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## **Disabilities Project Initial Report**

Enaya Othman

Arab and Muslim Women's Research and Resource Institute Digital Archive

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## Disabilities Project Initial Report

This report describes the processes, aims, and outcomes of the Disabilities Digital Archive, a project conducted as part of *Arab and Muslim Women's Research and Resource Institute's* vision to create data and oral histories regarding women's experiences and transform them into meaningful information. To this end, this project seeks to explore gendered disability and facilitate more complex understandings of disability at the intersection of gender, culture, immigration, and other modes of identity. By collecting data from Muslim community members in Milwaukee, including people with differences of ability and their families, caregivers, Imams and religious scholars, community organization leaders, and health care/mental health professionals, it presents a fuller picture to break down stigma and increase access to resources for people with differences of ability. This report presents initial findings and brief information on the following:

- a) Aims of the project
- b) Process of data collection
- c) Demographic information about participants
- d) Main themes emerged in the narratives
- e) Muslim Imams' perception and recommendations
- f) Health care providers' reflection and recommendations
- g) Digital Archive

### Aims

As AMWRI, we embarked on a mission to transform stereotypical perceptions and form a more inclusive society for people with differences of ability; the first phase of this undertaking began with the Marquette University Innovation Research Project "Gendered Disabilities" (2018-2021), followed by "Difference of Abilities" project funded by the Wisconsin Humanities Council (2019-2020), which is in progress. The findings from these research lines were utilized to create a digital archive and facilitate service for people with differences of ability. Thus, the Disabilities project has twofold aims: first, as part of digital archive, it constitutes a body of historical resource that documents the untold stories of a double-marginalized population as women and as people with differences of ability. In this sense, the collection in this archive unearths the body politics in the 21<sup>st</sup> century. This digital archive would also aim to initiate a forum or platform for honest discussion and exchange of reflections on this important topic as a social justice and minority issue.

Second, a major objective of the project is to provide service and build a bridge between service providers and those who need it. As many interviewers in this project stated, many of the individuals and families in this population remain unaware of the types and opportunities of service and support they could receive from various agents. Indeed, the



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project aims to function in various ways pertaining to raising awareness and creating changes in the society. From the community circles, public events, and workshops organized and upcoming conference for educational purposes and sharing main themes emerging from the study to briefing the community leaders, religious scholars, Imams, etc., it engages in the process of reducing stigma associated with disability and works for a better understanding of the emotional, financial, educational, social, and other types of needs of people with differences of ability.

### **Data Collection**

Regarding Muslims with ability differences or their caregivers, anonymous on-line surveys (which contained some open-ended questions) and face-to-face interviews were designed to collect narratives as a part of women's and men's oral histories documenting their immigration, cultural/ethnic background, minority and disability experience, and the way they intersect. Therefore, while participants are provided questions eliciting demographic information, they are further encouraged to share their experiences, which may be hidden from their families, communities, and possibly even from themselves. Respondents' authorship and authority over the narration have been prioritized, while their identities were kept anonymous (in the case of the surveys) and confidential (in the case of the interviews). To date, 39 surveys have been completed, and 26 interviews have been done.

To have a multifaceted understanding of disability in the Muslim community in Greater Milwaukee, we are also reaching to different parties such as Imams, health care/mental health professionals, and community leaders in the Muslim population. As of now (April 2020), data have been gathered from four Imams, two health care providers, and one community leader. Health care providers involved in this study include: a) an Assistant Professor who was a mental health counselor and treated refugees and Iraqi women who suffered from mental conditions such as depression and PTSD; and b) another professional counselor who works with a variety of populations, including Muslims and Muslim refugees. Another interview was done with a project coordinator who works with Mosques around the issue of ability differences.

Interview data were collected by trained students and research assistants. The participants were reached through AMWRRRI's membership and data sources as well as our community partners, such as the Milwaukee Muslim Women's Coalition (MMWC) and other local Muslim institutions. Further respondents were sought through the snowball sampling method.

### **Demographic Information**

All participants interviewed for this project are Muslims; the participants represent diverse ethnic and national backgrounds. As of April 2020, twenty six interviews have been collected, and twenty of them have been transcribed and are accessible on AMWRRRI's website. Of the twenty interviews, regarding the origin of countries, twelve people are from



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Palestine, one from Jordan, four from Pakistan, two from Bangladesh, two from India, one from Indonesia, one from Syria, one from Myanmar, one from Croatia, and one whose background is unidentified took part in the research. The age range varies from 18 to 65. Nineteen of the participants are first generation immigrants while five of them are American born; two participants did not specify their birth of country.

The project was created to provide insights into women's experiences, since women presumably face stigma more than men; furthermore, women's voices are silenced and their access to resources such as education, healthcare, and employment is limited. Of the twenty narratives displayed in the digital archive at AMWRRRI, eleven belong to mothers who take care of their children with differences of physical or intellectual ability; one interviewee is taking care of a sister with a disability; another woman talked about her life as a wife who takes care of her husband; three women narrated their own experiences as people with differences of ability; another woman was interviewed about her experience as a caregiver. Apart from these seventeen women, four men were included in the study; one of them reflected on his own experience, and the other three men accounted their role as fathers taking care of their children with disability.

### **Main Themes**

Examining the narratives collected from the people with differences of ability, their families or caretakers has yielded various issues requiring the attention of the community, policy makers, caregivers and health providers, and other parties involved professionally or personally. As the majority of participants were caregiver parents, they mostly drew attention on struggles to find programs in Milwaukee that meet the special needs of this population. Parents particularly addressed the deficiencies in respite care, day programs for fun activities and for skill-building, and programs where people with ability differences can work or volunteer. Finding friendships and activities outside the family are also a critical issue for many children with physical/cognitive/emotional ability differences. The rarity of such programs further obstructs children with differences of ability from developing social skills and relationships. A mother of a child with cerebral palsy and autism spectrum said, "if they can socialize, if he can play with somebody else, that is what we are looking for. Take a walk together. Do bowling, or games, things like that." This mother also noted that the lack of social interaction and peers' reluctance to develop friendship were how his son realized his differences. A striking outcome of the research is that most of the individuals were not aware of their rights and services that they could get as women, as caretakers, or people with differences of ability. The majority of interviewees referred to therapists, Medicaid, budget through IRIS, transportation service, etc. that were unfamiliar to them long before they heard about them.

The issues regarding health professionals involve cultural, religious, medical, and social concerns. The setting of certain types of treatment of therapy is remarked to be inappropriate; this includes the cases in which behavioral therapy is applied in clinics,



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whereas the situation requires the setting to be the home environment so that the real condition is observed in its own setting. Some participants mentioned the essential contribution of health care providers' being aware of the cultural and religious values of the person with difference of ability to the processes of treatment. On the other hand, participants also pointed out that healthcare providers sometimes associate mental disorders with the religious and cultural background or seek the sources of problems in them, which further deteriorate the individual's health.

Religion plays an important role in people's interpretations of the disability, approaches, and service they receive. The Muslim community in Greater Milwaukee constitutes a diverse local group bringing together people from different origins of country and nations, generations, and ideological orientations. Community Muslim organizations and institutions with a number of services and activities play an important role in forming a society around the common identity of being Muslim. Interviewers in this study, as members of this community, expressed their experience at these institutions, the attitudes they face from the community members, or the developments needed for people with differences of ability regarding this particular religious community. Some parents pointed out that there is no significant difference between the Muslim and other communities in dealing with disability, and that they could participate in any activities and events organized by religious institutions. Others placed emphasis on the necessity of transformation of perceptions and stronger involvement of religious leaders and scholars in coping with differences of ability. Some mothers highlighted the negative attitude and biases that exclude them from society such as staring; and one mother said that she was rejected from the Mosque when she wanted to bring her son with difference of ability with her.

Religion is also revealed to matter as a force/source that obliges them not only to take care of the family members with differences of ability but also to do it without a sign of complaint. Mothers and other caregivers in the family stress that the idea of group homes or assisted living facilities are out of question for a life time; if the parents pass away, the siblings are responsible for taking care of the concerned family member. Religion also shapes approaches and informs rationalization regarding "disability." The belief that disability is a "test" from God, both for the person with difference of ability and for the family/caregiver, is interpreted as a source of strength and patience. Yet, this is also asserted to lead to "unneeded sympathy." Not surprisingly, prayers were the most referred strategy to cope with the psychological effects of having a family member with difference of ability and being a caregiver.

A significant theme present in almost all narratives is the intersectionality of culture, immigration experience, and disability. The factors that lead to immigration, the struggles to integrate into American society along with getting familiar with the life for people with disability are woven together in many stories. Also, similar to religious beliefs, cultural conventions along with personal values are mentioned to hinder the idea of group houses. Cultural interpretations such as "evil eye" lead to delays or ignorance of the medical treatment, due to denial of the disease/impairment as a biological/medical condition. This also



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damages communication among family members. Particularly conditions that involve therapy as part of the treatment or well-being are overlooked; in these situations, particularly the older generation tends to regard therapy as a useless solution that must be replaced with faith and prayer. While people with differences of ability and their families expect health professionals to be conscious about cultural and religious values, they similarly have concerns regarding Imams and religious community members to be aware and insightful regarding the needs and situations of this population. Several mothers expressed the necessity of education to be given to the Mosque goers and community members by religious leaders and scholars on being inclusive. Religious leaders are also expected to disconfirm the misinterpretations such as “evil eye” or “being possessed by devil,” and instead encourage recognizing the medical conditions and accordingly seek solutions.

As anticipated, gender has an important impact on the way people experience disability, as well as on the role of caregiver. Women are expected to be the primary figures within family as the primary responsible for providing care. This emanates from culturally and religiously imposed domestic role for women and definitions of womanhood, which are ramified into economic and social domains. Mothers, whether educated and with a profession or not, are supposed to remain in the house and take care of the family member with difference of ability. Also, this assigned task is further revealed in other domains of life; for example, in the case of a son with difference of ability who has a sister and brother, the mother stated that this situation repelled the daughter's suitors because she was assumed as the future caretaker of her brother. Cultural construction of gender roles leads to stress for parents with daughters, due to the strong emphasis on the criteria for the female to be marriageable. Imposition on physical and other conceptions of “normality” regarding womanhood are more visible in case of women with differences of ability compared to the case with the male. A neglected issue is about gendered disability is the single mothers of children with difference of ability; women in this situation encounter more burden and struggles, such as finding a job that would allow them to balance the time among domestic, caretaking, and work responsibilities.

### **Imams' Perspectives**

Muslim Imams who also have administrative tasks in the Mosques in the US involve in a number of activities and roles including educational, cultural, religious events, and counseling. Along with these activities, considering their guiding and leadership roles, they can be asserted to have critical power and roles in raising awareness about disability and provide resources. Being certified by MUHSEN (Muslims Understanding and Helping Special Education Needs), having a class for special needs, providing copies of the Quran in Braille for the visually impaired, making the Mosque accessible for wheelchair, and forming support groups are some of tangible forms of creating inviting environments for people with disability. While some Mosques have these facilities, others fail being an environment for people with special needs. However, a common theme is their aspiration for accommodating the Mosques to welcome people with differences of ability. Giving talks about disability to





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eliminate biases is another way Imams adopt. To this end, some Imams give Khutba (preach) that addresses the special needs, in cooperation with MUHSEN. Referring to instances from the Prophet's life and giving examples from the Quran and hadith are the ways Imams who think creating awareness is the priority to do serve that purpose.

Some Imams think that the stigma associated with disability is disappearing in the Muslim community. This is predicated upon different reasons, such as education in America, increasing social awareness, Islamic literature, learning "authentic" Islam, as opposed to cultural Islam. Yet, some Imams shared similar resentful comments on how the population of the Mosques can repel individuals who bring their children or other family members with differences of ability.

### **Reflections of Healthcare Providers**

Healthcare providers referred to adjustment disorder experienced mostly by women in the process of adjusting to life in America. A counselor identified that women experience depression and PTSD due to trauma experienced back in homeland and due to the integration process in the US. The trauma experienced as a result of violence or war in homeland is reported to lead to stress and anxiety a few years later than the settlement in the US. A striking finding provided by healthcare providers is the denial of the mental disorders in the community due to stigma. As is the case with many other groups, stigma is observed to be stronger in cases of mental disability or disorder in Muslim community. However, one counselor noted that it is being broken as more people seek help and treatment. The stigma in the community is highlighted by a project coordinator who works with Mosques. The interviewee gave some examples of stigma and obliviousness, such as the feeling of shame to talk about disability and an Imam's claim that the community does not have people with differences of ability. Accounts from our interviewees indicate that denial and unawareness are found at the individual, family, community and societal levels.

### **Digital Archive**

We utilize digital archive a) to create an Oral history of a marginalized group and document their experiences b) to open discussion between community members, Muslim scholars and Imams, healthcare providers, researchers so that we could better understand people with differences of ability and their caregivers, and c) to locate service and facilitate access for people with differences of ability and their families. We, as AMWRRRI, aim to bring all our stakeholders together to tackle the issue of disability as a minority and justice issue and to raise awareness about reducing stigma associated with the feeling of shame. The issues of minority, underrepresented, and under-served need our attention and advocacy; the collection and circulation of the narratives of neglected/marginalized populations allows us to bring untold stories to light and present them to our community and larger diverse audiences.

Our digital archive on AMWRRRI webpage includes the narratives of people with differences of ability or their caregivers; the narratives consists of an abstract that summarizes the major themes of each interview followed by a link to the full interview. Each interview is



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represented by a number-letter combination, and their names are not revealed for the purpose of confidentiality. For the same reason, we edited some details that might reveal their identities. The digital archive also consists of an online survey for people with differences of ability or their caregivers to tell us their experiences. The survey was setup in a way that participants can use any electronic devices including their cell phones. Through the archive, we are also locating service for people with differences of ability by listing local and national, governmental, and nonprofit agencies and organization that provide resources and service to people with differences of ability and their families.

### **Next Steps**

AMWRRRI will continue to gather community and personal experiences through surveys and interviews, to encourage discussions, and monitor the discussion via the digital archive. After the period of grant, it will continue to advocate for awareness, inclusion, and accessibility, and to connect with local and national organizations to explore further resources. Disseminating the information collected and opinions and encourage discussions will be maintained as a crucial component of the project. To this end, an international conference is being planned to be held in Spring 2021. The conference aims to generate inclusive dialogues and interdisciplinary interactions between academia, community organizers, social and legal activists, health care service/providers, and religious leaders through critical analysis of how disabilities have been viewed in historical terms, as medical conditions and as social/cultural constructs, as well as through the norms that produce and reproduce perceptions of normalcy or normative bodies. While our two public events that were scheduled in March were cancelled due to the COVID-19 pandemic, our alternative is to produce and distribute a one-time newsletter that will contain a) a summary of the project, its process, and outcomes; b) some of the results of the interviews and anonymous surveys; c) news about the digital archive, including information on resources for people with ability differences and/or their caregivers; and d) a process for viewers to recommend solutions or community-based actions to address issues that have been identified. The newsletter will be distributed to designated individuals/groups and organizations (including Marquette University, and it will be posted or publicized in designated electronic/social media sites.