



**The world will be able only
when people with disabilities
enjoy their reproductive rights
and access high-quality
SRH services**

Today on world disability day, UNFPA emphasizes the importance of access to sexual reproductive health (SRH) services and enjoying reproductive rights for all. Around the world, more than 1.5 billion women, men, boys and girls are living with some form of disability, thus of every 5 persons there will be one with a disability. Regardless, basic human rights, including the rights of persons with disabilities, are still being violated particularly for women and girls. Physical, social, and legal barriers continue to limit access to health care, education, employment, transport, leisure activities, and family life for millions of persons with disabilities. More specifically, they often face barriers to quality SRH information, services and commodities; and often cannot practice their reproductive rights (RR). The ignorance and attitudes of individuals and society, including health-care providers, raise most of these barriers – not the disabilities themselves – and expose them to various forms of discrimination, abuse and gender based violence.

International declarations, agreements and conventions encouraging equal access to reproductive health care and treatment for persons with disabilities

- 1948** - Universal Declaration on Human Rights*
- 1982** - World Program of Action Concerning Disabled Persons
- 1993** - UN Standard Rules for Equalization of Opportunities for Persons with Disabilities
- 1994** - International Conference on Population Development (ICPD) - Programme of Action
- 2000** - Millennium Development Goals*
- 2006** - Convention on the Rights of Persons with Disabilities (in particular article 25)
- 2015** - Sustainable Development Goals

The ICPD Program of Action is right-based; it has recognized equal access for all persons including those with disabilities. It calls for all people, including persons with disabilities, to have access to comprehensive reproductive health care and protection from all forms of gender based violence. Additionally, since 2006, all Arab States have signed the Convention on the Rights of Persons with Disabilities (CRPD), and there is a growing commitment in the region to ensure that its provisions are fulfilled. However, only few countries have made systematic legal and policy reforms that have targeted the provisions found in CRPD.

Situation in the Arab Region

Disability prevalence rates in the Arab Region range from 0.2% in Qatar to 5.1% in Morocco and 10.6% in Egypt, which is far below the global average of 15.1%^{1,2}. These low rates may be a result of inaccuracy in data collection due to cultural and social sensitivities (i.e. families in many Arab States prefer not to disclose certain forms of disabilities) or could be explained by the fact that the populations in the Arab region, including the large populations of migrant workers in some countries, are relatively young and therefore less likely to have age-related disabilities. Moreover, the Arab states region experiences many man-made and natural disasters, which also affects the accuracy and quality of available data.

The regional disability prevalence is likely to increase over the upcoming years, due to an ageing population structure as well as ongoing armed conflicts. For example in Syria, where only 15% of children (12-19 years) have a disability, but doubles by age 40 to 32% and continues to increase as the population grows older (96% for persons over 65 years)³. Available data further shows that in the lower age groups, women are less likely to have a disability, but are in the majority among older persons with disabilities. Disabilities related to mobility are the most prevalent disability type in all countries and visual impairments are the second most prevalent type in most of them. Illness is the most commonly reported cause of disability in almost all countries.

In fragile contexts, regardless of their age or sex, persons with disabilities are likely to be more susceptible to certain communicable diseases such as HIV and STIs, because they are likely to lack access to health promotion and prevention programmes, adequate sanitation and safe water, and may live in inaccessible shelters that endanger their health and lives. But persons with disabilities are even more vulnerable during disaster situations, not only because they are often excluded from the humanitarian response design and the services are not adapted to their specific needs but also because they are at a heightened risk of violence. These persons therefore need particular attention and protection during humanitarian crises. UNFPA's Arab States Regional Office recently conducted a research that looked to what extent the needs of persons with disabilities were accommodated during the Covid19 pandemic. The results show that the majority of the response plans of countries in the Arab states region planned for a blanket response, a comprehensive approach that identifies and responds to the needs of persons with disabilities is missing⁴.

1 Disability in the Arab region. 2018. Economic and Social Commission for Western Asia ESCWA

* Although the Universal Declaration on Human Rights and the Millenium Development Goals strive equality, they do not specifically mention persons with disabilities in their documents

2 CAPMAS. 2017. Census data for Egypt. Available at: <https://www.capmas.gov.eg>

3 Humanitarian Needs Assessment Programme. 2020. Disability: Prevalence and Impact.

A Nationwide Household Survey Using Washington Group Methodology. Syrian Arab Republic. Available at: https://www.globalprotectioncluster.org/wp-content/uploads/Disability_Prevalence-and-Impact_FINAL-2.pdf

4 Afifi, M. and Diab, G. 2021. Leaving no one behind: Did the response to COVID-19 accommodate the needs for Persons with Disability? Perspectives from the Arab world. Unpublished

Barriers to access to SRH information and services

Persons with disabilities are entitled to sexual and reproductive health, which is a key component of the right to health. Yet they often face various barriers to such information and services. On a global scale, women with disability rank among the most discriminated against minority groups, hence it is not surprising that their experiences of childbearing and early motherhood have largely been ignored. For example, persons with disabilities are often denied the right to free and informed consent, bodily autonomy and self-determination in making choices about SRH, leading to forced sterilization, abortion and contraception with the paternalism excuse that “it is for their wellbeing”. This mainly affects women with disabilities, and is amplified by ignorance and judgemental attitudes of health-care providers.

Moreover, persons with disabilities experience very practical barriers in accessing health services, including SRH-services. For example, health facilities are often physically inaccessible, lacking adjustments such as ramps or moveable equipment, have long waiting times⁵. Additionally, information messages and materials are not adapted to persons with audio/visual or cognitive disabilities. It is of utmost importance that health workers and policy makers are aware of the different types of disability and take this in consideration in the provision of information and services. However, this requires knowledge of the different types of disabilities, may require extra time for adequate health service provision and the health workers need to have access to certain aids to strengthen their messages, and adapt them to the clients needs.

Full and effective participation and inclusion in society" is one of the general principles that underlie the Convention on the Rights of Persons with Disabilities adapted on 13 December 2006. Persons with disabilities are faced with many challenges when using the Internet and some use assistive technologies to help them access information. Efforts should be made to ensure all platforms use design of products, environments, programmes and services to be usable by all including people with disabilities. This should apply to all platforms that provide SRH services.

⁵ UNDESA. 2018. Realization of the sustainable development goals by, for and with persons with disabilities UN flagship report on disability and development.

Lack of access to quality SRH as a driver of disabilities

Maternal health considerations for women with disabilities

Although women with disabilities are increasingly choosing to become mothers, they may encounter negative experiences from others who doubt their ability to become pregnant, carry the baby to term, deliver safely and care for a newborn. The contrary is true, most women with disabilities are able to become pregnant, to have normal labor and delivery experiences, and to care for their children without any issues. However, research conducted in the United States shows⁶ that complications during pregnancy, labor or post-partum period are higher among women with certain disabilities. Women with a disability were more likely to report stressful life events and medical complications during their last pregnancy. Moreover, they were less likely to receive prenatal care in the first trimester and more likely to have a preterm birth ^{ibid}. Pregnancies among women with intellectual and developmental disabilities were associated with a higher likelihood of poor outcomes that include preeclampsia, preterm birth, caesarean section, longer hospital stays and fetal death⁷. These adverse pregnancy outcomes are often associated with bad health outcomes of the babies born to these mothers and could also lead to disabilities associated with a variety of health and developmental problems. Additionally, people with disabilities are at increased risk of unwanted pregnancies, sexually transmitted infections and sexual violence compared to persons without disabilities⁸.

Women with disabilities have reported that health care providers' initial reactions to the idea of pregnancy is to try to discourage them from considering pregnancy, to assume that they are seeking termination of their pregnancy, or to make negative comments about them being irresponsible in considering pregnancy and motherhood⁹.

Maternity related complications

Complications of pregnancy and childbirth are a leading cause of death and disability among women of reproductive age in low-income countries and fragile contexts. Every day, an average of 800 women die of causes related to pregnancy and childbirth. Yet maternal deaths are only the tip of the iceberg: for every death, at least another 30 women suffer serious illness or debilitating injuries^{11, 12}. Though these women are lucky to stay alive, the complications can have major social and physical consequences and lead to disabilities among mothers and their babies.

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- 6 Mitra M, Clements KM, Zhang J, Iezzoni LI, Smeltzer SC, Long-Bellil LM. Maternal Characteristics, Pregnancy Complications, and Adverse Birth Outcomes Among Women With Disabilities. *Med Care*. 2015 Dec;53(12):1027-32. doi: 10.1097/MLR.0000000000000427. PMID: 26492209; PMCID: PMC4648667.
- 7 Susan L. Parish, Monika Mitra, Esther Son, Alexandra Bonardi, Paul T. Swoboda, and Leah Igdalsky (2015) Pregnancy Outcomes Among U.S. Women With Intellectual and Developmental Disabilities. *American Journal on Intellectual and Developmental Disabilities*: September 2015, Vol. 120, No. 5, pp. 433-443.
- 8 UNDESA. 2018. Realization of the sustainable development goals by, for and with persons with disabilities UN flagship report on disability and development.
- 9 Iezzoni, L.I., Wint, A.J., Smeltzer, S.C. & Ecker, J. L., (2015). "How did that happen?" Public responses to women with mobility disability during pregnancy. *Disability and Health Journal*, 8(3), 380-387. doi:10.1016/j.dhjo.2015.02.002

About 50% of the nearly 120 million women who give birth each year, experience some kind of complication during their pregnancy, and between 15 and 20 million develop disabilities such as severe anemia, incontinence, damage to the reproductive organs or nervous system, chronic pain, and infertility¹⁰. The table below illustrates estimations of various pregnancy and childbirth related complications.

Complications of Pregnancy and Childbirth: Estimates for Low-Income Countries ¹¹

Complication	Incidence as a percent of live births	Maternal disabilities that may result
Severe bleeding (hemorrhage)	11	Severe anemia; pituitary gland failure and other hormonal imbalances; infertility
Infection during or after labor (sepsis)	10	Pelvic inflammatory disease*; chronic pelvic pain; damage to reproductive organs; infertility
Obstructed or prolonged labor	6	Incontinence; fistula*; genital prolapse*; uterine rupture, vaginal tears; nerve damage
Pregnancy-included hypertension (preeclampsia and eclampsia)	6	Chronic hypertension; kidney failure; nervous system disorders
Unsafe abortion	16	Reproductive tract infection; damage to uterus; infertility; pelvic inflammatory disease*; chronic pelvic pain

Obstetric fistula is certainly one of the most serious and tragic childbirth injuries. Left untreated, obstetric fistula causes chronic incontinence and can lead to a range of other physical illnesses, including frequent infections, kidney disease, painful sores and infertility. The physical injuries can also lead to social isolation and psychological harm: Women and girls with fistula usually feel shamed or disgraced, they are often unable to work, and many are abandoned by their husbands and families, and ostracized by their communities, driving them further into poverty and vulnerability. Globally, hundreds of thousands of women and girls in low- and middle income countries are estimated to be living with fistula, with new cases developing every year. Yet fistula is almost entirely preventable. Its persistence is a sign of global inequality and an indication that health and social systems are failing to protect the health and human rights of the poorest and most vulnerable women and girls and prevent them from obtaining one of the most preventable disabilities.

¹⁰ Barton R. Burkhalter, "Consequences of Unsafe Motherhood in Developing Countries in 2000: Assumptions and Estimates from the REDUCE Model" (Bethesda, MD: University Research Corporation, unpublished).

¹¹ C. Murray and A. Lopez, eds., Health Dimensions of Sex and Reproduction (1998): chapters 5 through 8

Moreover, the vast majority of the estimated 8 million perinatal deaths that occur each year in less developed countries are associated with maternal health problems or poor management of labor and delivery. For instance, obstructed and prolonged labor asphyxiates an estimated 3% of newborns, resulting in death for nearly 25% of these infants and brain damage for another 25%. In addition, women suffering from poor nutrition and infections during pregnancy are more likely to have low birth-weight infants who are more likely to die in the first week of life, and those who survive are more likely to suffer disabilities such as cerebral palsy, seizures, and severe learning disorders¹².

Impact of Covid19 on persons with disabilities

Covid19 has exposed pre-existing inequalities, the most vulnerable populations have increased chances of obtaining Covid19. For example, persons with disabilities may have underlying health needs that make them more vulnerable to obtaining Covid19, or a stronger manifestation of the symptoms. Moreover, persons with disabilities may require the aid of others, or may live in close proximity to one another, which increases the likelihood of becoming infected with Covid19. Especially since information about the disease, including symptoms or ways to prevent Covid19 is not adjusted to their specific type of disability. In other words, information about Covid19 is not provided in accessible formats, such as audio, braille, (large-print) graphics, easy language, etc. Additionally, marginalized populations, such as persons with disabilities, already have less access to health and social services. The movement restrictions, closure of schools, provision of digital health services, often combined with the closure of non-essential health services have further exacerbated pre-existing inequalities. As Covid19 continues to affect the world, it is important to identify how persons with disabilities are impacted. As most persons with disabilities have pre-existing health needs, they are likely to need long-term medication and may need support with basis tasks, however with movement restrictions and disrupted health systems, obtaining these medications is becoming increasingly difficult. It is therefore of utmost importance to tackle underlying social, economic, and gender inequities to empower persons with disabilities and enhance their life opportunities^{13, 14}.

¹² Tsui et al., eds., Reproductive Health in Developing Countries: 122-23.

¹³ UN-OHCHR. 2020. COVID-19 and the rights of PWDs. Available at: https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf

¹⁴ COVID-19 crisis challenges for PWDs, IPS Opinion – August 20, 2020

* A full list of recommendations can be found in Desk review on SRH/GBV related needs, challenges and barriers to accessing SRH care for Persons With Disabilities in the Arab States Region

Conclusions

The global SDG agenda, especially goal 3 and 5 and UNFPA's 3 transformative results cannot be achieved if persons with disabilities are left behind and without their full inclusion in health and non-health related policies, strategies and programmes. Therefore, UNFPA is proposing the following concrete actions;

- 1** Adapt SRH-services to the needs of the person with a disability, utilizing a holistic approach that is sensitive to the different types of disabilities. For example, service providers should be trained in inclusive services utilizing a holistic person-centred approach, and health facilities adapted to accommodate persons with disabilities (infrastructure, communication aids, etc.). Additionally, knowledge and skills of medical personnel (midwives, nurses, surgeons) has to be strengthened to prevent and treat maternity related disabilities, such as preeclampsia and obstetric fistula.
- 2** Increase the awareness among politicians, decision makers of existing international and national legislation. Through information sharing on the challenges and opportunities, both by the UN, NGOs and civil society.
- 3** Mainstream the disability in SRHR general policies, plans, programs and services so it becomes inclusive and accommodative for all, and ensure that nobody is left behind. One way to do this is to equally involve persons with disabilities in the various phases of policy and decision making processes as well as the programme design, implementation, monitoring and evaluation. This could for example be done by working closely with civil society organisations that advocate and represent persons with disabilities. Another way would review national budget lines with an equity and disability-lens to ensure the budget is disability inclusive
- 4** Improve data collection on and for persons with disabilities, for example; Incorporate indicators and analysis relating to persons with disabilities in the used assessment, monitoring and evaluation tools in SRH programs/services. National governments and donors should push for better data collection in development and humanitarian contexts.



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