**Exploring the Needs of Middle Eastern Young Adults with Intellectual Disabilities during Healthcare Transitioning to Adult Rehabilitation Services in Washington State**

Intellectual disability impacts more than 7 million individuals in the United States1. Intellectual disability is characterized by significant limitation in both intelligence and adaptive social behavior before the age of 22 years2. Young adults with intellectual disabilities (YAID) and their caregivers face many challenges while navigating the multifaceted aspects of the healthcare system3. This happens concurrently with growth and increased complexity of their healthcare needs as they transition into adulthood 4. The failure of YAID to successfully transition into adult care is common, and can lead to deterioration in healthcare outcomes and detach them from the healthcare system5.

Healthcare Transition (HCT) is the intentional, planned process of transferring care from a pediatric-based to adult-based health care setting6. It is a complex process that requires effective planning and organized execution, communication and collaboration between all stakeholders7 . For many refugees and immigrants, HCT in United State can be particularly challenging due to language barriers, cultural differences, and lack of knowledge about the healthcare systems8. Specifically, little is known about the experiences of HCT in Middle Eastern YAID and their caregivers. Greater use of qualitative and participatory research methods may be valuable in understanding these barriers and developing more accessible HCT knowledge that is culturally appropriate and engaging for this underserved population. The purpose of this study is to understand the perspectives and priorities of Middle Eastern YAID and their caregivers about HCT in Washington State. We will deploy qualitative and participatory action research methods to understand the lived experiences of this population, identify barriers to successful HCT, and co-create potential facilitating strategies with this community. Data analysis will be conducted using inductive thematic analysis. The findings of this study will shed light on the healthcare experiences of this marginalized community and offer a valuable resource for many stakeholders, including health care professionals and other YAID caregivers and service providers in Washington State.

**1. Introduction and Rationale:**

Healthcare Transition (HCT) is the intentional, planned process of transferring care from a pediatric-based to adult-based health care setting6. It is a complex process that requires effective planning and organized execution, communication and collaboration between all stakeholders7. For many refugees and immigrants, HCT in United State can be particularly challenging due to language barriers, cultural differences, and lack of knowledge about the healthcare systems8. HCT is often a challenging process because it progresses over time and varies according to the healthcare setting, service framework, and individual or family goals9. There are also associated risks that are common during HCT, such as loss or interruption of services, uncertainty and anxiety for youth and caregivers, and challenges with accessing resources10. Moreover, HCT is a vulnerable time for YAID and their families10 which highlights the need for investigating this phase. Many caregivers of YAID reported having fears about the expected roles and the suitability of adult care11. Moreover, many parents of YAID reported communication issues and frustration12. People with intellectual disabilities have also been historically excluded from their health care decision making process13.

Globally, Healthcare Transition (HCT) of Young Adults with Intellectual Disabilities (YAID) has been explored primarily using descriptive analyses (exploratory design), and a concern of this work is the limited input from the population themselves14. Moreover, it has been established that there is a problematic absence of participatory action research in this area14 with a need for engaging specific patients’ groups with complex medical conditions such as YAID15. Furthermore, minimal studies have focused on minority populations. The literature shows that children with intellectual disabilities from racial and ethnic minorities face many healthcare disparities16. One of these minority groups include immigrants. In the United States, there is a lack of studies investigating health services access barriers in specific groups of immigrants’ in the US17 including Middle Eastern immigrants.

This study is unique as it is the first to apply qualitative and participatory research methods to explore HCT with Middle Eastern YAID and their families in Washington State. Qualitative and participatory research methods have been used successfully but sparingly in previous literature, and have been called for in greater frequency with minoritized populations, including people with disabilities, to amplify their own stories and experiences to improve access and equity. For example, a participatory action research framework was successfully used by Kester et al. (2022) to develop a Transition Discoveries Quality Indicator Framework among young adults with disabilities in Pennsylvania18. Lindsjö et al. (2021) incorporated participatory action strategies such as story-dialogue method to identify and co-create health promotion strategies among Middle Eastern migrant women in Sweden19. Gibson et al. (2013) used photovoice narratives, audio diaries, and interviews to describe the developing gender, disability, and generational identities of Canadian young men with disabilities transitioning to adulthood20. However, to the best of our knowledge, no studies have specifically used these research strategies to amplify the voices and experiences of a multiply marginalized population of Middle Eastern YAID and their families during HCT knowledge13. Capturing the perspectives of Middle Eastern YAID and their caregivers during HCT is vital for future service development, as primary healthcare system consumers who continue to face significant health disparities.

**2. Objective:**

The purpose of this study is to understand the perspectives and priorities of Middle Eastern YAID and their caregivers about HCT in Washington State, identify barriers to successful HCT, and co-create potential facilitating strategies with this community. The findings of this study will shed light on the healthcare experiences of this marginalized community and offer a valuable resource for many stakeholders, including health care professionals and other YAID caregivers and service providers in Washington State. As the scope of this project falls within a ‘Discovery’ phase of research, no pre-generated hypotheses have been created because the goal in this phase is to understand lived perspectives from which to generate future research hypotheses.

Ms. Abuatiq is a graduate student, physical therapist, and a Middle Eastern woman. She is committed to help people with disabilities from all origins, languages, orientations, religions, ethnicities, and races. This project is the first step of her career as a primary investigator to explore the needs of YAID during HCT. Completing this project will empower her to sharpen her research skills and built her future work in helping YAID to successfully transition into adulthood.

**3. Study Design:**

We will deploy qualitative and participatory action research methods to conduct this work. Participatory action research involves active participation of community members or stakeholders in all aspects of the research process, with the goal of social progress or change for marginalized communities21. This framework provides an accessible research method for understanding the perspectives of YAID and their caregivers during HCT specifically.

*Participants***:** The inclusion criteria for the youth are: Middle Eastern immigrants now residing in Washington State who are 14 - 24 years old; any gender; have intellectual or developmental disability, and are able to participate in a total of three research visits of at least 1-hour duration each. The inclusion criteria for the caregiver are: 18 years or older, being the legal guardian of YAID; lives in the same household as the YAID; and is familiar with taking pictures using smart phones or digital cameras. A sample size estimate of 20 YAID-caregiver dyads will be recruited on a rolling basis.

*Community Partner:*Opening Doors for Multicultural Families (ODMF) is a local organization in Western Washington which provides culturally and linguistically relevant information, services, and programs for diverse families and individuals with intellectual and developmental disabilities. ODMF primarily serves immigrants, refugees, and/or people of color, providing culturally responsive services in multiple languages (including Arabic) to over 2000 families in the local region. ODMF will collaborate with the UW project team by participating in interviews and other activities that will serve to better understand the local healthcare contexts for Middle Eastern YAID and their families, helping identify other stakeholders within the Middle Eastern community or service agencies across Western Washington to support recruitment efforts, and serving as advisors in resource material development and event planning.

**4. Study Procedures:**

All study procedures will be conducted with ethics approval from the University of Washington Human Subjects Division. Prior to participating in any research activities, all participants will provide informed consent as well as caregiver permission and assent where applicable. Demographic data of the participants will be collected at the first visit and will include both youth and adult participant’s age; gender identification; education; employment status; disability status; household income; and the number of people with disability in the household. Research visits will involve one researcher (Abuatiq), the YAID and a caregiver together, and will be conducted in Arabic. At least one caregiver will attend all the visits. **Table 1.** shows the study timeline.

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| **Table 1.** The Study Time Schedule |
| **Study Procedures** | Year | **1** | **2** | **3** |
| Quarter | **1** | **2** | **3** | **4** | **1** | **2** | **3** | **4** | **1** | **2** | **3** | **4** |
| Semi structured interviews | Recruitment |  |  |  |  |  |  |  |  |  |  |  |  |
| Data collection |  |  |  |  |  |  |  |  |  |  |  |  |
| Data analysis |  |  |  |  |  |  |  |  |  |  |  |  |
| Writing + Dissemination |  |  |  |  |  |  |  |  |  |  |  |  |
| Photo voice narratives | Data collection |  |  |  |  |  |  |  |  |  |  |  |  |
| Interviews |  |  |  |  |  |  |  |  |  |  |  |  |
| Data analysis  |  |  |  |  |  |  |  |  |  |  |  |  |
| Writing + Dissemination |  |  |  |  |  |  |  |  |  |  |  |  |

Semi-structured Interviews:Semi-structured interviews will be deployed with both ODMF staff and YAID-caregiver dyads. Interviews are a valuable resource for primary source material from the interviewee’s own lived perspective on a particular topic, and can be used to guide the development of materials and resources to support access to services and supports based on the priorities stated and stories shared during the interview22. Semi- structured interviews allow for main topic areas to be discussed while still allowing the participant freedom to elaborate or address other topics that are important to them22. Each relevant ODMF staff will participate in a single interview. Each YAID-caregiver dyad will participate in two semi-structured interviews, which will occur at the onset and completion of the study, to better understand both child and caregiver perspectives of their experiences and expectations with HCT, barriers and facilitators to HCT in the community, and review resources and materials co-developed with and for the community. Using a participatory strategy, priority topic areas and the exact questions for the interviews will be determined by a stakeholder engagement activity with the project’s community partner, ODMF, and representative members of the Middle Eastern YAID community. Agreed upon questions will be translated into Arabic and compiled into an interview guide. Example/draft questions for ODMF staff to begin the stakeholder engagement process include:

1. What resources and supports are already available for Middle Eastern YAID and families regarding healthcare in general, and HCT?
2. What resources and supports are needed for Middle Eastern YAID and families regarding HCT?
3. What have you observed, or what have Middle Eastern YAID and families shared about their healthcare experiences after arriving in Western Washington in your work together with this community?

Example/draft questions for YAID and caregivers to begin the stakeholder engagement process include:

1. What are your/your child’s goals for the future?
2. What does health and wellness mean for you/your child and your family?
3. Describe how you currently access healthcare for yourself/your child?
4. What resources have been helpful to you in navigating the healthcare system here?

All interviews will be audio recorded in Arabic, transcribed verbatim, and subsequently translated into English.

Photovoice Narratives:Photovoice narratives will be conducted with YAID-caregiver dyads. This method offers a unique and accessible technique for understanding HCT, as it provides an accessible and inclusive research approach18. The benefits of photovoice are not limited to alleviating communication barriers, they extend to the engagement of research participants which mitigates power imbalances in the research process23. Moreover, photography is a common skill that is accessible to YAID and their caregivers, given the widespread use of smart phones and the availability of built-in accessibility features in most phones such as voice commands, screen magnification, and other adaptive control mechanisms. Further, the use of photos and audio narrations precludes the need for English literacy skills, and can be conducted in an individual’s native language to preserve the nuance and integrity of narrations. During the second research visit, YAID-caregiver dyads will be provided with written and verbal instructions for the photovoice portion of the study. For families who may not have access to a smart phone, digital cameras with SD cards will be provided by the research team. Research participants will be asked to take photographs of events, places, or individuals that they consider significant and related to specific research questions focused on HCT, which will be provided in a guide to each family. The participants can take as many photos as they would like, however, they will be asked to select the 3-5 most meaningful or important photographs related to the topic. Finally, during the third research visit, participants will share their descriptive narratives about the photos they selected. The third research visit will take place 2 months after families receive the photo narrative instructions and cameras (if applicable), to allow enough time to take and select photos. The narratives will be audio-recorded during the final interview in Arabic, transcribed verbatim, and subsequently translated into English.

**5. Plan for analysis:** Data analysis of interviews and photo narrative transcripts will be ongoing, and conducted using inductive thematic analysis method24, which will consist of independent analysis by two members of the research team using open and focused coding until themes emerge. Disagreements will be resolved by discussion. Delve software (Delve Tool, New York, NY) will be used for thematic analysis and to organize the codes and subsequent themes. Though the targeted sample size is 20 YAID-caregiver dyads, recruitment will stop when data saturation is reached. Data saturation is reached when information redundancy is detected or when no new themes or codes emerge from the collected data25. A researcher reflexivity journal will be kept by the primary researcher to use as part of the research audit trail and to document notes and perceptions about how her own experiences and positionality as a Middle Eastern immigrant may contribute to the production of research results. Once themes have emerged, these will be translated back into Arabic and shared with participants as a form of member checking, to ensure accuracy and avoid misrepresentation of results. Participants’ demographic data will be reported using descriptive analysis.

**6. Budget and Budget Justification**

This project will be part of Ms. Abuatiq’s dissertation work, and is also included in a proposed grant application for the Rehabilitation Research and Training Center (RRTC) on Community Living and Participation among People with Intellectual and Developmental Disabilities 2023. This grant is offered by the Department of Health and Human Services, administration for Community Living. The expected amount for this project in total, if funded, is $ 65,000.

Given the significant competitiveness of these larger awards, receiving the Stolov award will provide key funding to allow this project to begin. Specifically, the Stolov funding will be used to cover the cost of study implementation, including equipment purchase, participants’ incentives for their time, parking cost, and transportation fees, for the first 5 study participants. Translation services may also be needed as some Middle Eastern participants will speak other languages besides Arabic (which is Abuatiq’s native language). The translation cost of languages other than Arabic and English are needed for approximately half of the study interviews (12 interviews). The needed technology also includes five digital cameras and SD cards for photovoice narratives for the first 5 participants. All the equipment will be stored in the Co-investigator’s (Feldner) research office at the Center on Human Development and Disability.

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| Table 2. Budget Justification for Stolov Funds |
| **Study Items** | **Amount ($)** | **Justification** |
| Participants Incentives |  750 | $50 per YAID-caregiver dyad x 5 participants x 3 one-hour visits |
| Parking/transportation reimbursement | 375 | ~$25 x 3 visits x 5 participants |
| Translation Services | 250 | Professional translation service fees cost of phone or online interpretation is estimated at $50 per hour (source: <https://www.aolti.com/interpretation.asp>) x 5 interviews (assuming approximately half will be conducted in languages other than Arabic) |
| Digital Cameras and SD Cards | 600 | ~$100 x 5 cameras and 5 SD cards |
| **Total Compensation and Reimbursement Cost**  | 1,975 |  |

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