



Arab and Muslim Women's Research and Resource Institute

# Al'thr: "The Trace"

June 2020

## Welcome!

The Arab and Muslim Women's Research and Resource Institute (AMWRRRI) and the Milwaukee Muslim Women's Coalition (MMWC) have been partnering with other groups in the Greater Milwaukee area to understand the experiences and needs of Muslims who have differences of ability or who are the caregivers for individuals with differences of ability. Our long-range goals are to reduce the stigma of ability differences, break barriers, and increase access to resources for people with differences of ability. In order to promote social change and set an example in which our religious values align with our behaviors and actions, first we need to understand the needs and experiences of people with differences of ability. For that reason, our definition of difference of ability is intentionally broad. We define it as a condition that affects an individual's ability to do everyday activities related to mobility, communication, work, etc. Conditions include:

- **Mental Health** (e.g., post-traumatic stress disorder, anxiety, depression, bipolar disorder)
- **Intellectual** (e.g., Down syndrome, fetal alcohol syndrome)
- **Physical** (e.g., amputation, stroke, cerebral palsy, deafness, heart conditions, paralysis)
- **Substance Disorder** (e.g., drugs, alcohol)
- **Learning Difference** (e.g., autism, problems with speaking/reading/writing, ADD)
- **Chronic Illness** (e.g., seizures, diabetes, kidney disease, arthritis)
- **Speech and Language** (e.g., voice disorders, stuttering, aphasia, articulation)

Over the past 14 months, we have held focus groups (community discussion circles), created an anonymous survey, and interviewed people (Muslims with differences of ability and their families and caregivers, Imams, community organization leaders, and health care/mental health professionals). Interviews were conducted by trained students and research assistants enrolled at Marquette University.



On February 29, 2020, there was a public event on Muslims with ability differences at ISM West. Shaykh Noman Hussain, the keynote speaker, gave an inspiring presentation on the Islamic perspective of difference of ability and changes our communities must make. Assistant Professor Leeza Ong presented key results from the interviews and surveys; Associate Professor Enaya Othman discussed the newly created website for people to exchange ideas and get information on resources. Other speakers/facilitators included Janan Najeeb, Jeana Abromeit, and highly engaged participants. Similar public events were scheduled in March at ISM Main Center and the MARUF Center for Youth Innovation but were cancelled due to the COVID-19 outbreak. This situation motivated us to create this one-time newsletter.

Also, **Joohi Tahir**, Executive Director and Co-Founder of MUHSEN (Muslims Understanding and Helping Special Education Needs) will be giving an interactive online presentation, **"Power over Pity," on June 7 at 3:00 PM Central Time**. We will also post a recording of her talk on [AMWRRRI](http://AMWRRRI) and MMWC websites.

# Highlights from Survey, Focus Groups and Interviews

The following results are from data that were collected between November 2018 and December 2019.

## Online Survey Results

Forty five people completed the anonymous survey. Most of the respondents are female (79%). The majority are married (70%), have children (89%), are employed (71%), and experienced discrimination (81%). The main three types of ability differences that respondents reported are mental health, physical, and learning differences. The three major external challenges that Muslims with ability differences face include social acceptance (14%), discrimination/ prejudice/ stigma (13%), and finance (10%). Participants indicated that hurtful or ignorant remarks were the most common type of prejudice they encountered (25%), followed by being treated noticeably different from those without an ability difference (21%), and being bullied (13%). The top three biggest internal challenges that related to the difference of ability are stress/anxiety that affects mental health (19%), family stress as a result of a difference of ability (16%), and stress/anxiety that affects physical health (14%). When asked about how the Muslim community perceived differences of ability, the participants pointed out these three main perspectives: Disability is Allah’s will or a test from Allah (23%), it was destined to happen (14%), and the Muslim community relied on folk explanations (11%). On the other hand, when asked how broader U.S. society perceives differences of ability, the participants reported these three top choices: a condition to be treated with sensitivity (31%), as morally neutral (28%), and it was destined to happen (11%).



When investigating the gendered differences of abilities and their challenges, more than half of the participants indicated that females have greater challenges (53%). Their explanations included patriarchal culture, poor marital prospects, less social acceptance, seen as character flaw, less financial independence, fear of being sexually abused, mental health issues being seen as emotional issues, and being expected to serve as a caregiver to the family members. Participants stated these top additional supports and needs: Finding skilled and culturally sensitive healthcare professionals, finding fun activities where individuals with difference of ability are welcome, and finding resources for long-term planning for the future.

## Focus Group and Interview Results

A total of 10 caregivers participated in 3 different focus groups, and 13 caregivers and 2 individuals with difference of ability were interviewed. Most are married (90%), first-generation immigrants (80%), have a family member that is 18 years and older with an ability difference (81%), have associate degree or higher education level (91%), and work full time (64%). The majority of the caregivers provide care to adults (75%) who most commonly have ability differences in the arenas of intellectual, mental health, and autism. The overall analysis of the qualitative data produced several themes, based on the participants’ experiences of being mothers of their children with ability differences. We want to highlight two of them: Challenges and Disparity; and Needs and Wishes.

## Challenges and Disparity

Five subthemes emerged in response to questions about challenges and disparity that the mothers experience while caring for their children: Uncertainty in Caregiving; Limitations in Resources and Knowledge; Accessibility and Inclusivity Issues; and Stigma.

**Uncertainty in Caregiving:** This subtheme includes unpredictability of the child's activities in the public. Participants reported how their life is different caring for a child with disability. With all the participants have more than one child, they shared the trail of juggling between

caring for both children with disability and without disability.

**Limitation in Resources and Knowledge:**

Participants commented on the benefits of having medical insurance but

pointed out the impediments of obtaining the additional resources to meet the child's needs while working full time. They also discussed lack of awareness about resources that might be available.

**Accessibility and Inclusivity Issues:** Participants encounter accessibility and inclusivity issues while caring for their children. It involves inflexibility in the religion system, such as mosques. One mother described her experience:

*Taking him to the mosque was a challenge. When he was younger it was okay but aside from not being able to sit right, but then the older he got, I couldn't take him to the women's section anymore ... I couldn't even see him in the men's section ... it was just extremely difficult to be able to be there with him.*

**Stigma:** Lastly, within the Muslim community, participants shared their experiences of discrimination, prejudice and stigma. For example, they discussed ill-informed beliefs that affect a young adult's marital prospects, including the fear that having an ability difference contaminates the family gene pool for the next generation. Discrimination, prejudice, and stigma ultimately lead to shame and secrecy. One interviewee explained:

*I really don't want anyone to know about my daughter. I was not happy at all to learn that she [shared it] ...For me, I don't want anybody to know. ... This is part of our culture and we are very sensitive to these illnesses, it's*

*more than physical. If it's physical like being diabetic, we're ok, but emotional and psychological issues are different. In the end I want her to marry a good person, sometimes people in the community talk.*

**Needs and Wishes**

Three subthemes arose in participants' needs and wishes:

**Culturally Responsive Resources:** Participants expressed the need of having more healthcare/mental health professionals acquire knowledge of Islam and the Muslim culture in order to provide better care and appropriate recommendations and resources. One participant expressed:

*I think that healthcare providers and teachers and [people] that work with special needs, maybe educate them more because there are more and more kids being diagnosed with Autism 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, we frown upon it, unless it's severe then maybe you'd put them, but I think as long as I am able to handle her I want to keep my child with me.*

**Quality Support:** The participants asserted the quality of the support should be individualized, based on the situation. As an example, they suggested that Muslim leaders and Imams offer programs that build awareness of ability differences in the Muslim and mainstream community.



**Personal Changes:** Participants expressed the need to learn to ask for help or use different resources to provide the best care.

## Want to Be Interviewed or Complete a Survey?

We are still doing interviews by phone/Skype/Messenger! If you are interested – and you are a provider, Imam, or Muslim with an ability difference or caregiver/family member – contact us at 414 288-5761 or [info@amwrri.org](mailto:info@amwrri.org) or if you want to complete the anonymous survey go to: <https://www.amwrri.org>

## Why a Digital Archive?

In today's world, digitalization provides us with tools that alter and strengthen connections and access; it also creates opportunities to transform information-building, perceptions, and solidarity. Our [digital archive](#) on AMWRRI's webpage creates the opportunity for discussions between community members, Muslim scholars and Imams, and healthcare providers. Just as important, it will provide an important space to listen to and understand people with differences of ability and their caregivers. Our digital archive contains information on [services](#) and resources for people with differences of ability and caregivers. Categories include financial, educational, recreational and health, parental, child, and multiple sources. We intend to keep locating and adding more resources to our website. If you know of any services/resources that are missing from our website, please send us the information at [info@amwrri.org](mailto:info@amwrri.org)

The digital archive also presents a written record of the interviews of people with differences of ability and their families/caregivers. There is an abstract that summarizes the major themes of each interview; eventually, there will be a link to the full interview. The names of interviewees are not revealed for reasons of confidentiality; instead, each interviewee is represented by a number. In addition, we edited some details that might reveal their identities. The



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**What are your solutions or community-based actions? Send them to [info@amwrri.org](mailto:info@amwrri.org)**

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diversity enables us to reflect on the importance of culture and how culture intersects with health, age, gender, and nationality. The stories disclose how these conceptions influence one another and play important roles in the lives



and rights of people with differences of ability. Therefore, this archive is a valuable source for individuals, religious leaders, health care providers, nonprofit organizations, and local policy makers.

## Call to Action

We invite community members and institutions to take part in this critical duty to align our religious values with our actions in supporting and creating opportunities for people with differences of ability and their caregivers. Based on our analysis of the surveys, focus groups and interviews, we offer the following actions.

- Create programs for the Muslim community to educate members about differences of ability, dismantle prejudice and stigma, and raise awareness about the needs of people with differences of ability and their caregivers.
- As an individual, take action to educate ourselves about differences of ability.
- Educate the Muslim community about the Islamic perspective on ability differences.
- Make our organizations and mosques and community institutions accessible by creating ramps, being inclusive and welcoming people with ability differences.
- Encourage Muslims to become mental health professionals and other healthcare providers.
- Provide education to healthcare and other professional providers on the Muslim culture.



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