**[Start of transcript]**

**Interviewer:** Right, we are recording. And I will be asking you questions about your perspective regarding your child’s transition to adulthood in relation to her sensory sensitivities and sensory interests. And I’ll be doing something called a ‘semi-structured interview.’ And this means I have my planned questions in my script, but I’ll also be adapting them and following our conversation so that actually fits and makes sense for what we’re talking about.

**Interviewee:** OK.

**Interviewer:** Do you have any questions?

**Interviewee:** No, let’s, let’s roll.

**Interviewer:** OK, cool. Also if there are any questions that you don’t want to answer … they make you uncomfortable, you don’t have to.

**Interviewee:** OK.

**Interviewer:** And if there are any things that come to mind that we talked about earlier that you think about later, feel free to jump in. It doesn’t have to be linear at all.

**Interviewee:** OK.

**Interviewer:** All right. So, could you please start off by telling me about your child’s sensory sensitivities and sensory interests?

**Interviewee:** Sure. Should I … can I say her name because I’m … **[inaudible crosstalk at 00:56]**

**Interviewer:** Yeah, yeah you can

**Interviewee:** All right.

**Interviewer:** I’m going to go back … when I get the transcript, I’ll redact **[1:00]** it. So …

**Interviewee:** OK

**Interviewer:** … you can definitely say her name.

**Interviewee:** Helen is … she’s interesting. I’m not sure I have a total understanding, full understanding of her sensory issues. She definitely seems to have issues with sound. I think when she feels … what I’m noticing is when she … It’s not *always*—like, we, we went to a live concert and she was fine. But sometimes I think if she’s overwhelmed or there’s too much stimulus coming in, she’ll cover her ear and, like, hum **[imitates humming]**.

**Interviewer:** Yeah.

**Interviewee:** I think to block out stuff. So I’m not quite sure what it is. She’s also, recently, grown very attached to wearing headphones. Beats.

**Interviewer:** Yeah.

**Interviewee:** I mean, she listens to ... and, you know, I think that’s our, our fault. Because she was listening to these videos on YouTube a lot. And it was just like, “*I don’t feel like, hearing that*,” you know, “*let’s get her some headphones*.” So …

**Interviewer:** Yeah.

**Interviewee:** But now it’s hard to get her to take the headphones off. She wants to watch all the time. So I don’t know if it’s … you know, she’s, she’s …

**Interviewer:** Yeah.

**Interviewee:** … always listening to something. Like, she wants to listen to music or videos. She’ll take them off for school. She’ll take them off when she’s not … when she’s expected to focus …

**Interviewer:** Yeah …

**Interviewee:** but …

**Interviewer:** Oh, sorry. Go ahead.

**Interviewee:** The moment, the moment she goes into, you know … she’s allowed to have autonomy and do whatever she feels like …

**Interviewer:** Yeah.

**Interviewee:** … they immediately go on. But it’s, it could be a teenager thing, too. Who knows?

**Interviewer:** It could be. And what types of things does she listen to, do you know?

**Interviewee:** She definitely listens to music like, she’ll ... I noticed she looks up different pop songs on YouTube and she’ll just listen to the the music.

**Interviewer:** Yeah.

**Interviewee:** She definitely … YouTube videos a lot. She’s been … interestingly enough, she’s been watching a lot of YouTube videos in this … mostly two or three of them, of children, young children tantruming. And she keeps saying, “*It’s so funny. It’s so funny.*” And I’m like, “*It’s not really funny*,” but my ... I have a theory around it. And I’m, you know, I’m not sure if I’m right on it, but I … my theory is Helen, you know, she’s had a lot **[04:00]** of behavioral issues. And when she … one of the things that used to trigger her was kids being upset, or anyone really kind of being upset or tantruming or whatever. And, and she ended up, you know, it ended up being a problem for her and she ended up getting kicked out of the last school that she was in because there, there was a kid that was … he was just being defiant. And it just literally triggered her into a rage. And ever since then she’s been terrified of having … you know, she wants to go back to normal schools. She wants to go back to … but she can’t because no one wants to take her. So, she, I think, is watching these videos to desensitize herself. **[crosstalk at 04:57]** I’m sorry—to desensitize herself to the things and, if she finds them funny, it won’t throw her into …

**Interviewer:** Yeah.

**Interviewee:** … refit.

**Interviewer:** Yeah, absolutely. Getting used to them and making them like, a positive thing, not a negative thing.

**Interviewee:** I think she’s figured it out.

**Interviewer:** Yeah.

**Interviewee:** Because I noticed she watches a lot of videos of things that scare her. Or, like, she’ll watch things on surgeries, she’ll watch things on blood, blood draws.

**Interviewer:** Yeah.

**Interviewee:** She’ll watch, like, YouTube has become the, the thing that she goes to, to find out information and because she doesn’t ask questions or know how to ask …

**Interviewer:**

Yeah.

**Interviewee:** … or think to ask questions. So she goes, she, she just knows to search on YouTube for video explanations of everything and I, and I think, you know, I’ve, I’ve looked at it as, she looks at it for desensitizing herself, getting herself used to these …

**Interviewer:** Yeah.

**Interviewee:** … certain things that bother her. Also, she watches it to calm herself. So she watches a lot of bird documentary videos, and listens to birds. And you know, it really … she uses those things to uplift her mood, as well. So these … this is theory …

**Interviewer:** Yeah.

**Interviewee:** … but I really think it’s, it’s kind of a thing, and when she’s in class with this, with … with the pandemic that’s been going on … and she’s been having more virtual stuff. She, you know, she used to get more breaks, it seems like they take less breaks now. I don’t know why, but they …

**Interviewer:** Yeah.

**Interviewee:** … seem to be taking less breaks. And so she has been sneaking her, her cell phone in …

**Interviewer:** Yeah.

**Interviewee:** … and watching, you know, having images up **[7:00]** of ... like, she won’t want … put any videos on, but she’ll put up images, like, images of things that she likes, like, pictures, and she has to surround herself with these things. So I don’t know if you consider that a sensory need. But to me it’s, it’s kind of.

**Interviewer:** It’s visual, you know?

**Interviewee:** Yeah, she’s, she’s got … she needs a visual stimuli to …

**Interviewer:** Yeah.

**Interviewee:** … and what … so she said she, like, looks at pictures that calm her.

**Interviewer:** Yeah. So you talked about birds, what other things …

**Interviewee:** She’ll have pictures of her favorite video game characters. **[inaudible crosstalk at 7:36]** She has pictures of, like, My Little Ponies, those, those type of things, things that she really, really likes.

**Interviewer:** Yeah. And then, in your interest form, you also talked about her touching her face to your face.

**Interviewee:** Yeah, so …

**Interviewer:** Does she have other ...?

**Interviewee:** A lot of times … and I can’t, and I can’t quite figure out when she needs it, but she’ll come up to me and she’ll, like, put her cheek against mine and it’s, like … really push for pressure.

**Interviewer:** Yeah. Does she seek out ...? Oh, I’m sorry.

**Interviewee:** No, that’s all right. She … so, and she, she sometimes looks at me, like she wants to kiss me, you know. So I think she’s sensor ... needing pressure on her mouth and all this stuff. So, I don’t really know why it happens or what she’s looking for. But I think it’s, you know, I think it’s a comfort thing as well. She also will say that when she’s starting to get upset, getting hugs from me is helpful.

**Interviewer:** Yeah, like, that deep pressure.

**Interviewee:** But it has to be before she’s over the … like, if she’s just starting to ramp up, it has to be then. If it’s during or whatever, it’s … it becomes, like, too much like fight or flight, “*Get away from me*.”

**Interviewer:** Yeah, absolutely.

**Interviewee:** She also does have some visual things. And I … you know they were very prevalent when she was young. And then they went away and they seem to be coming back again. Where she’s looking through the peripheral, peripheral.

**Interviewer:** Yeah. Is …?

**Interviewee:** But I’m not quite sure what that’s about.

**Interviewer:** Is she looking, like, in the periphery in all contexts or some contexts?

**Interviewee:** I’m not quite sure. It’s not always …

**Interviewer:** Yeah.

**Interviewee:** … but, like, she’ll be … sometimes if she’s … I think it’s when she has a lot of energy, like, nervous energy, I’ll see her looking off through the **[10:00]** corner.

**Interviewer:** Yeah.

**Interviewee:** … and really kind of straining and so I don’t know if it’s out of … When I think about it, when she’s looking like that, I think it’s, again, maybe a soothing thing, where she’s doing it to settle down …

**Interviewer:** Yeah. Interesting.

**Interviewee:** … or something.

**Interviewer:** It seems like **[crosstalk at 10:20]** she has a lot of sensory things that, like, calm her down, like, I think they’re her positive interests.

**Interviewee:**

I, I, I get the impression they’re her calming strategies or things that keep her in check. And if you ask her why she does it, she gets upset. “*Cut it out.*”I’m like,“*All right*.”

**Interviewer:** Yeah.

**Interviewee:** I, I’m just curious, I just want to understand and she doesn’t … I think she’s almost maybe even embarrassed possibly. If you bring it up, like, she’ll do a lot of whispering [imitates whispering] those type of noises. And, and you’re like, “*What are you trying to say?*” And then she gets very upset, like, that you’re acknowledging she’s doing that.

**Interviewer:** Got you.

**Interviewee:** So I’m not sure what it’s about. But there’s that.

**Interviewer:** Yeah.

**Interviewee:** She, when she … now, as a result of … she used to be in residential care. Now she lives at home again. She … and she’s home because she asked to come home. And she doesn’t talk much. So if she’s really ... like, she actually said it was driving her insane being there …

**Interviewer:** Yeah.

**Interviewee:** … and I think it was because all the tantruming and the behaviors around her were constant. And she was trying to not imitate or be, you know … get upset by them.

**Interviewer:** Yeah.

**Interviewee:** So we had to take her out, you know, and she was doing really well for a while, but one of the things I noticed is when … she occasionally gets into an aggressive nature, like, she wants, she wants to fight. She tries to almost instigate you to restrain her.

**Interviewer:** Interesting.

**Interviewee:** Like, aggressively restrain her.

**Interviewer:** Yeah.

**Interviewee:** And I don’t know if it’s, it’s, you know … “*When I would lose control like this at school, they would restrain me*.” You know what I mean? So I don’t know if she has in her head … because everything for her is a rule. It has **[13:00]** to be … there has to be a rule for everything. So when she’s upset, she wants you to restrain her.

**Interviewer:** Do you think it’s the … is it the rule that she likes, right there? Or is it, like … does she want maybe that deep pressure that happens when you restrain her?

**Interviewee:** I don’t know. That’s, that’s the thing that I … you know, when I’m saying a sensory need for her, I don’t know if it’s because she thinks it’s a rule that “*I’m* *losing control* *so now you have to* …

**Interviewer:** Yeah.

**Interviewee:** … *you have to restrain me*.”

**Interviewer: [inaudible at 13:34]**

**Interviewee:** … or if it’s because she needs it? Because I’ll tell you, she fights. Like …

**Interviewer:** Yeah.

**Interviewee:** … even if you, you know, give in and say “*I don’t want to restrain you. I just want you to* …,” you know, and then if you do restrain her, she, she’ll fight you even more. So I don’t … it’s hard. It’s really hard to understand …

**Interviewer:** Yeah.

**Interviewee:** … if it’s an OCD, or, you know … I don’t know.

**Interviewer:** Yeah.

**Interviewee:** She does seem to calm, calm down eventually. But I don’t know if it could have been achieved without, you know, putting her in a restraint.

**Interviewer:** Yeah. Yeah, that makes sense. **[crosstalk at 14:17]**

**Interviewee:** Because she wants a hug when she’s starting to get …

**Interviewer:** Yeah, if ...

**Interviewee: [crosstalk at 14:20]** but if you try and just give her a hug when she’s … “*Why don’t I give you a hug?*” and it’s “*No*”—it has to be a different type of pressure. You know what I mean?

**Interviewer:** Yeah.

**Interviewee:** So another thing that she definitely, like … sound, like, again, she gets overwhelmed by sound and … but I can’t quite, you know … Like, she’s, like, the other day … her sister is very … she’s a songbird so she’s constantly singing. And I like to sing even though I don’t have a good voice, but I’ll, I’ll sing a lot. And Helen, you know, she’s been recently really expressing, “*I don’t like singing. Please, no singing*.” But she loves music. She doesn’t like … I don’t know what, what it is.

**Interviewer:** Yeah.

**Interviewee:** There’s something about me singing or her sister’s singing that just she’s like, “*Stop! Stop!*” you know.

**Interviewer:** Yeah, I know.

**Interviewee:** “*Please stop singing!*” So I don’t know what it is. I don’t know if it is too much stimulus coming in … too much, you know … Like, she’s not … there’s already too much that she’s dealing with: me singing …

**Interviewer:** Got it.

**Interviewee:** … is throwing her over the top. Because I know sometimes for myself, like, especially in the mornings when I’m just waking up, if someone’s being loud, like, if Hannah’s singing, I’m kind of like, “*Can you, can you turn it down a little?*,” you know.

**Interviewer:** Yeah.

**Interviewee:** So I’m assuming it’s … for Helen it’s **[16:00]** more severe.

**Interviewer:** Yeah, absolutely. You talked about tantruming too being something she doesn’t like, or didn’t like, in the past.

**Interviewee:** She still ...

**Interviewer:** Do you know ...?

**Interviewee:** … really doesn’t, but she’s trying to say it’s funny when she sees it.

**Interviewer:** Right? Thank you. Is it, like, the sound of the tantrum? Is it, like … do you know what part of the tantrum bothers her?

**Interviewee:** If I were to guess, like … well, when she was little-little, the sound of crying babies would upset her, but now that I’m getting to know her, I think it’s, it’s feeling, I think it’s more of a feeling—like, the emotion of it. Like, I think emotions that are heightened really affect her …

**Interviewer:** Yeah.

**Interviewee:** … in that manner.

**Interviewer:** That makes sense.

**Interviewee:** Just the way she reacts to certain things, you know, and, like, she’s very, very … With, with people she cares about, if they are showing that they’re upset, like, they’re crying or are having a hard time, it’s very upsetting to her. And she just wants, you know … she doesn’t know, like … she just wants to make it stop.

**Interviewer:** Yeah.

**Interviewee:** So, normally, her reaction would be a behavioral reaction of trying to hit or starts yelling at you to, you know, calm down—those type of things. So I don’t … those type of things are triggers for her, but I think … I don’t think it’s necessarily how loud it is. I think it’s the action of it.

**Interviewer:** Yeah, that makes sense. It’s kind of like …

**Interviewee:** Before we used to be … we thought it was … we used to think it was the, the sound, but the fact that we’re like, “*Well, you know, jeez, a firetruck could go by and it’s not a big deal*.”

**Interviewer:** Yeah. Yeah.

**Interviewee:** A child crying is very upsetting, or, you know, or someone showing the emotion of being frustrated, you know. And I almost feel like it’s, it brings her into this heightened emotional state of … she understands, she empathizes in a way so that she …

**Interviewer:** Yeah. Yeah.

**Interviewee:** … that she truly …

**Interviewer:** She is overly empathetic.

**Interviewee:** Yeah, like, she feels it way too much.

**Interviewer:** Yeah. Yeah.

**Interviewee:** Yeah. So that’s my, my take on it. But I don’t, you know …

**Interviewer:** Yeah.

**Interviewee:** It’s hard to tell because she can’t really tell you or explain to you, you know.

**Interviewer:** Absolutely. So when she is in scenarios where, like, maybe there are people tantruming or overly upset **[19:00]** or other sensory things that she doesn’t like, how does she manage or cope with those scenarios?

**Interviewee:** Yeah, she definitely, most of the time she … Like, the real triggering ones will just, will have her want to go and when ... it ... they, they trigger her into more of a violent thing and she tends to target two people: me and my daughter Hannah, like, but mostly my … her sister Hannah. Because she’ll be, like, very upset about it. And then she’s like, “*Where’s Hannah, where’s Hannah? I need to hit Hannah*.”

**Interviewer:** OK.

**Interviewee:** So it’s not … again, it’s not … I don’t even know if it’s a sensory need, but ... as much as a “*I have to repeat the pattern*,” you know, “*because the last time I got upset*,” you know, “*I hurt my sister and then it was over*.”

**Interviewer:** Got you. So it’s a kind of, like, pattern seeking is a big thing.

**Interviewee:** Yes.

**Interviewer:** You also talked about, like, headphones. Does she do that to block out sounds or just kind of to soothe her into comfort, or both?

**Interviewee:** You know, I think it might be both. I think she’s discovered that, “*Hey, I like, wearing headphones.*” And it really does block out noise.

**Interviewer:** Yeah.

**Interviewee:** She can still hear you, but I think she’s also noticed that if she’s wearing the headphones, and you’re talking to her, they’re probably like, “*Oh, she doesn’t hear me, I*,” you know, “*I’ll leave her alone*.” And I’m like, “*She can hear you*.” Because she’ll have the headphones on. And it depends if she wants to hear you. You know, she’s definitely learned to use it as a tool, but I think it definitely filters out the, the noise to her.

**Interviewer:** And you also talked about YouTube kind of as, like, a self-desensitizing system.

**Interviewee:** Yeah.

**Interviewer:** Do you think … when did she start that? And do you think it’s helping her at all?

**Interviewee:** I’ve kind of recently started to say, you know … I used to try and stop her from watching the tantrum videos because I didn’t understand why she was watching it. But I, I actually almost find it that she’s, she uses them even to, like … she wants to tantrum, she’s upset about something, so she’s going to go watch the tantrum video.

**Interviewer:** So, instead of tantruming herself?

**Interviewee:** Instead of tantruming herself. So I find that, like, the other day she was very upset about schedule changes.

**Interviewer:** Yeah.

**Interviewee:** And, you know, just, just people saying, “*Oh, I can’t make it now. Can we reschedule?*” **[22:00]** And she was really looking forward, you know … and it was just “*Why?*” You know, to her it’s like … She’ll use words, inappropriate words to describe her feelings like, you know, “*Why did they kill this?*” And it’s like, you know, “*I need … I want*,” you know … “*taking a knife and stabbing*.” You know, she’ll say things like that. And it’s, like, she’s really upset …

**Interviewer:** Yeah.

**Interviewee:** … it’s not that she wants to take a knife and stab. She’s, she’s, she’s … she goes to that …

**Interviewer:** Yeah.

**Interviewee:** … height, you know: “*What’s the worst thing I can possibly … to express how I’m feeling right now?*” Because she lacks the ability to truly express herself. So I do catch her watching those videos when I am, like, I think she, you know, she must be upset about something. Why is she watching these things? So I’m kind of just letting her because I find she … it’s upsetting to her if I stop her. So I’m like, “*All right*.” And she’s like, “*It’s so funny*.” And I’m like, “*OK, I’m glad you*…,” you know ...

**Interviewer:** And is ...? Oh, I’m sorry.

**Interviewee:** I … it’s hard because you want to say, “*It’s not funny, it’s not funny*.” And I, and I have, but that doesn’t go anywhere with her.

**Interviewer:** Yeah.

**Interviewee:** And I think, you know, she’s starting to say little things like … So, you know, she’s starting to show that she really needs to make up rules for herself. Like “*If I get unfocused with class, I lose 15 minutes of free time*.” Because I set up a kind of a thing like that because she was really … in the summer, she was really … Now we’re getting off base. We’re not even talking sensory, but I don’t … it’s her constantly trying to control …

**Interviewer:** Yeah

**Interviewee:** … her own ... by creating little rules. Like, if …

**Interviewer:** Yeah.

**Interviewee:** I, you know, if … and she doesn’t want to lose the opportunity to wear her headphones.

**Interviewer:** Yeah.

**Interviewee:** And she’s become very good. We are trying to limit how much screen time she’s doing, because she wants it all the time.

**Interviewer:** Yeah. Yeah.

**Interviewee:** It’s very much an addiction. And so we implemented a … one hour a day from noon to one, there’s no electronics.

**Interviewer:** Yeah.

**Interviewee:** And we, we stopped enforcing it. But she does it every day from noon to one. She’s, like, “*It’s time to rest*.”

**Interviewer:** And she knows ... **[inaudible at 24:49]**

**Interviewee:** Like, she’ll go in her bed. And I’m like, “*You don’t have to go to sleep*,” but it’s made her like, “*I’m taking … I’m resting at this time*.”

**Interviewer:** Yeah. Going back to, like, the tantruming videos. Do you ... is she using it, like, as her replacement **[25:00]** for her own behaviors?

**Interviewee:** I, you know, I’m starting to suspect yes.

**Interviewer:** Yeah, got you. And then, thinking, like, broadly about her sensory sensitivities and sensory interests: has she ever received services or interventions for them?

**Interviewee:** Well, right now we’re having ABA. But it’s more, like, teaching her how to use soothing, soothing and coping strategies …

**Interviewer:** Yeah.

**Interviewee:** … that, that, you know, I think are more … that apply to you and I more so than her. Like, I think she’s developing her own soothing strategies that don’t make sense to us, you know …

**Interviewer:** Yeah.

**Interviewee:** what I mean? So … but for social acceptance, you know, you can’t …

**Interviewer:** Yeah.

**Interviewee:** … do those things, you know. People won’t ... people are not going to want you around. So we’re … she’s trying really hard to learn. Like, she knows rotely, like, “*Oh, they should take a deep breath*.” So like, when I ... her young, her young cousin, that’s about four years old, he was having a tantrum, and we were all nervous, like, “*How is she going to react?*”

**Interviewer:** Yeah.

**Interviewee:** And she just looked at him and said, “*You need to take deep breaths*.” But she didn’t lose it and then she put her **[crosstalk at 26:30]** and then she walked away. And …

**Interviewer:** That’s good!

**Interviewee:** … at one point, she was like, “*It’s so funny. It’s so funny*.” And so, that … Helen’s, she’s very smart. And she’s very …

**Interviewer:** Yeah.

**Interviewee:** … her problem solving skills. I think that’s what she’s doing by …

**Interviewer:** Yeah.

**Interviewee:** … you know, trying to desensitize herself.

**Interviewer:** Absolutely. You talked about maybe, like, trying to give her, like, soothing strategies that are maybe more, like, socially appropriate. Do you mean, like, not watching, like, bird videos, instead of, like, taking a rest?

**Interviewee:** No, you know …

**Interviewer:** Yes.

**Interviewee:** … it’s OK. Like, we’ll ask her, you know, things like … that, like … watching a bird video, looking at a picture of a bird, we’re like, “*Oh, that’s fine*.” Like, if you go to her work desk at school and her work desk at home, there are pictures of birds everywhere and we’re, we’re kind of like, “*That’s OK. That’s cool*.”

**Interviewer:** Yeah.

**Interviewee:** You know? But you can’t, you can’t go to the point where you’re using these soothing strategies to the point that you, you can’t even focus. And ... but I think that’s … the problem is she can’t focus. And she’s trying to focus by soothing herself. So …

**Interviewer:** Yeah.

**Interviewee:** … it’s like, it’s a vicious cycle. And it’s, it’s I think very … you know, it’s trying to understand it, and how do we make it easier for her? I just … she’s, she’s trying to do it herself, you know.

**Interviewer:** Yeah.

**Interviewee:** She’s very, you know … **[28:00]** she’s definitely interesting.

**Interviewer:** Yeah.

**Interviewee:** And these are, you know … again, it’s … these are … I just … because I spend so much time with her and it’s, like, I’m studying her constantly.

**Interviewer:** Yeah.

**Interviewee:** So there ... you know, these are just my guesses.

**Interviewer:** Absolutely. That’s fine. On the demographics form, you indicated that she’s received early intervention for her sensory sensitivities.

**Interviewee:** Yes. OK. So, yes, she did. There was a lot of, like, deep pressure. She wore a compression vest …

**Interviewer:** Yeah.

**Interviewee:** while she was doing, you know … when she’d be sitting at table, we’d have her wear … and she was able to focus much more. She definitely … Oh, here’s another thing: she, she needs to sleep with a blanket completely around her head.

**Interviewer:** Like, over her face? **[crosstalk at 28:58]**

**Interviewee:** Over her face, to the point where I’m like, “*She’s going to … how does she breathe?*”

**Interviewer:** Yeah.

**Interviewee:** But she needs to do it to sleep. She’s gotten into needing to wear earplugs and an eye mask as well. And if she doesn’t have them, it’s very upsetting. So it’s, like, she needs to close everything out …

**Interviewer:** Yeah.

**Interviewee:** … in order to go to sleep.

**Interviewer:** Interesting. Has that always been ...? **[crosstalk at 29:16]** Oh sorry, go ahead.

**Interviewee:** … and she has a weighted blanket at the base of her bed that she doesn’t put up on her, but she has on her feet.

**Interviewer:** So, OK, but ...

**Interviewee:** … that she can get by without, but when she’s in her room at home, it’s … she definitely, like, I’ve tried saying, “*Oh, do you need this?*” “*Yes*.” And it has to be perfectly placed. And same thing with her sheets. Like, when she gets in her bed, everything needs to be … her bed needs to be made perfect. So she ... I mean, thank God, she knows how to make her bed and do these things. She does it, you know.

**Interviewer:** Yeah.

**Interviewee:** And, like, if … she can tell if something’s off, like, “*This isn’t right*,” you know.

**Interviewer:** Yeah.

**Interviewee:** She’s very in tune to how her blankets are … if they’re not on the bed right, you know.

**Interviewer:** Yeah.

**Interviewee:** But it’s like she needs a perfect environment.

**Interviewer:** When she was using, like, the deep pressure vest when she was little, did that help her focus or, like, regulate?

**Interviewee:** I felt like it did. I felt like it did. And it was to the point where we’re, like, “*We don’t want to take it off*.”

**Interviewer:** Yeah. But she doesn’t …

**Interviewee:** You have to: you can’t just leave it on all the time. So, you know, we kind of reserved it for, for when she would have ABA or sometimes if she seemed way too, like [waah, imitates sound]

**Interviewer:** Yeah.

**Interviewee:** … we’d try and offer it to her to see if she’d want it, you know, and she, she would occasionally take it.

**Interviewer:** Does she use it now or was that just when she was little?

**Interviewee:** That was just when she was little. We just kind of … again, I think it’s become a **[31:00]** situation of … she’s really starting to learn how to desensitize herself to certain things. And I think one of the things … at Boston Higashi, they don’t allow kids wear headphones.

**Interviewer:** Oh.

**Interviewee:** They’re not allowed to … yeah. They’re like, “*We’re ... they need to desensitize themselves* *that there is* …,” you know, “*They have to be … get used to loud noises* …”

**Interviewer:** Yeah.

**Interviewee:** “*They have to, you know … they want to live in the world with us. These are the things*,” you know, and, and same thing with food. Like, Higashi was incredibly successful with fixing some things that are were really sensory things, like foods, Helen will eat everything now.

**Interviewer:** Was she very sensitive to foods when she was younger?

**Interviewee:** She wouldn’t eat anything but bread—white, like, the classic white bread.

**Interviewer:** Yeah.

**Interviewee:** Goldfish crackers, you know, this … the same thing. She did like fruit. I did manage … she always liked fruit.

**Interviewer:** Yeah.

**Interviewee:** Vegetables, not so much. But now, you know, the kid eats salad.

**Interviewer:** That’s great.

**Interviewee:** Like, she wouldn’t even … One time, she had gotten sick on macaroni and cheese when she was a baby and then she stopped … not … she wouldn’t eat it anymore.

**Interviewer:** Yeah.

**Interviewee:** Now, she’ll eat it.

**Interviewer:** OK, I wouldn’t have thought that ...

**Interviewee:** And the she really kind of … I think it almost got to the point where her first year she got so skinny. Because they’re like, “*This is what you get to eat. This is what ...*”

**Interviewer:** Yeah.

**Interviewee:** “… *you’re eating*.” Eventually it was … she gave in. And then, once she gave in, she realized, “*Oh, I didn’t die. Oh, that wasn’t that bad*.”

**Interviewer:** Yeah.

**Interviewee:** And now she’s more willing. Like, she’ll look at some things and, like, she still gets that, “*I don’t want to try that. That looks gross*,” you know.

**Interviewer:** Yeah.

**Interviewee:** And it’s like, “*Well, you need to try*.” She’ll say, “*How many bites?*” You know, or, “*Can you just try it? We’re going to have this a couple of times* …”

**Interviewer:** Yeah.

**Interviewee:** “ … *so, and you can then decide if you really like it or not*.” That makes her mad. But she … we, I mean, we found things that were, like, well … she really likes eating chicken curry.

**Interviewer:** There you go.

**Interviewee:** She loves chicken curry, spicy.

**Interviewer:** Oh yeah.

**Interviewee:** She likes sauteed shrimp and rice. She likes, you know, things that, you know, “*You can’t feed a kid that—they’re not going to eat ... want to eat*.” But she loves them, you know. So she used to not like pizza, but now she’s like, “*I really like pizza. But I like it with pepperoni and mushrooms on it*.”

**Interviewer:** A lot of people don’t like mushrooms.

**Interviewee:** Yeah. It’s a sensory thing, too, right?

**Interviewer:** Yeah.

**Interviewee:** But she, she likes them … things that … You know, they were very good about, “*We know this bothers the* **[34:00]** *crap out of you. But you need to deal with it because …*”

**Interviewer:** Yeah.

**Interviewee:** “… *you need to live and there are going …*”

**Interviewer:** They kind of …

**Interviewee:** “*to be loud noises and you need to* …” So, I think she learnt through Higashi certain ways of “*I need to do this so that I can desensitize myself*.”

**Interviewer:** They kind of, like, exposed her to things that she didn’t like, because she had to.

**Interviewee:** And I think we try so hard to … it’s, it’s hard because what is right?

**Interviewer:** Yeah.

**Interviewee:** You know, should we be respecting them … that these are things are hard, but they’re in the minority, so they have to adapt to us.

**Interviewer:** Yeah, absolutely.

**Interviewee:** Other things that we did for sensory, with early intervention: playing with playdough, all the classic playdough, slime …

**Interviewer:** I loved that stuff.

**Interviewee:** … those type of things. She definitely enjoyed playing with them. The shaving cream. Those were all very good for her. She definitely loved being in water. She loves being in water.

**Interviewer:** Yeah.

**Interviewee:** So we taught her early on how to float, how to … “*If you fall into the water, you have to get to the side of*,” like “*if you, if you’re at a pool and you fall in* …”

**Interviewer:** Yeah.

**Interviewee:** … get to the side of the pool and then try to walk yourself out.

**Interviewer:** Yeah.

**Interviewee:** “… *don’t try and* …” but we really worked ... you know, “*Float, get on your back, float to the side of the pool and then walk out*.”

**Interviewer:** Yeah.

**Interviewee:** We would drill her on those things to … but because we knew she wanted to be around water, so

**Interviewer:** To make it safe.

**Interviewee:** She’s very drawn to water.

**Interviewer:** When she was at Higashi, she … did they help her with her sound sensitivity? You talked about food a lot.

**Interviewee:** Yeah. Well, the … all the kids are … they have … music is very important at Higashi and, you know, anytime they’d have, they’d have assemblies—all the kids have to go into assembly, you know—and some of the things they would use to help was exercise. You know, the kids were constantly exercising. So exercise seemed to kind of help out with that.

**Interviewer:** How about with her sensitivity to sound?

**Interviewee:** … to, to possibly sound, yeah and to just being overstimulated.

**Interviewer:** Got you.

**Interviewee:** So if she was … if she … every morning, they, you know, they would have the kids run before classes. So …

**Interviewer:** Good for them.

**Interviewee:** Helen was running, like, a mile every morning.

**Interviewer:** Better than me, then.

**Interviewee:** And kids would literally be, like … go from jumping and being all over to … [calm sighing sound], you know, or level. And then, they definitely would have … incorporate **[37:00]** a lot of movement breaks and a lot of, “*OK, we’re going to do exercise throughout the day to kind of level out the …*” **[crosstalk at 37:12]**

**Interviewer:** Yeah, and does she use those, like, physical techniques herself now that now that she’s not at Higashi?

**Interviewee:** We kind of force her to … we started having her … we introduced her to Peloton.

**Interviewer:** Nice.

**Interviewee:** I take a calendar and I write out every day a different workout. And to get … she is … when she, she doesn’t want to do them … but then, when she does them, she’s definitely much more Zen …

**Interviewer:** Yeah.

**Interviewee:** … and much more relaxed. And when … if, if we give her a break from them, she tends to … we start to see more behavior. So exercises we’ve found is definitely helpful to her, even though she doesn’t necessarily love it. And I think that’s, like, for all of us, you know, like, I don’t really like it, but I do it, you know. I don’t want to work out, but I got to work out and I go workout and I feel better.

**Interviewer:** Yeah. I feel like, “I’ll know I’ll like this later, but I don’t want to do it now.”

**Interviewee:** Yeah and then you keep pushing it off because you just don’t want to ... Well, it’s the same for her. But, like, if I have her … if I introduce it into her schedule … for me, I just had to say, “*OK, we’re going to do a streak*.” You know how people do running streaks and stuff?

**Interviewer:** Yes.

**Interviewee:** So I’m like, “*Let’s do a peloton streak.*”Because she kept asking for this … a Furby. And now if you want a Furby you’ve got to pay, like, 150 bucks, because they are … So I’m like, “*All right. You want a Furby, you have to have a 30-day streak*.”

**Interviewer:** It’s a fair deal.

**Interviewee:** “*No problem. No problem*,” she’d be like. But now that I’m starting to not have that incentive and trying to phase out the, the prizes …

**Interviewer:** Yeah.

**Interviewee:** … she, she’s ... no streak. There’s no streak. What’s the, you know, like, this week, I’m giving her a normal … you get two days off from working out. I don’t want to overstrain her body.

**Interviewer:** Absolutely.

**Interviewee:** I … you know, I … to support her, I’ve been exercising with her and I’m getting older and I’m feeling the strains of working out every single day. And …

**Interviewer:** Yeah.

**Interviewee:** So I’m kind of like, “*OK, we need two days off*.”

**Interviewer:** Yeah.

**Interviewee:** But she’s confused by it. Like, “*Wait, there’s no streak. This is a streak*. *This is all new. This is a new exercise program and it’s special*.” And, you know, it’s taking her time to adjust, but …

**Interviewer:** Got you.

**Interviewee:** … she’ll get there, but I think she’ll enjoy it more when … and I’m eventually going to start trying to have her … “*You write out the workouts*.” **[40:00]**

**Interviewer:** Absolutely.

**Interviewee:** You know, and see if … you know, I want her to incorporate exercise into her life because I think it’s really going to be key in keeping her level headed.

**Interviewer:** Absolutely.

**Interviewee:** You know, she takes medication, but, honestly, like, I would not credit the medication with what’s helping her.

**Interviewer:** You credit with, like, exercise and these other coping strategies?

**Interviewee:** Ex ... yes.

**Interviewer:** Got you.

**Interviewee:** It’s so … I’m almost to the point where I don’t know how much the medication is helping her. I’m sure it helps a little …

**Interviewer:** Sure.

**Interviewee:** … but it’s not signifi …

**Interviewer:** The biggest thing. You talked about how, when she was younger, she was more picky and, like, more sensitive to food. How else have her sensitivities changed, or sensory interests changed over time?

**Interviewee:** She, you know, she doesn’t need to play with the playdough and the … and, you know, she, she kind of outgrew that. She still likes it, but it’s not, like … she doesn’t seek those things out anymore. She, she still has … she still seeks out being under blankets. And, like, if we go … anytime we go visit somewhere new she … I have to explain to everyone, “*She’s going to go look for your bedroom and get in your bed and get under the blankets*.”

**Interviewer:** Yeah.

**Interviewee:** Because that’s, that’s what she does.

**Interviewer:** And she has always done that?

**Interviewee:** And “*Make sure you’re comfortable with that because, if you’re not, we probably shouldn’t come over*.” She’ll do it in a complete stranger’s home, you know, like, but … someone that’s a stranger to her. She doesn’t care. She’s … that’s a bit … I’m … “*Where’s the bed?*”

**Interviewer:** Yeah.

**Interviewee:** She goes looking around your house. “*Where’s the bed?*” She needs to get in the bed.

**Interviewer:** And it’s because she likes the, like, sensation of the blankets, like, over her?

**Interviewee:** She likes to be covered up in blankets.

**Interviewer:** Yeah. And this has always been the case?

**Interviewee:** That’s always been the case. But what I’ve noticed is, she’s starting to come out of the shell more because she’s, I think, starting to desensitize herself to, like …

**Interviewer:** Yeah.

**Interviewee:** kids, children ... “*I do not like children. I do not like babies*.”

**Interviewer:** Yeah.

**Interviewee:** But she’s starting to be like, “*Oh, oh, they’re cute*,” you know. And she’s able to come out and small **[? inaudible at** **42:31]**…

**Interviewer:** Yeah.

**Interviewee:** … **[inaudible at** **42:33]** And she’s wanting to … I think she really wants to be around people but can only handle it in small doses right now.

**Interviewer:** Absolutely. Would you say that her sensitivities are, like, more or less severe than when she was younger?

**Interviewee:** I think they … I would say it’s hard to say.

**Interviewer:** Yeah, that’s fair.

**Interviewee:** I think it’s different.

**Interviewer:** Yeah.

**Interviewee:** They affect her differently. I think she **[43:00]** has more control over them than she did when she was younger. When she was younger …

**Interviewer:** OK.

**Interviewee:** … there was just nothing … I mean, it got to the point, like I said, we had to put her in residential because we had … we couldn’t … she wouldn’t take … she’d bite us to get in the shower or the bath. And then we couldn’t get her out once she was in it.

**Interviewer:** Yeah.

**Interviewee:** And it was, like, literally fight, like, she’s hitting us, punching us, trying to get away.

**Interviewer:** Yeah.

**Interviewee:** You know?

**Interviewer:** Absolutely.

**Interviewee:** Always issues, like going to the bathroom. I think the potty training thing is a sensory thing. And, you know, Higashi applauded us, because when we brought her to school—and she was nine—to live there, she was potty trained. And she was potty trained at four.

**Interviewer:** OK.

**Interviewee:** It took us basically saying, “*You can’t leave the bathroom today. You have to sit on the toilet*.”

**Interviewer:** Yeah.

**Interviewee:**

“*You want a break from the toilet*.” This … it’s, it’s … it sounds abusive, but it was the only way we could get her to sit, you know.

**Interviewer:** Yeah.

**Interviewee:** She would be holding it and holding it and holding it. And I think it was a fear of—I don’t know—of the unknown, not knowing what it’s going to feel like. But the more she did it, the better it was and, like, after that one day, she was going to the bathroom by herself. Very rare accidents.

**Interviewer:** Because she wasn’t scared of that sensation anymore.

**Interviewee:** Yeah.

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

**Interviewee:** So I think a lot of, you know, sensory stuff is, like, how do you ... how … they can probably deal with their sensory things through desensitation ... desensitizing—but how to desensitize them without being cruel? It’s hard.

**Interviewer:** Yeah, absolutely. So, these changes that you’ve talked about, like her increased coping mechanisms, like her, her diet, like her potty training, or, like, when she was … were toileting, when she was quite … younger: do you think any of these changes are related to any independence that she’s gained over time?

**Interviewee:** She … absolutely.

**Interviewer:** Yeah.

**Interviewee:** She’s definitely become more independent. I don’t have to ask her to take a shower. She just takes a shower. I don’t have to, you know … if she wants a blanket on top or wool, like, something heavy, she comes and gets it. If she needs a break to get away from things, she goes. Whereas before, she would just have a meltdown. You know, and you would be there trying to calm her down.

**Interviewer:** Yeah.

**Interviewee:** It’s … she seems to be outgrowing the **[46:00]** over-the-top reactions. So, every time she experiences something new, it’s a learning experience for her.

**Interviewer:** And do you think, like … it appears as though she’s outgrowing these behaviors because she now knows she can cope with them and she has these coping mechanisms.

**Interviewee:** I think, I think she’s ...

**Interviewer:** ... unless she ...

**Interviewee:** I think she’s realizing that she’s, she’s starting to cope and desensitize to the point that, you know, “*These don’t really need to bother me, and I can walk them out*.”

**Interviewer:** Totally. When she is in a scenario that is overwhelming for her, like, in a sensory sense, does that cause or increase anxiety for her?

**Interviewee:** Yes. She definitely gets a fight or flight, like, “*Get me out of here!*”

**Interviewer:** How does she manage that anxiety?

**Interviewee:** She takes off.

**Interviewer:** Fair. That’s my next question. But that was kind of a give me.

**Interviewee:** She’ll take like … she, she … It’s interesting. Like, she’s not going to get lost. Like, she’ll go to safe places, so. Whereas I think some kids wander off.

**Interviewer:** Yeah.

**Interviewee:** She doesn’t wander off out of the house. If she’s having something, you know, she’ll just go to her room. Like, I’ve really taught her, “*Your room is your safe space*.”

**Interviewer:** Yeah. Got you.

**Interviewee:** You teach a dog, their, their crate is their safe space.

**Interviewer:** Yeah. Absolutely.

**Interviewee:** But when we’re out … for her, she’ll … she’ll want … she’ll just go to the car.

**Interviewer:** OK. That’s still a safe spot, though. It’s your car.

**Interviewee:** … getting to the car, how safe she is … like, she won’t be, like … I just … she just knows she needs to get to the car. So, you know, she’s gone out into traffic a couple of times because “*I have to get to the car. I have to get to the car. I have to* …” You know, like, we’re slowly starting to see her, “*Oh, I have to look* …”

**Interviewer:** Yeah.

**Interviewee:** “… *that there’s no traffic. I have to be aware* *of*” **[inaudible at 48:18]** You know, I’ve had so many heart attacks, and I still, like … she’ll get, she’ll get to a point where it’s going to be second nature to her. But I’ll still be having a heart attack every time I see her approach a road …

**Interviewer:** Yeah.

**Interviewee:** … or go out into a parking lot. Because I’m … like, she’s so busy blocking everything …

**Interviewer:** Yeah.

**Interviewee:** … to deal with what she’s feeling that she’s not able to be safe, you know.

**Interviewer:** Absolutely.

**Interviewee:** So until the day that I really, confidently feel that she’s desensitized herself to all these …

**Interviewer:** Yeah.

**Interviewee:** … environmental things, I’m going to be constantly, like [panicky sound] and it’s, it’s kind of a vicious cycle, because you sit there and **[49:00]** say, “*She has to get used to these things*.” But I’m so used to protecting her from these things that I don’t give her the opportunity. So I’m really trying to step back. But it’s so hard. It’s very hard to step back because I want her sane.

**Interviewer:** Yeah.

**Interviewee:**

You know, and I’m starting to also try to be like … she’s capable of saying … talking and saying words and stuff. And I just know, I instinctually know what she wants to say or what she’s feeling that I don’t let her do it. I explain it to people around her without letting her …

**Interviewer:** Yeah.

**Interviewee:** So now I’m … it’s so hard, you know.

**Interviewer:** Yeah.

**Interviewee:** Now when she’s having an ABA session, I’m going to leave the room because if I stay in the room, my instinct is going to be butt in.

**Interviewer:** Yeah. Absolutely.

**Interviewee:** And it’s funny because she has that too. Like, you know, like, when Hannah’s having a bad day, Helen’s just like, she can’t … she has a hard time ignoring it. She has this compulsion to …

**Interviewer:** Yeah.

**Interviewee:** “*I have to*,” you know, “*be involved, and I have to stop it*.”

**Interviewer:** Yeah.

**Interviewee:** “*Because I’ll be able to stop it*.” And … I don’t know, I’m going off on tangents.

**Interviewer:** That’s OK. No, that’s all right. Going back to the anxiety: has she always had anxiety or, like, by these sensory moments? Has it always been constant for her?

**Interviewee:** I think so. Yeah.

**Interviewer:** Yeah. And has she always, you know, used avoidance techniques when they’ve come up and then ...?

**Interviewee:** And so now … until now, like, like I said, she’s … I feel like, that’s what she’s doing … is she’s trying to … the things that cause her the biggest problems she’s really trying to ...

**Interviewer:** to work on.

**Interviewee:** to work on.

**Interviewer:** Yeah.

**Interviewee:** Not quite grasping the world around her and not quite understanding, not … things that, you know … this is why … she’s … with animals, sometimes she’s frightened by them because **[51:00]** she doesn’t know what they’re thinking or what they’re going to do. She loves them.

**Interviewer:** Yeah.

**Interviewee:** She wants to be near them. But, you know, at the same time, she can’t … it’s too, you know, “*I don’t know what they’re going to* …”—just like kids are unpredictable.

**Interviewer:** Yeah.

**Interviewee:** So she needs a lot of predictability in her life. And if she finds that “*OK. I can’t predict this*.” I think she’s starting to grasp that “*OK, I can’t predict this is going to happen or that’s going to happen. And I know it bothers me. So now I’m going to start to try and desensitize myself to it so that I can not be insane*.”

**Interviewer:** Yeah, absolutely. And then, thinking, like, ahead: what goals or hopes do you have for your, your, for your daughter in terms of her sensory sensitivities and sensory interests?

**Interviewee:** I just want her to not feel so **[52:00]** scared all the time. Like, I feel like, she is so nervous about stuff all the time. I just want her to be comfortable in her own skin, you know …

**Interviewer:** Yeah.

**Interviewee:** … because I think when she is, she can enjoy, she can … it’s … When she feels comfortable in her skin, you can see she’s happy … joy, you know …

**Interviewer:** Yeah.

**Interviewee:** that she wants to be part … wants to be near you. She wants to be, you know, included. And she craves that, she really craves it, but it’s too much for her right now. And I want her to get to the point where, if she craves it, she can do it, you know. I just don’t … again, I think … I hate to say it, but it’s almost up to her. I can’t … there’s not much I can do that … I think she just has to be … I’ve, I’ve always had with Helen, you know,

**Interviewer:** Yeah.

**Interviewee:** “*This is scary, but you’re doing it anyways*.”

**Interviewer:** Yeah. That makes sense.

**Interviewee:** Because, once you get over the scary part, and you, you … it’s like anyone, you know … And I think I, I started doing that with her because I, you know, I was always afraid of little things, and I would miss out on stuff. And it would … I feel, you know … because I was not … I was kind of shy and nervous …

**Interviewer:** Yeah.

**Interviewee:** … around people. And I felt like I was always missing out and I wanted to be part of it, but I couldn’t be part of it. So I, you know, I’m like, I don’t want my kids to feel that way.

**Interviewer:** Yeah.

**Interviewee:** And so they hate me sometimes for it. But you know, my, my younger ... **[54:00]** Helen, Hannah has sensory issues as well. We’re not talking about Hannah, we’re talking about Helen …

**Interviewer:** Yeah.

**Interviewee:** … but, but Hannah at least is able to verbally tell me. “*Thank you. Thank you because it’s so much easier for me now*.”

**Interviewer:** Yeah.

**Interviewee:** Like, you know, “*I hated you at the time, but because of you I can do things* *like*” … So Helen can go to movie theatres, she can watch movies.

**Interviewer:** Yeah.

**Interviewee:** She doesn’t need to wear her headphones to watch them. She can go to … like I said, we … I’ve taken her to live concerts.

**Interviewer:** Yeah.

**Interviewee:** I’ve taken her to a ... like, she loves amusement parks, and she can be around all those people and not be …

**Interviewer:** Yeah.

**Interviewee:** You know, she’s been able to enjoy those things.

**Interviewer:** That’s great.

**Interviewee:** And I’m no longer … you know, I don’t feel as imprisoned, imprisoned to my home because, you know, it … but it was very difficult growing up and getting through a lot of those things, because, you know, you have a child who’s losing their control, and you’re trying to keep control in public and …

**Interviewee:** … people judge you.

**Interviewer:** Yeah.

**Interviewee:** And I think that … that’s the biggest factor for a lot of parents is, you know, they’re trying to “*Stop that. Stop, stop, stop, stop*”—even with, you know, regular kids—“*Stop doing that, stop doing that, stop*,” you know, because they care so much about what others around them are going to think …

**Interviewer:** Yeah.

**Interviewee:** … instead of trying to figure out why are they acting like this? Why are they doing this, you know. So, as we ... I think most autistic … parents of people with autism will say, behavior always has a meaning.

**Interviewer:** Yeah, it’s communication.

**Interviewee:** I’ve got to plug the computer in.

**Interviewer:** Yeah, no worries. When you’re plugged in, I … you gave me a nice segue to my next chunk of questions.

**Interviewee:** OK.

**Interviewer:** Perfect. So we’re going to move on to our next chunk of questions. As your daughter has grown up and aged a bit, how has your and her community reacted to her sensory sensitivities and sensory interests?

**Interviewee:** Well, when you say “*her community*,” do you mean people that know her?

**Interviewer:** I mean it loosely. Like, her community could be her school, it could be, you know, you and her family ... places that you go out around your home.

**Interviewee:** OK. So ...

**Interviewer:** … if you have a religious group, things like that.

**Interviewee:** So, currently the school that she goes to, which is not a school for autism, they are very respectful of …

**Interviewer:** Great.

**Interviewee: [57:00]** and I’m like, “*Don’t let her get away with it too much because* ...”

**Interviewer:** Yeah.

**Interviewee:** “*You know, come on*.”

**Interviewer:** OK.

**Interviewee:** She, she’s like any other kid who is trying to avoid it because it’s boring, you know.

**Interviewer:** Yeah.

**Interviewee:** But, like, they understood that, like, sometimes she’ll be … when she’s insistent on something and they’d be like, “*Oh no, don’t worry about it*”—don’t ever do that to her. Because she’s usually right and then, then the bad happens. And you’re like, “*I can’t be mad at her for, like, having a complete meltdown. Because we didn’t listen to her*.”

**Interviewer:** Yeah, and do it.

**Interviewee:** Because she was trying to communicate … it just … we didn’t quite understand what she was trying to communicate, you know. So, like, I could say, for an example, she did … they were trying to do a science experiment. This was her first science experiment that she was doing. And they wanted to … she wanted ... she had chosen a project to grow crystals. So they had a hot plate and the glass beaker or whatever, and the teacher warmed up the hot plate and he was going to put the glass on there. And she’s like, “*No, no, it’s … Don’t do it. Don’t do it*.” And he’s like, “*No, it’ll be fine*.” But the hot plate got too hot and the moment he put it on with the stuff, with the crystals, it shattered and blew up **[inaudible at 58:34]**.

**Interviewer:** Yeah.

**Interviewee:** And she lost it.

**Interviewer:** Yeah, got you.

**Interviewee:** She lost it. And then like, you know, honestly, she … they were like, “*Totally our fault*.”

**Interviewer:** Yeah.

**Interviewee:** “*We didn’t listen to her*.” She was telling … instead of saying “*This is making her really nervous. Listen to her*,” you know

**Interviewer:** Yeah.

**Interviewee:** All right. Well, cool it, you know, or you can put it on and ask her, you know …

**Interviewer:** Yeah.

**Interviewee:** … and, like, try and find out what exactly she’s … So they really are starting to really understand. Also, like, if she yells at them or whatever, it’s her way of communicating that it’s difficult.

**Interviewer:** Yeah.

**Interviewee:** They need to be understanding.

**Interviewer:** Yeah.

**Interviewee:** And, you know, she doesn’t want you to skip it, but she needs you to know that it … “*This is really fricking hard*,” and “*I don’t get what the hell you’re trying to tell me*.”

**Interviewer:** Yeah, absolutely.

**Interviewee:** And that’s another thing. You know, sometimes they’ll try and say, “*She’s, she’s so good at this. We just want to skip and go ahead.*” Well, you know what, you’ve got to just go through it because skipping over something … she’s like, “*I’m missing out*.” Like, “*I just feel* …” like, “*No, I have to do everything, I have to be* …” **[inaudible at 59:52]** So they’re kind of really respectful of understanding **[1:00:00]** that, you know, we have to go through the order, if there’s an order to something. Another thing is …

**Interviewer:** Yeah.

**Interviewee:** [whispering to someone else] Hold on a second. We also noticed that she, like, will take off to do something all of a sudden.

**Interviewer:** OK.

**Interviewee:** And instead of being like, “*Get back here! What are you doing? Wah wah wah!*” [imitating scolding voice] we just let her do it. Because when Helen is like that, she, she has it in her mind what I want to do. Like …

**Interviewer:** Sure.

**Interviewee:** … and, and it always comes back and you’re like, “*Ah!*”

**Interviewer:** “*Now I see*.”

**Interviewee:** She doesn’t tell you.

**Interviewer:** Yeah.

**Interviewee:** So …

**Interviewer:** Yeah.

**Interviewee:** We’re kind of like, “*Let her* …” you know, “*Let her do her thing*.”

**Interviewer:** Yeah.

**Interviewee:** We’re more and more, “*Let her do her thing. She needs to do this; let her do it*.” “*Observe for safety reasons* …”

**Interviewer:** Sure.

**Interviewee:** “*But don’t, don’t scold her for trying to leave to do something*.” Like, “*It’s just … she’s not … it doesn’t come to her to ask permission to do it, you know*.”

**Interviewer:** Yeah. Absolutely.

**Interviewee:** Because she also ...

**Interviewer:** And then ...

**Interviewee:** obviously … Yeah. Go ahead.

**Interviewer:** And then, when she’s at school, do they, like, do they allow her to use her head ... her headphones when things get too noisy, like, are they understanding of those needs?

**Interviewee:** When she takes breaks, she’s allowed to use her phone. She’s, she knows she has five minutes.

**Interviewer:** OK.

**Interviewee:** It was interesting because in the morning, she’d be tired. And they, like, sometimes they’re like, “*Do you need to take a break?*” And she’s like, “*Yeah*.” And she would literally ... goes … they had a couch at the school, she’d go sit on the couch, close her eyes and do, like, a power nap for, like …

**Interviewer:** Yeah.

**Interviewee:** … five minutes and wake up and be like, “*OK, let’s go*.”

**Interviewer:** Oh, that’s great.

**Interviewee:** She, she got into power napping. And they’re like, “*She’s amazing*,” like.

**Interviewer:** It’s a good skill.

**Interviewee: [inaudible 1:01:58]** I think that one-hour thing to her has now become a habit, like, “*Oh, this is beneficial to take … shut down for one hour and just …*”

**Interviewer:** Yeah, absolutely.

**Interviewee:** “*… completely switch off*.”

**Interviewer:** And then, when she was younger, was, like, her and your community, like, more or less accepting of her sensory needs and her sensory interests?

**Interviewee:** I think we didn’t understand them. So they weren’t really accepting

**Interviewer:** Yeah.

**Interviewee:** But I feel like people are starting to understand autism a bit more and …

**Interviewer:** Yeah.

**Interviewee:** … are, are understanding that there are all sorts of … but I think we’re still learning how … what to do or how to help them.

**Interviewer:** Absolutely.

**Interviewee:** I can say that her school, you know, they’re, they’re definitely learning from her and she’s teaching them and there’s a lot of teaching there.

**Interviewer:** Yeah.

**Interviewee:** But she, you know … when I talk about school situations, **[1:00:03]** she was … she’s been expelled from two schools, because they weren’t willing to understand …

**Interviewer:** Yeah.

**Interviewee:** … why to help because of the safety of others.

**Interviewer:** Yeah.

**Interviewee:** So it’s, it’s tough, because, you know, like, for example, she wants to go back to the public school. They’ll never let her back.

**Interviewer:** Yeah.

**Interviewee:** And even if we say, “*She’s much better. She’s gotten, you know, desensitized to a lot of these things. She still has issues, but we’re getting closer and closer to pinpointing the things that set her off* …”

**Interviewer:** Yeah.

**Interviewee:** “*And we know, and, you know, I’m starting to notice certain times, it doesn’t always set her off. So it’s, it’s getting better*.”

**Interviewer:** Yeah.

**Interviewee:** “*But it still can … but it’s getting better. I can’t give you 100% guarantee*.” But,

**Interviewer:** Yeah.

**Interviewee:** ... you know. So, certain parts of the community …

**Interviewer:** Yeah.

**Interviewee:** It depends on how willing you are to be accepting.

**Interviewer:** Absolutely.

**Interviewee:** And to let Helen have the freedom to do what she needs to do to get through …

**Interviewer:** Yeah.

**Interviewee:** … and not be restricted. But there’s a lot of … that’s the thing, we just … we throw restrictions up to everyone and it’s …

**Interviewer:** Yeah.

**Interviewee:** You have to, to a certain … but for, for people like Helen, those restrictions can be hurtful.

**Interviewer:** Totally.

**Interviewee:** And so, you know, it’s like, they should get the special pass, like, they should be allowed to …

**Interviewer:** Yeah

**Interviewee:** But …

**Interviewer:** Absolutely.

**Interviewee:** You know, I think a lot of people get … “*I*,” you know, “*I have to control myself. Why do I have to control it?*” “*Because you can*.”

**Interviewer:** Exactly. It’s, it’s equity. It’s not equality.

**Interviewee:** So … but I don’t **[inaudible at 1:05:03]**, I don’t know if we’ll ever find a harmonious way to live. Because we’re very different.

**Interviewer:** Yeah. You’ve talked about, like, school—are there other spaces or places that are, like, more or less accepting of her and her sensory needs?

**Interviewee:** I definitely find the YMCA has been great.

**Interviewer:** Oh, that’s awesome.

**Interviewee:** They definitely try and have things where she can be involved. She did their regular camp and, like, she … The YMCA down in Hanover used to have—which is really sad, they don’t have it anymore. They had, like, a theatre arts program. And they had a lot of kids with autism, you know, fully verbal, but …

**Interviewer:** Yeah.

**Interviewee:** … were participating in it because …

**Interviewer: [1:06:00]** Sure.

**Interviewee:** … they were kind of like … like, they knew Helen had her quirks and stuff and they’re like, “*Meh*. *She may not be sitting here watching me … paying attention, but she’s absorbing it all, and we realize she’s* …

**Interviewer:** Yeah.

**Interviewee:** “… *she’s absorbing it all. Because if someone does something wrong, she comes and tells them that they’re doing it wrong. And she corrects them. And* …”

**Interviewer:** Yeah.

**Interviewee:** “… *she knows this play inside and out. And you know, so she has to get up and go skip across the room to get some energy, we let her do that. Even if everyone else is expected to sit and focus and pay attention, you know, so* …”

**Interviewer:** Yeah.

**Interviewee:** But she … it, it was great for her because she could participate in it. The only thing that made me sad was, again, you know … and it’s just … she didn’t … She’s included, but she’s not included, you know. And I think nerds of the world can understand, you know, like …

**Interviewer:** Oh yeah.

**Interviewee:** You know, “*You’re different. You can hang out here, but we’re not going to pay any attention to you. Because you’re weird*.”

**Interviewer:** Yeah.

**Interviewee:** I mean, “*We’re not going to try and get to know you or … because you’re weird*,” you know. And, you know, Helen doesn’t have friends because they don’t know how to communicate with her and they’re ... they’re, you know, people are still afraid to try …

**Interviewer:** Yeah.

**Interviewee:** And they get easily, like, “*Oh, she’s not listening to me. I* …” you know, “*I’ve tried talking to her. She doesn’t want to talk to me*.” And I’m like, “*That’s not necessarily true*.”

**Interviewer:** Got you. Yeah. And then ... oh, sorry, I didn’t mean to cut you off.

**Interviewee:** No, that’s OK. But for sensory needs and stuff … I think, you see, they’re trying, they’re trying to do things … because not everyone’s on the desensitized program like Helen is, or … they are, you know, they’re trying to have performances that have lower lights and all this stuff. You see it happening. To me, I will take Helen to those occasionally. But I tend to not take her to them.

**Interviewer:** Why not?

**Interviewee:** Because I want her to have more options. Because there’s not … that’s, you know … it’s just starting … you’re just starting to see those type of things.

**Interviewer:** Yeah.

**Interviewee:** But, I feel like it’s also segregating in a way.

**Interviewer:** Yeah. I can definitely see it that way too ...

**Interviewee:** You know, **[inaudible at 1:08:39, crosstalk]**

**Interviewer:** … then you’re relying on people to be accepting of you.

**Interviewee:** I …

**Interviewer:** Yeah.

**Interviewee:** I’m forcing people to accept her.

**Interviewer:** Yeah.

**Interviewee:** “*Why does she have to be so loud?*” “*Because she has autism. Deal with it*.”

**Interviewer:** Yep, absolutely.

**Interviewee:** “*She wants to see this just as much as you do, you know. She has to tune out* **[1:09:00]** *everything else while you learn how to tune her out*.” You know, it’s like, it’s gotten to that point where I’m like, “*You know, she’s the one that has the responsibility of, you know, holding her crap together, but we’re not*? *Because she, you know, she’s losing it; we’re not* …”

**Interviewer:** Yeah.

**Interviewee:** … *able to?*” you know, we’re always … “*Don’t*” … but we’re also a society that ignore it. But we’ve almost got to the point like, if someone’s screaming, “*Don’t get involved, don’t get involved. Don’t try and help*.” So, you know, that’s why I sit there and say, I, you know .. .there’s pluses and minuses to everything. And I …

**Interviewer:** Absolutely.

**Interviewee:** I, I feel like, accommodation should be optional.

**Interviewer:** Yeah, you’re right

**Interviewee:** It should be available but not mandatory.

**Interviewer:** And then, thinking towards the future, what are your hopes and goals for how her community will react and accommodate—or not maybe—her sensory sensitivities and sensory interests?

**Interviewee:** I think … I hope that we learn from Helen and that, for her that she’s able to teach us. You know, in non conventional … it opens our minds to learn in non conventional ways, just from instinct and stuff, like …

**Interviewer:** Yeah.

**Interviewee:** Go back to relying on instinct and knowing, you know, she’s doing the best she can. It may seem like she’s not but **[both at the same time at 1:10:39]** she is.

**Interviewer:** Yeah. Absolutely. We’re going to shift gears to our next chunk of questions. In this, like, transition to adulthood …

**Interviewee:** Yes.

**Interviewer:** … where do you see your daughter?

**Interviewee:** I … very scared and terrified because … you know, I hate that there’s a timeframe. I hate that, you know, “*You got to get your shit together by 22.*” I’m sorry for swearing.

**Interviewer:** That’s fine. You can swear.

**Interviewee:** “*You guys, you have till 22. And whether you can have it together or not*,” you know … because I’m seeing certain things about Helen. She’s 17. But she has certain behaviors that I saw in 11 and 12-year-olds, like wanting to, you know … “*Go away, mom*.”

**Interviewer:** Yeah.

**Interviewee:** And she’s, she’s now just starting to get into that at 17. So I’m, like …

**Interviewer:** Got you.

**Interviewee:** … you know, where they expect her to be at 22, by the time she’s 22 … maybe she’ll be like an 18-year-old. Maybe.

**Interviewer:** Yeah.

**Interviewee:** But I hate that there’s limitations, like, you know, sink or swim by 22. And, and I know that … other areas have … don’t have even that. **[1:12:00]** So I feel fortunate, at least I have till 22. But it definitely puts on a lot of pressure of, “*Oh, crap, what are we going to do?* *She’s, you know, she’s no longer going to be entitled*,” you know.

**Interviewer:** Absolutely.

**Interviewee:** I want her to work, but she’s going to really need someone to take the time to train her. Like, she could probably do a lot of jobs. And it’s not for all, all individuals with autism, but some ... She can do a lot more than you would expect her to be able to do because of her lack … her communication issues. And right now, we’re trying to figure out, what is she going to do, like, with her life, and she has till she’s 22 to figure it out.

**Interviewer:** It’s not a lot of time.

**Interviewee:** You know, and even, you know, if you don’t have autism, you go to college, you finish when you want to finish, you figure out …

**Interviewer:** Yeah.

**Interviewee:** … and, even then, when you figure that … when you’re done with that, you’re kind of “*I still don’t know what I want to do with my life*” type of thing. I don’t even, you know, my life has become, I’m a mother.

**Interviewer:** Yeah.

**Interviewee:** My life is to shepherd my children through life. But because they have a disability, it’s, like, you have to … you have to have it all figured out. And, and I just don’t think it’s very fair.

**Interviewer:** Yeah, absolutely. What about ...

**Interviewee: [inaudible at 1:13:27]** though, that’s the problem, it’s expensive so you have to, you know, you have to cut it off at some point. But I think it would be really great if you started seeing more and more businesses opening up positions that are specifically … to get the individuals in the door. Getting them more into the workforce, that would be wonderful. And I don’t, you know … some, some kids, it’s great to just have them be the, the little, the janitor or whatever, right? But, like, I don’t want my daughter to be pigeonholed because she has autism and doesn’t quite communicate that the most you can do is collect carts at the grocery store or, or bill … or wash tables off at the restaurant or make the little, you know, the silverware things.

**Interviewer:** Yeah.

**Interviewee:** She’s capable of doing more. She could probably be in the kitchen and cook, if you teach her.

**Interviewer:** Yeah, absolutely.

**Interviewee:** You know what I mean? She could do … she could be a prep, a prep person.

**Interviewer:** Yeah.

**Interviewee:** But it’s, it’s just … I would like to see more opportunities out there. And I’d like to see there to be more jobs by those companies for people to be assistants, like, instead of relying 100% on the government to determine if **[1:15:00]** you qualify or not to have assistance, it would be great if they had companies, say … you have to have, you have to hire so many people to be assistants so that they can …

**Interviewer:** Yeah.

**Interviewee:** … work in the community and be included. I would love … that would be, that would be great.

**Interviewer:** Yes.

**Interviewee:** Because then I would feel a little bit less nervous about how is she going to … I don’t, I don’t think the life of going to a day program, just continuing what … just continuing what she’s doing now … Well, actually, we’re not doing the norm. But I see for a lot of the kids what a day program is, and I think that would literally drive her insane. I don’t think she would be … I don’t think she would find contentment in it. Some do, and that’s great.

**Interviewer:** Sure.

**Interviewee:** But I don’t think … I think she needs to feel more independent and autonomous than those type of programs would allow her to be.

**Interviewer:** Yep, absolutely. In terms of independent skills, what, what is she able to do by herself? What does she need some help with?

**Interviewee:** All right. She, she can make simple meals like … she can, if she doesn’t want to wait for ... now, if she … before, she wouldn’t eat until I made her a sandwich. Now, it’s like, “*I’m hungry*.” And I’m like, “*OK, I’ll make you a sandwich*.” And then if I get distracted and don’t do it, she just does it now. She ...

**Interviewer:** Yeah.

**Interviewee:** Like, she still would love it if I made it for her, but she doesn’t need me to make it for her. She can do it. She can use the microwave. She can use the toaster. She can … if you give her a recipe, she can follow it and make anything.

**Interviewer:** Yeah.

**Interviewee:** Showering and personal hygiene: I don’t have to remind her, she does it all.

**Interviewer:** Yeah.

**Interviewee:** She changes her bed every two weeks.

**Interviewer:** That’s great.

**Interviewee:** I … that’s … thank you, Higashi, again.

**Interviewer:** Yeah.

**Interviewee:** They had the kids do their laundry. They had the kids fold their laundry, put them away. They had the kids do … you know, and Helen was doing this at age nine. So, you know, Helen when she came back from … the first weekend she came back from Higashi, she, she actually tried to eat … we made we made her the foods she likes because, you know, we weren’t … so she ate it. And she got up, she took her plate and put it in the sink. Because …

**Interviewer:** And that was new?

**Interviewee:** … at school …

**Interviewer:** And she didn’t do that before she went to Higashi?

**Interviewee:** Now she does. She … you know, if I ask her to do something, she does it. Unless she really doesn’t feel like it, like, exercise, time to exercise **[imitates sound of reluctance at 1:18:11].** She, she can play saxophone. To the point of she can listen to a song on the radio, and then just take out her saxophone and pretty much figure it out.

**Interviewer:** That’s very impressive.

**Interviewee:** And the .... her saxophone instructor, he is not a special needs instructor at all. He, he, he’s working on advanced jazz skills with her.

**Interviewer:** Wow. That’s awesome.

**Interviewee:** He still … he’s like, “*This should take you two months*,” and it’ll take her two, three weeks.

**Interviewer:** Wow.

**Interviewee:** And he still … he’s constantly like, “*Wow, this is unbelievable how she picks this stuff up*.”

**Interviewer:** Yeah, that’s fantastic.

**Interviewee:** My husband has taught her … she can … she can change … rotate his tires.

**Interviewer:** I cannot do that.

**Interviewee:** She, she knows how to put the car up and take the tires off, put the winter tire on and put the ... and he just stands back and lets her ... he’ll supervise her, but she can do it. We own apartment units. So anytime there’s, like, small little handiwork, he brings her along and lets her observe. And she … and then he’ll have her do it. So, oddly enough that I say this … she, she sent him a text out of the blue that said she wants to be a handyman and asked him if he would teach her.

**Interviewer:** Oh!

**Interviewee:** So she likes being helpful. She likes fixing little things and she does … it doesn’t require her to talk, it just requires her … She loves machinery; she’s always been fascinated with copying machines, and she’s like ... me **[inaudible at 1:20:02]** … If you have a problem with your copy machine, Helen seems to be able to fix it. No one taught her. She just intuitively knows how to … how it works and just knows …

**Interviewer:** Yeah.

**Interviewee:** Like, she can tell something’s broken before anyone else knows it’s broken or, or is having problems. My husband, my husband and Helen, we’re always like, “*They’re* ...” I say that my husband and my daughter are like the, the superheroes for electronics. Because “*I hear someone in … I hear an electronics in distress*.” And then it’s like, “*Something’s wrong. Something’s wrong. There’s distress somewhere*.”

**Interviewer:** Yeah.

**Interviewee:** I don’t hear anyone … “*No, it’s something mechanical*.” It’s like …

**Interviewer:** Yeah.

**Interviewee:** and then you really have to focus in and say, “*Yeah, you’re right*,” like, “*that doesn’t, you know, now that I’m listening* …” So she’s very ...

**Interviewer:** That’s a great skill.

**Interviewee:** So it’s a skill, but how do you apply it? How do you … you know?

**Interviewer:** Absolutely.

**Interviewee:** So, it … that’s … those are the things that, you know … I’m … with her, she can do a lot more than you would think. And she understands stuff more than you’d think. Speech and communicating is a struggle for her.

**Interviewer:** Yeah.

**Interviewee:** Just because you’re talking to her about something doesn’t mean she doesn’t necessarily … she’s not capable of understanding it. It’s just, it takes her a while to process what’s being said. And I notice, like, if I go outside with her, she’s very anxious outside. So we’re trying to desensitize her to being outside, terrified of bugs.

**Interviewer:** Yeah.

**Interviewee:** I go outside with her and we go for a walk: if I talk to her about anything, she does not process one word I say because she’s so trying to deal with the fact that she’s outside and there are bugs and, you know … Think about it, even for yourself, like, if something’s really causing you distress, it’s really hard to focus and, and, you know …

**Interviewer:** Yeah.

**Interviewee:** Or if you’re bored to death by something.

**Interviewer:** Yeah, it’s hard to change your attention.

**Interviewee:** But she can’t tell you.

**Interviewer:** Yeah.

**Interviewee:** Like, “*Can you just stop talking to me? Because honestly, I’m doing everything I have to do to* …”

**Interviewer:** Yeah.

**Interviewee:**

“… *hold it together.*

**Interviewer:** Absolutely.

**Interviewee:** “*But if, if you want to ask me these questions, when I’m somewhere calm, and I’m, you know, there’s not so much* **[inaudible at 1:22:38]** … *I will get what you’re saying*.”

**Interviewer:** Absolutely. You talked about her wanting to be, like, a handyman, or, like, help out with tasks. Did she ever express interest in her own way about other jobs, things like that?

**Interviewee:** Yeah, she does. For a while, she wanted to be a construction worker. She was saying she wanted to be a cashier. Because she’s very ... she could … I … when we … I’d always try and do self checkout, and make her do the self checkout …

**Interviewer:** Yeah.

**Interviewee:** … and handle the money. But when she was at the high school, for the short period that she was there, they were starting to have her ... because she had already mastered everything, like, making sandwiches and all that. So they were putting her on the register. Now, if someone asked her a question at the register, she probably wouldn’t be able to answer. But she can ring you up and tell you how much it is. But …

**Interviewer:** Yeah.

**Interviewee:** … she couldn’t have small talk, she wouldn’t have … she would lack in those skills.

**Interviewer:** Got it. Does she, like, have a ... like, does she understand money?

**Interviewee:** She wants ...

**Interviewer:** Like …

**Interviewee:** She was like, “*I want to be, I want to be a cashier*.” And it’s so … to me, it’s like she might not be able to do it right now.

**Interviewer:** Yeah.

**Interviewee:** But eventually she could learn it.

**Interviewer:** Yeah.

**Interviewee:** A friend of mine whose daughter is **[1:24:00]** verbal really said that taking a job at Starbucks was the best thing ever for her because it really taught her the art of small talk. And she … it became … she became a lot less socially afraid. You know, she could talk to anyone now.

**Interviewer:** Yeah, that’s awesome.

**Interviewee:** … whereas before she couldn’t ... but, you know, with … at Starbucks, you start off with “*How can I help you? What would you like? Do you want this and that?*” And it’s kind of a weird, scripted small talk, and then you usually …

**Interviewer:** Totally.

**Interviewee:** Branch out. For example …

**Interviewer:** Yeah. Back to money: does she have a concept of money beyond, like, just, like, subtraction and, like, in a, in a cashier type of setting?

**Interviewee:** Yes and no. I think her concepts of money are pretty normal for her age.

**Interviewer:** Yeah.

**Interviewee:** Like, “*I want this, I want that, I want this, I want that*.”

**Interviewer:** Totally.

**Interviewee:** I’m starting to say “*That’s* …” you know, instead of just getting it her, I’m like, “*Nope, that’s expensive*.” But then she’ll start … I created … we don’t have chores at our house that … everyone’s, everyone’s expected to just kind of help out.

**Interviewer:** Sure.

**Interviewee:** But my kids won’t help out unless they’re being paid. So if they really want something, they’ll start ... they’ll start cleaning the bathroom. They’ll start ... and they’ll start counting the money on the chores ... “*I did this chore*,” or“*I did that chore*.” I’m like, “*That … the carpet didn’t need to be vacuumed*.” “*But I vacuumed: that’s $3*.” You know, so they understand, like …

**Interviewer:** Yeah.

**Interviewee:** saving, in a way, like, she understands saving, she’s starting to understand, “*I have to save up for that*.”

**Interviewer:** Yeah.

**Interviewee:** You know, because she really wants to go to France. And I’m like, “*It’s really expensive*.” And, you know, but, she doesn’t quite understand that she can do all these chores and earn enough money to buy a ticket to go to France, but it’s still coming out of my pocket and I can’t afford it. So, like, it ...

**Interviewer:** Yeah.

**Interviewee:** She’s not quite grasping, it’s not the same as going out and having someone outside of the family give her the money.

**Interviewer:** Yeah.

**Interviewee:** Do you know what I mean? So …

**Interviewer:** I do.

**Interviewee:** … she has a basic sense of “*I have to save up for this*.” But she doesn’t understand that money doesn’t just grow out of my pocket, and I’m just giving it to her because she’s earning it. It’s …

**Interviewer:** Yeah.

**Interviewee:** You know, she does … I don’t think she quite understands that part yet.

**Interviewer:** Got you.

**Interviewee:** But I think she will.

**Interviewer:** Absolutely. Do you need to go? We can …

**Interviewee:** No.

**Interviewer:** OK, cool. Do you need to leave by 11.30? Is that what you said?

**Interviewee:** Yeah.

**Interviewer:** OK. I don’t think we’re going to finish up. We can at least finish this chunk of questions and maybe then we can find a time to finish up. Would that be OK?

**Interviewee:** OK. **[1:27:00]**

**Interviewer:** Sorry.

**Interviewee:** I am too chatty. I’m sorry.

**Interviewer:** No, that’s OK. I can be flexible. Chatty is great. We just have, like, two more questions in the section, then we’ll, we’ll reschedule for when we’ll finish. Does she ever express interest, like, in her own way about wanting to live on her own?

**Interviewee:** Not really. What she does express is that she does not want to go back to living in a group home setting type thing.

**Interviewer:** Yeah.

**Interviewee:** So she, she’s like, she wants to live home.

**Interviewer:** Got you.

**Interviewee:** And I think it’s because home she has more freedom, you know.

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

**Interviewee:** I think that she felt trapped for a bit while she was at Higashi, and it took us a while to realize what was going on because it was … she was so happy for so long there.

**Interviewer:** Yeah.

**Interviewee:** And then all of a sudden it just started to fall apart. So I think she’s afraid of being put back in a situation of having every single minute of her day scheduled and controlled.

**Interviewer:** Got you. Yeah.

**Interviewee:** Yeah, so, like, I was looking at a music school for her out in the Berkshires. And I thought this, this place would be great.

**Interviewer:** Got you. Yeah.

**Interviewee:** Because it would be, like, kind of like college for her.

**Interviewer:** Totally.

**Interviewee:** But when she saw the residence she’s, like, “*This is too far. I can’t go here*.” She got very scared.

**Interviewer:** Yeah.

**Interviewee:** So, I don’t know if that means, you know … would she be willing to live by herself? I think she probably could.

**Interviewer:** Yeah.

**Interviewee:** But I think she doesn’t want to be alone.

**Interviewer:** Not many people do.

**Interviewee:** You know what I mean? Like …

**Interviewer:** Yeah.

**Interviewee:** I think, you know, we … so it’s going to be … my goals too is to figure out how to teach her how to get along with people enough that she can find someone that’s compatible to live with.

**Interviewer:** Yeah.

**Interviewee:** Like we all are, right?

**Interviewer:** Yeah, absolutely.

**Interviewee:** We’re all looking for that companion and it’s just … it’s going to be a different process for her. And, you know, I would, I would feel comfortable if, if, you know, she …

**Interviewer:** Yeah.

**Interviewee:** I just … someone that needs a roommate, you know?

**Interviewer:** Yeah.

**Interviewee: [1:30:00]** … not bothered by some of her weirdness, you know, and is very flexible.

**Interviewer:** Yes.

**Interviewee:** She needs someone to be flexible and, you know, she can, she can abide by, you know, “*This is your space*” and stuff, so … and she can …

**Interviewer:** Yeah.

**Interviewee:** … abide by “*This is my food: you can’t touch that*,” those type of things, so … but I think it’s going to be … going … getting to desensitize her to living with people doesn’t mean it’s, it’s, like, an institution, you know what I mean?

**Interviewer:** Absolutely. And then, do you think she will be able to achieve more independence in the future?

**Interviewee:** I will die trying.

**Interviewer:** Absolutely.

**Interviewee:** Though I, I, I’m nervous about it because it’s …

**Interviewer:** Totally.

**Interviewee:** ... and I’m impatient. I think she’s capable. I just … there’s no, there’s no book, how-to book on it. So, she just shows me. She amazes me sometimes with the things that she’s able to do and the things that she knows.

**Interviewer:** Yeah.

**Interviewee:** That I’m like, she is capable, but it’s getting it out of her.

**Interviewer:** Absolutely. What do you think will help move her into adulthood and more, and more independence?

**Interviewee:** I think I’m going to have to … I mean, like, for, like, during summer camps … I was sending her to regular summer camps, and they just kind of, like, at the Y. So that was nice. Like, I … she’s told me, “*Don’t come in*.” Like, when I’d drop her off for the theatre camp, I no longer had to walk her in. She’d just get out of the car and go in with the kids.

**Interviewer:** Yeah.

**Interviewee:** But, but to start I was walking her in and then I think she started noticing, no one else’s parents are coming in. So she said, “*Go away*.” So I think just exposure again … so, I think, in order for her to get used to being in a more, like … that college, so to speak, I think what we’re definitely going to have to do is say, “*OK, you’re going to*”… they … and they have summer camp there.“*So you’re going to go try this place out for two weeks for summer camp*.”

**Interviewer:** Yeah.

**Interviewee:** And you’ll see, “*Oh. It’s not like Higashi residence*.”

**Interviewer:** Yeah, absolutely.

**Interviewee:** “*And you’re going to learn that … you might understand … you might like the independence you have there*.” So that’s … more opportunities for that in the … for, for our guys and girls would be great in life.

**Interviewer:** Yeah.

**Interviewee:** If they could create more things like that, **[1:33:00]** so that they can learn to be independent. I mean, we … that’s how we learned …

**Interviewer:** Yeah.

**Interviewee:** … by going off to college, right?

**Interviewer:** Yeah, absolutely. Do you think there are other, like, services or interventions that would help your daughter or people like your daughter?

**Interviewee:** It’d be interesting if … you know how they have buddy systems or, well, you know, how you … well, in a way, you’re … you have buddy systems but, like, in life, like, so … “*OK, I’m with … I need to get in a roommate and this special needs person needs a roommate. I’ll take a, a small … a lesser rent* …”

**Interviewer:** Yeah.

**Interviewee:**

“… *if I take on the responsibility of kind of teaching this person* …”

**Interviewer:** Yeah.

**Interviewee:** “… *how to get through life*.” You know what I mean? Like, if …

**Interviewer:** I do.

**Interviewee:** … something that like that existed. Even … I mean, we all fantasize about communities of … like that, like, communities for … but again, to me, it’s very segregational. Like, I would like her to be able to live wherever she wants to live.

**Interviewer:** Totally.

**Interviewee:** But have, you know, you know, have that service of “*These are people that they’re going to work, they’re going to live, they’re going to be your roommate, but they’ll also be there to kind of be the friend, bought friend*.”

**Interviewer:** Yeah, it’s import ...

**Interviewee:** So maybe they’ll develop a friendship. Or …

**Interviewer:** Yeah.

**Interviewee:** … because there’s a lot … I think, I think that could be beneficial.

**Interviewer:** Absolutely.

**Interviewee:** “*What’s in it for me?*” type of thing. “*Oh, you get cheaper rent*.”

**Interviewer:** Yeah.

**Interviewee:** “*You’re, you’re going to feel good about helping someone.*” And you know, I think it’s like nannies, nannies for adults, I guess in a way.

**Interviewer:** Yeah, absolutely. All right, so I will let you go. That’s, like, that’s a good stopping point. We have two more chunks of questions, but they do tend to go faster for everyone.

**Interviewee:** OK.

**Interviewer:** And it’s OK if they don’t for you.

**Interviewee: [inaudible at 1:35:14]**

**Interviewer:** What? That’s OK. No worries. What would be another good time for us to finish up?

**Interviewee:** OK, let’s see.

**Interviewer:** Because I don’t want to keep you late either today.

**Interviewee:** How about … can you do Tuesday October 6?

**Interviewer:** Tuesday, October 6? I can. At what time?

**Interviewee:** Let’s say 10 o’clock.

**Interviewer:** Yeah. Yup. We will finish up, then. Perfect. OK. That sounds good. **[1:36:00]**

**Interviewee:** If we can. Because lately I’ve been tired in the mornings, so if I fall asleep, we know we’re good.

**Interviewer:** It shouldn’t take too long this time. So we should be OK.

**Interviewee:** It’s good. This is all good. So 10 o’clock, October 6.

**Interviewer:** Yeah.

**Interviewee:** OK, great.

**Interviewer:** Yup.

**Interviewee:** And I will see … send you an email. I’ll also include a link to that last survey.

**Interviewee:** Yup.

**Interviewer:** And we will finish up then.

**Interviewee:** Thank you.

**Interviewer:** Thank you. I hope you enjoy whatever you have planned today.

**Interviewee:** It’s been … it’s always enjoyable to be able to just expound and say what you think. And to hear what ...

**Interviewer:** Yeah.

**Interviewee:** I hope ...

**Interviewer:** It’s so interesting.

**Interviewee:** You thought it was beneficial to be able to hear what I had on my mind.

**Interviewer:** Oh, yeah. It’s so … every parent has a different perspective. And it’s …

**Interviewee:** Yeah.

**Interviewer:** I just have all these ideas now.

**Interviewee:** Yeah.

**Interviewer:** So it’s awesome for me.

**Interviewee:** Yeah. All right. Thank you. I’ve got to go and get Helen.

**Interviewer:** All right. I’ll see you soon. Have a nice couple of weeks.

**Interviewee:** You too. Bye.

**Interviewer:** Bye bye.

**[End of interview]**