WOMEN WITH DISABILITIES: AN ESSENTIAL GROUP FOR MTCT ELIMINATION

A note on bottlenecks and priorities for action
ACKNOWLEDGEMENTS:

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pages 5, 9, 12 UNICEF, Mozambique, 2012 Consultation meeting of women with disabilities

page 16 UNICEF, South Africa, 2012 Consultation meeting of women with disabilities
According to WHO and the World Bank, over a billion people, about 15% of the world’s population and 16% of the world’s woman, have some form of disability. They have less access to health care and health promotion services. Women with disabilities are recognized as particularly disadvantaged, experiencing exclusion double burden to their gender and disability condition and often very vulnerable to abuse. (WHO-World Bank, 2011).

The Convention of Rights of people with disabilities (Article 4) details a specific list of challenges for countries to meet in this area, which provide a framework for action. This including taking measures to eliminate discrimination, promote development of universally designed programs, services and facilities and promote the training of professionals working with persons with disabilities as to better provide assistance and services.

In this report, we explore the situation of women with disabilities of reproductive age in two African countries and the relevance of this group for the elimination of mother-to-child transmission (MTCT) of HIV/AIDS. The exploration includes outcomes of structured conversations and interviews with key informants, group discussions and focus groups with women with disabilities that were carried out in Pretoria, South Africa (14-18 May 2012). It also includes inputs from a subsequent group discussion held in Maputo, Mozambique with women with disabilities, in which personal stories on access to services for the prevention of MTCT were collected.

The mission was composed of Rosangela Berman Bieler (Chief, Disability Section, UNICEF) and Sergio Meresman (Consultant, IIDI Foundation, UY)

For a list of interviewees see Annex I. We gratefully acknowledge the support and collaboration provided by the South Africa Country Office (CO) in preparing this mission, liaising with key government representatives and involving disabled people’s organizations (DPOs) as well as facilitating the logistics.

During the period of the mission, we conducted:

- A group discussion with CSOs working in the areas of HIV and disabilities and members of the international agency teams involved with PMTCT in South Africa.
- A group discussion with representatives of the Ministry of Health (MoH) involved in PMTCT and members of the Department of Women, Children and People with Disabilities (DWCPWD) who are focal points for HIV and disabilities.
- A meeting with DWCPWD Vice Minister Ms Henriette Bogopane-Zulu and her adviser Lidia Pretorius and
• Conversations with Dr Nonhlanhla Dlamini, Cluster Head, MNCH, NDoH; Josephine Sithole, Assistant Director, PMTCT; and Keshika Sivnannan, Assistant Director for Community Empowerment.

• A group discussion followed by individual interviews with women with disabilities who are mothers and have experience with maternal and child health (MCH) and MTCT services.

• Conversations with CO staff Mr Andre, Ms Sanjana Bhardwaj and Ms Geetanjali Narayan.

DATA ANALYSIS

The information from structured conversations and group discussions was transcribed, categorized into policy, programmatic and service access sections, grouped by similarities and differences and presented in the report under main findings.

LIMITATIONS

There are important limitations in our exploration that are related to the limited time on the ground and number of people interviewed, the lack of input from service providers, and the partial representation of types of disabilities in the focus group with women, which did not include women who are deaf or blind. Despite these limitations, this report aims to contribute to making the case for women with disabilities as an important group for MTCT elimination and highlight some of the apparent bottlenecks and priorities for action that emerge.

RATIONALE

Nine out of ten children with HIV acquired it through vertical transmission during pregnancy, labour and delivery,
or breastfeeding, known as mother-to-child transmission or MTCT (UNAIDS, 2010). Without interventions to prevent transmission, around 15-30% of babies born to HIV-positive mothers will become infected with HIV during pregnancy and delivery and a further 5-20% will become infected through breastfeeding (WHO/UNAIDS/UNICEF, 2011). Effective interventions exist that will all but eliminate new infections in children, and global efforts by governments and development partners are directed to ensuring that all women and children can access these.

Ensuring that no baby is born with HIV is an essential step towards achieving an AIDS-free generation. This implies that all pregnant women and their infants must have access to information and preventive interventions. Given the enormity of the AIDS epidemic and the recognition that vulnerable groups are most at risk for HIV, relatively little is known about women with disabilities and access to services to prevent MTCT.

The Convention on the Rights of Persons with Disabilities (CRPD) stresses that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.” This definition has improved the understanding of what disability is, but also has had consequences, significantly increasing estimates of numbers of people to be taken into account. The WHO disability report (2011) places current estimates of people with at least one disability as high as 15.2% in Kenya, 14.0% in Malawi, 21.4% in Namibia, 24.2% in South Africa, 35.9% in Swaziland, 14.8% in Zambia and 16.9% in Zimbabwe (per overall country population). Furthermore, the prevalence of disabilities is growing worldwide due to longer life expectancy in some countries and the increase in chronic health conditions, including HIV and AIDS.

VULNERABILITY

Although there is little data on HIV prevalence among persons with disabilities (PWD), a number of studies have confirmed that PWD experience barriers to HIV prevention interventions, voluntary counselling and testing (VCT) services and AIDS treatment that make them particularly vulnerable to HIV transmission (Groce, 2004; Hanass-Hancock and Nixon, 2009).

Girls and women with disabilities are at particular risk. As women they are a marginalized group who very often have limited choices relating to their bodies and their rights in general. Society accords them low status, and having a disability simply compounds the situation. A recent systematic review of HIV/AIDS and disability literature comprising 36 studies in the African context extensively analysed the evidence, provided confirmation that people with disabilities constitute a vulnerable group, and described the main factors at stake (Hanass-Hancock and Nixon, 2009).

There is currently no information on the access of women with disabilities to MTCT programmes. The strong likelihood of a limited level of awareness and access to VCT services and AIDS treatment amongst them led to our interest in exploring the bottlenecks and
ensuring the provision of equitable and effective access.

QUESTIONS PROPOSED

In order to refine the focus of our exploration and organize the questions to be answered in such a limited timeframe, we decided that the areas to be considered in the interviews and group discussions were the following:

- Legal and policy framework
- Programming
- Services

The overarching questions for each area were defined as follows in Table 1.

The interviews with key informants, group discussions and focus groups with women with disabilities focused on programming and services issues and used the four prongs of PMTCT to structure the exploration. See Annex 1 and 2 for a detailed list of guiding questions.

In addition to the interviews, structured conversations and focus group discussions, we:

- Collected information on current PMTCT and women with disabilities programming in the country.
- Examined the current HIV and disability legal and policy framework based on recent papers and essays.
- Gathered short stories of women with disabilities regarding their experiences accessing MTCT information and services in Pretoria.
- Engaged in conversations and the exchange of information with the CO to inform recommendations for future action.

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SECTION ONE: BRIEF OVERVIEW OF THE LEGAL AND POLICY FRAMEWORK IN SOUTH AFRICA

OVERARCHING QUESTION
What legal and policy framework is in place and how well does it cover women with disabilities as a relevant population for MTCT?

BACKGROUND
People with disabilities in South Africa have fought arduously to have their rights recognized and to overcome marginalization and exclusion. Several South African organizations and leaders of PWD have also championed the exploration of the HIV and disability interface since 1998. As a consequence of this fight and the political support mobilized throughout these years, the legal framework existing today in the country in relation to the health of people with disabilities and the policy framework in the area of HIV and disability are perhaps among the most advanced in the world. In addition, South Africa ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in November 2007, one of the first countries to do so. However, there is a wide consensus amongst activists and planners that ordinary people with disabilities in South Africa are largely unaware of the significant change in disability policy, including whether it would have any impact on their access to health services.

A recent review by Hanass-Hancock et al. examined the legal framework in relation to HIV and disability in 19 Eastern and Southern African countries, identifying the gaps and making several recommendations for the integration of disability into HIV-related laws, policies and programmes. Interestingly, the main gaps were not identified in the existing policy or legal frameworks but rather in the effective implementation of inclusive programmes. The recommendations of the report revolve around the issues of mainstreaming disability within HIV-related programmes, advancing research to provide evidence on HIV and disability, and ensuring the appropriate resources for persons with disabilities to access justice.

Another important recent document is the Framework for the Inclusion of Disability in the National Strategic Plans on HIV and AIDS, published by the South African Disability Alliance (SADA), the South African National AIDS Council (SANAC), the Office on the Status of Disabled Persons (OSDP) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). It reports on the issues, responses and challenges that have emerged in the field of HIV and disability in South Africa, including significant advances in legislation and programming and the mobilization of disability organizations and networks.
to generate awareness. This report also highlights the need to close the implementation gap.

At the time of our visit to Pretoria, the DWCPWD was working on a booklet that provides an overview of HIV and disability practices in South Africa from 1998 to 2008. This compilation of projects and initiatives is mostly DPOs-based and comprises:

• Implementation of sign language interpretation on call in five clinics
• Testing of inclusive health practices in three provinces
• Employment of disability activists in primary health care (PHC) services (Mpumalanga Project)

The Vice Minister of the DWCPWD and her team are longstanding activists in the field of HIV and disability with extensive experience and knowledge of the most effective approaches. Their approach is rights-based and prioritizes the direct involvement of DPOs and disability leaders. They highlighted the need to use the existing capacities and leadership of the disability movement to advance inclusive PMTCT programming: “At the end of the day, it is the disability sector that will ensure zero infections of women with disabilities.”

Senior representatives of the DWCPWD repeatedly noted the priority given to the concerns of people with disabilities on the government’s agenda. For example, recently, the President, the Minister of Social Development and the Vice Minister met with Disabled People South Africa (DPSA) and the South African Disability Alliance (SADA) to discuss mainstreaming the rights of people with disabilities into government programmes, providing job opportunities for people with disabilities, and funding. An HIV and disability project has been chosen by the Global Fund (Round 10) and includes a disability component. DPOs will receive funding. It was not clear whether these components include PMTCT activities.

PMTCT-RELATED LEGAL AND POLICY FRAMEWORKS

South Africa has implemented a number of key initiatives and high-level political commitments towards the elimination of new HIV infections in children by 2015. For instance:

• In April 2010, the President of South Africa launched a massive HIV Counselling and Testing (HCT) campaign.
In December 2011, the South African government launched the *HIV, STIs and TB National Strategic Plan (NSP) 2012-2016*, a multi-sectoral strategy built around a 20-year vision for South Africa that stressed three goals:

- Zero new HIV and TB infections
- Zero deaths associated with HIV and TB
- Zero discrimination related to HIV and TB.

This plan also set specific targets to address PMTCT, including:

- Reducing transmission of HIV from mother to child to less than 2% at six weeks after birth and less than 5% at 18 months of age by 2016.
- Strengthening the management, leadership and coordination of the PMTCT programme and ensuring its integration with maternal and child health programmes.

A National Strategic Framework (2011-2015) has recently been agreed and presented under the theme “No Child Born with HIV by 2015 and Improving the Health and Wellbeing of Mothers, Partners and Babies in South Africa”. This strategic framework guides PMTCT programming in the country and has been built from nine provincial and 52 district frameworks. It provides “a direct link between current policy and the implementation of PMTCT services integrated with Maternal, Neonatal, Child and Women’s Health (MNCWH) services and creating linkages for a multi sectoral response in the country with clear targets for the next five years.”

The National Strategic Framework is built around the four prongs of PMTCT and sets five strategic objectives as crucial to reach the goals of eliminating new infections among children by 2015 and keeping their mothers and partners alive. These are:

- Strengthening management, leadership and coordination for integrated PMTCT and MNCWH programmes.
- Scaling up PMTCT coverage and improving quality to reduce MTCT to less than 2% at 6 weeks and less than 5% at 18 months.
- Facilitating integration of PMTCT into PHC/MNCWH services.
- Strengthening monitoring and evaluation of the programme.
- Increasing awareness and community involvement in the integrated programmes.

Unfortunately, according to the information collected there are no specific recommendations or guidelines for including women with disabilities as part of this important strategy. Guidelines for service delivery to women with disabilities or minimum standards for setting up women with disabilities -friendly PMTCT sites, which would be of great help to implementation, have not been produced either. However, raising the issue in conversations with the UNICEF CO and with other counterparts in the group discussions, triggered interest and pointed to opportunities for this to be remedied.

Access and quality of care were identified in provincial workshops as important issues and can provide important entry points for disability-related interventions. The main concerns mentioned in this area were transportation, infrastructure and staff training.
This section focuses on programming aspects and possible bottlenecks as explored in structured conversations with representatives of key institutions.

As in many other countries, South Africa uses maternal and child health services as the main access point for all women to be tested for HIV and referred for counselling and medication when necessary.

During structured conversations with MoH officials, it was mentioned that Maternal and Child Health (MCH) coverage in South Africa is currently “about 90%”. This triggered a discussion on the likelihood that many women with disabilities would be part of the 10% that is not covered. This hypothesis is consistent with many testimonies collected from women with disabilities in group discussions in which there were several references to women not accessing health services (see Section III below). It is also worth noting that lack of access to health care comes up regularly in the global literature as a consistent area of concern for persons with disabilities in low and middle income countries. (WHO and WB, 2011, UNAIDS 2009)

Due to the unequal access of women with disabilities to MCH services, it has been anticipated that many of them might be missing diagnosis (WHO and WB, 2011). As was pointed out by one of the disability leaders participating in a group discussion, “Many times the women only find out they have HIV when they are pregnant or go for prenatal care around six months.”

A number of programmatic “platforms” were mentioned by representatives of the MoH and other relevant parties as key entry points for advancing PMTCT in the country. These are (a) the reengineering of Primary Health Care programmes and services, (b) school-health programmes, (c) the implementation of district-based teams who are responsible for outreach and of community health workers.

Although there are no specific provisions for women with disabilities amongst these initiatives, all three can potentially benefit them. Furthermore, the implementation of outreach teams could be a good opportunity to involve PWD and sign language interpreters to work with women with disabilities in general and the deaf community in particular.
Recent initiatives: Three women’s clinics have been created to address the sexual and reproductive issues of women with disabilities. Although it was not possible to review documentation on this project, it is envisioned that in the near future it will provide the bases for promising practices and services provision throughout the region.

**DATA COLLECTION BOTTLENECK:**

There is no estimate of the number of women with disabilities who should be attended by MCH or PMTCT programmes in South Africa today. At the same time, because the disability conditions of women attending MCH services are not currently recorded as part of the Prenatal Survey that collects data on all women accessing the services, it is not possible to estimate how many of these women are missing diagnosis or treatment. This is a missed opportunity that prevents programmes from disaggregating data on women with disabilities. Such identification also would in itself contribute to making the disability population more visible to health services and could potentially benefit programming by providing readily available indicators on women with disabilities.
OVERARCHING QUESTION

Are MTCT services prepared to respond to the needs of women with disabilities in terms of access to infrastructure, information and communication, data collection, monitoring and evaluation? What do women with disabilities experience and perceive as barriers in accessing the services.¹

I. AS WIDELY REPORTED IN THE LITERATURE, WOMEN WITH DISABILITIES INDEED FACE INCREASED VULNERABILITY TO ALL KNOWN HIV RISK FACTORS

01

Women with disabilities are very vulnerable in their relationships with men. Dependency and manipulative relationships were reported to be pervasive by all participants in focus groups and group discussions.

• “Women stay in relationships due to dependency without knowing their partner is infected.”

• “Women may be abused and not be aware of abuse... When someone comes to visit you at night.”

• “I have suffered discrimination just because my arm is malformed. Men think I should accept whatever they want just because of that.”

• “My husband left nine months after I delivered twins, and I didn’t hear from him for almost 20 years. When he came back, my family requested that he get tested, and he never came back. He died not long after.”

02

Sexual abuse is perceived as being much more frequent amongst women with disabilities and is often accepted as “natural”. Women with disabilities are less likely to report sexual abuse, and receive much less attention from family members, community members and from the police when they manage to report it.

• “My sister is disabled. She is 26, and mentally handicapped. She was abused two times in 2005. Because of her disability, she never received attention. We talked to the police several times, we knew the men because they worked in the neighbourhood. None of them went to jail. The case was never addressed... and the hospital never offered her a test... My mother never wanted her to do the test anyway; she thinks she would not know how to deal with the infection.”

• “I know of a 15-year-old disabled girl that has been abused by her neighbours. She does not have any information (on HIV). And her parents tolerate the abuse because she is disabled. The abusers only act
when they know that the family will not care.”

• “I know of a paraplegic girl who was abused while her mother was at work. The second time it happened many neighbours knew what was going on but when they talked with the mother she didn’t want to do anything. She was just more ashamed (of having a disabled daughter). Sometimes the family just do not see any alternative but to say nothing.”

• “There is a belief that if you have sex with a virgin you get cured from HIV. This is why there is so much rape – even of girls who are five, six, eight years old. Traditional healers say to men to have sex with their own daughters to get rid of HIV.”

03

Family members are often not sufficiently protective of girls and women with disabilities. Many HIV-exposed or infected girls and women with disabilities are cared for by families who lack basic knowledge on HIV transmission; as such they are also not well informed on when and where to get appropriate medical care for HIV. Due to the reluctance of their guardians in relation to their independence and sexual experiences, women with disabilities are subject to very limited support to attend the clinics, resulting in late diagnosis of their status. Lack of access to treatment and supportive counseling is likely to result in a high tendency of defaulting or refusing to take ARV in the course of treatment.

04

Women with disabilities are disempowered, unaware of their rights and unprotected by their families, who feel guilty about having a daughter with a disability. As a consequence of this, women with disabilities tend to have very low self-esteem and sometimes do not take proper care of themselves (and of their children).

• “Lots of mothers believe that having a child with disability is a punishment. They think their children will never be sexually active, and they do not need sex education, information or whatsoever.”

• “A friend of mine, she is blind. She is HIV-positive and so is her husband. They have a child that was born with HIV. She didn’t go to the antenatal appointments, she breastfed, neither of them uses protection and they do not want to go to hospital. She sometimes takes the medication but she is not careful and when they are finished she does not get more. People are ashamed and they do not accept.”

• “Some women, even if they know they are positive... they feel ashamed to go to the clinic and ask for medication.”

• Forced sterilization happens and is often consented to by a family member (without the woman’s consent).

05

Empowerment, awareness of their rights and involvement in community or disability organizations and “helping others” are perceived as protective factors and should be promoted.

• “I grew up as very brave disabled person. Always fought for my rights, used to fight, never accepted name calling. I went to tell my mom I was
pregnant at 24 years. Even today they don’t believe what I do in the house! I’m very proud of myself. I wish I can go to a conference for women with disabilities so I can express they can have confidence in themselves.”

• “I was lucky because I have been strong-willed since my school years.”

• “What made it easier for me is that I am a counsellor at the clinic. It motivates me that people with disabilities and HIV look for my counselling.”

II. WOMEN WITH DISABILITIES FACE VARIOUS BARRIERS IN ACCESSING HEALTH INFORMATION, COMMUNICATION AND SERVICES.

01

There are no provisions in the health posts to accommodate the needs of women with disabilities in terms of transportation, priority access or infrastructure. As a consequence, common limitations that affect everyone due to the scarcity of services have an even greater impact on access by women with disabilities because of their needs for personal assistance, transportation, etc.

• “Access to the services, to medicines and tests, are very complicated anyway. Even if you do not have a disability you need to go to the clinic very early to be seen. To be there early, sometimes you have to leave your house at 3 or 4 a.m. that is very common. So if you have a disability and you need to arrange for special assistance to leave your house and transportation to get to the clinic, just imagine how hard it is for the women.”

• “In the health posts they don’t give priority to women with disabilities.”

• “The queue waiting system (first come first served) highly impacts on women with disabilities because transportation is not available, very challenging. Women with disabilities fear to get mugged; most women arrive at 4 or 5 in the morning to ensure they will be seen.”

• “I have been to public facilities where bathrooms were not accessible, unable to close stall door.”

• “What kind of assistance is available? Not much help.”

• “Last year I was sick. Lots of cough. I had TB. They said that I had to go every day! I said give me the tablets, I will take care for my life. I’m disabled, I’d rather die than come here every day!”

Attempts to accommodate the needs of women with disabilities were also mentioned as being underway as a result of complains made.

• “They are trying to accommodate women with disabilities. In my clinic they want us to go early to be seen.”

• “You must fight to have your rights!”

02

Women with disabilities do not feel welcome in the health posts. Many reports and anecdotes illustrated the weight of stigma and prejudice against persons with disabilities as the prevailing experience among these women. The attitudes of health personnel and thoughtless treatment seem to be a big deterrent. Although this is probably an issue that affects all women in the health posts regardless
of any particular need or a disability condition (as one NGO representative put it, “Health staff tends to not understand or base their practices on right aspects”), this can only aggravate the barriers faced by women with disabilities.

Many examples and stories illustrated this situation in both directions: health personnel being judgemental or just not considering the needs or rights to equal treatment for women with disabilities, and women with disabilities being further inhibited from demanding services due to their perception of not being welcome, of not receiving fair treatment, and of their disability being a negative issue in the opinion of the staff.

• “I divorced in 2006 but I have a boyfriend. He requested I took the test. When I got to the clinic I was not treated well.”
• “I know women with disabilities fear being labelled by the nurses.”
• “There is a lot of discrimination in hospitals. I know of a deaf woman that goes to the clinic to get her medicines and she spends hours waiting. They just skip over her name even though they know that she is waiting.”
• “When I was pregnant I heard many comments from the nurses, like what kind of man did this to you? They think that you are going to make a lot of extra work for them (as a wheelchair user). In our association there is a woman who is positive but she has accepted it all right and is helping others.”

03 Health and sex IEC campaigns fail to include women with disabilities. The reproductive health issues of this population have not been included as part of public policies in the past and are still a largely unmet need in the present. Providing information and support to women with disabilities is a challenge due to a lack of understanding of disability issues by health personnel and a lack of appropriate resources.

• “Women with disabilities may not be able to place the female condom themselves. How can they prevent unwanted pregnancies? Unwanted pregnancies are very common, especially blind and deaf women.”

04 Communication with health personnel is often not accessible, especially for women with hearing impairments. There are no guidelines or recommendations on how to handle the communication needs of women.
with disabilities. This also affects the access of this population to reporting other issues in health clinics. Access to preventive information is also unavailable in adequate formats.

• “There is no sign language interpretation in police stations. The police are not trained on disability issues. They call someone to take the information and women victims of sexual abuse do not feel comfortable. Another issue is the interpretation from the different townships.”

• “I have been in talks where women with hearing impairments did not understand what was being said. It was impossible for us to communicate with them.”

• “If women with disabilities report faults in the provision of services they are not being taken seriously. Their complaints are not recorded, vague, lack of evidence. Employees are not trained to take the information in a productive way, do not take disability into consideration.”

• “There are information campaigns aimed to women living in rural areas. But they rely on radio and TV announcements. This is not inclusive of deaf women. These women would need to be reached through interpreting services (sign language) or education and awareness campaigns aimed to their families. It is a huge task, you need a door-to-door campaign, to give them information on HIV and sex education.”

• “It is very difficult for deaf people to communicate due to no interpretation. Lots of deaf people are also illiterate. It is a big challenge. Women with disabilities should be trained to give talks and work in hospitals, especially to women with hearing impairments.”

### III. LIMITED UNDERSTANDING OF THEIR NEEDS AND DISCRIMINATION OF WOMEN WITH DISABILITIES FURTHER INCREASE THEIR VULNERABILITY AND EXPOSURE TO RISKS

**01**

Stigma and discrimination towards PWD are still very predominant in society and amongst service providers. Stigma against women with disabilities increases if they are HIV-positive. The result of this is a very negative atmosphere that makes PMTCT and other services less accessible to women with disabilities.

• “There are always provocations, discrimination. But there is no help. Even teachers tolerated the abuse and never helped. You have to be a very strong person to bear it.”

• “Health personnel attitudes are very negative towards reproductive health of women with disabilities.”

• “They always ask if my boyfriend is disabled also.”

• “I got pregnant at 11. I stayed with my grandmother, she was very protective. But at the clinic, the attitude was not good. They asked why, how. People ask, how do you do it with a disabled person? I answered, at night I can do the same as you. After that they were very friendly.”

• “I am HIV-positive since 2008. HIV stigma is strong, but when the community discriminate the disabled this is the biggest challenge.”
CONCLUSIONS AND RECOMMENDATIONS

The explorative visit confirmed most of the existing presumptions in relation to the need to further include women with disabilities in PMTCT programmes. The most relevant conclusions in terms of the bottlenecks and recommendations for future action include:

**Women with disabilities are an essential group for achieving the eradication of mother-to-child transmission.** In concordance with the international commitment and efforts for eradication by 2012 and within its POs) in programming and services.

Expand effective linkages with DPOs to close the implementation gap: There is a widespread perception amongst the disability sector of an obvious gap between policy statements, programmes and the actual services that are available on the ground. This perception was clearly stated in the focus groups with women with disabilities. Effective linkages are needed between MCH and PMTCT programmes and the disability community to identify and reach out to the most excluded women with disabilities, such as those living in rural areas, women with communication limitations (hearing, intellectual and visual impairments) and women who are illiterate.

The most important aspects to improve are those related to women with disabilities’ access to MCH clinics and programmes. For this to be achieved some immediate priorities can be addressed:

- Disseminating accessibility standards and guidelines to promote removing the most noticeable architectural barriers in MCH clinics.
- Training persons with disabilities as community health workers.
- Implementing advocacy programmes with the communities to ensure that women with disabilities demand and use services in both rural and urban areas.
- Involving facilitators/interpreters in outreach activities with women with disabilities who have severe communication limitations.
- Disseminating guidelines for staff on how to deal with persons with disabilities.²
- Finding solutions to the transportation needs of women with disabilities, e.g providing vouchers.
- Involving disability organizations to disseminate messages and collaborate with EIC campaigns in adequate formats.
- Promoting the involvement of persons with disabilities living with HIV as expert patients to provide service at both community and health centres (both as a way to facilitate service delivery and to
enhance self-esteem and reduce stigma at the community and facility level.

**Make MCH programmes more inclusive by investing in outreach and family-based approaches:** Considering that about 10% of women are still to be reached in MCH and presuming that women with disabilities are part of that percentage, outreach efforts targeted to the most excluded and isolated women with disabilities will be an important effort in order to advance an equity focus and achieve the MTCT elimination goal.

Under this area, information and education will be key particularly in rural and poorer urban areas. In order to reach women with disabilities with basic information and promote consultation with services, particularly given the fact that the majority of them are most likely to be illiterate and have little contact outside the immediate family circle, the use of family-based approaches will be necessary. Interventions should include the provision of general information on mother-to-child transmission of HIV, preventive measures, infant diagnosis and PMTCT services.

**Map capacities to increase the use of community resources and involve persons with disabilities as health agents:** There is a lot of space for MCH and PMTCT programmes to take further advantage of capacities often available in the disability organizations and networks.

In the group discussions, it was mentioned that disability counsellors can provide peer support and other effective services in the community and the clinics as well. This would contribute to strengthening PHC programmes, which is one of the proposed platforms for improving PMTCT programming. The same mechanisms can be used to monitor and evaluate MCH and PMTCT.

Capacity mapping is also recommended to allow health personnel and programmes to better visualize these resources (independent living, CBR, peer counselling).

**Include women with disabilities in campaigns to reduce stigma and introduce zero tolerance to discrimination in health services:** Stigma and discrimination seem to be a major deterrent for women with disabilities to attend health services.

Some measures can be explored in the immediate term, for instance:

- Monitoring bullying and discrimination in health facilities and communities and developing sanctions for those who stigmatize women with disabilities at clinics or the community level.
- Training service providers on how to interact with women with disabilities.
- Involving women with disabilities and those living with HIV who have acquired disabilities as resources to promote the right to services and as expert patients.
- Identifying and promoting good practices as well as acknowledging good practitioners.
**ANNEX 1: STRUCTURED GROUP DISCUSSIONS WITH KEY INFORMANTS – GUIDING QUESTIONS**

**Legal and Policy Framework**
- Is there funding for specific programmes?
- Have there been campaigns to change social attitudes?
- What is the perception on stigma as a factor? Have actions been taken to address this?
- Are women with disabilities mentioned in policy documents and laws against gender-based violence?
- How effectively are these policies and laws enforced in general and in the case of women with disabilities?
- Are there experiences of claims or legal action?
- Have there been conferences on the topic?
- Is there funding for research?
- Have indicators been developed?

<table>
<thead>
<tr>
<th>AREA</th>
<th>OVERARCHING QUESTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legal and policy framework</td>
<td>What legal and policy framework is in place and how well does it cover women with disabilities as a relevant population for MTCT?</td>
</tr>
<tr>
<td>Programming</td>
<td>To what extent do programmes, operational plans and guidelines support effective linkages of MTCT, MCH and women with disabilities?</td>
</tr>
<tr>
<td>Services</td>
<td>Are MTCT services prepared to respond to the needs of women with disabilities in terms of access to infrastructure, information and communication, data collection, monitoring and evaluation? What do women with disabilities experience and perceive as barriers in accessing the services? What is the knowledge of these issues among women with disabilities themselves?</td>
</tr>
</tbody>
</table>
Programming

- What programmes exist that respond to the needs of women with disabilities in regards to MCTC?
- To what extent have MCTC (and MCH) managed to include women with disabilities?
- Is data on women with disabilities who are pregnant or mothers collected in routine health information systems? Is the disability condition visible and registered?
- Have specific surveys on women with disabilities who are pregnant or mothers been conducted?
- Are there any current or recent experiences of interventions that have improved inclusion of women with disabilities in programmes? (development of education resources, consultation mechanisms, staff training, etc.)
- What are the entry points for increased involvement of women with disabilities and their organizations and networks in the elimination of MTCT?

Services

- Research and identification of women with disabilities as a population
- Inclusive outreach
- Community engagement
- Accessible information
- Accessible infrastructure
- Accessible communication
- Inclusive data collection
- Inclusive monitoring and evaluation

ANNEX 2: FOCUS GROUP DISCUSSIONS WITH WOMEN WITH DISABILITIES – GUIDING QUESTIONS

We want to hear your story on:

HIV transmission (among women with disabilities of reproductive age)

- Are women with disabilities particularly at risk? Why?
- What are the main factors influencing prevention?
  - Lack of access to sex education?
  - Lack of access to information and communication?
  - Lack of access to safe sex? (condoms, etc.)
  - Lack of access to the HIV test?
  - Other?
- Is discrimination a factor?
- Are women with disabilities aware of their rights?
- What helps women with disabilities to protect themselves

Transmission of HIV to the baby
(during pregnancy, delivery and the breastfeeding period)

- Are women with disabilities particularly at risk? Why?
- What would be the main factors influencing a woman with disabilities getting pregnant if she does not want so?
  - Lack of access to information and communication?
  - Lack of access to the health centres?
  - Lack of access to family planning services?
• Violence and abuse?
• Other?
• Are stigma and discrimination factors?
• Are women with disabilities aware of their rights?
• What helps women with disabilities to protect themselves?

**Unwanted pregnancy among women with disabilities living with HIV**

• What would be the main factors influencing an HIV-positive pregnant woman with disabilities to transmit HIV to her child?
  • Lack of information and communication?
  • Lack of access to maternal and child health services?
  • Lack of access to support (e.g. advice, drugs, etc.)
  • Other?
• Are stigma and discrimination barriers?
• Are women with disabilities aware of their rights?
• What helps women with disabilities to protect themselves and their babies?

**Access to care and treatment for all women and children living with HIV**

• Are women with disabilities having access to care and treatment? Examples?
• What would be the main factors influencing women with disabilities’ access to care and treatment?
  • Lack of information and communication?
  • Lack of physical access to health services?
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>CBR</td>
<td>Community-Based Rehabilitation</td>
</tr>
<tr>
<td>CO</td>
<td>Country Office</td>
</tr>
<tr>
<td>DPO</td>
<td>Disabled People’s Organization</td>
</tr>
<tr>
<td>DWCPWD</td>
<td>Department of Women, Children and Persons with Disabilities</td>
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<tr>
<td>IEC</td>
<td>Information, Education and Communication</td>
</tr>
<tr>
<td>NSP</td>
<td>National Strategic Plan</td>
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<tr>
<td>PLHIV</td>
<td>People Living with HIV</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother-to-Child Transmission</td>
</tr>
<tr>
<td>PWD</td>
<td>Persons with Disabilities</td>
</tr>
<tr>
<td>SAFCD</td>
<td>South African Federal Council on Disability</td>
</tr>
<tr>
<td>SANAC</td>
<td>South African National AIDS Council</td>
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<tr>
<td>SASL</td>
<td>South African Sign Language</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
<tr>
<td>WWD</td>
<td>Women with Disabilities</td>
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</tbody>
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