

RATIONALE FOR AN APPROACH TO IDENTIFYING DISABLED PERSONS IN COMMUNITY BASED REHABILITATION PROJECTS

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ABSTRACT

This paper outlines the considerations that need to be made when taking steps to identify the disabled population in a given community, as part of planning for a community based rehabilitation (CBR) programme. An overview of the literature and lessons learned, and discussion of important issues is provided. It emphasises the extent of thought and considerations suggested for engaging in the first stages of CBR planning, in order to promote successful CBR efforts.

INTRODUCTION

This paper explores various issues that need to be considered in planning steps for the identification of disabled persons in isolated communities with limited rehabilitation resources. Basic epidemiological information about how many disabled persons live in the community of interest is required, before any appropriate and responsive planning by the community can be made with respect to provision of health care for the disabled population. Also, the most common causes of disability in the region should be clarified. Planning for social and health services cannot adequately proceed without such information.

There are several approaches that one could take in trying to identify disabled persons. However, important principles of programme planning in community based rehabilitation (CBR), gained through collective knowledge and experience, should be applied from the start, in order to maximize long-term successes in any community endeavour that seeks to promote health.

OVERVIEW OF CBR (1)

Community based rehabilitation became acknowledged and gained acceptance with its promotion by the World Health Organization (WHO) in the late 1970s. Initially, CBR consisted of small projects in developing areas of the world, primarily as a means of service delivery (2), with a focus on restoring functional ability in disabled persons.

In the 1990s, CBR evolved to include comprehensive intervention in education, prevention, social rehabilitation, and vocational training, along with a shift to changing community attitudes and other contextual factors, acknowledging that disabled individuals do not live in isolation, but are influenced by community factors such as attitudes and acceptance, promotion of social integration, opportunities in education and employment, and community ownership of CBR programmes. This was reflected in the joint position paper of WHO, International Labour Organization, and United Nations Educational, Scientific, and Cultural Organization (UNESCO) (3), whereby CBR was defined as "a strategy within community development for rehabilitation, equalization of opportunities, and social integration of all people with disabilities" and is implemented "through combined efforts of disabled people themselves, their families and communities, and with appropriate health education, vocational and social services." The International classification of functioning, disability and health (ICF, 2001) reinforces the notion of contextual factors impacting impairment, activity, and participation (4).

Another influential movement is the disability rights movement, that stemmed from the Independent Living Movement (5) and the creation of Disabled People's International (DPI), leading to the development of international laws intended to protect the rights of disabled persons (6,7). One should be aware of local laws in planning for CBR. For example, in Ontario, Canada, the recent Ontarians with Disabilities Act, 2001 (8), would need to be acknowledged, and may spur communities to examine the issues in greater detail. This act was passed to improve opportunities for persons with disabilities, and "provide for their involvement in the identification, removal, and prevention of barriers to their full participation."

When it comes to prevention of disability, it is helpful to look at health promotion literature. Since ill health in society is often outside the individual's control, and could be socially, economically, and culturally constructed, Whitehead (9) proposes socio-political health promotion as an approach that avoids individualised behavioral-change programmes, and emphasises participation in public health policy making, social education programme development, political advocacy, and critical consciousness raising. Appreciation of lay knowledge regarding disability issues is therefore important.

Community participation is recognized as an important component of CBR planning, though full ownership by communities may not be possible at the beginning of programme development, as some communities are ignorant about consumer ownership of development programmes (1). Social learning theory supports effort being made to motivate the local community to participate. Participation by those who would be impacted by a programme would also be important for successful programme evaluation and revision (10). Integration of disability into development programmes requires cooperation between health, educational, municipal, and employment sectors. One could expand the effort to include all important

subsystems in community life (11): economics, health and social services, government, education, transportation, recreation, environment, communication, in the identification of strengths and stressors. Multi-sectoral collaborations can be impeded by power and control issues; a focus on goals may assist in facilitating the process.

An estimated 70% of people with disabilities could be handled at a community level, while 30%, those with multiple and severe disabilities, would require specialist intervention (1). Therefore, it is important to develop mechanisms for referral in order to access specialist intervention, and methods to recognize when such referrals need to be made. Those with severe disabilities tend to be neglected when it comes to community interventions, and it is important to include them from the start.

CBR in the 21st century requires evaluation to be incorporated into program planning. The need for evidence based practice and sharing of effective methods internationally is driving a move towards the development of accepted systems and good practice guidelines.

EFFECTIVE PRACTICE

Lazenbatt (12) identifies eight characteristics of effective practice: 1) holistic view of health and social need; 2) health alliances and inter-agency work; 3) empowerment; 4) research-based approach; 5) multidisciplinary team work; 6) needs assessment; 7) community development; and 8) audit and evaluation in practice. Empowerment may require a change in attitudes of both lay persons and professionals. Research into patterns of care, population needs, and resource availability is required. Community health analysis uses various data sources to look at health needs, strengths, and limitations in the community (13). Partnership and trust is essential, and involves clarification of roles and expectations of each partner. Time commitment is an important element in building trust. Financial and other potentially contentious issues must be frankly discussed. Good communication is important for the health of the partnership. Both quantitative and qualitative evaluation is important, as it has been acknowledged that quantitative methods that meet the criteria of statistical robustness can leave minority and vulnerable voices unheard.

IDENTIFYING DISABILITY

Traditional biomedical models of disability focus on impairment and functional abilities when it comes to identifying disabled persons, and rating severity of limitations. This stemmed from the 1980 WHO publication "The International Classification of Impairments, Disabilities and Handicaps" (ICIDH) (14). Using this model, disability can be quantified by functional scales such as the Barthel Index (15), or even the ICF itself, if qualifiers of body function, body structures, and activities are included in data collected.

The social model of disability, traced back to 1976 by the Union of the Physically Impaired Against Segregation (UPIAS), and adopted by the DPI (16), separates 'impairment' of the physical body, from 'disability' which is "a consequence of the failure of social organization to take account of the differing needs of disabled people and remove the barriers they encounter" (17). Only each disabled individual would be able to voice societal barriers encountered that contribute to disability. Priestly (18) outlined the interrelatedness of concepts in his four category classification of disability. One relates to the medical model, in which disability is an individual condition. Another takes account of personal interpretation of disability from experience. A third looks at social structures in creating disability, while the fourth relates disability to cultural roles and expectations. The ICF provides a means of methodically enumerating environmental factors that can be qualified and documented for each disabled individual, but personal factors have not yet been developed.

Some severely disabled persons may not be able to indicate their level of activities and participation. Unfortunately, there does not seem to be good correlation between measure provided by patients and those provided by proxy, by their caregivers or family members (19). Therefore, even early stages of data collection in CBR planning may exclude the most severely impaired people. When looking at strength of patient/proxy agreement, it appears that agreement is higher when using dichotomized responses (yes/no) or those with numeric information (20,21), and one would recommend the use of such questions if required.

Another subgroup of disabled persons that may be under-represented is disabled women, who in their relative state of isolation may be more vulnerable to exploitation and violence than their male counterparts (1). On the other hand, in some cultures, disabled men may be less inclined to seek help than women when they run into difficulties in functional tasks.

In assessing needs, Thomas and Thomas outline several questions that need to be considered (1):

1. What are the expressed needs of clients/families/community?
2. What are the current priorities of clients/families/community?
3. What are the existing beliefs and attitudes related to rehabilitation in the community?
4. How do different groups estimate the efficiency of existing rehabilitation services if any?
5. What are the gaps in existing rehabilitation services?
6. What changes do they feel are necessary to existing services?

Such information should be gathered early in the process, to allow for an accurate overview of the breadth of locally perceived needs, wants, and interests.

INDICATORS

Decisions as to what indicators to collect during the initial data gathering stage are critical in the ability to draw conclusions from a study or project. Short and long-term indicators can be considered (22,23). Examples of short term indicators could include service utilisation or access, and activities of daily living, while long-term indicators could include such measures as participation of disabled individuals in community activities, and changes in community attitudes. Boyce (22) identifies four main types of indicators, including those covering 1) policy 2) rehabilitation care provision 3) social and economic issues, and 4) disability status. It is important to give thought to indicators early.

COMMUNITY PARTICIPATION

It is acknowledged that the word 'community' has different meanings, and could comprise of various affinity groupings. For the purposes of this paper, 'community' is defined as a geographical region. It is generally believed that community participation is key for sustainability, which is defined by Thomas and Thomas as "the ability of a programme to perpetuate itself using appropriate strategies until its goals are fulfilled." They also outline different levels of community participation, from passive recipient to active involvement at all levels. Presumably, the greater the level of community participation there is, the higher the chance of ownership and sustainability.

PLANNING A STUDY TO IDENTIFY DISABLED PERSONS IN A COMMUNITY OF INTEREST

Research Ethics Board approval is required prior to beginning a study. One must educate oneself as to the appropriate procedures to be followed, for institutions, as well as for populations. For example, the right of self-determination of First Nations people in Canada includes the ability to make decisions about research in their communities. The National Steering Committee recommends that fact finding and analysis be participatory, and had approved a Code of Research Ethics July 1997 (24).

Once ethics approval is obtained, one could conceivably initially conduct a house to house survey to identify disabled persons, but such a low profile method would not necessarily increase early awareness of disability in the community. From the literature discussed above, it seems obvious that one should involve as many community members as possible in the development of a project. Therefore, even the beginning steps of a study should be designed to cast a wide net.

Informational campaigns could be employed in order to alert residents to the impending study. These campaigns could enlist the involvement of the community, perhaps in planning

an "activities and participation awareness week" or similar activity. During a campaign week, existing information about disabled persons and local efforts to improve services for disabled persons could be published, through a medium that most would have access to, such as radio programmes, and school/community programmes. Existing national survey information should also be shared, if available. The goals of the study would also need to be outlined, clearly stating its objectives of assisting the community to identify the scope of disability and issues to consider, while clearly declaring what it cannot accomplish. It cannot come up with solutions for the community, but could enable the community to address possible solutions from within.

After the awareness week, fliers and posters could be employed, just as Badger et al. (13) did, to maximise participation in their study. Two levels of fliers would be suggested: one aimed at individuals, and one aimed at community leaders, such as teachers, religious leaders, community health representatives, health policy makers, physicians, heads of policing and safety, and community administrators. Preparation for this would entail identifying and contacting these administrators about the study, and enlisting their cooperation. Individual fliers could be handed out door-to-door, after translation into the local language. For those who are illiterate, one could also advertise through local health radio programmes. Essentially, these fliers, posters, and air-time messages would encourage disabled persons to identify themselves, either directly to the primary investigator, or through their local leaders. More severely disabled persons may be identified by their caregivers or health professionals, with their consent. Radio broadcasts could be repeated to encourage maximal participation. Sufficient time should be allowed for reflection, participation, and identification of disabled persons in the community.

Once all, or most, of the disabled persons in a community are identified, a next step would involve collection of more detailed data, both about individual participants, and about the community. Is it important to document bodily functions and structures, or is it enough to collect data on activities and participation? This would depend on the purpose such data is collected for. Careful consideration needs to be made in design of data collection sheets. It is likely that one would need to collect information about impairments, activities, participation, environmental and social factors, most pressing needs and wants, and existing knowledge about disability management. Once again, sufficient time would need to be allowed for this stage of data collection.

Community knowledge about disability issues, disability prevention, disability rights, and barriers to participation, can only accurately be assessed by a full community survey. However, such an effort may not be feasible. Therefore, it may be necessary to randomly sample community members for potential participation in such information gathering processes.

As for existing community programmes and resources that address disability issues, one could survey leaders in the various sectors, using qualitative methods. For example, school

principals, religious leaders, administrators, and heads of relevant public institutions could be asked to provide such information.

Thus, at least three different types of surveys, targeting three different populations, need to be developed. Additionally, one could survey family members of disabled persons, such as their caregivers, children, or parents, to further identify important issues.

Once the issues are identified, and a broad overview obtained, one should involve all sectors of the community, as identified above, in determining priorities for change. Those who would directly be impacted by proposed change, disabled persons, would need to provide feedback on such ideas. Efforts must be made to prevent a powerful minority from controlling the process, and allow all groups voice. Skilled facilitators may be crucial during this stage of the process. As previously mentioned, focusing on goals may be a way to work around potential barriers, if they develop. It may be helpful to look at accepted corporate strategies for cooperation as a model for communities (25). Programme planning could then occur, based on the priorities developed. Discussion of programme planning is beyond the scope of this paper, but community involvement would be crucial for long-term success.

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**The Leprosy Mission International Announcement
for the Wellesley Bailey Awards 2005**

The Leprosy Mission International (TLMI) invites nominations for the Fourth Wellesley Bailey Awards. The Awards will be presented in the first week of June 2005 at a unique awards ceremony in Dublin.

The Awards are presented to people who have had leprosy and who have made an outstanding contribution to society - this can either be nationally in their community, or internationally. The person nominated must have shown courage and achievement in overcoming the challenges faced through leprosy.

Two separate awards will be given: one male and one female. Unsuccessful nominations from previous years can also be submitted for reconsideration. Please note the person nominated must not be told and self nominations will not be accepted.

The deadline for nominations is 10 January 2005.

Further information and background information can be obtained from:

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