



**Interview with Providers:**  
**Gendered Differences of Abilities and U.S. Muslims**  
*Arab and Muslim Women's Research and Resource Institute*

Interviewer/Number of Interview: PEG1

Date of Interview: 12/16/19

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

Nature of the Organization that Employs the Respondent: The organization works with Mosques nationally and internationally to make them accessible to individuals with disabilities. The organization also has an established volunteer respite program that pairs volunteer respite workers with individuals and families that need extra support. Additional services are provided:

- Certification program for Mosques
- Weekend school classes, which are being held in 12 programs nation wide
- Care givers and sibling support
- Prayer accommodations so family can attend
- Respite program online- training
- Quran that is in braille
- Connect people with interpreters
- Major conventions
- Special education services and care

**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. Summarized information is put in brackets.

I: Thank you for agreeing to be interviewed for this project and for completing the consent form.

## **Demographic/Background Information**

I: What services do you provide to Muslims with ability differences (or their caregivers)? What is your role with this population?

R: Respondent works with Masjids nationally and internationally through the certification process. There are different checklists of things a Masjid must complete to earn the different levels of certification. This includes accessible bathrooms, caregiver support, ALS interpreters, weekend school programs, etc. Additionally, respondent organizes programs, helps to establish training programs for respite care volunteers and does speaking events to raise awareness.

I: How long have you been working with this organization?

R: 2 years, and was a volunteer for them 2 years before that.

I: With whom do you work – Muslims with ability differences, their caregivers, or both?

R: Both

I: What is your position title?

R: Project Coordinator.

## **The next question focuses on the Muslims with ability differences (or their caregivers) with whom you work or provide services to.**

I: Please explain the types of differences of abilities that the Muslim(s) have.

R: The organization serves all types of differences of abilities through their wide range of programs. The respondent stated that “physical and cognitive are most prominent” differences that they serve. This includes autism, Down syndrome, and cerebral palsy. The organization has a needs assessment on their website, and “autism was number one, Down syndrome was two and general developmental delay was three”. During conventions the most asked for services and volunteer support is for individuals with physical differences that need assistance being ushered around the convention and support and space for sensory issues for individuals with autism. Additionally, the organization has support groups for mental health services.

## **The next set of questions focus on perceptions about people with differences of abilities and experiences of prejudice or discrimination.**

I: Have you observed any prejudice, negative remarks, or discrimination directed towards Muslims with differences of abilities?

R: “There is a stigma in the community, that’s why [our organization] exists... people are ashamed to talk about it, and we definitely see that” states the respondent. When the respondent reaches out to Mosques to explain the benefits of being certified the Imams often say “oh we don’t have people with disabilities in our community”. At the end of the certification process “90% of the Masjids, once they become certified, are amazed by how many people come to the Masjid” seeking out a Masjid that is accessible to them and their family. The respondent states the stigma has gotten better over time, and awareness events are essential to breaking down the stigma. One of the items on the checklist to be certified is that the Masjid must have one event where they talk about the stigma of disabilities, and they must also hold general awareness events. The objective of talking about this stigma is to “change the perception of the general community on how they view people with disabilities”. Additionally, the organization has established youth trainings teach the next generation “how to interact with people with disabilities”.

I: If yes, would you describe an incident of prejudice, negative remarks, or discrimination?

R: The respondent did not have any personal stories but shared a story that sparked the creation of the organization. The mother of a child with autism would bring her to the Masjid. During one service her daughter was vocalizing and another mom moved their child away from her daughter. She also received comment saying that “it’s not obligatory for you to come to the mosque”. As a result of these comments and actions she did not attend the Mosque with her daughter for 10 years, these prejudice actions are what sparked the need for our organization.

I: Why do you think people have these prejudices and negative judgments?

R: It is not just Muslim’s who have prejudices and have negative judgements of individuals with differences of ability. Historically many groups have been prejudice towards this population. The difference is that Muslims have “lagged in progress in accommodating the people” in comparison to other groups. When talking about why our organization exists, the respondent says “Muslims need it..., that void wasn’t being filled in the Muslim community”.

**The next group of questions focus on the challenges that Muslims with ability differences face (or their caregivers face), and your suggestions for addressing their needs.**

I: From your perspective, what are the biggest challenges they face?

R: The biggest challenge is caregiver burnout. The respondent explained how neurotypical children are dependent when they are young but grow to be increasingly independent until they are fully independent. However, individuals with “severe disability never get out of this stage of dependency”. As a result caregiver burnout is a huge challenge. The respondent shares how many caregivers are unable to attend family and community events. Many caregivers during burnout are affected when it comes to mental health, it takes a toll on marriages and can lead to depression and can be severe

without proper support. Additionally, a big challenge is the parents concern of what is going to happen to my child when I die. Some more challenges that she has seen is finances, lack of resources and language barriers for 1<sup>st</sup> generation immigrants.

Here's a list of the biggest challenges:

- Burn out for caregivers
- Unable to attend family events, due to lack of caregivers
- Mental health impact – lack of support- depression , tolls on marriage
- Parents concerns about what will happen when the parents die
- Lack of employment
- Lack of activities
- Financial
- Lack of resources
- Language barriers for 1<sup>st</sup> generation immigrants

I: What additional support, help, or changes in attitudes are needed? What is needed to make things better?

R: The community needs to check-in on each other more, especially on individuals that have a difference of ability and their families. If the “wider community extends a hand it would alleviate a lot”. The community can extend a hand by getting involved in [our organization and other organizations that have respite volunteers, weekend program volunteers, and event volunteers]. “Making them (individuals with differences of ability and their families) feel included and accepted” is something that everyone should aim to do, don't ignore them”.

**The next group of questions focus on the challenges that you face as a person who works with or provides services to Muslims with ability differences (or their caregivers), and your suggestions for improvement.**

I: What are the biggest challenges you face?

R: [The respondent discussed internal organizational challenges.]

I: Is there anything else you want to tell me?

R: Our organizations hopes to continue to expand its chapters, creating more networks, connections and support. They hope to begin a day program for people with disabilities. A long-term goal that our organization has always hoped to accomplish is building a residential facility for Muslim individuals with differences of abilities to live.