

Interviewer/Number of Interview: EG23

Date: July 29, 2019

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

Year of Birth: 1960's

Gender: Female

Country of Origin: England

Year of Immigration: 2014

**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, slightly modified, or made more general. Summarized information is put in brackets.

**Abstract:**

The respondent is a Pakistani woman who was born in England and moved to the United States in 2014. She suffers from schizophrenia and depression. Several years ago she had physical disabilities such as leg and arm shakes, and learning disabilities and the sudden loss of speech and memory. In the interview, she discusses how she overcame some of her speech, memory, and learning disabilities and how she is trying to treat her other conditions as well. She discussed how her many conditions have impacted her family, her life, and her financial situation. She also discusses her life in America and her interactions and involvement within the Muslim community.

**Key Themes:**

Mental health, depression, schizophrenia, family, relationships, very helpful Muslim community, women's financial dependence on men, power imbalance in marriage, faith, self-motivation and personal strength to heal, and isolation regarding her mental condition. Transportation is a challenge.

I: What is your date and place of birth?

R: [Born in 1960s in England]

I: Okay, and when did you move to the United States?

R: In 2014

I: Okay, and were there any specific reasons for your move?

R: Financial problems and some harassment problems on the streets, which made me move to the U.S. where my husband has some businesses.

I: Okay, Great. Um...How do you identify yourself in terms of your national background?

R: Um. Pakistani

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

R: I graduated from university with a bachelor's degree.

I: Okay, Great. And what is your current marital status?

R: Married. [She and her husband separated before they moved to the U.S.]

I: Okay. And do you have any children?

R: [Has several male and female children; the youngest is a teenager and the oldest is in late 20s]

I: Okay, and do you currently work outside the home?

R: No.

I: Okay. Let's leave that and so the next set of questions focus on the types of different abilities that you or the person you care for has. We are interested in learning about the following types of differences of abilities and I have a little chart here to help us out. So, we have physical, chronic illness, learning, intellectual, mental health, speech and language, and addiction. Um, so first off I'll ask is the disability one that you have or someone you care for?

R: I have a disability. I'm suffering from schizophrenia and have shakes in my body. For example, loss of memory, and hard to recall dates, things, and places. [About 4 years ago I started to have speech and language problems; I stuttered and then couldn't talk at all. For 4 months I did exercises and speech therapy for myself at home. That helped me get some cure and some healing where the speaking disability was. By the will of God it went away. And, with a lot of willpower, I kept practicing at home.]

I: Okay, um let's see. And um what is your current living arrangement? Do you live with family?

R: Some of my children and I live together. My husband lives in a different house.

I: Okay gotcha. Um and what would you say the timeline of your diagnosis would be for your disability?

R: [A few months before we moved to the U.S., I had the beginning of the symptoms. It seemed that people were watching me and intentionally doing small things to me. Within several months of moving to the U.S., I started having more severe symptoms, such as hearing voices, feeling burning in my body. But luckily, after four or so years, it has improved. During that healing time, I was very much into my prayers, meditations, artwork, and my spirituality. I also started taking medications, which helped a great deal. I saw a psychologist who gave me the medications and

had regular visits to the doctor. I also started to socialize and open up to others more. I just kept pushing myself hard to get better.]

I: Um. What factors do you think might have contributed to your difference of ability?

R: [It could be depression and sadness about my marriage and basically raising our children on my own, which was overwhelming.]

I: Okay. And did you ever attend any therapy sessions of any sort?

R: No

I: So the next set of questions focus on perceptions about people with difference of abilities and experiences of prejudice or discrimination. So the question is, Compared to the broader US society, how do you think the Muslim community perceives differences of abilities that are very visible? For example, wheelchair something which is very visible upon first meeting.

R: Um I see American people actually very friendly actually, very kind and friendly, very happy people. They are like very welcoming. They greet you on the streets and um talk about weather and um morning greetings and everything. I don't see that they discriminate or take you strangely if you are disabled, crippled, or sick or something. [My neighbors were very good and I was grateful for their kindness. I responded by giving them small gifts.] So I thought that the people were very nice. And I also found one more thing, that people are comparatively more educated here than in the rest of the world.

I: And in relation to um your experience here with the Muslim community how would do you feel they were welcoming to you? Do you...

R: The Muslim community is very nice here, very kind, very helpful. But in England in the late 1990s, it used to be different. I was probably more healthy. I felt more happy among all of them. Whoever I invited, they just all came over and had big meetings and gatherings and assemblies. Since I came back, this time I see a big different now. Um, people are more religious in England, compared to Americans, American Muslims. I feel that little bit of change. But I am not sure about it because I don't go to the mosque regularly, and I haven't indulged myself in the community meetings and gatherings. [Transportation is a challenge.] So I am not very sure how it is here. But in England it is a very strong Muslim community and Europe a very strong Muslim community.

I: Okay and how would you say that the uh Muslim individuals, whether here or in England accept people with differences of ability?

R: Um, they are very fine, very kind. I don't see any discrimination at all. No

I: Okay good. Have you ever experienced any prejudice, negative remarks, or discrimination because of your difference of ability?

R: No

I: Given your experiences from the communities' perception, is there any impact on your willingness to participate in public and community events?

R: Yes. Um, I do go and see everyone, but I am reluctant to make a speech or reluctant to stand up and express myself because I feel that there is a disability there now in my speech level so. Um I just sit down and listen and take notes. I rather listen and learn something rather than to lead something.

I: Okay. In England were you more of a leader within your community?

R: Yes, I was

I: Okay gotcha. Um...hmm. Do you ever not go to certain events because there is more of a social aspect? So if there was more of a mixer, let's say where you uh ...a networking event, would you not be as willing to go because there is that social aspect to it or would you still be willing to go?

R: No No No. I am willing to go everywhere. Because I am a very social person. And I like to see everyone. I always like to be a little at the back now rather than the front because of my disability.

I: Okay. How do you think the communities' perception impacts the way you deal with your difference of ability?

R: Sorry, I didn't get the question.

I: So, does the community's perception impact the way you deal with your difference of ability? Like some other people have shared that the Muslim community isn't very in much support of um seeing a therapist so that you're not as willing to go see a therapist. Have you experienced anything like that?

R: No, No, I haven't.

I: Okay gotcha. Okay um. Okay so the next group of questions focuses on challenges that you face dealing with the issues we've been discussing so far. How have you dealt with them? And what is needed to make life better for caregivers and individuals with differences of abilities. So um, the big question here is what are the biggest challenges you've faced as a person with a difference of ability and then we can go through different categorizes here. So one category is being stretched too thin. Do you ever feel that is a challenge for you?

R: Uh ...yeah, I need a lot of support from my family and from especially offices like these. Like in the Islamic resource center and other benefit offices. I need support from there so I can function again well into society and community again. Uh because um I feel that you know from home there was not much support. And uh then I came here and I found I was looking at some flyers about domestic violence and about support and help for deprived women, you know restricted women who are restricted on their rights and everything. And I didn't know this I didn't exactly know where I am but when I went into the office here and I started looking at the

papers here and there at the front entrance, I found I was at the right place. And this is a woman coalition here woman union here who help and support women. So um, the support is great.

I: Awesome. I'm glad you found that here. Um, do you feel like you have any challenges with insufficient resources, information, or quality of care?

R: No. Everything is fine.

I: Um, and have you experienced challenges financially or work wise?

R: Yeah. In the past I didn't have [financial problems because I worked. But now I do. I do have insurance through my husband but he isn't very happy about it; I'm applying for Medicaid].

I: Hopefully that is headed in right direction. Um emotionally have you noticed any challenges, um I know you mentioned depression earlier, but depression, feelings of hopelessness, that aspect?

R: Yes, some. [I went through a lot of depression the last four years but I'm better now. But the Islamic Resource Center is a place where you can find all the links and contacts to the relevant offices.] So alhamd lilah (Praise be to god in Arabic), I have some help and some support.

I: [Where else do you get support – family?]

R: [Not much from my children; we don't discuss it much. They see me as someone who is sick. I don't get support from my extended family, either.] [I've learned from people's responses to me that] it's better to keep it in silence than telling every person on the street and every other person in the family and friends and community what is going on. We have to select people now. We have to be very specific who you want to explain the situation of your personal disability and weakness.

I: Do you feel like you need to be more maybe closed off with the Muslim community versus general American society or do feel equally keeping that personal?

R: Yeah. Equally.

I: Okay Gotcha. So to deal with the challenges that we just discussed, what are some strategies that you have used that work for you to overcome these challenges?

R: Taking one thing at a time. I'm really focused now. In the beginning, I was really depending on my husband a lot. Whatever he said I did because I was totally financially dependent on him. The house, the property, the car all belongs to him. As soon as I took a stand, first of all he took the car keys away from me and I'm not allowed to drive anymore. Now, I just write down what I have to work on first of all. Do I have to work on my medical assistance or benefits? Do I have to work on uh um on my finical problems, my social life, I take one thing at a time and really focus on that thing and then I work on that and I see improvements. I see the support and improvements now.

I: Okay. Good. From whom and where do you get help? You said the IRC has been a big help. It sounds like you have a good doctor as well. Anyone else?

R: I went to the benefit offices also and there was a lot of help from there. They are very kind people very like uh they were like explaining everything, how the system works. And this office has been the most helpful, and all the offices connected from this office. And then I try to meet some friends also. Um who did I really found helpful? There were like 2 people who were really really supportive. I found them in the community center of Islam, and I took their numbers and they brought in their cars here and there and different places. They were quite helpful.

I: Aw. Good. I'm glad you got connected with them. What about experiences with doctors or healthcare providers?

R: Yeah. It was all positive. Very important for me to find the best medical attention out there, to get the best doctor out there. And before I was independent, my husband was making all the discussions. He was choosing the doctors, nurses, and everything. I came forward and said No I want to change my doctor. It was difficult because he was not agreeing with it, but I said No. I would like to experience another doctor where they have the say about my medical conditions, my physical condition. So I Started taking more interest in this way. And it is quite important for me to go to the doctor regularly. I like to see some specialist especially. Which they are quite expensive, I know that. But once I have a Medicare card that might open doors for me to get to any doctors or any specialist or any center I would like to go.

I: Um ok. What, if any, challenges that females with differences of abilities face in life compared to males with a difference of abilities?

R: Uh. The biggest problem a woman faces is uh the financial thing. Besides having a good educational background, if you don't apply your education to the work field, so suddenly if you are sick, it is a setback. You don't know how to support yourself. So, you are very much dependent on people around you. If you have work experience, have some savings you are financially strong, it is easy for you to act upon anything you believe in. Because you see, I want to work on this thing and I believe in this thing, this has to be done this way, not the other way which people are showing me. You have your own way of going, your own way of setting things right. So, financially you have to be very strong to take this step. That's why I say the difference between men and women, I only see, I see very bright and intelligent women out there. But only what I see financially, if these women are strong they are able to work on a project. They can work on something that they believe in. If there is a financial problem, men intend to work on this as the very first thing. Where I came from, in Pakistan, women over there are much depend on men so they really face this challenge in life.

I: Hmm... Gotcha. Do you feel like um marriage ability could be a potential difference for men versus women with disabilities? If a young woman had a disability, is she more or less likely to get married than a man with the same disability?

R: Um. It depends on what she thinks about herself. If she thinks she needs more education, she can work in the society as a single person. It's all about... people vary to vary. It's all about differences in people. Um, there are people out there with a need to marry, some don't need to marry. They have other things to do in life. They have other goals, and uh other ambitions and uh things to accomplish. So, it depends on who the person is. Even if they are sick, they might find

help and get cured or find a reduction in their illness and sickness through medication and everything. But marriage is a totally different issue. It totally depends on if you would like to do it more not. Some people marriage at a very young age and some marry at an older age. Um, it depends on the person and what they really want to do in life.

I: Gotcha. Okay, thank you for sharing that. What addition support, help, or change of attitude are needed in the Muslim community regarding disability?

R: I'm not sure about America because I have not been here for a very long time.

I: Gotcha. Um... If you could um like educate others about um disabilities, what would you want them to know? So that they can be helpful and responsive?

R: What I will say is, no matter how severe the disability is or no matter how less it is, you shouldn't give up. You should really work hard to get better. You should find every possible way to get up on your two feet again. If you have fallen, if you are like weakened, you have to get up and face it, you know. You can do it, you can find help. There are good people out there. They are very supportive and educated. There are ways to get better. I believe in that.

I: Um... what are things help care providers should know when providing care for a Muslim individual? So that they can be culturally aware.

R: A health care provider.... Hm... Health care providers are basically, the medical and the nursing field and medical field are very kind and a very compassionate field. Those people are truly dedicated to this field and are so much into human care and care compassionate. [I received a lot of compassion, care and information from nurses and other medical care providers.]

I: Is there anything else you would like to share as we wrap up this interview?

R: Um... in the beginning I was trying to tell myself it was not fair on my part. Then later on, this is a world and I've seen so many people and situations. I cannot disagree with situations as to why I am in that situation. I will say this is my part of the burden in this world. I have to face this and I have to be thankful to God that it was not something I couldn't handle. I have to face this and it's ok \*laughs\*.

I: Yup. Just keep using your strength.