Jordan Literature Review

Literature Review – March 2021

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2   Executive Summary

The purpose of this literature review is to provide a map of the research landscapes regarding people with disabilities and disability provision more broadly, in Jordan. The aim is to provide a foundation in which to inform the commissioning stage of the Disability Under Siege project. The main areas of focus for the review will be, education, health, the arts and culture, and intersectional perspectives. The research highlights the challenges that disabled people still face in terms of inclusion and full participation.

This research is part of the 'Disability Under Siege' project, which aims to provide the intellectual, financial, and logistical resources required to deliver a transformational change in education provision for children with disabilities in conflict affected states (University of Birmingham, 2020). This project establishes best practices for disability education provision in settings of conflict and crisis through interdisciplinary, coproduced research. It additionally involves the establishment of sustainable partnerships within the local community, offering support organizations within these locations to expand inclusive education.

This literature review relied on document analysis, online mapping, and systematic keyword reviews of academic data bases, as methods to investigate the experiences of persons with disabilities (PWD)[1] through academic and grey literature. Examples of these were academic publications and organizational reports, in addition to other statistics and news. Additionally, interviews with experts and stakeholders were conducted to inform the generated data with useful insights and analysis.

One important policy finding is that the recent Jordanian constitution does not explicitly refer to disabled people as one of its targeted groups. However, it references equality and non-discrimination as a main factor in support of marginalized groups. This was supportive to the declaration of the Jordanian disability law, and the establishment of the Higher Council for the Rights of Persons with Disabilities. Jordan's position as a hub hosting several regional offices of international organizations (e.g. UNICEF, HI) has supported the establishment of numerous projects and initiatives with the goal to mainstream the disabled population in health, culture,

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[1] The use of 'people/persons with disabilities' is known as 'people first' language. It is the preference in many developing countries and the language used by the UNCRPD.

etc. This has led the country to uphold more of the convention because these organisations, which might be one reason why Jordan's policies and developments are more attentive to different groups' rights.

3 Introduction

Even before the declaration of the UN Convention of the Rights of Persons with Disabilities, Jordan was among a few Arab countries that had a strong framework for disability policy that considers both the rights-based approach and social model of disability. Jordan was one of the first countries to sign and ratify the convention and continued to ensure that rights were upheld by aligning existing policy with the language, models and approaches utilized by UNCRPD (UN Office of High Commissioner for Human Rights, 2012). In 1993, the country declared law no. 12 for disability that included 12 articles followed by the law no. 31 in 2007 after the ratification of the UNCRPD, which complied with the convention to ensure the rights of disabled people was covered by law. Jordan kept working on improving the situation for disabled people and introduced the newest disability law no. 20 in 2017 as a comprehensive policy to guarantee rights and non-discrimination protection. The disability law no. 20 for 2017 adopted the same definition of a disabled person as the UNCRPD.

Moving to disability statistics, there are discrepancies and conflicts between numbers and types of impairment identified by different organisations. According to the Higher Council for the Rights of Persons with Disabilities (2010-2015), the disability statistics are not unified among researchers and disability workers in Jordan. In 2004, 1.23% of the population were identified as disabled, while international statistics in the same year listed the disabled population as between 5% to 10% (Higher Council for the Rights of Persons with Disabilities, 2010 - 2015). According to the 2010 disability strategy, the Higher Council for the Rights of Persons with Disabilities and the Ministry of Social Solidarity collaborated in the screening of impairments in the different governorates of the kingdom (not including the capital). The results showed that only 0.5% of the population were disabled. This discrepancy in data is a result of several factors including differing definitions of disability which leads to some people not being counted, the social tendency to hide disability especially among women, and a lack of criteria for detection and identification (Higher Council for the Rights of Persons with Disabilities, 2010 - 2015). Unfortunately, from a survey of the available literature through the University of Birmingham and University of Leeds libraries, there is little research published on this discrepancy (Crock et al., 2017).

3.1 Objectives

This research analyses a sample of the efforts done to promote inclusion of disabled people in Jordan through an analysis of academic publications, policy documentation and grey literature related to disability across the domains of education, public engagement, health and wellbeing (e.g. familial, community support and attitudes) and arts and culture (e.g. representations of disability in performing arts, literature, visual arts, media and social media). Within the above domains three keys areas were identified. First, barriers to the inclusion of

disabled people, secondly, the gaps in existing research and policies and finally, examples of good practice.

4   Methodology

The methodologies for this literature review were twofold. First, an initial mapping of the available literature and research was conducted. Empirical research studies, national education, health and cultural policies were reviewed alongside grey literature from international organizations and local NGOs (e.g. UN agencies, international and local DPOs). A wide of variety of search terms were utilised in English and Arabic, which have been included in the appendix of this review. This was useful as numerous disability and culture initiatives, Ministry and other government reports have only been published in Arabic.

This has been balanced with a review of academic publications and studies that explore health, education and culture. The articles sometimes cover two or all of these topics and occasionally include an intersectional focus. The academic research was primarily conducted through the University of Birmingham's library database. The University of Leeds and the School of Oriental and African Studies University libraries databases were also used as well as Google Scholar. The key word search combinations have been included in the appendix of the review.

Roughly 30 academic articles were selected for this review. Inclusive education came up with the largest quantity of publications. However, there is a distinct lack of academic literature regarding disability and the arts in Jordan. This was initially found by conducting key word searches on Google Scholar and the University of Birmingham library data base. Once the lack of literature was determined by the consultancy team, a further semi-systematic review of academic data bases was conducted to ensure accuracy and validity to the claim. Below the details of data bases and key word searches used in the systematic review will be presented. The research team are also hoping to gain access to Jordanian University data bases which may reveal PhD and Masters level research projects on the subject. However, this may or may not materialize.

Several data bases were selected through the University of Birmingham's data base archive and the same key word searches were used in each data base. The list of key search terms is given in the appendix. The list of data bases used are as follows: *Middle East and African Data Base*; *Arts and Humanities Citation*; *Humanities Abstracts*; *Arts and Humanities Data Base*; *International Bibliography of Art.*

After exhausting all key word searches, not a single article was found relating to both disability and the arts in Jordan. The conclusion at this stage is that it is an unresearched area, which presents a unique opportunity for the Disability Under Siege project in Jordan. This is not to say that the two areas of interest – disability and the arts – do not interact and cross over in Jordan. On the contrary, we know from the practitioner workshops and online research that there are projects, individual artists, specific institutions, and businesses that promote and conduct artistic practices with PWD.

Reasons for the lack of representation or interest within the academy can only be assumed at this point. However, it is likely linked to broader issues of representation for PWD in Jordan and the failure of civil society organisations and other practitioners to elevate their research to the academic context.

This literature review was completed in cooperation with both the University of Birmingham and Tammey – a Jordanian social enterprise focused on youth and community development – which was useful to access a mixture of academic publications indicating overarching themes impacting the literature (e.g. inclusive education, culture) that could be analysed alongside primary data sources, such as focus group discussions and reports documenting community initiatives in Jordan. The majority of the documents reviewed were published after the country's ratification of the UNCRPD.

5 Research Limitations

This literature review faced some limitations due to scarcity of data in some fields and the limited time available in which this could have been addressed by conducting interviews or focus group discussions with stakeholders. While research on inclusive education is rich, this is not the case for arts and culture in relation to disability. As detailed above, scanning different research data found limited academic materials on disability mainstreaming within culture and arts activities. Nonetheless, a review of arts and cultural practices has been conducted and will be detailed in this review. The researcher has benefited from his knowledge of Arabic to attend one webinar organized by Tammey, where several NGOs presented initiatives to provide PWD the opportunity to engage in arts and cultural activities (please see the section titled 'the Arts, Culture and Awareness Raising'). On the contrary, the field of inclusive education has extensive reports from UNICEF and other government organisations in addition to some academic publications which aided the research team. Looking at the available sources under disability and health found that there is a greater focus on available medical and rehabilitation services to support the individual impairment rather than acknowledging disability as a concept following the social model of disability (Mohammad Almomani, McDowd, Bani-Issa & Almomani, 2014; Al-Zboon & Hatmal, 2016). There was a particular lack of literature, especially academic, concerning disability and the arts. Despite the numerous available sources about socio-economic impact of Covid-19 on disabled people worldwide utilization of these sources within the Jordanian context are not yet available.

6 Findings

6.1 Education

This section presents a chronology of inclusive education developments in Jordan using the UNCRPD as a point of departure to examine its influence on mainstreaming of disabled students in public education. There was a breadth of information available in this area due to a governmental focus on policies and practices as well as the work of international organisations to support the improvement of inclusive education. Among the documents

studied are the disability law of 2017, the Disability Strategy of 2010- 2015, the report of the Jordanian Government to the UN, in addition to studies prepared by some INGOs such as Humanity & Inclusion, and Australian Aid. A large quantity of academic work is available on the topic of inclusive education in Jordan, such as 'Counselling Gifted and Talented Students in Jordanian Inclusive Schools' (Al-Zraigat, 2012) and on social work students' development of best practices (Al-Makhamreh, Al-Hadidi and Al-Bakar, 2015). In addition, scholars have explored the perspectives of parents and teachers in their beliefs about disability and attitudes towards disabled children. There is comparatively little about how disabled children and adolescents feel about themselves and the disabled and non-disabled communities within which they live.

According to Al-Dababneh, Al-Zboon and Baibers, 'the most frequently identified explanation among the [parents interviewed for the research] was that [their child's] disability was a case of God's will' (Al-Dababneh, Al-Zboon and Baibers, 2017). Interestingly, however, this does not always come with a negative impact on the child. The findings of their research showed that many 'regard a child with a disability as a gift from God, and that families have to take care of these children […] which [can] impact positively on the progress of the child' (Al-Dababneh, Al-Zboon and Baibers, 2017). This, along with other variables discussed in the article, meant that *most* parents interviewed felt positively about their child's skills within education and had great hopes for their futures. In comparison, Abu-Hamour and Muhaidat found that parents of children with Autism tended to feel more negatively about the inclusion of their children in mainstream education (Abu-Hamour and Muhaidat, 2014). The authors caution that this is common among parents of disabled children who needed higher levels of support, whereas those who have a child that require less support tend to feel more positively about inclusion. In addition, Al-Zboon has researched substance misuse education at schools serving disabled people and found that many parents and teachers are encouraging their disabled children to take medication (particularly Ritalin) to enhance their abilities at school (Al-Zboon, 2018). These findings are alarming both because of the connections made with subsequent addiction/misuse and the ableism they demonstrate among the parents and teachers. Ableism can be defined as prejudice or discrimination favouring non-disabled people, often manifesting in a lack of belief in the equal capacity of disabled people to achieve in comparison to their non-disabled peers. It appears some parents use such medication to prove their child is not disabled, but instead simply unintelligent, which can be resolved with chemical enhancement (Al-Zboon, 2018).

Abu-Hamour and Al-Hmouz have researched some of the challenges facing 'special education' in Jordan for disabled children. Of primary concern are the 'management and supervision of special education services, lack of valid and reliable assessment tools, as well as insufficient financial resources' (Abu-Hamour and Al-Hmouz, 2014). Such issues lead to students more frequently getting expelled or dropping out and the scholars recommend a 'large scale study in the national level […] to identify these students and then provide them with appropriate intervention.' However, Abu-Hamour and Al-Hmouz also emphasise the importance of integration, suggesting that, in academia, there should be more research done on 'evaluating

accommodation and services provided to students with disability in school and university levels.'

Prior to 1964, disabled children lacked education services suited to their needs and abilities. There was no legal or education policy support for disabled students. This gap in the policy resulted in negligence and absence of proper care (Alshoura & Ahmad, 2015). In 1964, the Episcopal Church in the Middle East established the holy land institute for the hearing disabled students (Alshoura & Ahmad, 2015). In 1970, the Ministry of Social affairs established the Special Education Directorate to provide education and rehabilitation services for disabled students. (Alshoura & Ahmad, 2015). These institutional developments highlighted a shift in recognition of the importance of providing proper educational services for disabled children.

Within the area of education, there is a number of laws and policies encouraging the inclusion of disabled people. Article 3 of disability law no. 20 (2017) states that education, vocational rehabilitation and training are among the daily activities that a disabled person should be able to perform without any challenges. Following UNCRPD principles, article 4 affirms the right of disabled people to inclusion in all life activities and the different services, reaffirming accessibility and reasonable accommodation as essential factors for disability inclusion.

As a response to UNCRPD principle of non-discrimination, article 17, prohibits discrimination of disabled people to equal education (disability law no. 20 for 2017). The same article affirms the responsibility of the country to provide an alternative for disabled people if their access to the desired education entity is difficult due to lack of reasonable accommodation. Article 21 offers disabled students with the same rights but in relation to higher education. The strategy has followed in the same spirit where its fourth objective aims to have gender equality within inclusive education for all disabled people (Higher Council for the Rights of Persons with Disabilities, 2010 - 2015). Despite these policy protections, it has been reported that disabled students are typically rejected to study at medical schools (ESCWA, 2009). The report viewed this as severe and unjustified discrimination against those students.

The disability strategy of 2010-2015, included priorities to enhance access to education for disabled people. The priorities included adapting the education policies to comply with the UNCRPD and achieve inclusion in the different education entities. The priorities also included early identification of disabilities in the pre-school stage and enhancing the referral mechanisms. The education section in the disability strategy included items related to curricula adaptation, transportation accessibility and resource rooms which is considered a positive aspect. It also included an objective to ensure that disabled people are having access to quality higher education for boys and girls in all the governorates within an inclusive environment.

Looking at the situation of Syrian refugees in Jordan, according to the research done in 2018 on the disability situation in Jordan, the national disability prevalence is 13% and the prevalence of Syrian refugees with physical or intellectual disabilities is 30% (Thompson, 2018). Public schools are accessible for non- Jordanian children, however, the data on the enrolment of Syrian children with disabilities are not enough and there is no accurate data regarding this aspect. The Education Working Group in Jordan issued a report that revealed that of the

Syrian refugees only 51% of boys and 65% of girls with disabilities attend primary schools. (Australian Aid; Humanity & Inclusion; iMMAP, 2018)

One of the inclusive education good practices in Jordan occurred in Zaatari camp. Syrian volunteers were trained on interacting with disabled children and the different methods of inclusive education. The volunteers along with the parents of disabled children were also trained on producing low-cost education material (UNICEF & REACH, 2014).

According to the Jordanian government report that was submitted to the UN committee in 2012, university students with disabilities are entitled to pay only 10% of the university fees. Students with disabilities who have 65% or more of the total grades can have access to university. (UN Office of High Commissioner for Human Rights, 2012).

As per the law 3 for 1993, education is a right for all children according to their abilities. To comply with the law, the ministry of education has developed programs that respond to the needs of disabled people and matches their abilities. These programs included adding resource rooms – which hold the assistive equipment and materials that a disabled person can use to fully engage in lessons – to fit the needs of the students with learning disabilities and adding classes within mainstream schools that match the needs of the students with hearing disabilities and other classes for students with intellectual disabilities. The Ministry of Education also included adaptations to the environment of the schools by building ramps, adapting the latrines and making them more accessible for students with disabilities. Ministry of Education also worked on adapting the curricula to be more inclusive of disabled students; more teachers were trained on interacting with students with disabilities. The ministry also worked on providing transportation to and from schools for disabled students. (UN Office of High Commissioner for Human Rights, 2012)

Despite some efforts from the Jordanian government to ensure that disabled people enjoy their right to education in an inclusive and welcoming environment that respect their abilities, it is clear that there is still a long way to go. According to the report submitted to the UN committee, there is still a low number of students with disabilities enrolled in schools (UN Office of High Commissioner for Human Rights, 2012). This is due to several factors such as the lack of enough means of accessible transportation, the physical environment is still not fully accessible for students with disabilities, and the lack of adapted curricula, especially in the primary stage. Other two important factors that still limit the full participation of students with disabilities are related to the low awareness of disability among the students and the school community and the appropriate ways to interact with disabled people and the low numbers of trained teachers. These factors stand as a gap towards the inclusion of disabled children in the education system, however there is a progress according to the report of the Jordanian government (UN Office of High Commissioner for Human Rights, 2012).

6.1.1   Challenges to Inclusive Education

Although there are a number of laws related to the inclusion of disabled people in education, there still is a large gap in achievement. According to the statistics of 2004 as occurred in the disability strategy, 42% of disabled people who are 15 years or above are illiterate, while 6.4%

are able to read and write. The statistics showed that only 5.9% of Disabled people have completed their education beyond the secondary degree (Higher Council for the Rights of Persons with Disabilities, 2010 - 2015, p. 19). The ESCWA (2009) note the challenges related to IE include the lack of clear statistics of the mainstream schools that are accessible for students with physical disabilities and even the number of Disabled people impacted. The rapid expansion of school access has come over the quality of the education provided for children with disabilities, and caused overcrowded classes, therefore, there are some concerns on the quality of education provided at public schools (Australian Aid; Humanity & Inclusion; iMMAP, 2018). Stigma and negative attitudes are considered among the challenges that face disabled children in schools (Ministry of Education in Jordan, INEE, Unicef, 2015). The challenge faced by disabled children is two-fold; families on one hand tend to hide their disabled children fearing the stigma that might follow them if their communities know about their disabled children, and on the other hand, there is a lack of awareness in the schools of the ways to interact with disabled children and provide them with a quality education that suits their abilities, and sometimes schools do not accept disabled children (Ministry of Education in Jordan, INEE, Unicef, 2015).

Scholars Bashir Abu-Hamour, Hanan Al-Hmouz and Adballah Azzam Aljarrah have found 'a cursory examination of textbooks revealed a general absence of disability-related content, leading to the realization that there is a need to examine how textbooks contribute to the problem of inadequate care of PWDs' (Abu-Hamour, Al-Hmouz, Aljarrah, 2019). The authors note that '[a]lthough practitioners' experiences in recent years suggest that Jordanian elementary school textbooks have made significant progress in integrating diverse perspectives, particularly in terms of gender, culture, race, and ethnicity; issues related to disability, however, have been neglected and not addressed in the context of inclusive education' (Abu-Hamour, Al-Hmouz, Aljarrah, 2019). The article demonstrates that while Ministries and policies outlaw discrimination against PWDs in theory, in practice, they are making few efforts to *encourage* PWDs in the education system. Eman Al-Zboon's research supports such sentiments. He argues that, from interviews he conducted, 'curriculum experts believed that in the Jordanian education system, the inclusion of disability concepts does not receive enough interest from the [Curriculum and Textbooks Department] and is not a priority, describing a variety of barriers to its inclusion in the curriculum' (Al-Zboon, 2020). The situation is not without hope, however. Al-Zboon goes on to note that curriculum experts were highly positive in their belief in 'the importance of the curriculum in increasing awareness of disability issues and changing community attitudes, and supported inclusion of disability issues in the future development process of the curriculum. These positive attitudes of the experts can be used to encourage decision-makers to focus on the inclusion process, which could lead to the successful inclusion of disability issues in the curriculum (Al-Zboon, 2020).

Alongside these existing hurdles, the integration with migration causes an intersection of oppression for some populations. For example, Syrian disabled children in Jordan risk not being able to attend school due to the cost prohibitive nature of transportation and school supplies costs despite access to free public education. This can be a burden on Syrian families

who tend sometimes to send their children, especially boys to work instead of sending them to school. (Australian Aid; Humanity & Inclusion; iMMAP, 2018).

Looking at higher education and the situation of inclusivity within higher education institutes, students with disabilities face similar challenges to the ones at the pre-university stage. In addition to the lack of accessibility inside the higher education buildings; there is also a lack of consideration to the abilities of the disabled students. The instructors for example speak with a fast pace that does not enable students to follow what is being said (Alhmouz, 2014). This leads accordingly disabled students to find difficulties in answering questions and participating in the discussion. Some university professors also do not allow disabled students to record the lecture which is considered a challenge especially for students with visual disabilities (Alhmouz, 2014). Another challenge that disabled university students face is the lack of counselling centres and accessible resources such as books in braille (Alhmouz, 2014). Alhmouz (2014) argues that unless the higher education entities concerned consult with disabled students to know more about the challenges that they face in their university life; the situation will remain the same with no real change, and there is no evidence that higher education institutes have taken any steps to improve the involvement of disabled students in the identification of barriers.

According to Alhmouz (2014), disabled students in a number of Jordanian higher education institutes believe that having access to support material and resources would help them thrive in higher education, although many are not even aware of the disability laws that entitle them to such rights. When asked about the disability office in the universities, the students sampled mentioned that they do not find it easy to access those offices and they indicated that the staff in those offices were not able to provide them with the support they need due to their lack of disability knowledge and the skills to interact with disabled students. The same study also revealed that the higher education concerned entities deals with disability on an ad-hoc basis and do not have a structured framework to ensure disabled students receive quality services. In addition, the fund allocated for the disability offices in the universities is very low compared to the role it should play in supporting disabled students. Assistive devices also are not adequate and not available for most of the students. Al-Zboon's research into assistive technology has similarly shown that training, finance, attitudes and willingness of children to use devices has been hindering the use of assistive tools in Jordanian education (2020). Certain disabled student populations were impacted with students with mild learning difficulties being overlooked. They faced difficulties to find support and they do not receive the needed interventions to help them carry on with their studies, considering that learning disabilities sometimes are not visible (Alhmouz, 2014).

The Higher Council for Persons with Disabilities (2018) education strategy of 2018 - 2022 included planning for building new 300 schools that will be accessible for students from boys, girls, refugees and disabled students. It also included the renovation of 420 schools to be more accessible for students with disabilities. This report also highlighted that privileged children have access to early detection, early intervention services and the other early childhood services by 44%, while less advantages children have access to such services by 5%

According to Najm (2012) study, there is a gap in the training programs addressed for the special education instructors. The training programs lack the needed technical and scientific aspects. There is also no stability in the development professional plans of the special education instructors.

6.2 Health

This section focuses on the documents, reports and the policies related to the inclusion of disabled people in the health system. The documents analysed here are the disability law no. 20 for 2017, the disability strategy of the Higher Council for Persons with Disabilities 2010 – 2015, some reports from INGOs such as the ESCWA, Humanity & Inclusion, Australian Aid, in addition to academic research. Substantial academic research has been done on health and disability, including some addressing intersectional issues such as age (Almomani et al, 2014) and migration status (Doocy et al, 2012; Mateen et al, 2012; Pinheiro & Jaff, 2018). An example of other research includes Al-Heresh, Bryant and Holm's article on 'Community-Based Rehabilitation' (2013). Little has been done to address gender or sexuality within healthcare provision for disabled people. This section also includes an analysis of the report of the Jordanian government on the UNCRPD of 2012 and the shadow report of Jordan 2017. Although the area of health has many references of best practices, most of these focus on the medical treatment of specific impairments for the person with disabilities rather than discussing larger systemic issues, such as the socio-economic impacts. This gives an indication of the traditional medical model of disability as a major concept leading these interventions. A belief that disabled people only need treatment for their disabilities will improve their societal engagement, misses a critical analysis of the interconnectedness of a multitude of societal barriers to access.

The right to health is one of the basic rights that occurred in the UNCRPD, and Jordan being one of the states that ratified the convention, it became obligatory to ensure that disabled people "attain the highest attainable standard of health without discrimination" (United Nations, 2006). Article 23 of the disability law affirms the responsibility of the MOH and the other concerned entities to ensure the inclusion of disabled people and to include their needs in the health policies, strategies and programs (disability law no. 20 for 2017). The same article affirms the responsibility of the Ministry of Health and the other concerned entities to ensure the accessibility or the reasonable accommodation is applied in public and private health facilities. The same article also affirms that doctors and medical staff should be trained to communicate with disabled people to ensure that they are able to make decisions related to their health. Article 24 ensures that disabled people are enjoying the right to health insurance services on an equal foot with others and considers any health insurance contract invalid if there is any discrimination against disabled people (disability law no. 20 for 2017).

Looking on the health aspect in the strategy, it is notices that it aimed at having disabled people get quality habilitation and rehabilitation services in all governorates. It included priorities related to developing quality standards for service provision to enhance the quality of the services provided for disabled people. The priorities also included setting a monitoring mechanism to ensure coordination among the concerned entities. One of the priorities for this objective also is providing support for the assistive tools, the support services, habilitation

and rehabilitation services, and training for all disabled people and in the most needed areas. The strategy considered also ensuring that services cover all the governorates of the kingdom including the outlying areas (Higher Council for the Rights of Persons with Disabilities, 2010 - 2015).

The report "the current situation of Persons with Disabilities in Jordan" revealed that third of disabled people in Jordan are not covered by health insurance (Thompson, 2018). According to ESCWA (2009), only 58.5% of persons with physical disabilities are included in the health insurance. However, there is a discrepancy in the data related to the number or the percentage of disabled people who are covered within the health insurance services (ESCWA, 2009). Some of the challenges that face the inclusion of disabled people into the health system lie in the low funds, lack of coordination among the concerned entities, lack of trained medical staff who are able to interact with disabled people, the inefficient medical referral system, and the low coverage of the services targeted for disabled people (ESCWA, 2009).

The government has taken steps (in the second and third objectives of the strategy) to ensure that disabled people have an easy access to the different health services, such as providing free habilitation and rehabilitation services, especially for people with physical disabilities and those with Cerebral Palsy (CP) (UN Office of High Commissioner for Human Rights, 2012). There are also some efforts exerted on the early detection and early intervention level. Disabled people have legal protections in Jordan that guarantee their right to free will to make decisions about their health in terms of receiving medications or in case of surgical operations. The PKU test is available in a number of hospitals and health care units all over the country (UN Office of High Commissioner for Human Rights, 2012). Also, the Jordanian government provides limited trainings for the medical care staff on the ways to interact and communicate with disabled people as well as disability rights (UN Office of High Commissioner for Human Rights, 2012).

Although there are some steps taken to ensure easy access to the health services from disabled people, there is still a gap according to the report of the Jordanian government to the UN committee (UN Office of High Commissioner for Human Rights, 2012). Disabled people remain unable to access all the needed services due to the physical barriers and the informational barriers that still exist. The health facilities are still not fully accessible for disabled people and information is not provided in accessible methods that suit their needs whether in braille or in sign language.

Health coverage for Syrian refugees is a contested issue; between March 2012 and late 2014, Syrian refugees in host communities were allowed to receive primary health services for free (Australian Aid; Humanity & Inclusion; iMMAP, 2018). However, in 2014 the policy was adapted to require Syrian refugees to pay like Jordanians who are not covered with health insurance to receive health care services (Australian Aid; Humanity & Inclusion; iMMAP, 2018). This was again adapted in 2018 when a new policy was declared that requires Syrian refugees in host communities to pay like foreigners in return for receiving health services. According to Australian Aid, Humanity & Inclusion and iMMAP (2018) report, the cost could be more for refugees with disability as they might seek quality services that are not provided

in public health services. Another challenge that refugees with disabilities face is that the information is not always accessible or available for disabled people and the medical staff do not have the necessary capacities or skills to interact with disabled people (Australian Aid; Humanity & Inclusion; iMMAP, 2018).

Looking at the shadow report of 2017 (Information and Research Center- King Hussain Foundation, Identity Center, I am a Human Foundation for the Rights of Persons with Disabilties, IM, Individuell Människohjälp, Swedish Development Partner, 2017), disabled people highlighted that they face difficulties in accessing health facilities due to the lack of accessible buildings, difficulties in communicating with doctors and other medical staff, the absence of sign language translators inside the facilities and the lack of experience of the medical staff on interacting with disabled people.

One report (Higher Council for the Rights of Persons with Disabilities, 2018), states that there are gaps in the procedures of issuing the medical reports for disabled people and the lack of accurate rules to identify and measure disabilities. One of the gaps is that the Ministry of Health does not clarify which centres are accredited to provide the disability medical reports. The report also indicated that the staff of the medical centres are not aware of the rights of disabled people and the ways to interact with them.

According to (Higher Council for the Rights of Persons with Disabilities, 2018), the system of the private hospitals specified the criteria and the standards of building private hospitals and it did refer that it should consider the needs of "people with special needs" without explicitly mentioning the technical specifications required to make the buildings accessible as occurred in the code of construction. Also, the system for registering private health clinics did not refer to the needs of disabled people according to (Higher Council for the Rights of Persons with Disabilities, 2018).

On the other hand, the Ministry of Health have taken steps to ensure that disabled people have access to the health services available in the community. They organized a number of awareness sessions on early detection of disabilities and the procedures of referrals. The ministry also gave priority for disabled people in receiving services and issued official decrees for that. (Higher Council for the Rights of Persons with Disabilities, 2018). They also provided hospitals with ramps and equipment needed for serving disabled people

6.3   The Arts, Culture and awareness raising

This section will review the literature available discussing PWD integration and engagement with the arts, culture and awareness raising in Jordan. This section investigates the legislation put in place to include PWDs in cultural practices and governmental awareness – raising initiatives. Within this domain it was difficult to identify a large number of applicable resources. This may be due to the fact that people viewed this area as fun/luxurious and that not a priority for disability inclusion. Additional outreach to participants via email was required to gain a better understanding of involvement in these areas and also provided a direction for the literature search.

It was found that there is a distinct lack of academic literature regarding disability and the arts in Jordan. This was initially found by conducting key word searches on Google Scholar and

the University of Birmingham library data base. Once the lack of literature was determined by the research team, a further semi-systematic review of academic data bases was conducted to ensure accuracy and validity to the claim. Below the details of data bases and examples of key word searches used in the systematic review will be presented. It is also important to acknowledge that the data bases used and accessed were determined through the research's access to the University of Birmingham archives and data bases. The research team are also hoping to gain access to Jordanian University data bases which may reveal PhD and Masters level research projects on the subject. However, this may or may not materialize.

Several data bases were selected through the University of Birmingham's data base archive and the same key word searches were used in each data base. The data bases searched include: *Middle East and African Data Base*; *Arts and Humanities Citation*; *Humanities Abstracts*; *Arts and Humanities Data Base*; *International Bibliography of Art; and the University of Birmingham library data base*. The key words used for the review include: Jordan, disabilities, disability, impairment, art, psychosocial, middle east, intervention. Different combinations of key words were used systematically across all data bases.

After exhausting all key word searches in all the selected data bases and the University of Birmingham Library data base, not a single article was found relating to both disability and the arts in Jordan. The conclusion at this stage is that it is a very unresearched area. This is not to say that the two areas of interest, disability and the arts, do not interact and cross over in Jordan. On the contrary we know from the practitioner workshops and online research that there are projects, individual artists, specific institutions, and businesses that promote and conduct artistic practices with PWD. However, from an academic and research perspective it can be assumed that this is an extremely under researched area which presents a unique opportunity for the Disability Under Siege project in Jordan. Reasons for the lack of representation or interest within the academy can only be assumed at this point. However, it is likely linked to broader issues of representation and inclusion for PWD in Jordan.

The legislation in Jordan guarantees disabled people's participation in cultural life and enjoyment of different cultural activities. The ninth objective of the strategy addresses the inclusion of Disabled people in sports, political and cultural life. The specific objective related to cultural participation aims at larger participation of Disabled people in the different cultural activities including festivals, seminars and exhibitions (UN Office of High Commissioner for Human Rights, 2012). They also encourage self-expression through many different avenues such as writing and music. To enhance that aspect of the strategy, the Jordanian government encourages the printing of several books in braille and formed a musical band of people with visual disabilities (UN Office of High Commissioner for Human Rights, 2012). The Jordanian government encourages artists and authors with disabilities through financial support and introducing them in magazines, periodicals and books. The government also worked on producing books in braille, so they become accessible for people with visual disabilities (UN Office of High Commissioner for Human Rights, 2012). Some cultural centres are adapted to welcome disabled people through applying some physical adaptation to the environment and through applying the code of construction. The government also encourages disabled children

to take part in the non-curricular activities and competitions that take place (UN Office of High Commissioner for Human Rights, 2012).

Despite these efforts to facilitate the inclusion of disabled people in the cultural life, there are still gaps that hinder their full participation. These obstacles include the difficulty of accessing some buildings due to the environmental barriers that they include. These environmental barriers are common in a number of touristic places (UN Office of High Commissioner for Human Rights, 2012). There is also a gap in the number of accessible resources and guidelines that are addressed for disabled people, and there is a shortage of the audio and the sign language programs (UN Office of High Commissioner for Human Rights, 2012). The role of the OPDs is not highlighted throughout the strategy. There is a mention of the collaboration with the civil society organizations but with no clear mention of enhancing the capacities of the OPDs as representatives of the Disabled people although the OPDs contributed to the development of the strategy.

According to participants in the Amman workshop on Inclusive Arts Practices that was held in November 2020, a participant from an initiative for arts for visually impaired people, stressed that disabled people should enjoy the same art that others without disabilities enjoy but with more accessible ways. Ranin initiative had experience in creating cultural content for children with visual disabilities with audio and in Arabic language. They also work with children with different disabilities not only visually impaired children. Another initiative relied on teaching drawing through smell. This initiative worked on the inclusion between people with total visual loss and others with low vision and aimed at teaching them a new skill that will change their perception of how productive they could be. The initiative still faces a lack of support which will affect its sustainability. One of the initiatives also tackled the psychological disabilities and the stigma that people with psychological disabilities face in their communities. Another initiative worked on training people with disabilities on drama skills such as focus, imagination, vocals…etc. The main challenge remains in sustainability due to lack of support. More than 5000 people with different disabilities were trained within this initiative.

Regarding awareness-raising, the UN report on the status of the UNCRPD in Jordan noted it been addressed in several contexts such as the national disability strategy included an objective (#10) on awareness-raising of the rights of Disabled people to support their inclusion in the community (UN Office of High Commissioner for Human Rights, 2012). This objective targets media figures and journalists to advocate for the rights of Disabled people. It also includes involving Disabled people in the advocacy of their own rights. A number of trainings and workshops were conducted for media representatives and civil society organizations on the UNCRPD and the mechanisms of awareness-raising. The Higher Council for the Rights of Persons with Disabilities takes the responsibility of following up the development of the awareness programs (UN Office of High Commissioner for Human Rights, 2012). According to the report, awareness-raising activities and initiatives resulted in adopting the rights-based model in the media programs and looking at disability as part of the human diversity (UN Office of High Commissioner for Human Rights, 2012). Despite these efforts, there is still a gap in presenting disabled people in the image of dependability. There is also a lack of statistical and demographic data on disabled people in Jordan. The numbers are not clear, and the

geographical distribution of disability is not identified. This lack of data stands as a challenge for the awareness raising efforts and the capacity building plans.

According to the Higher Council for Persons with Disabilities (2018), the Ministry of Culture did not take serious measures to ensure that disabled people are included in the different cultural activities and initiatives. The strategic plan of the Ministry of Culture of 2017 – 2019 did not include any component related to inclusion of disabled people in the cultural events, which indicates lack of interest in the real application of inclusion. The Higher Council referred also to the legislations related to culture in the kingdom did not include any reference to making the journals of the ministry or the publications accessible for disabled people. The report indicates that the ministry of culture still overlooks the rights-based approach while interacting with disabled people and this is clear from their answers to the inquiries of the council on the steps taken to include disabled people. The answer of the MOC was that they published a couple of books for writers with disabilities and including disabled people in the editorial boards of some publications. The report indicates that the Ministry of Culture does not allocate any budget for improving the inclusion of disabled people into the different cultural events and facilities.

6.4   Intersectionality (Gender, Refugee Status and Age)

This section analyses intersectionality in relation to disability, namely gender, refugee status and age in Jordan. It gives particular focus to the additional barriers faced by disabled women due to multiple intersecting oppressions, particularly in the areas of civic engagement, health care and marriage.

Article 6 of the UNCRPD was aware of the multitude of oppressions that specifically face disabled women, "states Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms" (United Nations, 2006). Despite this, disabled women in the global south face additional challenges due to associated stigma attached to both marginalized identities. This negatively impacts their opportunities of equal access of education, employment and cultural activities. This multiplying effect of discrimination is further exasperated for women who are discriminated against due to economic and social circumstances. Skimming the literature found Jordan as one example (UN Office of High Commissioner for Human Rights, 2012). The Jordanian constitution is seen as a positive example as it refers to non-discrimination and equality as important founding principles with a specification of two marginalized groups. However, this not reflected by the 2010 - 2015 disability strategy in Jordan. According to it, women with disabilities think that the majority of programs are designed to suit the needs of men with disabilities and neglect their needs. Women have less opportunities of participation than men with disabilities as men dominate the disability movement in Jordan (Higher Council for the Rights of Persons with Disabilities, 2010 - 2015, p. 27). Women with disabilities are even excluded from the women's movement due to having disabilities (Higher Council for the Rights of Persons with Disabilities, 2010 - 2015).

According to the shadow report of Jordan by Information and Research Center – King Hussain Foundation, et al. (2017), the health strategies in Jordan for the years 2013 and 2017 did not include any component for improving the access to health services for disabled people. The reproductive health strategies did not include as well any component related to disabled women. Christine Sargent has additionally written her PhD on the emergence and recognition of Down's Syndrome in Jordan and subsequently published an article on the perception of mothers receiving prenatal diagnostics in relation to children with Down's Syndrome (Sargent, 2018; Sargent, 2020).

Regarding marriage and relationships, disabled women are reported to face challenges when they decide to get married and create a family. Some families prevent disabled women from getting married assuming they are unable to fulfil the responsibility of marriage. Some men also refrain from approaching families with disabled women for marriage. (Information and Research Center – King Hussain Foundation, et al., 2017).

There are some materials that address the intersection of gender and refugee status in the experiences of disabled people in Jordan. Bushra Rehman wrote her Masters thesis on 'Gender, Disability and Displacement' (2018) in which she addresses the multi-level oppression faced by disabled refugee women living in Jordan in accessing education, work and community space. Some of the women she interviewed declared feeling that others 'de-gendered' them, as disabled women are often stereotyped as asexual. Aitemad Muhanna-Matar (2020) has explored similar trends among attitudes towards 'masculinity' in relation to disability among refugee men in Jordan. She explains that her research 'analyzes the relationship between male health vulnerability, exemplified through physical disability and chronic illness, and the dynamics of renegotiating masculinities.'

More extensive research has been done on disabled refugees in Jordan without considering the specific intersections with gendered experiences. Doocy and others, (2013) for instance, have written about the overburdening of health care providers in Jordan without adequate resources to support the complex needs of disabled refugees. Importantly, their research incorporates the perspectives of disabled refugees themselves, such as that 'the majority of households [interviewed] perceived medical care to be expensive and cost was a barrier to care seeking'. This has not been common in other health-related materials that treat disabled people as passive subjects rather than active participants in research. Mateen and others' (2012) research into 'Neurological Disorders in Iraqi Refugees' lacks in this way, for instance. Similarly, Almomani and others (2014) have conducted research into disabilities among nursing home residents in Jordan, but do not engage enough with the social model of disability. The findings emphasize the need for more extensive medical treatment.

6.5   Accessibility

This section discusses the legislation and initiatives in Jordan related to accessibility with a particular focus on voting rights, construction codes and how to improve mainstreaming of accessibility.

The establishment for the Higher Council for the Rights of Persons with Disabilities is one factor behind the Jordanian national policy attention given to the concept of reasonable

accommodation (Higher Council for the Rights of Persons with Disabilities, 2010 - 2015). They have relied on the UNCRPD, Article 9 accessibility principles and articles to obligate government procedures to mainstream accessibility as a pathway to inclusion (United Nations, 2006). The disability law no. 20 for 2017 obligates the construction code that all buildings should apply it to ensure easy access for Disabled people.

Together the Higher Council for the Rights of Persons with Disabilities and other disability organisations have made efforts to improve accessibility of elections so that disabled people can have equal political rights to vote. According to Karmel (2015) their most significant success in 2012 was the establishment of the Independent Electoral Commission which introduced measures for access and adjustments to allow equal participation disabled people. However, Karmel (2015) documents many existing barriers that hinder election accessibility, these include the need to "1) make voting stations more accessible, 2) improve transportation for persons with mobility disabilities, and 3) enhance awareness so that all persons with physical disabilities know that they can vote and are aware of the special accommodations that have been made to enable them to do so. Even more work needs to be done to ensure that persons with mental disabilities are able to engage in the electoral process."

Despite the previous disability strategy (2010-2015), there is minimal reference to accessibility. It is certainly important to devote a specific objective to reference the concept. Scanning the strategy shows that the concept of accessibility is not crosscut across other strategies. Having accessibility crosscutting in all the objectives gives it a weight and encourages the concerned entities to pay attention to it (Higher Council for the Rights of Persons with Disabilities, 2010 - 2015). Similarly, analysis the human rights action plan of Jordan (2016- 2025), found that disability also has a limited reference. The third pillar of the strategy regarding the rights of marginalized groups references disability, but not elsewhere in the strategy. The first objective for example is about promoting and protecting the rights of disabled people. The expected results under this objective aim consequently refers to ensuring equity and equal opportunities for Disabled people to get their rights. The activities include providing training, education and rehabilitation tools for disabled people, and making information accessible for them (National Democratic Institude and the US Agency for International Development, 2016).

Referring to the shadow report of Jordan of 2017 by the Information and Research Center-King Hussain Foundation, et al., the national construction law was declared in 1993, and according to this law, the national construction council was established. The construction council was responsible for developing the code of construction and setting the criteria and the rules of constructing new buildings. Despite the law setting obligations related to committing to the code of construction, and although there is a fine that varies between 100 and 3000 Jordanian Dinars on not fulfilling the code of construction, there is still a gap in putting the law into action. The entities are not committed, and they do not fulfil the code of construction. This law needs to be activated in order to ensure that new buildings are accessible for disabled people and they do not face any difficulties in accessing them. The reasons given for not applying the code of construction are blamed on the lack of coordination among the concerned entities (Information and Research Center- King Hussain Foundation

et al., 2017). It is worth mentioning that the transportation strategy of 2015- 2017 did not include any component on accessible transportation for disabled people.

7 Discussion of Findings

Based on the findings of the report, it is clear that some areas have received far more academic attention than others. Further research into these areas to elevate them to the academic sphere would be beneficial in subsequently encouraging the development and transfer of theoretical approaches into the policymaking sphere.

As is discussed in the above 'Arts and Culture' section, the Ministry of Culture makes no priority of the inclusion of disabled people in the arts, with little budgeting allocated to this. Similarly, disability and culture gets little to no attention in the academic sphere. Too often the arts, cultural expression and community inclusion fail to be considered as having any importance, with health and education exclusively taking centre stage. Jordanian Universities and firms, nonetheless, play an integral role in communicating with community-based organisations and act as a pathway between theory and practice. The field would certainly benefit from research being conducted here. In addition, there is limited academic research on gender and disability specifically within education and health, although there are some publications covering intersectional experiences of gender and disability in relation to self-perceptions, which could be a useful starting point. Education and disability as a broader theme would also benefit from further academic research into the self-perception of disabled students, as considerably more attention has so far been given to the perception of teachers and parents of disabled students. In addition, due to the disparities in statistics on those with disabilities given by international bodies and national governments, there should be more research done on the causes of such disparities and what relation this has to how disability is conceptualised in different areas.

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10 Appendix: Search Terms

The following terms were searched in Arabic and English for grey literature:

- Disability inclusion in health in Jordan
- Inclusive education in Jordan
- Disability and culture
- Disability and education in Jordan
- Disability and arts in Jordan
- Disability politics in Jordan
- Disability-related project, programmes and initiatives in Jordan

The following terms were searched in English for academic literature:

- Jordan AND disability OR disabled OR disabilities AND education
- Jordan AND disability OR disabled OR disabilities AND education AND gender
- Jordan AND disability OR disabled OR disabilities AND education AND girls
- Jordan AND disability OR disabled OR disabilities AND education AND refugees
- Jordan AND disability OR disabled OR disabilities AND education AND attitudes
- Jordan AND disability OR disabled OR disabilities AND education AND perceptions
- Jordan AND disability OR disabled OR disabilities AND inclusive education
- Jordan AND disability OR disabled OR disabilities AND special education
- Jordan AND disability OR disabled OR disabilities AND teaching OR teachers
- Jordan AND disability OR disabled OR disabilities AND children
- Jordan AND disability OR disabled OR disabilities AND children AND refugees
- Jordan AND disability OR disabled OR disabilities AND children AND gender
- Jordan AND disability OR disabled OR disabilities AND health
- Jordan AND disability OR disabled OR disabilities AND health AND gender
- Jordan AND disability OR disabled OR disabilities AND health AND inclusion
- Jordan AND disability OR disabled OR disabilities AND health AND refugees
- Jordan AND disability OR disabled OR disabilities AND health AND Syrian
- Jordan AND disability OR disabled OR disabilities AND health AND Iraqi
- Jordan AND disability OR disabled OR disabilities AND health AND Palestinian
- Jordan AND disability OR disabled OR disabilities AND mental health

- Jordan AND disability OR disabled OR disabilities AND physical health
- Jordan AND disability OR disabled OR disabilities AND gender
- Jordan AND disability OR disabled OR disabilities AND women
- Jordan AND disability OR disabled OR disabilities AND refugees
- Jordan AND disability OR disabled OR disabilities AND refugees AND gender

The following terms were searched in Arabic and English for academic literature:

- Jordan AND disability OR disabilities OR disabled OR impairment AND art
- Middle East AND disability OR disabilities OR disabled OR impairment AND art
- Jordan AND disability OR disabilities OR disabled OR impairment AND creativity
- Middle East AND disability OR disabilities OR disabled OR impairment AND creativity
- Jordan AND disability OR disabilities OR disabled OR impairment AND Psychosocial
- Jordan AND disability OR disabilities OR disabled OR impairment AND Psychosocial Intervention
- Middle East AND disability OR disabilities OR disabled OR impairment AND Psychosocial
- Middle East AND disability OR disabilities OR disabled OR impairment AND Psychosocial Intervention
- Jordan AND disability OR disabilities OR disabled OR impairment AND Psychosocial Support
- Middle East AND disability OR disabilities OR disabled OR impairment AND Psychosocial Support