Community Based Rehabilitation (CBR) as Engagement: Context, Parameters and Potential

Willem (Pim) Kuipers
BA *DDIAE.*, BA (Hons) *Tas.*, MA *Calvin, MI.*,
Grad Dip Rehab *Griff.*, MAPsS

Submitted in fulfilment of the requirements of the degree of

Doctor of Philosophy

Faculty of Health Sciences, Griffith University.
February, 1998

Abstract

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Paradigms in rehabilitation and disability service delivery in economically developed countries are currently being challenged and reviewed. An analysis of rehabilitation and disability literature arising from these countries, identified a number of issues of concern. Utilising a systems framework, adapted from the work of Urie Bronfenbrenner, the analysis indicated that certain aspects of current paradigms, may have adverse impacts on people with disabilities. It was determined that new paradigms should be explored. An analysis of current trends of relevance to the disability sector, identified a number of important directions, particularly the significance of the community paradigm.

Community Based Rehabilitation (CBR), a disability service delivery approach which has arisen in developing countries, was proposed as an approach which was consistent with the identified trends and the community paradigm, and which constituted a constructive response to the identified concerns. It was noted however, that CBR lacked a strong research base and that fundamental principles had not been clearly elucidated. Based on the current literature, a detailed description and analysis of CBR was undertaken, and strategies, benefits and limitations of the approach were documented. The description of the parameters of CBR resulted in the elucidation of an evolutionary process, and the identification of key principles. It was proposed that the defining concept of CBR is 'engagement' between people with disabilities and their local communities. This concept was seen as having greater import, beyond the traditional contexts in which CBR has traditionally been employed. The possible application of CBR to economically developed countries was considered at a theoretical level.

In order to explore the potential of the notion of engagement, two multi-phase, qualitative studies were devised and conducted in South East Queensland. The inductive phase of the research, which involved both studies, resulted in the development of a model consisting of five bipolar axes. This 'model for enhancing engagement', described the process by which

engagement between users of human services (specifically people with disabilities) and their local communities might be maximised.

The subsequent deductive phase of the research consisted of an exploration of the potential utility of this model through the two studies. Within the limitations of the qualitative design, the research indicated that the model had practical utility in the current context. In order to confirm concepts within the model, and consider its congruence with the field of CBR, a final verificatory phase was employed. This phase drew data from other sources to provide a degree of confirmation of the concepts within the model.

The primary outcome of the research was the development of the 'model for enhancing engagement' between people with disabilities and their local communities. This model was described and its potential application was considered at a conceptual level.

Three subsidiary outcomes were also seen as contributions of the research. First, a descriptive and conceptual framework, based on the work of Urie Bronfenbrenner, developed and applied in the current studies may have further utility. Second, a detailed analysis of the CBR literature resulted in the documentation of an evolutionary process in CBR, the identification of key principles, and the proposal of the notion of engagement. Third, a comprehensive, multi-phase, qualitative research process devised for the research which meets requirements for rigour and effective data presentation.

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Acknowledgments

Firstly, I wish to acknowledge the assistance and forbearance of those who participated in the research. They were, the members and associates of Community Disability Alliance, particularly individual members of the Sunshine Coast branch; the members of the Returned and Services League and associated organisations who participated in the study, particularly Mr Bob Taylor; and the ICACBR, Queen's University, Ontario, particularly Associate Professor Mary Ann McColl who provided access to internal data.

I am particularly indebted to three people who read and commented on an early draft of the thesis or parts of it, Dr Maureen Fitzgerald, Medical Anthropologist, Senior Lecturer, Department of Occupational Therapy, Faculty of Health Sciences, The University of Sydney; Ms Penny Price, Lecturer and CBR Consultant, Faculty of Education, Macquarie University; and Ms Elizabeth Henley, Senior Lecturer, Department of Physiotherapy, Faculty of Health Sciences, The University of Sydney. Each gave of their time and energy generously.

I am very thankful for the assistance and guidance of my supervisors. Emeritus Professor Arthur Brownlea, Faculty of Health Sciences, Griffith University, provided substantial assistance and support in instigating and conceptualising many aspects of the study. Dr Nicholas Buys, Senior Lecturer, School of Human Services, Griffith University, assisted in many areas, particularly with practical refinement of the study and the thesis. Ms Robyn Twible, Lecturer, Department of Occupational Therapy, The University of Sydney, contributed her experience and enthusiasm for the field of CBR.

I owe by far my greatest debt to my wife, Kathy and our son, Nicolaas. Their support has been unstinting and their encouragement, immeasurable.

Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Willem Kuipers

Section A

CONTEXT

An Analysis of the Rehabilitation and Disability Services Context as Foundation for Exploring Alternatives

And the men of Issachar ...
had an understanding of the situation and the times,
they knew what Israel ought to do,
... and they led their people.

1 Chronicles 12:32 (Adapted)

Chapter One

Contextual Overview, Preliminary Issues and Definitions

1.1 Introduction

As the introduction to the thesis, the purpose of this chapter is to describe why and how the research was undertaken. The chapter commences with the rationale for the research. The primary research question is then presented. An overview of the thesis is provided, which describes the way in which the research question was addressed. The philosophical context of the research is identified. A descriptive framework, based on the work of Urie Bronfenbrenner which guided the conceptual flow of the research (and the thesis) is also described. The chapter concludes with the definition of relevant terms.

1.2 Rationale

Prevailing paradigms within rehabilitation and disability service delivery in economically developed countries are currently being challenged (Cocks, 1994). These paradigms and the associated models of service delivery, have been found wanting on a number of grounds, particularly social and community dimensions (Chenoweth, 1995; Cocks, 1994; Gregory, 1994; Schwartz, 1997). In this regard, service delivery may have failed to address the level of social dislocation and disenfranchisement from communities which currently constrain people with disabilities (Monach & Spriggs, 1994; Schwartz, 1997).

In response, a re-evaluation of current paradigms and a search for potential alternative paradigms and models is warranted. Indicators towards such an alternative may be drawn from a number of important contemporary trends. These newly emerging trends, which are guiding Western societies and many disciplines, emphasise key aspects which appear absent from traditional approaches to rehabilitation and disability service delivery. Consequently, the search for new paradigms, which are consistent with these trends, should extend beyond traditional service delivery models.

The rationale for the current research was to formulate a response to this situation. The study sought primarily to conduct and present a comprehensive analysis of disability service responses which would facilitate enhanced social and community integration of people with disabilities.

1.3 Research Question and Overview of the Current Research

From a personal perspective, the main question upon which the current research was based, stemmed largely from the researcher's experience over a number of years as a psychologist in disability and rehabilitation services. Having worked alongside people with disabilities in a variety of contexts, the researcher identified a need to explore a more constructive alternative to disability services, than those which currently predominate in South East Queensland, Australia. Consequently, the guiding question for the research was,

> **What constructive alternative to traditional disability services can be identified; and how might such an alternative be conceptualised to assist people with disabilities in South East Queensland?**

This exploratory question was addressed through three stages, which are represented by the first three sections of the current thesis. *Section A*, consisting of the first three chapters, comprises an *analysis of the rationale and context* of the research. In the early stages of the research, it was recognised that the study pertained to a number of complex issues which lacked a consistent conceptual theme. In response, it was determined that there was a need to use a single descriptive framework through the whole study and the thesis, which would provide a consistent and clear means of describing concepts and issues in this study. To this end, an ecological framework based on the work of Urie Bronfenbrenner (1979) was adapted and applied. This framework is described in the current chapter.

Second, it was recognised that a clear identification of concerns relevant to the rehabilitation and disability sector, would provide a comparative background, against which needs could be identified and potential alternatives explored. A critical review of selected issues, using the adapted Bronfenbrenner framework was undertaken. This review, which comprises Chapter Two, resulted in the identification of a number of issues of concern which were seen as potentially useful indicators for the consideration of constructive alternatives. A major observation of the critical review, was that community issues were often neglected in current approaches to the delivery of rehabilitation and disability services.

Third, it was determined that further cues for the identification of a constructive alternative would arise from an exploration of emerging trends in related contexts and disciplines. This exploration (Chapter Three), drew from a number of perspectives to conclude that a community oriented paradigm is emerging, which may have significant relevance to disability issues.

Having noted the potential of a community paradigm, the current research identified and explored a particular approach to disability services which was consistent with that paradigm. This approach - Community Based Rehabilitation (CBR) - was seen as an important emerging, yet largely unresearched area. An *analysis of the parameters of CBR* comprised the focus of *Section B* of the current thesis.

In recognition of the paucity of published research pertaining to CBR, it was determined that a comprehensive literature analysis of CBR was warranted. This analysis is presented in Chapter Four. A particular focus of this chapter was the exploration of the evolving nature of CBR in developing countries. In order to provide a measure of consistency and conceptual flow, the theoretical framework noted above, was utilised to assist in reviewing and conceptualising CBR. Arising directly from the literature analysis, the fifth chapter described the key principles of CBR and through a further synthesis of the literature, proposed the concept of 'engagement between people with disabilities and their local communities' as the essential feature of emergent forms of CBR. The final chapter of the section, Chapter Six, comprised an extrapolation from preceding chapters to consider the potential applicability of CBR to economically developed countries.

As will be apparent, Chapters One to Six are not solely a review of the literature, but comprise an *analysis* of relevant literature. This analysis was conducted through a cyclic process of thematic categorisation of concepts in the literature, the identification of common sub-themes and subsequent synthesis of various themes into consistent concepts. This process was assisted by the use of an electronic database for storage, investigation and retrieval of information. Consequently, these chapters are a central element of the research enterprise, informing and guiding the process, rather than acting as an introductory review.

Having identified the notion of engagement as a relevant construct, it was determined that its potential utilisation should be further explored. *Section C* of the current thesis comprised an exploration and *analysis of the 'potential' of the notion of engagement* to assist people with disabilities in South East Queensland. With reference to the original research question, an appropriate research methodology was sought and research contexts were identified (Chapter Seven). A grounded qualitative methodology was selected, and two community based

organisations provided the context for inductive and deductive phases of the research. A verificatory phase of the research utilised information from previous studies. In order to ensure a robust methodology, significant emphasis was placed on tailoring and detailing the research process. In particular, the need to balance rigour with explanation and reflexivity was considered important.

Each phase noted above, (inductive, deductive and verificatory), contributed to the development of a 'model for enhancing engagement between people with disabilities and their local communities'. This model, consisting of five bipolar continua, is reported in Chapter Eight. This chapter also addresses the issue of the appropriate presentation of qualitative data.

Section D which comprises the final chapter, describes features of the model and the research enterprise. Potential implications and critiques of the model are also presented

As is evident from the foregoing description, the current thesis has sought to balance theory with praxis. The research has sought primarily, to ensure outcomes of relevance to the practical level of rehabilitation and disability service delivery. The primary focus of the research is exploration of a potential alternative, as a basis for future practice. Notwithstanding this priority, some issues of relevance to social policy, disability theory and philosophy are also discussed.

1.4 Philosophical Stance of the Current Research

Qualitative researchers, Michael Huberman and Matthew B. Miles (1994) stated that to know a researcher's philosophy of research is to know how they construe and shape the social world and how they will give a credible account of it. In this vein, the current study has sought to elucidate the philosophical perspective of the researcher (and hence the project as a whole).

The current research project has arisen from an eclectic philosophical framework with the following hallmarks.

- A *realist* assumption. The current research assumes that phenomena do not simply exist in the mind, but in the objective world, and that there are some relatively stable relationships between social phenomena (Huberman & M.B. Miles, 1994).
- A moderate *phenomenological* position. Within the current thesis, the importance of understanding the participant's worldview and perception of reality was acknowledged. It is maintained that knowledge is perspectival, and therefore the perspective of the research

participant is central to any exploration. It also follows that the researcher's perspective must be made explicit (Altheide & Johnson, 1994).

- A *naturalistic* orientation. The researcher sought to avoid manipulation of research participants and the imposition of a-priori conditions on research (Gliner, 1994).
- A commitment to the *perspectives of people with disabilities.* A participatory approach was sought where possible, in order to explore issues from the perspective of people with disabilities. Despite this, it is acknowledged that the current research was primarily conducted from an academic, rather than emancipatory perspective.
- A *grounded* framework. The research enterprise within the current thesis sought to 'ground' research concepts through an interplay of repeated comparisons between the emerging concepts and the data. This form of social research is by nature, iterative and progressive. Generating theory and doing social research are seen as two parts of the same process (Strauss & Corbin, 1994).
- A *pragmatic* commitment. The current study, as an exploration within the human services, has sought to address practical issues, seeking a degree of social relevance. This commitment does not preclude the need for research to come under scrutiny from the academic community, it actually requires a further level of scrutiny - the service user community.
- An *eclectic* orientation, in which many sources are viewed as appropriate for data gathering. In the current study, this is reflected in the use and analysis of literature as a source of information, and in the utilisation and reanalysis of data from previous studies to meet research needs. The importance of literature as an element in the sequential research enterprise is reflected in the current thesis. Literature formed both a context and a source of information for the research (Holloway & Wheeler, 1996).
- A *postmodern* context. The current research enterprise acknowledged that it may not be possible to separate the content of what is presented from the meta-narrative of how it is presented (Altheide & Johnson, 1994). That is, the presentation of the research is inextricably linked with such factors as the context in which it is presented, the rhetoric used, the discipline from which it emerges, and so on. A postmodern awareness of the global and interconnected nature of issues is also evident throughout the thesis.
- An *analytical and exploratory* curiosity. The research grew out of the researcher's interests rather than imposed guidelines.

While acknowledging the calls to avoid overly prescriptive philosophical frameworks (Holloway & Wheeler, 1996), the above influences will be evident in the current study.

1.5 A Descriptive Framework for the Current Research

The subject area of the current research, incorporates a number of distinct disciplines, disparate service approaches, different philosophies, and divergent methodological positions. During the research process, it became evident that a theoretical structure, which had sufficient descriptive power to contextualise each of these differences, would be beneficial. Other than the social / medical model debate, the area of rehabilitation and disability service delivery, seemed to be lack comprehensive, critical frameworks. Reynolds (1971) stated that for a discipline to advance, there must be (among other things) concepts and frameworks which are independent of time and space, and which promote agreement about meaning.

In response to this need, a descriptive framework was sought which was sufficiently comprehensive to describe the various aspects of rehabilitation and disability service delivery within the broader social context. A primary rationale behind the search for such a descriptive framework, was to provide a unifying theme for the research as a whole, and to enable the researcher to contextualise factors such as,

- The various spheres of action and involvement in which a person with a disability might participate.
- The social forces and influences which may impact upon a person with a disability.
- The levels of formal and informal service delivery in which they may be involved.
- The various rehabilitation treatments and therapies in which they may participate.

A number of existing frameworks were considered from within the subject area (Cook, 1996; Helander, 1993a; Kisanji, 1995; Livneh, 1989; McColl & Patterson, 1995; Sherwen, 1992), however the purposes of the current study were considered outside of the goals of these models. After further review, a model devised by Urie Bronfenbrenner (1979) was adapted and extended. The use of this model as a framework, (a) facilitated the description of concepts, (b) provided uniformity for critical analysis, and (c) aided in the identification and clarification of issues in the exploration of potential alternatives to the current paradigm.

1.6 The Bio-Psycho-Social Ecology Model: An Adaptation and Extension of Bronfenbrenner's Social Ecology Model

Bronfenbrenner's Social Ecology Model (Bronfenbrenner, 1979) was originally devised as a description of human development and was intended to broaden and contextualise existing research and practice within that field (Petrie, 1996). While the focus of Bronfenbrenner's model is the ecology of human development, with adaptation it provides a helpful descriptive tool for comprehensively analysing the ecology of settings and services around a person with a disability. It can be used to describe social and other variables which impact on the life of a person with a disability.

The model conceives of the ecological environment around an individual as a set of nested structures, focusing on interaction between the characteristics of the individual with specific levels comprising the individual's context (Bronfenbrenner, 1979; Lefrancois, 1996). It is acknowledged that the use of this model in the current study extended its application beyond Bronfenbrenner's intention, however the comprehensive ecological nature of the original model, and its direct applicability to themes within the current study, warranted its utilisation. The present thesis drew on precedents which have extended and applied the model in human service settings. For example, Petrie (1996) applied the model in a study of the role of care providers, and Berry (1995) applied it in an exploration of families of persons with a disability and deinstitutionalisation.

Bronfenbrenner (1979) identified four levels of structure, the micro-system, the meso-system, the exo-system, and the macro-system. Together these describe the person's social environment or 'social ecology'. Within the field of disability and rehabilitation however, the influence of physical and psychological factors are also major considerations (Marks, 1997). Consequently, the current adaptation added a further two systems, the bio-system, and the psycho-system. These two 'intra-personal' systems are interrelated and closely linked. They pertain directly to the person, rather than their social ecology. In reference to the addition of two more system levels, the adapted model was termed the Bio-Psycho-Social Ecology Model. In the current context it was utilised to describe the person with a disability in his or her ecological context. Figure 1.6 schematically depicts the adapted model, with each level described below. This figure illustrates the bio and psycho-systems as parts of a whole to convey the interrelationship between these systems and a person's social ecology. It should be noted that this figure is for illustrative purposes, and not intended to suggest a mind/body dualism.

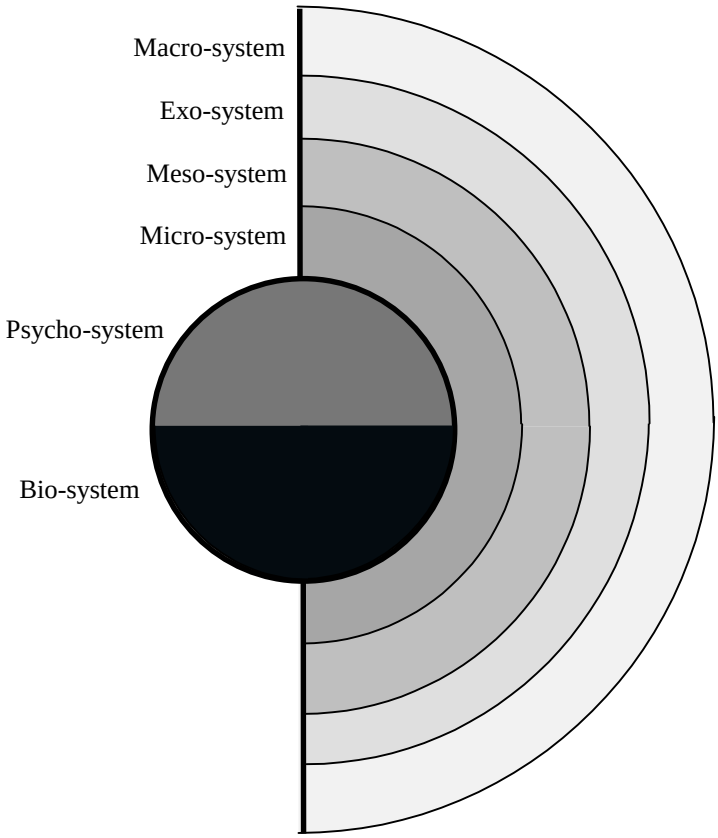

Figure 1.6 The Bio-Psycho-Social Ecology Model - An extension and adaptation of Bronfenbrenner's Social Ecology Model

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1.6.1 The Bio-System

This primary intra-personal system is the first addition to Bronfenbrenner's original model. It might be seen to consist of the physical systems of the body as they influence, and are influenced by, the rehabilitation process. It is used to describe biological and physiological systems as they exist and interact with other systems. In the current context, the description of this system assists in contextualising and categorising, among other things, medically defined conditions and impairments which can be influenced in the main, by primary and secondary rehabilitation and therapy.

1.6.2 The Psycho-System

This system which also pertains to intra-personal issues, is a further addition to Bronfenbrenner's model. It describes psychological systems as they influence and are influenced by other systems, most notably those systems in close proximity. Within the rehabilitation process, this system might be used to describe and contextualise the affect,

coping styles, and adjustment to injury of the person with a disability. These processes can be influenced by psychosocial rehabilitation and psychological interventions as well as internal and external events.

1.6.3 The Micro-System

This is the first level within Bronfenbrenner's original model. It was described as "a pattern of activities roles and interpersonal relations experienced by [in this case, the person with a disability] in a given setting with particular physical and material characteristics" (Bronfenbrenner, 1979, p. 22). It consists of immediate relationships within the home, family, peer group, and workplace (Lefrancois, 1996) which have a direct impact on experience (Schaffer, 1996). In the present study, the micro-system level is taken to describe immediate person-to-person social relationships, such as occur in the family and the person's close interaction and support network, as well as informal peer groups.

1.6.4 The Meso-System

In Bronfenbrenner's model, this system "comprises the interrelations among two or more settings in which the [person with a disability] actively participates ... such as among family, work and social life" (Bronfenbrenner, 1979, p. 25). Social settings described within the meso-system are more diffuse and more formal, than the immediate relationships which comprise the micro-system. In the present study, this level is taken to refer to broader networks of people, such as social groups, formally organised and structured groups, and formal elements of the person's local community. It is defined by the relationships and linkages between two or more micro-systems (Lefrancois, 1996; Schaffer, 1996).

1.6.5 The Exo-System

This level consists of "settings that do not involve the [person with a disability] as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the [person with a disability]" (Bronfenbrenner, 1979, p. 25). This level refers to formal systems such as, the social welfare system, the health care system, the mass media (Berry, 1995) and systems and organisations of disability service delivery. All of these formal systems are inextricably linked to, and influenced by, government policy and legislation. Consequently in the current context, systems of policy development and administration are seen as aspects of the exo-system.

1.6.6 The Macro-System

Bronfenbrenner (1979) stated that this highest level "refers to consistencies... that could exist at the level of the sub-culture or the culture as a whole, along with any belief systems or ideology underlying such consistencies" (p. 26). In the present study, this level is taken as referring to social ideologies, customs, social attitudes, social roles, status assignments, lifestyles, etc. It is the totality of all other systems evident in beliefs, lifestyles, values, etc. (Lefrancois, 1996).

Discrepancies and ambiguities regarding the exact components of each system are acknowledged (Berry, 1995; Lefrancois, 1996; Schaffer, 1996). However, given that the Bio-Psycho-Social Ecology Model in the present study was used as a general conceptual tool, specific detail regarding the nature of each category is not essential. As broadly outlined above, the model served as a basis for conceptualising and contextualising aspects of the present study and formed a unifying theme for the concepts and suggestions which emerged from the literature and the research.

1.7 Definition of Terms

1.7.1 Rehabilitation

Dealing with an area where different meanings are applied to terms in different countries, it is necessary to define a number of terms in the current thesis. In Australia, the term 'rehabilitation' usually refers to the formal provision of primary, secondary or tertiary level rehabilitative services (such as medical intervention, therapy and psycho-social interventions). In North America, (and in many developing countries) the term is used more broadly, and routinely refers to the whole spectrum of activities pertaining to people with disabilities. Since the current study drew from an international perspective, the broader definition was applied. Aitken and Walker (1987) provided such a broad, community based definition, stating that rehabilitation consists of "what is necessary in the community to help society discharge its acknowledged duty to ensure that there are no unnecessary barriers to the achieving of equality of opportunity for disabled people" (p. 60).

More specifically, Helander (1993a) provided an operational definition of rehabilitation which reflects the breadth of the concept used in the present study.

> Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self actualisation. Rehabilitation includes not only the training of disabled people but also interventions in the general systems of society, adaptations of the environment and protection of human rights. (p. 17)

Consequently, the definition of rehabilitation used in the current thesis, follows perspectives used internationally, encompassing both equalisation and maximisation of skills, independence, opportunity and social circumstances.

1.7.2 Disability

A commonly cited definition of disability, particularly within the field of CBR, is that provided by the World Health Organisation (WHO), in which a disability is considered to be "Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (World Health Organisation [WHO], 1980). While this may be a constructive definitional starting point to describe disability, it is important to recognise that disability can not be understood outside of its social and temporal context (Marks, 1997), or its cultural and developmental context (Helander, 1993a). Further, as implied in the Americans With Disabilities Act (1990), disability is also largely defined by individuals, who may or may not consider themselves disabled, irrespective of normative data. Marks (1997) stated "Rather than seeing disability as a clear cut, fixed condition, it is more

accurate to see disability as existing along a continuum with blurred and changing boundaries" (pps. 85-86). Consequently, while the current thesis acknowledges the predominance of traditional definitions of disability, and that these pervade many of the source documents of the thesis, it contends that disability is a socially constructed entity, without definable boundaries.

1.7.3 Human Services

The current research, while specifically addressing rehabilitation and disability issues, recognised the potential application of concepts within this thesis beyond this immediate setting. As such, at specific points, the research also explored issues which apply to the human services in general. Human services are defined as approaches which meet human need across a range of circumstances and contexts, including disability, ageing, family, child and youth services, ethnicity, substance abuse, corrections, and mental health (National Organisation for Human Service Education & Council for Standards in Human Service Education [NOHSE & CSHSE], 1996)

1.7.4 Community Based Rehabilitation

CBR is defined and discussed in detail in Chapter Four, however an introductory definition is warranted. A current definition of CBR devised by three United Nations agencies is,

> Community based rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services. (International Labour Organisation [ILO], United Nations Educational, Scientific and Cultural Organisation [UNESCO] & World Health Organisation [WHO], 1994)

Historically, CBR programmes have largely emerged in developing countries. Typically such programmes aim to improve the skills, and daily life of people with disabilities. They tend to include people with all types of disabilities, and seek to be sufficiently flexible in design so that they operate appropriately within different local contexts (Glynn, 1996a). A key characteristic of CBR programmes identified in the current study, is that they shift the focus of interventions from the individual to the community, or more specifically to the individual within his or her community context.

1.7.5 Developing Countries

While recognising the pejorative nature of the term 'developing countries', this thesis utilised the term to refer to what others have referred to as 'the third world' (Werner, 1993) or 'the south' (Gumbel, 1997). These countries, mostly in Africa, Asia, Central and South America, are characterised by lower literacy and life expectancy rates and gross national products below the international mean. Many of these countries are international donor aid recipients. 'Developing countries' would appear to be the most widely accepted term in literature emanating from those countries (Balasundaram, 1992; Monekosso, 1992).

1.7.6 Economically Developed Countries

Despite being somewhat cumbersome, this term is preferred for referring to the more technologically advanced nations, variously referred to elsewhere as 'the west' (Kalyanpur, 1996), 'developed countries' (M. Thomas & M.J. Thomas, 1996), 'the developed world' (Anderson, Fitzgerald, Yee & Wallace, 1996), or the 'the north' (Gumbel, 1997). These countries are mostly located in Western Europe, North America and the South Pacific. The majority of them operate under a welfare state approach, in which the state undertakes to supply its citizens with educational, health and social services, meeting costs through taxation (Mann, 1997).

1.8 Conclusion

This chapter has laid a foundation for the current thesis by describing the rationale for the study, the research question, and relevant terms used in the thesis. The chapter includes an overview of the thesis and the research process. A descriptive framework which was adapted to provide a consistent conceptual and descriptive structure for the thesis, was described. Philosophical assumptions which underpin the current study were also identified.

Chapter Two

Issues of Concern in the Rehabilitation and Disability Sector in Economically Developed Countries

2.1 Introduction

The purpose of this chapter is to identify a number of concerns in the rehabilitation and disability sector, against which a potential alternative may be contrasted. Utilising the Bio-Psycho-Social Ecology Model as a conceptual framework, the chapter explores a number of points relevant to disability service provision in economically developed countries. Rather than seeking to provide an exhaustive overview or empirical evaluation of the current state of rehabilitation, the current chapter examines a number of particular concerns which will guide the exploration of constructive alternatives. These concerns are summarised as follows.

- At the bio- and psycho-systems levels, a tendency towards 'medicalisation' of service delivery may be discerned.
- At the micro-systems level, a degree of social dislocation of service users is evident.
- At the meso-systems level, a neglect of genuine community participation may be noted.
- At the exo-systems level, current approaches to service delivery and policy development may be seen as somewhat remote and potentially insufficient.
- At the macro-systems level, it may be noted that attempts to change social attitudes are inappropriately focused.
- Across system levels, influential issues such as, demographic and economic changes, growing consumerism, managerialisation and 'balkanisation' have considerable impact within the sector.

A common theme of these concerns is their negative influence on, or lack of regard for, issues of relevance to the nexus between community and disability.

2.2 Issues at the Bio-systems and Psycho-systems Levels

The first two system levels in the Bio-Psycho-Social Ecology Model when applied to disability service delivery, may be seen to comprise primary and secondary (and some forms of tertiary) rehabilitation interventions which address physical and psychological processes, relevant to impairment and disability. While few studies have attempted broad scale evaluations of the effectiveness of physical and psychological rehabilitation (Söderback, 1995), it is generally held that traditional rehabilitation, directed towards the bio- and psycho-systems levels is clinically effective (Söderback, 1995), particularly in inpatient settings (Evans, Connis, Hendricks & Hasselkorn, 1995).

The strengths of bio- and psycho-system level rehabilitation intervention are evident in the clinical, experimental and professional approaches typically applied in these settings. In recent years however, a trend towards greater community and social emphases has emerged in rehabilitation. Despite this psycho-medical rehabilitation services in economically developed countries have sought greater clinical specialisation and increased technology, demanding higher expenditure (Mann, 1997).

Traditionally, critiques of rehabilitation at these levels have drawn heavily upon political and sociological perspectives (Craddock, 1996; Oliver, 1990). It is noted however, that relevant issues of concern may also be considered from a 'community' perspective. For example,

- Primary and secondary level rehabilitation interventions tend to occur outside of the person's natural community context. Interventions and assessments in such synthetic environments may lead to unrealistic and inaccurate perceptions of handicaps and disabilities (Drubach, Kelly, Peralta & Perez, 1996).
- The impersonal nature of psycho-medical level rehabilitation may mitigate against important relational issues. Gregory (1994) observed that in rehabilitation, the 'technological', the 'material' and the 'mechanistic' are supplanting the 'human' and the 'interpersonal'. Schwartz (1997) referred to this as the increasing 'commodification' and 'professionalisation' of services.
- The controlling character of the medically oriented model applied in these settings, encourages a degree of distance between professionals and service users which is not constructive (Monach & Spriggs, 1994).
- Outcomes at this level are typically defined as maximum physical functioning to the exclusion of other criteria, and are contingent upon criteria determined by the rehabilitation team rather than the consumer (Peat, 1993).

- Some approaches employed within these levels of rehabilitation foster dependency and marginalisation (Monach & Spriggs, 1994).
- The degree of professional specialisation necessitated by these approaches results in practitioners using limited, symptom based perspectives of the person in rehabilitation. This compromises the capacity of the system to provide total care (Peat, 1991a), and leads to partial, fragmented solutions that often break down (Kiernan & Hagner, 1995).
- Increasing specialisation and the use of interventionist strategies, is increasingly a feature of rehabilitation and disability approaches at the bio-systems and psycho-systems levels (Stricklin, 1997). This results in services, which due to expense and limited availability, are inaccessible to a majority of the population (Peat, 1991a).
- The reductionism inherent in approaches utilised at this level, gives privileged status to individualistic explanations which results in disability being viewed as a 'personal trouble', rather than a public issue (Barton, 1994). The failure to acknowledge that physical, cognitive, emotional, and social factors all shape illness and disability may result in 'victim blaming' (Marks, 1997).

The above points are not intended as a global criticism of rehabilitation service delivery at the bio-systems and psycho-systems levels. They are however, an indication that the manner and context in which such approaches occur, may not be conducive to cultivating community around a person with a disability. They suggest that at the bio- and psycho-systems levels, rehabilitation and disability service approaches in economically developed countries, may be overly medicalised, neglecting important human and interpersonal aspects.

2.3 Issues at the Micro-systems Level

The micro-system, which comprises immediate relationships in the home, workplace and peer group, may be considered as the social system which is most acutely influenced in the course of traditional rehabilitation and disability interventions. As Gregory (1996) has stated, rehabilitation and disability service providers should acknowledge the systemic context of their interventions which affect not only an individual, but an entire social system. It would appear however, that for some people with disabilities, the rehabilitation process, rather than strengthening their immediate social supports, contributes to their isolation (Ayer, 1984; Lagerwall & Hargö-Granér, 1996). The social dislocation of people with disabilities at the micro-systems level, is reflected in the finding that the social networks of people with disabilities tend to be smaller, less dense and less complex than those of their non-disabled contemporaries (McColl, 1995). A survey of the social contacts of 15 people with disabilities

found that on average, each person had about 20 professional service provider contacts, but less than two friends or peers (cited by Lagerwall & Hargö-Granér, 1996). Similarly, Walker (1995) found that the relationships of people with disabilities utilising disability services were characterised by social anonymity rather than interaction and friendship, by homogenous groups of people rather than a range of groups, and by a general lack of common interests with those they interacted with most closely[1].

Natural dimensions of care and support which typically exist within the immediate community network of friends, peers and family can not be provided by even the most responsive services (Taylor, Bogdan & Lutfiyya, 1995). Despite this, current rehabilitation processes tend to minimise the activity of the person with a disability, limit their role in the immediate community (Monach & Spriggs, 1994), and invest skills with a third party, thus disempowering the individual, their family, and support network (LaMarche, Reed, Rich, Cash, Lucas and Boll, 1995). This results in the current situation in economically developed countries in which people with disabilities are isolated from, and fail to draw benefit from their immediate communities. Conversely, their local communities also fail to benefit from, the participation and contribution of people with disabilities (Walker, 1995).

The micro-systems level, which describes close social relationships, might be seen to include self-help groups which are a common part of the disability landscape in economically developed countries. Such groups establish mutual peer support, enable people with disabilities to become skilled in many aspects of their condition (Rhoades, Browning & Thorin, 1986), foster a sense of egalitarianism between professionals and clients, and may be instrumental in reducing stress and promoting wellbeing (Rhoades et al., 1987; Suurmeijer, Doeglas, Briancon, Krijnen, Krol, Sanderman, Moum, Bjelle, & Van Den Heuvel, 1995). Despite these advantages, it is rare for such groups to achieve real partnership and participation in the community (Jackson, Mitchell & Wright, 1989; Monach & Spriggs 1994). It has been suggested that if such informal groups or networks demonstrated a greater commitment to participating directly in, the local community, and influencing issues at a community level, significant social outcomes and improved community awareness would ensue (Scotch, 1990). Unfortunately, there are few processes which facilitate the capacity of such groups to participate in the community.

[1] While it is acknowledged that this social dislocation may be the result of a number of factors, such as stigma, societal attitudes, barriers to access, etc., it is suggested that the professionalised nature of traditional rehabilitation and disability service delivery approaches, may also contribute to the weakening of relationships at the micro-systems level.

2.4 Issues at the Meso-systems Level

The next level within the Bio-Psycho-Social Ecology Model, the meso-systems level, describes a person's participation in formal social networks and the broader community. It is from this level of community interaction and participation that people derive a sense of membership, belonging and identity (Walker, 1995).

Despite a strong deinstitutionalisation movement over a number of decades, and an emerging paradigm of 'community membership' (Bradley & Knoll, 1995), it would appear that people with disabilities in economically developed countries experience little active involvement or participation in community life (Chenoweth, 1995; Walker, 1995). Clear and Green (1995), writing from the Australian context, stated "For all the achievements of the normalisation and deinstitutionalisation movement, it seems that very little ... reciprocal community involvement has occurred" (p. 43). Indeed, deinstitutionalisation may arguably have resulted in increased social disenfranchisement for people with disabilities (Chenoweth, 1995; Epstein, 1994).

Community relationships of people with disabilities are characterised by anonymity, rather than interaction and social connection (Walker, 1995). As Lundgren-Lindquist and Nordholm (1993) observed, societal disconnection or neglect of people with disabilities is a function of their lack of representation in community affairs. It is suggested that such a lack of genuine representation may be the result of an overemphasis on formal service delivery, as well as the failure of the disability movement[2] to prioritise participation in, and involvement with, the broader community as a major goal (Newell, 1996).

An over-emphasis on formal service delivery stifles the community integration of people with disabilities and weakens the capacity of the community to respond to disability issues (Momm & Konig, 1989; Stevenson, Grevell, Crisp & Ryan, 1996). Ife (1995) stated that a concomitant of the 'welfare state mentality' which exists in many western contexts, is the tendency for people to seek the support of governments and formal services, to the exclusion of local resources and informal means, thus further weakening community structures.

The failure of the disability movement to effectively foster community involvement for people with disabilities has been argued by Newell (1996). He observed that the disability movement

[2] The term 'disability movement' refers to a broad social movement, the formal structural face of which in Australia and the UK, is Disabled Persons Organisations (DPOs) or organisations *of* people with disabilities - as opposed to organisations *for* people with disabilities (Craddock, 1996). In North America it might be seen to be exemplified in the independent living movement and Centers for Independent Living (Craddock, 1996).

in Australia has relied on an individualistic consumer discourse and framework, at the expense of communitarian concerns. In North America, Centers for Independent Living, which are often hailed as a key means of promoting the involvement and participation of people with disabilities into community life (Balcazar, Matthews, Francisco, Fawcett & Seekins, 1994; Nosek & Howland, 1992; Nosek, Zhu & Howland, 1992), have been similarly critiqued (Lysack & Kaufert, 1994). It has been noted that active, mutual participation of people with disabilities in community life has typically been neglected both in the stated goals of such centres and in evaluations of their effectiveness (Matthews, 1992; Nosek & Fuhrer, 1992; Nosek, Fuhrer & Howland, 1992). Centers for Independent Living have been characterised as increasingly elitist (Nosek, Zhu & Howland, 1992), regularised and formalised (National Institute on Disability and Rehabilitation Research [NIDRR], 1994a), centre based (Seekins, Ravesloot & Maffit, 1992) and individualistic (Clay, 1992). As such, their community focus may be questioned.

Social barriers faced by people with disabilities are often more debilitating than limitations imposed by their disabilities (Kilbury, Benshoff & Rubin, 1992). Consequently, the lack of representation of people with disabilities in community affairs, and the failure of structures to promote such participation at the meso-systems level, is of concern. Aitken and Walker (1987) stated that, "In many places the community itself does not care, only because it does not know how to care" (p. 61). The issue then, may not necessarily be one of community hostility, but simply community ignorance (Grimes, 1995). It would appear that the failure to enable people with disabilities to actively participate in all levels of community life, represents a significant challenge to existing models of service delivery (Grimes, 1995).

In summary, it might be suggested that at the meso-systems level, rehabilitation and disability service approaches (including the disability movement) in economically developed countries, do not appear to facilitate the effective participation of people with disabilities in the broader community.

2.5 Issues at the Exo-systems Level

Applied to the current context, the exo-systems level may be seen to comprise formal systems of disability service delivery, as well as policy making and legislative systems which impact upon people with disabilities. While the greatest funding and human resources may be committed at the bio-systems and psycho-systems levels, among the four remaining systems, the level of formal service delivery and government legislation and policy (the exo-systems level) may be seen as the major domain in which state and federal resources are invested.

Within this system, it has been suggested that governments in economically developed countries are increasingly unable to meet their obligations (Mann, 1997). Condie (1991) stated that

> the disabled person is the victim of an uncoordinated, fragmented and incomplete system of care where inter-professional communication is poor, professional jealousies are rife, professional skills are inadequate for tackling the variety of problems which the patient [sic] demonstrates and, of course underfunding is comprehensive. (p. 72)

2.5.1 Service Delivery

Rehabilitation and disability services at this structural level, have been characterised as poorly linked and networked (Remenyi, 1994) and lacking consistency across and within services (Condie, 1991). They tend to be supply generated and resource or budget driven (Bodgan, 1996; Helander, 1993a), rather than demand influenced. Some have questioned the organisational quality of services in the context of regular threats of government restructuring and inappropriate management driven priorities (Dominelli & Hoogvelt, 1996; Helander, 1993a). Kiernan and Hagner (1995) stated that the narrow service focus, and fragmented approach of disability services, leads to partial solutions that often break down.

To clients, disability organisational structures often appear as monolithic bureaucracies which envelope and isolate people (Chenoweth, 1997a), and which allow few avenues for feedback or complaint (Monach & Spriggs, 1994). Specifically, in South East Queensland, they have been found to demonstrate a lack of consultation and choice (Brown & Ringma, 1989). Schwartz (1997) referred to this phenomenon of large bureaucracies becoming increasingly rigid as ‘paradoxical counterproductivity’. Lyons (1996) noted of services (also in South East Queensland) that “There is a sense of people being processed within the service system. Furthermore the view of people's needs may be distorted by systemic and professional frameworks and priorities with insufficient regard for individuals' own priorities” (p. 203).

Many rehabilitation and disability services have adopted personnel strategies which emphasise multi-disciplinary teams to promote, among other things, diversity and efficiency. Despite the use of such teams, professional practice has been found to remain mono-cultural (Goreczny, 1995), and has been characterised as inefficient and unresponsive (Bodgan, 1996).

At the exo-system level, considerable commercialisation (and privatisation) of professional practice has also been observed in the rehabilitation and disability sector (Rowitz, 1992b; Symington, 1994). Such privatisation, often due to efficiency measures (Rowitz, 1992b), may result in, (a) the loss of a public service ethic (Dominelli & Hoogvelt, 1996), (b) greater variability in type and quality of service (Whitt, 1996), and (c) the devolution of therapeutic relationships to procedural formalities. Within this trend, professionals increasingly become purchasers of care rather than service providers (Dominelli & Hoogvelt, 1996). Concerns over escalating organisational costs, without commensurate outcomes for people with disabilities are common (Finlayson & Edwards, 1995; Frank, Gluck & Buckelew, 1990; Leake, James & Stodden, 1995; Logan, 1991; Symington, 1994).

2.5.2 Policy and Legislation

The current analysis of the literature on policy and legislation indicates that within the rehabilitation and disability sector, the moral dimensions of public policy may have become blurred and remote from grass roots issues. The following points illustrate some concerns at this level.

- The policy making arena tends to be dominated by the bureaucracy and the market, rather than those whom it seeks to serve (Chenoweth, 1995; Hamilton, 1994; Newell, 1996).
- Policy making absorbs vast resources and time (Rist, 1994), consequently, influence over policy and legislation through lobbying and political activism, is almost exclusively confined to the middle classes (Barton, 1993).
- Policy resources and energies tend to be oriented towards wealthier, more influential elements - the elderly and vocational rehabilitees (Gregory, 1994).
- Current government policy seems directed towards private care (Gerstel & Gallagher, 1994), rather than towards community support.
- Policy making is often remote from people with disabilities, is fraught with complexity, and bureaucratic obfuscation (Chenoweth, 1997a).

The capacity of policy to actually result in real changes that affect the lives of people with disabilities has also been questioned (Newell, 1996). Policy and legislative approaches have been found wanting in terms of, (a) their capacity to assist people with disabilities to become

integrated into the broader community (Leavitt, 1995), (b) their capacity to bring about change in attitudes (Kirsten, 1996), and (c) their capacity to bring about employment outcomes for people with disabilities (Remenyi, 1994). The gap between policy rhetoric and reality is becoming increasingly apparent (Chenoweth, 1997a). Indeed, Barton (1994) concluded that the economic and social policies of the last decade have done little to enhance, and much to damage, the quality of life of people with disabilities. He suggested that they have resulted in a reduction of autonomy and choice, and greater scrutiny and control by professionals.

In Australia, a number of pieces of legislation and formal and informal policy have sought to ensure that people with disabilities live quality lives in the community[3]. Despite such initiatives, people with disabilities remain disconnected from their communities (Stevenson, Grevell, Crisp & Ryan, 1996), indicating that legislative responses alone, may be insufficient to ensure genuine community participation (Jonsson, 1996; Stevenson, et al., 1996).

Similarly, in the USA, the landmark piece of legislation, the Americans with Disabilities Act (1990), while achieving significant outcomes on employment issues, may not have had as substantial an effect on community issues, and may (at least initially) have had the reverse effect, provoking a public backlash (Shapiro, 1993; see also Pfeiffer, 1990). The failure of such approaches to start with community level consciousness raising, has been suggested as a major shortcoming (Shapiro, 1993). The use of legislative approaches to change public attitudes and behaviours may be mistaken (Monach & Spriggs, 1994). Rather than attempting to change attitudes through political intervention, attempts to move public interest at the grass roots level may be preferable (Logan, 1991; Monach & Spriggs, 1994). Community level change which is then supported by political action, may be the most constructive approach to long term change (Logan, 1991; Monach & Spriggs, 1994).

In summary, it may be observed that at the exo-systems level, rehabilitation and disability services in economically developed countries may not be readily accessible to consumers, and may not effectively facilitate community participation. Policy and legislative approaches may also be somewhat remote and ineffective change mechanisms.

[3] For example, the Commonwealth Disability Services Act (1986), the Queensland Disability Services Act (1992), the Commonwealth-State Disability Agreement, Institutional Reform, Intellectual Disability Services Operational Plans and initiatives such as the Quality of Care Project.

2.6 Issues at the Macro-systems Level

Negative attitudes, discriminatory social values and inappropriate beliefs constitute some of the greatest barriers for people with disabilities (Kilbury et al., 1992; Pernice & Lys, 1996). Wolfensberger (1994) stated that 'modernistic' values of materialism, individualism, sensualism and utilitarianism, mitigate against valuing the lives of people with disabilities. These phenomena fall within the domain of the macro-systems level in the Bio-Psycho-Social Ecology Model.

The capacity of the prevailing social model of disability to bring about change in community attitudes and values may also be questioned (Monach & Spriggs, 1994). Within the social model, the assertion that disability is a socially constructed entity, implies that negative social values, inappropriate beliefs and discriminatory attitudes, are socially structured inequalities that should be addressed at a structural level (Monach & Spriggs, 1994). Shakespeare (1993) stated that structural approaches, such as legislation, which are based on abstract notions of social justice and equality, tend to be weak and have little impact on the majority of people. Similarly, the Australian Disability Rights Commissioner noted that it is impossible to 'legislate attitudes' (Ragg, 1994).

Shakespeare (1993) advocated that real change at this level results from personal experience and genuine participation at a practical level. Societal attitude change in disability issues may be seen, in part, as a function of community level efforts directed at strengthening the partnership and participation of people with disabilities (Monach & Spriggs, 1994). Pernice and Lys (1996) found that direct contact with people with disabilities was a crucial variable in bringing about attitude change in non-disabled community members. The quality and the context of the various roles of people with disabilities in such community level participation, is also highly important (Minnes, 1994). Lasting social attitude and value change, arises in part from community level participation by people with disabilities in valued social roles. Such approaches to change may not be sufficiently emphasised in traditional rehabilitation and disability services. Within the descriptive framework employed in this thesis, change in attitudes and social values (the exo-systems level), may be seen to be a result of genuine and active participation of people with disabilities in local communities (at the micro-systems and meso-systems levels).

2.7 Issues Across System Levels

A number of concerns within the rehabilitation and disability sector may also be noted across the various levels of the Bio-Psycho-Social Ecology Model.

2.7.1 Demographic Issues

Firstly, demographic changes represent an important influence on rehabilitation and disability services in Western countries. Characteristics such as population ageing and resultant increases in population disability levels (Remenyi, 1994; Symington, 1994), increases in survival rates after injury (Peat, 1993; Symington, 1994), changing patterns of disease (Symington, 1994), the rise of HIV and related disabling conditions (Rowitz, 1992b), all contribute to the number of people requiring disability services. By extending the range and complexity of services required, these factors challenge current frameworks of service delivery (Peat, 1991a; Rowitz, 1992b; Symington, 1994).

2.7.2 Funding Issues

Closely allied with demographic changes, is the issue of escalating costs and trends in service funding. For example, in Australia, despite a rigorous cost containment and reform agenda, the programme costs to the Commonwealth of provision of disability services alone, increased by over 8% or $92 000 000 in one year (Commonwealth Department of Health and Family Services, 1997). There have been suggestions that the disability service delivery system in Western countries is overly costly (Frank, et al., 1990; Helander, 1993a; Rowitz, 1992b; Smull & Delaney, 1994). More importantly, the emancipation of people with disabilities may be increasingly threatened by public concern over costs and inefficiencies (Symington, 1994).

Individualised funding and service approaches have been advocated as a desirable direction for disability service provision (Murphy & Brownlea, 1993). Such individualised approaches to disability issues however, may contribute to the viewing of disability as a personal issue, rather than a public or community issue (Barton, 1994). In practice, these approaches may fortify the dominance of conservative, individualising and 'therapeutic' solutions (Ife, 1995) and "reinforce the welfare ideology of the self interested individual competing for scarce resources in the marketplace" (Monach & Spriggs, 1994, p. 149).

Within the predominant marketplace ethos, many people with disabilities have adopted a consumerist perspective, in order to align themselves within the more powerful prevailing consumerist discourse (Hamilton, 1994; Newell, 1996). In so doing, they may contribute to the

individualisation and 'financialisation' of disability issues, rather than fostering community or social justice oriented agendas (Hamilton, 1994; Newell, 1996).

2.7.3 'Management' of Care

Managed care (a clinical system that integrates financial management with the provision of care), is a key current and future cost containment strategy which impacts on disability issues (Abreu, 1996; Christiansen, 1996; Frank et al., 1990). Such systemic approaches to contain costs (Frank et al., 1990) are reported to be leading to a "dehumanization of the human services" (Rowitz, 1992b, p. 365). Under a managed care environment, the operationalisation and fragmentation of complex tasks, may have derailed concerns for social justice towards a preoccupation for technical arrangements between agencies (Dominelli & Hoogvelt, 1996). It has been argued that for such a system to be effective and beneficial to consumers, an informed and skilled community is essential (Whitt, 1996). Unfortunately, efforts to skill and inform communities have not enjoyed commensurate levels of support from governments.

2.7.4 Balkanisation of the Sector

The use of managed care systems and strategies such as case management[4] to deal with complex tasks and procedures, reflects the level of complexity inherent in the rehabilitation and disability sector. This complexity is confounded by a diversity of views, differing orientations and divergent values within the sector (Barton, 1994; Bradley & Knoll, 1995). Differences between and within consumer groups, practitioners, and other stakeholders, have resulted in a degree of division and factionalism in and amongst disability organisations. This 'balkanisation' may be seen as a consequence of the individualised and fragmented consumer perspective that has been adopted (Newell, 1996). For example, the divisions and conflicts between organisations *of* people with disabilities and organisations *for* people with disabilities are reported to have reached a state where they are seriously detrimental to progress within the disability sector (S. Miles, 1996a; Newell, 1996). Such divisions significantly weaken the external power, the internal cohesion, and the leadership capacity of all disability organisations (Helander, 1993). Unless addressed, these divisions will continue to result in the weakening of disability groups in general and the diminution of community support networks in particular (Riger, 1993). The current thesis concludes that in part, this balkanization has arisen from the belief that individual rights come before community rights (Hamilton, 1994).

[4] Case management may be seen as a standardised mechanism for connecting clients with the services they require, in the context of increasing fragmentation (Applebaum & Mayberry, 1996).

The dichotomy between the individual and the social, pervades many aspects of the rehabilitation and disability sector (Abberley, 1995; Oliver, 1996). It is expressed in 'personal versus political' factions (Oliver, 1996), and in divisions between the perspectives of many professionals versus the structural/social perspectives of the disability movement (Abberley, 1995). While some have sought to interpret this issue through frameworks which describe the exercise of power and ideology (Oliver, 1996), others have noted that a more constructive dialectic may stem from a community perspective (Hamilton, 1994; Ife, 1995; Joyce, 1993; Lyons, 1996). Such authors have suggested that a bridge towards constructive outcomes and resolution of individual/social dichotomies, may reside in a reorientation towards community issues, ensuring that people with disabilities are enabled to make a constructive impact at a community level (Hamilton, 1994; Ife, 1995).

In summary then, it may be suggested that across the system levels, a number of concerns may be identified which threaten basic elements of rehabilitation and disability service approaches in economically developed countries. As Leake et al., (1995) stated,

> If the current paradigm is retained, these shortcomings can only be addressed in terms of more money, more research, more trained professionals - but it should be clear that not enough 'more' will be forthcoming from governmental or private sources. These [concerns] can be accommodated only by a new paradigm. (p. 34)

2.8 Conclusion

Based on an exploration of literature, the current chapter has sought to bring into focus, a number of disparate issues of concern within the area of rehabilitation and disability service delivery in economically developed countries. These issues included concerns regarding current directions in service delivery and professional practice, current political and economic agendas, relevant social factors, and service user issues. While these concerns emanate from a number of areas and systems, a predominant theme suggests a need to explore more community related perspectives. This suggestion is facilitated in Chapter Three through an exploration of relevant trends, both inside and outside of the rehabilitation and disability sector.

Chapter Three

Trends Indicating Potential Directions for Rehabilitation and Disability Services in Economically Developed Countries

3.1 Introduction

Dramatic social, economic, political and technological changes, which pervade all aspects of life in economically developed countries, are prompting a challenging of current paradigms and stimulating new thinking in many fields (Chu, 1994b). In light of concerns identified in Chapter Two, the current chapter, documents and explores a number of these emerging trends which may have relevance to the rehabilitation and disability sector. This chapter contributes to current analysis by identifying emerging trends, against which a potential alternative for rehabilitation and disability services might be considered.

It is suggested within the current chapter that,

- Global/local perspectives indicate the need for more localised responses.
- Ecological perspectives indicate the benefit of holistic and socially sustainable approaches.
- Community perspectives reflect the importance of community focussed strategies.
- Emerging perspectives in empowerment reflect a more communal orientation.
- Postmodern perspectives reflect the importance of 'lay' and 'local' approaches.
- Values frameworks and perspectives are increasingly important considerations.
- Key trends identified in a number of other disciplines reflect the importance of community focussed initiatives.
- Emerging perspectives in the rehabilitation and disability sector also indicate the potential of community level initiatives within this field.

3.2 Global/Local Perspectives

Globalisation is considered a major influence on all cultures and societies (Naisbitt, 1994). Relevant features of the trend towards globalisation include, (a) increased privatisation under the influence of global corporate practices (Ife, 1995), (b) greater economic liberalisation (Waters, 1995), (c) increasing homogeneity of social and economic approaches across systems and nations (Wilkinson & Quarter, 1995), (d) deepening social and economic polarisation (Probert, 1993), and (e) greater universalisation of culture (Waters, 1995).

Globalising tendencies are also evident in the human services and disability sector. Noteworthy examples include, the cutting back of public services, dismantling of the welfare state (Ife, 1995), and increased involvement of the commercial sector in welfare and service provision (Dominelli & Hoogvelt, 1996). The effect of globalisation on the human services has been characterised as a change of focus from 'needs' to 'budget', from 'providing services' to 'managing service provision', from 'acknowledgment of complex processes' to 'training in narrow competencies', and from an emphasis on 'therapeutic relationships' to 'procedural formalities' (Dominelli & Hoogvelt, 1996).

In contrast with the prevailing trend towards globalisation, a corresponding trend towards increased localised action can be discerned at a social level (Labonté, 1994). In a number of arenas, an increased focus on the appropriateness and effectiveness of small scale, localised responses, countervails what has been perceived as disempowering state and international centrism (Labonté, 1994). The commitment to localised action, has been seen by some as a significant means by which increasing globalisation is balanced and complemented. Norberg-Hodge (1996) stated that "long term solutions require a range of small local initiatives that are as diverse as the cultures and environments in which they take place" (p. 35).

It is a contention of the current thesis that while a juxtaposition of the global and the local appear to be part of the postmodern reality, localised responses to globalising tendencies are not as yet, a major feature of the rehabilitation and disability 'landscape'. Despite evidence of a number of aspects of increased globalisation in the rehabilitation and disability sector (Dominelli & Hoogvelt, 1996; Ife, 1995), there appears to be little evidence of the development of corresponding localised responses or local processes (Logan, 1991). A recognition of the importance of localised praxis would appear to be a constructive balance to globalisation as it impacts on people with disabilities.

3.3 Ecological Perspectives

A second major trend identified in the current analysis was an increasing recognition of ecological perspectives. Ecological and 'green' frameworks are a significant influence on a number of aspects of contemporary Western society (Ife, 1995). A defining variable of such approaches is a recognition of the 'interconnectedness of systems' (Hancock, 1993). Through a growing acceptance of ecological perspectives, the concept of 'social ecosystems' has emerged, in which social phenomena are viewed, and priorities are evaluated, on the basis of their long term social feasibility and social impact (social sustainability). Within an ecological perspective, social sustainability may be sought through the application of principles of holism, sustainability, diversity and balance (Hancock, 1993; Ife, 1995). Any form of action within society (including human service provision), may be evaluated on the basis of the 'ecological footprint' that it leaves on the community and 'social landscape' (Labonté, 1996). Within such perspectives, the potential for sustainability based on ecological principles, is assessed to ensure that social and community interventions are optimally effective, systemically equitable, and responsible (Hancock, 1993; Labonté, 1994; Robinson, 1995).

Ife (1995) applied these principles to the human services in order to consider more holistic parameters in which such systems might operate. He stated that social institutions and service systems should be evaluated according to, their long term viability, their impact on other systems, the 'energy' and 'resources' they extract from the environment, their output, and the degree to which they may directly or indirectly impact upon future generations. Such ecological models "may be useful contributions to defining the determinants of health, ... indicating priorities and directions for action and for determining criteria for monitoring progress and assessing results" (Hancock, 1993, p. 41).

The rehabilitation and disability sector, is currently undergoing a transformation which equates with the 'paradigm shift' described by Thomas Kuhn (Cocks, 1994). In Kuhn's (1970) historical analysis of the way in which such paradigms change, a greater willingness to explore alternative ideas and concepts emerges. Kuhn suggested that such openness to new ideas is formative in the development of new paradigms. With regard to the issue presented above, notions of ecological holism and social sustainability, are important concepts which have relevance to rehabilitation and disability services in economically developed countries. The incorporation of ecological perspectives and attempts to build social sustainability may be particularly constructive as this discipline seeks to negotiate a direction through the current paradigm shift. It would appear however, that the utilisation of ecological frameworks in traditional rehabilitation and disability services is rare (Gregory, 1994).

3.4 Community Perspectives

A third social trend identified in the current study was the emergence or increasing recognition of a community paradigm. This paradigm has been seen as part of a current global dynamic (Stricklin, 1997), and has been described as a 'new social order' in which community ownership, community skilling and community self reliance are emphasised (Robinson, 1995). It is reflected in an increasing utilisation of local knowledge and skills, and the promotion of grassroots, pluralistic movements (Lysack, 1995a). The community paradigm is expected to gain ascendancy in economically developed countries such as Australia (Ife, 1995; Kenny, 1994; Rowitz 1992a; Trojan, 1988). Rowitz (1992b) stated that "By the year 2000, values related to human development and community priorities will begin to predominate in the areas of social policy" (p. 354).

While community approaches are notoriously difficult to define (Kenny, 1994), they differ from traditional approaches in that they facilitate a process of working *with* people rather than *on* them, and optimise local social support and social networks (Trojan, 1988). Community approaches operate through establishing and building common identity and solidarity (Hamilton, 1994; Kenny, 1994). They have been seen as an appropriate means for achieving real change and balancing perceived excesses of formalised professional services (Trojan, 1988). The Australian Human Rights Commissioner reflected this perspective of community self reliance in his recommendation that "we need to assume collective responsibility as members of our communities and not leave it to the government" (Burdekin, 1995, p. 16).

With particular relevance to the current research, Ife (1995) has predicted that in economically developed countries, 'community' is the institution which will succeed the family, the Church, the market, and the state, as the primary focus for meeting human need. In this case, it would appear that the emerging community paradigm, and community focussed strategies would be important considerations for the future of rehabilitation and disability services in economically developed countries.

3.5 Perspectives in Empowerment

In keeping with the emergence of a community paradigm, it has been observed that the concept of empowerment is evolving towards a more community contextualised expression (Price, 1990). There is growing recognition that existing conceptualisations of empowerment may be overly individualistic and perpetuate the isolation of individuals and the destruction of networks of support rather than build and strengthen community around individuals (Labonté, 1994; Riger, 1993; Zimmerman, 1990). Perspectives which recognise that empowerment exists at multiple levels (individual, organisational and community) and with multiple dimensions (intra-personal, social, behavioural, political) (Florin & Wandersman, 1990; Ife, 1995; Prestby, Wandersman, Florin, Rich & Chavis, 1990), appear to be gaining ascendancy.

Greater acknowledgment of the value of ecological considerations has resulted in an increased recognition of the need to contextualise the empowerment of people within communities (as ecosystems). Further, these perspectives have contributed to a broadening of the concept, to include the empowerment of communities themselves (Ife, 1995; Labonté, 1994). Given predictions of a forthcoming shift in power relations that will see communities becoming a source of major decisions in Western society (Rowitz, 1992a), greater understanding of community contextualised expressions of empowerment will be beneficial for rehabilitation and disability services.

Beyond traditional individualised understandings of empowerment, a shift towards the recognition of group level action and empowerment within communities has been identified (Armstrong, 1993; Robinson, 1995). Barton (1994) stated that collective action is considered a prerequisite for the realisation of lasting social transformations in the human services. Advantages of such groups include, members developing a strong sense of empowerment, increased competence, increased skills and a sense of belonging, identity and connection (Rhoades et al., 1986). Florin and Wandersman (1990) suggested that such collective 'mutual aid' efforts constitute a constructive response to 'service factionalism' and 'bureaucratic stultification' of formal systems and services. In economically developed countries, small group lobbying and voluntary organisations have provided an effective mechanism of change, initiative and energy in the human services (Joyce, 1993).

In the past, such group level action has been understood and described mostly as 'self-help groups', essentially an inward looking perspective. Recent initiatives reflect an evolution beyond the inward looking focus which characterises the self help movement, towards an active, outward looking, skilling and action perspective. This approach has been described as

small group ‘equality work’ (Brundtland, 1996). It is consistent with Robinson’s (1995) prediction of the emergence of self managing networks which promote community self reliance, information networks, and a people centred vision of development.

The emerging trend towards community contextualised expressions of empowerment may have considerable relevance to rehabilitation and disability services in economically developed countries. Approaches such as ‘small group equality work’ seek to build empowerment in the context of the community and within a co-operative, rather than individualistic framework. Such perspectives appear to comprise a constructive response to concerns identified in the previous chapter.

3.6 Postmodern Perspectives

Postmodernism, a philosophical framework which arose out of the arts, philosophy and social sciences, permeates many aspects of late twentieth century culture (Kenny, 1996). While the postmodern position is expressed in numerous perspectives and attributes (Bohm, 1994; Lysack, 1995b; Rosenau, 1994), a few key points relevant to the present discussion are identified here.

According to Kenny (1994), the postmodern position elevates the value of non-professional or ‘lay’ perspectives and is characterised by a distrust of broad universal discourses by experts. Postmodernists maintain that expert and professional claims to objective knowledge are unsustainable since ‘knowledge’ is produced and disseminated in contexts of power and vested interests (Hawes, 1996).

The particularist characteristics of the postmodern position suggest that interventions should be embedded in their specific social, economic, and geographical circumstances (Lysack, 1995b; Rosenau, 1994). Postmodern notions such as the concept of ‘critical regionalism’ emphasise that people are inextricably linked with their immediate environment, changing it, and being influenced by it. Consequently, localised, specific responses to social or physical issues, are always preferable to generic solutions (Ellin, 1995). Applied to the context of disability service delivery, it would appear that service responses which emphasise localised or community based practices may be preferable to more universal frameworks of disability issues.

Postmodernism also highlights the cultural atmosphere at the end of the twentieth century - an atmosphere which is characterised by change, transition and instability in every human activity (Prigogine, 1994). In this context, traditional ‘modernist’ frameworks which are based on

notions of constancy and predictability, may be of limited value. Postmodern perspectives acknowledge the inherent complexity of many issues - particularly socially oriented issues (Hawes, 1996; Kenny, 1994). Consequently, postmodern theorists would reject reductionism, and practices based on reductionist theories, as misguided (Bohm, 1994). Reductionism, which is linked with modernist notions of predictability, fails to acknowledge the inherent complexity of many social phenomena. In preference, postmodernists have sought to develop and utilise more holistic approaches (Bohm, 1994).

The implications of this recognition of complexity and change rather than reductionism and predictability have yet to be explored in depth within rehabilitation and disability services. It would appear however, that the utilisation of more holistic frameworks and scrutiny of the reductionist assumptions of the discipline, may be warranted.

An additional point within the postmodern perspective, particularly in science, is that meaning and values are seen as integral parts of every human endeavour (Bohm, 1994). Increased awareness of the importance of values to guide practice and inquiry, as well as greater recognition of the social construction of meaning, indicate the importance of a clear values framework (Lysack, 1995b). This point is expanded further in the following section.

Clearly not all aspects of postmodern thought are relevant to the topic under discussion, and some aspects run contrary to themes being explored[1]. Despite this, postmodernism reflects issues which pertain to the current context. A greater acknowledgment of aspects of postmodernism, may be of significant benefit to rehabilitation and disability services in economically developed countries. In particular, the place of 'lay' perspectives, recognition of the importance of 'locality', appreciation for the complexity of issues, an understanding of the benefit of holistic approaches, and an emphasis on the place of values are considered important.

[1] Postmodern philosophy may be seen to idealise 'the personal', and at its logical conclusion may be seen to neglect issues of social justice, and may result in unbridled individualism (Lysack, 1995b).

3.7 Values Frameworks and Perspectives

Consistent with postmodern emphases on the importance of values to guide action, within Western culture there is an increasing recognition of the need for the development of a values system which can provide a framework for life (Barns, 1997; Fukuyama, 1995). Despite only limited evidence in practice, it has been argued that values of human rights, social justice and empowerment are becoming established as social priorities in Australia (Burdekin, 1993; Ife, 1995) and gaining emphasis globally (Naisbitt, 1994). In keeping with the themes of the current thesis, it is noted that some authors have recognised that the promotion and development of human rights and social justice values, engenders greater social solidarity (Barton, 1994; Ife, 1995) and is inextricably linked with the recognition and support of communities (Burdekin, 1993, 1995).

It would appear that emerging values frameworks are not only gaining recognition, but are increasingly acknowledging the place of a community component. This is reflected in the call from a number of social theorists towards the development of civic and communitarian values (Cox, 1995; Hamilton, 1994). Such values may be particularly relevant to the human services which are reported to be suffering from a degree of 'social fatigue' or a waning of public interest (Logan, 1991). Cox (1995) stated that these consequences are the result of a failure to emphasise an appropriate commitment to community and communitarian values. It has been implied that an overemphasis on individual or economic concerns may have resulted in the destruction, rather than building of social networks and cooperation in human service agencies (Cox, 1995; Lysack, 1995b). It may therefore be concluded, that the social fatigue which human services appear to be encountering, may be the result of neglect or failure to promote, community focussed values frameworks. While much remains to be done in the nexus between disability issues and values (Hamilton, 1994; Leake, et al., 1995, McFarlane & Griswold, 1992), the trend towards the recognition of communitarian values, may have particular relevance to rehabilitation and disability services in economically developed countries. In light of growing social fatigue, the development of approaches which are consistent with community focussed values would seem pertinent.

3.8 Perspectives From Other Disciplines

In keeping with the community related themes identified in the preceding sections, the current literature analysis noted that community based or community related frameworks are increasingly finding expression in a number of diverse disciplines. In light of growing recognition of the interconnectedness of many sectors, and the need for multi-disciplinary approaches to many social issues (Chu, 1994b), these trends constitute an important precedent, from which parallels may be drawn to the rehabilitation and disability sector.

3.8.1 Economics

Community based economic systems are emerging in economically developed and developing countries (Ellwood, 1996; Ife, 1995). Finding expression in the development of initiatives such as community based economic cooperatives, these approaches enable individual communities to exercise greater control over factors which impinge on them directly (Wilkinson & Quarter, 1995). The implications and future scale of such approaches are predicted to be fundamentally important on a national and international scale (Naisbitt, 1994).

3.8.2 Agriculture

In areas such as agricultural extension, participatory and community approaches are gaining ascendancy. Pelletier and Shrimpton (1994) pointed out that the specialty of 'farming systems research' is moving towards a bottom up, community based approach. Community involvement and participation in such areas as 'agricultural catchment management' involves drawing from the skills and resources of the local community, to bring about changes in practices and policies which affect them (Wilkinson & Barr, 1993). Community based approaches are seen as a means of promoting the sustainability of rural communities, as well as the appropriate development of agricultural resources (Lawrence, 1995).

3.8.3 Theology

An interesting community based orientation has arisen in some theological expressions, which emphasises participatory processes and community action (Ringma, 1994). While finding different expressions across denominations and contexts (Ringma, 1994; Smith, 1994), this orientation is most clearly expressed in the Latin American "Communidades Eclesiales de Base" - CEBs (base ecclesial communities). The CEB movement, which emphasises locally based social change and activism, has been found to cultivate members' sense of responsibility for the condition of society (Smith, 1994), and promote non-hierarchical leadership structures (Cavendish, 1994). The CEB movement, through a strong community focus, has been found to develop members' organisational, communication and leadership skills (Smith, 1994), and has

been instrumental in substantial agrarian activism and reform (Adriance, 1994). Indeed the localised skilling, democratisation, mobilisation and empowerment of communities through CEBs, has been identified as an instrumental factor in the democratic transition from authoritarian rule to democracy in five Latin American countries (Cavendish, 1994).

3.8.4 Ecology

As noted previously, community based approaches are also being applied to the area of ecology (see Ellwood, 1996). More specifically, within an area of research and practice known as 'bioregionalism', communities are being encouraged to take responsibility for, and actively participate in, the preservation of local ecosystems. Brunckhorst (1995) noted that the bioregional approach, which has developed as a result of a mixture of economic, ecological and social imperatives, has proven to be an effective means for responding to deficiencies in management and institutional systems. The community orientation of bioregionalism makes change in ecological matters, both plausible and possible for community members. In addition to protecting ecosystems, such approaches have been found to stimulate and diversify local economies and strengthen social and cultural structures in the local community (Stocker & Pollard, 1994).

3.8.5 Health

The trend towards active community involvement in health[2] has emerged to the degree that "community participation in health care programmes is [now] considered to be axiomatic in health development" (Woelk, 1992, p. 419). Innovative health services in many countries are increasingly moving beyond a traditional individual focus, towards a community focus (Stricklin, 1997). Such approaches, seek a population context, attempt to reduce inequalities, and develop ways to use resources efficiently and effectively based on ecological and community priorities (Labonté, 1996). Chu (1994a) stated that in order to do so, more grassroots, consumer and community based approaches will be imperative. Initiatives towards greater community participation in health care issues have been found to result in improved outcomes with greater ongoing support for change (Wainer, Strasser, Harvey & Kelly, 1996).

A discernible shift can be identified in many countries towards primary health care and health promotion strategies which emphasise active community participation (Brown, 1994; King, 1990; Pelletier & Shrimpton, 1994; Trojan, 1988). Such strategies focus "on the community as the agent of change and [recognise] the capacity of individuals, and collections of individuals within communities, to articulate problems and to set priorities for their resolution" (Finlayson

[2] Based in part on the WHO's "Health for All" strategy (1977) and the Ottawa Charter (1986).

& Edwards, 1995, p. 73). Similarly, community health strategies involve seeking ways in which communities can take more control over factors which impact on their health (Mitchell & Wright, 1992), through addressing social inequalities and personal, social and structural barriers to health.

The suggestion that the rehabilitation and disability sector should draw from such trends in the health area has already been noted by Christie and Oster (1996). They cited the Ontario Ministry of Health's Rehabilitation Strategic Framework (1993) with the quote: "The rehabilitation system must also adapt to changes in health philosophy which embrace the community interdependence paradigm alongside the medical model" (p. 4).

In summary therefore, while the above exploration of trends is not exhaustive, it constitutes an indication of precedents which may be relevant to the current research. A growing acknowledgment of community focussed initiatives and approaches, is evident in economics, agriculture, theology, ecology and health. This trend provides an important indicator for rehabilitation and disability service delivery. Of particular relevance is the degree to which the community is integral in these examples. In many instances, the community is the *means or mechanism* by which outcomes are achieved rather than simply the *location* for initiatives. It is suggested that the development of rehabilitation and disability approaches which work integrally with local communities, has yet to be realised in economically developed countries.

3.9 Emerging Perspectives in Rehabilitation and Disability

A variety of community level initiatives also exist within the rehabilitation and disability sector in economically developed countries which seek to ensure the inclusion of people with disabilities into the broader community (Karan & Greenspan, 1995). It is suggested however, that while community oriented frameworks are increasingly being considered in economically developed countries (Ife, 1995), they may not be particularly prevalent or strongly community focussed. Furthermore, service delivery frameworks which move beyond traditional notions of placement in the community to fostering the *participatory involvement* of people with disabilities in the community, as well as the involvement of community members in disability issues, are uncommon. The current literature analysis sought to identify and highlight instances and aspects of positive trends within the rehabilitation and disability sector in economically developed countries. These were classified according to their major focus, namely, (a) models of service delivery, (b) the role of people with disabilities, and (c) the place and function of the community.

3.9.1 Service Delivery

Despite the absence of a clear community oriented service delivery framework across the disability sector, it would appear that traditional approaches and models of disability service delivery are currently undergoing a period of re-evaluation and challenge (McGrath & Davis, 1992). Specifically, a more community oriented approach has been called for (Bradley & Knoll, 1995; Burdekin, 1995; Fletcher, 1996; Fitzgerald & Anderson, 1992; Gregory, 1994; Hamilton, 1994; Kiernan & Hagner 1995; Smull & Delaney, 1994; Willer & Corrigan, 1992). This call is based on,

- A recognition that even in highly medicalised aspects of rehabilitation services, a strong community orientation results in improved outcomes, enhanced quality of care, higher morale, and lower costs (Drubach et al., 1996).
- The awareness many people with disabilities require greater community level care and support, rather than high technology interventions (Gans, 1997; Mann, 1997)
- A realisation of the rapidly changing nature of Western society and the potential which a community orientation might play in disability services, in the context of such change (Burdekin, 1995).
- The emergence of notions of 'community rights' in disability literature and a consideration of their potential impact on disability service approaches (Hamilton, 1994).
- A greater commitment to issues of local access for people with disabilities and the role of local non-professional services (Fletcher, 1996).
- Increased recognition of the need for greater community participation in disability issues (Gregory, 1994).
- Recognition of a growing requirement to ensure that disability services become more flexible and responsive (Smull & Delaney, 1994).
- Recommendations on the development of natural supports, the utilisation of community resources and greater emphasis on partnership with families and local communities in disability services (Fitzgerald & Anderson, 1992; Smull & Delaney, 1994).
- Recognition that the development of community support systems may be highly effective means for preventing secondary disabling conditions (Seekins, Clay & Ravesloot, 1994).
- Calls for rehabilitation professionals to have more involvement in communities, community development, community networking, health promotion and primary health care (Finlayson & Edwards, 1995; Gans, 1997; Peat, 1991a; Stalker, Jones & Ritchie, 1996; Townsend, 1988; Twible, 1995).
- The identification of the need for strategies which build tangible social connections in the community for people with disabilities (Bradley & Knoll, 1995).

- A realisation that disability professionals and services should also demonstrate a degree of accountability to society and to local communities (Townsend, 1993).

Kiernan and Hagner (1995) concluded that the major challenge facing the rehabilitation and disability service sector in this decade is the inclusion of the emerging community paradigm with the current service delivery system. This paradigm,

> offers viable models for assisting local communities to support their disabled children, youth and adults. At its root is community responsibility for and involvement in the health and wellbeing of its members. Services are driven by individual community needs and priorities and are committed to consumer participation and choice. (Oster, Simpson & Cosme, 1996, p. 7)

3.9.2 People with Disabilities

As noted in the previous chapter, it has been suggested that recent trends within the disability movement, have led to the emergence of a consumer perspective in which people with disabilities have cast themselves in a narrow, individualistic framework (Newell, 1996). In response, a call for greater orientation towards community, has emerged (eg. Barton, 1993; Hamilton, 1994; Leake, et al., 1995; Newell, 1996). Such authors have expressed a recognition that,

- Given the emerging community paradigm, it is important that people with disabilities build active partnerships with community members and leaders (Kiracofe, 1994).
- Community based 'grass roots' endeavours are one of the most important platforms for change for people with disabilities (Barton, 1993).
- People with disabilities may have a greater commitment to, and interest in, community issues than service providers (Linney, Arns, Chinman & Frank, 1995).
- Increased community involvement and natural supports for people with disabilities occur through building relationships in the community (Leake, et al., 1995).
- Genuine citizenship for people with disabilities comes about through membership and active participation in the community (Barton, 1993).
- "Informal advocacy efforts which engage and mobilise ordinary people in standing up for and standing beside people with disabilities are vital in building supportive communities and countering the great dependence of society on formal services" (Cocks & Duffy, 1994, p. 87).
- There is a need to question the belief that individual rights always come before community rights (Hamilton, 1994).

3.9.3 Community

A pattern was also discerned from the literature in which researchers suggested new directions in the interface between 'community' and 'disability'. Some of these publications have suggested that support and assistance might be provided to equip local communities and community members to more effectively welcome people with disabilities. Examples of such suggestions include,

- The assertion that community participation within disability service delivery must be fostered (Larsen & Foley, 1992).
- Recognition that "On a more local level, more attention needs to be focussed on developing the skills of the community to accept and support people with disabilities" (Chenoweth, 1995, p. 7).
- The suggestion that in the disability sector, there is a need for creative partnerships in the community, developing community resources and fostering self directed community initiatives (Simpson, 1995).
- The call for the development of approaches and structures which enable community members to 'stand up for and stand beside' people with disabilities (Cocks & Duffy, 1994).
- An emerging cognisance of the need to enable community members to assume collective responsibility for social issues and not defer to government and bureaucracy (Burdekin, 1995);
- The realisation that the focus in disability and rehabilitation approaches should be redirected towards the promotion of supports naturally present in the community (Leake et al., 1995).

It has been proposed that initiatives such as those suggested above, would serve to build supportive communities and counter the dependence of society on formal services (Cocks & Duffy, 1994). These examples illustrate that community based approaches are gaining ascendancy among some authors in the rehabilitation and disability field. They also indicate potential mechanisms by which these approaches might be realised. While they may be accomplished in different ways, and with different resources and practices, it is clear that the value of genuine community participation is gaining recognition. However, as Bradley and Knoll (1995) noted, there is currently no effective framework or methodology for linking people with disabilities into, and within the community. The necessity to foster community approaches in disability, is a major challenge for service provision, professional education and models of practice.

3.9.4 Seeking Alternatives Beyond Traditional Frameworks

Finally, it may be observed that within the rehabilitation and disability sector in economically developed countries, there is an emerging trend towards seeking alternative solutions for current issues beyond traditional frameworks and boundaries. The National Institute of Disability and Rehabilitation Research, in the United States, has noted that internationally, there has recently been a shift away from the western medical model to more culturally appropriate ways of delivering services (NIDRR, 1994b). The benefit of greater international collaboration and information sharing across national disability sectors has been recognised (Enders, 1993).

Suggestions have been proposed that disability service providers in economically developed countries would benefit from examining and exploring frameworks from the 'periphery', namely developing countries (Charlton, 1993; Couch, 1993; Ginsberg, 1993). O'Toole (1991b), writing from a developing country perspective, stated that given that "the challenge of meeting the needs of disabled persons has yet to be met [and that] traditional methods can do little more that scratch the surface, a radical reappraisal of our role as professionals, as promoters of community development, is necessary" (p.83). He went on to conclude that "The CBR approach offers such a role" (p. 83). In light of the previous chapters, an alternative, which combines the community paradigm with disability service delivery would appear to have considerable benefit. The current thesis provides an exploration of the parameters of this approach in the following chapters.

3.10 Conclusion

This chapter has identified a number of societal, theoretical and practical trends which may impact upon and inform rehabilitation and disability service delivery in economically developed countries. While the direct or practical implications for rehabilitation and disability of each aspect of these trends may be the subject of future debate, for current purposes, a number of more general themes can be identified. The important prevailing themes which summarise these trends include, (a) the recognition of an emerging orientation towards localised community issues, (b) contextualised integration within community frameworks, (c) recognition of the impact of interventions on the whole community, and (d) the capacity of the community for action.

In response to the current contextual analysis, an approach to rehabilitation and disability service delivery was sought which, (a) demonstrated a prevailing orientation towards community issues, (b) utilised a structure which was integrated with community frameworks, (c) which demonstrated an awareness of impacts on the community and (d) which facilitated the action of community members as a major priority. In combination with the issues identified in Chapter Two, these criteria indicated a context, against which potential alternatives may be explored.

An alternative approach which is consistent with the issues identified in Chapter Two and the trends identified in the current chapter is Community Based Rehabilitation (CBR). The following chapters explore the concept and practice of CBR. Through detailing the process, principles and strengths of the CBR approach, the following chapters indicate the means by which it constitutes a constructive alternative for rehabilitation and disability service delivery in economically developed countries.

Section B

PARAMETERS

An Analysis of Parameters of Community Based Rehabilitation

people no longer speak of
'community alternatives' or 'community based services'
because there is no alternative to the community

Bradley & Knoll (1995, p. 13)

Chapter Four

A Potential Alternative: Community Based Rehabilitation

4.1 Introduction

Within the previous chapters, the context for an exploration of an alternative approach to rehabilitation and disability service delivery was delineated. The purpose of the current chapter is to describe and analyse parameters of such a potential alternative. Within this analysis, it is suggested that within the disability area, CBR constitutes a constructive response to social dislocation, builds community participation, facilitates social change at a community level, and constitutes a potential strategy for responding to escalating demand, managerialisation, and balkanisation. The current analysis also indicates that CBR may be a valuable localising approach which is holistic, socially sustainable, community focussed, 'lay' oriented, consistent with community notions of empowerment and that it demonstrates a strong values base. These points are depicted in Figure 4.1 which illustrates that CBR is proposed as a response to many of the issues highlighted in Chapter Two, which is also consistent with trends identified in Chapter Three. The specific means by which CBR may be considered an appropriate alternative is detailed in the current chapter and chapters Five and Six.

Within this chapter, the nature and history of CBR is identified and an evolutionary trend, evident within CBR literature is highlighted. Using the framework of the Bio-Psycho-Social Ecology Model, the general strategies employed in CBR programmes are identified. Direct and indirect benefits which have been reported to arise from CBR projects are elucidated. The chapter concludes with an identification of some of the limitations of CBR approaches in developing countries.

It should be noted that the current analysis of CBR was mostly drawn from CBR literature since, within the limitations of being located in an economically developed country, the researcher was unable to explore CBR projects directly. As noted previously, an attempt was made to ensure as great a degree of objectivity as possible through drawing from a range of publications on CBR, as well as a process of literature synthesis through thematic categorisation to identify common points and themes.

<u>Chapter Two</u>: Issues of Concern in the Rehabilitation and Disability Sector in Economically Developed Countries

Bio-systems and psycho-systems levels: Overly medicalised services, ***neglecting important human and interpersonal aspects****.*

Micro-systems level: Disability services at this level are associated with a degree of ***social dislocation rather than community integration****.*

Meso-systems level: Service approaches and the disability movement ***do not appear to facilitate the effective participation of people with disabilities in the broader community****.*

Exo-systems level: Services ***may not be readily accessible, and may not facilitate community participation****. Policy and legislative approaches are remote and ineffective change mechanisms.*

Macro-systems level: Services ***reflect a tendency to achieve attitudinal change at a structural level*** *rather than through facilitating more active community participation of people with disabilities.*

Across systems: Concerns identified include ***demographic changes, economic impacts, predominating consumerist perspectives, the managerialisation of human services and a growing balkanisation within the sector****.*

Community Based Rehabilitation

<u>Chapter Three:</u> Trends Indicating Potential Directions for Rehabilitation and Disability Services in Economically Developed Countries.

A trend towards ***approaches which emphasise and facilitate localisation and appropriate localised responses to globalising tendencies.***

A trend towards ***strategies which reflect ecological holism*** *and the* ***maximisation of social sustainability****.*

The ***emerging community paradigm*** *and community focussed strategies.*

The emerging trend towards ***community contextualised expressions of empowerment****, particularly as expressed in 'small group equality work'.*

Recognition of ***postmodernism****, particularly* ***'lay' perspectives****, the importance of* ***'locality'****, and an emphasis on the place of values.*

Recognition of the place of ***values, particularly community and communitarian values.***

Growing acknowledgment of ***community focussed initiatives and approaches,*** *evident in many disciplines, including economics, agriculture, theology, ecology and health.*

Trends within the sector, including ***attempts to integrate service delivery into a community framework, growing commitment by people with disabilities to active participation in local communities, and a recognition of the role that community members will play in such a transformation.***

Figure 4.1 Indicators from Chapters Two and Three reflecting CBR as a potential framework

The current thesis recognises that the proposal of an approach which has emerged in developing countries, as a response to disability issues in economically developed countries is relatively novel. However, given the global nature of existence at the end of the twentieth century (Naisbitt, 1994) and the growing interdependence of nations (Goreczny, 1995), it is considered appropriate that a potential approach to rehabilitation and disability issues should be drawn from beyond the immediate Western context. O'Toole (1991a), suggesting that some of the more creative examples of models of service in rehabilitation have come from developing countries stated, "It may be a case of the West looking to the 'new world' for innovative ideas of meeting the challenge of working with [people with] disabilities" (p. 208). Dr. Enrico Pupulin (previous head of rehabilitation for the World Health Organisation) noted that Community Based Rehabilitation (CBR), is emerging as a paradigm with considerable depth and potential beyond developing countries (Pupulin, 1993).

Coincidentally, the completion date of this thesis, falls at the half-way point of the *Asian and Pacific Decade of Disabled Persons* (APDDP)[1]. A key point in the Agenda for Action of the APDDP is the promotion and development of the CBR approach. It is therefore considered fitting, that at the half-way point of the APDDP, the relevance of the CBR paradigm, which has evolved in the context of developing countries, should be considered for its application to economically developed countries. This is also consistent with the APDDP aim to develop and strengthen regional cooperation in rehabilitation and disability issues (Niwa, 1996).

[1] The APDDP (1993 - 2002) was proclaimed by *The Economic and Social Commission for Asia and the Pacific* which is the United Nations commission with responsibility for this region (comprising 53 countries and 2/3 of the total population of the world). This declaration, which has the potential to affect the lives of all people with disabilities within the region, is regularly referred to by authors from developing countries, but almost totally ignored by authors from developed countries such as Australia. This suggests a need for research which promotes a more international perspective in the area of rehabilitation and disability studies. The present study seeks to respond to this need.

4.2 Instigation of CBR

The specific origins of CBR are unclear with some authors suggesting that basic CBR concepts have existed for many decades (M. Miles, 1985) or have arisen out of deliberations of the 1969 Rehabilitation International [RI] conference in Dublin (O'Toole, 1991b). It is agreed, however, that the recent rise of CBR commenced in 1976 with its adoption by the governing bodies of the World Health Organisation [WHO] (Helander, 1993b) and was consolidated with the publication of the manual *Training in the Community for People With Disabilities* (Helander, Mendis Nelson & Goerdt, 1979) by the WHO. It was advanced by the 1979 *Alma Ata International Conference* (McColl & Patterson, 1995) in which the move toward community involvement in health gained momentum and through which, CBR was seen as consistent with the principles of the newly accepted primary health care model (O'Toole, 1991b). It was further advanced by the WHO's *Health for All by the Year 2000* strategy (Chermak, 1991; Twible & Henley, 1995), and through efforts made during the United Nations Decade of Disabled Persons (Pupulin, 1993). The United Nations afforded CBR global recognition in its 1983 report *World Programme of Action Concerning Disabled People* (Momm & Konig, 1989; McColl & Patterson, 1995).

CBR has seen dramatic growth since the late 1970s. For example, Tizun (1997) noted that in China there are now nearly 10,000 CBR stations. This growth was in large part facilitated by the WHO's dissemination of the manual to about 60 countries in the space of ten years (O'Toole, 1991b). Despite typically being located in contexts of severe economic hardship (which has been found to hamper many forms of development), CBR programmes have often flourished and shown rapid growth (Hai, 1993; Pupulin, 1993).

CBR appears to have been particularly successful in developing countries, in which traditional rehabilitation services were characterised by, (a) minimal impact - with up to 98% of people who required services, not able to obtain them (Peat, 1991a), (b) irresponsible transfer and uncritical acceptance of Western technology (Marincek, 1988), and (c) professional practices, patterned on Western models which required 'over-specialisation' of therapists (O'Toole, 1991b). Consequently, CBR may be seen to have emerged, not only as a response to the needs of people with disabilities, but also as a reaction to formal Western rehabilitation systems, which due to their professional, labour, and capital intensiveness were incapable of meeting the enormous demand in developing countries.

From a more critical perspective, the rise of CBR, has also been interpreted as a 'half-measure' engineered by the WHO. Lagerwall & Hargö Granér (1996) noted that some rehabilitation practitioners in economically developed countries view CBR as 'second hand rehabilitation' dumped on developing countries as a 'band-aid' to address disability issues. Such critical perspectives are explored later in the current chapter.

4.3 Definition of CBR

The most commonly cited current definition for CBR, was published in a United Nations joint position paper in 1994. It stated that,

> Community based rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services. (ILO, UNESCO & WHO, 1994)

The process of defining CBR appears to have posed far greater dilemmas for practitioners than may be apparent from the above, broadly inclusive definition. It has been noted that there are probably as many definitions of CBR as there are CBR projects (Enders, 1993; Peat, 1991a) and that definitions of CBR have changed considerably over time (S. Miles, 1996; O'Toole & McConkey, 1995). A thematic analysis of definitional statements indicated common hallmarks of,

- partnership and community participation,
- community membership for people with disabilities,
- initiatives by people with disabilities, their families and communities,
- improved quality of life and community membership for people with disabilities, and
- integration of services.

Despite this common basis, a number of different emphases and contrasting definitional perspectives are evident. For example, D. Krefting (1996a) and Cook (1996) emphasised *the delivery of basic rehabilitation services* to people in their communities, Twible and Henley (1995) emphasised *teaching people with disabilities* new skills, Momm and Konig (1989) emphasised *outreach* approaches, Chermak (1991) focussed on *government and policy change*, and M. Miles (1993) emphasised the *prevention of segregation*. Others have stressed the shift in focus *from the individual to the community* (Rehabilitation International [RI], 1995), *community behaviour change* (Tjandrakusuma, 1996) or *social development* (Chermak, 1991). More consistently, emphases have included *community integration* (O'Toole & McConkey, 1995), *community participation* (Lysack & L. Krefting, 1994), the use of *grass roots*

community development approaches (Momm & Konig, 1989; Tjandrakusuma, 1995), and the use of *primary health care* frameworks (McAllister, 1989).

This diversity of emphases indicates some of the complexity of defining an entity such as CBR. As indicated, the instigation of CBR appears to have been largely assisted by UN bodies. It emerged outside of a formal legislative framework. It does not comprise of a well defined service provision system, and it exists without a clearly articulated consumer movement (Lysack & L. Krefting, 1994). Each of these factors contributes to a lack of definitional consensus, which poses a significant barrier for unified action and debate (Finlayson & Edwards, 1995; Zinkin & Morley, 1993).

The lack of definitional clarity, also pertains to issues highlighted in the current research. First, if CBR is to be understood in detail, trends within the approach should be acknowledged. CBR is an evolving entity, an approach that has changed considerably over time and context, and continues to evolve. Consequently, recognition of the evolution of CBR should characterise such an exploration. Second, if CBR is to be explored comprehensively, the essential elements or philosophy of CBR should be clearly elucidated. Given the 'generic' nature of CBR, being more of a mass movement than a proprietary concept, such an elucidation will be highly clarifying for further research and practice. This is addressed in detail in the following chapter.

4.4 Example of a CBR Programme

CBR is inherently a practical approach to the provision of disability services. In order to convey the practical nature of CBR, an actual programme description has been included in the current analysis. Rather than seeking to describe the various facets and evolution of CBR through fabricating a description from multiple sources, and risk losing authenticity, the current thesis has drawn a description of a traditional CBR programme from the literature. The following example is edited from a programme description by Periquet (1989, pps. 95-96). It describes a traditional, structured CBR programme, for children in the Philippines.

This CBR project was initiated in Bacolod City, the capital of Negros Occidental province, in 1981. The first task was to prepare a training manual, designed for local use, that would enable community workers, to learn simple methods in the prevention and early detection of childhood impairments and techniques for the rehabilitation of disabilities in children. A committee composed of experts in rehabilitation, nutrition, special education, vocational rehabilitation and social services was organised. Using the WHO Manual *Training the Disabled in the Community*, and other relevant literature as key references, a manual was devised. This provided the community worker with information on four major disability groups: moving, speech and hearing, seeing, and learning, and included instructions on the application of simple rehabilitation techniques, basic terms and disability prevention. A section on administration

dealt with organising a CBR programme, establishing a referral network and gaining funds for the project.

The project was introduced into the community at each site with the creation of a local project committee to take responsibility for implementing and monitoring project activities. Sites were selected on the basis of community acceptance of, and commitment to, the project. Also considered was whether local community resources could be utilised for the project. In order to generate awareness of the project in the community, social preparation activities were carried out, and consisted of intensive information campaigns, such as public discussions, seminars, meetings, newspaper articles, radio and TV plugs and printed materials.

The following criteria were used to select community workers: (1) residency in the community, (2) willingness to train family members of disabled persons, (3) ability to read and write in English. Community workers were trained by the staff of the Department of Rehabilitation Medicine of the Philippine General Hospital (PGH), consisting of physiatrists, physical therapists, occupational therapists and speech pathologists. Local and visiting paediatricians, psychiatrists, nutritionists, special education teachers and other disciplines also took part in the training, the methodology of which included lectures, demonstrations and role-playing.

In order to sustain the commitment of the volunteer workers, incentives were given in the form of T-shirts and umbrellas with imprints of the CBR logo. The most appreciated incentive, however, was the increased standing in the community enjoyed by the volunteers, who were treated with great respect. Their advice regarding health and other non-disability-related matters was frequently sought. To standardise the monitoring / feedback structure of the project, appropriate forms were prepared. These included, case history forms, training manual utilisation forms, and progress report sheets.

Each community worker was assigned at least three disabled clients. They trained family members to perform simplified rehabilitation procedures and provided ongoing supervision. The progress made by the disabled client and family members was regularly observed and recorded by the community worker.

During this period a referral network was organised which included government agencies and private organisations such as provincial hospitals, special education schools, vocational training centres, and social and civic clubs.

The interest and enthusiasm of families were maintained by the improvement seen in the disabled clients. A subsequent evaluation by a local physiatrist and the training team of the PGH showed significant and definite improvements in functional performance which could not be explained on the basis of natural recovery from the lesions producing the disabilities. It was concluded that CBR is a cost-effective approach in the delivery of disability services, and was particularly relevant in rural areas which previously had no access to any kind of rehabilitation services.

4.5 Disability Groups to Which CBR is Applied

Community Based Rehabilitation manuals (Helander et al., 1989; Werner, 1987) have demonstrated a predominant emphasis on rehabilitation strategies for children in general as well as for adults with physical disabilities. Not surprisingly, children with a variety of disabilities and adults with physical disabilities appear to comprise the major population group for CBR programmes (Medina & De Jesus, 1995). CBR appears most commonly utilised to assist people with sensory impairments, such as visual and hearing impairments; motor impairments, such as cerebral palsy; and mobility impairments, such as amputation and paraplegia. Despite this, the CBR approach has also been applied more broadly and is being used to assist community members with a variety of disabilities. For example, CBR programmes have been instigated, to assist people with 'general mental health needs' (Ginsberg, 1993, Hanumantha-Rao, Venkatesan & Vepuri, 1993; Myezwa, 1995), to assist people with serious psychiatric illnesses (Thara, 1992), as a strategy for working with people with intellectual disabilities (Brouillette, 1994; Myezwa, 1995; Prajapati, 1995; Ran, Wen, Yonghe & Honglu, 1992), to assist people with head injuries (M. Thomas & M.J. Thomas, 1995), and as an approach to working with people with leprosy within their communities (Gershon & Srinivasan, 1992; McDougall, 1995). Despite debate regarding efficacy of CBR with some populations - such as people with intellectual disabilities (Myezwa, 1995), it would appear to have been applied relatively broadly across the disability sector.

4.6 Evolution of CBR

As initially instigated, CBR consisted of the simple concept of delivering basic rehabilitation services in the community (D. Krefting 1996a). It was predominantly oriented towards physical and functional rehabilitation (Zinkin & Morley, 1993), was occasionally highly 'medicalised' and impairment focussed (Gill, 1995; Maryniak, Ovcharenko, Pelekh & Palamarchuk, 1991), and consisted of a relatively narrow service delivery focus on impairment and disability (Mendis, 1993; O'Toole & McConkey, 1995; RI, 1995). Since it was almost exclusively based on the use of manuals for minimally trained workers or family members, some have argued that it was often practiced in a 'cookbook approach' using basic rehabilitation techniques and formalised strategies (S. Miles, 1996). The use of the manuals in CBR is reported to have led to hierarchical implementation, and resulted in overly rigid practice approaches (Gill, 1995).

Despite these limitations, CBR remained strongly community based and has undergone considerable evolution since instigation (Peat, 1993). This evolution may be characterised by,

- A fundamental shift “beyond a narrow focus on disability alone" (O’Toole & McConkey, 1995, p. 37), towards issues of relevance to the whole community, *including* people with disabilities (Lysack & Kaufert, 1994).
- A trend towards supporting more grassroots approaches and the expression of local culture in the rehabilitation enterprise (Hai, 1995; Lysack & Kaufert, 1994).
- A shift towards facilitating community responsibility for programmes (M.J. Thomas, 1997), while seeking to maintain a high level of consumer focus (S. Miles, 1996).

Commensurate with this transformation away from an emphasis on formal rehabilitation service delivery, has been a greater recognition of the importance of informal aspects of CBR. Peat (1993) observed that the substance of CBR has not been formally and professionally defined, but "has developed over the last 20 years largely within the non-government and non-organised sector: within the circles of family and neighbours of persons with disabilities" (p. 6).

This evolution of CBR is reflected in debate regarding the term ‘Community Based Rehabilitation’. S. Miles (1996) observed that evolving forms of CBR place less emphasis on the ‘R’ and look more broadly at community issues. She suggested that a new name be sought for "a community based strategy which promotes equality of opportunities" (p. 507). Terms such as ‘Community Integration Programmes’ (Momm & Konig, 1989) and ‘Community Owned Rehabilitation’ (RI, 1996) have also been suggested.

In practice, this shift has been expressed in initiatives to provide broader skills to family members and the local community (L. Krefting, Al-Kindy & Sheth, 1995; Twible & Henley, 1995) and increasingly, to devolve responsibility and direction of CBR initiatives to the individual with a disability, their family and their community (Jonsson, 1996). The focus of many CBR programmes is now on building community capacity (UNESCO, 1995), and developing existing networks between individuals and groups (S. Miles, 1996). As such, in CBR literature, outcomes are now starting to be expressed in community, social, and attitudinal variables (Dolan, Concha & Nyathi, 1995). Current descriptions of CBR programmes emphasise community motivation, education and changing attitudes rather than simply the provision of services for individuals with disabilities (D. Krefting, 1996a; RI, 1995).

In terms of the descriptive framework utilised in the current study (the Bio-Psycho-Social Ecology Model), this evolution may in part be depicted as a shift in focus away from individualised rehabilitation and disability service delivery at the bio-systems and psycho-

systems levels, towards enhancing services at the micro- and meso-systems levels. Similarly, the noted trend away from a formalised service delivery orientation towards more informal community level approaches, reflects a reorientation away from exo-systems approaches, towards more informal micro- and meso-systems levels.

While this evolution is clearly discernible (D. Krefting, 1996a; S. Miles, 1996; RI, 1996; Tjandrakusuma, 1996), it is by no means uniform. There are instances of relatively recent CBR studies which reflect highly regularised, professionalised and hierarchical approaches (Kalyanpur, 1996; Kay, Kilonzo & Harris, 1994; M. Thomas & Pruthvish, 1993). There are also differing perspectives on the structures within which CBR should be instigated and operate (Boyce & Johnston, 1996; Peat, 1993). However, for the present purposes, evolving forms of CBR, as identified in the current thesis, are seen as warranting further attention.

4.7 CBR Strategies

Although CBR has evolved beyond a readily identifiable set of rehabilitation procedures and techniques, a number of general strategies can be conceptualised using the Bio-Psycho-Social Ecology Model. While previously, CBR might have been characterised as a set of rehabilitation interventions focused towards the bio- and psycho-systems levels, it is increasingly evolving towards a more balanced and comprehensive approach, seeking to respond across all levels characterised by the Bio-Psycho-Social Ecology Model. This attempt to develop a holistic and integral response to the needs of people with disabilities, is considered a strength of more current forms of CBR practice.

4.7.1 CBR Strategies at the Bio-system and Psycho-system Levels

CBR strategies at this level have tended to comprise the application of basic secondary and tertiary level physical and functional rehabilitation techniques. Within CBR, intermediate level workers with limited training are typically the major resource. Despite this, many programmes have sought to emulate rehabilitation approaches commonly used in economically developed countries. Examples exist of highly medically or physically oriented treatment approaches (Maryniak et al., 1991), however such perspectives have been questioned. Zinkin and Morley (1993) stated,

> In general the actual professional curricula for rehabilitation workers are still predominantly physiotherapy oriented. For a more fruitful role in a CBR system, the rehabilitation worker should be educated by learning in groups to generate better answers to the local problems rather than by individually learning to copy foreign teacher's solutions. The better answers are often not found in the application of physiotherapeutical techniques but require attitudes, knowledge and skills developed in other disciplines. At least they require a preparedness to change as a result of learning from [people with disabilities].(p. 245)

Strategies employed within CBR at the bio- and psycho-system levels, reflect the traditional core of CBR practice. Central to such strategies is the provision of training for community level workers. Training typically involves building skills in, screening and identification of disabilities (Hanumantha-Rao et al., 1993; McAllister, 1989), basic treatment of common disabling conditions with an emphasis on recognition, and referral for less prevalent problems, or those requiring professional intervention (Ginsberg, 1993). Training and subsequent support of community level workers is facilitated through the use of general manuals (Helander et al., 1989; Werner, 1987), and development of a support structure in which professional staff act as a referral and resource focus for community workers. Outcomes of such processes in terms of improvement in function and accuracy of diagnosis have been found to be high (Finnstam, Grimby, Nelson & Rashid, 1988).

CBR practice at the bio-system and psycho-system levels is in the process of evolving away from a heavy reliance on manuals and techniques (L. Krefting, et al., 1995; O'Toole, 1991b). Early CBR practices resulted in a 'symptom oriented', 'authoritarian' approach to rehabilitation services (M. Miles, 1985). Newly emerging strategies at these levels emphasise the skilling of community members, such as teachers (O'Toole, 1991a), training family members (D. Krefting, 1996a), and the application of existing indigenous knowledge in meeting the rehabilitation needs of people with disabilities (Helander, 1993a; S. Miles, 1996). Training in CBR appears increasingly, to draw on adult education principles (Jones, 1997; Twible & Henley, 1993), emphasising trainees' life experience, and their knowledge of structures, resources and people. Reports of training and practice for intermediate level workers also appear to be shifting to include social perspectives of disability, enabling trainees to consider community, attitudinal and other factors which contribute to disability (S. Miles, 1994; Prasad, 1997).

4.7.2 CBR Strategies at the Micro-system Level

The provision of assistance for people with disabilities at the micro-system level (immediate social relationships) is a major focus of CBR programmes. D. Krefting (1996a) stated that "Families have the primary responsibility for caring for all of their members. They are the first line of support and assistance for people with disabilities at the local level" (unnumbered). CBR initiatives at the micro-system level are evident in efforts to,

- Support families as a key priority (D. Krefting, 1996a), thereby fostering the integrity of the most important micro-system around a person with a disability.

- Dedicate resources to facilitate micro-systems linkages between people with disabilities and others in their immediate community (Hartung, Kelly & Okamoto, 1989; L. Krefting et al., 1995; S. Miles, 1996).
- Foster the development of mutual and supportive relationships by linking people with disabilities together to share experiences and act as role models for others (D. Krefting, 1996a).
- Link people with disabilities to their immediate communities to act as a resource about disability in their community (L. Krefting et al., 1995).
- Use existing social relationships as a context to raise the self esteem and confidence of people with disabilities and engender a greater sense of self worth and control over their lives (S. Miles, 1996).
- Ensure that the use of traditional rehabilitation techniques is balanced with a strong philosophical position to promote the holistic development of people with disabilities (Hartung et al., 1989).

4.7.3 CBR Strategies at the Meso-system Level

At the meso-systems level (the level of interrelations between social settings), a number of strategies are evident from the CBR literature. The emphasis within CBR on generic strategies such as community development, to facilitate integration and provide greater local options for people with disabilities (Enders, 1993), provides a context and impetus for community level action extending beyond disability issues (Christie, 1996). This is reflected in CBR programmes which are "directed towards the whole community as well as the individual members who happen to have a disability" (Tjandrakusuma, 1996, p. 2). Examples of CBR practice at this level have included,

- Initiatives which have sought to build community capacity to more effectively integrate and support people with disabilities (UNESCO, 1995).
- The provision of assistance with the formation of local Disabled Person's Organisations as well as more general community / social groups (Aboobacker, 1997; S. Miles, 1996).
- Efforts to increase the knowledge and skills of the community on disability issues (Tjandrakusuma, 1996).
- The skilling and utilisation of local crafts- and trades-persons in the design and production of aids and appliances (S. Miles, 1996).
- The promotion of greater community networking through the dissemination of information about services available in a community (Aboobacker, 1997; Marincek, 1988).
- The facilitation of community cooperation through the development of community based income generation and business loan schemes for people with disabilities (Gershon & Srinivasan, 1992; S. Miles, 1996).

- The optimisation of informal and semi-formal local networks through integrating CBR with Primary Health Care, nutrition, child development and literacy projects (Christie, 1996).

Since the focus of any particular CBR activity should be determined by the community in which it operates, CBR programmes tend to be culturally unique, geared to the specific needs of a community (Peat, 1991a). Consequently, it is assumed that CBR programmes will interact with community members on a significant level. Training, particularly within emergent forms of CBR, may extend beyond the training of CBR workers alone and may seek to, motivate community leaders on disability issues (McAlister, 1989), focus on viewing disability as a broader development issue (S. Miles, 1996), and assist people with disabilities and others to work together to become agents of change at the community level (O'Toole, 1991b).

4.7.4 CBR Strategies at the Exo-system Level

CBR strategies at the exo-system level, may be seen to be comprised of approaches which influence and interact with formal systems of service delivery and legislative bodies. Examples of CBR activity at this level include,

- Initiatives which seek to build organisational links through networking and dissemination of information between local and national Disabled Person's Organisations (S. Miles, 1996).
- Recognition of the need to promote a legislative framework to ensure the sustainability of CBR programmes (M. Thomas, 1997).
- Facilitation and provision of support for the development of self-help organisations at the community level (D. Krefting, 1996a).
- Working towards the development of "comprehensive and appropriate policies concerning people with disabilities and their families and communities" (Kwok, 1995, p. 355).
- Enhancing multi-sectoral collaboration, and specifically the coordination of agencies to promote integrated education for children with disabilities (S. Miles, 1996).
- Facilitating the involvement with people with disabilities at an organisational level through networking between existing community and service organisations (Gershon & Srinivasan, 1992).
- CBR initiatives to develop appropriate referral systems and influence service delivery systems (D. Krefting, 1996a).
- Recognition of the need to address discriminatory legislation and ensure that the rights of people with disabilities are guaranteed (D. Krefting, 1996a).

4.7.5 CBR Strategies at the Macro-system Level

At the highest level within the Bio-Psycho-Social Ecology Model, CBR projects may be seen to demonstrate a focus on attempts to change community attitudes (International League of Societies for Persons with Mental Handicap [ILSMH], 1994). A principle of CBR is that,

> the best way to overcome the fear and misunderstandings that lead to social discrimination is to have the community members work with people with disabilities. In the process of working together, people start to understand each other and to learn about each other's needs. (D. Krefting, 1996b, p. 50)

In this capacity, CBR initiatives have sought to assist people with disabilities to become influential role models and community level advocates (RI, 1995).

As a consequence of the social nature of many newly emerging CBR programmes, it has been reported that participants have begun to realise that the relevance of the programme extends beyond immediate disability issues, to broader community and social planning issues (Kwok, 1995), and that they are part of influencing attitudes in the community. CBR strategies at this level may consist of activities directed towards overcoming social discrimination and ensuring equalisation of opportunities for people with disabilities (Prasad, 1997). Such change is typically facilitated through the involvement of people with disabilities and community members in the process of programme design and implementation, and through transferring knowledge about disability issues to community members. (D. Krefting, 1996a). It has been stated that the goal of a CBR programme

> is not to normalise disabled people to fit into a restrictive, unfair and in many ways disempowering society. Rather it is to join the struggle of other marginalised people to transform our social order into one that treats everyone - weak and strong, rich and poor, disabled and non-disabled - with equal opportunity and respect (Werner, 1993, p. 230).

While CBR programmes do not appear to ‘train’ directly on these issues, a strong agenda is discernible to ‘inspire the community’ (Werner, 1993) particularly through consciousness raising on disability rights issues (S. Miles, 1996), bringing about attitude change (Tizun, 1997), and creating receptive and supportive environments for people with disabilities (Dolan et al., 1995).

4.8 CBR Structure

There is little uniformity of structures across CBR programmes (Asindua, 1995). The recognition that the framework for each project should be influenced by community, social, cultural, demographic and resource factors (Helander, 1993a; Peat, 1991a), appears to have resulted in a multiplicity of structural approaches. While historically, CBR structures in developing countries may have reflected hierarchical Non Government Organisation (NGO) structures, a devolution to greater community influence is evident (S. Miles, 1996). It has been recommended that CBR projects should be autonomous community based and community run units (S. Miles, 1996; M. Thomas, 1993), with a strong referral system to relevant professionals and agencies (Carraro, 1997; Helander, 1993a).

It would appear that many structural components of CBR programmes are drawn from the local community (including leadership of the programme, volunteers, physical space, funding, involvement of businesses, etc.) (L. Krefting, 1995). Recent CBR authors have acknowledged that for community based initiatives to remain significant, the structure should exhibit a degree of coordination so that training, technical resources, skills, financial resources, research and advocacy efforts, can be pooled (M. Thomas, 1993). It has been recommended that CBR structures should draw support from government and relevant health, education or social welfare service structures (Helander, 1993a; O'Toole, 1991b), as well as mainstream development activities (D. Krefting, 1996b).

4.8.1 Sustainability

A concern to develop services for and with people with disabilities, which are sustainable within a local community, is evident throughout CBR publications. As a result, it would appear that CBR programmes are more socially and economically sustainable than other models of service delivery (RI, 1995). CBR authors have noted that sustainability is facilitated through the following strategies.

- Emphasising the need for accountability of a programme, not just to people with disabilities, but also to the community, other agencies and government (Narayan, 1993).
- Attempts at boosting the capacity of the programme to respond to changing circumstances on a local scale (Wormsley, 1990).
- Utilising a democratic management style which facilitates a greater degree of empowerment for participants (M. Thomas, 1993; Winkley, 1990).
- Ensuring a high level of consumer and community involvement in all aspects of the programme (Lysack & Kaufert, 1994; Pandey & Advani, 1995).

- Appropriate tailoring of the resource needs of the programme to ensure that they can be met by the local community (Hai, 1993).
- Ensuring clarity of goals and objectives, a high degree of skill transfer, and community involvement (Narayan, 1993).
- Building on and contributing to, the existing local knowledge base (Wormsley, 1990).

One of the primary instigators of CBR stated that the approach was designed in such a way as to be technically, administratively and economically maintainable using local and national resources (Helander, 1993b). Structural elements such as management skills, infrastructure, monitoring and evaluation procedures (RI, 1995), as well as programme and national policies (Yeadon, 1990), have also been seen as factors influencing sustainability of a CBR project. In light of concerns raised in Chapter Two, it is suggested that the emphasis on sustainability in CBR has resulted in a more reflective and locally sensitive approach to disability service delivery, as well as more socially viable programmes. CBR programmes appear to place a high priority on their long term social and economic viability.

4.9 Definition of Community in CBR

As noted earlier, within emergent forms of CBR, the entire community (rather than just the person with a disability) is the target of programmes (Lysack & Kaufert, 1994). Given the role of the community in CBR, a consistent definition of community is warranted. Most CBR programmes, recognising the importance of the immediate village community in developing countries, have tended to define community in a geographical sense (Werner, 1993). Typically such definitions emphasised, neighbour to neighbour interdependence, people giving of themselves freely, the centrality of families, traditional crafts-persons giving of their skills, and a lifestyle such that people with disabilities can participate meaningfully in work and subsistence (Werner, 1993). The accuracy of these perceptions of community may be questioned and are addressed later in this chapter. For the present purposes however, it might be observed that while traditional perceptions of community in CBR were highly localised and geographical, more recent definitions have tended to use multi-dimensional and functional rather than simple geographical notions of community.

A broader conceptualisation of community in CBR is illustrated by the definition, "community is understood to mean a group of people who interact with each other on a regular basis" (RI, 1995, p. 2). In the context of the current thesis, it is observed that more recent understandings of community within CBR reflect its potential application beyond a developing country, village

context and its applicability to more multi-dimensional conceptualisations such as the Bio-Psycho-Social Ecology Model.

4.9.1.1 Community Development

Current definitions of CBR place it as a strategy within community development (RI, 1995; ILO, UNESCO & WHO, 1994). This trend has correctly been identified as a radical reorientation of many aspects of CBR practice. It includes changing the role of professionals from service providers to community developers (O'Toole, 1991a), and by implication, changing the role of clients from service users to community members.

Community development is an approach which has been found to encourage greater self-reliance and foster community self-determination (Ward, 1993). It may take a variety of forms, from individual development to mutual support, or from basic community integration to participation in social change (Jackson et al., 1989). It has been reported to facilitate individual and community capabilities, and foster citizen influence in decision making (Florin & Wandersman, 1990). On a personal level, community development strategies have been found to be effective in responding to individual need (Ward, 1993), reducing social isolation and building community networks (Kwok, 1995). On a structural level, community development approaches appear to result in changes that will be supported by the community (Ward, 1993), facilitate effective linkage between formal and informal care structures (Kwok, 1995), address the distribution of power and resources, and increase people's control of and participation in services (Jackson et al., 1989).

As indicated earlier, the inclusion of CBR under community development, may enable people with disabilities to become more active participants in the community and the rehabilitation process. The result will be an approach which places less emphasis on formal rehabilitation service delivery (the exo-system level), and the application of rehabilitation techniques (the bio- and psycho-system levels) and instead prioritises broader community, education, employment and social issues (Christie, 1996; Enders, 1993; Ginsberg, 1993; S. Miles, 1996; M. Thomas & M.J. Thomas, 1996). This is seen to be consistent with the identified evolution of CBR.

4.10 Benefits of CBR

Having explored CBR strategies and structures, a number of benefits can be identified which arise out the CBR approach, particularly in emerging forms. In the context of issues of concern identified in Chapter Two, the current description of benefits reflects the potential of CBR as a constructive alternative. In the following sections, direct and indirect benefits which have been associated with CBR are described. With reference to the Bio-Psycho-Social Ecology Model, direct benefits may be seen to correspond specifically with certain levels, while indirect benefits apply more generally (Figure 4.10).

The term 'benefit' was chosen rather than the more narrow 'outcome' since many of the benefits which arise from CBR initiatives, particularly indirect benefits, are not amenable to objective measurement. Further, due to the nature and purpose of much CBR research, and the way it is reported, 'processes' of CBR are often indistinguishable from 'outcomes'. The current thesis notes that 'process' may itself be an intrinsic benefit, and also that not all benefits are necessarily represented by measurable outcomes.

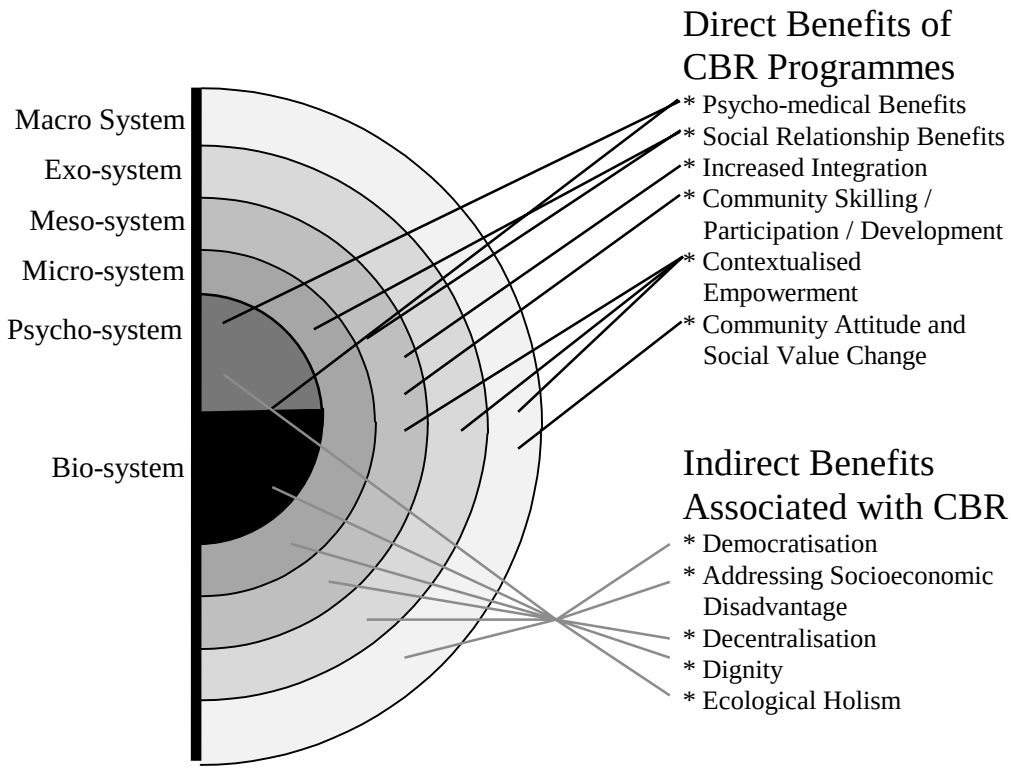

Figure 4.10 Benefits arising from CBR programmes

4.11 Direct Benefits of CBR Programmes

4.11.1 Psycho-medical Benefits of CBR Programmes

As a rehabilitation intervention system, substantial physical, functional and psychological benefits have been found to ensue from CBR programmes. Formal rehabilitation interventions comprise an aspect of all CBR programmes, they form a large part of the content of CBR manuals, and constitute a significant portion of training for CBR workers (Helander et al., 1989; Medina & De Jesus, 1995; Werner, 1993). Despite the use of basically trained, non-professional community workers using local resources, CBR programmes have been reported to show outcomes comparable with rehabilitation services in economically developed countries (Helander, 1993a) at a fraction of the cost (O'Toole, 1991b; Periquet, 1989). As an example, Finnstam et al. (1988) reported that at two year follow up of a CBR programme in Pakistan, 80% of participants showed ongoing improvement in function. A study exploring the magnitude of improvements in activities of daily living across disability type was reported by Lagerkvist (1992). He found that over 80% of participants showed an increase in independence in activities of daily living by three or more points on a 28 point scale. Similar improvements in function and activities of daily living were reflected in a study by Dolan et al. (1995) and in a review of a number of projects by O'Toole (1991a). While a proportion of these effects might simply be a reflection of the paucity or absolute lack of services prior to CBR intervention, it would appear that CBR interventions result in considerable physical and functional outcomes.

4.11.2 Social Relationship Benefits

M. Scott Peck (1987) observed that while formal structures and institutions can deliver services, they are unable to deliver care. As a socially oriented reaction to institutional forms of service delivery, CBR might be seen as a mechanism for facilitating care within the immediate social relationships of a person with a disability. In the CBR process, through the involvement and participation of family, friends, fellow workers and volunteers, the person's immediate community is strengthened (Marincek, 1988). Consequently it is assumed that this reliance upon the social ecology of a person with a disability, will enhance opportunities for building social relationships (and presumably caring relationships). Aitken and Walker (1987) saw CBR as a mechanism to facilitate such social relationships and care.

From a number of years experience with CBR programmes, O'Toole (1991b) stated that community based approaches, simply by function of their community orientation, meet many of the social and emotional needs of participants as they grow together in partnership.

Mitchell, Zhou, Lu and Watts (1993) found that through a CBR programme in China, the resources of families and the wider community were identified and reinforced. Dolan et al., (1995) noted an improvement in family attitudes and relationships as a result of a CBR programme. They stated that CBR initiatives "have helped to raise clients' self esteem and their integration into the family and local community. As such they have had an effect on the environment of disabled people" (p. 197). Vanneste (1997) found that the level of involvement of family in a CBR programme builds their faith in the abilities of their disabled family member.

Community based approaches reportedly provide a context which enables people to more readily define and articulate their needs and aspirations, on an individual (Ife, 1995) and social level (Mitchell & Wright, 1992). This is seen as an important factor in the building of close social relationships.

4.11.3 Increased Integration

Helander (1993a) asserted that CBR promotes the integration of the person with a disability into their community. O'Toole (1991b) noted that the number and nature of supportive, befriending relationships that were established through CBR were as beneficial to people with disabilities as the physical outcomes that ensued from the interventions.

It has been suggested that as a result of the strategies employed in CBR programmes, the visibility, participation, decision making and consequent social role of people with disabilities is promoted (L. Krefting, 1995; RI, 1995). Furthermore, the group and communal orientation of CBR projects has been found to result in greater group solidarity, and increased levels of involvement by people with disabilities in community and local organisations (Dolan et al., 1995).

4.11.4 Community Skilling / Community Participation / Community Development

In seeking to demystify the rehabilitation process and give responsibility back to the individual, the family and the community (Helander, 1993a; O'Toole, 1991b), CBR processes demonstrate a strong emphasis on developing a skilled community (L. Krefting et al., 1995; O'Toole, 1991b). CBR opposes professionalism and professional elitism (Ginsberg, 1993; S. Miles, 1996), and focuses on the community, rather than the professional as the major resource to meet the needs of disabled people (L. Krefting, 1995; Lundgren-Lindquist & Nordholm, 1993).

It would appear from the CBR literature, that as an inherent aspect of the CBR approach, community skilling has been taken as a 'given' and few examples exist of attempts to measure it as an outcome. Examples of community skilling initiatives include,

- Twible and Henley's (1995) report of an initiative to capitalise on existing knowledge, and build transferable skills in community members in order to 'demystify disability'.
- S. Miles' (1996) review of CBR programmes in southern Africa in which considerable outcomes for people with disabilities arose from community skill development and community consciousness raising on disability rights issues.
- Ginsberg's (1993) review of four CBR programmes in Kenya in which it was found that successful programmes emphasised community organising as a key activity, incorporated a community education component, exhibited community level administration and encouraged community ownership.

Although not directly evident in the CBR literature, such community level skilling has been noted to have a positive impact on the community, the relevant organisation and individuals who are stakeholders in the process (Prestby et al., 1990).

High levels of community participation are a feature of many current CBR programmes (Peat, 1991a; Mitchell et al., 1993; Myezwa, 1995). Hai (1993) observed that "Community involvement is the guiding principle of the [CBR] programme." (p. 217). Participation in CBR projects has consisted of the community's provision of volunteers, equipment, funding (L. Krefting, 1995; Ginsberg, 1993; Price & Radio, 1996); informal and formal organisational structures (M.J. Thomas & M. Thomas, 1996; Tjandrakusuma, 1996) and motivation (Peat, 1991a).

The commitment to community participation in CBR projects,

- Enables the community to gain more control over the project (Coleridge, 1993).
- Results in greater community responsibility and civic consciousness (Coleridge, 1993).
- Is believed to contribute to the success and sustainability of the programme (Kulmann, 1994).
- Is an effective mechanism for avoiding unnecessary compartmentalisation of services (Chermak, 1991), and facilitates the optimal use of formal health and rehabilitation systems (O'Toole, 1991b).

Community development is seen as the practice framework for CBR (Tjandrakusuma, 1995; RI, 1995). A number of instances can be identified in which the community development orientation of a CBR programme has resulted in broader community outcomes. Examples exist in which CBR interventions have been reported to result in benefits such as, the creation of

social, vocational and educational opportunities in the community (UNESCO, 1995); the building of accessible therapy playgrounds for the whole community (O'Toole, 1991b); housing, transport and land distribution improvements (Venkatesh, 1993); new social structures (O'Toole, 1991b); and improved Primary Health Care, nutrition, child development, and literacy programmes (Christie, 1996). O'Toole and McConkey (1995) stated

> CBR is an attempt to generate an exponential increase in appropriate skills, distributed to where the needs are by utilising hitherto unexploited resources in the community. The goal is for rehabilitation to be perceived as part of community development whereby the community seeks to improve itself. Once the community takes on the responsibility for the rehabilitation of persons with disabilities then the process could truly be called community based. In such a process rehabilitation becomes one element of a broader community integration effort. (p. 34)

4.11.5 Contextualised Empowerment

There have been a number of critiques of the suitability of 'empowerment' as a concept in CBR. M. Miles (1996) and Kalyanpur (1996) suggested that it amounts to Western, liberal, democratic cultural imperialism. Despite these critiques, a form of empowerment is a consistent theme in CBR literature. It is suggested however, that the nature and structure of 'empowerment' in the CBR context is demonstrably different from traditional Western perspectives. While empowerment in economically developed countries has been characterised as individualistic and conflict oriented (Riger, 1993), the nature of empowerment in CBR appears related to commitment to community, and is balanced by interconnectedness. It may be observed that such empowerment is more 'ecologically contextualised' (involving participation at the micro- and meso-system levels as well as exo- and macro-systems). Such 'contextualised' empowerment has been found to have a positive impact on the community, community organisation and the individual (Prestby et al., 1990) and corresponds with Riger's (1993) description of genuine empowerment.

4.11.5.1 Contextualised Empowerment of People with Disabilities

Instances of contextualised empowerment of people with disabilities as a result of CBR programmes include the following,

- S. Miles (1996) reported that within a CBR programme people with disabilities were increasingly taking control of their lives and playing a decisive role in services that were created.
- Dolan et al. (1995) found that increased group solidarity amongst participants in a CBR programme was an outcome of the project. They reported that people with disabilities became more active in local organisations and achieved greater levels of independence, integration and self actualisation.

- Venkatesh (1993) described a CBR programme in India in which people with disabilities collectively started to address broader political and social issues (such as income generation, primary education, rehabilitation, housing, transport and even land distribution).
- From a study of a CBR project in China, Mitchell et al. (1993) found that people with disabilities were increasingly treated as a valued resource in the community.
- Observations that in CBR programmes, people with disabilities, participated in decision making (Ginsberg, 1993), became more vocal and demanding of their rights (Myezwa, 1995), demonstrated greater degrees of self advocacy (Freyhoff, 1994), and initiated Disabled People's Organisations (Kulmann, 1994; Lagerwall & Hargö Granér, 1996).

4.11.5.2 Community Empowerment

Describing a community centred approach, in which the essential features are partnership and community participation (Peat, 1991a), CBR literature includes a number of instances of empowerment at the community level. Enders (1993) referred to the CBR approach as "An ecological approach ... that moves beyond sole focus on the individual's adjustment to disability and incorporates targeted efforts at developing the community's ability to include all its members" (p. 19).

L. Krefting (1995) and O'Toole and McConkey (1997) noted that in CBR, the community is a major target of the activities of the programme. Lagerwall and Hargö Granér (1996) found that the initiative for, and the power behind their CBR programme lay in the community itself. They saw empowerment of the community as an essential process and outcome of their project. Christie (1996) suggested from her experience of CBR programmes, that the process of CBR results in the enablement or empowerment of a community to action. In her example, a CBR programme in Guyana was the catalyst for a number of diverse community development initiatives such as programmes in Primary Health Care, nutrition, child development, disability management and literacy. Similarly, Aboobacker (1997) stated that on evaluation, a CBR programme in India was found to have an empowering effect on the whole neighbourhood.

Hai (1993) concluded from his evaluation of a CBR programme in Vietnam that

> The greatest success of the project lies in its impact on the lives of the people it has served: those with handicaps, their families *and the community at large*. This impact appears to be immeasurable. The changes it has brought about in this short time are often dramatic and have served to *stimulate interest and the awareness in the community that rehabilitation needs of members with handicaps can be met through their own community efforts.*[italics added] (p. 216)

4.11.6 Change in Community Attitudes and Social Values

Changes in community attitudes, social beliefs and social values have been identified as outcomes of CBR initiatives (Finkenflugel, Van Maanen, Schut, Vermeer Jelsma & Moyo, 1996; L. Krefting et al., 1995; RI, 1995). A fundamental tenet of many CBR programmes, is that the quantity, quality and context of interactions between people with disabilities and non-disabled community members, significantly affects community attitudes (Minnes, 1994). Consequently in practice, many CBR programmes achieve attitude change towards people with disabilities, through facilitating constructive and active roles for them in the community (D. Krefting, 1996b).

The following outcomes in community attitudes and social beliefs have been noted from CBR programmes.

- As a result of a CBR programme, attitudes towards people with disabilities significantly improved amongst family members and communities (Devarakonda, 1995; Myezwa, 1995, Rottier, Broer, Vermeer & Finkenflugel, 1993)
- The involvement and actions of people with disabilities in a CBR programme led to changes in their self image and the attitudes of those around them (Hai, 1993; Venkatesh, 1993)
- It was found that communities in which CBR projects were active, demonstrated more favourable attitudes to people with disabilities than other communities. (S. Miles, 1996, Mitchell et al., 1993)
- People with disabilities who participated in a CBR programme reported more positive community attitudes towards them (that they were regarded as more active members of society) (Myezwa, 1995) and saw attitudinal and awareness changes as a key benefit of a programme (Dolan et al., 1995).

It is has been suggested that such community attitude change should result in a community 'opening up' some of its resources and may lead to a shift of the balance of power and control (M. Miles, 1994).

4.12 Indirect Benefits Associated with CBR Programmes

4.12.1 Democratisation

Lundgren-Lindquist and Nordholm (1993) stated from their survey research in Botswana that "It is the decentralised and democratic front of CBR which gives it strength as an alternative" (p. 88). It has been observed that successful CBR programmes emphasise localised and participatory administration and leadership styles which are responsive to the community (Deetlefs, 1995; Ginsberg, 1993).

Since participatory and democratic action by people with disabilities is an essential element of their liberation (Shakespeare, 1993), it is noteworthy that community based approaches are based on similar principles to those which underlie participatory democracy (Ife, 1995). While it has been argued that CBR has not made a significant impact on national level policies and organisational agendas (Dolan, et al., 1995; M. Thomas, 1997; Zinkin & Morley, 1993), a few examples exist in which participants of a CBR programme worked with international and national human rights organisations to pressure governments on issues of concern to people with disabilities (eg. Werner, 1993). It would appear then that when appropriately conducted with community members involved in early decision making, CBR approaches can employ democratic processes which result in an increased sense of equality, as well as greater levels of responsibility for, and participation in, management matters (Peat, 1991b). These aspects may be considered as community level precursors for greater democratisation.

4.12.2 Addressing Socioeconomic Disadvantage

At one level, CBR may be considered a response to socioeconomic disadvantage through the provision of cost efficient rehabilitation for people with disabilities, who may be among the most economically disadvantaged community members (Lagerwall & Hargö Granér, 1996; Periquet, 1989). At another level, there is evidence that some CBR programmes have also sought to respond to broader socio-economic issues.

An evaluation conducted by Gershon and Srinivasan (1992) found that interventions which comprised part of CBR programmes, resulted in dramatic improvements in employment and occupational status, increased level of income and earning capacity, and marked improvement in housing standard for participants. S. Miles (1996) found that general poverty alleviation was emphasised by a number of CBR programmes in southern Africa. Longer term benefits of the focus on poverty alleviation were noted by Venkatesh (1993). He suggested that as people with disabilities become increasingly empowered through CBR programmes, they begin to

generalise their focus and seek to address issues such as income generation and broader socioeconomic issues.

4.12.3 Decentralisation

As an approach which seeks to devolve rehabilitation and disability services to a local community level, CBR is inherently a strategy of decentralisation (Chermak, 1991). This is evident in the variety of forms of decentralisation that CBR authors have documented or discussed. These include,

- Ginsberg (1993) in an evaluation of programmes in Kenya in which it was noted that a commitment to geographical decentralisation was a feature of successful programmes.
- Peat (1991b) argued from his experience of CBR projects that the decentralisation of power to the community is an inherent aspect of CBR.
- From his survey of CBR programmes in Zimbabwe, Myezwa (1995) noted a decentralisation of responsibility for disability issues to the community.
- The 'decentralisation' of decision making to people with disabilities and related 'decentralisation' of knowledge and skills from professionals and service providers to people with disabilities, their families and community members has been found to be an important factor of successful CBR programmes (Chermak, 1991; Ginsberg, 1993; L. Krefting et al., 1995; O'Toole, 1991b).

4.12.4 Equality and Justice

Zinkin & Morley (1993) stated that if rehabilitation is to

> play a role as development agent, the introduction of community-based rehabilitation is more equalising than [the] introduction of training in sophisticated therapies and costly techniques. [This] approach might be more appropriate in the usual situation where the burden of handicap rests on the least powerful, women and the poor. (p. 245)

The promotion of greater equality and justice has been seen a potential benefit of CBR programmes. Unfortunately, there is little documented research which indicates that participants experience greater equality or that justice is promoted as a result of CBR programmes. Some indication of the link between CBR programmes and the promotion of equality and justice can however be identified. For example,

- S. Miles (1996) noted that the motivation behind the establishment of a CBR programme was to provide "rehabilitation services in the community in a more equitable, sustainable and appropriate way than can be provided in a health or educational institution" (p. 502).
- L. Krefting et al (1995) and Werner (1993) provided examples of CBR participants taking part in social advocacy, on matters that promoted social justice and service equality for people with disabilities.

- A commitment towards the development of processes and structures within CBR which reflects principles of equity has also been noted (O'Toole, 1991b; Periquet, 1989).

4.12.5 Dignity

Helander (1993a) stated from his experience of CBR, that it promotes the dignity of people with disabilities. S. Miles (1996) found that dignity was promoted through enabling "disabled people to take control of their own lives and to play a decisive role in any services that are created" (p. 515). While similarly difficult to quantify, increased dignity for people with disabilities might be inferred as an outcome of CBR programmes. In a CBR evaluation study, Gershon and Srinivasan (1992) found that CBR resulted in increased respect and recognition for participants within their families, increased social and occupational status for people with disabilities, an increased level of income and earning capacity, and improved housing standard.

4.12.6 Ecological Holism

As an approach which "moves beyond sole focus on the individual's adjustment to disability and incorporates targeted efforts at developing the community's ability to include all its members" (Enders, 1993, p.19), CBR is by nature, ecological. This is reflected in examples of programmes being moulded by the skills and interests of the people involved (S. Miles, 1996). O'Toole (1991b) in a review of nine CBR programmes in different countries, found that all were introduced in response to locally felt needs and were the catalyst for further action.

Ecological holism in CBR is most clearly expressed in the nature of CBR processes rather than specific client outcomes. M. Thomas (1993) stated from her experience of CBR projects in India, that a feature of CBR is the emphasis placed on understanding the political, social, cultural, economic and service structure context of a community. Similarly, attempts to incorporate indigenous knowledge and local expertise about disability (S. Miles, 1996) and recognition of cultural artefacts in the development of programmes (M. Miles, 1985), reflect a wish to express greater ecological holism. Perhaps most importantly, CBR literature reflects an ecologically responsive approach to families as a resource for the delivery of disability services. The necessity for rehabilitation to be appropriately contextualised into the ecology of family life has represented a significant focus for a number of CBR authors (Gershon & Srinivasan, 1992; Lagerwall & Hargö Granér, 1996; O'Toole, 1991b).

4.13 Limitations and Critiques of CBR in Developing Countries

4.13.1 The Nature of the Context of CBR Programmes

CBR was instigated and exists almost entirely in developing countries, which are often characterised by an extreme paucity of services for people with disabilities. As such, it may be argued that the dramatic benefits attributed to CBR, and the success of CBR as a service delivery system, are artefacts of the baseline at which it is introduced. That is, any approach which provided some form of rehabilitation and disability services in such a 'service vacuum' would show impressive outcomes with far reaching benefits.

A counter argument to the above critique, is that the scarcity of resources in developing countries, and the poor living conditions of many people, may also be considered a poor environment for the development of services (Vanneste, 1997). Establishing and maintaining a service which relies heavily on community participation in such a context would appear highly problematic. Since the needs of people with disabilities take on a low priority in the context of significant poverty (Vanneste, 1997), disability services would be the most threatened. From this perspective, the success of CBR under such circumstances may be seen as an indication of the potency of the approach.

4.13.2 The Instigation of CBR Projects

As a service delivery system which, at instigation was ostensibly exported from developed countries to developing countries (Lagerwall & Hargö Granér, 1996, M. Miles, 1996), CBR has come under critique as often being introduced and managed in a Western fashion (Selim, 1995) by short term international consultants (O'Toole, 1991b). M. Miles (1996) stated that historically, CBR has been transposed through "largely monocultural Western or Westernised disability evangelists [who] exported community slogans muddled with the rhetoric of individual disability rights, to third world countries" (p. 488). Such critiques hold that concepts such as self advocacy, individual rights, equality, and freedom of choice, are Western ideals which lack relevance in developing countries (Kalyanpur, 1996).

The current thesis contends that discrepancies between the values of programme instigators and communities, is a problem affecting the human services world-wide. While this may be exacerbated by the cultural encounter which characterises CBR programmes sponsored by foreign NGOs, it is most effectively addressed by ensuring that the programme reflects an awareness of and responsiveness to the values of the community (Kenkel, 1986). The need to

draw on the strengths of local norms and resources rather than Western ideals has been strongly advocated in the CBR literature (Kalyanpur, 1996) and reflects current trends in CBR.

M. Thomas & M.J. Thomas (1996) questioned the appropriateness of applying community based approaches to developing countries, many of which have a historically socialist perspective, and a consequent reluctance to accept community ownership, preferring state centrism and state responsibility. This issue warrants further attention and exploration, particularly given the contradictory observation that the relationship between community based approaches and socialist theories is very strong (Dixon, 1989). Within the latter perspective, historically socialist developing countries may actually be ideal contexts for the instigation of CBR projects.

4.13.3 The CBR Model

The CBR model necessitates a degree of community participation. Consequently, the process has been identified as, (a) very time consuming (Selim, 1995), (b) overly dependent on the willingness and ability of community members to mobilise local resources (Vanneste, 1997), and (c) requiring considerable resources and infrastructure to facilitate action (Momm & Konig, 1989). Such critiques recognise the inherent gradual and incremental nature of community approaches. Grass-roots initiatives such as CBR are by definition, participatory, reliant on community resources and interconnected with existing networks and infrastructure. While the gradualist and participatory nature of CBR would appear central to the approach, these critiques indicate that CBR approaches may be unrealistic in some settings, particularly where highly organised structured responses are required.

M. Miles (1985, 1993) strongly criticised community based processes of the CBR model, suggesting that in fact modest sized institutions would be a more effective mechanism for disability service delivery in developing countries. Similarly, Gill (1995) suggested that if given a choice, some people may choose formal services over community based approaches. Such issues are in large part, related to values of service delivery and the availability of resources. In different contexts, different values will prevail which may influence the availability of resources for a particular approach. In the present case, these issues indicate that no one model, including CBR is likely to be appropriate for all people at all times.

A number of the critiques of CBR appear to have highlighted problems that were inherent in the approach as it was originally conceptualised (Kalyanpur, 1996; M. Miles, 1985; Momm & Konig, 1989). Such critiques have argued that,

- CBR inappropriately offers one strategy for all developing countries (M. Miles, 1985).

- It is inflexible and over reliant on manuals which grossly over-generalise (Kalyanpur, 1996; M. Miles, 1985).
- CBR fails to acknowledge indigenous knowledge, local practices and traditional support structures (Glynn, 1996b; M. Miles, 1996).
- It results in structures which rely unduly on key individuals and individual personalities (M. Thomas, 1997).
- It consists of strategies which are unsatisfying for workers and intermediate professionals and impracticable for communities (Momm & Konig, 1989; Vanneste, 1997).
- It fails to include people with disabilities in actual service delivery (RI, 1995).

Such points of critique should not be overlooked, since in a diverse approach such as CBR, there are undoubtedly a number of examples to which many or all of them apply. However, since they address traditional forms of CBR, they have limited application to newly emerging forms identified in the current study. Evolving conceptions of CBR may constitute a constructive response to many of these critiques.

4.13.4 Outcomes from CBR Programmes

Instances of poor or inadequate outcomes have been noted in the CBR literature. Myezwa (1995) found that clients with psychiatric disabilities and those with intellectual disabilities felt dissatisfied and saw little change in their condition as a result of a CBR programme. Vanneste (1997) found that while CBR programmes produced impressive functional outcomes for adults with physical disabilities this success was not reflected in the case of people with stroke or arthritis or in early intervention strategies. Such findings indicate the need for a greater understanding of the suitability of CBR with different populations. It would appear that to date, based on the success of CBR initiatives with people with physical disabilities, the approach has been applied to many other populations without appropriate exploration of its suitability.

Momm and Konig (1989) noted poor success and difficulties with implementation of CBR programmes and Rottier et al., (1993) cited an example of poor follow-up by trained community level workers. As a highly localised, community based approach, using minimally trained workers, effective quality control of service delivery is highly problematic within CBR.

Vanneste (1997) suggested from his experience of some CBR projects in Africa, that the benefit of CBR may be more in the effect of the ideology, rather than the actual rehabilitation outcomes. He contended that the community perspective in CBR, was empowering and

integrating, but that this did not automatically lead to measurable rehabilitation outcomes for people with disabilities.

Based on the literature, it would appear that findings from studies which have sought to describe the impact of CBR programmes on care givers have been equivocal. Some have suggested that CBR fails to lessen the adverse impacts of a person's disability on their care givers (Finkenflugel et al., 1996). Others have suggested that since CBR approaches seek to achieve appropriate localisation and contextualisation, they can be effectively integrated into daily life of the family and the community, and that rehabilitation tasks become less demanding for care givers (Rottier et al., 1993). The capacity of CBR programmes to meet the needs of care givers would appear to be a function of the effectiveness with which they are contextualised and linked to appropriate community supports.

4.13.5 Training in CBR

As an approach which rests largely on the training of community level workers, the content and delivery of training has constituted a challenge for the field of CBR (Lysack & L. Krefting, 1993; RI, 1995). It has been argued that the limited training offered to community level workers may lead to superficial service delivery (O'Toole, 1991b) and potential danger to people with disabilities. Despite the existence of established CBR training programmes at such places as the University of London and the University of Uppsala, Sweden, there are few studies of the effectiveness of short versus longer training in CBR.

It has also been suggested that CBR workers and recipients may want, and expect, training in physically oriented rehabilitation treatment techniques (M. Miles, 1993). However CBR is increasingly evolving towards a focus on community development principles. Training in CBR is similarly being oriented away from physical techniques towards issues of social and community change (Twible & Henley, 1993). In the terminology of the current thesis, training in CBR is moving from an emphasis on bio- and psycho-systems towards micro-and meso-systems. A disparity of expectations in training may pose significant confusion and frustration for CBR workers. It would therefore appear that public debate regarding the evolution of CBR may promote greater congruence between expectations of trainees and trainers.

Vanneste (1997) contended that the provision of quality community based services, demands more motivation and qualification than volunteers can be expected to have, and that it requires more rehabilitation skills than most CBR workers are willing to acquire without incentives. Such arguments would hold that the use of volunteers and the provision of short term training programmes, is inadequate. In practice however, many key CBR researchers and authors

appear to disagree (Coleridge, 1993; Hartung et al., 1989; Werner, 1993). They suggest that substantial and unique benefits are derived from the utilisation of basically trained volunteers and staff. Strong support for such 'grass roots' approaches has also been found in related areas such as community health (Lankester, 1992).

4.13.6 The Increased Burden on Stakeholders in CBR

Due to a variety of circumstances, people in developing countries, particularly in rural contexts, may have little time or energy to devote to helping people with disabilities (O'Toole, 1991b). Family involvement in disability may be a demanding proposition due to the breakdown of traditional social structures, community attitudes, time constraints, social circumstances and economic realities (O'Toole, 1991b; Rottier et al., 1993; Vanneste, 1997). In the CBR framework, which relies heavily on family and community members providing aspects of support or assistance for people with disabilities, such demands may be seen as unrealistic. The potential within CBR for overburdening parents, family members, the local health worker (M. Miles, 1985), or the local community (Momm & Konig, 1989), has been recognised as an issue of concern. Specifically, it is felt that such an approach adds extra responsibilities which may be unsustainable over time.

While the importance of such concerns should not be minimised, it might also be noted that the CBR approach is inherently an attempt to strengthen the fabric and supports of the local community (D. Krefting, 1996a). By fostering community based supports, CBR may be seen to build 'social capital' around people with disabilities and family members who may have few or no formal supports. Some authors have suggested that the 'locally appropriate' nature of the CBR response, results in more constructive outcomes in the long term. Consequently, CBR may be seen to build social links, thereby addressing the double disadvantage of socially isolated families supporting a person with a disability (Zinkin & Morley, 1993).

4.13.7 Infrastructure of CBR Programmes

It has been suggested that in order for a community based response such as CBR to be effective, a significant degree of social and community level infrastructure must exist in the community (Kalyanpur, 1996, Momm & Konig, 1989). M. Miles (1996) argued that for CBR to operate effectively, a given community should have reached a threshold level of social and educational development which in many developing country contexts, is not the case. Such suggestions appear intuitively to make sense[2], however given the apparent success of CBR programmes across socioeconomic contexts, it would appear that further research is required.

[2] They also provide a degree of support for the application of CBR to economically developed countries.

A recent study has also provided an interesting contrast to this argument. Based on his experience in CBR programmes in Africa, Vanneste (1997) questioned the relevance and degree of impact of social infrastructure on CBR projects. He contended that the strength of CBR, which he identified as local relationships, were mostly unaffected by such issues.

4.13.8 The Role of Women in CBR

The devolution of initiative and responsibility for rehabilitation to the community is a crucial element of CBR (Jonsson, 1996). This devolution may however, be interpreted as having considerable adverse impacts on women, who typically bear the greatest responsibility and play the most active role in CBR programmes (Lysack & L. Krefting, 1993, Peat, 1991b). Rather than being a strategy for emancipation, CBR may be seen to be a vehicle for further limiting women who are already greatly disadvantaged.

Lysack (1995a) contended that in reality, communities as a whole rarely participate in programmes. She suggested that participation only happens at the sub-group and individual level. Finkenflugel et al., (1996) stated that in CBR, in place of the word "'community' we could read 'family', and for 'family', 'mothers'" (p. 256). In this way, the use of euphemistic language about community in CBR is seen to be translated to added responsibility for women, particularly those in patriarchal societies.

Some CBR proponents have acknowledged the burden on women in setting aside time for children with disabilities and others, and consequently emphasise the need for culturally relevant disability programmes and practices, to minimise impact (Helander, 1993a; O'Toole, 1991b; Werner, 1993). Others have suggested the development of service structures such as respite, which can easily be integrated into a community approach and complement other CBR initiatives (Peat, 1991b). While such initiatives are seen as partial alleviation of responsibility on women in general, this issue is seen as a fundamental critique of CBR which currently lacks a convincing response. Further, the current review of CBR literature failed to identify any evaluations of specific service initiatives (such as those suggested) to gauge the success of attempts to minimise the impact of CBR on women.

4.13.9 The Localised Nature of CBR

The localised, community focused nature of CBR, while accepted as a 'given', might also be considered a limitation from some perspectives. CBR projects tend to be small scale, isolated projects which may not have significant influence on national agendas (M. Thomas & M.J. Thomas, 1996). Their orientation towards local, often rural community issues as their prime concern, may mitigate against gaining substantial political support (Momm & Konig, 1989;

Tjandrakusuma, 1996). Consequently, CBR as a general approach may be given low priority by governments and may be seen as a minor adjunct to more formal services (O'Toole, 1991b). The localised, low technology, gradualist approach which characterises CBR, may also contribute to its low visibility in comparison with more formal, institutionally oriented rehabilitation approaches. Traditional approaches, irrespective of the degree of coverage that they achieve, are usually firmly entrenched with vested interests (Marincek, 1988; Peat, 1991b), which are unlikely to be substantially or rapidly changed by more low profile, non-professionalised CBR approaches.

The small size and scale of many CBR projects, may lead to groups becoming discouraged and overwhelmed (Momm & Konig, 1989). As a system which does not depend heavily on formalised organisational structures, this would appear to be a potential weakness affecting the viability and sustainability of CBR programmes. The effective exploration and development of support structures within CBR while recognised as important, has yet to be realised (M. Thomas, 1993).

It might also be suggested that the small scale, non-professionalised nature of CBR, may lead to uneven coverage of services (Lagerwall & Hargö Granér, 1996). As a localised, community owned approach, CBR may not be conducive to providing uniformity and consistency within and between projects. At a national or regional level, CBR may be seen to lead to disparities and inequalities of services. Implications of lack of effective coverage may raise concerns over the capacity of CBR to ensure that services are distributed justly within a country or region.

In response, some CBR supporters would appear to argue that issues of *appropriateness* are of more concern that *uniformity* (Zinkin & Morley, 1993). While lack of uniformity and uneven coverage is of concern to CBR authors, it appears secondary to their interest to ensure that needs of people with disabilities and local communities are appropriately met. The CBR perspective would appear to emphasise that local and 'procedural justice' issues take precedence over normative and 'distributive justice' ones.

4.13.10 The Notion of Community in CBR

Although CBR is in essence 'community based', in some expressions it may have become dissociated from community realities. Basic tenets of CBR, such as commitment to the local community and community participation, may only be observed in a token fashion. Pandey and Advani (1995) found in their evaluation of a CBR project which was only marginally successful, that "Although the programme had been 'community located' it had not been 'community based'" (p. 129) they concluded that "The participation, involvement and

contribution of the community which is crucial to a CBR programme, has at best been marginally present in these programmes" (p. 133).

CBR has also been criticised for promoting the idyllic stereotype of communities as homogenous, caring and benevolent entities, demonstrating the ideal of 'gemeinschaft' (Lysack, 1995; M. Miles, 1993). Such stereotypes are unhelpful and misleading (Chu, 1994a; Lysack, 1995), and may result in poor implementation, based in naïve perceptions. In reality, societies in developing countries are often heterogenous, and many communities are dominated by powerful minority groups (M. Thomas & M.J. Thomas, 1996).

The above points indicate that failure to accurately consider the complex reality of the community context in which CBR programmes are implemented, may result in inappropriate programmes. Similarly, failure to achieve genuine levels of community participation in CBR may lead to inappropriate programmes, of limited relevance to the local community.

4.13.11 CBR and Political Expediency

The motivation behind governments and organisations in choosing community based, participatory approaches to disability and rehabilitation services should also be considered. Vested interests may see CBR as "an easy way out for a cheap solution" (Momm & Konig, 1989, p. 505). In circumstances where traditional services for people with disabilities already exist, bureaucrats or others may view the implementation of CBR as an excuse for diminishing existing services (Lagerwall & Hargö Granér, 1996). Under such conditions, CBR programmes might be interpreted to amount to little more than the mobilisation of people's resources for government programmes. Kalyanpur (1996) has cautioned against the implementation of CBR in contexts where the programme might enable governments to avoid their responsibilities to people with disabilities and communities.

On a related note, Lysack (1995) has observed that community solutions may be chosen because they are politically expedient. She argued that community approaches such as CBR can be seen as political 'motherhood' statements and tend to be employed when large scale, formal approaches fail.

Despite these concerns, inappropriate rationales for the implementation of CBR do not appear to have constituted a major concern for CBR authors, possibly due to their confidence in the CBR process. For example Cernea (1984), drawing from a related field, argued that irrespective of the economic, political or humanitarian motivation behind community based projects, the performance of projects which exhibit strong local participation is superior to

alternatives on many measures. It would appear that CBR authors would similarly contend that the hope for CBR rests in the process by which it is conducted, irrespective of the rationale behind its implementation.

4.13.12 Breadth of CBR

While the breadth and diversity of CBR approaches has been viewed as an asset, with each community and country implementing CBR in different ways (Tjandrakusuma, 1996), it has also been interpreted by some, as a potential weakness. Glynn (1996a) argued that the vague, all encompassing scope of CBR results in an unproductive degree of breadth. She suggested that where an approach is too broad, concepts become reduced to meaningless rhetoric.

Although the current research identified many articles which describe programmes as 'community based rehabilitation', discerning which programmes bore a relationship with the approach instigated by the WHO, was at times a difficult task. As a general approach rather than a clearly defined proprietary concept, CBR has been implemented in very different and often diametrically opposed ways. For example, Helander (1993b) stated that some interpretations of CBR, which emerged within ten years of the publication of the original WHO manual, contradicted what he saw as fundamental tenets of the approach as intended by the instigators. As with other critiques noted above, the breadth and diversity of CBR would appear to be both a potential strength as well as a source of weakness. The strength may be seen in the capacity of the approach to evolve in response to client and community need. Potential weaknesses include, over-expansiveness and lack of clarity.

4.13.13 CBR Research

As noted earlier in the current chapter, while there are many publications describing the nature of CBR and various perspectives and opinions regarding CBR, there is not a substantial body of research against which CBR might be more objectively evaluated (O'Toole, 1991b). The process by which community change and community participation are achieved in CBR has gone mostly unresearched (O'Toole, 1991b), as have attempts to measure the efficacy of CBR interventions and the roles and training needs of CBR workers and professionals (Wirz, 1996). While some quantitative studies exist, they lack comprehensiveness and depth (Boyce, 1997). The need for more substantial qualitative research of CBR processes has been established (Finkenflugel et al., 1996; RI, 1995). It is suggested that the current thesis is a preliminary step towards the development of such a qualitative research base on CBR processes.

As will be apparent from the foregoing analysis, CBR exists not only as concept, technique and approach to rehabilitation, but also as an ideology (Vanneste, 1997). It is contended that this ideological quality, while contributing to the extraordinary spread of CBR and the enthusiasm with which it is described, has also resulted in a failure to prioritise objective evaluation, rigourous research, thorough analysis, and critique of the approach.

Further, it is argued that the evolutionary nature of CBR, while recognised by a number of authors has not been clearly recognised and conceptualised. Consequently, some of the critiques which exist (for example, Gill, 1995; Kalyanpur, 1996; M. Miles, 1996), have failed to address issues relevant to newly emergent forms of CBR and instead have responded to stereotyped or outdated conceptualisations of the approach. Both the limitations and the strengths of newly emergent forms of CBR have yet to be clearly identified and evaluated. The current thesis may be considered a response to these concerns through its use of an appropriate methodology to explore a conceptualisation of CBR which recognises newly emergent forms.

4.14 Conclusion

In order to present a potential alternative to issues identified in Chapter Two and Chapter Three, the current chapter has provided a detailed overview and interpretation of CBR. Based on an analysis of the literature, parameters of CBR were identified and described with specific emphasis on its nature and practice.

CBR was defined and its processes and structures were elucidated. Utilising the Bio-Psycho-Social Ecology framework, key CBR strategies were identified. It was noted that a particular strength of these strategies was their focus on the micro- and meso-system levels. Direct and indirect benefits of CBR were described. It was suggested that CBR is in the midst of evolutionary change towards a more informal, socially oriented approach. A review of the limitations of the CBR approach was also presented.

The documentation and clarification in this chapter, responds to the need to establish a theoretical foundation for CBR. This goal is further facilitated in the following chapter, through a description of the philosophical basis and key principles of CBR.

Chapter Five

Key Principles of Community Based Rehabilitation

5.1 Introduction

CBR is increasingly being viewed, not as "a package of services, but a philosophy of care which inevitably embraces many forms of services" (O'Toole, 1991b, p. 62). Despite this, theoretical aspects of CBR remain largely unexplored, and there have been few attempts to describe the philosophy or key principles of CBR (Dolan et al., 1995; M. Miles, 1985; Zinkin & Morley, 1993). Peat (1991a) observed that "The 'core' to CBR has not yet been identified and this is a necessary step in its evolution" (p. 162). The current chapter seeks to respond to this need, by describing the key principles of CBR. In addition to its theoretical benefit to the field of CBR, this elucidation of the key principles guides and informs the subsequent 'potentiation' phase of the current research.

The chapter commences with an examination of the philosophy of CBR, in which a number of themes are identified. These abstract themes are combined with the practical dimensions of CBR (as described under 'strategies' in the previous chapter). From this synthesis, key principles of CBR are identified. These principles are understood and encapsulated as the concept of 'engagement', or more particularly, 'engagement between people with disabilities and their local communities'. The development and identification of the concept of engagement is seen as a contribution of the current thesis. The concept is described, and processes and expressions of engagement are elucidated. As noted above, the notion of engagement forms the basis for the subsequent 'potentiation' phase of the research (Section C).

5.2 Philosophy of CBR

While earlier forms of CBR may have focused somewhat exclusively on basic rehabilitation techniques and procedures (O'Toole, 1991b; S. Miles, 1996), a more theoretical undercurrent is emerging amongst authors who report on current CBR approaches (O'Toole & McConkey, 1997). Dr Padmani Mendis, one of the co-authors of a major CBR manual (Helander et al., 1989), noted that CBR has evolved considerably over the years and will continue to evolve, because it is based on a philosophical 'vision of empowerment' rather than a static concept (Mendis, 1993, p. 8). The current literature analysis has sought to identify themes which reflect this philosophical basis of CBR. Through a process which consisted of, the categorisation of major topics in the literature, followed by the identification of common points and a synthesis of concepts, a number of themes were derived. These indicate that CBR reflects,

- A commitment to **community.**
- An emphasis on **laity** as major contributors to disability related issues.
- An attempt to facilitate working together in **solidarity.**
- A commitment to **locality.**
- Concern for the **identity** of people with disabilities.
- A focus on **equity.**
- A strong theme of **activity.**
- A desire to achieve service **sustainability.**
- A priority on empowering and building the **capacity** of people with disabilities.
- A realisation of the need for **accessibility.**
- A **contextualised individuality.**
- An attempt to achieve greater service **flexibility.**
- A necessary acknowledgment of complexity and **variability**.

These themes are described in detail below.

5.2.1 Commitment to Community

The commitment to community in CBR is reflected in an emphasis on partnership and participation with the local community (Boyce, 1997; Lysack & Kaufert, 1994; Peat, 1991a; Peat, 1991b; Price & Radio, 1996), and through physically locating services in the community (L. Krefting, 1995; O'Toole & McConkey, 1997). CBR literature indicates a focus on providing skills to community members (Helander, 1993b; D. Krefting, 1996a; O'Toole & McConkey, 1995; Twible & Henley, 1995) and importantly, developing the resources of the entire local community (Jones, 1997; Lysack & L. Krefting, 1994; O'Toole & McConkey, 1995). The philosophical commitment to community is expressed in examples of CBR projects

drawing on the resources of the community and the 'sense of community' (Werner, 1993), by fostering and enabling the community to take responsibility for the rehabilitation of people with disabilities locally (O'Toole & McConkey, 1995). It has been stated that the provision of services by community members (ILSMH, 1994), results in community support, ownership and control of CBR programmes (D. Krefting, 1996a; M. Thomas & M.J. Thomas, 1996), and ensures that programmes are sustained by the community (D. Krefting, 1996a). Goals of CBR programmes which reflect a commitment to community include, motivating the community to assist people with disabilities (D. Krefting, 1996a; Price & Radio, 1996), integrating and involving people with disabilities into the community (D. Krefting, 1996a; M. Thomas & M.J. Thomas, 1996), and changing community attitudes (ILSMH, 1994; Jones, 1997).

5.2.2 Emphasis on Laity

A strong emphasis on laity rather than professionals is fundamental to CBR. The strengthening of skills of people with disabilities, family members and community members (O'Toole & McConkey, 1995, 1997), and building of partnerships (Peat, 1991a) to enable people with disabilities and community members to take responsibility in rehabilitation matters, is axiomatic to CBR practice (S. Miles, 1996). Within the structure of CBR projects, lay community members are ideally involved from instigation, to ensure decentralisation of power (Peat, 1991b). Such efforts are reported to improve community level informal networks and cooperation around people with disabilities (ILSMH, 1994).

In many CBR programmes, the training of community level CBR workers is a key focus (Barnes, 1993; Deetlefs, 1995; Dolan et al., 1995; Medina & De Jesus, 1995; O'Toole & McConkey, 1995), in some instances, leading to a pseudo-professionalisation of the CBR worker role (Carraro, 1997). However, in newly emerging forms of CBR, the philosophical commitment to the skilling of the community, rather than the professionalisation of CBR, is evident (Deetlefs, 1995; Medina & De Jesus, 1995; S. Miles, 1996; O'Toole & McConkey, 1995; Twible & Henley, 1995). S. Miles (1994) stated that her organisation's "vision in southern Africa is that disabled people will play the lead role in CBR programmes, only involving professionals when they feel that it is necessary" (p. 9).

5.2.3 Working Together in Solidarity

The principle of solidarity, or working together with common responsibilities, appears central to CBR philosophy (Leavitt, 1995) and strongly linked to principles of community and laity. From reports and examples of people with disabilities working together (Werner, 1993), it is evident that some CBR programmes are characterised by a strong sense of collaboration. This is reflected in community members working with people with disabilities (D. Krefting, 1996b),

and a stated commitment within CBR, to enhancing the capacity of organisations and services to work together (Boyce & Johnston, 1996). Helander (1993a) reported that such initiatives build the community and service delivery system from the grass roots level, engendering a strong sense of working together in a common cause.

5.2.4 Commitment to Locality

A commitment to locality is evident from many sources in CBR literature (Dolan et al., 1995; Enders, 1993; Lysack & Kaufert, 1994). The foundational philosophy of locality may be seen to be reflected in the inherent flexibility of design, which enables CBR programmes to more effectively operate at the local level within the context and framework of local conditions (D. Krefting, 1996a). Locally focussed programmes have been reported to result in services which are appropriate and responsive, distributed in relation to need (O'Toole & McConkey, 1995). Furthermore, the commitment to locality in CBR programmes maximises community involvement (O'Toole & McConkey, 1995).

5.2.5 Identity of People with Disabilities

CBR appears to be based on a fundamental belief that change in community attitudes regarding the identity of people with disabilities, is central to effective integration and rehabilitation (D. Krefting, 1996a). The CBR approach emphasises that changing community attitudes towards people with disabilities, and boosting their identity should be a key focus. As such it may be observed that CBR is a universal approach to change in communities (Thomas & Thomas, 1995; ILSMH, 1994), rather than a specific disability targeted intervention (Miles, 1996a; M. Thomas & M.J. Thomas, 1996). Where CBR projects are specifically and individually targeted, many complement this by also seeking to improve the role and identity of people with disabilities within the community and society.

5.2.6 Focus on Equity

Equity has been identified as a central tenet of CBR philosophy (Chermak, 1991; Leavitt, 1995). Attempts to achieve 'something for everyone' rather than 'everything for a few' (M. Thomas & M.J. Thomas, 1995), represent a strong focus on principles of equity. At a social level, this focus is partially demonstrated in the commitment to, and location in, local communities (S. Miles, 1996). The emphasis within CBR programmes on the development of the whole community, would appear to result in an equitable, socially oriented focus. Lysack and Kaufert (1994) suggested that the socially oriented focus of CBR goes so far as to address structural determinants of inequity.

5.2.7 Emphasis on Activity

A corollary of the commitment to laity in CBR would appear to be an emphasis on activity. CBR is both an active process which involves and responds to members of the community (O'Toole, 1991b), and an active process through which the community improves itself (O'Toole & McConkey, 1995). In this respect, the fundamental nature of activity in CBR, may be seen at both an horizontal or community level, and at a vertical or service level. At the horizontal level, people with disabilities themselves become active agents in the struggle for a fairer and more sustainable social order (Werner, 1993).

At the vertical level, the strong emphasis within CBR on action and practical application (Boyce, 1997) results in practical changes in the lives of people with disabilities. Unfortunately, as implied earlier, it also reflects a shortcoming of CBR, namely, an apparent neglect of the development of a theory base (Dolan et al., 1995; Zinkin & Morley, 1993). The CBR approach, at least historically, may be seen to reflect a commitment to activity without commensurate emphasis on philosophical conceptualisations and theoretical models.

5.2.8 Desire to Achieve Sustainability

Since CBR programmes often comprise services which derive support from communities, rather than government departments or formal structures, a commitment to sustainability is fundamental (S. Miles, 1996). While the desire to achieve sustainability is more of a practical principle than a philosophical one, it has become a guiding principle of the CBR approach (Narayan, 1993). Sustainability may be seen to arise from the social responsivity of CBR approaches and attempts to ensure culturally appropriate implementation (Enders, 1993; Helander, 1993a). The emphasis on sustainability ensures that CBR, as a non-institutionalised system of networks and cooperation, remains viable (ILSMH, 1994).

5.2.9 Building the Capacity of People With Disabilities[1]

The basic concept of capacity building in CBR, is reflected in the recommendation that "the long term goal of all CBR programmes should be to facilitate disabled people to take control of their own lives and to play a decisive role in any services that are created" (S. Miles, 1996, p. 515). Within CBR, building the capacity and empowerment of people with disabilities is interrelated with concepts of laity, solidarity and activity. The commitment in CBR to

[1] The term "building the capacity of people with disabilities" was chosen here to make a distinction between Western conceptualisations of empowerment and the CBR approach. While empowerment is increasingly referred to in CBR literature (Lagerwall & Hargö Granér, 1996; Stubbs, 1993), the current thesis contends that it is substantially different from traditional Western conceptualisations (Chapter Four).

initiation by, and decision making by, people with disabilities (Peat, 1991b) is an attempt to ensure decentralisation of power and greater community empowerment for people with disabilities. Such priorities are also reflected in CBR programmes through facilitating community level organisations of people with disabilities (DPOs) (Helander, 1993b).

5.2.10 Accessibility

The principle of access for people with disabilities is linked with the issue of equity. Within CBR, both of these principles are manifest at a community level. In CBR, the attempt to achieve the provision of basic services for all, rather than highly specialised, intensive services for a few (M. Thomas & M.J. Thomas, 1995), reflects a principle of service accessibility. Conversely, the community focus of CBR may be seen to reflect a commitment to addressing geographical and physical access in the setting in which it impacts most directly on a person with a disability (Chermak, 1991). At a broader level, the commitment within CBR to attitude change in the local community, reflects the belief that ensuring accessibility on a psychological and attitudinal level will also facilitate greater physical, social and political access (S. Miles, 1996).

5.2.11 Contextualised Individuality

CBR has been characterised as a person centred approach, recognising individuality and quality of life of the individual as primary objectives (D. Krefting, 1996a). As a consumer focussed strategy, people with disabilities are reported to be involved in the design and implementation of CBR programmes (S. Miles, 1996). It is noted however, that as with other concepts in CBR, the principle of individuality is expressed and understood within the context of community (RI, 1995). While a degree of individuality may be important in any rehabilitation programme, in the CBR approach, the nature of individual expressions and emphases are rarely decontextualised from the local community (Tjandrakusuma, 1996).

5.2.12 Service Flexibility

Flexibility is a basic concept within CBR, which also arises from its community orientation. Locally flexible programmes are said to ensure community involvement and result in different strategies in different areas (D. Krefting, 1996a), which are tailored to the cultural, social and economic context (S. Miles, 1996). Rather than narrowly focusing on a particular disability type, CBR programmes typically seek to respond to all, or the majority of people with disabilities in a community (Peat, 1991b). Consequently, CBR programmes are usually flexible and responsive to many practical implications of disability at the local level (Dolan et al., 1995).

5.2.13 Variability

While CBR might be described as basic disability service delivery in and by the community (D. Krefting, 1996a), in practice it embraces significant complexity and variability, through many forms of service delivery and action (O'Toole, 1991b). It may be integrated with the primary health care system and cover, medical, social, political, psychological educational and vocational issues as they impinge upon the multiple dimensions of disability (Dolan et al., 1995; Hai, 1993; S. Miles, 1996). The principle of variability within the CBR approach is reinforced by the diversity of different disciplines and people who influence CBR practice (Boyce, 1997). It is also represented in the evolution of CBR from a strategy relying on set of proscribed instructions, to an approach which is flexible enough to seek to incorporate local cultural, motivational, educational and socio-economic factors (Barnes, 1993; D. Krefting, 1996a; M. Miles, 1993; Periquet, 1989; Tjandrakusuma, 1996).

5.3 Synthesis of Key Principles of CBR

As has been alluded to earlier, CBR appears to be comprised of a combination of practical strategies and philosophical values, neither of which appear to have been clearly elucidated. The current research has sought to reconcile and integrate these two facets of CBR, to identify the fundamental tenets or key principles of CBR.

'Strategies', which reflect the practical nature of CBR, have been described in the previous chapter as the means by which CBR services are delivered. When combined and synthesised with more philosophical points identified in the current chapter, they may be seen to describe the fundamental essence of CBR. The integration of these aspects is depicted in Figure 5.3. It is considered an important outcome of the literature analysis. This figure illustrates that the concept of 'engagement', which encapsulates the key principles of CBR, reflects the philosophical basis and the identified strategies of CBR. It further illustrates that the philosophy and strategies of CBR mutually influence each other.

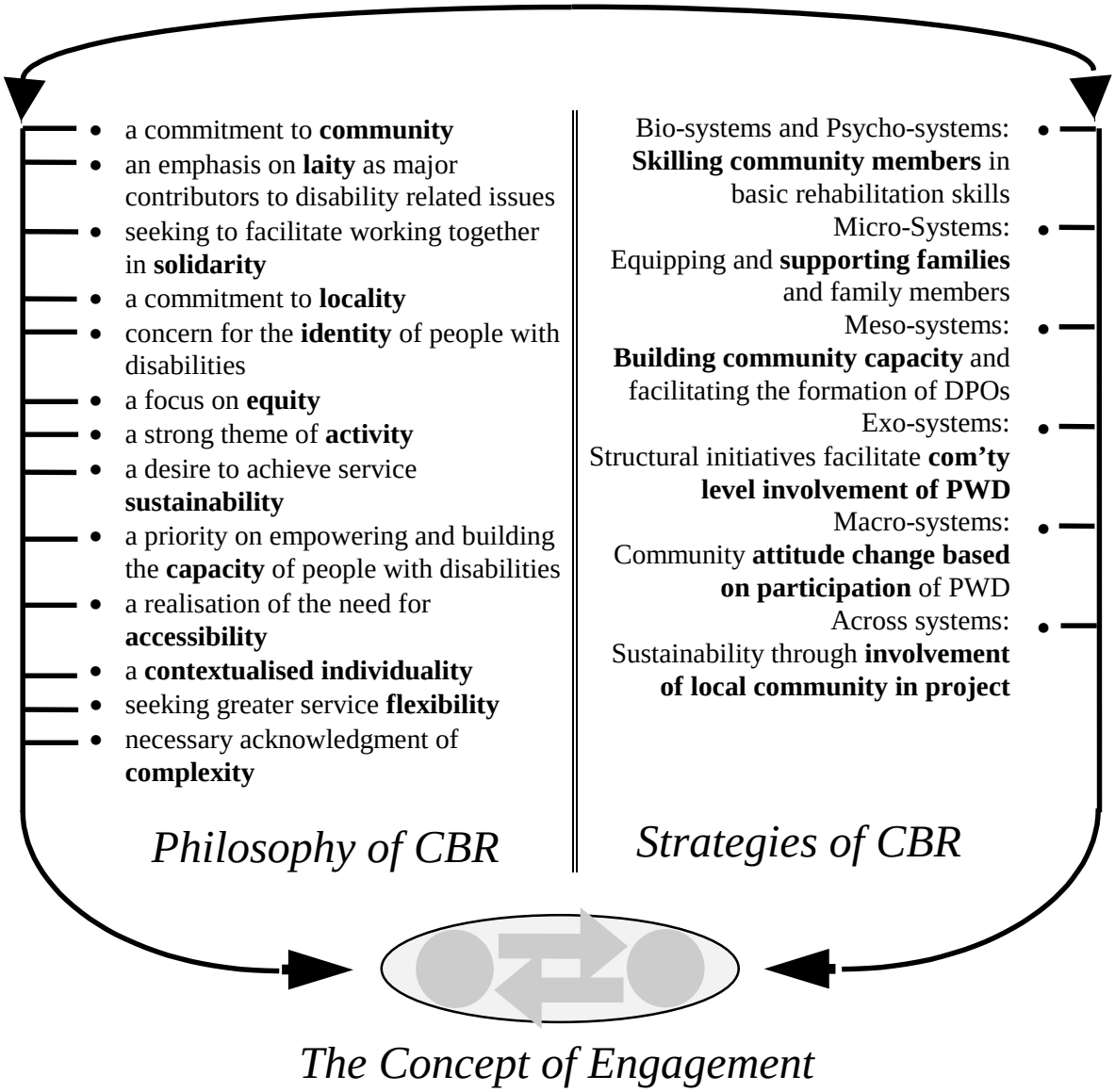

Figure 5.3 The synthesis of the concept of engagement

5.4 Engagement

The conceptual analysis that comprises this phase of the study, sought to distinguish the essential tenet which synthesised the philosophy and strategies of CBR. As depicted in Figure 5.3, through a process of literature analysis and synthesis, the core theme of CBR identified in the current study was the concept of 'engagement'. The concept of engagement, illustrated in detail in Figure 5.4, is defined as *a mutual or reciprocal, participatory involvement between people with disabilities and their local communities*[2].

[2] Figure 5.4 should be considered a simplification for illustrative purposes. It illustrates the process of engagement. It does not seek to imply that people with disabilities and local communities are mutually exclusive groups.

Based on the current analysis, it is contended that engagement is the essential tenet of CBR. Engagement would appear to be manifest most clearly at the micro- and meso-systems levels and particularly addresses social and community related concerns of importance to people with disabilities. This definition is expanded further below, through the identification of a number of expressions and processes of engagement.

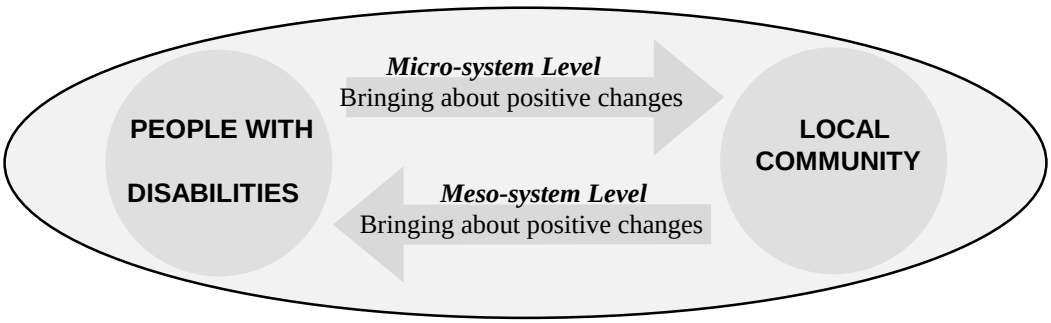

Figure 5.4 Diagrammatic representation of concept of engagement between people with disabilities and local communities.

5.5 The Concept of Engagement: Expressions of Engagement

As represented in Figure 5.4, engagement in CBR appears to be expressed predominantly at two levels: the micro-system level, at which people with disabilities work together and with others to bring about changes in their community; and the meso-system level, which comprises action at the broader community level, in which people with disabilities may be seen to draw benefit from the local community. These expressions of engagement are discussed below.

5.5.1 Micro-Systems Level Expression of Engagement

In CBR, micro-systems level engagement between people with disabilities and their non-disabled counterparts in the community, appears to be achieved in the first instance by facilitating networks between people with disabilities (Dolan et al., 1995; Gershon & Srinivasan, 1992; Lundgren-Lindquist & Nordholm, 1993; Oster et al., 1996). On the basis of these networks (local groups or community rehabilitation committees), contact is enhanced and optimised between people with disabilities and their immediate communities (Gershon & Srinivasan, 1992; Kwok, 1995; Lundgren-Lindquist & Nordholm, 1993; Venkatesh, 1993).

Specific examples of such engagement can be identified in a number of CBR publications. For example, in a study by Dolan et al. (1995) in which small group processes were facilitated, the commitment to engagement between people with disabilities and the broader community resulted in a high level of solidarity within the group of people with disabilities, as well as instances of their becoming more active in their local communities and achieving greater levels of independence and integration. Similarly, Gershon and Srinivasan (1992) reported on a CBR project with powerful social outcomes in which a networking approach was utilised with employers, industrial centres and training facilities. In a different context, Oster et al. (1996) described a process of engagement in which recipients of a CBR service were supported to work together to take action to identify issues of concern, obtain the information they needed, and then to act on their concerns.

In terms of outcomes of micro-systems level engagement, O'Toole (1991b) stated that real change in disability issues results from effective dialogue and contact between people with disabilities and non-disabled community members. Such contact, which results from enabling people with disabilities to become active contributors to their immediate communities, results in changes in community attitudes (Venkatesh, 1993) and a sense of 'belonging' on the part of people with disabilities (Kwok, 1995).

5.5.2 Meso-Systems Level Expression of Engagement

Meso-systems level engagement between people with disabilities and the local community in CBR, may be seen to be achieved by actions which enable community processes to influence and contribute to issues of importance to people with disabilities. These activities typically occur beyond the immediate micro-system of the person with a disability. Such actions may include, (a) the involvement of formal community mechanisms in the planning and implementation of disability related activities (O'Toole, 1991a), (b) the co-opting of community leadership (Myezwa, 1995), or (c) the use of strategies of lobbying and influencing community behaviour, with the goal of the community taking a degree of responsibility for disability issues (O'Toole, 1991b).

Meso-systems level engagement, stemming from the community, has been noted as a factor of successful CBR programmes (Ginsberg, 1993). It may be manifest as a process of enabling the community to take greater initiative in disability issues (Oster et al., 1996). A number of CBR commentators have noted the importance of CBR initiatives, which are directed towards the whole community (Tjandrakusuma, 1996), which build on the resources of the community (Lundgren-Lindquist & Nordholm, 1993), and which extend to fostering an engagement through community initiatives on disability issues (Balasundaram, 1994; Enders, 1993; D.

Krefting, 1996a; Oster et al., 1996). Coleridge (1993) noted that such action not only benefits people with disabilities but also the community as it raises the level of community responsibility and civic consciousness. O'Toole (1991a), describing outcomes of a CBR programme, concluded that "The community has become more aware of disabled persons within their midst and played a major role in planning ways of meeting their needs" (p. 208).

5.5.3 Micro- and Meso-systems Expressions of Engagement Result in Change at the Macro-systems Level

Social beliefs and community attitudes and behaviour towards people with disabilities (which may be described as macro-system level interaction), are optimally influenced through social contact (Kilbury, Benshoff & Rubin, 1992; Minnes, 1994). Specifically, the extent of social interactions (Kilbury et al., 1992), the context in which they take place (Lyons, 1996), and the quality of those interactions (Minnes, 1994), have been noted as important contributors to genuine attitudinal change. In order for significant change of social beliefs and attitudes to occur, it would appear that opportunities must be developed for greater levels of interaction to take place, within empowering contexts, in a way that enhances the skills of people with disabilities.

Within CBR, engagement at the micro and meso system levels would appear to facilitate such change. At the micro-systems level, close networking between people with disabilities results in a number of positive social and support outcomes (McColl, 1995). Negative attitudes towards people with disabilities are ameliorated by close, equal status contact (Kilbury et al., 1992; Lyons, 1996; Wright, 1989). Such contact might be seen as a direct result of the action of such small groups. At the meso-systems level, engagement is reflected in the community being seen as the resource for disability action. Jonsson (1996) reflected the influence that meso-systems level engagement has on macro-systems level attitudes, when he stated that, "Negative attitudes, prejudices, discriminatory behaviour will not diminish unless local communities become responsible and involved in opening up the society for [people with disabilities]" (p. 1).

Engagement at the micro- and meso-systems levels, fosters interactions between people with disabilities and broader community members. This participatory engagement optimises the extent, context and quality of interactions. Within CBR, it is recognised that a basis of real change in society is effective dialogue and interaction between people with disabilities and community members

5.6 The Concept of Engagement: Processes of Engagement

5.6.1 Community Processes

The concept of engagement, as it has emerged from the current literature analysis, concerns mostly community processes (community motivation, education and change) rather than individual disability specific interventions (D. Krefting, 1996a; Lagerwall & Hargö Granér, 1996). Consequently, less formal approaches such as community development and community change agency are emphasised over formal rehabilitation service delivery (Finkenflugel et al., 1996; D. Krefting, 1996a; S. Miles 1996; Myezwa, 1995; O'Toole 1991b; Twible & Henley, 1993, 1995). Engagement at the community level is seen to promote, increased skills within the community (Myezwa, 1995), increased awareness of disability issues (O'Toole, 1991b), greater equity for people with disabilities (Lundgren-Lindquist & Nordholm, 1993), the decentralisation of power, responsibility and resources (D. Krefting, 1996a; Peat, 1991b), and ultimately, greater sustainability of the intervention (Oster et al., 1996).

5.6.2 Reciprocal Process

Figure 5.4 demonstrates that engagement is inherently a reciprocal process between people with disabilities and local communities. In this reciprocal process, CBR initiatives seek to invest into the community as well as draw from community resources (Lundgren-Lindquist & Nordholm, 1993). Reciprocity in CBR is expressed in, examples of maximising community / disability dialogue and partnership in CBR programmes (Peat, 1991a), attempts to ensure a degree of reciprocal responding to need (O'Toole, 1991b), and outcomes which reflect mutual benefit, both for people with disabilities and their local communities (Coleridge, 1993).

5.6.3 Active Process

As reflected in the philosophy of CBR, engagement is described as an active process. The arrows in Figure 5.4 illustrate that people with disabilities play a key role in this active process (S. Miles, 1996; M.J. Thomas & M. Thomas 1996) and also draw significant benefit from it (Coleridge, 1993). The active role of people with disabilities in CBR may result in a shift in the balance of power related to people with disabilities (Coleridge, 1993). In CBR programmes, the active participation and support of community members and community leaders is sought (Kulmann, 1994). This has been reported to build the capacity and capability of the community, particularly as community members take up some responsibility for disability initiatives (Balasundaram, 1994).

5.6.4 Social Processes

Engagement is also focused on social processes such as social beliefs, expressions of acceptance or prejudice, and attitudes resulting in discrimination or inclusion. Based on the premise that the quality and quantity of contact between people with disabilities and the general public affects attitudes (Minnes, 1994), active engagement between communities and people with disabilities is emphasised as a means of changing negative attitudes, prejudices and discriminatory behaviour (Jonsson, 1996; D. Krefting, 1996a; Myezwa, 1995). In turn, increased awareness of disability issues in the community leads to greater levels of social engagement and greater social opportunities for people with disabilities (Oster et al., 1996; O'Toole, 1991b).

5.7 Conclusion

Based on an analysis of the literature, the philosophical basis of CBR has been proposed. Synthesised together with strategies of CBR described earlier, the current chapter identified key principles of the approach which were encapsulated as the concept of engagement. This was further outlined through a description of its processes and expressions. As a proposal of the 'core' of CBR, it is suggested that this concept is a significant contribution to the development of theory within the field, and a step in the evolution of CBR (Peat, 1991a).

The concept of engagement is proposed as a fundamental principle of CBR, upon which more specific models may be devised and extrapolated. Given the locally specific nature of CBR (D. Krefting, 1996a), detailed service models might be based on this notion, rather than specific CBR practices - which may lack applicability beyond their initial context. Following an analysis of the applicability of CBR to economically developed countries in Chapter Six, this thesis will explore the potential of the concept of engagement to inform and contribute to disability issues in an economically developed setting.

Chapter Six

The Application of Community Based Rehabilitation to Economically Developed Countries

6.1 Introduction

Preceding chapters have proposed CBR as a potentially constructive alternative to current models of disability service delivery in economically developed countries. The purpose of the current chapter is to consider and explore the suitability of applying CBR to this context. Since the application of CBR to economically developed countries is relatively novel, relevant literature is summarised and extrapolations are drawn from examples of CBR in developing countries. Potential benefits and limitations of the approach in economically developed countries are described.

While numerous features may be identified which distinguish developing countries from economically developed countries, those which have particular relevance for people with disabilities and their local communities are explored. Within this focus, substantial contrasts may be drawn between the two contexts such as, significantly different structures for the delivery of disability services; different degrees and manifestations of poverty; divergent perspectives of rights, particularly human rights; variability in the availability and development of technology; different factors influencing employment, unemployment and underemployment; dissimilar social roles, particularly the role of women; and significantly different family and community structures (M. Thomas & M.J. Thomas, 1996).

The chapter concludes that the differences between developing and economically developed countries indicates that the application of approaches such as CBR across contexts should be circumspect. It is suggested that rather than transferring practices, technologies, manuals or structures, the focus for the transfer of CBR should be based on principles which transcend local circumstances.

6.2 The Context of CBR

CBR, has been substantially moulded by the developing country context in which it has emerged and evolved. In this regard, Peat (1993) stated, "Finding its initial acceptance and application in developing countries, where funds and services are extremely scarce, the core characteristics of community based rehabilitation have been largely shaped by the conditions of those societies" (p. 4).

The social and economic climate in many developing countries is characterised by poverty and powerlessness. At a community level, these factors result in a form of 'surplus powerlessness' which fosters apathy, withdrawal and 'deconstruction' of community (Labonté, 1994). Such a context would not appear to be conducive to the development of a grass-roots, community oriented approach to disability service delivery. However, despite these liabilities, CBR has grown considerably in developing countries in the last two decades. The current study contends that the context from which CBR has emerged, has resulted in the development of a particularly viable and sustainable approach to disability services. The initial context of CBR, rather than constituting an obstacle for the transfer of concepts to economically developed countries, may be more correctly seen as a 'crucible' through which a robust approach to disability services has been refined.

Despite obvious differences, some parallels exist between the service environments in developing and economically developed countries. For example, conventional human services in developing countries may be characterised by limited resources, ineffective services and lack of coordination. This portrayal is also consistent with many of the negative predictions of the future landscape of disability services in economically developed countries. Trends documented in Chapter Two, such as underfunding and 'fractionalisation' of services, which result from demographic and funding changes, may be most appropriately addressed through a model which has arisen from a context of more extreme service limitation.

While there may be similarities between the service environment in developing countries and that evolving in economically developed countries, the marked differences should not be discounted. Any comparison between such contexts will be tenuous if seeking to make direct application from specific practices, structures or strategies. The current study is based on the view that the most appropriate mechanism for making a viable comparison between contexts is to determine fundamental underlying principles and seek to apply these in a contextually relevant way (Kuipers, 1997).

6.3 The Bio-Psycho-Social Ecology Model as Framework for the Application of CBR to Economically Developed Countries

The current chapter might be seen as relating both to the concerns regarding disability service delivery in economically developed countries noted in Chapter Two, and the description of CBR in Chapter Four. The Bio-Psycho-Social Model is a suitable framework for comparing and contrasting such different approaches and contexts. Using the model, it might be concluded from Chapter Two, that in economically developed countries, the rehabilitation and disability service delivery system demonstrates relative strengths at the bio- and psycho-systems levels and also at the exo-systems level. In contrast, the strengths of the CBR approach lie mostly at the micro- and meso-systems levels. A degree of complementarity between CBR and current approaches to rehabilitation and disability service delivery in economically developed countries might therefore be suggested (Figure 6.3).

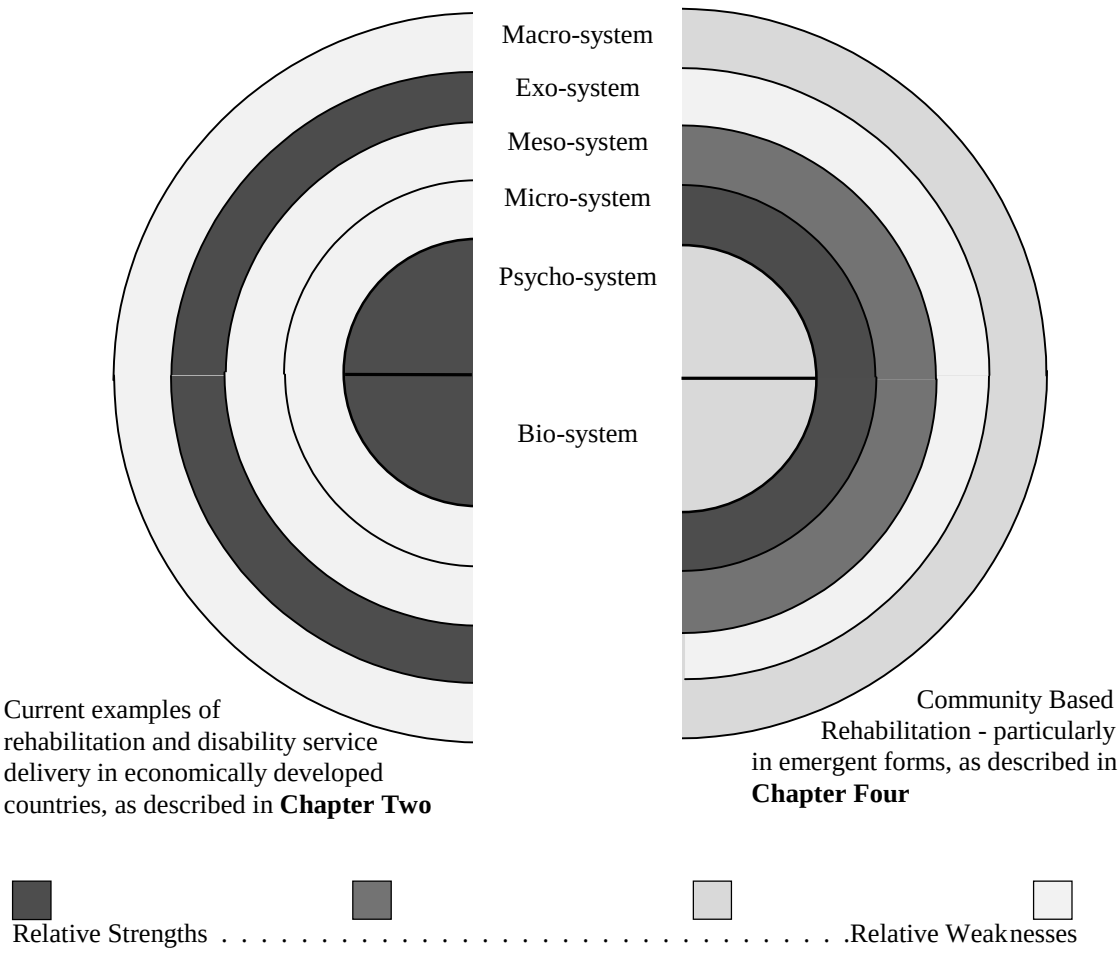

Figure 6. 3 A comparison of rehabilitation and disability service delivery in economically developed countries with CBR, using the Bio-Psycho-Social Ecology Model

This figure illustrates an interpretation of the literature analysis in Chapters 2 and 4. The criteria on which the interpretation was made were, (a) the researcher's judgement of the importance attributed to each level from the literature, and (b) the nature of the focus within each context (i.e. the individual, familial, community, social, organisational or systemic focus of services in economically developed countries compared with CBR). Although speculative, this comparison illustrates that the CBR approach may be considered a potential response to shortcomings identified in the analysis of approaches in economically developed countries. Conversely, it might be suggested that that if utilised within these countries, the weaknesses within CBR may be balanced by the strengths of existing approaches to rehabilitation and disability service delivery.

6.4 The Nature of CBR in Economically Developed Countries

While CBR has emerged and evolved predominantly in developing countries, it is not exclusively a phenomenon of those regions. A number of researchers have recognised the potential of the CBR approach and considered its application to economically developed countries (Christie & Oster, 1996; Enders, 1993; Lysack & Kaufert, 1994; Marincek, 1988; Oster et al., 1996; Peat, 1991b, Peat, 1993, Peat & Boyce, 1993; Votava, 1994). Despite this interest, the application of CBR to economically developed countries remains novel (Wirz, 1996)[1].

6.4.1 Community 'Based' as Opposed to Community 'Placed'

In economically developed countries, community based services for people with disabilities, particularly people with intellectual disabilities, are not uncommon. A major focus of such interventions, is the individual's integration into the community. While there are creative exceptions (Shoultz, 1991; Schwartz, 1997), it has been recognised that the physical presence of people with disabilities in the community *with tangible social connections* has been rarely achieved (Bradley & Knoll, 1995). It is suggested that a deficiency of such approaches is that they fail to appropriately *engage* the local community. They may be *placed* in the community but are not genuinely *based* in the community.

[1] As noted previously, CBR is an indistinct entity and while there are numerous examples of published research which are called 'community based rehabilitation' or which reflect aspects of a CBR approach (Anderson et al., 1996; Clarke, 1987; Commonwealth Rehabilitation Service, 1984; Fitzgerald, Yee, Goebert & Okamoto, 1992; Hoeman, 1992; Shilony, Lacey, O'Hagan & Curto, 1993), those which did so without reference to the WHO-CBR model, or the evolution of that model were not included in the current analysis.

Illustrative examples from studies which are referred to as 'community based rehabilitation' but fall short of a community emphasis include, a community based vocational rehabilitation project that does not appear to develop links with the community (Symington & Weston, 1987), a highly professionally driven model which fails to start with, or focus on, the community (Townsend, 1987), an approach which utilises community therapy services but does not facilitate active participation with the broader community (Veach, 1993), and a highly medicalised strategy which recommends that medical doctors should be the focal point for community based rehabilitation[2] (Clarke, 1987).

L. Krefting (1995) maintained that CBR becomes genuinely based in the community through being located in the community, being supported by people in the community, being owned and controlled by the community, and through being sustained by the community. Wirz (1996), writing about the disability services in economically developed counties stated that

> an examination of these [services] shows that although there may be geographical relocation to 'the community' the professionals frequently retain control. ... Far less common are ... services which try to provide a true disability service with disabled people being involved in planning, partnership ... and flexible methods of working. Such disability services are closer to CBR programmes. The Northern countries could do well by examining what lessons they can learn from the South with regard to these differences. (p. 4)

6.4.2 Formal Versus Informal Emphasis

The majority of researchers who have suggested the application of CBR to economically developed countries have recommended that it should be implemented through formal, structural mechanisms, as comprehensively as possible. They have suggested that for CBR to be effectively implemented in economically developed countries, it should be accompanied by, the development of appropriate policy, supportive legislation, service delivery structures, appropriate financial resources, appropriate educational systems for training health professionals and community workers, management systems for CBR services and CBR personnel, communication and referral systems, appropriate levels of coordination of programmes, public information systems, and structures to facilitate the training, placement and recognition of intermediate level workers.

In contrast, in developing countries, CBR emerged in a far less formalised manner, with few structural supports. This distinction highlights a dichotomy within CBR, which is particularly

[2] This is despite evidence that general practitioners are typically the weakest link in the community care chain, showing little involvement in the process, often undermining and bypassing community services in preference for hospitals (Strong, 1994).

relevant to attempts to apply CBR to economically developed countries. Peat (1993) stated that CBR "has developed over the last 20 years largely within the non-government and non-organised sector: within the circles of family and neighbours of persons with disabilities" (p. 6). Such recognition of the informal emergence and essence of CBR, as distinct from more formal CBR practices, has also been recognised by others (Marincek, 1988; S. Miles, 1996).

The emphasis by researchers in economically developed countries on formal rather than informal mechanisms, was reflected in a recent study contrasting CBR programmes in developing countries and economically developed countries. Boyce and Johnston (1996) noted that CBR workers in developing countries characterised themselves as, more consensus oriented, less centralised, more self reliant, and more future oriented, than did CBR programme staff in economically developed countries. These findings imply that CBR programmes in economically developed countries may have yet to capture the evolving grass-roots, informal and less professionalised nature of CBR programmes in developing countries.

As noted previously, the nature of a CBR programme and its development and implementation, should be dependent upon a number of factors, including, (a) the existing disability service delivery system, (b) the medical system, (c) the type of disability being addressed, (d) cultural factors, (e) educational factors, and (f) socioeconomic factors (Peat, 1991b). Consequently, it may be suggested that when implemented in economically developed countries, CBR programmes would be substantially different in approach, structure and processes than examples in developing countries. Al-Turaiki, Ozerol and Al Falahi (1996), describing the technologically advanced disability and rehabilitation services in the Kingdom of Saudi Arabia noted, “Practically all of the existing programmes and organisations [in Saudi Arabia] ... lack the 'Community Based Rehabilitation' [perspective] and thus the ultimate goals of social integration are either misunderstood, uncomprehended or ignored" (p. 38). They recognised that key emphases of CBR - social integration and community inclusion - are particularly relevant where existing services are characterised by high levels of technology and formal means of service delivery. It is the contention of the current study, that in economically developed countries, due to the highly formalised nature of existing disability services, the quality of the medical system, the existence of welfare systems and higher levels on socio-economic indicators, that the most appropriate implementation of CBR would be towards more informal, social and community emphases (see also Figure 6.3).

6.5 Suitability of CBR to Respond to Issues in Economically Developed Countries

In order to explore the potential application of CBR to economically developed countries, a number of issues have been identified which were seen as relevant to disability and rehabilitation services in the Australian context, as well as more generally.

6.5.1 Current Approach to Disability Service Delivery.

As noted in Chapter Two, a trend towards greater utilisation of external management systems and increased bureaucratisation of disability service delivery, has been identified in economically developed countries. Whitt (1996) stated that in such an environment, services are most effective when they operate within the context of a strong primary care base and an informed community. Characteristics of the CBR approach (to target the community as a whole, to foster community skills, and to empower through the development of self help skills (Lysack & Kaufert, 1994)), would appear to result in a more informed community with a stronger community care base. The introduction and establishment of such an approach may be an appropriate balance for these trends, and may eventually result a more responsive health care system (O'Leary, 1994).

Similarly, the current climate in economically developed countries, characterised by resource constraints, contracting economies, limits on expansion of traditional rehabilitation roles, trends towards deprofessionalisation or generic skilling, recognition of the need for more socially responsive models of service delivery, and changes in professional-public relationships, may be conducive to the introduction of CBR (Ginsberg, 1993; Lysack & Kaufert, 1994; Peat, 1993; Peat & Boyce, 1993;). Leake et al. (1995) stated,

> The crisis situation in disabilities services is analogous to that faced by health care systems throughout the Third World: the supply of personnel, funds and facilities is incapable of meeting needs according to the desired standards of care, and will remain so in the foreseeable future. The solution is also analogous to that widely adopted in the third world, out of necessity: promote community involvement, tap community resources, and train community members. (p. 32)

Despite potential relevance of these circumstances, the application of a community paradigm to this context is not simple. As noted previously, the rehabilitation and disability service delivery structure in economically developed countries has been characterised by, a deficit focus, a limited therapeutic orientation, narrow service framework, fragmentation, time limitations, and a closure focus (Kiernan & Hagner, 1995). Many of these characteristics appear contradictory to CBR principles. They may be seen as a potentially unsuitable context

for a community based approach. Consequently, it would appear that due consideration should be given to the manner in which CBR might be applied in economically developed countries. Given the characteristics of the rehabilitation service delivery environment in this context, CBR might be most productively introduced as a complement to, rather than replacement for, formal services. In this respect, the informal, social nature of CBR would be emphasised.

6.5.2 Social Model of Disability

Within many economically developed countries, the social model of disability is gaining ascendancy, emerging as an empowering framework through which disability issues may be understood and researched (Marks, 1997). The social model emphasises the power of significant groups to define the identity of others. Consequently, "the social model locates disability not in an impaired or malfunctioning body, but in an excluding and oppressive social environment" (Marks, 1997, p. 88). It follows therefore, that within the social model, the focus is to challenge this handicapping environment, whether physical, legal, social, or other (Barton, 1994).

Recent publications have drawn a parallel between emergent forms of CBR and the social model of disability (Coleridge, 1993; S. Miles, 1996). They have noted specific examples of action by community based disability groups to influence disabling attitudes, and challenge physical and social barriers in their local communities. These approaches to CBR may be seen to be consistent with a social model of disability.

With specific reference to the current context, Newell (1996) noted that Disabled Persons' Organisations [DPOs] in Australia currently lack a cohesive social influence. Such organisations have historically been strong advocates of a social model of disability and they have been instrumental in social change on disability matters. Their current decline leads to a substantial social void which will have an adverse effect on people with disabilities. Under these circumstances the CBR approach might be constructively fostered to respond to some of the social and community change functions fulfilled by such organisations. Enders (1993), recognised the potential of CBR to meet this need. She stated, "An ecological approach could be fostered that moves beyond sole focus on the individual's adjustment to disability and incorporates targeted efforts at developing the community's ability to include all its members" (p. 19). While CBR might constructively embrace such a social orientation, it would by nature be highly localised. In light of concerns raised regarding DPOs in Chapter Two, such a localised community focus may have substantial benefits including greater representativeness. It should however also be balanced by more integrated national efforts to influence political and social agendas.

6.5.3 Rural Issues

The provision of quality disability services in rural and remote areas has proven complex and difficult, particularly in Australia (Centacare, 1993; Gething, Poynter, Redmayne & Reynolds, 1994b). In rural areas the population, including people with disabilities, is more sparsely dispersed and physically isolated. This results in an inability to achieve the critical mass of service users necessary to establish a sufficient client base for the development of formal services (Gething, Poynter & Redmayne, 1994). In rural areas, disability services which exist are often remotely controlled by metropolitan areas and lack coordination at the community level (Jackson, Seekins & Offner, 1992). Rural disability services have been characterised as, highly medicalised (Nosek & Howland, 1992), often overspecialised, failing to target the more general needs of users (Allen & Seekins, 1994; Nosek & Howland, 1992), and offering limited choices (Proctor, Wells & Seekins, 1992).

Further, due to the paucity of community resources and services in rural areas (Nosek & Howland, 1992), people with disabilities may also have difficulty participating in community life due to restrictive housing, transportation and architectural barriers, or they may be required to move out of their communities to obtain services (Nosek & Howland, 1992). As a result, the physical presence of people with disabilities in rural areas is diminished, and consequently, community awareness of disability issues is further limited (Jackson et al., 1992).

To contextualise these complications, it has also been noted that the strengths of communities in rural areas is greater than urban areas (Gething et al., 1994b). In general, rural communities are reported to demonstrate, less reliance on the 'system', greater willingness for families to accept responsibility for the needs of relatives with disabilities (Nosek & Howland, 1992), and a preference for obtaining services at a community level (Gething et al., 1994b).

Despite numerous reviews of disability issues in rural Australia and elsewhere, prevailing formal models of service delivery have rarely been challenged. In Australia, for example, review recommendations have emphasised traditional concerns such as, increased funding for existing and similar models of service delivery (Gething, Poynter & Redmayne, 1994), policy and resource solutions rather than practical responses (Centacare, 1993), and increases in the number and extent of services under current models (Gething, Poynter & Redmayne, 1994). In rural areas of Australia, traditional professionalised (often highly medicalised) approaches still predominate (Bishop, Hodgson & Coman, 1996; Darling Downs Regional Health Authority, 1994).

Within the context of the current research, it would appear that, given the paucity of services, the geographical isolation, and the nature of rural communities, a community based approach may be a particularly constructive alternative[3]. It has been noted in the literature that rural communities are often highly conducive contexts for the introduction of CBR (Lysack & Kaufert, 1994). More specifically, it has also been noted that due to the nature of Australian Aboriginal communities in remote and rural areas, community based approaches may be a particularly appropriate response to the needs of indigenous people with disabilities (Gething, 1994; Glynn, 1996b). However, despite such recognition, culturally inappropriate, conventional medical or outreach services are most commonly provided for people living in rural aboriginal communities (Gething et al., 1994b; Gething et al., 1994c).

6.5.4 Sustainability

As indicated earlier, achieving sustainability of human service programmes (particularly rehabilitation and disability services) in economically developed countries, is highly desirable (Rissel, Finnegan & Bracht, 1995). Despite this, the issue of ensuring sustainability of services (as opposed to durability of individual outcome) has received little attention (Rissel et al., 1995). Where sustainability of services has been explored (often outside of traditional rehabilitation and disability service delivery literature), the focus has been on financial sustainability, maintaining funding (Pelletier & Shrimpton, 1994), or on structure and outcomes (Ager, 1990).

Within CBR, as it has arisen in developing countries, sustainability has been explored and considered on a number of levels, as a multi-dimensional entity. Examples of some of the factors identified which contribute to sustainability were noted in Chapter Four. The current thesis contends that the emphasis and understanding of sustainability which has emerged in CBR literature has the potential to contribute to the development of disability services in economically developed countries. In light of issues raised in Chapter Two, the development of services which are sustainable within their local communities, would be of significant long term benefit to people with disabilities in these countries.

[3] Indeed parallels have been drawn between rural areas in economically developed countries and circumstances in developing countries (Proctor et al., 1992; Rojewski, 1992). Consequently, the relevance of a model that arose in developing countries may be extrapolated.

6.5.5 Attitudinal Issues

Changing community attitudes towards people with disabilities is a key issue facing services in economically developed countries. It also appears to be one of the more intractable issues to address (Pernice & Lys, 1996). There is substantial theoretical and experimental support for the view that community members' feelings and beliefs about people, and consequently their behaviour towards them, are influenced by the context of their interactions (Lyons, 1996). Ideally these interactions should be characterised by equality (Kilbury et al., 1992), and should enable people and groups to appreciate their common humanity and develop common goals and interests (Wright, 1989).

Susman (1994) observed that one of the more important ways of reducing stigma and changing community attitudes has involved people with disabilities working together to present positive images of themselves and assuming their full personhood as citizens. The emphasis in CBR on the action of people with disabilities working together to bring about change in the local community is consistent with such perspectives on attitude change (Chapter Three). CBR may be an effective mechanism to bring about such change in economically developed countries.

6.5.6 Community Participation

Based on the experience of the WHO in the instigation of CBR programmes in developing countries, M. Miles (1996) suggested that the effectiveness of a particular programme is influenced by the level of economic, social and educational development of the local community. That is, genuine participation by community members may only be viable when people's basic economic, social and educational needs have been met. In economically developed countries, this is largely the case, such countries demonstrate higher measures on economic, educational and social indicators. Consequently communities in economically developed countries may be highly suitable contexts for the establishment of CBR programmes.

A further indication of the potential suitability of CBR to these countries is the trend in which people in economically developed countries are increasingly expressing a desire for greater levels of community involvement in service delivery than is currently available (Ife, 1995; Peat & Boyce, 1993). While greater grass roots, community participation in disability service delivery may be viewed as desirable, it is not without its liabilities. Potential problems exist with ensuring confidentiality and privacy, role ambiguity and role conflicts, and increased possibility of inappropriate decisions over clinical matters (Peat & Boyce, 1993). Consequently, it would appear that the introduction of CBR should occur at a level at which

these issues may be addressed. The degree and extent of community participation in community based disability services, should be targeted to the nature of the community, the needs of individuals, and the issue being addressed (see Chu, 1994).

6.6 Potential Benefits of CBR in Economically Developed Countries

In addition to the benefits of CBR described in detail in Chapter Four, a number of potential benefits might be postulated for the application of CBR to economically developed countries.

- As noted in Chapter Two, a major concern with the rehabilitation and disability sector in economically developed countries is the cost of service delivery. Lagerwall & Hargö Granér (1996) stated that CBR had the potential to significantly reduce the costs of disability services in economically developed countries.
- In relation to the inability of existing services to meet demands (Chapter Two), Peat (1993) suggested that the introduction of CBR to economically developed countries would deliver improved coverage of services, thereby more effectively responding to unmet needs.
- The focus in CBR on providing skills to the person and their micro-system, gives families greater skills and improves continuity of care, assists in prevention of secondary conditions, and facilitates reintegration into the community (La Marche et al., 1995).
- The application of CBR to economically developed countries has been identified as a means by which disability services might move away from a narrow individual focus, to seeing the family and the micro-system as the *focus* of rehabilitation or even as *participants* in the service delivery process (Lagerwall & Hargö Granér, 1996).
- The CBR approach may also mitigate prevailing cynical attitudes to disability service provision and professionals which exist in economically developed countries (Peat & Boyce, 1993).

In instances where CBR has been applied to an economically developed country context, researchers have found that, it has enabled people with disabilities to take an active role in service provision, resulted in a degree of empowerment, and fostered the development of independent organisations of people with disabilities (Lagerwall & Hargö Granér, 1996; La Marche et al., 1995). Specifically, in an application of a community based approach, it was found that people with disabilities took control, advocated for themselves and critiqued the nature and the means of delivery of services (La Marche et al., 1995)[4].

[4] While these reported outcomes are substantial, it should be noted however the current literature analysis failed to identify any studies which *comparatively* evaluated CBR against traditional models of service delivery in economically developed countries.

At a societal level, the potential value derived from the application of CBR to a developed country context may be seen to extend beyond improvement in disability services to the building of a more responsive care systems in general (O'Leary, 1994). Since disability may be seen as a microcosm of society (Barton, 1994), it may have implications for society and the nature of care in society (Helander, 1993). Enders (1993) observed that, the establishment of community disability services may be the basis for building inclusive support systems across the whole community. Peat and Boyce (1993) stated, "community rehabilitation services may provide a base for further community development in health, education, housing employment and health and social services. Thus community services may become part of a wider decentralisation and democratisation of social services" (p. 282).

6.7 Potential Limitations of CBR in Economically Developed Countries

While a number of general limitations of the CBR approach have been suggested in Chapter Four, limitations may be identified which pertain to the application of CBR to economically developed countries. These are outlined below.

6.7.1 Vulnerability of CBR

In economically developed countries, traditional service delivery approaches are firmly entrenched within funding channels, organisational structures and bureaucracy. In contrast, the grass-roots oriented CBR approach, may be seen to be dependent on too many factors for success and consequently may be overly vulnerable[5]. Since CBR programmes do not exist as monolithic structures, they will to a large extent, be dependent on,

- Social factors such as, the nature of the community in which they are based, the social infrastructure, existing formal and informal agencies and services, the people involved, and the capacity of the people to work together to develop partnerships (O'Toole, 1988).
- Physical factors in the community such as, population mix, general health status, socioeconomic class, topography, transportation systems, and local employment rates (Peat, 1993).
- Political factors including, national political, organisational political, professional political, and legislative issues (Peat & Boyce, 1993).

[5] CBR authors claim that many of the factors which result in vulnerability are also the factors which ensure the relevance and appropriateness of CBR approaches. This paradox would appear to reflect a choice within CBR approaches, electing to seek relevance to communities rather than enduring resistance to influences.

- Personal factors such as, the morale of the community, the nature of family relationships, personal resources, and educational background of community members (La Marche et al., 1995; Peat, 1993).

6.7.2 Professional Roles

CBR programmes have been found to cause significant role confusion for professionals (Mitchell & Wright, 1992). In economically developed countries, where disability services are highly professionalised, the introduction of a CBR approach would necessitate considerable changes in professional service delivery approaches and roles. This is likely to be resisted by those professionals who are entrenched in current service provision methods.

In cases where professionals are committed to assisting people with disabilities to engage their local communities through CBR, different problems may emerge. It is suggested that the vastly different nature of a community approach, isolation from traditional professional support structures, and the lack of traditional professional career paths may result in frustration and 'burn out' (Peat, 1993). It would appear that the establishment of CBR in economically developed countries may require significant education of both the disability community and the service delivery community, particularly with regard to professional roles.

6.7.3 Political Factors

As noted previously, CBR programmes may be viewed by political and bureaucratic interests as a means for rationalising existing services and avoiding responsibility to meet their social obligation to provide necessary services for people with disabilities (Lagerwall & Hargö Granér, 1996; Peat & Boyce, 1993). In this regard, rather than strengthening the community structure around people with a disability, CBR may become the catalyst for reducing services. Ife (1995) suggested that community based approaches may potentially be appropriated within a conservative political agenda in order to enable governments to shift the burden of care to the family and the local community. He saw that the introduction of community approaches may be a 'back door' means of having the private market move into government services. Barton (1993) argued that such approaches perpetuate the 'new right' perspective of the 'active citizen' (the person who does good to others only in a private capacity), which leads to a re-emphasis of charity models. Politically, it has been observed that community based approaches may confuse or blur the distinction between 'the individual' and 'the social' (Monach & Spriggs, 1994).

Since a goal of CBR is to effectively skill people with disabilities and community members, it seeks to facilitate enhanced, rather than fewer services. In response to the above concerns, it would appear that in economically developed countries, a major component of such skilling should be a degree of politicisation of CBR groups to ensure that existing necessary services remain, and are enhanced. Such politicisation within CBR groups would effectively link 'the social' and 'the individual' through involvement in 'the community'. It may also moderate the potential appropriation of the approach by those pursuing political agendas.

CBR may also be viewed as inconsistent with organisational agendas currently favoured by governments in economically developed countries. It has been suggested that community based approaches are out of step with prevailing economic and social priorities, including the drive for greater efficiency and tighter accountability of welfare programmes (Kenny, 1994). Freyhoff (1994) argued that CBR, in which activities take place predominantly within families and communities, is extremely difficult to evaluate quantitatively and does not correspond with traditional administrative structures. As such, CBR approaches may be viewed as unacceptable by bureaucrats and service developers in economically developed countries.

6.7.4 The CBR Process in Economically Developed Countries

A consideration of the applicability of CBR to an economically developed context, should also include an examination of CBR processes. As a community oriented approach, which seeks to bring about a measure of social change, CBR processes tend to be time consuming. Change is often slow and iterative, rather than on a large scale (Mitchell & Wright, 1992).

The informal, grass roots nature of CBR processes may not appear to make a great impact on large scale public professionalised service delivery structures. Outcomes achieved in CBR programmes may simply blend in with, or be subsumed by regular services (O'Connor & Watson, 1995). The nature of outcomes derived from less formal, community oriented programmes, while contributing substantially to the welfare of people with disabilities, may not be evident on traditional outcome measures. Consequently, CBR services may simply 'blend in' and inadvertently conceal important statistics (such as access rates and service gaps in the community). In so doing they may adversely affect future resource allocation to less tangible areas where funds may be most required.

While CBR exhibits a degree of macro- and exo-systems focus of CBR, its emphasis on community level issues may prevent it from effectively bringing about change at a structural and policy level (RI, 1995). The capacity of community based approaches to bring about broad scale social change and challenge the status quo, has been questioned (Dixon, 1989).

Approaches which seek to build self reliance and focus on local community issues, may not be effective mechanisms for bringing about structural and political change. Consequently, it would appear that future implementation of CBR in economically developed countries should examine possibilities for joint action between local groups to engage political and social agendas, both at the community level and higher.

CBR is essentially a cooperative, community oriented response to disability issues, and as such, may not be ideal for all people. Community based approaches usually require people to work together in groups. This may exclude some people, who are uncomfortable in such settings, who are unable to meet with others regularly (Mitchell & Wright, 1992), or who are too sparsely located for such approaches to be viable (Glynn, 1996a).

It may also be observed that informal, iterative, community oriented processes may be insufficient for many people, particularly those with special needs (O'Connor & Watson, 1995). Community based approaches may not be the most appropriate response for people whose needs are highly individualised or intensive. It is interesting to note however, that even in these contexts, community based approaches may play a significant role. Finkelstein (1996) argued that the medical and specialised disability needs of individuals with high needs, could be most effectively met through the action and politicisation of local groups and communities. In response to the difficulties individuals often experience gaining high cost equipment or modifications, he suggested that active, community based disability groups may play an important role in ensuring that locally appropriate services are provided to those in need within their communities.

6.7.5 Community

People with disabilities may experience weakened family relationships and their families may also experience a degree of alienation from social circles and neighbourhoods (Kwok, 1995). In such cases, an approach based on the assumption of a supportive community at the micro-system and meso-systems level, would be misguided. A socially isolated family with weakened relationships is unlikely to be an effective resource for a person with a disability. Given the lack of community strength already existing in economically developed countries, this issue is an important consideration. In response, proponents would argue that the CBR approach is an inclusive, community building strategy. Consequently, it may be the most appropriate response to address such alienation through building greater micro and meso-system level supports.

At the cross-community level, the localised nature of CBR programmes may be seen to perpetuate inequities between communities. Community based approaches are to an extent, limited by the resources available in each particular community (La Marche et al., 1995). Existing resource discrepancies between communities may be amplified under a community based approach, which would lead to greater inequity through uneven coverage of services for people with disabilities (Lagerwall & Hargö Granér, 1996).

A further potential liability of a CBR approach in economically developed countries, would be the emergence of a plethora of small community based groups, all focused on obtaining financial support and social assistance for their members. Such 'fractionalisation' may result in a lack of focus for disability as a social movement (Marincek, 1988). It may even contribute to a community level 'balkanisation' similar to that noted in Chapter Two. To prevent such developments, a degree of national level coordination would be highly constructive to facilitate the fostering, development and coordination of community based approaches.

It is suggested that the emergence of the 'virtual community' and the 'electronic community', particularly in economically developed countries, may constitute a challenge for CBR. Whether an essentially interpersonal approach to disability can be translated to electronic media may be a significant hurdle. A reconsideration of the nature and processes of support, services and local action in CBR may be warranted in light of current telecommunications. This is considered a potential subject for future research.

6.7.6 Women and Families as Carers in CBR

As noted in Chapter Four, a fundamental critique of community based approaches, is the level of responsibility placed on the family, and in particular, women (Mittler, 1994). Women and families are recognised as the largest providers of care in CBR (Peat, 1991b). Applied to economically developed countries, the CBR approach would likely place considerably greater burden on women and families, than traditional, formal rehabilitation service approaches.

Within economically developed countries, there is an assumption that professionals meet the majority of needs of people with disabilities (Monach & Spriggs, 1994). However, despite high levels of individualised, professional service provision the family remains the largest provider of care (Rowitz, 1992b). Notwithstanding the existence of formal services, women in economically developed countries play the greatest role in providing care (Gerstel & Gallagher, 1994), and this situation will likely remain so for the near future (Rowitz, 1992b). It is suggested that the substantial role of women and families as carers in economically developed countries may be obscured by the perception that services are comprehensive. In contrast,

within the CBR framework, the responsibility borne by women is at least consistently recognised (O'Toole, 1991b; Peat, 1991b). While the CBR approach may rely heavily on women and families as carers and participants in service provision, the fact that this situation is acknowledged may constitute a more healthy starting point than the assumption that professionals comprehensively meet the needs of people with disabilities.

It has been suggested that CBR programmes, if effectively implemented, may be a means for families, and women in particular, to establish meaningful and constructive support networks with their neighbourhood and the wider community (Kwok, 1995). In this regard, rather than generating greater responsibility for women, the CBR approach may be seen to build greater community supports around people with disabilities and their carers.

It is noteworthy that in economically developed countries, with increasing employment of women, it has been found that caring patterns are being transformed from prescribed networks (family) to more voluntary networks (community) (Gerstel & Gallagher, 1994). As such, community based approaches, in which care is shared within the community rather than the responsibility of one woman within the family home, may be a slowly emerging possibility. Under such circumstances, a CBR framework which recognises and supports multiple levels of community care, not just the family may be required. Such a system, focussing on micro- and meso-systems of community, is suggested in the current thesis.

Finally, on a structural level, it has been proposed that the application of CBR to economically developed countries should be supported by, a framework of increased respite care, increased home help, and greater employer flexibility (Peat, 1991b). Such proposals would necessitate a more politically and socially active form of CBR in which care providers are empowered to advocate their right of choice and their legitimate demand for support to fulfil their caring role (Kwok, 1995).

6.7.7 The Notion of Community and CBR

As noted in Chapter Four, the field of CBR has lacked a comprehensive definition of community. Consideration of the application of CBR to economically developed countries would appear to accentuate the need for a clearly defined concept of community. It would appear however, that discussion and description of community is essentially polemical. Brown (1994) stated that the notion of 'community', consists of a number of disparate concepts, suffers from problematic definitions, and is generally a contested topic.

Consequently, an attempt to locate rehabilitation and disability service delivery within the community paradigm may be considered contentious. A number of potential limitations can be identified, namely,

- Community based approaches tend to use romantic and somewhat naïve notions of community (M. Miles, 1994a). It is assumed that community is inherently good, must be maintained (Lysack, 1995), and should equate to the idyll of "rural communities deciding democratically to love one another" (M. Miles, 1994a, p. 14).
- Community participation, which is a key aspect of CBR, lacks a clear and practical operational framework.
- Despite the rhetoric of CBR, communities as a whole, rarely participate in projects. While certain sub-groups or individuals will participate actively in CBR projects (Lysack, 1995), full community participation is an unrealistic expectation.
- Within CBR literature, community participation is often proposed as a mechanism for liberation of individuals and the community. However, many of the mechanisms and processes of CBR may be inconsistent with individual empowerment (Lysack, 1995). Further, the small scale nature of community based approaches may restrict people to their immediate locality when (for privacy or other reasons) they may prefer to obtain services from elsewhere (Ife, 1995). At some levels then, the CBR approach may be seen to limit rather than liberate.
- The apparent level of simplicity and naïvete associated with aspects of community based approaches, indicates a great need for notions of community (particularly in economically developed countries) which reflect greater degrees of complexity, diversity and pluralism.

Given the different manifestations of community in economically developed countries and the emergence of such concepts as the 'virtual community', there is a need for greater clarity. It is incumbent upon theorists in the CBR area, to incorporate frameworks of community which can accommodate non-geographical notions of community, greater recognition of change in community, and some acknowledgment of varying life cycles, interaction patterns and leadership styles within communities (Chu, 1994).

The current thesis suggests that for the application of CBR to economically developed countries, 'community' may be understood as a form of cohesive social organisation in which members share in varying degrees of political, economic, social or cultural activities and aspirations (see Helander, 1993). This encompasses the possibility that community may exist as an ideal as well as a reality (Hamilton, 1994), and may exist without reference to place, ethnicity and geographical boundaries.

6.8 Implications for Research

As indicated above, there are a number of concerns relating to the application of CBR to economically developed countries. These concerns emanate from, the nature and practice of CBR, the context and circumstances in economically developed countries, and the interaction between these two.

As noted in Chapter Two, traditional disability services in economically developed countries demonstrate considerable strengths at the bio- and psycho-systems levels, and relative deficiencies at the micro- and meso-system levels. Consequently, it might be suggested that in economically developed countries, a CBR approach should be employed which responds less to basic psycho-medical needs, and more towards relational, community, and socially oriented needs of people with disabilities. Such a focus is highly consistent with the evolutionary trend in CBR, which is seen as a shift in emphasis from the bio- and psycho-systems levels to the micro- and meso-system levels. It is therefore argued that the future research and application of CBR to economically developed countries, should seek to explore these more current emphases.

Second, given the identified research needs in the CBR field (Pruthvish & M. Thomas, 1993), and that this is a largely unresearched topic, studies seeking to explore CBR in economically developed countries should focus on fundamental principles and conceptual level issues. They should explore broad potentials, not seek to reach formal conclusions.

Third, given the absence of a methodology for linking people with disabilities in the community (Bradley & Knoll, 1995), it is suggested that studies relevant to the application of a community based approach to economically developed countries should seek to explore this process. Finally, as noted in the current literature analysis, research in this area should seek to utilise the scarce resources of the community in an optimal manner (Hanumantha-Rao et al, 1993), it should encourage more diverse social structures (Logan, 1991), and it should seek to build the level of care within the community (Helander, 1993). These implications guided the research phase described in Section C.

6.9 Conclusion

The current chapter comprised an exploration of the possible application of CBR to economically developed countries. Drawing on existing examples and extrapolating from CBR in developing countries, this chapter has identified the suitability, potential benefits, and limitations of the CBR approach in economically developed countries. It was suggested that within economically developed countries, the CBR approach might be expressed most appropriately in informal rather than formal service delivery, focusing on micro- and meso-systems levels. This is also considered consistent with evolutionary trends within CBR. The need for conceptual level research which explores the utilisation of CBR in an economically developed context was noted.

Section C

POTENTIATION

An Analysis of the Potential of Engagement

"All there is to thinking," he said,
"is seeing something noticeable
which makes you see something you weren't noticing
which makes you see something that wasn't even visible."

Norman Maclean

Chapter Seven

Methodological Process

7.1 Introduction

In response to the original research question, previous chapters have proposed CBR as a constructive alternative to balance traditional rehabilitation services in economically developed countries. These chapters suggested that the essence of CBR is 'engagement between people with disabilities and their local communities'. The primary purpose of this chapter is to describe the method by which the potential of the notion of 'engagement' was explored in the current study. This process is referred to as the 'potentiation analysis'.

Based on the suggestion that engagement occurs primarily at the micro- and meso-system levels, two studies were devised and implemented to correspond with each of these levels. These studies ran parallel, through inductive and deductive research phases.

The purpose of the first of these studies (the CDA study) was to explore the potential of the notion of engagement at the micro-system level (ie. people with disabilities working together and with their immediate networks, to have an impact on local communities). The use of interviews and follow-up feedback with a number of people with disabilities, contributed to the development of a grounded conceptualisation or 'model for enhancing engagement'. The potential of this model was then explored through a participatory 'workshop'.

The second of these studies (the RSL study) explored the potential of the notion of engagement at the meso-system level (ie. local communities and community groups having an impact on disability issues). Working with a large community organisation, interviews and data from needs analyses also contributed to the development of the model noted above. The potential of the 'model for enhancing engagement' was explored in this study through its application to organisational service planning. In order to provide a measure of confirmation of the model, a verificatory phase was devised in which findings were compared with data drawn from a previous studies.

Since a qualitative methodology was adapted specifically for the current study, a detailed description is provided for, (a) the choice of methodology, (b) the way in which integrity of the method was assured, (c) the methodological process, and (d) the way in which data was analysed.

7.2 Preamble: The Identification of an Appropriate Method

Research methods in the human services and in the rehabilitation and disability field in particular, have been the subject of significant current debate. The prevailing emphasis of research in this area has fallen into a traditional positivist, quantitative, 'scientific' framework (Fitzgerald, 1997; Symington, 1994). Such research has been criticised as largely irrelevant to people with disabilities, impractical for workers in the field (Walker, 1993), and a contributor to the oppression of people with disabilities by offering limited control to participants (Barlow & Harrison, 1996). The social relevance of such research has also been questioned. It has been argued that traditional research methods fail to appreciate important social factors such as the importance of 'connectedness' between people, and the place of social and community processes (Price, 1990; Riger, 1993). Within the current study, an attempt was made to allow the choice of methodology to be influenced by, the nature of the research problem, the needs of people with disabilities, and a desire for social relevance. A methodology was sought which was appropriate for the following criteria.

7.2.1 Appropriate for Exploring Disability Issues

A number of disability researchers have called for research which avoids the myth of the independent researcher, which does not stereotype people with disabilities, and which uses appropriately flexible methods (Bach & McDaniel, 1995; Barnes, 1996; Barton, 1994; Shakespeare, 1996). They have suggested that research should seek to achieve fair representation of people with disabilities by explaining what the research is about, by giving people with disabilities the opportunity to revise the research, by providing opportunity to question the researcher, and by avoiding the use of overly structured interviews and questionnaires which obscure the voice of the participants (Chesler, 1991). In general, research with people with disabilities should promote greater diversity of alternatives and avoid reductionism (Symington, 1994). Qualitative approaches have been strongly endorsed as the most appropriate means for gaining insight into the perspectives of people with disabilities and exploring or facilitating new options and alternatives (Hagner & Helm, 1994; Spencer, 1993; Symington, 1994).

7.2.2 Appropriate for Facilitating Empowerment

Despite calls for research to join with the disability movement and become an empowering enterprise (French, 1992), the present study acknowledged that few research initiatives actually *empower* participants. It may be patronising to claim that a research project initiated by an 'outsider' can be empowering or emancipatory (Barton, 1994). Consequently, the current project sought at a minimum, a methodological position which did not disempower participants, and which sought where possible, to operate in an empowering manner.

It was noted that research conducted in the community, in a 'real world' setting, is more empowering than in contrived settings (Florin & Wandersman, 1990; Ward, 1993). Further, participants should be involved in, have access to, and have opportunity to critique the research enterprise (French, 1992). It was also noted that the provision of feedback (the reporting of results for review by participants), is empowering (Trojan, 1988), and that 'attitude' and 'approach' are important aspects of facilitating empowerment in research (Cornwall & Jewkes, 1995). Qualitative approaches have been recommended for enhancing empowerment of research participants (Florin & Wandersman, 1990).

7.2.3 Appropriate for CBR Research

Since a central theme of the current research was the potentiation of the notion of engagement which arose from an analysis of CBR, methodological imperatives were also sought from relevant CBR literature. Despite limited empirical research in CBR, calls have been made for, interdisciplinary studies which promote the formulation of conceptual models, and which examine innovative alternatives within the approach (Boyce, 1997; O'Toole, 1991b; Pruthvish & M. Thomas, 1993).

CBR researchers have recommended methodologically rigorous research which emphasises and explores 'process' (Boyce, 1997; Finkenflugel et al., 1996; Katzenellenbogen, Joubert, Rendall & Coetzee, 1995; O'Toole, 1991b), and multi-method qualitative approaches, incorporating open interview and focus group formats (Lysack & L. Krefting, 1993; Osser, 1995). It was determined that qualitative approaches, which utilise thematic categorisation of the content of interviews to generate models, would be consistent with the identified need within CBR for the development of conceptual frameworks.

7.2.4 Appropriate for Research in Community Settings

Community researchers appear to prefer participatory methodologies within a phenomenological framework, exploring issues from the perspective of the participants (Cornwall & Jewkes, 1995). As such, an emphasis on inductive approaches is noted (Brown, 1994; Ward, 1993), and the use of minimal structure is common (Brown, 1994; Damodaram, 1991). Ward (1993) recommended that research in community settings should be 'issue driven' and oriented towards social change. In research with community groups, it has also been stated that studies should, to the maximum extent possible, be initiated by the group, and work within existing structures (Chesler, 1991).

Research in community settings typically deals with a complex array of variables and issues, for which qualitative methods have been seen as most appropriate (Hagner & Helm, 1994). More specifically, it has been recommended that research within community settings should be 'grounded' research (Ward, 1993), utilising the iterative cycles inherent in 'practical action research' (Florin & Wandersman, 1990; Robinson, 1995).

7.2.5 Appropriate for Model Development

Within the literature on research methodology, a recurring theme indicates that qualitative approaches are the methods of choice in settings where a phenomenon has not yet been explored, and where there is a need to develop models or theories (Hagner & Helm, 1994; Holloway & Wheeler, 1996; Strauss & Corbin, 1994).

In this context, approaches have been recommended which incorporate 'looser' inductively oriented designs, when the intent is exploratory and descriptive, in combination with 'tighter' more deductively oriented strategies, when the researcher is acquainted with the setting, and concepts have been more clearly delineated (Huberman & M.B. Miles, 1994; Strauss & Corbin, 1994). In particular the 'grounding' of theory through continual and close linking with data has been seen as an important priority in model development, leading to 'rich and valid' conclusions (Strauss & Corbin, 1994).

7.3 An Appropriate Method - A Grounded Qualitative Approach.

Based on the criteria identified above, it was determined that a grounded qualitative approach would be an appropriate research method for the current study. Particular benefits were identified as follows,

- These approaches provide a more holistic framework than other methods (Ife, 1995; Krathwohl, 1993; Lord, Schnarr & Hutchison, 1987; M.B. Miles & Huberman, 1994).
- They assist in developing well grounded explanations of phenomena, placing an emphasis on 'meaning' which constitutes a basis for developing a greater understanding of an issue (Krathwohl, 1993; M.B. Miles & Huberman, 1994).
- They contribute to the process of model building through an iterative evolutionary interplay between theory and data (Strauss & Corbin, 1994).
- They are based on the premise that the results of research must be located in the knowledge of the participants. Therefore, in early exploratory stages of research, an inductive approach is appropriate (Ainge, 1994; Lord, Schnarr & Hutchison, 1987; Ward, 1993).
- They allow for the combination of inductive and deductive approaches, particularly where deductive strategies are based upon insights gained in inductive research (Holloway & Wheeler, 1996; M.B. Miles & Huberman, 1994).

Grounded qualitative research methodologies do not follow a prescriptive format, and are difficult to delimit (Strauss & Corbin, 1994). They have been described as a 'bricolage' or close knit set of practices which provide solutions to practical problems through pragmatic, strategic and self reflective processes (Fitzgerald, 1997). The principles employed in the development of the current research method are detailed later in the chapter.

7.4 Integrity of the Method

7.4.1 Trustworthiness and Rigour in a Grounded Qualitative Approach

Within qualitative research methodologies, the requirement for sound, trustworthy and rigorous research is met procedurally rather than statistically. Consequently, descriptions of the strategies employed by qualitative researchers, to ensure trustworthiness and rigour have typically been verbose, yet often failing to allow the reader to readily identify specific strategies used (M.B. Miles & Huberman, 1994). In the present study, while the emphasis was on understanding, rather than identifying causal relationships, measures were taken to ensure a high level of

reliability and validity[1] through appropriate ad and post hoc procedures (Altheide & Johnson, 1994). To avoid laborious verbal descriptions of such measures (Constas, 1992), outlines were devised in table form (Appendix 7.4.1). This table identifies each requirement, notes strategies employed, and identifies how each strategy was met, (either procedurally, through the process of conducting the research; or descriptively, through measures of reporting and presentation of results and methods). As depicted in Appendix 7.4.1, the criteria sought in the current study were,

- *Reliability and Confirmability*. A number of strategies were employed to assist in achieving a level of consistency within the study and to facilitate replicability.
- *Transferability and External Validity*. In any study, it is assumed that the findings will have larger import. External validity refers to whether the conclusions drawn from a study are transferable to other contexts. In the current study this was achieved through promoting diversity of source data, clarity of procedures and diversity of application.
- *Consistency and Internal Validity*. In an exploratory study such as the current one, a goal of the research is an authentic portrait of the issue under investigation (M.B. Miles & Huberman, 1994). Strategies employed to promote the level of internal validity in the current study comprised efforts to promote descriptive, interpretive and theoretical understanding in the study (M.B. Miles & Huberman, 1994).

7.4.2 Minimisation of Threats to Integrity in a Grounded Qualitative Approach

In addition to the promotion of trustworthiness and rigour, the current study also recognised that measures should be taken to avoid circumstances which compromise the quality of research. Such potential 'threats to integrity', which are mostly procedural issues, have been described within the methodological literature and are detailed in Appendix 7.4.2. The present study sought to identify and minimise these potential threats through employing specific strategies throughout the research process. These are described in Appendix 7.4.2.

[1] While the terms *reliability* and *validity* can be applied to qualitative research, they are not measured numerically (Hagner & Helm, 1994). Reliability in qualitative settings may be more appropriately covered under *confirmability* and validity may be addressed with the concepts *transferability* and *consistency*.

7.5 The Research Method

7.5.1 Iterative Research

Strauss and Corbin (1994) asserted that grounded approaches explore plausible relationships among concepts, and that this plausibility is strengthened through continued research at various points, rather than at a single instance. Consequently, the method employed in the present study was iterative, involving the incorporation of a number of research sites and populations. This allowed for a gradual refinement of the method, to suit data needs. The iterative nature of the research necessitated the use of a flexible approach to meeting data needs and the selection of data management tools which could facilitate such a process (Richards & Richards, 1994).

7.5.2 Phases of the Research

The research method followed a cyclic process of *identification-exploration-synthesis* consisting of four distinct phases, preparatory phase, inductive phase, deductive phase and verificatory phase. This process, using multiple data sources is depicted in two ways, stylistically (Figure 7.5.2a) and in more detailed form (Figure 7.5.2b).

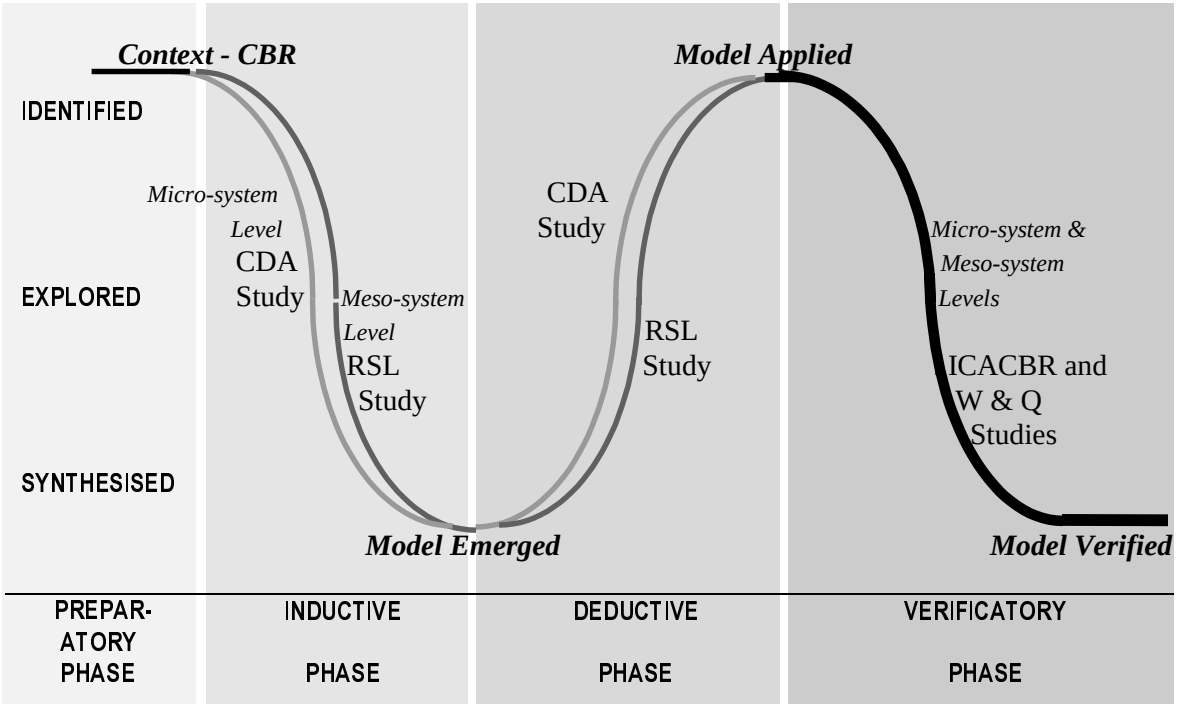

Figure 7.5.2a Schematic illustration of the research process used in the potentiation analysis.

The four phases were,

- A *preparatory* or preliminary phase, in which questions were refined, a research focus was identified (ie. the key principle of CBR - engagement), opportunities for research were considered and evaluated, and in which the parameters of the current projects were defined.
- An *inductive* phase, which consisted of an exploration of the notion of engagement through two studies at the micro- and meso-system levels. This phase resulted in the development of a preliminary descriptive model.
- A *deductive* phase in which the potential of the model was explored, through practical utilisation of the model in the two studies.
- A *verificatory* phase in which the researcher drew from previous research, independent of the current project, to verify conceptual components of the model.

A potential problem with research using multiple data sites is that conclusions tend to be universal rather than particular. However, the use of multiple sites also increases generalisability and ensures that the findings are not wholly idiosyncratic (Miles & Huberman, 1994). Such a strategy has also been found to deepen understanding and explanation, which is precisely the nature of research which is required in the CBR context (Pruthvish & Thomas, 1993), and which was sought in the current research.

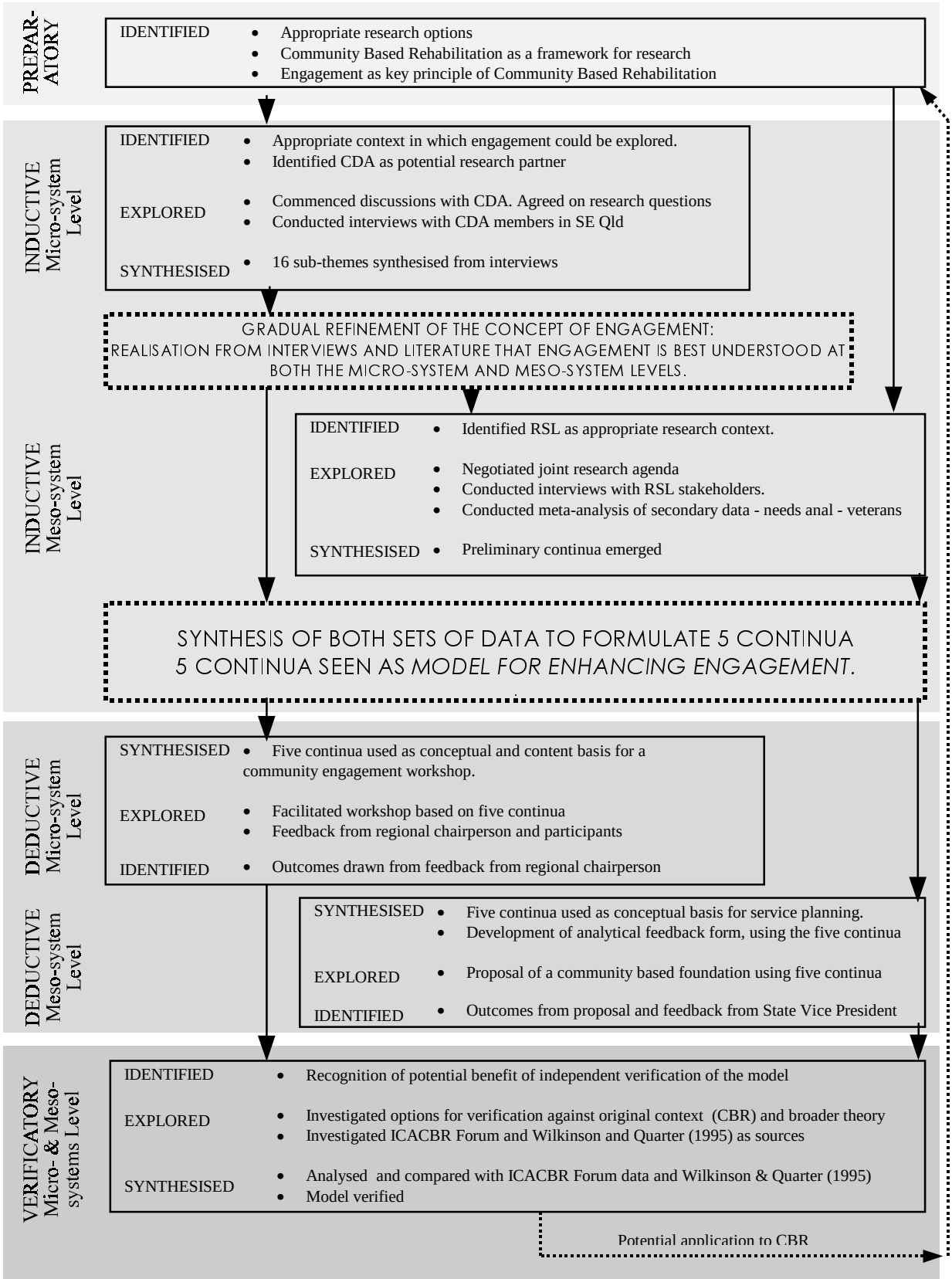

Figure 7.5.2b Overview of the research process used in the potentiation analysis.

7.6 Preparatory Phase - Initial Conceptualisation

As noted in Chapter One, the original research question grew out of the researcher's experience of a number of years of work as a Rehabilitation Psychologist in disability and rehabilitation services in South East Queensland. Based on the premise that innovative approaches tend to emerge at the periphery of practice rather than in the established models (Butler, 1993; Charlton, 1993; Ginsberg, 1993), a number of projects in remote and rural areas, or with unconventional populations, were explored. Over a period of nine months, the researcher progressively established contact and commenced negotiation with, five existing human service or disability related projects in Queensland to investigate their research potential to demonstrate innovation in aspects of service delivery. These were:

- Darling Downs Regional Health Authority - Remote and Rural Allied Health Pilot Project.
- Community Health , South West Region (Dalby) - Community Networking Project.
- Rural Lifestyle Options (Beaudesert) - Rural Disability Service Development.
- Unicare (Qld) - Involvement of Uniting Church parishes in disability service delivery.
- Cairns - Informal lobby group of service users of the Commonwealth Rehabilitation Service

In each case, it proved infeasible to conduct research within these projects. In most cases the projects appeared or purported to display a strong community orientation, but on closer examination, utilised a traditional, professionally based pattern of service delivery. In two cases, after negotiation, research involvement proved to be impractical due to logistical constraints.

Concurrently with the exploration of these projects, the literature analysis resulted in the identification of CBR as an innovative approach to disability service delivery. The analysis of the parameters of CBR resulted in the identification of engagement as the key principle, which was seen to have relevance to the current context. Such use of literature to generate questions, guide aspects of the research process, and stimulate theoretical sensitivity, has been advocated within qualitative research (Holloway & Wheeler, 1996).

Informal discussions were then initiated with numerous people with disabilities, service provider agencies, peak bodies and government agencies, to identify a potential research context which would provide an opportunity to explore the potential of this notion of engagement in South East Queensland. A small community association, Community Disability Alliance (CDA) was identified as an organisation which espoused a number of features which were consistent with the principles of CBR, and with whom a research partnership could be forged. A common research agenda was negotiated with CDA in early 1995.

7.7 Inductive Phase - Model Development

The current study sought to conduct an analysis of the potential of the concept of 'engagement' to contribute to disability services in South East Queensland. That is to explore within the current context, the potential utility of what has been identified from the literature analysis as the key principle of CBR - engagement between people with disabilities and their local communities. Engagement was explored under two levels, drawn from the literature and described in Chapter 5, namely,

1. *The micro-system level*. People with disabilities working together and with their immediate networks, to have an impact on local communities. In this instance the broader community was seen as the *target* of action by small, community based groups of people with disabilities.
2. *The meso-system level*. Local communities and larger community groups having an impact on disability issues. In this instance the community and community organisations were the *resource* [2]for people with disabilities in the community.

These two levels are depicted in the figure below (Figure 7.7).

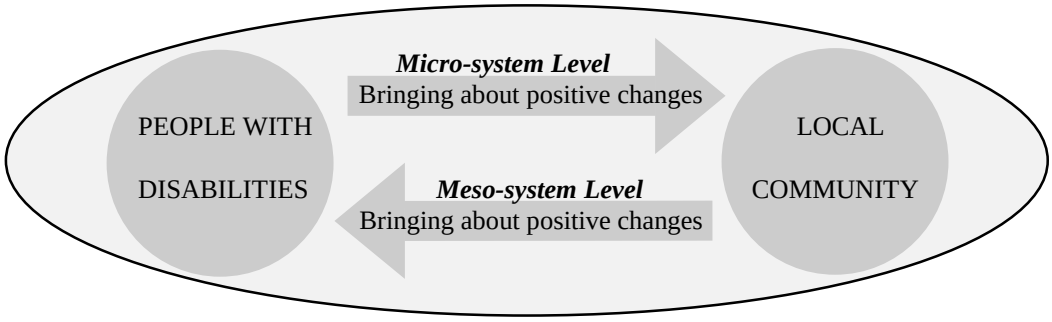

Figure 7.7 Engagement between people with disabilities and local communities.

[2] The concept of community as *target* and *resource* recurs in CBR literature (Lysack & Kaufert, 1994; Krefting, 1995)

7.7.1 Micro-system Level: CDA Study - People with Disabilities Engaging the Local Community Through a Community Disability Group

7.7.1.1 Community Disability Alliance

Community Disability Alliance (CDA), was chosen as a research site since its method of operation reflected a micro systems approach. It is a small, localised disability organisation, consisting of a head office in Brisbane (with two full time paid employees) and a number of volunteer regional groups throughout the state. Regional groups tend to be comprised of a variety of people with disabilities from a local area who seek to bring about changes in their local communities, mostly seeking to improve access for people with disabilities. The current research project maintained contact with CDA for a total of 32 months (March 1995 - Nov 1997).

At the commencement of the research project, the organisation was in a state of considerable change, having undergone a number of staff changes in a short period of time. The number of regional groups and people with disabilities active within those groups was greatly diminished. This adversely affected the running of the organisation (for example, it was difficult to achieve a quorum at state council meetings - even when airfares and accommodation were paid (personal communication, CDA State Coordinator)). The CDA head office had also undergone considerable directional change, and was actively pursuing a more centralised and formal organisational approach[3] (CDA Strategic Plan, 1995-1998).

Regional CDA groups have tended to be very small groups comprised mostly of adults with acquired physical disabilities. These groups typically struggled to remain viable[4] (personal communication, CDA State Coordinator). In 1996, the state of the organisation resulted in the management committee seeking, and obtaining funding for a project to instigate four new regional groups. The organisation chose an organisational/structural approach to regional group development. The project to initiate these four groups cost in excess of $30,000.00, drew considerable time and structural resources from the organisation, lasted one year, but did not result in the development of any new groups (CDA Management Committee Minutes).

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[3] The shift towards bureaucratisation, which is common to such organisations, is characterised by increasing specialisation of task, hierarchy of command, record keeping, formalisation and an impersonal orientation to work relations (Devlieger, 1995; see also Lyons, 1996).

[4] Such organisations have been found to be highly vulnerable with 'mortality rates' of over 50% in one year (Armstrong, 1993; Florin & Wandersman, 1990).

7.7.1.2 Method

A formal research link was established with CDA in March 1995. In the initial months, this involved the researcher attending regional meetings, speaking with paid employees and members, attending state council meetings, and speaking at committee meetings. This degree of involvement with research participants was actively sought in the current study, to inform the research, boost the credibility of the researcher, and ensure reliability of information (Gliner, 1994).

Ongoing contact led to the gradual building of relationships with people with disabilities who were members of CDA, and resulted in the negotiation of a common research agenda (Gliner, 1994; Holloway & Wheeler, 1996; Mays & Pope, 1994). While the goals and interests of the researcher were clearly stated from the outset, care was taken to ensure that research priorities were influenced by the members of the organisation (people with disabilities) rather than the management of the organisation (paid employees). Consequently, the external and internal validity of the study may be seen to be enhanced through its greater relevance to the participants as eventual end users (Altheide & Johnson, 1994; Chesler, 1991).

Given the sentiments expressed by CDA members, and the state of the regional groups, it was determined that one of the data requirements of the present study would be to explore and identify mechanisms by which these local groups/committees might be more effectively developed and sustained[5]. This was considered consistent with the researcher's agenda to explore the potential of the notion of engagement.

Individual interviews were conducted with 13 people with disabilities associated with CDA in South East Queensland (Appendix 7.7.1.2). This included all of the people with disabilities who were in contact with CDA in South East Queensland who made themselves available to the study. Two people declined to participate in the study and one was no longer available due to relocation prior to interviews. Most interviews took place in the participant's homes.

Such criterion based, purposive sampling of participants, as used in the current study, is common in qualitative research (Miles & Huberman, 1994). It is reported to result in accurate data (Gliner, 1994), and is appropriate where generalisability is sought to theory, rather than to other contexts (Miles & Huberman, 1994).

[5] Known as 'reciprocal shaping' of the research method, this approach has been recommended by Strauss and Corbin (1994), who noted that it results in greater sensitivity of the method, which boosts internal validity.

Interviews were preceded with a brief letter outlining the purpose of the interview and the main two-part question around which the interview would be structured, namely,

> *How might groups of people with disabilities have an impact on local communities? - What are the competencies, supports and processes which would assist people with disabilities to establish, build and maintain successful community based disability committees and groups?*

The deliberately broad nature of the question encouraged participants to volunteer information in their own words, thereby enhancing accuracy and limiting researcher influenced bias (Ward, 1993). In order to keep the initial question simple, the term 'engagement' was not used.

At interview, the researcher placed a copy of the question in large font before each interviewee to serve as a visual cue. Each interview lasted from 50 to 120 minutes. Since a number of CDA members had expressed concern about being recorded on tape, the researcher took written notes of the interview content. Notes consisted of major points with key verbatim quotes. Each interview was 'written up' by the researcher as more detailed notes, within 24 hours of the interview. This form of data recording (generating an outline using descriptive words or phrases to be used as a guide for the development of more comprehensive notes when the interview is completed) is supported by qualitative research commentators (Miles & Huberman, 1994; Rodgers & Cowles, 1993). It has been utilised in a number of studies (Brown, 1994; Finkenflugel, et al., 1996; Lord, et al., 1987; Packer, Race & Hotch, 1994), since it limits the obtrusiveness of the researcher (Krathwohl, 1993). In the current study the quality of this method was further assured by the researcher's familiarity with, and understanding of the area, having worked as a psychologist in the disability sector for many years (see Appendix 7.4.1).

At completion of the interviews, notes and transcripts were analysed using the NUD*IST software package for coding and analysis of data (See Appendix 7.7.1.2b). The raw data was initially categorised into 16 categories. Interpretations and conclusions were drawn from the statements in these categories and returned to each of the interviewees for comment, clarification and confirmation of the accuracy of interpretations (Appendix 7.7.1.2c). Feedback forms were received from 11 interviewees.

Such participant feedback or 'member checks' have been strongly endorsed as a means of providing triangulation of data (Brown, 1994; Gliner, 1994), and boosting accuracy and reliability of data and hence internal and external validity (Brown, 1994; Gliner, 1994; Huberman & Miles, 1994; Mays & Pope, 1994). They are also consistent with recommendations by Shakespeare (1996) that an emphasis in disability research should be, to achieve fair

representation of people with disabilities through providing the opportunity for participants to question and revise interpreted results (see also Altheide & Johnson, 1994).

Information from the feedback, served to refine and confirm aspects of the researcher's interpretations and assist in the preliminary development of a model which depicted the process by which engagement was enhanced. After analysis of feedback information, again using NUD*IST software, the 16 categories were synthesised to four second order concepts which were seen as important themes in model formation That is, the information derived from interviews and feedback responses, indicated four broad conceptual themes which contributed to the process of developing a model of enhancing engagement at the micro-system level. These four themes were 'set aside', pending information from the parallel RSL study.

7.7.2 Meso-system Level: RSL Study - A Community Organisation to Engaging in Disability and Human Service Issues

Through the iterative research process, it became evident from experience gained in the CDA study and the ongoing literature analysis that the meso-systems level of engagement would be best explored in a separate context from CDA[6]. A project to explore the potential of the notion of engagement at the meso-system level was sought and discussions were again held with a number of disability and human service agencies. This coincided with an approach made by the Returned and Services League of Australia (RSL) to the Centre for Strategic Human Services at Griffith University, by a State Vice-President of the RSL to conduct research on the potential role of the RSL in aged care and human services in South East Queensland. While the initial intentions of the organisation were somewhat parallel to the current project, negotiation between the RSL, the researcher and a supervisor, resulted in a jointly agreed research agenda which would meet the information requirements of the organisation, and further the aims of the present study. Research such as this, which combines researcher initiated priorities with participant initiated requests is consistent with 'real world', community oriented approaches. It facilitates higher levels of internal and external validity (Holloway & Wheeler, 1996; Krathwohl. 1993; Mays & Pope, 1994; Miles & Huberman, 1994). The second research site also provided a degree of triangulation of data sources (Holloway & Wheeler, 1996; Mays & Pope, 1994).

The research involvement with the RSL was established due to its organisational compatabilty with a meso-systems level approach. As a large organisation with an interest in assisting people with disabilities and other human service users, it represented a suitable site to explore the

[6] While the researcher had identified a need to conceptualise these issues, at this stage the Bio-Psycho-Social Ecology Model had not yet been developed and applied to the research. - A case of terminology being developed in response to research need (Kemmis & McTaggart, 1988; McTaggart, 1993).

potential of the notion of engagement at the meso-systems level (communities or community organisations as a *resource* for disability issues).

7.7.2.1 The RSL

The Returned and Services League of Australia (RSL) is a voluntary organisation for returned military service men and women, and ex-service men and women. The organisation began in 1916 as the Returned Sailors and Soldiers Imperial League of Australia. National membership of the RSL is currently around 250,000 (membership has been as high as 373,900) (Hill, 1993). External perceptions of the RSL range from a recognition of the organisation's strengths, such as courage, valour and empathy for one's 'mates' (Schwartz, 1993), to severe criticism that the organisation is out of step with the community at large, and not in touch with current thinking (Hill, 1993). The most common pubic perception of the RSL is as a place where old men go to drink beer and relive their war experience (Schwartz, 1993).

In terms of the provision of human services, the RSL is the principal advocate for veterans and their families and is one of Australia's most skilful, respected and powerful pressure groups (Hill 1993). Furthermore, the localised structure of the RSL means that it is represented in nearly every local community in Australia. Despite this, the organisation has not had good relationships with many human service organisations, and has been characterised as overly judgemental of welfare recipients (Schwartz, 1993). Hill (1993) echoed the sentiments of some describing the RSL as a highly insular, predominantly male, "militarist, war mongering organisation" which is "reactionary, even fascist" (p. 32).

The research challenge of the second study was to consider ways in which larger, more diffuse systems such as a community organisation like the RSL, in this case, with little experience of community based human services, might have a constructive impact on disability and human service issues.

7.7.2.2 Method

A formal research arrangement was initiated with the RSL in October 1995 and resulted in the awarding of a scholarship (the $5,500.00 *RSL - Australia Remembers Human Services Research Scholarship*) to assist with research costs. The researcher commenced the project by attending some sub-branch meetings of the RSL and accompanying the State Vice President to a number of meetings with RSL management, and staff of the Commonwealth Department of Veterans Affairs (DVA). It was noted that the RSL had an interest in greater involvement in the human services, and that management was considering the development and instigation of a formal nursing service to meet the needs of older veterans and people with disabilities. While they

acknowledged that such services already existed, they thought that they might provide a service which was tailored to their member's needs.

Given the diversity of issues at this level (the more diffuse meso-system), it was resolved that data should be drawn from a number of sources to ensure greater breadth of focus. Information was sought from two major sources, (a) key stakeholder interviews, and (b) needs analyses of veterans. Such use of multiple perspectives has been recommended for boosting validity (Strauss & Corbin, 1994).

7.7.2.2.1 Key Stakeholder Interviews

Face to face interviews were conducted with a total of 27 people. Since the focus for this stage of the research was primarily at an organisational level, key stakeholders of organisations (often at management level) were interviewed. These comprised,

- Thirteen people who fulfilled management roles within direct care provider agencies or were seen as representing relevant human services (Blue Nursing Service, Australian Pensioners and Superannuates League, Queensland Council of Carers, Council on the Ageing, Commonwealth Department of Veterans Affairs).
- Six people who fulfilled management roles within the RSL in South East Queensland
- Eight Welfare Officers of various RSL sub-branches in South East Queensland.

The researcher conducted interviews in the offices and homes of 27 people in each of the first three categories above (Appendix 7.7.2.2.1). These interviews were preceded by a brief letter of introduction from the RSL, outlining the purpose of the research. All interviews commenced with the question,

> *How might the RSL have an impact on human service issues in the community? - In what way might the RSL become more involved in aged care and disability issues?*

Each interview lasted from 40 to 90 minutes. In keeping with the CDA study interviews, the researcher took written notes consisting of major points with key verbatim quotes. Each interview was written up by the researcher, within 24 hours of interview. As with the CDA study, at completion of the interviews, notes and transcripts were analysed using the NUD*IST software package. Systematic analysis of the transcripts revealed 11 initial categories which described the data and informed the process of model development. Subsequent synthesis of these categories led to the identification of four second-order conceptual themes.

7.7.2.2.2 Veterans Needs Analyses

In addition to interviews conducted with organisational stakeholders, it was agreed with the RSL, that an overview would be required of the needs of RSL members, veterans and older

adults in the community. In order to meet this information need, a needs analysis, rather than interviews was suggested. Prior to commencement of the needs analysis however, preliminary interviews and research with various service providers indicated that a number of needs analyses had recently been conducted with this population. Further investigation by the researcher, identified a total of 11 needs analyses that had been conducted by various organisations in South East Queensland in the last three years. It was agreed with the RSL, that the collation and combination of all of these studies would be an objective measure of the needs of the aged and veteran service user community in this region. These data were combined in a simple adapted meta-analysis.

7.7.2.2.3 Meta-Analysis of Needs Analyses

The needs of the older adult and veteran, service user population (including the frail / disabled older adult population), has been a topic of considerable recent research in South East Queensland. Eleven needs analyses were identified which had been conducted by a variety of agencies, The Department of Veterans Affairs - Veterans Advice Network, Kedron-Wavell RSL, ACH Group Inc., National Ageing Research Institute, Logan and District RSL, The Centre for Strategic Human Services (Appendix 7.7.2.2.3).

Cumulatively, these studies explored the needs of a total of 729 veterans (including RSL members) and 211 non-veteran older adults, most of whom were frequent users of human services. Since the aged and veteran population in South East Queensland had already been subjected to so many studies, and since the use of other studies provided a ready source of independent information, it was concluded that the current research should synthesise all of the previous needs analyses, to gain a picture of the needs of veterans and the aged in South East Queensland[7]. Such 'recycling' or tailoring and adaptation of secondary data has been seen as an appropriate strategy in community based research (Beaulieu, 1996). Secondary data from multiple sources provides a level of objectivity and independence from researcher bias.

Raw data were obtained where possible, and analysed and summarised with information from needs analysis reports. Basic re-categorisation of the data resulted in an identification of major needs of the older adult service user community in South East Queensland. Cumulative analysis of these studies resulted in a ranking of the priority of those needs.

[7] The existence of such an amount of data on this population, raises concerns regarding the role and purposes of such research. Conducting this many needs analyses must have considerable social costs for the population. 'Recycling' such data constitutes a more socially responsible form of data gathering.

7.8 The Emergence of a Model Of Engagement

In overview, the inductive phase of the research drew data from,

- in-depth interviews with 13 CDA members,
- subsequent written feedback from 11 CDA members,
- interviews with 27 stakeholders associated with the RSL, and
- information from needs analyses involving a total of 940 older adults.

These data were analysed with the aid of the NUD*IST programme, using a descriptive-interpretive analysis, which consisted of decontextualisation, recontextualisation and categorisation of data. This process comprised the inductive phase of an exploration of the potential of the notion of engagement. It led to the emergence of a preliminary model which indicated the process by which engagement might be further 'potentiated' in the current context. The model was seen as descriptive of the process of enhancing engagement between people with disabilities and communities at the micro-system and the meso-system levels.

7.9 Deductive Phase - Model Utilisation

A consistent criticism of qualitative research, is the failure of many studies to go beyond the inductive stage of research (M.B. Miles & Huberman, 1994). Acknowledging the limitations of applying qualitative methodology in a deductive fashion (Ward, 1993), the current research sought to continue to explore the 'potentiation' of engagement to contribute to disability services in South East Queensland, through a more deductive application of the preliminary model within the two existing studies.

In keeping with the 'real world' orientation of the research, the emerging model was utilised differently in the two studies, contingent on the nature and requirements of each study. In each case, the model was applied to the most pressing need for that context as identified by key stakeholders. In the CDA study, it was agreed that the research might be used to assist one of the regional groups and enable it to more effectively engage the local community. The Sunshine Coast regional group was nominated since it had declined considerably in the last few years and was in danger of collapse, effectively operating with only two members. In the case of the RSL study, it was agreed with the RSL State Vice President, that the focus of the deductive phase of research would be to develop a framework which would assist local RSL sub-branches to explore their potential involvement in community human service issues, particularly for the older adult and disabled population.

7.9.1 Micro-system Level: CDA Study

An appropriate mechanism was sought by which the preliminary model might be used to assist the Sunshine Coast regional group to more effectively engage their local community. Initially, a curriculum based organisational training approach (Kaye, 1990) focusing on running effective meetings, strategic planning, committee procedures and similar strategies was proposed. After subsequent liaison with CDA members, staff and a number of independent group facilitators, this approach was rejected in favour of a 'workshop' incorporating principles of community development. This was seen as most consistent with the tenets of the model.

Based on discussion with a number of community development consultants, it was decided by the two remaining CDA members that a consultant who lived locally within the Sunshine Coast community should be enlisted. At a state level, CDA committed $1000.00 to the costs of the workshop. Liaison between the researcher and a local consultant resulted in a workshop format which was based on principles of community development, and highlighted the five continua of the preliminary model. (Appendix 7.9.1).

Using the preliminary model as a guide, a two day 'community engagement' workshop was held with the Sunshine Coast CDA group (Appendix 7.9.1b). The workshop took place on 28 and 29 September, 1996. Six participants took part in the workshop. The researcher also took part as a participant observer.

The usefulness of the preliminary model as a framework for a workshop in developing a community based disability group, was measured on changes in group approach as reported by the Sunshine Coast regional group chairperson in bi-monthly follow up telephone calls for 12 months.

7.9.2 Meso-system Level: RSL Study

Based on interviews and meta-analysis of the needs analyses used in the RSL study, the five continua, which comprised the preliminary model, were used to explore and evaluate possible models of service delivery for the RSL. Using the model, the researcher developed an analytical feedback form which was mailed to all interviewees (See Appendix 7.9.2). A total of fifteen feedback forms were returned with comments. These forms constituted both a data source and a means by which research participants could check research results, make amendments, and comment on the research process.

Two measures of the usefulness of the model were chosen. Firstly, subjective evaluation was provided by interviewee feedback on the feedback form. Secondly, in order to gain a more

objective measure of the usefulness of the model in enabling an organisation to more effectively engage community human services issues, interviews were held with the State Vice President of the RSL in February and November, 1997, who reported on developments within the RSL relevant to the recommendations based on the model.

7.10 Verificatory Phase - Model Application

Krathwohl (1993) stated that the transferability of concepts generated in research may be shown when there is a demonstration that a phenomenon, or a relationship exists beyond the instance in which it was identified. In order to explore whether the identified model was more than idiosyncratic, it was decided that a measure of the conceptual applicability of the research would be sought through further verification (Holloway & Wheeler, 1996; M.B. Miles & Huberman, 1994). Known as qualitative theory testing (Richards & Richards, 1994), this was sought through theoretical and conceptual triangulation.

7.10.1 Micro- and Meso-system Levels - ICACBR Project: Verifying Themes of the Model

In order to provide a final measure of affirmation for the emerging model, the researcher sought avenues to verify whether the constructs within the model might also apply to a CBR context. Since the initial research agenda arose out of a literature analysis of CBR, and was based on principles of CBR, it was seen as appropriate that the derived model should be 'cross-checked' against data which were reflective of current CBR practice and thought. A number of potential avenues were investigated to provide a means by which the model might be verified from within a CBR context. The most authoritative source available (within the practical confines of the present study) proved to be from an international gathering of CBR experts which took place in Canada in late 1994, in which the fundamental aspects of CBR were discussed.

The researcher obtained transcripts of interviews and focus groups involving 32 experts in the field of CBR, which were conducted by the International Centre for the Advancement of Community Based Rehabilitation (ICACBR- Queen's University, Canada). This forum sought to explore core characteristics of CBR through focus groups and face-to-face interviews in Toronto, Canada in November, 1994, and in subsequent interviews held in Allahabad, India. All interviews/discussions were audio recorded and subsequently transcribed for analysis as qualitative data. These data had previously been used as part of an internal research project (McColl & Patterson, 1995). The current researcher obtained the transcripts from the chief investigator of the ICACBR study, Associate Professor Mary Ann McColl.

While 32 people were involved in the forum (Appendix 7.10.1), most of the data comprised interviews with 12 key informants who represented a cross section of CBR programmes in India, Indonesia, Bangladesh and Canada. These key informants were directors of CBR programmes or were chosen to represent their various CBR programmes on the recommendation of their directors. The basis of their inclusion in the forum was their familiarity with organisational and practical aspects of their CBR programmes. Issues of confidentiality were cleared with the chief investigator, who noted that all participants had agreed to be recorded, and recognised that the content of the recordings may be the subject of research. The transcripts consisted of responses to eight questions, namely,

1. What are the goals of your CBR programme?
2. Whose needs does your CBR programme attempt to serve?
3. How does the community participate in supporting your programme?
4. Describe the role of the professional in your programme.
5. What changes have resulted from your CBR programme interventions?
6. How is your organisation linked with other organisations in the community, in government and elsewhere?
7. How is the continued operation of your CBR programme to be sustained or ensured?
8. What is the role of people with disabilities in your programme?

While the transcripts required considerable technical manipulation to be suitable for computer analysis using NUD*IST, they were able to be analysed in their entirety. In this instance, the NUD*IST programme was used to enable the researcher to,

- Investigate whether there was evidence of the five continua in the statements that comprise the focus group discussions and subsequent interviews.
- Draw comparisons between the nature or number of statements.
- Consider whether the CBR experts emphasised the 'community engagement' ends of the five continua.

7.10.2 Micro- and Meso-system Levels - Wilkinson and Quarter's Theory of Community Based Development: Verifying Concepts of the Model

Holloway and Wheeler (1996) advocated returning to literature as an important part of qualitative research, to stimulate theoretical sensitivity and to validate the researcher's categories. In order to provide a such a measure of confirmation of the model which arose out of the present study, a literature search was undertaken for similar models which may have been developed in different disciplines and which arose from empirical research. While a number of publications confirmed aspects of the model (Ife, 1995; Brown, 1994, Hildebrandt, 1994, Trojan,

1988), one study was identified as providing a framework which would inform the model derived from the current project (Wilkinson & Quarter, 1995). This study - which comprised a PhD thesis for the first author, came from the field of economics and sought to develop a theoretical framework for community based economic development.

The Wilkinson and Quarter study explored the development of community based economic cooperatives at both an interpersonal and organisational level as well as more community and associational levels, in this regard it may be seen as having explored these issues at the micro-system and meso-system levels. To an extent, their study overlapped with the current study in that it sought to explore the 'community basing process'. (The Wilkinson and Quarter study also considered other factors which pertain more specifically to their subject matter and are less relevant to the current project). Their depiction of the *process* of community based development (or as it is described in the present study 'engagement') was somewhat less detailed than the model which emerged from the present study, but still informed the current study. The application of Wilkinson and Quarter's theoretical framework of the process of community based development resulted in a measure of confirmation of concepts of the model.

7.11 Conclusion

The current chapter has provided an overview of the methodology of the 'potentiation analysis' stage of the research. The rationale for the selection of the research method was presented, and measures taken to ensure integrity were noted. Two studies were outlined which served as sites to explore the key principle of CBR (engagement). These studies, which explored the potential of the notion of engagement in the current context, resulted in the development of a 'model for enhancing engagement'.

The methodology by which this model was derived consisted of a cyclic process of identification, exploration and synthesis, through inductive, deductive and verificatory phases. Inductive and deductive phases comprised long term studies with two community organisations which were chosen to correspond with micro- and meso-systems levels of engagement. Verification of the model was achieved by comparative analysis with existing data which described the nature of the CBR process, and subsequent comparison with a similarly focused theoretical paradigm. The model and other findings of the potentiation analysis are reported in Chapter Eight.

Chapter Eight

Findings

8.1 Introduction

The purpose of this chapter is to present findings from the potentiation analysis phase of the current research project. Within the chapter, a balance has been sought between accurately portraying the nature and scope of the raw data, and succinctly presenting the results of the studies. As a qualitative study, it was recognised that the *content* of results was inextricably linked with the *process* by which those results were derived.

The chapter commences with a brief description of the way in which results are presented. The body of the chapter comprises a presentation of the findings within the three phases of the analysis, namely,

- The inductive phase of the research, conducted at the micro- and meso-system levels, which resulted in the development of a 'model for enhancing engagement' consisting of five bipolar continua.
- The deductive phase in which the potential of the model was then further explored within each of the studies.
- The verificatory phase in which the model was verified against data drawn from an unrelated study arising from the CBR tradition, and a theoretical paradigm devised in another discipline.

8.2 Preamble: The Presentation of Results

8.2.1 Content

Partly due to the distinctive nature of data obtained in this form of enquiry, qualitative research reports have tended to be overly descriptive and conceptual (M.B. Miles & Huberman, 1994; Strauss & Corbin, 1994). Grounded approaches in particular have been seen by some readers as unnecessarily inaccessible, overly temporal and individualistic (Strauss & Corbin, 1994). In order to respond to these concerns, and provide succinct but accurate data, the researcher devised 'data matrices' for the presentation of the content of results. A description of these data matrices is appended (Appendix 8.2).

8.2.2 Process

As with the presentation of the *content* of results, the appropriate display of the *process* through which results emerged, has been problematic for some qualitative researchers (Rodgers & Cowles, 1993). Much published qualitative research has been criticised for presenting large tracts of unintelligible raw data and going directly to final conclusions without appropriately depicting the processes in between (Holloway & Wheeler, 1994; M.B. Miles & Huberman, 1994; Rodgers & Cowles, 1993). Within the current thesis, presentation of the *process* by which constructs and themes emerged, was viewed as central to the thesis. In response to these concerns, 'conceptual audit trails' were devised to provide a clear depiction of stages of the research process and the relationships between the categories and concepts which emerged from the data (see Appendix 8.2).

8.2.3 Presentation

In order to balance comprehensive presentation of findings with accessibility, the use of data matrices and audit trails was dictated by the nature the research process. As indicated earlier, the current research consisted of an iterative process with gradual refinement of concepts. Rather than providing data displays for all preliminary concepts through each phase of the research (which would necessitate the presentation of almost 50 data matrices and would add unnecessary confusion), the researcher devised data matrices for each of the concepts which comprise the final model at the points of synthesis. In this way, raw data is directly linked with the outcomes of the research and the identified model (Figure 8.2.3). Similarly, audit trails were devised to depict each phase of the research (Figure 8.2.3).

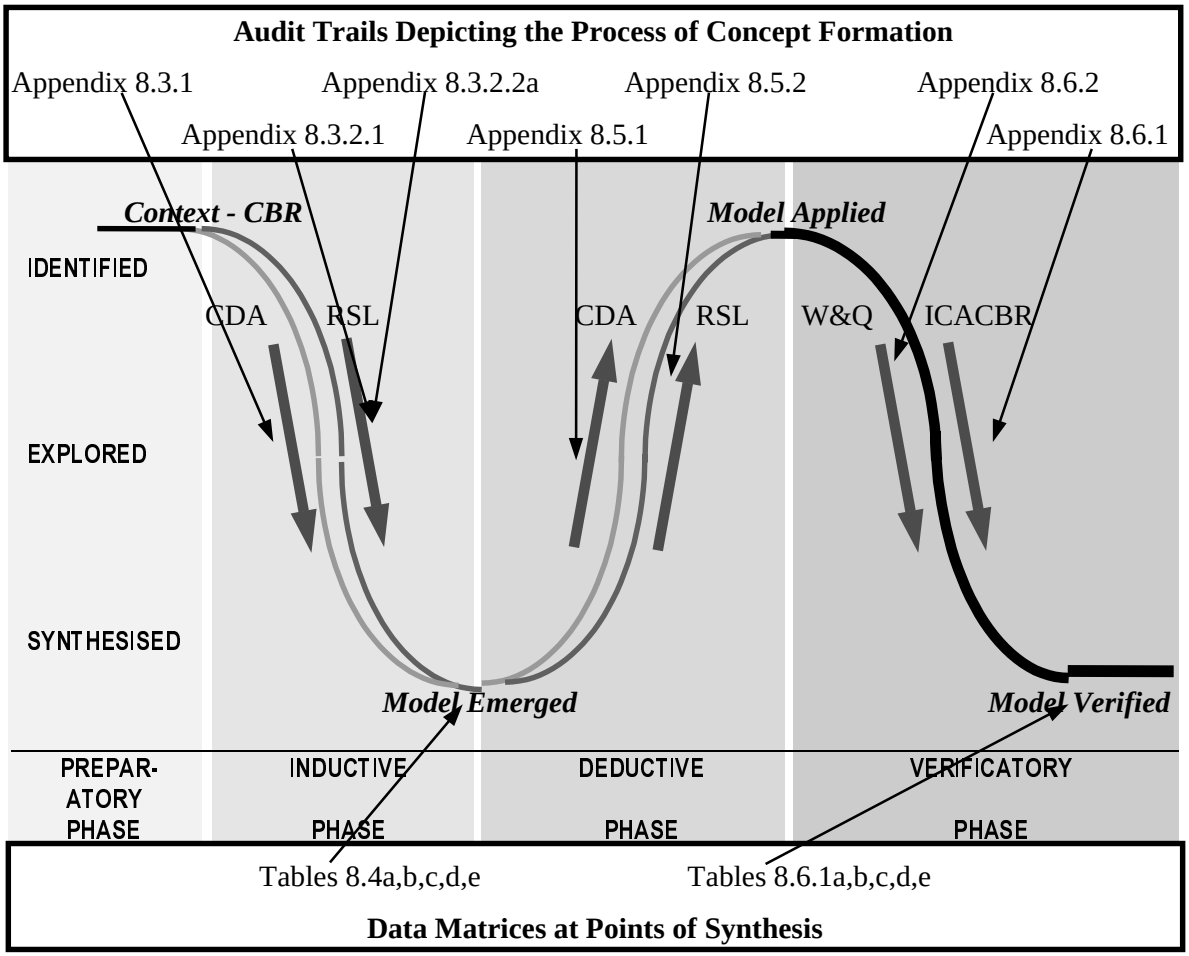

Figure 8.2.3 The use of audit trails and data matrices within the current thesis.

8.3 Inductive Phase

8.3.1 Micro-system Level - CDA Study

Interviews conducted with 13 people with disabilities who were associated with CDA, were thematically analysed with the assistance of NUD*IST qualitative data analysis software. This resulted in the identification of 16 preliminary categories (Table 8.3.1), which comprised a summary of interviewees responses.

Table 8.3.1 Sixteen Preliminary Categories Which Emerged From The Inductive Phase of Research at the Micro-System Level

16 Preliminary Categories	• Group Member's Qualities • Member's Knowledge/ Skill • Group Leadership • Group Philosophy • Group Structure • Group Action / Approach • Setting up Group • Maintaining the Group	• Community Setting • Accountable to Community • Advantage to Community • Parent Organisation • Policy Environment • Funding Support • Physical Support • Outcomes

As the first phase of data analysis, these were seen as preliminary categories which emphasised specific details relating to the group, grass roots skilling, and community issues. To provide a measure of clarification and confirmation of the accuracy of the interpretations, these were returned to interviewees for review and comment (Appendix 7.7.1.2c). This data management process was depicted as an audit trail (Appendix 8.3.1).

Eleven feedback forms were returned by interviewees. Through a subsequent process of coding, decontextualisation, categorisation, and recontextualisation of respondent's comments, four major themes were identified (Table 8.3.1a).

Table 8.3.1a Four Themes Which Emerged From The Inductive Phase of Research at the Micro-System Level

Emerging Themes as Contribution to Model	• Community based disability groups should have a "bottom-up" management approach. • Community based disability groups reflect a predominant emphasis on local "community" and social issues rather than on disability at an individual level. • Community based disability groups show a commitment to "doing it ourselves" and avoiding unnecessary professionalisation. • Community based disability groups emphasise the importance of basic values for planning and choosing directions.

These four themes were synthesised descriptors of respondents' perspectives on the research question. They reflected the strong community orientation, the grass roots nature, and the independence of the community based disability group. The themes were 'set aside' for inclusion into the emerging model, pending further information from subsequent phases of the research.

8.3.2 Meso-system Level - RSL Study

8.3.2.1 Interviews

Interview notes and transcripts from interviews with 27 RSL stakeholders (management, welfare officers and service providers) underwent similar analysis as the CDA study. In this case, the data were summarised by eleven preliminary categories (Table 8.3.2.1) which, like the CDA study, were predominantly classificatory in nature.

Table 8.3.2.1 Eleven Preliminary Categories Which Emerged From the Inductive Phase of Research at the Meso-System Level - Interviews

11 Preliminary Categories	• Organisational Structure • Instrumentalist Emphasis • Humanist Emphasis • Competition • Cooperation • Relationships with Other Groups	• Relationships with Service Providers • Relationships with Community • Needs of Members • Practices • Values

Subsequent synthesis of these categories led to the identification of four themes which were considered as descriptors of key aspects of interviewees perspectives on engagement (Table 8.3.2.1a).

Table 8.3.2.1a Four Contributing Themes Which Emerged From the Inductive Phase of Research at the Meso-System Level - Interviews

4 Emerging Themes as Contribution to Model	• A community based response would emphasise "people" and "issues concerning people" rather than structures, data, statistics or categories • Such a response should recognise the divisive nature of exclusive services and boundaries in a community framework • There is an ongoing tension between bottom up and approaches and hierarchical approaches • There is a tension between professionally delivered individual services and lay services which tend to focus more on social issues.

These four themes reflected the importance of 'human' and 'community' issues and emphasised the division between 'professional' versus 'lay' and 'individual' versus 'social' approaches. The process through which these themes emerged was depicted as an audit trail (Appendix 8.3.2.1).

8.3.2.2 Meta-Analysis of Needs Analyses

Within the RSL component of the study, a meta-analysis of needs analyses was also conducted. This data provided a degree of 'real world grounding' of the research process and the emerging model, within the expressed needs of human services users in the community. Eleven needs analyses were combined and cumulative totals of needs were drawn according to the frequency of reporting (Appendix 8.3.2.2). The cumulative total of needs identified in the eleven needs analyses, resulted in a rank ordering of the most commonly cited needs (Table 8.3.2.2).

Table 8.3.2.2 Contributing Themes Which Emerged From the Inductive Phase of Research at the Meso-System Level - Needs Analyses

Preliminary Categories	• Identification of major needs of (veteran, older adult and frail older adult) service users in the community through meta-analysis 1. Transport 2. Home and garden maintenance 3. Socialisation and loneliness 4. Safety and security 5. Information and education
Contribution to Model	The expressed needs of (veteran, older adult and frail older adult) service users in the community resulted in: • The further clarification of concepts of "Amateur" and "Social". • Clarification of contrasting positions of "Professional" and "Individual" which were not preferred by community based service users.

Five major needs were identified, transport needs, home and garden maintenance, socialisation and loneliness issues, safety and security needs, and the need for general information and education. It was noted that none of the major five needs identified required highly professionalised or complex formalised service responses. Most could be addressed through strategies which build and reinforce the links between the target group and their local community. The process through which these themes were included in the current study was depicted as a conceptual audit trail (Appendix 8.3.2.2a). This information was included with the other data sources and contributed to the model building process.

8.4 A Model For Enhancing Engagement Between People with Disabilities and their Local Communities

Based on the synthesis of information obtained from the preceding process, ten constructs were identified. These constructs were depicted as five bipolar continua. These continua were seen as the components of a model which incorporates and describes the process of enhancing engagement.

Since this stage in the research process was a point of synthesis (Figure 8.2.3), data matrices were devised to represent the association of each of the constructs with the data from which it emerged. These data matrices are comprised of two illustrative statements drawn as exemplars of the raw data from the CDA study and the RSL study. The "code" column contains the researcher's code to track the source of each statement[1]. The third column, "# Text Units", is the number of text units (from the NUD*IST coding system) attributed to that construct within each study. Text units allocated through the NUD*IST programme are an indication of the total number of lines of text which relate to a particular concept throughout a research project. They are not a direct tally of instances of statements about a concept. While it is recognised within the current study that qualitative data, by nature is rarely amenable to accurate quantification, it is maintained that some sense of the significance of a concept can be conveyed quantitatively by such measures. In the current study the "# Text Units" column is proposed as a rough but useful measure of the frequency with which a comment reflecting a particular construct was made[2].

The interpretation of the model is described in detail in Chapter Nine, however at this stage it is important to note that, based on the content of the data, and the relative values in the "# Text Units" column, the right hand side pole of each continuum was seen as the 'community engagement' pole. It was suggested that movement along the poles towards the right side, depicts the process of enhancing engagement.

[1] The explanation of the data code and details of each data source are described in Appendix 8.4.

[2] It must be emphasised that the number of text units is not a direct quantitative measure of the importance of a concept. A number of factors may influence the number of text units attributed to a particular concept. Given these qualifications, the number of text units may be considered as an imprecise but informative indication that the constructs identified by the researcher were not merely isolated instances, but a reflection of consistent and substantial themes in the raw data.

8.4.1 Constructs Comprising the Model

Five synthesised data matrices follow (Tables 8.4a-e). Each of these depicts,

- a bipolar continuum (shaded box)[3],
- representative statements which demonstrate the nature of the data from which each construct (ie each pole of the continuum) emerged,
- the number of text units which correspond with that construct in the CDA and RSL studies.

The first of these tables, Table 8.4a, reflects that data sources in both studies included a notion of the distinction between a 'top-down' and a 'bottom-up' organisational structure. A top-down structure might be described as one in which decisions are made centrally and the power base lies with management. The contrasting position, as described by interviewees, relates to the fostering of decisions made by service users. At this end of the continuum, the power base lies with the membership.

Table 8.4a Synthesised Data Matrix Describing Top-Down versus Bottom-Up Organisational Structure and Depicting the Derived Bipolar Continuum (Shaded)

Two statements from each of the two studies representing 'top-down organisational structure'	**Code**	**# Text Units**
Bureaucracies don't like free agents, they want us in the treadmill of applying for funding, stalling and doing what they want.	C ii jd 70	**17**
This is a continual problem, to some extent we need strong leaders, but strong leaders are autocratic and that isn't good for a community based group	C ff bj 11	
The RSL is run with the authority structure like the Army. The structure is very strong. Any change in the RSL would have to come from the top down.	R ii hd 18	**118**
The RSL is like the public service, too much bureaucracy. The RSL is bunch of people batting for themselves. All the hierarchy is interested in, is OAMs and all of that stuff. ... There are too many chiefs.	R ii jw 5	

Top-Down Organisational Structure

Bottom-Up Organisational Structure

Two statements from each of the two studies representing 'bottom-up organisational structure'	**Code**	**# Text Units**
At first we sought to address paths and toilets, but there was a need for a group which really represented people with disabilities. We gathered the energetic ones that we knew. We started to tell council that we were a potential resource and information source for them. This then led to having input into places like shopping centres, parking ...	C ii al 31	**139**
In this field of disability, [the motto] "for and by people with disabilities" is crucial to leadership.	C ff sk 117	
To get it going [a community based link with local high schools], you need enthusiasm, strong school participation and good public relations.	R ii ar 25	**109**
A model of community care. It has to be fostered by the sub-branches but coordinated by the hierarchy. It needs steam. We need a system of area helpers who access the coordinator.	R ii mc 27	

[3]The rationale for the choice of descriptors or names for the poles on each continuum is noted at 8.4.3.

Table 8.4b comprises a representation of themes in the data which indicated two contrasting positions, described as a 'professionalising' versus 'amateurising'[4] approach. Based on interviews and feedback, a professionalising approach may be described as one which relies on paid people or experts and is oriented towards specialised services. At the opposite end of this continuum, an amateurising approach may be described as one which relies on people who volunteer or choose their involvement. It is oriented more towards generalist responses.

Table 8.4b Synthesised Data Matrix Describing Professionalising versus Amateurising Approach and Depicting the Derived Bipolar Continuum (Shaded)

Two representative statements from each of the two studies representing 'professionalising approach'	**Code**	**# Text Units**
You need a variety of professional skills and not just people with disabilities. You need accountants and lawyers and people with skills in lobbying and dealing with government and group dynamics.	C ii pc 27	**38**
Professionals resign and leave and take all of the information and the skills that they've learned with them, that's why we can't use professionals.	C ii sk 146	
Maybe what we need is some more professional coordination	R ii gh 22	**119**
We need a paid person to set up this sort of thing, also do things like liaise with hospitals, link people together. Since DVA took away the social workers that they employed last year, there has been an increased load on sub branches	R ii jw 19	

Professionalising Approach ⟷ **Amateurising Approach**

Two representative statements from each of the two studies representing 'amateurising approach'	**Code**	**# Text Units**
The group (or individuals in it) need awareness of policy and legislation What they really need is to know how to find it out and how to use it.	C ii nc 55	**133**
We also need to educate people with disabilities that these government processes aren't magic. They can develop these competencies themselves.	C ii al 66	
Don't waste all the money by giving a bloody public servant a job, use it here where it is needed [amongst our members in the community].	R ii pa 80	**112**
The RSL shouldn't go professional - have professionals doing welfare sorts of work, the cost would be too prohibitive. ... The contact with people part should be coming from the sub-branches. There is a rapport between us that is like nothing else. We have to work here in our own area.	R ii sc 16	

[4] "Amateurising" refers to the original meaning pertaining to the word "amateur" - one who *chooses* to do something rather than one who does something for gain.

Table 8.4c represents the data and constructs pertaining to an 'individualising' focus as opposed to a 'socialising' focus. The continuum on which these two constructs lie, may be seen to distinguish between a focus on the specific problems of individuals as opposed to a more social and community focus. This may be manifest in distinctions between focusing on, and achieving outcomes with individuals as opposed to working with groups, addressing broader underlying societal issues.

Table 8.4c Synthesised Data Matrix Describing Individualising versus Socialising Focus and Depicting the Derived Bipolar Continuum (Shaded)

Two representative statements from each of the two studies representing 'individualising focus'	**Code**	**# Text Units**
Groups move from a point of mutual support [for their members] to addressing issues of access for all - you get sick of all the navel gazing.	C ii jd 16	**25**
Yes, important to have clear focus of issues ... Some of my worst experiences in disability groups have been with parents of children with disabilities! - One track minds - can't see anyone else's viewpoint!	C ff al 12	
[The organisation] is raising all sorts of money for bricks and mortar in Greenslopes and in medical services.	R ii bt 10	**92**
Welfare Officers are pension and welfare advocates, that's what we do. Our role is getting information and helping [our members] with pensions, disability pensions.	R ii sc 6	

Individualising Focus ⟷ **Socialising Focus**

Two representative statements from each of the two studies representing 'socialising focus'	**Code**	**# Text Units**
CDA should be representative of all people with disabilities in the community there needs to be an awareness of people with disabilities as well as an awareness of the [broader] community.	C ii af 70	**142**
frequently need to have a wider vision, eg government responses, consultations etc. As these will ultimately have a bearing on local community. A good example is the current draft guidelines for accessible public transport [DOT] open for comment in Queensland. If people don't comment it will be assumed that the guidelines as stated are OK.	C ff al 228	
The RSL could act as a lobby group. Now that would be very important! They could be a formal way of linking to the needs of veterans and old people	R ii mo 38	**112**
What the RSL needs if their people are ageing, is strategies to become good representatives of others and to be educators and educated. The RSL could be a good mechanism to allow older people in the community, particularly veterans, to be genuinely involved in important issues	R ii ws 40	

Table 8.4d represents the two ends of a continuum which was described as a 'positivising' versus 'humanising' orientation. Based on the data, positivising may be described as a position which emphasises 'hard' issues such as outcomes, data and accuracy. In contrast, humanising may be seen to emphasise 'softer' human issues pertaining to the effect on people, their feelings and personal and interpersonal needs. This distinction may also be characterised as a distinction between efficiency versus emancipation.

Table 8.4d Synthesised Data Matrix Describing Positivising versus Humanising Orientation and Depicting the Derived Bipolar Continuum (Shaded)

Two representative statements from each of the two studies representing 'positivising orientation'	**Code**	**# Text Units**
Some groups [particularly if they have a] statewide focus get very distracted from what they should be on about, responding to government inquiries, etc etc - you can't do everything.	C ii jh 17	**28**
Funding issues seem to take priority over the focus and direction of groups, many people are wary of participating because of this	C ff js 520	
We need central dissemination of information based on information gathered at the sub branch [level] and then a monitoring role [at executive levels]. That sort of thing would boost our membership.	R ii mc 47	**121**
We should have day services in the major War Veteran's Homes. They should also have a more social day club services for their patients and people in the community. The RSL employs 2 welfare workers who mostly do hospital visitation. We employ 5 people in Qld who work as advocates with government departments, etc. We have to extend our welfare network and we should base that in the War Veterans Homes.	R ii rd 59	

Positivising Orientation ⟷ **Humanising Orientation**

Two representative statements from each of the two studies representing 'humanising orienttion'	**Code**	**# Text Units**
Sometimes the frustration of things really gets to me, I'm a human but with CDA I'm not just pushing on my own, I feel safe in that group. CDA is a support not just to fight on our own but also to work together. ... There isn't a lot of acceptance in the community but there certainly is in the group.	C ii jm 12	**71**
Care must be taken to ensure input from all people with disability, regardless of ability to attend meetings.	C ff lr 38	
The big thing from my view is not so much having a service but linking people together. Families are one of the most important things for old people. The RSL should encourage old people to do things for themselves and also help their families to help them.	R ii gh 45	**111**
The RSL should be on about welfare. Welfare is all about talking to people ...[not] controlling people.	R ii jw 55	

Within Table 8.4e, the final bipolar continuum which comprised the derived model is depicted. This reflects the construct of 'exclusiveness' as opposed to 'inclusiveness'. Excluding attention may be characterised an approach which might limit the availability of services to certain people and seek to develop intensive services for a few. The corresponding position

described as 'including attention' would emphasise the promotion of a more inclusive approach, seeking to meet the needs of as many as possible. This position may include the choice to develop extensive services for all.

Table 8.4e Synthesised Data Matrix Describing Excluding versus Including Attention and Depicting the Derived Bipolar Continuum (Shaded)

Two representative statements from each of the two studies representing 'excluding attention'	**Code**	**# Text Units**
Agree to a point. Many groups fail because they are exclusively for people with disabilities and within the group, expertise are missing. Disability is not the sole criterion [for participation] in a group like this.	C ff pc 22	**20**
Someone to be there, has to be someone who knows, not just someone. In order for the parent organisation to give support, feedback, conviction, etc. it must be truly representative of the people with disabilities and therefore must [be run] by people with disabilities.	C ff sk 449	
The RSL has tunnel vision, they only see the issues of veterans, they don't understand other people's issues.	R ii yz 23	**114**
The RSL has a pervasive philosophy of entitlement, not caring for need. The RSL are seen as very exclusive in Queensland. RSLs with lots of money still aren't interested in the community, they are interested in "bricks and mortar' and possibly in buses and then they might think about other things.	R ii hd 12	

Excluding Attention ⟷ **Including Attention**

Two representative statements from each of the two studies representing 'including attention'	**Code**	**# Text Units**
there are no internal boundaries in CDA between roles of people with disabilities and roles of people without disabilities	C ii bj 14	**105**
Agree, some of these statements [regarding the philosophy of community disability groups] have overtones of "us and them". My experience has been that consultation and working together - sometimes reaching realistic compromise is much more productive.	C ff pc 152	
The RSL might have a role in informing the broader community about disability and aged issues. A role in changing attitudes.	R ii fh 13	**74**
One of the big issues for us is information. The RSL, being in all communities, could play a really important role in keeping communities informed. They could run information sessions in the local communities.	R ii yz 28	

8.4.2 The Model

Drawing from the contributions depicted in the preceding tables, a descriptive model emerged from the inductive phase of the research. This was conceptualised as a set of five bipolar axes (Figure 8.4.2). The following figure also includes further descriptors of each pole of the five continua. Many of these descriptors were drawn from, or based on interviews and feedback from participants, some were drawn from explanatory reference material such as a thesaurus. They were included to provide clarification and further description of each construct.

ORGANISATIONAL STRUCTURE

Top-Down	**Bottom-Up**
Decisions made centrally	*Decisions made by service users*
Power base lies with management	*Power base lies with membership*
PRIVILEGE	EGALITARIANISM

APPROACH

Professionalising	**Amateurising**
Relying on paid people	*Relying on people who choose to do it*
Structure - promotes professional services	*Structure which supports volunteers*
More specific technical services	*More broad general services*
DEPENDENCE	INTERDEPENDENCE

FOCUS

Individualising	**Socialising**
Focusing on individual's needs	*Focusing on groups*
Addressing specific conditions	*Addressing community and social issues*
Responding to individual's problems	*Responding to social problems*
INDIVIDUALISM	COLLECTIVISM

ORIENTATION

Positivising	**Humanising**
Prioritising outcomes	*Prioritising people*
Focusing on statistics	*Focusing on social issues*
Asking "What is the problem?"	*Asking "How does it affect people?"*
Things	*People*
Smooth and efficient functioning	*Emancipation*
INSTRUMENTALIST	HUMANIST

INVOLVEMENT

Excluding	**Including**
Limiting services to insiders	*Providing services to whole community*
Setting boundaries on who is eligible	*Setting boundaries on what is available*
Developing intensive services for a few	*Developing extensive services for all*
COMPETITION	COOPERATION

Figure 8.4.2 A model for enhancing engagement between people with disabilities and their local communities

The model development process was depicted in overview in Appendix 8.4.2 which emphasises the iterative nature of the process. Socially relevant research is never conducted in a vacuum. Consequently, the influence of other factors, such as the researcher's experience and worldview, input from supervisors, and the writings of other researchers can not be ignored as contributors to this process. Acknowledging these influences, the current project sought as far as possible, to extract categories and themes from the raw data alone, (and sought to make those processes explicit).

8.4.3 Terminology used in the Model

An underlying theme noted from the interviews and feedback, was that issues which corresponded with constructs in the model, were best described as an active, ongoing process. Consequently, when names were chosen for the five axes of the model (Figure 8.4.2) an attempt was made to convey a sense of this ongoing process. Despite the drawback of cumbersome grammar, it was decided that the gerund form, (the *ing* form of a word) would reinforce the awareness that the model describes a process. Consequently 'humanising' was used rather than humanistic, 'professionalising' rather than professional, and so on. This process orientation within the raw data is depicted in Table 8.4.3.

Table 8.4.3 Examples of Data Depicting the 'process' Theme (Emphasis Added).

Representative statements from each of the studies depicting a 'process' orientation	**Code**
The other thing is that there would have to be continuity. It would be terrible to set something up and then withdraw it when the committee changes or the RSL decides that its priorities have changed. ***It has to be ongoing****!*	R ii kb 24
Need initial enthusiasm - but you also need the capacity to follow up that initial impetus with action and development not just planning . ***You need flexibility to move and develop - flexibility to change direction****. Also need some form of continuity and assurance that the group will survive beyond the first 12 months*	C ii pc 30
I was just saying to someone before that it is a group of mixed people - some people who have disabilities congenital disability, who haven't had ... a rich life of experiences that have provided them with a tool to do that kind of linking and helping others, and ***it has been a long process and it is still going to be a long process*** *in helping them to achieve that*	I f1 sb 346
Action Aid started the CBR program in Uganda, it went to Kenya, and [now] Bangladesh, because it involved our organization. They are actually developing a whole guideline in terms of how to include CBR activities in all of their activities that they do - so that there is an example of, ***if the partnership really develops, it can have tremendous potential and impact, but it is going to be a process of learning and it is going to be a process of frustration*** *in order to make it happen.*	I f1 he 529

8.4.4 The Process of Enhancing Engagement

As noted earlier, engagement is defined as *a mutual or reciprocal, participatory involvement between people with disabilities and their local communities.* The process of enhancing engagement may be seen as movement along the poles towards the right end of each of the five continua. This is explained further in Chapter Nine. In summary, based on interviews, feedback and needs analyses, participants indicated that the process of engagement between people with disabilities (or other service users) and their local communities was characterised by the fostering of a process which,

- enhances a *bottom-up* rather than top-down organisational structure,
- utilises an *amateurising* rather than professionalising approach,
- is focused on *socialising*, rather than individualising,
- is oriented towards *humanising* rather than a positivising, and which
- is *including* rather than excluding in involvement.

8.5 Deductive Phase

Based on the model which describes the process of enhancing community engagement at the micro- and meso-system levels, the deductive phase of the present study sought to explore the potential of that model. The goal of this phase was to utilise the model to facilitate the process of enhancing community engagement at the micro- and meso-system levels. That is, it sought to explore the conceptual applicability of the model, whether it may have benefit beyond being descriptive.

8.5.1 Micro-system Level - CDA Study

The implementation of the model within the CDA study, involved the development of a community engagement workshop based on the five continua (Appendix 7.9.1). Outcomes from the workshop were measured through follow up with the regional committee chairperson on a bi-monthly basis for twelve months after the workshop (Table 8.5.1; Appendix 8.5.1). Based on the increased networking of the group, its greater flexibility, and greater involvement with the media and the local community, the potential benefit of the model was indicated. That is, in the current study, when applied through a workshop setting, the model was found to have a degree of utility.

Table 8.5.1 Outcomes from a Deductive Application of the Model at the Micro-systems level - CDA Study

Outcomes	Feedback from the local chairperson over a twelve month period indicated that since participation in the community engagement workshop, the group: • Has played an instrumental role in initiating a formal network of disability groups on the Sunshine Coast (previously the group had not done any networking). • Saw membership rise from two to a total of 19 comprising an active listed membership of 14 and average attendance of 6 at meetings. This showed some decline towards the end of the twelve month period. • Changed its management structure and meeting dates and format to be more flexible for members • Used the local media more effectively, developing press releases, holding public launches of beach access wheelchairs. • Promoted disability issues to the local community through organising a Disability Awareness Week • Held talks in local schools to promote disability awareness.
Contribution to Model	• Preliminary indication of the utility of the model, when applied in a workshop setting with a community based disability group.

8.5.2 Meso-system Level - RSL Study

The utilisation of the model at the meso-system level, comprised the development of an analytic feedback form, based on the five continua, to assist the RSL to explore potential routes for involvement in human services. Analysis of the initial data, confirmed the utility of the model to assist stakeholders to consider and plan ways of promoting a higher level of engagement with service users in the community. In order to more consistently evaluate the usefulness of the five continua in this context, two measures were chosen. The first was a simple tally of those respondents who made some comment on the model and the measure of agreement with the recommendations which were based on the model (Table 8.5.2). Analysis of the feedback responses confirmed the utility of the model to describe potential options, and to enable relevant stakeholders to consider ways of more effectively engaging in community based human services (Appendix 8.5.2; Table 8.5.2).

In order to gain a further measure of the usefulness of the model in enabling an organisation to more effectively engage community human service issues, interviews were held with the State Vice President of the RSL in February, 1997 and November, 1997. Feedback indicated that at an organisational level, the use of the model in service planning for the RSL was beneficial (Table 8.5.2). The organisation had considerably revised their initial intention to instigate a formal nursing service in preference for approaches which fostered greater engagement. That is, in the utilisation of the model in an organisational setting, practical expressions of enhanced engagement were noted.

Table 8.5.2 Outcomes from a Deductive Application of the Model at the Meso-systems Level - RSL Study

Outcomes	Feedback from respondents indicated: • That the majority (11 out of 15) found the model useful in enabling them to consider engagement in community disability issues. • That a slightly smaller majority (9 out of 15) agreed with recommendations based on the model towards greater engagement in community disability issues.
Outcomes	Feedback from the State Vice President of the RSL indicated that since the study based on the model of engagement: • The RSL had investigated and commenced the process of legal incorporation of a community foundation. (The current researcher has subsequently been asked to meet with the RSL's solicitors in order to develop a legal and constitutional basis for the foundation). • RSL War Veteran's Homes also decided to explore community based approaches further and had has subsequently employed a community liaison officer on a trial basis to promote linkages for service users in specific communities. (The current researcher was asked to advise the RSL WVH community liaison officer regarding outcomes of the research and implications for her position).
Contribution to Model	• Moderate support for the utility of the model, when applied to assist a community based group to consider disability issues.

8.6 Verificatory Phase

8.6.1 Micro-system and Meso-system Level - ICACBR Study

The incorporation of data from a previous research project conducted in Canada, provided a measure of verification to the model derived in the current study. Relevant details of the study have been provided (Appendix 8.6.1). Analysis of transcripts indicated that the constructs which comprise the current model were all present in the content of interviews and focus group discussions of the CBR experts. The nature and 'strength' of the data relevant to the model is depicted in five matrices which follow (Tables 8.6.1a-e). The present study concluded that the incorporation of data from the ICACBR study verified the existence of all five continua. Further, in confirmation of the directional nature of the model, the data indicates that CBR experts, when describing core characteristics of CBR, strongly favoured right hand side or 'community engaging' pole of each continuum (Table 8.6.1).

Table 8.6.1 Results of Verificatory Phase - Comparison with Perspectives of International CBR Experts

Outcomes	• All five continua reflected in transcripts • Statements from transcripts demonstrate strong loadings against each of the 'community engaging' axes of the five continua.
Contribution to Model	• Measure of verification to concepts within model • Measure of validation that Community Based Rehabilitation favours those points on the five continua which describe 'engagement' between people with disabilities and their local communities.

The following five matrices reflect the data derived from the ICACBR transcripts. Table 8.6.1a indicates that the dichotomy between top-down and bottom-up organisational structures, which was identified as a construct of the model of engagement, was also reflected in the discussions of CBR experts at a gathering at the International Centre for the Advancement of Community Based Rehabilitation in Canada. It also indicates that more than double the "# Text Units" were relevant to 'bottom-up', rather than 'top-down' organisational structure[5].

Table 8.6.1a Synthesised Data Matrix Indicating Verification for Top-Down versus Bottom-Up Organisational Structure

Two representative statements from the ICACBR study representing 'top-down organisational structure'	**Code**	**# Text Units**
... we have got professionals as resource people, and a lot of wonderful things, but they are also gatekeepers, decision- makers, and they may make good decisions and they may make bad decisions, they may make decisions that are very helpful and empowering, and they may make decisions that keep the power all to themselves, but you know different people have different backgrounds that they come from - but that's the reality, that people that get the money and have the knowledge tend to make those decisions, which is why we need - lobby groups have to really fight against that reality, but it's a reality - it's the way the world works.	I f4 lh 286	**377**
Our persons with disability are more passive in parts that they play - a more passive role in the past in our program. You must understand that in India disability is considered a stigma, a social stigma and people who are disabled are made to depend on family members and others. When we approached, and other people have been approaching them it seems that they are coming out of their shell and they are sort of trying to play a more active role in the program.	I f8 rk 85	

Top-Down Organisational Structure ⟷ **Bottom-Up Organisational Structure**

Two representative statements from the ICACBR study representing 'bottom-up organisational structure'	**Code**	**# Text Units**
And we are seeing that after (the programme has) grown up, women as decision makers has now been enhanced. And maybe the reason for this is that the very approaches (of) CBR which leaves emphasis on partnership and involvement through ownership of planning and invitation. I think the (CBR approach) seems to have raised the status of women within the community.	I f1 rs 88	**816**
Recently we have started an integrated school where disabled and able-bodied children are studying together - and so for most children this is their first learning or experience of going to school. But this is not our idea. We have not done this - this was a demand which came from the community - so if you were to believe that this is an indicator of community participation it has definitely increased in recent months, say four or five months, but it has passed through very difficult phases. We had to really work very hard to elevate participation.	I f3 ni 472	

[5] It may be noted that the "# Text Units" in the ICACBR study are substantially larger that in the CDA study or the RSL study. This is an artefact of, (a) the format in which the data was presented to the NUD*IST programme, and (b) that the ICACBR raw data consisted of full transcripts of extended conversations. Despite this difference, comparisons between the relative number of units within a particular study are still valid.

Table 8.6.1b below, indicates that the constructs of 'professionalising approach' as opposed to 'amateurising approach' were also reflected in transcripts from the ICACBR data, with a greater number of text units allocated to the 'amateurising' end of the continuum.

Table 8.6.1b Synthesised Data Matrix Indicating Verification for Professionalising versus Amateurising Approach

Two representative statements from the ICACBR study representing 'professionalising approach'	**Code**	**# Text Units**
we involve physicians for their technical knowledge and professionalism, we want to involve them also, and also for training of these and people, and social scientists for our researching, also researchers, especially from the universities, we want to involve them because this is a very new program, so we want to have expertise from them; and also need staff from outside for designing and technical inputs, because we don't have training facilities in Bangladesh, so that is lack of (experts) in the country so we need neighbouring countries and experts from outside.	I r4 er 8	**877**
I don't see the solution as bringing out more or starting more schools, because I think even if you create more number of professionals, what will happen, especially in India is they will tend to remain in (institutions) rather than going to the (poor / rural areas)... and so ultimately your problem remains.	I r4 ?? 241	

Professionalising Approach ⟷ **Amateurising Approach**

Two representative statements from the ICACBR study representing 'amateurising approach'	**Code**	**# Text Units**
And the second goal is involvement of community to improve the quality of life of those persons with disabilities	I r1 rs 70	**1027**
... transfer of skills and knowledge to the community and family members. It is an essential part of our program, and here again, I would like to repeat what Rajni had mentioned, but we don't train any special community workers, we have a ... technique so that they can take over the function of rehabilitation services, mainly because we don't believe in diluting the services and we don't want to provide any substandard programs, so we would rather train the family members in the techniques which are needed for that particular individual, rather than giving them a broad spectrum of what rehab techniques can be done, and then the family members continue. We also try to motivate the persons with disabilities and try to make them more aware of their needs and their rights.	I r4 rs 130	

Table 8.6.1c presents the continuum 'individualising' versus 'socialising' focus. Representative statements extracted from the ICACBR data, indicate that these issues were reflected in the discussions of CBR experts in Canada. Text units allocated by the NUD*IST data analysis programme also reflect greater amount of text (and discussion) related to the 'socialising' end of the continuum. This corresponds with the process of enhancing engagement identified in the current thesis.

Table 8.6.1c Synthesised Data Matrix Indicating Verification for Individualising versus Socialising Focus

Two representative statements from the ICACBR study representing 'individualising focus'	**Code**	**# Text Units**
... the argument people make - What we need is a school of OT and PT, - that's madness because you'll never, ever, create the ratio that you expect these professionals to work at - in Canada it is about one to 4,000, or something like that, in some of the poorer countries the ratio is one OT to 1 million people. So the argument - what on earth is that OT going to do? - They'll never, ever be able to practise as you think the OT practice model is about, so what's the point?	I f4 mp 218	**538**
Earlier, all of us were more geared to the institution and the diagnoses, we are changing our attitudes and we are learning a lot. We are becoming more aware of what are the issues of disabled. And as a result the professionals are getting involved with the government organisation.	I f5 rk 364	

Individualising Focus ⟷ **Socialising Focus**

Two representative statements from the ICACBR study representing 'socialising focus'	**Code**	**# Text Units**
... the CBR program, the goal is to change community behaviour, attitudes, knowledge and skills to enable community members to have a better understanding of disability issues to improve the quality of life with people with disability, so that the people with disabilities have equal opportunity for participation in society.	I f1 es 171	**1118**
The community, the local community, have started to assume more and more responsibility , and play a big role.. (The) village leaders and the policy makers, political leaders, the community are ensuring that they will support the project and the program in future. For advocacy groups of persons with disability, this is sort of getting some initiative in the communities they are taking some responsibilities now. They are approaching the government agencies and other agencies to address issues and to settle the problems, we expect these groups to take over in some areas.	I f7 rk 24	

Table 8.6.1d reflects similar verification of the constructs 'positivising' versus 'humanising orientation'. As with previous constructs, the 'community engagement' end of this continuum (humanising orientation) showed higher loadings on "# Text Units" column, reflecting that this end of the continuum comprised a greater part of the discussion than the corresponding end.

Table 8.6.1d Synthesised Data Matrix Indicating Verification for Positivising Orientation versus Humanising Orientation

Two representative statements from the ICACBR study representing 'positivising orientation'	**Code**	**# Text Units**
generally there is a silence, and there is a cultural kind of bitterness here because of lots of NGO's - they keep going to different villages distributing aids and appliances without really asking whether they are needed or not.	I f1 ai 267	**261**
I can tell you that the outcome of those goal sheets are quite positive in most cases we can say that yes, the person has the communication display or yes the partners and the client have been trained on the system, they have their computer for writing, all very tangible things that you can sort of tick off. What I'm saying about outcomes as regards quality of life is, we really don't know whether that person is out there more independently. ... That's something that we are not doing as good a job with as measuring the actual goals themselves	I f5 bc 152	

Positivising Orientation ⟷ **Humanising Orientation**

Two representative statements from the ICACBR study representing 'humanising orientation'	**Code**	**# Text Units**
Along with attitude change there are activities we can initiate, particularly to begin with our major goal that those attitudes which are barriers to the social, emotional, and I would say community integration of these people should be taken care of.	I f1 ai 223	**401**
When I ask one of my other individuals, say with a lower extremity or higher extremity impairment, to visit someone that is in the hospital, it gives the individual who is in the hospital a certain sense that yes I can go back to farming with some modifications. Then we go from there. It funnels down right through the community right to that farmyard. Support is very important in our program. If there is no support there is no program. That is what it boils down to, so I work with a lot of individuals .	I f3 de 189	

Finally, Table 8.6.1e indicates a degree of verification of the 'excluding attention' versus 'including attention' continuum. These themes were clearly present in the ICACBR data and the 'community engagement' pole (including attention), comprised a greater part of the participant's discussion than did the corresponding pole. This concept therefore may be seen to have been substantially more utilised by CBR experts in their discussion of CBR.

Table 8.6.1e Synthesised Data Matrix Indicating Verification for Excluding Attention versus Including Attention

Two representative statements from the ICACBR study representing 'excluding attention'	**Code**	**# Text Units**
Again, the Yeehong club is a very focused group and the people we try to serve are Chinese speaking adults who have suffered a stroke. Originally we set the age at 40 or older.	I f1 sl 90	**179**
It strikes me, especially listening to Darrell and Barbara and YY that you tend to be focused on individual industries or disabilities - especially Darrell.	I f6 pp 421	

Excluding Attention ⟷ **Including Attention**

Two representative statements from the ICACBR study representing 'including attention'	**Code**	**# Text Units**
initially we were very concerned with providing support to individuals and families in the most natural environment. I think very quickly our focus shifted to the integration of that person into the community, and how to build those bridges. I guess in the last two years I have seen a very dramatic shift in terms of who CBR actually serves. More and more now I see that CBR needs to serve the community, and certainly the disabled people within that community are part of that community, but I guess .....with the people that graduated from our program is that they are becoming much more related to the community development as opposed to the individual	I f2 nm 301	**651**
Well, I think one of the things which we are doing is that we are not making that kind of demarcation, discrimination or categorisation of people with disability, without disability. Irrespective of their special abilities, I would say differential abilities, all people from the community are welcome to join the program.	I f8 ai 457	

8.6.2 Wilkinson and Quarter's Theory of Community Based Development

A final measure of confirmation of the emerging model was sought from relevant literature sources. Wilkinson and Quarter's (1995) study of a theoretical framework for community based development, was found to overlap with the current study in its efforts to explore the process by which activities become genuinely community based. (The Wilkinson and Quarter study also considered other factors which pertained more specifically to their subject matter, these factors were considered less relevant to the current project).

Based on interviews with 17 members of community based economic cooperatives, Wilkinson and Quarter identified two aspects of the 'community based development process'. It was noted that their identification of two major themes could be directly equated with the model derived in the current study. Wilkinson and Quarter suggested that the community based development process is an empowering process, and consists of the implementation of both 'strategies of self reliance' and 'involvement strategies'.

With regard to the current results, these strategies were seen as more general descriptors of constructs derived from the present research. That is, parallels could be identified between the Wilkinson and Quarter 'strategies' and the constructs or poles of each continuum which describe the process of enhancing engagement between people with disabilities and their local communities. Namely,

1. *Strategies of Self Reliance* - fostering the abilities, resources and judgement of; and utilising the knowledge and skills of (in this case people with disabilities).

Applied to the current study, the grass roots, people oriented emphasis of this concept from the Wilkinson and Quarter study may be seen to have parallels with following constructs, 'bottom-up organisational structure', 'amateurising approach', and 'humanising orientation'.

2. *Involvement Orientation or Strategies* - mechanisms and efforts which build participation at the maximum possible level, which are to some extent dependent on the strategies of self reliance.

Applied to the current study, this aspect was seen to have parallels with, 'socialising focus' and 'including involvement' constructs.

In this regard, it was noted that the Wilkinson and Quarter (1995) study provided a degree of theoretical verification to the constructs of the model derived in the current study (Table 8.6.2). The process by which this verification occurred was depicted through a conceptual audit trail (Appendix 8.6.2).

Table 8.6.2 Results of Verificatory Phase - Comparison with Literature

Outcomes	• Parallels noted between the current study and Wilkinson & Quarter (1995) • Community based development process reflected in two categories: 1. Strategies of self reliance 2. Involvement orientation or strategies
Contribution to Model	• Measure of verification of derived model • Triangulation with theory

8.7 Conclusion

The current chapter described the outcomes of the potentiation analysis phase of the current study. This consisted of the development of a model for enhancing engagement between people with disabilities and local communities. The initial conceptualisation on which the model development process was based, proposed that engagement occurs primarily at two levels, the micro- and meso-system levels. The current chapter described the results of research which explored engagement at these two levels, through two studies. The inductive exploration resulted in a model for enhancing engagement. Through a deductive research process in each of the two studies, the model was found to demonstrate a degree of utility. Subsequent verificatory research processes also indicated the potential consistency of the model with CBR issues as well as with a theoretical framework of the community based development process.

Section D

CONCLUSION

A Model Derived From an Analysis of the Potential of Engagement

"I am done with great things and big things, great institutions and big successes,
and I am for those tiny invisible molecular moral forces
that work from individual to individual,
creeping through the crannies of the world like so many rootlets,
or like the capillary oozing of water, yet which if you give them time,
will rend the hardest monuments of man's pride."

William James

Chapter Nine

Discussion and Conclusions on an Exploration and Analysis of the Potential of CBR as Engagement

9.1 Introduction

The purpose of this final chapter is to describe and draw conclusions on relevant outcomes which have arisen from the current research. The primary outcome was,

- The 'model for enhancing engagement' between people with disabilities and their local communities.

In addition, a number of secondary outcomes arose from the research, namely,

- The application of a descriptive and conceptual framework, The Bio-Psycho-Social Ecology Model.
- A comprehensive analysis of the CBR literature which documented the evolution of CBR and identified key principles encapsulated in the notion of engagement.
- The design and utilisation of a comprehensive, multi-phase, qualitative research process which meets requirements for rigour and effective data presentation.

Since the secondary outcomes have been discussed in the body of the thesis, they are briefly noted in the current chapter. The major foci for the current chapter are the 'model for enhancing engagement', the research process and methodology. In contrast with a traditional 'discussion'section, the current chapter explores theoretical aspects of the outcomes of the research. It commences with an overview of the way in which the initial research question was answered. Characteristics and implications of the 'model for enhancing engagement' are described. The model is compared and contrasted with current issues in the disability field and relevant developments in the field of CBR. The research methodology is briefly discussed and the process through which the model was developed is described. Finally, a number of dimensions are suggested. Such dimensions have relevance to possible implementation of the model in economically developed and developing countries. The model for enhancing engagement is proposed as a starting point for further research in community based approaches to disability service delivery.

9.2 The Research Question

In concluding this thesis, it is appropriate to return to the initial question which guided the research as a whole. As stated in Chapter One, the research question was,

> **What constructive alternative to traditional disability services can be identified; and how might such an alternative be conceptualised to assist people with disabilities in South East Queensland?**

As a foundation for developing a response to the question, an exploration of the limitations of traditional approaches to rehabilitation and disability service delivery was conducted. Identified concerns indicated possible attributes of a potential alternative. An examination of relevant trends across a number of areas also provided further indicators towards the identification of a potential alternative.

In response, CBR was proposed as a constructive alternative to traditional disability services. The parameters of CBR were explored in detail, using an adapted conceptual and descriptive framework. This analysis of CBR resulted in the identification of key principles which were encapsulated in the concept of 'engagement'. The thesis proposed that the notion of engagement was an essential means by which CBR could be applied to a number of contexts.

An analysis of the potential of CBR to assist people with disabilities in South East Queensland, resulted in the development of a 'model for enhancing engagement'. While the model emerged from studies in the current context, it was seen as an important means by which a CBR approach might be conceptualised and more widely utilised, to assist people with disabilities in economically developed and developing countries.

9.3 Characteristics of the Model for Enhancing Engagement

The primary outcome of the current research was the 'model for enhancing engagement' consisting of five bipolar continua (Figure 8.4.2). Data matrices in Chapter Eight systematically demonstrate how the constructs of the model emerged from the raw data. Similarly, audit trails which are appended to Chapter Eight, illustrate the process by which the constructs and poles emerged. Consequently, the current chapter does not reiterate the links between the data and the model, but proceeds to discuss the model, examine the methodology employed, and consider the potential implementation of the model.

As may be expected, the nature of the model reflects the initial interview questions from which it arose. In keeping with an exploration of the potential of a concept, the questions, selected for the inductive phase of the research, were speculative rather than definitional. They required participants to consider and give opinions on promoting engagement. Consequently the model, which arose from participants responses to those questions, might be seen as a model *for* reality rather than a model *of* reality (a distinction made by Woelk, 1992). The model depicts an ongoing process oriented towards future possibilities, rather than current descriptive categories. The derived model may be considered as a model *for* promoting or enhancing engagement between people with disabilities and their local communities.

The characteristics of the model are consistent with Steward's (1995) suggestion that models in the rehabilitation and disability field should be 'speculative illustrations' of a changing world, rather than 'prescribed route maps' for practice. Strauss & Corbin (1994) argued that the speculative nature of models such as this, does not deny their potential soundness or utility, rather, it provides a constructive starting point for further applied research.

9.3.1 The Directional Nature of the Model

Consisting of five bipolar continua, the model may be described as 'directional' in nature. As noted in Chapter Eight, the right hand side poles of the continua, indicate the process of enhancing community engagement. This conclusion was drawn based on both the *content* of the data, and the relative *amounts* of data from interviews and feedback.

As reflected in the conceptual audit trails, the *content* of the analysed data, indicated that research participants viewed the constructs in a bipolar fashion. The content of interview and feedback data, also indicated that participants saw the right hand side pole of each of these continua as representative of the process for enhancing community engagement.

It was also clear that the *amount* of data (the amount of text which comprised the categories for each pole), reflected an emphasis on those poles which described the process of enhancing community engagement. Comparisons between the "# of Text Units" column in the data matrices for each of the studies, provided a basic measure of this emphasis (see Chapter Eight). In the CDA and ICACBR studies in particular, the frequency of text units was heavily polarised on the right side or the 'community engagement' end of each continuum. As measured by frequency ratings, respondents consistently emphasised the importance of the community engagement pole of each continuum over its counterpart.

In the case of the RSL study, while the data strongly supported the ten constructs which comprise the five axes, a preference for the 'community engagement' pole was not displayed. This was considered an artefact of differences of opinion between various RSL stakeholders. Some RSL interviewees, particularly in early stages of the research, rejected community based approaches, and emphasised the opposite end of each continuum. It should be noted that a goal of the RSL study was to assist the organisation and relevant stakeholders to explore their involvement in local human services and develop a common platform for further discussion. Twelve month follow-up indicated that substantial community oriented initiatives had taken place. That is, in relation to the original intentions of the organisation (to set up a formal nursing service, 7.7.2.2) compared with outcomes noted at 8.5.2, relevant RSL members may be seen to have recognised the importance of community engagement by moving towards those ends of the five continua. The directional nature of the model, appears to have assisted the organisation to enhance their level of engagement with local service users.

9.3.2 The Continua Which Comprise the Model

The model for enhancing engagement may be interpreted as response to a number of concerns raised in Chapter Two. With further research, including application and evaluation, the model may be used to facilitate constructive processes and strategies to counteract the social dislocation of people with disabilities, which was noted as a theme in Chapter Two. The application of the model would appear to mitigate against the neglect of community issues and growing balkanisation which were seen to characterise disability services in economically developed countries. The strong grass roots emphasis within the model indicates a focus on achieving change at the local level, rather than solely through hierarchical or legislative processes.

The model is also consistent with many of the trends noted in Chapter Three. The constructs within the model are indicative of a values framework, and may be used as a starting point for the identification of a set of values for community based, disability or human services. The model is consistent with the trend towards utilising ecological imperatives, and many of the continua suggest a strong emphasis on ecological holism. The combination of 'social' and 'human' factors in the model may also have substantial benefit in the emerging move to contextualise empowerment within a community framework. This is seen as an important topic for further research.

With regard to CBR, the development of the model for enhancing engagement may also facilitate broader application of the CBR approach. The model is seen as an explication of the key principles of CBR It is consistent with CBR strategies, particularly the emphasis on maximising micro- and meso-system level interactions. It also equates with a number of principles of sustainability. The model may facilitate the evolution of CBR by providing a degree of conceptual consolidation and contributing to debate on this topic. As a basis for further research, the 'model for enhancing engagement' may contribute to the development of 'community' around people with disabilities. By identifying a number of important directions for enhancing engagement, the model contributes to the practical realisation of the goal of CBR, namely, to shift the focus of interventions from the individual to the community.

9.3.2.1 Top Down / Bottom Up Organisational Structure

The first of the continua which comprise the model, describes change or movement away from centralised power and decision making, towards more egalitarian, 'grass roots' structures. This continuum is reflective of a number of points made in the early chapters of the thesis. A transition towards bottom-up organisational structures and strategies would appear to be highly constructive within disability services and may mitigate many of the concerns identified in Chapter Two. It would substantially counteract the identified lack of participation and involvement in services by people with disabilities. The continuum is also consistent with trends noted in Chapter Three, in which a number of disciplines have sought to increase the participation and involvement of community members. In relation to Chapter Four, the direction suggested by the continuum characterises evolving forms of CBR practice. It indicates an organisational structure which many CBR programmes are seeking to attain.

9.3.2.2 Professionalising / Amateurising Approach

The implication within the second continuum is a move away from specialised, professional services, towards the use of more general approaches which rely on 'lay' community members who choose their involvement. Such a move appears highly consistent with CBR practice at the micro- and meso-systems levels, particularly with its emphasis on the skilling of community members. It is also consistent with issues raised in Chapter Three, in which the emphasis on lay and local issues is recognised as a relevant aspect of postmodern approaches which currently influence Western society.

9.3.2.3 Individualising / Socialising Focus

The third continuum which comprises the model, represents a change process away from an individualistic focus, towards a more social / collective focus. With regard to concerns noted in Chapter Two, such a transition may be seen as a constructive response to the tendency in economically developed countries, for services to 'individualise' disability. Individualisation of issues and people with disabilities removes them from their social context and contributes to social dislocation. The converse, a more socialising focus, is consistent with the trend repeatedly noted in Chapter Three, towards community perspectives and emphases. A socialising focus also equates with the evolving nature of CBR towards a greater emphasis on, and attention to, social issues.

9.3.2.4 Positivising / Humanising Orientation

This continuum represents a transition away from a 'hard', instrumentalist and positivist orientation, towards a more 'soft', person focussed orientation. Such a transition would have parallels with a move away from the high levels of medicalisation and reductionism inherent in some disability approaches, particularly at the bio- and psycho-system levels. A transition towards a human orientation, seeking to avoid reductionism, is consistent with more holistic and ecological frameworks described in Chapter Three.

9.3.2.5 Excluding / Including Involvement

The fifth continuum describes a transition from intensively oriented approaches limited to certain individuals, towards more extensive services for the whole community. Such a direction is highly consistent with many of the basic tenets of CBR. A movement away from 'excluding involvement' towards 'including involvement' may also mitigate against many of the issues of concern noted in that chapter such as growing consumerism, competitiveness and balkanisation. It was noted in Chapter Two that these issues of concern may threaten the effectiveness of future disability services.

9.3.3 Deductive Utilisation of the Model

While the 'model for enhancing engagement' arose from inductive processes, it was utilised in deductive settings within the two studies. These deductive phases were incorporated in response to the wishes of participants, and also to explore the potential utility of the model. They were not intended to demonstrate causal relationships.

In the CDA study, the model was used as the basis for a workshop for a regional CDA group. As a result of the workshop, the Sunshine Coast CDA group appeared to develop a broader perspective of their role in the community. They initiated greater community networking and became more inclusive, cooperating with other disability organisations and service providers. Based on reports by the chairperson, the group became more responsive to members, demonstrating greater flexibility in meetings. The activities of the group may also be seen to have broadened, in their attempts to promote disability awareness through the local media, local activities, and presentations in local primary schools.

In the RSL study, the model was used to assist the organisation to explore options for greater community involvement. As a result of the analytic feedback form which proposed suggestions based on the model, the South East District of the RSL appeared to move considerably from their initial idea of developing a formal nursing service for their members. Based on reports by the Vice-President, increasing numbers of RSL stakeholders recognised that a medicalised nursing service would be an unnecessary duplication of service which already exist. He noted that the RSL was prompted to consider the potential advantages of setting up a community foundation to foster and financially support local, community based initiatives which will benefit the frail aged and disabled in their communities. He noted that while many stakeholders in the RSL (and the RSL subsidiary - War Veterans Homes), preferred 'bricks and mortar' outcomes, they increasingly saw the benefit of promoting linkages in the community, hence the appointment of a community liaison officer.

In each of the above examples, the constructs of the model, and particularly the continua within the model, appear to have assisted organisations to move in a small way, towards greater community engagement. While the current study did not attempt to demonstrate causation, the deductive phase of the research does suggest that the model for enhancing engagement may have potential application. Further confirmation of this suggestion, and the demonstration of causal relationships is considered an important topic for future research. Since these studies demonstrate a process of movement along the continua, subsequent research may also seek to explore possible points along each of these continua.

9.3.4 Verification of the Model

The final phase of the research included seeking verification of the concepts in the model. From the ICACBR study, which was the major source of verification, the concepts and directions of the continua were clearly present in the data. This provided an indication of the relevance of these concepts to the field of CBR (from which the original notion of engagement emerged). Again, while this source does not demonstrate that the model is exhaustive or definitional of CBR, it reflects that the concepts within the model may be highly relevant to the CBR context.

The second source of verification, the link with Wilkinson and Quarter's theory of community based development, also provides a degree of support for the model. It is an indication that the concepts in the 'model for enhancing engagement', are comparable to other sources of theory which relate to community issues.

9.3.5 Potential Applications of the Model

The 'model for enhancing engagement' is proposed as a potential mechanism for combining the community paradigm with the current paradigm of rehabilitation and disability service delivery. Applied in practical settings, the model may be an effective mechanism for linking people with disabilities within the community.

As a description of the process through which engagement might be fostered, the model may be seen to have both practical and conceptual implications. General arenas for implementation of the model are speculated upon and discussed later in this chapter. While prescriptive statements outlining how the model should be used, would be contrary to the spirit of the model and this thesis, for purposes of clarity and utility some practical applications may be suggested. For example, the model might be used:

- *To guide goal setting in individual rehabilitation and disability programmes*. Using the model as a guide, a team developing an individual rehabilitation programme may seek to,
    - maximise 'bottom-up' decision making, giving power to the individual and their family,
    - foster the role of 'amateurs' in the client's life and rehabilitation,
    - consider outcomes which relate to community participation in addition to physical and other functioning,
    - build the rehabilitation skills of family and community members who choose to be involved,

- consider the individual within his or her social context, evaluating the social implications and benefits of various programmes or courses of action,
- promote collective action, which involves the person with a disability.

- *To inform service planning*. Using the model, service planners may be challenged regarding their priorities on such things as the use and prevalence of technology in the service, the nature and extent of organisational and personnel structures, training emphases, and the importance placed on physical features such as buildings and offices. On the basis of the model for enhancing engagement, they may seek to develop services which,
    - facilitate the involvement of disability groups in community life,
    - focus on and promote, broad social and community change rather than only addressing individual issues,
    - increasingly promote decision making by service users,
    - foster, support and skill volunteers, rather than only professionals,
    - attempt to be systemic in their interventions,
    - are oriented towards human needs, rather than organisational agendas,
    - involve whole communities, rather than limiting the involvement of others in the service.

- *To assist in the evaluation of disability services*. For example, using the model evaluators may review services on the basis of the extent to which they,
    - establish a 'bottom-up' organisational structure,
    - emphasise social and community outcomes in addition to more narrow individual outcomes,
    - demonstrate human resource emphases which promote the skilling and support of amateurs,
    - promote active mutual participation with the community and utilise the community as a *means* of service delivery as well as the *location* of service delivery
    - prioritise processes which respond to social and community issues rather than solely individual issues,
    - exhibit outcomes which are oriented towards human concerns rather than positivist quantification and instrumentalist concerns,
    - emphasise whole community involvement and cooperation rather than quotas and boundaries.

On a more conceptual level, the abstract nature of the model also permits broader generalisability. For example the model might be used as follows.

- *To influence policy development.* In this context, government departments and individuals who have an influence over policy and legislation may seek to reconsider,
    - policy approaches which lead to hierarchical management structures,
    - possible over-emphases on professionalised specialisation and registration,
    - inappropriate individualised services,
    - instrumentalist outcomes and
    - competitive and restrictive services which limit the involvement of community members.

Rather, policy developers may seek to promote legislative agendas which,

- foster grass roots involvement in all aspects of service delivery,
- build community skills,
- build the common identity and solidarity of people with disabilities.
- support natural dimensions of care and support in families and communities,
- accommodate social and collective community action,
- foster community level attitude change resulting from participation, and
- recognise the importance of processes, rather than structures.

- *To assist in the analysis and development of disability theories and philosophies.* For example using the model, theorists may explore the extent to which a particular theory or philosophy recognises that handicap and disability may be adversely affected by,
    - hierarchical organisational structures,
    - dependence on professionals,
    - reductionist individualistic frameworks,
    - positivistic orientations and
    - exclusive, competitive perspectives

They may also consider ways in which the theory,

- supports collective, social, human, and grass roots philosophies as a means of responding to the above factors, and
- emphasises ultimate goals of participation, interdependence, collective social action, human emancipation, and inclusive cooperation.

9.3.6 The Model for Enhancing Engagement in the Context of CBR

Having essentially arisen out of an exploration and analysis of CBR, the derived model also demonstrates application to issues within CBR. As noted earlier, the model comprises a number of principles which may be applied differently in different settings. While prescriptive statements about the application of the model would be inappropriate, some practical aspects of these principles may be suggested.

The conceptualisation of *CBR as a process*, which was suggested in Chapters Four and Five, has been strongly endorsed by the current research. The model for enhancing engagement, depicts an ongoing process. This suggests that CBR should not be viewed as a set of concrete procedures, defined by manuals, but as a *process of engagement*. CBR, as conceptualised in the concept of engagement, may be seen as an ongoing process of orientation towards community level issues. It may be understood as a continual reorientation of rehabilitation and disability approaches towards community priorities.

The issue of the growth and expansion of CBR has been touched upon earlier. Based on the current model, it would appear that growth and *transfer of CBR* from one context to the next, may be most appropriately achieved through building grass roots movements. Some commentators have argued that CBR should be propagated through, developing frameworks for the management of CBR service structures, implementing structural changes, developing formal systems, and facilitating policy and legislative initiatives (Peat & Boyce, 1993). While such initiatives are considered important, the current model emphasises more 'bottom-up' approaches to the growth and extension of CBR. The utilisation and application of the current model, should be consistent with its basic nature. Consequently, grass roots approaches relying on people with disabilities as the main actors should predominate. As noted above, while structural and policy approaches and formal systems are important, the model for enhancing engagement suggests that CBR should be characterised by a community engagement process.

The current model bears relevance to questions of the future focus and orientation of CBR. While a predominant trend towards engagement has been discerned in the current thesis, contrasting directions were also noted. For example, M. Miles (1985; 1989; 1993; 1996) has proposed that CBR should be reconceptualised and redesigned as an information distribution approach, comprising the dissemination of culturally and linguistically appropriate rehabilitation information. The current model however, strongly emphasises relational processes over more technical, information distribution processes. The model also highlights socially oriented responses, in preference to individualised responses. As such, the derived

model would appear to indicate that M. Miles' proposal is inconsistent with the enhancement of community level engagement.

In a similar vein, there have been a number of calls for CBR to be more oriented towards clinical rehabilitation and formalised disability service delivery (Kalyanpur, 1996; Kay et al., 1994; M. Thomas & Pruthvish, 1993). Utilising the derived model, such suggestions may be seen as reflecting the opposite position to the community engagement poles ('individualising', 'positivising' and 'professionalising'). The suggestion for greater specialisation would appear to be incompatible with the emphasis within the current model on 'socialising, 'humanising' and 'amateurising'.

Finally, the current model contributes to the question of the *nature of community participation in CBR*. While traditional applications of CBR comprise a strong orientation towards community participation, this has mostly been conceptualised on a contributive level (the community contributing labour, resources, etc). Woelk (1992) saw the contributive level as only the most basic level of community participation. He suggested that more advanced conceptualisations of community participation extend beyond contribution, to the development of associational or organisational process which promote ongoing participation. The model derived in the current thesis is consistent with such associational processes. The 'socialising', 'including' and 'bottom-up' emphases of the model, if expressed in service delivery would result in the development of structures which would promote participation. Consequently it may be seen as a means by which more ongoing and balanced participation may take place.

It is suggested that the current model may be a starting point for the development of associational structures relevant to people with disabilities. Future research may explore the use of the model to enable organisations, and individuals, to achieve increased levels of reciprocal participation. It would appear that the application of the current model to traditional CBR contexts in developing countries is an important avenue for future research. It is suggested that the model may have application to CBR in developing countries,

- on a practical village level, particularly in the development and delivery of grass roots approaches,
- in the planning of interventions and approaches to service delivery, and
- in the conceptualisation of new directions for CBR.

The major challenge within the field of CBR is the promotion of research to explore such applications.

9.3.7 The Model for Enhancing Engagement in the Context of Current Issues in the Disability Field

With regard to current issues in the disability literature, the model for enhancing engagement may be seen as consistent with a number of recent recommendations. First, it equates closely with calls to maximise *social capital* (Cox, 1995). Communities with a high level of social capital are characterised by overlapping and diverse horizontal networks for communication and exchange of ideas and practical help (Gillies, 1997). This would appear highly consistent with emphases in the current model. The foci within the model on more 'social', 'human' and 'inclusive' approaches to disability, may facilitate greater social capital and counteract processes of isolation and marginalisation (see Chenoweth, 1997b). It is suggested that the model indicates a conceptual basis for building exchanges between people with disabilities and other community members. Further exploration of these concepts is considered important, particularly since some have argued that the maximisation of exchanges is a key to social change in disability issues (Engwicht, 1993).

As a representation of a conceptual position, the derived model represents a perspective which supports *'associational groups'* (community based, semi-formal mediating structures between individuals and formal services or bureaucracies). Schwartz (1997) saw the stimulation of associational groups as an important element of future approaches to disability and human services. The emphasis within the model on the maximisation of relationships, particularly at the micro- and meso-systems levels, is consistent with Schwartz' call. This emphasis would appear to facilitate groups and relevant structures, which assist in bridging the gap between the individual and bureaucracies or formal services.

In promoting mutual engagement between people with disabilities and community members, the model equates with perspectives which hold that fostering community participation is essentially a *'dialogical endeavour'* (Kelly & Van Vlaenderen, 1996). Engagement, and the process of enhancing engagement, would appear to be closely related to the facilitation of dialogue as a mechanism of building community participation. The 'socialising', 'including' and 'bottom-up' characteristics of the derived model appear to emphasise dialogue as a means of fostering community participation.

The emphasis within the model on supporting lay, grass roots and inclusive perspectives, may be seen as building what Schwartz (1997) has described as *'vernacular cultural practice'*. Schwartz argued that the fostering of locally appropriate, informal, community focussed

services, is the most effective way of responding to the needs of people, particularly people with disabilities.

On a more political level, the model is consistent with the suggestion that human services should promote an environment of *local social participation* "in which a myriad of grass roots organisations can make their voices heard and engage with local democracy" (Lister, 1997, p. 25). The socially oriented, participatory nature of the model appears highly consistent with grass roots political action. The action of small scale, localised disability groups such as the CDA group in the deductive phase of the current research, reflects Lister's notion of local democracy. It would also appear to provide a constructive balance to prevailing bureaucratisation and globalisation noted in Chapter Two.

In a similar way, the model for enhancing engagement may be seen as consistent with Barton's (1994) emphasis on the promotion of *collective solidarity*, as a mechanism of disability action. The model strongly reflects collective and community oriented conceptualisations of action and empowerment. It may be seen to be highly consistent with community oriented perspectives of empowerment (Rappaport, 1987; Riger, 1993), and by indicating specific directions, may contribute to the more practical conceptualisation and realisation of such perspectives. The building of more self reliant and competent communities, families and individuals through greater engagement, would appear to be a significant contributor to community contextualised notions of empowerment. Based on the current model, indications for future research on empowerment may focus on the exploration of processes of 'community self reliance' and 'community resilience', rather than individualised notions of empowerment.

The model for enhancing engagement also equates with *community ecological perspectives* (Ife, 1995) highlighted in Chapter Three. With an emphasis on 'including', 'bottom-up' and 'socialising' perspectives, the model may be viewed as a mechanism through which service delivery may become more ecological. The current thesis contends that attempts which move disability services beyond a focus on the individual alone, towards the development of the community's ability to include all its members (see Enders, 1993), will be highly beneficial. The development of disability services which build the competence of a community as part of their ecological approach, would appear to be an important goal (Hawe, 1994), to which the current model contributes.

The model might be seen as a reflection of a trend identified by Stricklin (1997), who noted that "Community-based care is emerging as the cornerstone of health care, not its alternative" (p. 159). It has been contended that in the emergence of a managed care environment, there is

a great need for a 'buffer' of community supports (Stricklin, 1997). If the needs of people with disabilities are to be met within this environment, a more self-reliant, networked and informed community is crucial. The current model, by providing cues for strategies which will enhance community engagement, may facilitate frameworks for *community based care*. Kiernan and Hagner (1995) recognised the need for greater research in this area. They argued that the major challenge facing people in the rehabilitation and disability field, was the amalgamation of the community care paradigm with existing models of disability service delivery. The derived model, which has arisen from the nexus of these two paradigms, indicates potential directions for change and may constructively contribute to this research discourse.

Finally, it should be recognised that the implementation of a model such as this, is not without concerns. As noted in Chapters Four and Six, localised approaches may lead to greater localised injustice. Community oriented approaches tend to foster greater variability between communities which leads to inconsistency, and adversely impacts on under resourced communities. This is seen as a topic which should attract considerable attention for social research. An important priority for such research should be the development of mechanisms which will foster greater accountability between communities and the exploration of the role of uniform rights legislation within such a context.

9.4 Methodological Issues

9.4.1 Integrity of the Research and Outcomes

As noted in appendices 7.4.1 and 7.4.2, specific measures taken throughout the process of model development, in both inductive and deductive phases, ensured a substantial degree of integrity within the research process. Within the limitations of the 'real world', qualitative nature of the studies, the process and resultant outcomes may be considered as methodologically robust. This was enhanced by the use of phases of research (inductive, deductive and verificatory) through consistent cycles of identification, exploration and synthesis (Figure 7.4.2a).

The incorporation of a deductive phase is unusual in qualitative research and provided an opportunity for 'grounding' in a real world setting. The subsequent use of a verificatory phase, using unrelated data sources, further contributed to the level of confidence with which outcomes may be viewed, and subsequent extrapolations made.

Despite these points, some methodological questions might be raised. First, concerning the inductive phase of the research, it may be questioned whether the constructs which comprise the model are simply a function of the nature of the groups chosen. That is, "Were these constructs elicited purely due to certain characteristics of the CDA and RSL organisations?"

In response, it is acknowledged that the nature of these groups had an influence over the research outcomes. While such inevitable influence may be seen as adversely affecting outcomes, in the current study the particular influences of these groups were actively sought. That is, a research involvement was initiated with each of these groups because of their specific characteristics and suitability as sites for an exploration of the potential of engagement at the micro- and meso-system levels. The specific attributes of these groups (their focus, influence and method of operation) were seen as an ideal context for the current research endeavour.

Second, it might be suggested that the outcomes which were noted from the implementation of the model with the CDA and RSL groups (deductive phase), may not be directly attributable to the model, but the result of extraneous factors or simply the passage of time. For example, each group may have been encouraged by the involvement of the researcher (and the community development consultant in the CDA study), which may have significantly influenced the outcomes. Alternately, these outcomes might have occurred irrespective of any research involvement. This issue is acknowledged as one which challenges all qualitative, participatory research approaches. While they demonstrate a number of strengths, they do not establish causation. The presence and role of the researcher and the lack of control over variables can not be ignored in such research. However strategies such as participant checking and long term (14 month) follow up, tend to mitigate against such bias. More importantly, as noted earlier, the goal of the current study was not to determine or measure causal relationships, it was primarily to explore the potential utilisation of engagement in the current context. The deductive phase, of the research sought to support this potentiation by providing a practical indication of the utility of the model. The identification of causal relationships and the quantification of outcomes is considered a beneficial focus for future research.

Third, the question of participants responding in a compliant manner to match researcher's expectations, should also be raised. That is, "Did respondents try to tell the researcher what they thought he wanted to hear?". In reply it should be noted that the current research, particularly in formative stages, was exploratory. In the early stages while the literature analysis was commencing, the researcher had no vested interest in a particular preconceived outcome. Further, the studies which comprised the context for the research differed considerably, thus decreasing the likelihood of such conformity of response. In the case of the

RSL study it may be noted that a number of participants initially rejected community based approaches. Despite this, the constructs within the model were strongly endorsed by the RSL participants, and the depiction of the model as continua and a change process, was corroborated. Finally, the use of data from an independent external source (ICACBR), also contributed to the confidence with which the results may be viewed.

The question of the accuracy of the researcher's interpretations of data is also pertinent. The identification of themes from qualitative data, is a systematic process of straight forward differentiation and allocation, as well as more subjective extrapolation and interpretation. However, raw data such as those utilised by the current research, rarely fit neatly into boxes. On occasion, statements were found to be ambiguous, or complex, or multi-conceptual, or contradictory (and sometimes all of the aforementioned!). In order to ensure a degree of accuracy, a commitment was placed on triangulation at a number of levels (Appendices 7.4.1 and 7.4.2). Greater objectivity was sought through the incorporation of verification as a part of the research. Also, in order to confirm to the reader that data were not simply unsubstantiated interpretations, but consistent patterns, data matrices included a measure of the frequency of text units attributed to a particular construct.

The comprehensiveness of the model may also be questioned. For example, "Does the model include all of the poles and constructs which constitute the process of enhancing engagement?" The issue of whether the model is exhaustive and definitional is important for the potential application of the model. While a degree of confidence about the model might be established, based on the goals of the research and the methodology used, the existence of further constructs or poles can not be ruled out. While measures were taken to ensure that the process of model development was as sound as possible, and the subsequent model showed a degree of practical utility, in the final analysis, the model is exploratory and preliminary. Further research is required to substantiate, confirm, contribute to, or challenge the concepts in the model.

Finally, it may be questioned whether the CDA and RSL studies constitute appropriate sites for an exploration of the potential of a principle drawn from CBR. While it is recognised that these studies were not by any means, traditional CBR projects, it is contended that they are consistent with the identified evolution in CBR, and appropriate for the application of CBR to economically developed countries. The evolution in CBR towards less formal responses, in combination with the nature of existing services in economically developed countries, indicate the suitability of more informal approaches (Chapter Six). Consequently, the CDA and RSL studies are seen as appropriate sites for the application of CBR to the current context.

A further indication that the constructs which emerged through the CDA and RSL studies are consistent with CBR, was achieved through the incorporation of the ICACBR data. Despite the fact that none of the questions which comprised the focus groups and interviews in the ICACBR study explicitly addressed the central themes of the model, strong evidence was found for all of the constructs which comprised the current model. It is therefore suggested that the enhancement of engagement, which was derived from a key principle of CBR and which the current research project has characterised as consisting of five continua, is indeed an important concept relevant to the field of CBR.

9.4.2 Data Presentation

Within the current thesis, results were presented by means of data matrices and conceptual audit trails. As described in Appendix 8.2, these strategies were adopted to address many of the concerns raised regarding data presentation in qualitative research. It is suggested that these techniques were successful in enabling the researcher to elucidate and account for the data. The current thesis proposes that the further development and utilisation of such strategies in qualitative research, in the rehabilitation and disability field, would be of significant benefit.

9.4.3 The Process of Model Building

Theorist, Paul Davidson Reynolds (1971) maintained that models and theories should, among other things, be abstract (independent of time and space) and intersubjective (establish agreement about meaning of the concepts among the audience). These principles were sought throughout the current model development process, through the use of, multiple and varied data sources, participant checking, the use of multiple methodologies, and reference to wider bodies of literature.

In the current thesis, the model building process was based on disability and more general literature as rationale, and CBR literature as source. A number of theoretical concepts were generated from the literature analysis, which evolved into a formal conceptualisation. In order to explore the potential of this conceptualisation, an iterative research project was devised which resulted in the generation of a number of relational statements comprising a model. The deductive phase of the research indicated that the model had practical utility. Verification against theory and CBR related data, provided a measure of confirmation of constructs within the model.

The model development process utilised in the current thesis, equates with similar attempts to develop models in the human services. For example, in a major Australian model development

project in a related discipline, a similar multiple methods approach was used[1] (Chapparo & Ranka, 1997a; 1997b). In this example, as in the present study, a model was developed on the basis of extensive literature review, conceptualisation and field testing.

9.4.4 The Descriptive Framework

The extension and adaptation of Bronfenbrenner's (1979) Social Ecology Model, the "Bio-Psycho-Social Ecology Model", proved to be highly beneficial to the current research enterprise.

Within the thesis, the Bio-Psycho-Social Ecology Model,

- Provided a mechanism by which issues of concern in rehabilitation service delivery could be identified.
- Facilitated the exploration of emergent trends across disciplines.
- Enabled the researcher to systematically explore, conceptualise and evaluate CBR.
- Facilitated an identification and recognition of the micro- and meso-system levels, in relation to other levels.
- Provided a means by which the application of CBR to economically developed countries might be considered.
- Resulted in specific foci for the potentiation analysis stage of the research.

In general, the Bio-Psycho-Social Ecology Model constituted a comprehensive framework, through which constructs and issues could be conceptualised, contextualised and compared.

Based on this application, it may be seen to have considerable relevance to research and practice in the rehabilitation and disability service delivery field. The use of this model in planning, delivery and evaluation of services, may promote more holistic, socially balanced approaches. A particular strength of the model to rehabilitation and disability service delivery is the recognition it provides to community level issues. This would appear to furnish a constructive balance to many service approaches currently in use in South East Queensland.

[1] Though the Chapparo and Ranka studies drew from a less broad data base, using only therapists as participants and information sources.

Based on the apparent utility of the Bio-Psycho-Social Ecology Model as reflected in the current study, it is suggested that it may also be a beneficial tool in the ongoing development of CBR. The need for such a consistent descriptive and theoretical framework has been envisaged by CBR theorists (Boyce, 1997; Helander, 1993), but not yet realised in practice. Boyce (1997) stated,

> In CBR research, information should be gathered which allows us to link various dimensions of the issue and to integrate information at personal and policy levels. These levels or sources of information include the individual, family, community and state/society. (p. 28)

The present thesis suggests that the Bio-Psycho-Social Ecology Model constitutes such a mechanism for linking and integrating a variety of issues across personal, familial, community, state, and societal levels. The utility and application of the Bio-Psycho-Social Ecology Model to other areas of research and practice is considered a primary focus for future studies.

Despite being specifically adapted for the current thesis, it should be noted that the concepts within the Bio-Psycho-Social Ecology Model are not unique. For example, a bio-psycho-social framework has been a central tenet of theory and practice within the discipline of occupational therapy for many years (Hopkins & Smith, 1993). It is anticipated that this model may have considerable value as a descriptive and explanatory framework beyond the current context.

9.5 The Notion of Engagement and the Model for Enhancing Engagement

The initial notion of engagement, arose from an analysis of the parameters of CBR described in Chapters Four and Five. It was depicted in diagrammatic form in Figure 5.4. In addition to its current usage, it is suggested that the concept of engagement as key principle of CBR, may have further application for two major reasons. First, given that CBR is a complex and indistinct entity (Glynn, 1996b), it is suggested that an identification of key principles of CBR and the model of engagement will be clarifying for the progress of research and practice. Second, an elucidation of key principles such as in the current thesis, may facilitate the application of CBR to different contexts. It is suggested that attempts to transfer CBR from the setting in which it has evolved (developing countries), may be most constructively done on a basis of extrapolation from underlying principles, rather than the direct transfer of existing structures, strategies or techniques.

In the current thesis, the notion of engagement served as the foundation for the potentiation analysis, which led to the 'model for enhancing engagement' (Figure 8.4.2). Since the applied studies which led to the model were intended as an exploration of engagement, it is suggested that these two concepts are compatible or at least reflect similar issues. A suggestion for the combination of the two figures is presented below (Figure 9.5). This figure illustrates the synthesis of two concepts, based on the research. It reflects three important issues. First, it depicts the nature of the process of enhancing engagement more clearly than the five bipolar continua. It 'contextualises' the five continua within the nexus between people with disabilities and the community.

Second, the figure below indicates that the process of enhancing engagement between people with disabilities and local communities is a reciprocal process. The community is both the target and resource for disability action. Engagement is enhanced when the connections between people with disabilities and local communities are characterised by, a bottom-up organisational structure, an amateurising approach, a socialising focus, a humanising orientation, and an including involvement. This process occurs in both directions

Finally, Figure 9.5 emphasises that the process of enhancing engagement occurs predominantly at two system levels, the micro- and meso-system levels. As reflected in the literature analysis, these are the primary levels at which engagement should be fostered. The synthesis of concepts illustrated by figure 9.5 is considered a potential starting point for further exploratory and applied research.

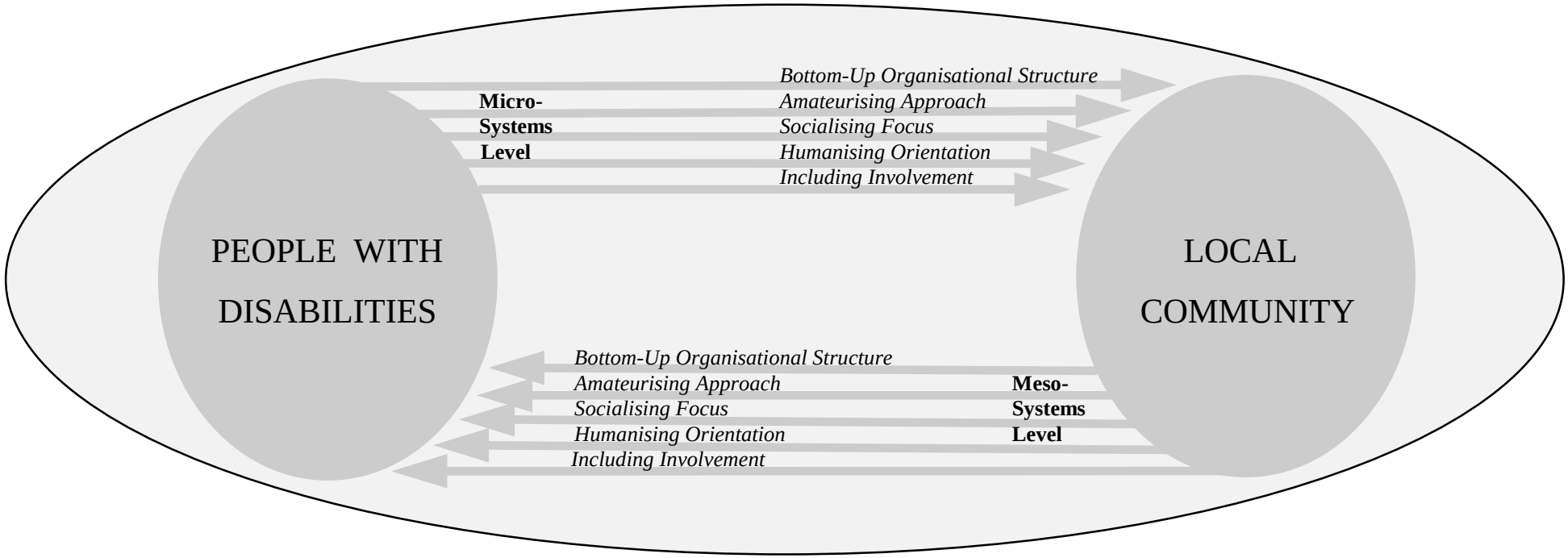

FIGURE 9.5 A diagrammatic illustration of the process of enhancing engagement between people with disabilities and their local communities.

9.6 Reciprocal Engagement: Suggested Dimensions

The preceding analyses of context, parameters and potential, have provided a number of insights into the possible realisation of enhanced engagement between people with disabilities and their local communities. These insights are by no means complete. A number of factors can be identified which may facilitate the development of new approaches to rehabilitation and disability service delivery around the notion of enhancing engagement. The nature of many factors will depend on the context in which the model is implemented. While the identification of particular factors, and the sequencing of factors may be the subject of debate, the purpose of the current section is to raise suggestions based on the research experience, which may inform future implementation of the model.

In order to provide a more practical example and more clearly describe dimensions for enhancing engagement, a 'goals - strategic processes - actions' framework was used along the five continua of the model. That is, end goals were proposed, next strategic processes necessary for these goals to be realised were identified, and finally, required actions were noted. This is illustrated in Figure 9.6. In this example, enhanced engagement between people with disabilities and local communities at the micro- and meso-system levels was chosen as the two part goal. Utilising the five continua, a number of strategic processes were proposed which were consistent with the process of enhancing engagement. A number of corresponding actions, based on tenets of the research were then identified as means of realising this goal. The result is a number of dimensions which are illustrated in Figure 9.6.

This depiction of dimensions is not considered an exhaustive listing and it is acknowledged that the varying degrees of importance and the sequences of actions and processes may be debateable. The intent of the current section however, is to provide one example which illustrates possible dimensions of enhancing engagement.

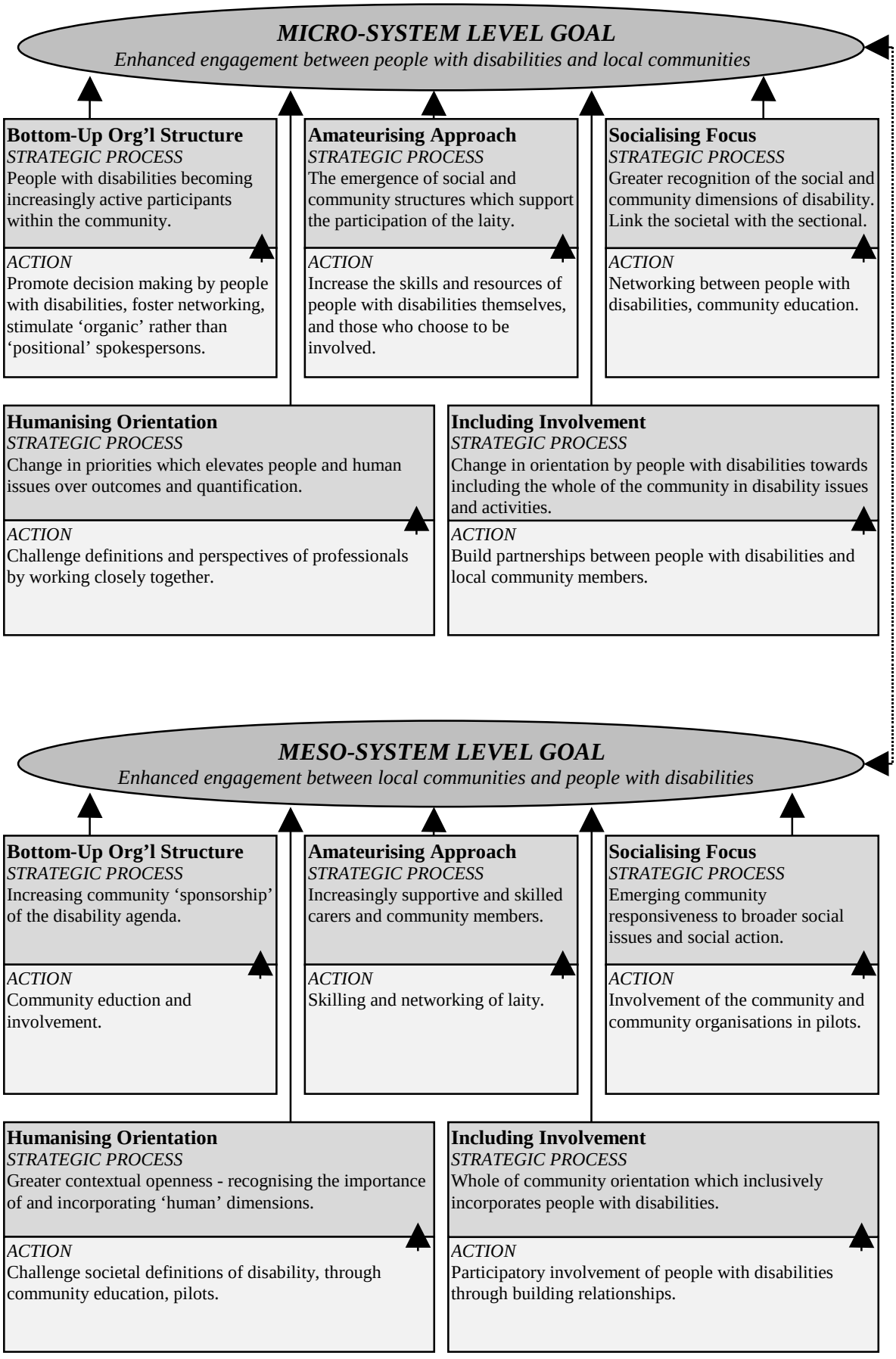

FIGURE 9.6 Possible dimensions of enhanced engagement between people with disabilities and their local communities.

9.6.1 Themes Inherent in the Dimensions

Figure 9.6 illustrates the way in which strategic processes and practical actions can be identified which are consistent with the continua of the model for enhancing engagement. The strategic processes demonstrate movement along each of the continua which will result in enhanced engagement. The identified actions suggest more concrete activities which are also consistent with the model. From such an example, discrete and measurable objectives can be drawn which will facilitate the process of enhancing engagement in a way which is relevant to a particular context.

The following discussion of these themes in Figure 9.6 is deliberately general in nature. Rather than provide examples within a particular context, some of the important themes within the 'dimensions' are identified, and mechanisms by which the dimensions might be realised are described below. This (a) ensures relevance towards both developing and economically developed countries, and (b) maintains consistency with an argument of the thesis - that extrapolation between contexts should be *based on principles rather than specific practices*.

9.6.1.1 Networking

Networking is a major theme evident in the suggested 'dimensions'. Networking is seen as the establishment of social and interpersonal connections within a community to achieve a desired outcome and facilitate engagement of people with disabilities. Effective networking at the micro- and meso-system levels is a vital means by which engagement is fostered. Networking is integral to 'socialising' and 'including' processes and building 'bottom-up' structures.

Interestingly, a key factor which facilitated the success of the disability rights movement in earlier decades, was the existence of strong networks of people. Scotch (1990) found that the establishment of both formal and informal groups, across disability type, was an essential component in the development of a collective identity which was the unifying force within the disability rights movement. Such networking is important to engagement.

9.6.1.2 Role and Image of People With Disabilities

The role which people with disabilities hold, and the image of disability which is portrayed is also important within the suggested dimensions. The participatory, lay approach which is inherent in the model, relies on skilling disabled community members changing the perception of their social role. Positive images which result from changed roles, vie for the minds of the public alongside negative stereotypes. Thus the basis for constructive change is laid.

In this vein, Wolfensberger (1992) argued that positive social changes result from the enhancement of the social roles of people with disabilities. He suggested that through a number of defined strategies, the enhancement of the image and competency of devalued individuals results in positive outcomes. Similarly, Susman (1994) argued that the stigma associated with disability was reduced when people with disabilities presented positive images of themselves and assumed their full personhood as citizens and consumers.

9.6.1.3 Critical Mass

A third concept inherent within the dimensions, is the notion of facilitating community change through fostering change at a smaller group level. Pilot projects would appear an ideal means of facilitating such change. The emphasis within the model on people with disabilities working together and co-opting others would appear to be a means of reaching a critical mass and facilitating community change. Kenkel (1986) postulated that change occurs in a community when a critical mass of people experiment with change and are observed to do so by others. The social nature of the derived model facilitates their acting as role models for change and encourages others to do so.

9.6.1.4 Challenging Definitions

The dimensions noted in Figure 9.6 may be seen as illustrating a means by which current definitions of disability are challenged. Actions and strategies which build solidarity and community in preference to individual, positivist and professional conceptualisations, radically challenge community and professional definitions of disability. Barton (1994) argued that challenging of definitions which isolate and marginalise people and replacing them with those which engender solidarity and dignity is a fundamental prerequisite for change in disability issues.

9.6.1.5 Organic Versus Positional

The dimensions reinforce the perspective that those representing disability issues should be people with disabilities not able bodied experts who speak for them. Oliver (1996) contended that positive change in disability issues is most productively promoted from an ‘organic’ perspective (people who have personal experience of disability) rather than a ‘positional’ perspective (people who do not speak from a first hand perspective). As illustrated by the dimensions, the model for enhancing engagement fosters the skills of a broader range of people with disabilities to engage societal and community issues for themselves. This sort of approach fosters and supports ‘organic’ advocates at a community level and mitigates against the emergence of experts who speak on behalf of people with disabilities.

9.6.1.6 Sectional Versus Societal

Finally, the suggested dimensions also illustrate that the model for enhancing engagement fosters a greater linking between the 'sectional' and the 'societal'. Fostering the role of the person (in their community context) as an engaged community member and citizen, is integral to the actions and strategic processes suggested in Figure 9.6. Oliver (1996) contended that a major issue facing the disability field was the need to promote greater inter-weaving of sectional interests with societal issues. Engagement between people with disabilities and local community members would appear to facilitate such linking. Engagement emphasises that the community should be a primary emphasis. This serves to balance both sectional and societal requirements.

In summary, a number of themes evident from the example of dimensions noted in Figure 9.6 illustrate that enhancing engagement is potentially far reaching in scope and magnitude. The themes are also consistent with processes of change which are relevant to the disability field.

9.6.2 Mechanisms for Realising the Dimensions

The successful realisation of the dimensions suggested in Figure 9.6 would be dependent on a variety of situational, contextual and other factors. For each project these will vary depending on needs of the community, disability services available, barriers for people with disabilities, community attitudes, social services, and so on. In order to further illustrate such factors, examples of some mechanisms are suggested which would be of relevance to economically developed and developing countries. Namely,

- community education and training, which is an important means of stimulus to enhancing engagement
- community integrated policy, which supports enhanced engagement
- pilot projects, which provide practical contexts for the application of engagement and
- community partnerships, which promote cooperation on disability issues.

9.6.2.1 Training and Community Education

The dimensions suggested in Figure 9.6 demonstrate a requirement for substantial training and community education. A reconsideration of professional training is required, as is the provision of appropriate training and support of individuals in the community and in community organisations. In developing and economically developed countries, professionals hold substantial power in rehabilitation and disability services. Consequently, any consideration of training issues should balance community education with influencing the training of disability professionals in light of the model for enhancing engagement. The dimensions and the model indicate the following suggestions.

- Training should be oriented to encourage professionals to 'give away' their skills to community members, particularly those with disabilities ('amateurising' and 'bottom-up', grass roots perspectives).
- Community education should train and support persons with disabilities, and their significant others so that they can better address their own needs and develop stronger relationships with their fellow community members.
- In keeping with the nature of the model, roles and training should be participatory in nature.
- Given the 'socialising' and 'including' aspects of the model, professionals should be skilled to understand the needs of communities as well as the needs of people with disabilities. In this respect they should be both community developers and disability professionals.
- A community development approach to training would appear highly compatible with the model. Skills enhancement of community members should seek to build the problem solving capacity of a community.
- Training within such a community based approach, should enable professionals to transcend discipline barriers to incorporate cross sectoral action.
- Workers and professionals should enhance their skills in roles such as partner, planner, collaborator, facilitator and community resource.
- The localised nature of the model indicates that training should take place in the community. Community members then may be seen as trainers for professionals

Assisting professionals to accept the principle of community involvement, and getting them to accept people with disabilities, families and community members as active participants in the rehabilitation process, will constitute a major attitudinal change. As Peat (1991b) has noted, there is a pressing need for frameworks which will assist in the development and application of professional training to community based practice. It is anticipated that further research utilising the model for enhancing engagement may assist in the development of such frameworks.

9.6.2.2 Community Integrated Policy

A second mechanism implicit within the dimensions is the need for community integrated policy. This is seen as consisting of two integral parts, (a) policy which supports community based pilots and approaches and (b) policy which is substantially influenced by communities. First, it may be seen that policy and organisational support will be beneficial to the establishment of community based disability initiatives. While it was noted that many CBR projects have arisen without a strong policy framework, the presence of supportive policy would substantially contribute to its legitimacy and expansion.

Second, it was noted earlier that traditional policy and legislative approaches have limited value as mechanisms for change in issues which affect people with disabilities in local communities. In contrast, the derived model with its emphasis on community engagement and participation between people with disabilities and communities, envisages an approach which fosters grass roots influence. Empowered and active communities which have input into policy processes ensure that policy and legislation will be relevant to the needs of people. While few examples or guidelines exist for such mechanisms, they may be promoted by the dimensions noted in Figure 9.6. For example, policy might be developed which provides incentives and benefits support for people with disabilities to participate in community development training. Furthermore, policy which was responsive to community level issues would be conducive to implementation of the actions and strategies noted above.

9.6.2.3 Pilot Projects

A third mechanism which is highlighted by the example of dimensions is the need to establish working pilots to promote, explore and refine these notions. Pilot projects which extend beyond short term trials and which are properly researched will be constructive means of further exploring ways to implement the model for enhancing engagement.

Unfortunately community based processes have been found to be difficult to evaluate using traditional frameworks in pilots. They do not correspond with traditional administrative structures and their major outcomes (meaningful changes in families and communities) are difficult to measure (Freyhoff, 1994). Consequently research and evaluation of pilots should emphasise informal process evaluation. Attempts to measure the quality of community based pilots might do so against principles inherent in the model and identified community needs. In essence, pilots may be seen as training experiences and valuable sources of information which will yield data through action research methods.

Pilots might be established in locations which are currently under-resourced and disregarded in traditional frameworks. Given the paucity of disability services in rural and indigenous contexts, as well as the potential strength and interconnectedness of these communities, and the preference for people to obtain services locally (Gething et al., 1994b), they may be ideal contexts for establishing pilots.

Current telecommunication technologies also represent a potential context for establishing pilots. While such approaches are highly dependent on the quality of the telecommunications infrastructure and the uptake of the technologies, they may be used to facilitate a number of aspects of disability services. The new frontier of technology in this area may serve constructive purposes of linking and coordinating individuals and extending parameters of community and inclusion. Often such technologies have been isolating, and limiting to interpersonal linkages, however they may also be developed to maximise social inclusion and cooperation. The current model suggests principles which, if inherent in the development and implementation of such technologies, would build greater responsiveness to the needs of people with disabilities. For example, computer based localised networking and information dissemination would provide a means of building partnerships and skills for people with disabilities who may have limited mobility.

9.6.2.4 Partnerships in the Community

The dimensions strongly emphasise the importance of building alliances and cooperation in communities around disability issues. Ideally such partnerships should be with as extensive a range of non-disability organisations as possible. Partnerships with community organisations and agencies are a means by which people with disabilities can participate within community structures and bring about constructive changes in the community. They are also a means by which the community can contribute resources and endorsement to disability groups.

Partnerships with disability organisations will also be developed. With reference to issues noted in Chapter Two, links with formal service providers may prove difficult. Similarly links with DPOs may have areas of difficulty. While it is noted that DPOs are becoming widespread in economically developed countries and developing countries, their links with communities are often tenuous. Despite these drawbacks, partnerships with DPOs and formal services may provide such organisations such with the balance that they require. They may be instrumental in establishing community based groups within service and funding structures which will contribute to their support base. In this way DPOs and formal services may also be seen as *targets* and *resources* for community based disability groups.

9.6.3 Summary

In keeping with the focus of the current thesis, the discussion of dimensions by which the model for enhancing engagement might be realised has emphasised a broad scope of issues rather than specific detail. Utilising a 'goals - strategic processes - actions' framework, an example was drawn which illustrated a practical interpretation of the model. A number of important themes drawn out by such an interpretation were highlighted, and some of the mechanisms which facilitate the model were identified. Each of these is seen as prime sites for future research of the model for enhancing engagement.

9.7 Conclusion

The current chapter has provided a discussion of a number of issues relevant to the derived 'model for enhancing engagement'. A number of key features and components of the model were identified. The model was explored in light of the two major contexts to which it pertains, the disability sector in economically developed countries, and CBR. Methodological strengths and limitations were identified, and the descriptive framework of the thesis was discussed. Finally, the chapter speculated on the possible dimensions by which the model might be realised. Potential directions for future research arising from the model and the thesis as a whole, were indicated at relevant points throughout the chapter.

In essence, the model for enhancing engagement, which arose from a potentiation of principles of CBR, may be a means by which the CBR approach might be furthered in both economically developed and developing countries. The conceptual, principle based, nature of the model assures its application to assist people with disabilities in both contexts.

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Appendices

Appendix 7.4.1

Strategies Employed to Ensure Trustworthiness and Rigour

Methodological requirement	***Strategy Employed***	***Achieved***
Reliability and Confirmability	Explicit description of the theoretical framework of the research and methods (Mays & Pope, 1995; M.B. Miles & Huberman, 1994).	Descriptively
	Clear description of context of fieldwork, documentation of data gathering and analysis. The use of a decision or audit trail (Holloway & Wheeler, 1996; Mays & Pope, 1995).	Descriptively
	Presentation of analysed or traceable raw data for scrutiny (Mays & Pope, 1995).	Descriptively
	Triangulation of data sources and participant checking (Brown, 1991; Gliner, 1994).	Procedurally
	Parallels established between research design, data gathering procedures, data gathering settings, theory and conclusions (M.B. Miles & Huberman, 1994).	Descriptively
Transferability and External Validity	Triangulation of data sources (theoretically diverse sampling of research participants and contexts) and methods (Brown, 1991; Gliner, 1994; Holloway & Wheeler, 1996; Huberman & M.B. Miles 1994; Mays & Pope, 1995).	Procedurally
	A plausible, coherent explanation of the phenomenon under scrutiny (Mays & Pope, 1995).	Descriptively
	A clear and explicit account of the method and analysis (Mays & Pope, 1995).	Descriptively
	Extended involvement with participants (Gliner, 1994; Holloway & Wheeler, 1996; Mays & Pope, 1994).	Procedurally
	The use of a decision or audit trail (Holloway & Wheeler, 1996, Mays & Pope, 1995).	Descriptively
	Linking data and conclusions to their sources (Holloway & Wheeler, 1996).	Descriptively
	Participant checking (Brown, 1991; Gliner, 1994; Huberman & M.B. Miles 1994).	Procedurally
	Relevance and benefit evident to the participants (Altheide & Johnson, 1994; Chesler, 1991).	Procedurally
	Demonstration that the relationship exists beyond the instance in which it was identified (Krathwohl, 1993).	Descriptively
Consistency, Internal Validity	Triangulation of data sources and methods (Brown, 1991; Gliner, 1994; Holloway & Wheeler, 1996; Huberman & M.B. Miles, 1994; Mays & Pope, 1995).	Procedurally
	Extended involvement with participants, credibility of the researcher to the participants (Gliner, 1994; Holloway & Wheeler, 1996).	Procedurally
	Internal coherence and comprehensiveness of the account (M.B. Miles & Huberman, 1994).	Descriptively
	Participant checking (Brown, 1991; Gliner, 1994; Huberman & M.B. Miles, 1994; Mays & Pope, 1994).	Procedurally
	Triangulation of theory (Gliner, 1994; M.B. Miles & Huberman, 1994).	Descriptively
	The researcher's understanding of the area and self awareness such as an account of research philosophy, etc. (Altheide & Johnson, 1994; Rodgers & Cowles, 1993).	Procedurally
	Account of the research which describes or explains the phenomenon under study (Altheide & Johnson , 1994).	Descriptively
	Explanation credibility - participants see the problem as important and methods seem credible (Krathwohl, 1993; M.B. Miles & Huberman, 1994; Walker, 1993).	Procedurally
	Translation Fidelity - the design and outcomes of the study reflect and are applicable to the problem (Krathwohl, 1993; Walker, 1993).	Procedurally
	Grounded nature of data and model (Krathwohl, 1993; Strauss & Corbin, 1994).	Procedurally

Appendix 7.4.2

Strategies Employed to Minimise Threats to Integrity of the Research Project

Potential Threats	***Minimisation Strategies***
Obtrusiveness of researcher and method (Krathwohl, 1993)	• Use of non-mechanical recording • Participant observer approach
Gaining entry and securing acceptance by participants (Holloway & Wheeler, 1996; Krathwohl, 1993)	• Prolonged involvement with participants, participation in meetings and activities other than research meetings • Involvement supported by organisations
Data overload (M.B. Miles & Weitzman, 1994; Richards & Richards, 1993)	• Use of comprehensive data management software - NUD*IST • Purposive sampling of participants based on knowledge and experience • Selective data management in initial stages through note taking
Overemphasis on first impressions (Krathwohl, 1993)	• Prolonged involvement with participants in an exploratory study
Coincidental co-occurrences, over-emphasis of some aspects as a result of the novelty of certain data, uneven reliability of information (Brown, 1991; Gliner, 1994; Krathwohl, 1993)	• Triangulation of sources
Lack of raw data integrity (Krathwohl, 1993; M.B. Miles & Huberman, 1994)	Data management strategies such as: • Write up field notes directly after interview • Note key words and phrases and complete after interview • Systematic use of abbreviations, underlining etc.
Inaccurate perception of key issues by researcher (Brown, 1991; Gliner, 1994; M.B. Miles & Huberman, 1994)	• Prolonged involvement with participants • Triangulation of sources and methods • Cross validation from participants - participant checking
Inaccurate perception of key issues by participants (Brown, 1991; Gliner, 1994; M.B. Miles & Huberman, 1994)	• Triangulation of sources • Informants selected on basis of close involvement with the issues
Imbalanced cross section of participants (Gliner, 1994)	• Selection of participants based on involvement in area • Participants drawn from a number of sites.
Miscommunication (Brown, 1991; Gliner, 1994)	• Use of triangulation of method and data source • Use of participant feedback strategies
Recording inaccuracy (Richards & Richards, 1994)	• Use of comprehensive data management software - NUD*IST • Use of participant feedback strategies
Misrepresentation of data (Holloway & Wheeler, 1996; Mays & Pope, 1995)	• Use of participant feedback strategies • Presentation of an audit trail

Appendix 7.7.1.2

Participants Interviewed in the CDA study

Code	Role in CDA	Descriptors
AF	Member	Woman with physical disability, not defined
AL	Associate	Woman with Multiple Sclerosis
BJ	Member	Man with Osteogenesis Imperfecta
DF	Member	Man with disabling heart condition, also care provider
JD	Associate	Woman with lower limb amputation
JH	Associate	Man with Paraplegia
JM	Member	Man with visual impairment
JS	Member	Woman with Paraplegia, previous local group president
LR	Associate	Woman with post polio condition
NC	Member	Man, care provider
PC	Member	Woman with Multiple Sclerosis, previous director of organisation
RP	Member	Man with Cerebral Palsy, current chairman of organisation
SK	Member	Woman with Multiple Sclerosis

Appendix 7.7.1.2b
Data Storage, Retrieval and Analysis

Technology

The use of computer analysis facilitated the development of heavily 'data conditioned' concepts and theories (Richards and Richards, 1994) which was a prime goal of the current study. The selection of technology in the current research process was influenced by the following criteria:

- Outcomes of the research (in terms of synthesised ideas, concepts, models, theories) should be directly traceable to the data that gave rise to them (Strauss & Corbin, 1994).
- Data should be readily coded and retrieved - i.e. The capacity to divide the raw data (text) into segments and to locate and display all instances of coded segments was required (Miles & Weitzman, 1994).
- The process and technology should facilitate model development - i.e. The technology should enable the researcher to make connections between codes (or categories of information) to develop higher order classifications and formulate propositions or assertions in a conceptual structure that fits the data (Miles & Weitzman, 1994).

In response to these requirements, the NUD*IST (Non-numerical Unstructured Data Indexing, Searching and Theory-building) software package was utilised (NUD*IST for Windows, Version 3.0.4d, (Qualitative Solutions and Research, 1995)). This package allowed for the transformation of notes, through a process of coding and higher level categorisation. For the current purposes, the NUD*IST programme facilitated and automated the process of description, interpretation and subsequent analysis of interview and participant feedback information. This was seen as most consistent with the grounded qualitative nature of the current research, in which faithfulness to the substantive data is fundamental (Strauss & Corbin, 1994).

The researcher, using the NUD*IST programme was able to analyse raw qualitative data through the construction of an indexing system based on thematic concepts (or 'nodes' of data on a particular theme). This thematically organised system, could then be further analysed and explored. Themes were combined in a variety of ways and linked to other relevant data referenced in the project.

Coding

Coding is a process of identifying similarities, attributing a code and then abstracting the important concepts and dimensions for easy access and retrieval. As Richards and Richards (1994) pointed out, it is not possible to separate coding and retrieval of data from theory building.

Decisions about what is a category of significance, what concepts are developed, what ideas explored, redefined or ignored in the study, necessarily involves theoretical considerations. As such, the whole process is a contribution to theory. Despite this, the process of coding by computer as in the present study, provided an account of the method which stands independently, so that another researcher could analyse the same data in the same way and come to essentially the same conclusions (Mays & Pope, 1995).

Qualitative methods involve "the recognition of categories in the data, generation of ideas about them, and exploration of the meanings in the data." (Richards & Richards, 1994, p. 446). In the current study, this may be seen as a process of (a) decontextualisation (identifying and coding segments or units of meaning in the data), (b) subsequent recontextualisation (categorising and thematically reassembling segments with other segments that deal with the same topic) and (c) synthesis.

To facilitate this process, coding was conducted in three stages:

- Open coding or developing descriptive codes. The data was initially clustered and described through examining the data as a whole, comparing concepts and themes and categorisation of these themes.
- Axial coding or interpretation. Data were reanalysed and combined in new ways and interpreted by developing and exploring new connections between the categories
- Selective coding or patterning. This stage was more inferential and explanatory. It involved systematically relating selected categories to validate, define and develop concepts.

Such stages of coding and analysis are described using different terminology in a number of qualitative texts. They are seen as the primary means by which concepts or themes are identified, categories are built, and theory finally emerges and is integrated. (Holloway & Wheeler, 1996; Miles & Huberman, 1994).

A limitation of the NUD*IST software is that it lacks a visual display of conceptual level diagrams that might be developed in the analysis process (Richards & Richards, 1994). For the purposes of the current study, displays and drawings depicting conceptual models based on data themes, were generated by the researcher and a supervisor (Emeritus Professor Arthur Brownlea) on white board.

Appendix 7.7.1.2c

Cover Letter and Feedback Form used in CDA Study

C/- Rehabilitation and Disability Studies
Griffith University Qld 4103

17 October, 1995

Ph (07) 3875 5213 Fax (07) 3875 7007
Home address: 41 Villa Street
Annerley Qld 4103
Ph (07) 3892 3728

Dear,

Thank you for participating in our recent interview. As you will be aware, I have been conducting interviews over the past few months with people involved in a few different disability groups which try to bring about changes in local communities.

You may recall when I spoke with you, I asked whether you would be willing to give me some feedback on my interpretations of those interviews. That is what the attached document is about.

I am very sorry it is such a large document. Please don't be too "put off" by its size, it isn't as daunting as it first appears. What I have done is transcribed the major points from all of the interviews and categorised then into what I saw as the major themes (sixteen altogether). These are outlined on the reverse of this page. I have summarised the main aspects of each theme with an "interpretation" statement and then developed that into a "judgement" statement (which identifies issues that might be considered or which have implications for my research in the future). I would very much value your feedback on all of this.

What I am asking you to do is as follows:

1. Comment on the 16 themes (there is space on the last page). Are these an accurate description of the issues as you see them? Do you think the main issues have been covered? Do you think other themes should have been emphasised?

2. Comment on whether you think each of my 16 "interpretations" and "judgements" about the statements are accurate. Are there important things that I have omitted or got wrong? What would you add or emphasise more? What would you delete or emphasise less?

3. Share any suggestions you have about this process or the ideas generated by it.

If you think this is too much to do, could I ask you just to look at the "interpretations" and the "judgements" and comment on each of these.

Thank you in advance for your assistance. I have enclosed a reply paid envelope which allows you to return this at no cost to you. If possible it would be very helpful to me if I could have your feedback before 31 October, 1995

Regards

Pim Kuipers

Appendix 7.7.1.2c (cont'd)
Cover Letter and Feedback Form used in CDA Study

I have categorised the statements from all of the interviews into 16 categories which fall under 6 main themes. They are as follows:

Theme A ***The people in the group***

1. Group member's qualities
2. Group member's knowledge & skills
3. Group leadership

Theme B ***The way the group operates***

4. Group philosophy
5. Group characteristics and structure
6. Group action/approach

Theme C ***Getting and keeping the group going***

7. Initial phases of setting up the group
8. Maintaining the group

Theme D ***The community the group works in***

9. Community setting
10. Accountability to community
11. Advantage to community

Theme E ***Things which support the group***

12. Parent organisation
13. Policy environment
14. Funding support
15. Physical support

Theme F ***Outcomes***

16. Outcomes

Appendix 7.7.1.2c (cont'd)

Precis of Feedback Form used in CDA Study

(The spaces in which participants wrote their comments have been deleted in this example)

1.0 GROUP MEMBER'S QUALITIES

1.1 Interpretation of Participant's Statements

For a local community based group to function well, it should be made up of a variety of different types of people with disabilities, who are strong and clear about what they want, have the support of families and who understand what the group is seeking to achieve. These people will understand the importance of building and fostering the group in order to achieve real outcomes in the community.

Comments_____

1.2 Judgements and Conclusions

To establish and build community based disability groups which bring about changes in their local communities, we should:

i. Try to recruit a variety of people with disabilities (through providing training on how to recruit and involve people into groups),
ii. Encourage strength and clarity of purpose in groups (through opportunities to motivate each other - such as developing mission statements),
iii. Encourage a variety of responses to issues (through training as in 1.3.i)

Comments_____

2.0 GROUP MEMBER'S KNOWLEDGE & SKILLS

2.1 Interpretation of Participant's Statements

The sorts of skills and knowledge that are required for community based disability groups are what might be called "community action and information skills". These skills would seek to build empowerment and confident action in the local community and would focus on dealing with bureaucracy.

Comments_____

2.2 Judgements and Conclusions

Ways of helping people to develop skills for establishing and building these kind of groups should emphasise:

i. Ways of researching and obtaining information
ii. How to act on issues within local bureaucracies
iii. Lobbying government, councils and business
iv. Local community information

Comments_____

3.0 GROUP LEADERSHIP

3.1 Interpretation of Participant's Statements

Selection and development of leaders is clearly very important for this sort of community based disability group. There appears to be an overlap of points between this topic (3.0) and the previous topics (1.0 & 2.0). This indicates that leadership responsibilities may be shared by a number of group members or that leadership responsibilities are (or might be) delegated to members.

Comments_____

3.2 Judgements and Conclusions

Leadership development should be a priority for community based disability groups. (It might be most effective if offered to all members of these groups. If people choose to develop their enhanced skills more and take on more leadership responsibilities, they can do so).

Comments_____

4.0 GROUP PHILOSOPHY

4.1 Interpretation of Participant's Statements

Clarity of purpose and long term vision are central aspects of disability groups which seek to bring about changes to local communities

Comments_____

4.2 Judgements and Conclusions

It may be very beneficial for each local group and for organisations to clarify what they are doing through developing mission and vision statements. From these statements goals might be identified for the short and longer term future.

Comments_____

Appendix 7.7.1.2c (cont'd)

5.0 GROUP CHARACTERISTICS AND STRUCTURE

5.1 Interpretation of Participant's Statements
Community based disability groups provide a significant amount of mutual support for members. While they require some structure, this does not appear to be a key issue The important characteristics appear to be that these groups:
i. are action oriented
ii. span across different types of disability,
iii. focus on local issues and
iv. are flexible.
Comments_____

5.2 Judgements and Conclusions
Even though this kind of group exists to bring about changes in local communities, they also provide a significant amount of support for members (this support function should not be ignored). The factors which characterise these groups (action oriented, cross disability, localised, flexible) are also the factors which distinguish them from nearly all other disability groups. A focus on assisting people to develop skills in teamwork may be advisable.
Comments_____

6.0 GROUP ACTION/APPROACH

6.1 Interpretation of Participant's Statements
A number of themes are evident:
i. the local community - using local resources, working with local groups/networks, focusing on attitudes of people in the local community, meeting needs of people with disabilities locally
ii. bringing about change
iii. action
iv. relevance and credibility
Comments_____

6.2 Judgements and Conclusions
The focus of these groups appears to be (and should be) discrete communities. Community based disability groups might be seen as local agents of change. Skill development in becoming more effective "community change agents" may be beneficial.
Comments_____

7.0 INITIAL PHASES

7.1 Interpretation of Participant's Statements
The common thread in the process of these groups becoming established appears to be as follows: The **awareness** of the extreme difficulty of circumstances leads to strong **emotions** (frustration and anger). In response, when people **group together** and share and obtain **information**, they are then **motivated** to some form of **action** to bring about **change** in their local areas.
(Awareness > Emotion > Grouping > Information > Motivation > Action > Change)
Comments_____

7.2 Judgements and Conclusions
It may be very beneficial to research the initial phases more fully with a view to identifying relevant issues. A clearer understanding of the initial phases of these groups would enable us to know how people with disabilities might be assisted to develop new groups and also the kinds of supports that are needed to help the groups get going. In the interim, the stages noted above may form a useful starting point.
Comments_____

8.0 MAINTAINING THE GROUP

8.1 Interpretation of Participant's Statements
This appears to be one the central difficulties of such groups. (The emphasis on keeping numbers of people indicates that there may be an identifiable "critical mass" of group members which is required for a group to remain strong over time).
Comments_____

8.2 Judgements and Conclusions
Providing input into approaches, structures, strategies and training which enable members to maintain these groups more effectively must be a major priority. (Consider value of researching "critical mass" of community based disability groups).
Comments_____

9.0 COMMUNITY SETTING

9.1 Interpretation of Participant's Statements
Various factors which relate to the nature of the community in which the group operates are important to these groups. Groups should seek to know the communities in which they are working.
Comments_____

9.2 Judgements and Conclusions
It will be important for groups to respond differently to different communities. In the initial stages of setting up these groups some study should be made of the nature of the community and its resources to determine how the group might most effectively operate.
Comments_____

10.0 ACCOUNTABILITY TO COMMUNITY

10.1 Interpretation of Participant's Statements
It is good for community based disability groups to be accountable to local communities and councils
Comments_____

10.2 Judgements and Conclusions
It would be valuable to establish clear lines of accountability with councils (and with communities if possible). Training in public relations may be advisable.
Comments_____

11.0 ADVANTAGE TO COMMUNITY

11.1 Interpretation of Participant's Statements
These groups serve a unique constructive function within communities
Comments_____

11.2 Judgements and Conclusions
There may be a need to slowly educate communities about the potential role of these groups. It may be very beneficial to strengthen the community development skills of people in these groups to assist them to achieve their goals through a community development approach
Comments_____

12.0 PARENT ORGANISATION

12.1 Interpretation of Participant's Statements
It is a valuable resource to have a structure in which there is a supportive parent organisation. This structure can be a constructive means to get groups going, to provide support, to assist with training, to provide resources, etc.
Comments_____

12.2 Judgements and Conclusions
There appears to be a need to clearly define the links and relationships between local groups and the parent organisation. The role of a parent organisation in providing resources and assistance to independent groups which operate independently in different areas, might also be considered.
Comments_____

13.0 POLICY ENVIRONMENT

13.1 Interpretation of Participant's Statements
Community based disability groups are a means by which disability related policy and legislation is actually brought to bear on local communities and people with disabilities within those communities.
Comments_____

13.2 Judgements and Conclusions
Developing and enhancing group members knowledge of policy issues may be beneficial
Comments_____

14.0 FUNDING SUPPORT

14.1 Interpretation of Participant's Statements
For these groups to function effectively, it is necessary to have an appropriate level of funding to ensure that group members are not out of pocket.

Groups should have funding which is dependable and sufficient. Most groups appear to think that they should not have to raise funds themselves. There is some concern about funding arrangements under which they may feel beholden to government.
Comments_____

14.2 Judgements and Conclusions

There may be a need for delineation of government policy with regard to funding of these kinds of groups.

Comments_____

15.0 PHYSICAL SUPPORT

15.1 Interpretation of Participant's Statements

Some sort of central office is highly valued. A central reference point for people with disabilities and other community members is important, particularly as a group gets larger.

Comments_____

15.2 Judgements and Conclusions

It may be constructive to lobby local councils to make resources and space available for community groups such as this.

Comments_____

16.0 OUTCOMES

16.1 Interpretation of Participant's Statements

There is a strong theme of action within the local community in these groups. This sort of action is done by a variety of means including drawing people's attention to negative situations and through lobbying and also through positive means such as awards. Major outcomes appear to be in:

i. improvement of access (particularly in public places),
ii. informing communities,
iii. empowerment and
iv. ensuring government policy is realised at a local level.

Outcomes which relate more directly to group members include mutual support and broadening of understanding of disability issues.

Comments_____

16.2 Judgements and Conclusions

Clearer identification of and focus on the importance of these outcomes may assist in ensuring the maintenance of these groups. The nature of outcomes sought might be different for each group in each different community.

Comments_____

Having read all of the statements and interpretations from the questionnaire, please comment on the major themes and categories that were used to summarise the statements. Are they accurate?

Theme A	***The people in the group***
	1. Group member's qualities
	2. Group member's knowledge & skills
	3. Group leadership
Theme B	***The way the group operates***
	4. Group philosophy
	5. Group characteristics and structure
	6. Group action/approach
Theme C	***Getting and keeping the group going***
	7. Initial phases of setting up the group
	8. Maintaining the group
Theme D	***The community the group works in***
	9. Community setting
	10. Accountability to community
	11. Advantage to community
Theme E	***Things which support the group***
	12. Parent organisation
	13. Policy environment
	14. Funding support
	15. Physical support
Theme F	***Outcomes***
	16. Outcomes

Comments_____

Other general comments _____

Appendix 7.7.2.2.1

Participants Interviewed in the RSL Study

Code	Descriptors
AR	RSL Member - Welfare Officer
BT	RSL Member - Executive Management
EP	Aged Care Service Provider / Peak Body Committee Member
FH	RSL Member - Welfare Officer
FM	DVA Veterans Adviser
GH	RSL Member - Welfare Officer
HD	DVA Veterans Social Group Facilitator
JW	RSL Member - Welfare Officer
JM	DVA Veterans Adviser
KB	Manager Aged Care Service Provider / Peak Body
MB	DVA Veterans Adviser
MC	RSL Member - Executive Management
ME	DVA Veterans Adviser
MO	Manager Aged Care Service Provider
NA	RSL Member - Regional Management
NS	RSL Member - Welfare Officer
PA	RSL Member - Welfare Officer
RD	RSL Member - Executive Management
RH	RSL Member - Regional Management
RW	DVA Veterans Adviser
SC	RSL Member - Welfare Officer
SW	Assistant Manager - Aged Care Service Provider
TC	Assistant Manager - Aged Care Service Provider
TK	RSL Member - Executive Management
WS	Manager - Aged Care Peak Body
YZ	Manager - Aged Care Peak Body

Appendix 7.7.2.2.3

Needs Analyses Utilised in the RSL Study

Code	Descriptors
AB	Focus Group (15 Frail Older Adults) - Ashgrove Blue Nursing Service Conducted by Department of Veteran's Affairs *December, 1995*
GL	Focus Group (50 Older Adults) - The Gap Leisure Club Conducted by Department of Veteran's Affairs *November, 1995*
TS	Focus Group (105 Veterans and Older Adults) - Toowong Senior Citizens Club Conducted by Department of Veteran's Affairs *December, 1995*
GA	Focus Group (16 Frail Older Adults and Veterans) - The Gap Anglican Church Friendship Circle Conducted by Department of Veteran's Affairs *December, 1995*
GU	Focus Group (25 Older Adults) - The Gap Uniting Church Social Group Conducted by Department of Veteran's Affairs *December, 1995*
QK	Questionnaire (376 Veterans) - Kedron Wavell RSL Conducted by Kedron Wavell RSL and Department of Veteran's Affairs *1994 - 1995*
VA	Nine Focus Groups (54 Veterans) - "Validation of Veteran's Needs" Study Conducted by ACH Group Inc. Private Consultants *June 1996*
VN	Ten Focus Groups (50 Veterans) - Client Needs Validation Project Conducted by the National Ageing Research Institute (Uni. of Melbourne) *July 1996*
VL	Written Questionnaire (192 Veterans) - Veterans Needs Survey Conducted by Logan and District RSL Branch *1996*
VB	Focus Group (10 Veterans) - Needs Survey in the parish of Balmoral Uniting Church Conducted by Centre for Strategic Human Services (Griffith Uni.) *February, 1995*
VT	Telephone Needs Study (47 Veterans) - Parish of Balmoral Uniting Church Conducted by Centre for Strategic Human Services (Griffith Uni.) *February, 1995*

Appendix 7.9.1
Overview of Workshop Conducted with
Community Disability Alliance - Sunshine Coast

CDA Workshop Maroochydore September, 1996

Three main points, under each of which we will explore the five axes:

A. Activating the community development process - initiating and fostering a relationship of a developmental nature with individuals.

Introduction:

- Definition of community
- Definition of community development
- Building developmental relationships

The importance of:

- Working together rather than individually
- Responding to people rather than things and statistics
- Building cooperation and joint agendas rather than competing
- Taking control for ourselves rather than being managed by others
- Doing it ourselves rather than relying on the experts and professionals

B. Facilitating developing and maintaining a process of moving the individual's private concern to public action

Introduction:

- Linking with others
- Resourcing people
- Linking people together
- Obtaining agreement
- Implementation
- Planning the group action

How might we:

- Work together rather than individually
- Respond to people rather than things and statistics
- Build cooperation and joint agendas rather than competing
- Take control for ourselves rather than being managed by others
- Do it ourselves rather than relying on the experts and professionals

C. Fostering and maintaining the public process and action

Introduction

- Supporting a group in a wider public process
- Fostering a group
- Developing a project plan

How <u>specifically</u> will we as a group:

- Work together rather than individually
- Respond to people rather than things and statistics
- Build cooperation and joint agendas rather than competing
- Take control for ourselves rather than being managed by others
- Do it ourselves rather than relying on the experts and professionals

Appendix 7.9.1b
Flier for CDA Workshop

The Facilitator:

Community Disability Alliance

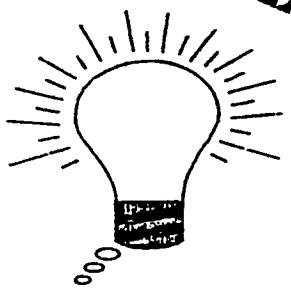
... TO INSPIRE, EDUCATE AND LOBBY COMMUNITIES TO FIND WAYS TO ENSURE THE INCLUSION OF PEOPLE WITH DISABILITIES AS EQUAL PARTNERS IN COMMUNITY LIFE

RSVP Before 20 September, 1996 to:

CDA Sunshine Coast Branch Presents a ...

Community Development Workshop

RESCHEDULED



28 & 29 September, 1996
16 Duporth Ave, Maroochydore

Being a change agent here on the Sunshine Coast

We know that it is important to work together to achieve real change here on the Sunshine Coast on disability issues ● ● ●

- But how can we do it realistically?
- How can we develop strategies that will help us to be an effective influence on issues of concern for people with disabilities?
- How do we build links with other organisations?
- How can we do we work out how to address access and other problems?
- How do we develop action plans that are relevant to us and to our community?

● ● ● A Community Development workshop, running over two mornings, sponsored by C.D.A.

Community development can be a very valuable process for empowerment. Through community development, many community groups have seen social change and personal growth. These workshops will help us to explore what community development is, and why it can be so successful. We will examine the key issues for people with disabilities on the Sunshine Coast. We will develop a framework for analysing problems and together we will be able to work towards strategies for change in our communities. (We will also spend some time chatting and enjoying ourselves!!)

9am - 2pm Sat & Sun,
28th & 29th Sept. '96
16 Duporth Ave Maroochydore
Lunch Provided!

Who? Where? When? How much? Lunch?

Who should attend?

- CDA members,
- People with disabilities who are interested in bringing about change in the community
- Allies of people with disabilities

Where will it be held?

Maroochydore C.R.S. Training / Meeting Room - 3rd Floor, 16 Duporth Avenue, Maroochydore (Accessible toilets and parking)

When ?

- 9am - 2pm Saturday 28th Sept AND 9am - 2pm Sunday 29th Sept.
- In order to give us some time to work together, (but not to wear everyone out in the process), we have organised the workshop to run for two half days.
- It would be best if people could come for both mornings

How much will it cost?

- It is FREE (CDA is covering all the costs for the workshop).

What about morning tea and lunch?

- The good news is that morning tea and a light lunch will be provided free.

Appendix 7.9.2
Cover Letter and Feedback Form used in RSL Study

C/- Rehabilitation and Disability Studies

Ph (07) 3875 5213 Fax (07) 3875 7007

September, 1996

Dear,

You will recall that some time ago, I interviewed you about your thoughts on the potential involvement of the RSL in aged care and human services. (I have attached a copy of my letter of introduction as a reminder). Thanks again for giving of your time for that interview.

All of my interviews are now complete and I am ready to develop the conclusions. I am aware that sometimes in research projects such as this people who are interviewed feel that they would like to follow up on the way in which the conclusions were drawn and also to have an opportunity for input into the final stages of the project. Hence this follow-up letter.

I have prepared a very brief overview of the main themes that arose from my interviews and the needs analyses of veterans in this region (yellow page). Secondly, I have identified four major options that arose from the research (green page). I have provided an overview of three of these options and described the fourth (my suggested option) more fully. Obviously I have not gone into great detail, mostly because I don't want to make this request too time consuming.

My request is that you read through the pages that follow (themes and suggestions) and make any comments you would like regarding the content or the process of drawing these conclusions. I am interested in both positive and negative comments or if you have no comment please indicate that and return the two coloured pages to me using the prepaid envelope. If possible I would appreciate your feedback by **Friday 27 September.**

I must stress that the points raised here are **not** those of the RSL and that this is no indicator of what the RSL may or may not do in future. These are issues which have arisen from my research and for which I take full responsibility. While this information will be used in a report which will be submitted to the SE District of the RSL, the RSL is under no obligation to act on the report in any way.

Thank you for your willingness to participate in this study. If you could take the time to review the following pages, it would be greatly appreciated. I look forward to using your feedback to inform the final report of this study.

Regards

Pim Kuipers

Your Name.....

Organisation.....

Do you have any general comments about the research or how it is being conducted?
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Major Themes Interviewees

When I asked people from community service organisations, peak bodies, government departments and the RSL about their views on the RSL's possible involvement in aged care and human services, many different perspectives emerged. It seemed to me that the best way of summarising the key aspects of these different perspectives was to see them as a series of two sided continua.

Both RSL members and others pointed out that the RSL has a strongly hierarchical organisational structure. This infrastructure may have potential benefit for any initiative.	Community agencies feel that in order for a human service initiative to be successful, and genuinely respond to need, it must have significant "grass roots" input.
Top Down Organisational Structure	***Bottom Up Organisational Structure***
Some interviewees supported more traditional service approaches which focus on individual's needs and try to address specific problems that individuals may experience (eg. Assistance with direct care and medical treatment).	A number of interviewees observed that what may be beneficial are approaches which can focus on broader social issues and problems that groups face rather than addressing direct care problems.
Addressing Individual Problems	***Addressing Broader Social Questions***
Some interviewees stressed the importance of issues like identifying problems, achieving outcomes, collecting statistics and managing data.	Some interviewees noted the importance of emphasising caring about people and thinking about how various things affect people's lives and helping people to have more control over their lives.
Emphasising Evidence	***Emphasising Human Issues***
Some of the people interviewed emphasised that an initiative of the RSL should limit services to members only. They thought it would be pointless for the RSL to develop a service unless it only provided assistance to RSL members.	Some pointed out that depending on how it was set up, an initiative might affect lots of people in a community. It would be important to consider effects beyond the members who are directly served.
Meeting Needs of Members	***Looking at the Effect on Non-members***
Some interviewees tended to see that the sorts of services that should be developed were ones which employed paid professionals to deliver technically skilled services.	Others thought that what is required is a structure which supports and encourages volunteers. This would seek to use and build general skills rather than technical skills.
Professional Emphasis	***Broader Amateur Emphasis***

Do you have any comments on these themes?
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Major Themes Veterans' Needs

This project also included a review of 12 needs analyses conducted recently with veterans, aged people and relevant service providers . All together the 12 needs analyses reviewed, obtained information from 729 veterans, 196 non-veteran aged people, and 53 providers of services to the aged. The review indicated that the greatest needs faced by veterans and aged people in the community were, **in order**:

1. Transport
2. Home and garden maintenance
3. Socialisation and loneliness
4. Safety and security
5. Information and education
6. Recognition / acknowledgment and commemoration of war service

Do you have any comments on these points?

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Other Themes

A number of other issues were noted and considered in drawing up the suggestion which follow on the next pages. These included the following:

- The RSL has a strongly localised organisational network. In terms of coverage of communities, it is probably the most localised voluntary organisation in the country
- Due to a number of factors such as history and membership and reputation, the RSL has the potential to gain access to significant finances (through funds held within the organisation, through art unions, through attracting government support and through its capacity to encourage corporate sponsorship).
- The Department of Veterans Affairs is supportive of moves by the RSL into the provision of community based aged care services.
- War Veterans Homes is a large and highly successful aged care residential service provider which comes under the umbrella of the RSL. As the caring arm of the RSL , it is a potential resource for expertise and infrastructure.
- Community Link is a small emerging initiative within the RSL that seeks to facilitate closer and more mutual links between veterans and their local communities. At this stage Community Link is focused on developing links between RSL sub-branches and local schools.
- Welfare Officers (who fulfil a number of human service functions at the sub-branch level) often report feeling overwhelmed by escalating workload of the voluntary position and express concern over legal issues such as liability and insurance.
- The issue of the different perceptions of appropriate roles of men and women in providing care for aged people was often expressed. It is important that perception of these roles be acknowledged and considered in any suggestions.

Do you have any comments on these points?

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Suggestions

A number of different models of operation were considered for the recommendations of this research project. The four major possibilities are considered below, the fourth which is explained in greater detail is the model which appears to be consistent with a number of important variables identified in the study. These suggestions identified in this study are:

1. Developing a formal organisation to deliver professional services (employing nurses and others) to support people in their homes.

This involves setting up a new organisation which would be a direct-care service provider. This would allow specific problems faced by individuals, particularly medical conditions and day to day care issues to be addressed. Such a specialist provider could tailor services to respond to members (and veterans) specific needs. The service might be aligned with War Veterans' Homes. It would provide an in-house agency to which Welfare Officers could make referrals to respond to any appropriate health, general care, maintenance or other domestic needs. Such a model:

- would be consistent with the RSL's organisational approach,
- would address specific problems faced by members,
- would provide a strong data gathering infrastructure while providing direct care
- would be highly professional
- would relieve pressures on welfare officers
- is consistent with the push to provide formal services

2. Developing an informal approach which is focused on skilling RSL officers to more effectively meet members' needs

This approach would acknowledge that many of the needs reported by veterans are not the sort that require formal professional services. The focus would be on providing the necessary skills at the local RSL sub-branch level, so that Welfare Officers (and hopefully many others) could more effectively respond to members needs. Such a model:

- would be a "grass roots" approach to service provision
- would address more social issues rather than individual or medical ones
- would be empowering and focus on care rather than structure
- would be strongly focused on building volunteers' skills and experience
- may increase demands on Welfare Officers and other members (particularly women?)
- is consistent with the RSL' s strongly localised network of sub-branches
- is consistent with the Community Link initiative

3. Developing an information based approach

This suggestion would acknowledge the importance of information to RSL members (particularly with regard to pensions, benefits and services available). It would provide the RSL with a technologically advanced and practical response to needs. Such an approach:

- is consistent with the RSL's organisational structure and be focussed at "grass roots" needs
- would address both individual and social issues
- would have as its strength data gathering, management and dissemination
- is focused on members needs but could be used by agencies providing services to members
- could be facilitated by volunteers but would be coordinated professionally

Do you have any comments on these suggestions?

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4. Developing an RSL foundation to address members needs in the community

The fourth suggestion, which I propose as my recommendation, would consist of the setting up of a perpetual fund in the form of a community based care foundation. Interest returns from the financial investments in such a perpetual fund would be made available in the form of small grants to respond to needs of RSL members in the community. In relation to the five continua, such an approach:

- Would enable the RSL to use it's strong organisational expertise and structure to develop and administer the dissemination of grants. Funding requests might be generated by Welfare Officers at the local community sub-branch level, which would maintain a "grass roots" focus.
- Would allow the RSL to purchase any services required to respond to their members individual needs while also enabling broader social issues affecting people in the community to be addressed through sponsoring the development of innovative new services.
- Would focus on care and helping people to have more control over their lives. In this structure a data base of required services would emerge. This information might be used in the RSL's lobbying to government
- Would assist RSL members by providing them with better care and services not currently available and at the same time benefit other aged people in the community by releasing community service providers to meet needs beyond the veteran population.
- Grants provided by a foundation might be used on an individualised basis (for example to employ a professional to deliver technically skilled services for an individual) as well as to supporting volunteers (for example to provide a seeding grant to a group of volunteers wishing to purchase a vehicle to respond to transport needs of aged members).

It is anticipated that funds for such a foundation might come from a variety of sources such as:

- capital from within the RSL (eg. sales of buildings, currently unused funds, etc.)
- funds held by sub-branches (sub-branches might choose to invest currently unused funds with the foundation with interest going to the foundation),
- government grants (such as DVA grants for innovative service delivery),
- corporate sponsorship in response to the RSL's strong community reputation
- individual donation or bequest.

Such a foundation:

- Would be administered by a board of directors who would set the criteria for the disbursement of funds
- It would be highly flexible to be able to respond to changing needs of members and not lock the organisation into employing staff and professionals.
- Might be used to fund services by local service providers (such as domiciliary nurses, home maintenance services, social groups, etc) to meet the needs of RSL members.
- Would support existing local services to more effectively meet members and veterans needs in their homes.
- Might cultivate new services or foster greater cooperation and coordination between services in meeting the needs of members and veterans
- Acknowledges that small scale grants promote job creation, diversify expenditure, support families and promote health care diversity.
- Would help to foster and build appropriate services in local communities and help the current aged and welfare services which are struggling, to more effectively provide services to members and veterans.
- Would assist Welfare Officers who currently report feeling unable to provide all the services required of them. It would enable them to have more of a monitoring role over services which are supported by the foundation

Do you have any comments on this suggestion / recommendation?

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Appendix 7.10.1

Participants in the ICACBR Forum, Toronto, Canada

Code	Descriptors
AD	No information provided
AF	Academic, Faculty of Medicine, University of Montreal, Canada
AI	Academic, CBR Specialist, University of Allahabad, India
BC	CBR Project Representative, Toronto, Canada
CA	No information provided
CB	No information provided
CM	Senior Policy Analyst, Canadian Government
DE	CBR Project Representative, Alberta, Canada
ER	CBR Project Representative, Bangladesh
ES	CBR Project Representative, Indonesia
FA	Chair ICACBR
GD	Representative, Disabled Persons International, Canada
HE	Academic, CBR Specialist, Queens University, Canada
HV	No information provided
JK	Academic, CBR Specialist, Manitoba, Canada
JL	Academic, CBR Specialist, Queens University, Canada
KA	CBR Project Representative, Nepal
KO	Director CBR Outreach Programme - Ontario, Canada
KR	No information provided
LH	No information provided
LT	Academic, CBR Specialist, Queens University, Canada
NI	Academic, CBR Specialist, University of Allahabad, India
NM	Academic, CBR Specialist, University of Calgary, Canada
MN	Postgraduate Student, Queens University, Canada
MP	Director ICACBR, Academic, CBR Specialist, Queens University, Canada
PP	CBR Project Representative, Toronto, Canada
RK	Academic CBR specialist, University of Bombay, India
RS	Academic CBR specialist, University of Bombay, India
SB	CBR Project Representative, Toronto, Canada
SL	CBR Project Representative, Toronto, Canada
YA	CBR Project Representative, Indonesia
YS	CBR Project Representative, Toronto, Canada

Appendix 8.2

Presentation of the Content, and Process of Obtaining Results in the Current Thesis

Content

In order to provide conceptually convincing evidence that the results and conclusions are grounded in the data, many qualitative researchers have relied on detailed quotes and examples of raw data (Strauss & Corbin, 1994). Such use of extended, unreduced text has been criticised as a weak and cumbersome form of display (M.B. Miles & Huberman, 1994). Fitzgerald (1997) stated that in qualitative reports, "The reader should not have to wade through the language to get to the ideas" (p. 57). At the other extreme, some qualitative researchers, seeking to avoid such unwieldy presentation of results have failed to provide adequate data to demonstrate the basis for their conclusions (M.B. Miles & Huberman, 1994), resulting in unconvincing research with poor replicability.

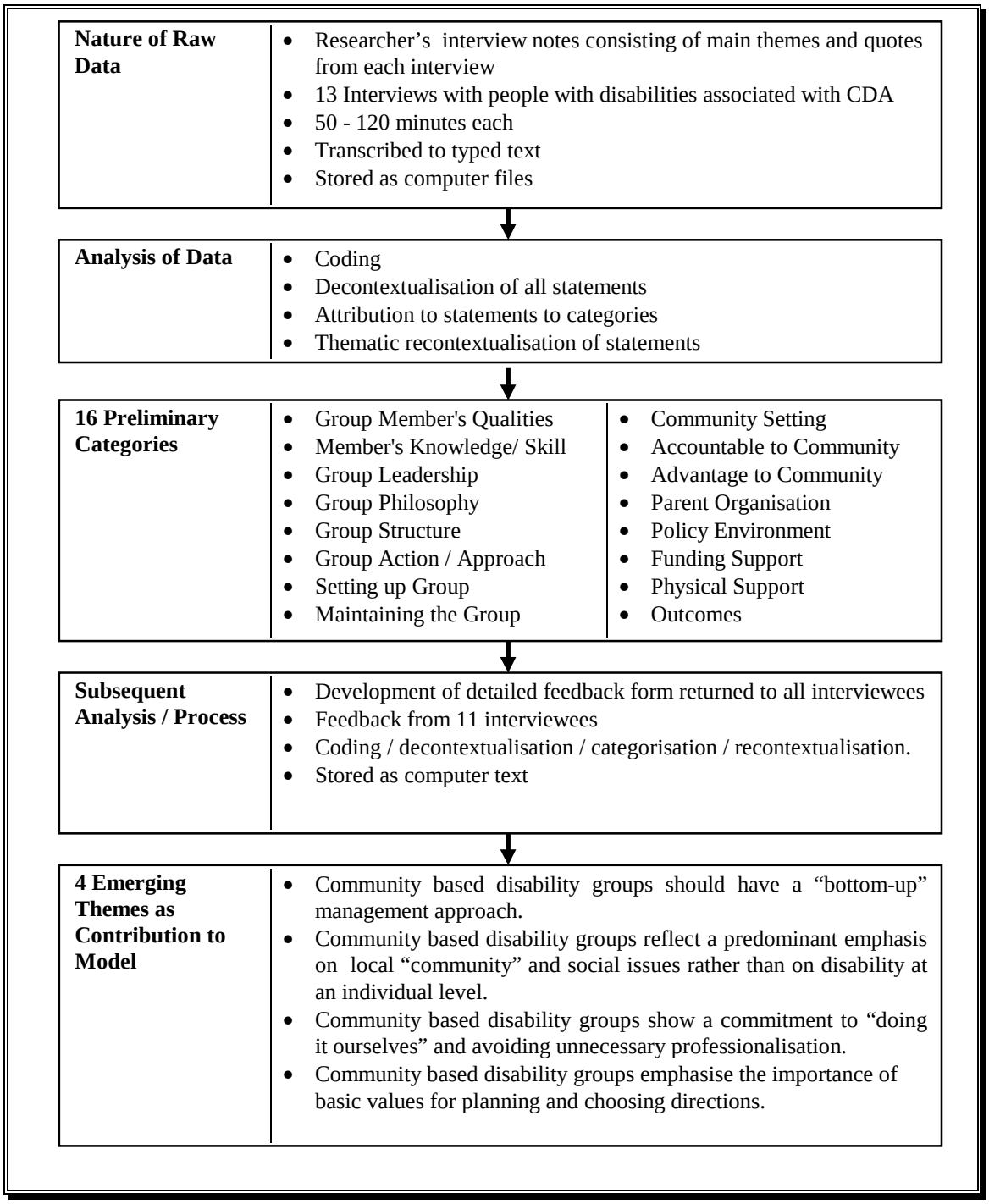
The present study sought to balance these potential flaws by constructing succinct summaries of results which maintain 'faithfulness to the substantive data' (Strauss & Corbin, 1994) through the use of data displays (M.B. Miles & Huberman, 1994). These data matrices, consist of assemblies of information in a systematic format. A goal of this form of presentation is to assist the reader to clarify key variables and to demonstrate how they emerged (M.B. Miles & Huberman, 1994). Presented as tables in the text of the current chapter, they enable the user to gain a flavour of the raw data, assist the user to follow the researcher's interpretations, and enable the user to begin to track the processes by which conclusions were drawn (M.B. Miles & Huberman, 1994). Data displays or matrices typically use specific quotes of raw data - usually representative exemplars of a point (M.B. Miles & Huberman, 1994), ideally with appropriate numerical measures of quantity, frequency or rating. For the present study, data displays were developed for each of the constructs generated at the points of synthesis.

Process

The present research also sought to develop and provide a systematised depiction of the conceptual evolution of the findings and the process by which the constructs and themes emerged. A particular advantage of such a depiction is that relationships between higher order categories and the data can be demonstrated. A method, known as a conceptual audit trail has been suggested, but as with data displays, there are few precedents (Rodgers & Cowles, 1993). It has been proposed that diagrams which depict a conceptual audit might be chronological and demonstrate the progressive phases of the research, covering content and analysis (Rodgers & Cowles, 1993). In the present study, diagrams depicting the conceptual process were devised and are presented in the appendices, linked to sections throughout this chapter.

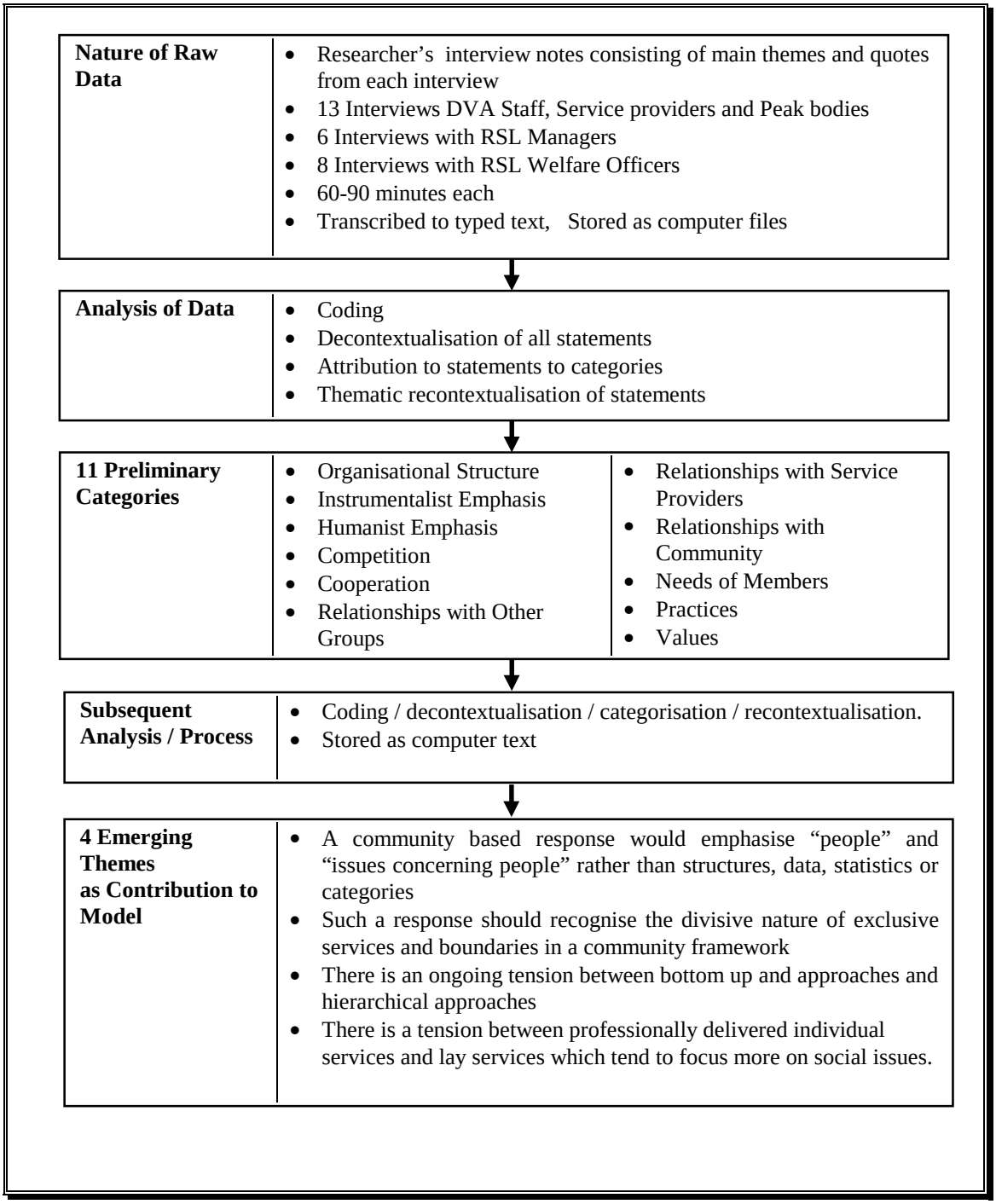
Appendix 8.3.1

Conceptual Audit Trail - Inductive Phase of Research at the Micro-system Level.



Appendix 8.3.2.1

Conceptual Audit Trail - Inductive Phase of Research at the Meso-system Level - Interviews



Appendix 8.3.2.2

Tabular Representation of Meta-analysis of 11 Needs Analyses of Veteran and Older Adult Service Users

Code	Number	Transport	Home & Garden maintenance	Socialisation Loneli-ness	Safety and security	Information Education	Recognition / acknowledge-ment / commemoration	Improve services - funding, coordination	Pension entitlements / advcacy legal	Recreatonal / Library	Improve community services not formal services	Health	Respite/ Support for carers	Counsellin g	More retirement villages
AB	15 a	•	•							•					
GL	50 a										•				
TS	105 av	•	•	•	•										
GA	16 av	•	•	•	•	•									
GU	25 a	•	•	•	•	•				•					
QK	376 v	•	•	•		•		•							•
VA	54 v *	•	•		•	•	•	•	•			•			
VN	50 v *	•	•	•	•	•	•	•	•			•	•		
VL	192 v		•						•	•				•	
VB	10 v	•		•	•		•								
VT	47 v	•	•	•							•				
Total	211 a 729 v	9	9	7	6	5	3	3	3	3	2	2	1	1	1

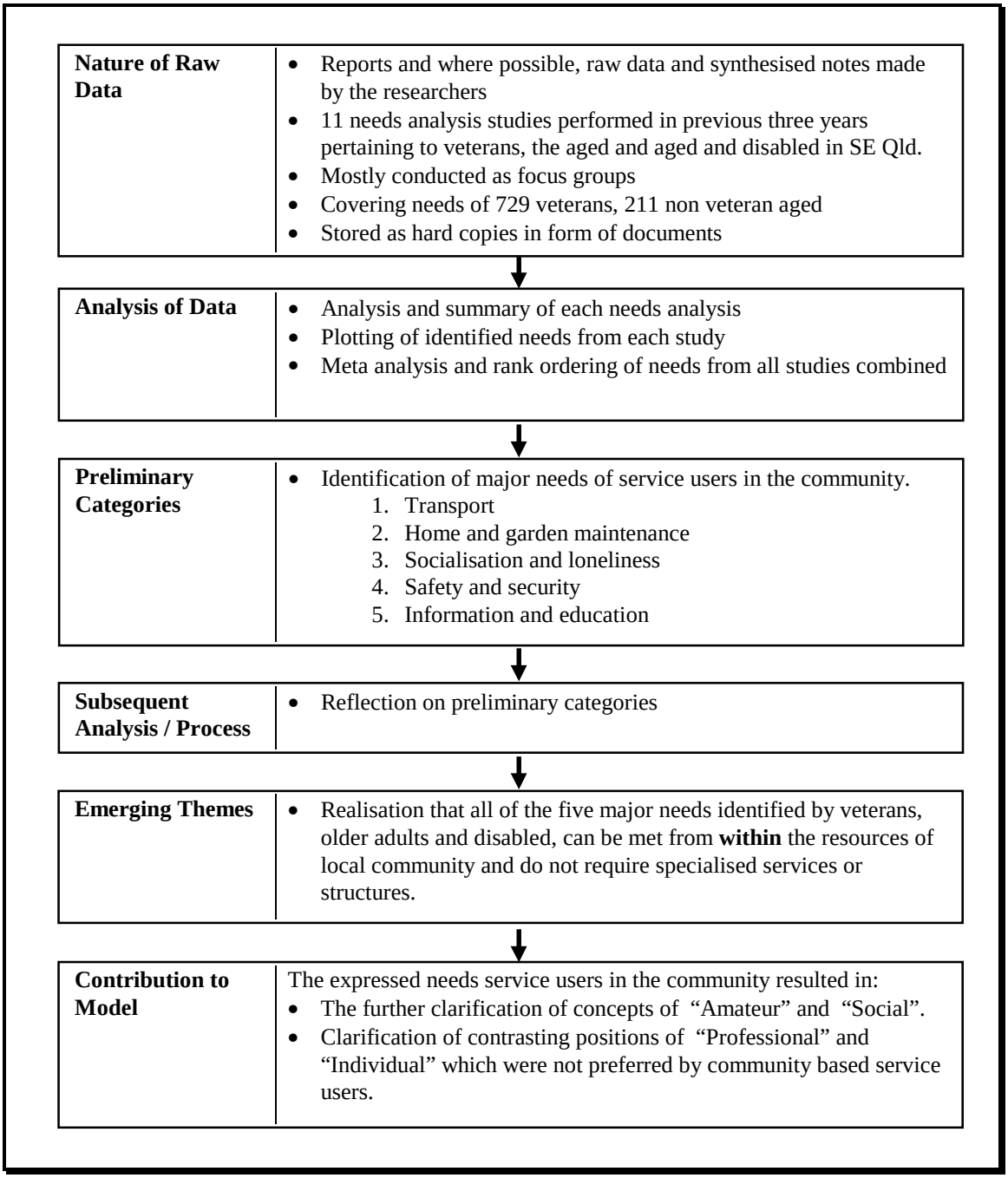
v - Veterans (including RSL Members)

a - Older Adults

* needs analysis also includes areas beyond SE Qld

Appendix 8.3.2.2a

Conceptual Audit Trail - Inductive Phase of Research at the Meso-system Level - Needs Analyses



Appendix 8.4
Data Sources and Explanatory Codes

Raw data for the present study was coded to aid interrogation of the data, cross checking and reference. A four part code was utilised (for example C ff js 123). This code consists of :

- The first capital letter which identifies the study from which the data came:

  C CDA Study

  R RSL Study

  I ICACBR Study (Queens University)

- The second set of lower case letters which identify the stage of the study or format of the data:

  ii Interview - Initial

  ff Feedback Form

  fg Focus Group

  qu Questionnaire

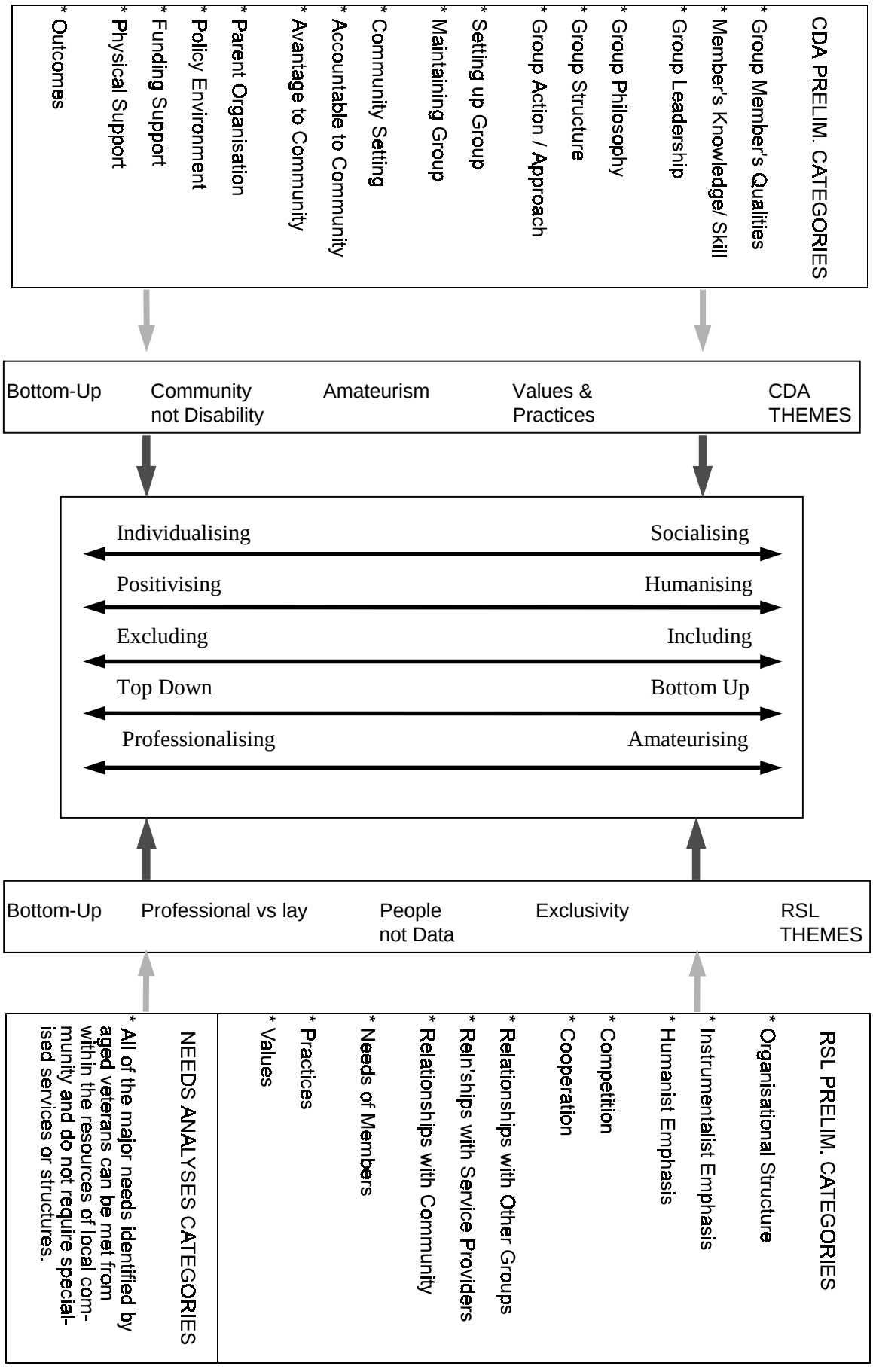
- The third part of the code, two lower case letters identify the person who was the data source:

  xx Code used for each person (see Appendices 7.3.1.2, 7.3.2.2, 7.3.2.3)

- The fourth part of the code identifies the line number within the NUD*IST computer document storage system used in the present study.

Appendix 8.4.2

Conceptual Evolution of the Themes and Influences that led to the Five Continua.



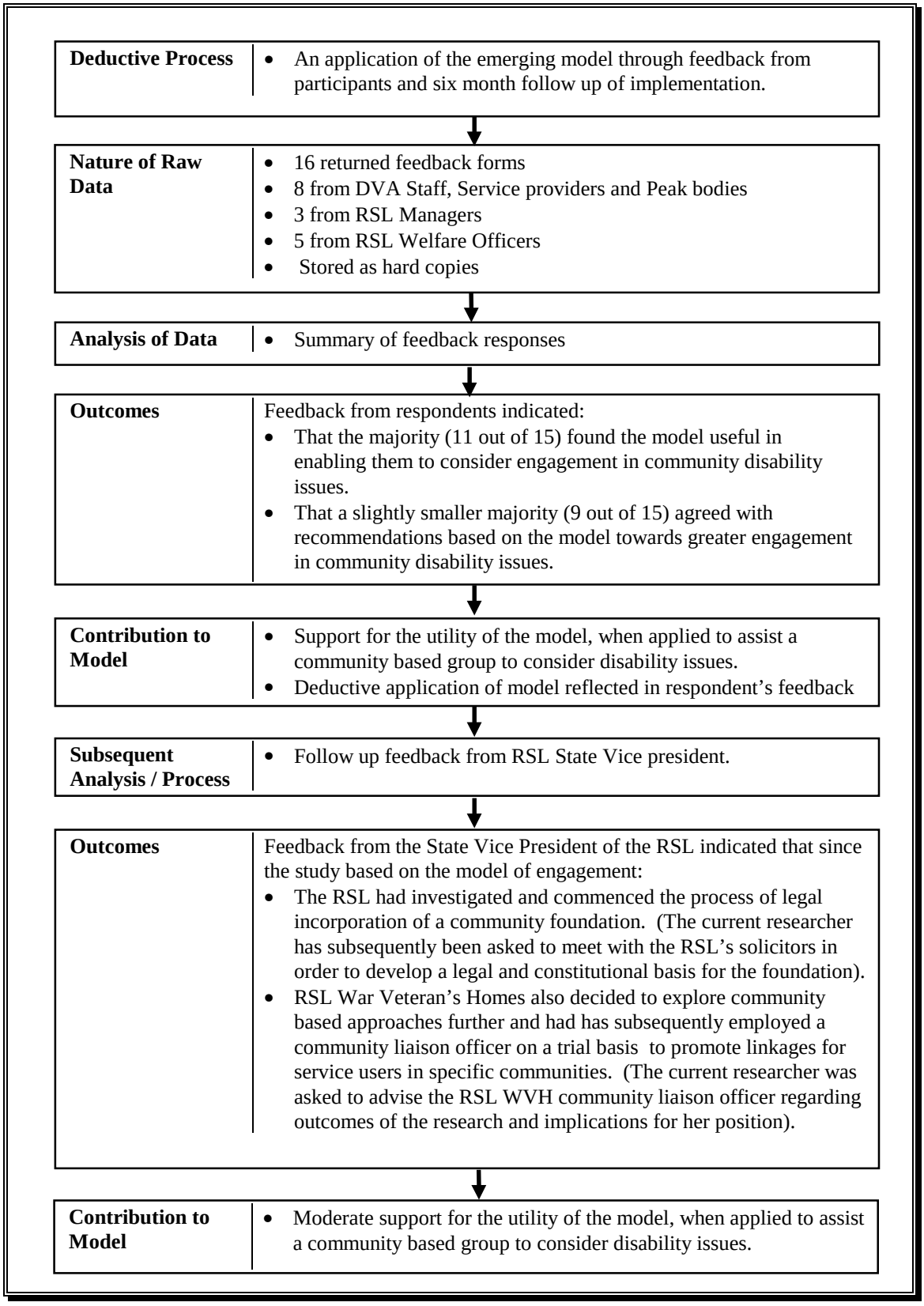
Appendix 8.5.1

Conceptual Audit Trail - Deductive Phase of Research at the Micro-system Level

Deductive Process	• An application of the emerging model through development implementation of a community development workshop.
Nature of Raw Data	• Researcher's notes from participant observation in the workshop. • Bi-monthly telephone follow-up with local chairperson over 12 month period • Stored as hard copies
Outcomes	Feedback from the local chairperson over a twelve month period indicated that since participation in the community engagement workshop, the group: • Has played an instrumental role in initiating a formal network of disability groups on the Sunshine Coast (previously the group had not done any networking). • Saw membership rise from two to a total of 19 comprising an active listed membership of 14 and average attendance of 6 at meetings. This showed some decline towards the end of the twelve month period. • Changed its management structure and meeting dates and format to be more flexible for members • Used the local media more effectively, developing press releases, holding public launches of beach access wheelchairs. • Promoted disability issues to the local community through organising a Disability Awareness Week • Held talks in local schools to promote disability awareness.
Contribution to Model	• Preliminary indication of the utility of the model, when applied in a workshop setting with a community based disability group.

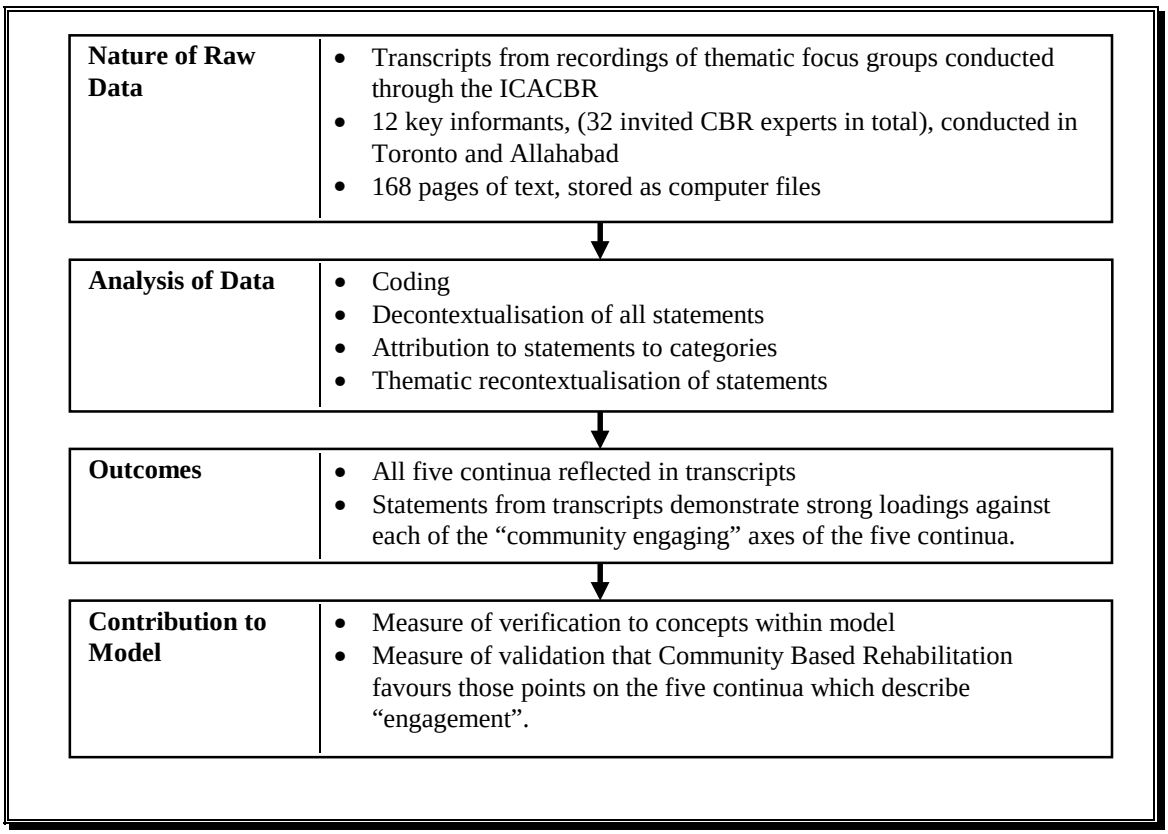
Appendix 8.5.2

Conceptual Audit Trail - Deductive Phase of Research at the Meso-system Level



Appendix 8.6.1

Conceptual Audit Trail - Verificatory Phase of Research - ICACBR Study



Appendix 8.6.2

Conceptual Audit Trail - Verificatory Phase of Research - Theory