

Interviewer/Number of Interview: EG20

Date: July 22, 2019

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 45-54 years old

Gender: Female

Country of Origin: Jordan

Year of Immigration: [Mid-1990s then returned to Jordan after several years being in the U.S. Re-immigrated to U.S. around 2017]

**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 a Jordanian woman who immigrated to the U.S. with her husband in the mid-1990s. After several years of being in the U.S., they returned to Jordan. They re-immigrated to the U.S. around 2017. They have several adult children and one child who is under nine years old. One of her adult children has epilepsy and an intellectual ability difference. In the interview, the respondent compares how ability differences are handled in the U.S. and Jordan. She made several recommendations for change in the Muslim community, schools, and health care. She also noted the importance of culture in explaining stigma and prejudice that people with ability differences face. She cautioned against attributing such behaviors to Islam. She also explained the importance of the family's (especially parents') acceptance of the ability difference and making the issue public, rather than hiding it in secrecy.

**Key Themes:**

Epilepsy; intellectual ability difference; Islamic teachings regarding ability differences; changes needed in Mosques, Islamic Centers, and Islamic schools; cultural norms that underlie stigma, criticism, and negative judgments; cultural changes that are needed; faith/religion; how being a parent to a child with an ability difference has made her a better person.

I: When and where were you born?

R: [Respondent is in the range of 45-54 years old. She was born in Jordan.]

I: Okay. And when did you move to the US?

R: [Mid 1990s then returned to Jordan after several years being in the U.S. Re-immigrated to U.S. around 2017]

I: Why did your family move to the US?

R: [The first time, for my husband's education. The second time, simply for my son who has the ability difference so that he would receive better services and have a better quality of life. He was born in the U.S.]

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

R: \*pause\*...What do you mean?

I. Um. I might say I am Irish American.

R: I am Jordanian. Not yet American. I just have my green card. I'm in the process of being American.

I: Okay. So what is the highest level of education that you have completed?

R: I have a bachelor's degree.

I: Okay. And where did you complete uh your degree?

R: In Jordan.

I: And what is your marital status?

R: I'm married.

I: And do you have children and if so what are their ages and genders?

R: [Respondent has several adult children and one child who is under 9 years old.]

I: And do you currently work outside the home at all?

R: Not since I have gotten to the U.S.

I: So that I have a better understanding of your situation, what are the differences of abilities that you care for in your home? So I have a different chart if that helps at all. \*Shows interviewee chart\*. So, we have physical, chronic, learning, intellectual, mental health, and speech-language.

R: \*Looks at Chart\*. [One of her adult children has epilepsy and an intellectual disability. He is diagnosed as operating at an age of 11.]

I: What is the current living arrangement with your son?

R: He is living with us.

I: Okay. Perfect. And could you describe how the different of ability that your son has impacts his day to day life?

R: He takes medication for epilepsy, which makes him really tired all the time and sleepy all the time, drowsy all the time. So, basically he needs help in everything. Like, I prepare his breakfast, I give him a shower, and I clip his nails. He brushes his teeth on his own, but you know all those activities that adults do on their own, he needs help with. For instance, though he would eat unassisted, I have to prepare breakfast. Otherwise, he is extremely slow. He is extremely slow in everything, even when he talks and walk. Understanding the surroundings is not his strength. So he needs guidance all the time.

I: Safety wise?

R: Safety-wise.

I: Yeah. So, someone has to be with him at all times. Academically, how did his disability impact him?

R: Now, back in Jordan there were services but it does not compare to here. But they do have a section for special needs and he would take classes on his level. So, although he finished high school, you could say he finished like sixth grade. So he can read, write both English and Arabic. He does math, like simple calculations. Simple multiplying, he does that.

I: Good!

R: I enrolled him in several activities that would enhance his abilities.

I: Gotcha. And what is the timeline of his diagnosis and his difference of ability and how that played out over his development and childhood?

R: I think he was lucky; we were lucky because he was diagnosed at age one. We were here in the states because he was born in the States and until three and a half years we stayed here. So, his pediatrician evaluated him at age one at his regular check-up. I noticed differences, but I thought he was just a quiet child. But at age one, his pediatrician told us he had a global delay. And we started early interventions, where he went to school at age one and we worked with him until he was three and a half. Speech therapy, physical therapy. And he was enrolled in Pre-K and then we went back to Jordan.

I: Okay, I see. And epilepsy was that from a young age?

R: No. Epilepsy was at adolescence. He was like I think sixteen years when he had his first seizure.

I: And how often does he typically have a seizure.

R: Ah. He would have seizures sometimes twice a month. Maybe once a month, ah sometimes three times a month.

I: Okay.

R: We did a follow up with the neurologist back in Jordan. But when we came here a year ago, the neurologist said that he takes too little of a dose. The neurologist said that we have to prevent this seizure from happening because sometimes there is the risk of dying, not from the seizure but from the fall. His dose was almost doubled.

I: Okay.

R: In the morning and the evening. I think studies say statically that if he is epilepsy or seizure-free for a year, eventually he can be cured and they might take him off medication. So since we came, (to America), he has only had one episode.

I: That is good.

R: Yeah, compared to once a month.

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

R: You mean what caused the disability he has?

I: Yup.

R: It didn't vary. It was obvious that it was due to the delivery. [Due to the placement of the baby in the birth canal, surgeons couldn't do a C-section. When her son was born, he was obviously hypoxic.]

I: Um, do you feel like there are some people who think that the disability is from God or other outside forces that led to the events that occurred? Do you believe in any other outside forces that might have influenced?

R: Ah, I believe that it was meant to be, because you know, some people go through worse than that and the child comes out normal. So I think, you know, it was meant to be. And it's from God, so when I realized that, I kind of stopped blaming myself for not asking for a C-section or you know all of these stuff...

I: And can you describe any sort of care that he has received over the years? You described speech therapy, any other kinds of therapy?

R: Physical therapy, speech therapy, and early intervention, which means he goes to school and they try to stimulate him with certain activities so he can be more aware of his surroundings. But the problem was when we moved back to Jordan, most services are really primitive, compared to the U.S. Now it's much better, but we missed that. So it was kind of a struggle in Jordan. And then we looked for a physical therapist who graduated from the states and she had her center there and we used to follow up with her and a speech therapist also.

I: Okay. So the next set of questions focuses on perceptions about people with difference of abilities and experiences of prejudice and discrimination. The question is, compared to the broader U.S. society, how you think the Muslim communities perceive differences of abilities that are very visible, like outward being in a wheelchair vs, intellectual, where it is not visible at first sight.

R: At first sight, my son doesn't stand out as someone different. But the moment he starts to talk or walk, you can see he walks different, he talks different. There is maybe more acceptance towards people who have obvious differences, like in a wheelchair. They don't look down on them maybe, but they would look down on people with an intellectual disability.

I: Do you think there is any reasoning for that in particular?

R: I think we always look for perfection, and if something is imperfect, right away we talk about it and we criticize it, whether it is a disability or something else. I guess it's the culture, not the religion though. Because our religion is the opposite. I think we don't have the minorities in our religion. We created our own culture -- we reject anything that is imperfect and then we start to talk about it and criticize it. So maybe that is why.

I: Interesting. Have you or the person you cared for experienced prejudice, negative remarks, or discrimination because of their differences of ability?

R: Actually, he was bullied all the time at school to that extent and his brother had to go through that with him because bullies would tell him your brother is mentally retarded and kind of like tease him. And for instance, they would try to hit my son [with the ability difference], and his brother would defend him and get hit himself. The bad part about it is that his brother never told me until he was a young man. And I was like why didn't you say something. I could have done something.

I: Have you as his mother, experienced any discrimination or prejudice as a result...

R: \*Sighs\* I would have you know those looks. But I guess I always stated without having to talk, that I loved this guy. And he is the one for me. I would always hug him, love him, and praise him in front of others. So I guess no one that I knew or was close to me said any word that would prejudice or discriminate against him. As I told you, from strangers, I would get the looks.

I: Given your experience with the community's perceptions here in the Milwaukee area, is there any impact on your willingness to be in public situations with your son?

R: Back in Jordan, he was a part of our life big time. My husband and I would take him to social events like weddings, invitations for lunch, for dinner. So I think that everyone knew that he is part of our life. I'm sure they did think something was weird with him or with us. But as I told you, we always made sure that he was with us. I knew a friend for instance, whose husband never told his friends at work that he has a disabled son. While my husband, on the other hand, would talk about him our son. He would post pictures of him on Facebook. So no one ignored that he was a part of our life. So, I guess this is what helped. But of course here, you do not have to fight for acceptance or you don't have to make an extra step or take an extra step to be

accepted. Because no one would give you looks or give you remarks. I think people are more compassionate here.

I: Okay, good to know. Is there any type of events at the mosque or at one of the centers that isn't maybe set up or accessible to your son or other individuals with disabilities?

R: Yeah, especially if they have autism, for instance. Yeah. It is. I guess in the mosque you would be in your local community again. A person I know has a son with disabilities who is in a wheelchair. He has cerebral palsy. She said that kids were like dancing around his wheelchair and making remarks in the mosque. And she was like, "I was shocked". So, yeah. I don't think that they do their best to accommodate to people. That was one mosque. But the mosque that I go to has really done a superb job to accommodate people with disabilities. They make them feel welcomed, they make their parents feel welcomed. They are part of the community and they can do their worship, where they help with maybe sitting or stuff like that. This is the only mosque that is equipped to accommodate with people with disabilities and their families.

I: I've heard some good things about that Mosque. Okay, how does the community's perception, if at all, affect the way you care for your son? Do you feel any pressure from outside of your family on the way YOU operate and care for your son?

R: I don't know. We were very lucky you know that we were at home all the time. He is not like, physically disabled or mentally. So, he would go to school. So, as I told you, I just changed my job to basically go along with his needs. You know, I would go in the morning with him and come back home with him and go to school with him. So I am supervising everything. If he has anything, I would be right on the scene. So I guess I was lucky and others aren't.

I: Okay, from your experience do you think the Muslim community has any expectations for you as a caregiver?



R: Like do they expect me to...to just stay home and take care of him? I am doing that basically. Like he is with me all the time. Everywhere I go, he is with me.

I: As a Muslim woman, what are your expectations for yourself, being a caregiver for your son?

R: I think being a Muslim helped me a lot. If anything, it helped me to have positive energy about my situation. Because I realized that this was from God. And if I am taking care of my son to the fullest, Allah would reward me in this life, and in the life after. So not only in this life. And actually I do believe that when Allah sent me my son, he taught me a big lesson in life. I became a better person in so many ways. I think I've grown, like I don't think that I would be the same if I had not had him in my life.

I: I see. Okay. So the next group of questions focus on the challenges that you have faced dealing with the issues we have been discussing, how you have dealt with them, and how it is needed to make life better for caregivers and individuals with differences of abilities. What are the biggest challenges you have faced as a person who cares for someone with a difference of ability?

R: In back home, I think back home, the biggest challenge was being accepted -- for them to accept my son's presence. Besides, nothing in Jordan is really accommodated to provide for people with disabilities. Recently, it has been better. Like when he graduated school I was so nervous because he would say, "I need to go to university", like his siblings. He was actually a high achiever, which made it very challenging for me to make him understand he is different. He is different.

I: It is okay.

R: So, basically as I told you, to be accepted, to have activities that accommodate people like my son. Maybe if they have some lectures or workshops that educate people more about people with disabilities, people who are a part of the community because they can be very productive by the

way. They can be very productive, and they are very special and add to the community. Being different is not such a bad thing. Even educated people don't accept people with disabilities. And this is the biggest challenge I guess.

I: Okay. I just have a couple of different categories we can go through. For different challenges, some people have expressed being stretched too thin, maybe they do not have enough outside support, or resources that allow them...

R: In Jordan, there aren't resources. And no support. Even family. [Some of our family members are] more understanding, more loving, more supportive. And as a community, no resources. For instance, schools are not made to accommodate people with disability. And resources, financially, financial support. Financial support, like there, it is very expensive to care for a child with a disability. You get no support from the government or...and eventually you feel frustrated. Because, yeah, you don't have resources.

I: And how do you say that differs from your experience in America?

R: I think it is completely the opposite. Like here, you come to a place where people with disabilities are respected, where they are treated as people who have brains. They are supported, like for instance...insurance. I mean back home (in Jordan) you would get health insurance. It is not good because it is in the government section of health insurance and usually that isn't a good thing. So you go to private and find care. Here it is completely different. For instance, I feel like my son has a life. I am talking about simple things you might think are funny. Here, we bought him a tricycle, which was a big thing for him. It was the first time he rode a bike. For him, it was... it meant a lot. So, they go that far to include them in everything basically. So. Yeah. They are even training him to get a job.

I: Oh that is awesome.

R: DVR? Like division of vocation rehabilitation.

I: I also know there is the Milwaukee Center for Independence. So i didn't know which one.

R: And you go through GoodWill and so many other good things. So back home, they are starting to do that, by the way. In Jordan, he tried to be trained to get a job, but the problem was the people. They did not accept. They are not accepting. This is also you know, also another challenge. Even if they were trained for a job, eventually they end up quitting.

I: Hmm... I see. Have you experienced, or any other members of your family or your son experienced emotional distress at all due to your situation or being overwhelmed or depressed?

R: I don't think to the extent of being depressed. But I think growing up, they didn't understand why he was being treated different by me and his father, being pampered, giving him extra care. I think it did cause some dilemma for them. So until they grew up, they thought we loved him more than them. They did not understand that growing up.

I: Alright. From whom do you typically get help from? I know you mentioned your kids are really good with your son.

R: Yeah. My husband also. And a sister.

I: Have you had any positive experiences getting help from others?

R: I never asked. \*Laughs\*

I: Gotcha. Um have you had positive experience with health care providers or therapists?

R: Yeah. Back in Jordan there was a very good speech therapist who was very loving, caring, and patient. And he really benefited from that therapist.

I: And could you describe your experience with the early intervention aspect when you were here?

R: In the US, it was awesome. It was wonderful. They were really really good people, who you know worked with kids. And they went out of their way to work on them, stimulate them. They would give me guidelines, what to do with him, what to do at home. They even came and visited us at home. I think he was lucky because at this critical age, I think one year, I think that made a huge difference.

I: Gotcha. And you mentioned he is training potentially for a job. Are there any other things or groups he is involved in the community now?

R: Here we are involved in activities that are done in ISM. And they have events every now and then that include people with special needs. [He is actively involved in one of the celebrations.]

I: That's awesome. What, if any, are challenges that females with differences of abilities face that are different compared to males? If any.

R: I guess we always look at females with vulnerability. That it is someone we want to protect, in our culture at least. I would be more concerned for a daughter who has a special need or something just because we are overprotective of females. I guess that we are afraid of abuse or something. I am concerned about abuse for my son, as well, although he is a male. I think this is the difference, being overprotected.

I: Okay. In addition to that, how do you think it impacts education or employment, being male versus female with a disability?

R: Maybe here it is not that big of a difference I guess. It is not treated, you know, as something different. If my son was a girl, I would be more concerned. I would go through everything for him. But I would just be more concerned about a girl's safety.

I: What additional health, support, or changes in attitude are needed in Milwaukee or in the Muslim community in general?

R: I think they need to be educated. I think if we preach our religious teaching, our religion deals with human beings as precious, whether they are abled normal to disabled you know. So if we preach our own teachings, if we apply our teaching as a religion of love, and of compassion, and of respect, and you should go out of your way to help any person, whether the person is a Muslim or non-Muslim. So, you know, what about Muslim people? And what about people in need? So, I guess that would maybe help people in charge or responsible for the Islamic Centers, if they talk about those kinds of people. And I think in schools, in Islamic schools that we have, if they try to apply that and educate our little kids and apply that, naturally they will grow to be the adults that like to deal with those people. I think that would be a great help. And I think also, someone should be responsible for the disabled persons who come to the mosque because they do have the right to pray. They do have the right to be a part of the community. Like for my son, he goes and prays with my husband. So if I were to send him without my husband, I would be concerned. So, I think there should be people in each community who are responsible for the safety and wellbeing of those categories in specific.

I: Like an advocate for them...

R: Yes, that, too.

I: Okay, that is a good idea. What are things a healthcare provider should know when caring for a Muslim with a disability? Are there any accommodations so that they can be culturally competent when caring for someone?

R: \*Thinking\* I don't know. Maybe just know a little bit about our religion. We do have some certain practices. For instance, females have our hijab and you need to respect our privacy and teachings. I can't think of other specific things.

I: That was a good example. Is there anything that the schools in the Milwaukee area should know when providing education for Muslim individuals with disabilities?

R: Um \*long pause\* because I haven't been here through that school time, I don't think that I can be of big help with this question.

I: Okay! No problem.

R: I think food is one of the things.

I: Okay. Why do you say food?

R: Because we eat Kosher food. For instance if the teacher wants to give the students ice cream, please tell the parent so s/he can bring a box of kosher ice cream.

I: Mmhmm. Let's see. Is there anything else you would like to share with me, regarding your experience in relation to our project at all? Any additional remarks?

R: \*Long Pause\* This interview has brought to my attention that we are using the Islamic community name, while I think that a lot of negative practices are not from the Islamic religion, but rather from the culture itself. Which is really bad in a lot of areas. And I think we should put that in mind. It is not the religion, it is being away actually from our religion when we act badly. I think that all religions and teachings like Christianity, Judaism, and Islam come to make people's life better in all aspects. So I guess we should separate being Muslim, being Jordanian, or being Iraqi or being Syrian. The culture must be considered, you know, just to be fair.

I: Gotcha. Thank you for sharing.