

Interviewer/Number of Interview: NK34

Date of Interview: 2/8/2020

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 65 years or older

Gender: Female

Country of Origin: Pakistan

Year of Immigration: Mid-1990s

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:

Mother of son with cerebral palsy talks about her immigration here, problems with her ex-husband and other son, a lack of support from her community, and an incident at the daycare where her son was allegedly sexually assaulted. She also discussed severe economic issues she experienced once she immigrated and before she found employment. She hopes that education within the Muslim community can help people learn to be more accepting, although she does not think change will come in her lifetime. One of her biggest needs at this point is respite care and transportation for her son. She also worries that recent immigrants do not know about resources that are available.

Key Themes:

Ignorance around causes of cerebral palsy, which has some cultural components; patriarchy in Pakistan; social isolation; importance of family; economic hardship; burnout

Needs: Respite care; transportation; knowledge of available resources; Muslim community being made more aware, informed, and sensitive; reducing ignorance in Muslim community; dismantle old beliefs; ways to reduce social isolation

I: Why did you move here?

R: Because my brother had initially come here to America, he sponsored us. [She came with her son who has cerebral palsy; the other two children stayed in Pakistan with her husband's family. Respondent explained the reasons for this and what happened.] But then mine was a very very hard situation back there. [My husband] was not willing to accept [my son with cerebral palsy] as his child. And then my father came from the other end. And you know in my religion you can marry four times. I'm not criticizing the fact of it at all, but you know they justify it saying that our beloved prophet, he... I mean you have to look at the history, you have to look at the terms and conditions that were set up. Not because of the fact, and God forbid me even saying this about our loving prophet but never once did he marry because he was in love or because he had an affair with somebody. It was a widow, it was a divorced woman, a woman in need... and none of these men are doing these things. None of them! And [my husband, now ex-husband] has totally, till today, disowned this child. I have been struggling for the longest time. Struggling, sick, and tired. My husband got married to another woman claiming that is his right and he can marry up to four times. Where it is in my country you have the right but you still had to get permission from the first wife. It was so male-dominated. It still is! I mean I am talking about my country, so male-dominated. You cannot have a say. [She described advice she got from a lawyer and the hopelessness of the situation with her husband, and how he took the valuables that she brought into the marriage, but with no recourse from her. With her father's intervention, though, ultimately she was able to get a divorce.]

I: Your two sons didn't come?

R: No. I think it was 3 and a half years then until they got reunited with me.

I: Was it hard being apart?

R: It was a nightmare! *** [Respondent described her life at that time and how she received financial support from a family member who lives in the U.S. It took 5 years for her to become a US citizen.] So for those 5 years we almost were going to become homeless. It was that bad. For 10 months I couldn't find a job. I found one at a government facility but I would have to leave at 2 o'clock to go and pick [my son with a disability] up. No employer is going to hire you if you say you have a handicapped child and you have to go leave to pick them up and bring them home. I would have to leave at 1:30, maybe 1 o'clock even depending on the distance. Oh my god it was so terrible. When he had a cold I would get home and look up all the free clinics and stuff like that. When we got there we would be waiting for 2-3 hours. Then, I got a break and got a job at MPS.

I: Was it full time or part time?

R: Full time! Yeah, full time with benefits and everything, yeah.

Also, [during this hard time, before I got the job], a family member connected me with St. Anne's [and one of their programs], where I got help. And for that I am very grateful. On one

hand I am very grateful to them, on the other I am very upset about how he was treated at St. Anne's. I had to pull him out of there. [Respondent described how her son was at St. Anne's for many years but several years ago was physically and sexually assaulted at St. Anne's. The assaults were confirmed by a doctor at a local hospital. Police were called. They investigated but couldn't find any witnesses.]

I: Did anything ever come of this?

R: No, nothing! I was talking to my friend who called a lawyer and they told me I have to produce witnesses. And I said, how can I produce witnesses if the police cannot even produce witnesses? I don't have any! I thought maybe because my accent is different, our names are different, we were treated very differently. Nothing came out of it. I suffered in the long run. I didn't send him to any daycare for 2 years. He was with me day and night. I am pretty sure I am more traumatized than him. I am sure he is also, but I think I am more traumatized. And I told the officer, you know what? I have lost all faith in humanity. In America this thing can happen? For the longest time I couldn't come to terms with it myself, that somebody, [would do this], you know? An innocent, angelic person, how can you do that to him? Two years. It was so rough. I had to go through a blizzard, do outside chores, go to the grocery store, everywhere I go I had to bring him. And the most time that I feel guilty is when I have to take him to and from a doctor's appointment. I mean, he was getting unnecessary germs. And then one night I was praying, in the middle of the night, I was crying, I was praying. Please, God, show me that there is a way. You know? Within a week this idea was planted in my mind. I talked to my family members and his care manager. And she was giving me hope. So it's been a year now and he is going to this one called curative care. But you know what, he went to St. Anne's 16 years. Who do you trust then? Who do you have faith in? Even today, I do not really and truly trust them. I cannot trust any daycare.

I: Does your son have a diagnosis?

R: Cerebral Palsy. [He is nonverbal, can't walk, doesn't have teeth, and can only eat soft/pureed foods.]

I: When did you find out?

R: He was born with it, but in Pakistan they don't tell you. When he was 11 months old he had his first seizure. And my other son... to be honest I did not want to have another child but whoever comes will come. Then after my second son was born I saw a lady gynecologist. You know what that lady gynecologist told me? She told me that my labor, since it was 14 hours, because that doctor had taken too many cases on his hands, and he was not accountable, that bad luck happens. It happened to you. This doctor told me that every time I had a natural birth I would have a child that was this way. She said my pelvic bone is very very small. [My first son] was born, his head got squished, and then he lost all his oxygen. Your doctor should have told you your pelvic bone is very small. Since you are pregnant again I will have to C-section you, and remember that every other time you get pregnant you will need to C-section your child and they will be ok.

I: Were there any positive experiences with getting care that you have received?

R: You know, 8 years ago he comes from the day care and I brought him up [the stairs], I have a chair lift now but I had to bring him up. He came back from the daycare he could not sit, he could not walk, and he was totally bedridden. I called 911. We went to St. Lukes and stayed overnight; they could not figure out what happened. He's nonverbal. They did many tests and did not find anything. We [went to another hospital] and stayed for 4-5 days and they did all the tests they could and could not find anything. [Respondent described how they next went to Mayo Clinic and stayed for three weeks. During that time, staff at MPS stood behind her and advocated for her so that she wouldn't lose her job.]

I: Did they give you a lot of support during that time?

R: Yes, I told them I am going up to Mayo clinic and can anyone come up with me? He doesn't have any teeth so he is on a puree diet. I asked them for some recipes and when I came home my table was filled with food. All of them, all of the teachers, didn't even tell me. They asked when I was leaving, and when I came in the morning the whole table was filled with food.

I: That's so sweet!

R: I know, I know. I am very grateful to these people. Then came February and he was there for 3 months. [She described how, at that point, she made the decision that she had to resign from her position at MPS.] [She explained that the Mayo Clinic doctors made changes in her son's medications, which helped.]

I: Do you feel like you have gotten a lot of support from your family members?

R: From [many of] my family members yes, 100%. Very cooperative, very helpful, other than my other son. My other son is like his dad. No support. None whatsoever.

And you know, [my son with CP] gets his budget through IRIS. They give an X amount of budget for us. And that budget is they give 40 amount of hours and they don't give beyond. And his budget, because he is total care, they pay for his daycare and he still has money left over for respite care. [She described great difficulty finding qualified people to provide respite care. That is one of her biggest needs at this point.] I imagine that the majority of [new immigrant families whose children have disabilities] need help, but they don't know the system. They don't know how to go about applying for benefits for their disabled child.

I: Wow. To change gears a bit, how do you think the Muslim community perceives differences that are very visible?

R: They stare at him. I don't see any American child doing that. And you know, to be honest, we are totally isolated. We are not invited.

I: Do you think that has to do with-

R: His disability? Yes. His difference.

I: Do you think that there have been any forms of discrimination or prejudice that you've experienced because of-

R: No. Not with the Americans. Within the Muslim community. A lot. A lot. Only recently I started going to a mosque in Greenfield, one of the participants who does the lessons, her son, I am guessing he is 10 years old? He finished the Quran and they were celebrating. And she told me to come to the mosque through WhatsApp. I said I would have to bring my son with me and she said oh, that's fine then don't come. It was on a Sunday and I said my son was going to be there and she outright rejected, that's fine then you cannot come. We are totally shunned like that, you know? People are not comfortable inviting us.

I: What do you think can be done to open that up, and to help people not have these views anymore?

R: You know, I don't do that so I really wouldn't have an answer to that. I don't hold any, you know? Mistreating and looking down on this population.

I: Do you think more exposure or education would help?

R: Definitely. Exposure not so much. But to be honest, the kids who are born here, they have exposure through the schools. They are made aware of people who are different than you. They grow up to be accepting of this population. So exposure, I don't think so. Education? Probably.

I: Do you think that the Muslim community has expectations for you as a caregiver for your son?

R: I would say as a mother, not from my religion.

I: Do you ever get a break? Or get to go out and be social?

R: No, never.

I: What are some of the biggest challenges that you have faced being his only caregiver?

R: Burnt-out. I recently am feeling very very burnt out. Because there's no help other than him going to the daycare. And the daycare is at such specific times and then you have to time yourself to go pick him up. All your errands. And you know, this thing is finished for him, that thing is finished for him, he's on a pureed diet. That's another chore I have to take care of! The laundry I have to take care of, the cooking I have to take care of. Outside errands I have to take care of. All the bills I am taking care of. It's a lot on my shoulders. Even if I find someone out there that is a respite care worker I want to find someone who can pick up and drop off him. I ask his daycare to ask some of the bus companies. I would want someone to come pick him and then I get some of that time just by myself. I could still go get him in the afternoon. I have called

5 companies. 3 of them don't take IRIS funding. One has but they don't have a vacancy for a wheelchair person. And the fifth is very far. So there's no respite care worker, no transport for him. I don't know. Very hard, very hard.

I: That does sound so hard. I wish there were more community supports for you.

R: To be honest, I bet if I go to a church and ask I am pretty sure I would get tons of help. Isn't that sad? I'm ashamed to say it.

I: So you're saying a church more so than a mosque would be willing to help you?

R: I'm pretty sure, but I haven't gone! But from what I've seen and how people are praising the church, you know? So I said I am pretty sure that if I go to the church that I could get help, you know? I would get much more help. I am like hitting a brick wall with the Muslim community.

I: Have you ever considered moving from Milwaukee to somewhere else because of a lack of available resources?

R: Not Milwaukee. I am seriously debating it. [She described how a specific different region in the U.S. is easier on her body/joints, but that economically, Wisconsin's benefits for a disabled child are far better. Parents get paid for caring for the child in Wisconsin.]

R: Just cry. And ask God, why me? Which I do very rarely. I mean I am trying my level best to find a respite care worker. I am trying my level best to find him transportation.

I: Is there anyone in your life right now that you can turn to for help when you need it?

R: One of my sisters [who lives on the East coast]. [Respondent discussed ways that her sister has helped her and her son.]

I: Do you think being a woman, you experience more challenges with helping your son out?

R: In this country, no. In my country, yes, but in this country, no. People are more helpful! They will open the door for you if there is no automatic door. They will look at him and smile. That totally makes my day if someone gives him a smile. They look at him and smile. But not my community.

I: Do you think that if you had a daughter with this difference that things would be different?

R: No, other than if she had periods that would be a problem, you know? Because I have heard that if you have a girl and you remove her uterus then they start putting on weight. For him it's like, you know in 2011 he used to weigh 114 pounds. Now he weighs 76 pounds. Since that time he has been gradually losing weight.

I: Is that something you are concerned about?

R: No, I went to a dietician about it. He used to have 1 ensure, and they just said to increase it to 2. But even the daycare is not concerned because he eats well! He has one ensure at the daycare and one here. They eat at 11:15 and so between 11 and 3 o'clock becomes a very big gap so I told them to give him one ensure. Because when he comes home I give him a snack also.

I: That's nice! What do you think, in healthcare, in schools, in the Muslim community, the broader US community, what changes in attitude are needed?

R: In the healthcare world I say no. You are not treated like an outcast there because of your religion, your accent is different or because you are disabled. I guess because there are laws in place. Maybe that's the reason why people cannot, at least outwardly. But as an individual you are allowed to do that because it becomes a he said she said. So I think the Muslim community really needs to be educated and more accepting. To be honest, I don't think I will see this change in my life. I don't think so. I am hoping! I can hope for the best, but not happening very soon.

I: What would you need people to know about your situation or your son that would change their attitudes?

R: First and foremost that my son is not contagious. When people see him they pull their child away to be by themselves. People in the Muslim community! And my child is not contagious. And it's like, you know? The majority, I would say 99% of my family members aren't like that. Be it my extended family, my brothers and sisters. They don't think that if they mingle with us for too long that they might get like that. Nothing like that. It's people who come to the house the first time, or we go to their house... I don't remember the last time we went to somebody's house for the first time... But you know it's very degrading when they pull their child away.

I: Do you think that's something that can be discussed at the mosques?

R: I don't know, I don't go to the mosques often. I go on Fridays when my sister is here. But I haven't heard the Imam's talk. They should be, you know? I think this topic more, talking on this topic more and more and more. To bring up awareness! I mean when you are in this country don't you see the way that people with special needs are treated? It is very sad.

I: It is. Is there anything else you'd want to share before we end the interview?

R: I want things changed in the Muslim world, not in America. To be honest I don't have anything against people who were born and raised here generations and generations ago. I mean they are more accepting of someone who is handicapped, you know?