece right. And this is something I really focused on when I was running Options in the UK was every single piece of this puzzle matters. We can't let up on a single piece. So the wording of the advert, the way that, um, if we're going to put an advert in a newspaper, the way that's worded, every word in that really matters. The way that, that very first communication with the person,

Ben: Um, every step in that process from them hearing about there's this opportunity to be in somebody's life, to them actually doing that. That all really matters. And we shouldn't, it seemed like I could just see this incredible opportunity with this 11 year old boy who's going to get wasted because we were, well at the very first step in his life was then, you know, starting to get services. I'm already going down this, this rat hole of, um, words and, um, ways of identifying him and what he needs and it's like, which is just completely contrary to what would, what it could be. Um, so I could see, I see the challenges for families.

Genia: Yeah. I think that the, well yeah, I have so many thoughts about this. I agree with you that it's a massive challenge to families and it's, um, and it's, it starts before families have even a chance to consider that it's happening. You know, like the, because they, they, when things initially, whether it's a sort of diagnosis at birth or, um, you know, a health issue or it's a developmental issue that, that comes up and, and appears over time. Um, the language and the, the weirdness lens immediately comes into effect. And you're talking about the puzzle, like the, all the thousand pieces of the puzzle have to be attended to and done right. And, and I, I agree with you, but I also think one of the things I've been thinking about a lot lately is just don't mess it up in the first place.

Genia: You know, like if we can just help people, help families to not, um, this is sort of like, this is aspirational, not, not practical. But if we can just help families to not change their perception of what their kids, who their kids are and what their kids need, and we're really just, um, working in service of figuring out how to get there, then it avoids so much. But then, it is aspirational because as I said, families, it just comes right away. You know? So one of the things that I've noticed, I'm, I'm a midwife. Um, and so I'm dealing with a lot of families that in the very beginning of their journey and even before, um, you know, And you know, I'm involved with lots of families that have had kids in the, um, neonatal intensive care unit. Right from word 'Go', families are being told that their, their kids and their kids' lives are somehow fundamentally different, um, and almost alien.

Genia: And then it just, that just opens the door then for all these other messages to land at, land and be absorbed. And I'm really hoping, one of the big reasons why I started Good Things in Life is because I wanted to have, um, create a space where people could be coming together around a shared vision of a good life for their kids as opposed to a place where people are

coming together around, you know, a shared diagnosis or treatment modality or that kind of thing. Because I think it's frames the conversations. And, um, what you were saying about having, um, but the, the family is sitting in this room and surrounded by these 10 service providers who are framing this conversation and it's shifting. Um, I think it's really important and valuable for families to have a place to gather with other people where the conversation gets recentered around just life.

Ben: Yeah. Well, it's all, it's all about balance, isn't it? Um, so I think when perspective, so we've got to be able to have that.

Genia: Yeah.

Ben: Yeah. It's easy to lose that, I think.

Genia: Yeah. Yeah. And it's not that the conversation about, it's not that, I don't think either one of us are saying that, um, there's never a place for a conversation about habilitation. Like that's not the point is that it's totally invalid. But the domination of the conversations outside of sort of typical conversations about, you know, what kids, what kids need and what makes for a good life is a fundamentally shifts.

Ben: Yeah. [inaudible] a little bit about how this is kind of trendy, uh, movement towards like, you know, the label. You know, you heard people are sort of afraid to like label and MSL disregarding it in the same breath. You see this lot from providers literally. Like, sometimes you'll see the, on their website like a liittle, a days are like scrubbing out the dis, you know?

Genia: Right. Yeah.

Ben: All we want to think about is your abilities, well, it's still, it just comes back to balance again. We need to look at and understand both, um, as much time as we spend focusing on capacity and what people can do and who they are as people. We also need to remember that the disability, it's more than a label. It's not just uh

Genia: Yeah, yeah. Yeah. I, yes.

Ben: Um, it's, you know, there's a reason what it takes. What's the saying? Um, labeled jars not people will. They [inaudible] to me recently he said the reason there's a label on the jar is so we know what's inside. And when, you know, the label of autism communicates a hell of a lot and we put a, spend the time to know and understand what that means in somebody's life. And it's the same, although I will, you know, I will say about them people are given labels that have very little meaning and people are labeled with things like challenging behavior or that's a different thing. But you know, when somebody has a disability, we need to spend time to get to know what that disability is, what it means, what it doesn't mean, and the person themselves should be supported to develop that understanding as well. Um, that, that's important that we, we don't just disregard it.

Genia: Yeah, I totally agree with you and I hope I wasn't implying that. I think that conversations need to ignore the reality of, of disability. Um, the, um, yeah, I don't think that at all. I do think that we are, we are, I think that the sort of like labeled jars not people and the scrubbing out of the disability, the dis when we're talking about disability and those kinds of

movements. It's almost like a pendulum swing in the opposite direction in an effort to, um, to uh, deal with the, the problem of being so impairment focused that you lose sight of a whole person.

Ben: We do that all the time. And uh, if you look at our work as a kind of an industry, um, I have more of a service provider lens. I think we do that all the time. We, we sort of, um, figured out one thing's bad and then [inaudible] a hundred miles an hour and it's like, um, we connect back to that word again, balance. Like we can, you know, we can, we can still consider it. Like it's very often people just want to, when they think about how people live in the community, and specifically I'm thinking now about housing. People just want, they want all the supposed specifically professionals I think in our work. They just want just give me one thing that I can hang on to and that is the right answer. And it doesn't work like that.

Genia: No it doesn't.

Ben: And it's the same with so many things that we've, what we do. People want something they can kind of cling on to and just this is the right way of doing things and this is what we have to be doing and everything else is bad and wrong. And it's just not like that. It's, we can look at everything in, in a balance. Right. I think, I think we kind of screw around with people's lives a little bit because we spent so long, you know, as an example, we spent so long, for so long people were segregated and institutionalized. And then we kind of went in completely the opposite direction. Like, you know, you almost like people with disabilities aren't allowed to hang out together and spend time together. [inaudible], like you said, the pendulum, we spend so hard in the other direction that now, um, there's some professionals and service providers that almost like telling people that your disability isn't valued and you shouldn't be spending time with other people with disabilities.

Ben: And it just comes back to that balance of we, it's kind of interesting, like I was looking at this, um, and I hadn't thought about, I haven't totally thought this through yet, but I did just look at the other day. There's a diagram that's quite possibly, quite popular on social media rights, segregation and there's all these little dots and they're circled people with disabilities on the outside. There's integration whether on the inside, but that's still a little circle. And then there's inclusion and people with disabilities are everywhere. And that is, that is kind of seems that was ultimately where you want to be heading to. But then we need to remember like within that little bubble where there's little dots everywhere and the people with disabilities are just included in the everywhere within that bubble, we still need to remember. And um, people with disabilities might want to self-segregate at times they might gather with other people with disabilities within that little bubble and self-segregate and that isn't an absolutely terrible thing for that to happen. So it's again, it's that balance thing. It's like I think people, they want to cling onto one thing and then I think I just worry about the harm that that does to people sometimes.

Genia: I think that we, it, it's easy and it happens very frequently that people forget about the point. Like the, so for example, with the, um, moving away from, from segregation. Um, there's a, there's a couple of things there. One of the points was that that, that we were moving away from that being done to people as opposed to people being able to form affiliations and alliances and come together with people as they choose. And, and also we get into the, the, there sort of, um, I think we lose sight sometimes of the difference between what ought to be true versus what is the reality. So, you know, people coming together, people with disabilities coming together as a group, um, may have many positive,

um, outcomes and be highly desirable as long as it's, again, not done to them, but people are choosing to come together.

Genia: It doesn't change the fact that people who come together in a group, people with disabilities to come together as a group will have a harder time, um, get being sort of accepted as a group than they would if they were developing one. You know, showing up somewhere in a kind of just as one person, like the, the discrimination and devaluation of people with disabilities exists in our culture. Um, and um, and, and that doesn't change even if people want to come together. And so the sort of like, I feel like we get caught in trends and I've been around long enough to see these trends cycle around and around, we get caught in trends and the um, and distracted in some ways by the, like the, um, I'm trying, I can't think of the right expression, but like the, the pithy little like labeled jars not people. And without actually spending time to remember kind of where that's where that's coming from.

Ben: Yeah. It has a meaning. [inaudible]

Genia: It has a meaning. Yeah. Like if I go out, I was just going to say, if I go out with my sister, um, who has a disability and my son who has a disability, the number of questions I get about what service I work for is exponentially higher than if I'm just out with one of them. And so just like, I, it doesn't mean that we're not going to go out as a family. Right. It's not, we don't, we're not forbidden from going out from it as a family, but the fact that my sister and my son will have a harder time, um, having sort of typical access to, um, community acceptance if they're together is true. It's going to be harder if they're together than if they're on their own.

Genia: Phew! I kind of wish a lot of this was simple and easy. How about you? I'm curious. Has your answer to that multiple-choice question changed? Next week, in the second part of the interview, Drew and I talk about how to find support workers that are a good fit for someone with a disability. Before I sign off here today, I want to pose one more question. We are quickly approaching the end of 2019. It is a time of year that prompts us to reflect over the past year, where we were, how far we've come, whether we have made progress or achieved our goals. I'm interested in how this past year has gone for your son or daughter with a disability.

Genia: Was it a good year? Did the supports that they have in place help them live the life they want? Having a good support worker or teacher or educational supports or therapist is lovely. But only when you are clear about the kind of life they are helping your son or daughter to achieve can that support lead to the good things in life. We'll be diving into this more and more over the next weeks. If this is something that is important to you, and you don't want to miss an opportunity, then go to goodthingsinlife.org/tellme. I will be sure to let you know about all the things that Good Things in Life is offering to help make sure that you are making the most of 2020. Have a lovely week!