



## **Bringing a Change**



**Communicating to communities on sensitive themes like sexuality & domestic violence**



## **Bringing A Change**

*Communicating to Communities on Sensitive themes like sexuality & domestic violence*  
(Based on an International Workshop organised by AIFO at Montesilvano-PE (Italy) in October 2005)

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# Introduction

Organisations involved in health care, disability & rehabilitation and other development programmes often wish to **communicate to the communities** for informing and educating **for promoting changes** in attitudes, behaviours and skills that promote healthier and more active lives.

Such activities are often called IEC (Information, Education and Communication) and include leaflets, posters, radio and TV shows, film shows, talks, etc.

To be effective IEC activities must have the following:

- Specific and clear objectives of the things it wishes to change and how
- Clear monitoring system to measure if the desired change has been produced

Setting up objectives and monitoring systems of IEC activities must be done **before** starting these activities.

## Communicating about sensitive issues

Some issues such as sexuality, drugs addiction, prostitution, domestic violence, alcoholism, etc. are considered as sensitive for the IEC activities, because they are linked with social taboos, myths, religious issues, traditions or the fundamental way in which societies are organised and social prejudices. Such issues may be perceived as threatening to parts of the communities.

Different communities in different parts of the world may differ in the way they perceive the sensitivity of some themes.

IEC activities related to sensitive issues require particular care and some specific strategies.

## Advocacy

Advocacy activities are a specific group of IEC activities that aim to promote a specific change that can benefit many communities or all the population of a country especially through policy changes and new legislation. Advocacy is an objective of IEC activities that requires specific communication strategies.

## This Book

This book is about Information, Education and Communication (IEC) strategies in communities, especially in relation to sensitive themes and advocacy activities. The

book is based on sharing of experiences and discussions during an international workshop organised by Italian Association Amici di Raoul Follereau (AIFO) in Montesilvano (Pescara, Italy) in October 2005.

38 persons from Africa, Asia and South America participated in the international workshop organised by AIFO/Italy from 24 to 28 October 2005. Participants came from 16 countries, including big delegations from 3 countries - Brazil, India and Italy. The workshop had simultaneous translation in Portuguese, English and Italian.

## General Notes

This book takes note of on-going debate among organisations of persons with disabilities on the use of terms "persons with disabilities" and "disabled persons". For this reason, this book uses the two terms in alternate manner.

Most of what is written in the book applies to both men and women. However, for practical reasons, while talking about individuals, the book uses both "he" and "she" alternatively.

While talking about leprosy, as recommended by IDEA (the international federation bringing together persons affected with leprosy), this book uses the terminology "persons affected with leprosy".



**Prof. Luigi Gravina, AIFO's vice-president during the inauguration of the workshop**

# Part 1

## Informing, Educating & Communicating (IEC) on Sensitive Issues

### Introduction

During the first part of the international workshop, some of the participants were asked to make a presentation to explain their activities related to IEC on two sensitive issues - sexuality and domestic violence. The presentations were grouped in three sessions -

- (a) Experiences of IEC activities on sexuality issues linked to Primary Health Care (PHC)
- (b) Experiences of IEC activities on sexuality issues linked to Disability and Rehabilitation
- (c) Experiences of IEC activities on domestic violence

In each session, after the presentations, participants were divided in smaller groups to discuss some specific issues and then come back for a plenary discussion.

This chapter of the book presents a brief summary of the main presentations, group and plenary discussions of each session, accompanied by some comments. The final part of this chapter draws conclusions and the lessons learned from the three sessions to propose some strategies for organising IEC activities.



**Participants from Brazil showing off the Bahian traditional dresses & dances**

## Part 1 A

### Informing, Educating & Communicating on Sexuality issues linked to Primary Health Care

#### AIFO: Importance of Information, Education & Communication activities

Dr Enrico Pupulin, member of AIFO's Board of directors in Italy made an introductory presentation on this theme.

"AIFO's mission to work with the most marginalised persons in communities. AIFO has identified these "most marginalised " groups as persons affected with leprosy and persons with disabilities", he said.

Regarding communication, Enrico said, "Communication to the communities is sometimes taken as something prescriptive, as if it is an order and thus given in an aggressive and prescribing manner. But if the aim of the communication is to promote empowerment of persons it must be bidirectional. It must include making contact with persons, listening to them, observing them, learning from them, learning not just from the verbal communication but also from non-verbal reactions and what is left unsaid. Communication depends upon many factors including culture, gender, age, educational background, religion, etc. "



Enrico continued, "If communications are posed in judgemental terms such as right and wrong or better and worse or normal and abnormal, they lead to violence in communication. Violence in communication is also linked to power abuse, so that we look at positive aspects of our own communication and look at negative aspects of the others, we criticise the others, both as persons, their way of being and their way of acting or behaving. This is not empowering communication. It leads to loss of self esteem, frustration and anger in the listeners. To avoid this, communication must be for trying to understand differing point of views, trying to appreciate the position of others. Understanding others does not mean that you necessarily agree with them but it leads to a dialogue and negotiation for coming to a consensus."

Enrico's presentation touched on the importance of context in which communication takes place. Communication is not neutral, it is not just about giving information, it is also about relationships between persons that are linked to issues of power, conflict, ideas of right and wrong, cultural and religious beliefs, etc.

## Comsaude: Fighting Against AIDS/HIV infection in Porto Nacional (Tochantin, Brazil)

Dr Eduardo Manzano, President of the Brazilian NGO Comsaude started by providing some general information about his country, "Brazil is a country of strong contrasts. The south of the country is very developed, while the north and the north-east is less developed with problems of hunger, malnutrition, child labour, sexual exploitation of children, etc. AIDS/HIV infection is a serious problem among the vulnerable population groups. About 600,000 persons are supposed to be infected in Brazil with this virus. Over the past few years, the number of infected women is increasing rapidly. Till ten years ago, there was one woman affected with HIV for every twenty men, now there are eight infected women for every 20 men. This has implications for children as well, and most of the infected women are in child-bearing age. For this reason we place great emphasis on educating the population about risks and prevention of HIV infection."



**A leaflet for men explaining how to use a condom, from Comsaude (Brazil)**

Talking to community about HIV/AIDS invariably leads to discussions on issues related to sexual practices. Dr Manzano explained, "Our workers were initially embarrassed to talk to people about sexuality issues and even people in community were embarrassed, but with practice, now both sides feel it easier to talk about it. Persons diagnosed with HIV, initially may have feelings of guilt, fear or refusal and need counselling. A survey was done that showed that 96% of Brazilians know that using a condom is the best way to prevent HIV infection. Our campaign focused on use of condoms for preventing spread of AIDS. Such campaign has the risk of trivialising the issue of sexual intercourse, but it has been efficacious as the spread of HIV in Brazil has slowed down."

Dr Manzano continued, "In our work, we like to emphasise that sexuality is not just sexual intercourse but we also talk about importance of love. Yet, perhaps this campaign is not very efficient in reaching adolescents, since the rate of teen age

pregnancies continues to be high. So far, the issue of links between drugs addiction and HIV infection has also not been tackled properly."

He emphasised the importance of involving HIV affected persons in the IEC campaign for educating communities.

Dr Manzano said, "When a HIV patient can win his or her fear and come out, it has two advantages. First of all, such persons acquire greater self-confidence and can tap into community resources of the social solidarity to support them in case of need. At the same time, if they can speak to the communities, they are much more effective in influencing community behaviour, much better than any campaign with posters, etc."



**Leaflet about use of prophylactics from Comsaude**

Dr Manzano's presentation touched on two useful aspects of IEC activities related to sexuality in primary health care activities:



**Poster on Risky Behaviour that can lead to HIV infection, used by Comsaude for IEC activities**

- Initially talking about issues like sexuality can be embarrassing for both workers and clients but with practice, this becomes easier.
- Using persons affected with HIV can be much more effective in reaching the community compared to using posters or leaflets.

Looking at the IEC materials presented by Dr Manzano, the participants noted that from these materials it seems that in Brazil it is possible to use very explicit images and language to talk about sexual issues.

For example, the poster on risky behaviours shown by Dr Manzano had both homosexual and heterosexual couples, giving an impression that issues of alternate

sexuality can be discussed openly in Brazilian society. Many participants felt that such materials will not be acceptable in their communities.

### **WATCH: Promoting Health among Marginalised Rural Groups, Especially Women, in Nepal**

**Ms. Sarmila Shrestha** works as health coordinator for a Nepalese NGO called WATCH that works in primary health care and community development activities in rural communities focusing on marginalised groups of women. Sarmila informed, "WATCH works with 272 women groups and many other community groups in 135 villages spread over three districts of Nepal. IEC activities are very important for our work and we use a variety of IEC materials such as posters, videos, books, etc. in our work. We have a rural training centre in Devdaha village in Rupandehi district of Nepal that focuses on capacity building of poor farmers."

Regarding specific IEC activities related to sexuality, Sarmila explained, "Working with poor rural women means that sexuality issues are touched for talking about sexually transmitted diseases, family planning issues linked to problems such as anaemia and malnutrition due to frequent deliveries, social problems of prostitution, trafficking of girls, etc. This information is given through posters, wall charts, flip charts, pocket calendars, cartoon strips, street plays, songs and dances, etc. To raise issues such as sexuality in our communities, you must be well known to the communities and they should know that you are a good & reliable organisation, that you are not there to exploit them or to create problems with their traditions."

"For dealing with such issues we organise meetings limited to women participants or only to men participants, since in our culture it is not easy to speak about such issues in common meetings where both men and women are present. To avoid embarrassing women, it is women workers who speak to them and explain the message to them. Flip chart is a useful tool for health workers since it has pictures on one side and on the other side, there is text that can be read by the health worker. With a flip chart, we are sure to touch on all the aspects without forgetting any aspect."

WATCH also works with HIV positive girls and women as well as with special at-risk groups such as sex workers. These activities are also carried out in urban area through a dispensary in Kathmandu. Sarmila says, "For example, we have a cartoon strip called "Illusion and Reality" that explains the beautiful promises made by men to lure away minor girls for "lucrative jobs" and how it leads to sexual exploitation of minor girls in the brothels in India and other places and how these girls come back when they have AIDS and are disowned by their families. Another comic strip is called "Gift of Love" and explains how to negotiate the use of condoms."

Regarding the work with female sex workers, Sarmila further elaborated, "Community blames them for all the problems, the clients are not blamed. Working with such marginalised and oppressed groups can create problems for health workers in the community. Community can black-list you and treat you as a problem because they say that you are disturbing the community. The organisations should be prepared for this and should continue to work in spite of all these problems."



**A meeting of women groups in Nepal**

Sarmila felt that even medical professionals discriminated against female sex workers and against HIV positive persons, and that HIV/AIDS is seen only as a medical issue and not as a social issue, but unless we tackle the social aspects, we can not resolve any of these problems.

Sarmila confirmed, "Speaking about sexual matters initially to community members and in international meetings, can be very embarrassing initially but with practice it becomes easier to tackle. It is important that we can learn to speak about these issues clearly since the stakes for health of communities and especially of women's health are so high. Health workers also need specific training and support for tackling these issues in the communities."

The presentation by Sarmila gave some indications about raising up sensitive and taboo issues in traditional cultures:

- To raise up sensitive issues in a community, the persons and the related organisations should be well known to the community. Mutual knowledge and understanding about the organisation that is raising issues in a responsible and dignified manner, are important.
- More sensitive information can be shared in the community in gender-based separate groups. Eventually, more explicit information about sexuality can be discussed in individual one-to-one sessions, where confidentiality is guaranteed.
- There are specific vulnerable groups such as sex workers that may not be easy to reach through general interventions targeted at communities even if in a

gender specific way. For reaching such groups, group-specific strategies and interventions may be needed.

- Health workers need to learn to deal with their own feelings and emotions on the subject before they can raise up the issues with the clients. Promoting a sharing of experiences, discussing challenges faced and strategies utilised, can be useful. Initially this may be easier in gender specific groups of health workers.



**Community education posters in Nepal**

**KULIMA: Sexual Myths Among Macuas Population Groups in Nampula (Mozambique)**

**Mr. Victor Sousa** works as health coordinator for Kulima, a national NGO in Mozambique. He is based in Nampula in the north, where the NGO is involved in a project called "Education for Community Health". The project covers six districts of Nampula province and its activities include training of community volunteers, community mobilization through workshops, dancing and street theatre initiatives for prevention and care of infectious diseases such as water-borne diseases, sexually transmitted diseases, leprosy, etc.

Victor explained the sexual myths and traditions of Macuas indigenous population groups in Nampula province, "Macuas have their own language. For them sexuality is not a taboo issue and they have many myths related to sexuality. Macuas adolescents, when they reach the age of 12 years, they are prepared by the community for their sexual initiation. The initiation rites include collective circumcision for boys and learning "to be a man" from older men, which means learning to control fear and pain.

For girls, the initiation means an operation for opening of outer labia of the vagina and learning about sexual intercourse from elder women who simulate the sexual act."

Regarding the sexual customs of Macuas, Victor explained, "During menstruation the women must eat a special bread called Mussiro and they can not have sexual relationships in this period. When a woman is pregnant, at that time also, no sexual relations are allowed. After the death of her husband, the women belongs to the oldest brother of the husband. Some times these traditional costumes can be linked to problems. For example, collective circumcision ceremony, if not done properly creates wound infection and complications for boys. Or, for example, among women, AIDS transmission can happen in the family, when a widow is forced to have sexual relations with her husband's brother. We need to create awareness about these issues. However, speaking about sexual issues is not a taboo in their community and the issues can be raised in a non-judgemental way. We take care that our communication is not perceived as a criticism of the traditions and our goal is community can find a different way of continuing the tradition."



### **Community theatre for informing and educating (Nampula, Mozambique)**

The presentation from Victor illustrated that IEC interventions must be country and culture specific. At the same time, the presentation raised the issue of language of the minority population groups. IEC materials and interventions that do not keep note of these specific issues, can not have an impact on the specific target groups in the communities.

## Discussions

Following the presentations from Brazil, Nepal and Mozambique, workshop participants identified and discussed four themes in smaller groups and then came together in plenary to present a summary of their conclusions for a wider discussion.

The first group decided to look at **strategies for reaching adolescents in urban situations on sexuality issues**. The group concluded that identifying leaders among adolescents who can serve as "multipliers" for reaching other adolescents is a useful way. However, the group felt that it is equally important to hear the ideas and feelings of adolescents and not just think of giving advice and information. For interacting with adolescents, the groups recommended the participatory methodologies developed by Paulo Freire. The group underlined the importance of monitoring the impact of communication strategies so that more effective methods can be developed with experience. At the same time, the group felt that respecting cultural differences is very important, persons are different and may not be a homogenous group, even if they belong to same age group.



The second group decided to look at the **attitudes of family members of female sex workers**. The group concluded that underlying social issues related to female sex workers can be very different. Without understanding these underlying issues it is not possible to think of strategies or target groups etc. The group felt that often projects use words like

communication strategies but without any real knowledge of what is happening and why it is happening. The group felt that if projects do not identify and understand the real issues of social pressure, of peer pressure, of poverty, of greed, etc. and think just in terms of disease, then their communications are not effective.

The third group decided to look at the strategies for promotion of **positive sexual behaviours**. The group felt that there are misconceptions in the community about diseases such as tuberculosis or leprosy so that affected persons are excluded from ordinary sexual relationships. The affected person may be ignored by the spouse or an unmarried affected person may not find a spouse. The group felt that besides communications targeted at communities, for such issues inter-personal communication with family members can also be useful.

The fourth group looked at the issues of **cultural differences regarding sexuality**. They felt that persons from developed countries and western culture have prejudices regarding other cultures. Sometimes, outsiders look at specific issues in communities without actually understanding the local cultural context. The group felt that in the western society itself, there are gender related issues linked to sexuality. For example, the group felt that sexual promiscuity among men is tolerated but is looked down at among women.

After all the presentations, in the plenary session, the participants briefly discussed their own attitudes to discussing sexuality issues. Different participants noted that there are important cultural differences but in spite of it, the participants were making conscious efforts to listen to diverse point of views. Some male participants explained their surprise to hear Sarmila make her presentation about sexuality in a clear manner and felt that if women can raise such issues it will lead to their empowerment.



**One of the group discussions**

## Part 1 B

### Information, Education & Communication on Sexuality issues linked to Disability & Rehabilitation

#### AIFO: Sexuality, An Essential Component of Our Human Identity

Dr. Sunil Deepak, director of medical support department of AIFO introduced the subject of sexuality issues linked to disability and rehabilitation by affirming, "sexuality is an essential part of human identity. It becomes even more important for persons with disabilities, as it may seem that because of the disability 'a person is not enough of a man or a woman' to deserve sexual expression. Persons with disability point out that often they are seen as child-like, as if they do not any sexuality. Sometimes care-givers and parents are afraid that unscrupulous persons will take advantage of their disabled son or daughter and exploit them sexually. So they may over-protect their son/daughter, limiting their opportunities for social interaction. At the same time, physical and attitudinal barriers surrounding disability can mean that persons with disability live isolated lives with little opportunity for affective social relationships."

Sunil added, "There are many myths linked to sexuality for persons with disability. There is also a gender dimension to this issue. Generally speaking disabled men have more opportunities for sexual expression compared to disabled women. For example, many societies accept that disabled men can go to prostitutes but no similar opportunity exist for disabled women. At the same time, persons with disabilities point out that prostitution is not an answer to their need for sexual expression and attitudes in society need to be changed."



One of the designs from the book by Gabriele Viti ( [www.gabrieleviti.org](http://www.gabrieleviti.org) )

Finally Sunil explained that often the sexuality aspect is ignored in projects dealing with disability and rehabilitation or is seen only as a problem. The objective of this session is to look the way rehabilitation projects and community-based rehabilitation (CBR) programmes are dealing with issue of sexuality.

Sunil showed a book prepared by an Italian wheel chair user, Mr. Gabriele Viti, called "Kamasutra per Disabili" (Kamasutra for Persons with Disability).

This book discusses barriers to sexuality surrounding persons with disabilities and has some explicit pictures about disabled persons having sexual intercourse.

Sunil said, " It is an example how issues can be brought out into open for discussion. Probably similar books may not be acceptable in many countries since such images can be treated as obscene or illegal materials." He invited the participants to take a look at the book and reflect on possible strategies for raising the issue in a positive manner.

### **AMICI India: Disability and Sexuality in CBR Programmes in India**

Amici India coordinates different projects supported by AIFO in India and is based in Bangalore. This presentation was made jointly by **Mr. Jose Manikkatham**, AIFO representative in India and by **Mr. Jayanth Kumar**, CBR coordinator at Amici India.

Jose and Jayanth explained, "Even if there is loss of function, persons with disabilities need physical and emotional experience of their sexuality like everyone else. For all the CBR programmes, it is important to raise the issue of sexuality and to involve persons with disability, both men and women, as well as parents, to express their views on this subject. We have discussed this subject with different stakeholders involved in CBR training programmes and looked at issues such as anatomy, community attitudes, popular beliefs, women and sexuality, audio-video materials on sexuality, specific issues for the parents, etc."

Jose and Jayanth continued, "During these discussions persons involved in CBR training felt that these materials should be culturally sensitive. They agreed that people are very embarrassed to talk about such subjects and there are no appropriate teaching and learning materials on this subject. Even the new national law on disability in India, that is otherwise very comprehensive, does not mention the issue of sexuality. Capacity building of CBR staff should include specific training on this subject. At the same time to tackle this issue with persons with disability involved in a project, there must be both male and female CBR workers in the projects."



Finally Jayanth shared some personal experiences about his own life as a blind person, about his marriage and his family life. He said, "I can not see myself. Some times, I ask myself, how do I appear and look to other persons? For blind persons like me, people think that we do not have any sexual feelings. Sighted persons can get information from

different sources, from films or from internet, but we have to get information from other youth like me, from peer groups. Materials on this subject in accessible formats such as Braille or audiocassettes can be useful."

About the gender aspect, Jose pointed out, "It is very rare to see a women with a disability married to a non disabled man, while some disabled men do find non-disabled spouses. In a rights based approach, sexuality issues should also be part of other discussions about development."

The presentation from Jose and Jayanth was based on their discussions with persons working in different CBR programmes in India and it raised up a significant issue that CBR training courses normally do not touch on sexuality issues and there are no suitable materials on this subject for CBR programmes. Jayanth also raised up the issue of learning materials about sexuality issues in Braille and audio-cassettes that are accessible to blind persons.

#### **SRMAB: Raising Gender & sexuality Issues in Bangalore (India)**

SRMAB or the 'Sri Raman Maharishi Accademy for Blind' is an NGO based in Bangalore that runs a school, an agricultural training institute and some income generation workshops for blind persons. At the same time, SRMAB is involved in a number of CBR programmes at community level in rural areas in Mandya district in Karnataka in South India. **Mr. Srinivasan** from SRMAB raised up the gender issue in sexuality. SRMAB actively promotes inclusion of disabled girls and women in education and employment systems and is actively involved in advocacy regarding implementation of disability law. Finally Mr. Srinivasan underlined the importance of negotiating with families so that women with disabilities can marry.

#### **SSBI: Raising Disability and Sexuality Issues in a CBR Programme in Liberia**

SSBI is a Liberian NGO active in Gardnersville in the periphery of the national capital Monrovia in Liberia. **Mr. Lamuel Boah** is coordinator of the community based rehabilitation (CBR) programme in SSBI. Lamuel explained that they had never discussed the sexuality related issues in their project in a systematic manner. Therefore, they decided to hold discussions with CBR workers and disabled persons on this subject before coming to the workshop. These discussions showed that, " The community is composed of people with diverse political, cultural, religious and ethnic backgrounds. Disabled people do not live in isolation. It will therefore be difficult to understand the opinion of disabled men and women, as it relates to sexuality, if we do not understand the perceptions of the community. Some non-disabled men sexually abuse disabled women by visiting them at night and ignoring them during the day. This

is because, non disabled men feel that a public relationship with a disabled woman causes shame, embarrassment and has a stigmatizing effect."

Regarding the gender issue, Lamuel explained about his discussions with disabled women, "The women said that sexual feelings are not experienced by men alone but that women also experience the sensation and love to express their sexual emotions to the opposite sex. Unfortunately, women can not express these feelings for fear of being devalued by men. Women with disabilities believe that sex is important because sex produces children and that having children bring out the quality of a woman. The women also feel that sex is the real enjoyment of life and that it satisfies the greatest human desire."



Lamuel explained that men with disability share similar views, "Sexuality is considered very important in the lives of men with disabilities because the men feel that sex produces children and having children brings out the real value of a man."

As a follow up to these discussions held in the community, Lamuel explained that they would like to start a counselling activity on this subject that will be carried out by a person with disability.



**Community health services in Liberia**

## **SETI: Sexuality issues in relation to intellectual disabilities in Alexandria (Egypt)**

Fr Emad Bishoy from an Egyptian NGO called SETI in Alexandria (Egypt) explained that their project works mainly with children having intellectual disabilities such as cerebral palsy. Their activities focus on suburban low income areas of the city. The project supports and works in collaboration with organisations of the parents of disabled children. Emad said, "Information, education and communication activities have key importance in our work. We hold regular meetings in each of the different community areas where we work. Our objective is to promote inclusion of disabled children in all aspects of life and for this purpose we want to identify community volunteers to join our work. We also promote sports and leisure activities for the disabled children and one of the disabled girls from our project area Bakous, received silver medal as part of the basketball team in the para-Olympics held in Tunisia in 2004."

Regarding more specific sexuality issues, Emad explained, "The major issues for us include marriage issues, sexual abuse of disabled persons and desire of parents for female sterilization and hysterectomy (surgical removal of uterus) of their disabled daughters.



**Disabled children, parents and volunteers in Alexandria CBR project**

He continued, "Behaviour management is another issue as sometimes adolescents with mental disability do not know how to deal with their sexual impulses in public. We encourage open sessions on these themes with the parents to promote discussions. Parents can have both positive and negative feelings about issues of marriage and sexual expression. Fear that their disabled children can have children with similar disability is often an important issue for parents."

Regarding these difficulties, Emad mentioned, "It is not easy to raise these issues in our communities since for many persons talking about these issues is a sin. In our teaching and learning materials for the CBR workers we have description of male and female reproductive organs but often the teachers skip these parts. We try to push for sexual education for both parents and disabled children, including how to protect them from sexual abuse. There are no laws as such in Egypt regarding sterilization or marriage of persons with mental disabilities but it is the community attitudes that

determine how families behave. To find appropriate teaching materials that can be used with parents and disabled persons is a big challenge. There is hardly any published materials on this subject, suitable for community work."

The discussions following Emad presentation showed that there are no easy answers to these issues. Participants agreed that as Emad had said, it is important to promote open discussions in the community and help persons to come to informed decisions about their lives and about the choices they have. Participants also agreed about lack of suitable teaching and learning materials on this subject for community-based rehabilitation programmes.

## Discussions

Following the individual presentations, the participants were divided into four groups and asked to reflect on two statements made during the individual presentations. The groups were divided on the basis of language (English speaking, Portuguese speaking & Italian speaking). The two statements on which, the groups reflected were:

(a) *"To make disabled persons understand that the satisfaction at mental (inner) level is more important in human life rather than physical level, through counselling at cognitive level."*

(b) *"The meeting held with parents included those with children with disabilities between the ages of 10 to 15 years. The groups of parents included women with disability and fathers. Among the issues raised were: Fear that their children will be sexually exploited."*

Following the discussions, the groups came together in plenary to share the main ideas that came in their discussions.

Group one had decided to focus on fear of parents for the **sexual exploitation of their children with mental disabilities**. The group felt that the subject touched aspects of prejudices as well as of discrimination. On one hand there is "over-protection" of the minors because parents feel that their child is vulnerable to exploitation. This fear of sexual exploitation of girls with mental disabilities is legally recognised since there are laws that allow abortions for women with mental disability who have been raped. One way to face this issue is to make sure that children with disability go to regular schools and only then non-disabled children can know what does it mean to be a child with disability. Promoting employment opportunities for persons with disabilities is another aspect, for example, by proving incentives to firms that employ persons with disabilities. Such integration may exist at legislative

level but may not be applied. Another aspect is the discrimination in the family against children with disabilities.



**One of the group discussions**

Group two decided to look at the issue of **mental versus physical satisfaction** in terms of expression of sexuality. Group felt that mental and physical satisfaction are complementary and integrated and can not be separated. Both kinds of satisfaction are needed for all human beings including for persons with disabilities. Counselling can help persons to lead a better life and to understand the merits and disadvantages of life partnerships. Community awareness is necessary to reduce barriers surrounding disabled persons. The group also felt that empowerment of persons with disabilities is much more effective in making a change rather than just talking about sexual rights.

Group three also focused on the same theme, **mental versus physical satisfaction**. The group felt that sexuality is not just about sexual intercourse but it is also about love, intimacy, affection and human dignity. We all need these elements in our lives. Sexuality is a sensitive issue and must be addressed properly. Both CBR personnel and clients need to understand that sexuality is about human relationships. We all, disabled persons, family members, friends, health workers, CBR workers, etc. need information about biological functions of our bodies and about sexuality. For some of us, understanding about interpersonal relationships is also needed.

The fourth group reflected on **meaning of sexuality in European culture** and the way **sexuality issues for disabled persons** are perceived. As in different developing countries, the group felt that in Europe also we have similar stereotypes and misconceptions about sexuality of persons with disabilities. It is important to reflect

on role of sexuality in our lives and how we transmit our ideas in the society. Sexuality is a way to express ourselves, to know each other, to relate to others and this experience is often negated to persons with disabilities. Majority of disabled persons do not have possibilities for direct sexual experiences. Persons with specific disabilities such as mental disabilities face even more barriers.

The four presentations provoked lot of comments and discussions in the plenary. Some of the **additional issues** that emerged from these discussions included the following:

When **sexuality is negated**, it means negating the status of adulthood, the possibility of growing up, it means persons with disability must remain as children. It is like a prison from which you can not come out.

**Violence and gender** are other themes that are closely linked to sexuality of persons with disabilities. There are differences among men and women and women face more discrimination. To be a woman and to be disabled, means that you have even less opportunities for services and opportunities. To denounce violence, the small everyday violences of actions and attitudes, requires empowerment. To be in peer group, to talk about it to other persons in your same condition can help in empowerment.

**Information on sexuality** must be accessible to persons with disabilities. On conditions like HIV & AIDS, often information is not accessible to persons with disabilities while some of them may be at equal or grater risk to AIDS. When persons have cognitive disability, often it is discussed by professionals & media merely in pathological terms like when they talk about serial killers.

**Peer counselling** has an important role in strengthening empowerment of disabled persons. In sexuality there is nothing called "normal", sexuality is about human diversity, we are all different in our sexuality. It is important to try to not put a label on everything but rather initiate a dialogue for increasing our understanding. This is true also for the parents of children with disability, it is important to avoid preconceived notions about their fears and their beliefs, but rather promote an open dialogue and to understand their feelings. They love their children, sometimes, their love may be greater for the child with disability. For finding solutions and for promoting empowerment, it is important to avoid preconceived ideas. To decide for others is violation of their human rights, when people are empowered, they ask the possibility to take their own decisions.

**Sexuality is a taboo argument** even for non-disabled person, it is an issue that is completely ignored. We have to recognise that to talk about it is difficult, it is even

more difficult to talk about children and sexuality. IEC on this subject is very difficult. Communication should not be limited to just information but organising festive occasions where persons with disabilities can meet other persons, can be together for outings, occasions that are easily available to non-disabled persons, is also important.

**Changing the environment** where persons can freely talk about need to know more about sexuality and especially sexuality of persons with disabilities is needed. The cultural context surrounding sexuality creates barriers. Good looks, desirability and sexual performance are areas in which popular media, TV, communications all influence and **create stereotypes** that act as barriers around expression of sexuality of persons with disabilities.

**Three AIFO regional coordinators, from left - Jose (India), Deolinda (Brazil) & Massimo (Mozambique)**



## Part 1 C

### Information, Education & Communication on Domestic Violence

#### Introduction: Vulnerability, power to influence and roots of violence

Dr Enrico Pupulin opened the session on communication strategies linked to domestic violence. He mentioned the new document of the World Health Organisation (WHO) on International Classification of Functioning, Disability & Health (ICF) and how different personal and environmental factors influence us and what we can do, by increasing impairments, limitations and restrictions. These factors include culture, gender, age, physical strength, religion, etc. Abilities and disabilities can be seen as variations in a continuum, in which no one is "perfect" , everyone is part of the variations in different ways.

We need to influence persons, institutions and environments surrounding us for defending our rights including the right to survival, right to have our personal cultural and religious values. Vulnerable and disempowered persons lack the "power" to have that influence and thus are considered to be of less value. Living in a city gives us more power to influence compared to living in a rural area or in a mountainous area. To have powerful relatives gives us more influence compared to be from a poor family. Our influence depends from both, our personal characteristics and from our environment.

When different characteristics are seen as counter-positions it sows the seeds of violence. For example, when persons make comparisons like "I am better because I am young and you are worse because you are old" it creates counter-positions that do not help in the dialogue and create conditions for violence. Comparisons like normal-abnormal, better-worse, right-wrong create contra-positions.

Violence is not just about physical abuse, but it is also about trying to make others submissive, trying to humiliate others, etc. Communication itself can become violence if it does not respect the others. In violence in communication, persons focus on positive aspects about themselves and negative aspects of the other side. The vulnerable and weaker groups are usually the receivers of violence. Violence leads to frustration, loss of self-esteem, somatic disorders in the receivers. Victims of violence can also react by being violent on those who are weaker in their own group. For example, frustration due to violence received becomes family violence.

It is difficult to speak of family violence. The victims of family violence can sometimes identify with the humiliation and frustration of the violent person in the

family, usually husband or father, and try to justify it. It is difficult to speak ill of your own mother or father and it can create strong feelings of betrayal and guilt.

### **Children and Domestic Violence: Experience of Vila Esperança (Goias, Brazil)**

Max Robson from Vila Esperança project in Brazil spoke about their experience. Domestic violence is a major problem that affects the lives of children, elderly and women. It affects persons of both sexes, and is not linked to social, cultural or religious context of the families. Often it remains hidden under the silence. Violence may also be accompanied by early neglect and sexual exploitation and thus have serious consequences on lives of children. In Brazil, violence is the principal cause of death among young people between 5 to 19 years.



**Educator with children at Vila Esperança**

Educators can play a significant role in identifying at risk situations. Aggression and other strange behaviour towards others and environment can be signal for its presence, especially in children in pre-scholar age group (4 to 6 years). These children may have other problems related to learning, speech and cognitive capacities. Single parent families with low economic level, lack of basic necessities, matrimonial conflicts are also linked to family violence in our context.

Violence is not just physical aggression, not providing necessary care to children is also a form of violence. Verbal violence with humiliation, lack of respect, rejection, exaggerated punishments can be as devastating as physical violence. Silence, lack of dialogue, indifference, denigrating your work, insulting you in front of outsiders, are other ways of psychological violence. The victim of such violence have low self-esteem. Often the aggressors make the victims feel responsible for the violence, that they deserved it or they "forced the other to be violent".

Alcoholism is another worsening factor for domestic violence.

Schools and educators can play a key role in rebuilding of self-esteem of children, who are victims of violence. They can also initiate a dialogue with family members to

explore the situations and to suggest solutions. These actions are more effective when they are carried out in close collaboration with the communities. One such initiative of Vila Esperança called "projeto Lalabà" works with groups of children, groups of educators and groups of mothers to promote discussions on children with problems of aggression. The purpose is not to lay blame but to promote discussion on impact of violence on children and how support is available from other mothers and educators.

### **Taking up Issues of Domestic Violence in Mongolia**

**Ms. Tulgamaa Damdinsuren** spoke about the work carried out by Disabled Women's Association of Mongolia (DWAM) in collaboration with National Centre Against Violence on domestic violence faced by persons with disabilities. DWAM is involved in awareness activities on the issue of domestic violence.



They note some challenges in these awareness activities on domestic violence -

- negative attitudes in the community about persons with disability;
- the law often considers persons with disability as "criminal" because persons with seeing, hearing or mental disabilities are not able to communicate effectively;
- often children with disability are hidden at home and isolated, and this is especially true for children with mental disability;
- disabled children do not get opportunity to go to school and especially girls are easy victims of rape and cheating.

Since community attitude is that disability is some kind of punishment from God and creates more difficulties for the family. There is psychological violence against them in families, even more so when they need specific care or treatment that require families' resources.

### **Violence Against Women & Children - An experience from Mandya (Karnataka, India)**

**Sr. A. Cheenuthuvattuhulam**, called Sr Leela by everyone, from Mandya district in India presented the IEC activities of her project for fighting against domestic violence. Sr Leela feels that domestic violence is result of misuse of power by one

person against other family members and affects children, women and elderly persons.

Domestic violence can take many forms and variations. It can be episodic, meaning that it happens once in a while, or it may be regular. Domestic violence can be psychological abuse, financial abuse, or/and physical assault and sexual assault.

Violence against females can take many forms - female foeticide or infanticide, dowry harassment and death, sexual abuse, trafficking for prostitution and public humiliation. Children may be direct victims of violence or they may face psychological trauma by witnessing violence at home.

Though it is thought that poorer families have more violence, in a study done by the project, the violence rate was found to be almost double in better off families compared to the poorer families. It was not clear from this study why men in better off families are more violent. Another study carried out in the area showed that 40% of affected women remain silent and do not make formal protest against the violence. Other studies from Karnataka have shown that from 22 to 60% of women may be facing violence in some form in the families. Mostly such acts by the men are justified as being useful for "maintaining order and security" in the family and are thus unpunished.



**Disabled children participate in a public function for advocacy in Mandya (India)**

There is a new legislation in Indian parliament on domestic violence that may help to take stronger positions against aggressors.

Sr Leela told some life stories of women who find themselves as victims of family violence and explained the work of her project in helping women to organise themselves in women groups for promoting their empowerment. At the same time, the project encourages women to send their daughters to school.

### **Violence under silence: Abuse of women in Nepal**

**Ms. Sarmila Srestha** presented the vast experience of WATCH Nepal about the theme of gender violence in Nepal. Sarmila said, "Violence starts before the baby girl is born and it continues during all her life. Before the child is born the violence is

through sex selective abortions and battering of pregnant women. During infancy, girls are victims of infanticide, differential access to care, food and education, emotional and physical abuse. During childhood the girls face incest and sexual violence, forced into child prostitution, grow up amidst discrimination for their access to medical care, education and food."

This violence continues throughout adult life through forced prostitution, marital rape, family violence, dowry deaths and even in old age, elderly women face elders abuse, and sometimes are blamed as witches, etc. Usually the violence is by husband or his family and can become severe during pregnancy, when direct violence is directed towards her belly.

WATCH promotes wide awareness campaigns and discussions on this theme and believes that the wall of silence surrounding the women victims needs to be broken. Women need to learn that by raising their voices, they are not bringing dishonour but are asking for human rights but they also need support from their families. Community needs to critically look and change the way men and women look at themselves and see their roles in the family.

WATCH also organises women groups to discuss these issues and to undertake collective action to the problems by involving the communities. Promoting school education for girls is part of this strategy.



**Two posters used by WATCH to create awareness about violence against women**

## Discussions

The individuals presentations were followed up by plenary discussions on the theme of domestic violence. The main additional issues that were raised up during these discussions included the following:

In Italy, domestic violence can be punished if there is a formal complaint or if officially one come to learn that some one has been victim of violence. This is because in European society individual rights are considered more important than role of family and community. How feasible can be such positions in other countries and cultures?

Violence is not just against women, women can also be a participant in the violence in the family, especially as part of psychological violence and verbal violence towards children. Violence by women against other women, such as mother-in-laws being part of violence against younger women in the family is another such aspect.

Men may also be victims of violence, their rights may also be violated and we need to work with them as well.

Most cultures look at violence between husband and wife as something internal to the family. The only way to change society's perception but building dialogue on these issues, to bring them into open. Family violence can not be solved from outside, but answers and changes must come from inside the family. Couples may together need to discuss and look for solutions. Art, dance, play etc. can be mediums of help to the child victims of violence, to help the victims to rebuild themselves, to understand others, to feel part of the group.

Violence is related to economic dependence of women. It may be taken as part of life because it happens everyday as part of family life so that women and children may not identify it as violence. It may be considered as part of life, part of being a woman. A study from Indonesia showed that men spend more on cigarettes than on children, it is another kind of violence.

Violence is diffuse but hidden. Developing IEC activities against family violence requires first understanding the different issues surrounding it. The words themselves, "family violence" seem to say that it is something minor and unimportant and we have to change that. There is a question of social beliefs. Communities may believe that some "discipline" is necessary for growing up but outsiders can see it as violence.

## Part 1 D

### Communicating about sensitive and difficult issues in the community

Based on the discussions around the themes of sexuality and domestic violence, **Dr Sunil Deepak** from Medical Support department of AIFO/Italy, looked at the emerging lessons about communication strategies at community level for bringing a change.

Understand the different factors related to the problem before designing your communication materials: It is important to understand the issues related to the problem that we want to tackle through our communication. This means understanding how that problem affects persons, who does it affect, in what ways, what are the underlying factors, etc.

It is equally important to identify what and who we wish to change through that communication. Therefore the first step in defining a communication strategy is to collect all the information about that particular problem.

Clarify why do we want to communicate: This is a key question that we need to ask ourselves and we need to think deeply about the reasons of our decision. Are we communicating to inform about something? Are we communicating because we wish persons to do something? Are we communicating so that people change their behaviour? Understanding the answers to this question help us to design our communication to be more effective.

Communication for information is different from communication for awareness raising. Communication for change in behaviour is different from communication for promoting some action.

Decide whom do we wish to reach through our communication: Once we understand the different aspects of the problem we want to tackle through our communication, we need to identify the specific group of persons we wish to reach.

According to the target groups, communication messages and materials will be different. For example, communication to husbands in rural families will be different from the communication to decision makers in the village committee. Communication to women victim of violence "to break the walls of violence" will be different from communication to elders committee to find a shelter for affected women.

The communication has to be specific to the groups it wishes to reach. Giving messages to different target groups by the same communication material is less effective.

Whom do we wish to reach will also determine the medium of communication. Educated persons can be reached by leaflets or newspapers, uneducated persons may be reached better by radio or street theatre.

Understand what do we wish our communication to achieve: When planning communication strategies, think what you wish your target groups to do after receiving your communication message.

If we wish the persons to do something, we have give all the related information about it. The communication must explain the benefit it will bring them in a language that they can understand. For example, if we wish the persons to come and take a particular treatment, we need to explain where that treatment is available, what are the timings of the clinic and what is the cost of the treatment.

Generally speaking positive messages work better than negative messages. This means giving information about benefits that the target group will receive. In addition, interactive communication, where your target groups can intervene, ask questions, make comments, etc. works better than passive methods.

Additional issues for communication on sensitive theme: For tackling sensitive themes, the community must know us and have knowledge about our reliability and seriousness.

Before deciding about communication strategies on sensitive themes, the phase of understanding key issues, underlying reasons, views and support of community institutions, understanding of local cultural context, etc. are all fundamental.

Some communications may need to be individual or in restricted groups given in a reserved environment, to promote discussions and confidentiality.

All communication materials and messages should be specific to the local social and cultural context. This is even more important for communication on sensitive themes.

### **Traditions and sensitive areas of communication**

To conclude the sessions on communication strategies on sensitive themes, workshop participants were asked to reflect in smaller groups about the different sensitive themes for communication and share reflections about related communication strategies.

**The first group** reflected on issues surrounding **traditional values** in both developing and developed world. For persons living in Europe, some issues are difficult to understand and even more difficult to accept. However, it is important to look at common values and to involve the community in looking at the issues. It is also important that while traditions are seen in a positive light, especially if traditions can be maintained in terms of their values but their practice should be more flexible. Tradition can be a positive value, when it is flexible and changes with changing community. If traditions are rigid, they can become an obstacle. It may also be useful if in tradition, we can separate values from rituals and practices. Thus while values remain, rituals and practices can be changed so that they respond to the changing perceptions and ideals about human rights, equality, etc. However the changes must come from within and they can not be imposed from outside, so the process of empowerment must come from inside.

**The second group** reflected on difficulties linked to **communicating about leprosy** since the disease is linked to strong community prejudices. Ancient religious thinking and cultural myths strongly influence how we perceive the disease today at community level. The diagnosis of leprosy can be devastating for the person, even if as health workers we look at it as a disease that is easily curable. It can still affect family relationships, access to education and work, marriage prospects and opportunities for expression of sexuality, etc. Globalisation is affecting the life at grassroots level even in far away communities, leading to conflicts in cultural values. In the same way, communication is difficult about children with disability since community attitudes are guided by prejudices.

**The third group** continued to reflect on issues of **sexuality and violence** and how communication strategies must negotiate with cultural values. For example, at programme level we may wish to give equal priority to girls and boys but this creates with local culture. In the same way, there are issues of political context and in some countries it is not possible to challenge them as non-governmental organisations because governments do not like it. We say that the change must come from within, affected persons have to become main actors of the change but in situations of working with leprosy affected persons, we have to recognise that it is not easy to convince them to fight age-old prejudices and practices. Our own attitudes can be a problem and we need to recognise this and look at them critically. We may take for granted that staff understands all the issues and that they share our vision, but staff is from the same community and they may have similar deep seated ideas depending upon their own cultural context. Thus, our staff may communicate the message the programme wants them to but they themselves are not convinced about it. Often, we can not communicate among ourselves clearly and honestly so it is difficult to communicate to the communities and expect them to change, when we can not change ourselves first.

**The fourth group** looked at the issues that families can not face easily. These are issues of **human dignity relative to sensitive areas such as disability, alcoholism, leprosy, alternate sexuality, etc.** Some times families feel diminished and humiliated but they don't know how to face it through dialogue. For example preconceived notions against disabled persons are sometimes so deep rooted that it is not easy to face them and articulate them clearly. For example, issues of drug addiction and alcoholism produce deep wounds that are not easy to face. A leprosy affected person who has problems of drugs or alcoholism, finds so many doors closed that there does not seem to exist any space for dialogue. Issues of alternate sexuality such as homosexuality are also very difficult for families and communities to tackle. Deep seated notions linked to culture, religion, political context affect not just our communities but also affect our educational institutions, health care structures and how we listen to problems, how open we are for a dialogue.

The participants felt that there is not enough dialogue around sensitive themes. This lack of dialogue creates additional difficulties. Changing the traditional and discriminatory attitudes and behaviours may be difficult but sometimes the change may start in a small way with just one or two persons who become the seed for a wider change.

## Part 2 Advocacy for Bringing Change

### Introduction

**Ms. Francesca Ortali** from AIFO's Project Office started the session on advocacy by sharing her reflections about the word "advocacy" and its different meanings. She said that advocacy is about defending something. To defend something first you need to understand that something, "For example if I am thinking of an action related to access to health services for disadvantaged population groups then I must clearly define what I mean by 'disadvantaged groups' and by 'access to health services'. I have to define the objective clearly and the strategy for reaching that goal. I think that advocacy is a strategy for bringing a change in a problematic situation and communication activities are part of this strategy."

**Mr. Gianpiero Griffo** from Disabled People's International (DPI) - Italy, added his reflections about advocacy. He felt that advocacy is defending something, to safeguard and promote something. This safeguarding works if concerned persons themselves can be empowered to take action. Peer counselling is one way in which persons with disabilities can build capacities of each other for promoting advocacy for safeguarding of their human rights. An example of advocacy is participating in a discussion with governmental partners and decision makers so that adequate laws are there for safeguarding the rights of persons with disability. Gianpiero concluded, "We in DPI feel that advocacy for issues related to disability must be done by disabled persons themselves."

**Mr. Davide Sacquegna** from Communication & External Relations office of AIFO shared his ideas about advocacy. He said, "The word 'advocacy' comes from Latin, 'to call towards' and means communication activities for bringing a change at social and/or political level. For AIFO this means that we are not communicating about ourselves but we become the voice of those who can not raise their voices, with all our humility, we become their voice. You, the participants coming from different countries, you who work with communities, you are the main actors, you give the words to our voice."

### Experiences from the field on Advocacy

#### Advocacy for human rights of leprosy affected persons in People's Republic of China

**Dr Michael Chen** from the Chinese non-governmental organisation of persons affected by leprosy HANDA, spoke about the work of his organisation regarding advocacy for respect of human rights of leprosy affected persons. "We, persons affected with leprosy, we can provide suggestions and ideas for changes in policy based on our own life experiences. We can lobby the decision makers so that their decisions keep account of our concerns", he said.



**Handa volunteers mobilising public opinion in China**

Michael continued, "For example, each year we celebrate 11 March as the international day of dignity and respect. Among other things we ask persons affected with leprosy to speak and interact with public, to give performances so that people can become aware that persons with leprosy live among us and they have equal right to live with dignity and respect. We work together with other NGOs and we try to involve mass media persons.

Michael added, "Working with mass media is not always easy. They are looking for sensational stories or something that looks interesting in the news so they can change our words. We want them to show real persons, real stories and to avoid stereotypes. We do this by promoting wide public participation. A picture of a volunteer holding the hand of a leprosy affected person is a very strong and effective message, much more effective than big speeches about rights, etc."

About the challenges faced by Handa in its advocacy work, Michael felt, "This is not easy. Persons affected with leprosy are often not willing to come forward, as they are afraid. Misrepresentation by media is another problem that we need to look at carefully. We also need to get prior governmental approval before we can organise any activity."

Finally about the future plans, Michael explained, "For our future work we hope to organise some activities for influencing governmental officials. We want to do research with a legal agency so that we can provide realistic advice for changing government policy."

### **Advocacy activities related to persons with disabilities in Pakistan**

**Mr. Sibghat Rehman** from RCPD project in Peshawar explained their project activities for advocacy, "The issues related to persons with disabilities are so many in our country. Sometimes, families mistreat the persons with disabilities, disabled girls are neglected for education and health care, disabled children rarely participate in social gatherings, non-disabled children discriminate against the disabled children, etc. The advocacy activities of RCPD include organisation of rural women's seminars, radio and TV programmes on disability issues, public processions, publication of articles in newspapers and magazines, etc. RCPD also promotes and actively promotes participation of disabled youth in para-Olympic games. For

many of the advocacy activities, RCPD works together with organisations of disabled persons of Pakistan."



**Two pictures from Peshawar CBR project on community advocacy activities**



### **Advocacy activities by Persons with Disabilities in Mongolia**

**Ms. Selenge Khayankhayarvaa** from Association of Disabled Women of Mongolia presented the advocacy activities of her organisation, "For seven decades Mongolia was a socialist country that took relatively good care of persons with disabilities. Since 1991, market reforms have been introduced in Mongolia that have created problems like poverty and unemployment. This last period has also seen the birth of many NGOs, including organisations of disabled persons (DPOs) and of a federation of disabled persons. We wanted to promote a new national policy to safeguard the rights of persons with disabilities. Many persons contesting national elections in 2004 were asked to pledge their support for this policy. After the elections, a NGO called Consensus was involved in preparation of papers on legal environment for protection of human rights of disabled persons, with support from AIFO (Italy). Some surveys and discussions with stakeholders were carried out and on this basis, a draft document was produced."

About the present situation regarding the proposals from disabled persons, Selenge informed, "The draft law has been submitted for consideration to the national parliament in Mongolia. This advocacy action involved DPO representatives, federation of DPOs, professionals, government officials and legal advisors. Once this law is passed, our advocacy action must continue. We need to support capacity building of DPOs so that they can monitor its implementation, we need create public awareness about the law through the mass media."

### **Sexual and reproductive rights of women affected with leprosy in Bahia (Brazil)**

**Dr Eliana de Paula Santos** from Bahia branch of the Brazilian organisation of leprosy affected persons called MORHAN presented her project's experiences with advocacy activities, "The concept of health is much larger than the focus on health services. Women, if they have access to education and information, they can promote health in their own communities. If we look at sexual and reproductive rights of women, these should be seen as part of the right to health. We looked into the access to family planning and neonatal care for women affected with leprosy and we found that they face discrimination and obstacles."



As MORHAN we decided to denounce the situation in our health committee of Bahia state, in the municipal health council and in the municipal council on rights of women. We participated in the state conference on health. We reached the network of gynaecological and obstetrics services and

asked that leprosy affected women need to access to governmental services like all citizens."

Eliana added, "We have to keep in mind the gender and racial perspectives and for this we can not work in isolation, we have to network with others. We work with community forum against violence, women organisations, university, state and municipal bodies."

### **Information and Advocacy activities in South Sulawesi, Indonesia**

**Dr Herry Faisal** from South Sulawesi provincial community-based rehabilitation (CBR) project presented their advocacy activities, "Our programme covers a population of about 1.7 million persons in South Sulawesi province of Indonesia. We aim to actively involve community members for promoting full participation of persons with disability in the community life. For this we need to create positive perception about capacity of disabled persons. In 2004, we carried out a study on impact of our IEC activities. We found that knowledge and involvement of local authorities was low, community awareness about disability issues was low, there were doubts about the sustainability of the project. Following this study plans for made for informing and reaching the community and different awareness activities were organised. As a result, CBR programme was included as part of sub-district development plans and leprosy workers and other health workers joined the programme."



**Public Awareness activities in South Sulawesi (Indonesia)**

## Sharing of experiences by AIFO coordination groups from Italy

AIFO is a grassroots organisation composed of peripheral groups with an intermediate level of coordination (regional co-ordinations). **Mr. Luigi Gravina**, Vice-President of AIFO introduced the capillary structure of AIFO spread all over Italy, involving hundreds of volunteers from all over the country.

Representatives of four such coordination groups participated in the meeting. These were **Ms. Anna Maria Bertino** from Liguria coordination, **Mr. Sergio Zovini** from Lombardy coordination, **Ms. Cristina Pirri** from Tuscany coordination and **Ms. Antonia Santonastaso** from Campania coordination. They shared some of their activities of communication, information and education in Italy. These activities do not have specific advocacy goals but are more for creating public awareness. These activities can be linked to fund collection but even more important is their role in promoting a change of mentality among Italian public. Training courses on inter-culture and other issues linked to globalisation and international inequalities are organised for school teachers. Many public awareness activities such as sale of honey in public squares and organisation of conferences are concentrated in the month of January to coincide with World Leprosy Day, celebrated on the last Sunday of January of each year.

## Drawing Lessons: Planning & Implementing Advocacy activities

**Dr Sunil Deepak** from medical support department of AIFO facilitated the session on advocacy and drew lessons about advocacy activities from the different presentations and discussions.



### Advocacy is part of communication

Advocacy activities are part of information, education and communication (IEC) activities. There can be many different objectives of communication activities such as providing information, creating awareness, promoting change in behaviour, advocacy, etc.

For non-governmental organisations (NGOs), advocacy means specific communication strategies to defend the interests of specific disadvantaged population groups such as poor persons or women or persons with disabilities or persons affected with leprosy. The word advocacy comes from "to advocate for" or "to defend" or "to safeguard" something or someone. It is some what similar to when a person is brought to the tribunal and there is a lawyer (an advocate) to defend the accused. For effective advocacy, the affected persons themselves need to play a leading role.

Advocacy requires identification of "at-risk" situations and then a specific strategy for defending the target group from that situation.

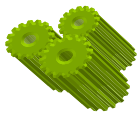
As seen from the different project presentations above, for many projects the meaning of "advocacy" is not very clear and they use this word to speak about their awareness-raising activities.

**Lobbying** is another word commonly used while talking about advocacy.

The word "Lobbying" coming from "lobby" or the corridor, the place outside parliaments or meeting rooms where decisions are being taken. When decision makers make new laws or policies, some times these can have a positive or negative influence on the commercial activities. To defend their interests, the commercial bodies and businesses appoint persons whose job is "to influence" the decision makers, so that the new law or policy will not have negative impact on their business. These persons sit outside in the lobby where decisions are being taken and make friendly relations with decision makers and influence them in different ways to vote in a particular way. These persons are also called "lobbists".

For example, if a government is taking decision about smoking, lobbyists from tobacco industry can try to influence the government decisions as it will affect their business interests.

Learning from these experiences, NGOs fighting for interests of vulnerable and poor population groups can also have their "lobbists" whose job is to make sure that the new policies or laws are made in keeping in mind the needs of the vulnerable and oppressed groups.



### **How does advocacy work in practice**

An example from an AIFO supported project can help us to understand how advocacy can work in practice.

**Example:** "Our city council was discussing a new law to restrict advertising of soft drinks near the schools. The companies making these soft drinks were putting pressure on the council that this law should not be made. They said that if such laws will be made, these will reduce their sale and this means that they will have to close their factory and so many persons in the community will lose their jobs. They also said that soft drinks are not harmful and banning such advertising is against personal liberty guaranteed by constitution of our country.

Our organisation wanted that this new law should be approved, because we felt that our children are influenced by clever advertisements made by soft drinks companies, they spend lot of money on such drinks that have no nutritional values and create problems such as obesity, caries of teeth, etc. We felt that children should limit drinking soft drinks and instead should drink herbs-based drinks made locally as they do not have sugar, are healthier, cheaper, etc.

To counteract the influence of soft drink companies on our city council, we created a team of persons to do the following jobs:

- One person collected information from health care workers about incidence of teeth caries, obesity and diabetes from our community, to show that soft drinks are bad for health of our community. We prepared a small & simple document on this.

- One person went to the council meetings to observe how they take decisions. The person tried to understand - what is the procedure for proposing new policies, how is it modified, how is it approved. At the same time, this person observed if there are council members who are informed or concerned about health issues and can become our allies.
- One person did research on similar policies and laws from other cities from our country and from international level, for preparing a document.
- One person did research on the soft drink companies, to check how and where they produced their drinks, how many persons were working there, if there were any existing problems in these companies, etc.
- One person collected newspaper stories on this theme and talked to public to understand their feelings.

After a period of information collection, observation, research and documentation, we were ready. We now had all arguments to answer any objections.

- We presented our documents to city council members. We provided more information and arguments to our allies among the council members.
- We had identified a councillor who is interested and supportive and she was willing to table a motion in the council. We worked with her to prepare the text of the motion, we prepared the documents to answer the possible objections from industry, we prepared alternate texts in case the first text will not be accepted, we prepared a list of possible councillors to be part of committee to review the policy document, etc.
- We started a public awareness campaign on this subject by asking health workers and professionals, school teachers and school children to support us.
- We networked with other organisations working in the community. Many of them share and understand our concerns and joined us in informing communities.

The counsellor supporting us presented the motion in the council meeting but the industry persons had also prepared other counsellors who reject our proposal. After discussion, the city council decided to nominate a committee to prepare a compromise text. We have managed to get three counsellors, who are on our side, in this committee. Now we shall help them to prepare the compromise text in such a way that is useful to the community. If this policy will be approved by council, we shall help in monitoring its application."



### **Making an advocacy strategy**

Based on the example explained above, we can define some basic ideas about preparation of an advocacy strategy:

- Advocacy is a team work and it needs support for preparation, study, documentation, etc. Therefore advocacy requires planning, including the planning for human resources and financial resources.
- Advocacy usually requires medium or long term planning.
- Making and maintaining human relationships is a key part of advocacy strategy. Identifying and maintaining relationships with decision makers is required.

- Networking to bring together all concerned partners for joint advocacy is required.
- Do not underestimate the stake-holders who have conflicting interests to your objectives, study their strategies carefully.
- Advocacy may also include activities of public awareness, information campaigns, etc. but the main objective of advocacy is usually influencing some specific law or policy at local or national levels inside the countries. Advocacy is also possible at regional and international level, for example through the policy or strategy documents of international organisations such as WTO, WHO, etc.



## Conclusions

Almost all projects working with vulnerable population groups conduct Information, Education & Communication (IEC) activities. However, often these activities lack clear analysis of the situation for identification of specific goals of IEC activities. Often, there is no monitoring of the impact of the IEC activities and a reflection on the most efficient or effective IEC strategies.

At the same time, there are some sensitive and taboo themes affecting the communities, that are very difficult to tackle through IEC activities. These themes include sexuality, domestic violence, alcoholism, drug addiction, mental illness, etc.

This international workshop organised by Italian Association Amici di Raoul Follereau (AIFO) in collaboration with Disability and Rehabilitation team of the World Health Organisation (WHO/DAR) touched on two main themes -

- (a) IEC activities on sensitive themes - sexuality aspects in health care, sexuality aspects in CBR programmes and domestic violence.
- (b) Organisation of advocacy activities

Representatives coming from Africa, Asia and South America shared their experiences on these themes and reflected on the related challenges. The participants agreed that the themes are important and neglected. The participants also asked for preparation of specific training materials on these two themes.

# Bringing A Change

Communicating to communities on sensitive issues like sexuality & domestic violence

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