Workshop

Sexual and Reproductive Health and Rights (SRHR) of People with Disabilities

Introduction

This short guide to Sexual and Reproductive Health and Rights (SRHR) of people with disabilities aims to provide:

- Some basic information on the topic for organisations working with people with disabilities
- Practical examples as a basis for further discussion within the organisations
- Lessons learnt and ideas collected through the case work providing some basic guidelines on what to consider when approaching the topic
- Some ideas on how to include SRHR in a participative and effective way into the everyday work of organisations

The document does not provide all-encompassing overview on all the topics included in the field of SRHR but aims at giving some input for further elaborating on the topic within organisations working with the objective of inclusion of people with disabilities.

Mitglied der actalliance

Brot für die Welt

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1. A theoretical approach to Sexual and Reproductive Health and Rights (SRHR) of people with disabilities

a) What are sexual and reproductive health and rights?

Sexuality
...is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors (WHO, 2006: Defining Sexual Health).

Sexual health
...is about well-being i.e. enhancement of life and personal relations in terms of sexuality.
It is also about the absence of disease, dysfunction or infirmity that are related to sexuality.

Reproductive health
...is about well-being in relation to reproduction or giving birth. It is also about absence of disease, dysfunction and infirmity in all matters relating to the reproductive system, its functions and processes.

Sexual and Reproductive Health (SRH)
...is not just the absence of diseases but is a state of physical, emotional, mental and social well-being related to sexuality and reproduction.

Sexual and Reproductive Rights
...are fundamental human rights. They embrace human rights that are already recognised in international, regional and national legal frameworks, standards and agreements.

They include rights to:

- Highest attainable standard of sexual health, including access to sexual and reproductive health care services.
- Seek, receive and impart information related to sexuality.
- Sexuality education: all people have the right to have access to education and information that can help them make safe and healthy choices about their bodies and relationships.
- Respect for bodily integrity.
- Choose their partner.
- Decide to be sexually active or not: The right to participate in all the decision making process that affect their sexual and reproductive health and development is a basic right for all women.
- Consensual sexual relations.
- Consensual marriage.
- Decide whether or not and when to have children.
- Pursue a satisfactory, safe and pleasurable sexual life.
- Equity and non-discrimination.
- Comprehensive reproductive health care including family planning and maternal health services.
- Give informed consent to all medical procedures including sterilisation and abortion.
- Be free from sexual abuse and exploitation.

Disability and SRHR

Disability is often seen to remove people's ability to engage in 'normal' sexual practices and or their capacity to incite 'normal' sexual desire in others. They either cease to be considered sexual beings or if they persist in behaving in a sexual manner, their desires and behaviours can only be construed in terms of deviance.

Historically, people with disabilities have been denied information about sexual and reproductive health. Many have been subjected to forced sterilization, forced abortion or forced marriages. The presence of a disability does not remove sexual desire and pleasure from individuals neither does it cause the person to be hypersexual.

People with disabilities must be acknowledged as sexual beings and have access to information and resources to make informed choices about sexuality as well as sexual and reproductive health.

People with disabilities have the same need for SRH information as everyone else. In order to do so, they have the right to make reproductive decisions such as sterilization for themselves.

b) What is the legal context of SRHR and people with disabilities?

There are many international human rights documents that provide a framework for claims concerning sexual and reproductive health and rights for people with disabilities. Some of them have been in place for decades, yet still we are far away from fulfilling these rights.

■ The UN Convention on the Rights of People with Disabilities (2006)

Several articles of the convention have direct relevance to SRHR:

Article 9 addresses access to information and medical facilities.

Article 16 calls on state parties to put measures in place to protect people with disabilities from all forms of violence and abuse, including gender-based violence and abuse.

Article 22 states the equal rights of people with disabilities to privacy, including privacy of personal health information.

Article 23 calls for elimination of discrimination against people with disabilities in all matters relating to marriage, family, parenthood, and relationships, including family planning, fertility, and family life.

Article 25 requires states to provide equal access to health services for people with disabilities, including SRH and population-based public health programmes.

See the following **link.**

■ UNFPA (1994): International Conference on Population and Development Programme of Action (ICPD PoA)

The ICPD specifically calls for elimination of all discrimination against people with disabilities in matters related to SRH as follows:

Principle 8: States should take all appropriate measures to ensure, on a basis of equality of men and women, universal access to health-care services, including those related to reproductive health care which includes family planning and sexual health.

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

■ The Convention on the Elimination of Discrimination against Women (CEDAW 1979)

Article 10 calls for the inclusion of age-appropriate education on SRHR into primary and secondary school curricula.

Article 16: Women have the right to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.

See the following **link.**

■ The Fourth World Conference on Women, Beijing Declaration and Platform for Action (FWCW Platform for Action 1995)

Declaration
Paragraph 32 [We are determined to] intensify efforts to ensure equal enjoyment of all human rights and fundamental freedoms for all women and girls who face multiple barriers to their empowerment and advancement because of such factors as their [...] disability [...].

Platform
Paragraph 232(p) [Governments must] strengthen and encourage the implementation of the recommendations contained in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, paying special attention to ensure non-discrimination and equal enjoyment of all human rights and fundamental freedoms by women and girls with disabilities, including their access to information and services in the field of violence against women, as well as their active participation in and economic contribution to all aspects of society.

See the following **link.**

■ **Standard Rules on the Equalization of Opportunities for People with Disabilities (Standard Rules 1993)**

Rule 5: States should recognize the overall importance of accessibility in the process of the equalization of opportunities in all spheres of society. For persons with disabilities of any kind, States should (a) introduce programmes of action to make the physical environment accessible; and (b) undertake measures to provide access to information and communication.

Rule 9: States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.

Rule 9.2: Persons with disabilities must not be denied the opportunity to [...] experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counselling.

See the following **link.**

■ **The Declaration on the Rights of Disabled Persons (UN Assembly 1975)**

Paragraph 3: Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens [...].

Paragraph 10: Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory . . . nature.

See the following **link.**

■ **Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (The Mental Health Care Principles 1991)**

Principle 1.4: There shall be no discrimination on the grounds of mental illness. "Discrimination" means any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights. Special measures solely to protect the rights, or secure the advancement, of persons with mental illness shall not be deemed to be discriminatory.

See the following **link.**

■ **World Programme of Action Concerning Disabled Persons (1982)**

Paragraph 74: Marriage and parenthood are often unattainable for people who are identified as „disabled", even when there is no functional limitation to preclude them. The needs of mentally handicapped people for personal and social relationships, including sexual partnership, are now increasingly recognized.

Paragraph 151: [A]ttention should be given to: The preparation of special materials to inform disabled persons and their families of the rights, benefits and services available to them and of the steps to be taken to correct failures and abuses in the system. Such materials should be available in forms that can be used and understood by people with [...] communication limitations.

See the following **link.**

c) Challenges to the fulfilment of SRHR for people with disabilities

■ Social- cultural context

Disability in lots of different social and cultural contexts is still associated with supposedly spiritual or mystical causes. These associations often cause misconceptions of the person living with a disability. These misconceptions also include assumptions on sexuality and parenthood including for example misconceptions that people with disabilities are asexual, not sexually attractive or can´t be a parent. Additionally women with disabilities or members of the LGBTQI community who live with a disability often have to face multiple discriminations because of gender/sexuality and disability. Societal misconceptions, religious beliefs and general discrimination against people with disabilities are often a root cause for further barriers preventing people with disabilities from fulfilling their sexual and reproductive rights.

■ Political and legal context

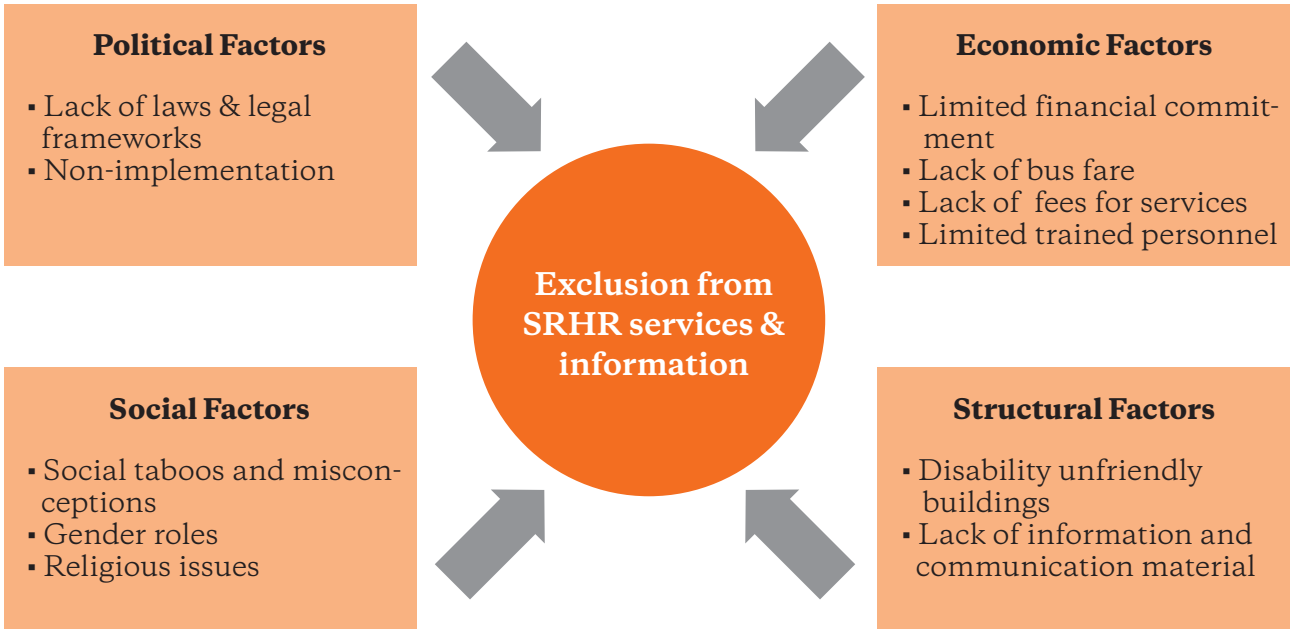
Even if there are laws in place protecting for example women´s reproductive rights or the right to live free from any sort of (sexual) violence, women and children with disabilities are often overlooked. Necessary SRHR services the state should provide to its citizens such as information, education and health services in the field of SRHR are often not accessible for people with disabilities based on above mentioned assumptions on the sexuality of people with disabilities. Child protection and family policies are not designed to provide support for parents with disabilities, often ignoring the mere possibility. Especially people with intellectual disabilities often face strong restrictions concerning their right to have a relationship, be a parent and generally make decisions concerning their sexuality. Apart of this legal obstructions, even if rights- based policies are in place in many cases this does not guarantee their implementation.

■ Economic barriers

People with disabilities often have less access to the official labour market and therefore face stronger economic constraints when it comes to accessing health or educational services, e.g. paying transport or service fees. On the other side there is little or no funding for the specific topic SRHR of people with disabilities. This results in little or no education for service providers on the topic making it more difficult for e.g. health service providers to attend people with disabilities properly.

■ Technical and structural barriers

These barriers include the lack of physical access such as transportation, ramps, adapted examination tables, but also the lack of accessible information and communication material, such as material in Braille, large print, simple language and pictures or sign language interpreters.



2. A practical approach to sexual and reproductive rights of people with disabilities

a) Case studies

In the following section you can find different case studies from the daily work of six organisations from six different countries. The cases were chosen with the following criteria:

- Concerning sexual and reproductive health and rights of people with disabilities
- Confronting organisations with challenges on how to approach the situation
- Showing a variety of difficulties faced by people with disabilities concerning their sexual and reproductive health and rights.

These cases present the basis of this discussion for the following section b) reflecting on important, fundamental issues to have in mind when working on SRHR with people with disabilities. The cases have been made anonymous as far as possible. Their content was discussed within a workshop following the guiding questions attached to each case.

Case 1

(Main players in bold)

George, a young man with learning difficulties, started participating in the day care centre four years ago taking in part in activities such as trips, festivals, excursions, etc. As his mother also has a disability and his father has very small salary, the family is living in very poor conditions. George was trying to find a workplace. The day care centre supported George in the process of registration to the labour office. Despite high unemployment, he was employed several times, yet for short periods of time, as he could not demonstrate sufficient responsibility for these positions (a guard in a shop, the security guard of an exhibition hall, etc.). Many employers failed to pay him after one month of work. Nevertheless, he is still trying although his condition is worsening. This also explains why George attends the day care centre (and trainings) irregularly.

About two years ago, George came to the day care centre with his girlfriend Maria and told us they want to marry. The staff discussed this issue with both of them and tried to involve the parents in the discussion. Yet the parents did not find the time or interest to participate.

Maria is an orphan; she went to a boarding school and then came to the capital. Here she found a place to stay and a person who cared about her – she started to live with George and his family in their small house. They began to visit the day care centre together and participated in classes more frequently. This allowed the staff of the centre to monitor their situation more closely.

Soon Maria became pregnant, yet neither Maria nor George was getting prepared for the child. The staff, including a psychologist, tried to consult with them and recommended them some specialists. A well-known gynaecologist agreed to consult and help Maria for free. The day care centre provided the family with dairy products, clothes and shoes.

After the birth of their **son Michael** the problems within the family increased. The conflict between **George´s mother** and Maria was escalating. The staff of the day care centre tried to mediate, as the mother had asked for help. She claimed that the couple insulted her and didn´t feed her. Discussions with both sides were conducted regularly. The young people didn´t fully realize the importance of family support for them. For a short period, George and Maria rented a small room in order to live separately. However, very soon they could not afford to pay for the apartment anymore. The landlord took their passports (which is not legal) in order to get the rent. The day care centre´s **Legal Consultant** assisted the family in the process of writing a petition to the **police** and the examination of witnesses. After all these situations and many discussions with each family member, they understood: they have to be more tolerant with each other and acknowledge the support of their family.

Being close to this family for more than two years, the baby´s development and the parents' involvement are very clear and obvious. Even though George has a significant disability himself, he demonstrates responsibility and care for the child. He is trying to earn money for their living and to take care of the baby. Unfortunately Maria has been sure that her child is healthy and has been ignoring the doctors' advice to go to the clinic. One reason is the money (the medicines are too expensive); another reason is her unwillingness to stay in the hospital for a week or two. A few months ago after one and a half years, Maria left the baby and her husband and disappeared. George

told us she needed to take care of her sick grandmother. Today, George and his mother take care of small Michael. He was born early and his development is slightly delayed. It is too soon to say if Michael has a developmental or intellectual disability, but some staff members suspect so.

Guiding Questions Case 1:

- Do I recognise this situation / have I experienced a similar situation? Is there something about this case which would not be at all possible in our context? If so, why?
- Does my organisation have a policy / common approach / agreed approach to relationships between beneficiaries?
- Do you practise supported decision making? If so, how?
- Is there a difference in our approach to sexual and reproductive rights if the person concerned has a physical disability rather than an intellectual disability? If so, why? Is the difference in approach justified?
- Which (organisational) instruments or actions were or could be helpful in this specific situation? What are "Dos and Don´ts" in this kind of situation?

Case 2

(Main players in bold)

The case study is of a woman with visual impairment named **Lisa**. She went to school up to 2nd grade and then dropped out as she was no longer getting the necessary provisions for the boarding school. She is divorced and is currently staying with her mother, her father passed away.

Lisa became pregnant by a man who refused responsibility 9 years ago. Her **brothers** were very angry with her and even refused to take her to hospital when she told them that she was not feeling well during the pregnancy. She ended up having a miscarriage. However, they took her to the hospital after the miscarriage. Lisa got married 5 years later but could not conceive for two years. She started having problems with her **husband** as he wanted a child. According to local tradition, a 'full' woman should be able to bear children once married. This comes as a compensation for the bride price the husband pays.

Thus the husband constantly abused her both physically and verbally. He also started sleeping around. Lisa became sick and told her relatives that she wanted to go for HIV testing (having attended a workshop of the local organisation on SRHR). But she insisted that if she was found positive, she would stay with the husband, despite his responsibility for her infection. However, her brothers did not comply with her wishes, they took her from her husband and she now stays with her aged **mother**. From her own perspective, this happened because her brothers are used to making decisions on her behalf. Lisa was found positive for HIV and is now on antiretroviral therapy and she gets her medication from the local clinic on a monthly basis.

Lisa is bitter because the brothers, despite being younger than her, always make decisions on her behalf. Thus she rightly pointed out that her relationship with her brothers is not good at all. She even suspects that the brothers conspired with the hospital staff to have her sterilized, when she had the miscarriage. She pointed out that maybe if she had a child, she would still be with her husband. She is also angry with **men** in general resulting from the abuse she suffered.

The brothers however have a different view and think that whatever action they take or decision they make is meant to 'protect' their sister as a person with a disability and as a woman (women are regarded as persons who need to be protected and having a disability is associated with incapacity to make sound decisions). They feel that they have that responsibility as they have adopted the role of their father who passed away.

From the **hospital** side, Lisa is able to access her HIV medication and she highlighted that she gets information from the health staff as every time she goes to get her medication, they talk about the condition but she cannot access information through written material as there is none available in Braille. Lisa survives from buying and selling things like sweets and fruits at the local school and gets very little money to cater for herself, her mother and her sister's two children. One of the children has since completed school and the other one is doing Grade 4. She asked her sister for the child to assist her whenever she wants to go somewhere like to the clinic to collect her medication. Lisa is is part of a local decision making body hence her illness and social problems were affecting the

smooth functioning of the committee. It is through one of the workshops of the local organisation that Lisa narrated her story and fortunately the local responsible politician (who is very supportive of disability issues) was present and he immediately tasked the committee and his council to investigate the issue. This included taking Lisa to hospital to ascertain whether it is true that she was sterilized without her consent.

Guiding Questions Case 2:

- Do I recognise this situation / have I experienced a similar situation? Is there something about this case which would not be at all possible in our context? If so, why?
- Do you have workshops with your beneficiaries on the subjects of sexuality and reproduction? As a group? Or on a case by case basis (with psychologists / social workers / other)?
- Is there a difference in our approach to sexual and reproductive rights if the person concerned has an intellectual disability rather than a physical disability? If so, why? Is the difference in approach justified?
- Which (organisational) instruments or actions were or could be helpful in this specific situation?

Case 3

This case is of a **6 years old boy named Stan** who has an intellectual disability. He was sexually abused and raped several times. He had been attacked by a **male relative** of the boy´s mother. Stan is participating in the local organisation´s school programme. As a result of the boy's behaviour at the local school such as making verbal and physical gestures that show situations of abuse, the **staff**´s attention was drawn to the case. The **mother** found blood on the underwear more than once. These also were signs that led the teachers and the social worker to suspect abuse or rape. After several counselling sessions with the boy, it became clear that he had been attacked and raped by a certain man.

When the **social worker** approached the mother, the mother was not surprised; she seems to have known about this fact. When asked why she had not done anything to stop the rape, she said that she could not say anything because the rapist is her relative and a well-respected and religious person in community. Family problems would have been created and she feared that. That is why the staff focused mainly on strengthening the boy, making him aware of what is happening, teaching him how to protect himself, how to call for help and how to run away from the situation when it arises. They also worked with the mother to strengthen her to keep an eye on her son, not to let him leave the house on his own, and to be attentive to where he is going. Both parents were guided on what Stan's rights are and how to protect them.

They now accept their son and what has happened and started to defend his rights in front of others in the village. They are doing it very strongly now. The actual attacks have stopped at the moment. There were several attempts by the attacker to re-attack, but the boy managed to flee. The boy remains vulnerable to attack since the attacker is still free.

Guiding Questions Case 3:

- Do I recognise this situation / have I experienced a similar situation? Is there something about this case which would not be at all possible in our context? If so, why?
- If an accusation sexual abuse is made, what steps do you instigate to ensure fair treatment / a fair hearing / fair representation of all concerned?
- Which (organisational) instruments or actions were or could be helpful in this specific situation? What are "Dos and Don´ts" in this kind of situation?
- Are there "points of no return" for you? If you reach this point, what do you / would you do? Have you ever been in this position as an organisation?

Case 4

The **mother** of a young woman named **Alicia** came to the local organisation reporting that her daughter, who is deaf, has been raped or sexually abused in her village. She got pregnant as a result of that rape. It seems that Alicia was able to narrate the story of her rape when it was later discovered by her mother that she was pregnant. She identified the perpetrator as a man living in that village; he was later reported to the police and arrested. The law on sexual and reproductive rights allows a woman who has been raped to choose within the first three months of pregnancy to either to continue with the pregnancy or terminate the pregnancy.

The normal procedure is that the local police office where the case had been reported has to inform the victim of abuse about this right and then file an application for termination if desired. However, in this case the police although aware of the case on time did not inform Alicia and bring the application for termination of pregnancy within the three months of pregnancy of the victim before the Magistrate to grant such an order. Alicia was not given the opportunity to exercise her sexual and reproductive rights by not being given an opportunity to decide whether she wants to terminate her pregnancy or not. After expiration of the three months a local organisation was informed by the mother of these events.

The organisation arranged a meeting between Alicia´s mother and the **policewoman** who was investigating the case with the aim of finding out, why Alicia had not been given the opportunity to decide on her sexual reproductive rights.

It is in this meeting in which it transpired that the application to terminate pregnancy was not initiated at all despite the permission by law to do so. By the time the organisation intervened, it was already late to file the application for termination as three months had already passed. Additionally staff reviewed the criminal record to determine the stages undertaken by the police to protect the victim. It is in the record that they found out that the application to terminate pregnancy was not filed at the Magistrates Court. The criminal case against the perpetrator is pending at the Magistrate Court and the victim is having a baby which she did not decide to give birth to, because of the decision of the policewoman not to file the application for termination for the victim.

When confronted with this the policewoman claimed she had not had any means to communicate with Alicia as she is deaf and therefore wouldn´t have understood her.

Guiding Questions Case 4:

- Do I recognise this situation / have I experienced a similar situation? Is there something about this case which would not be at all possible in our context? If so, why?
- If an accusation sexual abuse is made, what steps do you instigate to ensure fair treatment / a fair hearing / fair representation of all concerned?
- Which (organisational) instruments or actions were or could be helpful in this specific situation? What are "Dos and Don´ts" in this kind of situation?
- Are there "points of no return" for you? If you reach this point, what do you / would you do? Have you ever been in this position as an organisation?

Case 5

This case is about a woman named **Sandra** who has an intellectual disability. She often leaves the house without informing anyone and stays out for long hours, sometimes nights without coming back. Her **parents** are too old to be able to hold her back. Locking the doors was not successful since Sandra keeps the keys with her and sneaks out. Her **sisters** are married and live outside the house.

The **brother's wife** tries to help but is not able to do so. Sandra keeps talking about her experiences while out of the house, where certain **men** take her, what they do to her, which places, which cars and so on. She mentions more than one name. In a counselling session with the social worker, Sandra drew on paper one of the attacks very clearly, which was a manifestation of the rape. She is not aware of the fact that she is sexually abused. Her mother was not convinced that her daughter is being raped. She thought she is making it all up. Yet her father was convinced and recognized one of the attackers. He first blamed the mother that she hasn´t been closing the doors and allows the daughter to leave the house. Her sisters and her sister in law could influence the situation but don´t want to interfere. The organisation approached the family with the result of the counselling sessions

that there are signs that abuse and rape is taking place.

The **social worker** trained Sandra not to accompany men in their private cars, not to leave the house without telling her mother. However, this has not been successful. The organisation tried to find a place for Sandra to be registered in a day and night home for elderly or in a home for (non-disabled) women who were abused, but no one agreed to take her in.

The relevant **governmental organisations** only showed negative attitudes and gave no solutions, due to the lack of places to protect people with disability from abuse and no expertise in the field. The relation with them was characterized by a lack of cooperation.

The **relevant NGOs with protected homes** refused to take the woman into protection homes for abused women fearing she would be abused by the other women, but also due to a lack of expertise in dealing with people with intellectual disabilities.

The organisation tried to help the woman in training her, raising the awareness of her family members, raising her situation to ministries and personal face to face meetings with ministers, but nothing helped. The social workers believe that the woman is attacked and needs protection, but there is nothing that can be done on an official level. They feel very helpless in this situation especially when facing negative attitudes from family members and official bodies. From time to time the organisation hears from people and villagers but it did not succeed in solving this issue. The abuse is still going on.

Guiding Questions Case 5:

- Do I recognise this situation / have I experienced a similar situation? Is there something about this case which would not be at all possible in our context? If so, why?
- Do you have workshops with your beneficiaries on the subjects of sexuality and reproduction? As a group? Or on a case by case basis (with psychologists / social workers / other)?
- If an accusation of inappropriate sexual behaviour / sexual abuse is made, what steps do you instigate to ensure fair treatment / a fair hearing / fair representation of all concerned?
- Which (organisational) instruments or actions were or could be helpful in this specific situation? What are "Dos and Don´ts" in this kind of situation?

Case 6

The organisation involved is a centre for assistive technology, which provides individual services to **beneficiaries** at different age and with different type of disabilities. Most of them are at **school-age, between 6 and 20 years old**.

Three **special educators** work with each beneficiary individually using the person-centred approach. The team also establishes communication and cooperation with the family of the beneficiaries. In most cases, the relationship between the beneficiaries and the special educators is personal, close and open, as well as with their parents. Usually, beneficiaries receive services (i.e. meet the educators) once a week. Children are, without exceptions, accompanied by their parents or other close family members. On average (although the services are largely individualised), a beneficiary visits the Centre for Assistive Technology for a period of a year and a half.

The prime role of the special educators is to enable and provide support to the beneficiary in using computer, assistive technology and internet, as tools for their personal development. The work is based on individual assessment of the needs with regards to assistive technology and an individual plan, which sets the to-be-achieved goals.

However, due to the longer period of personal cooperation between the beneficiary, their family and the special educator, their bond becomes personal and exceeds the strict framework of service delivery. Situations occur beyond the plan and its realization, and the special educators seek to find an ad-hoc, yet individualised response. For example, as some beneficiaries approach puberty, they manifest behaviours that result from the development of their sexual impulses: touching themselves during the session, rubbing genitals on the floor, chairs, try to engage in excessive physical contacts with the special educators or other colleagues and similar reactions.

The organisation does not have any formal manual on how to react in these situations; as noted, the special educators seek to respond in an improvised, yet individualised manner. The main goal is to explain to the beneficiary what socially acceptable behaviour is.

One of the first reactions is to talk openly to the beneficiaries and **the parents**, to share information and practical tips. Parents are often aware of the development and sometimes share very useful and practical advices and information. Beneficiaries are often shy and reluctant to talk about sexuality.

In general, most parents have willingness to cooperate with the special educators: they already face the issue themselves and share with us information, practical tips, and even relevant literature. Rarely, parents are not comfortable talking about the sexual development of their children.

The special educators are trying to find an individualised solution together with the parents. Sometimes, though, they are caught by surprise by the beneficiary's behaviour and conduct internal consultations for the best response. In several instances, the organisation has contacted relevant organisations and professionals working in this field. For example a focus group with our beneficiaries on sexual and reproductive education was organised. Also several courses for five of the beneficiaries on the topic were organised.

These situations are not very often and are usually dealt with successfully. They may, however, be uncomfortable for the persons involved. Improved understanding and knowledge of the special educators and brief internal instructions to address these issues would be helpful.

Guiding Questions Case 6:

- Do I recognise this situation / have I experienced a similar situation? Is there something about this case which would not be at all possible in our context? If so, why?

- Do you have workshops with your beneficiaries on the subjects of sexuality and reproduction? As a group? Or on a case by case basis (with psychologists / social workers / other)?
- If an accusation of inappropriate sexual behaviour / sexual abuse is made, what steps do you instigate to ensure fair treatment / a fair hearing / fair representation of all concerned?

- Which (organisational) instruments or actions were or could be helpful in this specific situation? What are "Dos and Don´ts" in this kind of situation?

b) Lessons learnt or what to have in mind

- **Sex is beautiful... for all!** There has to be good balance and clear differentiation between protection and prevention measures concerning (sexual) abuse and a sex-positive approach from a rights-based perspective.

- Disability, limited access to education and poverty are often connected, making it more difficult for people with disabilities to **make informed decisions on sexual and reproductive topics**.

- An inclusive approach **working with all possible stakeholders** such as parents, caregivers, community and its leaders, relevant government institutions, DPOs and NGOs is necessary to improve the situation of people with disabilities concerning sexual and reproductive health and rights.

- There is a great **need for education on sexuality, sexual and reproductive rights of people with disabilities** for everyone involved: people with disabilities, their families, their caregivers, communities, government and service institutions.

- **Sexual and reproductive health and rights are a part of every life stage** and there has to be continuous support for people with disabilities on this issue (by parents, caregivers, government, DPOs, NGOs, etc.).

- Challenges faced by organisations in the field of sexual and reproductive health and rights of people with disabilities often are very much alike, although embedded in different contexts and demanding for **locally adapted solutions**. Exchange can further new ideas and motivation to work on the issue.

The following table is a short overview of some of the basic "Do´s and Don´ts" to have in mind when working on the topic of SRHR of people with disabilities. There are a lot of things that can be helpful and done, but also some clear Don´ts one should not forget about.

Do...	Don‘t...
Support sexual and reproductive needs of people with disabilities.	**Ignore the sexual needs** of people with disabilities.
Include and enrol all stakeholders, e.g. family, community (leaders) and institutions.	**Discriminate.**
Provide workshops and trainings on sexual and reproductive rights of people with disabilities for people with disabilities and all stakeholders.	**Put obstacles** in the way of people with disabilities having a family or relationships.
Raise awareness on the topic of self-determination of people with disabilities and SRHR.	**Close your eyes** on cases of discrimination or abuse.
Take an individual **case by case approach**.	**Delay official reports.**
Empower people with disabilities and their families to know their rights.	Overlook **cultural issues** concerning people with disabilities and SRHR.
Provide **sensitisation regarding responsibilities and consequences** concerning sexuality and reproduction.	**Fear talking** about sexual and reproductive rights of people with disabilities.
Advocate and **create awareness** for the right of people with disabilities to have a family.	
Promote **self-awareness and build capacities** of staff members concerning sexuality and SRHR.	
Advocacy to change policies.	
Provide **support and mediation** for all stakeholders.	
Provide **accessible information** and support concerning health issues.	
Connect people with disabilities with relevant institutions and professionals.	
Improve relationship with parents; involve them in a **“school for parents”**.	
Work with a **multidisciplinary team** with families and people with disabilities.	
Provide **counselling** for people with (intellectual) disabilities and their families.	
Provide **legal support services**.	
Provide access and funds for women with disabilities to live in protected homes.	
Create procedures to **hold the police and government accountable**.	
Ask for support from other NGOs and DPOs.	
Provide peer support.	
Produce a software or game for sexual education.	
Initiate more SRHR related activities.	
Provide organisational basic **guidelines on SRHR**.	

c) Possible helpful instruments

Depending on the size and type of organization it might be helpful to provide written information to staff, beneficiaries, members and participants on the topic of SRHR.

The following three documents might be helpful instruments in this context. Three basic principles for each of these documents are:

1. It has to be suited to the local (institutional and social) context
2. It has to be helpful for the organisation and adapted to its structure
3. The elaboration should be as participative as possible involving the feedback of all relevant stakeholders.

1) House Rules

Depending on the organisation it can be helpful to have some basic rules concerning social behaviour everyone agrees on.

If possible the house rules should be created with participative instruments by a group of:

- Staff members
- Clients
- Parents
- Volunteers
- Board members and other important stakeholders

(Possible) Principles:

- Respect and tolerate each other
- Individual approach, easy to read format
- Respect for sexual and reproductive health and rights of people with disabilities

Rules of behaviour
What is appropriate and accepted behaviour?

Privacy
Dos

- Be informed of your space (workplace, schedule, colleagues)
- Respect for personal space
- Privacy of information
- Personal needs (toilet, bathroom, bedroom)

Don‘ts

- Violate the space of others
- Sexual harassment
- Spread private information

Safety
Dos

- Define limits of acceptable behaviour (e.g. shake hand)
- E.g. use kitchen equipment from… to…
- Etc.

Don‘ts

- E.g. Excessive self-touching
- Touch intimate parts of others
- Use gas equipment

Dress code
Dos

- E.g.: Clean (hair, hands, nails)
- Decent look

Don‘ts

- E.g.: Very short dress
- Clothes very tight around intimate parts

Responsible personal: Duties, contact,…

Important: Any conflict, question, strange situation shall be addressed to (define contact) - DO NOT try to solve it alone.

2) Information leaflet for parents

In lots of institutions parents are the most important stakeholders concerning the sexual and reproductive rights of their children. But often there is little or no information for them concerning the sexuality and rights of their children. One easily accessible way to provide information is by a leaflet including general information as well as indications for further information.

Other ideas to inform parents on the sexual and reproductive health and rights of their children for disabilities:

- Self-help groups for parents
- "School for parents"
- Good practice examples

The following table is a proposition for a leaflet that can be amended or shortened as required.

Parents - do you know, what sexual and reproductive health and rights mean?

Information

- Definition of SRHR
- Statements from relevant documents

Do

- Accept the sexuality of your child
- Encourage your child to socialise with others
- Find information and educate your child
- Have open discussions
- Ask for help

Don't

- Make decisions on behalf of your child
- Overprotect your child
- Ignore your child's sexual development and needs
- Be afraid to discuss sexual issues with your child
- Use gas equipment

Resources

Links and contacts SRHR:

- Organisations (SRHR)
- Institutions (SRHR)

Related links and documents:

- Books
- Manuals
- Journals
- Social Media

3) Guidelines for staff

Guidelines for staff can be an overlapping document with the house rules mentioned above. Depending on the organisation you might already have some guidelines only for your staff, so in this case it would be important to check existing guidelines on their compatibility with sexual and reproductive health and rights of people with disabilities.

General recommendations regarding SRHR of people with disabilities are:

- Raise awareness among staff members and provide them with information on SRHR of people with disabilities.
- Provide guidance in individual cases (e.g. define a contact person for SRHR).
- Give separate information and/or guidelines on the topic of violence and sexual abuse: If possible it is be preferable to separate sexual and reproductive health and rights as issue from issues concerning violence and abuse to avoid confusion.
- Reflect on if it is recommendable to work on this guidelines also together with other stakeholders, to ensure that everyone is informed and understands certain limits.

Possible chapters to include in guidelines for staff:

1. What are SRHR especially of people with disabilities?
2. How can we make sure to respect SRHR of people with disabilities?
3. Where can staff find guidance/counseling?
4. Do´s and Don´ts in the daily work situation.
5. Documentation and monitoring structure.
6. Contact person in the organization and further information

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