

# Sexual and Reproductive Health Need of Adults and Youth with Disabilities

Adults and youth with disabilities have the same sexual and reproductive health (SRH) needs anyone else and yet they often face barriers to information and services. The ignorance and attitudes of society and individuals, including health-care providers often raise more of these barriers than the disabilities themselves.

## **Stigma and Discrimination**

People with disabilities are often viewed as asexual or sexually inactive, and therefore, without a need for SRH education and services. Research shows however, that people with disabilities are as sexually active as people without disabilities.

### **Information and Access Barriers**

Persons with disabilities often cannot obtain even the most basic information about SRH and are therefore often unaware of even basic facts about themselves, their bodies, and their rights to define what they do and do not want. Other barriers include inaccessible transportation to clinics and facilities that lack ramps, adapted examination tables, materials in Braille, sign language interpreters, etc. Furthermore, health care providers often stigmatize patients with disabilities or lack disability-related knowledge and skills, and in turn, the ability to provide them with appropriate counseling and care.

## **Denial of their SRH Rights**

Historically, persons with disabilities have often been denied the right to establish relationships and to decide whether, when, and with whom to have a family. Similarly, disability related SRH policies and programs often concentrate on the prevention of pregnancy but ignore the fact that many women with disabilities will eventually want to be pregnant.

### **Violence and Abuse**

People with disabilities are often 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 also 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, legal, and social service systems are often unresponsive and inaccessible.

### **Forced Sterilization**

Although, forced sterilization is forbidden by the *Convention on the Elimination of all Forms of Violence Against Women*, women and girls with disabilities still confront lingering perceptions that they are unfit to be mothers. And although the practice of eugenics has long since fallen into disrepute, sterilization of girls and women with disabilities is often justified by caregivers as a means to reduce the burden of managing their menstruation and prevent pregnancy. Others argue that sterilizing girls and women with disabilities will protect them from becoming pregnant if they are raped. But this practice can actually increase their vulnerability by making their sexual abuse more difficult to detect.

## Young People with Disabilities Left Behind

Young persons with disabilities are sexually active and have the same concerns about sexuality, relationships, and identity as their peers. Research reveals that adolescents with disabilities feel socially isolated and lack social confidence and sexual self-esteem. Parents, teachers, and health-care providers report feeling anxious, untrained, and unconfident about discussing sexuality with children and adolescents with disabilities, especially those with intellectual disabilities. Young persons with disabilities have been found to have low levels of SRH knowledge, with girls and young women having the lowest levels. Young persons with disabilities report low levels of access to family planning, SRH information and testing for HIV and other sexually transmitted infections.

## Many people with disabilities have greater needs for SRH education and care than those without because:

- They are up to 3 times more likely to be victims of physical and sexual abuse and rape.
- They are more 3 times more likely to become infected with HIV
- They are less likely to receive prenatal care and family planning services
- Women with disabilities are less likely to receive Pap tests, mammograms, and cervical cancer screenings
- Adolescents and adults with disability are more likely to be excluded from sexual education programs



## **Kupenda's SRH Advocacy and Interventions**

## **Supporting SHR Information and Service Access**

Kupenda trains health care providers, teachers, community leaders, and parents of children and youth with disabilities about the SRH rights and needs of people living with disabilities. These *Disability Advocacy Trainings* are tailored to the unique needs of each stakeholder group and enhanced by live testimonies from people living with disabilities. At the end of these trainings, participants are supported to develop action plans outlining how they will help children with disabilities in their communities access medical care and schooling where they will be taught about their SRH rights and be able to receive related care. Trainees then return to their villages and are supported by our staff to implement these action plans through our monthly reporting system and incentivized with cell phones, certificates and badges to support their work and enhance their reputations as *Community Disability Advocates*.

### **Abuse Prevention and Care**

Kupenda engages village chiefs, elders, law enforcement leaders and Child Protection Centers to prevent and address the abuse of people living with disabilities in their communities. In partnership with these key stakeholders, we run abuse prevention trainings, tailored to different community groups as well as family members of people with disabilities and people with disabilities themselves. Local leaders who have completed our *Disability Advocacy Trainings* and become certified as *Community Disability Advocates* also help our field staff to conduct abuse screening interviews with children and youth living with disabilities and their parents. This allows the leaders and staff to identify children who are at risk for abuse or who have already been victimized and make timely referrals for care, counseling and safety planning.

## **Government SRH Policies and Programming**

For more than 20 years, Kupenda and its affiliate Kenyan organization, Kuhenza for the Children, have been trusted disability advisors to the Ministry of Health and Education in Kilifi, Kenya. As such, we regularly advocate for increased SRH services for people living with disabilities in Kilifi by sharing details and data about their need and their rights to contraception. HIV testing, family planning services, and accessible transportation, clinics and information.

### **Traditional Healers and Birth Attendants**

In many low- and middle-income countries traditional healers and birth attendants are residents' sole or primary source of SRH information and care. This is especially true in remote or impoverished areas where families may not have the means to travel or health facilities for care. In response, Kupenda provides workshops that educate these trusted community leaders about the SRH needs of people living with disabilities in their communities so they can provide more effective counseling, care and referrals. After each training, approximately 65% of the participants join our team of *Community Disability Advocates* who work to improve the lives of people living with disabilities in their communities. One of the most effective activities conducted by this group includes accompanying women who are pregnant to health facilities. This enables the expectant mothers to receive timely care before, during and after delivery and strengthens partnerships and mutual respect between the traditional healers' and health facility staff.

## **Youth SRH Education**

In partnership with the Ministry of Health, local nonprofits, the International Red Cross, and Child Protection Centers, Kupenda arranges school-based SRH trainings for children and youth. These sessions include trainings on abuse prevention, reproductive health, lifeskills, and prevention of HIV and other sexually transmitted diseases. We engage youth through games and role-playing exercises to make the trainings engaging and participatory while helping them to retain and practice the skills they are learning.

### **Parent Education**

We educate parents and caregivers about the SRH needs and rights of people with disabilities, so they have the knowledge and skills necessary to provide related care to their children and to advocate for their rights. We share this information by facilitating community-based Parent Workshops and by establishing and training parent support groups.

### Information, Education and Communication Educational Materials

We have developed a Disability Law Guide, A Disability Law Summary Guide, and a Disability Handbook that outlines the most common disabilities, and those with high levels of stigma, in low income countries. Each of these resources uses clear, simple language and graphics to help community leaders, teachers and families impacted by disabilities understand the SRH needs and right of people living with disabilities, and especially children and youth. We disseminate these materials at our trainings, during counseling sessions, to parent support groups, community events and through our free, open source online library.