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Population and Development

# Disability in the Arab region: A challenged vulnerability



2021

# List of acronyms

<b>ASRO</b>	Arab States Regional Office
<b>DALY</b>	Disability-adjusted Life Year
<b>DEC</b>	Development Experience Clearinghouse
<b>ESCWA</b>	Economic and Social Commission for Western Asia's
<b>FGD</b>	Focus Group discussion
<b>GBV</b>	Gender-based Violence
<b>ICPD</b>	International Conference on Population and Development
<b>LMICs</b>	Low- and Middle-Income Countries
<b>MENA</b>	Middle East and North Africa
<b>SDGs</b>	Sustainable Development Goals
<b>SRH</b>	Sexual and Reproductive Health
<b>SRH&amp;RR</b>	Sexual and Reproductive Health and Reproductive Rights
<b>TFR</b>	Total Fertility Rates
<b>UNCRPD</b>	UN Convention on the Rights of Persons with Disabilities
<b>UNFPA</b>	United Nations Population Fund
<b>UNHCR</b>	United Nations High Commissioner for Refugees
<b>UNRWA</b>	United Nations Relief and Works Agency for Palestine Refugees in the Near East
<b>WGSS</b>	Washington Group Short Set Questions
<b>WHO</b>	World Health Organization
<b>WMA</b>	World Medical Association

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Prepared by:

KPMG International Development Advisory Services (Jordan)

Reviewed by:

Dr. Shible Sahbani, SRH Regional Advisor, UNFPA ASRO

Dr. Mohamed Afifi, SRH and HUM Specialist, UNFPA ASRO

Dr. Afrah Thabet, SRH Specialist DA, UNFPA ASRO

Ms. Yasmine Baligh, Programme Associate, UNFPA ASRO

# 1. Executive summary

Disability is increasingly understood as a component of the international development agenda, producing rights-based approaches to disability-inclusive development. Responding to the Convention on the Rights of Persons with Disabilities (2006) and the 2030 Agenda for Sustainable Development, there has been a global push to expand the inclusion of persons with disability. Specifically, to ensure: universal access to sexual and reproductive health-care services, including for family planning and providing information and education; and the eradication of gender-based violence, and; ending all forms of discrimination against women and girls, including the elimination of violence and harmful practices, such as child and early marriage and female genital mutilation. The overall aim of this formative research study was to develop an in-depth understanding of the sexual and reproductive health and reproductive rights concerns, gender disparity and gender-based violence, effects of age in order to address challenges related to disabilities in the Arab region.

## The research had three specific aims:

- To analyse existing evidence, policy environment, service delivery infrastructure, programmatic experience in addition to the available data and indicators related to sexual and reproductive health and reproductive rights (SRH&RR) and gender-based violence (GBV) of persons with disabilities in each of the selected countries of the Arab region.
- To enhance our understanding of the perceptions of persons with disabilities about their sexual and reproductive health and reproductive rights and GBV related needs in addition to their experiences in accessing SRH and GBV services and information in the selected Arab countries.
- To explore the perceptions of and the potential role of family and/or primary caregivers for persons with disability in supporting their needs.

## Methodology

To accomplish these aims, an exploratory and qualitatively weighted formative research study was conducted, using a literature review, semi-structured interviews, and focus group discussions. The approach strikes a balance between rigor, relevance, and feasibility. A multi-stage methodology was used to select four Arab countries, which reflect the diversity of conditions and challenges facing persons with disabilities. The final sample included countries at different levels of development, and in acute or protracted humanitarian crises. Based on this sampling strategy, Morocco, Palestine, Jordan, and Sudan were selected as country case studies.

The research was also informed by an ecological approach, to orient research findings and help organize an understanding of SRH and GBV among persons with disabilities, which is a complex, multidimensional and multi-dynamic phenomenon. Key findings, lessons learned and corresponding recommendations are made for practical guidance and advice on entry points and opportunities to advance the United Nations Population Fund's and stakeholder position in the area of disability inclusive programming and development at regional and country levels, laying the foundation for future programming, research, and advocacy work, summarized below.

A total of 45 semi-structured qualitative interviews were conducted for this study with a breakdown of 29 in-depth interviews with persons with disability; one focus group discussion (FGD) with six females with disabilities; five FGDs (composed of four to six persons per group) among families or caregivers of persons with disability; five FGDs with stakeholders (composed of four to six persons per group); and five key informant interviews were conducted with stakeholders such as (governmental sectors such as health, social development, education ministries national non-governmental organizations (e.g. unions, councils and centres for persons with disability and health organizations); and UN agencies (e.g. UNFPA, UNHCR, and UNRWA). Persons with disability participants were from 15-53 years old.

Additionally, the research team conducted a desk study of published academic and grey literature. The literature search and review affirm that academic and grey literature sourced from the Arab region is limited, and with deep gaps at the country level. In total, the search produced only 30 relevant academic articles and 42 from the grey literature, for a total of 72 articles reviewed. The academic and grey searches focused on literature from the case study countries, also noting some general references.

## Key findings

Persons with disabilities listed the barriers that influenced their access to sexual and reproductive health services and information as: the expenses related to treatment; difficulty communicating with doctors and health service providers; the lack of trust in service providers and others; logistical barriers such as access to healthcare facilities, and; the shame related to seeking information and services.

The interviews revealed that there is a general lack of understanding of sexual and reproductive health issues from the perspective of unmarried persons with disabilities. Marriage was often perceived as the entry point for seeking and obtaining knowledge and understanding of SRH issues. Additionally, the study shed light on the sensitivity of SRH issues in the region, revealing various stigmas, cultural beliefs, and norms that can initiate feelings of embarrassment and shame when persons with disability attempt to discuss these issues.

Disability surfaced as a central characteristic of individual identity, making it challenging to identify and distil the influence of other marginalized characteristics, such as age or gender, in participants' responses to questions focusing on gender-based violence. In turn, violence was widely identified by participants across different disabilities and genders as an issue of primary concern. It occurs against persons with disability both in the domain of the household and outside the household (e.g. among friends, neighbours, co-workers, health care providers and from strangers encountered in public spaces).

In all four case study countries, stakeholders revealed there is a lack of detailed data available that captures SRH and GBV for persons with disabilities. Strategies and recommendations for improving access to SRH among persons with disabilities addressed some underlying barriers. These included factors such as stigma, embarrassment and shame related to SRH involving the in-depth mapping of resources, information, and services available to persons with disabilities. The current policies and institutional frameworks, therefore, appear to call for expanding the rights and access of persons with disability to SRH services. However, those persons are not able to enjoy these rights as services are "equal" but not "equitable" for persons with disabilities.

## Five lessons learned from the research findings

### Lesson 1

The research found a lack of disaggregated data by age, gender or disability status among the case study countries. This situation exists despite gains in census data collection, including the use of Washington Group Questions, which capture data on persons with disability. Countries using Washington Group Questions on their censuses, include the State of Palestine Census 2017, Jordan Census 2015, and Morocco Census 2014. While Sudan in its 2008 census did not use Washington Group Questions, indicators related to disability were included such as “limited use/ loss of leg(s)”, “limited use/loss of arm(s)”, “difficulty in hearing/deaf”, “difficulty in seeing/blind”, “difficulty in speaking/mute”, “mental disability” and stakeholders shared plans to include the Washington Group short set of disability questions in the upcoming census form. Moreover, Palestine included disability data in some national surveys such as the Domestic Violence Survey, 2019 and the Multiple Indicator Cluster Survey (MICS) which included special modules for collecting data on the prevalence of functional difficulties among children aged 2-17 years according to the information given by the mother or the caretaker. Additionally, stakeholders from Morocco reported to conduct national research on disability every ten years in order to collect information on the conditions and manifestations of disability. Furthermore, research studies in the region devoted to understanding SRH among persons with disabilities were limited. A knowledge gap exists, therefore, and hinders the formation of a shared and collective understanding of the issues and priorities of persons with disabilities. Efforts to understand and monitor the SRH and gender-based violence experiences and needs among persons with disability should focus on developing specific, age and gender disaggregated indicators for SRH and gender-based violence. There is also a critical need to distinguish between gender-based violence and disability-based violence. A revised research agenda should further prioritise SRH issues from the perspective of persons with disability themselves.

### Lesson 2

SRH was characterized by interviewees and focus group participants (e.g. stakeholders and persons with disability) as a sensitive topic throughout data collection. The sensitive nature of the topic was also emphasized through the non-responsiveness or silence among unmarried persons with disabilities. Additionally, this study revealed that a myriad of assumptions and stigma was experienced by persons with disabilities. The study also identified core issues of vulnerability (especially related to violence), deprivations of persons with disabilities' reproductive rights (denied/limited access to sexual and reproductive health information and services and other forms of social exclusion fuelled by assumptions, stigma, and various cultural/societal norms). In many cases, persons with disabilities advocated their right to have normal sexual development, sexual drive, and a desire to get married and start a family. However, harmful assumptions by members of the family/community (e.g. parents, neighbours, and healthcare providers) and stigma regarding persons with disabilities' sexual development, reproductive capabilities, and eligibility for marriage exacerbate barriers for persons with disabilities seeking sexual and reproductive health services and information.

### Lesson 3

Throughout the analysis, persons with disability expressed that disability was a central characteristic of their identity, making it challenging to identify and distil the influence of other marginalized characteristics such as age, gender, and refugee status. The dominance of intersecting identities in this context masked conclusions about the current situation of GBV within this population. It also emerged that person with disabilities face intersecting forms of marginalisation, discrimination, oppression, and exclusion leading to violence at both the household and community levels. New approaches are needed to address the mutual and intersecting processes of marginalisation, discrimination, oppression, exclusion experienced by persons with disabilities in this context, especially through the lens of intersectionality. These characteristics should be explored in-depth to develop an understanding of how gender, refugee status, and age may intersect and influence SRH and GBV related experiences for persons with disabilities.

### Lesson 4

Participants indicated that equal treatment was perceived as the delivery of services but without acknowledging or accommodating the special needs of persons with disabilities (“I get the same treatment as everyone else”). The finding underscores the importance of equity, which recognizes that persons with disabilities may have distinct needs that must be met to achieve equal SRH outcomes. It was often reported that provisions of equal treatment fail to acknowledge the special needs and accommodations needed by persons with disabilities. It also prevented them from receiving quality sexual and reproductive health care and services that meet their needs.

### Lesson 5

It was often suggested that improvements to service infrastructure and capacity development of service providers was needed to ensure that specialised accommodations are available, such as sign language interpreters. Further improvements to facilities, specialized facilities or departments for persons with disabilities, and increased enforcement of laws that prevent violence against persons with disabilities is required. However, findings from this formative research show that it is important to acknowledge the distinction between equity versus equality when addressing the specific barriers that exist for persons with disabilities in accessing SRH services and information. There is a need to improve accessibility, cultural sensitivity, and equity (support services needed to serve persons with disabilities) throughout the region. In sum, persons with disabilities are have the right to equitable access to SRH information and services and further efforts are needed to ensure that health policies have upheld their commitment to inclusion, providing universal healthcare for all.

## Summary of key recommendations

Scaling up research and inclusion efforts, and the tailoring of existing interventions are needed to ensure that SRH services and information can be more inclusive of persons with disabilities in the region. The following recommendations are based on research findings and promote these objectives.

## Research and data

1. The research findings should be communicated with relevant ministries, institutions, and the National Bureaus of Statistics. Developing specific SRH and GBV indicators (disaggregated by sex and age) for persons with disability is critically prioritized to improve data availability and quality. Such evidence is necessary to inform future policy and programmes.
2. A revised regional and national SRH research agenda is required, emphasising the inclusion of persons with disability. Adopting the inclusion agenda, with a distinct focus on SRH and GBV for persons with disabilities throughout the region, would contribute to enhanced evidence and the development of tailored and inclusion-focused policy, programs, and advocacy initiatives.
3. Build towards more engaging and empowering inclusion efforts in further research studies. This can be achieved by amplifying the voices of persons with disabilities, especially refugees or internally displaced, and people who have direct experience with disability. UNFPA ASRO's research agenda should ensure that the perspective of persons with disability is sought and considered.
4. More detailed research studies, especially from an intersectional/life cycle approach, are needed for understanding country specific SRH concerns. As part of the initiative, a basic understanding of the assumptions, stigma, and various cultural/societal norms experienced by persons with disabilities seeking SRH services should be used and promoted as an entry point for policy development.
5. Further investment in documenting and exchanging experiences of best practices between different countries in the regions is required. A regional database or observatory hosted by UNFPA ASRO could facilitate such an exchange. Availing a regional data base for SRH and GBV research and data sources, is believed to enhance exchange of information and a shared understanding of the needs and situation affecting persons with disability in the region in general and in relation to SRH in specific.
6. Exchange experiences of best practices from other regions or countries. A regional database or observatory hosted by UNFPA ASRO could facilitate this. Establish a knowledge database where statistics and research regarding persons with disability can be readily shared throughout the region, so that countries within the Arab region can share and exchange information about persons with disability. Then in the future, this platform can be developed for sharing lessons learned. This knowledge database can also contribute to a shared understanding of the needs and situation affecting persons with disability in the region.

## Laws and policies

7. Efforts by policy makers to improve access to SRH services for persons with disabilities should consider the core issues of vulnerability and deprivation to comprehensively expand and improve the inclusion of persons with disabilities.

## **SRH and GBV programmes**

8. Develop programmes that provide targeted information and support for persons with disabilities, to ensure that they are protected from sexual or other forms of violence, and the risk of being victimized. Effective programming needs to target female and male persons and different types of disability. It should empower persons with disability with tailored tools that facilitate identification and reporting of violent acts towards them.
9. Strengthening the capacity of organizations that serve persons with disabilities is essential; through proper and effective outreach and awareness activities, the different circles of influence such as parents, friends, local communities, and society at large understand the rights and needs of persons with disabilities regarding SRH issues at different stages of their lifecycle.
10. Expand the scope of training for parents and care givers on how to provide improved support systems and become better advocates for persons with disabilities, especially in relation to their SRH needs.
11. Training for parents and care givers on how to provide improved support systems and become better advocates for persons with disability, especially in reference to SRH needs.

## **Services-related recommendations**

12. More equitable access to SRH services and information can be promoted by ensuring that evidence from research studies contributes to inclusion policy revisions and/or policy development and more human rights/inclusion focused practical guidelines for treating persons with disabilities. This may include non-stigmatizing and inclusive program development and training for doctors, healthcare workers, and data collectors about the specific needs of this population.

## 2. Introduction

### 2.1 Background

Globally, one billion people (approximately 15% of the global population) experience disability and are, therefore, a focus of the 'leave no-one behind' agenda.<sup>1</sup> According to the UN Convention on the Rights of Persons with Disabilities (UNCRPD), persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.<sup>2</sup> Evidence suggests that often, people with disabilities experience a wide range of challenges such as exclusion, limited access to quality health care, education, and/ or employment opportunities.<sup>1</sup> Persons with disabilities face layered disadvantages causing them to be at higher risk of developing secondary conditions/ health problems which may have a downstream effect on education and work since it can lead to impaired cognitive skills and physical conditions.<sup>3</sup> Yet, persons with disability still encounter barriers to care pertaining to accessibility (e.g. time distance, affordability, and accommodation at health facilities).<sup>3</sup> Furthermore, people with disabilities may experience social and structural barriers and are more likely to be excluded from social and cultural aspects of everyday life.

Disability is increasingly understood within the context of human rights and is closely linked to wellbeing.<sup>4</sup> It is also important for international development, leading to approaches in rights-based disability inclusive development.<sup>5,6</sup> According to the World Health Organization, a majority of people with disabilities live in low- and middle-income countries (LMICs), where evidence suggests that people with disability are disproportionately affected by poverty. This demonstrates how disability, poverty, and health outcomes can be interlinked.<sup>7</sup> Additionally, persons with disabilities may experience additional layers of discrimination or stigma due to one or more additional layers of vulnerability or marginalization, including gender, age, economic status, ethnicity, sexuality, race, and nationality.<sup>8</sup>

Over the last decade, a major global focus on disability as a development priority has been witnessed. Against the backdrop of the Convention on the Rights of Persons with Disabilities in 2006 and the 2030 Agenda for Sustainable Development, there has been a substantive push to improve inclusion efforts to target people with disability globally, giving recognition to the inclusion of persons with disabilities as a fundamental part of ensuring sustainable development for all.<sup>9</sup> Specifically, the 2030 Agenda for Sustainable Development Goals (SDGs), SDG 3, target 3.7, works to ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes by 2030<sup>10</sup> and SDG 5 prioritizes the eradication of gender-based violence (GBV) and ending all forms of discrimination against women and girls, including the elimination of violence and harmful practices like child and early marriage and female genital mutilation.<sup>11</sup>

Although the literature reveals overlaps between GBV and sexual and reproductive health and reproductive rights (SRHRR) in certain areas, such as forced or coerced abortion or sterilisation, early and child marriage, and female genital mutilation,<sup>11</sup> this study applies an understanding of SRH as articulated by Starrs et al. (2018).<sup>12</sup> This definition of SRH includes a diverse set of priority issues including but not limited to healthy pregnancy and childbirth, contraception, post-abortion care, and GBV. For this study, the research team focused on GBV as a specific component of SRH, since

persons with disability are at increased risk of violence and women with disabilities have an increased vulnerability to GBV and abuse.<sup>13,14</sup> A report on ending GBV, and realizing sexual and reproductive health and reproductive rights among young persons with disability suggests that young persons with disability are almost four times more likely than their peers without disabilities to be exposed to abuse, with young persons with intellectual disabilities, especially girls, at greatest risk.<sup>11</sup> Nevertheless, still disabled women generally face barriers to accessing sexual and reproductive health services, in part due to the assumption that they are asexual.<sup>15</sup> Barriers to accessing information, education and services related to sexual and reproductive health and GBV were exacerbated during the COVID-19 pandemic among persons with disabilities, especially among girls and women.<sup>15,16</sup> Combined with existing inequalities within access to health information and services, these disruptions may further exacerbate existing health disparities related to sexual and reproductive health among persons with disabilities. Therefore, it is essential that future SRH programmes for persons with disabilities are designed to be responsive of the impacts of pandemics including COVID-19 to ensure that SRH information and services are inclusive.<sup>16</sup>

## 2.2 Arab regional context

Despite that many countries in the Arab region share a common language, religion, and cultural similarities, the region's diversity is reflected in countries' differences in humanitarian contexts; socio-economic development indicators, social/cultural norms, ethnicities, political systems and national identities.<sup>17,18,19</sup> For example, several countries in the region have been affected either directly or indirectly by armed conflicts of varying intensity including the Arab Israeli conflict; Iraqi wars; Arab Spring; and the Syrian and Libyan civil wars.<sup>20</sup> These armed conflicts have resulted in the rise of disabilities between the affected populations. Furthermore, several countries in the Arab region are currently undergoing political turmoil and economic stress due to the COVID-19 pandemic.<sup>21</sup>

Commitments made to inclusion and international development agendas (Convention on the Rights of Persons with Disabilities in 2006, United Nations International Conference on Population and Development (ICPD) in 1994, the United Nations Disability Inclusion Strategy, and the 2030 Agenda for Sustainable Development) have also afforded a special opportunity for developing an in-depth understanding of the social and structural challenges of exclusion in the region.<sup>10</sup> For example, there has been growing commitment in the region to acknowledge disability not only as a medical condition, but an effect of barriers in the physical and social environment.

The Economic and Social Commission for Western Asia's (ESCWA) 2014 seminal report, entitled, *Disability in the Arab Region: An Overview*, was a first attempt to collect and analyse data relating to disability in Arab countries.<sup>22</sup> While the second edition of the report shows the considerable efforts of many countries to enhance the availability and quality of disability/related data<sup>23</sup> including the Washington Group recommended questions,<sup>24</sup> according to the report, the Arab region has low disability prevalence rates when compared to other regions.<sup>23</sup> ESCWA suggests that this may be due in part to the young average age in several Arab countries given that age plays a role in disability prevalence rates with disability being positively correlated with ageing (therefore younger are likely to have less disabilities).<sup>23</sup> Furthermore, in many Arab countries, the prevalence rates were higher among men than among women,<sup>23</sup> demonstrating that gender and age are additional layers of vulnerability

in this context. This is especially pertinent considering that these groups may only represent a small percentage of the overall population thus, hardest to reach and least likely to benefit from general developmental gains.<sup>23</sup>

Research suggests that in many ways, SRH is shaped by the cultural, economic, and social norms of a particular context. Zahlan et al. (2020) suggests that in the Arab region, there are several prominent cultural sensitivities and taboos surrounding SRH which may affect the accessibility and utilization of SRH information and services.<sup>25</sup> For example, the region's diversity is also reflected in the total fertility rates (TFR) which vary among countries, thus reflective of the differences in contraceptive accessibility and use.<sup>26</sup> Moreover, according to Kabakian-Khasholian et al. (2020) despite progress to improve health outcomes and advance universal health coverage, political unrest, armed conflict and the resulting humanitarian crises has impeded access to SRH services and shifted national priorities away from sexual reproductive health issues.<sup>27</sup> Moreover, many Arab countries adopted SRH policies after the 1994 United Nations' International Conference on Population and Development in Cairo to increase access to comprehensive sexual and reproductive health services for persons with disability, regardless of marital status and age.<sup>16</sup>

Although a majority of countries in the Arab region (with exceptions of Sudan and Somalia) are signatories of the Convention on the Elimination of all forms of Discrimination Against Women, national response to GBV continues to be fragmented (e.g. some countries have criminalized GBV while others have not).<sup>27</sup> According to World Health Organization (WHO) data in the Arab region,<sup>29</sup> 37% of women have been subjected to intimate partner violence or non-partner sexual violence.<sup>30</sup> Furthermore, displacement or consistent movement and relocation caused by crisis exposes women to vulnerability and insecurity including various forms of GBV.<sup>31, 32, 33</sup>

Addressing SRH and GBV within humanitarian setting is crucial especially for refugees with disabilities who are at a greater risk of deprivation of sexual and reproductive health and reproductive rights and exposure to violence. Unfortunately, they are less likely to be included in efforts to address GBV in refugee camps and other humanitarian settings.<sup>11</sup> Yet, in Arab countries, limited data is available that captures the SRH among persons with disabilities including service delivery of sexual and reproductive health in terms of availability, accessibility, and affordability. This also indicates a greater unmet need relating to an increased risk of poor health outcomes associated with potential health complications and poor life quality.<sup>10</sup>

## 2.3 Research rationale

The Arab context is uniquely complex and relatively conservative. SRH and GBV are considered taboos in general and among disabled people in specific as well. Therefore, this formative research study was commissioned to shed light on these issues specifically for persons with disabilities. This study was rooted in a socio-ecological framework with a goal to develop tangible recommendations for policy, programmes and service delivery. Through this approach, this research provides a holistic picture of the needs, and barriers to SRH services and information from the perspectives of persons with disability themselves, their families and/or primary caregivers, in addition to policy and programmatic stakeholders.

Our definition of SRH includes a diverse set of priority SRH issues, including but not limited to, healthy pregnancy and childbirth, contraception, abortion, and GBV. For this study, we focused on GBV as a specific component of SRH, since persons with disability are at increased risk of violence and women with disabilities have an increased vulnerability to GBV and abuse.<sup>13,14</sup>

## 2.4 Research objective

The overall goal of the study was to develop an in-depth understanding of the sexual and reproductive health and reproductive rights (SRH&RR) concerns, gender disparity and GBV, effects of age to address challenges related to disabilities in the Arab region. Additionally, this study identified and explored gaps pertaining to the scarcity and quality of available data on disability in the region in relation to SRH and GBV for different age groups.

## 2.5 Research scope and aims

To organize our understanding of this complex and multidimensional issue, our study was grounded in the socioecological model. Application of the socioecological approach shed light onto the various layers of influence, capturing interactions of an individual with their physical and sociocultural environment.<sup>34</sup> These layers of influence included the intrapersonal, interpersonal, organizational, community and public policy spheres.

### The specific research aims of the study were threefold

1. To analyse existing evidence, policy environment, service delivery infrastructure, programmatic experience in addition to the available data and indicators related to SRH and GBV for persons with disability in each of the selected countries of the Arab region.
2. To enhance our understanding of the perceptions of persons with disability about their SRH needs in addition their experiences in accessing SRH and GBV services and information in the selected Arab countries.
3. To explore the perceptions of and the potential role of family and/or primary caregivers for persons with disability in supporting their SRH needs.

## 3. Methodology

### 3.1 Methodology for qualitative data collection and analysis

To achieve the specific aims of this study, we adopted a qualitative formative research approach. The study design ensured representation of ideas, opinions, suggestions, and recommendations concerning SRH among varied levels of stakeholders in each of the selected countries in the region. The stakeholders were identified as: persons with disability, their families, in addition to policy and programmatic stakeholders.

### 3.2 Sample and sampling techniques

A multi-stage methodology was used to select four Arab countries, which reflect the diversity of conditions and challenges facing persons with disability. The final sample included countries at different levels of development, and in acute or protracted humanitarian crisis. Based on this sampling strategy, Morocco, Palestine, Jordan, and Sudan were selected as country case studies for this research study.

**Table 1. Overview of disability prevalence and data availability in each selected country**

Country	Census/Survey	Year	WGSS*	Disability prevalence rate
Jordan	Census	2015	✓	2.1
Morocco	Census	2018	✓	5.07
Palestine	Census	2017	✓	2.1
Sudan	Census	2008	×	4.80

\*Washington Group Short Set Questions (WGSS)

**Sources:** Disability in The Arab Region, ESCWA 2018 and Palestinian Central Bureau of Statistics (PCBS) 2017

Within each country, the research team recruited a representative sample using the snowball and convenience sampling techniques. The sample for this study was gender balanced, inclusive of different types of impairments and marital status, and comprised of different humanitarian (e.g. internally displaced or refugee) and geographical (rural and urban) contexts.

**Table 2. Sampling strategy and total sample per participant group**

Participant group	Sample	Sampling strategy
Persons with disability	35	Convenience
Family caregivers	26	Convenience
Policy and programmatic stakeholders	31	Purposive

A total of 34 semi-structured qualitative interviews and 11 focus group discussions were conducted for this study with a breakdown of 29 in-depth interviews with persons with disability; one focus group discussion (FGD) with six females with disabilities; five FGDs (composed of four to six persons per group) among families or caregivers of persons with disability; five FGDs (composed of four to six persons per group) among stakeholders; and five key informant interviews were conducted with stakeholders such as (governmental sectors such as health, social development, education ministries national non-governmental organizations (e.g. unions, councils and centres for persons with disability and health organizations); and UN agencies (e.g. UNFPA, UNHCR, and UNRWA). Persons with disability participants were from 15-53 years old and more information regarding the demographic characteristics of this group are presented in Table 3.

**Table 3. Demographic characteristics of persons with disability participants**

Demographic characteristics of participants that identify as persons with disability	Number
<b>Country</b>	
Palestine	13
Jordan	9
Sudan	8
Morocco	5
<b>Sex</b>	
Female	20
Male	15
<b>Marital status</b>	
Single	20
Married	14
Widow	1

<b>Place of residence</b>	
<b>Urban</b>	23
<b>Rural</b>	8
<b>Camp</b>	4
<b>Types of disability</b>	
<b>Physical</b>	20
<b>Deaf</b>	6
<b>Blind</b>	5
<b>Physical and intellectual</b>	4

While the participants in the FGDs for family members and caregivers were 26 including fathers, mothers, brothers, sisters, grandparents, and friends for persons with different types of disabilities mainly the intellectual disabilities and from different geographical areas (e.g. urban and rural settings). A total of 31 informants participated in the stakeholders FGDs and KIIs which included 18 females and 13 males belonging to different governmental non-governmental entities (please see Appendix C for list).

### 3.2.1 Data collection procedures

The interviews lasted for approximately 45 minutes to one hour while FGDs lasted for approximately 1.5 hours. Moreover, interviews/FGDs were conducted in the language of the country (either Arabic or French). All interviews and FGDs were semi-structured meaning that data collectors used an interview guide with open ended questions and probes (see Appendix D for data collection instruments). Interviewers were trained on qualitative interviewing techniques, research ethics, and how to conduct data among persons with disabilities surrounding potentially sensitive topics such as SRH and GBV. Data sources included semi-structured interviews and/or FGDs with the three types of participant groups (e.g. 1) participants who self-identify as persons with disability, 2) families and/or caregivers of persons with disability, and 3) stakeholders who work with persons with disability).

In addition, the methodology involved a consultative approach to the design, data collection, and analysis involving collaboration and partnership with persons with disability and organizations that serve them to provide a holistic integration of varying perspectives and insights into the experiences of persons with disability and their needs in the Arab region. Many of the data collectors who conducted interviews and FGDs were well oriented in the disability context in their respective countries, working closely with programs and centres that serve persons with disability. Additionally, one data collector had a disability and three were certified sign language interpreters. Introductory information sessions about the study's objectives and methodology were conducted with persons with disability through unions and centres prior to data collection which helped the research team to understand the disability context in terms of limitations. Moreover, the coordination for data collection with persons with disability and their families was conducted closely with persons with disability serving organizations and centres who also hosted some interviews or FGDs.

### 3.2.2 Data analysis

All individual interviews and FGDs text were recorded and transcribed into English by a bilingual transcriber. Translation was frequently checked by the bilingual research team to ensure quality and adequacy of capturing study themes and context. All English transcripts were then uploaded into Dedoose qualitative data analysis software and analysed. Furthermore, to increase rigor of analysis, the research team engaged in four inter-coder reliability exercises in which three members of the research team coded excerpts from a transcript and discussed how codes were applied.

Data analysis was conducted using qualitative research software, Dedoose and conventional content analysis was used for the coding of transcript text.<sup>34</sup> Conventional content analysis helps reduce data conceptually to describe a particular phenomenon through the development of categories and concepts.<sup>34, 35</sup> The research team also used Attride-Stirling thematic analysis approach for the development of themes.<sup>36</sup> Through this process, meaningful segments of text were extracted to identify overarching themes to demonstrate the 'richness of the phenomenon'.<sup>37</sup> Table 4 presents an example of how codes were developed into themes using thematic analysis.

**Table 4. An example of the analysis process in qualitative interviews**

Global theme	Basic themes (Codes)	Illustrative quote
Marriage as gateway or prerequisite for knowledge and understanding of SRH	Reproductive rights Marriage	If I presented this topic to my close people in life, they would say that it's shameful and that I'm a girl and can't ask this, but I didn't stay silent on this. I looked for information on my own, but I didn't talk to someone specialised. I wanted to know if I can be pregnant, and I wish to contact someone who is specialised in these topics. If I got married and was pregnant, will my legs carry me while I'm pregnant? I wish to become a mother, but can my body handle it? This is what I think about. (female, person with disability, Jordan)

### 3.3 Search strategy for literature search

Additionally, the research team conducted a desk study of published academic and grey literature. Any quantitative findings referenced to in this report were extracted from publicly available sources such as published literature and reports.

In order to develop a foundation to this formative research study, the research team conducted a review of published documents in the scholarly and grey literature that focus on the social and structural challenges faced by persons with disability related to SRH and GBV taking into consideration age and other associated vulnerabilities (see Appendix B for a complete list of reviewed literature). The intent of this literature review was to gain an overview of SRH and disability in the regional context and to accomplish Specific Aim 1: to analyse existing evidence, policy environment, service delivery infrastructure, programmatic experience in addition to the available data and indicators related to SRH and GBV of persons with disability in each of the selected countries of the Arab region.

A review of academic literature was conducted of studies published from 2015 to 2021, and literature published in English on persons with disabilities and SRH in Arab countries, while the review of grey literature involved literature in Arabic, English, and French from 2011-2021. These desk reviews focused specifically on identifying and mapping available information, using various databases such as PubMed, Google Scholar, Open Grey, Development Experience Clearinghouse (DEC) and UN websites e.g. UN Women, UNFPA, UNHCR and WHO and ministry websites such as ministries of health, social development, and education in the selected countries.

In addition, searches were conducted on websites of some national non-governmental organizations which advocate or provide sexual and reproductive health services or guidelines. The research team defined grey literature as documents published online or available only in hard-copy, but outside of the sphere of academic, peer-reviewed literature (for example, policy statements, treatment protocols, training manuals, clinical guidelines, technical reports, and national guidelines/ strategy documents). Data sources also included any relevant references of the documents initially identified to ensure a thorough and rigorous review of documentation. To ensure comprehensive search terms across different aspects of SRH those included and articulated by Hameed et al. (2020)<sup>38</sup> were used. Some examples of search terms included in the literature review were 'disability'; 'Morocco', 'Jordan', 'Palestine', or 'Sudan' and the key search terms for SRH. These search terms helped to identify relevant scientific peer reviewed materials (see Table 5 for all search terms used).

**Table 5. Search terms included in the systematic review**

TERMS	Intrapartum, reproductive health, reproductive services, reproductive outreach, reproductive programming, urogenital disorders, menstrual health, premarital, sexually transmitted infections (STIs), HIV/AIDS, PMTCT, HIV testing, STI testing, comprehensive sexuality education (CSE), family planning and contraception, abortion, gender based violence (GBV), sexual violence, female genital mutilation, sexuality, sexual health, sexual dysfunction.
Terms related to the geographical context	Arab region, Arab states, Morocco, Jordan, Palestine, Sudan
AND	Disability

All search results were screened using the following search criteria (Year, Specific Topic, and Country).

### 3.4 Ethics

The research study was designed following guidelines from the World Medical Association (WMA) Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects and in congruence with the United Nation’s Convention on the Rights of Persons with Disability. Moreover, best practices for protection of human subjects with disability in research were also employed.<sup>39</sup> Additionally, given the current climate due to COVID-19 pandemic and restrictions, and political situation in Sudan, specific measures were taken to maintain the research ethical principles for face-to-face data collection so specific ethical concerns regarding safety, do no-harm, privacy, transparency, confidentiality were implemented.

The research team ensured that certain safety measures were taken before data collection to limit contact (especially considering the military occupation in Sudan which began during data collection). During qualitative semi-structured interviews and FGDs, the confidentiality of participants' (e.g. persons with disability, their families and/or caregivers, or stakeholders) was protected. Transcripts were de-identified and assigned an identification number to protect participants' privacy. Furthermore, participants were informed that they may withdraw from the study at any time. Moreover, the research team ensured provision of emotional support during interviews and FGD by giving participants time to express significant emotions and providing some participants with an information sheet that provides an overview of resources available that provide special psychosocial support. "Do-no-harm" principles were considered throughout the research process and applied with a gender, age, and equity lens.<sup>40</sup>

To minimize the risk of emotional distress, the researchers fostered an emotionally supportive environment which involved the establishment of group norms among participants in FGDs. In addition, participants were free to withdraw from the study, leave the virtual chat room, or refrain from contributing at any time. As for data privacy, sharing files between researcher computers, if necessary, was done through a secure transfer, after which the files were deleted. Investigators also ensured that any notes taken during qualitative semi-structured interviews and FGDs refrained from including identifiers and participants were only referred to as numbers. After each session, notes were typed, and original copies destroyed.

### 3.4.1 Informed consent procedures

Given that this study involved persons with disability, as research participants extra care and consideration was taken when assessing the capacity of a potential research participants' ability to provide voluntary consent. For all persons with disability who participated in this study, a consent process took place that ensured that their rights were protected (e.g. the research participant can exercise free choice without constraint or coercion).<sup>39</sup> Furthermore, all consent processes involved the disclosure of research intent to all potential research participants, outlining potential benefits and risks with participation. In each country context, partnering organizations helped recruit research study participants (e.g. persons with disability, family members and/or please care givers) to participate in research activities.

### 3.5 Limitations

The research process encountered limitations, primarily related to the field research. Some were anticipated and identified as risks during the inception and design process. Others emerged during the field study, usually as events related to context. In all cases, the limitations were jointly assessed between the research team and UNFPA ASRO, with agreement on mitigating measures. To meet these challenges, the frequency of status meetings was changed from monthly to biweekly.

Among the most significant challenges faced were time and resources. The process would have benefited from more of both. COVID-19 remains a process variable, which places some limitations on access to persons with disability and stakeholders.

It was correctly assessed during inception that the ethical clearance process would be a challenge. Two countries were eventually dropped from the study, as it was determined the clearance process would not be completed in time. One new country was added on short notice, with the result that sample size dropped from five to four countries.

For countries that were dropped, lost was the investment made in presenting the clearance application, the initial gathering of literature and efforts to recruit and train field researchers. Further, the process had to be repeated in the one new country. These were necessary changes, but presented a significant disruption given the time and resource limits.

The field process was negatively affected also by events in Sudan, after the military seized power. Field work was largely completed, but finalisation was hindered by security concerns, and cuts to power, internet and communications. The research team acknowledges the efforts of the Sudan field study team under these difficult conditions.

Challenges and limitations are also a base for lessons learned. Field researchers noted that the topics of SRH and GBV are relatively new, and both personally and culturally sensitive. This appeared to apply as much to stakeholders as the disable persons interviewed.

## 4. Summary of findings

### 4.1 Results and findings from the literature review

Section 4 comprises a summary of the results and findings from two sources; a search and review of academic and grey literature (Sections 3.1 and 3.2) and key informant interviews and focus group discussions from the four country case studies (Section 3.3).

#### 4.1.1 Results of the literature review

The literature search and review affirm UNFPA's original hypothesis, that academic and grey literature sourced from the Arab region is limited, and with deep gaps at the country level. In total, the search produced only 30 relevant academic articles and 42 from the grey literature, for 72 articles reviewed in total. The academic and grey searches focused on literature from the case study countries, also noting some general references.

PubMed was used to search for academic articles, configured for English language publications. Only articles published from 2011-2021 were considered for further review. Relevant articles were reviewed by type (epidemiological study, intervention, descriptive research, or policy); ecological model level; disability type; lifecycle classification; and key findings. The initial search yielded 53 articles (Region=23, Jordan=14, Palestine=2, Morocco=6, and Sudan=8). Of these, 22 articles were duplicates, leaving 31 articles. On application of the exclusion criteria, only three relevant articles from the region or countries were selected.

The academic literature search was then complemented by a Google Scholar search, using the same parameters. The search identified an abundance of irrelevant literature, due to the widespread use of "disability adjusted life years" or DALYs, which are typically used to assess the magnitude of disease, health risks, and premature death in academic research. The DALY metrics fail to capture a complete picture of disability as defined by the UNCRPD, and do not contribute to accomplishing Specific Aim 1. The review focused on understanding SRH within the context of seeking SRH. It did not explore SRH as a determinant of disability. Articles mentioning "disability" in the context of DALYs, therefore, were excluded from the literature search.

For grey literature, searches were conducted using Open Grey and DEC. No documents relevant to the study (documents on GBV SRH, and disability) were discovered. Open Grey produced 209 documents related to disability in the DEC (Jordan=92, Palestine=48, Morocco=46, and Sudan=23). However, only one article was found relevant to the 24 searching terms of the study.

As a final source, 15 documents were referred to by key informants or stakeholders during qualitative data collection activities. The request for references was made during the country study interview process. These sources were included and reviewed.

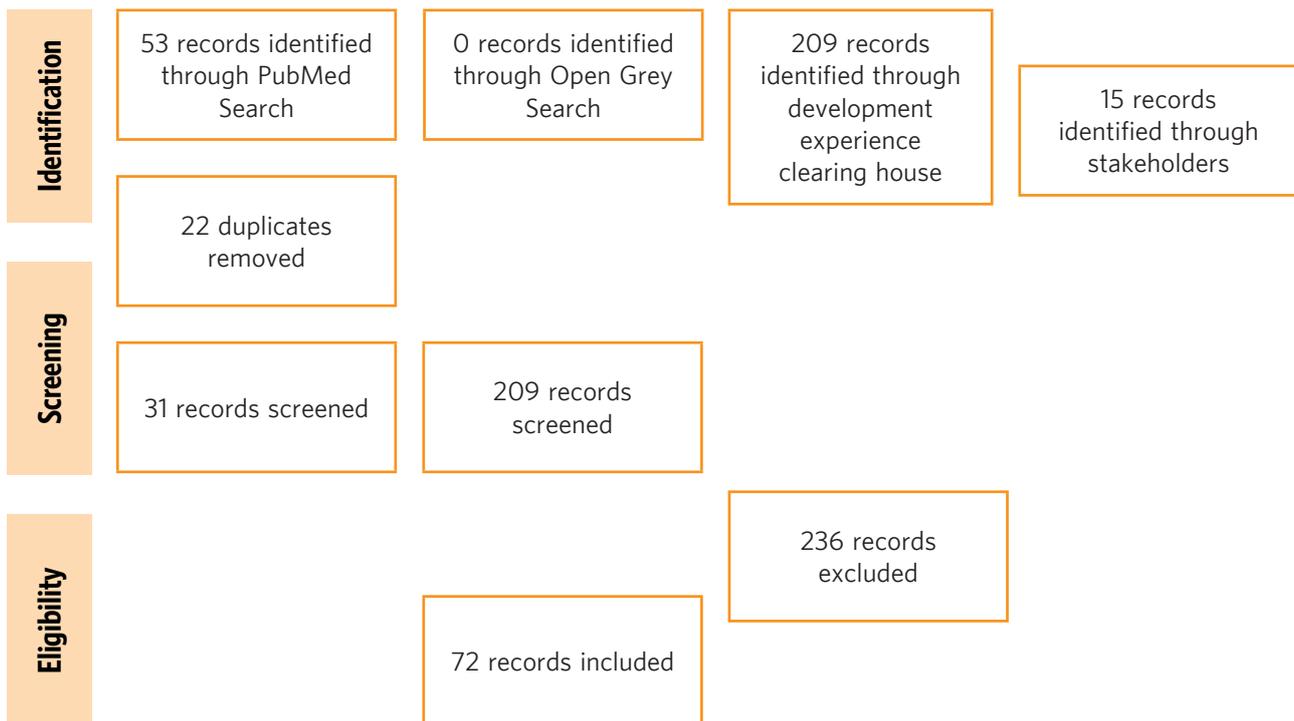


Figure 1 Visual representation of literature review

### 4.1.2 Existing academic literature

The existing literature offers almost no content of direct relevance to this formative research exercise which sought research on SRH among persons with disabilities in the Arab context. Some literature was of secondary relevance, providing content of relevance, including on the societal context in which SRH can be approached in national situations. The search, therefore, affirmed UNFPA’s hypothesis that SRH issues in the Arab region are understudied specifically for persons with disability.

The search identified a limited body of academic literature on disability sourced from within the Arab region,<sup>41,42</sup> and originating from the four case study countries.<sup>43-56</sup> Of articles and documents reviewed, few addressed SRH issues as their primary subject, and none were written from the perspective of persons with disability themselves. The finding suggests that academic institutions may not yet prioritise SRH among persons with disability living in Arab countries.

Among highlights from the literature review, Eissa Saad & Borowska-Beszta’s (2019) theoretical review and comparative analysis of disability in the Arab countries assesses the historical and cultural perceptions/practices, causes, and the prevalence of disability throughout the Arab region<sup>57</sup>. Their manuscript proposes that consanguineous marriage and child/early marriage are a cause of disability in the region, in which children of consanguineous parents or young mothers are at an increased risk.

Other articles focused on disability and marriage, which is not a traditional component of SRH but can be a gateway issue given the social importance of marriage in the Arab context.<sup>58,59</sup> Although the lifecycle approach was not adequately represented in the literature, some articles focused on menstruation.<sup>60,61</sup>

Several articles discussed how traditional herbal and mechanical methods are used to induce abortion in the Arab region and may contribute to a high prevalence of permanent disability.<sup>105</sup> However, these articles primarily focused on the causes of disability in relation to SRH issues, rather than the experiences of persons with disability with SRH.

The African Disability Rights Yearbook, included a chapter on 'The Sexual and Reproductive Health Rights of Women with Disabilities in Africa', establishing the extent to which the standards set out in the African Women's Protocol and the CRPD promote and protect the sexual and reproductive health and reproductive rights of women with disabilities in Africa. Although this chapter does not explicitly focus on Arab countries, Sudan is referenced in the Doebeller case, in which the African Commission concluded that subjecting school girls to caning in public (a provision of the Sharia penal code) undermines their fundamental rights to dignity and to be free from inhuman and degrading treatment.<sup>62</sup>

A country report on Morocco by Kanter, Sore & Van Sant (2015) assesses the 2014 census data, which collected information on disability in Morocco. The report identifies human rights concerns for people with disabilities living in Morocco, suggesting that some categories of disabilities (excluding mental disabilities) receive less awareness and fewer resources. The report also notes the belief that disability is a punishment or "God-given" is widely held in the country.

Several documents authored by the Women's Refugee Commission (WRC).<sup>63</sup> explore the inclusion of persons with disability in humanitarian responses, however, there is little focus on SRH. In a 2010 report, entitled, "Disabilities among Refugees and Conflict-Affected Populations" reported that in Jordan, 41% of disabled refugees surveyed reported that they did not have access to health services, and only 23% said they had access to treatment or health care specific to their disability.<sup>64</sup> The survey protocol did not appear to make a specific reference to SRH services. Notwithstanding, the survey recorded these findings, and concluded that SRH services are not sufficiently accessible to refugees with disability in Jordan. Furthermore, the WRC developed a GBV toolkit, "Building Capacity for Disability Inclusion in GBV Programming in Humanitarian Settings", as a project implemented in humanitarian settings in four countries including Jordan.<sup>65</sup>

Barragués Fernández (2020), reviews progress toward the sustainable development agenda concept of 'leave no one behind' and examines the way different review processes have reported progress on SRH, as articulated in the SDGs. Jordan is mentioned in the article <sup>66</sup> highlighting that Jordan's national report to the Universal Periodic Review (2018) notes that forced sterilisation is a punishable offence under the amended Criminal Code of 2017, establishing criminal liability of persons and doctors responsible for removing the uterus of girls with disabilities, in addition to granting these victims the right to financial compensation.

Eide et al. (2015) conducted a household survey on the impact of disability on access to quality health services in four countries including Sudan, to contribute a limited (both in number and geographically) knowledge base.<sup>67</sup> The study does not address SRH issues explicitly. However, it was included given the limited amount of other literature published and the secondary relevance of the findings in a formative context. The study finds that a lack of transport, availability of services, inadequate drugs or equipment, and costs are the four major barriers for access with substantial variation in perceived barriers between countries, Eide et al. also suggest that this variation is reflective of the socio-economic differences between the country contexts.

### 4.1.3 Overview of policy environment and programmes

#### The analysis of SRH and GBV

Policies in the four case study countries highlighted the broad reference made to vulnerable groups and universal health coverage, which lacked detailed specifications of the unique needs of persons with disability. The lack of specification implies, incorrectly, that the needs of vulnerable groups are homogenous. The needs of refugees, indigenous groups, and ethnic minorities can differ from the needs of persons with disabilities. These nuances appear lost in some literature.

Disability is addressed across several social policy documents, specific to disability, healthcare, education, refugees and reporting to international convention instruments, among others, and a range which can include policy relevant data and analysis. Note was also made of the contribution of international actors in Jordan and Palestine, which receive significant development assistance relative to Sudan and Morocco and were influenced by donor policy.

#### Jordan's policy framework

The Jordan literature review showed that it already employed an adapted version of the Washington shortlist for disability questions, in the general census of 2015.<sup>68</sup> Phase II of the Jordan National Strategy for Persons with Disabilities 2010-2015 which is based on the provisions of the Convention on the Rights of Persons with Disabilities emphasized the rights of persons with disability, the necessity to combat all forms of discrimination, and mentioned GBV against persons with disability in the strategy. The strategy was designed to strengthen policy making, monitoring and support schemas geared towards serving persons with disability, utilizing participatory management, good governance, accountability, and transparency.<sup>69</sup>

In 2018, a position paper issued by the Higher Population Council and the Higher Council for the Rights of Persons with Disabilities, with a group of experts from government and civil society, revealed that 39% of persons with disabilities have no knowledge of reproductive health services and 25% persons with special needs have not received reproductive health services. The Higher Population Council, Higher Council for the Rights of Persons with Disabilities, also published a position paper on the rights of persons with disabilities in reproductive health and sexual education programmes.<sup>70</sup>

In 2019, the Higher Council for the Rights of Persons with Disabilities adopted the National Strategy for the Deinstitutionalization of Persons with Disabilities in Jordan which determined that persons with disabilities have the right to live with their family; the right to education, training and employment; and the right to a dignified life, within an inclusive and "normal" setting.<sup>71</sup>

Jordan's Ten-Year Strategy for Inclusive Education (2019-2029) confirms that the education system currently does not adequately respond to the needs of students with disabilities. There are significant gaps in equal access to educational programmes in terms of physical access to educational facilities and access to curricula. To fill the gap, 79% of the total number of persons with disabilities of school age do not receive any form of education.<sup>71</sup>

## Policy Framework for Palestine

Palestine acceded to the Convention on the Rights of Persons with Disabilities in 2014. Five years later, Palestine's Initial Report on the Convention on the Rights of Persons with Disabilities provided a status update on implementation report to the response of the State of Palestine to its obligations contained in the Convention and in fulfilment of its obligations to implement its provisions.<sup>72</sup>

In 2018, the Ministry of Health, in cooperation with UNFPA, published the National Strategy for Reproductive and Sexual Health in Palestine 2018-2022. This strategy assessed the status of sexual and reproductive health in Palestine and the actions needed to improve SRH and GBV, broadly based on national priorities that include safe pregnancy and childbirth, and reproductive and sexual health. The strategy considered the sustainability of the health sector and approached reproductive and sexual health as an essential element of health service delivery. The National Strategy did not specifically mention persons with disability but focused on the population in general.<sup>73</sup> The framework can be extended to persons with disabilities.

The Nations Human Rights oPt, Ministry of Social Development, and the Independent Commission for Human Rights published the Guidelines of The Rights of Persons with Disabilities in 2020, with COVID-19 specific recommendations on support and protection services to be provided to persons with disabilities. Movement restrictions posed a risk of aggravating the social exclusion of persons with disability. Women with disabilities were particularly isolated and exposed to violence and abuse in this setting.<sup>74</sup> In 2020, the Ministry of Health published the National Health Strategy 2021-2023 and mentioned the focus on the health needs of vulnerable people including persons with disabilities.<sup>75</sup>

## Sudan Policy Framework

The Sudanese literature on policy frameworks was the most limited of the case study countries, noting also that Sudan has a high prevalence rate of persons with disabilities compared to other Arab countries. Sudan's National Disability Strategy 2018-2030 set out the government's national vision on disability, proposing a partnership with multiple stakeholders, in government and society. Also, it constituted the framework that guides these institutions in formulating their public policies and executive programs to ensure a complete execution of the plan, but in realistic phases.<sup>76</sup>

In 2020, the Ministry of Labour and Social Development and National Council for Persons with Disabilities-General Secretariat published a Matrix Plan 2021, which represents the first third of the plan (2021-2023) for the transitional period. This plan aimed at achieving the active participation of persons with disability in all aspects of society. However, this period did not mention SRH or GBV.<sup>77</sup>

## Morocco Policy Framework

Morocco pioneered an integrated national health and disability strategy and a national action plan to implement the strategy during 2012-2015. The government included disability services embedded in reproductive health in its strategies, and also involved persons with disability as members in the national strategy committee.<sup>78</sup> Moreover, the Law No. 103.13 on violence against women, entered into force in September 2018. This law increased the penalties for certain acts of violence committed against women with disabilities.<sup>79</sup>

#### 4.1.4 Service delivery infrastructure

The literature on service infrastructure assesses that the available SRH and GBV services in the case study countries do not meet the requirements of policy, where it exists, or the needs of persons with disability. Sudan<sup>80</sup> is most deeply affected, as it has neither policy nor a service framework. While disparities remain, there appears to be some progress in Jordan, Palestine and Morocco.

Service delivery infrastructure is a vital component of ensuring the availability and accessibility of adequate SRH and GBV services to persons with disabilities. Infrastructures should include special adjustments such as a ramp, signs fit for persons with visual impairments, and sign language interpreters for persons with hearing impairments. In Palestine, as a part of the GBV response plan, the newly built public health clinics are required to have a ramp built.<sup>81</sup>

However, these health care facilities do not provide adequate SRH services specific to the persons with disabilities as their national guidelines do not explicitly provide plans for those with intellectual disabilities. The review of SRH and GBV technical guidelines for the case study countries revealed no clear direction is provided to health care providers on how to properly care, and interact for these clients. Furthermore, Khatib, S. (2020) stress that the SRH and GBV services depend on qualified and well-trained professionals who are knowledgeable about disabilities, trained to communicate effectively and respectfully, especially to persons with mental and intellectual disabilities, and have the right attitude at the work place, as professionals providing care to this group.<sup>82</sup>

This highlighted the need to focus on training, awareness raising campaigns, communication, continuing education, etc. In terms of SRH and GBV services, the health care providers should be prepared at different levels to initiate and improve the SRH and GBV services for persons with disability.<sup>83</sup> The literature also focuses on the need for continuous and planned investments, and operational planning to start the process and then to monitor and evaluate the status of these services to identify areas of improvement.<sup>84</sup>

While some policies geared towards SRH and GBV are available, discrepancies exist between the situation on the ground and at the policy level. Creating and planning service delivery are essential to ensure the establishment of service infrastructures, ensuring longevity, quality, and accessibility of such services requires frequent monitoring and evaluation in addition to the availability of resources to ensure continuity and to identify areas needed for improvement. Therefore, when planning, policy makers should also consider constructing an operational plan with phased implementation and to construct and use a well-defined monitoring tool that would ideally identify areas of improvement.

Accessibility of SRH services pose a challenge to persons with disability and their care givers. Although some infrastructure may be developed and running, SRH and GBV services tend to be in urban settings making them hard to reach for those coming from villages or camps. Discrepancies in coverage of SRH and GBV services were reported between rural and urban areas in Morocco.<sup>79</sup> Some initiatives reported to improve the access of persons with disability to SRH services for example the Health Work Committees in Palestine, supports the Ministry of Health in providing SRH services in remote areas and targeted people with disabilities.<sup>82</sup> In other cases, these services are only offered in the private sector and cost more than many can afford. Recently, during the COVID-19 pandemic, it was also witnessed in Jordan and Palestine<sup>85</sup> that infrastructures providing health and GBV services for persons with disability were interrupted and this encouraged the authorities to find a way to balance between maintaining health services and protecting people.

Unfortunately, the available services don't always meet the needs of the different groups of persons with disabilities such as physical, sensory, and psychological support. In cases of cognitive disabilities and autism, these services are burdensome, for example there are no accommodations for health services to suit the SRH and GBV for persons with cognitive disabilities in most of the Arab region.

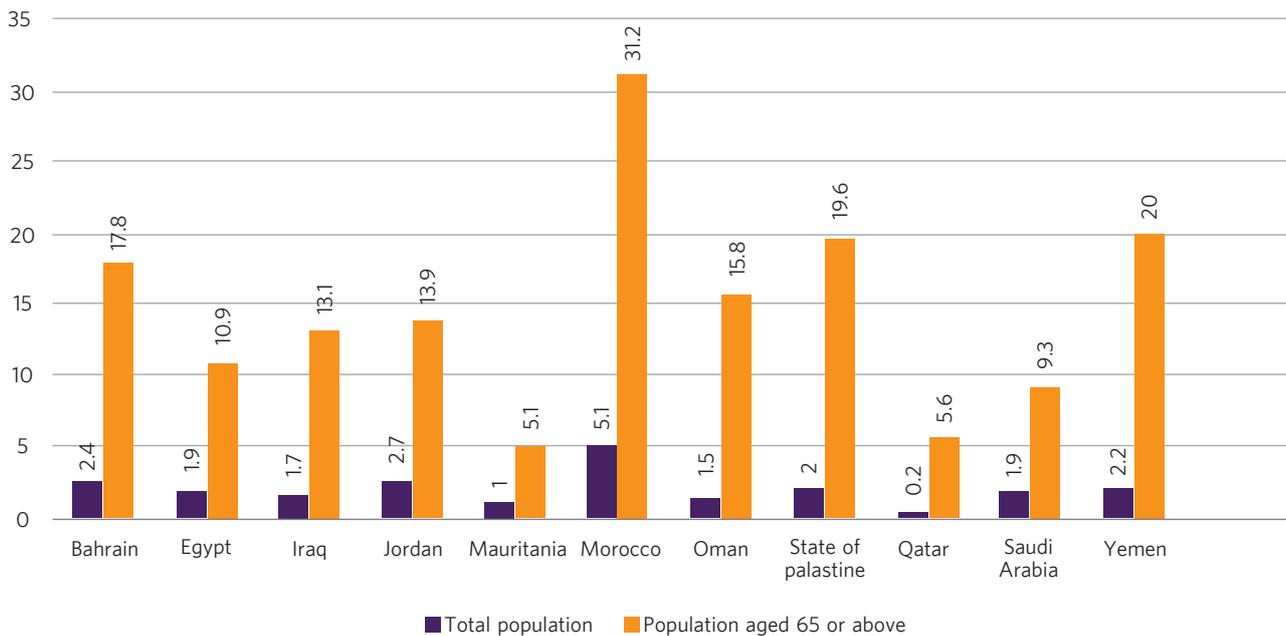
#### **4.1.5 Available data and indicators related to SRH and GBV of persons with disability**

The literature review extracted information on the sources and types of data on disability currently available in the four case study countries, the instruments used in data collection and the implementing entities and/or organisations. The focus was on SRH and GBV data and indicators and their availability. The review also examined data utilization from a service perspective through research studies that target disability from SRH and GBV point of view.

The results suggest that some relevant data is gathered through the national census process, although the indicators may not be specific to disability. Otherwise, the body of instruments (state and UN managed surveys) for SRH and GBV data is limited to non-existent, in the case study countries. Where SRH and GBV data is being gathered, it is through specialised studies of limited geographic/demographic scope. It is not being systematically gathered through healthcare monitoring.

The definition of persons with disability differs between countries in the region, making accurate comparisons difficult. Notwithstanding, health statistics and indicators on SRH including family planning, maternal and child health services, morbidity and mortality tend to be available. However, more detailed data and indicators in national statistical instruments tend to be inadequate. Therefore, disaggregation by disability status, sex and age are not available, making countries to rely on census data to estimate the magnitude of the problem.

In Arab countries, the main source of demographic data for disability comes from the national census. According to ESCWA in 2018 and Figure 2 showed the disability prevalence in some Arab countries, where only three Arab countries didn't use the Washington Group on Disability Statistics (WG) in their census and households surveys, namely, Bahrain, Mauritania, and Sudan.<sup>10</sup> Both Bahrain and Mauretania have aligned their national response categories with those of the WG. However, in Sudan, the National Disability Council put forward a proposal to include the Washington Group short set of disability questions in the coming census form.<sup>76</sup>



**Figure 2. Total disability prevalence rates and rates for people aged 65+, 2007-2018**

**Source:** DISABILITY IN THE ARAB REGION, ESCWA 2018

The general availability of data about disability among refugees and internally displaced persons in several Arab countries is limited.<sup>10</sup> The Institute of Development Studies in Jordan determined lack of data on refugees with disabilities was due to unregistered refugees and<sup>86</sup> on estimation (approx. 30% of Syrian refugees in Jordan with physical or intellectual needs).<sup>87</sup> In addition to the national censuses still the UNHCR capture statistics about the disability among registered refugees in camps in Jordan and Sudan and UNRWA captures the same data from Palestine camps.

Disaggregation of disability data by age, sex, region, and marital status is not systematically done for SRH and GBV. For example, in Jordan (Population Housing Census Department of Statistics, 2017) reported that 11.2% of those over five years of age have a disability<sup>88</sup> and in Palestine, disability data revealed 53.7% of persons 14 years of age or older are married.<sup>89</sup> However, SRH data is not gathered. Morocco prioritized the integration of the disability dimension into the national health information system through the development of audited indicators in the strategic plan to capture the realm of this problem.

Some countries partake in regular surveys to collect information on the conditions and manifestations of disability rather than only relying on census data to estimate the prevalence. For example, in Morocco, a national research on disability is done every ten years. The last one was carried out in 2014 and revealed that 6.8% is the prevalence of disability at the national level. This survey explored the obstacles which prevent the disabled from accessing and benefiting the health, employment and other services in the country.<sup>90</sup>

Another descriptive study (Giacaman R, 2021) reported on disabilities caused by military occupation. The study specifically measured the prevalence of lower and upper limb injuries caused by Israeli ammunition among 6525 Palestinians from the West Bank and Gaza. These injuries resulted in amputation of upper and lower limbs in some cases and at least 1200 cases requiring limb reconstruction.

Within the general literature, the availability of data was limited or non-existent, as was evident that data is systematically gathered, through census instruments or at the point of service delivery. The data, therefore, can be used to identify broadly the scope of need according to demographics, but not the more gradual information that would be required to address specific disability types. The available data about the utilization of SRH and GBV services was limited to the reported number of beneficiaries from certain SRH and GBV programmes at the institutional level. Moreover, the lack of SRH and GBV data for persons with disability is prominent among all age groups but more so seen among children, adolescents and old persons.

There was no evidence that indicators measuring critical aspects of SRH and GBV are being systematically used in national systems, such as access to maternal and child health, family planning and STDs. This is an unmet need for persons with disability. Although the case study countries use the Washington Group on Disability, almost none have reported an interest in creating health statistics using disaggregation of national health statistics by disability status, hindering the possibility of making inferences and statistically meaningful conclusions needed for policymaking. Additionally, inclusion of the quality of SRH and GBV from the perspective of persons with disability is absent.

#### **4.1.6 Life cycle approach applied to existing documents and literature**

This section focuses on available literature, programs, and surveys that touch on the life cycle needs of persons with disability including through youth, adolescence, adulthood, and reproductive age.

There were few articles from the academic literature that focused on menstruation, but often SRH was more generally referenced, meaning it was difficult to discern if this broad approach is inclusive of all stages of the life cycle. More noticeably was the scarcity of literature focusing on senior age groups, demonstrating a significant evidence gap in the available literature.

Furthermore, existing grey literature from SRH and GBV including studies, manuals and guidelines found in the four selected Arab countries did not focus on or include the disabled. On the other hand, among those that included disability were primarily focused on women in the reproductive age as targets for SRH and GBV interventions and services. They rarely covered SRH among females in the post-menopausal age, or males.

Some studies do assess the risk to persons with disabilities. For example, a study conducted by the Jordanian Higher Council for the Rights of Persons with Disabilities assessed the SRH services, specifically antenatal and postpartum care received by persons with disability among females in adolescence, married women, and menopausal women. This study revealed that 10% of reproductive health service centres received requests for hysterectomy for girls with disabilities, highlighting the lack of autonomy among adolescent females with disabilities.<sup>91</sup>

However, the literature review revealed that attention to SRH and GBV among adolescent and childhood groups, both males and females at all different stages of their life cycles was very rare. Only one study from Palestine reflected the experiences of Palestinian men and male youth with disabilities in SRH which revealed that men with disabilities (according to their wives) steer away from participating in sexual or child rearing activities because they believe that no one will understand them or service providers will not be able to answer any questions they may have.<sup>92</sup>

One recent study in Jordan identified potential challenges that persons with disability across all age groups in Azraq camp face. This study focused on access to health and protection services faced during the lockdown, but as a direct impact of the lockdown, the majority of those who were undertaking rehabilitative sessions were affected and endured regression in their previous advances. Although the evidence isn't too informative and doesn't give specific implications on age group, it shows that disabled persons at all age groups experience barriers to health and protective services.

Initiatives targeting SRH and GBV among persons with disability in these countries were mainly conducted by NGOs, which although useful, were limited in terms of the coverage among persons with disability and the utilization of the interventions at the national level. For example, in Palestine, JUZOOR produced a SRH manual to support parents and caregivers for better care towards children and adolescents with mild and moderate intellectual disabilities.<sup>93</sup> A more detailed initiative was undertaken in Morocco, where a health needs and changes assessment for children with disabilities was done.<sup>94</sup> This assessment guided the production of a support manual for parents with children with disabilities highlighting the key messages and themes needed in order to tend to these children.

In Sudan, evidence on GBV highlighted that children with disabilities were more likely to experience GBV than those without disabilities,<sup>95</sup> and any persons with disability in other countries, regardless of age, were more likely to be exposed to GBV than those without disabilities. However, these kinds of studies cannot fully assess the magnitude of the problem and only provide qualitative information. In comparison, the Violence Survey in 2019 in Palestine showed that 37% of women with disabilities are married and of those, 30% and 42% of them reported experiencing GBV with in the past year in the West Bank and Gaza, respectively. 50% of those women who experience GBV reported being subjected specifically to psychological violence and of these, 20% also experienced physical violence by their spouses. Moreover, 27% of adults in Palestine with disabilities haven't been married and have experience violence from a family member.<sup>96</sup>

In Morocco, a perception study of SRH of persons with disability included findings from those 15 years<sup>79</sup> and more about their experience as adolescents with disability and most of them didn't consider that the adolescent life is affected by the fact of their disability while the psychological and socio-cultural conditions complicate their experience to be engaged in emotional and/or sexual experiences during adolescence.

## 4.2 Findings from the case study countries

This section presents overarching key findings from primary data collection activities including, qualitative semi-structured interviews and FGDs with persons with disability, families/caregivers, and stakeholders in each of the selected countries. Some of the excerpts presented have been edited or paraphrased for readability and grammatical correctness, including removal of distracting phrasing and identifying information. All major changes are indicated by square brackets.

## 4.2.1 Sexual and reproductive health and reproductive rights for persons with disabilities

In the following section, we applied an ecological approach to orient the final discussion and help organize our understanding of this complex phenomenon with several interlinked and overlapping themes. This study explored SRH concerns, gender disparities and GBV related to disabilities in four countries (Morocco, Palestine, Jordan, and Sudan) in the Arab region, revealing that there is a general lack of understanding of SRH issues from the perspective of unmarried persons with disability because marriage is often seen as the entry point for obtaining knowledge and understanding of SRH issues. Additionally, this study sheds light on the sensitivity of SRH issues in the region, revealing various stigmas, cultural beliefs, and norms which may initiate feelings of embarrassment and shame when discussing SRH with the targeted population.

Disability was perceived as a central characteristic of one's identity, making it challenging to identify and distil the influence of other marginalized characteristics such as age or gender in participants' responses to questions focusing on GBV. Violence was also widely identified by participants across different disabilities as an issue of concern in various domains such as the household level and outside the household level (e.g. among friends, neighbours, co-workers, and health care providers). Persons with disability listed several barriers which influenced access to SRH programs, services, and information such as expenses related to treatment; difficulty communicating with doctors/health service providers; trust; logistical barriers; and shame.

Overall, in all four countries, stakeholders revealed that there is a general lack of detailed data available which captures SRH and GBV for persons with disability. Moreover, strategies and recommendations for improving access to SRH among persons with disability addressed some underlying barriers to access, stigma, embarrassment, and shame regarding SRH, involving the in-depth mapping of resources, information, and services available to persons with disability; and the necessity of further training and capacity development to adequately assist the needs of persons with disability in the selected contexts. Therefore, the following themes were identified:

**Table 6. Overview of themes**

Levels of influence	Global themes	Basic Themes (codes)
Intrapersonal, Interpersonal, Community	Marriage as gateway or prerequisite for knowledge and understanding of SRH	<ul style="list-style-type: none"> <li>• Marriage</li> <li>• Community perceptions of SRH</li> <li>• Individual perceptions of SRH</li> <li>• Perceived SRH priorities</li> <li>• Preferences</li> <li>• Lack of understanding</li> </ul>
Intrapersonal, Interpersonal, Community	Stigma, embarrassment, and shame	<ul style="list-style-type: none"> <li>• Stigma</li> <li>• Cultural norms</li> <li>• Cultural beliefs</li> <li>• Challenges</li> </ul>
Intrapersonal, Interpersonal, Community	Intersectionality of disability and gender	<ul style="list-style-type: none"> <li>• Disability</li> <li>• Perception of self</li> <li>• GBV</li> </ul>

Intrapersonal, Interpersonal, Community	“There is no person with a disability that hasn’t faced violence”: violence against persons with disabilities	<ul style="list-style-type: none"> <li>• Violence and disability</li> <li>• Reaction to violence</li> <li>• Accessing violence services</li> </ul>
Interpersonal	Perceptions, roles, and experiences of family and caregivers	<ul style="list-style-type: none"> <li>• Family relationships</li> <li>• Familial support networks</li> </ul>
Public Policy	Data and indicators related to SRH and GBV of persons with disability	<ul style="list-style-type: none"> <li>• Data</li> </ul>
Organizational/ Institutional	“I get the same treatment as everyone else”: Cultivating an enabling environment for SRH programs, services, and information for persons with disability	<ul style="list-style-type: none"> <li>• Barriers to access</li> <li>• SRH quality</li> <li>• SRH services</li> <li>• Satisfaction with service</li> <li>• Information and support</li> <li>• Support networks</li> <li>• Enabling environment</li> </ul>
All	Strategies and recommendations for improving access to SRH among people with disabilities	<ul style="list-style-type: none"> <li>• Suggestions</li> <li>• Preferences</li> </ul>

In addition, a socio-ecological approach was applied to the analysis to orient the final discussion and help organize our understanding of this complex phenomenon. The socio-ecological approach provides insight into the layers of influence, including intrapersonal, interpersonal, organizational, community and public policy. The socio-ecological approach also helps to acknowledge the complexities of SRH for persons with disability involving a more comprehensive approach that integrates multiple levels of influence to help develop our understanding of SRH concerns, gender disparities and GBV related to disabilities in the four countries (Morocco, Palestine, Jordan, and Sudan). Table 7 provides an overview of the various levels of influence in the socio-ecological model.

**Table 7. Levels of influence of the socio-ecological model**

Levels of influence	Description
Public Policy	Local, state, federal policies and laws that regulate or support healthy actions and practices for disease prevention, early detection, control, and management
Organizational/ Institutional	Rules, regulation, policies, and informal structures, which may constrain or promote recommended behaviours
Community	Social networks and norms, or standards, which exist as formal or informal among individuals, groups, and organizations
Interpersonal	Interpersonal processes, and primary groups including family, friends, peers, that provide social identity, support and role definition
Intrapersonal	Individual characteristics that influence behaviour, such as knowledge, attitudes, beliefs, and personality traits



**Source:** Theory at a glance [Cited Nov 4, 2021]\*

## 4.2.2 Marriage as gateway or prerequisite for knowledge and understanding of SRH

The first theme, **'marriage as gateway or prerequisite for knowledge and understanding of SRH'** describes how marriage emerged centrally as a gateway or entry point around several aspects of SRH throughout interviews with persons with disability. Additionally, participants described marriage as a right for persons with disability, expressing marriage-related concerns. For example, one participant expressed the importance of the right to marry and to form a family for persons with disability when he shared:

First, it's important the girl with the disability to find her life partner. Why? because a lot of girls with disabilities don't receive the right to form a marital family life. Also, the image from society is that this girl has a disability so why does she need marriage or to give birth, why should we include her when we talk about sexual and reproductive matters. They are deprived of these rights that any girl should have whether she has a disability or not.

(Male, person with disability, Palestine)

Here, the participant not only describes the importance of the right of persons with disability to marital or familial life, but also expresses how societal norms and beliefs may deprive or prevent persons with disability from accessing these rights. One participant from Jordan described the importance of marriage as a right for persons with disability, framing it within the context of equal rights:

I am a person with a disability and I have rights and responsibilities like any other human. I need to get married and be part of society just like anybody else.

(Male, person with disability, Jordan)

Throughout interviews and FGDs with persons with disability and families, concerns were raised relating to the physiological possibility or riskiness of pregnancy and overall reproductive function in addition to more socially constructed notions pertaining to beliefs about parenting ability or fitness to parent. For example, one participant described marriage as 'worrisome', expressing concerns with the potential physical complications of having children:

Some persons with disability call me and tell me they are thinking of getting married and ask me if it is easy and how to deal with life and if I am thinking of having children. They go into details. Honestly, this matter is worrisome for them, it is not easy for any person with a disability. They are thinking that they might fail. Although, it won't fail. Medicine now is very advanced. Any human, even the elderly, now have less problems.

(Male, person with disability, Palestine)

Marriage was also identified as a central theme that emerged from participant responses to questions. Marriage was perceived as a prerequisite to legitimize seeking SRH information for persons with disability, illustrating how challenges or experiences relating to access to SRH services or information

were perceived to generally concern the interests of only married people. For example, individual perceptions of SRH were grounded in perceived conceptions of sexuality (within marriage), family planning, pregnancy, childbirth, and even premarital genetic testing to safeguard themselves from having offspring suffering from disability. The following excerpt illustrates how the concept of marriage highlights how persons with disability prioritize their SRH information needs and describing varied aspects of accessing SRH services. For example, one participant shared how she sought answers to whether she could become pregnant, despite the stigma associated with having these questions as an unmarried woman when she said:

If I presented this topic to my close people in life, they would say that it's shameful and that I'm a girl and can't ask this, but I didn't stay silent on this. I looked for information on my own, but I didn't talk to someone specialised. I wanted to know if I can be pregnant, and I wish to contact someone who is specialised in these topics. If I got married and was pregnant, will my legs carry me while I'm pregnant? I wish to become a mother, but can my body handle it? This is what I think about.

(female, person with disability, Jordan)

Another participant from Morocco added:

I feel that persons with disability ask themselves, if they have a disability, how could I search on this topic and say I need information on sexual and reproductive health or tell someone I want to get married, have intercourse and have children. The person here closes themselves off and decides not to ask.

(female, person with disability, Morocco)

These two experts demonstrate how societal norms and stigma centred around marriage and disability may prevent persons with disability from seeking SRH-related care and information. Furthermore, participants also identified challenges related to SRH information and services and corresponding recommendations.

Furthermore, families were mixed on whether persons with disability should get married and have children, expressing judgments or assumptions regarding persons with disabilities' reproductive ability and qualification to conform to normative order and perform prescribed gender roles.

For example, in a FGD with female caregivers in Palestine, when asked by the interviewer if persons with disability have the right to marry, some agreed, saying 'of course' while others disagreed implying that if a male person with disability is not capable of working then they should not be married, adding

The woman needs someone physically and mentally capable.

(female, parent/caregiver, Palestine).

One female caregiver in Jordan, voiced concerns pertaining to marriage for her son with disability when she said,

I am prepared for him to stay away from these things completely...it's a big responsibility.

(female, parent/caregiver, Jordan)

While another male caregiver in Jordan voiced

To bear children and have sexual intercourse, this is something I removed completely from my head for her because she is not eligible to get married.

(male, parent/caregiver, Jordan)

Here, parents, caregivers or family members' opinions can act as restrictive or prohibiting persons with disability right to marriage, with the underlying assumption that persons with disability are not suitable for married life (thus a major barrier to accessing SRH services and information in this context). One participant explained:

I have a daughter that a guy came to ask for marriage. I told him that I don't recommend this for him. He said he is willing, and I said I don't approve. A man wants a woman that can talk and listen; she can't hear, and your children could be born with the same disability. It's better if she stays with us. I would rather leave them with me and suffer with them myself, than bring it on someone else.

(male, parent/caregiver, Jordan)

Others disagreed sharing their personal experience with family members with disability who had successful marriages and families, arguing that marriage can help bring persons with disability happiness:

It's not wrong and it makes them feel better. My brother is happy in his marriage. When the disability is mild or moderate like that, they can get married and take care of their children. My brother is married and happy and I really like how he takes care of his wife, children, and home.

(female, parent/caregiver, Palestine)

In several interviews, persons with disability discussed the importance of advocating for their reproductive rights, indicating a desire to be treated as 'normal' when expressing reproductive and sexual needs. Several participants also advocated for increasing awareness around SRH issues related to persons with disability, to dismantle culture norms surrounding SRH topics that inflict feelings of shame, especially regarding persons with disability's capabilities to reproduce. For example, one participant shared:

A person with a disability really needs to know about this and to know that reproductive and sexual health is very important to them. Reproductive and sexual health for persons with disability is very hard to talk about in our society. Currently it is considered a sensitive topic and is not talked about much.

(Female, person with disability, Morocco)

While another participant added:

The needs of persons with disability in this matter are a lot. Sexual and reproductive health is a problem especially for people with physical disabilities that use crutches or wheelchairs, and their needs are many. We need awareness on the level of society. There should be a permanent health facility with high quality services.

(Male, person with disability, Morocco)

These excerpts illustrate how stigma and cultural norms act as a barrier to accessing SRH knowledge, information, and services. Additionally, several preferred channels of enhancing awareness were identified, such as media (e.g. television programming), social media, and lectures. More interestingly, parents were identified as an important source for supporting SRH awareness and should be included as targets for such awareness sessions.

### 4.2.3 Stigma, embarrassment, and shame surrounding SRH

Although cultural norms and stigma appeared under the key theme, '**marriage as a gateway or prerequisite for knowledge and understanding of SRH**', it also emerged as a dominant theme as the source of embarrassment and shame surrounding SRH throughout interviews and FGDs.

It should be noted that silence is a valuable part of communication in qualitative research that indicates a participant's lack of knowledge, comfort level, cultural norms, or even the interviewers' skills to illicit participant responses. Charmaz (2004)<sup>98</sup> argues that researchers should also pay attention to silences to understand implicit meanings which can further contribute to understanding a phenomenon in qualitative inquiry.<sup>99,100</sup> Despite SRH being the focus of this study, it appeared that several participants were uncomfortable speaking about the topic, citing marriage as a prerequisite for having experiences with SRH services/information or being engaged and interested in SRH issues. Furthermore, other participants highlighted that in this context, SRH issues are sensitive which may have influenced

participants comfort level with the topic, willingness to share personal experiences, and/or the level of personal reflection. For example, one participant shared:

This topic is very sensitive. I feel that persons with disability ask themselves, if they have a disability, how could I search on this topic and go say I need information on sexual and reproductive health or tell someone I want to get married, have intercourse and have children. The person here closes themselves off and decides not to ask.

(Female, person with disability, Morocco)

On the interpersonal level, this excerpt highlights a widely held perception that SRH issues were perceived by participants as a sensitive topic. Furthermore, it was also expressed that some participants felt shame or embarrassment when discussing SRH. For example, one participant mentioned:

In our reality, especially in what we are talking about reproductive health, you find that people tell you this is a shameful topic to get into or talk about. You find a lot of ignorance on this topic among people.

(Male, person with disability, Palestine)

This excerpt illustrates the sensitive nature of SRH and how on the interpersonal level it can be perceived to be a shameful topic. This idea that SRH issues evoke feelings of shame, was also discussed in FGDs with stakeholders, one stakeholder shared:

The biggest hardships that person with disability go through is sexual and reproductive health related matters. Because it is a closed door, nobody is willing to open it or even talk about it. People think that person with disability are not capable of getting married or having sex because of their disability.

(Stakeholder, Palestine)

Interviews and FGDs revealed several stigmatizing attitudes or beliefs throughout the four countries. According to Goffman (1963), stigma is an, "attribute that is significantly discrediting" (p. 3).<sup>101</sup> In this study, various stigmatizing attitudes or beliefs were discussed such as the notion that persons with disability are considered by some as 'asexual', 'scary', 'disgusting', incapable of giving birth/ having intercourse, or non-qualifying for the right to marriage or the right to a family. For example, one caregiver shared an experience where a doctor suggested that his daughter would be better off if she did not get her period, illustrating the perception that persons with disability should not be worried about SRH because of the stigmatizing attitudes or beliefs listed above. For example, one male caregiver in Jordan shared:

I ask about the period. The girl hasn't had her period for six months. I asked the doctor, and he says to leave her like this and it's better for her and for me this way, no fuss for me and it doesn't affect her body. I have yet to take her to the gynaecologist for this problem.

(Male, Parent/Caregiver, Jordan)

Another participant also implied that doctors may unintentionally gatekeep SRH services and information from persons with disability, especially since persons with disability may be disproportionately subjected to judgment based on their disability status. For example, one participant discussed how the doctors convey information regarding the physiological possibility or riskiness associated with pregnancy may deter persons with disability from even considering pregnancy when she said:

Most doctors scare persons with disability away from getting married and having children. They tell them that if they have children, they will die.

(Female, person with disability, Morocco)

This excerpt shows how communication pertaining to a potentially exaggerated or misdirected concern regarding the reproductive health of persons with disability and their potential children may make them fearful from getting married and/or pregnant. Additionally, families also spoke of embarrassment or shame more generally, when describing the perceived stigma or shame associated with having a family member with disabilities, demonstrating that stigma, embarrassment or shame can be a main driver in the breakdown of familial support networks or ties. For example, one participant shared:

Even some families don't take a person with a disability with them to family occasions so that they don't carry the stigma of having a person with a disability in their family.

(Female, Parent/Caregiver, Sudan)

Another interview also highlights how families may perceive a stigma with having a family member with disabilities. One participant who is deaf, shared, that a family would tell their daughter not to use sign language in front of people just in case, they thought she was crazy (female, person with disability, Jordan). This participant continued that although stigma, embarrassment and shame occur on the interpersonal level, it is rooted in societal norms or the community level:

It's the society mostly because the parents affect the society. If there is a culture of shame around persons with disability and deaf people in the society, this affects the parents and makes them want their children to die. The society affects the parents negatively and makes them feel ashamed of their children. If the society is more aware, then the parents are more aware, and with the suitable environment, the person with the disability can progress. Since the time she was born till now, she always hears from society: "oh poor person, they are retarded". Do they think we are crazy? The word "retarded" is not for us. The society is retarded, not the person.

(Female, person with disability, Jordan)

#### 4.2.4 Intersectionality of disability and gender

It is also important to acknowledge that throughout interviews with persons with disability, it seemed that disability was perceived as a central characteristic of one's identity, making it challenging to identify and distil the influence of other marginalized characteristics such as age or gender. In this formative research study, intersections between disability and gender, were especially apparent in participants responses to questions focusing on GBV. Participants often spoke of GBV and violence against persons with disability interchangeably, highlighting how the concept of intersectionality should be considered when understanding the experiences and perceptions of persons with disability. In this respect, a major theme that emerged, intersectionality of disability and gender: violence against persons with disabilities which uses intersectionality as a framework for understanding GBV among persons with disability.

The theoretical concept of intersectionality was first introduced in the feminist writings of Crenshaw (1991) to provide a lens to better understand the mutual processes of marginalisation and exclusion in terms of race and gender.<sup>102</sup> In other studies the concept of intersectionality has evolved to recognize that multiple identities of an individual exist, and these identities may influence and impress experiences of marginalisation, discrimination, and oppression in different ways.<sup>103</sup> These identities can be based on various biological, social, and cultural categories such as gender, ethnicity, socioeconomic status, or disability.<sup>104</sup> Furthermore, the concept of intersectionality illustrates how different forms of oppression (e.g. racism, sexism, ageism, and disability biases) often overlap or intersect, therefore these characteristics should be explored in depth to develop an understanding of how potentially gender, refugee status, and age may intersect and influence SRH-related experiences for persons with disability.

GBV looked at through an intersectional lens that recognizes the multiple identities of an individual helps to establish the complexities of experiences of violence among this population. When asked about GBV, persons with disability would often speak of violence against persons with disability making it challenging to understand the impact or experience of GBV among this population.

#### 4.2.5 “There is no person with a disability that hasn't faced violence”: violence against persons with disabilities

The research surfaced concerns for two kinds of violence: gender-based violence and disability-based violence. While gender-based violence was an object of the research, disability-based violence was raised often as a concern, by both male and female persons with disability. The difference between the two was not often possible to discern.

Violence was widely identified by participants across different disabilities, age, gender, and country. Additionally, varied types of violence were identified by participants in interviews and FGDs such as physical, psychological, and sexual violence in addition to negligence. One male participant from Sudan reflected on the different types of violence, when he shared:

There is violence that is done based only on the disability itself, social violence which means secluding persons with disability from social life, sexual life, and marital life. This way they are secluded and socially isolated. The most common types of violence are psychological and gender-based violence. This violence is done by members of society that aren't highly aware.

(Male, person with disability, Sudan)

Participants in every country acknowledged and described violence as an issue of concern for persons with disability. When participants were questioned about who might be the perpetrators of a violent act towards persons with disability, several levels of perpetrators were identified. Participants also described different domains of violence occurring at the household level (either perpetrated by a partner or a parent), starting from close family members such as parents and/or siblings; for example a male participant from Sudan stated that “[Persons with disability] are treated with a lot of violence from some of their families to the point where they feel that they aren't human” which was further echoed by another participant from Palestine who reported that “sometimes it comes from the parents especially when the person with the physical disability is constantly at home”.

Within the context of lock-downs and stay-at-home orders during the COVID-19 pandemic, other participants also mentioned being at home as a risk factor for violence. This was also supported by a female participant from Morocco who indicated that despite the protective effect of the COVID-19 pandemic, stay-at-home orders may have increased the vulnerability of persons with disability to experience violence from their families; “The pandemic caused people to be protected from the outside world or from going out. People stayed at their homes and if there was any violence, it was from the family”.

One female Jordanian participant also reported that “my older brother hit me and took my money”. Unluckily, an extreme form of sexual violence was even reported from a female participant in Palestine, “we have one case of a girl that was sexually harassed by her brother and father”, as reported by a member of FGD in Palestine. Furthermore, one participant reported that if violence is from inside the family then it's hard for them to speak out against it, while another participant in Palestine, implied that society encourages violence against persons with disability.

For example, one participant shared the story of a girl with disabilities who was experiencing violence from her family, this participant described:

She was hit by her father and stepmother. When she became more aware that they don't have the right to hit her and she has rights too, she started conveying this idea to her family. We started to target her parents, I would start to talk to her father and explain to him that she has her rights and that she is capable of work and helping them at home. She worked for a while but then when she finished, the hitting resumed which means we didn't solve the problem. We must now always keep her in vocational training, so she starts making money for the house or find her a job. She once attempted suicide. She took too many pills and then called us to help her. I called her stepmother to take her to the hospital immediately. After that her parents left her alone.

(Female, person with disability, Palestine)

While another participant described a scenario where a woman may experience violence at the household level from her husband:

The wife or woman with a disability faces violence from the husband especially when he's not understanding of the disability and tells his wife that she should be thankful he married her with her disability.

(Male, person with disability, Sudan)

A participant in Morocco also described violence that is perpetrated by both her in-laws and her immediate family in response to her decision to marry. She shared:

I was subjected to violence from my family because my mother-in-law was completely against the marriage of her son to me and because her son loves me. She doesn't accept the idea of her son marrying a person with a disability. I was also subjected to violence from my own family because they weren't approving of my marriage and think a person with disability does not need to get married. I face psychological violence from my mother out of her fear for me and because she is against divorce. They think that my husband married me for [the] wrong reasons and that a person with a disability doesn't have the right to get married... [My husband] treats me well and deals with my disability very normally. He helps me a lot but now because of the situation, I live currently, along with my daughter at my mother's house because my mother also refuses the idea of me staying with my husband and says that it's enough.

(Female, person with disability, Morocco)

Moving outside the household, among friends, neighbours, co-workers, and even health care providers there were several experiences of violent acts against persons with disabilities. A female participant from Palestine mentioned that "the neighbours around them, if they see a disabled person around them, they harass them" while another male from Palestine added that it could be "friends at work." Additionally, a participant in Jordan shared an experience which she considered violent, that was perpetrated by a healthcare worker when she described her experience giving birth. She explained:

In the morning, they suddenly gave her a labour induction injection and she thought it was a sedative. She started feeling pain and when she would tell them, they told her to wait. There was no communication at all, and she would tell them that she is feeling pain during the internal examinations, but they were aggressive with her and forced the examinations on her. They would suddenly open her legs and put in the tube for internal examination. She says she suffered with the pain during this examination and considers what happened to her as violence. The doctor turned out to be an intern. He had six students with him when they opened her legs to do the internal examination and it was their training. She says she got very angry, and the treatment was horrible, they thought she was stupid.

(Female, person with disability, Jordan)

Finally, community itself was perceived as a significant entity to commit violent acts towards persons with disability. A Sudanese female revealed that “the possible perpetrators are always the family, parents, and the society around us. Sometimes it’s the state authorities.” Moreover, a Jordanian male participant also accused the society “because they are not aware on accepting persons with disability. Perhaps it’s because in their whole life, they never saw a person with disability before. There were no persons with disability at schools, even in books we are not portrayed. There is nothing that conditions them on how to deal with persons with disability or work with them.” Similarly, a female from Morocco attested that psychological violence comes “just from the street.” A Palestinian male participant also agreed; “in the streets, a lot of people call out profane words.” Participants also cited concerns for sexual violence, one participant shared:

I have a disabled sister. She was once walking in the market with our mother. A guy grabbed her breasts even though she was with our mother, there is no safety.

(Female, Parent/Caregiver, Jordan)

Furthermore, families in Sudan discussed how persons with disability are particularly vulnerable to violence, since they often depend on others for daily life activities, one participant shared:

Persons with disability get affected by it a lot because their needs are many and they can’t fulfil them by themselves and depend on others which put them in a position of potential violence, like being yelled at or getting bored by them. They are affected psychologically, and it makes them feel inferior.

(Female, Parent/Caregiver, Sudan)

Also, persons with disability participants discussed how persons with disability may be afraid to report incidents of violence because of embarrassment, fear of detention, fear of being threatened by murder, fear of being kidnapped, among other reasons.

#### **4.2.6 Equity versus equality “I get the same treatment as everyone else”: Equity as the means to cultivating an enabling environment for SRH programs, services, and information for persons with disability**

Although equality is a fundamental component of universal health coverage, findings indicate that equity is a crucial means to cultivating an enabling environment for access to SRH programs, services, and information for persons with disability since equity ensures that specific needs of persons with disability are acknowledged and met in order to overcome barriers and achieve equal SRH outcomes. Persons with disability listed a number of barriers which influenced access to SRH programs, services, and information such as expenses related to treatment (indicating limitations among health insurance plans); difficulty communicating with a doctors/health service providers (especially reported among participants who are deaf); trust (participants described their opinion that they felt that doctors and health service provided lacked the necessary knowledge and compassion to deliver proper care);

logistic barriers (proper health facilities may be located far away or ill equip with handicap accessible facilities or bathrooms); and shame (participants discussed how they felt embarrassed or shameful when seeking medical care).

Difficulty communicating with a doctor/health service provider was reported among several participants who are deaf, one explained:

As I said, as someone who can move easily and I don't need facilitations in communicating with the service providers but people with disabilities especially girls, if she is deaf or have a mild mental disability then she faces a lot of challenges to get this service.

(Male, person with disability, Palestine)

Participants also indicated that they may perceive doctors or health service workers lacking the necessary knowledge and compassion to deliver proper care. For example, one participant shared:

At least in the maternity centres, there should be operating rooms just for women with disabilities and there should be special beds for persons with disability. There should be vigorous follow up from experts for some pregnant women with extreme disabilities. There should be more accessibility and compatibility in fertilization centres for the males. I visited some fertilization centres, there is no technology for persons with disability of both sexes, there are no tools, no awareness, and no understanding of the case. It is most dangerous when a person with a disability enters a hospital, and there is no one or no expert to understand their case. It is a good thing when they guide me or bring awareness on this topic in the private or public sector but then the same person that offered the guiding, if I find her the second day at the hospital or health centre, she will fail in dealing with my case as a person with disability, and regardless of my sex. For example, the hospital beds aren't suitable for persons with disability, the medical equipment, the way the nursing staff deal with persons with disability, lack of sign language interpreters, not disclosing the case to the deaf or blind, not taking the free prior and informed consent of the persons with disability based on the law. They make decisions for them, without consulting the person with the disability or perhaps asking the parents but not them. These are all violations from a legal perspective and a human rights perspective for persons with disability.

(Male, person with disability, Palestine)

This excerpt offers suggestions on how care for persons with disability can be developed to meet their needs. Furthermore, stakeholders discussed how persons with disability may require special treatment, for example:

We know that disability is complicated because there are many types of disabilities, and every disability needs a special way of treatment especially regarding sexual health. We have the problem of medical staff not knowing with accuracy how to deal with persons with disability and knowing their special needs in reproductive health and gender-based violence.

(Stakeholder, Morocco)

This demonstrates that there is a lack of awareness and knowledge among doctors and healthcare workers to properly care for and meet the treatment needs of persons with disability. However, another stakeholder from Jordan shared that:

Our problem is, there are some dimensions that we need to take into consideration. There is the social and cultural dimension, related to information, do people with disabilities or their parents have access to the information or the ability to reach this information? There are also the services, are the service providers qualified to deal with such cases and provide them with services? Are the services accessible from the point of infrastructure or from the point of communication? Are they accessible to some types of disabilities or all?

(Stakeholder, Jordan)

Additionally, a participant with a hearing disability pointed out:

There are a lot of problems and challenges, most importantly is the language and communication barrier for the deaf. There is difficulty in diagnosing the deaf and pointing out the problem. I know of a deaf girl that asked for medical care when giving birth but because of the language barrier, she didn't understand what the doctor was saying while giving birth to twins and in the end one of the twins died.

(Female, person with disability, Sudan)

Several participants reported that persons with disability received the same treatment as everyone else, which does not take into consideration their special needs. For example, one mother shared about her blind daughter, that:

She was treated the same as any other woman giving birth. There was no consideration. For example, they didn't let me get inside to help her to change her clothes or help her get on the bed.

(Female, Parent/Caregiver, Palestine)

Additionally, participants mentioned logistical barriers related to the access of SRH program and services for persons with disability, suggesting that health centres or clinics may be located far away or ill equipped to meet the needs of persons with disability. One participant from Sudan described:

There is the challenge of lack of awareness and the lack of institutions specialized in persons with disability. The few institutions that are available are far away from persons with disability as they are always concentrated in the centre. The most important challenge is that persons with disability don't know where to ask for help.

(Male, person with disability, Sudan)

Several participants shared how their perceptions of SRH services, and their quality are mixed. Qualitative interview and FGD participants revealed that the quality of SRH services is mixed providing several anecdotal examples where persons with disability did not receive the proper treatment or care in health facilities. For example, one stakeholder shared that:

Sometimes, women with disabilities receive a lot of sympathy from workers, nurses, and midwives but there is no law that protects women with disabilities. Sometimes, women with disabilities face violence in how they are treated. One of our colleagues has a visual disability. She went to give birth at one of the hospitals, and the medical staff started complaining on how they could deal with her, until one of the doctors handled the birth. She had bleeding and needed blood units. We face such problems because there is no law to protect women with disabilities in birth and there is even no culture on how to deal with persons with disability at hospitals.

(Stakeholder, Sudan)

Another example, provided by a person with disability in Palestine explained:

One girl with visual impairment when she came to give birth, they told her to go outside to wait instead of bringing the person accompanying her to her. Other problems were mentioned like they would leave the IV till blood comes out for persons with disability. They don't offer them the service sufficiently.

(Female, person with disability, Palestine)

This demonstrates how in certain contexts; doctors may lack skills or the general awareness to facilitate the proper treatment of patients with disabilities. Participants who self-identified as persons with disability indicated that very few doctors or healthcare workers have the training and awareness of the various needs for persons with disability, and when they do, participants attributed it to the possibility that they have someone who has a disability in their family.

Overlapping with the previous theme 'stigma, embarrassment, and shame surround SRH', several participants expressed sentiments or feelings of embarrassment or shame when seeking SRH services. In these instances, stigma, embarrassment, or shame act as a prohibiting barrier to accessing SRH services or information. For example, one participant explains:

Maybe the culture of shame in our society may hinder us to reach out to such places. I may feel shy to seek medical help.

(Male, person with disability, Jordan)

While another participant explained:

Most ladies that aren't married do not go to health clinics because first, they might be embarrassed, and it could come back to the parents' culture or the people they live with. If they tell their mother that they need to go to the doctor or the gynecologist, they will ask her why she wants to go if she is not married.

(Female, person with disability, Palestine)

This may be due to cultural barriers or social norms on the community level that make SRH issues a sensitive topic in the region. One participant said:

Reproductive and sexual health for persons with disability is very hard to talk about in our society. Currently it is considered a sensitive topic and is not talked about much.

(Female, person with disability, Morocco)

While another caregiver in Palestine explained:

The issue is more of a social issue. The subject of sexual health being shameful is prevalent in our society. There should be someone specialized because persons with disability need more help than others since they could have mental disabilities and can't understand the information from the internet or their friends. Since the problem is socially related, I know of biology teachers that omit the subject and don't teach it at all. There are also religious precautions and prohibitions. If we want to give this information to this group, there is supposed to be an entity special for that.

(Male, Parent/Caregiver, Palestine)

In this excerpt, the caregiver emphasizes the necessity of targeted information and awareness for persons with disability to be able to access this important information in culturally or religiously conservative contexts:

If it's the authority or the ministry or a health centre or foundation, what did they offer us for these children? do you know who we resorted to? We resorted to our dignity and our own money and our women and that's it. Do you know what the three of us think of? think if we die or our wives die, what will happen to our sons? What is the use of all the talk? I sat for so many discussions. Last time I sat in the municipality to talk and what did they do, they didn't even put ramps for people with physical disabilities.

(Male, Parent/Caregiver, Palestine)

Challenges with communication were especially emphasized with participants who experience deafness. One participant in Jordan shared:

For two years after marriage, I couldn't get pregnant. I would go to get tests and my father in-law had relatives at a private hospital. When I had done the tests, they would tell me everything is fine. They had me do tests for my ovaries. When they would insert the device, it would hurt a lot and they would keep telling me everything is fine. I was forced to do the tests and didn't [know] why I had to do them. They had my husband do a test for his sperm and they also didn't explain why he had to do it. They said he had a problem and gave him stimulants for his sperm and stimulants for my ovaries. When I took these stimulants, I started experiencing severe pain. I went to another doctor, and he said these medications were wrong for me and could've caused other problems. During these visits, I wouldn't understand what was going on because everyone else and the parents would take things into their hands and not explain things to me.

(Female, person with disability, Jordan)

This excerpt shows a breakdown in communication, where patients with disabilities experienced breakdowns in communications which kept them uninformed about treatments being conducted on them. Another participant also shared an experience where she had asked for an accommodation, but it was not met by healthcare workers, for example:

At the public centre, I would tell them not to call my name but to approach me when my turn came up, but I waited for 2 hours and I would miss my turn because I wouldn't hear when they called me.

(Female, person with disability, Jordan)

While another participant described an experience that a lack in communication lead to improper SRH treatment:

During my first pregnancy, I went to a governmental health centre. They didn't know sign language. I went with my husband, who is deaf like me. At the beginning when we had a late period and went to the centre, they told us there was no baby and gave me some medications. I wanted to know why I had pain in my stomach and was vomiting but the doctor laughed and told me to leave.

(Female, person with disability, Jordan)

## 4.2.7 Perceptions, roles, and experiences of family and caregivers

Ideas of independence/resilience could be an important part of the intrapersonal experience of persons with disability that cut across several dimensions of everyday life and relationships. Interpersonal factors such as reliance on others and other socio-ecological influences (an enabling environment) could be seen throughout the transcripts of interviews and FGDs with caregivers. Data showed that family and/or caregivers were often identified as the primary support system. For example, one participant in Morocco identified parents “as a support system should they experience GBV. The family plays a great role for you to be strong,” (Female, person with disability, Morocco). Furthermore, a participant from Jordan describe the important role that parents can play in uplifting their child with disabilities when she says:

If their parents treat them negatively, it will affect their child’s spirit. They will feel abnormal in society. It depends on how they are treated by those around them, their parents, society and their friends and themselves, their personality.

(Female, person with disability, Jordan)

Other participants described how parents could also act as gatekeepers to their SRH information and services, describing a situation in which parent deny a doctor visit to the gynaecologist:

And it could come back to the parents’ culture or the people they live with. If they tell their mother that they need to go to the doctor or the gynecologist, they will ask her why she wants to go if she is not married.

(Female, Parent/Caregiver, Palestine)

Parents and/or caregivers play a key role as a source of information for persons with disability regarding SRH. For example, one participant in Jordan shared that her family told her to insert an intrauterine contraceptive device (IUD). She described that:

I went to the centre, and they told me it is not good to insert one and I became afraid and changed my mind. I depended on natural ways of family planning. I heard about family planning from family and not from health centres.

(Female, person with disability, Jordan)

Additionally, parents and/or caregivers discussed their role in teaching their child with disabilities about puberty and menstruation. One caregiver from Palestine explained:

I would go in with her to the bathroom to shower her for example. Me or her sister would go inside with her to show her how to use sanitary pads and how to deal with menstruation and how to wear her clothes.

(Female, Parent/Caregiver, Palestine)

While another caregiver describes the prominent role, he has in helping his son throughout daily life, for example he explained:

My son's needs are completely different. The same care we provide him at home moves outside. We must drive him to and get him from school and university. Even after he got employed as the mosque's Imam, he needs to be taken there. Each stage of his life has its needs. I have to be always ready to be by his side.

(Male, Parent/Caregiver, Palestine)

#### 4.2.8 Data and indicators related to SRH and GBV of persons with disability

Overall, in all four countries, interviewed stakeholders revealed that there is a general lack of detailed data available which captures SRH and GBV for persons with disability. In Sudan, Morocco, Palestine, and Jordan it appears that questions/indicators pertaining to disability have been included in the census, which is routinely collected. Furthermore, participants in both countries mentioned several ongoing and planned activities for persons with disability which contribute to the improved quality and availability of data relating to persons with disability. For example, in Sudan indicators were developed to capture the percentage of persons with disability benefitting from a specific project, among other studies on persons with disability through the Ministry of Social Development and the development of a persons with disability database for the National Council. In Jordan, it was reported that the Higher Council for Persons with Disability was a central partner in reviewing and developing the National Strategy for Sexual and Reproductive Health, having included amended indicators on the level of output or results that monitor persons with disability.

Furthermore, The National Team for Domestic Violence Protection which is used to monitor cases of GBV and domestic violence, had previously neglected to disaggregate the number of cases by disability. However, the monitoring of disability in all annual national reports has reportedly improved. Stakeholders in Jordan point out that although improvement to monitoring procedures have been made, there are still questions pertaining to if and whether cases of violence get reported or registered which may require further investigation. While in Morocco, a national survey was conducted in 2014 which is the main source of data on disability in Morocco. In one FGD with stakeholders, it was mentioned:

Unfortunately, there is shortage of data on persons with disability in general and when available, they are not accurate. The last census in Sudan that included persons with disability was in 2008. It didn't indicate the percentage of women with disabilities and persons with disability clearly. There is data that comes from health insurance, prostheses entities, women and children's units and violence against women prevention units, but the data isn't accurate. The problem of data isn't only at the National Council for Persons with Disability, but it exists at most ministries that work with persons with disability.

(Stakeholder, Sudan)

A stakeholder from Morocco described the evolution of national data collection activities that are carried out every ten years (e.g. the general census of the population and the national research on disability) when they described:

The [national research on disability which was carried out] in 2014 and the previous one in 2004 demonstrated the developments on persons with disability issues. What we call the general census in Morocco, in 2014 for the first time, we integrated persons with disability in a very educated way. In the old census, the type of disability wasn't clear but now in the last census, the dimension of disability was integrated, and many indicators were included, which enabled us to get many results and percentages regarding disability.

We have two official documents in Morocco, the general census of the population and the national research on disability. Regarding follow up indicators on different components and needs of persons with disability; health needs and employment, schooling, and social welfare and so on, these indicators are transformed to the systems of each sector. Each system like the health system has its indicators.

(Stakeholder, Morocco)

Furthermore, in Jordan, stakeholders reported that indicators regarding persons with disability are captured well in the census and are monitored over time, saying:

Regarding the information and the indicators, the good thing is that persons with disability are monitored well in the census. You can find since 1979 till 1994 and up to 2004, 2015 there is data that present the types of disability and... the last document that came out, especially for persons with disability, from 2015 and it's available on the site.

(Stakeholder, Jordan)

Stakeholders in Sudan also acknowledged limitations in data quality and availability related to gender and refugee status. One stakeholder shared that they:

...have included the Washington Group questions in the census to know the number of persons with disability in Sudan and the categorizations regarding them. The survey of the National Council can be more detailed since we include access to services, the services that persons with disability receive, the problems they face in receiving services and their suggestions to improve the services. The census defined which states have a high percentage of persons with disability, but it wasn't clear to us the percentage of women with disabilities.

(Stakeholder, Sudan)

However, although questions from the Washington Group have been helpful in identifying the number of persons with disability in Sudan, according to stakeholders, the questions included do not provide information on any relationships between gender and disability. Therefore, improvements are needed to facilitate and gain insights on the various challenges or issues women with disabilities face regarding access to health services. Stakeholders mentioned that a survey has been developed to be distributed among women with disabilities to help enhance insights on how to intervene programmatically in primary and reproductive health care facilities.

Another stakeholder from Morocco shared that although Morocco collects data on disability, the relationship between disability and SRH indicators could be improved:

Regarding reproductive health, you don't find direct information on it relating to disability. The disability isn't clear in the indicators. In the Health Ministry information systems, for the reproductive health indicator, we don't have clear indicators for persons with disability. This is something we, at the National Centre, are working on.

(Stakeholder, Morocco)

While one stakeholder from Jordan shared:

No one can give you information like this: X health centre has had visits from 100 pregnant women, from whom two were deaf, two blind [and] three had Down Syndrome. Because, honestly, this is something that isn't being observed.

(Stakeholder, Jordan)

Furthermore, key informant interviews with stakeholders in Sudan revealed that data on refugees can be unreliable, with one stakeholder reporting that:

We have a lot of refugees in Sudan, and we have a real problem with data. From our general observations, we notice that inside marginal areas [borders], which is where most refugees are, there are many persons with disability, but we do not have detailed data on them like type of disability. Even regarding refugees, since we are facing the consequences of the problems in neighboring countries, there are military forces on East and West fronts, but the same problem prevails; we don't have enough data. We could get the data on refugees from UNHCR but still the data isn't accurate because the camps aren't in one place, but they move around depending on the services provided in the camps for refugees. The movements from one camp to another causes a difficulty in defining the numbers. There is a general problem, not just for persons with disability, in gathering the data and categorizing it.

(Stakeholder, Sudan)

The lack of data availability on persons with disability reveals a need for more inclusive approaches in each country context. One stakeholder participant from Sudan revealed:

The process of having indicators or the follow up system to monitor the health services is one of our problems because the capacities available are different from the level of modern indicators and modern information. If indicators were available to measure the different sides of the health services for persons with disability - separate indicators on reproductive health and indicators on primary health care for persons with disability - then we'll be able to know where the real gap is. Now we know where the gap is, but we can't create a more professional follow-up system. Another thing is that we need to train the general staff in the council and the staff in the states to learn how to use these indicators and how to write reports based on these indicators and how to include them in their recommendations and plans or programs or laws that will support the indicators to be implemented or the programs that come out of it to be directly implemented. This is one of our biggest challenges.

(Stakeholder, Sudan)

Lack of data availability may be due to pragmatic limitations such as social, political, or religious acceptability. A stakeholder in Jordan discussed how although the Washington Group indicators have helped understand the prevalence of disability among the general population, more qualitative insights are needed to provide a more in-depth analysis of the situation in the country. For example, one participant shared:

Let me just mention something. I think in general it's important to collect data of course on the population of the percentage of the prevalence of persons with disability. The government did that in the last census, with the Washington Group questions, which is something very positive. Besides that, we also need qualitative information about the barriers that persons with disability face to access different services and programs, as well as their enablers. We are also going to start a new participatory assessment exercise this year in order to look better at these barriers, these enablers and these capacities in the community, and listen to their recommendations and solutions, so some of the focus group discussions that we will arrange will be persons with disability, so we are better able to insure that our programme is inclusive.

(Stakeholder, Jordan)

While initiatives such as the Washington Group have made progress in developing a wide range of potential indicators to capture disability, to our knowledge, none of these indicators have been used to develop understanding of persons with disability SRH.

#### 4.2.9 Strategies and recommendations for improving access to SRH among people with disabilities

Strategies and recommendations for improving access to SRH among persons with disability also emerged during interviews and FGDs. These strategies and recommendations addressed some underlying barriers to access, stigma, embarrassment, and shame regarding SRH, involving the in-depth mapping of resources, information and services available to persons with disability, and the necessity of further training and capacity development in order to adequately assist the needs of persons with disability in the selected contexts. For example, participants discussed how services at health centres and hospitals could become more accommodating to persons with disability by introducing improved and accessible infrastructure and capacity development to facilitate specialized accommodations such as sign language interpreters at hospitals and health centres to serve patients with disabilities, one stakeholder participant reasoned:

If I provide sign language at health centres or hospitals - and we do have sign language provided from the Ministry of Health with help of [local organizations] - this way her problem is solved because she will speak in sign language and be understood and she will understand the information and explanation given to her as well as we can address her with requests. Available sign language at hospitals and health centres will serve all the women with hearing impairments visiting the hospitals and health centres regarding sexual and reproductive health.

(Stakeholder, Jordan)

There were also discussions pertaining to lifting SRH dialogues in the health sector to mitigate feelings of embarrassment or shame surrounding these issues. It was further shared that there is a societal assumption that persons with disability are asexual in Morocco, therefore contributing to the belief that persons with disability do not have a right to sexual life. This harmful myth sustains stigma, embarrassment and shame for persons with disability in seeking SRH care. One participant said:

Persons with disability have the right to a sexual life and to form relationships with others. If this stereotype/ myth was gone, these persons with disability will need information and learning the skills that will help them manage their sexual and reproductive health. They will also need services related to sexual and reproductive health. Also, they need a safe environment that protects them from exploitation and harassment.

(Stakeholder, Morocco)

Concerted efforts to dismantle such myths and stigma are an important foundational step in providing universal access to SRH. Additionally, it was recommended that needs of persons with disability be advocated to decision and policy makers in the various ministries to elevate the need for inclusion and inclusive policy development:

We need to increase the awareness of decision and policy makers in other institutions, starting from the ministers in the different ministries, and the administration. They need a complete awareness development on persons with disability and their issues and challenges, so they can [uplift] their inclusion in policies. The issue of persons with disability in Sudan has been barely given attention since the country had experienced a major shift. During the transitional phase, we included it as a priority to take care of persons with disability, and this makes us step forward in different areas on many levels and raise awareness.

(Stakeholder, Sudan)

Stakeholders from Morocco, also added:

It is crucial to address the sensitivity in the mentality of the Moroccan society, I mean the taboos. We still face embarrassment and even the care provider feels embarrassed to deal with these things. There should be trainings and awareness bringing on these topics for all workers in these areas on how to deal with a teenager that can't even speak out about the issues they face. Families also stay silent about these things, and we can reach them by bringing awareness to them. The trainings should be intensive and specialized for all care givers and experts in this area to contribute as well to spreading awareness and helping families lift the barriers that stand in front of reaching sexual and reproductive health services and being healthy emotionally. So, we need more workshops and focus on educating the families and health care providers as well as raising the awareness of persons with disability. We need to get rid of negative images and connotations from society to protect persons with disability and improve the situation.

(Male, Parent/Caregiver, Morocco)

Furthermore, stakeholders implied that it was important to have a foundational understanding of the current situation for persons with disabilities in order to develop effective policies and useful strategies that have a more distinct and targeted effort to meet their needs. Stakeholders in Morocco described how in the last 15 years, the country has been able to develop inclusive strategies for persons with disability in Morocco:

Fifteen years [ago], we didn't have specialized services for persons with disability, especially regarding reproductive health and gender-based violence. But afterwards, when the convention was signed by Morocco, it opened the doors to integrate persons with disability in the strategies of protection from violence and access to sexual and reproductive health services. This is through forming the strategy and organizing health for persons with disability from the Ministry of Health in 2011. This allowed us, the Centres for Persons with Disability, and the Ministry of Health to work with UNFPA since 2015/2016 on creating services including sexual and reproductive health and violence protection for persons with disability. Morocco, since the start of 2000s was working on a national multidisciplinary strategy to combat gender-based violence, but it talks about this in general and for all sectors. In 2014/2015, we started to focus on persons with disability in the national strategy for combating violence and inclusion of persons with disability. In this regards we were able to conduct more than one research to define the current situation for persons with disability and the violence directed at girls and women to know how do persons with disability face violence. Through knowing the current situation, we worked in 2017/2018 on putting a package of basic services for gender-based violence protection and we have worked on it to be accommodating to all types of disabilities. It was available for everyone in general, but we worked on it to be suitable for any type of disability. After that, we worked on a guide to enable health workers to identify persons with disability that are facing violence in 2018/2019. In addition, we have provided inside the National Centre and the rest of institutions in country - we are a network of institutions, and the National Centre in Rabat is the main centre, but we have 12 branches belonging to the National Centre - we have created detection units to receive and safeguard persons with disability victims of violence, regardless of the type of disability or type of violence. In addition, the national strategy to combat gender-based violence in the past 5 years integrated persons with disability in its content.

Starting next year, the ministry of health will be working on a new strategy, 2022 - 2027. Regarding the preparation of the national strategy for health and disability, persons with disability are participants in all workshops to prepare the strategy and I am witness to this. We, the National Centre participate in the workshops and persons with disability join us. You can't plan for the health of persons with disability without their participation.

(Stakeholder, Morocco)

This excerpt illustrates the importance of participatory approaches in the development of inclusive policies. Other stakeholders in Jordan echoed similar sentiments, noting the importance of involving persons with disability in defining their needs and the development of inclusive and equitable SRH services:

It is important that persons with disability are an integral partner in defining the needs and fulfilling them. Even at the service delivery level, we are working now to ensure their participation in the services to people with disabilities. We have already some success stories. I have some volunteers and service providers that have disabilities themselves. They help in two ways, defining the needs and providing services.

(Stakeholder, Jordan)

Not only should the development of useful policies and programs be grounded in the voices of persons with disability themselves, but interview and FGD participants also indicated that there is a need for substantive improvement for the evidence basis which involves the development of indicators for persons with disability, routine data collection, and data accessibility. Gaps in the evidence base can lead to detached or divided efforts and what is needed is a shared/collective understanding of the issues and priorities of persons with disability. One stakeholder in Jordan said, "I feel that it's not a common understanding, so we need to work more and make sure we all have this common understanding." This can be done through improving data, developing clear and specific indicators for SRH of persons with disability, and thus developing the knowledge basis on SRH issues.

Additionally, a male family/caregiver in Sudan acknowledged that SRH is taught in schools, with the focus being often on marriage. He further recommended that information regarding SRH issues should have a "special awareness brought to people with disabilities." Moreover, one social worker in Morocco suggested including SRH issues in the educational curriculum, despite resistance conservative voices in society which consider this 'a threat to morality,' They went on to explain,

The school must play a primary role in this and consider sexual education the same as nutrition education or environmental education because it paves the way to protect us against STDs and avoid unwanted pregnancies, protects against rape, and paves the way to a better sexual health.

(Male, Teacher for persons with disability, Morocco)

However, in providing inclusive and equitable SRH services for persons with disability, it should also be emphasized that equitable does not necessarily mean equal, as persons with disability have special needs that must be accommodated and considered. While one stakeholder remarked that "it's important just to know that persons with disability have the same needs for sexual and reproductive health services as everyone else" and "there is no need to do any sort of separation," persons with disability also made suggestions which acknowledge their special needs and that one-size-fits-all models for universal access to SRH care and information will not be sufficient.

In interviews with persons with disability, suggestions such as weekly lectures on SRH topics (Sudan), provision for a certified sign language interpreter during pregnancy and birth (Jordan and Palestine); a special foundation or support group for married persons with disability (Morocco), increased enforcement of laws that prevent violence against persons with disability including informational materials and curriculum devoted to the topic (Sudan), improvements in health insurance coverage (Palestine), improvements to facilities and even specialized facilities or departments for persons with disability, and increased awareness throughout society (all countries). One participant from Morocco explained:

Awareness starts at the family, the surrounding environment, and the educational institutions. They need to raise the children and teach them about respecting the body and accepting/ respecting others. The curriculum should include these topics and awareness should be brought to school staff and families inside homes which I think is most important. The person needs to develop respect and awareness before they are integrated into society. They need to develop a social awareness and awareness of all the groups in society.

There is a lack of awareness on these topics [such as SRH issues] even from civil society organizations that have a big responsibility to spread awareness on these topics and discuss them, as well as educational and rehabilitating institutions. Even though we put effort in presenting the issues that persons with disability face, but we don't put the spotlight on topics such as these. Bringing awareness, guidance and counselling is important and we need to monitor and do surveys. This is very important for persons with disability in general and for women with disabilities in particular. We need to have a focus on reproductive health, for women and men. This type of research is missing in the Arab world. The system is progressing but rather slowly.

(Male, person with disability, Morocco)

Stakeholders in Sudan pointed out that training on issues related to the needs of persons with disabilities is important to enhance communication and quality of health services. They indicated that they currently lack sign language interpreters and specialized training to care for persons with disability. A stakeholder reflected that:

Even in courts, the burden and responsibility are on the deaf person to hire a sign language interpreter and that's a challenge for them. Sign language isn't an official language in the country and there aren't many people trained on it. Therefore, there is difficulty in communicating with people with hearing disabilities. The training for service providers is a general training...and there should be a plan for training in the future but now the training is weak and especially in the services provided for people with hearing and mental disabilities because they need special follow up [with a] social worker and psychologist.

(Stakeholder, Sudan)

Training and capacity development are also crucial for addressing data scarcity on persons with disability. One stakeholder in Jordan pointed out, "even when we talk about carrying out assessments and then we include, for instance, the Washington Group questions on disability, that will require more time and more human resources who will require training." Stakeholders in Morocco shared that the national centre organizes a forum each year and in 2017, the national forum addressed the topic of reproductive and emotional health of people with mental disabilities and especially the issue of marriage for people with mental disabilities and autism. Stakeholders share that in this forum they:

...Discussed the reproductive and emotional health for people with mental disabilities and autism from the perspective of marriage in Islam, lawful marriage in Islam, and not from the perspective of reproduction for the sake of reproduction nor sexual health for the sake of sex, but the topic of birth and sex within the frame of the institution of marriage. We discussed the topic from the perspective of experts in Sharia, law and psychophysiology and others. The forum was a great one and we came out with a guidebook on marriage for people with mental disabilities under the UNFPA, and that we issued in 2018 through the forum. This guide demonstrates the path that the family and workers should follow to insure the marriage of persons with disability. For example, the sections of the book include conceptual information on marriage of persons with disability and we have a section on caregiving in different areas for people with mental disabilities and autism to insure a complete marriage. We added a section on practice and procedure for the marriage of a person with mental disability.

(Stakeholder, Morocco)

Demonstrating how effective and useful dialogues on important issues concerning SRH of persons with disability can be addressed. Although these recommendations and suggestions may be useful for policymakers, it is still important to acknowledge how long-term conflict has the tendency to erode public domain, thus making it more challenging for the government system to improve. Stakeholders in Sudan shared that:

We now struggle to have qualified staff and we struggle with the institutional structure of the council to be able to face the big challenges. We are a country that faced many conflicts for long periods that had their effects on the council and it transformed it from an oversight institution to a government institution that only performs governmental roles as part of the general system of the government. The real role of the council needs updating by qualifying the staff, supporting the institution's structure in the capital and the states, and even on the level of the demographic structure for the country. Despite the motivation of the people working with us and collaborative people, there are still a lot of challenges in front of the council.

(Stakeholder, Sudan)

One stakeholder from Jordan said that the in-depth mapping of information, resources, and services could help enhance persons with disability and refugee persons with disability access and understanding to relevant government services, this stakeholder suggested:

Besides that, as far as disability and age task force, we also map the services available to persons with disability with a focus on their specific needs. Targeted interventions allow better ability for referrals. But I think that a larger mapping exercise is also needed to understand the services which are available to refugees with disabilities. I mean what can they access, how? where? about the accessibility of the infrastructure and so on. I think if we had bigger mapping like involving, not only the humanitarian sector, but the government services and so on, that would be useful to all. As far as the DTF, we tried to do this from our side but it's a huge exercise that requires collaboration and involvement of different actors as well.

(Stakeholder, Jordan)

## 5. Conclusion and recommendations

Section 5 provides a summary of lessons learned and expanded version of the corresponding recommendations. These offer practical guidance and advice on entry points and opportunities to advance the United Nations Population Fund and partners' understanding and interventions in the area of disabilities and development. SRH is a sensitive topic in the region with marital status playing a significant role, modifications of approaches, research and data gaps, and a deeper exploration on how social norms and perceptions play a role in limiting access to SRH services and information for persons with disability must be considered.

This formative research study contributes to an underdeveloped research topic on the SRH needs and reproductive rights of persons with disability in the Arab region. Based on findings from the literature review and primary data collection, the research team has identified the following key lessons learned and corresponding recommendations for laying the foundation for future programming, research, and advocacy work.

### Key lesson 1

Despite gains in census data collection, such as the inclusion of Washington Group questions, which capture the situation of persons with disability in each country, there is a lack of disaggregated data and research studies devoted to SRH and GBV among persons with disability in the region. Some stakeholders reported this as a major gap which involves further development of indicators for persons with disability, routine data collection, and data accessibility. Gaps in the evidence base can also lead to detached or divided efforts and what is needed is a shared/collective understanding of the issues and priorities of persons with disability. This can be done through improving data quality by developing clear and specific indicators for SRH of persons with disability that can be disaggregated by disability type, age and gender, and therefore improving the knowledge base on SRH issues to be more comprehensive and inclusive. Furthermore, few articles/documents pertaining to persons with disability address SRH issues, and none of the reviewed documents were written from the perspective of persons with disability themselves. Stakeholders also emphasized the importance of participatory approaches in the development of inclusive policies.

Overall, there is an evident knowledge gap, with an incomplete and fragmented understanding of the status of SRH of persons with disability in the Arab region. The situation can have a detrimental effect on future programmatic and policy development. Proper investment is needed to fill these important gaps and provide a comprehensive understanding of the current situation for persons with disability in Arab countries. Otherwise, limited information on the current situation and status of persons with disability - especially in areas of conflict and within humanitarian settings - may contribute to policy failures and ineffective programmes.

### Corresponding recommendations

1. The research findings should be communicated with relevant ministries, institutions, and the National Bureaus of Statistics. Developing specific SRH and GBV indicators (disaggregated by sex

and age) for persons with disability is critically prioritized to improve data availability and quality. Such evidence is necessary to inform future policy and programmes.

2. A revised regional and national SRH research agenda is required, emphasising the inclusion of persons with disability. Adopting the inclusion agenda, with a distinct focus on SRH and GBV for persons with disabilities throughout the region, would contribute to enhanced evidence and the development of tailored and inclusion-focused policy, programmes, and advocacy initiatives.
3. Build towards more engaging and empowering inclusion efforts in further research studies. This can be achieved by amplifying the voices of persons with disabilities, especially refugees or internally displaced, and people who have direct experience with disability. UNFPA ASRO's SRH research agenda should ensure that the perspective of persons with disability is sought and considered.
4. Invest further in documenting and exchanging experiences of best practices between different countries in the region. A regional database or observatory hosted by UNFPA ASRO could facilitate this. Availing a regional data base for SRH and GBV research and data sources, is believed to enhance exchange of information and a shared understanding of the needs and situation affecting persons with disability in the region in general and in relation to SRH in specific.
5. Exchange experiences of best practices from other regions or countries. A regional database or observatory hosted by UNFPA ASRO could facilitate this. Establish a knowledge database where statistics and research regarding persons with disability can be readily shared throughout the region, so that countries within the Arab region can share and exchange information about persons with disability. This platform can be developed in the future for sharing lessons learned. This knowledge database can also contribute to a shared understanding of the needs and situation affecting persons with disability.

## Key lesson 2

SRH was characterized as a sensitive topic throughout data collection. The sensitive nature of the topic was also emphasized through the non-responsiveness or silence among unmarried persons with disability. Additionally, this study revealed that a myriad of assumptions and stigma was experienced by persons with disability. The study also identified core issues of vulnerability (especially related to violence), deprivations of persons with disability's reproductive rights (denied/limited access to SRH information and services and other forms of social exclusion fuelled by assumptions, stigma, and various cultural/societal norms).

Additionally, persons with disability expressed and vocalized needs for more information on family planning, pregnancy, puberty, and menopause. In many cases, persons with disability advocated their right to have normal sexual development, sexual drive, and a desire to get married and start a family. However, harmful assumptions by members of the community (e.g. parents, neighbours, and healthcare providers) and stigma regarding persons with disabilities' sexual development, reproductive capabilities, and eligibility for marriage exacerbate barriers for them to access SRH services and information. Furthermore, emphasis should be focused on the SRH lifecycle of persons with disability, to gain a broader understanding of what are their needs at different stages of the life cycle.

### Corresponding recommendations

6. Efforts by policy makers to improve access to sexual and reproductive health services for persons with disabilities should consider the core issues of vulnerability and deprivation to comprehensively expand and improve their inclusion.
7. Develop programmes that provide targeted information and support for persons with disabilities, to ensure that they are protected from sexual or other forms of violence, and the risk of being victimized. Effective programming needs to target both males and females with different types of disability. It should consider the difference and inter-sectionality between gender-based and disability-based violence. Also, empower persons with disability with tailored tools that facilitate identification and reporting of violent acts towards them.
8. Training for parents and care givers on how to provide improved support systems and become better advocates for persons with disability, especially in reference to SRH needs.

### Key lesson 3

Disability was perceived as a central characteristic of one's identity, making it challenging to identify and distil the influence of other marginalized characteristics such as age, gender, and refugee status. The dominance of intersecting identities in this context thus masked conclusions about the current situation of GBV within this population. It also emerged that persons with disability face intersecting forms of marginalisation, discrimination, oppression, and exclusion leading to violence at both the household and community levels. Here, the research surfaced concerns for two kinds of violence: gender-based violence and disability-based violence. While gender-based violence was an object of the research, disability-based violence was raised often, by both male and female persons with disability. The difference between the two was not often possible to discern.

New approaches are needed in order to address the mutual and intersecting processes of marginalisation, discrimination, oppression, and exclusion that can be related to other characteristics such as age, gender, and refugee status experienced by persons with disability in this context, especially through the lens of intersectionality. These characteristics should be explored in depth to develop an understanding of how gender, refugee status, and age may intersect and influence SRH including GBV related experiences for persons with disability.

### Corresponding recommendations

9. More detailed research studies, especially from an intersectional/life cycle approach, are needed for understanding country specific SRH concerns. As part of the initiative, a basic understanding of the assumptions, stigma, and various cultural/societal norms experienced by persons with disabilities seeking sexual and reproductive health services should be used and promoted as an entry point for policy development.
10. Strengthening the capacity of organizations that serve persons with disabilities is essential; through proper and effective outreach and awareness activities, the different circles of influence such as parents, friends, local communities, and society at large understand the rights and needs of persons with disabilities regarding SRH issues at different stages of the lifecycle.

## Key lesson 4

Participants felt that equal treatment ('I get the same treatment as everyone else') in healthcare settings prevented them from receiving quality SRH care and services that met their needs. For example, it was suggested multiple times that there is a need to improve infrastructure and capacity development to facilitate specialized accommodations such as sign language interpreters at hospitals and health centres to serve patients that are persons with disability. Further improvements to facilities, specialized facilities or departments for persons with disability, and development/enforcement of laws that prevent violence against persons with disability are needed. However, findings from this formative research show that it is important to acknowledge the distinction between equity versus equality when addressing the specific barriers that exist for persons with disability in accessing SRH services and information. There is a need to improve accessibility, cultural sensitivity, and equity (support services needed to serve persons with disability) throughout the region. In sum, persons with disability have the right to equitable access to SRH information and services and further efforts are needed to ensure that health policies have upheld their commitment to inclusion, providing universal healthcare for all.

### Corresponding recommendation

11. Equitable access to sexual and reproductive health services and information should be promoted by ensuring that evidence from research studies contribute to inclusion policy revisions and/or policy development and more human rights/inclusion focused practical guidelines for treating persons with disabilities. This may include non-stigmatizing and inclusive program development and training for doctors, healthcare workers, and data collectors about the specific needs of this population.
12. Expand the scope of training for parents and caregivers on how to provide improved support systems and become better advocates for persons with disabilities, especially regarding sexual and reproductive health needs.

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## 7. Appendix A: Literature Review

Relevant Country	Year	Title (Document name )	Author / origin
All Arab countries and Palestine	2018	DISABILITY IN THE ARAB REGION, ESCWA 2018 <a href="https://www.unescwa.org/sites/www.unescwa.org/files/publications/files/disability-arab-region-2018english_1.pdf">https://www.unescwa.org/sites/www.unescwa.org/files/publications/files/disability-arab-region-2018english_1.pdf</a>	ESCWA
Palestine	2015	Country Assessment towards Monitoring and Reporting Sexual and Reproductive Health and Rights [SRH] in Palestine	(MIFTAH), (ICHR, (UNFPA) and (CEDAW)
Palestine	2019	Convention on the Right of Persons with Disabilities	United Nations, the Committee on the Rights of Persons with Disabilities
Palestine	2018	Effective response to GBV( Gender-based Violence), national guide Palestine	Ministry of Health (MOH), General Administration of Women's Health and Development
Gaza, Palestine	2021	Knowledge, Attitudes and Practices Among Men in the Gaza Strip Related to Sexual and Reproductive Health and Rights and Child-Rearing	independent consultants: Nadia Al Bayoumi, Riyad Diab, Bassam Abu Hamad, Al-Quds University, with the support of the UNICEF, WHO, and UNFPA
Palestine	2020	The Rights of Persons with Disabilities Amid COVID-19	Nations Human Rights oPt), (Ministry of Social Development) and (the Independent Commission for Human Rights)
Palestine	2019	Guide to Harmonization of Sexual and Reproductive Health Services for Women and girls with disabilities	(HWC)Health Work Committees
Palestine	Not published	The Sexual and Reproductive Rights Package for Children and Adolescents with Mild and Moderate Intellectual Disabilities	Juzoor for Health and Social Development.
Palestine	2016	WEST BANK AND GAZA DISABILITY IN THE PALESTINIAN TERRITORIES Assessing Situation and Services for People with Disabilities (PERSONS WITH DISABILITY)	World Bank

Palestine	2021-2023	National Health Strategy 2023-2021	(MOH) Ministry of health
Palestine	2018-2022	The National Strategy for Reproductive and Sexual Health in Palestine 2022-2018	(MOH) Ministry of health
Palestine	2021	Disability-Inclusive Education in the occupied Palestinian territory (oPt): West Bank & Gaza	handicap International
Palestine	2020	The international day of persons with disabilities on December 3ed 2020	Palestinian Central Bureau of Statistics (PCBS)
Jordan	2017	The reality of reproductive health programs for people with disabilities in the Hashemite Kingdom of Jordan.	The Higher Council for the Rights of Persons with Disabilities
Jordan	2019	The National Strategy for the Deinstitutionalisation of Persons with Disabilities in Jordan	The Higher Council for the Rights of Persons with Disabilities
Jordan	2015	Phase II of The National Strategy for Persons with Disabilities 2015-2010	British Council
Jordan	2015	Phase II of The National Strategy for Persons with Disabilities 2015-2010	British Council
Jordan	2019	Ten-year strategy for inclusive education (2019-2029)	Ministry of Education The Higher Council for the Rights of Persons with Disabilities
Jordan	2017	The reality of disability in Jordan based on the data of the 2015 Population and Housing Census	Population Housing Census Department of Statistics (DOS)
Jordan	2018	position paper On the rights of persons with disabilities in reproductive health and sexual education programmes	The Higher Council of Population Higher Council for the Rights of Persons with Disabilities share - net Jordan
Jordan	2016	Report of the main results of the general population and housing census 2015	Population & Housing Census Department of Statistics (DOS)
Jordan	2015	Sudan health profile	world health organization WHO

Jordan	2017	Reply from CSOs to the List of Issues in relation to the initial report of the Republic of Sudan	CSOs
Jordan	2018	National Disability Strategy 2030-2018 الخطة الاستراتيجية الوطنية 2030-2018	National Council for Persons with Disabilities المجلس القومي للأشخاص ذوي الإعاقة
Morocco	2020	Matrix Plan 2021 مصفوفة خطة العام 2021	Ministry of Labor and Social Development وزارة العمل والتنمية الاجتماعية National Council for Persons with Disabilities- General Secretariat لمجلس القومي للأشخاص ذوي الإعاقة، الأمانة العامة
Morocco	2016	United Nations Population Fund Country programme document for Morocco	UNFPA – Country programmes and related matters
Morocco	2021	accountABILITY toolkit African Regional Human Rights System Legal Standards on the Rights of Women and Girls with Disabilities	Women Enabled International
Global		Facts Sexual and Reproductive Health and Rights of Women and Girls with Disabilities	Women Enabled International
Sudan	2019	Women Enabled International Submission to the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health Report on Medical Education and Health Workforce Strengthening	Women Enabled International
Sudan	2018	Women Enabled International Submission to OHCHR: Maternal Mortality of Women and Girls with Disabilities	Women Enabled International
Sudan	2021	Sexual harassment against women with disabilities in the world of work and on campus	UN WOMEN Purna Sen and Rosario Grima Algora
Sudan		Meeting basic needs of women and girls with disabilities during COVID19-	UN Women and Women Enabled International
Morocco	2021	Issue brief: Making the SDGs count for women and girls with disabilities	UN WOMEN Sophie Browne
Global	2020	Women with disabilities in a pandemic (COVID19-)	UN Women and Women Enabled International

Morocco	2018	FEMMES ET JEUNES EN SITUATION DE HANDICAP WOMEN AND YOUTH WITH DISABILITIES Guide relatif à la fourniture de services fondés sur les droits et sensibles au genre en matière de violence fondée sur le genre et de santé et droits sexuels et reproductifs	UNFPA women enabled international WE Decide acid
Morocco	2017	SHADOW REPORT International Convention on the Rights of Persons with Disabilities CRPD	التحالف من أجل النهوض بحقوق الاشخاص في وضعية اعاقة Collective for the Promotion of the Rights of Persons with Disabilities (CPD) CPD
Morocco	2015	Integrated public policy to advance the rights of people with special needs لسياسة العمومية المندمجة للنهوض بحقوق الاشخاص في وضعية اعاقة	Kingdom of Morocco Ministry of Solidarity, Women, Family and Social Development لمملكة المغربية وزارة التضامن والمرأة والأسرة والتنمية الاجتماعية
Morocco	2015	Strategic directions of health and disability through integrated public policy to advance the rights of persons with disabilities in Morocco التوجهات الاستراتيجية للصحة والاعاقة من خلال السياسة العمومية المندمجة للنهوض بحقوق الاشخاص في وضعية اعاقة في المغرب	Kingdom of Morocco Ministry of Solidarity, Women, Family and Social Development لمملكة المغربية وزارة التضامن والمرأة والأسرة والتنمية الاجتماعية
Morocco	2015	The second national research on disability - summary of results البحث الوطني الثاني حول الإعاقة - خلاصة النتائج	Kingdom of Morocco Ministry of Solidarity, Women, Family and Social Development لمملكة المغربية وزارة التضامن والمرأة والأسرة والتنمية الاجتماعية
Morocco	2015	National Action Plan for Health and Disability 2021-2015 مخطط العمل الوطني للصحة والاعاقة	Ministry of Health - Kingdom of Morocco
Morocco		Les incapacités et le handicap au maroc	Kingdom of Morocco. Haut Commissariat au Plan

Morocco	2018	Enquête Nationale sur la Population et la Santé Familiale (ENPSF - 2018) National Population and Family Health Survey (ENPSF - 2018)	Ministry of Health. Ministry of Health DPRF / DPE / SEIS Rabat, Morocco PAPFAM project League of Arab States Cairo, Egypt
Morocco	2019	Perception De La Santé Sexuelle Et Reproductive Chez Les Personnes En Situation De Handicap(s) Physique(s) Et/Ou Sensoriel(s)	l'UNFPA, Rabat Sale, Kénitra, Marrakech-Safi, Fes Mekrnes et Loriental
Jordan	2021	Impact of restricting access to health care services on Syrian refugees in Jordan: evidence from cross-sectional surveys.	Siam, I. K. A., & Gómez, M. R.
Jordan	2016	Health Service Access Survey among Non-camp Syrian Refugees in Irbid Governorate, Jordan	Rehr, M.
Jordan	2020	Accountability for sexual and reproductive health and rights in development practice: building synergies	Barragués Fernández, A.
Jordan	2018	Engaging organizations of persons with disabilities in humanitarian responses	Buscher, D.
Jordan	2015	"I See That It Is Possible" Building Capacity for Disability Inclusion in Gender-based Violence Programming in Humanitarian Settings	Women's Refugee Commission
Jordan	2013	Building capacity for disability inclusion in gender-based violence programming in humanitarian settings	Women's Refugee Commission
Jordan	2015	Reproductive health services for Syrian refugees in Zaatri camp and Irbid City, Hashemite Kingdom of Jordan: an evaluation of the minimum initial services package	Krause, S., Williams, H., Onyango, M. A., Sami, S., Doedens, W., Giga, N., ... & Tomczyk, B.
Jordan	2018	What's Missing? A Human Rights Approach to Reproductive Health Policies in Jordan	Khayyat, R.
Jordan	2015	Advancing reproductive health on the humanitarian agenda: the 2014-2012 global review	Chynoweth, S. K.
Jordan	2014	Physical disability, gender, and marriage in Jordanian society	Jalal, S., & Gabel, S.
Jordan	2020	The human rights of women and girls with disabilities: sterilization and other coercive responses to menstruation	Steele, L., & Goldblatt, B.

Palestine	2019	Negation of the Right of Women with Disabilities in Palestine to Marry: Cultural Considerations for Disability	Elkhateeb, I., & Peter, D.
Palestine	2018	A long way to go: a systematic review to assess the utilisation of sexual and reproductive health services during humanitarian crises	Singh, N. S., Aryasinghe, S., Smith, J., Khosla, R., Say, L., & Blanchet, K.
Arab countries	2019	Disability in the Arab world: a comparative analysis within culture	Eissa Saad, M. A., & Borowska-Beszta, B.
Palestine	2019	Sexual health policies in stroke rehabilitation: A multinational study	Vikan, J., Nilsson, M. I., Bushnik, T., Deng, W., Elessi, K., Frost-Bareket, Y., ... & Fugl-Meyer, K. S.
Morocco	2021	Characteristics of Menarcheal Age, Menstrual Hygiene and Socio-Demographic Factors in Girls with Down Syndrome in Morocco	Oulmane, Z., Hilali, M. K., & Cherkaoui, M.
Arab countries	2021	Reproductive Health in Arab Countries	Abdelbaqy, M. A.
Morocco	2019	Maternal healthcare experiences of and challenges for women with physical disabilities in low and middle-income countries: a review of qualitative evidence	Nguyen, T. V., King, J., Edwards, N., Pham, C. T., & Dunne, M.
Morocco	2017	Sexual violence against men and boys in conflict and forced displacement: implications for the health sector	Chynoweth, S. K., Freccero, J., & Touquet, H.
Morocco	2014	Sexual violence and sub-Saharan migrants in Morocco: a community-based participatory assessment using respondent driven sampling	Keygnaert, I., Dialmy, A., Manço, A., Keygnaert, J., Vettenburg, N., Roelens, K., & Temmerman, M.
Sudan	2013	Intra-partum fever and cerebral palsy in Khartoum, Sudan	Abdullahi H, Satti M, Rayis DA, Imam AM, Adam I
Sudan	2016	Policies and processes for social inclusion: using EquiFrame and EquiPP for policy dialogue: comment on» Are sexual and reproductive health policies designed for all? Vulnerable groups in policy documents of four European countries and their involvement in policy development»	MacLachlan, M., Mannan, H., Huss, T., Munthali, A., & Amin, M.
Sudan	2012	Inclusion and human rights in African health policies: Using EquiFrame for comparative and benchmarking analysis of 51 policies from Malawi, Sudan, South Africa and Namibia	MacLachlan M, Amin M, Mannan H. et al.

Morocco and Sudan	2015	The Sexual and Reproductive Health Rights of Women with Disabilities in Africa: Linkages between the CRPD and the African Women's Protocol	Murungi, L. N., & Durojaye, E.
Sudan	2014	Analysis of Disability Statistics from Sudan Census 2008	Musa, S. E. A. D.
Sudan	2015	Perceived barriers for accessing health services among individuals with disability in four African countries	Eide, A. H., Mannan, H., Khogali, M., Van Rooy, G., Swartz, L., Munthali, A., ... & Dyrstad, K.
Global	2009	Promoting sexual and reproductive health for persons with disabilities (WHO/UNFPA Guidance note). Retrieved from <a href="http://whqlibdoc.who.int/publications/9789241598682/2009_eng.pdf">http://whqlibdoc.who.int/publications/9789241598682/2009_eng.pdf</a>	World Health Organization and UNFPA
Sudan	2012	Core concepts of human rights and inclusion of vulnerable groups in the disability and rehabilitation policies of Malawi, Namibia, Sudan, and South Africa	Mannan, H., McVeigh, J., Amin, M., MacLachlan, M., Swartz, L., Munthali, A., & Van Rooy, G.
African region	2013	Inclusion of vulnerable groups in health policies: Regional policies on health priorities in Africa	Schneider, M., MacLachlan, M., Eide, A. H., Amin, M., & Mannan, H.
Arab countries	2017	Functional Impairment and Painful Physical Symptoms in Patients with Major Depressive Disorder Treated with Antidepressants: Real-World Evidence from the Middle East	Hong J, Novick D, Moneta MV, El-Shafei A, Dueñas H, Haro JM. Functional Impairment and Painful Physical Symptoms in Patients with Major Depressive Disorder Treated with Antidepressants: Real-World Evidence from the Middle East. Clin Pract Epidemiol Ment Health. 2017 Sep -13:145;30155. doi:17450/10.2174/17901713010145. PMID: 29238391; PMCID: PMC5712648.

## 8. Appendix B: List of identified stakeholder organizations

Stakeholders that participated in this study	
Name	Country
Institute for Family Health	Jordan
Higher Population Council (HPC)	Jordan
Department of Statistics (DoS)	Jordan
Ministry of Health (MoH)	Jordan
UNHCR DATF	Jordan
UNHCR	Jordan
Humanity & Inclusion	Jordan
Royal Health Awareness Society	Jordan
UNFPA	Jordan
Mohammed VI National Center for the Disabled	Morocco
Rabie Al-Omar Association for Persons with Special Needs	Morocco
Ministry of Health and Social Protection	Morocco
Ministry of National Education (Regional Academy of Education and Training in Tanga Tetouan Al Hoceima region)	Morocco
UNFPA	Palestine
General Union of Persons with Disabilities- Tubas	Palestine
General Union of Persons with Disabilities -Gaza	Palestine
Stars of Hope Association, West Bank	Palestine

Stars of Hope Association, Gaza	Palestine
Star Mountain Center	Palestine
Juzoor for Health and Social Development	Palestine
Palestinian Benevolent Society for the Care of the Deaf	Palestine
Ramallah municipality	Palestine
The Palestinian Medical Relief Society (PMRS)	Palestine
UNRWA	Palestine
Ministry of Education	Palestine
Ministry of Social Development	Palestine
Palestine Association of Visually Impaired Persons	Palestine
Union of Health work Committees (UHWC)	Palestine
Community-based Rehabilitaion (CBR) - Ramallah	Palestine
Betunia Municipality	Palestine
National Council for Persons with Disabilities (NCPD)	Sudan
Sudanese Association for the Care of the Deaf	Sudan

## 9. Appendix C: Data collection instruments

Interview Guide: Stakeholders who work with persons with disabilities, people who are involved with organizations that serve persons with disabilities (e.g. social workers, psychologist, coordinators).

Focus Group Discussion Guide: Stakeholders who work on health strategies and policies -high-level policy makers in governmental and non-governmental organizations (e.g. ministry of health and ministry of development affairs, UNRWA)

\*Note that not all questions are necessarily relevant for all stakeholder interviewed, it will merely be a basis for guided questions to be asked.

### Key:

IQ = Interview question

P = Probe

### Interview Plan:

\*Small talk to develop rapport with the informant(s). Introduce facilitators. Describe the general outline of the interview and review confidentiality agreement.

Explain why we are here:

"We appreciate your contribution to help us in identify the availability and relevance of data related to the SRH&RR of PERSONS WITH DISABILITY, for example specific indicators, statistics as well policies, and service delivery infrastructure with a specific focus on sexual and reproductive health and reproductive rights and GBV among persons with disabilities in each of the selected countries of the Arab region."

Explain how all answers will be treated confidentially:

"Thank you for taking the time to talk with me today. I would like to ask you some questions about your perspectives and experiences working with persons with disabilities. As mentioned in the consent form, all of your responses will remain confidential. I will remove any identifying information that you share, for example any names of people or places, and the way I report your answers will not allow anyone to link anything you say to your identity. While we're talking today, if you ever feel uncomfortable with a question or simply do not want to answer it that is completely fine and has no undue influence on you, just let me know. Is it okay for me to record this interview?"

### Focus Group Discussion Guide 1:

**IQ 1:** What problems have persons with disabilities experienced in accessing SRH and GBV services in your country?

**IQ 2:** Can you give examples of challenges and barriers?

**IQ 3:** From your experience which categories of persons with disability are more prone to GBV in your community?

- P:** What types of disability, age groups, gender and socioeconomic status are considered more vulnerable)?
- P:** What about men and boys with disabilities, are there specific types of violence that they experience? What examples can you provide? Where does it happen?
- IQ 4:** What GBV specialized services (like health, psychosocial support, GBV case management, safety and security, legal) are available for survivors?
- IQ 5:** Is there a high-level institution or entity that leads advocacy for persons with disabilities sexual health and reproductive needs at the regional or country-level?
- IQ 6:** What types of data are currently being collected on disabilities in the region?
- IQ 7:** To what extent is data collected on disability and does such data include indicators relating to sexual & reproductive health & reproductive rights, gender gaps, and gender-based violence?
- IQ 8:** To what extent is the data collected on persons with disabilities disaggregated by age group, residency/population group status (e.g. internally displaced or refugee
- IQ 9:** What has been the learning outcomes of programs targeting this population in the country region?
- P:** What was successful and what was challenging?
- IQ 10:** Which existing policies facilitate the provision of SRH services for people with disability, and which policies produce barriers (either unintended or intended)?
- IQ 11:** Which organizations/ entities provide SRH services for persons with disabilities and what services do they provide? (P: How do you see the quality of these services in term of dealing with Persons with disability?)
- IQ 12:** To what extent is high quality data (e.g. data that is accurate, complete, consistent, and reliable) being collected on persons with disabilities relating to SRH and GBV?
- IQ 13:** If you are improving the quality of health services, are these services offering the same quality of care to persons with disabilities as to other clients?
- P:** If not, what should be done?
- IQ 14:** Are you assessing facilities from the perspective of persons with disabilities?
- IQ 15:** Have you considered adaptations for persons with disabilities?
- P:** such as ramps, easy-to-understand written or graphic formats for information, Braille, or sign language interpreters, depending on the local needs
- IQ 16:** Are you updating policies, norms, and procedures from the perspective of persons with disabilities?
- IQ 17:** Do they refer specifically to issues of concern to persons with disabilities?
- IQ 18:** Do you think the national policies and plans for SRH consider the needs of persons with disability who are refugees or internally displaced people?
- IQ 19:** Are you integrating disability-related sessions into the pre-service training of medical and paramedical staff?

**IQ 20:** What should be done to make sure people with disabilities get their rights

**IQ 21:** How has the COVID19 affected the prevalence of GBV?

**IQ 22:** How has the COVID19 affected the access of Persons with disability to SRH and GBV services?

## Discussion Guide 2:

**IQ 1:** Please tell us briefly about your background and areas of responsibilities in your organization.

**IQ 2:** Please tell us in few words about the general services that you provide to disabled people in your organization.

**IQ 3:** What would you say are the major challenges that persons with disabilities face in your country?

**IQ 4:** Do you have any experiences helping a person with disabilities access health services in general, in your country?

**P:** Is there a high-level institution or entity that leads advocacy for persons with disabilities at the regional or country-level?

**IQ 5:** In your country, do you have any agency that have specific mandate related to SRH of persons with disabilities?

**P:** What about SRH services for persons with disabilities in your country, how would you describe the availability of SRH and GBV services for persons with disabilities?

**IQ 6:** How would you describe the suitability and quality of services for persons with disabilities? Can you give examples reflecting on your experience of persons with disabilities?

**P:** What are your views on the utilization of SRH services among persons with disabilities, what would you say are the health needs of persons with disabilities?

**IQ 7:** What is your understanding of sexual reproductive health services which persons with disability may need, what services available, what are the greatest concerns of persons with disabilities in relation to sexual reproductive health services?

**P:** What are some of the reasons that hinder access to these services? (Please probe about, lacking information about the availability of such services, lack of suitability or preparedness to cope with the specific need of persons with disabilities, also if related to attitudes of health care providers? As well are there social and financial barriers accessing such services?

**P:** How can SRH services and be improved to facilitate access to those services by persons with disabilities?

**P:** Could you walk me through what that would look like?

**IQ 8:** What are the opportunities and recommendations to improve and strengthen access and use of sexual and reproductive health services by persons with disabilities?

**P:** In your opinion, from where and how do persons with disabilities get information on SRH issues and when they have specific SRH need, from whom or where do they reach out for help?

- P:** What is your perception of some of the information that is conveyed to persons with disabilities on SRH?
- IQ 9:** What are the policies related to SRH information and services among persons with disabilities, and are there barriers and enablers to the implementation of these policies?
- IQ 10:** Can you describe some of the socio-cultural factors, taboos and customs that influence persons with disabilities' access to sexual and reproductive health information and services.
- P:** What are some of the misconceptions and perception that would influence access to sexual and reproductive health information and services among persons with disabilities?
- IQ 11:** What challenges have you witnessed persons with disabilities experiencing in accessing SRH and services your country?
- P:** Could you walk me through an example?
- P:** What is your experience or observation on refugees or internally displaced persons with disability face in accessing their SRH and services
- IQ 12:** Now, we will have some specific questions about exposure to violence for persons with disabilities, in your experience could you tell me more about how persons with disabilities may be affected by violence?
- P:** what are the factors that might exacerbate their exposure to violence? Gender, marital status, type and severity of disability, place of residence (living camp), for example?
- P:** What about physical, psychological, sexual violence and GBV?
- P:** From your experience, when and where does violence against disabled persons mostly occur? Who are the most common perpetrators?
- IQ 13:** In your opinion, what are community responses when violence occurs against disabled person?
- P:** What is done to prevent violence?
- P:** Are there specific services for persons with disabilities to help them as survivors?
- P:** What social and legal services exist to help address these problems (e.g. health, police, legal counselling, social counselling)?
- IQ 14:** Who provides these services for persons with disability?
- P:** How could these efforts be improved?
- P:** What GBV specialized services (like health, psychosocial support, GBV case management, safety and security, legal) are available for survivors from violence among persons with disabilities?
- IQ 15:** How would you describe the magnitude of the issues of sexual violence over time?
- P:** Has it gotten worse, better, or stayed the same?
- IQ 16:** How has the COVID19 affected the access of persons with disability to their SRH and GBV services?
- IQ 17:** Can you describe the influence or impact of the COVID19 pandemic on the prevalence of GBV among persons with disability?

**IQ 18:** Finally, can we ask you if you ever get any specific training about SRH of disabled?

### Closing:

- Thank people for their time and ideas and express how helpful it has been to facilitators.
- Explain next steps: "We will look at all information and will make a report of findings to which will be available on with UNFPA website

Focus Group Discussion Guide: Families and Caregivers for PERSONS WITH DISABILITY

### Key:

IQ = Interview question

P = Probe

### Focus Group Discussion Plan:

\*Small talk to develop rapport with the informant(s). Introduce facilitators. Describe the general outline of the focus group discussion and review confidentiality agreement.

Explain why we are here:

"We want help in identify gaps in the availability and relevance of data (data scarcity or poor quality), policies, and service delivery infrastructure with a specific focus on sexual and reproductive health and reproductive rights and GBV among persons with disabilities in each of the selected countries of the Arab region."

Explain how all answers will be treated confidentially:

"Thank you for taking the time to talk with us today. I would like to ask you some questions about your perspectives and experiences caring for a person with disabilities. As mentioned in the consent form, all your responses will remain confidential. We will remove any identifying information that you share, for example any names of people or places, and the way I report your answers will not allow anyone to link anything you say to your identity. While we're talking today, if you ever feel uncomfortable with a question or simply do not want to answer it that is completely fine, just let us know. Is it okay for us to record this discussion?"

### Discussion Guide:

**IQ 1:** Please tell us briefly about your relationship to a person with disabilities, describe your general responsibilities, and how long you have been caring for this individual.

**IQ 2:** What would you say are the major challenges that persons with disabilities face on a day-to-day basis?

- IQ 3:** Can you tell us about your experience in caring for persons with disability and dealing with his/her puberty's physiological and psychological changes and handle it (Refer to menarche for female's)?
- IQ 4:** Do you have any experiences helping a person with disabilities access health services in general?
- IQ 5:** In your opinion, what are the specific needs for persons with disabilities in relation to SRH? What topics are important to them?
- IQ 6:** Have you ever experienced any challenges in communicating specific issues related to SRH with your son/daughter? Or cared person?
- IQ 7:** How would you describe your preparedness to deal with specific SRH needs for your son/daughter? Or cared person?
- IQ 8:** What is your understanding of sexual reproductive health services, are these services accessible to persons with disabilities?
- IQ 9:** What are your views on the utilization of SRH services among persons with disabilities, what do you think some of the barriers that may prohibit persons with disabilities and or their caregivers from accessing those services?
- P:** In your opinion should parents/caregivers be involved when their persons with disabilities need SRH services?
- IQ 10:** What are the opportunities and recommendations to improve and strengthen access and use of sexual and reproductive health services by persons with disabilities?
- IQ 11:** How has the COVID19 affected the persons with disability ability to receive SRH services and maintain?
- P:** In your opinion, from where and how do persons with disabilities get information on SRH and when they are in SRH need, who do they reach out for help?
- IQ 12:** What type of SRH information should be available for persons with disabilities? What are the rightful communication methods to reach out for persons with disabilities?
- IQ 13:** While persons with disabilities are in schools (either general or for persons with disabilities do you think that schools or centres provide them with the necessary SRH information they might need?
- P:** How do you suggest involving such schools or centres in providing relevant SRH information for persons with disabilities?
- P:** Can you think of other way or resources that might facilitate providing persons with disabilities with relevant SRH information?
- IQ 14:** Could you identify taboos and customs?
- P:** What are the myths, misconceptions and perception that influence access to sexual and reproductive health information and services among persons with disabilities?

Now we will shift to ask specific questions about exposure to violence for persons with disabilities.

**IQ 15:** In your experience could you tell me more about how and why persons with disabilities may be affected by violence?

**P:** What are the most common forms of violence that persons with disabilities may experience?

**P:** From your experience, when and where does violence against persons with disability mostly occur, and who are the perpetrators?

**P:** How do you think persons with disability and their families deal with violence?

**P:** Could you walk us through what types of information or advice you might provide to persons with disabilities to protect themselves from violence?

**P:** what are the best approaches to teach persons with disabilities about how to protect themselves from violence?

**IQ 16:** What do you think can be done to improve the SRH of disabled and access to services of SRH and GBV?

**IQ 17:** Can you describe the influence or impact of the COVID19 pandemic on the prevalence of GBV among persons with disability?

### Closing:

- Thank people for their time and ideas and express how helpful it has been to facilitators.
- Explain next steps: "We will look at all information and will make a report of findings to which will be available on with UNFPA website.

## Semi structured interviews Guide: Persons with disabilities.

<b>Name of country:</b>	<b>Date:</b>
<b>Time discussion started:</b>	<b>Time ended:</b>
<input type="checkbox"/> Physical <input type="checkbox"/> Mental <input type="checkbox"/> Intellectual <input type="checkbox"/> Sensory	<input type="checkbox"/> City <input type="checkbox"/> Village <input type="checkbox"/> Camp
<b>Gender:</b>	
<b>Participant summary #:</b>	
<b>Facilitator(s) name(s):</b>	

### Key:

IQ = Interview question

P = Probe

### Interview Plan:

\*Small talk to develop rapport with the informant(s). Introduce facilitators. Describe the general outline of the interview and review confidentiality agreement.

Explain why we are here:

"We want help in identify gaps in the availability and relevance of data (data scarcity or poor quality), policies, and service delivery infrastructure with a specific focus on sexual and reproductive health and reproductive rights and GBV among persons with disabilities aged 18-49 in each of the selected countries of the Arab region."

Explain how all answers will be treated confidentially:

"Thank you for taking the time to talk with me today. I would like to ask you some questions about your perspectives and experiences working with persons with disabilities. As mentioned in the consent form, all your responses will remain confidential. I will remove any identifying information that you share, for example any names of people or places, and the way I report your answers will not allow anyone to link anything you say to your identity. While we're talking today, if you ever feel uncomfortable with a question or simply do not want to answer it that is completely fine, just let me know. Is it okay for me to record this interview?"

## Interview Guide:

**IQ 1:** Can you please tell me a little about yourself?

**P:** Age, disability, how long have you been disabled? Are you married? If yes, please inquire about having children?

**IQ 2:** What is your understanding of sexual and reproductive health and reproductive rights? For example, what are the components of SRH?

Read the definition of the WHO of RH.

Then ask the following questions:

**IQ 3:** What are the topics or issues of SRH&RR are important to persons with disabilities? Is sexual and reproductive health important to you or persons with disabilities in general?

**P:** Could you explain why or why not?

**IQ 4:** Have you ever experienced or accessed health care facility for an issue related to SRH? If yes, can you describe to use this encounter? For example?

**P:** How did you find the quality of care? What was it like to seek SRH services? Do you feel like you were treated well?

**IQ 5: P:** What are some of the challenges you have experienced when trying to access health services?

If the respondent answered with no, please inquire about the possible challenges that might face persons with disabilities while accessing SRH services/

If the participant is married, ask the following questions:

Do you have personal experience in seeking preconception care or family planning, or antenatal care or childbirth services?

**P:** Do you know about any other persons with disability experience in seeking preconception care or family planning, or antenatal care or childbirth services?

**IQ 6:** In your opinion, how would persons with disability like to receive SRH information and services?

**IQ 7:** Do you feel that services relating to sexual & reproductive health & reproductive rights and gender-based violence take into consideration the needs of persons with disabilities in your country?

**P:** can you specifically describe What are those needs?

**P:** what are your suggestions to improve the SRH services for persons with disabilities?

For refugee or internally displaced Persons with disability ask Q13

**IQ 8:** Can you tell us what is the effect of being a refugee or internally displaced person on your ability to maintain SRH or access SRH and GBV services?

**IQ 9:** How has the COVID19 pandemic affected your ability to access SRH services?

Now I will ask you specific questions about exposure to violence for persons with disabilities:

**IQ 10:** In your experience, could you tell me more about how persons with disabilities may be affected by violence?

**P:** What are the most common types of violence that persons with disabilities may experience? (physical, psychological, sexual violence and GBV)

**P:** Who are the possible perpetrators?

**P:** How do people in your community perceive violence towards people with disabilities?

**P:** How do you think people with disabilities deal with violence? (Probe on gender-based violence/ physical and sexual violence)

**P:** If a Person with disability suffers from violence is s/he likely to tell anyone about it? Who is s/he likely to talk to (family members, other person? health workers, community leaders, community-based protection networks, police/security or other authorities or anyone else)?

**IQ 11:** In your opinion, how can you describe the preparedness of persons with disabilities to protect themselves from violence? For example, do they have proper education about violence? Resources to protect themselves? Others?

**P:** What are the barriers and challenges to accessing GBV-related services for persons with disabilities?

**IQ 12:** What do you think can be done to improve access to protection from violence services for the persons with disability?

**IQ 13:** Do you think violence increased in COVID19 pandemic among persons with disability in your community?

### **Closing:**

- Thank people for their time and ideas and express how helpful it has been to facilitators.
- Explain next steps: "We will look at all information and will make a report of findings to which will be available on with UNFPA website.



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