SCALING UP COMMUNITY BASED REHABILITATION: ADAPTING HEALTH CARE QUALITY IMPROVEMENT METHODS

Meeting Report
3-4 February 2003

Noncommunicable Diseases and Mental Health
World Health Organization
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The meeting report is written jointly by WHO teams, Disability and Rehabilitation and Health Care for Chronic Conditions, in consultation with external advisors, participants of the meeting Scaling Up Community Based Rehabilitation: Adapting Health Care Quality Improvement Methods, held on 3-4 February 2003.

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1. **INTRODUCTION AND AIMS**

This meeting was jointly planned and organized by the World Health Organization (WHO) Headquarters teams, Disability and Rehabilitation and Health Care for Chronic Conditions. Both teams are part of the Noncommunicable Diseases and Mental Health Cluster (NMH), Management of Noncommunicable Diseases Department of WHO.

The aims of the meeting were:

- To adapt the “Breakthrough Series Collaborative” (BTS) quality improvement method to give greater community, family and service user involvement
- To explore the value and limitations of an adapted BTS when applied to chronic conditions and disability

The participants in the meeting brought with them:

- Significant personal experience of working in the field of disability and rehabilitation particularly the application of WHO’s Community Based Rehabilitation (CBR) strategy at Member State level
- Significant personal experience of using the BTS method to improve outcomes for service users in health and health care, in a wide range of settings
- Direct involvement in WHO’s continuing programme of work in disability and chronic conditions at Headquarters.

The workshop participants are listed in Appendix 1. The workshop was facilitated by Peter Key of Dearden Consulting (UK).

2. **WHO AND PEOPLE LIVING WITH CHRONIC CONDITIONS AND DISABILITY**

A significant proportion of the global population lives with a chronic condition or disability, or both. People living with chronic conditions or disability:

- Aspire to live the fullest possible lives, to maximize their functional levels and their participation within their communities
- Often need the support of families and communities if they are to realize their personal life goals
- Need access to health care systems predicated on the principles which underlie primary health care:
Health care which reflects and evolves from the economic conditions and socio-cultural and political characteristics of the country and its communities.

Health care which addresses the main health problems in the community, providing promotive, preventive, curative and rehabilitative services accordingly.

Health care which promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available resources.

The needs of this broad population group are addressed through two principal programmes of work within WHO. These are:

**Community Based Rehabilitation (CBR)**
CBR is an inter-sectoral strategy, fully supported by WHO, whose aim is to improve the lives of people with disabilities. The strategy has been in place for more than twenty years and is widely supported and implemented by Member States and other UN Agencies.

At the core of the strategy is the concept that communities should be working with disabled people, their families, and other concerned citizens, via formal and informal leaders, local governments, and other stakeholders to ensure equal opportunities for all community members. This makes the implementation of CBR highly contextual, given the variability in political and social systems around the world. Generally, however, the process of identifying and addressing the obstacles to social integration and equalization of opportunities for people living with disability, will involve collaboration between:

- People living with disability and their families
- Local communities and community leaders
- Disabled People’s Organizations (DPOs)
- National and International Nongovernmental Organizations
- International Agencies
- Ministries of Health, Education, Labour, Finance and Social Security

**Innovative Care for Chronic Conditions (ICCC)**
The ICCC programme shares much common ground with CBR, but has a different starting point. The interest of ICCC is in preventing and managing chronic conditions within health care, focusing on all people living with chronic conditions even those who are not disabled. For example, people diagnosed with diabetes in its early stages of development have a chronic condition, but are not disabled. Effective management of the condition may prevent or delay the progression of the disease, but in its later stages of development, diabetes can result in a major disability.

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1 A global review of primary health care: emerging messages. Document WHO/MNC/OSD/03.01, in preparation
The broad goal of the ICCC programme is the achievement of better prevention and management of chronic conditions, resulting in better outcomes. Better outcomes are seen as being dependent on:

- Creating a positive policy environment at national and local levels
- Building effective links and collaboration between communities and health care organizations
- Building effective partnerships between people with chronic conditions and their families, members of the community who provide support and the health care teams who help them manage the medical elements of their chronic condition

These relationships are summarized in the ICCC Framework (Appendix 2).

ICCC is a much more recent programme than CBR and has yet to be implemented on the same scale.

### 3. CHRONIC CONDITIONS, DISABILITY AND THE BREAKTHROUGH SERIES MODEL (BTS)

The ICCC and CBR programmes of work have very similar goals in terms of improved outcomes for people living with disability and/or chronic conditions. They both adopt a strategic approach. This places high value on the involvement of people with disability or a chronic condition, their families and their communities in working collaboratively with health systems and other agencies.

The implementation of such a strategic approach is, however, dependant in part on a range of methodologies being available to support local change process.

As described above, the core aims of the meeting were to explore the extent to which the Breakthrough Series (BTS) method of quality improvement would be a valuable methodology to support the implementation of the CBR and ICCC strategies.

BTS is a simple yet powerful model for accelerating health care improvement. Since 1995, thousands of health-care teams in the USA, the United Kingdom, Sweden and other developed countries have participated in BTS collaboratives, with dramatically improved outcomes and reduced costs in a variety of clinical and operational areas.

A BTS Collaborative would normally consist of a group of health care organizations (minimum number being 10 and average being 25) working together and learning together over an extended timescale (normally 6 to 13 months), to improve outcomes in a specific clinical or operational area.

Under the guidance of technical experts, local change teams from participating organizations will study, test and implement the latest knowledge available in order to produce rapid improvements in their services and outcomes.
Whilst there is a “classical” BTS Collaborative approach (which is described in more detail below) the application of BTS has been very flexible in practice. There are, however, three care principles which are always present:

i) This is a collaborative process involving multiple organizations or stakeholders who share an interest in achieving better outcomes in a specific area of activity

ii) BTS Collaboratives are working with “known knowledge” – their concern is to implement best practice rather than to conduct research

iii) BTS Collaboratives start with an assumption that there will be rapid change in the way in which clinical and operational service will be delivered.

4. THE MEETING PROCESS

The meeting was used to test and adapt the BTS model, to give greater involvement of people with disability or chronic conditions, their families and communities, in the change process.

The “classical” BTS Collaborative would normally be very limited, in that change teams would be comprised of health professionals in the main.

The BTS Collaborative method is broken into five elements (which in practice, are sequential).

These are:

1. The process of selecting the topic to be addressed by all of the organizations involved in the Collaborative.

2. The process of planning and preparation for the Collaborative, including the use of technical experts and the development of frameworks for change.

3. The period of pre-work when organizations participating in the Collaborative prepare themselves for the change process.

4. The extended period of change, when local teams are coming together for Learning Sessions, are implementing their own changes applying the Plan / Do / Study / Act Model for Improvement and are receiving external supports of varying kinds.

5. The final period when outcomes are reviewed and learning is shared widely outside the Collaborative.

These elements are represented figuratively in Appendix 3.
Meeting participants were organized into two mixed teams to ensure access for each to direct experience in CBR, in the use of the BTS model and in WHO policy development for people living with disability and chronic conditions.

To ensure that the process of adapting and testing the BTS model was grounded in reality, each team worked through the five elements in the context of a particular member state (the focus for one team was India, for the other it was Guyana).

5. **TOPIC SELECTION**

The first element in the BTS model is the process of topic selection. For the purposes of the meeting, participants selected the following topics as the focus for adapting the model:

- **Guyana Group** Preventing impairment and secondary complications due to diabetes
- **India Group** Ensuring access to education for disabled children

With these topics agreed, the groups simulated the process of local topic selection. Their focus was on answering the following questions:

- *Who would be involved?*
- *What criteria might be used to decide a topic?*
- *How would this be different for the classical BTS model?*

The main conclusions to emerge from the two groups were:

**Who Would be Involved?**

When the BTS model is applied to disability and chronic care, a wide range of stakeholders would need to be involved in the process of topic selection. This might include:

- The Ministry of Health
- People living with disability and their families
- Disabled Peoples Organization (DPOs)
- Other Ministries
- Health care professionals
- CBR staff
- Local leaders
What Criteria Might be used to Select a Topic?
The range of criteria that might be used to select topics would include:

- The current burden of disease and disability and the scale of impact on the quality of lives for individuals and their families
- The potential to bring about change
- The social and economic impact of the topic
- The availability of data

How would this be different from the classical BTS model?
There are a number of areas where the use of BTS in the context of disability and chronic conditions would be different to the classical model when topics were being selected.

These include:

- The wide range of stakeholders who would need to be involved from a variety of sectors
- The involvement of government
- The timescales that would need to be allowed to ensure a proper process of involvement with multiple stakeholders

The process of topic selection would also need to be designed to take full account of local contextual considerations. There could not be an assumption that a standard approach would fit differing Member State circumstances.

6. PLANNING AND EXPERT INPUTS

The second element of the BTS model brings together the process of planning for the Collaboratives and incorporating expert advice on best practice. In simulating this part of the model, the two groups concentrated on the following questions:

- Who are the “experts” in this context?
- What processes would be used for planning?

Who are the Experts?
This is an area where the application of BTS to chronic conditions and disability might differ significantly from the classical model. The expectations of both groups were that a much broader understanding of “expertise” would need to be applied, which went beyond the technical and research-based platform of the health professional and valued the perspectives, knowledge and expertise of a wide range of interested parties. On this basis, the “Experts” might include:
Local leaders/O pinion leaders
People with disabilities, their families and DPOs
NGOs
Health care providers and researchers
Community volunteers
CBR workers
Employer representatives
Leaders in education
Central and local government representatives
Policy advisers
Quality improvement advisers

What processes would be used for planning?
Both groups saw this planning stage as a vital period of engagement with stakeholders; however, they identified very different processes for initiating planning:

One group preferred a very open and participative approach at the outset, where all of the different stakeholders would be involved in the initial engagement. This “wider group” would agree a broad planning framework, which would include targets for change. A much smaller Advisory Group would then be charged with further developing the larger group ideas, analysing evidence and developing a framework of changes.

The other group preferred an approach where an existing national level Advisory Group, with augmented memberships, would be asked to review evidence, identify the gaps between current practice and best practice and begin to develop the framework of changes. The extended Advisory Group would then act as champions and catalysts in winning the support of the extended group of stakeholders who would be involved, for the Collaborative and its outcomes.

Both processes were seen as viable and appropriate to their local context.
7. PARTICIPANTS AND PRE-WORK

The third element in the BTS model involves the selection of local teams to take part in the Collaborative and the organization of pre-work to be undertaken by those teams. In the context of people living with disability and chronic conditions, the groups concentrated on the following questions:

✧ What might be the membership of local teams?
✧ Who would participate in the Collaborative?
✧ What sort of pre-work would be appropriate for local teams with what membership?
✧ How would pre-work be organized and supported?

The main conclusions from the groups were:

Membership of Teams
For both groups, the selection of an appropriate “population base” was critical in thinking through local team membership. The units of population chosen were 30K in one case and 70K in the other. In both instances, this reflected the typical population size for a significant level of local government. This had the advantage of being large enough to ensure that there was a local government infrastructure that could be engaged with and small enough to retain a sense of community identity.

Membership of the local teams who would participate in the Collaborative might then include:

✧ People living with disability and chronic conditions and their family members
✧ Local representatives of DPOs
✧ CBR workers or managers
✧ Educators/Teachers
✧ Community leaders
✧ Health care providers from primary care
✧ Data collectors

One of the identified constraints on the constitution of local teams was the availability of “professionals” such as trained health care staff and teachers, to be involved as team members.
Pre-work for Local Teams
Both groups also saw the scope and context of pre-work in this context as differing significantly from the classical BTS model. In particular, it was anticipated that for local teams with this sort of membership, much more attention would need to be given to capacity building and external support. In their pre-work, local teams would probably have to:

✧ Collect baseline information and assess the impact of the problem area
✧ Develop key measures of success
✧ Give attention to clarifying roles and accountability within the team
✧ Develop their own team working and change management skills
✧ Begin the process of mobilizing community support
✧ Produce flow-charts which describe what happens now to people with disability or chronic conditions in the selected topic area

Given the different nature and complexity of the pre-work phase in this context, more time would probably be needed by local teams at this stage than with the classical BTS model.

Support for Local Teams During Pre-work
Although the selected topics were very different (diabetes and access to education) and the national contexts were very different (India and Guyana), both groups also identified the same need to deliver external support to local teams during the pre-work phase of the process.

This was based on the view that local teams would need help in building their own capacity and in organizing some of the more technical processes (such as data collection and flow-charting), if they were to complete pre-work successfully.

The suggested population from both groups was to create an Advisory/Support Group which would bring together different resources at the level of the whole collaborative, to work directly with local teams during the pre-work phase. Such a group might include representation of:

✧ All of the central government Ministries with an interest in the outcomes of the Collaboratives
✧ Local and international NGOs and support groups
✧ The UN agencies who sponsor CBR as a strategy
✧ Any other sponsoring groups who had been identified and involved at the planning stage
This support during the pre-work phase could use a variety of methodologies including face-to-face work, telephone and radio conferences, written materials and workbooks and training events.

8. LEARNING SESSIONS AND SUPPORTS

The fourth element of the BTS model is the core of the change process. It is during this phase that local teams are working to implement changes, which will produce improvements in outcome and measuring their progress and impact. Local teams are also joining in Learning Sessions, which bring together all of the participants in the Collaborative for shared learning and review and to receive new inputs from subject experts etc. Between Learning Sessions, local teams are also receiving direct support from the central team whilst working on local agendas.

In the context of people living with chronic conditions and disability, the groups were asked to consider:

- Whether the organization of Learning Sessions would need to be different from the classical BTS model?
- What sort of supports could realistically be provided to local teams between Learning Sessions?

The Organization of Learning Sessions

The main conclusions of the group were:

- The design and organization of Learning Sessions should be based on clear principles, to include:
  
  (a) Maintaining the visibility and role of people living with disability and chronic condition in the process
  (b) Respecting the contributions of all team members, irrespective of their background
  (c) Maximizing the opportunities to build the “learning community” in which all teams and all team members are simultaneously both teachers and learners
  (d) Keeping a clear focus on action.

- The design of Learning Sessions would need to take account of capacity building and work done by local teams in the pre-work phase.

- The design of Learning Sessions would need to take account of population differences within the Collaborative. In Guyana for example, 80% of the population live in the coastal strip and 20% live in very remote and inaccessible communities. For the latter, if several days travel is involved in attending a Learning Session, it would be inappropriate to make that session too short.
The design of Learning Sessions would need to take account of the extent and nature of the support it was possible to provide to local teams between Learning Sessions. Where giving access to support is problematical, this could be compensated for, by extending Learning Sessions and building in more face to face contact.

The particular membership of local teams could require special attention to be given to teaching core skills in areas such as data analysis and the use of evidence, as part of the design of Learning Sessions.

The Learning Sessions provide an ideal opportunity to involve the media and so influence community awareness of the needs of people living with disability and chronic conditions.

Learning Sessions also provide an ideal opportunity to engage with government representatives and other interested parties who might not otherwise be involved in the Collaborative’s work.

In many parts of the world, the timing of Learning Sessions would need to take account of weather conditions and peak activities in the agricultural cycle.

Providing Support between Learning Sessions
Both groups identified local geography and access to communications technology as the major obstacle to the provision of effective support between Learning Sessions. Whilst the organizers of Collaboratives would seek creative solutions, they would not necessarily be able to fully compensate for:

- The travel time involved in reaching some remote communities
- The absence of reliable surface mail
- The absence of telephones, radio or internet communications

In those circumstances, greater use would need to be made of the Learning Sessions themselves to support local teams.

9. REVIEW AND SPREADING THE LEARNING

The final element of the BTS model concentrates on reviewing outcomes with the Collaborative participants and taking action to share those outcomes with a wider group of interested parties.

In the context of chronic conditions and people living with disability, the key questions that the two groups were asked to consider were:

- Who might be the target audiences and outcomes from the wider dissemination of Collaborative outcomes?
- What processes might be used for wider dissemination and the spread of good practice?
The main conclusions of the group were:

**Target Audiences and Outcomes**
For both groups, a key objective at this stage in the BTS model would be to broaden the base of involvement of stakeholders in the topic under review and more generally, in considering the needs of people living with disability and chronic conditions. Specific outcomes from broadening the base of involvement might include:

- Raise awareness of the needs of these groups
- Changed attitudes towards these groups
- Raised awareness of how progress can be made through processes such as the BTS model
- Increased commitment to participating in future projects
- The opportunity to repeat the process with a new Collaborative addressing the same topic, or a different topic.

**The Process of Dissemination**
The methods of dissemination that could be employed in this context are no different to those which would be used in any large-scale change process. They could include:

- Making full use of “champions” who have emerged from the Collaborative
- Producing written material, including newsletters and good practice guides targeted at different audiences
- Organizing dissemination conferences and exploiting opportunities to contribute to other conferences
- Working with the national and local media

What would be different in this context is the opportunity that is presented by the engagement of a wider group of stakeholders throughout the BTS Collaborative process. These contributors represent a considerable resource and potential for active networking.
10. CONCLUSIONS

The main aims of the meeting were to see if the BTS collaborative model of quality improvement could be adapted for use in the context of chronic conditions and disability and to assess its value.

As this report describes, the meeting methodology involved two groups working in parallel to "test out" the BTS model and its different elements, in two very different contexts.

In reviewing the outcomes of the meeting, the views of the participants were that:

✧ BTS is a valuable methodology, which with some adaptation could produce real benefits to people living with disability and chronic conditions

✧ The involvement of people living with disability and chronic conditions, their families and communities, in the BTS model is readily achievable, but would have implications for timescales and the levels of support needed by local teams

✧ The need for clear strategies such as "Community Based Rehabilitation" and the "Framework for Innovative Care in Chronic Conditions" remains. As a methodology for improvement, BTS underpins those strategies, but does not replace them

✧ Whilst BTS is seen as a valuable methodology in this context there are currently no grounds for advocating its use ahead of other methodologies for improvement.
Appendix 1

SCALING UP COMMUNITY BASED REHABILITATION:
ADAPTING HEALTH CARE QUALITY IMPROVEMENT METHODS
3 – 4 February 2003 (W H O Headquarters, Geneva)

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Innovative Care for Chronic Conditions Framework

**Positive Policy Environment**
- Strengthen partnerships
- Support legislative frameworks
- Integrate policies
- Provide leadership and advocacy
- Promote consistent financing
- Develop and allocate human resources

**Community**
- Raise awareness and reduce stigma
- Encourage better outcomes through leadership and support
- Mobilize and coordinate resources
- Provide complementary services

**Health Care Organization**
- Promote continuity and coordination
- Encourage quality through leadership and incentives
- Organize and equip health care teams
- Use information systems
- Support self-management and prevention

**Links**
- Prepared
- Informed
- Motivated
- Community Partners
- Health Care Team
- Patients and Families

Better Outcomes for Chronic Conditions

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Appendix 3

Breakthrough Series
(6 to 13 months time frame)

Select Topic

Expert Meeting

Planning Group

Participants

Prework

Develop Framework & Changes

LS 1 → LS 2 → LS 3

Support

E-mail Visits

Phone Assessments

Senior Leader Reports

Congress, Guides, Publications, etc.

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