

Interviewer: Allie Volcheck, AV09)

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Year of Birth: 1983

Gender: Female

Country of Origin: American-Palestinian

Year of Immigration: N/A

Abstract:

This American-Palestinian mother cares for her two children, a daughter and son, who are both diagnosed with Autism Spectrum Disorder. She shared a lot of her personal experiences of raising children with disabilities within the Muslim community. She was happy that she is beginning to see positive change and acceptance towards individuals with disabilities within the Muslim community but believes there is a lot more room to grow and offers some ideas on future changes. She also provides insight on what it is like raising a female Muslim daughter with a disability in comparison to raising a son with a disability.

Key Themes: Autism Spectrum Disorder, cultural stigma, Muslim community, females with disabilities, Parenting

I: So now we are recording, okay so do you just want to start with your name, your age, and then where you were born?

R: My name is *****, 36 years old and I was born in Milwaukee, Wisconsin.

I: Okay, so how do you identify yourself in terms of national background?

R: uhm, I identify myself as Palestinian-American

I: Okay, and what's the highest level of education that you have completed?

R: 4 years bachelors

I: Okay, and where did you complete it?

R: uh Northeastern Illinois University

I: Okay, and what is your marital status?

R: Married.

I: So you, do you just have two children?

R: Just the two

I: and then one boy and one girl?

R: Correct.

I: And you said you worked outside the home?

R: I do.

I: Okay, could you tell me about your position and how many hours you work?

R: So I am actually work at, actually the name has changed now ***** and I'm actually a supervisor of a histocompatibility lab which is also known a transplantation lab. We do testing to support transplantation uhm whether its organ transplantation or bone marrow transplantation. Currently I work outside of the home roughly I would say 30, 30 to 32 hours per week and then the remaining hours, I would say 10 to 15 at home. So part of my time is working from home but most of my time is actually in the lab.

I: Okay that's awesome! Uhm so the next set of questions, you can look at that too, we are going to focus on the types of differences of abilities uhm for people you provide care for. So, we are especially interested in types of uh abilities that are listed there.

R: Sure

I: Just physical, chronic illness, learning, intellectual, mental health and speech language. So we have a better understanding of your role as a caregiver. If you could just identify the types of differences of abilities for people you provide care for.

R: So I actually have two children uhm both with autism diagnoses, so autism spectrum disorder and both at different levels of intellect from a disability standpoint. So my daughter that is 11 , soon to be 11 years old, has is what I would classify as uhm an intellectual disability, uhm so it's difficult to categorize so as best as I can I would say intellectual. Uhm and then with my son he's a little more far advance we would say right now that there are only some real minor delays but everything else is, we wouldn't classify it as a disability.

I: Okay, uhm and what is the living arrangement with you children with disabilities? Are they here full-time, or...

R: They are here full-time, they live with both parents

I: okay, (laughs)

R: That's my daughter very curious.

I: Uhm do you think there are any factors that might have led to the physical or mental conditions that your children experience?

R: Uhm no I think that is an interesting thing, its almost like a pandoras box. So no really you could go down the path of what causes it was either environmental factors, genetic factors, I think what we know right now sciences don't really know exactly what causes it we just know

it's a combination of genetic and environmental factors that could have contributed to that disability with autism spectrum disorder.

I: Definitely and do you think that your family's identity of being Arab or Muslim has influenced these conditions in any way?

R: I don't believe so since it's number are prevalent across ya know the country and I believe the last number I heard was 1 in 56 are affected.

I: Mhm. And have there been any health or medical conditions that have been cause or you think have been caused coming from these differences of abilities?

R: Yeah know what's interesting is uh you go back and look at whether there was anything that happened during pregnancy , there's all these different theories of a potential cold or flu during pregnancy that could cause autism or potential vaccinations uhm and the truth is that we just don't know. Both children were normal pregnancies uhm although *** (daughter) was born with the umbilical cord wrapped around her neck, we don't know if it was that brief moment that lack of oxygen uhm and with my son no complications at all.

I: Okay and then during their childhood has there been significant health or medical conditions that you've noticed.

R: I , uhm, nothing related to the disability. Seeing my 8- year old son is definitely what we call our x-ray boy lots of broken bones or foreign objects swallowed over the years. But nothing related to the disability though.

I:Okay. Uhm what are the biggest challenges you face as a caregiver?

R: I think what people don't realize is uhm life is that it's completely different when you have a family member with a disability what I say quote, unquote normal things of going to a restaurant, or going to the grocery store or taking vacation isn't necessarily possible all the time. Uhm so

everything is very calculated, and we like to stick to routine, uhm we stick to routine as much as possible. So going just randomly to go meet friends at a restaurant in a large group and just wait 20-30 minutes for your food is just not gonna happen for our family.

I: Yeah, uhm are there any other financial barriers or problems you've had or feelings of lack of support from your community members or your friends?

R: Uhm we've been very very fortunate with yeah know being able to uhm be able, sorry I apologize that cat thinks this is her territory and she UNINTELLIGIBLE it all up. We've been very fortunate with having yeah know the financial means to support our children now that being said there are also limitation with what services you get out there which is completely separate from community resources. So like I said we've been fortunate with being able to financially provide for our kids.

I: Uhm and you said that you stick to a routine and that was a good strategy for you guys are there anything else you use as kind of a strategy for...

R: We use a lot of uhm visual aids to help as much to prepare or to understand what is going to happen. Uhm and when people say visual aids, well what do you mean so it could be taking a picture of a place we are going to go and kind of talk about a new place that were going. Uh we sometimes do social stories or watch videos of certain things and say this is what we are going to do uhm just to help to prepare mentally its just a different way of talking to you kids like hey were going somewhere new and how exciting. There needs to be some mental preparation of going to a new place.

I: Yeah, definitely. Uhm from what, besides you family, where do you get support or help either the community or different healthcare providers, counselors or things such as that?

R: Well we've been again very very fortunate, uh over the years we've gotten support from our schools. Uhm our daughter who is 11 like I mentioned is more severe on the spectrum and she is nonverbal, so we worked with the school's speech therapist to really work on methods of communication and ways of being able to communicate. Now when our kids were younger, we also received support from ABA agencies which is applied behavior therapy which really helped manage the day to day behaviors, the understanding change, sitting down for a task, those types of things. At a certain point they outgrow those uhm and only recently has our Muslim community uhm embarked on this initiative of embracing special needs and individuals with disabilities. So this is relatively new from a Muslim community aspect.

I: Mhmm. Would you tell me more about what it was like before and after you realized there was a greater acceptance by the Muslim community?

R: I think what, what is historically known in the Muslim community is and it's not necessarily uhm religion it's more cultural aspect there is a stigma about people with disabilities and uhm...
Sorry

I: It's okay

R: (Steps away to care for child). I apologize, so like I said there is this more cultural stigma associated with disability of this, I don't know why, this uhm almost shame of it will injure your risk of anyone in your family getting married or the fear that the disability might be inheritable by your future generation . Uhm when we look at the religion itself, and any religion, talks about embracing these special individuals with needs so I think the biggest challenge has been has only recently been seen really of teasing out these cultural stigmas and what actually should be followed is the religion and the acceptance uhm and the ability to accommodate those with special needs.

I: Uhm and what do you think brought the change and this kind of shift and more acceptance was it more of a community effort or was there any kind of leadership that you noticed?

R: So what's interesting is there are a couple of new leaders uhm in the United States, uhm Muslim scholars, that are well known in the community and it just happened that one of them said hey I realized that there is this huge gap in our community and he started this organization called MUHSEN which is Muslim Understanding and Helping Special Education Needs. So it was founded by uhm a scholar of ****Unintelligible 11:23**** he founded this organization and then the organization really took off and was directed by really families with special needs who said yes we need this I can help carry this through. So it took the voice of one known scholar in the community to say hey we should do this that we see this initiative that embracing across the U.S. for Muslims with special needs.

I: Yeah, that's really cool. Uhm do you know if your children have experienced discrimination or any type of different treatment based on the condition that they have?

R: Uhm I think that it is difficult for my kids to really understand if someone insulted them unless it's so black and white and I think that's the beauty of autism is everything is black and white and you're oblivious to some of the judgements or things that come about from peers or elders from a discrimination aspect. We felt it, I'm not gonna lie, I think especially in today's world of ******* 12:40** in this world of Trump where you're discriminated against for being a minority, you're discriminated against for being a woman, you're discriminated against for being a Muslim unfortunately that's all three strikes for my daughter. Uhm so it's something that is definitely on the forefront of our minds.

I: Yeah, uhm have you had any besides the ** support you've gotten from your Muslim community and the support you've been able to get from different behavioral programs is there any other examples of positive experiences you've gotten from your friends, or co-workers, or..

R: I think what's interesting is, so I mentioned I wok in a laboratory, and uhm yeah know most of the work we do in the laboratory requires full-time work for you to be there at minimum 40 hours per week and uhm as soon as we found out our daughter was diagnosed with and that we will need to have 30 plus hours of in-home therapy I uhm quickly went back and said I just can't work anymore I need to be there for my child uhm and luckily they were so supportive and they said we will make whatever schedule work we are here to support you and your family here and uhm they really made it work from a scheduling aspect. Uhm the other bit of advice that I think the best thing anyone has ever said to me cause after a diagnosis you go through all these different emotions of denial and grieve, and wonder did I do something wrong did I purposely have something happen uh yeah know a trauma or something that could've contributed to this? Is I work with a research scientist and when he found out that both of my kids had autism diagnosis he came up to him, and I barley know him, he said uhm I stayed up all night and I researched why he said and I tried my best to give you an answer to why your children have autism and he said I couldn't no matter how much I tried , cause that's my job is to really find the problem, diagnosis it, to come up with a solution, I couldn't find the answer to why. He was like there are so many separate theories out there, there is the rainy day theory, there's this theory and that and he said sorry I couldn't give you an answer. To me that was really uhm emotional and helpful from a support aspect even someone just understanding that this is what I do and I'm sorry I can't help you was really uh very meaningful for me.

I: Wow, thank you for sharing that experience. Uhm I guess what additional support or mindset, or just changes in attitudes do you think would be most beneficial not only for your situation but just for everyone who is either a caregiver or struggling with a difference of ability?

R: I think there is a two fold to that I think you have individuals that just really have never interacted with anybody with a disability and just don't know how so you'll see them hesitant to interact with anyone with a disability uhm and the bit of advice there is ask, ask what works, what doesn't and don't shy away from being able to interact with someone with special needs because you'll learn there's something quite amazing and pure about it. Uhm then the other fold is (coughs) is individuals who think, who have this precursor of what disability is uhm and have this mindset of well if there is special accommodations given to them I don't understand what the problem is they have all these available tools and it's so easy. Yeah know I kind of say to them I don't want a pity party but if there is no entitlement with someone with a disability and understanding that these accommodations I I would love to not have I would give anything not to have accommodations but that's just given the situation we have.

I: Yeah, definitely. Uhm so the next set of questions are on the perception of different disabilities and expectations of caregivers. Uhm so for your experience do you think that the Muslim community has any expectations of you as a caregiver? Or do you feel any kind of pressure?

R: Yeah know, I think when we've looked at this backwards mentality of this cultural stigma with disabilities uhm you could by that when you have parents bringing their children, or their individuals or their loved ones to community events uhm that there is this expectation of why did you bring them there, wow you should stay at home uhm so it could be a negative expectation of when you are in the community which can make some caregivers feel unwanted and as hard as it is for individuals to get out to a community event shy away from continuing to do that. So and I

from the local community wish that I could say that there were these awesome expectations expected from me but because its so new and so uh this idea of special needs and what it is at this stage I feel like it's just a lot of people that are in the category of they just don't know. So they just don't know what is detailed or expected when it comes to special needs families

I: Yeah, definitely. Uhm as a Muslim what are your expectations of yourself being a caregiver of a person with a disability?

R: So, you know now that you have asked this question I take back and want to kind of comment on the previous question.

I: Yeah, definitely.

R: Yeah know we mentioned that uh that in Muslims there's this, in the Muslim community especially for females theirs expected behavior to have women be modest, dress modestly we either it's by close or covering your hair with a hijab or scarf uhm I think as a daughter with a disability I think some expectations are for me are for my daughter to dress modestly, it's my responsibility as a parent to make sure she dresses modestly. So that being said, I have expectations for myself as far as a Muslim parent to is I hope that I raised my kids to be safe, secure, and give them all the tools to succeed as far as they can in life. Now, I would love for them to learn religion and be good Muslim examples, absolutely! But I understand, fully realize that that might not be the case and that's okay and I think that's hard for people to understand, as my daughter is older she may not dress modestly, she may not cover her hair and in the religion it clearly states that it's okay there's a cognitive disability there isn't this conscious choice of her purposely not covering up she just doesn't know. Uh so we will do our best but ultimately know that although there are these traditional Muslim expectations of the parents to how you raise your

kid raise law abiding citizens that we realize that we know there are certain things in the religion that might not be followed because of their cognitive disability.

I: Yeah, definitely. Uhm so you've already kind of answered this but if you want to say anything else on how the Muslim community perceives people having physical or intellectual disabilities or mental illness, besides you said that there's lack of understanding and knowledge that have been present?

R: I agree that with that it's definitely lack of knowledge and understanding. I still am trying to understand it myself of what is it to have all these precursors or these opinions about disabilities is it population genetics where their worried it might weaken their genetic pool of their potential offspring in the future, uhm I don't know. But then again there's this flip side that yea know without anyone in the family hasn't traditionally had a medical condition, that's usually kept very secretive and hush hush because you don't want to worry people. So I don't know if it's because of not worrying people or if it's because of shame or if it's because of preserving the family name, uhm not quite sure what it is because if I did know then I could hopefully pass to you...

I: Yeah

R: Providing that knowledge and education for you of that secret piece that's missing. Uhm yeah it's a mystery to me.

I: Do you – have you ever felt the need maybe when meeting a knew person in the Muslim community or speaking to someone about kind of wanting to, like you said, keep things more secretive or do you think other people struggle with that often?

R: Have I met other people, sorry? I don't know how to answer, sorry.

I: Yeah.

R: Other people that feel like it needs to be hush hush?

I: Yeah.

R: Uhm, 95 percent of the people I meet with a family member with disabilities wants to keep it hush hush. I have a lot of people approach me because we are so open, we don't hide as much as people say oh your so hidden that's because change is hard.

I: Yeah.

R: Not because we are hiding. But because were open about our-our situation and being caregivers of especially our daughter with disability uh we have a lot of people approach us and say oh my gosh I have a family member with this or my daughter or my son has this but I don't want anyone to know. And yeah know I think we've struggled a little bit like to understand both sides of it's hard to explain to the children themselves depending on the type of disability of really understanding, comprehending what's all entailed or all what that means. So our son has autism spectrum disorder, we really haven't had a talk with him yet, like hey you have autism not that it's secretive because he over-reacts to everything and it's not hindering his daily life. So it could be a talk that we have one day but that for the time being it's like again he thinks black and white he thinks autism is what his sister is and he's not what his sister is so it could be age, that level of understanding once he's a little bit older to have that conversation but 95 percent of the people I meet in the community do not disclose that not for the perspective that their child doesn't understand, cause they don't want other people to know cause they think that their child with a disability or family member with the disability will outgrow it and no one will ever know. That they will never have that label attached to them, whatever that label is.

I: Yeah, definitely. How do you think that the Muslim community perceives the disabilities of your children specifically, especially with you guys being very open and honest?

R: I think uhm again, uh you have a two folded perspective from people I think on one side people that kind of have some knowledge of disability think uhm that I'm some kind of awesome supermom, I really am not.

I: You seem like one to me (both laugh).

R: But on the flip side it's -it's what why doesn't you child do this, uhm so you know it's a double sided perspective of for certain people it's like oh my gosh you do so much, other people it's like what have you don't to delay your child. Why haven't you given them opportunity to advance?

I: Yeah.

R: It happens all the time (Both laugh).

I: Uhm, do you think that your community's perception has impacted how you and your husband decided to provide care for your children?

R: Uhm I'll be honest, it's not because we've wanted to by any means I just think it's just the nature of character, and children, it's kind of like all hands-on deck. But in the past, I don't think we have mingled to much at community events or let that affect how we raise our children. Really, we focus on what our children need and it might not, yeah now if it's not going to community events at 8 pm at night because our children go to bed at 7 pm then we make that decision. Uhm, but I don't think it's impacted, we kind of try to shield that out.

I: Yeah.

R: And avoid that noise so that it doesn't distract us from of our goal of raising our kids.

I: Definitely, uhm very understandable. Uhm so you had kind of mentioned this before but uhm do you think- what do you think the specific challenges are that distinguish a female having a disability compared to a male with disabilities?

R: I think it's huge! Uhm so, if I look at again traditional cultural aspects and teasing out the religion aspect, the cultural aspect is yea know uh a female gets- if she's a great girl and does all the right things, a prince will come ask for her hand in marriage and she'll live this happy life and that's all that parents wish for their daughters is to have a loving home and a secure husband and yes that was long long ago. Uhm and then on the side of the religion aspect so that might not be the case for someone with a disability especially from a female aspect of getting appropriate suitors.

I: Mhm.

R: From a religious aspect there's this expectation of yeah know that clearly states that women must dress modestly, talk modestly, uh interact modestly uhm and that is completely thrown out the window when you have no social yeah know, no social awareness. With a disability that you have so when my daughter come home and changes into really tight boy shorts uhm it's like we have yea know that's frowned upon because it's not modest. Uhm, if we go to the mosque where it's required to cover up, not-more by the people attending then the actual religious officials at the mosque. You get a glare though, what are you doing uhm that your female daughter isn't covered. Uh I think again as it being more and more accepted in the religion, Muslim official are like thank you for even being here.

I: Mhmm.

R: Uhm, so as a female I think there are more expectations as a female and when you don't have that- that bar is raised so high for a female and your not able to perform to that standard that's when you get frowned upon more then a male Uhm it's yea know

I: Mhm, diffidently.

R: It's known that females have to fight more, harder to get yeah know the to get honored and respected the integrity that they seek for and it's not always the case for females with disabilities.

I: Yeah, it just makes everything for heightened. Uhm so what are some things that healthcare providers, schools, and just the community itself- uhm like what are- if someone were to ask you one thing I should know? Or what are some very fundamental basic things I should know to be most supportive to your family and all families with children with disabilities?

R: Uhm I think when you look at disabilities, no matter what category or type of disability ultimately, we forget that that's a person and we label them with a disability. So when we talk about this label uhm that's the stigma that were trying to break through that it's a person that has this disability it's not a disability of the person and speaking to the person in the first person context when speaking about them. And that because my child- if I could say there was one thing that I could scream about from the top of my lungs is because my child is non-verbal does not mean she doesn't understand, so please don't talk about her when she's in a room talk to her and she might not respond but she absolutely understands what's happening and she's just like any other 11 year old girl.

I: Mhm.

R: And people forget!

I: Yeah.

R: Yeah. So that's the one message I would say that they're-they're still people so with my daughter's level of disability she still understands and what I've seen with people with physical disabilities, although we haven't experienced it ourselves there's so much they can do for themselves that they're not completely helpless.

I: Yeah, definitely thank you for that. Uhm so that was the end of all the formal questions is there anything else you would like to say about your experience or just like anything really

R: Uhm so one thing I will say is, that we haven't talked to much about we talked about the Muslim community and some of the obstacles with just being included in the community but I think what people don't realize is even though you might think you have the financial means to support your kid a lot of insurance doesn't cover a quarter of the services that entail for some of the items needed for those with disabilities whether it be physical therapy, occupational therapy, speech therapy so families are constantly thriving to find resources to support their kid. So just because someone is not present at a community event it might be because they are so occupied with trying to find resources or when they do find resources, driving them to therapy, other families might be busy with sports and hustle after school for us it's therapy.

I: Mhm.

R: Uhm, although right now were kind of at this standstill in between therapies uhm because every- even if you find a resource that has services that you need for your child there's always a waitlist. So that's one thing that if you don't care for family with special needs it could not mean that you don't want to reach out it could be that your so occupied with finding what they need for their family at that time.

I: Mhmm., definitely. Uhm thank you for telling me that. So uh that is the end of all our interview questions

