

1|EG40

Interviewer/Number of Interview: EG40

Date: March 27, 2020

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

Year of Birth: Information is not being made available. Respondent is in the range of 25 to 34 years

Gender: Male

Country of Origin: India

Year of Immigration: About 10 years ago

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 is in the age range of 25-34 years old and is currently living in Milwaukee, Wisconsin. He first came to the United States about 10 years ago to pursue higher education and job opportunities; he currently works in a professional position. The respondent has three children who are an infant and two four-year-old twins – a son and a daughter. In this interview, the respondent discusses the history and impact of his daughter's differences of ability on his family. The respondent's daughter was diagnosed with autism spectrum disorder and a mixed receptive-expressive language disorder at a young age, and has great difficulty communicating with others. The respondent describes his struggles in balancing supporting his family with caring for his daughter and talks about how his family works together to support her and fulfill her needs. The respondent also emphasizes how awareness is the most fundamental resource needed to combat stigmatization, which applies to Mosques as well as society in general. He highlights various organizations that have helped him as a father and caregiver. He also explained that more could be done to educate the caregivers on what they need to do and what not to do.

Key Themes:

Autism spectrum disorder, caregivers, children with disabilities, mental health, receptive-expressive language disorder, importance of MUHSEN, stigma within society and Muslim community, generational differences in acceptance/understanding of people with ability differences, norm of keeping disabilities "hidden" or "secret." Muslim community and society need to be better educated about ability differences. Caregivers need more support about what to do and where to go for resources. Workplace policies need to be changed to support families.

Transcription:

I: [Introduces self and asks respondent for his age and where he was born]

R: [In the range of 25 to 34 years and born in India]

I: Okay, and when did you move to the United States?

R: [About 10 years ago]

I: Okay, and what was the reason for your immigration?

R: Higher studies, and then I stayed here to work... To find more jobs I was continuing my career.

I: Okay great. And how would you identify yourself in terms of your national background? For instance, I might say that I'm Irish-American.

R: I'm an Indian by birth, so we are also considered Asians. So that's who I am.

I: And what is the highest level of education that you have completed?

R: Bachelor's degree.

I: And what is your marital status?

R: Married.

I: And do you have any children?

R: Yes, I have three kids.

I: Okay, can you tell me their genders and their age?

R: [One infant and a set of twins who are 4 years old – one is a male and one is a female]

I: And then do you currently work outside of the home?

R: Do you mean right now? Like these past few weeks?

I: Not necessarily due to Coronavirus, but on a regular basis do you work outside of the home?

R: Yes.

I: And what is your occupation?

R: [Respondent is in a professional occupation]

I: Okay, and how many hours per week do you work?

R: 40... Well on paper anyway.

I: Okay, and before we move onto the next set, our interviews revolve around the stigma of disabilities. May I ask who in your family has a disability so I can preface these questions appropriately?

R: Yes, it's my [4 year old] daughter.

I: Okay great. So, the next set of questions focuses on types of differences of ability that your daughter in this case has. We are interested in learning about the different types of disabilities including physical, chronic, developmental, intellectual, mental health, and addiction. Could you describe to me what kind of difference in ability your daughter has?

R: So, developmental is one. I think some intellectual, not physical. What were the other choices you had?

I: Physical was first, then chronic illness...

R: Chronic illness... how would you define that? Is that the lifelong thing?

I: Yes.

R: But it's not the same thing as a disability, correct?

I: It can fall within disability, but that's more like cancer that results in a disability if that makes sense.

R: Right so no chronic.

I: And mental health was one of the other ones.

R: Yes, mental health, yes.

I: Okay, and speech and language?

R: Yes.

I: And then does she have an official diagnosis?

R: Yes.

I: Can you share that with me?

R: Yes, she has autism spectrum disorder, ASD. And speech and language, I forget what it's called... expressive and...

I: Receptive?

R: Yes, expressive and receptive language disorder -- that's what it's called. Developmentally she is -- at an official score -- rated as half her age.

I: Ok that goes into my next question: How does her difference in ability impact different aspects of her life intellectually, socially?

R: So socially, my son goes on playdates with neighbors, but we don't send her, because we think that neither she is ready to play that part, and our neighbors aren't equipped to deal with the kind of behavioral issues she has. So socially we have to keep her home because of that. We do go to engage sometimes, if there is a family that already has a disabled child and they know the issues. There's some level of social advantage there, but generally no she's limited in her social life. She doesn't go to school, like my son goes to the K-4 program and my daughter has full time therapy. It was a choice between preschool and therapy, so we chose therapy. If school starts in September, we're going to delay her by one year and get her ready for school, but we're sending our son to school. We want to put her in intensive therapy to make sure she is more ready for school next year. That's one of the better things that's helped in her life.

I: Can you explain the timeline for the diagnosis of your daughter, when you may have seen different characteristics that lead to medical seeking?

R: Well since they are twins I kind of caught onto it as early as the pre-months, maybe 18 months. I started the speech therapy before she was two years old, and around two and a half years she was diagnosed. November of 2017, I believe. Since then she has been enrolled in early access programs and whatever other programs they have. She has been on therapy on and off since that diagnosis.

I: What factors, if any, do you think may have contributed to your daughter's difference in ability?

R: Oh, I don't know, some people say a number of things but scientifically there's no known cause. Recently I've heard of a breakthrough study that says that there's something in the brain where nerves are not insulated enough due to a deficiency in a certain chemical, and that could be a cause, well I shouldn't say a cause but maybe a correlation somehow. I am a bit skeptical of vaccines too *laughs* since there's no known cause everything is a potential cause in my opinion.

I: And how would you describe the nature of care or support she needs, keeping her age in mind of course, in this time given her difference in ability. What kinds of things does she need extra help in that maybe your son doesn't need help with?

R: She needs help in healthcare, in keeping her occupied. She needs more help in keeping her body regulated but generally she's ok; she doesn't need that much care. Recently she's potty training and she's increasingly getting better at self-care. She's not at the same level of my son but you can't expect that. She requires the care typically required of a two-and-a-half-year-old.

I: Okay I see. The next set of questions focuses on perceptions about people with differences of ability and experiences of prejudice and discrimination. So, the first question is: compared to broader US society, how do you think the Muslim community perceives differences of ability that are visible? For instance, someone in a wheelchair.

R: That's hard to say... could you provide some more context?

I: Yes, so the next question is where we're comparing and contrasting. We're trying to see if the Muslim community perceives invisible versus visible differences differently than the greater US society.

R: Yes, that's a huge problem. I don't see that specifically with Muslims but... My perception is that when you look for Muslims in America you will see many different flavors. Second generation migrant Muslims or third generation, those who are more American by birth or by

culture, will be more aware of other disabilities that may not be visible. For people that are first generation migrants they are not as aware of visibilities that are not visible, and as a result they are not very accommodating. I have had personal experiences with that.

I: When we talk about invisible differences, we often talk about mental health and addiction. What does it feel like the perception is within the community about those types of differences?

R: I think addiction has some level of blame associated with it. I don't think that's restricted to the Muslim community. I think for many people – and to some extent myself – there is blame associated with addiction versus other mental health issues.

I: The next question is: Have you or your daughter in this case experienced any prejudice, negative remarks, or discrimination because of her difference in ability?

R: *sighs* Oh my daughter... Yeah, some. Kids will generally ignore or avoid her; families who are somewhat aware of our issues will not invite her over. There is a level of discrimination and bias yes.

I: Do you feel like in any instances that being Muslim or Asian contributed to those negative interactions?

R: No. To add some context, being a migrant does put us in a position where there is a lack of opportunities for social interactions that may be available to other people if that makes sense.

I: Is there any specific example of remarks or actions that individuals have done to you or your family or your daughter?

R: Yes. I do remember one specific incident, and this was not my daughter it was with another family that we socialized with and had the same disorder. This kid was 6-7 years old and we went into the mosque for Ramadan where we all gathered. He has autism and he was sitting on a table or climbing on a table or something, and they were regulars and that mosque, but the president of the mosque – I'm not sure if she was aware of the condition or not – basically just shouted at him with no regard for his condition. The way he was treated I was very distraught by that. That's one thing, and the other thing I would say is that in a lot of mosques around the nation there is no accommodation for kids or people with disabilities to do prayers or worship or anything like that. Recently here there is a mosque that does a very good job of doing that and providing extra accommodations for families with kids with disabilities. Usually that is not the case, but, fortunately we have one mosque that does an excellent job of catering to the needs of families with kids with disabilities.

I: Is that the Brookfield Mosque by any chance?

R: Yes.

I: Okay that's what I've been hearing through these interviews. We'll come back to the mosque situation a little later. Given your experiences with the community's perception, is there any impact on your willingness and your family's willingness to go out into the public, attend events, that kind of thing?

R: Yes. In every one of our decisions, in any event, even on vacation. We walk around asking what kinds of accommodations exist. Say there are two mosques, and both of them are pretty active in social events, but one is much more active than the other. We tend to not attend any of these events because there are no accommodations for our daughter, and she engages in inappropriate behavior – well not really inappropriate, just not generally what kids go through. It can be uncomfortable because there are no accommodations and no arrangements. It's like a free-fall so we don't attend these events. And generally, also, any event that would put us in a situation where we need to take all these other precautions where her safety would be a concern, her flight risk would be a concern, or all that. That's what our decisions are usually based on.

I: As a Muslim, what are the expectations of yourself for being a caregiver for your daughter?

R: As a Muslim I think I am responsible. I say I am... what's the right word for it... I am accountable for her future, her assistance, for whatever support she needs. I see that as an added responsibility – more so than a difficult child – but I don't know how to put that in words.

There is a term in Urdu that's called *Amada*, but I don't know the exact translation. It loses its meaning if I don't put it in the right words.

I: That's okay! I think responsibility gets across well. The next group of questions focuses on the challenges that you have faced in dealing with the issues we've been discussing, how you've dealt with them, and what is needed to make life better for caregivers and people with disabilities. So, the umbrella question here is: What are the biggest challenges you have faced as a caregiver to your daughter?

R: Okay... well, balancing work life is challenging. I feel that I fall short of that. The way I am dealing with this and the intensive therapy schedules and meetings, I see it as a big project that is going to go on for many years. I see it as a big project in its infancy, that's really how I look at it, that's how I manage it. That's how I can keep some sense of sanity even. Trying to balance work – all the workload – and all of these meetings and keeping up with all the therapy and strategizing about the therapy and getting training, the time aspect of it is very challenging. Because there are no special accommodations when looking at it from an employment perspective – as a caregiver – to give that extra care because, let's face it, kids with disabilities do require extra time and a lot more effort. Treating all families the same way from an employment perspective is not correct. There are no laws or policies in place for all that, and it puts a huge burden – time wise – as the caregiver and it makes it hard to do justice to my daughter. That's the most important thing for me, time. Otherwise, resources wise, I think there are still a lot of gaps in laws as well as therapies or care and services that are available. Navigating through all of it is tough because you don't always know the next step; you don't always get to see the bigger picture. You don't always get to plan the life of your kid because you don't really know what to do. You're always trying to figure it all out, and each case is different, just navigating through all of these avenues and figuring out the best service, the best decision to get the best results for her.

I: Gotcha. I have a list of other potential challenges and I'll throw some out and you can let me know if any ring true for you and your family. Another category is finance, insurance, that aspect. Any commentary on that?

R: Finances... So, I would say that has not been a challenge. For me I could see how it could be, I see the potential, but I've been pretty good. Both the states I've lived in are pretty good at providing funding. Her therapy is totally paid by the state as she has a diagnosed disability so she can get Medicaid. So, all of our therapy services are covered and any additional expenses, some atypical purchases or investments for her are covered by the CLTS waiver program by Wisconsin. Wisconsin State provides a lot of financial support that has helped offset some of this financial stress that could have been if these funding sources were not available. I know for a fact that if there was no Medicaid, my employer insurance would not cover her therapies.

I: Another category is the emotional toll as a caregiver that caring on a 24/7 basis might result in. Some caregivers experience different mental health statuses or emotions throughout their caregiving process.

R: Oh yes that's very very tough. It takes a toll; it's a constant battle every day. We go through an emotional rollercoaster because of the things we have to deal with, and now that we have to stay at home – all of us – 24 hours a day together it is even more so the case. The toll there is huge, and the only outlet that I have had recently was a support group that I joined at the Brookfield Mosque and that has been amazing. It not only gives you the opportunity to talk about it and get it all out, but also it helps you meet other families that are facing similar things, and sometimes even worse things, and you think to yourself "It could always be worse." There's a lot of work that comes out of the support group. We've had opportunities to meet the families and get to know them, and that gives the kids – especially kids with special needs – the opportunity to just be themselves. Of all the families we are friends with, the ones we are closest to are the ones that have kids with disabilities because those are the ones we can connect with.

I: Going off of that, the next question was about strategies that you use as a family or individually to tackle some of these challenges. Other than that support group – which sounds like a huge positive – are there any other strategies that you and your family have used to conquer these challenges?

R: Out of the support group we always have families that have kids with similar ages, and especially if there's a family that has a disabled kid, we try to socialize with them and that gives us the opportunity to talk about things that we have in common, and it gives the kids the opportunity to be themselves and socialize. It gives the opportunity to be in a more nurturing environment, so that's another thing in terms of strategies. I can't think of anything else *laughs*.

I: Any strategies or people you've reached out to navigate the therapy aspect and getting all of those services?

R: So what I did when I moved here to Wisconsin I contacted the Katie Beckett Program, I contacted a bunch of ADA therapy centers, I contacted speech therapy services, I contacted all the *indiscernible* programs. So I started out with a *indiscernible* program coordinator who gave us all the information and resources, and I communicate on a very regular basis with a therapist, and she provides assistance in that regard. And I read up and in our support group meetings we discuss what's new, what's coming out. For example, there are families there with kids with disabilities of all ages. Someone's dealing with school issues, someone's dealing with how to get trained for employment. I keep myself informed and try to go into places where there is a meeting or anything related to my daughter's life.

I: And then, have you had any positive experiences getting help from others whether that be friends, family, healthcare providers? You can talk about each if you want to as well.

R: Help in terms of any help they provide?

I: It can come in many forms but yes whatever you feel is applicable.

R: So I get a lot of help from my mosque, it's very very supportive. When my wife went into labor I got in touch with the child care provider through the mosque. That happened because we went to the mosque and there were these people who work here and do these things, and they just do it to be helpful. I've got help in terms of childcare. Even from another family that has sometimes provided childcare for a couple of hours. I get a lot of advice and support from the therapist.

I: What about your experience with your family in relation to your daughter's disability? Have they assisted, do they accept? How do they react?

R: So I am away here and most of my family is back home in India. They've only seen her a few times [and] their interactions with her were limited so they don't really understand it. They think she's going to grow out of it and the first step is understanding what it is. I don't think even now that they do understand, it's just a different culture, different country. They are very much concerned about her progress, they're happy when she talks. They cheer her progress and understand that she may be delayed, but they don't understand the close threat of her disability.

I: You talked about how maybe because they live in a different country than you are, or potentially generational?

R: Yes. The prevalence of autism in India is not as high and people in India are not as aware of autism as people in the United States, so they are already at a disadvantage. There is also more of a stigma – generally speaking – of hiding disabilities there. So people try to hide and that's a big thing there. So I don't know how it all affects, but they don't have a lot of exposure to our daughter. One part of it is understanding what the condition is, and the second part is understanding her particular condition.

I: You talked about hiding kids with disabilities and noticing that in your home country, have you noticed that at all in the Muslim community here in the United States? Or is that more of a thing of that past here?

R: Oh no, no it is not a thing of the past. I don't have to go very far. I think my wife tries to hide it. She does, and she doesn't let me talk openly about it. I would be a lot more open about it, but I see that, and it's just how it is. I think part of it is probably because of the fear of how our daughter may be treated if people knew.

I: Do you feel like that idea of hiding or not going out as much is different between you and your wife because of being a mother vs. a father at all?

R: I think there may be some truth to that, but in my opinion it's just because we're two different people.

I: Okay, the next question goes a different way here: If any, are there unique challenges that females with differences of ability face when compared to males that have the same difference of ability?

R: Yeah. I feel for my daughter, I feel more for my daughter. I think the same kinds of worries would not be there if it was my son. I am concerned because it is my daughter, I am concerned with how she'll deal with all of this and what her life will look like. I think autism is more prevalent in males than females, so she's going to have to deal with all these things. My biggest concern until recently was getting her potty trained, and now she is, and that's a huge burden off my back. And now I think about what's going to happen when she's 10-11? She doesn't even understand that concept of "me" and "you" or something belonging to someone, or the concept of shame. All of these things have me concerned, and I would not be as concerned if it was my son.

I: Since she is female, the concerns about puberty or maybe that kind of aspect... Any other kinds of "because she's female" concerns?

R: Generally no because I would be worried about my son's future as well. Having to live independently by themselves, what will happen to them? Generally, not even just for my daughter, living independently, getting a job, getting married, all of those things. What will life be like for them? Those concerns aren't just limited to my daughter.

I: For an adult who has a difference in ability, when comparing males and females do you feel like one has a greater challenge gaining education, employment, or marriageability?

R: I've never thought about it in that context. I would say no. For example, in our culture – whatever culture we have left *laughs* – a male is supposed to get a job and provide and that's how we have it in my family. I work outside the home and my wife is the homemaker so that's the arrangement we have. I think employment wouldn't be as much of a concern for my daughter, but marriageability would be. All of this goes hand-in-hand, one might be easier for the male, one might be harder or vice-versa.

I: Some other things that other parents have mentioned to me, usually for older children with differences of ability, is that they're concerned about their other children's marriageability as a result of having a sibling with a disability. Has that ever come across your mind?

R: No, no, that would just be foolish. I would be ashamed of myself if I ever thought that way *laughs*. But I will say, in relation to that, that my son's life is tremendously affected by her disability. It may not be his marriageability, but his life in general, his view on life, his behavior, maybe even his career path will be affected by it.

I: How have you balanced caring for your daughter and her needs in relation to caring for your son's? How has that been a challenge?

R: We were fortunate with respect to that. We have an atypical daughter, but we also have a son of strong understanding. It has helped in that regard that he is a little more understanding and more mature for his age. We all take care of her and we're part of a team. I know it sounds weird, but that is the reality of it. He's still a kid, but we talk about this and we treat him almost like a grown up kid and forget that they're the same age. There's always a balance between treating him like a kid and treating him like an adult and saying "Hey look, here's what we gotta do." Without that, I don't know how we could have done all the things we do. That's how I see that, but they do a lot of things together, they play together. We try to do team games like

boardgames to teach her. We get a lot of this done with sibling time that they're excited for. I try to do different things with my son like more intellectual things, or teaching him different things. With my daughter it's just very very basic conversation because she doesn't understand much. So he's often asking me "Why don't you do that to me?" and it's a struggle because I'm giving her more, and doing something that I would do with a two-year-old or a two-and-a-half-year-old. I don't treat her the same way and sometimes he gets jealous. That's definitely a struggle because he has different needs and she has different needs, but he doesn't always understand that what I do with her doesn't have to be the same thing I do with him. He's still a kid and he's jealous *laughter* so there's a little bit of a struggle there but otherwise it's all good.

I: Ok, so the next question is what additional support, help, or changes in attitude are needed regarding the stigma of disability, specifically within the Muslim community?

R: Definitely more awareness. The Brookfield Mosque is doing an excellent job and here's why: the imam over there, his dad has a disability right? So what it started with was awareness. He was aware of the things and challenges that a person with a disability faces. He was in a position to do something and he had the drive to do it. So he got involved in a huge non-profit organization that supports kids with disabilities. They do all these certifications and get mosques to certify themselves and they become active. I think more of that needs to happen, and more of the financial support needs to go to MUHSEN, and they need to do more, but funding is always a limitation. More and more mosques could be acquainted with MUHSEN and that's how they could raise awareness. That's the only organization that I know of in the United States that's doing an excellent job. If they were present in more places and more mosques, that could definitely raise awareness in the community. That's the first step, and then people will be more empathetic towards kids with disabilities, and not only those that are visible. So give funding into these programs and organizations like MUHSEN so they can create more awareness and provide more help in more places.

I: So, mosque, leadership, and organizations such as MUHSEN. Do you feel any responsibility as a parent to help lead that change? What potentially do you think you could help spark in the community?

R: There are a couple ways I could do it. I could donate my time and volunteer and help out with the MUHSEN group. I could also provide financial donations. So far, I've only donated money *laughter*, I'm strapped for time and don't have time. If I could, I would, but I need to work, and I have my daughter. Volunteering at MUHSEN kind of defeats the purpose if I'm putting all the pressure on my wife. I could do that, but my priorities are with my family at the moment.

I: Do you feel like what you bring to the mosque environment can also impact that change within the community? Like even bringing your daughter to the mosque or events or different things like that.

R: Yes, it will raise awareness although that is a difficult task to do. That's the thing, her just being there doesn't really help anything unless we talk about it openly. That's the other portion of it, and I can't talk about it openly apparently so...

I: Gotcha. So, the next section is: What are things that you would tell healthcare providers, schools, and the mainstream community to help them be more supportive and useful to you and your family. We can walk through each one, so what would you tell healthcare providers so that they could be more supportive and useful to you, your daughter, and your family?

R: So, my first experience at the pediatrician was my daughter. They had periodic checkups and gave me these questionnaires, and in the questionnaire, there was a red flag for my daughter. The pediatrician at the moment said there was nothing wrong and that she was fine and this and that and she pushed it off a couple times. I think it was about nine months or one year, so we lost about six months of critical time. Of course, we changed our pediatrician after that; I didn't like how that was handled. Pediatricians are not experts in mental health, but sometimes they act in that capacity because they are the first point of contact usually before diagnosis. If they have a lackluster attitude towards these kinds of things instead of airing on the side of caution,

it's the child that loses. Pediatricians could do a better job of handling these kinds of situations, but I think the mental health community as a whole does an excellent job of providing any help or support or advice. If they don't know the answers, they'll direct you to someone who does. So I haven't had a negative experience with any of the mental health providers, and I don't think there's anything I can add for them to do.

I: And by mental health providers you mean the therapist she works with?

R: Yes, right now it's a therapist, before it was the early access volunteer and another team, which I forget what it was called, but it was some kind of organization that catered for kids once they were older than three years. All of these resources have been at my disposal, and I took advantage of that. All of these people that I've interacted with throughout her journey I've had positive experiences with except for that one pediatrician.

I: And then, what would you think the mainstream community should know to be supportive of you and your family and your daughter?

R: Well, not every kid is the same. What you may see is a kid throwing a tantrum and just being difficult. People are usually quick to judge and are oblivious to the reality around them. That just applies to everything *laughter* not just disability. In general, people are quick to judge, and you see this everywhere. If you look at it from our lens of our reality, you will see that our reality is quite different. I think there could be more awareness in society, like what a typical autistic kid looks like, or what they may do, or what you should do based on their behavior. I think that could happen to raise awareness with the general public, so they act in a proper way and are supportive when a situation arises. I hear stories of people helping others because they had someone in their family with the same disability, but you don't necessarily hear about someone helping a disabled kid; probably not because they didn't want to, but because they didn't know how.

I: So, we have two more questions. The next one is: Is there anything else that you would like to talk about or discuss regarding the stigma of disability and the progress that is hopefully being made to unravel that.

R: You'll have to rephrase that *laughter* I didn't follow you.

I: It's an open-ended question. Is there anything else you would like to share about the stigma of disabilities and your experiences?

R: Yeah. We talked about stigma in general and you touched on the topic of emotional toll. What about stigma within the family? We talk about general people, but it starts from home. People may have an impact, but they have very little impact. As parents and caregivers, we have the most impact on the child's life, and it could be more tough to educate parents and caregivers of children with disabilities on what they need to do and what not to do. To help them deal with these types of things and how to navigate through society, how to handle communicating. No one provides guidance on how to communicate things and put it in simple terms, and I think more could be done to educate the caregivers so that they themselves are optimistic in the first place.

I: That's a really good answer. I always like to end with the final question of: If you were to describe your daughter to someone who doesn't know her or only might be able to see the cover – they don't read the book they judge the cover. What underlying things do you want to share with the world about your daughter?

R: Usually I would say that she's quiet, she doesn't speak much but she's a happy kid. She likes to be social. It depends on who I'm talking to, like if it's a neighbor the most I'll say is usually that she doesn't talk much. It depends on the situation, but I do not mention autism. I've mentioned it to a few of my friends, but I'm not allowed to talk about it.

I: Any other things that you'd like to discuss on record?

R: *laughter* No I think I've spoken enough.