SOCIAL RELATIONSHIPS, SEXUALITY AND REPRODUCTIVE RIGHTS & PERSONS WITH DISABILITIES

International Workshop Report

March 2013

The International Workshop on "Going Beyond the Taboo Areas in CBR" was organized by AIFO/Italy with support from the Disability and Rehabilitation Team of the World Health Organization (WHO/DAR), Disabled Peoples' International Asia-Pacific (DPI/AP), International Disability and Development Consortium (IDDC), Mobility India and Global CBR Network.

The workshop focused on two separate themes - the first day (29 November 2012) was devoted to issues related to social relationships, sexuality and reproductive rights; the second day (30 November 2012) concentrated on issues linked to violence and abuse. This first part of the report focuses exclusively on the issues of social interaction, sexuality and reproductive rights.

Cover image: Elisangela and Moses from Santarem CBR Project (Parà, Brazil) - image by S. Deepak.

ISBN Number: 978-88-907108-5-8

This report has been compiled by Sunil Deepak, with contributions from Anita Ghai, Thomas Shakespeare, Nandini Ghosh, Giampiero Griffo, Francesca Ortali, Alick Nyirenda, Ricardia B. Denis, Neha Naqvi, Heather Payne, Pramada Menon, Philipa Bragman and Renato Libanora. Copy editing by Robin Lauckner.

Going Beyond the Taboo Areas in CBR

Workshop Report, Part 1

Supporting Social Relationships, Sexuality and Reproductive Rights of Persons with Disabilities through CBR

INDEX

ACRONYMS

AIFO	Italian Association Amici di Raoul Follereau
CBR	Community-based rehabilitation
CRPD	Convention on Rights of Persons with Disabilities
DPI/AP	Disabled Peoples' International Asia-Pacific
DPO	Disabled peoples' organization
IDDC	International Disability and Development Consortium
NGO	Non-governmental organization
PwD	Person with disability
WHO/DAR	Disability and Rehabilitation Team, World Health Organization

SUMMARY

An international workshop on “Going Beyond the Taboo Areas in CBR” was held after the “First World CBR Congress” in Agra (India). On the 29 November, the first day of this workshop, about 90 participants from 25 countries took part in the sessions dealing with “Supporting Social Relationships, Sexuality and Reproductive Rights of Persons with Disabilities through CBR”. The workshop included formal presentations, personal testimonies, film clips, sharing of experiences and discussions around the workshop theme.

Barriers and challenges

The discussions highlighted the innumerable barriers of negative attitudes and wrong beliefs that affect the rights of persons with disabilities to social relationships, sexuality and reproductive health as envisioned by article 23 of CRPD. At the same time, persons with disabilities lack access to reliable information about these issues.

The lack of adequate learning material suitable for the CBR context and the lack of training opportunities for persons with disabilities, their families and CBR personnel are significant challenges.

Overcoming the barriers

The discussions underlined the importance of involving and supporting persons with disabilities in self-advocacy for social relationships, sexuality and reproductive rights. Families and CBR programmes can be important allies of persons with disabilities in the activities of advocacy and support.

Many CBR programmes in different countries have experience regarding promotion of these rights for persons with disabilities. There is a need to share this experience and existing teaching and learning material.

Promoting easy to read and understand material that is accessible to persons with learning disabilities is a key issue. Greater networking and links among CBR programmes, as well as with persons and organizations active in this field but outside the disability world, are needed.

Conclusions

The workshop participants concluded that:

- Social relationships, sexuality and reproductive rights are fundamental components of human rights for everyone including people with disabilities
- Persons with disabilities need information on issues regarding social relationships, sexuality and reproductive rights from an early age and families need to play a key role in providing this information
- Social relationships, sexuality and reproductive rights are important for the work of CBR programmes and should be part of the training of CBR personnel.

INTRODUCTION

Social relationships, intimacy, affection, sexuality, desire to have children, and desire to have a family are all fundamental parts of the human experience. These life experiences define our identities. However, often they are denied to persons with disabilities. There is little about these issues in manuals, training courses and debates related to CBR programmes.

An international workshop on "Going Beyond the Taboo Areas in CBR" was held after the "First World CBR Congress" in Agra (India). On the 29 November, the first day of this workshop, about 90 participants from 25 countries took part in the sessions dealing with "Supporting Social Relationships, Sexuality and Reproductive Rights of Persons with Disabilities through CBR". The participants included persons with disabilities and family members, DPO representatives, national and sub-national CBR managers and staff, national and international NGO representatives, health professionals and teachers. Annex 3 provides the full list of workshop participants. The workshop included formal presentations, personal testimonies, film clips, sharing of experiences and discussions from the field around the workshop theme.

This report presents the key ideas and discussions that emerged, for the programme see Annex 1. Discussions at the workshop focused on sexuality, reproductive rights and related aspects of social relationships. Article 23 of the CRDP provides a relevant base for these topics dealing with reproductive rights and related areas of social relationships of persons with disabilities. The discussions considered sexuality, as a core part of being human, to be an explicit right.

Given the nature of the workshop, all participants were asked to ensure an environment of confidentiality, respect and sensitivity. This report follows the same principles and does not mention names of specific persons. Consequently in the following pages indented paragraphs report statements made at the workshop anonymously and without a full explanation of the context.

Apart from the report a webpage has been created where presentations made during the workshop and some resource material on the theme of social relationships, sexuality and reproductive rights are available. This webpage can be accessed at the following link: http://www.aifo.it/english/disability/documents/cbr_sexuality/index.htm

This report presents an analysis and an overview of main issues in relation to social relationships, sexuality and reproductive rights that emerged from the different presentations and discussions during the workshop. Most of the discussions and presentations focused on difficulties, barriers and challenges. There were a few positive examples of activities that answer those challenges and overcome those barriers. There were also some ideas of what can be or should be done in this area.

Reproductive health, reproductive rights and sexuality

A working definition for these terms is given in the document "Defining sexual health, Report of a technical consultation on sexual health", 28-31 January 2002, Geneva, published by the WHO, Geneva 2006. Extracts from this document are reproduced here.

Reproductive health
"… Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capacity to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant."

Reproductive rights
"… the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. This includes the right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in human rights documents." Since human reproduction generally requires sexual activity, sexual rights are closely linked to reproductive rights.

Sexuality
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.

BARRIERS AND CHALLENGES

Any discussions regarding disability must necessarily touch on barriers including physical, attitudinal, cultural, social and economic barriers.

Any discussions about social relationships, sexuality and reproductive rights need to contend with an additional barrier - that of the socio-cultural taboos. Talking about some of these issues may be difficult and in some contexts, even dangerous.

Thus, the presentations and discussions during the workshop invariably touched upon different barriers.

> The man in the wheel chair said, “We went for our honeymoon, but privacy was a problem. We both had our assistants with us.”
>
> When we decided to get married we had to think of practical issues like shopping and running a house. Now my parents are alive so they help us. But when they will no longer be here, what will happen?
>
> When you grow up you start feeling desires and your sexuality expresses itself. You ask yourself: is it right or is it wrong? Is it wrong to desire love, intimacy and a family?
>
> Just look around you, in any culture, do families encourage their daughters with a disability to think of love and sexuality?
>
> It is not just the attitude of the community but also the attitude of persons with disabilities themselves that are barriers.
>
> Lack of accessible services in the hospital such as latrines is another barrier. When a woman with a disability comes to the hospital for delivery of her child, if she cannot use the latrine then how can she stay in the hospital?
>
> Some midwives were trained in sign language, but because of high turnover they left. Now there is no one with knowledge of sign language.

The main barriers to realization of social relationships, sexuality and reproductive rights were wrong beliefs, negative attitudes, lack of skills, lack of accessible information, lack of training material and opportunities and some specific difficulties for parents and families.

Barriers related to beliefs and attitudes

Few discussions during the workshop were about physical barriers. Most of the discussions and sharing of experiences concerned **peoples’ wrong beliefs and negative attitudes about the sexuality of persons with disabilities**. Often the barriers surrounding women with disabilities were even bigger.

> People believe that women with disabilities are less vulnerable to HIV and are therefore HIV-free. Thus men want to have sex with women who have a disability. For this reason wives do not want to become friends of women with disabilities - they are afraid that these women will “steal” their husbands from them.

People think that women with disabilities are not capable of having sex and cannot bear children.

Women with a disability are seen as non-desirable and not having sexual desires.

If a woman with a disability gets pregnant, the health workers ask her - "How did you become pregnant?" They cannot believe that a woman with disability can have sex or that a man would have sex with such a woman. Their attitude puts off women with disabilities. So when women with disabilities are pregnant they don't want to go to hospital for check-ups.

Professionals also have negative attitudes, so it is not just an issue of lack of skills or knowledge.

Families and communities have negative beliefs such as "persons with disabilities are asexual", "they do not have any sexual desires", "they cannot have sex" and "they cannot have children". They may also disapprove of persons with disabilities getting married, having children or adopting children and becoming parents.

There is an attitude that a person with disability may marry only with another person with disability.

In Uganda, women with disabilities may have night lovers. Men only come to them during the night. They don't want to be seen with the women with a disability during the day. They may be willing to pay money for the maintenance of their children, but they don't want to seen as husband of a woman with a disability.

My cousin had an intellectual disability. My parents were anxious not to leave him with my sister. My sister could stay with other male cousins but she was not allowed to be alone with this cousin with a disability.

Sexuality is not just about preventing HIV infection. There is also discrimination in societies against persons with a disability becoming parents and having a family or adopting children.

The film from CHANGE showed that society could take away your children because as a person with intellectual disability you are not considered fit to be a parent.

I had a half-brother who was half paralysed and had osteogensis imperfecta. After he got a girl pregnant, we all thought - how could he get that girl pregnant? We thought that he must have fallen in love. We had not understood; I realized yesterday during our discussions that he had feelings that he could not express to others.

Some discussions briefly touched on the influence of religion and mythological stories on people's perceptions.

Religions can also create barriers for persons with disabilities.

In India, we have the mythological story of Ramayana, which includes an episode that explains our cultural view about women's sexuality. In that episode, a woman called Surpanakha goes to Prince Lakshman and expresses her desire for him. He cuts her nose, making her disabled. Thus, this story is talking about a woman

expressing her sexuality and a man disfiguring her so that she cannot have any claim to sexuality.

If negative attitudes and misinformation in families and communities are a problem for most persons, often there are additional barriers of self-stigma and negative self-beliefs among persons with disabilities. They may feel that they are not fit for intimacy and sexual relationships.

> The man in the wheel chair said, “It took me 4 years to convince her that we could be together.” His wife, also a wheel chair user said, “I never thought that persons like us can get married”.
>
> The message from my family was that I am not suitable for marriage. That I am not good looking, because of my disability. That no one will love me or want to get married to me. These are the ideas that shape my thinking and make me feel that I am not good.
>
> Persons with disabilities due to leprosy think that through sexual contact their disease can be transmitted to their partners so they avoid sexual contact. Their partners may also think similarly, and thus avoid intimacy. There is a need to provide information.

The barriers are even greater for the persons with disabilities who do not fit the heterosexual norm.

> We are trained not to talk of sexuality in terms of pleasure but to focus our discussions exclusively on negative aspects - sexual abuse and the need for protection.
>
> It is difficult to articulate when one’s desires are for same sex relationships.

Lack of skills and accessible information

Another important area of discussion was about the difficulties facing persons with disabilities, in accessing information and in developing skills in relation to social relationships, sexuality and reproductive rights.

> A deaf person said that it is difficult for him to be a proper husband and perform as a man in a marriage. No one had ever told him anything about marriage or sex.
>
> Persons without a disability also may not get information about sexuality. However, it is much worse for persons with disabilities. For example, teenage girls do not know what is menstruation, so when they get their first period they think they have cancer. Many girls think that they can become pregnant by touching a boy.
>
> When they explain about using condoms, it is not clear enough for blind persons to understand what they are supposed to do. User-friendly family planning services are needed.
>
> Professionals always give advice like “should not get married” or “should not have children”. Information on such issues is missing. Sometimes, national guidelines do exist on some issues but professionals don’t know about them.

Many persons with disabilities want to talk about issues like social relationships, sexuality, having children, using contraception. But they don't know to whom they can talk.

Lack of training opportunities and material for CBR workers

A third area that emerged from presentations and discussions is training opportunities and training material suitable for CBR workers on the theme of social relationships, sexuality and reproductive rights.

For CBR workers, dealing with young adults and finding answers to such issues is very difficult.

Sexuality is not just about having sex, it is also about touching each other, affection, and intimacy. How do we discuss these issues in the context of a CBR programme?

CBR workers are community workers with limited training; their attitudes and knowledge reflect those of the community. Like everyone else in the community, they cannot speak of their own sexuality, so how can they talk to PwDs about their sexuality? So it is not only an issue of lacking knowledge and skills, it is also lacking capacity and confidence to talk about such issues.

How do we deal with such issues? No manual covers these topics.

Social relationships are part of life, as CBR workers we need to be mature in our understanding of sexuality only then we can help others to help them. CBR workers' training needs to touch on this.

Some difficult issues for CBR programmes dealing with sexuality and reproductive rights

CBR workers shared their experience about the sensitive nature of sexuality related problems and the strong taboos in their communities. Lack of suitable professionals and institutions where such questions can be discussed, makes it very difficult to deal with these issues.

A volunteer asked me to accompany her for a home visit. She wanted my advice about an adolescent boy with a learning disability. The boy masturbated in public. His grandfather asked us to have the boy operated on and his penis removed.

A girl's mother approached me because her daughter rubbed herself against men in public. She was very upset and afraid about it. The mother asked me to find some way that her daughter could be controlled.

We need to talk about comprehensive sexuality. Negotiating with the family and community about issues such as at what age information about sexuality can be shared with a person with a disability and what kind of information can be shared is not easy. Issues like sexually transmitted diseases, abortion and rape are difficult to handle.

In rural areas, parents of girls with profound and complex disabilities do not know how to handle issues like monthly menstruation. They ask for a hysterectomy to avoid the risk of pregnancy. However, doctors and institutions refuse to carry out

such operations so they go to quack-doctors, and ask for illegal operations. Such operations do other harm to their children and sometimes put their lives in danger.

Menstruation, sexual relationships and sexual abuse are important areas of worry and preoccupation for parents of children with intellectual disabilities. For example, they worry that that the girl will become pregnant and that they will not know who is the father of the child.

Hysterectomies are performed to protect girls and families. It is a kind of legitimate abuse but it is not an answer to the problems.

Living with lack of space is another issue in urban areas. Sometimes, mothers with sons with a disability are scared. They understand that their sons have no opportunities to relieve their sexual tensions. They are afraid that their sons might rape them.

We were discussing sexuality related concerns with interested parents. Some parents acknowledged that their children needed to release their sexual tensions, but their question was: can parents teach their adolescent sons and daughters with disabilities about masturbation? They felt that there were some blurred areas between taking care of their children and sexual abuse of the children.

“How much detail must I tell her? Won’t she just get confused?”

“She cannot speak or understand, how can I possibly teach her about relationships, and what is the chance that she would even understand it?”

The discussions about barriers and challenges were often emotionally charged. Many participants expressed the satisfaction that at last they were able to speak about these issues. One of the participants said, “There are no forums where we can raise such issues. We know that some persons and families need answers, but we don’t know where to get those answers. Finally, at least we could speak about it without fear of being misunderstood.”

FINDING SOLUTIONS AND OVERCOMING BARRIERS

There were a few reports from CBR programmes of good practices in supporting social relationships, sexuality and reproductive rights for persons with disabilities. There was some exchange of experience, some examples were from developed countries and not part of CBR programmes. However, it was felt that these could inspire solutions that can be applied in the context of CBR.

Advocacy and support

Promoting dialogue on the issues of social relationships, sexuality and reproductive rights and supporting initiatives of advocacy and self-advocacy can be important strategies for CBR programmes. The discussions also touched on the UN Convention on Rights of Persons with Disabilities (CRPD) and advocated using CRPD as an advocacy and monitoring instrument in CBR programmes.

> A deaf girl was excluded from the initiation ceremony, in which all the girls of her age were taking part. In practice this meant that she was not seen as fit to be wife. In our community, without initiation, she will not be not recognized as a woman. We advocated that she should be included in the initiation ceremony and her family found a sign language teacher, who was willing to provide support. Thus, finally that girl was included in the ceremony. Now she is married.
>
> Self-advocacy helps women to become more knowledgeable partners in relationships. We organize women's meetings to talk about issues like self-esteem and safe sex. Women with a disability also need to understand that they can say "no" to having sex if they do not want it. They have the right to make their own choices and decisions.
>
> When I raised the issue that I wanted to get married, my family started to talk about it but they did not take any practical steps. I waited for one year and then I had to push them. I told them, if you don't think of my marriage, I will find a girl by myself and get married. So self-advocacy is needed for men also.
>
> It is important to remember the context of human rights while discussing this issue because after ratifying the UN Convention on Rights of Persons with Disabilities, the state has the obligation to ensure that people can exercise their rights. Achieving the rights to our sexuality and to have a family is more difficult than other rights. Perhaps we can think of article 23: "*Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others*".

Overcoming the barriers

There were other examples of information accessible to persons with disabilities and of CBR programmes providing such information.

> In Indonesia they are using anatomical dolls to explain the human body to persons with disabilities. People can see them, touch them, ask questions and thus understand better.

When we started talking to persons with intellectual disabilities, they came up with so many suggestions about issues for which they wanted accessible information. Their suggestions included issues related to contraception, use of Depo-Provera to prevent pregnancies, and even about the technicalities of how to become pregnant. They needed easy to read material accompanied with clear illustrations. We decided to produce accessible “Easy Read” material using simple language and illustrations. Persons with intellectual disabilities were our experts in producing this material. They decided if the language was accessible. They worked with illustrators to produce the kind of illustrations they wanted.

The maternity hospital staff did not have the skills to answer the needs of women with disabilities. However, we helped women with disabilities who were pregnant to visit the hospital for childbirth. They helped the staff to learn their specific needs and slowly hospital staff acquired some skills.

As a European, I was seen as a foreigner, thus people came to talk to me about sexuality related issues. Probably they thought that as a foreigner, I would not have prejudices and they could talk to me. Many persons with disabilities, including girls, need a safe environment where they can talk and ask questions about sexuality, family planning, pregnancy. We cannot be too direct in asking questions on these issues, but if we start by talking of marriage, and provide a safe environment, slowly the issues come out and people can raise the questions.

In our research, we had a meeting on social relationships. Men and women met separately. We also invited a group of transgender persons, to understand the barriers they face. These issues can be discussed in peer groups.

In bigger groups it is more difficult to talk, but in smaller and more homogenous groups, people are more willing to share. Issues like incest can come out in small groups.

We conducted training on “Disability and Sexuality”. A training module was developed that included - body awareness and cleanliness, practical training on managing menstrual cycles, pre-marital support through counselling on aspects of a healthy marriage, contraception, sexual needs and care of children.

There was a time when issues like domestic violence were considered taboo, but we were able to raise them and now it is much easier to talk about it. Today it is still difficult to talk of sexuality, especially female sexuality. Religions also place barriers. We need to challenge all these barriers, and then slowly it becomes easier to speak about them. We should not accept the status quo and we should try to push the boundaries of our discussions.

One of the activities in CBR is to promote body awareness as part of self-care. This is not sex education, but it builds awareness so that persons can understand what you can do in public and what should be done in private. For example, children with disability need to learn that they cannot be naked in public.

In one block we were able to convince a proactive community development organization to allow us to run training sessions on a government programme for adolescent girls (Kishori Shakti Yojana), with special focus on sexuality education.

We were able to design and conduct a training module on disability for ICDS workers (persons working in village community nursery schools in India called Aanganwadi), which included the needs of mothers with disabilities. It focused on different government and non-governmental facilities and how to access these.

Forging links with other movements

There was some discussion about these topics being new and difficult for CBR programmes, but they have been tackled successfully in other spheres. Thus, it was suggested that making links and networking with organizations that are active in the area of social relationships, sexuality and reproductive rights for other groups of persons, should be pursued.

Forging links with the feminist movement has been difficult, but still we need to continue this effort.

We need to go out and build links with other movements including the feminist movement and the lawyers fighting for human rights. We need to mainstream.

Linking to other rights based forums, groups and associations for help, assistance and mediation is important. There are many networks that can be helpful, such as support networks for women, women's commissions and human rights commissions. Influencing these networks to take up the concerns of persons with disabilities and acting as catalysts and mediators in their dealings with the persons with different disabilities creates synergies. The range of strategies adopted can vary from awareness generation to protests and rallies.

DIFFERENCES OF OPINION

The discussions also brought out some areas where there were differences of opinion. One such issue about which some participants expressed reservations was linked to the right to same sex relationships and alternate sexualities. Other participants felt that same sex relationships and alternate sexualities are human rights issues and organizations working on human rights of persons with disabilities need to support all the persons with disabilities to realize their sexuality, including those who seek same sex relationships and alternate sexualities. There were also differences of opinion about providing family planning information including access to abortion services to persons with disabilities.

Another issue that was briefly mentioned but not discussed, concerned sex workers in some countries who specialize in working with persons with disabilities. It was felt that it was a complex issue and requires careful consideration. It was not possible in the one day of the workshop to express and understand all the different points of view on controversial topics especially as some of these discussions were emotionally charged. Nevertheless these are important issues for reflection for all CBR programmes.

Some of the views expressed during these discussions included the following:

> Some persons said “eradicate homosexuality”, but I was wondering if we have right to say like this? This way of looking at homosexuality brings out negative attitudes in society. In CBR we talk of diversity and of accepting diversity, so I feel disturbed by similar positions.
>
> If we all believe in inclusion and human rights, it is not good to say, “get rid of some group”. People also say similar things about PwDs and immigrants. If we want a world of inclusion for everyone, we need to respect everyone even if we can’t understand them. The human rights framework includes everyone. I was saddened and shocked about some of the statements yesterday.
>
> I was not happy with discussions on homosexuality in this workshop. What is the link with CBR? A lot of other work needs to be done in CBR programmes.
>
> We need to be able to face our own fears and our insecurities. People come from very different cultures and religions. Some have prejudices about homosexuality. However, it is part of human nature. All religions talk about love, we should follow the teaching about love.
>
> On this issue participants had very strong feelings, so we have to rethink, to figure out how can CBR manage. How can conflict be a positive force?
>
> We did 6 months training on sexuality and human rights for nurses and yet they said “we want to kill homosexuals”.

RESOURCES FOR PROJECTS WORKING IN THIS AREA

Persons from organizations working in the field of sexuality and reproductive rights felt that there is plenty of existing teaching and learning material on this theme. However, persons from CBR projects felt that the existing material does not meet the specific needs of different groups of persons with disabilities and that little material is suitable for CBR workers. CBR training courses do not cover this field.

Sometimes, organizations may develop specific material dealing with the theme of social relationships, sexuality and reproductive rights. However, information about this material remains limited. Persons preparing such information may encounter difficulties.

> The CBR project in Kolkata (India) wanted to use informative material on issues like menstrual cycle, contraception, sexual needs, laws related to family and sexuality. When we looked for existing suitable material, we found a lot of material but it needed to be adapted for different groups of persons with disabilities. An external consultant, who had good expertise in the issue of sexuality, was identified for preparing the modules. However, that person did not have understanding of different disabilities and so the material did not turn out as we had hoped. Such experiences are common, information remains inside organizations and there is little standard material on this issue that can used by different CBR programmes.

Participants were asked to provide information and contacts about any existing teaching and learning resources on this theme. This information is presented in **Annex 2** of this report.

PRIORITY ISSUES FOR CBR PROGRAMMES RELATED TO SOCIAL RELATIONSHIPS AND REPRODUCTIVE RIGHTS

To conclude the discussions on the theme of social relationships, sexuality and reproductive rights, a participatory exercise was carried out to identify the significant issues. In a second step, these were prioritized.

Methodology

Participants were divided into small groups of 4-6 persons. Each group was given one subject. Each person of a group had to write 3 statements about their subject. All papers from a group were folded, mixed and put in the centre of the table.

Group members had to pick one paper from the centre of the table and put a tick on the statement with which they agreed most. The papers were passed around the members of the group until each member had marked all papers. Statements receiving ticks from more than 50% of the group members were considered significant by that group.

The significant statements from each group were shared in a plenary meeting.

Results

The subjects of discussion for each group and their related significant statements are presented below. The numbers in the brackets next to each statement express the percentage of persons of the group who felt that the statement was significant.

The outcome of this exercise should be taken as general indications about areas of concern and reflection in the groups rather than as scientifically measured opinions of all the participants. This is because each group was composed of a small number of persons. Only when opinions from different groups match or are similar can they be considered significant.

Marriage and sexuality
Marriage is a social institution and is needed for a healthy society (66%); there has to be equality between partners in marriage (66%); guidelines for persons with mental illness, intellectual disabilities and multiple disabilities explaining who can marry are missing (66%); marriage is not just for sex but it is for leading a happy life (66%).

Sex education
Sex education is a right and should be given early in an inclusive, open and informative manner. The education should come from a variety of sources, and should be accessible to all the persons including persons with all the different disabilities to enable persons to make informed choice about their sexuality (100%).

Sexuality and public and private body images
Teaching and training about sex, relationships, different body parts and loving our bodies to people and children with disabilities (100%); person's public image affects their private image and their perception of self (100%); body structures do not matter as sex is in the eyes of the beholder (66%).

Sexuality and reproductive health
Easier to talk with persons and communities about reproductive health issues than about sexuality (83%); right to abortion is a human rights issue, it must be decided by law and no one has the right to take another life (83%); parents should provide information to their children with disability above 9 years old about sexuality and reproductive health issues. (66%).

De-sexualization of body
Right of the persons to learn about their desires and to enjoy sex (75%); de-sexualizing persons, that means considering them without any sexuality, because they have a disability is similar to denying the right to life (75%); self-confidence makes person become sexy and attractive (75%).

Sexuality and abuse
Early education about body awareness, public and private behaviour is needed from childhood (100%); persons with disabilities are overlooked and neglected for sexuality and abuse issues (100%); abuse and sexual abuse are real dangers for girls with disabilities and they need education to be able to negotiate sex (83%); care givers, family members and friends are the primary abusers (83%).

Sex and homosexuality
We need more education and openness to talk and discuss on issue of sexuality and homosexuality (100%); heterosexual relations are correct while homosexual relationship are not (50%).

Polymorphic experience in sexuality
Sex is in the mind, physicality is only a part of it (83%); sexual joy can be from all the body parts not just genitals (66%); families should know about sexuality, body awareness should start at home and at an earlier age (66%).

Sexuality and attitudes of CBR workers
CBR workers need to understand sexuality issues in terms of human rights (60%); promoting self-advocacy on sexuality and reproductive health issues is important in training of CBR workers (60%); training of CBR workers in sexuality issues should not be seen as a medical issue (60%); training about sexuality and reproductive rights in CBR programme is very important (60%).

Sex and actual performance of sexual act for persons with disabilities
Everybody has the right to get pleasure from themselves or from other persons (80%); sex goes beyond rights, it is a basic human instinct such as home and shelter (80%); self-acceptance and expressing oneself through the married life is important (80%); education about sexuality is critical, it should occur at different levels, including in the schools (80%).

Conclusions

This exercise highlighted three areas where most groups expressed similar opinions:

- Social relationships, sexuality and reproductive rights are fundamental components of human rights for everyone including people with disabilities

- Persons with disabilities need information on issues regarding social relationships, sexuality and reproductive rights from an early age and families need to play a key role in providing this information

- Social relationships, sexuality and reproductive rights are important for the work of CBR programmes and should be part of the training of CBR personnel.

Annex 1

WORKSHOP PROGRAMME

29 November 2012. **Supporting social relationships, sexuality and reproductive rights of persons with disabilities through CBR**	
Session 1 **Testimonies and sharing of experiences** moderated by **Francesca Ortali**	• Introduction and rules of engagement for the workshop - *Sunil Deepak, Italy* • Film clip from Mindscapes of Love and Longing - *Arun Chadha, India* • Sexuality and disability - *Alick Nyirenda, Zambia* • Self-advocacy training for right to sexual and reproductive health - *Ricardia B. Dennis, Liberia* • Sexuality and Disability - Breaking the Silence - *Neha Naqvi, India* • Sexuality and reproductive rights - *Heather Payne, UK/India* • Love/Lust/Desire: Queerness and disability - *Pramada Menon, India* • Social Inclusion, sexual education and reproductive rights of people with learning disabilities: CHANGE experience - *Philipa Bragman, UK*
Session 2 **Key issues**	• Some key issues regarding sexuality, reproductive rights and disability - *Tom Shakespeare, UK/Switzerland* • Gender, disability and sexuality: access to reproductive health and contraceptives for women - *Anita Ghai, India* • Supporting sexuality and reproductive rights at community level, Bengal experience - *Nandini Ghosh, India*
Session 3 **Participants' views**: facilitated by **Renato Libanora and Nandini Ghosh**	Participatory exercise in plenary on identifying key issues related to social relationships, sexuality and reproductive rights

Annex 2

EXISTING RESOURCE MATERIAL

ASK SOURCE, London, UK is an international online resource centre on disability and inclusion. Online resources of Ask Source are organized under the following sub-headings - cross-cutting issues; health and functional rehabilitation; education; livelihoods; social inclusion; and humanitarian. You can check the online resources of Ask Source on the theme of sexuality and reproductive rights at the following link:

http://search.asksource.info/cf/search/search.cfm?search=disability%20and%20sexuality&db=biball

CHANGE, London, UK is involved in different issues linked to persons with learning disabilities including health, parenting, employment, sexuality and advocacy. They also produce "Easy Read" documents, books and manuals that are easy to read and are accessible to persons with learning disabilities. Some of their books related to sexuality and reproductive rights are "My Pregnancy, My Choice", "You and Your Baby", "Sex and Relationships Pack", and "Safe Sex and Contraception". These and other books and material can be ordered from their website: http://www.changepeople.co.uk/. Some of the CHANGE easy to read and understand material including "Talking about Sex and Relationships" and "How to Make Information Accessible", can be downloaded free of charge from their website. Check the following link for the free CHANGE material: http://www.changepeople.co.uk/freebies.php

CREA, New Delhi, India is involved in research and training activities on the themes of gender, sexuality and reproductive rights. Much of their material is available on their website http://web.creaworld.org/home.asp. They also run a website on issues related to disability and sexuality at http://www.sexualityanddisability.org/. Some of their literature (including a paper on sexuality and disability) is available from Bookshare, an online library of digital books for people with print disabilities. For Bookshare material you can explore the following two links:
https://www.bookshare.org/ /aboutUs/howBookshareWorks

https://www.bookshare.org/search?keyword=tarshi&search=Search

BEMFAM "Que legal saber!" is a Brazilian organization working in the area of sexuality and reproductive rights in different states of Brazil. They also run a sexuality and reproductive health programme for young people with visual disabilities and their teachers. They produce teaching and learning material on the theme of sexuality and reproductive health in Portuguese. You can check their material at the following link: http://www.grupobemfam.org.br/bemfam/materiais-educativos/

Hesperian Foundation, California, USA works in the area of teaching and learning. Some of their learning resources are well known to CBR programmes including "Disabled Village Children" and "Nothing About Us Without Us". Their book "A Health Handbook for Women with Disabilities" has different chapters on issues related to sexuality and reproductive rights such as Chapter 4: "Understanding our Bodies" and Chapter 12: "Sexual Health". The book can be ordered from their website or specific chapters can be downloaded after a free registration at the following link:
http://hesperian.org/books-and-resources/

TARSHI (Talking About Reproductive and Sexual Health Issues), New Delhi, India also works in the area of sexuality and reproductive rights. Their website provides access to their online resources and other useful websites at the following links:
http://www.tarshi.net/asiasrc/onln_resources/reports.asp

http://www.tarshi.net/asiasrc/onln_resources/journals.asp

http://www.tarshi.net/asiasrc/onln_resources/newsletters.asp

http://www.tarshi.net/asiasrc/onln_resources/sexuality_weblinks.asp

Final Note

If there are other printed or online resources about disability and sexuality and reproductive rights that could be useful for community programmes please send information to sunil.deepak@aifo.it

For reference the WHO publications on Sexual Health are detailed at their website: http://www.who.int/reproductivehealth/publications/sexual_health/en/index.html

Annex 3

LIST OF REGISTERED PARTICIPANTS[1]

Country	Name
Afghanistan	Muhhamedreza Asadi
Afghanistan	Ali Moshiriroodsari
Afghanistan	Abdul Ahad
Afghanistan	Arsalah Habibi
Afghanistan	Hafizullah Turab
Afghanistan	Abdul Baseer Toryalay
Afghanistan	Ahmad Saleem
Australia	Timothy Lawther
Egypt	Alaa Sebeh
India	Sneha Mishra
India	Kanagasabapathi Vaikundanathan
India	Bobby Zachariah
India	Neha Naqvi
India	Dipika Srivastava
India	Dilip Patra
India	Sr Maria Kuttikkal
India	Nageshwara Rao
India	Fr Trevor
India	Sr Deepti Mary Verghese
India	Sr Ida Francis
India	K. Savithramma
India	Adi Sayanathan

[1] This is list of persons registered for the workshop. 8 persons from this list did not participate or participated only in part of the workshop.

India	Suresh
India	Praveen
India	Dr Anamma
India	Sr Lissy Francis
India	Dr N Manimozhi
India	M. V. Jose
India	Nyjil George
India	Sr Marykutty Abraham
India	Ramesh Giriyappa
India	Rajshekhar Jayaraman
India	Mamatha Eraiah
India	Kalavathi Jayashankar
India	Jayanth Kumar
India	Chaluvaraju Shivaramu
India	Basavaraju Kempaiaia
India	Nandini Ghosh
India	Anita Ghai
India	Pramada Menon
India	Zulekha Islam
India/UK	Heather Payne
Iran	Keyvan Davatgaran
Iran	Mohsen Iravani
Italy	Dr Sunil Deepak
Italy	Francesca Ortali
Italy	Giampiero Griffo
Liberia	Janice Cooper
Liberia	Fallah Bomia Cymbianoh

Liberia	Ricardia B. Dennis
Liberia	Renato Libanora
Liberia	Mayaedeh Kemeh
Liberia	Mavi Casalieri
Mongolia	T. Batdulam
Mongolia	Tulgamma Damdinsuren
Mongolia	Enkhbuyanat
Mongolia	Dr Batjurgal
Namibia	Mercy Kufuna
Namibia	Ton Derai Shumba
Nepal	Bibek Kumar Paudel
Nepal	Sarmila Shreshtha
Niger	Soumana Zamo
Norway	Jenny Schaanning
Norway	Bergdis Joelsdottir
Pakistan	Abia Akram
Palestine	Haneen Alsammak
Palestine	Husam Elsheikh Yousef
Palestine	Ola Abu Alghaib
Palestine	Zaker Qalalweh
Palestine	Mohammed Abu Alghaib
Philippines	Rosales Fleurdelis
Rwanda	Jean Baptiste
Sri Lanka	Ronald Sujeevan Pragatheeswaran
Sri Lanka	Amirthanathan Marianathar
Tanzania	Subira Mkumule
Timor-Leste	Joel Morais Fernandes

Timor-Leste	Joaozito Dos Santos
UK	Jane Crawford
UK	Philipa Bragman
UK/Switzerland	Thomas Shakespeare
Vietnam	Min Chau Cao
Zambia	Tom Lwendo Mungala
Zambia	Alick Nyirenda
Zambia	Masiliso Zaza
Zambia	Lucy Muyoyeta
Zambia	Yvonne Tomali Chingambu
Zambia	Muzaza Nthele
Zambia	Benson Zemba
Zambia	Celleb Callan Chabauni
Zambia	Felix Silwimba
Zambia	Stanfield Michelo
Zambia	Florence Chiwala Salati
Zimbabwe	Greaterman Chivandire

Italian Association Amici di Raoul Follereau (AIFO) is a Non-Governmental Network Organization representing 60 Italian organizations and groups spread all over Italy. At international level AIFO focuses its work in 2 main areas:

- Fight against leprosy integrated in primary health care programmes
- Community-based rehabilitation (CBR) programmes

www.aifo.it/english

ISBN Number: 978-88-907108-5-8

AIFO, Italy, 2013