

Interviewer: Meredith Gillespie, Interview 1 (Recording titled as MG03)

Date: November 12, 2018

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

Year of Birth: 1962

Gender: Female

Country of Origin: Palestine

Year of Immigration: 1966

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 Palestinian woman from Milwaukee, Wisconsin. She and her husband have one teenager and four young adults. The second oldest son suffers from paralysis as a result of spina bifida. She is a leader and activist in the Milwaukee Muslim community and runs a non-profit. She discussed her life as a mother, caregiver, and community activist. Although she experienced a lot of emotional difficulties with handling all of her children and her son with differences in abilities, she notes that neither she nor her son has experienced any negative perceptions or discrimination based on her son's disabilities. She does note, however, that although family and friends are helpful for providing logistical and emotional support, formal respite care is something that people in Milwaukee need desperately to care for these children.

Key Themes:

Caregivers, physical disabilities, spina bifida, family support, community support, adults with disabilities, need for respite care, parents (especially mothers) who do not challenge stigma/prejudice

Interview:

I: The beginning of the interview is just a little bit about you. So could you start by giving a short background, age place you were born?

R: Sure. I was born in Palestine. I came to the United States when I was 4. I was born in 1962. I have [one teenager and four young adults. The second oldest son suffers from paralysis as a result of spina bifida]. I am a college graduate, my husband is [a professional in the medical field].

I: That's a great background. So you moved to the U.S. when you were four, so what were the reasons why you moved to the U.S.?

R: My parents were coming here to visit, my dad as a single man had been here, so they came here and planned to stay for a year or two but then the '67 War broke out and the Palestinians that were not in the country were not allowed back.

I: When did you move to Milwaukee, or come here first?

R: We came directly to Milwaukee. To an extent I am a naturalized citizen but I am a third generation.

I: Yes, so how would you define your national background? Where do you relate yourself to?

R: Well, I am proud of my Palestinian heritage but, you know, I've lived in America all my life and I define myself as American, so I classify as American and an Arab, and Muslim.

I: Okay. You mentioned earlier that you are a college graduate. So when did you complete that and where do you go to school?

R: [She attended a local university/college and got an undergraduate degree in a science-related field.]

I: Wow! That's great.

R: And then grad school, and then I worked in that field for a period of time.

I: Great, so you have some major scientific background then. So, are you married?

R: Yes.

I: And where is your husband from?

R: He is originally from [the Middle East] and is a professional in the medical field.

I: Great. So you mentioned you have one teenager and four young adults. The second oldest son has a disability. So what are the ages of everyone else and what is his age?

R: [Information is not being made available.]

I: Do you currently work outside the home?

R: Yes, I currently run [a non-profit in the Muslim community].

I: Great. And is that your main position or do you do any other types of work around Milwaukee?

R: I'm involved in many other types of organizations as an activist.

I: And what is your day to day like here?

R: [Information is not being made available.]

I: That's great. So how many hours a week would you say you work [at the nonprofit]?

R: Doing things for it, probably 60 hours a week.

I: Wow, that's wonderful. Thank you for giving me some of your background. So the next few questions are about the different types of abilities that your son has, and then just your experiences as a caretaker. So, what type of disabilities or differences in abilities does your son have?

R: Well, he has paralysis from the waist down. So he is in a wheelchair. He also has some issues with his fine motor and things like that as well. Although he is able to write, he is able to type, he

is able to do things, but certain fine motor things he does have issues with. Also as a result of being in the wheelchair and the spina bifida he also has some scoliosis which has affected his breathing. So many times his breathing is a bit labored, so when he talks he talks kind of choppy. But he is a very bright boy.

I: So my other question was his about his language skills. So that is really just a cause of his breathing, then?

R: Yeah, he is able to speak and he is on top of things, and he understands things and can participate, he's quiet but he is, you know, knowledgeable.

I: What is his current living situation?

R: He lives at home. He actually went to a Wisconsin university and then he was on campus.

I: Looking more into his differences in abilities, what was the timeline of when you found out that he had Spina bifida and how has that developed over time?

R: I didn't know until he was born. Although, it's something that should have easily been seen, it was not something the doctor paid attention to or something. So I did not know, but when he was born. It has been a long haul, to be honest with you, because we've gone through many surgeries. I was just talking to my husband the other day actually that the first ten years of his life, if least if not more, but at least ten years, I was taking him in for therapy four times a week. And then after that it decreased to two times a week just because I had other kids and I couldn't do it anymore, and then when he started going to school they started doing some additional therapy, so that helped me kind of decrease to two times a week, and then there were, you know, many times he was hospitalized for many different things.

I: So were you working a good amount at that time when he was a child?

R: No, I basically had to kind of leave what I was doing and that became, between him and my

siblings, it was not do-able at all, especially because of my husband's schedule.

I: So what is the type of care that you provide to him? What are some of the day to day things you do for him?

R: It's a lot of care because he cannot go to the bathroom by himself, so he needs to be catheterized and he needs to be bathed, he needs everything done, because he can't do it- he can't cook his breakfast or cook his lunch. But now he can kind of make a simple sandwich or something like that but basically he is totally dependent. We have to wash his clothes, we have to clean his room, do everything for him. Get him dressed.

I: So looking at your experience as a caregiver do you think the Muslim community has any expectations for you as a caregiver for your son?

R: In what way?

I: Just like the way you are supposed to raise him or the way you as a mother should live your life knowing that you have a child with different abilities.

R: No, I don't think so. I don't think that people know my day-to-day life, so to speak. I think really only families who have a child with special needs are the ones that really realize what I go through. And on the contrary, I think that there are many in the Muslim community that know I have a child like this and know what I do in the community and what I do here, and a lot of times I get tons of praise and people are you know, the words I often hear are "I don't know how you do it" like astonishment at how I juggle all of the hats I have to wear, so to speak. But no, I don't think I've ever run into any issues with the Muslim community expecting something different.

I: So what are some of the things that you face as a caregiver or some of the challenges that you face? Some people say that they are stretched too thin or they feel like they can't detach themselves from that portion of your life, so what are some things you feel?

R: Definitely, I think because as parents, and we are the ones that have to take care of our kids. So I do feel attached in the sense, you know, now that my kids are older, especially because he is an adult, you would think, “Well okay I want to take off for a few weeks for vacation by myself or go overseas,” for example, or I want to decide just one weekend just like that, last second, “I want to fly to New York this weekend,” that was never an option because I’ve got a special needs child that needs a lot of care and cannot be left alone. So I don’t think that is particular to being Muslim. I know a lot of families that are not Muslim that have special needs kids and they’re in the same boat.

I: Have you faced any financial issues? Obviously you had to get a lot of surgeries when he was young and things like that?

R: No, luckily we’ve always had insurance for him. And also the state of Wisconsin, I assume this is across the country but I’m not sure, but for kids, he had insurance that covered him, but when he turned 18 there is the-- what do they call it? Medicaid?-- things like that, people who have disabilities have insurance and things like that so that covers a lot of that. The funding for surgeries and things like that. And I think our situation is a lot better than a lot of others because [of my husband’s profession].

I: What about your emotional health throughout your son’s life?

R: I think that especially when I had a lot of kids and they were younger, there were times where it was emotionally draining. And mostly because I wanted to keep his responsibilities on me rather than having his siblings do more, which retrospectively I shouldn’t have done that. I should have given them responsibilities so they could help out, so to speak, so I didn’t want his disabilities to affect them, and so I took the brunt of the work, so to speak. And he required a lot of work, to be honest with you. And I think that was also a feeling that, because he required so

much more, that maybe I didn't have enough time then to spend with the others because they were doing fine. At the end of the day, they are all good kids and they did well and they're successful, but there is also always a kind of a mother's guilt sort of, like "did I have to spend too much time with him hauling him to therapy back and forth." During that time I could have been maybe reading with one of them or doing something else with one of them, so there is always that. And definitely I say that there were many, many years where it was very stressful. But I think that's the difficulty, if you're going to raise your own child and your child has special needs, I think that's something that most families talk about and they have to deal with. But at the same time, I think that we have to note that as a result of all of that, that it helped me to be incredibly effective with my time. And that is then translated into me later on being able to do and juggle things effectively, because that is what I have to do when I have five kids. And so, just realizing not to waste time, so to speak.

I: So in regards to his schooling, did you feel like Milwaukee was sufficient for his schooling? Did you ever consider moving? What was that experience?

R: So we live [in a community outside of Milwaukee]. He was in the public schools because private schools cannot accommodate him. But I honestly thought that they did a great job. I thought they were very helpful, and I know that there are a lot of parents that you hear around that complain. I don't know how Milwaukee is, but even in my town there were parents that would complain, but I always found the teachers, therapists, physical therapists and the speech therapists -- everyone we had to work with -- were very kind and were really trying to work with him and accommodate him.

I: Did you feel like there were other forms of support that you could access outside of school for him?

R: No. And I think that that is something especially in terms of what I really, really wish I had when he was younger and my kids were younger was some kind of respite care. I am lucky to live in a city where my family of origin are, and so that was respite. Like every once in a while a parent or sibling would come if I needed to go shopping or whatever. So having my family was a tremendous, tremendous help that way. But I wish that there really was some formal form of respite care where you could just say, once a week, I am going to have an experienced caregiver, not just a babysitter because that's the thing, you need someone that is skilled, with these kinds of kids, and that was not available.

I: So you had your family, it sounds like, for emotional and logistical support. But did you have anyone else that you relied on, like friends or anything like that?

R: Not to take care of him. Like I said, I just didn't feel that you know, comfortable leaving him with anyone. So that was not something that I did. So that was usually taking him with me or a family member that would stay with him.

I: In regards to emotional support and everything, did you feel supported by your family and friends?

R: Yes, I definitely did. And I am a person of strong faith, and so I felt that that was a tremendous support for me. That kept me well-grounded. And then just family and friends and also some other, at school, families that had children with special needs, just chatting with them everyone once in a while. So, and even when I had young kids and even when I had him, I was always busy and I was always an activist. So I think that also gave me another purpose. Even if it was writing or doing something, I always found a way to have an outlet to get that stress out, so to speak.

I: Did that ability in your life to do things like that, did that increase with his age?

R: Yes. My work in that increased definitely, as he grew older and spent more time in school. And then again, he was in college on campus, so after he finished high school, that kind of became a whole new life for me.

I: That's great. So now the questions are going to be geared more towards perceptions about people with differences of abilities and experiences of prejudice or discrimination within the Muslim community and the U.S., American community in general. So, compared to broader U.S. society, how do you think the Muslim community perceives differences of abilities that are visible?

R: I've always been very public with him, I take him everywhere. And he is known by everybody. So I haven't honestly countered anything different or peculiar in the Muslim community. On the contrary, like whenever I go anywhere, I always find that there are a dozen people trying to help me get him in the van or doing something like that to help out. A lot of times, getting him out of the van, if anyone is passing by like if I'm at the mosque they will always jump to take him inside for me. I don't ask them, this is just something that they do. So I think that... or like they'll sit with him, so I haven't personally had any issues in that way. I think the thing that I've noticed growing up, but this is even in the broader community, not just specifically in the Muslim community, but because he went to public schools here, is the fact that growing up for example when there were birthday parties for kids and things like that, events of course, he wasn't invited. So I think that as a mother always concerned me. But that is not just in the Muslim community that that happens.

I: Do you think that those perceptions are different for people who have differences in abilities that are cognitive or perhaps, someone that struggles with their mental health?

R: [pause] in the Muslim community?

I: A little bit of both. Muslim community compared to the US community, they could be the same or they could be different.

R: I think it's the same thing across the board. Because some of the kids I remember being at least, like in some of his classes or therapy, some of them had cognitive issues. And it was the same thing. They were kind of isolated by themselves. So whereas they were integrated into the classroom, not the kids with cognitive issues but him, because his disability is physical it's not mental, that didn't change the fact that students were probably nice towards him but they were not his friends per say. It's not like someone would call him or talk to him, or he wouldn't go and hang out with him. So I think that's the difference. But the kids that I say that had cognitive issues I definitely don't think they interacted with anyone.

I: Do you know of anyone within the Muslim community, whether it's a caretaker or someone who has a difference in ability, that has faced any discrimination or negative perception based on that?

R: I think at least, in a couple of instances, it's basically an individual that maybe has, whether its family members or in laws that just are not very educated, you know? And in that case, it's sort of like, they are like, "Oh my gosh I want to hide the fact that I have a child with a disability." But what bothers me is the fact that the parents particularly the mothers, who end up being the caretakers, they allow that to happen. Even though they grew up here and they know that that is not the norm and there is nothing to be ashamed of, it's not like you go out and buy a kid with a disability, you know what I mean? And they allow that kind of attitude to affect them, rather than to challenge it. So to an extent, because like I said I have a son whose disability is very blatant compared to others, because he is in a wheelchair, there are other people who have disabilities that are not as known or not as obvious, so I almost want to shake them [laugh] or I

guess I am disappointed that they don't kind of stand up and challenge that kind of thinking.

I: And that's interesting because it seems like there are a lot of different perceptions of caretakers in the Muslim community based on their experiences, so it sounds like there are a lot of ways to interpret and respond to these questions.

R: Yes. And for me, like I said, I can honestly say that I've never had issues.

I: Okay, so let's see. How has your faith, especially being a Muslim woman, how has that impacted the type of care that you choose for your son?

R: I think, as being an individual considering myself to be very faithful, and there are many that consider me to be knowledgeable in my faith, I think that has really helped me help him to be the best that he can be. Because I think that this is something that has given me tremendous strength and focus in my faith and it's helped me to advocate for my son. And it has helped me to push him to be the best that he can. And just to accept what God has given us.

I: So obviously you cannot speak for your son, but when it comes to his experience as an adult with a disability, what is his situation when it comes to independence, work study and things?

R: He studied, he graduated, and is constantly updating his resume and is keen on finding a good job. And he actually did a couple of like 3-4 internships that lasted 3-4 months, but I think this is the sad part. Because of his physical issues, he is just slower doing things like everyone else, like typing. It just takes him a longer time. And here, everything is about money, and time is money. So whatever he has taken hasn't really lasted. And I feel bad for him because he did school and he went through all of that but he is not really finding a job in that field, and I don't know that he really will, unless he manages to find someone that is okay with him doing things slowly, which probably won't happen. So he did everything that he was supposed to do, like he graduated from high school with honors, and he went to college and graduated from there, and has been trying to

find a job, but now he is kind of up against a wall.

I: How is his relationship with your other children?

R: Oh, they get along. They fight with each other, but everyone gets along with him. [laughs]

I: [laughs] Sort of an indication that they get along, that they're able to fight, right?

R: [laughs] Yes. So he is a very kind kid very kind. They all get along.

I: Some last questions. Do you find that in your Mosque or in your community that people can possibly be more reserved sometimes when it comes to seeking help from other caregivers [of people with disabilities]?

R: Yeah, I don't know about, again, I think people tend to rely on family if they need someone. Because, like I said, it's not easy and I think that people would even be fearful of how to take care of some kids who have special needs, so I'm sure if I wanted to go to the Mosque and ask for people to help me, or a particular day or something I could definitely get people to do that. But I don't think that's the issue. I think what most families want is just regular respite help, I think that's what they need so they can do what they want to do.

I: Do you have anything else on this subject or your experience as a caregiver?

R: Um, yeah, I think that you know like I said that there were periods of times when he was younger and I had younger kids that I felt definitely overwhelmed, but over time, they grow up and he grows up and I think things do get easier, to an extent. But yeah these are kids that will always have extreme needs that we we have to work our lives around.

I: Those are all of the questions that I have. My only question would be are there any other people that you can think of that I should reach out to, in your community or otherwise?

R: There were several that I had given to Enaya, some information for a few, and they came for the original meeting here. There were some that did not come, I can see if they would be

interested in participating in the study.

I: Great, I will be sending a follow-up email so you can get me those individuals' information then. Thank you so much for allowing me to take a little glimpse into your life. I think your perspective is really valuable.