

Interviewer/Number of Interview: EG39

Date: March 13, 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 55-64 years old

Gender: Female

Country of Origin: Bangladesh

Year of Immigration: Early 1980s

**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:**

This married mother of three children, who emigrated from Bangladesh, is a caretaker for her adult son who has Cerebral Palsy and Autism Spectrum Disorder. She and her family recently moved to Milwaukee and have been struggling to find programing for their son. She also discusses topics such her responsibilities as a caregiver, community response, her believed reasoning for her son's disability, and her fears for the future.

### **Key Themes:**

Respite care; day programs for fun activities and for skill-building; programs where people with ability differences can work or volunteer; finding the balance between caring for the child with an ability difference and helping him/her be independent; being stretched too thin, which also affects the amount of time/energy a parent can give to the other children in the family; depression; social isolation for the child; marriageability of a sibling (e.g., if suitor's family thinks their child will end up caring for the sibling with the disability when the parents die); Also, people's lack of acknowledgement or eye contact with the individual, as if s/he was invisible. The importance of family support; the importance of faith and religion.

### **Transcript:**

I: Where were you born?

R: I was born in Bangladesh.

I: Okay, and when did you move to the greater Milwaukee areas?

R: We came here [a few years ago].

I: Okay, and why did you move to the Milwaukee area?

R: We moved here to help out our older son with his children; we are babysitting his kids.

I: That will keep you busy! (Both laugh)

R: Oh yea.

I: Okay great, and how do you identify yourself in terms of national background?

R: Uhm, what does that mean?

I: So I might say I'm Irish-American, what would you say in regards to that?

R: I'm Asian-American.

I: Okay, great. What year did you move to the U.S.?

R: I moved [in the early 1980s].

I: And what was the reason for your immigration?

R: I got married to an immigrant.

I: Okay, and what is the highest level of education you've completed?

R: I have associates degree [field not identified to protect respondent's identity].

I: Wonderful. And where did you complete that?

R: Uh [at a college in another region of the U.S.].

I: Okay, and the next question is what is your marital status?

R: I'm married.

I: Mhhmm, and do you have any children?

R: I have 3 children who are in their 20's and 30's.

I: Okay, and do you currently work outside the home?

R: No I don't.

I: Okay. Babysitter, grandma, right? (Both laugh) Okay, so this next set of questions focuses on the types of differences of ability that you or the person you care for has. We are interested in learning more about the following types, so it kind of goes through each category uhm if you want to pause me and talk about each one feel free. Uhm so the first one is physical disability, chronic illness, learning, intellectual, mental health, speech and language and addiction.

R: So the first question is about physical?

I: Hmm.

R: Okay, so he has mild cerebral palsy.

I: Okay.

R: And as a result, [one side of his body] is much more involved than his other side. He doesn't want to use his hand on the [affected] side. When he was young he could not walk until we used an AFO [ankle foot orthosis] because his foot was tighter and he wouldn't really release the foot. So he-we also had a surgery on that.

I: Huh.

R: And uhm also when I ask him to brush his teeth he only brushes on one side he doesn't want to brush on the other side and uhm as a result uh things like dressing, things like that, everything uh getting – uh it's difficult for him to do those things.

I: Hmm.

R: Getting up into the car and getting out the car, he doesn't want to put his weight on his [affected] foot as much.

I: Gotcha.

R: So, it's a struggle. So, he does walk on the treadmill and do his bikes, stationary bikes, and just to keep him flexible.

I: Hmm, keep him moving. Uhm, the next one was chronic illness. Does that apply?

R: He has asthma. And uh also swallowing problem. He doesn't like to swallow chewy meats; we always have to mash it up. So, for some reason he doesn't like very chewy uh food.

I: Hmm.

R: When he was young he was very outgoing and talkative but as he grow uh he started noticing his differences and then he shut down so.

I: That's difficult.

R: It is probably 11, age 11 he has been on a [prescribed drug for anxiety/depression].

I: Hmm, gotcha. That kind of covers our mental health section so that good. Uhm learning and intellectual are the next two.

R: We tried many things and uh in the beginning we tried putting dots on the numbers so that he could add and uh number line. But what he was doing was just following the direction but not really adding things.

I: Hmm.

R: Not really realizing what's going up or down, or if its more or less. All he was doing was following the directions that you count all these dots.

I: Hmm.

R: And you write down the number and things like that. And uh he still doesn't understand so I don't think he can handle money.

I: Hmm, okay.

R: And writing. When he was younger, it was kind of legible but now it has gotten even worse so he writes but nobody understands what he's writing. Letter formation is really bad.

I: Hmm.

R: And also when he writes in a sentence his subject of the sentence is before the predicate. So the end of the sentence is before the beginning of the sentence. But when he speaks in the phone, sometimes he dictates, that's when he does a perfect job. So, at time his sentences are right.

I: Gotcha.

R: But when he's writing it he switches it like, it's like sick sentence.

I: Hmm, gotcha. Okay uhm, let's see, what is the living arrangement with your son? I assume he lives...

R: He has always stayed with us, and he will continue to stay with us. We will help him out as long as we are capable.

I: The next question is would you describe the difference of ability that the person that you care for has? So I think you mentioned the Cerebral Palsy, is that the diagnosis?

R: Yes, Cerebral Palsy and he has Autism Spectrum, mental retardation; he has like a 7-8 year old understanding.

I: Hmm.

R: And the biggest problem is isolation, because he cannot find somebody to match his ability or like him.

I: The next question is about the timeline. About when was the diagnosis for the difference established, the timeline of care, that sort of thing?

R: When he was young, 4-5 years old, he didn't physically look different, like for down syndrome you can tell right away.

I: Hmm.

R: He didn't look any different except for his foot, which he wouldn't put down and then -so we were in denial longing that he had any problems. So we tried to put him in regular uhm d- uh with the 4 year olds but within a month I realized that he couldn't keep up with them. So that's when we realized that he needs to go to a special class, not with the regular kids. We thought that if we held him back maybe we could mainstream him, but there were subjects he couldn't learn at all. So... from then on we put him in a life skill class where- in a regular school and he would just go there and they would do their own stuff like tracing circles or very minimal things, or looking at the life style- life style of a uh insects and things like that to give them different kinds of knowledge.

I: Hmm.

R: But it wasn't- I think the gap kept on getting bigger and bigger between him and the regular children.

I: Hmm. Uhm so you talked about the realization within the school setting, was there any medical diagnosis timeline on that side as well?

R: I think at 7 he got tested at [a hospital in the U.S.] and that's when they said that he had Autism Spectrum.

I: Hmm.

R: And we were kind of shocked. We just didn't realize -- his answers were very off when they asked him certain questions. Also they tried to do some other MRIs a couple of times to see if there was a problem in the brain or were there some kind of uhm.. physiological reason because he didn't look very different, he don't look very uh-uh- uhm physically different.

I: Hmm.

R: So it took us a long time to realize.

I: Hmm.

R: That mentally he's not there.

I: And for the cerebral palsy was that diagnosed at birth or later on?

R: It was diagnosed later- like uh six- sixteen months when he wouldn't walk. That's when he was diagnosed.

I: Okay, gotch you . And what factors if any do think might have contributed to your son's difference of ability?

R: Uhm before he was born in ultrasound we saw that his stomach was inflated [and the doctor thought there was a blockage in his urethra]. I don't know if that's the reason or also he was born one month premature. And then in the 90s they did move the premature babies for different tests and uh one of the tests when they were taking him his heartbeat went down and he was kind of blue and they had a tough time to get bring him back.

I: Hmm.

R: So I don't know if the cerebral palsy happened then or whether it happened at birth. So we don't know at what point uh it affect-it affected his brain, the lack of oxygen.

I: Hmm. You kind of touched on this a little bit earlier but how would you describe the nature of care that you provide for your son on a daily basis, what areas do you- does he need assistance in?

R: He needs help with brushing and dressing [and bathing]. We do try to teach him to clean up after toileting but still we have to check sometimes he does a good job sometimes not so we cannot really totally rely on him.

I: Hmm.

R: For food we try to [give him smoother food] and [not give him] chewy meat like beef, lamb, and things like that. He basically eats chicken and [some fish].

I: During the day, do you keep him preoccupied or does he kind of do his own thing? What kind of things...

R: Here- after coming [to Milwaukee] we are still looking for a place where he could go. [In the city where they previously lived, there was a sheltered workshop where he would work.] The government came and just abolished it everywhere that sheltered workshop is not there anymore. So now it's a problem like a daycare where you go and look for it, seems like it's a daycare or a social gathering there is nothing for them to really work on.

I: Hmm.

R: And uh and then if they can socialize, if he can play with somebody else that's- that's what we are looking for. Take a walk together. Do bowling, or games, things like that. And if he can also work on his skills, like brushing his teeth, [washing his face], and things like that.

I: Hmm okay. Okay so the next section focuses on perceptions about people with difference of ability and experiences of prejudice and discrimination. Compared to the broader U.S. society how do you think the Muslim community perceives differences of abilities?

R: I think he was more comfortable with the older people, like his aunts and uncles, than with the children of his age. The kids of his age were really not paying him attention. He was just sitting there on one side and they are really not getting involved with him.

I: Hmm.

R: So, that's how it has been and uh- that's how he's got the feeling that he's different.

I: Hmm.

R: So he had one friend [when we lived in our previous city]. There were other friends who weren't very social but still he would communicate with them at his workshop so he doesn't have that neither here.

I: Hmm.

R: So we are still looking for a group where he can match and do things together.

I: Hmm.

R: And there was [another program at our previous city for kids with different abilities.]

I: Hmm, cool.

R: Yea, it's continuing. We try to find it here but there is no group like that but, there's one on one therapy- music therapy. But we are still looking.

I: Okay uhm- how do you think the Muslim community perceives visible versus invisible differences?

R: It depends on person who you're with; some people are very supportive and some just dismiss. I don't blame them, if you go through- if you have somebody in your family, they are much more caring.

I: Hmm.

R: Somebodies nephew, niece they understand it better. If people don't have this kind of thing, I think some are scared probably.

I: Hmm.

R: I wouldn't say that it's any different in Muslim community than in other communities.

I: Okay.

R: It's similar.

I: Okay good to know. Uhm, have you or your son experienced any prejudice, negative remarks or discrimination because of his difference of ability?

R: Hmm..not- nobody would say it to our face.

I: Uh-huh, Hmm.

R: But behind I cannot tell.

I: Yea.

R: Cause... I feel that my uh daughter when we uh- tried to get her married to some of the people I uh think people probably backed off because they thought she has somebody to take care of.

I: Hmm, Hmm.

R: And I don't know it could have happened.

I: Hmm, you can't be for certain, yea of course. Uhm given your experiences with the communities perception of differences of ability, has that had any impact on your willingness to uhm be engaged in the community, do certain activities, any limitations due to perception?

R: Uhm the community... uh no we participated in everything.

I: Okay.

R: If there was a music program, if there was picnic, we always took him and uh we did our best so we did not hold back.

I: Hmm.

R: Except if it was for adults and we had to put him somewhere then it was a problem because uh we had to find someone reliable to- sometimes it was a problem. I don't think I ever left him with a babysitter.

I: Hmm, gotcha. From your experience do you think the Muslim community has any expectations of you as a caregiver?

R: I think we try to hold on as long as possible rather than- also it might be good or bad that we try to do more for them and rather then letting him become more independent.

I: Hmm.

R: So... uhm being Muslim it's uhm- we uhm obviously think of him as a blessing but it took us a long time to get there I would be honest with you and uh so I don't know if as a Muslim it is any different.

I: Okay. The next group of questions focuses on the challenges that you have faced dealing with the issues that you've been discussing, how've you dealt with them and what is needed to make life easier for caregivers and individuals with differences of ability? So the first questions is what are the biggest challenges you've faced as a person with-uh caring for a person with a difference of ability? ... So the first topic is being stretched to thin. Have you experienced that as a caregiver?

R: Uhm at times I did when he was young. I felt that I couldn't pay attention to my daughter as much. I couldn't take her to dances, or extracurriculars activities because I didn't want to take my son out.

I: Hmm.

R: So I probably neglected her a lot.

I: Hmm. Have you experienced challenges with insufficient resources, information or quality of care?

R: The thing we didn't know that these children can get Medicaid, it took us a while to find out.

I: Hmm.

R: Uh I think one of his physical therapists got us in touch with the system and that's when we found out that his therapies were covered.

I: Hmm.

R: And most of the copayments were picked up by the Medicaid. Although we had good insurance from my husband's job the other things is that I never uh went out to get a job because I wanted to stay home and take care of him.

I: Hmm.

R: I haven't worked for just one year I probably had one project when my daughter was a little older and she could watch him.

I: Hmm.

R: Other than that I never had a job.

I: Uhm gotcha, you talked about the lack of day programs, at least in Milwaukee so far, that's your experience.

R: Yea.

I: Uhm any lack of medical care, therapies that you needed that you weren't able to get connected with at least initially?

R: No we did have a good insurance all the time so he did- he did get a lot of physical therapy, occupational therapy, even speech. But uhm no amount of therapy can correct it. It's ...

I: Hmm.

R: It would get better then get worse.

I: Hmm.

R: So we tried.

I: Uhm financially or work related you kind of discussed you weren't able to hold a job because you were focusing on caring for your son, but financially and work has that impacted your family?

R: Uhm we were comfortable.

I: Hmm.

R: And whatever we had we managed.

I: Hmm.

R: Although, well my son had to go to college, my daughter had to go to college and then- I think we managed.

I: Hmm, have you or any of your family members experienced any motion-emotional challenges throughout uhm your uhm journey being a caregiver and a family who has a member with a difference of ability?

R: Yes, I think it affected all of us. Uh it affected my husband probably subconsciously and I think the year after he was born he has been on medication for depression and he's still on those medications.

I: Hmm.

R: And uh it also affected my other children, but they turned out to be nicer and uh sometimes they say yes we turned out this way because of him.

I: Hmm.

R: And uh I uh- I held through all of this I just had to do whatever I have to do.

I: Hmm. Of course, yes. Uhm physically has it been challenging on you whether stress could have potentially caused physical uhm implications or uhm any physical requirements that your day-to-day caregiving requires that's challenging for you?

R: Uhm I think we do get tired we have to give him bath, brush him everyday and all these things but we are still able to manage it.

I: Okay, great. Uhm to deal with the challenges that we just talked about what are some of the strategies that you've used or your families used uhm to help uhm get through those challenges?

R: Uhm... I think uhm we prayed, mostly the prayers helped.

I: Hmm, of course.

R: And uh yea religious centers help us. Keeps us calm and give us hope.

I: Uhm you talked about uh getting the resources from the daily programs but did you ever reach out to family, friends, community members for support uhm over the years?

R: Uhm sometimes if we needed someone to watch him.

I: Hmm.

R: But it was rare.

I: Yea.

R: We managed on our own.

I: Hmm, gotcha. And did you ever have any positive experiences reaching out to the family members or community members for help?

R: Yes, they were always helpful.

I: Great. Uhm okay, what if any are the challenges that females with differences of abilities could face in life compared to males with the same difference of ability?

R: Uhm well I have a male child.

I: Yea so I know your experience is on that side but...

R: Uhm I think it's worse for the female. I can...

I: Okay.

R: I would think so.

I: And why do you think that is?

R: Uhm they have to handle periods and things like that- I would really feel sorry for how they are going to manage all these things.

I: Hmm.

R: Boys don't have to go through that.

I: Hmm, uhm any differences for employment, education or marriageability that you would like to touch on? To preface the question -- if there was a female with a difference of ability and a male with basically the same difference of ability -- how does that differ when it comes to employment potentially?

R: I think it will depend on the individual.

I: Mhm.

R: If the individual is more outgoing she can- uhm I had a -he had a friend who was a little older but she was a little better then my son and she used to go and do cleaning the hotels and things like that.

I: Hmmm.

R: With the supervisor.

I: Hmm.

R: Then she also worked in a flower shop so... I think it depends on the individual and what's out there.

I: Hmm.

R: So if we can find somewhere where he can go and volunteer we would like him to do that.

I: Of course.

R: It would be good for him!

I: Hmm. And uhm marriageability uh do you think there's a difference between females and males with differences of abilities?

R: Uhm it all depends on the individual, their level of maturity and how they can handle. But my son is not there at all.

I: Hmm.

R: So, he cannot even take care of himself.

I: Of course, yes. Uhm what additional support, help or changes in attitude are needed?

R: Uhm there should be some places where they can go and do something, according to their level, and I think they- they are able to do certain things even if it stuffing, or doing labeling, that was good for them.

I: What are the things that healthcare providers, schools, and the mainstream muni-community should know to be supportive and useful to you and your family?

R: Uhh...I think uh the community that we are involved with do ask him -come twice a year uh the nurse comes and takes all the measurements and things like that. And uh as we need it we are able to go and get his treatments if he has asthma or can't- ear infection or something, cold that's not going away.

I: Hmm.

R: We didn't have any problem receive the- and in school- schools were very helpful they had their own school [Name of school]. And uhm now the employee thing I don't [unintelligible] although he's not going to be working in a real sense even if it's a volunteer thing.

I: Hmm.

R: We would like to see that.

I: Hmm. Gotcha, and then is there anything else you would like to share regarding your experience as a caregiver?

R: Uh.. I think what worries us is what will happen when we are not here and uh I hope there are good uhm group homes, and things like that...

I: Hmm.

R: And uh although my older children they say that they will take care of them but I don't know, they have their own lives.

I: Hmm, yea that's...

R: [unintelligible] that every parent has..

I: Yea that's definitely a common theme as I've done these interviews uhm of concerns for the future of course yes.

R: Yeah.

I: Uhm, is there anything you would like the community to know about your son and his abilities, that uhm maybe that they might not see upon uhm meeting him?

R: Uhm he's really friendly but he might not talk, and even if you just nod to him he thinks it's a great thing. I think he should be acknowledged and that really makes his day so I think we have to be extra careful uhm for people who- these children need a lot of love and support.

I: Hmm, yea of course yes. Uhm.

R: Although they are adults, they are still kids in their minds.

I: Yes, at heart yes.