**[Start of transcript]**

**Interviewer**: It works some days, sometimes it doesn’t … So to recap what we talked about I think like two weeks ago, in terms of your daughter’s sensitivities we talked about how sometimes sounds overwhelm her, how she uses headphones. We talked a bit about like crying kids and like tantrumming kids being agitating towards her.

**Interviewee:** Yes, yes.

**Interviewer**: We talked about her like looking at like her visual … looking at things in the periphery in her vision.

**Interviewee:** Yes.

**Interviewer**: We also talked about her using like videos of like birds and things that she likes as a calming system for her. We also talked about how she was kind of pattern-seeking and has a little bit of rigidity towards her systems.

**Interviewee:** Little bit, she … it’s not a little bit [*laughs*].

[0:51]

**Interviewer**: [*laughs*] A lot.

**Interviewee:** [*laughs*] Yeah.

**Interviewer**: Alright, we talked about it a lot. I was trying to couch it nicely [*laughs*]. And we also talked about how exercise and movement can kind of be calming for her and kind of like modulate her a bit.

**Interviewee:** Yeah.

**Interviewer**: And you also talked about a lot of like self-desensitization and exposure as ways that she’s kind of learned to cope, as coping mechanisms. And for her transition, we talked about how she’s a little bit developmentally below that of her age, but how she’s very good at like mechanical things and fixing things. You talked about like mechanics and working with your husband and you talked about how you think she could grow into independence through more opportunities and more exposure.

**Interviewee:** Yes.

[1:31]

**Interviewer**: Is that an accurate summary of what we talked about?

**Interviewee:** Yeah, yeah.

**Interviewer**: Ok, awesome. So now we’re going to put these things together. So thinking about her sensory sensitivities and sensory interests and thinking about her transition to adulthood. How do they intersect?

**Interviewee:** … [*sighs*] … [*laughs*] …

**Interviewer**: It’s a hard one.

**Interviewee:** It’s hard because I don’t know the answer to that.

**Interviewer**: Sure, that’s ok.

[2:01]

**Interviewee:** I … I feel like … it’s a big concern of mine for her that she, she has a lot more potential than she’ll be able to actually achieve, because, because of, you know, the nonunderstanding of … of her. Because she’s not verbally capable of fully explaining things to … she tries desperately but it just, she doesn’t have the words that she needs to … to really help herself [*inaudible*…] and stuff like that.

**Interviewer**: Yeah, absolutely.

**Interviewee:** My only hope is that, you know, we will find employment for her where, you know, they take into account that she needs these, you know, these type of breaks or … she’s not going to be your typical employee obviously, she’ll definitely kind of do her own thing but she will get the work done, so it’s, I don’t know if that answers your question?

[3:23]

**Interviewer**: Yeah. So you just talked a little bit about her kind of like language being the thing that kind of I think drives this concern that her potential is greater than like what she will be able to achieve?

**Interviewee:** Yeah.

**Interviewer**: Is that difference also related to her sensory sensitivities or more related to her verbal abilities?

**Interviewee:** I’m not sure …

**Interviewer**: Ok, that’s ok.

**Interviewee:** I’m not sure.

**Interviewer**: That’s perfectly ok. Thinking about her sensory sensitivities, do you see them as an obstacle, a vehicle, or a bit of both, or neither towards her independence?

**Interviewee:** You know, just because I don’t fully understand them it seems like they’re an obstacle. But for all I know, it’s, you know [*laughs*] … it’s, it’s … her sensitivities are … could be very useful, but it just right now they seem like they cause more pain than good because we don’t really know how to tap into those [peculiars/periods??] of hers and she hasn’t quite figured it out, and, you know, hopefully one day we will, I don’t know.

**Interviewer**: Yeah. But you think [*inaudible* …]

[4:48]

**Interviewee:** I feel like it is definitely more of a burden than an aid to her.

**Interviewer**: But it sounds like you think it could have potential to be a vehicle, if you were able to kind of capitalize on them?

**Interviewee:** Yeah, if you could figure out how it could be utilized in a way that, you know, like a typical developing brain … you know, lacks.

**Interviewer**: Yeah.

**Interviewee:** I think then it would be great for Helen. Like I think they just did something on *60 Minutes* about different work …

**Interviewer**: Oh really?

**Interviewee:** … potentials for autism, yeah. You should look it up, it’s pretty good.

**Interviewer**: Oh, yeah, I’ll write that down.

[5:29]

**Interviewee:** You know, like the first fifteen minutes is usually when someone makes an opinion of someone and how people on the spectrum are usually below the first fifteen minutes because, of, you know, anxiety and [*inaudible* …] all the sounds and, you know … so there’s apparently some companies that are recognizing that and instead of interviewing like a standard interview they’re doing more cognitive testing to see different capabilities and I’m watching this going, yeah, Helen could do exactly … like all the cognitive tests they were doing, I’m like, Helen … that’s Helen, like she could do all these things very efficiently and no problem, whereas the rest of us wouldn’t be as efficient and just the way she processes things, visually as well as, you know, just she’s definitely [*inaudible* …] I don’t know how to use it but she definitely is able to figure out when something is not right.

**Interviewer**: Yeah, you mentioned that.

[6:44]

**Interviewee:** So … she, she just, but she doesn’t … I think she just doesn’t, the barrier is being unable to appropriately or tell you it’s, it’s not right and why it’s not right. But, usually, you know, you find out because she’s right and then you, you, after the fact you’re like, “*Oh, oh, I’m sorry*” … like [*laughs*] …

**Interviewer**: Yeah [*laughs*].

**Interviewee:** You know, I’m like “*Ahhhh*!” [*laughs*]

**Interviewer**: Yeah, she knew the whole time [*laughs*].

[7:19]

**Interviewee:** Yeah. So, you know, that’s, that’s the key, like we’ve got to figure that out, like how can we get her, you know, to show us, you know, in a nonverbal manner I guess, and is she capable of, you know, if we let her, is she able to fix the situation without having to have someone else do it? I think one of the things that I’m struggling with right now with Helen is … she’s so used to not being allowed to just … do things that she … for example, like every morning she’s been like, she’s gone back to a “*Good mornin*g,” and I’m like, “*Good morning*,” and she’s like, “*What will be for breakfast today*?” and, you know, it’s always, she always wants the same thing and so I ask her and then I try and see if she wants something different and then … but like the thing that she wants, she’s fully capable of going and making some toast – to go put toast in the toaster and then butter it and put a little jelly on. She can do it.

**Interviewer**: Totally.

[8:39]

**Interviewee:** But she *won’t* do it because she thinks *I* have to do it and it’s like, “*Ok, you can do it*,” and then if I don’t get up and do it fast enough she’ll start talking about how she’s starving, it’s going to be late, you know, she’s going to miss breakfast because I didn’t do it fast enough. Not understanding that – you know, here’s the rigidity – not understanding that, you know, *you* can get up and you don’t need *me* to get up and I’ll tell her that, and she’s like, “*No, no you need to make* …” [*laughs*] … so it’s like [*sigh*]. Trying to work with her teacher, you know, the flexibility of that has been our biggest challenge and I don’t know if it’s sensory driven or if it’s just the need to have the same structure about everything or, you know, for all I know, you know, the toaster makes a noise that she doesn’t like and I, you know, that’s why she doesn’t want to do it. Yeah, she could do it, but she would rather not have to deal with the toaster. Who knows? But, you know, it’s one of those things, I don’t know what’s causing, causing the rigidity of it and she’s, damn it she’s [rigid?] … “*Please, just make your own toast*” [*laughs*] …

**Interviewer**: [*laughs*] Yeah.

**Interviewee:** It’s not hard.

**Interviewer**: [*laughs*] No. That’s a good segue to my next question actually, so thank you. What do you anticipate as being challenging for her as she does gain more independence in regards to her sensory sensitivities?

[10:23]

**Interviewee:** Can you repeat the question?

**Interviewer**: Totally. What do you anticipate as being challenging for your daughter as she does gain more independence, in regards to her sensory sensitivities?

**Interviewee:** I think again it’s just being able to step outside of the structure. You know, no structure is not good. She craves almost too much structure and just I think just getting outside of that and saying, “*Yeah, I can do these things but there is wiggle room*.” That’s going to be her biggest challenge, but once she achieves that I think, you know, she’s going to be like, it’s going to open a whole new world for her.

[11:11]

**Interviewer**: Absolutely.

**Interviewee:** You know, it’s just how do we get her there and can we get here there, is that even possible? I hope so.

**Interviewer**: Yeah. What do you think will help her in that arena?

**Interviewee:** It’s kind of, kind of maybe the same approach I’ve taken with her her whole life, is kind of like – and it means I have to do it too – is, you know, take off the seat belt and just kind of say, “*You’re going do it, I’m not doing it*,” and walk away from her and force her to do something she’s afraid of.

**Interviewer**: Like high exposure.

[11:52]

**Interviewee:** Exposure. And I have to be able to not hover and be worried that she’s not going to do it. I just have to have more confidence that she is fully capable. You know, the thing is, it’s like I *know* she is, but there’s still that anxiety on my part of “*Can she do this*?”

**Interviewer**: Totally.

**Interviewee:** So one of the things, and it’s interesting because, for example, I, we were just at, we went to Kennedy Lake Park.

**Interviewer**: I love that place so much.

**Interviewee:** Yeah [*laughs*]. And, you know, everyone’s like, “*Oh, is she going to be able to wear a mask*?” I said, “*Wearing a mask is not a problem, it’s a rule, so she’s going to follow the rule*.” So she followed the rule and then she was really wanting to get a candied apple because it’s one of those things like, “*I go to Kennedy I have to get a candy apple because I always get a candy apple*.” So I sat there and I’m like … “*Alright, I’m going to give you like ten dollars and you’re going to go get the apple yourself and just bring back change*,” and that’s all I said to her. And so she took the money and she went and I just watched from afar. Meanwhile, her sister’s freaking out like, “*You’re just going to let her do it by herself? She doesn’t even know how to like get someone to pay attention to her to put in an order, or say ‘excuse me,’ or like, she’s just going to* …” I’m like, “*I know*.” And it was very painful, but, you know, she got it. They finally noticed her, she said what she wanted, she waited for change, she came back, handed me the change, and ate her apple. And I was just like, “*See, she did it*.”

**Interviewer**: That’s awesome.

[13:39]

**Interviewee:** But of course I was watching the whole time, like you know. But it seemed like *we* were more nervous than *she* was, you know [*inaudible* …] but I could see she was getting a little like … she was just saying her order to no one.

**Interviewer**: Yeah.

**Interviewee:** And we, she, you could see she was looking to see why they weren’t listening to her, so she wasn’t understanding the, you know, I have to get their attention.

**Interviewer**: Sure.

**Interviewee:** But, again it’s, it’s exposure and I think that little things like that, I have to like step back and just be like [*laughs*] …

**Interviewer**: Let her try.

[14:24]

**Interviewee:** It’s *hard*.

**Interviewer**: I’m sure.

**Interviewee:** It’s just like, alright, am I going to be able to just give her the money and one day just not watch?

**Interviewer**: Maybe.

**Interviewee:** And say, “*I’ll wait for you over here*.”

**Interviewer**: Exposure for both of you, right? [*Laughs*]

**Interviewee:** Yeah. It’s really challenging because, you know, you worry about what the person’s going to think. Are they going to treat her nicely? Is she going to get what she wants or is she going to, you know, are they going to take advantage of her and not give her her change? Is she going to walk away not taking the change because she’s just so like, “*I’ve got to get the hell out of here*,” you know?

**Interviewer**: Sure.

**Interviewee:** Those type of things, but …

**Interviewer**: Absolutely.

**Interviewee:** Yeah, so it’s definitely exposure on both our parts and I think the world will need that too, like more exposure to individuals like Helen, they’ll see that, “*Ok, she’s not like us but there’s definitely a value to her and she is definitely* …” Like I said, when people get to know her they see, you know, “*I really like this person, like she’s definitely different and I don’t understand her half the time, but there’s something about her that … I’m really glad she’s part of my life*.”

**Interviewer**: Yeah, absolutely.

[15:49]

**Interviewee:** So, so that’s it.

**Interviewer**: Besides like exposure on both of your parts, do you think there are any like services or interventions that could kind of like help her transition to adulthood but also kind of cope with the sensory sensitivities and maybe also cope with her rigidity?

[16:06]

**Interviewee:** I really hope, and I don’t know if there are, I just haven’t quite looked into it, I mean I hear about Mass Rehab [Massachusetts Rehabilitation Commission] being like, potentially help her with working. I don’t know how it will work and I don’t know, just because you hear about the struggle for autistic individuals to get jobs, so I sit there and say, “*Alright, will she get a job if she has like a, you know, kind of a rep to get her through the door*?” I don’t know, that’s one of those things I really would like to see, you know, she’s nearing eighteen and she’s well aware that kids her age are graduating. You know, she recently was like, “*I need to graduate, because this school is for kids*.” And it’s like … “*What’s your rush*?” [*laughs*] But to me, I’m almost to the point where, you know, she’s not going to get a high school diploma.

**Interviewer**: Yeah.

[17:25]

**Interviewee:** But maybe I should continue along this typical path of, ok she’s turned eighteen, she’s probably maxed out where, I mean she’s not maxed out, she could probably still learn more, but the benefit, the time benefit to it is, I’m not sure worth it. So what would be great is if she can go from transition into a program that works on finding what she would be good at, what she would enjoy doing, having someone kind of help her like go and try different things and see, you know. I don’t know if that even exists [*inaudible* …].

[18.10]

**Interviewer**: Maybe.

**Interviewee:** I have to, I have to look.

**Interviewer**: I’ve heard there’s also a couple of resources that might be helpful for you, all about like job opportunities.

**Interviewee:** Yeah, because I feel like I’m getting to the point where she is really kind of getting like most teens when they’re about to graduate, like, “*I’m out of here, I need to do, like move on to the next part of my life*.”

**Interviewer**: Yeah.

**Interviewee:** And, you know, because she can’t graduate like a normal person, she can’t do that and so I would love for her to have something, you know, I guess a different version of that for her so she doesn’t feel like she’s being left behind or punished because she’s, you know, different.

[18:57]

**Interviewer**: Absolutely. Do you feel like there are gaps in the available services and interventions for kids like your daughter?

**Interviewee:** I do … It’s like I keep being, you know I’m told a lot of stuff, “*Oh, you should go try this, you should go try that, you should try this*,” and when I go, I feel like a lot of it’s dead-ended. It’s not, it’s more like, “*Oh here’s a pamphlet you can read about stuff and there you go, that’s what we can do for you, now you’ve got to do the rest on your own*.” So, I just feel like I, a lot of times people are like, “*There’s tons of services*,” and I’m like, “*But they’re not useful for her*.” Do you know what I mean?

**Interviewer**: Yeah.

**Interviewee:** Like, I’m like, yeah, I could use this service and I could use that service, but they really, they’re kind of like, I feel like it’s just creating a job for this person, it’s not really benefitting or helping Helen. It might give *me* a break, you know, from … Like, for example – and I’m trying to figure out how to use it because I’m like, can we use this more than we are? – she, once a week, it’s back to happening so it’s good, once a week she goes out with, with someone to do, to be in the community and to me, I look at it more as respite than anything because what she’s doing is she’ll take Helen to … “*What do you want to do Helen*?” and I was like, “*Helen won’t* …” You know, I need someone to say, like “*Ok, today we’re going to try this, today we’re going to try that*.” Instead, it’s “*What do you want to do Helen*?” and Helen will say, “*Let’s go to the mall*,” and she’ll want to walk around the mall, and “*Let’s eat, let’s go and have pizza*,” you know, and it’s always the same thing and like, Helen’s got that down, you know. So they’re out for several hours. I have no idea if it helps. I don’t, you want to be a fly on the wall. Like, ok, are they engaging her in conversation successfully? Is she, you know … or are they just kind of being her shadow like I am a lot of the time? So to me she, when this started back up she was so happy and excited. So I’m like, there is a benefit to it, but how much is she gaining from it? I know that, you know, occasionally they would have, pre-COVID, they would have things where, “*Ok, we’re going to go out to eat and then we’re going to go and meet up with a group that goes bowling every week*,” and so she would get to do, to participate in an activity with others, on her own terms, because, you know, she wants to talk and so she’ll … she won’t, she’s more of a person that likes to be around it but not necessarily participate actively.

**Interviewer**: Sure.

[22:15]

**Interviewee:** So, it’s one of those things and I’m like, I’d like maybe something like, more of that for her.

**Interviewer**: Yeah, like more learning opportunities maybe?

**Interviewee:** More learning, because it’s once a week and it’s like … to me, and it’s again it’s letting that cord out a little bit for me, so it’s teaching me a little bit like, ok she’s fine, she’ll be ok, she can do this, and it’s really nice because I’m like, oh my god, I’m starting to realize that I get like two hours a day every week where I know she’s going and doing something that she enjoys somewhat. And I’m, you know, I’m kind of getting some … I’m calm now, like I can relax, she’s safe. So I would like to see, you know, I wish it was more than just once a week.

**Interviewer**: For sure.

[23:16]

**Interviewee:** And I know that, you know, one of those things when she turns twenty-two, “*Oh, well let’s put her in a day program*,” I’m like, “*No*!” … I want that, I wish that day program thing was more of a transitioning thing to getting you into …

**Interviewer**: Yeah.

**Interviewee:** Do you know what I mean? Like there’s so many individuals that are in a day program and I’m like they probably could be working, they probably could be doing so much more with their life, but there’s nothing to get them there. You know what I mean?

**Interviewer**: I do.

[23:52]

**Interviewee:** It’s like you’re stuck in this waiting pattern and this is it. You either take this or you, you take nothing and that’s like, my biggest worry about Helen is, I know she wouldn’t be happy in a day program for the rest of her life. It wouldn’t feel, *for her* she would feel like she had no control of her life, she wouldn’t be able to make decisions, she … it would just be constantly the grind of … it would be like going to school for the rest of her life [*laughs*]. Like [*inaudible* …]

**Interviewer**: Yeah.

[24:26]

**Interviewee:** [*inaudible* …] “… *this time, you’re doing what we’re telling you*.”

**Interviewer**: It must be really hard.

**Interviewee:** And it’s like, you know, I’m sure it’s enjoyable sometimes, but like having really not the same choices that, you know, you or I might have.

**Interviewer**: Absolutely.

**Interviewee:** If we don’t like a job, or, we can leave. If she doesn’t like the day program, she can leave and find another one that’s probably the same but different, you know? So, I guess I would like to see more, more variety or more options out there than what I currently know of.

[25:15]

**Interviewer**: Absolutely. Thinking a little bit broadly, how has Helen’s sensory sensitivities and like sensory interests impacted your hopes, goals, and expectations for her as she does navigate adulthood?

**Interviewee:** [*sighs*] … It really causes us a lot of concern … just… because it, it does seem like an impediment to … that people are not willing to necessarily understand or tolerate, so, you know, just, she loves wearing her headphones. She also loves having multiple screens around her going on, doing things, and it seems like she’s not paying attention, how could she, if she has all these things going on? But she *is*, it’s like she’s doing these, these other things are what keep her even-keeled and, you know, like, you know at school, even with school it’s like, “*You need to turn that off now, you need to turn that off now*.” And she’s starting to make some gains with her ABA [applied behavior analysis] therapist because the ABA therapist is tolerating it. She’s like, “*Ok Helen, I don’t feel like you’re paying attention to me*.” So I rat Helen out, I’m like, “*Yeah, she’s opening up like eight different windows right now, with a different image on each window, and she needs to have those in the background so that she can, you know, they’re there*.” And so she gives, she’s like, “*Ok*,” so now before a session she’s like, “*Ok Helen, have you opened, have you got all your windows open and are you ready*?”

**Interviewer**: Is this on Zoom? Is there like a telehealth situation right now, is that what you’re talking about?

**Interviewee:** Yeah, it’s Zoom.

**Interviewer**: Ok, yeah.

[27:25]

**Interviewee:** So, but when they’re in *person*, instead of having that, Helen’s learning to say, you know, “*I’m going to take a fifteen-minute break*,” and she sets her alarm on her watch and, you know, goes and sits on the computer and does it. Like, it’s almost like she’s able to do it, like take breaks to do it, but when it’s Zoom, you don’t take breaks, it’s more like, you’re still on, you’re not allowed to separate. You know what I mean?

**Interviewer**: Yeah, it’s hard.

**Interviewee:** So, they’d be like, “*Ok, we’re going to take a five-minute brain break, let’s play something, what do you want to play*?” And again, it’s like, yeah you’re taking a break from academics but you’re not really giving *her* the break that she wants, which is, let me, you know, go and surf YouTube or watch this video eight times, or, you know. So …

[28:22]

**Interviewer**: But it sounds like she, like with understanding that she needs these windows the therapist is kind of beginning to understand what her needs are, so that she can succeed?

**Interviewee:** Yeah, which is *great* for *them* [*laughs*], but it’s like, ok, one, if this therapist ever decides to leave and take a new job, Helen’s going to lose that because the next therapist that comes along might not see it the same way and Helen won’t be one to … be able to say, “*This is how it was and it really worked and it helped me* …” You know, and I can say it, but I don’t think I could adequately … because I don’t, I still don’t even fully understand it. Like I’m still trying to figure Helen out.

**Interviewer**: Yeah, absolutely.

[29:15]

**Interviewee:** And what her needs are, so yeah it brings a lot of concern because it’s … I think it’s probably a lot, it’s probably right there in front of our noses and because it’s not like the ordinary thing for us, it doesn’t, you know it doesn’t compute.

**Interviewer**: Absolutely, thank you. And we’re going to move on to our next chunk of questions. This is the last one so we’re almost done, they’re just short ones. As a caregiver, as a mom, as a parent of someone with ASD [autism spectrum disorder] but also some sensory sensitivities and sensory interests, what does transitioning to adulthood mean to you?

[29:59]

**Interviewee:** You mean besides falling off a cliff like most people keep describing it?

**Interviewer**: Or that, that could be it [*laughs*].

**Interviewee:** It is terrifying and it’s like, you know it’s coming and you just can’t prepare for it. Like, you think you have all, everything, but you’re still questioning, “*Do I have everything done that I’m supposed to do in order to get her to* …” It’s just so … unknown, like there’s no clear right way of doing something. Like what works for someone is not necessarily going to work for Helen. But, like as far as all the damn stuff we have to do [*laughs*], just like filing for guardianship, but we can’t do it now, even though she’s not really going to change in the next year, we have to wait till right before she turns eighteen. You can’t do it too soon and you can’t do it, you know.

**Interviewer**: Ok.

**Interviewee:** Like there’s just things like that. Like, ok so in order to get guardianship, what do we need? And ok, you’re going to need something from, you know, a doctor, a psychiatrist, a social worker, like all the hoops I have to jump through. I’m like, can’t you just sit with Helen for five minutes and say, “*Yeah, ok I get it*”? Why do you make us jump through all this stuff? But you can’t do anything too soon because it won’t be valid because it expires. And I’m like, she’s not changing. It’s not like she has a cold and it’s going away.

**Interviewer**: Yeah.

**Interviewee:** You know. Same thing with stuff like, like MassHealth and all that. You have to reapply every frigging year. She’s not on MassHealth anymore because I’m like, this is ridiculous. It wasn’t really giving us much more. Our insurance was already covering all of it, but why do I have to fill out a five-page thing on yes she *still* has autism, yes she *still* doesn’t, you know, why do I have to do this every year? This is ridiculous.

**Interviewer**: Sounds pretty frustrating.

**Interviewee:** You know, I think I feel like I’ve gone off on a tangent but …

**Interviewer**: No, that was relevant.

[32:30]

**Interviewee:** Transitioning, is it going to be more of the same? Yes. And who’s going to do this for her when I’m not around and how do I get her to the point where, or get her set up so that it just happens? To me, I really hope maybe one day there’ll be a change in the bureaucracy, red tape, and all this stuff that, you know for someone like Helen, that it doesn’t have to be a push paper let’s do this, you have to do it, oh here we go again, once again this year we have to go reapply for guardianship, yes she still needs, yes she still has autism, yes she still can’t talk, she still … like. Doesn’t it seem like a colossal waste of time?

**Interviewer**: Yeah, that’s hard. I’m really sorry.

[33:27]

**Interviewee:** Yeah, so to me it’s like, it’s not, it’s just I see transitioning as, it has the potential of being debilitating in the fact that just the stress doesn’t end …

**Interviewer**: Sorry, say that again please?

**Interviewee:** The stress doesn’t end it just becomes a new stress and a new, like now we’ve got to figure this out.

**Interviewer**: Absolutely.

**Interviewee:** You know, but it’s not, but it’s that more challenging because you have to have the right forms or the right permissions, or the right, you know, you can’t just say, “*Ok, that’s not working I’m just going to change it*.” Like you know, like I said, “*I don’t like my job I’m just going to change jobs, I’m going to apply for another job*.” Well, you know, for Helen it’s probably going to be like, well if she works this job she loses this benefit, if she makes this amount of money she doesn’t get to, you know she gets no help. She … it’s just like it’s a set up to never be able to achieve more and never, you know, be … I just I feel like her shot at happiness is limited, unless she can, unless she can actually say, “*You know what, I really don’t need anything except to do this*,” and it doesn’t, you know, I could, “*If I could just every day wake up and know that there’s going to be food in my fridge and that I have Internet and I’m warm, and that’s it and that’s provided for me and I don’t have to do anything for it, then I’ll be happy*.” You now, but I don’t even think she would be, I think she would still want to see people and go and do things, but everything is, everything is a chore.

**Interviewer**: Yeah, I can imagine that.

**Interviewee:** I just don’t see transitioning … if anything it just means like, oh, now I have even less to help Helen.

[35:50]

**Interviewer**: That must be very frustrating, I’m sorry you feel that way. Has this perspective changed over time?

**Interviewee:** [*sighs*] … No, I’ve always kind of felt like, I don’t take advantage of, like I said, I don’t usually take advantage of a lot of services because to me, I’m like, I don’t want her to get used to having that because when she turns twenty-two she’s not going to get it.

**Interviewer**: Yeah.

**Interviewee:** Or she *might not* get it, you know, *maybe* she’ll get it but you know she has to be in a certain window, you know, meet certain criteria, so you don’t want to, you know, play her up *too* much, because if you play her up *too* much and say she’s capable she’s not going to have, she’s going to have even less. So, it’s like, you know, I’ve always felt like I’m going to have to lie [*laughs*] to get her *some* help. But she probably wouldn’t need the help if … you know if the world was different [*laughs*].

[37:05]

**Interviewer**: Yeah, absolutely. What do you see happening in Helen’s future?

**Interviewee:** [*sighs*] I don’t even, I can’t even go there. Like, I can’t … I know what I want to happen, I don’t know if it’s possible. I really would love for Helen to be able to not need me or necessarily need someone 100 percent of the time, that she could be self-reliant for some things in life, but have the ability to get assistance if she really needs it and it not being impossible. I just, I worry that that’s not, I just …

**Interviewer**: Yeah, I can imagine.

**Interviewee:** I just, I don’t know. I can’t … [*sighs*] … She, you know, what’s probably most likely going to happen is she’s going to end up in a day program, living in a group home, unhappy, because I can’t, I will want her to move out of the house – not because I don’t love her and I don’t want her here – but I need to say, “*Hey, this isn’t forever*,” it’s like, you know, “*You’ve got to one day go*.” But she’s just going to be going to somewhere and she’s not even really going to have much say, because I don’t know how else to make it happen. I feel like it’s got to be there or there’s got to be somewhere, there’s got to be someone, that I just haven’t found it or figured it out yet.

[39:12]

**Interviewer**: Yeah, that makes sense.

**Interviewee:** But I really, you know, I really want her, I want her to be able to have a “Helen life,” not, you know, I just, to me I sit there and say … I worry that her mental health is going to go down the shitter, because she’s not going to want and go and live in a group home. I think she would like to have … I think if I could have it she would like to have a roommate or someone that’s her peer that, almost like a life partner.

**Interviewer**: Yeah.

**Interviewee:** Do you know what I mean? That can help her navigate life. You know, just like we all look for a life partner.

**Interviewer**: Absolutely.

**Interviewee:** We have own lives, you know, we have ours, but we also have, like I have my husband who’s there to support me in ways when I need it. And that, you know, it’s very, I … Helen’s got a lonely life right now. You know, she doesn’t have any prospects of a life partner, nor do I know how to find that. So it’s going to be, I see it as being a prescribed thing, not her choosing.

[40:54]

**Interviewer**: Thank you for sharing that, I really appreciate it. I have one final question for you.

**Interviewee:** I’m sorry, I’m getting depressed just talking about this [*laughs*].

**Interviewer**: No, it’s ok, I’m sorry it’s upsetting you.

**Interviewee:** You’re going to get off the phone and be like, “*What a downer*!”

**Interviewer**: No, no, no you are not a downer. You’re also not the only parent who has been sad about talking about this. I think it’s a testament to how real this is for you. So, you’re not a downer, it’s valid and it’s ok. How have Helen’s sensory sensitivities impacted this perspective you just articulated?

[41:35]

**Interviewee:** I think they’re the things that separate her. If she didn’t have these sensitivities she could be just considered a quiet person. Do you know what I mean?

**Interviewer**: Yeah.

**Interviewee:** But she comes across as weird. So yeah, like I said, it doesn’t seem very much like a benefit, it’s more of a burden and, you know, I wish we could convince people of the benefit of it.

**Interviewer**: Absolutely. I hate to end on such a low note but that’s actually all of my questions. Would you like to add anything else?

**Interviewee:** No. I just, I just, you know, put the intention out there that, you know, this world will continue to grow and in ways that help those that need help and be open to different things and, you know, you do see things. It’s not very pretty right now but I think it’s a sign that there’s change happening.

**Interviewer**: It could be pretty.

**Interviewee:** It could be possibly pretty if everyone was just like, “*Fine, let’s do this*!” [*laughs*].

**Interviewer**: Yeah [*laughs*], absolutely. Well, thank you so much for taking so much time to talk with me and thank you for being so honest and vulnerable, I know this isn’t an easy topic for a lot of people so I appreciate it so much.

**Interviewee:** No problem, thank you Rachel.

**Interviewer**: Yeah, do you know anyone else who might want to participate in our study, by any chance?

[43:29]

**Interviewee:** You know, I could put the word out to a couple of people that might be able to do it.

**Interviewer**: Yeah, that would be lovely if you don’t mind, would you like me to send you, like how can I help you do that, what’s best?

**Interviewee:** Send me like a …

**Interviewer**: A thing?

**Interviewee:** Yeah, you know that I could forward, you know, to them, with like a link to get in touch with you to learn more information, but I could let them know, “*Oh, you should do this*.”

**Interviewer**: Yeah, that would be lovely if you don’t mind. I will, after our conversation like in a few minutes, and after the video renders, I will send you a thank-you gift card for compensation, we so appreciate your time and effort and also I don’t know if these will be dead-end resources to you but I have a couple things I’ve compiled from talking to parents, specifically related to job opportunities, so maybe I can send those to you. Maybe they will [*inaudible* …]

**Interviewee:** Yeah, you know, to me it’s like any help that, you know, a lot of them do end up to be kind of dead-ends but I’d rather say, “*Alright I checked that out or I checked that out*,” than not, you know, don’t leave any stone unturned, so to speak.

**Interviewer**: Yeah, I’ll send that to you. And then final question is you mentioned that you need like a lot of paperwork for guardianship, would results from these reports be helpful or is it too early in that process?

**Interviewee:** Probably not, it probably wouldn’t be helpful because it’s not, you know, the way, like all her doctors know, it’s just, it’s just the … rubber stamping.

**Interviewer**: Ok, I was going to offer to send you the reports if it would be helpful, but …

**Interviewee:** No, it’s not like I have to convince anyone that Helen needs guardianship.

**Interviewer**: Ok.

**Interviewee:** It’s just the fact that it’s blatantly obvious that she needs it and that you have to, you know, to me it’s even a waste of time for all the doctors to go and fill out the frigging forms and, you know, it’s just …

**Interviewer**: It’s frustrating, sounds like it.

**Interviewee:** It’s not easy.

**Interviewer**: It does not sound like it. Well if there’s anything I can do to be helpful please let me know, I’m happy to help in whatever way I can, you’ve been so helpful to us, we want to …

**Interviewee:** Yeah, any resources that you see, that you come across, or hear about, you know, would be great. Even if your group establishes like an online resource that we could go and just scroll through things, that would be great.

**Interviewer**: Absolutely, yeah. What I’m doing from all these interviews is parents tell me things and I’m kind of compiling them and then when I’m done I’m going to distribute it, but I’ll show you what I have now in case they’re helpful immediately and then once I’m done you’ll get a bigger list.

**Interviewee:** Fantastic.

**Interviewer**: Awesome, thank you so much.

**Interviewee:** Thanks.

**Interviewer**: Have a lovely day.

**Interviewee:** You too, bye.

**Interviewer**: Bye.

**[End of transcript]**