

Contextual factors around the sexual abuse of people with disabilities in East Africa

Knowledge based upon a descriptive
literature review of applied research

This study was carried out by Mary Ann Waddell, independent researcher at University College
London, in partnership with Advantage Africa and the FIRAH

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The mission of the FIRAH (Foundation of Applied Research on Disability) follows two main directions, which are complementary and merge:

- The call for projects : selection and funding of applied disability research projects
- The Resource Center : sharing knowledge in applied disability research

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Internationally concerned, the Resource Center Applied Research and Disability aims at creating connections and bonds between researchers and field stakeholders¹. It develops and disseminates research in order to promote an inclusive social transformation and to facilitate the full involvement of persons with disabilities.

» <http://www.firah.org/centre-ressources/>

¹ Field stakeholders

Persons with disabilities, their families, and their representative organisations. Any Human Rights organisation working with persons with disabilities. Service providers and other organisations working with Persons with disabilities. Service providers and other organisations working in mainstream that are required to meet the needs of persons with disabilities such as architects, teachers, companies, industries etc. Researchers and research institutes. Local, national and international decision makers.

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1/ Presentation of the document

The present document was conducted as part of the applied research “An assessment of the social, cultural and institutional factors that contribute to the sexual abuse of persons with disabilities in East Africa” lead by Advantage Africa, and funded by FIRAH’s (International Foundation of Applied Research on Disabilities) call for projects in 2012. The fulfilment of this work was entrusted to Mary Ann Waddell, independent researcher formally at the University College of London.

The goal of this literary review is to report on existing knowledge about applied research on the thematic of the sexual abuse of persons with disabilities in East Africa. It resulted in the selection of 39 relevant research papers which were each categorised using a set of predetermined criteria. Of these research papers 15 were selected as being particularly relevant or interesting because of their potential for being applied with practical effect, especially with persons with disabilities and their own organisations

What FIRAH means by the very general terms of applied research is:

- First, it is proper research based on precision and method rules allowing the implementation of a scientific approach involving teams of one or more researchers or lecturer researchers whose research is one of the statutory missions.
- Applied research differs from basic research. Its purpose is to increase independence and social participation of people with disabilities. It is not only aimed at producing theoretical knowledge but also tackling practical issues related to the needs and concerns of people with disabilities and their families. The collaboration between these people, professionals and researchers is a fundamental element to the achievement of this type of research.
- In this sense, this type of research is designed to produce directly applicable results. In addition to usual publishing (scientific articles, research reports) applied research is also designed to produce other publications called “ relative materials²” which can take various forms: development of good practises, methodological guide, training tools, and are destined to different field stakeholders (people with disabilities, professionals, policies makers).

² Relative materials

Shaping of the findings and knowledge gained from applied research into products, services and contents to meet the expectations and needs of people with disabilities. These application supports are adjusted to be used by field stakeholders.

This work does not intent to be comprehensive but to identify the results and knowledge generated by research that could be useful for field stakeholders in order to improve the quality of life and social participation for people with disabilities.

Each title in the annotated bibliography contains a link with free or paying access to the work in question, and each reading note contains a link to the Resource Centre database.

This document can be freely disseminated provided the source, author and relevant organisations are acknowledged.

Each note contains a link to the documentary note relative to the research on the Research Centre website.

2/ Methodology

Inclusion Criteria and Search strategy

At the start of the project a set of inclusion criteria was established so as to decide which applied research would be included in the study. FIRAH's definition of applied disability research was used. For the purposes of devising specific literature search criteria, the research project to which this literature review contributed was divided into three key topics (a) sexual abuse and violence (b) persons with disabilities, and (c) Kenya and Uganda. The decision was made to include research papers which were relevant to either all three criteria, or at least two. For example some references were included which address sexual abuse in Uganda and or Kenya, but did not feature disability. Other references were useful because they featured sexual abuse and persons with disabilities, but were outside east Africa. In general, research from at least within the African continent was prioritised. Also, there were a number of research papers which focused upon children with disabilities. These were included where they were felt to be relevant and useful.

Searches were made using a university library database (allowing access to health and social science research databases and articles available through subscription only). The open internet was also used. Studies available through subscription only were included as the majority of academic research papers are only available through subscription. Studies which are inaccessible because they do not have their full content available on the internet were excluded unless there was a very good reason for including them.

Searches were undertaken of:

- a) Health and social science databases (yielding mainly peer-reviewed research).
- b) On the open internet of international NGOs (yielding mainly grey literature i.e. non peer-reviewed, research).
- c) Snowballing (identifying new journals, authors or research teams from the references found through methods a) and b).

Search outcomes

Almost 40 applied research papers were included in the final descriptive literature review because they were highly relevant to the research area and of good quality. Of those, 15 were selected as most relevant and useful, and as having potential for direct application to improve the lives of persons with disabilities themselves. After reading each of the selected research studies the researcher summarised the content of the paper, either using the author's summary or in her own words.

The Synthesis Paper

After completion of the literature review, the researcher used the categorised resources she had compiled to write a synthesis paper. After reading all of the papers in the literature review the researcher drew upon this large body of information to compile the synthesis. She looked at both the research methodologies and the findings. The synthesis is an objective summary of the situation as laid out in the research and is referenced throughout. Hence, the synthesis paper provides a valuable summary of the state of the knowledge concerning the Sexual Abuse of Persons with Disabilities in East Africa.

3/ Synthesis

This summary allows to underline the thematic of the 39 research works we identified. Full references of these documents are found under the sections “reading notes” (page 17) and “annotated bibliography” (page 35).

» **Abstract**

Examination of the literature indicates that there are particular social circumstances which seem to increase the susceptibility of people with disabilities in the East Africa region to sexual abuse, and that as victims they may be shown less concern and receive less adequate responses from society than other members of the general population. This paper will outline these circumstances as reported in the literature and indicate some possible intervention strategies.

» **Introduction**

A perceived prevalence of sexual abuse against children and adults with disabilities worldwide is becoming recognised and is causing growing and serious concern. The issue is moving up the research, policy and intervention agendas.

Globally based research indicates that it is probable that people with disabilities are at increased risk of sexual abuse when compared with the general population (Hugues et al., 2012; Jones et al., 2012). There is evidence that this is a significant problem in Africa. In a study of four African countries every single one of 956 young people with disabilities interviewed said they had suffered sexual violence. On average each had suffered 2.6 types of sexual violence (African Child Policy Forum, 2010). Many victims suffer multiple violations and many perpetrators commit multiple violations (Save the Children & Handicap International, 2011). The literature indicates that there are particular social circumstances which seem to increase the susceptibility of people with disabilities in the East Africa region to sexual abuse and that as victims they may be shown less concern and receive less adequate responses from society than other members of the general population. This paper highlights general social attitudes and weaknesses of practice that may serve to perpetuate the problem. It is important to bear in mind that there are local differences in beliefs (Hanass-Hancock, 2009) and there are families and services in which people with disabilities receive excellent care (Ingstad & Grut, 2007).

The nature of sexual abuse

There is no agreed definition of sexual abuse. The African Child Policy Forum (2010) lists twelve types of sexual abuse including rape, sexual touching, being forced to pose naked, prostitution and circumcision. Yet participants in another African study talked only of sexual penetration (Save the Children & Handicap International 2011). Definitions of sexual abuse for

legal purposes are found in national legislation, for example The Sexual Offences Act, 2006 in Kenya and The Domestic Violence Act, 2010 in Uganda. Some people would regard circumcision as abusive while others would see it as a rite of passage (personal communication). Other circumstances may be regarded as abusive such as denial of the right to a sex life (Asindura, 2000), forced sterilisation (Hanass-Hancock, 2009), women being given contraceptive pills without their consent (Saulo, Walkira, & Darj, 2012) or parents forcing marriage on daughters who have disabilities (Pasha & Nyokangi, 2012; Aderemi, 2013). Some women feel themselves to be used as sex-partners by men who would not be seen openly with a woman who has a disability or who have no intention of long-term commitment (Ingstad & Grut, 2007; Human Rights Watch, 2010).

This variation in perceptions of what constitutes abuse is important because there is no obligation on family, community or the state to provide emotional support or judicial redress to someone reporting a situation unless it is culturally and legally regarded as being wrong.

The consequences of sexual abuse

The damaging physical, psychological and social consequences of abuse may stay with victims for years, whether they are children or adults, male or female. In the immediate aftermath a victim is likely to endure pain from injuries such as tearing of genital tissues or pelvic dislocation. It is widely believed that victims may then carry longer term physical and mental consequences such as pregnancy, sexually transmitted disease including HIV, genito-urinary dysfunction and depression. However quality, rigorous evidence for this is lacking and more research is needed (Asindura, 2000; WHO, 2013). Norah Groce (2005) reports that following sexual abuse children have significantly increased chances of mental health problems throughout their lives. Apart from mental illness victims may feel troubled, disrespected, disgusted and powerless (Pasha & Nyokangi, 2012). Finally, victims sometimes suffer long-term social consequences because of the moral judgments made about them within their communities. A girl who has been a victim of rape may never be considered acceptable to marry and women victims may be blamed not only for the attack but for the moral failing of the community (Maxwell, Belser & David, 2007) or they may simply be rejected by the community (Asindura, 2000).

Who the perpetrators are

While strangers or unrelated members of the community may be abusers, often the perpetrators are parents, carers or teachers, individuals taking advantage of positions of trust, and some are repeat offenders. Individuals may even seek employment in schools or institutions because of the easy access it gives to potential victims. (Groce 2005; Stopler, 2007; African Child Policy Forum, 2010; Save the Children & Handicap International, 2011). Even children with disabilities in special schools have admitted to being abusers (Maart and Jelsma, 2010).

» **Contextual Factors Around the Sexual Abuse of People with Disabilities in East Africa**

Krug explains that violence, including sexual abuse, is:

“...a complex interplay of individual, relationship, social, cultural and environmental factors, a product of multiple levels of influence on behaviour”
(Krug et al., 2002).

This section will explore the principal social contextual factors which heighten the vulnerability of people with disabilities to sexual abuse. Although these factors will be described under six sub-headings they are, as Krug’s analysis indicates, deeply interrelated.

Society sees people with disabilities as different

In some East African communities, people with disabilities are regarded as less intelligent, less productive or not deserving of positive attention (Stopler, 2007; African Child Policy Forum, 2010; Groce 2005). Worse still they may be looked upon with active hostility, as a threat to social norms or be associated with witchcraft and curses (Save the Children & Handicap International, 2011). Such views devalue people with disabilities, lowering the moral threshold for them as victims and lessening the seriousness with which society may view abuse of people with disabilities (Groce 2005; Save the Children & Handicap International, 2011).

Justification for abuse is sometimes appropriated on the grounds that people with disabilities are fortunate to receive such attention (Stopler, 2008; Hanass-Hancock, 2009) or that people with learning difficulties do not feel pain (Pasha, 2012).

Society holds misconceptions about the sexuality of people with disabilities

In addition to general stereotyping some perceptions specifically about the sexuality of people with disabilities increase their susceptibility to sexual abuse.

A coupling of two beliefs widely held in Africa puts people with disabilities at increased risk of rape. The first of these beliefs is the notion of “virgin cleansing,” which holds that sleeping with a virgin can cure one of sexually transmitted diseases, including HIV. The second belief is that people with disabilities are commonly considered to be asexual and therefore presumed to be virgins and so possible channels for virgin cleansing (Yousafzai & Edwards, 2004; Groce 2005; Okello, 2009; Hanass-Hancock, 2009; African Child Policy Forum, 2010).

In contrast people with disabilities may be viewed as hypersexual (Aderemi, 2013). The sometimes friendly, naïve or unguarded behaviour of people with learning disabilities can be taken advantage of or misinterpreted as a sexual invitation (Asindura, 2000; Hanass-Hancock,

2009; Pasha & Myaka, No date), as can the tactile communications of the deaf-blind (Moss & Blaha, 2001).

A low level of belief in the existence of homosexual orientation in Africa can lead to the denial of the possibility of boys or men as possible victims of unwanted male sexual attention (Instituto Promundo, 2012). In some East African countries homosexual acts between males are widely regarded as unacceptable and in some countries as criminal offences. Although there is evidence of males with disabilities as victims (Yousafzai & Edwards, 2004; Save the Children & Handicap International 2011) this is to a large extent unrecognised as problematic and not discussed openly.

The perceptions of people with disabilities

People with disabilities may acquiesce to abuse either on account of not recognising it for what it is, or on account of their disempowered status.

Some people with intellectual disabilities and other young people with disabilities who have missed out on education about sexual relationships may not be aware that this behaviour towards them constitutes abuse. Or not appreciating the possible consequences for injury, pregnancy or sexually transmitted infections they may not resist (Asindura, 2000; Save the Children & Handicap International, 2011; Hanass-Hancock, 2009; African Child Policy Forum, 2010; Rohleder, 2010). Naidu et.al. (2005) talk of acts by caregivers of women who are dependent for their intimate care, such as sexual touching or unnecessarily observing them getting dressed. The subtlety of these acts may make it difficult for victims to recognise them as abuse; or because of their dependence they may feel that they have no alternative but to accept it.

Being stigmatised, marginalised and habitually in disempowered positions may lead individuals into misinterpreting sexual interest for affection, just wanting “to be loved” (Hanass-Hancock, 2009), or they may “come to believe that the only options available to them are celibacy or violent sexual encounters,” (Naidu et.al. 2005). Women may acquiesce wishing to become mothers in order to gain social acceptance or self-affirmation (Rohleder, 2010; Msemi Ngololo, 2011). Young people perceiving themselves to have low status may enter into risky relationships in order to boost their social status (Mall & Swartz, 2012). Having lower social status or reduced ability to communicate may render women with disabilities less able to make independent choices or negotiate sexual pleasure or safe sexual practice (Yousafzai & Edwards, 2004; Yousafzai et. al., 2005; Hanass-Hancock, 2009).

People with disabilities may be physically vulnerable or trapped

Individuals with little physical ability to defend themselves or flee can be easy targets. It is thought that perpetrators may also select people who will have difficulty identifying them, such as people with visual impairments and those who cannot talk and so could not easily report offences. (Yousafzai & Edwards, 2004; UNDP, 2005; Yousafzai et al., 2005; Rohleder, 2010)

Victims dependent on caregivers at home or in institutions may be trapped in abusive relationships, reluctant to report their abusers for fear of loss of that care or of other reprisals (Yousafzai & Edwards, 2004; Groce 2005; Naidu et al., 2005; Save the Children & Handicap International, 2011). Children placed in institutions for their protection may fall prey to further abuse (Stopler, 2007) as the institutions often lack external oversight enabling any carers who are perpetrators to offend continually (Groce, 2005; Save the Children & Handicap International, 2011; Stopler 2007). Families may not report abuse because of the stigma, shame or fear that it will expose them as inadequate caregivers. Thus the victims are denied access to intervention and justice (Save the Children & Handicap International, 2011; Pasha, 2009). Parents sometimes arrange partners for their children with disabilities. This may be to protect them from perceived predatory attentions in the community or to ensure their daughters will have children to look after them after the parents have died. Well-intentioned though these actions might be they nonetheless place people in enforced relationships (Pasha & Nyokangi, 2012; Aderemi, 2013).

Duty bearers in welfare services may be ill equipped to help

Some community services have particular roles in safeguarding people with disabilities. These are education services which could provide information about sex and relationships and the services which should provide welfare, medical care and justice to those who have been abused. However, despite national and international guidelines, and in most countries legal and procedural guidance being in place, these agencies and the services they provide often have shortcomings.

Knowledge about safe sex, about the nature of abuse and that everyone, including people with disabilities, deserve to be treated well empowers individuals to protect themselves. The main sources of such information are schools, community meetings, parents and other relatives, friends, health facilities and media, with schools likely to provide the most reliably accurate information (Yousafzai et al., 2005; Saulo, Walakira & Darj, 2012). However, for people with disabilities there are access barriers. Both young people and adults in Uganda complained of the difficulty for people with restricted mobility to get to meetings where they could learn about HIV (Yousafzai et. al., 2005). School enrolment rates in East African countries

for children with disabilities are very low (Groce, 2005) and many students with disabilities do not transition to secondary classes where sex education is delivered. In addition, there are a variety of communication barriers which can restrict access to information. For example, a HIV health worker was concerned that because she did not have information in an adapted format her clients who only read Braille would continue to be at increased risk (Saulo, Walakira & Darj, 2012). Teachers do not always have the right knowledge and skills to help students with disabilities to protect themselves. Mall & Swartz (2012) found that some educators believed that providing sex education to the hard of hearing would be immoral. Some teachers explained to Aderemi (2013) that they give warnings and misinformation to students with intellectual disabilities because they felt that the best thing for these particular students was to be scared away from sex. Professionals who are not provided with proper guidelines have to rely on their own judgment about what is best to do. If even teachers need training regarding sex education the majority of young people with disabilities who do not get to school are at risk of being uninformed or misinformed by other members of the community.

Similarly, in the health sector there are obstacles of access, communication, knowledge and attitudes in relation to health workers practice. Weaknesses here matter because in the general population healthcare providers are most likely to be the first ones victims report sexual assault to (WHO, 2013). People with disabilities have been turned away from HIV testing because health workers believe them to be asexual and therefore not at risk (Yousafzai et. al. 2005; Saulo, Walakira & Darj, 2012). People with visual and hearing impairments have said they are inhibited about using family or friends as intermediaries because of the loss of their privacy or the fear that the interpreters would gossip (Yousafzai et.al. 2005; Saulo, Walakira & Darj, 2012). Often medical staff do not know what evidence to collect for the courts (Save the Children & Handicap International, 2011).

There are problems with legal redress. In East African countries people often turn first to quasi-legal systems or traditional authorities where cases may be dealt mediated by heads of families or community elders, thus bypassing the statutory agencies. These may lead to low-level, informal settlements such as an exchange of cows between families as compensation (Asindura, 2000; Stopler, 2007) or requirement that the victim marry the perpetrator (Save the Children & Handicap International, 2011).

Even the official justice system presents challenges. Police demand bribes, complainants often cannot afford travel or legal costs to pursue their cases in court and sentences are lenient and not always served (Stopler, 2007; Save the Children & Handicap International, 2011). The significance of poor responses in the case of people with disabilities should be viewed with some caution because sexual abuse cases occurring within the general population are often also dealt with poorly (Armstrong, 2013). Nevertheless it is clear that people with disabilities face extra obstacles such as negative attitudes, inaccessible facilities and communication

barriers (Hanass-Hancock, 2009; Okello, 2009). Children with disabilities in particular are often not taken seriously when they try to report abuse (Groce, 2005; Save the Children & Handicap International, 2011). One African study of children with disabilities found that 75% of boys and 25% of girls who reported having been raped felt that nothing had been done about it (African Child Policy Forum, 2005). Very highly specialist skills are needed to support people with intellectual difficulties through the court system, although it can be done (Dickman, et. al., 2006). Because of low levels of reporting and prosecution perpetrators are not discouraged, the statistics under represent the matter to governments and it is likely that victims feel disregarded.

Structural factors impact on the vulnerability of people with disabilities to sexual abuse

Ignorance, attitudinal and communication barriers have effect at another level; they drive people with disabilities to the margins of society and keep them away from education, the workplace and services, and from being seen as equal citizens.

Every participant in a study in Kenya told of impairment leading to economic and social challenge for themselves and their families, with many or most living in poverty (Ingstad & Grut, 2007). Often women excluded from the labour market resort to prostitution, which though it may strictly speaking be consensual, is not their free choice (Yousafzai & Edwards, 2004; Msedi Ngololo, 2011). Sometimes poverty drives families to selling their daughters into prostitution, with disabled daughters being favoured because of being expected to be more compliant (Groce, 2005). Poor girls and women with learning disabilities are at risk of being lured into sex in exchange for small gifts (Asindura, 2000; Yousafzai & Edwards, 2004). Poverty is also a barrier to access to services, for example, it costs money to own a radio which is one of the best sources of information about HIV and other relevant services, and poor people may not be able to afford condoms or may not attend health centres where they are given out free (Yousafzai et al., 2005).

Possible intervention options

This section will revisit the principal contextual factors around the sexual abuse of people with disabilities in the East Africa region and outline possible interventions. The interventions proposed are based on an approach which a number of East African countries, Burundi, Djibouti, Ethiopia, Kenya, Uganda and Rwanda, have set for themselves with respect to provision for people with disabilities by ratifying the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD sets out the rights of people with disabilities and states' obligations with respect to these rights.

“Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.” and “should not be subjected to cruel...or degrading treatment” (UNCRPD 15 &17). (Meaning (UNCRPD articles 15 & 17)).

Tanzania, Eritrea, Somalia and South Sudan have not yet signed the Convention.

An important perpetrator of sexual abuse against people with disabilities is that they are marginalised and regarded negatively. Until they are routinely included in mainstream society, such as in schools and the workplace, their “existing and potential contributions to the overall wellbeing and diversity of their communities” (UNCRPD preamble) will not be seen and the devaluing stereotypes which make abuse towards them seem less serious will not be dispelled. An indirect effect of better education and of inclusion in the workplace would be to reduce the poverty which keeps people with disabilities from the services or drives them to prostitution.

People with disabilities may acquiesce to abuse either because of not having been taught to recognise it or because of low self-esteem or lack of agency. The attention given to an individual while teaching them about abuse in itself potentially gives them the message that they should not be treated thus and that they should have a “sense of dignity and self-worth” (UNCRPD 24.1.a).

In addition to the diminished personhood often accorded to people with disabilities many societies hold myths which can be appropriated to legitimise them as subjects for abuse. Where people with disabilities are viewed as asexual or hypersexual their need for education about abuse may not be recognised and their reports of having been abused may be disbelieved or dismissed. Special thought could be given to the vulnerability of males with disabilities, given evidence that they are among the victims of sexual abuse, in the context of societies which find sex between males an intensely difficult subject to consider. Finally, where a community does not agree what constitutes abuse people who know they are guilty can claim they did not know that what they were doing was wrong. Awareness-raising enables communities to “combat stereotypes, prejudices and harmful practices relating to persons with disabilities” (UNCRPD 8.1.b). The principal mechanisms for community sensitisation are public information campaigns and community initiated meetings, in which people with disabilities would be likely to have a significant role.

Community sensitisation helps people to know what the proper course of action is on humanitarian grounds but leaves them relying on their individual judgments as to what counts as abuse, room for excuses and no standardised mechanism for trial or redress. A legal framework defines for the community and any quasi-judicial body exactly what constitutes abuse and unequivocally what must be officially reported.

Professionals in education, health, the police and judiciary also seem confused about whether people with disabilities should receive education about abuse or whether they should be taken seriously if they report having been abused. Office holders need protocols, evidence-based where possible, and explicit and nuanced training to give them the skills to manage these complex and highly sensitive situations. The UNCRPD endorses equal access to justice (13) and health care (25.d) for people with disabilities, including training for duty bearers, and in the case of the courts it mentions procedural adjustments.

Abuse is often dealt with in the first instance by the community, the victim turning perhaps to family or a friend. The matter is then sometimes passed on to health, welfare and police and judicial services. Multiple agencies can potentially be involved. It would seem sensible that the various statutory agencies and community come together to create an integrated approach.

Services such as health clinics and courts were identified as being physically inaccessible. The UNCRPD states that community services and facilities should be accessible (19.c) as should the environment and means of transport (9.1) to get to the facilities. The other barrier within services was communication. The UNCRPD mentions that the school environment should be equipped for adapted communication including having teachers trained in sign language and Braille (24.4). For the health and justice services it only mentions the principle of equal access and general training (13.1 & 25.d). The UNCRPD recognises that accommodations must be “reasonable,” and not impose a “disproportionate or undue burden” (2), which is important for countries whose resources are limited. There is evidence that it is better to bring in professional interpreters than for welfare personnel to be expected to use rudimentary adapted language skills (Mall & Swartz 2012; see also Yousafzai et al., 2005).

Underreporting of abuse and rarity of prosecution lead to underrepresentation of the sexual abuse of people with disabilities in government statistics. This lack of evidence contributes to poor recognition of this endemic problem and lack of incentive for the issue to be addressed. Disaggregated data should be collected (UNCRPD 31.1 & 2) to demonstrate that sexual abuse is being perpetrated against people with disabilities; and within that, the levels of abuse against males and females, children and adults and different impairment groups. This would support the provision of better targeted and appropriate services across the sectors. Policies and services should be “inclusive” (of people with disabilities), that is that within mainstream services people with disabilities receive the same standard of provision as the general population. The examples above demonstrate that inclusion cannot be achieved without disability specific measures, such as adapted communication methods (Plan, no date). Simply labelling a policy or service as “inclusive” can hide the fact that people with disabilities are in fact being passed over (Stopler, 2007).

The evidence demonstrates that there is a wide gap between how the UNCRPD says attitudes, services and facilities should be and the day-to-day reality on the ground for people with disabilities.

4/ Reading notes

The 14 research presented below are based on the main bibliography; each of them being summarized. This research was identified as most relevant to the Resource Center criteria.

The criteria are as follows:

- The connection between research results and the practical implementation of the principles of the UN Convention,
- The collaboration between researchers and field stakeholders,
- The identification of applied or applicable results to improve the quality of life of people with disabilities.
- The use of a research method

Each reading note is linked with the documentary database's notice in the Resource Center website.

- ❖ Groce N. **Violence against children with disabilities.** Unicef: Thematic group on violence against children. 2005. 35 pages

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Culture. Social protection – abuse & welfare. Autonomy-social & psychosocial support & support for legal capacity. Independent living – community living. UN Convention-equality & non-discrimination, access to justice. Social perception-raising awareness. Advocacy & self-advocacy. Emotional and sexual life. Gender. Child & teenager.

» **Author's note**

[Extract from the introduction] This report presents the findings of the Thematic Group on Violence against Disabled Children, convened by UNICEF at UN Headquarters in New York on July 28, 2005 and charged with the task of providing comments and recommendations on violence against disabled children to be made available for the UN Secretary General's Report on Violence against Children. In this report, key issues on violence against children with disabilities will be reviewed. Some of the issues raised will be familiar to those who work on violence against children. Other issues will be disability-specific and even experts and advocates on violence against children may be unfamiliar with them or have not thought deeply about the implications that such practices have in relation to violence against and abuse of disabled children.

» **Commentary**

This report presents the findings of the Thematic Group on Violence against Disabled Children convened by UNICEF in 2005 to be made available to the UN Secretary for a report on violence against children. It will be of use to researchers, advocates, policymakers and anyone wishing to gain a general understanding of the issue of violence against children with disabilities.

The report comprehensively describes the scope of violence against children with disabilities worldwide, the nature of abuse, where it takes place, the reasons why children with disabilities are at increased risk and it touches on the long-term effects on them. The Thematic Group calls for civil society and governments to recognise violence against children with disabilities as an issue and to take protective action.

This article does not give primary research data but it does set out the opinions of experts selected by the UN Secretary General. It will be of use to researchers, advocates and policymakers

- ❖ Save the Children. **Out from the shadows: Sexual violence against children with disabilities.** London: Save the children UK. 2011. 32 pages

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Social protection – abuse, welfare. Autonomy – support for legal capacity. UN Convention and European and national conventions – access to justice. Social perception / raising awareness. Emotional and sexual life. Child and teenager.

» **Author's note**

Out from the Shadows focuses on sexual violence against children with disabilities. This report sheds light on what remains an under researched issue, and it makes recommendations on how to tackle it. As well as a global literature review, it includes research findings from four African countries.

» **Commentary**

This report aims to raise awareness of the sexual abuse of children with disabilities in Africa. It will be of interest to researchers, policymakers and advocates in the field and is written in a style accessible to the non-academic.

A background literature review draws on material from across the globe and primary data from 89 interviews with survivors of sexual abuse and additional interviews with other involved individuals is summarised, although little raw data is presented.

From their literature search the authors found that children with disabilities are at disproportionately high risk of sexual abuse compared with the general population and that this abuse happens in countries at different levels of socioeconomic development. The study scopes across cultural and structural reasons why children with disabilities are at high risk and makes recommendations for how services can be improved.

- ❖ **Stopler L. Hidden shame: Violence against children with disabilities in East Africa.** Netherlands: Terre des Hommes. 2007. 60 pages

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key Words**

Accessibility – adapted information and communication. Social protection - abuse / welfare. Autonomy – support for legal capacity. UN Convention – access to justice. Social protection / raising awareness. Services and care centres. Advocacy. Family. Emotional and sexual life. Child and teenager.

» **Author's note:**

This report focuses on violence against children with disabilities in the East African countries of Uganda, Kenya and Tanzania. This research describes ways in which governments are taking responsibility to protect children with disabilities, and areas that are not yet up to the standards to which signatories of the convention have committed themselves.

» **Commentary:**

This article focuses on policy around violence against children with disabilities in East Africa. It is principally of interest to policymakers and advocates, including those who shape the international development policies of donor governments.

The nature of violence against children with disabilities and its causes are explored by means of interviews with duty-bearers in Uganda and Kenya, but the voices of the victims themselves seem absent.

The main strength of this paper is in its examination and questioning of policy. Although written some time ago, and before the CRPD would have taken effect, its relevance lies in the way it examines the role of policy.

Informal and formal routes for victims to seek redress are described and appraised. The authors outline national laws and policies, expose their shortcomings and take the position that inclusive (mainstreaming) approaches fail to serve people with disabilities.

This paper is unusual in that the authors turn their attention to the policy of the donor government. They request that their government's international development policy disaggregate disability as a separate issue so that progress in this field can be identified and measured.

- ❖ Ingstad B., Grut L. **See me and do not forget me: People with disabilities in Kenya.** Oslo: SINTEF Health Research. 2007. 68 pages

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Accessibility. Education. Employment. Autonomy. Independent living. Social perception. Services. Family.

» **Author's note**

This report is a contribution towards describing the lives of people with disabilities in Kenya. The report presents results from two field works conducted during two weeks of May/June 2005 and two weeks of October 2006. The work was done on behalf of the World Bank. We hope that work will be useful for actors in Kenya, whether governmental authorities or NGOs working for the benefit of people with disabilities, and that it will contribute to the improvement of the living conditions for people with disabilities in Kenya.

» **Commentary:**

This report, based on interviews with people with disabilities, gives a broad overview of life with disability in Kenya and looks more deeply at the relationship between disability and poverty. It is intended to provide information for government and non-government actors working for the benefit of people with disabilities. The article is very broad ranging in looking at types and causes of disability and at how the social and physical environment can cause disability and affect those already disabled. This is therefore a good introduction for those not already familiar with disability issues. Researchers from SINTEF Health Research, helped by local Disabled People's Organisations to identify informants, interviewed 91 people living with a range of disabilities.

The first half of this article is given over to extensive background information on the history of disability services in Kenya, discussion of the nature of disability, how social factors interact with disability and the mechanism of qualitative research.

Turning to the interviews, the authors make many connections between poverty and disability (how poverty causes disability and how disability causes poverty) based on observation and testimonies, although some connections the authors acknowledge are based on inference. A number of participants' stories are described and give evocative illustrations of life with disability in Kenya. The observations incidentally demonstrate not only the effects of poverty on the individual but also the effects of poorly resourced health services on people with disabilities.

The positive role played by disabled peoples' organisations and self-help groups is illustrated.

Recommendations are made for improvement in education, policy and research. The limitations of general services in reaching people with disabilities are touched on and disability-specific services are called for.

- ❖ Boersma M. **Protecting Children with disabilities from violence in CBR Projects: Why we need to work with a different form of child protection policy for children with disabilities.** Disability, CBR & Inclusive Development. 2013. 11 pages

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Social protection – abuse / welfare. Access to justice. Social perception / raising awareness. Family. Child.

» **Author's note**

Children with disabilities encounter more violence in their lives than their peers without disability. Organisations involved in Community Based Rehabilitation (CBR) come across many cases of violence against the children they work with. Many organisations have no policy on child protection since it is not within the scope of their expertise. Others work with child protection policies that are hard to apply in the realities they deal with. Through research done in Ethiopia, with a recent update, the author attempts to show that there is a need for policies in CBR, that follow a community approach rather than an individual approach to child protection.

» **Commentary**

This author proposes that an alternative to traditional child protection policies may be more effective in protecting children with disabilities from violence. This is of particular interest to those engaged in child protection and to Community Based Rehabilitation (CBR) organisations. Current policies are child-centred, recommend transfer of the child from the abusive environment to a safe facility and pursuit of each case through the courts.

The author points out that often in low-resource settings there are no safe places to transfer children to. Community Based Rehabilitation workers reduce the violence suffered by children with disabilities within the home by educating and supporting the parents. For example, parents may stop beating a child into “paying attention” when they understand the child is deaf. Going to the police and courts can add to the trauma for the child where officials do not take them seriously or know how to help them. Helping the community at large understand children with disabilities could also help reduce the violence.

The author therefore proposes a family-centred / community-centred approach rather than a child-centred approach and education for CBR workers on how to manage situations of abuse.

- ❖ Hanass-Hancock J. **Interweaving Conceptualisations of Gender and Disability in the Context of Vulnerability to HIV/AIDS in KwaZulu-Natal, South Africa.** *Sexuality and Disability* (27). 2009. 13 pages

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Culture. Social protection – abuse / welfare. Social perception / raising awareness. Services. Emotional and sexual life. Gender.

» **Author's note**

In KwaZulu-Natal disability and gender are associated with myths and stereotypes that exacerbate the vulnerability of people with disability (PWD) to HIV/AIDS. The present analysis results from a three year qualitative study of 25 people with disabilities and their caregivers. It outlines the interweaving patterns of stereotyping gender and disability and how this may increase the vulnerability of PWD to HIV/AIDS. The paper emphasizes that access to prevention and treatment is still an unfulfilled goal and that an enormous gap in service delivery persists. Sexual abuse and exploitation have become a major threat to fighting HIV/AIDS within the group of PWD. PWD are particularly vulnerable HIV/AIDS through the threat of sexual abuse. Potential contributors to this are sexual purification rituals, sexual exploitation and the process of the judicial system. The notion that PWD are asexual, virgins, sexually overactive, cursed, dirty or clean increases their exposure to abuse and subsequently HIV/AIDS. Additionally, misconceptions regarding sexuality, gender and HIV/AIDS have exposed women and girls with disabilities, in particular, to abuse and HIV. Yet, effective responses are still scarce and people with disabilities are often denied access to sexual education as well as prevention and treatment of HIV/AIDS.

» **Commentary**

This paper from South Africa contributes towards consideration of why and how HIV protective services should be designed to include people with disabilities.

The author contends that HIV protective programmes have limited reach towards the disabled population, largely because of misguided beliefs about disability. This is firstly because these programmes do not address the issues of abuse and exploitation to which this section of society is especially exposed and secondly because many consider that people with disabilities should not be included in the programmes.

Qualitative research is used to explore beliefs about disability. A number of perceptions and circumstances lead to people with disabilities being at increased risk of abuse or exploitation. For example women with disabilities are less valued as marriage partners, are more likely

therefore to engage in multiple sexual relationships and moreover have less power in negotiating safe sex. An example of exclusion of people with disabilities arises from a widespread belief that people with disabilities are asexual and therefore do not need inclusion in HIV protective programmes. Women participants identified sexual abuse as a very significant problem in their lives.

There is an underestimation of sexual abuse of people with disabilities. Interventions recommended centre round education of society and in particular those who implement HIV protective programmes.

- ❖ Dickman B., Roux A., Manson S., Douglas G., Shabalala N. **How could she possibly manage in court? An intervention programme assisting complainants with intellectual disability in sexual assault cases in the Western Cape.** In: Watermeyer B. et al., Disability and social change: A South African agenda. Cape Town: HSRC Press. 2006. Pages 116-133

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Social protection – abuse / welfare. Access to justice. Social perception / raising awareness. Advocacy. Emotional and sexual life.

» **Author's note:**

[Extract from the introduction] In sexual assault cases involving a complainant with intellectual disability it is not only the complainant who needs support and preparation. Liaison between all the agencies involved in the case is crucial for a satisfactory outcome. [...] In this chapter we provide an overview of an effective intervention programme that has been running for 14 years at CMH, a non-profit, non-governmental organisation which offers a comprehensive mental health service to indigent people living in Cape Town. The majority of CMH's clients have intellectual disability.

» **Commentary:**

This chapter describes the Sexual Assault Victim Empowerment (SAVE) programme which supports victims of sexual abuse with intellectual disabilities in South Africa to take cases to court. It is based on examination of case files and interviews with victims and their carers. The programme has been established for over a decade and has succeeded in bringing about good outcomes.

This piece is useful to parties interested in shaping prosecution procedures because it describes factors which the intelligent lay-person may not envisage and which are vital to proper conduct of cases. For example it illustrates the manifold mental capacities beyond straightforward IQ which are required for a complainant to be a competent witness. Each of these capacities needs to be separately assessed.

The chapter describes the interventions by a range of highly specialist professionals, such as social workers and specialist psychologists, in supporting not only complainants but also parties in court. It gives references to further documents which describe protocols.

- ❖ Pasha N. **Responses to situations of sexual abuse involving teenagers with intellectual disability.** *Sexuality and Disability* (27). 2009. Pages 187-203

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Culture. Social protection – abuse / welfare. Access to justice. Social perception. Services. Family. Emotional and sexual life. Teenager.

» **Author's note**

This paper reports on significant findings from an ongoing study on the care and support services for sexually abused individuals with intellectual disability in South Africa. Only one aspect of the study is presented here, namely the professionals' views regarding responses to situations of sexual abuse involving a group in question. So far, data presented in this study were obtained by means of interviews conducted individually and in groups, with participants recruited from the police services and schools that cater particularly for learners with intellectual disability. Findings revealed that sexual abuse among teenagers with intellectual disability is widespread. The responses are discussed under three broad areas, namely: protocols, reporting and preventive efforts. The findings will be available for use in maximizing care and support services for sexually abused people with intellectual disability in South Africa.

» **Commentary**

This South African study investigated the responses of family and professionals, other than those in the justice system, to teenagers with intellectual disabilities falling victim to sexual abuse, with a view to contributing towards a functional community response.

This paper is of interest to people attempting to formulate procedures to increase reporting sexual abuse perpetrated against young people with intellectual disabilities. It must be noted that parental responses may be regionally or culturally specific.

Twenty participants from the police services and a special school were consulted in interviews or focus groups. The researchers found family often do not report incidents and even prevent others such as teachers from filing reports, for a variety of reasons, some well-intentioned. Many families do not participate in community programmes aimed at encouraging them to report through facilitating their understanding of intellectual disability and crime. Thus sexual abuse of teenagers with intellectual disabilities tends to be contained as a family matter and dealt with informally or even denied. This is problematic because teachers are required to report abuse but can only do so with parental consent. The authors call for procedures therefore to be revised.

This paper is useful because it considers the role of parents as stakeholders in instances of sexual abuse for this group and sheds light on their rationales for concealment which may in turn direct towards useful points of intervention.

- ❖ **Aderemi T. Teachers' Perspectives on Sexuality and Sexuality Education of Learners with Intellectual Disabilities in Nigeria.** *Sexuality and Disability* (32). 2013. Pages 247-258

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Education. Social protection – abuse / welfare. Social perception. Family. Emotional and sexual life. Teenager.

» **Author's note**

This paper reports on teachers' opinions on sexuality of Nigerian learners with intellectual disabilities and awareness of their risk of HIV infection. Teachers considered learners with intellectual disabilities as 'hypersexual' and incapable of intimate relationships. Learners with intellectual disabilities were reported to be at risk of exposure to HIV infection due to sexual abuse, transactional sex and lack of sexuality and HIV education. Teachers expressed confidence to deliver sexuality and HIV education but lacked skills to communicate relevant information to learners with intellectual disabilities in accessible formats. Teachers' negative attitudes, misconception and lack of skills to deliver sexuality education to learners with intellectual disabilities have to be addressed through training.

» **Commentary**

The study focuses on teacher readiness to deliver education on sexuality to teenagers with intellectual disabilities. It is useful for those concerned with teacher training or with the protection of this group of young people from abuse or inadvertent outcomes of consensual relationships.

This study developed from a background of a recently introduced national school sexuality and HIV education programme which does not cater for the needs of people with intellectual disabilities, evidence of poor knowledge around HIV and sexuality among people with disabilities and lack of information regarding how teachers feel about teaching this subject to students with learning disabilities. 12 teachers from public special schools were interviewed. Participants believed this group of students to be sexually active, engaging in consensual activity, with or without understanding of its fuller nature, or non-consensual engagement. They identified a number of reasons why students with intellectual disabilities may be especially vulnerable to abuse.

The new national programme does not feature in the curricula of special schools or primary schools where most learners with intellectual disabilities are, leaving the matter to teachers' judgment and initiative. Teachers' varied in their levels of confidence to deliver this teaching

and in the accuracy of their perceptions around the relationships their students were forming. This study illustrates the haphazard nature of delivery of sex education to a population at heightened risk of abuse.

- ❖ World Health Organisation. **Promoting Sexual and Reproductive Health for Persons with disabilities.** WHO/UNFPA Guidance Note. Geneva: WHO. 2009. 40 pages

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Social protection – welfare. Social perception – raising awareness. Emotional and sexual life.

» **Author's note**

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. This note outlines a general approach to programming and does not address specific protocols for the SRH care and treatment of persons with disabilities.

» **Commentary**

This report is aimed at policymakers and experts in sexual and reproductive health. This report is about sexual and reproductive health for people with disabilities, not specifically about abuse. It outlines the perceptions and realities about disabled people's sexuality and sexual lives, including abuse, and therefore makes the case for inclusion of disability in awareness raising and interventions in sexual and reproductive health programmes.

The report sets out an approach of inclusion at institutional level, from the WHO itself downwards and in inter-agency relationships. The key messages, such as the need to make services and communications accessible, that people with disabilities do engage in sexual activity, and the need to make policies inclusive are given. The report stresses that inclusion of people with disabilities in sexual and reproductive health services need not require significant extra resources.

This was published in 2009 before the Convention on the Rights of Persons with Disabilities had had time take effect. Mainstreaming is advocated and the twin-track approach is seen as necessary in only very few instances, a belief which has changed since 2009. However if these points are borne in mind the report frames sexual life for people with disabilities, including abuse, well in the wider social context and has a lot to offer regarding approaches to intervention.

- ❖ Sahaya International and GRACE. **The deaf Peer's Education manual**. 2007.
156 pages

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Adapted information and communication. Education. Social protection – abuse / welfare. Raising awareness. Emotional and sexual life. Child and teenager.

» **Author's note**

The purpose of this manual is to provide deaf youth and adults, teachers, parents and guardians with a tool for addressing basic health awareness within an independent framework utilizing optimal communication. The activities are participatory/interactive, and are designed with/by Deaf Kenyans fluent in Sign Language (SL), and acknowledge the use of other SL variations. This manual is designed to blend with the school curriculums/co-curriculum activities, plus other issues that affect students while in school. It also befits other settings such as seminars and workshops.

» **Commentary**

This is a training manual about sexuality, relationships and HIV for hearing-impaired young people in Kenya, designed for use in school. But it would be equally useful for non-hearing-impaired young people, even in non-low-resource settings and in other facilitated youth groups such as clubs. The full manual is freely available online. The purpose of this manual is to support the education of hearing impaired youth in Kenya with HIV/AIDS education but it sets this within comprehensive information about sexuality such as anatomy and physiology, relationships and hygiene.

The activities are appropriate for low-resource settings; they use facilitated group-work and role-play and materials such as drawing, discussion, or glasses of water. Detailed step-by-step instructions are given for the facilitators. Every step is accompanied by detailed illustrations. The content of the training is very detailed and covers things like the physical and emotional changes of growing into adulthood; how to recognise friendship, infatuation and love ; sex, pregnancy and birth, HIV and routes of transmission and non-transmission, dealing with harassment; prostitution; relationships and life skills.

- ❖ Maxwell J., Watts Belser J., David D. « **Abuse, violence and self-defense**». **A health handbook for women with disabilities**. Berkley, California, The Hesperian Foundation. 2007. Pages 287-312

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

and

- ❖ Niemann S., Jacob N. « **Preventing sexual abuse** ». **Helping Children who are blind**. Berkley, California, The Hesperian Foundation. 2000. Pages 115-124

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

and

- ❖ Niemann S., Greenstein D., David D. « **Preventing sexual abuse** ». **Helping Children who are Deaf**. Berkley, California, The Hesperian Foundation. 2004. Pages 167-178

[Access to the reading note and to complete documents into the documentary database of the Resource Center.](#)

» **Key words**

Social protection – abuse / welfare. Autonomy – social and psychological support. Emotional and sexual life.

» **Author's note**

A health handbook for women with disabilities

[Extract from the introduction] Abuse can happen to any woman. Around the world, many women are treated badly by strangers and by people they know. They may be beaten, raped, shamed, sexually assaulted, hurt or abused in other ways, or even killed. Many times no one knows about the abuse because women feel ashamed or afraid to speak about it. They think no one will care or they are afraid they will be blamed for having caused the abuse. Many women are treated badly because they have less power than the person abusing them, or because they are alone, weak or vulnerable. Disabled women and girls are even more likely to be abused, hurt, or sexually assaulted than nondisabled women. They are seen as even weaker and less important. A woman's disability never makes violence, abuse, or neglect. Women with disabilities deserve to live in safety, with people who care about them and treat them well.

Helping children who are blind

[Extract from the introduction] As children become more independent, they meet more people and relate to them in many different ways. Just as they must learn to move around the house and community safely, they also must learn about personal safety. This chapter is about protecting children from sexual abuse.

Helping children who are deaf

[Extract from the introduction] It might seem strange to find information about sexual abuse in a book on helping children who cannot hear well. But, sadly, children who are deaf are more at risk for sexual abuse than children who are not deaf. So it is very important for families with deaf children, and those whose care for or teach deaf children, to know about it.

» **Commentary**

Each of these three books devotes a section to sexual abuse of people with disabilities. They are written for people with disabilities, their families and community workers, in low-resource settings. They are empowering in tone, practical in the guidance they give and are written in language accessible for people with little formal education. Care has been taken to make the material relevant to any culture.

“A Health Handbook for Women with Disabilities,” gives a whole chapter to abuse, including eight pages (298-305) on sexual abuse. It explains for women what sexual abuse is, why it is never acceptable, what the health and emotional consequences of sexual abuse are and advises women and their health workers about what they can do after sexual abuse has happened.

“Helping Children Who Are Deaf,” and “Helping Children Who are Blind,” each has a chapter on sexual abuse outlining the nature of sexual abuse, giving clear guidelines for parents to help their children learn to protect themselves, advice on how to respond if the child has been abused and some activities for communities to learn about how to prevent or respond to sexual abuse.

5/ Annotated bibliography

The bibliography contains the thirty-nine 39 research references that have been identified for the literature review. These references were selected for their relevance to the Resource Center criteria. However, flexibility had to be adopted in the application of the criteria in order to better report on the needs in terms of research.

A link to each research is available by clicking on the title (the majority of them are on free access).

- ❖ **Aderemi T. [Teachers' Perspectives on Sexuality and Sexuality Education of Learners with intellectual disabilities in Nigeria](#). *Sexuality and Disability* (32). 2013. Pages 247-258**

This paper reports on teachers' opinions on sexuality of Nigerian learners with intellectual disabilities and awareness of their risk of HIV infection.

- ❖ **Boersma M. [Protecting Children with disabilities from violence in CBR Projects: Why we need to work with a different form of child protection policy for children with disabilities](#). *Disability, CBR & Inclusive Development*. 2013. 11 pages (accès payant)**

Through research done in Ethiopia, with a recent update, the author attempts to show that there is a need for policies in CBR, that follow a community approach rather than an individual approach to child protection

- ❖ **Dickman B., Roux A., Manson S., Douglas G., Shabalala N. [How could she possibly manage in court? An intervention programme assisting complainants with intellectual disability in sexual assault cases in the Western Cape](#). In: Watermeyer B. et al., *Disability and social change: A South African agenda*. Cape Town: HSRC Press. 2006. Pages 116-133**

This chapter describes the Sexual Assault Victim Empowerment (SAVE) programme which supports victims of sexual abuse with intellectual disabilities in South Africa to take cases to court. It is based on examination of case files and interviews with victims and their careers. The programme has been established for over a decade and has succeeded in bringing about good outcomes.

- ❖ **Gosh N. [Addressing sexuality and reproductive rights at the community level: experiences from west Bengal](#). 2012. 8 pages**

A power point presentation about the role of CBR in dealing with sexuality and abuse. Gives case examples, explains the role of CBR workers in this role and discusses the balance between dealing with the issue within the family and taking it to the authorities.

- ❖ **Groce N. [HIV/AIDS and people with disability](#). The Lancet (361). 2003. 2 pages (free access after registration on the website)**

A short piece explaining that people with disabilities are at higher risk of sexual abuse than previously thought and listing the contextual factors why this is so. A call for research to establish the prevalence of the problem.

- ❖ **Groce N. [Violence against children with disabilities. Unicef: Thematic group on violence against children](#). 2005. 35 pages**

This report presents the findings of the Thematic Group on Violence against Disabled Children, convened by UNICEF at UN Headquarters in New York on July 28, 2005 and charged with the task of providing comments and recommendations on violence against disabled children to be made available for the UN Secretary General's Report on Violence against Children. In this report, key issues on violence against children with disabilities will be reviewed.

- ❖ **Groce N., Trasi R. [Rape of individuals with disability: AIDS and the folk belief of virgin cleansing](#). The Lancet (363). 2004. 2 pages**

A short commentary on issues around sexual intercourse cleansing sexually transmitted diseases but focusing on people with disabilities in particular as victims. Explaining the belief and discussing evidence that it is a widespread belief and practice.

- ❖ **Hanass-Hancock J. [Interweaving Conceptualisations of Gender and Disability in the Context of Vulnerability to HIV/AIDS in KwaZulu-Natal, South Africa](#). Sexuality and Disability (27). 2009. 13 pages (paying access)**

This paper from South Africa contributes towards consideration of why and how HIV protective services should be designed to include people with disabilities.

- ❖ **Hughes K. et al., [Prevalence and risk of violence against adults with disabilities: a systematic review of observational studies](#). The Lancet (39). 2012. 30 pages**

Research to establish whether people with disabilities are at higher risk of violence than the general population.

- ❖ **Human Rights Watch.** [As if we weren't human: Discrimination and violence against women with disabilities in Northern Uganda.](#) NY: Human Rights Watch. 2010. 20 pages

The report is about women with disabilities in Northern Uganda as the population was recovering from the Lord's Resistance Army conflict.

- ❖ **Ingstad B., Grut L.** [See me and do not forget me: People with disabilities in Kenya.](#) Oslo: SINTEF Health Research. 2007. 68 pages

This report, based on interviews with people with disabilities, gives a broad overview of life with disability in Kenya and looks more deeply at the relationship between disability and poverty.

- ❖ **Jenkins R., Davies R., Northway R.** [Zero tolerance of abuse of people with intellectual disabilities: Implications for nursing.](#) *Journal of Clinical Nursing* (17). 2007. 3041-3049 (paying access)

A research study conducted in Wales (UK) on whether nurses report abuse of people with learning difficulties. The study found that, even where there is supposed to be "zero tolerance" all abuse is not reported. Reasons include, perceptions of what constitutes abuse, judgement regarding the severity, denial of the problem, protecting colleagues who are perpetrators, whether victims would be believed. Very few cases were reaching the courts.

- ❖ **Jones L., Bellis M.A., Wood S., Hughes K., McCoy E., Eckley L., Bates G., Mikton C., Shakespeare T., Officer A.** [Prevalence and risk of violence against children with disabilities : a systematic review and meta-analysis of Observational Studies.](#) *The Lancet*. 2012. 9 pages (paying access)

A systematic meta-analysis of studies worldwide to explore the risk of violence against children with disabilities, whether disabled children are at higher risk than non-disabled children and the quality of evidence regarding these two questions.

- ❖ **Kvam M., Braathen S.** [Violence and abuse against women with disabilities in Malawi.](#) SINTEF Health Research. 2006. 68 pages

A research study on the nature of abuse, violence and neglect against women with disabilities in Malawi, based on interviews.

- ❖ **Maart S. Jelsma J.** [The sexual behaviour of physically disabled adolescents.](#) *Disability and Rehabilitation*. (32). 2010. 6 pages (paying access)

A qualitative study comparing the sexual activity of physically disabled youth in special schools in South Africa with non-disabled peers. The sample was small and confined to special schools. The study demonstrated that young disabled people in South Africa are engaging in apparently consensual sexual activity, girls and boys suffered forced sexual activity and even that both

disabled girls and boys forced sexual activity on others. Sexually transmitted diseases were more common among disabled youth. The authors recommend specialised sex education for this group of young people.

- ❖ **Mall S., Swartz L. [Sexuality, disability and human rights: strengthening healthcare for disabled people](#). *S. Afr. Med. J.* **102 (10)**. 2 pages**

A short editorial piece. Clinicians may have conflicting feelings about supporting sexual expression of disabled people which may emanate from their own conflicted feelings or from their perceptions that they may be setting their patients on a course of disagreement with other duty bearers.

- ❖ **Mall S., Swartz L. [Perceptions of educators of deaf and hard-of-hearing adolescents of HIV risk factors for these youths](#). *African Journal of AIDS Research*, **11 (4)**. 2012.**

A qualitative study, interviewing personnel caring for hard-of-hearing students in a special school in South Africa about risk of HIV. Participants recognised their students to be sexually active and felt that they are at higher risk than the general population due to communication difficulties and need for social affirmation.

- ❖ **Maxwell J., Watts Belser J., David D. « [Abuse, violence and self-defence](#)». *A health handbook for women with disabilities*. Berkley, California, The Hesperian Foundation. 2007. Pages 287-312**

It explains for women what sexual abuse is, why it is never acceptable, what the health and emotional consequences of sexual abuse are and advises women and their health workers about what they can do after sexual abuse has happened.

- ❖ **Moss K., Blaha R. [Introduction to sexuality education for individuals who are deaf-blind and significantly developmentally delayed](#). 2001. 126 pages**

This was written for parents and other caregivers of children who are deaf-blind and with developmental delay. The book is intended to support preparation of the more profoundly deaf-blind for adult life. It explains how differently this group of people experience the world, even from those with other disabilities, and the therefore very different considerations in their growing up. It does not teach communication skills for the deaf-blind but does deal comprehensively with preparing children for sexuality in adulthood and dedicates an entire chapter to abuse.

- ❖ **Msedi Ngololo M. [Prevention of HIV/AIDS and violence against women and girls with disabilities](#). Center for Women Policy Studies. 2011. 21 pages**

This is an opinion piece written for the Center for Women Policy Studies by invitation. It is for interested professionals and other citizens. The author makes the case that women with

disabilities (in Tanzania) are at heightened risk of HIV. The main social contextual factors around this are outlined and she calls for policy and services to respond appropriately.

- ❖ **Niemann S., Jacob N. « [Preventing sexual abuse](#) ». [Helping Children who are blind](#). Berkley, California, The Hesperian Foundation. 2000. Pages 115-124**

Chapter on sexual abuse outlining the nature of sexual abuse, giving clear guidelines for parents to help their children learn to protect themselves, advice on how to respond if the child has been abused and some activities for communities to learn about how to prevent or respond to sexual abuse.

- ❖ **Niemann S., Greenstein D., David D. « [Preventing sexual abuse](#) ». [Helping Children who are Deaf](#). Berkley, California, The Hesperian Foundation. 2004. Pages 167-178**

Chapter on sexual abuse outlining the nature of sexual abuse, giving clear guidelines for parents to help their children learn to protect themselves, advice on how to respond if the child has been abused and some activities for communities to learn about how to prevent or respond to sexual abuse.

- ❖ **Okello R. [Cultural Stigma and Myth: Disabled women in Kenya are vulnerable to sexual violence](#). The WIP. 2009. 2 pages**

Women's stories gathered by an interest group, the Federation of Women Lawyers in Kenya (FIDA-K), on the physical and sexual abuse of disabled women.

- ❖ **Pasha N. [Responses to situations of sexual abuse involving teenagers with intellectual disability](#). *Sexuality and Disability* (27). 2009. Pages 187-203 (paying access)**

This paper reports on significant findings from an ongoing study on the care and support services for sexually abused individuals with intellectual disability in South Africa.

- ❖ **Pasha N. [Sexual abuse of teenagers with intellectual disability: an examination of South African literature](#). *Procedia-social and behavioral sciences* (69). 2012. 7 pages**

A literature review on the subject of sexual abuse of teenagers with learning difficulties in South Africa. The article does describe a study on people with physical disabilities. The paper discusses beliefs which increase the vulnerability of people with learning difficulties to sexual abuse and the challenges of bringing cases to court.

- ❖ **Pasha N., Nyokangi D. [School-Based sexual violence among female learners with mid intellectual disability in South Africa](#). 2012. 14 pages (paying access)**

A qualitative study of sexual abuse experienced by female students with learning difficulties at two special schools in South Africa. The information is taken mainly from interviews with the victims themselves. The types of abuse and the way they felt about it are described. The findings contradict notions that people with learning difficulties do not feel suffering as a

result of sexual abuse and that they are not able to understand what is happening to them. The paper discussed boyfriend arrangements made by parents and school staff.

- ❖ **Pasha N., Myaka L.** [A custom distorted: Belief's about sexual abuse involving teenagers with intellectual disabilities at a rural setting in South Africa.](#) **10 pages**

A report of a qualitative study about the vulnerability to sexual abuse of teenagers with intellectual disabilities in South Africa. Heightened risk of abuse is connected with the belief that teenagers with intellectual disabilities are sexually provocative and that having sex with them can confer social and business benefits.

- ❖ **Rohleder P.** [« They don't know how to defend themselves ». Talk about disability and HIV risk in South Africa.](#) **Disability and rehabilitation, 32 (10). 2010. 10 pages (paying access)**

A qualitative study interviewing carers of people with disabilities regarding their perceived risk of exposure to HIV infection. People with disabilities, learning difficulties, visual impairment and physical disabilities were perceived to be at increased risk because of social vulnerabilities and communication barriers.

- ❖ **Sahaya International and GRACE.** [The deaf Peer's Education manual.](#) **2007. 156 pages**

The purpose of this manual is to provide deaf youth and adults, teachers, parents and guardians with a tool for addressing basic health awareness within an independent framework utilizing optimal communication.

- ❖ **Saulo B., Walakira E., Darj E.** [Access to healthcare for disabled persons. How are blind people reached by HIV Services?](#) **Sexual and reproductive healthcare (3). 2012. Pages 49-53 (paying access)**

A small qualitative study around access to HIV health education for blind people in Uganda. The study found limitations in the accessibility of HIV educational material for blind people.

- ❖ **Shabalala N., Jasson A.** [PTSD symptoms in intellectually disabled victims of sexual assault.](#) **South African Journal of Psychology (41). 2011. 13 pages (paying access)**

A study of how people with learning difficulties experience post-traumatic stress disorder [PTSD] following sexual abuse. The authors found that the signs and symptoms of PTSD in people with learning disabilities are slightly different from the general population.

- ❖ **Save the Children.** [Out from the shadows: Sexual violence against children with disabilities.](#) **London: Save the children UK. 2011. 32 pages**

This report aims to raise awareness of the sexual abuse of children with disabilities in Africa. It will be of interest to researchers, policymakers and advocates in the field and is written in a style accessible to the non-academic.

- ❖ **Stopler L.** [Hidden shame: Violence against children with disabilities in East Africa.](#) Netherlands: Terre des Hommes. 2007. 60 pages

This article focuses on policy around violence against children with disabilities in East Africa. It is principally of interest to policymakers and advocates, including those who shape the international development policies of donor governments.

- ❖ **Touko A., Mboua C.P., Tohmuntain P.M., Perrot A.B.** [Sexual vulnerability and HIV Seroprevalence among the deaf and hearing impaired in Cameroon.](#) Journal of the International AIDS Society (13). 2010. 8 pages

This quantitative cross-sectional study examines sexual behaviour of a target group of hearing-impaired persons in Cameroon.

- ❖ **United Nations.** [Report of the independent expert for the United Nation Study on violence against children.](#) United Nations. 2006. 34 pages

This report was prepared for the United Nations on violence against children. Information was taken from consultations in many countries including government personnel, children, civil society organisations and others and government responses to questionnaires. It describes violence against children as a widespread and often hidden issue. It describes the contextual factors around violence against children and makes recommendations. There are a few references to children with disabilities and sexual abuse. Many of the contextual factors and intervention points around violence against children would also be protective around exposure of children with disabilities to sexual abuse.

- ❖ **Van den Bergh P., Hoekman J.** [Sexual offences in police reports and court dossiers: a case-file study.](#) Journal of Applied Research on Intellectual Disabilities (19). 2006. Pages 374-382. (paying access)

A study of how cases of sexual abuse perpetrated by or on people with learning difficulties are dealt with in the Netherlands. It describes the complexities of bringing cases to court. This article is of interest to academic researchers and those concerned with judicial processes around sexual abuse of people with intellectual disabilities.

- ❖ **World Health Organisation.** [Promoting Sexual and Reproductive Health for Persons with disabilities.](#) WHO/UNFPA Guidance Note. Geneva: WHO. 2009. 40 pages

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.

- ❖ **World Health Organization.** [Responding to intimate partner violence and sexual violence against women.](#) WHO Clinical and Policy Guidelines. Geneva: WHO. 2013. 58 pages

These guidelines aim to provide evidence based guidance to health-care providers on the appropriate responses to intimate partner violence and sexual violence against women.

- ❖ **Yousafzai A., Edards K., D'Allesandro C., Lindstrom L.** [HIV/AIDS information and services: the situation experienced by adolescents with disabilities in Rwanda and Uganda.](#) *Disability and Rehabilitation*, 27 (22). 2005. 7 pages

A qualitative study exploring access to information about HIV/AIDS among disabled youth in Uganda and Rwanda. The study only looked at youth in school. It was found that the best quality of information came through school, rather than parents or others in society. A number of disability associated factors created barriers to accessing information. Young disabled people were seen as especially vulnerable to sexual abuse.

Summary

Sexual abuse can have serious and long-term physical, emotional and social consequences for individuals. People with disabilities, female and male, children and adults, suffer abuse not only at the hands of strangers but also at the hands of familiar people who are normally trusted such as family members, teachers and other carers. In the East Africa region a number of cultural beliefs lower the perceived moral threshold around sexual abuse of people with disabilities and if victims report having been abused, they are often not taken seriously. Professionals in education, health, the police and judicial services are often poorly equipped to provide support and welfare facilities tend to be inaccessible for people with disabilities.

Community sensitisation and inclusion of people with disabilities in mainstream daily life should help empower them and correct the misperceptions which place them at increased risk of sexual abuse. A number of East African states have undertaken to ensure measures are put in place to improve a range of statutory services across the key sectors of education, health, police and justice.