Promoting sexual and reproductive health for persons with disabilities

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Suzanne Reier/WHO (top)
Disability and Rehabilitation team/WHO (middle)
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Acronyms

APAES	Federation of Associations of Parents and Friends of People with Disabilities
CEB	Chief Executive Board
CCA	Common Country Assessment
DAR	Disability and Rehabilitation Unit
DESA	Department of Economic and Social Affairs
DM	Department of Management
DPI	Department of Public Information
DPI	Disabled Peoples' International
DPKO	Department of Peacekeeping Operations
ECA	Economic Commission for Africa
ECE	Economic Commission for Europe
ECLAC	Economic Commission for Latin America and the Caribbean
ESCAP	Economic and Social Commission for Asia and the Pacific
ESCWA	Economic and Social Commission for Western Asia
FAO	Food and Agriculture Organization of the United Nations
GBV	Gender-based Violence
HI	Handicap International
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
IASG	Inter-agency Support Group for the Convention on the Rights of Persons with Disabilities
IBP	Implementing Best Practices Initiative (Consortium)
ICPD	International Conference on Population and Development
IDA	International Disability Alliance
IDP	Internally Displaced Persons
IFHOH	International Federation of Hard of Hearing People
ILO	International Labour Organization
MDGs	Millennium Development Goals
MTV	Music Television
NGO	Nongovernmental organization
NUDIPU	National Union of Disabled Persons of Uganda
OHCHR	Office of the High Commissioner for Human Rights
POA	Programme of Action
PRSP	Poverty Reduction Strategy Papers
RI	Rehabilitation International
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
SWAp	Sector-wide Approaches
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDAF	United Nations Development Assistance Framework
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNFPA	United Nations Population Fund
UN-HABITAT	The United Nations Human Settlement Programme
UNICEF	United Nations Children's Fund
UNIDO	United Nations Industrial Development Organization
UNHCR	United Nations High Commissioner for Refugees
UNWTO	World Tourism Organization
USAID	United States Agency for International Development
USDC	Uganda Society for Disabled Children
VCT	Voluntary Counselling and Testing
WBU	World Blind Union
WFD	World Federation of the Deaf
WFDB	World Federation of the Deafblind
WHO	World Health Organization

1. Introduction

An estimated 10% of the world's population – 650 million people – live with a disability. Persons with disabilities have the same sexual and reproductive health (SRH) needs as other people. Yet they often face barriers to information and services. The ignorance and attitudes of society and individuals, including health-care providers, raise most of these barriers – not the disabilities themselves. In fact, existing services usually can be adapted easily to accommodate persons with disabilities. Increasing awareness is the first and biggest step. Beyond that, much can be accomplished through resourcefulness and involving persons with disabilities in programme design and monitoring.

Now is the time for action concerning SRH of persons with disabilities. On 3 May 2008 the Convention on the Rights of Persons with Disabilities came into force. This is the first legally binding international treaty on disability. It mentions SRH specifically. Both UNFPA Executive Director Thoraya A. Obaid and WHO Director-General Margaret Chan have welcomed the Convention and have emphasized the importance of addressing the needs of persons with disabilities.

This guidance note addresses issues of SRH programming for persons with disabilities. It is intended for SRH experts and advocates within UNFPA and WHO as well as those in other development organizations and partners. Those who address issues of family planning, maternal health, HIV and AIDS, adolescence, and gender-based violence (GBV) may find this information particularly helpful. SRH, in particular, deserves attention because these needs have been so widely and so deeply neglected. At the same time, however, the approaches discussed here apply broadly to all aspects of health programming for persons with disabilities. This note outlines a general approach to programming and does not address specific protocols for the SRH care and treatment of persons with disabilities.

Now is the time for action concerning sexual and reproductive health of persons with disabilities.

This guidance note recommends action in five areas:

- Establish partnerships with organizations of persons with disabilities. Policies and programmes are consistently better when organizations of persons with disabilities take part in their development.
- Raise awareness and increase accessibility in-house. Attention to the needs of persons with disabilities should be an integral part of current work. Separate or parallel programmes usually are not needed.
- Ensure that all SRH programmes reach and serve persons with disabilities. Most persons with disabilities can benefit from inclusion by SRH programmes designed to reach the general community.
- Address disability in national SRH policy, laws, and budgets. UNFPA, WHO and other reproductive health partner organizations' staff should work with organizations of persons with disabilities to make sure that all legislation and regulations affecting SRH reflect the needs of persons with disabilities.
- Promote research on the SRH of persons with disabilities. A stronger evidence base will help improve SRH programmes for persons with disabilities.

2. A significant constituency with neglected needs

2.1 A significant constituency

Persons with disabilities are identified in the new Convention on the Rights of Persons with Disabilities as "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".

Persons with disabilities make up a significant part of the world's population – an estimated one in every 10 people, amounting to 650 million people (1). This includes persons who are blind, deaf, or have other physical impairments, intellectual impairments, or disabilities related to mental health. Persons with disabilities can be found in every age group and among both men and women. An estimated 30% of families live with an immediate family member who has a disability (2). Thus, the great majority of persons with disabilities are part of the 80% of the world's population that lives in developing countries (1). In general, the needs of persons with disabilities are less likely to be met in developing countries. Still, developed countries also continue to face significant challenges, particularly as their populations age. Indeed, disability is everyone's business.

While persons with disabilities make up 10% of the world's population overall, a disproportionate 20% of all persons living in poverty in developing countries are persons with disabilities (3). Stigma, prejudice, and denial of access to health services, education, jobs, and full participation in society make it more likely that a person with a disability will live in poverty.

Often already marginalized, persons with disabilities become even more vulnerable when humanitarian crises occur. Between 2.5 and 3.5 million of the world's 35 million displaced persons also live with disabilities, according to a 2008 report by the Women's Commission for Refugee Women and Children (4, 5). The numbers may be even higher, given the injuries caused by the civil conflicts, wars, or natural disasters that displaced people are fleeing.

The needs of persons with disabilities are often overlooked or neglected.

Disability is everyone's business.

Despite these large numbers, the needs of persons with disabilities are often overlooked or neglected. Worse, many persons with disabilities are marginalized, they are deprived of freedom, and their human rights are violated (1). Historically, as part of this pattern, persons with disabilities have been denied information about sexual and reproductive health (SRH). Furthermore, they have often been denied the right to establish relationships and to decide whether, when, and with whom to have a family. Many have been subjected to forced sterilizations, forced abortions, or forced marriages (6). They are more likely to experience physical, emotional, and sexual abuse and other forms of gender-based violence. They are more likely to become infected with HIV and other sexually transmitted infections (STIs) (7). In crisis situations these risks are multiplied.

The United Nations system and its partners seek to clarify their roles and strengthen their capacity and collaborative efforts to support the

implementation of the new Convention as a matter of human rights. Furthermore, a world that neglects 20% of the poor in developing countries cannot achieve the Millennium Development Goals (MDGs) and other international agendas, including the Programme of Action of the International Conference on Population and Development (ICPD) (see Box 1 and Box 2). Disability concerns must be integrated into all the programmatic and policy goals associated with SRH and reproductive rights.

"Governments at all levels should consider the needs of persons with disabilities in terms of ethical and human rights dimensions"
– ICPD Programme of Action.

Box 1. The Convention on the Rights of Persons with Disabilities addresses sexual and reproductive health

The 61st United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities on 13 December 2006. It is the first international human rights treaty of the 21st century. The Convention entered into force on 3 May 2008.

The Convention is the most rapidly negotiated and adopted international human rights convention in history. In addition, more countries came forward to sign the Convention on the first day it was open for signature than for any other Convention in the history of the United Nations. This high level of support indicates the critical importance that the international community places on the rights of persons with disabilities.

Several articles of the Convention have direct relevance to SRH, reproductive rights, and gender-based violence (see Appendix A):

- Article 9 calls for accessibility, including access to medical facilities and to information.
- Article 16 requires states parties to take measures to protect persons with disabilities from violence and abuse, including gender-based violence and abuse.
- Article 22 asserts the equal rights of persons with disabilities to privacy, including privacy of personal health information.
- Article 23 requires states to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships, including in the areas of family planning, fertility, and family life.
- Article 25 requires that states ensure equal access to health services for persons with disabilities, with specific mention of SRH and population-based public health programmes.

The Convention is a legally binding instrument once ratified by a country. States parties are then required to ensure that all laws, policies, and programmes comply with its provisions. In particular, Articles 23 and 25 require specific attention to the issues of persons with disabilities in matters of SRH and reproductive rights.

The challenges are not necessarily part of having a disability, but instead often reflect lack of social attention, legal protection, understanding, and support.

Box 2. The International Conference on Population and Development Programme of Action recognizes the needs of persons with disabilities

The International Conference on Population and Development Programme of Action (ICPD PoA) recognizes:

> the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. It also includes their right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in human rights documents. (Paragraph 7.3)

The ICPD PoA explicitly calls for governments at all levels to consider the needs and rights of persons with disabilities and to eliminate discrimination against persons with disabilities with regard to reproductive rights and household and family formation:

> Governments at all levels should consider the needs of persons with disabilities in terms of ethical and human rights dimensions. Governments should recognize needs concerning, inter alia, reproductive health, including family planning and sexual health, HIV/AIDS, information, education and communication. Governments should eliminate specific forms of discrimination that persons with disabilities may face with regard to reproductive rights, household and family formation, and international migration, while taking into account health and other considerations relevant under national immigration regulations. (Paragraph 6.30)

> Governments should ensure community participation in health policy planning, especially with respect to the long-term care of the elderly, those with disabilities and those infected with HIV and other endemic diseases. Such participation should also be promoted in child-survival and maternal health programmes, breastfeeding support programmes, programmes for the early detection and treatment of cancer of the reproductive system, and programmes for the prevention of HIV infection and other sexually transmitted diseases. (Paragraph 8.7)

2.2 Sexual and reproductive health needs largely unmet

All too often, the SRH of persons with disabilities has been overlooked by both the disability community and those working on SRH. This leaves persons with disabilities among the most marginalized groups when it comes to SRH services. Yet persons with disabilities have the same needs for SRH services as everyone else. In fact, persons with disabilities may actually have greater needs for SRH education and care than persons without disabilities due to their increased vulnerability to abuse.

The challenges to SRH faced by persons with disabilities are not necessarily part of having a disability, but instead often reflect lack of social attention, legal protection, understanding and support. Persons with disabilities often cannot obtain even the most basic information about SRH. Thus they remain ignorant of basic facts about themselves, their bodies, and their rights to define what they do and do not want. (They may have little experience relating to and negotiating with potential partners.) Persons with disabilities may be denied the right to establish relationships, or they may be forced into unwanted marriages, where they may be treated more as housekeepers or objects of abuse than as a member of the family. As a group, persons with disabilities fit the common pattern of structural risks for HIV/AIDS and other sexually transmitted infections – e.g. high rates of poverty, high rates of illiteracy, lack of access to health resources, and lack of power when negotiating safer sex. (For further guidance concerning HIV, see *Disability and HIV. UNAIDS, WHO and OHCHR policy brief*, April 2009.)

Box 3. Folk belief about HIV leads to rape of persons with disabilities

While persons with disabilities have always been at risk for violence, a specific new concern has arisen in the HIV/AIDS epidemic. In many countries there is a common folk belief that, if someone with HIV has sex with a virgin, the virus will be transferred from the infected person to the virgin. The practice, known as "virgin rape", reportedly has even involved rape of infants and children. Persons with disabilities – often incorrectly assumed to be sexually inactive (hence virgins) – are also now at risk. Both men and women with disabilities, regardless of age, are at risk for "virgin rape". Accounts from many areas report that persons with disabilities have been raped repeatedly (8). Obviously, any SRH programme that seeks to protect people from such sexual violence must include persons with disabilities in all outreach efforts.

Persons with disabilities are up to three times more likely than non-disabled persons to be victims of physical and sexual abuse and rape. Persons with intellectual and mental disabilities are the most vulnerable. Persons with disabilities are sometimes placed in institutions, group homes, hospitals, and other group living situations, where they not only may be prevented from making informed and independent decisions about their SRH, but where they may also face an increased risk of abuse and violence.

Violence against persons with disabilities is compounded by the fact that the victims may be physically and financially dependent on those who abuse them. Furthermore, when they come forward to report such abuse, the medical (both physical and mental), legal, and social service systems are often unresponsive and inaccessible.

Persons with disabilities face many barriers to care and information about SRH, GBV and other violence, and abuse. First is the frequent assumption that persons with disabilities are not sexually active and therefore do not need SRH services. Research shows, however, that persons with disabilities are as sexually

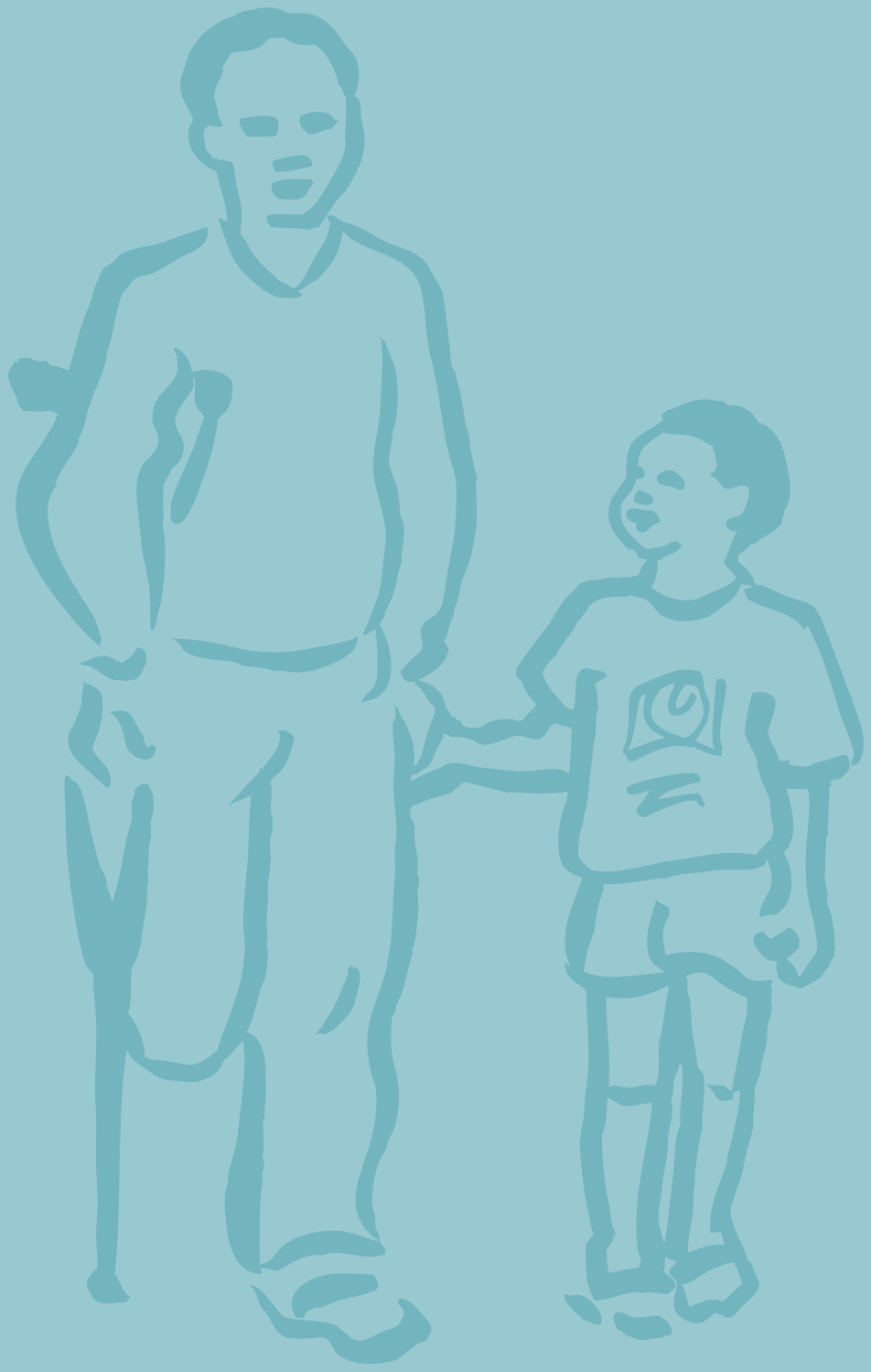
active as persons without disabilities (9). Despite this, too often their sexuality has been ignored and their reproductive rights, denied. At best, most existing policies and programmes concentrate on the prevention of pregnancy but ignore the fact that many persons with disabilities will eventually have children of their own. At worst, forced sterilization and forced abortion often have been imposed on persons with disabilities.

Furthermore, SRH services are often inaccessible to persons with disabilities for many reasons, including physical barriers, the lack of disability-related clinical services, and stigma and discrimination. In many situations barriers to health services include:

Persons with disabilities constitute a significant stakeholder group that should have a place at the table.

- lack of physical access, including transportation and/or proximity to clinics and, within clinics, lack of ramps, adapted examination tables, and the like;
- lack of information and communication materials (e.g. lack of materials in Braille, large print, simple language, and pictures; lack of sign language interpreters);
- health-care providers' negative attitudes;
- providers' lack of knowledge and skills about persons with disabilities;
- lack of coordination among health care providers;
- lack of funding, including lack of health-care insurance.

In a humanitarian crisis the physical layout and structure of camps and settlements can make it difficult or impossible for those with disabilities to reach not only health services but also shelters, food distribution points, water sources, latrines and schools (10).



3. Specific considerations for sexual and reproductive health programming

3.1 Multiple challenges

All efforts to include fully persons with disabilities, their needs, and their concerns in health policy and programmes must confront multiple challenges. People's impairments are not the source of these challenges. Instead, these are the challenges that the world imposes on persons with disabilities:

- **Lack of awareness, knowledge, and understanding**. Although one person in every 10 has a disability, persons with disabilities are often "invisible". Policy-makers and providers often greatly underestimate the number of persons with disabilities. If they think there are few persons with disabilities, they may assign them low priority among groups needing attention. Also, they may assume incorrectly that persons with disabilities are not sexually active and so do not need SRH services.
- **Prejudice and stigma.** Public attitudes differ from place to place and among different types of disability. The great majority of persons with disabilities face prejudice and stigma in their daily lives. This prejudice underlies the deprivation of a wide range of human rights, from freedom of movement and association to health and education and pursuit of a livelihood.

The great majority of persons with disabilities face prejudice and stigma in their daily lives.

- **Physical and attitudinal barriers to health services**. Physical barriers to access may reflect simple lack of awareness and forethought or else the assumption that "it costs too much" to remove these barriers. Changing misperceptions and prejudiced attitudes, however, may be more difficult to address than removing physical barriers.
- **Exclusion of persons with disabilities from decision-making**. Too often even programmes with the best intentions have treated persons with disabilities as a "target" – passive recipients of services. In fact, persons with disabilities constitute a significant stakeholder group that should have a place at the table whenever health programmes are planned and decisions are made. Their involvement is the best assurance that programmes will meet needs effectively.

3.2 Issues requiring special attention

Meeting these challenges to the SRH of persons with disabilities involves some specific considerations. Many of these considerations apply to the SRH of all people, but they can take on a new light from the perspective of persons with disabilities.

3.2.1 Gender and disability

While many issues faced by persons with disabilities apply equally to men and women, some issues are gender specific. Among the special issues more often faced by women with disabilities than by men are forced marriage, domestic violence, and other types of physical, emotional, and sexual abuse, the burdens of household responsibilities, and issues concerning pregnancy, labour, delivery, and childrearing. Nonetheless, men with disabilities are also at greater risk of sexual abuse than men who do not have disabilities.

Women and disability. It has been said that to be a woman and a person with a disability is to be doubly marginalized. Among obstacles faced particularly by women are the following:

- **Survival rates**: In many societies the survival rate for women with disabilities is lower than that for men with disabilities. For example, Helander (11) reports that in Nepal the long-term survival rate of women who were disabled by polio is only half that of men who had polio.
- **Unstable relationships**: Considered in some societies as less eligible marriage partners, women with disabilities are more likely to live in a series of unstable relationships, and thus have fewer legal, social and economic options should these relationships become abusive.
- **Maternal morbidity and mortality**: Women with disabilities are not only less likely to receive general information on sexual and reproductive health and are less likely to have access to family planning services, but should they become pregnant, they are also less likely than their non-disabled peers to have access to prenatal, labour and delivery and post-natal services. Physical, attitudinal and information barriers frequently exist. Often community level midwifery staff will not see women with disabilities, arguing that the birthing process needs the help of a specialist or will need a Cesarean section - which is not necessarily the case. Of equal concern is the fact that in many places women with disabilities are routinely turned away from such services should they seek help, often also being told that they should not be pregnant, or scolded because they have decided to have a child (12).
- **Women without disabilities in households with family members with a disability**: Parents of children with disabilities often find themselves socially isolated. Stigma, poverty, and lack of support systems take a toll on such families. The burdens often fall disproportionately on women in such households. Thus, support systems for care providers, as well as for persons with disabilities, are crucial – both formal systems, such as social security and health insurance, and informal social networks, such as community support groups. Furthermore, in a number of societies, if a child is born with a disability, it is assumed that the mother has been unfaithful or has otherwise sinned. She suffers significantly as a result of this assumption. Even without such stigma, the physical, mental and financial stresses, coupled with social isolation, result in rates of divorce and desertion often twice as high among mothers of children with disabilities as among their peers who do not have children with disabilities. There are a number of ramifications of this – most striking, a cycle of increasing poverty.

Men and disability. Men with disabilities also face gender-related issues:

- **SRH education**: In many societies, while women receive instruction about SRH either at home or in school, young men are left to pick up information "on the streets" – casually, through other men's comments, jokes and innuendoes. Young men with disabilities are often shielded from even this information, unreliable and incomplete as it may be. Young men with mental and intellectual impairments are particularly likely to be deprived of SRH information.
- **Sexual exploitation**: It is widely believed that men are not sexually abused. This is not true, however. In particular, men with disabilities are susceptible to sexual abuse, from both male and female perpetrators. Accessible abuse reporting and effective intervention programmes are as important for men with disabilities as they are for women with disabilities.

It is important to assure that sexual and reproductive health services are friendly to youth with disabilities.

3.2.2 Life-cycle approach

Like everyone else, persons with disabilities have SRH needs throughout their lives, and these needs change over a lifetime. Different age groups face different challenges. For example, adolescents go through puberty and require information about the changes in their bodies and emotions, and about the choices they face concerning sexual and reproductive health related behaviour (see Box 4). Adolescents with disabilities need to know all this information, but they also may need special preparation concerning sexual abuse and violence and the right to protection from it. It is important to assure that SRH services are friendly to youth with disabilities.

On reaching the age for having a family, women and couples with disabilities, like everyone else, have the right to decide whether and when to have children and a right to sound, unbiased information on which to base these decisions. Health-care providers owe all clients, whether they have disabilities or not, encouragement, support, and appropriate services over the years – both when they want to have children and when they want to avoid pregnancy.

Box 4. In Jamaica, working together to provide sexual and reproductive health information

Informing young persons with disabilities about SRH is often difficult because parents, educators, and SRH counsellors often do not know how to broach the subject. As a result, many young people with disabilities do not receive even basic information about how their bodies develop and change as they mature. Frequently, young persons with disabilities have not even been taught basic vocabulary about their bodies, and so they are not able to describe what is happening to them or whether someone is taking advantage of them. Many are taught to be compliant and to trust others, and so they do not have experience setting limits with others regarding physical contact. Like all other young people, they are eager to be liked and included. Because they are lonely or want a boyfriend or girlfriend, others may take advantage of them.

In Jamaica a coalition of the Government, UNFPA, and the European Commission have worked with local organizations of persons with disabilities to prepare a set of three manuals concerning young persons with intellectual disabilities. The manuals are addressed, in turn, to health-care providers and counsellors, parents of children and adolescents with intellectual disabilities, and children and adolescents with intellectual disabilities. The series is filled with easy-to-understand material, clear pictures, and thoughtful, straightforward suggestions. Also, the series is designed so that the three manuals link to one another, tying together information about SRH with a guide for training for parents to work with their children on SRH issues and a manual to be used by parents with their children. A supplementary DVD and picture story pamphlet help reach adolescents and young adults with disabilities who have low literacy levels or who would find it difficult to follow a complex discussion.

For more information contact: http://caribbean.unfpa.org or http://www.jamr.org

3.2.3 Mental health and psychological needs within SRH care

Mental health is related to many aspects of SRH. These include, among others, perinatal depression and suicide, mental health and psychological consequences of gender-based violence, or HIV/AIDS, feelings of loss and guilt after miscarriage, stillbirth, or unsafe abortion. For persons with disabilities, social barriers may increase the chances of mental health difficulties in these circumstances. It is crucial to pay close attention to the mental health or psychological well-being of persons with disabilities, their families, and other care providers. Measures to promote the mental and psychological well-being of these individuals should be incorporated into all policies and programmes.

3.2.4 People disabled later in life

The SRH of individuals who have become disabled through accident or illness after puberty is often overlooked. These individuals sometimes do not see themselves as members of a disability community, and often they lack the social supports that many people who have grown up with a disability rely on. Indeed, these young people and adults often hold the same prejudices and misperceptions about disability as do some persons without disabilities. Persons disabled later in life may be more likely to confront depression than those disabled from birth or in childhood. Thus, the role of professionals who provide mental health and psychosocial care is particularly important.

3.2.5 Needs of persons with disabilities in emergency response and recovery

In emergency settings persons with disabilities often suffer compounded problems of neglect and abuse combined with a particularly difficult physical environment. Emergency preparedness and response plans must provide explicitly for persons with disabilities in all aspects, from evacuations to access to resources upon resettlement, such as food, water, and health services. SRH care is an essential component of such services. To assure awareness of the needs of persons with disabilities, organizations that routinely respond to such emergencies must include persons with disabilities and their families in all their planning processes (10).

3.2.6 Persons with disabilities in ethnic, minority, and other marginalized groups

There are persons with disabilities in every ethnic and minority community and in other marginalized groups such as refugees, internally displaced persons, and indigenous people. For these people SRH and other health services must be doubly sure to remove barriers to care related to their communities' status as well as to their disabilities. Persons with disabilities in marginalized communities are often insufficiently linked with local organizations of persons with disabilities. Special outreach efforts may be needed.

3.2.7 Persons with disabilities in institutions

Many persons with disabilities in both industrialized and developing countries continue to spend much or all of their lives in nursing homes, group homes or other residential institutions. A disproportionate number of individuals with intellectual and mental disabilities are inappropriately consigned to prisons. In such institutional settings persons with disabilities usually do not receive education or information about their reproductive rights. They are often not provided resources such as condoms or other family planning options, nor is testing for HIV or other STIs usually available. Sexual abuse and violence are common. SRH professionals may need to address these populations specifically to ensure that they receive appropriate services.

4. Towards full inclusion: a framework

Staff in the United Nations system, other international development organizations, and their partners have unique opportunities to move SRH services towards full inclusion of persons with disabilities. We are well positioned to act in five areas to bring positive change. These five actions are illustrated below in Figure 1.

Fig. 1. Five actions towards full inclusion of the sexual and reproductive health of persons with disability.

Policies and programmes at all levels are consistently better when organizations of persons with disabilities take part in planning from the outset.

4.1 Establish partnerships with organizations of persons with disabilities

The best way to begin thinking about SRH issues for persons with disabilities is to establish a dialogue with local organizations of and for persons with disabilities and other advocacy organizations working on behalf of persons with disabilities. Global organizations of persons with disabilities can often help identify key people and groups to contact in your community or country (see Appendix B).

Organizations of persons with disabilities work on behalf of, and are led by, persons with disabilities. Some organizations of persons with disabilities represent people with all types of disabilities; others are "disability-specific".

"Nothing about us without us"

Speaking with representatives of such organizations, or bringing them together for discussion, can immediately introduce you to local groups and give you an understanding of their health and social services situation and concerns both locally and globally. "**Nothing about us without us**" is a key principle among persons with disabilities. The Convention on the Rights of Persons with Disabilities reflects this principle. It underscores the importance of including persons with disabilities at all stages of policy development, programme planning, and implementation. Too often, persons with disabilities and organizations of persons with disabilities are consulted only after a policy or programme has been designed. Persons with disabilities must be more than just recipients of SRH programmes and resources. Policies and programmes at all levels are consistently better when organizations of persons with disabilities take part in planning from the outset.

Once you become familiar with local organizations of persons with disabilities and their agendas, you can establish an on-going advisory team that includes representatives of these organizations. Also, it is worthwhile supporting these organizations to implement their own activities for the SRH of persons with disabilities. Training persons with disabilities to provide SRH education and other types of SRH information and services has succeeded in a number of countries.

4.2 Raise awareness and increase accessibility in-house

UNFPA, WHO, and other stakeholders must raise awareness within their own organizations – that is, in-house – about the needs and rights of persons with disabilities (see Box 5). Staff members need to be aware of the issues surrounding disability and SRH. They need to understand the importance of including disability issues in all policies and programmes, including those in humanitarian situations. Such awareness must also reach partners at the country level, to help inform country-driven processes for programme design (see Box 6).

Inclusion does not have to be an overwhelming task. It should be an integral part of current work and usually does not need separate or parallel programmes.

The SRH of persons with disabilities is not a unique, complex, or highly specialized issue. It is, however, an issue that needs more attention and greater creativity, and it needs more attention now. It cannot wait until after other populations or issues are addressed.

The inclusion of SRH concerns of persons with disabilities in on-going programmes and policies does not have to be an overwhelming task. It should be an integral part of current work and usually does not need separate or parallel programmes.

4.2.1 Capacity development training for staff and policies for inclusion

Among the best ways to promote awareness and build capacity in-house is to integrate disability-related sessions into existing training. Whenever possible, experts from organizations of persons with disabilities should conduct this training or work with and advise training staff.

Also, it is important to promote full coverage of persons with disabilities in our own organizations' human resources policies. Our own offices, work spaces, and communication should be accessible to persons with disabilities.

4.2.2 Partnering with other United Nations agencies and coordinating relevant actors

Partnerships with other United Nations agencies, the World Bank and governments can amplify the inclusion of persons with disabilities in UNFPA and WHO activities. Inclusion of disability considerations in the Common Country Assessment (CCA)/United Nations Development Assistance Framework (UNDAF), Poverty Reduction Strategy Papers (PRSP), and Sector-wide Approaches (SWAp) is proving to be a productive place to start. It is also important to ensure that national and local counterparts working with these international organizations, and all organizations funded at the local and national levels to implement their policies, have policies and activities for inclusion of persons with disabilities, with clear indicators and benchmarks.

Coordination among actors is key to moving the agenda forward, preventing duplication of effort, and addressing gaps in effectiveness. In addition, cultivating new partners such as those in the private sector is important. UNFPA and WHO staff should be prepared to work with and coordinate efforts of legislators and other policy-makers, different ministries, various United Nations agencies, NGOs, and other players in civil society.

Box 5. Ten key messages that raise awareness
1. Disability is everyone's business.
2. Persons with disabilities are not necessarily sick.
3. Persons with disabilities have sex too.
4. Access means more than ramps.
5. Persons with disabilities want the same things in life that everyone wants.
6. For persons with disabilities, prejudice can be the biggest barrier.
7. Everywhere and always, persons with disabilities are entitled to self-determination, privacy, respect, and dignity.
8. It is best and usually easy to mainstream health services that accommodate persons with disabilities.
9. Persons with disabilities are a crucial constituency in all programmes.
10. Programmes best suit persons with disabilities when persons with disabilities help to design them. "**Nothing about us without us**" is a key principle.

Box 6. WHO Task Force improves internal policies and practices

The WHO Task Force on Disability is an initiative launched by the Director-General to help mainstream disability issues across the Organization and to ensure that WHO responds to the challenge of the new Convention on the Rights of Persons with Disabilities. At the six-month mark of this two-year project, the response from across the Organization has been very gratifying: for example, improvements have been made in the accessibility of the WHO web site and of the buildings, development of a new human resources policy on disability, and ongoing work to address the needs of persons with disabilities in various technical programmes. In the area of Reproductive Health, for instance, collaboration with the Department of Reproductive Health and Research and with UNAIDS has produced a policy brief on the intersections between HIV/AIDS and disability, improved technical guidance on contraceptive choices for women with disabilities, and, in partnership with UNFPA, this guidance note.

4.3 Ensure that all sexual and reproductive health programmes reach and serve persons with disabilities

Review all current programmes to ensure that persons with disabilities have access to all programmes and services offered to the community. With modest adaptations broad-based SRH programmes can fully serve most persons with disabilities.

4.3.1 Types of programme

Mainstreaming in all programmes. Existing programmes can meet the SRH needs of most persons with disabilities. Modest adaptations can accommodate a wide range of disabilities, and these adaptations usually can be identified easily with the help of persons with disabilities.

Most persons with disabilities do not need disability-specific services but rather will benefit from inclusion in sexual and reproductive health efforts designed to reach the general community.

Persons with disabilities are a crucial constituency in all programmes. Therefore, persons with disabilities need to be consulted, and the needs of persons with disabilities should be addressed in all programmes at all levels – international, regional, national, and local.

Simple awareness can go a long way, too. Asking yourself a few questions quickly identifies unmet needs. For example:

- 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? If not, what should be done?
- Are you assessing facilities from the perspective of persons with disabilities? Have you considered adaptations for persons with disabilities such as ramps, easy-to-understand written or graphic formats for information, Braille, or sign language interpreters, depending on the local needs?

- Are you updating policies, norms, and procedures from the perspective of persons with disabilities? Do they refer specifically to issues of concern to persons with disabilities?
- Are you integrating disability-related sessions into the pre-service training of medical and paramedical staff?

Disability-specific programming when needed. Disability-specific services are warranted when individuals or communities are difficult to reach through broad-based programmes. For example, individuals with intellectual disabilities often benefit by SRH education efforts that are targeted to their level of understanding and learning patterns – slower-paced and presented in a straightforward format, repeated, and reinforced. Such targeted approaches are already familiar to SRH workers and public health professionals, who routinely design population-specific programmes to address difficult-to-reach populations.

Such disability-specific outreach efforts are the exception, however, rather than the rule: most persons with disabilities do not need disability-specific services but rather will benefit from inclusion in SRH efforts designed to reach the general community.

4.3.2 Activities to raise awareness and address misconceptions, stigma, and lack of knowledge

Wherever people are brought together to discuss sexual and reproductive health issues, the inclusion of persons with disabilities will quickly raise awareness.

Many health professionals, partner organizations, and communities will need training or awareness-raising on how to address the SRH of persons with disabilities. Although there are some special considerations for persons with disabilities concerning SRH, most of the impediments to providing good-quality services are related to providers' attitudes and basic lack of general knowledge about disabilities. The required information can easily be integrated into existing training strategies and curricula. Training about persons with disabilities and their needs should be addressed both in in-service SRH training for current providers and in pre-service training offered in medical, nursing, midwifery, public health, and hospital administration programmes. Persons with disabilities themselves should be co-facilitators or presenters of such training whenever possible.

Raising awareness about SRH for persons with disabilities requires fighting misconceptions, stigma, and discrimination in communities (see Box 7). A key message is that negative attitudes and barriers in societies are often more disabling than the actual impairments. Another key message at all levels is that persons with disabilities are entitled to self-determination, privacy, respect, and dignity in all situations. It is also important to promote awareness of the capabilities and contributions of persons with disabilities.

In particular, persons with disabilities, their families, the health and development community, and members of the general public need education about rights and about harmful practices such as forced sterilization, forced abortion, and forced marriage. Furthermore, people need to know whom to contact and where to go to obtain protection against such abuses.

The mass media can play important roles in raising this awareness. SRH professionals, working with organizations of persons with disabilities, can include information about the SRH of persons with disabilities in mass media outreach efforts and programmes such as the UNFPA and UNAIDS collaborations with MTV (Music Television). Even something as simple as including someone with a visible disability among people shown in a poster or TV spot about SRH can help to create a positive image.

Similarly, wherever people are brought together to discuss SRH issues, the inclusion of persons with disabilities will quickly raise awareness. Hotlines and web sites that provide information on SRH or disability issues are additional avenues for raising public awareness.

Sexual and reproductive health personnel must work to overcome stigma and uphold the rights of persons with disabilities.

Box 7. Address lack of knowledge, fight stigma, and raise awareness

Lack of knowledge about disability

Lack of knowledge about disability can lead to harmful assumptions. Even health-care professionals and development experts often make unfounded assumptions about the nature and quality of the lives of persons with disabilities. For example, persons with disabilities are not necessarily ill: one can both have a disability and be in good health. It is important for practitioners to understand that "disability" is a relative, interactional concept and not an absolute state. That is, "disability" is defined by the interplay between a person's impairment and the total social and physical environment.

Stigma against persons with disabilities

In many societies stigma against persons with disabilities goes hand-in-hand with ignorance. In its most extreme form, stigma can lead to withholding or delaying critically needed health care and sometimes, as a consequence, lead to death. Stigma also can lead to denial of the right to health information and the right to self-determination. In some communities where stigma against persons with disabilities is severe, persons with disabilities may be hidden away from society. Reaching such individuals with SRH information and services is important but difficult. SRH personnel must work to overcome stigma and uphold the rights of persons with disabilities.

A small but growing group of cross-cultural studies finds that community attitudes towards persons with disabilities vary significantly from one society to another. Substantial differences have been found even between ethnic or tribal groups that live next to one another. For example, in one society blindness may be severely stigmatized, while, in a different nearby ethnic group, persons who are blind are well regarded, but persons with mental health and psychosocial disabilities find themselves excluded from the community. SRH programmes must become aware of local attitudes towards persons with disabilities.

Awareness of the right to sexual and reproductive health, respect, and dignity

Included in the rights to SRH of persons with disabilities are:

1. The right to information that will enable them to make responsible and informed choices about their sexual and reproductive health.
2. The right to decide when and with whom to be sexually active.
3. The right to freedom from sexual abuse and violence, including unnecessary and unwarranted abortion and sterilization.
4. The right to decide freely and responsively whether and when to have children and how many children to have.
5. The right to keep and raise their children (see Appendix A).

Persons with disabilities also have a right to be treated with respect and dignity while using services. Not only is this the decent way to treat any human being, but it also greatly increases the likelihood that persons with disabilities will be willing to use services. For example, a woman with a disability who is pregnant will be unlikely to return to a clinic if she is scolded for wanting a child, and a man with a disability will be less likely to ask for a packet of condoms if he is teased. SRH experts and advocates must work closely with organizations of persons with disabilities and other disability service providers to ensure that all persons with disabilities are treated with dignity and respect.

Equal inclusion in all socioeconomic development is a concern to persons with disabilities. The rate of poverty for persons with disabilities is double that of the general population (11). In turn, poverty underlies poor health generally and poor sexual and reproductive health specifically.

4.3.3 Activities to improve access

Improve accessibility of health system, facilities, and services. Physical access to buildings and clinics as well as other indoor and outdoor facilities is crucial to persons with disabilities (see Box 8). Accessibility should be considered not only for hospital and clinics but also for places where public health education is provided, locations where condoms are sold or distributed, domestic violence shelters, drug and alcohol intervention programmes, and all other facilities that provide services related to SRH.

Many adaptations, cost little or nothing. Common sense and a willingness to innovate can go a long way.

Keep in mind that physical accessibility alone does not meet the needs of all persons with disabilities. Communication materials and media must also be accessible.

Many adaptations to increase access can be made at little or no additional cost. For example, a clinic or a community HIV/AIDS education programme can be moved from an upper floor to a ground floor room, allowing individuals with physical disabilities to attend. A foldable cot available in an examination room, which can be set up quickly for patients who are unable to climb on to an examination table, is a small, one-time expense. Forms that are simpler and have larger print benefit everyone.

Improve home-based care and community outreach. In many communities health workers, social workers, and midwives provide SRH services in people's homes. These workers may skip the homes of persons with disabilities, however, assuming that they do not need services. All those who provide home-based health, nutrition, and social services must be trained and monitored to ensure that persons with disabilities are identified and included in all home-based care and community outreach efforts.

Accessibility of commodities. "Accessibility" also means that resources such as condoms and other commodities are available and provided to persons with disabilities with the same rights to confidentiality, self-determination, and respect that everyone deserves.

Physical accessibility alone does not meet the needs of all persons with disabilities – communications, material and media must also be accessible.

Box 8. Examples for improving access to services

The following list, while not exhaustive, contains examples of ways in which many SRH services can be made more inclusive:

Physical access

Illustrative approaches to increase physical access include:

- ramps for wheelchair users;
- larger bathrooms with grab bars;
- lowered examination tables.

Access to information and communication

Increasing access to information and communication might include the following:

- sign language or captioning to improve access to health-care resources and public health announcements;
- information presented in simple, easily understood graphic formats;
- materials in large print or Braille;
- information given by radio, cassette tape, or CD in addition to print;
- demonstrating activities such as condom usage rather than just describing them;
- giving information more slowly and stopping more often than usual to ensure comprehension by all.

A growing number of technological advances, including the availability of information via computer, have significantly improved the quality of life of persons with disabilities in industrialized countries. Such new technologies should be made accessible to all persons with disabilities, including those in developing countries.

For example, in Kenya a sexual and reproductive health NGO offers special HIV voluntary counselling and testing services for deaf persons. These services entail confidential HIV counselling and testing at clinics managed by deaf staff; mobile VCT activity and community mobilization in urban and rural deaf communities; support to deaf clients in need of referral and care; establishment of post-test support groups within deaf communities; and development of communication materials. (Liverpool VCT, Care & Treatment: http://www.tinyurl.com/liverpoolvct)

4.3.4 Activities to establish indicators and benchmarks

All health programmes should monitor and evaluate whether persons with disabilities are receiving adequate and appropriate services and that they are satisfied with the services. To do so, programmes must establish indicators and benchmarks. Routinely generated statistics should include persons with disabilities as part of the general clientele and also report specifically on services to persons with disabilities.

Special considerations about access to SRH education

Education levels. SRH education for children, young people, and adults with disabilities is often severely limited or nonexistent in the home. Access to SRH information in school is limited by the fact that persons with disabilities often are denied even the most basic education. At best, many receive education at only the lowest primary levels, and few remain in school long enough to reach upper-level biology classes where specific SRH education is offered. As a result, many persons with disabilities cannot read or write, and even those who are literate may not have enough education to be health literate. When developing programmes for persons with disabilities these efforts should be well integrated into other programmes addressing the needs of persons with little education or low literacy who need information.

Transportation. Transportation is a key problem for many persons with disabilities. Especially in rural areas, some people are unable to walk to clinics, community centres, or other places where SRH services are available. Given the high rates of poverty found in this population, many are unable to afford buses, taxis, or other transportation that could take them to services. Even where transportation is available and affordable, the vehicles often are inaccessible to those with physical impairments. Thus, persons with disabilities may need mobility equipment such as tricycles or prostheses, personal assistance services, or financial support to be able to reach mainstream SRH services. Again, when considering transportation schemes designed to improve health service access, considering the needs of persons with disabilities will enable planners to enlarge their view to address all members of the communities.

Living in institutions. Access also is an issue for persons with disabilities in institutions, group homes, and other residential facilities. They often cannot reach services on the outside and may not have access even to internal health services. Institutionalized persons with disabilities must not be forgotten. SRH workers need to work with communities and with other professionals to remove barriers to access for such groups.

Summary. While different groups may need different types of adaptation, it is important to recognize that there are not endless numbers of adaptations, and many cost little or nothing. Common sense and a willingness to innovate can go a long way to assuring services for persons with disabilities. Persons with disabilities in the community can guide efforts to ensure accessible environments.

4.4 Address disability in national sexual and reproductive health policy, laws, and budgets

4.4.1 Inclusion in policies and laws

Policies should be thoughtfully developed with the needs of persons with disabilities in mind. In line with Article 4 (General Obligations) of the Convention, UNFPA, WHO, and other agencies must recognize the knowledge and expertise of persons with disabilities and urge collaboration in policy-making with organizations of persons with disabilities.

UNFPA and WHO staff should take the lead in making sure that all sexual and reproductive health legislation reflects the inclusion of persons with disabilities.

UNFPA and WHO staff should take the lead in making sure that all SRH legislation considered in each country reflects the established human rights framework for inclusion of persons with disabilities. Also, it is important to support integration of the SRH of persons with disabilities into the purview of national human rights institutions, protection systems, and police and judiciary systems. Working with parliamentary groups at the national and regional levels, SRH experts should review existing and new legislation – including national health insurance schemes – to identify where and how such legislation ensures the rights of persons with disabilities. Tools developed by international organizations to assess the human rights situation in countries should cover the rights of persons with disabilities.

In addition, it is crucial to look at whether and how these laws are actually implemented. Mapping and involving national human rights institutions and working with police and judiciary help assure implementation. Further, it is crucial to look at how persons with disabilities can seek redress for violations of their human rights and whether these mechanisms for redress are effective. In countries that have adopted the Optional Protocol along with the Convention, individuals and groups can petition an international committee of experts, the Committee on the Rights of Persons with Disabilities, once they have exhausted the processes for redress in the country.

It is important to note that national policy efforts should be conducted with governments "in the driver's seat".

4.4.2 Budgeting for inclusion

Policies and programmes must be budgeted realistically if they are to make a difference. It is important to remember that the costs of ***not*** including persons with disabilities far outweigh the costs of inclusion. Furthermore, leaving out persons with disabilities could result in failure to meet many of the MDGs. Budgets should account for inclusion of persons with disabilities in all programmes and not just in disability-specific programmes.

All budget elements related to SRH, including both public and private medical insurance schemes, should be reviewed to ensure that persons with disabilities are included on an equal basis with others. Additionally, funds should be made available to ensure accessibility – for example, for retrofitting clinics to make them physically accessible or paying sign language interpreters.

4.5 Promote research on sexual and reproductive health of persons with disabilities at local, national, and international levels

Worldwide, relatively little research has been done about the SRH of persons with disabilities. This includes both disability-specific studies and the inclusion of persons with disabilities in larger, population-based studies. To develop a better evidence base, research on SRH of persons with disabilities needs promotion and funding. Also, indicators on persons with disabilities should be included in health surveys and other studies of SRH issues at local, national, and regional levels. Finally, studies of health costs, such as those that track people's out-of-pocket health expenditures, should address the cost of disabilities.

Box 9. United Nations Inter-Agency Support Group for the Convention on the Rights of Persons with Disabilities

At its 12th session in September 2006, the United Nations Chief Executives Board (CEB) took the decision to establish an inter-agency support group for the Convention on the Rights of Persons with Disabilities. The first meeting of the Inter-Agency Support Group (IASG) was held on 13–14 December 2007 at United Nations headquarters in New York. The second meeting was held on 19–20 June 2008 in Geneva, hosted by the Office of the High Commissioner for Human Rights (OHCHR) and co-chaired by the Department of Economic and Social Affairs (DESA), which together constitute the joint Secretariat of the Convention on the Rights of Persons with Disabilities.

The Inter-Agency Support Group consists of:

Food and Agriculture Organization of the United Nations (FAO)
International Labour Organization (ILO)
United Nations Development Programme (UNDP)
United Nations Educational, Scientific and Cultural Organization (UNESCO)
United Nations Population Fund (UNFPA)
World Tourism Organization (UNWTO)
United Nations Children's Fund (UNICEF)
United Nations High Commissioner for Refugees (UNHCR)
World Health Organization (WHO)
United Nations Industrial Development Organization (UNIDO)
United Nations Secretariat:

- Department of Economic and Social Affairs (DESA)
- Department of Management (DM)
- Office of the High Commissioner for Human Rights (OHCHR)
- Department of Public Information (DPI)
- Department of Peacekeeping Operations (DPKO)
- The United Nations Human Settlements Programme (HABITAT)
- United Nations Regional Commissions (ECA, ECE, ECLAC, ESCAP, ESCWA)

Box 10. Checklist to evaluate current and future programming for accessibility and inclusion		
	Yes	No
Has everyone in your office undergone training on disability?		
Are you and your staff familiar with the Convention on the Rights of Persons with Disabilities?		
Have you and your staff established a relationship with local organizations of and for persons with disabilities, and have you set up a system with them for ongoing dialogue and exchange of knowledge about SRH and the needs of persons with disabilities?		
Have you and your staff reviewed all on-going internal policies and programmes to ensure that the needs of persons with disabilities are addressed?		
Do you and your staff review all proposed new activities and programmes to ensure optimal participation of persons with disabilities?		
Have you and your staff established clear benchmarks for inclusion, and are monitoring and evaluation systems in place to ensure that these benchmarks are being reached?		
Have you and your staff reviewed all local and national legislation and regulation affecting health and health care to identify where persons with disabilities should be included?		
Have you and your staff reviewed national laws related to persons with disabilities and access to sexual and reproductive health to see if they are in line with ICPD and the Convention?		
Have you and your staff looked at whether and how these laws are actually being implemented?		
Is information on implementation of laws available to organizations of and for people with disabilities and other concerned members of civil society?		
Have you involved national human rights institutions and worked with the police and the judiciary? Analysed gaps and challenges?		
Is information available on how to seek redress in case of violation of the human rights of persons with disabilities?		
Have you and your staff reviewed budgeting to ensure that inclusion of persons with disabilities is funded?		
Have you promoted awareness of disability in your community?		
Have you included disability issues in surveys and research?		

5. Conclusion and next steps

Persons with disabilities represent a significant portion of the world's population and are part of every community. Attention to the SRH needs of persons with disabilities is important to ensure the protection and promotion of their human rights, to move forward the international development agenda, and to build a truly inclusive society. Although the full picture of SRH issues for persons with disabilities is not yet clear, it is certain that there are significant unmet needs. Like everyone else, persons with disabilities need information about SRH. In order to do so, they have the right to make reproductive decisions for themselves. They must have the same access as everyone else to programmes, services, and resources that support them in their decisions.

UNFPA and WHO staff members, their partners, and all others who work on SRH issues must ensure that the SRH of persons with disabilities is considered and addressed at local, national, regional, and global levels. Legislation, funding structures, policies, and programmes must all be designed to take into account the rights and needs of persons with disabilities. SRH experts and advocates can help create a dialogue with and within the disability community to foster more open discussion of SRH issues.

Like everyone else, persons with disabilities need knowledge about sexual and reproductive health, and they have the right to make reproductive decisions for themselves.

With the recent entry into force of the Convention on the Rights of Persons with Disabilities, such efforts could not be more timely. Addressing the needs of this 10% of the world's population presents a unique challenge to UNFPA and WHO staff. The potential for making a significant difference is enormous. We all stand to gain when everyone, including persons with disabilities, is included.

Table 1. What can we do for the sexual and reproductive health of the 650 million persons with disabilities?
A summary guide to promoting inclusion

KEY MESSAGES

Remember:

- This is a large group of persons
- Persons with disabilities are sexually active, and yet their sexual and reproductive health needs often go unmet
- The task of meeting these needs need not be overwhelming

START by identifying local organizations of persons with disabilities and setting up partnerships.

Include persons with disabilities as partners in programming and implementation at all stages – (1) policy development, (2) programme planning, (3) implementation, and (4) monitoring and evaluation.

ACTION: Raise awareness and accessibility in-house	**ACTION:** Ensure all SRH programmes reach and serve persons with disabilities	**ACTION:** Ensure that SRH policies and budgets address the needs of persons with disabilities	**ACTION:** Promote research on the SRH of persons with disabilities
Developing capacity of in-house staff • Ensure attention to the SRH concerns of persons with disabilities • The issue cannot wait until other populations or issues are addressed • To meet development goals, we must address the needs of persons with disabilities • Ensure full inclusion of persons with disabilities in the workplace	**Mainstreaming programmes plus disability-specific programming** • Recognize that 10–20% of clients may have disabilities • Conduct systematic review of programmes for inclusion of persons with disabilities • Strengthen capacity of health system, facilities, and staff to meet needs • Mobilize public and political will • Monitor and evaluate whether inclusion takes place. Use indicators • Ensure that statistics report services for clients with disabilities	**Ensuring inclusion in laws and policies** • Review whether legislation and policies include disability • SRH legislation/policies should reflect human rights framework for inclusion of persons with disabilities • Check whether policies are actually carried out **Budgeting for inclusion** • Budgeting should be realistic, in line with legislation and policies	**Collecting data on disability** • Include disability in demographic and health surveys and local studies on SRH concerns • Conduct research to clarify needs for and gaps in services for persons with disabilities
Ensure Access by addressing barriers **Improving in-house accessibility** • Address physical barriers • Address information and communication barriers • Address attitudinal barriers	**Ensure Access** for services **Reviewing accessibility of services, information, commodities** • Improve access to facilities • Improve access to information and communication • Improve home-based care and community outreach • Improve access to commodities	**Ensure Access** by planning **Setting policy and budgeting for accessibility** • Include accessibility of persons with disabilities in all policy and budget planning • Consider accessibility to public and private medical insurance schemes	**Ensure Access** for research **Conducting research to promote accessibility** • Promote studies to explore more accessible services

Pay special attention to:

- Gender
- A life-cycle approach
- Mental health and psychological needs of persons with disabilities, their families, and care providers
- Emergency response and recovery situations
- Ethnic, minority, other marginalized groups
- Persons with disabilities are not a static group
- Partnering with other UN agencies, coordinating actors

Appendix A. Sexual and reproductive health-related excerpts from the Convention on the Rights of Persons with Disabilities

From Article 9 – Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

   (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;

   (b) Information, communications and other services, including electronic services and emergency services.

From Article 16 – Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

From Article 22 – Respect for privacy

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

From Article 23 – Respect for home and the family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

   (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

   (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

   c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

From Article 25 – Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

   (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.

Appendix B. Selected list of organizations of persons with disabilities

The organizations below are part of the International Disability Alliance (IDA) with many national members. For a more extensive list of organizations of persons with disabilities and NGOs working for or with persons with disabilities, see the website for the UN Secretariat of the Convention (DESA): http://www.un.org/disabilities/

Arab Organization of Disabled People is a coalition of organizations of people with disabilities in the Arab world. It was founded in 1998 in Egypt, and includes 14 other countries. The objective is to provide representation of disabled people in the Arab world.

Disabled Peoples' International (DPI) is a network of national organizations or assemblies of disabled people, established to promote human rights of disabled people through full participation, equalization of opportunities, and development. http://www.dpi.org/

European Disability Forum (EDF) is an independent European nongovernmental organization that represents the interests of 50 million disabled people in the European Union and stands for their rights. It was created in 1996 and is based in Brussels. http://www.edf-feph.org/

Inclusion International (II) is a grassroots organization of persons with an intellectual disability and their families, which advocates, with its member societies in over 115 countries, for the inclusion of people who have an intellectual disability in all aspects of their communities, based on shared values of respect, diversity, human rights, solidarity and inclusion. http://www.inclusion-international.org/

International Federation of Hard of Hearing People (IFHOH) is an international nongovernmental organization of national associations of and for hard of hearing and late deafened people. IFHOH provides a platform for cooperation and information exchange among its members and interested parties. As an umbrella organization and through its individual organizations, IFHOH works to promote greater understanding of hearing loss issues and to improve access for hard of hearing people worldwide. Established in 1977 as a registered non-profit organization, IFHOH currently has 47 general and associate members in 30 countries. http://www.ifhoh.org/

Rehabilitation International (RI) is a global network of people with disabilities, service providers, researchers, government agencies and advocates promoting and implementing the rights, inclusion and rehabilitation of people with disabilities. RI was founded in 1922, and is currently composed of over 700 member organizations in nearly 100 nations, in all regions of the world. http://www.riglobal.org/

The World Blind Union (WBU) speaks on behalf of approximately 160 million blind and partially sighted persons in 178 individual member countries, representing approximately 600 organizations. The WBU advocates the human rights of persons who are blind and partially sighted and seeks to strengthen their organizations and advance the participation of all persons who are blind and partially sighted including women and youth. http://www.worldblindunion.org/

World Federation of the Deaf (WFD) is the international nongovernmental organization representing deaf people worldwide. A non-profit organization, WFD works for human rights and equal opportunities for deaf people everywhere. http://www.wfdeaf.org/

World Federation of Deafblind (WFDB) is a non-profit, representative organization of national organizations or groups of deafblind persons and of deafblind individuals worldwide. The aim of WFDB is to be a forum for exchange of knowledge and experiences among deafblind persons and to obtain inclusion and full participation of deafblind persons in all areas of society. http://www.wfdb.org/

The World Network of Users and Survivors of Psychiatry (WNUSP) is a global forum and voice of users and survivors of psychiatry, to promote their rights and interests. http://www.wnusp.net/

Appendix C. Key recommendations to all humanitarian actors concerning persons with disabilities in emergency situations

Make camp infrastructure and all facilities, services, shelter, organizations and information accessible to displaced persons with disabilities. The needs of persons with disabilities should be addressed at the start of the emergency during the site selection, planning and design of camp infrastructure and services.

Set up a standard, centralized data collection system to collect disaggregated data on the number, age, gender and profile of displaced persons with disabilities in order to enhance their protection and assistance. Attention should be paid to maintaining the confidentiality of information. Disability awareness training should be provided to all data collection officers.

Conduct community-based information and awareness-raising campaigns to promote greater tolerance, respect and understanding of persons with disabilities. Promote the inclusion of people with all types of disabilities in camp management structures, community decision-making processes and at all stages of the program cycle, ensuring age and gender diversity.

Promote full and equal access to mainstream services for persons with disabilities (e.g. shelter, water and sanitation, food and nutrition, nonfood distributions, health and mental health services, education, vocational and skills training and adult education, income generation and employment opportunities, and psychosocial programmes).

Provide targeted services, as needed, for persons with disabilities (e.g. specialized health services, physical rehabilitation and prosthetics clinics, assistive devices, nutritionally appropriate food, learning support needs, education, case management, protection monitoring and reporting mechanisms).

Ensure that displaced persons with disabilities have full access to all durable solution options and to objective information regarding durable solutions in a format that is accessible and easy to understand.

Build alliances with local disability providers to support the integration of refugees and IDPs (internally displaced persons) into local disability services. Encourage local displaced persons' organizations to integrate disabled refugees and IDPs into their activities. Ensure that services provided to displaced persons with disabilities are also made available to persons with disabilities in the local community.

Source: *Disabilities among Refugees and Conflict-affected Populations: Resource Kit for Field Workers*. Women's Commission for Refugee Women and Children, New York, June 2008.

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