

Interviewer/Number of Interview: EG12

Date: July 25, 2019

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

Year of Birth: 1950's

Gender: Female

Country of Origin: India

Year of Immigration: Early 1980'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. Summarized information is put in brackets.

Abstract:

Mother of a child with a type of dwarfism talks about her struggles going back and forth between states for surgeries, therapies, and all the associated financial burdens. She shares her son's experiences in achieving so much, yet closing himself off from the world. Currently she works in special education and has great sympathy and compassion towards children with autism spectrum disorder and how they should be treated. She described a very profound experience that gave her strength as a mother of a child with an ability difference and as a teacher of children with special needs: "God gave me a child and not anyone could just take care of that kind of child. So God chose me to take care of that kind of child, so I will take care of that one. So that gave me a lot of strength."

Key Themes:

Dwarfism, autism, social isolation of children with ability differences, treatment of Muslim males after 9/11, financial hardship with medical expenses, parents not knowing about resources that are available, parents feeling extremely overwhelmed, the stigma of mental health issues in Muslim society, sexual abuse of females with ability differences like autism and cognitive issues, long term impacts of bullying on a person's confidence and willingness to engage others, harmful/inadequate therapists and teachers, and the need for providers to understand Muslim culture. Inner strength as a parent and teacher.

I: Why did you move to the United States?

R: For my husband.

I: Ok. And how do you identify yourself in terms of national background? Like I might say I'm

Irish American. What would you say?

R: I am just from India.

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

R: I've completed a Master's degree.

I: Alright. And what is your marital status?

R: Married.

I: And do you have any children?

R: [They have several sons who are in their 20's and 30's.]

I: Do you currently work outside the home?

R: [She works in special education.]

I: That's awesome! And how many hours a week do you work?

R: At least 25 to 30 basically.

I: Ok! Wow, that's a lot. So the next set of questions focus on the types of differences in abilities that the person you have cared for has. We are interested in learning about the following types of differences in abilities: Physical, Chronic Illness, Learning, Intellectual, Mental Health, Speech and Language, and Addiction. So that I have a better understanding of your situation, what, if any, are the differences in ability that your son has? So I just have a chart here that breaks it down.

R: Physical.

I: And you've said he has dwarfism, correct?

R: Yes, and he's got Achondroplasia.

I: And can you describe what that is exactly?

R: That is a kind of dwarfism that is basically they cannot grow as tall as [others]. Most of the

time the achondroplasia patients grow 3 feet tall basically. But our son is almost 5 feet tall, [due to growth hormones and months of intensive, grueling limb lengthening treatment at a hospital in Eastern U.S.]. [When we returned to Milwaukee, he still needed to undergo 3-4 hours of physical therapy a day. For quite a few years, we would periodically go back to the hospital out east. Basically, the treatment on his legs wasn't that successful so he had surgery, which took a year to heal. Eventually, he also had surgery on his arms, which took over a year to heal. He can walk now. He received some home schooling; he attended regular high school and graduated. He also got two undergraduate degrees – one in-state, and another out-of-state.]

I: Nice! Wow, very accomplished.

R: Accomplished, yeah. And he accomplished what he loves to do. But due to the backlash, he doesn't want to be with the people. Like if he knows you, he will do it. If you come to my house he will stay in his room and not want to come out because people ask questions, and people give him a look. It was very bad when he was a teenager and when he was in his early 20's. Now he's getting better, but still he doesn't want to see the new people. He just goes to the places where he has to go kind of. He's very good, he's very talkative, but he pick and choose the people. He is not just going to open [up] with anybody. If I ask him to come he will say no. He accepts the fact of what he has, but it still looks like to me that he doesn't feel comfortable with the people.

I: Ok. What is the living arrangement of the person you care for? Does he live at home, does he have his own place?

R: He has a job in Illinois and lives there.

I: Would you describe the timeline of diagnosis with your son. Did you know immediately?

R: Diagnosis was the really bad part for me. Because, when this has started, when he was born he looked to me like he was born natural. And then when he was growing, I saw that this kid is

not growing like kids are supposed to grow. Then at 6 months we both told the doctor and he said you both, husband and wife, are short, so maybe he is going to be a short person. So I said, ok. But then [at] 1 year, I said no and then the doctor started [being concerned] about this kid's growing not being right. His growth is not supposed to be like this. So, the he referred us to go to an endocrinologist in Milwaukee. [Our son was monitored for a year or two. Then we took him to the Mayo Clinic, and he underwent many more tests over several years. From the time we first started working with doctors, it took five years to receive an accurate diagnosis. After many misdiagnoses at Mayo Clinic, a doctor at Mayo finally made an accurate diagnosis, which was just in the nick of time of avoiding an invasive medical procedure.]

I: Wow! So the next set of questions focuses on perceptions of people with disabilities and experiences of prejudice or discrimination. Compared to the broader US society, how do you think the Muslim Community perceives differences of ability that are very visible in contrast with ones that are invisible like addiction?

R: They don't want to share with the people. Maybe I told you before, I didn't go to India for 11 years because I don't want to take my children because the people will say something there. But in American society, because the people who know me and they know him also. Because you know, when he was young he does not care about his growth because he doesn't understand anything. In the Muslim community, my husband says that a lot of people who always saw him growing up in Milwaukee, ask about him and they say, how is he? I see that even when we go to Friday prayer, my son is one of the last people [to get there] and one of the first people to leave. He doesn't want to meet with the people, unless he finds some friends or something so they can go out and talk to each other. But I want whatever will make him comfortable. I don't want him to be uncomfortable. [Recently, a friend of mine mentioned that she has a friend in another state

who has an adult daughter who is a doctor and has achondroplasia. My friend asked me if my son would like to meet her. I asked him and he says no, I am happy, I don't want it. So there is nothing for me to do. Like it happens, where normal girls and boys just marry those girls and boys [with differences] you know. I said ok. You have to find them. But sometimes as a mother if somebody say something I think, ok, let's connect them. But he said I am not interested.

I: Ok! So how do you think the Muslim community perceives disabilities like mental health or addiction; things that they can't see?

R: Mental health and addiction... Mental health, I mean I know a couple of people who have the problems but they keep the children away from everybody. They just take care of them at home. And I just offered to one of the brothers, because I work with an autistic student and he has [a child with] autism, and I just say if you need any help just give me a call. Never. I never got a call, but I know that when they (people with autism) see the new people they get off also. But you know, a couple of visits might make him comfortable, otherwise they get off with new things; they can't handle it. But they don't want to do that. And he was just saying my wife is getting really really overwhelmed because their kid is like 18 years old now. He is off of school, maybe 'til 21 he can go to school. And you know, there is a lot of time that you have to spend with that one. And you know, it's hard for the parents but the parents don't want to see other people looking down on them. And you know, maybe people will accept it, but as a parent I don't think they are accepting it kind of. I want to hide. This is my child and I want to hide and I will raise him, whatever the pain is, kind of. I don't want to share things with others. So very few people share, especially with the mental health. Like some are really slow, or [have] mental health issues. They just don't want to share. And I saw another family, and we know them very well, and he's mentally ok, he's not very violent or anything but he is very very slow. He is like

15 years old and maybe has a first grade level of education kind of. But, at the same time, I just heard that she went to India after, she just went to India this year so she went to India after 12-13 years. So she did not want to go there either. Because you can't handle it, like the question of why your child is like that kind of.

I: Hmm. Ok, gotcha. Has the person, in this case your son, experienced prejudice, negative remarks, or discrimination because of their disability?

R: Maybe some people ask questions or shrug you off like you do not belong here kind of. Or, I mean for my son when he was like in a school, he looks to me, it looks like sometimes the teacher or the principal wants him to do things, but even for his high school graduation he doesn't want to go. Even his principal asked him to come. Personally! But he doesn't want to. So he keeps to himself, and when I think about why he keeps to himself I think that maybe he has some experience in his life which he is a very closed person and doesn't want to share anything. So maybe that's why he wants to keep himself in. He doesn't want to talk to anybody. So why he didn't go to any places and stuff... why?

I: Yeah, like what does that stem from? Do you know if he experienced any bullying as a child due to his difference of ability?

R: Yes, especially in the elementary and middle school. But there's a reason, the kids don't understand things and ask, ask the cousins, sometimes push you. It's easy to push you, kind of.

I: Do you think that being Muslim ever contributed to his experiences of being bullied? Or just his disability?

R: Oh, being Muslim? I am sure it did. I don't know about my son but I know about the other children.

I: Some of your other boys? Gotcha.

R: Yes [especially since 2001].

I: Ok. Given your experience with the community's reaction, is there any impact on your willingness to be in public situations with your son? I know you have described that your son doesn't like to be in public situations and you said that you didn't want to go back to India because of your worries-

R: Yeah I did. And I see a lot of people are doing the same thing. Like in India the people are... I am not sure how they act and react but you are not ready to see their reaction or action, whatever it is. So you avoid those things kind of.

I: Did your son's disability ever impact your son's willingness to participate in events here in Milwaukee, like in the Mosque or different things like that?

R: For me?

I: Yeah, for you.

R: Nope.

I: But for him it does?

R: For him, yeah. I really want to share his life, but for him. He has a disability and has accomplished so many things in his life. Like, you know that kid never played any sports but he loved sports and he's an encyclopedia of sports. So he said if he gets married if she doesn't like sports then she can't be with me.

I: That would be a problem!

R: Yes, that would be a problem!

I: So you want to share his talents and you want him to feel confident and connected, what kind of resources or programs would have been helpful for him growing up? What would have allowed him to be confident in himself? Do you think like any support groups, or going to a

therapist perhaps, or being in groups with other kids with disabilities?

R: We did go to the therapist but it was not a really good experience for me. I was really shocked when I went because he was not participating, he was keeping himself in. If anybody would come and knock on the door he would just go and close the door and stay inside when he was young. So I thought this was a really bad thing, you know? I don't want him to be sad, that's the main reason I wanted him to go for the limb lengthening surgery. One thing was to reach things because of his disability and stuff, but his hands are very small and still don't have enough strength. So we took him to the therapy. The first therapist, first session, I was really shocked at how the therapist talked. Mom, I am so sorry for you because these people (referring to people with dwarfism) don't live much longer. Like they don't have a lifespan like normal people. Like they die early like in the 50's, 60's whatever it is. So he was telling me about my son's lifespan. So I said I don't want to hear that one! If I have a child [with dwarfism] don't you think I know that? So you know, he says I am sorry for you mom. These people don't live that long, their lifespan is not much. But he is a child! You have to talk to him about what is his problem and then you fix that. But after that I didn't want to go to any therapist.

I: I don't blame you.

R: I am done with him. Like my son needs to know when he is like 14 or 15 years old he needs to know that he is not going to live longer.

I: Inappropriate.

R: Very inappropriate! And it was nothing to do with his lifespan. That's not your job to make his life longer or fix his health issues or anything.

I: Odd! Ok, how did the community's perception impact the way you cared for your son growing up? Did you feel any social pressure to be the caregiver for your son?

R: Like people feel sorry for me kind of?

I: Yeah, that could be one aspect.

R: Some say that. Some people say that one. But once I was watching the Oprah show, and there was a lady there who had a child who was like a 3-4 year old child. And she said he has heart problems and has already had like 2-3 surgeries. And he has to keep going with the surgeries.

And then she asked, as a mother, how do you feel about that? And she said, do you know what? I feel like a chosen person. Because God gave me a child and not anyone could just take care of that kind of child. So God chose me to take care of that kind of child, so I will take care of that one. So that gave me a lot of strength. So if a special child is there, the parents are special there to take care of them. Not everyone can take care of special children. Those parents are very very special. So if you feel about yourself that way, you don't care about the rest of the world.

Because if your child is very special to you, you think, "I am special because I have a special needs child" and then your world is great. So that's how I feel myself.

I: That's a good perspective to have.

R: [This way of thinking profoundly affected how I worked with children with special needs as a profession.] I felt strength in myself. I tell myself I have to be a part of this child and make some difference to him. So the next year and for 3 years I worked with the autistic students. And those students were brilliant but they were non-verbal. So we have a system, we have to give them a keyboard.

I: AAC device?

R: No, not the device. Everybody used those devices but this was some prompting system. So if you give them a question they can hear, and they can process, but they cannot say the answer. So we give them a keyboard and multiple choice answers, like the sky is blue, green, red, yellow. A,

B, C, D. So they will say, A, blue. So they just press the A and I knew he gave me the answer. So they have to do a lot of work. The teachers have to work with them and we have to double up the system, the whole system so only 4 years they have to follow the system and after that one they are done. The school district didn't want to do it, because the parents were forcing them to do it. Rapid Prompting System! That is what is.

I: So this next group of questions focuses on the challenges that you faced dealing with the issues we've been discussing so far, how you've dealt with them, and what is needed to make things better for caregivers and individuals with differences of abilities. What are the biggest challenges that you've faced as a caregiver for someone with a disability?

R: There is a lot of challenges. A lot of challenges. And maybe you remember, I brought the XXX family, and they are having a lot of challenges with that child. But they adapt, it's what they are supposed to do. Like they still don't have, like, a (wheelchair) ramp, so somebody is supposed to carry him and he is like 50 pounds. Somebody will carry him and somebody will bring the wheelchair out for him. So every morning they bring the wheelchair out, they bring him and then put him in the wheelchair and then the bus can take him to the school. And in the summer they don't have the program, like the busing program for him so he is just home now. So, my son does not really have a physical disability. Like he can walk, he now just has social problems. But this kid has the problem, the physical problem and he cannot go anywhere. So still they are having the issues with that one. But they have adapted and still are just doing it the way they can do it. So if there are more things available for them, if they have it, that would be good for them. But you know, I don't know. I talk to many different people about doing something for them but it's never happened. But that kid goes to school and comes back home and he never goes anywhere else because nobody's there to take him. [Transportation for the parents can

sometimes be a barrier.] All the brothers go out and play with the friends, and that kid just has to stay home. So I am sure that there are a lot of parents with those kinds of issues with their kids. And if they need extra help I am sure they provide some help if they reach for it and help is available, but not everyone knows how to get it.

I: So do you think having resources that are easily available would be important?

R: Yes, that will be helpful.

I: And potentially funding for different things?

R: Yeah.

I: For you personally and your son, did you have any challenges in regards to financial assistance and work? You said you went to work, but you talked about a lot of surgeries and being away from home, so how did that impact you financially? Was there a challenge there?

R: There's a lot of problems with that, you know. And financial problems, I worked, but I was always on family leave or sick leave. [We had good health insurance part of the time but the medical bills were extremely high, and we couldn't pay them off – had to pay a little each month.]

It was a really really hard process as a mother. You know? One thing, you just feel the pain of your child, and at the same time it is a lot of hectic schedules that they have. Like if you want them to improve something you don't know if it's going to improve or not but you have to try. Get whatever is available and say ok, I'll try this, I'll try that.

I: Gotcha, that's a busy schedule. What do you think, if any, are the challenges that females with differences of abilities face in compared with males with a disability?

R: I don't know with the females. I can tell you about the students, when we have the female students. During when I was working there, there was a male assistant. He was laid off. He did

something to a female student there.

I: So like more concerns about abuse and rape.

R: Abuse. I don't know what he did to her, nobody knows, but he got fired. So they said there is something happening, and nobody wants to go in on the details and I didn't know all the details also. I am sure there is something for the males also. But you have to be very careful, you have to keep teaching your children like if they understand. Like for my son I don't have a problem with him understanding because he is 100% there mentally. But for the kids who are not there mentally 100%, I see teachers and aids [using a lot of disrespect and ineffective strategies. I've found that if you treat the students with respect, they're much more likely to respond appropriately.]

I: Yeah, there needs to be a mutual respect there.

R: Yeah.

I: If you could tell something to either healthcare providers or schools to help them be best equipped to deal with Muslims with disabilities, what would you like to share with them?

R: First thing, they have to learn the culture. They understand the Muslim culture and the requirements with a disability. Culture has become one stigma, and Muslims have become another stigma, and disability has become another stigma. So all together I think that is the worst thing that will happen to the students that way. So they need to understand a little bit of the culture. Like culturally what we expect, you know? If there is a girl, what is the expectation? If there is a boy, what is it? Like if there is a girl and she has to go to the bathroom and they have to take them they have to make sure that a female adult is there. Usually a lot of females work there (in schools) and male doesn't. So sometimes they have to ask for the male if they are so heavy. Not because there is a male there, but because the female cannot handle it so they ask the male to

come and help kind of. But they have to respect, they have to understand the culture. And they have to understand the disability. Like I am sure they understand some disabilities, but culturally, talk to the parents, what are the expectations on how we have to handle your child. And respect that one! At the same time, asking is one thing. I am sure they are required to ask. But you have to follow [through] and respect it. That's a different thing. So you have to respect it and you have to follow it at the same time. Because you have heard and see a lot of, lot of if the kids don't listen because those ladies come with a lot of their own issues and then if the kids don't listen they take it out on them. You know, you've [probably] heard a lot of stories with the special ed students. It happens in the schools. Not like the disability people are ok to handle for them sometimes. But I heard they pinch them, they hit them, all kind of things there. Some are really good, they really want to help those kids and they really want to help as a mother to another mother and are very respectful... and some, they just want to work for money and they have their own problems. So you have to respect. First, talk to the parents, whatever they said, please follow it. And follow it in a respectful manner. I know those kids are not the same always every day. They are going to be depending on their mood, that doesn't mean they want to but they don't have control over it.

I: That's good advice, thanks for sharing. [This concludes the interview.]