

Interviewer/Number of Interview: EG31

Date of Interview: 12/12/19

Name of Interviewee Assigned by Researcher (to protect identity): Respondent

Year of Birth: Information is not being made available. Respondent is 25-34 years old

Gender: Female

Country of Origin: U.S.

Note: In the transcript, *I* refers to Interviewer, and *R* refers to respondent/interviewee. To protect the identity of the interviewee, some responses to questions are not provided. In such cases, this statement will show in the transcript: Information is not being made available. In other responses, specific details that might identify the family members are omitted or made more general.

Abstract:

The respondent was born in Illinois and her parents immigrated to the U.S. from Pakistan in the 1990's. She has two children under six years old – one boy and one girl. Her husband works full-time. She is the primary caretaker of her son who is on the spectrum of autism. This interview touches on the particularities of her son's needs at home and at school as well as distancing and educating family on what having this specific disability means. At the end, the interviewee compares religious and gender differences in a cultural lens.

Key Themes:

Socialization, Improvisation of care, Educating family, Gender expectations, Improvements in religious settings, Cultural shifts, Insurance, Understanding religion and health, generational differences in levels of understanding regarding ability differences, ignorance around vaccinations and autism.

Transcription:

I: How do you identify yourself in terms of national background?

R: I'm American born and raised but my parents were both born and raised in Pakistan and they immigrated over in the 90's.

I: Okay and what was their reasoning for immigration?

R: It was political tension in their country and then more opportunity I guess you could say because they were starting a family. There were just more job opportunities here and most of my dad's family was actually immigrating at the same time so to kind of keep their family together. The chance arose that he was able to come, my parents, so yeah they just came over.

I: Good to know. And what is the highest level of education that you have completed?

R: For me, I do have a high school graduation and there are some college credits but we had our son before I could completely finish. So for now I'm waiting for them to be old enough and then I'll go back to finish up my degree.

I: Oh Gotcha. And what is your marital status?

R: I'm married.

I: And do you have any children?

R: Yes [2 children under 6 years old, a boy and girl]

I: Great I'm sure they keep you busy. And do you currently work outside the home at all?

R: No, my son [who is the oldest] is the one who has autism. With him there's a lot of therapy involved. So how we're working with it is my husband is working full time and then I'm dealing with therapy and appointments and all of that.

I: Okay so the next set of questions focuses on the types of differences of ability you or the person you care for has. We're interested in learning about the following types of differences of abilities: physical, chronic illness, learning, intellectual, mental health, speech and language and addiction. So, you mentioned your son has autism. How does that affect different areas and how does that affect day to day life?

R: If we just went through it by category that would help narrow it down. Physical I would say the one thing with autism that stands out is the low muscle tone. A lot of times that's one of those things where he tries to [do something but has trouble]. He hasn't needed physical therapy but because he's a sensory seeker and avoider, it depends where we're at and the activities he does. So for instance, physically, thankfully, he does really well for sports and things like that. He's in [a physical activity] now; he's been doing that for about a year but since he's a sense seeker he likes to crash and bang a lot. He broke a [bone earlier in the year] so that led him to where we couldn't do a lot of things for 6 weeks until he healed. So in that sense, finding limits is one of the things, but we're trying to find a sweet spot while keeping him active but keeping him safe.

I: Yes, totally. The next category is chronic illness, I don't know if that applies.

R: Chronic illness I would say I know a lot of people with autism have a lot of sensitivities when it comes to diet. So gluten, eggs, and dairy. So for him (son) we just got him retested and his

dairy allergy is weird. [Certain dairy he can have, and whether it's cooked or not is a factor also.] We're still trying to find out what kind of sensitivities there are because he's not 6 yet. With a child allergies kind of cement themselves when they're 6 and up then you can narrow it down to the specific thing that's triggering or whatever.

I: Okay the next category is learning.

I: Learning. So with autism you have speech delays and things like that. So initially, the way they grade/bill for insurance they categorize it for speech therapy they call it a mixed expressive receptive language disorder and that's how they treat him and will bill the insurance. So basically with him he has vocabulary, he can talk, he has speech but expressing and receiving language is limited to his realm if that makes sense. So whatever he learned is in a box and if a concept is outside the box it won't make sense and it won't translate. A lot of times it's like building bridges. If you can build off an idea he already knows or model it or visually show it, that's how you teach vocabulary because a lot of times just auditory language does not process. If it's new it'll go completely over his head and won't get it. So for that we need to really sit down and explain to him. We recently had a neuro-psych eval done for insurance purposes and same thing for that we're having a little trouble testing because he presents as he understands language like he'll go along with conversation but it's actually kind of difficult to gauge where his understanding stops. So he has enough vocabulary to get by and roll with the punches, but when things go over his head we're like okay where is the gap? Memory, he has great memory. It's almost uncanny. There are times, for example, when we had an opportunity to go to a mock appointment at American Airlines at O'Hare Airport. He loves planes. Now he has memorized the way to the airport and we've only been there once. So every time we go on the highway to Chicago, he's like, "oh are we going on a plane?" We build language and things that are repetitive, like songs and games; he's all over it. So memory is one of those things that's a real strength. So we've started teaching him the Quran and he's actually pretty far in memorizing the prayers. I didn't expect him to jump right in as much as he did but he has gotten pretty far.

I: What about school?

R: He has the option if he's not feeling it that day he can stay in the smaller classroom. You know, he does as he sees fit. So, for now I think it's gym, library, morning meeting. All of those I think he does in gen ed and then when he's having a day he doesn't want to participate in actual class he can ask to go back. And the entire time he's with the gen ed it's always with a parent. He's doing really well thankfully and we're just trying to stick with that. And then we just have to touch base in spring break and see if he's doing well. He doesn't qualify right now for an extended school year because he's meeting all the guidelines and he has not had enough learning deficits to meet that extended school year program. So, we'll see. And then for first grade if it's, in my mind, working the way it is we're going to keep doing the same thing because I don't see why we have to push it. It is what it is.

I: Yes, okay. And then how do you describe the nature of care that you provide for your son that might not be average for a neurotypical kid?

R: It's a lot of, how do I explain it...MacGyver-ing and rolling with the punches. It's a lot of thinking on your feet, you really have to. The hardest thing for my son is transitioning and he does not like surprises. We couldn't, for the longest time, do anything spontaneous. It would freak him out like it just does not register. For him it's like, "what are we doing". He's in feeding therapy right now because we were having the same kind of thing with food where especially if he's stressed out he'll stick to one kind of food. He's really good at having, thankfully, a varied diet but we know he's stressing out when he's only sticking to one kind of food. So things like that, again, he's not as heavily needs-based as some other kids might be, doesn't need as much assistance. But there are times when you really need to find how to work with him. For school he also has a pack sport they do and for him one of his limitations is, he does not like to mix settings if that makes sense. So, what's done at school will only be done at school and we won't do any of that at home and vice versa. So, we're having trouble translating what we do at school to home. He won't do homework at home, he doesn't want to do that because "we do that at school. Why would we do that anywhere else"? But again, reading and writing, those kinds of things/tasks and skills we do everywhere. We don't just do it in a classroom. You really have to find how to convince him and make it appealing to him to do everywhere.

There are things where he can't physically bear to have touched a handle so we're trying to teach him difference. Part of it is also cultural, there's a difference with that. Where I'm sure there's also a difference with that but even when we're out and about I've kind of gotten an offhand, "well you know all kids are like that. It's not just yours" and I'm not going to outright tell every person that walks down the street, "Hey he has autism". I'm not going to hang a sign but there's that age right now that he's a kid and they'll dismiss it. Or I'll get a, "oh my kid did that all the time". That kind of thing where I'll be struggling and he's holding onto the wall not wanting to go in the elevator and we're holding up a line of 5 people. That thing where he's young enough and frankly cute enough...I'll get that too, "he's too cute, it's okay". But we'll get things where we have actual issues going on and they'll just be saying every kid does that. But culturally I have noticed a lot that if you spank a kid, it will fix the problem. When no, that's not the deal. Where it's he's disobeying or I haven't put enough authority to make him behave properly or however in their heads it is. That kind of thing.

I: And you mention culture. Would you say that the Arab and Muslim community is, I don't want to say harsher, but more critical perhaps?

R: I would say yes because again there's a discrepancy...how do I explain it...We're Pakistani, my parents are and for me there's more of a disconnect because the irony is that religiously you're supposed to be a lot more open and caring to those with disabilities. That's not always the case culturally. So, a lot of times with culture you get the weird, "oh he got the evil eye" or something like that where you just need to read the correct prayer to be fixed or cured. How do I translate this...there's this word called "zid" and it's where you're stuck on the same behavior where you dig your heels in and say this is all I'm going to do and that's it and generally it's used for kids. "I want that specific thing and that's it." It's the whole concept of parents are the authority and that kind of a thing. But it does not translate all that well when you throw culture in. Quite honestly, my siblings know my son's diagnosis; my parents do not and neither do my

in-laws because it would turn into a situation of [causing a lot of stress] for my dad. Once I mentioned [to him] that our son was seeing a counselor and he got immediately angry saying, "There's nothing wrong with your son. He just learns differently and takes more time" that kind of a thing. You know [for some people there's the cultural belief] that autism is a disease that needs to be cured versus it's just someone's brain wired differently. And explaining that to someone, that people are created different ways, again ADHD that's also one of those things that's not really talked about because then it's, "you're just too hyper" or the terminology is just thrown around where even if you provide the education, it's not taken literally as it is. It'll be used as, "She's arguing too much, she must be bipolar", you know what I mean? The true understanding isn't there, so work is needed around educating the older generation. My siblings and I see [autism] through a different lens. But with the older generation, it's a lot more, "No, it's an issue of faith". My dad's perspective would be that the doctors are just looking for a reason. The in-laws in my family were adamantly against therapy of any kind. They think it's for kids that are ill or physical disability where it makes sense to them if you've been in a car accident then you get therapy, but "why would you need it anywhere else".

And the same thing with counseling or emotional therapy, that concept is not really there. Quite frankly, I've noticed that, culturally, in any Middle Eastern or South Eastern Asian culture, therapy is not looked at as great. You need more sleep? You need to pray more. That will fix everything. So, that's the viewpoint that I need to bridge that gap. The concept is not really there. You get happy or sad or whatever and that's it. You fix it. That's it just fix it.

And the whole problem is, my son is not broken, he's just different and I can't explain it to you in any other way. The other thing I've also heard culturally, "there's something in the water in America, every third kid has some kind of disease" or something like that "in our day, in our neighborhood we never heard of this kind of thing", well no offense but you all are from a third world country, that's why you left. Frankly I wish I could say that openly to my parents' face -- it is what it is. And it is more prevalent now because media is more prevalent, but we're also seeing it more and catching it earlier so it's inconclusive or to coin a phrase, fake news that was around where vaccines cause autism, there are still a lot of my cousins who live back east that say "no don't give your kids vaccines. Your kids could get autism." and I was like, "no, that's not what happens." [Respondent described a scary situation regarding a family member who wasn't vaccinated.] Just certain things happen where the fear overtakes any kind of education or any kind of learning you can give because you don't know what it is and it scares you. At the beginning, our son's primary method of soothing himself was to slam his head on the ground. To me it was like, okay we need to find a different way and everyone was like, and "what is he doing? Is he possessed?" That kind of thing. So it's one of those backward cultural things that's "it is what it is" or it's from the devil" which it's not, you know.

I: Gotcha. So, when you were talking about that you said that a way to break down the stigma would be education. Who do you think that falls on within the Muslim and Arab community?

R: Honestly, I think religiously. Religious leaders from institutions, it falls on them because personally even now, I'm not sure if you're aware but masjid, if they had a lot more outreach I'd

be so happy because we have noticed, I've been following them on Facebook and stuff like that since we're looking at places that would be accessible to my son, you know. And again you know with wheelchairs and stuff like that, that's a big thing you need as well, but also for children with other disabilities, you know, other disabilities like that exist and frankly if you're not able to bring your kid to the masjid and you can't mingle with other aspects of religious community, you're really isolated honestly. You know, I haven't been in the masjid with my kids ever because it's going to be too crowded. In our area, we have a smaller one here but when there's actual religious holidays, it's packed to the brim so, my son gets overwhelmed. So, if they had a thing like a sensory room where it's quiet with no bright lights or devices it would really help. Or even just the Imam talking about it, the idea that it's not from the devil, it's not something that just happens to your kid. Sure, we don't know the exact causes but again the way people should be treated, a reminder of how religiously how people with disabilities and their families should be treated. I think it would really help because the disconnect is that, the way I know unfortunately, is with faith it's kind of like you go on Fridays, you pray, you put a pin in it, and then you come back again the next week. So, there's not a lot of application going along. You're saying yes you're religious whatever the case may be but again it's kind of like my son ironically where you're limiting it to the location of. So, personally it would open it a lot. Again, culturally a lot stems from faith. Sure, you know certain things like evil eye, we believe that, I get that, but it's to an extent. It has its place in religion and that's it, you can't apply it to every topic. So, specifically, you know, that's the education topic. One thing that stands out is that my mother in-law watches Pakistani news channels, and they had a story kind of about autism and immediately they're like, "it's a disease." Recently, my mom listened to a conversation on a group chat and the person asked, "someone please tell me a dietary cure for autism, I'll be so thankful." My only response was, "well sorry, there's no cure. You can help your son get support or whoever it is but there's no cure because they're not broken." So, that idea where if your child is not fitting the box, something's wrong with them and the idea that instead of creating a world to fit around your kid, you have to force your kid to fit into a shape that they're not meant to be in.

I: Yea. So, kind of jumping to a little bit different aspect, how do you think it differs for a female with a disability versus a male with a disability?

R: Culturally?

I: Culturally, yes.

R: It's very earth and heaven distance. Not even sky and ground. Earth and heaven distance. There's a phrase, culturally, and I hate to say it but it goes like...(11:37 Arabic spoken, could not transcribe) so, the phrase is, "if he's lame, deaf, blind, whatever the case may be, if he gets married, he'll be set" he just has to be a man. I cannot tell you the crisis I went through when my daughter was being diagnosed regarding her feeding issues [and being a very finicky eater]. There was such a moment of sheer terror when they said it was a good idea to get our daughter also diagnosed or checked and see if there's anything we can catch early on. And there's just such pure panic that if it turns out that is the case, what do I do from a cultural standpoint?

Because, unfortunately, it is very much still a man's world. It does not matter who he is if he finds somebody, he'll be fine from the fact he's a man. And unfortunately, for girls [culturally, it's a matter of] do you marry well or not. We're still stuck in the 1800's quite frankly. So, even with a lot of girls I've noticed, they can get PhDs or whatever the case may be, that's nothing if you're not a good housewife. Which if she has a doctorate, what the heck are you talking about. But it's really that backward thing where you have to know your place. It is really irritating because, again, there's a difference, a break from people who obviously still live in that mentality and then Americans who are their children. There's a big difference where not everyone wants to fall into that box. It is what it is. With disability it is still very prevalent that well, if you're going to get married, these are the circles you can look in; they're going to want someone who's completely...you know they can have their pick of any other girl. Where do you fall on the totem pole kind of thing? A friend's mom has severe depression; so when the mom was looking for potential suitors for her daughter, someone told her, "I consider you a sister and I'd say, don't say you have depression when you're trying to look for suitors because it's going to reflect poorly. They're going to say, 'we're bringing in a girl for our son who is going to bear his sons, is she going to pass that on to our future bloodline?'" So, really backward things like that where, sure, there might be genetic components but that doesn't mean you're going to [get it]. You know, we're not going to get into eugenics, God forbid. It is heaven and earth difference where if you're a guy, it's fine, it still can be dealt with. With men, I'm not going to say you can declare it per say.

I: Are there other obstacles you've experienced?

R: It's been three times the insurance, variations of it, cancel on us. They didn't cover certain things, or things like that where I literally needed to sit down for hours on end calling and calling and calling and calling trying to figure out what is going on. School is very limited, in the sense of, they can only deal with what is at school. They can't support you with what is at home. Then the doctors and clinicians can only deal with what they see in their clinic. So, for us the biggest missing piece has been in-home services, in the sense that we're having behavioral therapy, but we only see that in clinical setting and they can only offer suggestions. They can't come in our house based on our insurance and see what I'm dealing with at home in a specific setting and say, "okay this is how we're going to work on it". You know, you need either amazing healthcare, or you need a lot of money in order to do that. So, in a sideways kind of thing a lot of people take when they find out their kid has autism, the forefront of therapy I guess you could say or a main one, I'm sure you know, is ABA [applied behavioral analysis], where it's huge and everyone and their momma is running after it. For us, immediately it was my first question because I had researched it before we went for our [appointment with the] developmental nutritionist. I had said, "Okay what are we going to do?" I asked, "Do we need ABA? What do we do?" and he said, "No, thankfully, your son, I don't think he needs things broken down to that level because ABA is very much like, we're going to break things down military style, this needs to be accomplished and then this and this. Everything is really broken down into steps of how you're going to achieve that with a scoring system with a lot of statistics and things like that.