

Interviewer/Number of Interview: Nicole Kvist - NK01

Date: September 21, 2019

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

Year of Birth: 1965

Gender: Female

Country of Origin: USA

Year of Immigration: N/A

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 adult child with a visual impairment due to neurological factors. She believes that the education of teachers as well as students would be helpful to those with disabilities. She discusses the social impact the visual impairment had on her son and her ideas for creating a network for children in the next generation. She also has stated that families can be more protective of daughters with differences in ability and keep them closer to home.

Key Themes:

Faith; the importance of empowering children with ability differences to thrive; the importance of not lowering expectations; generational issues regarding acceptance of differences of abilities; because of the stigma, not communicating with some extended family about the son's ability difference and early signs of it; negative comments from son's college peers about being Muslim (Islamophobia); as a parent, needing to be an advocate in son's education and ensuring that the IEP would be created to meet his needs; peers in K-12 who misinterpreted his behavior because they lacked awareness of how visual impairment affects communication. Gender issues.

Suggestions: Need teachers, including those in Islamic schools, to be more educated and aware of ability differences and mental health issues and know how to facilitate communication in the classroom about these issues; need more guest speakers who are Muslim and knowledgeable about ability differences and to start this training/awareness when children are young.

Interview:

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

R: American-Palestinian.

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

R: Masters.

I: Great! In what?

R: Education.

I: Are you still a teacher then?

R: Yes, well kinda-sorta. I work more in administration, but yeah.

I: Ok! Where did you complete [your master's degree]?

R: [Information is not being made available.]

I: Ok, great! And, are you married?

R: Yes! I have 6 children.

I: How many boys and how many girls?

R: [She has a mix of males and females.]

I: And what's like their age span?

R: [All of her children are 21 years or older.]

I: Ok, great. And you currently still work outside the home?

R: Yes.

I: And you are an administrator?

R: [They have a family business in an educational field.]

I: How many hours do you work outside the home a week?

R: Maybe 20?

I: Ok! So that was all of the background information that we need, so now we are onto... well

this next question is on what kind of difference in ability is in your family.

R: Ok, so I have a son that is visually impaired. So he has low vision.

I: Ok, and what's his living arrangement? Does he live here full time with you?

R: [Not long ago, he bought a condo in the Greater Milwaukee area.]

I: Now could you describe the timeline? Was this from birth that he had it?

R: He started having- well I'm not sure because it's vision so it's hard to tell from birth if he had problems, but it sounds like it probably was from birth. But he had seizures starting from when he was about 5 months old. And they pretty much lasted until he was 4 years old. But they weren't consistent seizures, they were only fever related. So whenever he had a fever he would seize, he would have a seizure.

I: Wow, I can't even imagine. That's so tough.

R: Yeah.

I: Do you think there was anything that might have contributed to this? Like you said illness I guess?

R: Yeah we never really got an answer if the vision was from the febrile seizures, so we were never sure about that. But it is neurological, his vision. So it's not something that glasses can fix or something like that.

I: Ok. Can you now describe that nature of care that you provide or provided him as he was growing up?

R: Honestly growing up he would get different glasses, things like that. But glasses never really helped him that much because it wasn't that issue. Care-wise, being more careful and actually because we have 6 children we actually let him participate in everything they participated in. We just kind of kept him in the middle or things like that, but he was able to bike ride and go

sledding and do everything everyone else was doing, but when school came around things changed a little bit.

I: Oh, I bet. What is the nature of care that he received from others?

R: At school he had an IEP (Individualized Education Plan). He would get different seating in class, and as he got older he got a note-taker because he couldn't see that thing, I think it's called the projector? They used to use these things-

I: The overhead?

R: The overhead! They used to use those in middle school. So once he got older the type of modifications he needed for his education changed. So we would always make sure everything was in place in his IEP. He used different tools, such as magnifiers and a computer. As soon as he was able to use his computer more, things became a little easier for him. Because he could use programs that could zoom into things.

I: And I bet even text to speech type stuff.

R: Yes. He did do that too, yes.

I: That's awesome! So now that we have that background on you and your son, I want to ask a couple of questions about perceptions on people with differences in ability and experiences of prejudice or discrimination against them. So considering the Muslim community, as compared to the broader US society, how do you think the Muslim community perceives differences in ability that are very visible?

R: I think it has changed from generation to generation, but with him growing up, you know I think it was looked at negatively- having a child that had a disability, like maybe they weren't going to have a quality of life like the other children, like our other children. But now I think people are more educated, not as ignorant about it. So, I think there are more groups, more

support groups, more communication, and more talks about it. So it has definitely changed but I think him growing up, in general, to sum it up, that he probably would not have the same quality of life as other children.

I: Alright, thank you. And then almost the same question, but how do you think the Muslim community perceives differences in ability that are less visible.

R: Well his is less visible, honestly. I think maybe they just perceive him as being different, but not curious to know, maybe, what's going on. And maybe some people don't share as much. I know with him growing up we didn't share as much about exactly what was going on with him. But now it's easier to talk about it I think because there aren't as many of those stigmas about having a child that has a difference in ability.

I: So then are you saying it's easier to talk with him specifically or like his family members or...

R: Family members, at least my kids have been very supportive of him, so that's always been easy to talk to [them about that]. Immediate family? Honestly, sometimes yes, sometimes no still. It depends on the generation of the person. The people who are younger understand more and are more receptive, you know? Don't have stereotypes or negativity towards it. But still the older generation, you know they might say something like, "Oh, poor him". You know? Or something like that even though he graduated college, just like his siblings, bought his own condo. One thing is, he doesn't drive. That's the one thing, his mobility. And even when he was younger they told us that that would probably be the one issue. You know? That he would excel at everything else but that mobility would be the issue. So sometimes [people] have hung onto that, like "Oh, but he can't drive". But he can do so many other things.

I: Definitely. And there are a lot of other people who just don't drive for their own reasons too.

R: Right! This is a perfect time to be a person who can't drive.

I: Exactly. Do you think your son has faced any discrimination or negative remarks because of his difference? Or that you being out as a family have experienced any remarks because of his difference?

R: In general you mean or specifically within the Muslim community?

I: I think in general.

R: I think the fact that his disability is not noticeable... He has in school. He would sit and be talking to someone but because of the way his vision is he might see the person the next day or a couple of days later and not recognize them. So they would say hello to him but he wouldn't say hello back because he just wasn't recognizing who it was. So people started treating him differently for that reason, not understanding that it was a visual issue not a social issue.

I: Right. I guess then when you guys all go out do you experience anything? Do you see anyone judging your family I guess?

R: No. I think again because it's not really apparent. That could be the reason.

I: Do you think that the fact that your son was Muslim or Arab was a factor to how your son was treated in school when people made comments? Or was it simply the misunderstanding?

R: I think maybe I don't have a lot of examples from middle school or high school so much as related to him being Muslim or Arab but I think there were a few instances in college where he had roommates who did make some negative comments to him about him being Muslim. Yeah, he did have that experience when he was at [deleted information]. And he did occasionally say that in fact one of his roommates made some negative comments to him about him being Muslim.

I: You'd think in college it would be better.

R: Yes.

I: Why do you think people have these negative judgements about disability or about being Arab or Muslim in general?

R: I think the disability part is just more of a cultural thing. Like I said about the older generation. I just guess it was something that their attitude was passed on about it from generation to generation as it being negative, or them not having a [good] quality of life, people having differing abilities. In regards to being Arab or Muslim, honestly I think it was just the climate for him. Being in school at that time, and the climate here in America at that time, and the comments were made comparing his religion to Christianity and why is he not a Christian? You know, just negative comments made to him.

I: Definitely. I am so sorry that happened to him.

R: It was sad, actually. It was.

I: Did you notice in your son or did you as a family have any impact on your willingness to be in public situations? For example if he didn't want to go out because he thought people would judge him or thought he wouldn't do something correctly. Or maybe you as a family thought you didn't want to attempt something because of some reason.

R: Honestly no. Usually if we wanted to do something we just pretty much did it. And he's pretty good about that too. No, I don't think so.

I: That's good! How do you think the community or the Muslim community has impacted the way that you care for your son?

R: Honestly just having faith, you know? And staying connected to the mosque and things like that, obviously that did impact us in the way we brought him up, but day to day life? It was our faith that drove us for sure to do the best that we could with him and give him the opportunities that we could but it really was early on deciding that he was going to experience things just like

the other kids. We actually had a conversation about it as should he go bike riding or should he not go bike riding. And then we just said you know what? We are going to pray for his safety and we are going to take every precaution that we can but he should go bike riding. And like I said, he would just go between the other kids. And sledding he would just pretty much do everything that they could do. The only road block, again, was driving. When they started driving he wasn't able to drive. So, otherwise yeah.

I: That's awesome. Do you think the Muslim community has expectations of you as a caregiver?

R: I don't know. I'm not sure.

I: Alright. I guess, something that I have heard before is that they wouldn't allow their child or whoever be taken care of by anyone else. That they would keep their home open to them.

R: Ok, I see what you're saying. You're saying like as he gets older? Yeah I guess we do have the attitude that we are hoping that we can put things in place for him and for right now we are his support system, meaning me, my husband, and our other children are his support system. But we do worry about him now that he's older. So again, we are trying to put things in order for him but we just have to pray and have faith that God will take care of him too. So really we do just depend on ourselves.

I: So your expectation on yourself is that you will help him out with certain steps.

R: Yes, and that's what we've been doing. Our plan is to continue to do that. Like I've said, he's pretty self-sufficient especially in the time and age where there's Uber, and you can get your groceries to come right to your house. So yeah, he's got it all. I'm even like, what? You ordered all this already? So anything he wants he is able to do. He's pretty independent right now but you know, time will only tell.

I: Yeah! So now these next questions look at challenges, and challenges can be a lot of different

things. Things like feeling like you're not getting help from family or community, not having enough information or resources, finances, or the emotional or physical toll of your expectations or things not being the way you thought they'd be. So considering that, what would you say are some of the biggest challenges that you've faced as a caregiver for someone with a difference in ability?

R: The biggest challenges were for him growing up and going through the different phases through school. I was always making sure it was communicated what his needs were, whether it was through elementary school, or through middle school or high school and college. So kind of making sure that the communication was effective and there. So that people would understand what his needs were and that he would be successful. And sometimes that wasn't all so easy because that would depend on plugging yourself in to whoever was in charge at that time whether it was with the IEP's or at school. You know, finding things that he liked to do that he could do. You know, it was a lot of making sure that you were just always aware of everything that was going on all the time. He had a gym class one time and they were doing ping-pong or basketball, so talking to the gym coach and at that time they let him just do weight lifting. Because vision isn't really that important when you're just lifting weights. So, it was always being there, having the time to be there and connect with who we needed to connect with in the schools to make sure that he was able to be successful.

I: Did you find that easier to do as someone with an education background?

R: I think it did help. I do. I think it did help. Because we were able to, most of the time, whatever we wanted implemented for him or thought he needed, we found a way to do. And I think that does help. I think having an education does help. I'm not sure but I think it does.

I: Did you have to ask for many things? Because what I hear you saying is that if you needed

something you ended up getting it, but did you often have to advocate for your own son to-

R: Sometimes, yes. Sometimes we did. If we were at an IEP meeting and they would put x amount of time for something we would say, well let's look at that again. Or if he had tests he often needed more time to take tests because of the vision. So we would have to ask for that. So yeah, many times we did have to ask for things but then it was always implemented.

I: Was it hard for you or for your son when he got to the age where his siblings were driving and he wasn't?

R: It was. There was a moment. There was a moment there. It was probably one of the hardest things for him and for us too. You know as his parents -- knowing that the rest were all going to drive. We knew that they were all going to move along and it seemed like nothing else was holding him back. He would always say, he even would say it, you know. "I just do it different," you know? But the driving was one that we just couldn't get past. But now we explained to him that car payments, and gas, and insurance... for a while he was trying to watch his budget with Uber, but now he just goes and comes the way he wants. And you know he seems to like it. And he's happier about it.

I: Well that's good to hear. Did you ever feel like you, as his mother, didn't get enough support from others or did you feel like you were the one taking on all of his needs?

R: I think it wasn't that we didn't really receive support but looking back we didn't really seek support either? We just thought that he's our son, we are going to take care of him. I don't think we ever sought [support] outside of education, you know dealing with education. Everything else you know we just thought that we would handle.

I: How do you think support could have been offered to you then where you personally would have taken it?

R: Sometimes you know there were just moments when he was younger, where he had seizures, sometimes I thought more communication would have helped. Later on we found out that there were other children in the family who also had febrile seizures. So maybe if we would have talked about it more then we wouldn't have been as surprised by it either. So just being more open would have been good support. I think that's just the hard part for Muslims is to be more open. We just try to handle it within the family.

I: Yeah, definitely in some cases that is good and maybe in others not so much. Did you ever consider moving away from the Milwaukee area because you didn't get the resources you needed in the school?

R: No, we did move from [one Milwaukee suburb] to Brookfield for the resources in that school district. We did do that. But not out of Milwaukee, no.

I: Were you seeking the community here or was it just for the better school district?

R: It was at that time for the school district, yeah.

I: Ok. What are some strategies that you have used to deal with any sort of challenges that you've faced such as relieving stress for you or for helping your son?

R: Prayer. Prayer is definitely a strategy that we've used. Just supporting each other. We do that as a family. We do support each other. We can talk to each other. And other than that, recently there has been a support group here in Brookfield, so I participate in that. And you know, other than that just educating ourselves, that was our support. So just trying to educate ourselves early on about what was going on with him. And then just prayer and our faith.

I: Was the support group in Brookfield where you heard about this?

R: No.

I: So then can you tell me more about that support group in Brookfield?

R: So I'm part of the planning for that, so we started it out. It's called Mushen. And to get the mosque accredited, to be more friendly for people, adults and children with disabilities. And part of that group, we decided to be a support group. So that was about 2 years ago? A little over 2 years ago. So there aren't that many people attending but there are families. I think at one point we had about 5 families who attended. And it's been the same families. Occasionally there have been other families who would come in and join. But it's every month or every other month.

I: Oh yeah! I have heard of that before, and I think I may have spoken with some other people that go. I just wanted to know in case we could reach out there as well.

R: Yeah!

I: And back to our questions, there are only a few more!

R: Oh, I'm fine.

I: Alright then, from whom and where do you usually get help for yourself?

R: For myself? Well right now, like I said, he is pretty independent. I do participate in the Mushen group which is really nice because it's more networking now than anything. And I like being able to help someone else who has a younger child. So that actually makes me feel really good. But support-wise, my husband and my children. That's where I seek my support more than anything.

I: That's so nice. And have you ever had any positive experiences getting help from others in the community or in your workplace? Or from healthcare providers when he was younger?

R: When he was younger I think he had some good counselors. In the middle school there was always a special person that took to him and was very friendly and would always stay in close contact with us, so they were very supportive. When he got older, because of his vision there were some social things that came into play also. Because he didn't always recognize people he

didn't make a lot of social connections, like close connections with people outside of his siblings. But when he was at [a Wisconsin college] he did make some friends. They had disabilities but they were very close with him and to this day he still considers them very close friends of his. But there was a man at the mosque that asked him to volunteer for a computer class, and he just loved it. He loved the fact that - he's a professor at one of the colleges.

I: The man who asked him?

R: Yes, a Muslim brother. And he's still in contact with this professor and they still work together on different things. But just something as small as someone reaching out to him, even though [the professor] knows that he has a challenge, and asking him to do something with computers. Because that's his field, it just changed his whole- he was so happy about it. So those little things that I think are important in our community is integrating the children with challenges. Because as they get older, it's not that easy.

I: And everyone is good at something!

R: And that is true. Sometimes it's just finding the person to have the patience to say, I'll do this, or I'll give this person an opportunity. But it could mean the world to a child with a disability for sure. Exactly.

I: I love that answer. Do you think that females face challenges with disabilities than males with the same disability? Such as being less marriageable or having less support or opportunities for education and employment?

R: I could see that being the case. I could see it. There is actually a girl that volunteers at our place of business who has a disability and her mom wants her in a safe environment. She doesn't want to put her somewhere else. So I think with girls, you're more protective of them as Muslims. So they might not have as many opportunities because it's either they stay home or

very limited what the mother might let her do or where the mother might let her go. Because she does worry, about her more so.

I: So I what you're saying is it's more the protectiveness rather than others viewing her differently?

R: Some people view her as someone who probably won't get married. I do see that. Again, with the older generation. I think with us we are more open-minded. You know? Everybody has somebody I think. Or can find somebody. You know, there is still a lot of stigma with that. Especially the girls.

I: Yeah. Definitely. Do you think there are additional supports or changes in attitude needed in this community?

R: I think in all communities, yeah. I think more education, especially with the mental health also, that aspect of it. I think we just need to all educate ourselves more about children with differing abilities, or the mental health issue which we talked about earlier. Yes. I think there could be growth all the way around, with all communities.

I: Do you think you know- So you're saying education is something we can do. Is there anything else?

R: I think in our schools, our Islamic schools [there could be] training. Teacher training would be helpful too, regarding children with disabilities and or mental health. That would be helpful. Maybe the curriculum? Focusing on the curriculum too and the health to teach our children also to be more aware.

I: So you're saying schools that are geared towards the Muslim population?

R: Yes.

I: Alright, so then what do you think in the broader nation that schools or healthcare

professionals could know that would be helpful to you? Or could have known in the past?

R: What are the schools?

I: Just things that you wish people knew or had known while you were sending your son through the school that could have helped you or supported you. Do you think maybe learning more about Muslim people in general?

R: I think that was starting out when they were in school here where sometimes they'd have speakers come out, and I know we've had speakers come out [before], but I always thought that was a wonderful idea, to have a Muslim speaker come out who speaks good English, and can articulate more things about Muslims because they're going to see our children fasting during Ramadan, praying during school, so maybe being able to bring that information... So I think that would be, that's always been helpful. And I think that there are organizations that do that. And speakers in the community that do that. But I think that the more we can do that and bring people into the Mosques, just to educate themselves, but I always say that it's the day to day interactions that we have has Muslims that are defining us. It's the day to day. Whether we are going to the grocery store, or whatever, going for an appointment somewhere, or at work, the people we interact with at work, who we are as Muslims will show. And then we don't have to always be trying to be on the defense. Because if people get to know us they're usually pretty receptive.

I: ... Yeah, definitely. So, education through meeting people and talking to people is what you're saying.

R: Yes, and having the speakers come and talk to the schools. That's what we're talking about too. And whether it's educating about Islam or even somebody once mentioned educating [my son's] class about his impairment, you know? The more they would have known about that... that was later they knew. You know maybe we should have let him talk to his class about what

his vision was. That way they wouldn't feel so odd when he didn't say hello in the hallway. They would go up to him and say hey, it's me! Hi! So you know those are things we could have done too looking back.

I: Right! Or having professionals suggest it to you would have been helpful.

R: Yes.

I: Is there anything else you would want to tell me about your entire experiences, what you've seen, what you wish could have been done or anything else?

R: I think they've been trying it a little bit with social outlets for our children with differing abilities. The Mosques have been trying different things. But it would be nice if they could start it when they are younger because a lot of children with differing abilities do develop, it seems to me, social issues also. It seems to me that they don't have that group of friends because of their disability. So maybe moving forward trying to make, implement something for these kids so they do have a little network of people.

I: Yeah, I like that idea. And then I guess do you know anyone I guess specifically who might want to participate in this?

R: [She felt more comfortable talking about other interested parties with the recording device off.]