

New Paradigm of Health care for Persons with Disability

**A Multi-Country Action Research Joint Initiative of
WHO/DAR & AIFO/Italy in Collaboration with DPI**

Hotel Kaire, Rome (Italy), 10-12 December 2007

MEETING REPORT



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INDEX

	Page
Executive Summary	3
A. Background	3
B. Main Conclusions	3
C. Specific issues regarding persons with disabilities, persons with chronic conditions and/or their families	4
D. Specific issues regarding health care professionals	6
E. Different groups of persons involved in the participating projects	6
Annex 1 Background document	7
Annex 2 Rome meeting programme	13
Annex 3 Summary of initiative activities	14
Annex 4 Participants of Rome meeting	15
Annex 5 Different groups of persons involved in the participating projects	17
Annex 6 Presentations by different projects during the meeting	Separately



Meeting Inauguration: from left Anwei Skinses Law (IDEA), Alana Officer (WHO/DAR), Emanuela Minotti (AIFO/Italy) & Gianfranco Griffo (DPI)

EXECUTIVE SUMMARY

A. BACKGROUND

“New Paradigm of Medical Care for Persons with Disabilities” is a multi-country action research initiative organised as a joint programme between Disability & Rehabilitation team of World Health Organisation (WHO/DAR) and Italian Association Amici di Raoul Follereau (AIFO/Italy), in collaboration with Disabled Peoples’ International (DPI).

There are two main aims of this initiative:

- Study the feasibility and impact of a paradigm shift among groups of persons with disabilities, persons with chronic conditions requiring some kind of continuing or periodic medical care, so that they assume a more active role in their self-care
- Study the feasibility and impact of a paradigm shift among health care professionals so that they play a more facilitating role rather than a prescriptive role in providing medical care to persons with disabilities and persons with chronic conditions requiring some kind of continuing or periodic medical care

Annex 1 provides the Background document for the Rome meeting, **Annex 2** provides the meeting programme, **Annex 3** provides a summary of activities under this initiative between 2005-2007, and **Annex 4** provides a list of participants from 11 countries in the Rome meeting, including 7 projects participating in the study.

B. MAIN CONCLUSIONS

The study aimed to look at the two areas of research through five steps: (1) Forming groups of persons with disabilities and persons with chronic conditions; (2) Groups share experiences and analyse their own needs of continuing or periodic medical care; (3) Groups receive information and learn skills for their self-care from health care professionals; (4) Individuals from the group use the information and skills in their self-care; and (5) The expertise of the group is recognised by the health care professionals.

Three of the participating projects (ASODISPIE/Colombia, San Salvador/El Salvador and Reggio Emilia/Italy) were able to complete all the five steps. **The remaining 4 projects** (TASH/India, Karigiri/India, CIMUDIS/Dominican Republic and CARDOS/Ethiopia), had started the process but were in varying stages of completion.

All the seven participating projects shared their processes, successes and challenges during the meeting and came to the following two main conclusions in relation to the two study aims of the initiative:

B.1 The paradigm shift among persons with disabilities and persons with chronic conditions requiring continuing or periodic medical care is feasible and positive. It is not automatic and requires careful nurturing but once the process is started, it can be empowering to persons themselves and to their families, in a process that is much wider in scope than the medical care issues and contributes to a better quality of life.

B.2 The paradigm shift among health care professionals is feasible and desirable. It is not easy to convince and involve the health care professionals but once they do get

involved in the process, it can lead to more work satisfaction and improved quality of work.

The projects shared details about their processes, strategies, discussions and insights regarding each of the five steps. The difficulties and failures faced by some projects during different periods of study implementation provided equally useful insights as did the positive results and successes.

C. SPECIFIC ISSUES RELATED TO DIFFERENT STUDY-STEPS FROM PERSONS WITH DISABILITIES, PERSONS WITH CHRONIC CONDITIONS AND/OR FAMILY MEMBERS

(C.1) Forming groups

C.1.1 Coming together as group of persons with disabilities, of persons with chronic conditions and/or their family members is a key first step in the process for the paradigm shift that becomes an active subject in ensuring participation, continuity and sustainability.

C.1.2 Many persons with disabilities do not require any specific continuing or periodic medical care. For them disability may be part of their lives.

C.1.3 Forming a group is not automatic and needs care and facilitation in the beginning. An external facilitator can be useful in the beginning. However with greater experience and capacity building, persons with disabilities and/or persons with chronic conditions can and should also play this role.

C.1.4 Forming a group, sharing experiences and ideas can be a powerful tool to break isolation, to identify and access opportunities and strategies. Groups have to be based on participation, reciprocal confidence and relationships, and this requires time. Forming groups can pass through ups and downs, so it is important not to give up but to resist and find ways of overcoming initial difficulties.

C.1.5 Persons with disabilities, persons with chronic conditions and family members, may face different obstacles to find a place for meetings, barriers to travel and access meeting places, barriers to effectively participate and share in the groups. All these need to be acknowledged so that satisfactory solutions can be sought that respect dignity of persons.

C.1.6 Once groups are formed, they liaise and advocate for respect of their human rights.

(C.2) Identifying health care needs

C.2.1 Some persons with disabilities/chronic conditions and families, who have long experience of living with their disabilities/conditions and repeated experiences with health services, may already have lot of knowledge and skills needed for their own medical (health) care. We need to acknowledge and value these knowledge and skills.

C.2.2 Understanding and learning about the body processes and principles of self-care is part of controlling persons' own lives and taking control of decisions that influence quality of their lives. They may be used to delegating this responsibility to health care professionals and others. Some of them may not feel comfortable with taking greater

responsibility about their own care. This is equally legitimate. At the same time, for those of who wish, they need the possibility of learning more about themselves, their bodies and about different skills needed for their care.

C.2.3 Persons are human beings and not just bodies with disabilities. Often health professionals ignore global dimension of persons and focus only on their medical care needs. Their own interaction and sharing of experiences can give them the opportunity to look at their global dimension, identify areas not being addressed by health professionals and sought answers to their unmet needs.

(C.3) Understanding and learning skills related to self-care

C.3.1 Usually health care professionals are too busy and do not have time for interacting with persons with disabilities/persons with chronic conditions. Perhaps they feel threatened by their ideas of self-care? However, those that do start interacting as facilitators and not as prescribers, seem to appreciate this role.

C.3.2 Some theoretical knowledge is fine but it should be linked with practical on-the-hands training. Learning sessions need to be interactive.

C.3.3 Persons may not be comfortable in mixed gender groups or mixed age groups to discuss all their body needs. Training sessions need to have the possibility of organising meetings limited to only women or only men or only young adults, etc. according to their needs.

C.3.4 Those persons who had long experience of living with a disability or chronic condition requiring continuing or periodic medical care, may also learn new ideas and skills in such learning sessions.

C.3.5 Finding simple ways to express ideas and information that are understandable to non-professionals is not always easy. Not all professionals may be good facilitators for these learning sessions. Support from proper and simple learning materials may be needed that is sensitive to specific living and cultural contexts.

(C.4) Using the skills of self-care for improving quality of care

C.4.1 Learning about self-care does not mean that these newly acquired skills will be automatically used in by the persons. The skills may be used some times. These skills do not substitute the role of health care services.

C.4.2 Sometimes skills may be related to other resources that may not be available and for these need, continue to look for support from health care services.

C.4.3 Skills of self-care as well as the whole process of coming together as a group can lead to empowerment, in terms of greater awareness of rights, about issues affecting persons' lives and for collective action to fight against barriers and to find answers to unmet needs.

C.4.4 Forming a group for self-care focusing on health needs can be a starting point for looking at other areas and needs of persons' lives. There may be need to network with other similar groups at local, national, regional and international level. Networking with

persons and organisations of persons with other kinds of disabilities or chronic conditions is also required.

(C.5) External recognition for the group's skills in self-care

C.5.1 Persons with disabilities, persons with chronic conditions and/or family members can become experts in some aspects of self-care. They can advise and support other persons and families dealing with disabilities or chronic conditions in their lives in ways that no other health professional can do. They know about living with their conditions, they understand challenges that persons and families face in ways that no other experts can ever understand.

C.5.2 For some issues persons with new disabilities or chronic conditions or families can relate to the group and ask opinions and questions in ways that are not possible in health care services.

C.5.3 Groups can be allies of health professionals and make the bridge between services and individuals and families for effective communication. We should be part of all multi-sectoral teams dealing with our conditions.

D. SPECIFIC ISSUES RELATED TO DIFFERENT STUDY STEPS FROM HEALTH CARE PROFESSIONALS

D.1 Health care professionals often do not learn about needs of persons with disabilities and chronic conditions. Thus when they receive requests related to persons with disabilities they tend to delegate to "rehabilitation" professionals or find ways to not to accept such requests.

D.2 Training of health care professionals tends to focus on disability or specific medical conditions and does not teach them to look at global needs of a person.

D.3 Health professionals may be few and overworked and thus find difficult to participate in a dialogue about paradigm shift.

D.4 Health professionals tend to focus more on crisis, emergencies, services provision and clinical roles rather than engage in dialogue, interact and learn.

D.5 Those health care professionals who do manage to engage in a dialogue for a greater role of persons with disabilities, persons with chronic conditions and/or family members in their own care and their right to take decisions about their own lives, find it improves quality of their work.

D.6 There are areas of health care expertise that cannot be delegated to affected persons or families and health care professionals need to provide services in these areas. At the same time, there are many areas where affected persons can play a more active role and health care professionals need to review these with self-care groups in a more open manner.

E. DIFFERENT GROUPS OF PERSONS INVOLVED IN THE DIFFERENT PROJECTS

The projects worked with groups of persons and family members with different disabilities and a chronic condition (diabetes) including mental illness, physical disabilities, spinal cord injury, polio, learning disabilities, epilepsy, etc.

Annex 5 provides a list of different groups of persons involved in each project participating in the Rome meeting.

Background document

INTRODUCTION

The multi-country action research initiative based on case-studies approach was proposed in the Joint Action Plan of Disability & Rehabilitation team of World Health Organisation (WHO/DAR) and Italian Association Amici di Raoul Follereau (AIFO/Italy) in 2004.

In April 2005, a first international meeting for the initiative was organised jointly by WHO/DAR and AIFO in Rome (Italy), in collaboration with Disabled Peoples' International (DPI). Following the meeting a research protocol was prepared and shared with a number of Governmental and Non-Governmental organisations involved in disability and rehabilitation and proposals for pilot projects were invited.

During 2005-06 proposals for pilot projects for conducting action research with different groups of persons with disabilities were received and among these, 10 proposals based in 9 countries were approved. Seven pilot projects received a financial contribution from WHO/DAR, while other three were asked to look for alternate sources of funds.

Thus a few of the pilot projects were able to start their activities and the action research in early 2006 while some others started it in late 2006, while some others started it during first semester of 2007.

The planned meeting in Rome, from 10 to 12 December 2007, will bring together the research facilitators from the projects that have started the activities and completed at least one study report by the end of September 2007. This meeting concludes this phase of research.

FUNDAMENTAL PREMISE OF THE ACTION RESEARCH STUDY

The research study is based on the consideration that medical care paradigm for persons with long term and often, life long medical care needs is different from the medical care paradigm used for persons having acute and usually, time limited medical care needs.

This consideration about the need for defining a new medical care paradigm was raised up in the WHO publication, Innovative Care for Chronic Conditions (WHO, 2000) in the following way:

Health care is organized around an acute, episodic model of care that no longer meets the needs of most patients. Dramatic decreases in communicable diseases have highlighted this mismatch between health problems and health care, and chronic conditions are on the rise. Patients, providers, and most importantly, policy makers must grasp this concept and begin to shift their thinking away from a solely acute model of health care to one that is inclusive of and evolving toward care for chronic conditions...Chronic conditions require that patients make lifestyle adjustments to manage their problems. Lifestyles do not change with a medication. **Because the management of chronic conditions requires lifestyle and daily behaviour change, emphasis must be upon the patient's role and responsibility in health care.** Focusing on the patient in this way constitutes a dramatic modification in current clinical practice. At present, systems relegate the patient to the role of passive recipient of care, missing the opportunity to leverage

what he or she can do to promote personal health. Health care for chronic conditions must be reoriented around the patient.

Some of the basic issues related to the two different paradigms can be summed up in the following way:

Acute Care Paradigm

- The person was well, suddenly falls ill and requires quick medical care.
- The person has no or limited knowledge about his/her condition and about the medical care needed.
- Health professionals are experts. They diagnose and provide some treatment and give advice.
- No life style changes are required, person follows the treatment advised, gets well and goes on with her/his life.

Chronic care Paradigm

- The person requires regular or periodic medical care for many years or whole life.
- Gradually persons and families may acquire knowledge & skills for managing medical care and thus rely on self-care, going occasionally to health services for complications and severe problems.
- Life-style changes are required.
- Health professionals, need to become facilitators so that persons are better prepared for self-care, providing medical care for complications & in case of need.

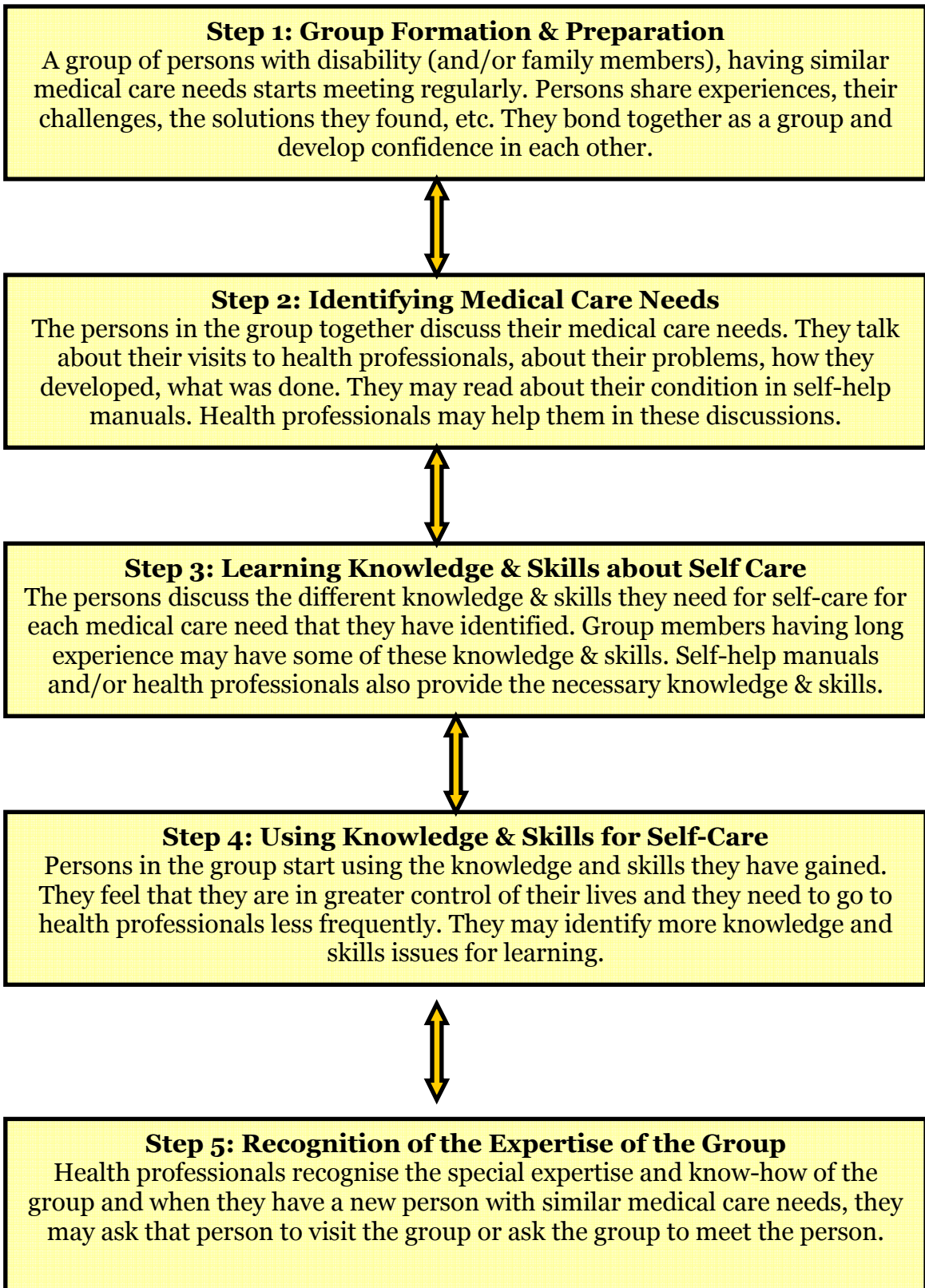
MAIN ACTION RESEARCH QUESTION

This multi-country action research initiative wants to answer one main question:

By coming together as a group, persons with disabilities having similar medical care needs, can they learn self-care and play a more active role in improving their own medical care?

To answer this question, pilot projects were asked to – (1) identify and create groups of persons with disabilities having similar medical care needs; (2) identify the main medical care needs; (3) in collaboration with health professionals, provide knowledge and skills for self-care for answering the identified medical care needs (4) assess if quality of self-care and medical care by persons with disabilities and/or family members has improved; (5) if the knowledge and skills of persons with disabilities can be recognised and given some role in medical care system.

These steps are represented in the next diagram for easier understanding:



Example 1: Persons with Spinal Cord Injury

Step 1: Group Formation & Preparation

A group of persons with spinal cord injury starts meeting regularly. Persons share experiences, their challenges, the solutions they found, etc. They bond together as a group and develop confidence in each other.



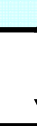
Step 2: Identifying Medical Care Needs

The persons in the group together discuss their medical care needs. They talk about their visits to health professionals. They identify some areas for medical care: (1) urine, bladder & kidney issues (2) pressure sores (3) rigidity of joints (4) sexuality & parenthood related issues.



Step 3: Learning Knowledge & Skills about Self Care

The persons discuss the different knowledge & skills they need for self-care for each medical care need that they have identified. Group members having long experience explain to others about bladder care, how to change catheters, how to prevent infections, joint rigidity & bed sores. Professionals also share knowledge & skills with them.



Step 4: Using Knowledge & Skills for Self-Care

Persons in the group start using the knowledge and skills they have gained. They require lesser visits to health services for urine & kidney infections, they feel more autonomous...



Step 5: Recognition of the Expertise of the Group

Health professionals recognise the special expertise and know-how of the group and when they have a new person with spinal cord injury in the hospital, they invite group members to come to hospital and talk to this person, to share experiences and to advise. Many new groups are starting.

AREAS OF DISCUSSION DURING THE MEETING

The above process in five steps is an over-simplification of the reality. While the research has a very narrow focus, towards medical care issues. In reality medical care issues are a small part of lives and persons with disability may have other issues that they feel are more urgent or important.

Therefore, an important challenge for the meeting will be to continue to focus the discussions and reflections on the medical care issues and basic research question.

While the action research involving groups of persons with disabilities may have given lot more useful and important information to each project, in the meeting we may not be able to discuss them adequately. For example, sharing of experiences, knowledge and skills in the groups can have important impact in terms of empowerment, access to basic services like pensions, facilities like free or reduced costs for transportation, disability certificates, etc. Having a limited time for this meeting means that we may not be able to discuss these issues.

In terms of the information each project facilitator will be asked to present during the meeting, their own experiences for each of the five steps mentioned earlier.

Practical information about the presentations: Each participant will get around 1 hour (60 minutes) for his/her presentation. Make sure to prepare your speech for about 45 or 50 minutes and leave 10 minutes for questions and clarifications.

We expect all of you to speak in English and to make a power-point presentation in English. If you are not very sure of preparing the power-point presentation in English, prepare it in the language of your choice and send it to us by first November (01.11.2007), we shall get it translated into English for you. If you need help for English translation of your speech, write down your speech in your language of choice and send it to us by first November (01.11.2007) and we shall get it translated into English for you.

Some of the information that we would like to hear from participants include the following. These are only given as examples and if you wish to add aspects in your presentation, you can do so. Just make sure to respect overall time limit. If you have a lot to say and you feel time is not enough to present everything, put everything into writing and limit your presentation to main issues, asking persons to read the full document.

INFORMATION TO BE PRESENTED ABOUT STEP 1 (PREPARATION)

- ◆ General information about the area of intervention of the project.
- ◆ Number of different groups, kinds of disabilities present in the group members, number of components of groups, presence of parents, etc.
- ◆ Number of meetings held so far
- ◆ Brief information about working of the groups and its evolution during the period of the study – leadership issues, any conflicts, sense of confidence, participation & inclusion of all members, gender issues, etc.
- ◆ Kind of issues that came up during discussions, any dominating issues, etc.

INFORMATION TO BE PRESENTED ABOUT STEP 2: IDENTIFYING MEDICAL NEEDS

- ◆ What specific medical care needs were identified for each group of disabled persons included in the study?
- ◆ How were these needs identified?
- ◆ What was the contribution of persons having long experience of disabling condition in understanding of the medical care issues?
- ◆ What was the contribution of health care professionals in identifying these issues?
- ◆ Were any books, manuals or documents used for identifying the medical care needs?

INFORMATION ABOUT STEP 3: CAPACITY BUILDING OF THE GROUP WITH KNOWLEDGE AND SKILLS ABOUT THE IDENTIFIED MEDICAL CARE NEEDS

- ◆ How was capacity building of group members carried out about specific medical care issues?
- ◆ Was it possible to provide knowledge and skills for all the medical care issues?
- ◆ Were there any discussions on what skills can be taught and what aspects should remain under supervision of professionals?
- ◆ Who provided capacity building – professionals? Other disabled persons with long experience? Manuals and books or self-learning courses?
- ◆ Were there any discussions on roles and responsibilities of professionals?

INFORMATION ABOUT STEP 4: IMPROVEMENT OF SELF CARE ACTIVITIES BY PERSONS WITH DISABILITIES

- ◆ Have the new knowledge and skills made any difference?
- ◆ Are disabled persons and/or families comfortable with idea of greater role in self care?
- ◆ Are professionals comfortable with idea of greater role played by persons with disabilities in their own care?
- ◆ Are persons identifying new areas of knowledge and skills that we want more capacity building?

INFORMATION ABOUT STEP 5: RECOGNITION OF EXPERTISE OF THE GROUP

- ◆ Are professionals recognising the importance of first hand experience, knowledge and skills among group members and inviting them to speak to other persons with disabilities?
- ◆ Are other persons with disabilities recognising the importance of talking to group members and benefiting from their experience, knowledge and skills ?
- ◆ Do the group members feel confident that they have a useful role to play and can help other disabled persons, especially those facing similar medical care needs?

PROGRAMME of Rome Meeting 10-12 Dec. 2007

Monday 10 Dec.07	
09.00	Inauguration Ms. Emanuela Minotti, Vice-President AIFO Ms. Alana Officer, coordinator WHO/DAR, Geneva Prof. Urbano Stenta, representative Italian Foreign Ministry Mr. Gianpiero Griffo, Board member Disabled People's International Ms. Anwei Skinses Law, IDEA International
10.00	Coffee break
10.30	Introduction – Sunil Deepak
10.45	Discussion on expectations, methodology, etc.
12.00	Colombia presentation by Marlene Wiens
13.00	Lunch break
15.00	India/Asia presentation by Prem Kumar
16.00	Coffee break
16.30	Discussions
18.00	End of Day 1
Tuesday 11 Dec.07	
09.00	Reggio Emilia/Italy presentation by C. Ruggerini
10.00	Coffee break
10.30	El Salvador presentation by J. Lemus
11.30	Mumbai/India presentation by H. L. Kaila
12.30	Discussions
13.00	Lunch break
14.30	Rep. Domenicana presentation by C. Franciosa
15.30	Coffee break
16.00	Addis/Ethiopia presentation by Y. Kassahun
17.00	End of day 2
18.30	Social dinner
Wednesday 12 Dec.07	
09.00	Summing up, challenges & achievements
10.00	Coffee break
10.30	Next steps...
12.30	Formal closure of the workshop

SUMMARY OF INITIATIVE ACTIVITIES 2005-2007

- (1) The idea of the initiative based on case-studies approach was agreed in the joint plan of action 2004-05 between WHO/DAR & AIFO/Italy in May 2004
- (2) A first joint meeting by WHO/DAR and AIFO/Italy in collaboration with DPI was organised in Rome/Italy in April 2005 involving DPOs and organisations working with persons with disabilities. It was agreed that Dr S. Deepak from AIFO/Italy will coordinate the study with technical support from WHO/DAR.
- (3) A research protocol based on case-studies approach was developed and proposed to projects willing to participate in the study in October 2005.
- (4) Between 2005-06 interested projects submitted applications expressing interest in the initiative. Some of the projects received financial support from WHO/DAR during 2006-07 for participating in the study.
- (5) Between 2006-07 an email-based discussion group for participating projects was initiated and projects were asked to regular reports. Some projects that received funds from WHO/DAR faced some problems and did not provide any reports including KASI/Tanzania and HCS/Jordan. Project in CBR/Palestine was unable to secure funds and could not start the activities.
- (6) A mid-term verification meeting was organised in Rome/Italy in December 2007. Participants were invited from projects providing regular reports according to the study protocol and thus projects from Tanzania, Jordan and Palestine were not invited to this meeting.

New Paradigm of Medical care for Persons with Disability
A Multi-Country Action Research Joint Initiative of WHO/DAR & AIFO/Italy
Mid-Initiative Verification Meeting
Hotel Kaire, Rome (Italy), 10-12 December 2007

PARTICIPANTS

A. Participating Projects

- 1. COLOMBIA:** Ms. Marlene Wiens & Ms. Rocio Nunes Espinel (2 persons)
- 3. ETHIOPIA:** Mr. Yibeltal Kassahun (with Mr. Tsige Amberbin, accompanying person – 2 persons)
- 6. DOMINICAN REPUBLIC:** Ms. Cristina Franciosa (with Ms. Amancia Segura, accompanying person, 2 persons)
- 8. INDIA (KARIGIRI):** Mr. Prem Kumar Ramaswamy
- 9. INDIA (TASH):** Mr. H. L. Kaila
- 10. EL SALVADOR:** Mr. Jorge Lemus
- 11. ITALY:** Dr. Ciro Ruggerini & Dr Sumire Yamaguchi (2 persons)

Other Partner organisations

- 13. Disabled People International (DPI):** Mr. Gianpiero Griffio
- 14. IDEA International:** Ms. Anwei Skinses Law (with Lian Law, accompanying person, 2 persons)
- 16. Italian Foreign Ministry:** Prof. Urbano Stenta

International Observers from other Projects

- 17. Amici India:** Mr. M. V. Jose
- 18. WATCH Nepal:** Ms. Sarmila Shrestha
- 19. CBR Mongolia:** Ms. Tulgamma Damdinsuren & Mr. Ebe

WHO/DAR

- 20.** Ms. Alana Officer, coordinator WHO/DAR team

AIFO/Italy

- 21.** Ms. Emanuela Minotti, Vice-President Board of AIFO (for inauguration)

22. Ms. Francesca Ortali, Project office AIFO
23. Ms. Felicita Veluri, Meeting secretariat
24. Dr Sunil Deepak, Global coordinator of the research initiative

Different Groups of Persons with Disabilities, Persons with Chronic Conditions and/or Families involved in different projects

Project/Country	Groups Involved
ASODIPSIE, Puedecuesta, Colombia	Spinal cord injury, Spina Bifida, Cerebral palsy & Down syndrome
ALMES, San Salvador, El Salvador	Spinal cord injury
Different partners, Karigiri, India	Leprosy affected persons, persons with psychosocial disability & persons with epilepsy in India, Sri Lanka & Philippines
CIMUDIS, Santo Domingo, Dominican Republic	Women with physical disabilities (paraplegia and poliomyelitis)
University, Modena, Italy	Learning disabilities, epilepsy, multiple disabilities
CARDOS, Addis Ababa, Ethiopia	Leprosy related disabilities, physical disabilities
TAH, Mumbai, India	Persons with diabetes Mellitus, persons with leprosy related disabilities and persons with mental illness