

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

INTRODUCTION

The multi-country action research initiative 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.

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:

Step 1: Group Formation & Preparation

A group of persons with disability (and/or family members), having similar medical care needs 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, about their problems, how they developed, what was done. They may read about their condition in self-help manuals. Health professionals may help them in these discussions.



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 may have some of these knowledge & skills. Self-help manuals and/or health professionals also provide the necessary knowledge & skills.



Step 4: Using Knowledge & Skills for Self-Care

Persons in the group start using the knowledge and skills they have gained. They feel that they are in greater control of their lives and they need to go to health professionals less frequently. They may identify more knowledge and skills issues for learning.



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 similar medical care needs, they may ask that person to visit the group or ask the group to meet the person.

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.



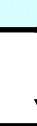
Step 2: Identifying Medical Care Needs

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?

DRAFT PROGRAMME

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