

Interviewer/Number of Interview: Nicole Kvist - NK14

Date: July 24, 2019

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

Year of Birth: 1968

Gender: Female

Country of Origin: U.S. [Jordanian-Palestinian national background]

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 mother of an adult daughter with cognitive delay speaks about her experiences in the schools and Muslim community. Originally from Chicago, she moved to Milwaukee in the late-1980s. She wishes that she had been more aware of the resources that are available, rather than her assuming that programs didn't apply to her. She suggested that perhaps the experts could be more proactive in letting their clients know what is available. She expressed belief that her role is to be the sole caregiver, which leads to difficulties for her to ask for help. She also suggested that healthcare providers, teachers and others who work with special needs, could be better informed/educated on the religion of Islam and how its religious values are different regarding transitioning into daycares and adult care facilities and things like that. She discussed stigmas/prejudices in the Muslim community regarding people with ability differences.

Key Themes:

Mild Cognitive Delay, prejudice/stigma in the Muslim community, need to educate Muslim community about ability differences, her faith and culture call on her (and her other children when the parents are dead) to care for their sibling who has ability differences, belief that the mother has sole responsibility for her daughter, healthcare providers/teachers need to be better understand Islam in order to better serve Muslims with ability differences (or caregivers).

I: Why did you guys move here?

R: I got married and moved here.

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

R: Jordanian-Palestinian

I: What's the highest level of education you've completed?

R: 2 years of college.

I: Where did you complete it?

R: At [a community college in Illinois]

I: And you're married?

R: Yes.

I: And do you have only two children or?

R: I have seven children. [All but one are 18 years or older.]

I: And then how many are there boys versus girls?

R: [Information is not being made available.]

I: Do you currently work outside the home?

R: No.

I: Ok so those were the background questions and we are done with those. So are there differences in ability or disabilities with you or anyone in your family?

I: Just my daughter [who is in her late 20's].

R: Could you tell me what that-

I: Mildly Cognitively Delayed.

R: Thank you! So then do you currently provide care to her?

I: Yes

R: And does she live here full time with you?

I: Yes

R: Would you describe her mild cognitive delay? How it impacts her life and your life a little bit?

I: A little slower. Does not retain information long. Can only perform one-step commands. 2-3 step commands she gets confused.

R: When did you get the diagnosis?

I: She started off with the Birth-3 program in Waukesha County and then was turned over to the early childhood, and then I think after kindergarten they labeled her as mildly cognitive delay.

R: Would you describe what kind of care you provide for her? Like do you need to write out her schedule?

I: No, she's pretty self-sufficient. She takes care of her physical daily hygiene. She showers, she also has two other conditions. She has alopecia areata, so she lost almost all of her hair when she was ten years old, no eyebrows, no eyelashes, no hair. And also she has a benign essential tremor, so she's on medication for that. She pretty much does everything. I provide transportation, get her in programs, sign her up for things daily, and that's about it.

R: What kind of professionals does she see? Does she see speech path, OT, PT?

I: No.

R: So these next questions focus on the Muslim community and their opinions within their own community. So do you think that, compared with the broader U.S. society, the Muslim community has differences in the way it perceives disabilities that are really visible?

I: Definitely. Growing up, I had a friend that had a child that was disabled and every time she came to visit, her mom left that child in a room and wouldn't let him come out. I believe that our

culture does not accept very well disabled people.

R: What do you think about those with disabilities that are less visible? So I know your daughter has her hair loss, but prior to that, do you think that someone looked at her with her disability that they would judge her? Or someone with mental health issues?

I: I think they would have judged because she would have been slower in learning and things like that so they would have judged. And whether it was a disability or not very intelligent, I think our community is very judgmental.

R: Do you think with mental health issues too?

I: Definitely. It's like I- growing up here, in Chicago in the 80's as a Muslim, I think people with disabilities [were] basically shunned out. Even in like my regular public school, disabled kids, back in the 80's were like in a corner of the school and they were all confined into one classroom. They weren't mainstreamed, they weren't in everything. In general society has come a long way but I think as a Muslim community we are still a good 10-15 years behind.

R: Is there anything you could maybe think of, like maybe better education of each disability, that could help change everyone's perspective?

I: I definitely believe that the groups that have started in our community, Muhsen and things like that, you know, special needs groups and things like that. I think that's helping to understand, for people to understand because you hear more ADHD, Autism, things like that -- they're more visible. These kids are not being shunned; you see them more visibly. I think the more we continue to educate our community, hopefully we will get ... caught up.

R: Have you or your daughter experienced outward prejudice like negative remarks or discrimination?

I: Regarding her disability? I'm not sure completely. I think like I've said, innuendos of her not

being intelligent, but then also her alopecia, “Oh, why do you look so different?” Her face, you know has no eyebrows, has no eyelashes, so even if she wore a wig she has no eyebrows, no eyelashes. And her lower jaw is a little bigger on the bottom so her face structure is a little different, and I think people can notice that and I think oh, they started making comments, things like that. “Why does she look so different?” Her sisters stood up for her and stuff but yeah, I believe we’ve run into a few.

R: Do you think that the fact that you guys were Arab or Muslim also factored into some discrimination you’ve faced in regards to her?

I: The discrimination that I’ve said we’ve faced is in regards with our own community. She has never received or been on the tail end of discrimination outside of our community. So it’s basically our community.

R: Do you think that there is an impact on your daughter or your willingness to go into public or be in public situations because of that?

I: No.

R: How do you think that your community or the Muslim community impacts the way that you deal with her difference?

I: I don’t deal with her differently. I take her into the Muslim community, I don’t really care what people say and everything. She is part of the community and she has every right to go to everywhere and if anyone says anything I will not be quiet. I don’t -- she goes with us to the mosque every time unless she doesn’t want to go.

R: That’s great! Do you think there are certain expectations placed on you from the Muslim community to be a caretaker and to have her with you all the time?

I: Not from the community but just like from our religion and our culture. I would never, as long

as I am able to take care of her, I will never put her in any type of home or facility or anything. And even my two older children say -- you know, I hope to live until 120 but- when something happens to me that, you know, they will take her. That's our culture, our religion. We don't, even like older people, you don't send them to nursing homes. You keep your parents with you, you keep them in your house. That's something our culture basically frowns upon.

R: Yeah. Definitely. So do you have those expectations placed on yourself too -- it's part of your religion but do you set certain expectations for yourself, like, "I am going to provide this and do this to the best of my ability"

I: Yes. I do. As long as I am able to do things, drive her, I don't ask for help from anyone. My children, my older children, anyone, friends, family, anything. If I am unable to do it due to prior commitments or something I will ask people to help me. But I feel the sole responsibility to take her back and forth to her classes, provide her with her medical care, get her what she needs, hospital, you know, doctor visits, tests, whatever needs to be done. My sole responsibility.

R: What do you think would be the biggest challenge you've faced as her caregiver? Do you feel maybe sometimes you're stretched too thin, or you don't have enough support or resources?

I: I think having my other children, the ones that were older than her and the ones that were younger than her, was basically pretty much good support. Maybe I personally would have wanted to do one thing different -- to learn how to manage her tempers and ways of calming her down quickly. She goes from 0-100 very quickly if she gets angry and everything. And over the years I learned how to, but I wish I got more quickly education on how to deal with a child with a disability who loses her temper quickly. I probably would have wanted to get more education on that. But other than that I pretty much feel I had a good support system with my children.

R: That's wonderful. Do you think that it would have been more helpful to have the teachers or

pediatricians or anything to educate you more, or for them to be more educated about what she has?

I: Pediatrician basically really not much. Alopecia doctor pretty [much] was helpful for her alopecia. She did see a psychologist at one point when her younger sister started passing her in school and driver's license, so. And then I sat with that psychologist and she said every time one of her younger siblings reached a milestone that she was never going to reach, that was going to be a difficult time. So seeing that psychologist was good. Teachers were great resources, I think they provide a lot of information, including about when she turned 18 I should take legal guardianship on her. I would have never known that on my own and everything. I do regret some things, like transition meetings that I thought were for people just graduating high school or the 18-21 programs that [were] transitioning into day programs. I was like "oh no, she's not going to that" so I never really attended those meetings. Which, now I understand that those were really good informational [meetings]. So I think that our community really needs to understand those transition meetings that they have or fairs or whatever with all these ADRC that doesn't really come out is not just for disabled individuals to get day programs or stuff that there's a lot of information that you could use. I just presumed, oh, my culture, I'm taking care of her. I don't need any help. But [I] did not realize there was help- financial and things like that, regarding her.

R: Do you think that was because the school- or wherever she was- didn't do as good of a job explaining or advertising?

I: I think they put it out there. They advertise it. But I just looked at it as transition to day programs. And I'm like, oh those are not interesting to me and tossed it. Maybe if they had reached out. I think that maybe some schools with- if they have disabled children or adults that are Muslim, they should maybe reach out to them more and inform them that this is not just

basically for children and adults going into day programs or daycares during the day, things like that. That there's lots of other information and benefits you can obtain.

R: Did you ever consider changing school districts if you didn't feel like you had enough support from the teachers and staff there?

I: I lived in Waukesha, she went to Waukesha until we moved here. All my kids transferred over to Elmbrook. I took her to visit Brookfield Central in 2007. Did not like Brookfield Central at all. [She discussed specific instances of what she didn't like (e.g., special needs children not being mainstreamed, all of them sitting at the same lunch table). In addition, she determined that the special needs teacher did not make accurate judgments regarding her child's special needs and was going to make accommodations that didn't fit any previous IEPs – some recommendations made no sense.] And I had friends that were in the school district of Elmbrook and basically I was told if your child was already in the Waukesha school district, keep her there. Don't bring her to Elmbrook. Our special education, once you hit middle school, starts to deteriorate, and high school is even worse. I didn't like that so that's why I kept my child in Waukesha. The first year she was grandfathered in and I did open enrollment. She stayed for four years of high school and then two years of their 18-21 sale program. So we transported her for six years back and forth.

R: Wow, you're really dedicated.

I: Yeah, for sure.

R: That's amazing. To deal with any of these challenges you've had to go through, are there certain things or strategies that have worked for you?

I: Not really, I just pretty much- it just pretty much played itself you know? Fell into place. I went and picked her up in the afternoon, so it was not hard in getting her places and services and

things like that.

R: Yeah, and I'm sure your family was a good support too, it sounds like they have been super helpful.

I: Definitely.

R: Do you get help for yourself if you ever need support or a break?

I: No.

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

I: Basically my children. I have had a couple of aunts who reach out to her, take her out to a special lunch or things like that. Uncles that like- "Let's go to a movie when you come down to Chicago". They -- her extended family -- aunts, uncles, cousins -- really make her feel just like anybody else.

R: That's great! Have there been any teachers or people in the Muslim community or at the mosque, or other health care providers that have helped or reached out to you?

I: Just the norm.

R: Alright. Do you think there are any challenges that females with a difference of ability or disability could face that are different compared to males with the same disability?

I: I mean, I really don't know how to answer that one.

R: Yeah, that's alright. I guess what we are wondering is do you think that females or males have a difference in the support they get, or chances for employment, or are less marriage?

I: I believe the women that have special needs or disabilities are unmarriageable for sure.

R: Do you think there's any support or help that could be offered or changes in attitude that are needed based on that?

I: More education; just keep on educating people that they're like you, just a little different. You

shouldn't treat them any different things like that. Just as you wouldn't treat anyone any different because of their color, race, sex, or religion or stuff. They are humans too. Whether they are severely handicapped, physical, or just mildly.

R: Definitely. Is there anything you would want schools or healthcare providers to know, or anyone in the mainstream community that would be more useful for you or to give others better help in the future?

I: I think just, you know, I think that healthcare providers and teachers and you know that work with special needs, maybe educate them more because there are more and more kids being diagnosed with Autism and things like that and they're Muslim- to maybe have them educated about the religion of Islam and how our values are different regarding transitioning into daycares and adult care facilities and things like that. We don't look, you know we frown upon it, unless it's severe then maybe you know then you'd put them, but I think as long as I am able to handle her I want to keep my child with me.

R: I definitely think that people knowing that would be helpful. And do you think maybe giving better education instead on how to continue better care in the home possibly?

I: Yeah.

R: Is there anything else you can think of that could be helpful to me or the community.

I: Nope, I think that's pretty much it.

R: Ok great! Do you have anyone else besides your daughters who are in a similar situation and would want to be a part of this research?

I: No not really.

R: Alright, that's totally fine. Thank you so much!