**[Start of Transcript]**

**Interviewer:** Right, we're recording.

**Interviewee:** I’m going to go get a tissue.

**Interviewer:** Yeah, go for it.

**Interviewee:** Hope it's allergies.

**Interviewer:** Hope so too. It's a transitionary period. It's totally allergies. Or just stress **[laughs]**

**Interviewee:** I’ll just walk around.

**Interviewer:** And I'll be asking you questions about your perspective regarding your son's sensory sensitivities in relation to his transition to adulthood. And I’ll be doing something called a semi structured interview, which means I have my plan questions, but I'll be adapting them to follow our conversations that actually fit for what we're talking about and fit for you. And if there are any questions that you don't want to answer for whatever reason, you do not have to. We wanna make this comfortable and positive.

**Interviewee:** All right.

**Interviewer:** And if there are things you think about that we talked about earlier later in the interview, you're welcome to bring them up. It doesn't have to be like a perfectly linear conversation.

**Interviewee:** OK.

**Interviewer:** Any questions?

**Interviewee:** Nope!

**Interviewer:** OK, awesome, I'll start. Could you please start off by telling me about your son's sensory sensitivities and sensory interests?

**Interviewee:** Sure. So he is very sensitive to high pitched noises, so things like sirens or babies crying or any kind of you know, squeak or high-pitched noise. It's incredibly painful for him, I think. He also has, I think also he has very sensitive hearing, you know, there's…one sort of anecdotal thing I can tell you, and then one sort of kind of the actual thing. **[00:01:44 inaudible]** So, the anecdotal thing is we were like on the school playground – he probably was about 12 and he's like, *“mom! There's a siren!”* 'Cause he's always been so sensitive and I was like, *“there's no siren, honey.”* I mean, I couldn't hear a thing and about I would say, I don’t know, 30 seconds later, I heard a siren came by. And then we…his hearing was sort of…the doctor's using that like little tuner fork kind of thing or something. We were at the Mass General Tourette's Clinic, movement disorder clinic and she had said that his hearing was extremely sensitive. He's like almost like amazed, just like *“wow!”* So he does have a sensitivity to high pitch noises. I think the low pitch no. I mean, I think if it happened suddenly he just doesn't like it 'cause it could startle him, I wouldn’t consider it a sensory thing. What else…oh smells. He's incredibly sensitive to smells. Like so if I'm cooking and it involves any sort of like onion or garlic, or really anything, really anything. I mean, he just he gets so upset and we've had to really kind of handle his use of room spray **[chuckles]** when I'm cooking and things like that. And even if people are eating, you know, so there's that. And I think sensory-wise, what does he seek out? You know, it's changed over time, when he was younger, we used to do what I called ‘burrito’ and we just kind of randomly came up with that, but I guess it's probably a thing now. And so he used to like to be like, you know, it just made him happy and you know, respond and he likes certain textures, like sort of there's a blanket he has - it's about to fall apart, but he loves this blanket and he’ll like put it on his cheek, and it's got like…it's soft but also kind of like a little roughness to it because of the balling of the cotton, you know, so something about that he likes. Oh, I'm just I’m thinking…I know that's it for the sensory is sort of like things that bother him and I'm just trying to think if there's other things that he uses for…he kind of does this **[gesturing]**. He does it less than he used to. He used to do this all the time when he was younger and you should…but that's really faded away. He'll do it once in a blue moon now. I think that's it, I think. Yeah, I think that's probably about it. Yeah.

**Interviewer:** **[00:04:22]** I’m gonna ask some clarifying questions if that's OK? For smells, is it he is just heightened and has a heightened sense to all smells, or there are certain things that he dislikes more than others?

**Interviewee:** I think it's both. I think he has a heightened smell, and there's definitely things he dislikes more than others, like he…anything that even borders on like pungent like a, you know, like a savory smell. So dinner can be a problem like whether you know 'cause, but like if we're baking or you know things like that, those things don't bother him. So it's more of that savory type of smell.

**Interviewer:** What about like perfume or like cologne or something?

**Interviewee:** So I personally don't wear a lot of perfume, when I have, you know, if I'm getting dressed up to go somewhere special, he hasn't complained. So no, I wouldn’t say that. My husband will definitely wear cologne when we go out and he hasn't commented on that, so I don't know that he's really exposed to a lot of that. But I would say no, that he doesn't.

**Interviewer:** And then with the burrito, like deep pressure you talked about, does he seek out that in other contexts?

**Interviewee:** Yeah, I'd say no, not especially. So not out of the norm. But yeah, I mean he likes to cuddle in his blankets, but everybody kind of likes to do that. Yeah no, I would say not now. It's interesting, he has changed a lot. So I was just thinking too with clothes sensitivity, I guess he doesn't really wear pants, he wears like the trackpants, so clothes need to be soft. He has just started being able to wear clothes that are around the ankle, you know, that's the style now seems to be tight around the ankle, and I knew when that style came out I became worried immediately. I was like, “oh my gosh, it’s gonna be tough.” And even now he’ll like pull his pants up, but it doesn't seem to bother him. Like when he was younger, he would really be vocal about it. Yeah, so.

**Interviewer:** Will he like wear jeans or anything a little more scratchy?

**Interviewee:** So, I think when he was younger, no way. Like he actually only ever used to wear shorts and it was a big deal just to get him to wear pants. But now I think if the material were soft enough…I guess we just never transitioned him to that yet, 'cause it's almost like…he's so far away, quite frankly, and I want the school focused on other things, and that's hard enough **[laughs].** And so for me that's gonna be something that I'll work on with him when he comes home and he's into his adult life. And I think I have a sense it will be successful. I think as long as we do it in sort of very gradual increments depending on how he responds. And also sort of just softer cotton, I’d probably start him off with like a cottony, kinda soft Chino type thing.

**Interviewer:** Absolutely, thank you. Sorry I didn't mean to cut you off.

**Interviewee:** Oh no, it's OK. I talked too long **[00:07:45 inaudible]**.

**Interviewer:** Talk as much as you want, this is where it's good. Does he have any sensitivities or like sensory preferences in terms of like taste in food?

**Interviewee:** Well, I know he's pretty limited, and especially before he started going to school, you know, really I mean his food sort of consisted of chicken tenders, hamburgers, you know the…I guess the typical that you hear. He loves rotisserie chicken. You know, but without sort of stating all of them, it's very limited. In terms of textures and stuff, I don't know, so it's funny, at the residence he'll tell us what he's had for dinner and we're like, *“oh my gosh! that's amazing that he ate that.”* But he eats all that there. I don't know, I'm not there. It's hard to and if I try to make it from here, no go.

**Interviewer:** Got you.

**Interviewee:** So in terms of textures, I don't think he has too much sensitivity to that. He’ll eat French fries with spaghetti meatballs, apples, strawberries, so that's a little different texture. He's not a big ice cream guy. I don't know, did that answer it or?

**Interviewer:** Yeah, definitely. I mean, if you don't think there's a textural thing, then there's not a textural thing.

**Interviewee:** Yeah, I don't think there is too much, yeah.

**Interviewer:** And then, in terms of like his limited diet, is there like a theme there? Is it like familiar foods, maybe like bland foods, you know?

**Interviewee:** I'd say familiar and just sort of those fast food, simple foods type of thing.

**Interviewer:** **[00:09:42]** And then before we move on, you mentioned that he will have some like visual stimuli with his hands. Does he seek out or did he seek out other types of visual stimuli?

**Interviewee:** When he was younger, well, he loves fans and he still does love fans, but I think again that's improved a lot with him. I mean, we used to literally go places to try to find big industrial fans, he just loves them so much. And I can only think, you know, of course, being autistic, and he knows the names of 'em, the different brands of them and the whole thing. But yeah, I think it's actually the movement of those fan blades. It's almost like a love hate thing, like he'll want me to turn on and then he’ll like back up. And I feel like with anything like super good it almost gets overwhelming. So yeah, I think that kind of movement. Other visual…let me just think. Give me examples of some other visual things that kids like.

**Interviewer:** Let's think, that's good. Most people don't actually have a lot of visual ones. Pictures of certain images have come up, like someone talked about birds a lot, seeking out spinning objects like tops and stuff or like wheels, kind of like the fans. Lights, could be sensitivity to certain like too much light, whether it's indoor, outdoor, wanting like shades closed or wanting them open, sunglasses.

**Interviewee:** So the spinning, yeah. I mean when he was young he used to always spin the wheels on his cars, but he doesn't do that anymore. So I think it is visual, like the spinning kind of thing, a fan or whatever.

**Interviewer:** Yeah. So you kind of alluded to this a lot, but how have his sensitivities changed overtime?

**Interviewee:** I think they have decreased. I'm sorry, sensitivities or the…OK. So the sensitivity, for visual sensitivity, I think it's decreased a lot, but I think his sensitivities still are fairly…his auditory ones are still very significant and impactful in terms of how he can exist in his environment.

**Interviewer:** Totally. What about his sensitivity to smell, how has that changed over time?

**Interviewee:** That's actually something that's new. That I think started about maybe…I'm gonna say maybe three years ago or something, so I don't know, you know, and I don't recall that in his younger days or even before he went to the school. I don't know, maybe it's a offshoot living in a residence with all boys, I don't know.

**Interviewer:** **[00:12:40]** Maybe. I'm kidding **[laughs]**. And what about the deep pressure, how has that changed over time?

**Interviewee:** Yeah, I don't think he really seeks that out anymore, so I think it's minimized.

**Interviewer:** Is that the same for his like textural preferences for clothing?

**Interviewee:** Yeah, I think that has minimized too. I think I'm finding more and more I can like just get a shirt and a pair of pants and not have to like keep my fingers crossed. I feel like you know, with autism parents, it's kind of like yeah, there's the actual sort of concrete information, but then there's a whole thing of like, a lot of times how I will assess things – even though it's not the most scientific way, it's like do I feel fear when I'm about to present this to my child? And it's like if I realized, *“wow, I haven't worried about this in a while,”* I know that that's decreased. So, in terms of the clothes, I feel like I can go to TJ's or whatever and pick up a pair of pants and…either I've gotten really good at picking him out or he's just gotten less sensitive. I think it is less sensitive. That said, I do gravitate towards certain materials, like I always wanna feel 'em to make sure they're soft and flexible, but I'm that way too. So.

**Interviewer:** Yeah, I mean, I think we all have preferences in every domain.

**Interviewee:** Yes, yeah, you're right, 100%. So **[crosstalk]**

**Interviewer:** Please go ahead.

**Interviewee:** No, I was just gonna say I think that that has decreased, the **[00:14:23 inaudible]** tactile stuff.

**Interviewer:** Got you, thank you. And what about his like palette, his diet, how has that changed?

**Interviewee:** So that's actually…his palette It's just really expanded. And I think that sort of him not expanding his palette here, I think it's more of sort of the wanting to keep things the same, versus an actual aversion to the food. Yeah, so he's very like segmented, this only happens here and this only happens here. He's got very strict rules about what happens at home and what happens at school and the residence. And that goes to other areas too. But so yeah, I think his taste in foods has definitely expanded. And in terms of that, one thing too I can say is like, before he would scream and yell if I wanted him to try something new, he absolutely wouldn't do it, and now *he definitely* will like *every* time.

**Interviewer:** That's awesome! It's great, that's great progress.

**Interviewee:** Yeah, yeah, it's one of the wonderful things I would have to say about his placement at the at the Meyer Institute.

**Interviewer:** That's wonderful. And then these changes that you've talked about, do you think they're related to any change in independence overtime?

**Interviewee:** To what? To change to what?

**Interviewer:** Any independence that he's gained overtime.

**Interviewee:** I guess I just don't know. You know, I often think of things as just sort of a often never just one singular component that creates a change. I think it's, you know, him continuing to learn, to learn how to interact in his environment, whether it's verbally or functionally, I think it's him being exposed to many more people. I think that just sort of broadens people in ways that are hard to really kind of clarify and define. Yeah, because when he was here I…have you been to Williamstown?

**Interviewer:** Yeah, not really **[00:16:41 inaudible]**, but I have, yeah.

**Interviewee:** Yeah, so it's a small small town, right. And so I mean, really his world just became so so so so tiny as he got older. When he was younger we could do playgroups and stuff, but then around you know, I’d say 10, 12, you know, it was really the mom and Sam show, and it was just everything. I mean like I was just his playmate, his everything. It is what it is. And plus, with our community being so tiny, I didn't even know parents that had kids with autism or it was never, you know, interact with them. And then this service, like at the South Shore you know, like oh my gosh, ‘autism swim’ and this and that. Nothing like that here. So long winded way of saying, you know. At 14 he went to go he went to the Meyer Institute and his world just like opened up and he had you know, very focused teaching and so who knows, it could be maturity. It’s hard to pin-point.

**Interviewer:** Absolutely, that makes sense. When your son is faced with like sensory experiences that he dislikes or doesn't prefer, how does he manage or cope or like handle those situations?

**Interviewee:** Often not very well. You know, he will complain loudly. He will try to create a resolution to it, like he’ll…with the smells he'll want to start spraying, but at that, we have to explain to him, *“no, we're cooking, we're eating, we don't want the chemical spray,”* and it's a whole thing. It's a whole, you know. He'll get mad, *“oh no!”* Start yelling and we’ll say, *“look, if you're gonna yell, you need to just go to your room. It's OK to yell but you gotta do that in your room, that's hurting our ears.”* So he will complain verbally, and it’s loud. But I have written these social scripts for him, so he – this is off topic a little bit, he very much wants to control his emotions, I think. Because he will…if there's something new that comes up he’ll want me to write a social script, and all that is that I do in my own sort of mom way, is just, *“when I smell something bad, here are the things I can do.”* And so I just write down all this stuff, deep breathing and then when he can act on it, you know. So I mean it's a combination of that and then he’ll go like, *“I've got to read my social skills!”* **[chuckles]** So that's how he handles it. With the noise, with the auditory stuff, it's hard, he gets very depressed, he gets sad. It makes him sad. For some reason it triggers a lot of anxiety and sadness, especially a siren, babies crying, things like that, or anything that he perceives. I know when I'm watching TV like at night, even after he's gone to bed, if there's a siren on the TV, **[00:19:14 inaudible]** to mute it. Otherwise he’ll come barging out of his room, you know. I don't know if that answers the question.

**Interviewer:** Yeah no, it did. Does he ever try to employ tactics like headphones, earbuds, hands over his ears for sounds?

**Interviewee:** Yeah, when remind. So those are all things I tell him, you know. I just recently said with the…I think he's just actually been really way more sensitive, I'd say over the past like six months, I'd say four months, you know, and I think it's got to do with the COVID and it’s got to do so much. I mean he was home for five months and then he's just transitioned back there. So it's so hard to know. I'm sorry your study is happening at this time **[laughing]**.

**Interviewer:** Honestly, it's why it is because we couldn’t do the other study.

**Interviewee:** 'Cause I'm like all the variables are changing.

**Interviewer:** That is life.

**Interviewee:** *Yes*, exactly right. So that is life. So just recently he’d just become inconsolable with the noise and so I just reminded him, *“you can put your fingers in your ears,”* and I do encourage him to hum. I know that seems like…but I feel like you can hum softly because that will drown out the noise. So now he tries to remember to. So yes, he tries to employ those. But like times he gets so emotional and he forgets. And if I remind him then he will. And he always has to have his noise protector and his you know, he always has those, always has to make sure he has those so.

**Interviewer:** Absolutely, thank you. And has he ever received specific interventions or therapies for his sensory sensitivities?

**Interviewee:** No, I wish, but no. I just haven't been able to find the interventions.

**Interviewer:** Yeah, absolutely. And you talk about anxiety a bit with regard to noise, do his other sensitivities also cause anxiety?

**Interviewee:** I don't know if I classify the smell as anxiety, he gets very upset. No, no, I think just the auditory, yeah.

**Interviewer:** And how does he cope with the anxiety for the sounds? The humming or the deep breathing?

**Interviewee:** So right, we do deep breathing. He will sometimes have to be prompted, sometimes not. I wish I could say he has a way of coping. He just gets…I guess his way of coping is to come to me or his dad or whoever is there, and say, *“it breaks my heart,”* like he'll just start talking, and some and stuff says doesn't make sense, but it's his way of saying how much that bothers him. So his way of coping is really to reach out to me. And that's actually something we need to figure out. Like he called me, FaceTimed me *three times* from school yesterday [**00:22:46 inaudible]** upset about. So I think he will reach out to an adult and kind of like just verbally, you know, say a lot of stuff about his feelings and to cry, sometimes he starts to cry, and just really talk about it and complain and we have to get him to calm down.

**Interviewer:** Have sounds always caused anxiety for him?

**Interviewee:** Yes, god! I remember when he was just tiny, and this was before I kind of really knew the extent and we were…where were we? I think we were at the beach, we were at York Beach. And I was so afraid to walk by anybody with the baby, 'cause as soon as that baby would cry or make some sort of fussing noise, Sammy – and so he's like 5 or something, I don't know, he would just *run over and slap* his hand over the baby's mouth. So, you can imagine, right? Oh my God, if you're a mother or father and this random kid…so I mean even then, as I reflect on that yeah, always always had auditory **[00:24:04 inaudible].**

**Interviewer:** And has that anxiety looked the same overtime or has like the presentation of that anxiety changed?

**Interviewee:** I think the presentation has changed, I think before he just probably chanted a lot and screamed a lot, we didn't really know what it was about. And now he's much…he's verbal, so he can tell us.

**Interviewer:** For sure, thank you. And now thinking a bit more broadly and towards the future, what goals or hopes do you have for your son in regards to his sensory sensitivities and sensory preferences?

**Interviewee:** Yeah, I do have goals that will one, they’ll sort of physically lessen. Barring that, that he can find ways to cope with them, so *he* can learn how not to be upset, because then that will make him a more settled and happier person. And every parent wants that for their child no matter what their situation is. So, I just don't want…'cause I do truly believe the auditory one causes him pain and then he just sort of transitions…translates that into emotional pain or whatever. So I would love for that to physically stop. I would also love for him to find ways to cope and to know that he has control, you know, whether that be moving out of the room, whether that be you know, using his fingers in his ears, or putting his, yeah. So yeah, did I fully answer that question?

**Interviewer:** **[00:25:50]** Yes, that was a perfect answer. Thank you.

**Interviewee:** OK. Aww, that was nice. **[00:25:56 inaudible]** conversation with someone the other day. I love hearing that I had a perfect answer.

**Interviewer:** There are no wrong answers here. Everything you say is correct, but that was a very spot on concise answer, so thank you. We're gonna shift to our next chunk of questions. We're doing great. Thinking about community, as your son has grown up and aged a bit, how has his and your community reacted to his sensory sensitivities and sensory needs?

**Interviewee:** Well, I'm not really around him in the community out there. What I can say about our own small town I think people have just a broader understanding now, so much more. It’s incredible how different it is. So although autism is very sad and in my mind I think intervention by schools **[00:26:49 inaudible/poor audio]** still quite frustrating for me. That said, I think there's been so much positive change. So before when he was young, people – and that could have been due to his age also, I don't know. People would stare in almost like angry stares or annoyed stares or frustrated. Or sometimes they would even say things, I am experienced with that. And now I feel like this awareness around autism is such that I think there's more compassion. So at the worst, people will just sort of move away. Oh yeah, and I've had people like take their kids and like shield them from my son, like give him and me a dirty look and then be like **[makes sound],** what the hell! But now at the worst, I think it's more people just sort of kind of subtly get annoyed and move away, which you know, at the end of the day, I'm like I get that like, *“good Lord!”* You know, if you're not used to it, you know. But it's just not with the same sort of…I don’t know what I really want to say. And at the best, and this is not uncommon, almost sometimes either people would directly approach me because they know someone with autism or they'll you know, or they'll see if they can help Sam. Or they will kind of give him like a gentle smile like kind of understanding. So, I do think it's changed significantly in our community.

**Interviewer:** **[00:28:30]** That's wonderful. So you say people are like more accepting and accommodating of him now than when he was younger?

**Interviewee:** Yeah, yeah. I don't know what they would do if I wasn't immediately there 'cause they see me like on it, but yeah, definitely more accommodating, more accepting, more understanding. They're *much more* informed, I think.

**Interviewer:** That's wonderful. Do you know if the Meyer Institute if they are understanding of his sensory needs as well?

**Interviewee:** I would say 100%. I would say that's one of the things they do best, is they’re very – and knock wood, I never like to say things and then feel like I jinxed it, a little bit of my suspicious nature or superstitious nature – yeah, I think they are incredibly understanding, informed and really try to create the most appropriate positive interventions to address it.

**Interviewer:** That's wonderful.

**Interviewee:** And I think that's one of the big things that makes the parents or, you know, and you always get a call to let you know, if he had a hard time. I think in the residential programs it's a little trickier, but for obvious reasons, you know. So, yeah.

**Interviewer:** Awesome, thank you. What about other aspects of your community, like maybe family or religious groups?

**Interviewee:** Sorry, just remind me of the question?

**Interviewer:** Just thinking about like how different parts of community understand and react to his sensory needs. So you’ve talked about like school and you’ve talked about like you an like general people. What about like family or religious groups?

**Interviewee:** So again, I feel like it's a time difference. I feel like before it was kind of like, oh my God, like I've literally had some family members say, *“how can you even deal with that?* *What if you just asked him?”* One friend said, *“what if you just told him this?”* or *“what if he just asked him that?”* But now I do feel like people are much more understanding and they'll say things like, *“is this going to be OK for Sam? Will this be OK?”* You know. So yeah, I think yeah, religious groups, you know, it's very tough. It's interesting you mentioned that; that's one of the things I want to focus on moving out into his adult life. I just think the whole setup of any sort of organized religion is very tough for people that can't control movements, can't control…don't socially understand how to modulate the volume of their voice or when to say things and when not, you know, 'cause everything is so scripted often, you're supposed to be quiet when you're, you know. And understandable it's you know, that's part of the meditative process that I consider you know a service to be. So how am I gonna answer that? I think that that religious, our religious, they're not that conducive, but I think that they would try if they could. They **[00:31:51 inaudible]** huge thing to change. So yeah, that's one thing that I wanted to try. Gosh, I don't know if I even answered your question.

**Interviewer:** You did! You did great. These are all perfect answers truly. Again, thinking a bit more broadly and towards the future, what hopes or worries do you have in terms of how Sam's community will react to his sensory needs?

**Interviewee:** My hope is that they will understand how to react in a calm way and provide support to him that's, effective and respectful. My worries are that he would be yelled at for his behavior. And then I'll just back up a little and say I'm not saying that you can't take a direct position with someone who's you know, *“OK, you need to calm down.”* But I guess…so my worry is that he could be met with anger or yelling by people that become frustrated or flustered or angry, I suppose. And then at the very worst there could be physical harm, so I mean that's you know the biggest worry, emotional and physical harm as a result of it.

**Interviewer:** Absolutely, thank you for sharing that. We're going to move to our next chunk of questions. In the transition to adulthood, where do you see your son?

**Interviewee:** In what respect?

**Interviewer:** Like, how independent is he? How far has he come, how far does he need to go?

**Interviewee:** I don’t I think he has come super super far in terms of functional skills like cooking. He has made some progress, I don't think it creates any independence for him, he still relies very much on the adults around him and he always expects to have an adult there. Also too **[00:32:32 inaudible]** just the functionality of knowing how to be like, *“what am I going to have for dinner?”* and sort of planning like that. Other than riding transportation, he can’t do that by himself, he can't, he would not be someone who could just walk down to the store. Yeah, he always has to have an adult with him, he just doesn't have a sense of how the world works and what to do and when to do it. Like right now I'm pushing very hard for the school to work on what we call purchasing, where he is taught how to walk into a store, pick out an item...like I work on it when we go to the grocery store here a little bit and find it, and really look at what is money. So, I would say he still has a long way to go for sure, to achieving independence.

**Interviewer:** **[00:35:26]** How is he in terms of physically taking care of his body and his space?

**Interviewee:** He's really good with that, I would have to say residence folks there they did an amazing job with that. And maybe you know, it's always this thing of when you live at home, of course mom is going to do stuff, autism aside right, you know, than when you're on your own. So yeah, I'm told he knows how to do his laundry and sometimes I will have him do it here but I'm kind of guilty, I just do it, that he is very good with that. We do observe him brushing his teeth, flossing and he washes his hair. I think...I don't know if he can adjust the... so now my husband takes care of the shower thing for him, but I think Stanley knows how to turn it on, but even if he doesn't know how to modulate the hot water, the water temperature, he can get in and out and dry off. So those self-care things are good and he not only does he make his bed, he *must*, he's very anal about having a very perfectly made bed. Yeah, those things. He gets his socks on, his shoes on and he says, *“is it shorts weather or pants weather mom?”* Like he’ll do things like that. Yeah, I mean, I don't know if this relates to the question, but he still definitely... we have to remind him, especially when he's home and maybe it's different when he's at the residence, *“close the door when you go into the bathroom,”* he still doesn't have that body awareness, so he'll come out of the bathroom with no underwear on, privacy, so that kind of thing.

**Interviewer:** I'm sorry if you answered this, but how is he with preparing simple meals like snacks or sandwiches?

**Interviewee:** Simple meals he's pretty good. We've taught him how to make popcorn, he knows how to make what we call cream cheese crackers, which is basically those big English cream crackers with cream cheese. What else does he know how to make? You mean how to make completely independently?

**Interviewer:** Yeah, or with support, you clarify both.

**Interviewee:** **[talking to Jared]** Hey Jared, what else does Stan know how to make? **[to Rachel]** He says popcorn and **[talking to Jared].** Just really a couple of things, I think. I think the rest he’d need support, like if you're standing next to him saying, *“OK, put this on, do this,”* he'll do it.

**Interviewer:** Got you. Is he able to help you going shopping, I mean perhaps pre-COVID?

**Interviewee:** Yeah we go to the grocery store. And if I say, *“Sam, find the sign…”* – and we'll be standing right near it, *“find the sign for green Peppers.”* I’ll try to pick something that he doesn't know what it is, like bananas he knows what those are. So yeah, he can read the signs, pick out the food, put them in the grocery cart, and yeah I have been working with him on this. And he sometimes needs some prompts but he can do self-checkout, he can use the credit card there with that. He's home on Fridays, so will do stuff like that on Fridays. Yeah, and talking to him I'm realizing, I think we need to you know, our prompts with the kitchen stuff, like instead of standing right there and saying, do this, we can stand back and say OK

**Interviewer:** **[00:39:24]** Yeah, you’re there, you can catch him if he makes a mistake, you know. Related to the credit card and the purchasing, how is he with money, money management, the concept of money?

**Interviewee:** So, he is just at the baby phases of that. He before never used to understand what money was, how it was used, the fact that it is used, things like that. And now the Meyer Center does have him do some vocational stuff, and so we really... and that was one of my objectives that I had wanted them to work on, and I don't know that they have, I don't know that they have or it's kind of restricted their ability to do so, I don't know. But I really wanted him to connect – I have had a lot of conversations with him about it – connect that money isn't just this inanimate object, it is used to purchase things, because then that can be a motivator for wanting to work and things like that. And I think he is starting to get it because he has... last year he started using phrases like, *“I have a money job.”* And I have had him get money out of the ATM with his card and then go purchase something. So I would say he has sort of the basic understandings because he loves the movie Jumanji now, and he loves all the toys, so we will say, *“oh you earned money from your job, so you can take the money out.”* Add he will say, *“I have money, I can get a toy, I can get a Jumanji toy.”* So, he's just starting

**Interviewer:** Yeah, that's wonderful. What is his job?

**Interviewee:** So, that's hard to know, because it's so hard to get information on that. I have seen janitorial skills, clerical skills, I don't know what breakdown of that is, I've seen data entry, I think he does like copying, data entry. I don't know what encompasses the janitorial skills but that speaks for itself to some extent. Copier, copy machine. I think that's kind of it, wrapping silverware, that's one that's done down there, yeah.

**Interviewer:** This is through the Meyer Institute?

**Interviewee:** Through the Meyer Institute, yeah.

**Interviewer:** Got you. Does he ever express interest in wanting to live on his own one day?

**Interviewee:** No, as a matter of fact that's a subject I'm getting nervous about bringing up because I don't want him to get sad, because his feelings is when he's done with school, he will come live at home. And I think the best thing for Stan is to continue to live in a group home environment so he can have a level of independence **[00:42:32 inaudible]**. That really grows so much more when you’re out of your parents home, autistic or not

**Interviewer:** Oh yeah, for everyone.

**Interviewee:** For everyone. And I think especially so for kids like Stan – in my understanding he just went in his room so I can talk really loud about him **[chuckles]**. Typically developing kids they just sort of have this innate, natural desire to become their own self, become more independent, and say, *“I can do it,”* you know. Even when they're little, my other one says, *“mommy I can do it,”* you know. I think that social sort of sense that, *“I am my own person”* is missing with kids like Sam. And it’s through being around other people in a different environment that is not the home, for Sam at least **[00:43:29 inaudible]**. But he does say things now, like, *“I'm like a grown up now*” and he'll really emphasize that he's twenty-one and he's not a kid, he's a grown up. I don't know what his head thinks about what that means to him. I just wanna say really quickly at 12 I have a call that I have to be on.

**Interviewer:** OK, we are about halfway, we have maybe like a third of our questions left, they do tend to go a little bit faster. Would you like to reschedule another time to finish off our call?

**Interviewee:** Sure, yeah.

**[00:44:04 Talk about rescheduling interview and chi-chat about accents]**

**Interviewer:** Thank you for letting me know. I will ask one more question to finish off this, and then we can reconvene next week. Does Sam managed some type of social life, does he have some friends from school?

**Interviewee:** No, no, it's always contrived, if he's going to engage with another student, it's you know, because it was set up.

**Interviewer:** Got you. Awesome. OK we will finish the next week that way you are not late for your meeting and that way you can kind of mentally prepare as well. Well it was so wonderful to talk to you, thank you for making time.

**Interviewee:** Thank you, I appreciate it.

**Interviewer:** Of course, anytime. I look forward to finishing off this conversation a week from now.

**Interviewee:** OK, great. Thanks so much. Bye bye

**Interviewer:** Bye.

**[End of Transcript]**