**Title**
A sustainable approach to community based rehabilitation in rural and remote Australia

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**Word length: 3,659**

**Abstract**

This paper presents a summary of an extensive review of the health, disability and rehabilitation literature conducted for the purposes of informing the formulation of a sustainable approach to community based rehabilitation in rural and remote Australia. It begins with a review of definitions of disability and rehabilitation, which is followed by differentiating 'rehabilitation in the community' and 'community based rehabilitation'. Finally, a network of community based rehabilitation coalitions is proposed as a sustainable approach to community based rehabilitation in rural and remote Australia. Each coalition would have a community rehabilitation facilitator and community specific database of resources, as well as a register of local community rehabilitation assistants who can support the work of health professionals by providing rehabilitation interventions under the latter's direction. In this approach, rehabilitation is conceptualised as being about people's lives rather than only a series of interventions provided by health care professionals. As such, rehabilitation becomes everybody's business.

Keywords: Australia, community based rehabilitation, rural, remote, disability

## Introduction

Healthcare professionals, funding providers and the wider community have increasingly become aware of the value of rehabilitation for individuals experiencing functional limitations as a consequence of injury, illness, surgery or the ageing process. This has resulted in rehabilitation programs located in communities that are supported by traditional hospital based services. In these community programs it is common for health care professionals to provide rehabilitation interventions in the client's home. This model of service delivery, known as 'rehabilitation in the community', is not appropriate for most rural and remote communities due to the difficulties often associated with distances, low population densities and workforce shortages. The central premise informing this paper is that the existing paradigm of rehabilitation service provision needs to be augmented in order to maximise rehabilitation outcomes for individuals, their families and the communities in which they participate. It argues for this change by reviewing the salient literature and proposing a framework for the way forward.

## Project Activities

This paper presents the results of a project which sought to identify and recommend optimal approaches for community based rehabilitation in rural and remote communities of NSW. Over six months, the project team:

1. Established a stakeholder group;
2. Conducted a detailed search of the literature;
3. Consulted with providers of rehabilitation services to rural and remote NSW;
4. Consulted with the Queensland Health Community Rehabilitation Workforce project members;
5. Invited the stakeholder group to provide comment on the emerging framework for rural and remote NSW; and
6. Developed a final framework for community based rehabilitation.

## Literature Review

Exploration of the terms 'disability' and 'rehabilitation' was a critical starting point for this review of the literature. As revealed in the following discussion, defining disability and rehabilitation is not straightforward. In contrast, we draw a clear distinction between rehabilitation in the community and community based rehabilitation.

### *Defining Disability*

According to Robertson and Long[1] the medical model views disability as a variation from the physical norm that can disadvantage the person physically and in relation to quality of life. In the model, disability is often viewed as a loss, or a deficit, where disability is defined by tasks a person can no longer perform. [2] It is a model that is based on the assumption that disability is a physical condition that is less desirable than the norm, and that can be treated or changed through medical or therapeutic intervention. According to this view, barriers experienced by people with disabilities arise from individual functional limitations resulting from disability, as opposed to the idea that social factors limit individuals. [1]

Over time, the idea of 'disability in need of charity and of treatment' has been challenged by the disability movement (disabled people themselves). This is reflected in the emergence of three key ideas: the social model of disability, independent living, and the civil rights movement[3]. The social model of disability views disability as a result of social discrimination toward people who are different. [1] This represents a significant move away from the charity,

medical and welfare focus of the medical model towards a model that emphasises social connectedness, citizenship and support. [4]

The social model is predicated on the belief that disability is defined by culture, a concept about which there has been much debate. For the purposes of this literature review, we have chosen Royeen and Crabtree's[5] approach to culture, defining it as the:

> *sum of the experiences, values, beliefs, ideals, judgements and attitudes that shape and give continuous form to each individual. It is ... ideological (emphasing beliefs, values, ideals, thoughts) and material (social, linguistic, relational). It is ... everchanging.*

This means that what is perceived as a disability in one society or culture may not be viewed as such in another.[3] Thus, consideration needs to be given to the ways in which disability is perceived in different societies, not only in terms of materialistic and economic influences, but also in response to a number of cultural variables.[3]

The ecological model which is based on the premise that people and their environments are interconnected. In other words, "reciprocity and interaction occur among systems within which we live...systems can be defined as social organisations...that people interact with directly and indirectly". [1]

Throughout the literature these different approaches to disability have been presented in opposition to each other[3], yet no single model provides a complete approach to addressing disability. Rather, we are proposing an integrated view of disability that encompasses elements from all models in a way that will best serve to meet the needs of people with disabilities, their carers and communities. This integrated view has been recognised in The International Classification of Functioning, Disability and Health[6], which proposes a way of describing the impact of health conditions, including their impacts on physical, emotional and psychosocial ability of someone to function independently in their own environment. Like the social and ecological models, the classification seeks to redress the negative way in which disability has been perceived by focusing on the abilities of people with disabilities.

***Defining Rehabilitation***

Traditional western perceptions of rehabilitation during much of the 20th century focused on medical intervention to increase physical capacity, utilising a case management plan established and implemented by medical and allied health professionals.[7-8] Usually institutionally based and city centric, using qualified and differentiated personnel and sophisticated technology[9], medically based rehabilitation is costly and inherently inequitable in that it usually only reaches a small proportion of people with disability who would benefit from rehabilitation services, particularly in developing countries and in rural and remote areas of developed countries.[3-4]

However, the sociocultural and economic influences that have reshaped perceptions of disability have also had an influence on the nature of rehabilitation service delivery, evidenced in a move away from the medical approach towards a process whereby people with disabilities or their advocates make decisions about the rehabilitation services *they* [our emphasis] require.[3-4,10-11] This move is reflected in the person-centred rehabilitation and re-enablement literature, which lends some support to the view that rehabilitation is a process experienced and owned by clients.[12-14]

Person-centred rehabilitation is precisely that – rehabilitation planned together with a client and his or her carers, families and friends, around their goals, needs and existing circumstances.[15] From the person-centred perspective, rehabilitation can be defined as:

> *…help for the person to live fully again after being injured. It is about helping people to feel good about themselves, heal in body, mind and spirit, learn to do daily activities and move around again, earn an income, and remain accepted and valued by others. There are 3 goals in rehabilitation: healing, becoming able and rejoining the community.*[10]

Wade[7], on the other hand, suggests that "rehabilitation is a problem solving process just like any other problem solving process with its own specific focus on activity limitation, its own set of goals particularly optimisation of a person's social participation and wellbeing..." Combining the fundamentals of the various approaches suggests it is important to recognise that rehabilitation not only focuses on physical intervention, but also provides interventions which acknowledge that a person's physical, mental, emotional, social and spiritual needs impinge upon each other.[2,16-18]

All this suggests that determination of rehabilitation outcomes cannot be separated from the process of defining the patient's well being in the light of how society views 'the good life'. [2] Like disability itself, what this 'good life' entails will be culturally defined[19], suggesting that an understanding of the influences of cultures and subcultures is vital to achieving successful rehabilitation.[20]

Rehabilitation, therefore, can occur in a diversity of settings, for example, specialist hospitals and general hospitals as inpatients, day or outpatients, or in community clinics, community facilities, domiciliary rehabilitation, group settings, correctional facilities, camp settings, wilderness therapy settings and schools.[1,9-10] Thus, "the neighbourhoods in which we live, the stores where we shop, the schools where we are educated…the work spaces where we contribute are as much therapeutic settings as hospital based units". [21] Two approaches to achieving rehabilitation outcomes within the community context are discussed next.

**Rehabilitation in the Community**

Under the umbrella of medical[22] or physical rehabilitation[23], 'rehabilitation in the community' refers to rehabilitation services and programs provided by relevant health professionals in the community context. Most commonly this means health professionals going into a person's home to deliver interventions similar to those offered in inpatient rehabilitation programs. Health professionals working in these services may be based in community health facilities or provide outreach programs from inpatient rehabilitation services.[24] As such, rehabilitation in the community services and programs are influenced strongly by the medical model.

Rehabilitation in the community is frequently referred to as home- or domiciliary- based rehabilitation.[25] This is because the service is provided in the person's home. While there is great variation between these services, from the work of Geddes and Chamberlain[26] they seem to fall into four categories: 1) early discharge supported with rehabilitation; 2) additional post-discharge rehabilitation; 3) inpatient rehabilitation substitution; and 4) long term programs focusing on maintenance of function. Regardless of category, the primary focus of rehabilitation in the community services and programs is improved function in individuals.

Rehabilitation in the community should not be confused with community-based rehabilitation.[25]

**Community Based Rehabilitation**

According to Boyce and Lysack[27] community based rehabilitation (CBR) emerged in the 1970s with the intention to deliver "low-tech rehabilitation services" particularly to the large number of disabled people living in developing countries.[28] Then in the late 1980s with the emergence of human rights for people with disabilities, CBR shifted towards a greater focus on people and community development. Currently, CBR is defined as:

> *a strategy within community development for rehabilitation, equalization of opportunities, and social inclusion for all children and adults with disabilitie.s*[29]

Definitions of community development, a central focus of CBR, share a common element; that is, it is a process of bringing people together to achieve a common goal usually related to changing quality of life.[30] Some definitions involve the process of 'building networks' and improving the capacity of individuals and organisations[31], while others focus more on improvements within the community, for example, changes in infrastructure and environmental improvements.[32]

In terms of health related community development, we favour Allen's[33] approach, whereby community development is viewed as the process of involving communities from the ground up in their own decision making about factors related to health. This is closely related to the WHO definition of community development which is:

> *The utilization* [in an integrated program] *of approaches and techniques which rely on local communities as units of action and which attempt to combine outside assistance with organised local self determination and effort, and which correspondingly seek to stimulate local initiative and leadership as the primary instrument of change…*[34]

Both emphasise the importance of "conceiving health promotion programs through a negotiated partnership with the communities whose cooperation and participation the health promotion practitioner seeks".[35]

According to Labonte[36], this approach to community based health initiatives is founded on a set of values predicated on the belief that individuals have absolute worth; that people are able to learn and change; that people can work effectively together to change conditions that may be beyond individual control; that one individual may change one aspect of their life and that this may improve their overall health; that community participation and group process are enhancing in and of themselves, and that people are genuinely interested in participating in their own health. The ultimate goal, of course, is that community competence is improved and its capacity enhanced.

Achieving these goals requires a thorough knowledge of the health and health associated problems of the area involved.[35] It requires a thorough knowledge of the community itself, including its population, class structure, age structure, resources, power groups, power people, knowledge of normal processes of community action.[35] It also requires the establishment of community partnerships that both empower and engage individuals and groups through capacity building, community coalitions and community networking.

Capacity building is another aspect of community development, focusing on the building of social networks within the community and developing group and individual problem solving skills.[30] Community partnerships are broader, extending to collaborative efforts with less direct citizen participation and cultural diversity, and also to efforts with greater outside funding and institutional control.[37] One form of partnership is a community coalition.

Community coalitions are a means of pulling together the abilities, expertise and resources of numerous stakeholders to address a particular issue. Community coalitions can be groups of individuals, factions and constituencies who agree to work together to achieve a common goal through partnerships which coordinate existing prevention and health promotion efforts in communities and encourage or sponsor new ventures.[38-40]

Community coalitions, of course, could be networked. Networks have been established for community treatment of individuals with severe mental disorders in rural communities[41], particularly in relation to rehabilitation.[42-47] In Fried et al.'s[41] study community networks are defined as multidisciplinary sets of organisations that interrelate in some manner with individuals in the community. There appears little reason why such networks cannot also be utilised in community rehabilitation, particularly in rural and remote communities. Rural networking can help service providers reduce costs, manage scarce resources, compete effectively and possibly increase their bargaining power.[48]

**Implications of the Literature Review**

Rehabilitation in the community is an approach that often focuses on meeting the physical or medical needs of a person by outreach from a centre in a way that is largely determined by a particular institution or group of professionals.[3] On the other hand, CBR is a partnership between people with disabilities, their families and friends, their broader communities and rehabilitation service providers, which builds the capacity of all in a socially inclusive way. It is an approach that integrates people with disabilities into mainstream life by assisting them to meet their physical, social, employment, educational, economic and other needs, and which enables the communities in which they live to benefit from what they, as part of the community, then contribute.

Various barriers would need to be overcome for CBR to be implemented in Australia. Geographical barriers, particularly distance and travel time, are obvious difficulties, as is the low population density. Add to this, the already limited number of trained rehabilitation professionals, particularly those with community development skills, and it is easy to see why expectations of service provision by rural and remote residents are already inherently low. Often in CBR programs, traditional service providers are being viewed as handing over their responsibilities to already highly vulnerable and overstretched individuals, families and communities, constraints which naturally impact on the number of volunteers available, the amount of time they have to give, the cost of travel and overall perceptions of volunteering and quality of service provision. These barriers are such that, in rural and remote regions, it is probably unreasonable to base a model of CBR service delivery on volunteerism.

Any model of CBR will have to take into consideration the unique cultures existing in rural and remote communities; ensuring cultural safety and security particularly for Indigenous people is paramount. Failure to do this will inhibit the development of social capital and impede community ownership of whatever model is suggested. A particular challenge may be coming together with professionals from other health and non-health disciplines and working

as a team – that is if a team can be brought together in workforce-challenged rural and remote areas of the State. It is also important that any model of CBR for rural and remote Australia ensures that roles and lines of accountability are clearly defined.

**The Way Forward: A Network of Community Based Rehabilitation Coalitions**

Although the project brief was to focus on NSW service needs, it is our belief that the way forward proposed here has a wider relevance for much of rural and remote Australia. The concept of a *Network of Community Based Rehabilitation Coalitions* addresses the rehabilitation and general life outcomes sought by individuals, their families and most other members of their communities. These outcomes are to be actively participating in families and communities in ways they choose, and to aggressively ward off the decline in function and participation that can accompany disability, ageing and ill-health. The resourcefulness of individuals in relation to their own rehabilitation, and the valuable contribution of individuals to the rehabilitation of others in the course of their everyday working and personal lives are central to this innovative approach.

The concept of a *Network of Community Based Rehabilitation Coalitions* is informed by the principles of CBR; it is a blueprint for building a network of community coalitions. It employs a strengths based approach that draws upon existing community assets to increase community knowledge and utilisation of diverse rehabilitative forces. As such, it acknowledges the valuable formal and informal contributions of individuals and communities to the rehabilitation of themselves and others, but avoids over-reliance on volunteers.

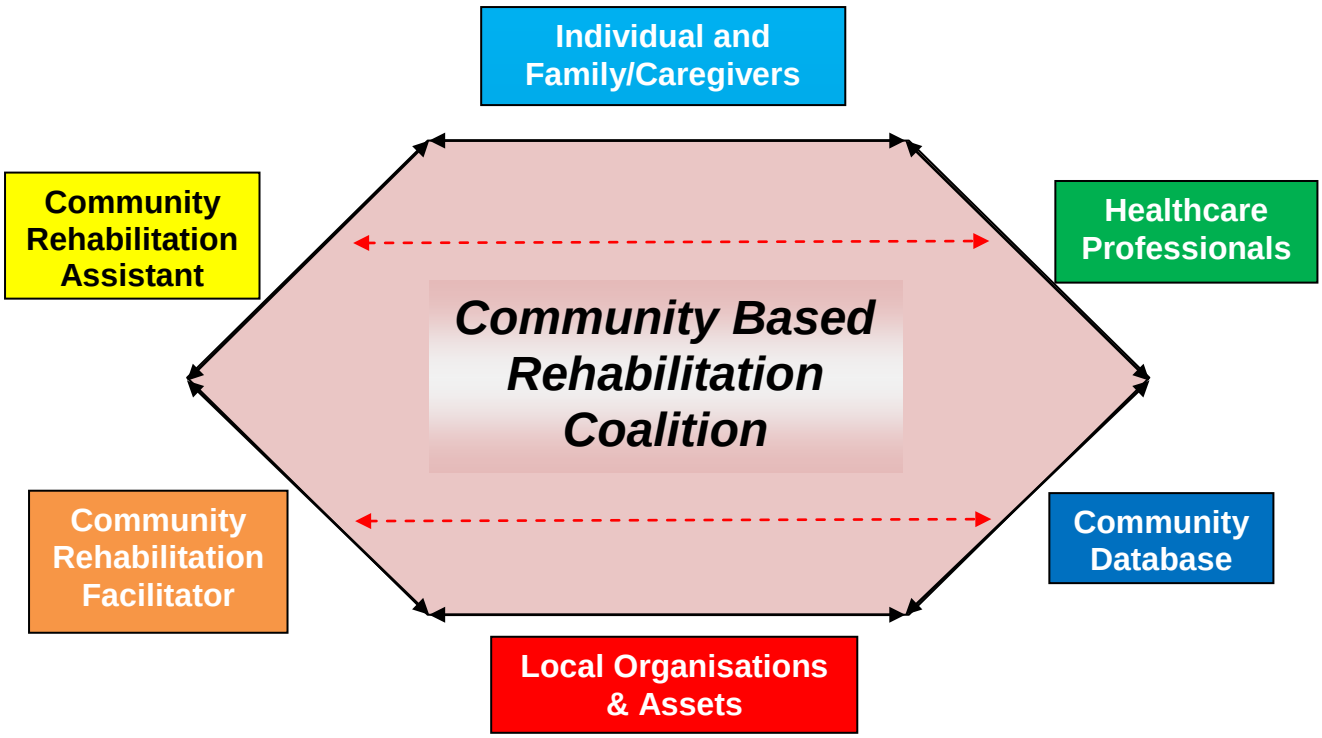
Most importantly, a *Network of Community Based Rehabilitation Coalitions* is designed to embrace existing and new services and programs associated with rehabilitation in the community. It is not proposed as an alternate to rehabilitation in the community, but as an important and encompassing framework within which such services and programs can be delivered.

The core components of a CBR coalition are:

1. Individuals who desire rehabilitation, and who may have supporting family/caregivers living nearby;
2. Healthcare professionals;
3. A Community Rehabilitation Database;
4. A Community Rehabilitation Facilitator;
5. A register of Community Rehabilitation Assistants; and
6. Locally available organisations and other community assets

Figure 1 illustrates the interactions of these core components in a CBR coalition.

**Figure 1: Community Based Rehabilitation Coalition**




Briefly we discuss community based rehabilitation databases, facilitators and assistants.

***Community Rehabilitation Databases***

In each Local Government Area (LGA), a Community Rehabilitation Database would be developed and maintained as an online resource. It would contain details of all services within the LGA and beyond (in the case of specialist services) of relevance to rehabilitation for members of that specific community and it would be accessible to community members.

***Community Rehabilitation Facilitators***

Each LGA, depending on population size and remoteness/accessibility, would have one or more Community Rehabilitation Facilitators. This position would be situated in, and administered by, the most appropriate organisation with a base in the respective LGA, as agreed by local government and other local organisations. The Community Rehabilitation Facilitator/s would:

- Establish an interagency network (if not already established) and collaborate with the local interagency network to facilitate wellness, rehabilitation and access for all members of the community;
- Develop a health profile of the LGA population;
- Conduct an initial community assets audit;
- Identify existing service providers and existing service support organisations from within or outside the LGA which are relevant to rehabilitation of community members and build links with them for the benefit of community members;
- Identify and establish the most appropriate and effective mechanisms for inviting and involving local consumers (individuals and their families) to contribute to the development of the Community Rehabilitation Database; and

- Gather information from Service Providers, Service Supporters, Community Representative/Leaders, and Individuals/Families who want improved support and rehabilitation services.

***Community Rehabilitation Assistants***

Community Rehabilitation Assistants are Allied Health Assistants and Enrolled Nurses who work under the direct (or in-direct) supervision of health professionals such as Physiotherapists, Occupational Therapists, Speech Therapists or Registered Nurses. They will be drawn from the local community they serve. They extend the reach of health professionals they work with, can provide health professionals with useful contextual knowledge and insight, including cultural sensitivity issues, can enable the health professional to operate more efficiently, and constitute a pair of hands for the health professional on the ground in a given community, with this replicated across communities for any given health professional.

**Recommendation and Conclusion**

In order to operationalise this concept further, feasibility needs to be explored through dialogue with potential stakeholders in rural and remote communities. Potential communities could include rural towns, remote centres and Indigenous controlled communities. Following this, we recommend that a pilot community, as a collaborative group, be identified to develop a *Community Based Rehabilitation Coalition*, and to seek funding to support a pilot project. The pilot, involving stakeholders drawn from health, disability, federal, state and local governments, and non-government local community groups, would collaboratively develop a detailed plan, implementation strategy and evaluation processes. Finally, the *Community Based Rehabilitation Coalitions* framework has relevance for metropolitan communities, and opportunities for a metropolitan pilot site are also warranted. In fact, this will be important to ensure that the *Community Based Rehabilitation Coalitions* framework is not seen as a second rate health service for rural and remote communities.

**Acknowledgements**

The authors would like to acknowledge the NSW Institute of Rural Clinical Services and Teaching for funding the project and its Executive Director, Ms Linda Cutler, for valuing clinician concerns regarding access to rehabilitation for people living in rural and remote NSW. We are grateful to the members of the Stakeholder Group for their participation and in some cases for hosting a visit by the Project Team.

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