



**MARRYING
COMMUNITY
DEVELOPMENT AND
REHABILITATION:
REALITY OR ASPIRATION
FOR DISABLED PEOPLE?**

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EDITED BY THERESA LORENZO



AFFIRM

ADVOCATE

ACCOUNT

ACKNOWLEDGEMENTS

This publication was made possible through funding from the Vice Chancellor's Strategic Goals Fund, University of Cape Town. This assistance is gratefully acknowledged. We are also grateful to the National Research Foundation's Thuthuka Programme, South Africa-Netherlands Research Programme on Alternatives in Development (SANPAD), the UCT Research Committee and UCT's Programme for Enhancement of Research Capacity (PERC) for funding.

We thank Jane Motau, senior CRW in Winterveldt, for co-ordinating the field-work component of the DYESL study, participating in the research workshops and co-authoring papers, as well as Catherine Makwela and Anna Madonsela for assisting with data collection.

The work of all members of the DYESL research team is acknowledged.

Appreciation is extended to Prof Roy McConkey for contributing the foreword and Margie Schneider, Lauren Graham and Hasheem Mannan for their contributions to improving the coherence of the chapters in this publication.

Published by Disability Innovations Africa, Disability Studies Programme, School of Health and Rehabilitation Sciences, University of Cape Town

Disability Innovations Africa

ISBN 978-0-9870203-1-4

First published 2012

Edited by Hilda Hermann

Design, layout and production by Bronwen Müller

Cover photo: Ezekiel Oweya

Printed by Megadigital, Cape Town



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AIMS AND INTENTIONS OF DISABILITY CATALYST AFRICA

The situation of disabled people calls for a catalyst to prompt the changes and shifts to the status quo that will ensure their participation as active citizens. Disability Catalyst Africa intends to create spaces for dialogue, debate and action among different players in higher education institutions, civil society organisations and government, particularly local government. It also intends to generate awareness on disability-inclusive development and facilitate self-representation of disabled people in academic and public forums.

The pillars are **affirmation**, **advocacy** and **accountability**. The series of Disability Catalyst Africa should appeal to those at every level who are able to influence disability inclusion in their institutions to make a difference in the lives of disabled people, their families and communities.

AUTHORS

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Jane Motau

Jane Motau has been a community rehabilitation facilitator in Winterveldt since 1992. She has supervised undergraduate students from the occupational therapy department at the University of Limpopo, Medunsa campus. She has worked extensively with children with disabilities and witnessed their progress



into adulthood. Her 20 years working in an impoverished areas has given her insight into post-apartheid progress and challenges in inclusive development.

The four authors of *Chapter Three: Stories from the field* were postgraduate students in Disability Studies at University of Cape Town. They were part of a research team, which included six academics, that explored the experiences of community disability workers in rural areas in South Africa, Botswana and Malawi.



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FOREWORD

2011 was a landmark year for disability. The first ever World Report on Disability was published jointly by the World Health Organisation and the World Bank. It maps out our current understanding of disability and the universal impact it has on the lives of individuals and societies in rich and poor countries alike. As Professor Stephen Hawking noted in his introduction to the report: It highlights the different barriers that people with disabilities face – attitudinal, physical, and financial. And he goes on to claim: Addressing these barriers is within our reach. Is he right? I suspect the answer is both Yes and No.



This book would unequivocally shout – YES! On these pages you are provided with a succinct summary of the actions that would make a real difference to all the world’s citizens who are called ‘disabled’; whether they be male or female, young or old, rich or poor. In common with the growing international consensus on community-based rehabilitation (CBR), the actions are grouped across five main domains – health; education; livelihoods; social inclusion and empowerment. For each domain, the authors identify the specific actions that would remove the barriers and produce better lives for upwards of 10% of our fellow citizens who live with disability. Moreover all their proposals are rooted in evidence from research and development studies undertaken mostly in Africa so they cannot be dismissed as either fanciful or unworkable. In a world that has recently seen barriers disintegrate between East and West in Europe; between black and white in Africa; is it too much to hope that in this new millennium, the barriers between ability and disability will also disappear?

What is stopping us? Put simply we lack the human resources and will-power to make it happen. Indeed the World Report on Disability arguably underplayed the significance of this vital component to progress. Relatively little space was devoted to critically examining current staffing arrangements in disability services and exploring how they might be aligned to the new thinking that the report espouses and to which disabled youth and adults aspire. Making the case that more personnel are needed is the easy part. More intractable are the debates around the roles such personnel will fulfil and their relationships with existing staff in mainstream and specialist services.

This book provides no universal solution but it does advance the debate in



two important respects. Firstly, it identifies and justifies the need for what has been termed ‘mid-level’ workers. They will fill the gap between the professionally qualified therapists, nurses, doctors and so forth who traditionally have been the bedrock of specialist rehabilitation services and the personnel who work in universal services such as primary health care and education, who could potentially assist children and adults with disabilities but lack the necessary time and expertise to address their specific needs.

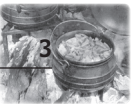
Secondly, the authors helpfully define the job roles and tasks such community workers could undertake. Particularly appealing is the marrying of community functions with rehabilitation functions so as to create a worker who embodies the skills needed to fulfil the intentions of modern community-based services to persons with disabilities. Moreover, this thinking is just as applicable to affluent countries as they adjust to times of austerity and begin to re-evaluate the value for money to be gained by investing in new staffing models in health and social services especially.

Nonetheless, these new styles of professionals have a daunting task ahead of them and much care is needed to ensure that they are adequately prepared for and supported in these new roles. Ongoing research and development projects led by the University of Cape Town will garner vital information to refine these endeavours nationally and internationally.

In the coming decades of this century, as these ideas turn from the pages of text into the pages of people’s lives, we will know better not only if barriers can fall but how best to demolish them. For that to happen action is needed now. It is hoped that this book will strengthen the will and determination of government officials, service providers, professional organisations and training agencies to embark on bold initiatives to give disabled persons the support they need, yet so often lack.

Roy McConkey

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N. Ireland and Visiting Professor, University of Cape Town.**



PREFACE

The intention of *Disability Catalyst Africa Series 2* is to provide an analysis of needs of disabled people to inform the current debate on human resources required to meet these needs, particularly for service delivery in rural areas or under-resourced urban areas. The needs are related to the prevention of impairments and the removal of barriers to accessing services and participating in schooling, work as well as social and political activities. Disabled people negotiate numerous transitions across their lifespan and each time they are faced with difficulty barriers to overcome. Service providers need to be aware of these challenges and contribute to removing them at a community level. Community development should integrate disability issues so that the rehabilitation of disabled people leads to their full inclusion as equal citizens in their communities.

However, Africa does not have the resources to support the training of profession-specific technicians or community workers for community-based services and development. This *Disability Catalyst Africa* consolidates disability research in one province in South Africa from which to draw valuable lessons to inform the training of generic community rehabilitation workers. The first paper uses the CBR guidelines as a framework to analysis current disability research in the Western Cape in order to identify the competences needed for community based service delivery. Rule's framework for curriculum development illustrates of the complexity of factors that need to be inform the training that is developed.

The second paper on community rehabilitation workers as catalysts for disability inclusive youth development shows the benefits of building research capacity of community based services to be able to monitor barriers to participation and the renewal of programmes to address these needs. A practitioner who is able to integrate rehabilitation outcomes into community development processes and who can co-ordinate access to resources for the disabled person and the family or caregivers will have addressed current inequities in the system.

The CBR Africa Network (CAN) was established in 2001 and has sought to foster collaboration between service providers and activists across sectors in government, civil society organisations and higher education institutions. Countries need active forums to share these experiences in how to meet and plan disability-inclusive service delivery strategies and programmes together to achieve equal opportunities for disabled people. Networking helps strengthen the country associations of CBR activists.



Marrying rehabilitation and community development affirms, advocates and accounts for actions of various stakeholders to monitor the rights of disabled people to be equal citizens. If this issue acts as a catalyst to higher education institutions, professional boards and their professional associations to debate and dialogue about the human resources for disability-inclusive development, its purpose would have been achieved.

Theresa Lorenzo

CHAPTER ONE

EXPLORING CAPACITY FOR DISABILITY-INCLUSIVE DEVELOPMENT

by Paul Chappell and Theresa Lorenzo



INTRODUCTION

Within South Africa's Department of Health, there has been a compelling commitment to address the comprehensive needs of people with disabilities at community level. Nationally, this has led to an emphasis on strengthening primary health care (PHC) services and community-based rehabilitation (CBR) as a coordinated entity with the support of secondary- and tertiary-level services (Department of Health, 2000). Within its commitment to improving public health services, the Department of Health is in the process of reshaping the provision of primary-level services and community-based care in line with the national Healthcare 2010 plan and the draft Healthcare 2020 policies.

Coinciding with these policies, government departments need to look at their human resource management to better address the needs of people with disabilities in local communities. This desktop analysis has been conducted to inform the development of the curriculum for a proposed Higher Certificate in Disability Practice, and career pathways for community disability practitioners. Although this desktop analysis has relevance to the whole of South Africa and other African countries, its main focus will be on the Western Cape as this is where the pilot study for the proposed community disability practitioner will commence. Using an array of published and unpublished reports and studies from 1994 to the present, this desktop analysis aims to provide an overview of:

- a needs assessment of persons with disabilities in the Western Cape (highlighting both positive and negative key issues in relation to working with individuals, families, groups and communities), and
- the potential competencies of community disability practitioners and how these coincide with existing rehabilitation professionals and members of the PHC team.

This desktop analysis begins by providing background information on disability and inclusive development. This is then followed by a brief discussion on existing disability and rehabilitation professionals. It then outlines the theoretical framework and international documents (i.e. UN Convention for the Rights of Persons with Disabilities – UNCRPD; CBR Guidelines) pertaining to the desktop analysis. The analysis will then look at each individual CBR component within the CBR Guidelines and highlight relevant UNCRPD articles addressing this issue. Each component also contains a presentation of findings from research in the Western Cape, which raise some key potential roles for the proposed community disability practitioners. Once all the components have been presented,



the discussion aims to integrate these findings into structuring a relevant curriculum for community disability practitioners. The desktop analysis ends with a proposed curriculum that draws out the roles of the proposed disability practitioners and how these complement and differ from those of other disability and rehabilitation professionals.

Integrating disability and rehabilitation into an inclusive development approach

Generally disability and rehabilitation services are recognised as having fundamental importance in improving the quality of life and functionality of people with disabilities in relation to their physical, psychosocial and vocational wellbeing (Department of Health, 2000; Kahonde et al, 2010). However, in light of the rising disability rights movement and introduction of the Millennium Development Goals (UN, 2000), more pressure is being put on disability and rehabilitation services to incorporate an inclusive development approach. According to Finkenflugel and Rule (2008:84), an inclusive development approach means that disability and rehabilitation services should aim to include people with disabilities in key mainstream development programmes and strategies. Key mainstream strategies include such issues as equalisation of opportunities, poverty reduction, self-advocacy and community development.

One such strategy that incorporates disability and rehabilitation into an inclusive development approach is CBR. Although its implementation differs from country to country, there is general consensus around its definition. According to WHO (2010), CBR is defined as ‘a strategy within a general community development for the rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of all people with disabilities’. Unlike other conventional disability and rehabilitation programmes, which tend to be merely medical and institutional, CBR is resolutely based within a community development framework. The rhetoric of CBR places equal emphasis on inclusion, equality and socio-economic development. It also recognises that rehabilitation is not a static feature of an individual, but rather a complex, multidimensional and changing experience (Schneider and Hartley, 2006).

As CBR is part of inclusive development, one of its key components is the reduction of poverty among people with disabilities. This focus coincides with other global initiatives that aim to address development and poverty, such as the Millennium Development Goals (UN, 2000). Several scholars, such as Loeb et al (2007) and Duncan et al (2011a), also recognise that there is a strong interaction between disability and poverty,



often in a vicious cycle. For instance, poverty could be a cause of impairment, such as inadequate nutrition, or it may cause disability through limited employment or education. Poverty is therefore seen as a complex struggle between impairment, oppression and marginalisation. Coleridge (2006) articulates that one of the first steps in tackling poverty is to give a voice and full participation to those most affected by poverty. Recognising disability as a rights-based issue and focusing on the concept of equalisation of opportunities could provide CBR programmes with an appropriate platform to address poverty alleviation.

The concept of equalisation of opportunities was first made prominent through the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (UN, 1994). The Rules define equalisation of opportunities as ‘the process through which the various systems of society and the environment, such as services, activities, information and documentation are made available to all, particularly persons with disability’ (UN, 1994:21). The Rules also provided extensive background for the development of the UN Convention for the Rights of Persons with Disabilities (UNCRPD) (UN, 2006), which South Africa ratified in 2008. Not only does the UNCRPD ensure equalisation of opportunities for people with disabilities, it also coincides with the conditions for disability-inclusive development as set out in Table 1. Only 20 of the 50 Articles from the UNCRPD are outlined in Table 1, as these were seen as areas of critical interest in the curriculum development of community disability practitioners.¹

DISABILITY AND REHABILITATION

Personnel

In order for disability-inclusive development approaches to be successful, consideration needs to be given to who will implement the service. Many authors describe three levels of personnel as perceived by WHO and UNDP: grassroots workers, mid-level rehabilitation workers and professionals (Wirz, 2000; Bury, 2005; Chappell and Johannsmeier, 2009).

Grassroots workers

Many rehabilitation programmes use grassroots workers who are often volunteers who may or may not have received some form of basic

TABLE 1: SELECTED ARTICLES FROM UN CONVENTION FOR THE RIGHTS OF PERSONS WITH DISABILITIES	
Article No.	Topic Area
5	Equality and non-discrimination
6	Women with disabilities
7	Children with disabilities
8	Awareness-raising
9	Accessibility
12	Equal recognition as a person before the law
16	Freedom from exploitation, violence and abuse
17	Protecting integrity
19	Living independently and being included in the community
20	Personal mobility
21	Freedom of expression and opinion and access to information
22	Respect for privacy
23	Respect for home and the family
24	Education
25	Health
26	Habilitation and rehabilitation
27	Work and employment
28	Adequate standard of living and social protection
29	Participation in political and public life
30	Participation in cultural life, recreation, leisure and sport

Source: UN, 2006

training. These include people with disabilities, family members and other community personnel such as teachers, community development workers and home-based carers (Rule et al, 2006). On reflection of CBR within an African context, some people argue that, given the absence of different services, families and communities were always a source of care and training for people with disabilities long before the 'officialisation' of the strategy (Asindua, 2002).

In the Western Cape, there have been a number of projects set up (mostly by non-governmental organisations) to try and increase the number of grassroots workers in the health and disability fields. For example, in 1987, the South African Christian Leadership Assembly (SACLA) based in Khayelitsha was responsible for setting up an eight-week training programme for community health and rehabilitation workers. This cadre of workers carried out daily home visits and participated in health discussions in the community and schools (Mbullu, 2005).

Since then, there has been a steady increase in community care and home-based carers in the Western Cape. According to Jebatha and Obrey (2011), these carers continue to be trained by and linked to non-governmental

organisations, but receive no formal supervision from health and rehabilitation professions at district level. This cadre of grassroots workers has largely resulted from two significant events: firstly as a major objective of the Expanded Public Works Programme Social Sector Plan (EPWP, 2004) to address the skills shortage and high unemployment levels in the country; and, secondly, as a cost-effective response to dealing with the care needs of an increasing number of people sick with AIDS-related illnesses. According to Jebatha and Obrey (2011), these workers are trained in the early identification of families in need, advocacy, counselling, patient care and support related to HIV and AIDS and other chronic conditions, and initiating and supporting income-generating projects.

Mid-level rehabilitation workers

Due to the expense and difficulties in getting professionals to work in the community, trained mid-level rehabilitation workers were incorporated into the delivery of community rehabilitation programmes (Rule et al, 2006). According to Wirz (2000), there appears to be no general consensus on the role of mid-level rehabilitation workers, although they could be seen as supervisors of grassroots workers or monitoring the implementation of CBR. The lack of a general definition has meant that most CBR programmes around the world have tended to adapt the role and training of mid-level rehabilitation workers according to local need.

In South Africa, a number of disability and rehabilitation programmes use mid-level rehabilitation workers, otherwise known as community rehabilitation facilitators (CRFs) or community disability practitioners. This cadre of workers has received a minimum of two years training in CBR. Despite the development of mid-level CRFs, not much attention was given to developing their career pathways when setting up the training programmes. Apart from being involved in the physical and social rehabilitation of people with disabilities, CRFs have been instrumental in raising awareness of disability issues among families and community members (Chappell and Johannsmeier, 2009). This is done by forming support groups, working with disabled people organisations (DPOs) and running community workshops. According to Peat (1997) and Rule et al (2006), having people with disabilities as community workers also helps provide positive role models to other people with disabilities in the community. Of the trained CRFs in South Africa, just over a quarter of them are disabled people or family members of disabled people (Rule et al, 2006).

Professionals

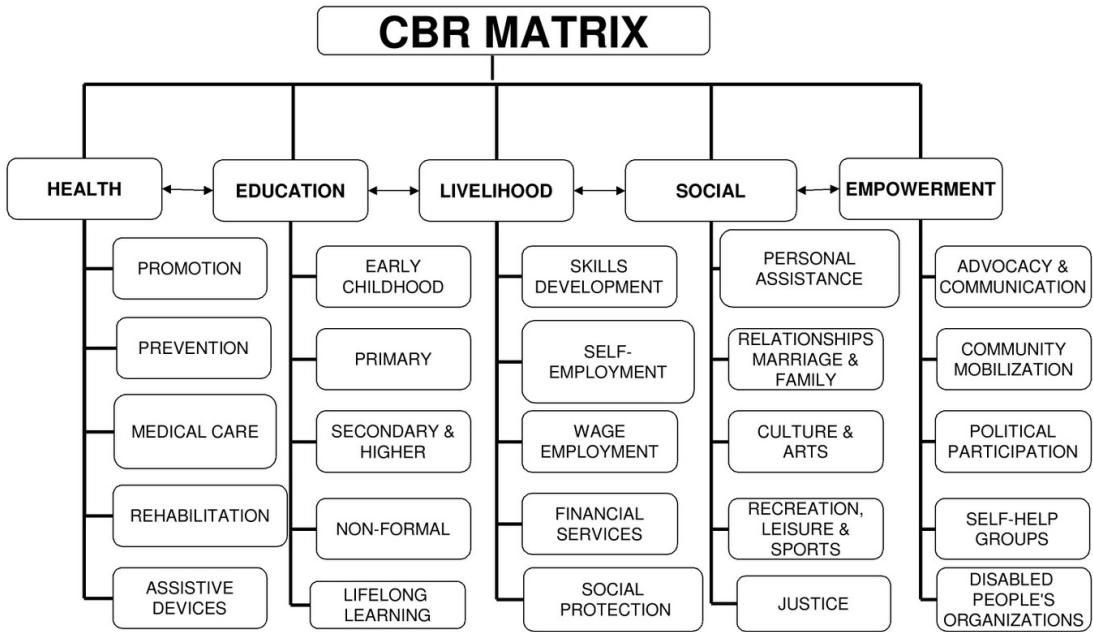
Unlike institutional rehabilitation programmes, the competencies of professionals in disability-inclusive development programmes tend to move away from direct, hands-on interventions and focus more on training mid-level cadre and offering specialised referral services (Finkenflugel and Rule, 2008:83). One of the primary aims of professionals in this context is to revise their practice and share their skills with people with disabilities and community members (Wirz and Chalker, 2002). In doing so, they need to recognise and respect the experiences and expertise of people with disabilities.

According to Bury (2005), the role of professionals in CBR appears to be difficult for some rehabilitation professionals who have always been perceived as the ‘experts’ and have usually dominated rehabilitation services. This difficulty could also be attributed to the fact that, during their professional training, the majority of professionals receive minimal input on CBR and the role of its cadres. Chappell and Johannsmeier (2009) found in their study, which explored the impact of CRFs, that this lack of knowledge led to poor supervision of mid-level rehabilitation workers and a limitation of their roles.

Theoretical framework

Given that disability-inclusive development is a broad construct and does not just pertain to physical rehabilitation, the CBR Matrix (WHO, 2005) and CBR Guidelines (WHO, 2010) were used as part of the theoretical framework for this analysis. According to Chappell and Johannsmeier (2009), the CBR Matrix and Guidelines conceptualise a visual framework for inclusive development that ensures people with disabilities play an integral part in all development programmes and strategies. Further, the CBR Guidelines are resolutely based upon the UNCRPD (UN, 2006). As depicted in Table 2, the five topic areas of health, education, livelihood, social and empowerment, each have five key elements that inform the implementation of CBR. Both the topic areas and their elements are underpinned by the principles of participation, inclusion, sustainability and self-advocacy. According to WHO (2010), these principles should inform and affect the activities within each topic area.

FIGURE 1: CBR MATRIX



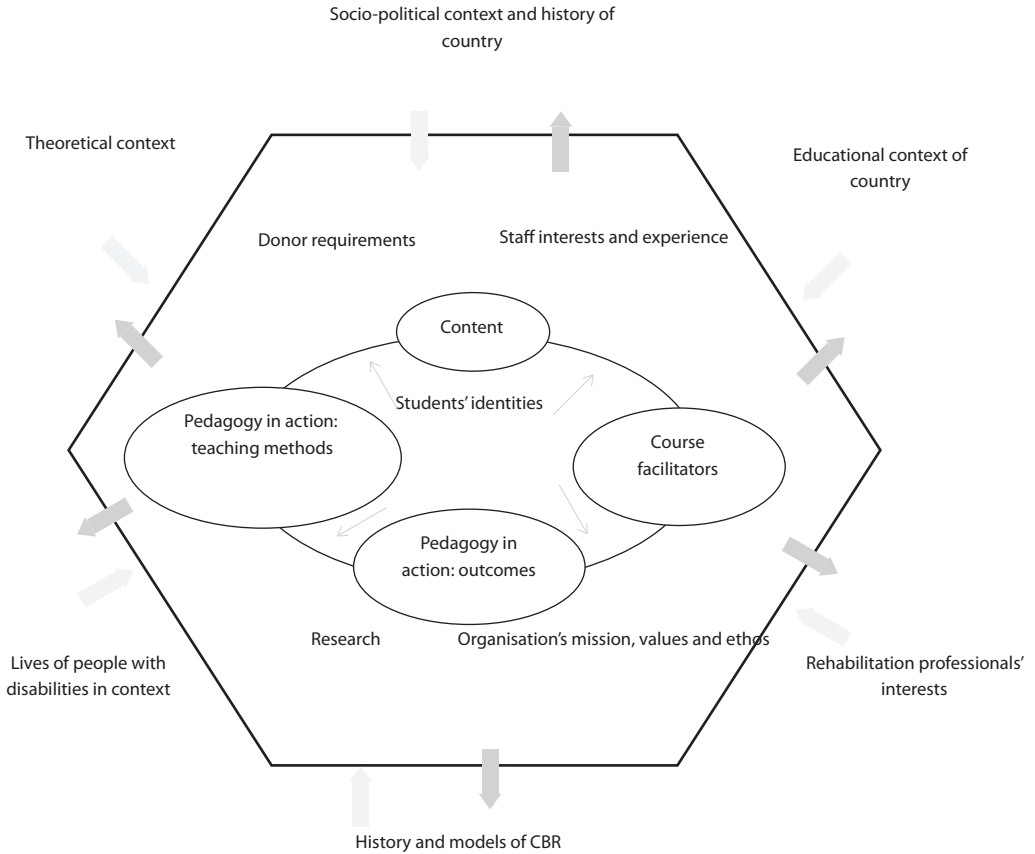
Source: WHO, 2005

The reason for incorporating the CBR Guidelines as part of the theoretical framework was two-fold. Firstly, it incorporates important key components that may enhance the quality of life of people with disabilities and their families. Secondly, the guidelines have a strong focus on empowerment through facilitation of the inclusion and participation of disabled people, their family members, and communities in all development and decision-making processes. Taking these factors into consideration, it was felt that the topic areas identified in the guidelines could form the basis of the curriculum and competencies of community disability practitioners.

A number of factors need to be taken into consideration when incorporating the CBR Guidelines into the curriculum development for community disability practitioners: theoretical context, staff capacity, etc. In view of this, Rule (2008) developed a conceptual framework that addresses some of these issues, which was included as part of the framework for this analysis. According to Rule (2008:250) the organisation or training institution offering the curriculum is both subject to external factors as well as itself influencing the external environment (see Figure 2).

Some of the external factors that may influence curriculum development include the socio-political context and history of the country, the lived experience of disability, educational context and other rehabilitation professional's interests. Rule (2008:252) goes on to indicate that, although

FIGURE 2: EXTERNAL FACTORS AFFECTING CURRICULUM CONSTRUCTION



Source: Rule, 2008

each external factor is indicated as a discrete entity in this framework, there is interaction among these factors that may also affect the student and the training organisation, and thus the curriculum.

These questions will be answered:

- What are the dominant models of rehabilitation and disability programmes that are practised?
- Which of the key issues facing people with disabilities will the community disability practitioners be able to address?
- How will the scope of practice and competencies of community disability practitioners differ from/be the same as those of existing home based carers/community development workers/therapists/other members of the PHC team?
- How will the proposed community disability practitioners work with existing rehabilitation professionals and PHC personnel, existing and proposed health teams?

- How will the certificate curriculum work with/listen to issues raised by the disability movement?

HEALTH COMPONENT

According to the CBR Guidelines (WHO, 2010), in order for people with disabilities to achieve their highest attainable standard of health they need to have good access to health care and rehabilitation services close to their homes. Furthermore, they and their families should become active participants in the planning of health and rehabilitation interventions. In line with the Guidelines, the health component contains the five key elements: promotion, prevention, medical care, rehabilitation and assistive devices. This coincides with the UNCRPD (UN, 2006), which clearly states in Article 25 that States are required to ‘recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination of disability’. Furthermore, with Articles 20 (accessibility) and 26 (habilitation and rehabilitation), State parties should undertake to ensure that people with disabilities are able to access health services that are gender-sensitive, including health-related rehabilitation.

Health promotion and prevention

According to the CBR Guidelines (WHO, 2010), ‘People with disabilities and their families should be provided with knowledge, skills and support to assist them to achieve good levels of health.’ It goes on to state that ‘Health promotion materials and programmes should be designed or adapted to meet the specific needs of people with disabilities and their families.’ However, although people with disabilities living in the Western Cape appear to be aware of their impairments, many are excluded from particular health promotion and prevention activities. This was highlighted in one particular study that looked at HIV and AIDS knowledge and perceptions among people with disabilities living in Nyanga. In their study, Wazakili et al (2006) found that people with disabilities had very limited factual knowledge about sexuality and HIV and AIDS. Parents in the study limited sexuality talk with their disabled offspring to hygiene matters only. A similar situation was identified among adolescents with physical impairments attending special schools in the Cape Town Metro. In comparison to a national survey on adolescent sexual practice, Maart and Jelsma (2010) found that adolescents with physical impairments were significantly more sexually active than their non-disabled peers.

Furthermore, those with physical impairments were less likely to use condoms than their non-disabled peers. Although the issue of HIV and AIDS has played a major component in the scope of practice for home-based carers, very little focus has been given to disability, sexuality and HIV and AIDS. Therefore this continues to be a major gap in relation to health promotion that is not being addressed by PHC teams.

In relation to the involvement of caregivers of people with disabilities, it was interesting to observe that a number of studies reported that parents lacked information about the health condition of the person with a disability in their family. For example, Keikelame and Swartz (2007) found in a qualitative study among parents of children with epilepsy living in Khayelitsha that they were poorly informed about epilepsy, its causes and its management. As a result, this may have led to poor adherence and parents undermining their child's rights to make informed decisions and choices. A comparable situation was identified by Botha (1995), who found that mothers of pre-adolescent daughters with spina bifida lacked information about spina bifida and expectations of the development of the child. Furthermore, the mothers also reported very little coordination in services for children with spina bifida.

Access to rehabilitation services

In critically reviewing health-related studies completed in the Western Cape, it appears that, overall, there is general satisfaction with regards to access to rehabilitation services by people with disabilities. For instance, Kahonde et al (2010) found in their study that people with physical disabilities reported satisfaction with access to rehabilitation services and the way in which rehabilitation service personnel interacted with them. Apart from demonstrating positive attitudes, participants indicated that rehabilitation staff supported them emotionally. Similar results were found in the Maart et al (2007) comparative study of people with disabilities living in the Eastern and Western Cape. The results of these studies coincide with those of Patterson et al (1999:86), which states that 'the attitudes of health workers towards people with disabilities are thought to exert a significant influence on the quality of client treatment'. This highlights the fact that not only is it important for community disability practitioners to have the necessary technical skills, but also that attention needs to be given to their attitudes towards people with disabilities and their interpersonal skills.

Despite the satisfaction with access to health and rehabilitation services, various studies have indicated that getting transport to health care

facilities in the Western Cape proves to be a serious problem for people with disabilities (Kahonde et al, 2010; Maart et al, 2007; Eide et al, 2008; Jelsma, 2007; Duncan et al, 2011a). For example, Kahonde et al (2010) and Maart et al (2007) found in their studies that people with disabilities living in urban and peri-urban areas indicated that taxis or buses would not stop for them and that they had difficulties accessing overcrowded public vehicles. As a result of poor public transport, many people with disabilities indicated having to hire transport from neighbours or family for a small fee, which strained them financially. A similar scenario was identified among households with individuals with psychiatric impairment. For example, Duncan et al (2011a) found that, when an individual experienced a severe psychotic episode at night, caregivers incurred taxi fare costs (at after hours rates) to travel to medical emergency units at provincial hospitals. In view of these studies, the consequences of inaccessible public transport and the cost of getting to health centres means that many people with disabilities miss follow-up rehabilitation appointments and vital health information. According to Jelsma (2007), these gaps can have a significant influence on the perception of health-related quality of life among people with disabilities.

Another significant gap that has been identified is the involvement of family members/caregivers in the rehabilitation process, in particular the transition from hospital to community care (Kahonde, 2010). This lack of family/carer involvement has resulted in their stress and frustration in not understanding the significance of home programmes. Allen et al (1995) found a similar situation among caregivers of children with severe intellectual impairments in Paarl-East. Their quantitative study found that many of the children with severe intellectual disabilities who took part in the study had major functional difficulties (e.g. speech problems, inability to dress or walk). Their caregivers appeared to be unaware of the severity of their child's impairment or what was required to assist them.

Considering the first caring environment experienced by a person with a disability is usually their family, Finkenflugel (2006) argues that family members should be involved in all aspects of the rehabilitation process. This is an important aspect that needs to be considered within the curriculum, especially if services are to be more community-based. Part of the service needs to include support to family members as this is where the 'burden of care' often falls. The benefit of educating caregivers is highlighted in a study conducted by Behr (1997) that evaluated two CBR programmes for disabled children and their caregivers in the Western Cape. The programmes consisted of weekly meetings, which included physiotherapy interventions to assist the functional abilities of children through activities that caregivers could include in daily home

care. As a result of this intervention, caregivers not only reported being more knowledgeable about dealing with their child's impairment, but were also more confident in addressing negative perceptions of disability in the community.

Assistive devices

According to the CBR Guidelines (WHO, 2010), access to assistive devices are an important part of any development strategy. For example, without assistive devices,³ many people with disabilities would be unable to function independently or gain an education or employment, continuing a cycle of poverty. The UNCRPD (UN, 2006) makes it very clear in Articles 4, 20 and 26 that States should promote the availability of assistive devices and provide information about them.

In the Western Cape, although most people with disabilities reported being satisfied with access to assistive devices (Kahonde et al, 2010), in some cases people with disabilities did not receive devices due to poor human resource management. This is highlighted in a longitudinal study conducted by Kumurenzi (2011) in a public rehabilitation institution in the Western Cape. It was found that, due to poor documentation and record-keeping by therapists, a number of people with disabilities were not referred properly for assistive devices or other support services. In cases where they were referred, therapists indicated that they were often unable to follow up on whether these referrals were successful due to their workload. Many therapists also reported being unable to follow up on clients who had defaulted on treatment or home programmes. In analysing these results critically, it appears that there is a breakdown in the continuum of care between tertiary-level institutions and community. In addition, given the identified environmental barriers to accessing health care facilities (e.g. poor access to public transport, lack of finances), it is understandable why many people with disabilities may fault on treatment or following up on the collection of assistive devices. In this context, there is a great need to improve on the continuum of care in order to encourage the social development of people with disabilities.

Relating this to the potential competencies of the proposed community disability practitioners, it is possible that they could play a key role in the continuum of care between institutions and community. For example, community disability practitioners could be responsible for carrying out follow-up visits on people with disabilities to ensure the uptake of assistive devices and home programmes. They are also in the advantageous position of being able to refer individuals to rehabilitation therapists and other support services.

EDUCATION COMPONENT

According to the CBR Guidelines (WHO, 2010), the goal of the education component is to enable people with disabilities to access education and lifelong learning, leading to fulfilment of potential, a sense of dignity and self-worth, and effective participation in society. In order for this to be accomplished, it is essential that local educational institutions are made accessible and welcoming to youth and adults with disabilities, along with the relevant support services. The education component contains five key elements: early childhood, primary education, secondary and higher education, non-formal and life-long learning. This coincides with the UNCRPD (UN, 2006), which clearly emphasises in Article 24 that 'State parties should ensure an inclusive education system at all levels'. Furthermore, 'State parties should also ensure that effective individualised support measures are provided in environments that maximise academic and social development, consistent with the goal of full inclusion.' In analysing the education component critically, although at first it appears to have very little to do with the health sector, in fact it is very closely related. For instance, many children and adults with disabilities require access to assistive devices to enable them to function independently in educational institutions (WHO, 2010). In relation to scope of practice, Chappell and Johannesmeier (2009) found that CRFs proved to be effective personnel in advocating for children with disabilities to access mainstream education. This was done by working closely with families and educators. This desktop analysis revealed the apparent lack of research on inclusion in higher education, lifelong learning and non-formal learning.

Primary and secondary education

Despite the CBR Guidelines and UNCRPD, a large proportion of young people with disabilities in South Africa are still not in formal education (Department of Education, 2001). Schneider (2000) reports that youth with disabilities under the age of 18 are more likely to only reach primary-level education and even less likely to reach Grade 12. In reflecting on this situation critically, it appears that policy guidelines on inclusive education are not really being implemented at school level and demonstrate a concerning gap between policy formation and implementation.

Some studies have explored the experiences of children with disabilities in the educational system in the Western Cape. One in particular explored the functionality of primary school learners with paraplegia in mainstream schools. In this study, Vosloo (2009) found that many of

the learners with paraplegia reported that mainstream schools did not provide enabling environments, which meant they were restricted from attending certain classes and activities. These restrictions were caused by inaccessible transport, architectural barriers, lack of assistive devices, and teacher/teacher assistant's lack of medical and disability information. The lack of awareness surrounding impairments was also found to be a leading cause of stress among educators who had learners with Down's syndrome (Engelbrecht et al, 2001) or epilepsy (Lupondo, 2010) in their classroom. Although the needs of learners with disabilities and educators are important, it is essential to consider the needs of parents too. For instance, in a quantitative study looking at ways of integrating therapists to support inclusive education in the Western Cape, Struthers (2005) found that parents required emotional support, advocates to work with them in support of their children addressing physical and attitudinal barriers, and developing a supportive community.

Gcaza (2001) conducted a qualitative study that looked at the impact of inadequate mobility devices on special school learners with physical impairments in the Western Cape. The study found that, as a consequence of not having access to assistive devices, many of the learners with physical impairments felt deprived of their right to good education, social and rehabilitation services.

Recognising the broad construct of rehabilitation, Vosloo (2009) recommends that, in order to encourage mainstream schools to develop inclusive environments, they should receive medical and disability information from a multi-disciplinary team. This team should consist of health and rehabilitation professionals, parents and educational specialists. In providing information to mainstream educators, the team can then assist schools in developing structured educational plans inclusive of the needs of learners with disabilities.

LIVELIHOOD COMPONENT

According to the CBR Guidelines (WHO, 2010), people with disabilities should be able to gain a livelihood, have access to social protection measures, and be able to earn enough income to lead dignified lives and contribute economically to their families and communities. The livelihood component contains five key elements: skills development, self-employment, financial services, wage employment and social protection. This coincides with the UNCRPD (UN, 2006), which stipulates in

Article 27 that ‘State parties should recognise the rights of persons with disabilities to work on an equal basis to others’. Similar to the education component, the livelihood component is very much linked to health and functionality, and should form a critical requirement of the community disability practitioner.

Skills development

Under the element of skills development the CBR Guidelines (WHO, 2010) recognise four main types of skills: foundation skills, technical and professional skills, business management skills and core life skills. By gaining a combination of these skills, it is envisaged that youth and adults with disabilities should have equal opportunities to decent waged or self-employment prospects. The CBR Guidelines (WHO, 2010) also stipulate that rehabilitation personnel should play a key role in identifying and promoting opportunities for persons with disabilities to gain skills.

In analysing disability and rehabilitation literature, it appears that skills development for people with disabilities remains an area of concern. This was particularly found in a national comparative study, which looked at the livelihoods of non-disabled youth and youth with disabilities. A study by Lorenzo and Cramm (2012) reports that in nine sites across five provinces a significant number of youth with disabilities indicated a lack of access to skills training and lifelong learning as barriers to gaining meaningful employment. Despite the availability of various skills-development programmes, young people with disabilities reported a lack of finances as the main obstacle to accessing these programmes. In light of the lack of finances, it is clear that the challenges faced by youth with disabilities are not too dissimilar to others living in poverty. However, given the negative misunderstandings about disability and the often inaccessible physical environment, the issue of poverty is more prominent amongst youth with disabilities.

Access to employment (waged, self- and entrepreneurial)

Given the complex struggle between poverty and disability, access to employment should always be considered an option for people with disabilities. For this reason, various national policies in South Africa, such as the Employment Equity Act (1998) and the White Paper on an Integrated National Disability Strategy (1997), advocate for the creation of work opportunities for persons with disabilities. These may be positions within the open labour market or the development of small, medium and

micro enterprises and community entrepreneurship projects (Lorenzo et al, 2007). Not only do these employment strategies assist in addressing issues of poverty, they also increase awareness of people with disabilities in civil society. Despite these policies, people with disabilities continue to face barriers such as discrimination from employers, which not only exacerbates their alienation from civil society, but also their financial insecurity. This is highlighted in a study of five individuals with psychiatric impairments living in peri-urban areas of Cape Town. In this study, Duncan et al (2011a) found that some of the participants lost their jobs or were unable to hold down permanent employment either due to illness or unregulated labour practices (i.e. they were retrenched at the onset of a psychiatric episode). This lack of income not only impacted on the family household, but also on the individual with a psychiatric impairment's self-esteem in not being able to provide financially for the family. Taking into account the difficulties people with disabilities have in accessing the open labour market, Van Niekerk et al (2011) explored the use of supported employment as a potential strategy to facilitate employment. Supported employment consists of a range of activities such as individual work assessments, job matching, finding and coaching. According to Van Niekerk et al (2011:85), the assumption made by supported employment is that, with the right intensity of support, 'even the most severely disability can (should be) integrated into competitive employment'.

In lieu of poor access to employment in the open labour market, and in an attempt to ensure financial security, several studies completed in the Western Cape demonstrate how individuals with disabilities are operating in informal income-generating activities. For instance, Duncan et al (2011a) found in their study that all five individuals with a psychiatric impairment were involved in informal economy activities, depending upon their fluctuating mental health. Interestingly, in a mixed-method study exploring the interplay between poverty, disability and occupation, Watson (2007) found that women with disabilities living in Khayelitsha and Nyanga were more likely than men to undertake entrepreneurial activities to supplement their grant. A similar scenario was reported by Lorenzo (2005) among women with disabilities living in Khayelitsha.

Social protection

According to UNCRPD (UN, 2006) Article 28, States should 'recognise the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability'. In this respect, persons with disabilities should have the same access to social security measures (e.g. grants and poverty-reduction programmes)

as others in the community. Through analysing studies carried out in the Western Cape, it appears that the majority of people with disabilities requiring social support are able to access disability grants without difficulty (Jelsma et al, 2008; Loeb et al, 2008). It was found that access to disability grants played a significant role in relation to household incomes and in changing the perceptions of those with disabilities (Loeb et al, 2008; Duncan et al, 2011b). In analysing the recipients of disability grants, Jelsma et al (2008) found that the majority tended to have greater functional problems related to physical impairments. Other conditions, however, such as chronic pain or cognitive or sensory problems tended not to be recognised as grounds for receiving the grant. Given this situation, clearer criteria need to be formulated on who can access disability grants. As put forward by Jelsma et al (2008), the International Classification of Functioning, Disability and Health (ICF) may provide a useful framework within which to formulate such criteria.

On critical reflection of the provision of social grants, some studies have highlighted a negative consequence of long-term dependence on disability grants. For example, in a study carried out in the Cape Metropole, Van Niekerk et al (2011) found that people with disabilities felt that the current grant system in South Africa actually creates a disabling environment. This point was reiterated by Engelbrecht and Lorenzo (2010), who found that employment in the open labour market was often null and void for individuals with disabilities dependent upon social grants. In the context of wanting to encourage economic empowerment among people with disabilities, these studies highlight the need for careful revision of current social security legislation and guidelines in South Africa. This situation also highlights the need for more comprehensive work assessments as outlined by Van Niekerk et al (2011).

SOCIAL COMPONENT

Within any civil society, being actively involved in the social life of one's family or community plays a significant role in the development of a person's identity, self-esteem and quality of life. This is also captured in the CBR Guidelines (WHO, 2010), which recommend that people with disabilities should also have meaningful social roles and responsibilities in their families and communities. In this context, people with disabilities should be recognised as valued members of their families and capable of making positive contributions towards the development of their communities. The social component contains five key elements: relationships,

family and marriage; personal assistance; culture and arts; recreation, leisure and sports; and access to justice. These coincide with UNCRPD (UN, 2006) Article 19, which states that ‘State parties should recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.’

Despite the recommendations put forward by the UNCRPD, critical reflection of the literature indicates that people with disabilities living in the Western Cape do not experience full inclusion in the community. For example, Maart et al (2007) found that people with disabilities living in peri-urban areas of the Western Cape experienced significant barriers in relation to accessing housing, food sources and legal services. Duncan et al (2011a) found that the resilience of the household is further compromised when an individual has an untreated psychiatric impairment.

Personal assistance

Many people with disabilities often require the help of a personal assistant to enable them to participate fully in the community. Frieg and Hendry (2002) found in their quantitative study in the Western Cape that very few people with disabilities dependant on fulltime caregivers were recipients of or had knowledge of the governments Grant in Aid.⁴ As a result, people with disabilities had to depend upon family members, which, in turn, increased the stress and burden of care on families. Critical analysis of the results not only highlights the continual lack of support for caregivers, but also a failure of the PHC team to pass on essential information to families of persons with disabilities.

Relationships and marriage

According to Article 23 of the UNCRPD (UN, 2006), ‘State parties should take effective and appropriate measures to eliminate discriminations against persons with disabilities in all matters related to marriage, family, parenthood and relationships, on an equal basis with others. In review of the literature there are very few studies that address people with disabilities living in the Western Cape and their experiences of relationships and parenthood. However, one particular study conducted by Wazakili et al (2006) points out that the influence of unemployment and poor community attitudes impacted on how people with disabilities living in Nyanga form relationships and their choice of sexual partners. Not only do these results reflect the inter-connection of the CBR components,

they also point out the lack of support from rehabilitation personnel surrounding issues related to sexuality, relationships and parenthood. As aptly suggested by several authors, although easier to engage in discussions surrounding the inaccessible environment, the topic of disability and sexuality continues to be a silent taboo (Finger, 1992; Sait et al, 2009).

Reflecting on this situation critically, if we are to recognise sexuality as an important component of people with disabilities lived experience, it needs to be included in the curriculum of all levels of health and disability practitioners.

Recreation, leisure and sport

The CBR Guidelines (WHO, 2010) clearly outline that involvement in recreation, leisure and sport activities can play a significant contribution not only towards the health and wellbeing of people with disabilities, but also in strengthening their inclusion in the community. Studies within the Western Cape, however, reveal that access to recreation and sporting activities for people with disabilities are often inadequate. For example, in a study looking at access to recreational activities for students with disabilities at the University of the Western Cape, Wright (2007) found that there was a lack of disability awareness among administrative staff, which meant that a lot of recreational facilities were inaccessible. Furthermore, students with disabilities reported lack of finances as another contributing factor towards their lack of involvement in recreation and sports. The barriers experienced by learners with disabilities in accessing recreational facilities are also found among other people with disabilities living in peri-urban communities of the Western Cape. This has been highlighted indirectly by Maart et al (2007), who found that many people with disabilities avoided places that had stairs, curbs, escalators and uneven terrain. These barriers effectively reduced their social interaction with others, which also impacts on people with disabilities in terms of forming meaningful and intimate relationships with others (Shakespeare, 2000).

Access to justice

Raising awareness around laws and legislation that may affect people with disabilities is an important aspect of disability-inclusive development. According to the CBR Guidelines (WHO, 2010), without access to justice the voices of people with disabilities are not heard and they are then unable to exercise their rights, challenge discrimination or hold decision-makers accountable. As a result, they become more vulnerable and marginalised.

In analysing the few studies that looked at people with disabilities access to justice in the Western Cape, a number of disabled people reported several barriers such as inaccessible buildings and the attitude of legal staff (Maart et al, 2007). Barriers to justice are particularly noted among those with intellectual disabilities and the reporting of sexual offences. For example, Dickman et al (2006) report that due to misconceptions surrounding disability and sexuality, and the lack of disability awareness among police and legal professionals, it has been uncommon for cases of sexual abuse of those with intellectual disabilities to go to court. Despite this, Dickman et al (2006) also demonstrate how a project run by Cape Mental Health has effectively educated prosecutors and detectives about the needs of individuals with intellectual disabilities requiring legal services. As a result of this programme, individuals with intellectual disabilities and their families reported an improved satisfaction with legal services. In reviewing this report critically, it raises two important issues: firstly, it outlines the need for effective disability awareness raising among police and legal professionals; and secondly, it highlights the need for sexual health education programmes that promote awareness of sexual rights for individuals with intellectual disabilities.

EMPOWERMENT COMPONENT

Empowerment is the final component, which cuts across the other four components of the CBR matrix. Empowerment involves being capable of fighting for one's rights, and being recognised and respected as equal citizens and human beings with a contribution to make. In view of this, the CBR Guidelines (WHO, 2010) depict that people with disabilities and their family members should play a key role in making their own decisions, and take responsibility for changing their lives and improving their communities.

The role of the community disability practitioner is to contribute to the empowerment process by promoting, supporting and facilitating the active involvement of people with disabilities and their families in issues that affect their lives (WHO, 2010). The empowerment component consists of five key elements: advocacy and communication, community mobilisation, political participation, self-help groups and disabled people organisations.

Advocacy and social mobilisation

To achieve empowerment of people with disabilities, it is important that they are trained in self-advocacy skills and are aware of the different communication methods with which to engage community members (WHO, 2010). The benefits of self-advocacy are highlighted in studies conducted by Lorenzo (2001, 2005) among women with disabilities in Khayelitsha. Using an action research process and storytelling, the women began to engage with the possibility of taking more control of their own lives. Lorenzo (2005) concluded that, by assisting the women to become more active and competent participants in their own development, they have the potential to make significant impacts on their families and the development of their communities.

Disabled people's organisations

As a response to social barriers and reaction against the control of people with disabilities by others, DPOs have been instrumental in lobbying for the equal participation and social inclusion of all people with disabilities. Given the rhetoric of DPOs, the CBR Guidelines (WHO, 2010) advocate that they should work in collaboration with community rehabilitation programmes to ensure the implementation of the UNCRPD and community-based inclusive development. As clearly stated by WHO (2010) 'CBR involves the combined efforts of people with disabilities themselves, their families, organisations and communities and the relevant governmental and non-governmental health, education, vocational and social services.' From this it can clearly be depicted that people with disabilities play a pivotal role in the planning and implementation of CBR. As denoted by Rule (2008), CBR is a process of empowerment in which people with disabilities and their communities participate in a process that leads to decisions by and for themselves.

Although people with disabilities should be at the forefront, DPOs have criticised professionals who have implemented community-based inclusive-development programmes without consulting people with disabilities and their families (Chappell and Johannsmeier, 2009). Thus, a pivotal role of community disability practitioners should be to work with DPOs and ensure people with disabilities are made aware of their existence.

There are several national and local DPOs in the Western Cape, including Disabled People South Africa (DPSA), Western Cape Forum for Intellectual Disabilities (WCFID), Cape Mental Health, Western Cape Network on Disability, and Association for Physical Disabilities (APD). Their main functions have been to provide support and counselling to people with

disabilities and their families, training at grassroots centres (e.g. disability awareness, skills training), research, and advocacy and lobbying. According to Lorenzo et al (2006), many of these DPOs have been at the forefront of the disability rights movement and continue to play a proactive role within local communities. Evidence of this was found in a newspaper article in which the Western Cape Network on Disability met with the Department of Transport to advocate for more disability-friendly transport in Cape Town (Luhanga, 2011). In outlining the current impact of inaccessible public transport (i.e. people with disabilities unable to get to work), the Network highlighted what needed to be put in place to make the public transport system universally accessible.

DISCUSSION

The following discussion aims to answer the questions developed within the theoretical framework of constructing a curriculum for community rehabilitation facilitators (Rule, 2008). The proposed curriculum is informed by the disability and rehabilitation research reviewed in the first section of this chapter.

Dominant disability and rehabilitation models in the Western Cape

Although the White Paper on an Integrated National Disability Strategy (INDS) (ODP, 1997) and the National Rehabilitation Policy (Department of Health, 2000) pertain to a social model of disability, it appears from the literature analysed in this review that many of the disability and rehabilitation services in the Western Cape seem to operate within an individual, impairment approach (Kumurenzi, 2011). Most programmes have tended to focus on the physical functionality of an individual, with very little emphasis given to contextual factors such as environmental barriers (e.g. accessibility, attitudes) or personal barriers (e.g. depression, pain).

In relating these findings to the development of a curriculum for community disability practitioners, more emphasis needs to be given to equal opportunities and creating an enabling environment by removing barriers. Instead of focusing just on needs related to the person's impairment, practitioners and academics need to recognise the complex interaction among features of the biological, psychological, cultural, social, political and economic factors of disability. This integrated approach would provide

community disability practitioners with a more holistic perspective of working with people with disabilities.

Curriculum development in the context of key issues facing people with disabilities in the Western Cape

The desktop analysis used the five components of the CBR Guidelines – health, education, livelihood, social and empowerment – in the context of disability and rehabilitation research in the Western Cape. In doing so, various positive and negative key issues were identified in relation to the needs of people with disabilities living in the Western Cape (see Table 3 on pages 30–34). Consideration needs to be given as to how these key issues may be addressed in the curriculum of community disability practitioners.

Through analysing the most positive key issues, it appears that the majority of these occurred within the health component of the CBR Guidelines. For instance, several studies reported good access to rehabilitation and health services (Kahonde et al, 2010; Jelsma et al, 2007; Maart et al, 2007), and reasonable access to assistive devices (Jelsma et al, 2007). In relation to the other components in the CBR Guidelines, studies reported good emotional support for people with disabilities (Kahonde et al, 2010), good access to social grants (Loeb et al, 2007), strong DPO activity (Lorenzo et al, 2007; van Niekerk et al, 2006) and some community awareness raising on disability issues (Lorenzo, 2005; Luhanga, 2011).

Despite these positive key issues, there are numerous negative issues that have not been adequately addressed and impact on the quality of life of people with disabilities living in the Western Cape. Interestingly, the majority of these negative issues related to the livelihood, social and empowerment components of the CBR Guidelines. For instance, several studies reported barriers to housing and food sources (Maart et al, 2007; Loeb et al, 2007; Watson, 2007), access to public transport (Kahonde et al, 2010; Lorenzo, 2008), access to justice (Dickman et al, 2006) and access to skills development and employment (Van Niekerk, 2011; Lorenzo et al, 2007; Engelbrecht and Lorenzo, 2010; Duncan et al, 2011a). In terms of the health component, studies reported people with disabilities lack of involvement in health promotion and prevention activities, especially surrounding sexuality, relationships and HIV and AIDS (Wazakili et al, 2006; Maart and Jelsma, 2010). Furthermore, due to poor record-keeping and follow-ups, people with disabilities often did not receive their assistive devices (Kumurenzi, 2011), thus breaking down the continuum of care between institutions and communities.

In recognising people with disabilities as part of a family unit, several of the negative key issues related to the involvement of family/caregivers. For example, within the health component there appeared to be a lack of involvement of family members in home programmes (Kahonde et al, 2007) and many studies reported the lack of understanding parents had of their child's impairment (Allen et al, 1995; Botha, 1995; Keikelame and Swartz, 2007).

In the context of the key issues identified in the disability and rehabilitation literature, five courses are proposed for a Higher Certificate for community disability practitioners (see Table 2 below). As well as providing a basic overview of the five components of the CBR matrix, these courses will also address some of the negative issues identified in the previous section. For example, in light of poor record-keeping and follow-ups, during the disability information, management and communication systems course, students will be taught about record-keeping and referral services. In doing so, the course aims to improve communication and follow-ups in services for people with disabilities.

TABLE 2: POTENTIAL COURSES FOR HIGHER CERTIFICATE IN DISABILITY PRACTICE	
Proposed courses	Credits
Inclusive development and agency	15
Health, wellness and functional ability	30
Promoting healthy lifestyles	10
Disability information, management and communication systems	15
Work integrated practice learning	50

Potential competencies of community disability practitioners in the context of other health professionals

In developing the competencies of community disability practitioners, consideration needs to be given as to how they will coincide with the competencies of other disability and health practitioners. Given the key issues facing people with disabilities in the Western Cape, in the context of the five components of the CBR Guidelines, Table 3 suggests the potential competencies of community health workers who specialise in rehabilitation and disability practice (CDP) compared with other members of the PHC team.

In relation to competencies of other mid-level rehabilitation workers, Finkinflugel and Rule (2008) and Chappell and Johannsmeier (2009) report that CRFs' roles were often limited by other health professionals,

especially in terms of advocacy and lobbying. This limitation was often due to a lack of understanding of the competencies of community disability practitioners. When reflecting on this situation in the context of the proposed community disability practitioners, it is essential that other professionals in health, education, social development, justice and financial institutions are made aware of the programme and the ways in which they will work together. This can be achieved by running continuing professional development (CPD) accredited training programmes for professionals who may act as supervisors for community disability practitioners. The training programme should be run in conjunction with the Higher Certificate programme and provide information about the curriculum alongside supervision skills. A similar programme was used at CREATE in the training of CRFs in KwaZulu-Natal, which, according to Rule et al (2006), provided a valuable platform on which to promote inclusive development and disability rights.

TABLE 3: POTENTIAL COMPETENCIES OF COMMUNITY DISABILITY PRACTITIONERS (CHW NQF 5) IN RELATION TO THE FIVE CBR COMPONENTS AND RE-ENGINEERING PRIMARY HEALTH CARE

HEALTH COMPONENT (Key elements: promotion, prevention, medical care, rehabilitation, assistive devices)						
Key issues		Home-based carers NQF 4	Community Health Workers – rehabilitation and disability specialisation		Rehabilitation therapists	Doctors/nurses
			NQF5	NQF 6-7		
Positive key issues	Good access to medical care	Provide basic nursing care and First Aid training	Identify PWD	Identify PWD and basic health screening	Identification of PWD and full ADL assessment	Medical and nursing care
	Provision of assistive devices	Refer to support services	Refer to health and other support services	Make basic assistive devices, e.g. APT (CRFs) Refer to health and other support services	Provide and train in use of assistive devices	Assess and refer to rehabilitation services
	Good access to rehabilitation services		Refer to rehabilitation services	Provide basic rehabilitation intervention, e.g. exercises, ADLs at community level	Provide specialised rehabilitation programmes at hospital and community level	
	Provision of emotional support to PWD improves QOL	Identify mental health risk factors and refer	Screen for mental health problems Provide basic counselling skills and support	Provide basic generic and HIV/AIDS counselling skills	In-depth assessment and treatment of psychiatric conditions	Provide specialised mental health treatment and support
	PWD understand functional abilities and home programmes	Identify need for home-based programmes	Monitor uptake of home-based programmes	Implement home-based programmes for PWD and their families	Develop home-based programmes for PWD and their families, and train community workers to implement and monitor	

Negative key issues	Excluded from health promotion and prevention activities		Advocate for inclusion of disabled people in health promotion activities and campaigns	Organise health promotion activities and campaigns	Design and develop health promotion and disability prevention activities and campaigns	Specific health promotion
	Poor access to sexuality, HIV and AIDS and disability knowledge	Basic HIV and AIDS counselling and support	Educate PWD and their families on HIV and AIDS			HIV and AIDS treatment, care and support
Negative key issues	Parents lack information on child development and health condition, e.g. spina bifida, epilepsy	Refer disabled persons to support services and follow up	Provide information to individual and family on impairments	Educate individual and family on impairments	Design and develop educational material on impairments	Disseminate disability information
	Poor education of caregivers on functional abilities and home programmes					Inform individual and parents on diagnosis and prognosis
	Poor adherence to home programmes and treatment		Monitor uptake of home programmes	Implement uptake of home programmes	Design home programmes	
	Lack of co-ordination of services		Report writing, record keeping and follow-ups	Report writing, record keeping and follow-ups	Report writing and record keeping	Report writing and record keeping
	Transition from hospital to home and community and vice-versa		Keep open channels of communication across care pathways			
	Stress for family members and caregivers Burden of care falls on family members, especially severe intellectual and mental impairments	Family support, i.e. help with household activities	Individual and family stress-management	Provision of information on support services, and development of support groups for caregivers	Family support and counselling	

EMPOWERMENT COMPONENT (Key elements: advocacy and communication, social mobilisation, political participation, self-help groups, DPOs)						
Key issues		Home-based carers NQF 4	Community Health Workers – rehabilitation and disability specialisation		Rehabilitation therapists	Doctors/nurses
			NQF 5	NQF 6-7		
Positive key issues	Strong DPO activity		Raise awareness about DPOs to disabled people	Work with DPOs (capacity building)	Build capacity of DPOs in knowledge of rehabilitation	
	Raise awareness of disability		Identify barriers and facilitators of participation	Conduct disability awareness workshops with PWD to various stakeholders, e.g. community leaders, educators, PHC (CRFs)	Monitor and evaluate	
	Effective participation				Monitor and evaluate	
Negative key issues	Lack of support groups for PWD and family/caregivers		Identify and refer disabled people who would benefit from joining a support group	Organise and run support groups for PWD and family/caregivers	Give support and training to facilitators of support groups	
	Poor knowledge of rights		Educates PWD and families about disability rights	Disseminate material on disability rights	Design educational material on disability rights	
	Limited awareness of relevant policies		Educate disabled people and families about national and international disability-related policies	Organise campaigns on national and international disability-related policies	Monitor national and international disability-related policies	Monitor and evaluate disability-related policies

EDUCATION COMPONENT (Key elements: ECD, primary, secondary and higher, non-formal and lifelong learning)						
Key issues		Home-based carers NQF 4	Community Health Workers – rehabilitation and disability specialisation		Rehabilitation therapists	Doctors/nurses
			NQF5	NQF 6-7		
Positive key issues	Advocate mainstreaming with families and teachers		Identify barriers and facilitators to inclusive education with PWD, families and educators	Advocacy and lobbying for inclusive education with PWD, families, and educators (CRFs)		School health screening
Negative key issues	Poor physical access to mainstream educational institutions					
	Poor access to assistive devices for independent functioning in educational institutions		Follow up referrals to rehabilitation therapists	Assess for assistive devices and referrals to therapists	Assess ADLs and provision of assistive devices	

LIVELIHOOD COMPONENT (Key elements: skills development, self-employment, waged employment, financial services and social protection)						
Key issues		Home-based carers NQF 4	Community Health Workers – rehabilitation/disability specialisation		Rehabilitation therapists	Doctors/nurses
			NQF 5	NQF 6-7		
Positive key issues	Knowledge of and access to social security (grants)	Referrals to Dept of Social Development for grants	Referrals to Dept of Social Development for grants	Referrals to Dept of Social Development for grants	Assess and refer for disability grants	Assess for social grants
Negative key issues	Advocate mainstreaming with families			Advocacy and lobbying for employment with PWD and employers		
	Poor access to employment opportunities (waged, self-, entrepreneurial)		Identify and screen disabled people who are unemployed		Vocational rehabilitation and career advice	Health screening for employees
	Dependence on social grants		Refer disabled person to rehabilitation therapists for work assessment	Screen for job matching Disseminate knowledge of employment legislation	Assess work skills and habits Match existing skills to job opportunities Monitor employment opportunities	
	Unable to contribute economically due to poorly managed impairment(s)					
	Lack of supported employment programmes					
	Poor access to skills development (foundational, technical, professional, business management, core life skills)			Referrals to skills training activities	Referrals to skills training activities Training PWD and family in entrepreneurial activities	Training in life skills and vocational rehabilitation
Access financial security and poverty alleviation programmes		Referrals to Dept of Social Development				

SOCIAL COMPONENT (Key elements: relationships, marriage and family; personal assistance; culture and arts; recreation, leisure and sport; access to justice)						
Key issues		Home-based carers NQF 4	Community Health Workers – rehabilitation and disability specialisation		Rehabilitation therapists	
			NQF 5	NQF 6-7		
Positive key issues	Engage spirituality of disability –potential, choices and hopes		Identify barriers and facilitators to accessing cultural, spiritual and leisure activities	Advocate and lobby for inclusion in cultural, spiritual and leisure activities	Life skills training	
	Ensure meaningful social roles in family and community		Support functional roles disabled person can do in family	Assess functional roles in family and ways disabled person can contribute to family life		
Negative key issues	Support for nurturing sexual development and parenthood	Provision of condoms to individuals	Identify barriers to access to sexual health services	Advocate and lobby for provision of information about sexual functioning and lobbying for access to sexual health services	Assess and treat related to sexual functioning, e.g. following acquired disability	Provide family planning and sexual health services
	Barriers to housing – flooding and fire		Identify barriers to accessing better service delivery	Advocate and lobby with communities and PWD for better service delivery	Monitor and evaluate actions taken to address barriers to participation	
	Barriers to food sources/ security					
	Barriers to legal and political services					
	Barriers to public transport					

Working with the disability movement

As identified by WHO (2010), CBR and inclusive disability development involves the combined efforts of people with disabilities, their families, organisations, and relevant governmental and non-governmental services. Despite this, in critically analysing the disability and rehabilitation research, it appears that people with disabilities do not play a particularly active role in the implementation, monitoring and evaluation of rehabilitation services. Furthermore, although DPOs were involved in some studies that evaluated rehabilitation services, their roles tended to focus on identifying disabled research participants only. Despite this, the disability movement has confidently demonstrated its ability to advocate and lobby for changes in service delivery, specifically within the context of inclusive education.

Given the active role of the disability movement, it is essential that the proposed curriculum for community disability practitioners actively participates with the disability movement. Doing so will ensure that the curriculum remains in context with the key needs identified by people with disabilities. This can be achieved by undertaking the following activities:

- Ensuring representatives from the disability movement are involved in the selection and interview process of potential students.
- Actively encouraging persons with disabilities to apply for admission to the undergraduate programme.
- Ensuring persons with disabilities participate in the construction of the curriculum and teaching the modules.
- Involving persons with disabilities in the tutoring and assessment of students undertaking the programme. The benefit of this is two-fold: firstly, it enables continuing professional development of people with disabilities; and, secondly, it will enable community disability practitioners to see people with disabilities not just as service users, but also as service providers.

CHAPTER TWO

COMMUNITY REHABILITATION WORKERS AS CATALYSTS FOR DISABILITY-INCLUSIVE YOUTH DEVELOPMENT

by Theresa Lorenzo, Jane Motau and Paul Chappell

ABSTRACT

Purpose: This paper intends to describe and compare the livelihoods assets of disabled and non-disabled youth and to discuss the renewed need for the community rehabilitation workers to facilitate the participation and inclusion of disabled youth in socio-economic and political development opportunities in order to cultivate responsible citizenship.

Methodology: A cross-sectional survey was conducted over a period of one month. A snowball sample of 50 disabled youth and 50 non-disabled youth of both sexes, aged 18 to 35 were selected. Data were collected through fieldworker interviews using a structured questionnaire on demographics and livelihood assets. The data was analysed using descriptive statistics.

Results: Disabled youth have access to schooling, but retention through secondary to higher education is minimal. This barrier limits their employment possibilities. Social assets for the disabled and non-disabled youth differ in relation to having intimate partners and inclusion in free-time activities. Disabled youth have limited knowledge of availability of social workers, non-governmental organisations (NGOs) and disabled people organisations (DPOs). Inaccessible public transport and public services create further barriers to accessing development opportunities.

Conclusion: The paper reveals the need to renew the CRF's role in accessing skills development for disabled youth who have limited livelihood assets, particularly in relation to education and employment. We argue that CBR as a strategy for community development can effectively raise awareness and mobilise resources in this regard.

INTRODUCTION

Over the past three decades, CBR has emerged as an effective method of accessing health and rehabilitation services, as well as opportunities for education and employment for disabled people and their families (McConkey and O'Toole, 1995; Hartley, 2002). The rhetoric of CBR, therefore, places equal emphasis on inclusion, equality and socio-economic and political development of disabled people. The new Community Based Rehabilitation (CBR) Guidelines (WHO, 2010) launched at the CBR Africa Network conference in Abuja, Nigeria, in October 2010 set out practical steps for governments, disabled people's organisations (DPOs)

and non-governmental organisations (NGOs) to work collaboratively in addressing unmet needs that create huge inequities in education, employment, social inclusion and political participation of disabled people. Yet very little research has been done on the experiences and needs of disabled youth living in a developing world context.

The years between childhood and adulthood are the years when young people are expected to acquire skills, go through the physical and emotional changes of puberty and assume a social identity that will enable them to fully participate in as equal citizens in their communities (Groce, 2004). Groce identified the needs of both non-disabled and disabled youth as access to education and skills training, employment, and inclusion in social, cultural and economic affairs. All these needs are recognised in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2006) and the CBR Guidelines (WHO, 2010). Despite the fact that South Africa ratified the UNCRPD in 2008, a large proportion of disabled youth are still not in formal education (Department of Education, 2001). Cramm, Noeber, Finkenflugel and Lorenzo (in press, 2013) report that disabled youth are more likely to only reach primary level education and even less likely to reach Grade 12, let alone higher education. This gap is an ongoing problem that was noted a while back (Schneider et al 1999) and has not changed in 14 years. If disabled youth succeed in completing basic schooling, they have more chance of gaining post-schooling skills for decent work and employment.

This paper presents the inequities in access to social and economic development opportunities for disabled youth in Winterveldt, South Africa. Given this situation, it explores the role of CRWs in addressing the need for disability inclusive youth development.

CBR and development initiatives in Winterveldt

Winterveldt is a large rural area that was formerly in the Odi District of North West Province, one of nine provinces in South Africa. It was previously part of the Bophuthatswana homeland. Since 2007, it has been part of Gauteng. Winterveldt is divided into a rural northern half, and an urban southern half called Klippan. Population densities are much higher in the southern portion of Winterveldt. With no infrastructure for health, education, safety and protection, law and order, churches and NGOs moved in to help people with their basic needs. One of these organisations was Sisters of Mercy, run by the Catholic Church with a subsidy and medication from government provides medical care and education to the public, including primary health care (Shipham and Meyer, 2002).

In 1990 a CBR programme was initiated in Winterveldt, in collaboration with St Peter's Catholic Church. The church was responsible for running a non-governmental clinic and an outreach programme for disabled people. The initial CBR programme was implemented by CRWs who addressed the needs of mothers of disabled children for day-care centres and the establishment of a self-help organisation for disabled adults (Shipham and Meyer 2002).

Then in 1996, the national government donated a substantial amount of money towards the development of Winterveldt, which was a significant breakthrough for the area. As a result, the community changed significantly; roads were tarred and 11 public schools, including one school for intellectually disabled children, were built. Water was supplied to the area for the first time, whereas previously people had to buy water for 20c per litre. Common water points are now available for most people to access water (Vivian, 1997). Gardens and parks were developed, businesses started, people began to see purpose in their daily lives, and even crime and violence started to decrease. Two government health clinics, Kgabo Health Centre and Dube Clinic, were provided with facilities for outpatient and maternity care, and an ambulance service. Kgabo Health Centre offers a 24-hour fully comprehensive service. The CBR programme is now based at this health centre, with three CRWs who are supported by the district physiotherapist and occupational therapist as well as a social worker. Final year undergraduate occupational therapy students at the University of Limpopo, Medunsa campus, do clinical placements once a week. They carry out home visits with the CRWs but much of the awareness campaigns and income generation programmes were not sustained. There are no active programmes for disabled youth. It is within the context of wider development initiatives that we carried out a survey to determine the access to resources for disabled youth.

Conceptual frameworks for study

The first paper in Disability Catalyst Africa Series 2 has described the five components in CBR guidelines in detail so it would not be repeated here. These components inform the role and responsibilities of the CRWs who are trained to facilitate inclusion of disabled people across sectors of health, education, employment and livelihoods, social and empowerment. Empowerment component focuses on political development and organisation of disabled people so as to mobilise and advocate for their rights as equal citizens.

The Sustainable Livelihoods Approach (SLA) informed the development

of the survey questionnaire. The core concepts of SLA are that people are at the centre of development and not the governments or resources that serve them (McClaren, Philpott, Mdunyelwa and Peter, 2003). Thus, it focuses on people and a respect for their views. The process typically commences with an analysis of people's context, assets and livelihoods and those factors that impact to change these aspects over time. It is particularly concerned with sustainable poverty reduction through the application of external support working together with people in a way that is consistent with their current livelihood strategies. Another core concept is that it is holistic in its attempt to identify the most pressing constraints facing people, as well as the opportunities that are open to them. In this way it identifies factors that can most effectively be adjusted to produce better outcomes. It also builds on strengths rather than focusing on weaknesses, thereby recognising people's inherent potential. It attempts to build the gap between macro and micro levels by emphasising the importance of macro level policies and institutions upon the livelihood options available to individuals and communities. Finally, that sustainability on an environmental, economic, social and institutional level is central to this approach.

METHODOLOGY

Winterveldt was one of the study sites selected for a cross-sectional survey exploring the livelihood assets of disabled youth that was initiated in 2007 by the Occupational Therapy Division and Disability Studies Postgraduate Programme in Department of Health and Rehabilitation Sciences, Faculty of Health Sciences at the University of Cape Town (UCT).⁵ CRWs were the fieldworkers at this study site as University of Limpopo are involved in CBR programme clinical placements for their undergraduate students. It was therefore possible for CRWs and OT students to follow up with programmes to address needs that would be identified.

Questionnaire

A questionnaire was developed for the purpose of the DYESL study to explore disabled youth livelihood assets – namely their human, social, financial, physical and natural capitals. Some of the questions allowed for multiple responses from participants. Therefore within the results that follow, the numbers and percentages presented include multiple responses. Each participant was asked to complete an informed consent form prior to

the interview. The questionnaire received ethical approval from Universities of Cape Town (UCT), Witwatersrand (WITS), Pretoria (UP) and KwaZulu-Natal (UKZN).

Respondents

A sample of 50 disabled and 50 non-disabled youth between the ages of 18 and 35 was selected. Disabled youth living in Winterveldt were identified by the CRWs through a snowballing strategy. Respondents were youth who were at home at the time the CRW came to the house during the period of the survey. CRWs then found a matched non-disabled youth, who was not more than five years older or younger and who lived on either side of or across the road from the disabled youth. Attempts to match for sex were not successful. All impairment types were included provided the youth was able to respond in interviews in their mother tongue or with assistance from a proxy. Data were collected over a period of approximately one month with each fieldworker completing four to six questionnaires a day.

Data collection and analysis

CRWs carried out individual interviews with respondents in their mother language that took approximately 30 to 45 minutes. Descriptive statistics were used to outline demographic characteristics and the five livelihood assets. The data set was analysed using PASW (SPSS) Statistics v. 18. For details of the training of fieldworkers and rigour of the study see Lorenzo and Cramm (2012).

RESULTS

The results describe the demographic details of respondents and the five livelihood assets of the SLA, namely, human (education, health and employment), social, financial, physical and natural.

Demographics

The study population consisted of 50 disabled youth [23 males (46%) and 27 females (54%)] and 50 non-disabled youth [8 males (16%) and 42 females (84%)]. The mean age of the disabled youth was 26 (SD=4.81), whereas the mean age for the non-disabled youth was 24 (SD=4.55). In

terms of type of impairment, a large majority (n=32, 64%) had physical impairments, while 36% (n=18) had some form of intellectual impairment and 16% (n=9) had sensory and communication impairments. A number of respondents had multiple impairments and all were noted. In terms of onset of disability, 74% of respondents were born with their impairment, while 26% of respondents acquired their disability in childhood before 14 years of age.

The majority of both disabled youth (n=30, 62.5%) and non-disabled youth (n=31, 67.5%), reported still living with their parents. Furthermore, more non-disabled youth lived with a partner or their own children (n=5, 10.9%) compared to the disabled youth (n=2, 4.2%).

Human assets: Education

Almost all non-disabled youth (n = 48, 98%) reported that they had attended school. Of this group, 79.1% (n = 46) completed Grade 12. The majority of disabled youth (88%) reported attending school, although only 7% reached Grade 12. A large majority of non-disabled youth attended mainstream schools (85.7%) compared to the only 31.6% disabled youth. No respondents reported attending tertiary institutions. Disabled respondents who attended school identified barriers related to attitudes of teachers and learners, the physical environment and finances. In addition, disabled youth indicated severity of impairment, in particular intellectual impairment, as a major reason for not attending or completing school. This is compared to non-disabled youth who cited teenage pregnancy, ill-health and financial difficulties as the main barriers to completing school.

Human assets: Health

Respondents were asked to indicate the health professionals seen most frequently and at which facility. Categories of community rehabilitation facilitators (CRWs) and home-based carers (HBCs) were collapsed as it was felt that youth did not seem to differentiate between the two categories of workers. The community workers were seen most frequently through home visits. Doctors and nurses are seen most frequently in hospitals and clinics by both groups, with rehabilitation therapists, psychologists and social workers only seen at hospitals.

Human assets: Employment status

In relation to employment status, 88% of all youth who participated indicated that they were not working. More disabled youth were unemployed

(n=48, 96%) compared to non-disabled youth (n=40, 80%). Of those respondents from both groups who indicated that they were working, most were engaged in informal work and self-employment such as domestic work and gardening. These opportunities were usually infrequent and often badly paid. Disabled youth indicated their poor health as the main barrier to employment (n=27, 57%), followed by lack of skills development and job creation. Some 87% (n=38) of non-disabled youth indicated a lack of jobs as the main barrier to getting work.

Financial assets

Disabled youth reported more sources of income than non-disabled youth; 50% of non-disabled youth indicated receiving zero income compared to only 12% of disabled youth. The major source of income for disabled youth was access to government social grants (82%), while only 38% of non-disabled youth indicated receiving any financial support. Only one person from each group indicated receiving a salary, but this could be indicative of time of data collection being during the day and only week-days.

Social assets

Respondents were asked to identify all the people who provide them with support or help. Disabled youth receive most support from their immediate households, followed by their extended family, neighbours and religious organisations then social workers. Similarly, non-disabled youth receive most support from their immediate house hold, followed by their extended family then a partner/boy- or girlfriend and friends (see Table 4).

Sources	Disabled youth	Non-disabled youth
Immediate households	n=36, 72%	n=35, 70%
Extended family	n=32, 64%	n=32, 64%
Partner/boy- or girlfriend	n=13, 26%	n=30, 60%
Friends	n=16, 32%	n=25, 50%
Neighbours and religious organisations	n=25, 50%	n=19, 38%
Social workers	n=23, 46%	n=13, 26%

We then looked at support from community structures such as social workers, NGOs and DPOs, in terms of knowledge of, availability and accessibility of services. Interestingly, a large proportion of both disabled and non-disabled youth reported a lack of knowledge regarding availability

of social work services, NGOs and DPOs as a barrier to receiving support from community structures.

Respondents were also asked to indicate what they do during their free time. The majority of both groups enjoy visiting friends, watching movies at home and partaking in cultural, church or other religious services. Despite these similarities, there were large differences between the two groups in terms of attending other social structures. For example, more non-disabled youth (n=21, 42%) reported frequent involvement in sports than disabled youth (n=12, 24.5%); as well as going to the cinema (n=21, 42%) more frequently compared to disabled youth (n=9, 18.4%). More non-disabled youth (n=14, 28%) visited nightclubs or shebeens and taverns compared to only 8 disabled youth (16.3%).

Physical assets

This section of the survey identified type of housing, facilities, transport and public services. The majority of disabled and non-disabled youth live in brick houses. For both groups, 90% have access to electricity and 75% to water. The majority of both groups reported an outside toilet (91%) in their dwelling.

In looking at access to public transport, disabled youth seemed to experience fewer barriers than non-disabled youth (see Table 5). These results were similar for other forms of public transport such as buses and trains.

Barrier	Disabled youth	Non-disabled youth
Attitude of taxi drivers	n=9, 60%	n=10, 83.3%
Attitudes of passengers	n=7, 46.7%	n=10, 83.3%
Finance	n=6, 40%	n=11, 91.7%
Distance	n=4, 26.7%	n=10, 83.3%

Similar proportions of youth appear to access public services such as police, community policing forums, local government councillors, municipalities and the Department of Home Affairs. More non-disabled youth seem to access the Department of Labour, banks, internet cafes and post offices, compared to disabled youth. More disabled youth (n=35, 70%) access the Department of Social Development than non-disabled youth (n=23, 46%), which correlates with the number of disabled youth (n=41, 82%) receiving some form of government grant compared to non disabled youth (n=19, 38%).

Natural assets

In response to questions about the type of resource-based activities that households engaged in, both groups indicated access to land as a resource. A similar proportion of disabled and non-disabled youth indicated fetching water, while a fewer youth in both groups indicated fishing or farming.

DISCUSSION

The discussion tries to synthesise the similarities and differences in barriers and enablers experienced by the disabled and non-disabled youth. We then explore the CRWs' potential as catalysts to facilitate disability inclusive development for youth by building on similarities and addressing differences that would foster mainstreaming in development opportunities.

Similarities in barriers and enablers for both groups

The main barriers to work for both disabled and non-disabled youth were lack of skills development and lack of job opportunities. Disabled youth also identified poor health as an additional barrier. CRWs appear to have the competences to facilitate the mainstreaming of disabled youth into development programmes on the basis that the needs are similar and not disability-specific. Both groups of youth accessed health services more frequently through hospitals and clinics so there is an opportunity to explore the extent of this problem.

Inadequate knowledge and information about availability of services created a barrier to accessing social workers, DPOs and other NGOs. CRWs were also not aware of any DPOs in their area. Barriers to disabled youth development such as lack of access to banks, post offices or internet cafes, which are all means of communication, and accessing information about the availability and utilisation of services and programmes. Sipuka (2010) found a similar situation when researching young disabled women's opportunities for economic development. Lack of access to land was a barrier that was also identified by Van Niekerk, Lorenzo and Mdlokolo (2006) and Sipuka (2010) in the development of disabled entrepreneurs. The barriers to transport were surprisingly similar for both disabled and non-disabled youth, namely attitudes of taxi drivers and passengers as well as limited finances. Inaccessible public transport was also identified as a barrier to social and economic development by disabled women in Khayelitsha (Lorenzo, 2008) and disabled people who accessed supported

employment opportunities in greater Cape Town metropole (Engelbrecht and Lorenzo, 2010).

Differences in barriers and enablers between disabled and non-disabled youth

The most significant difference between disabled and non-disabled youth appeared to be in forming intimate relationships and having partners. The household demographics revealed that more disabled youth were still staying with parents and families compared to non-disabled youth who stayed with partners or spouses. The most observable difference between support systems for disabled youth compared to non-disabled youth is with partners or having a boyfriend or girlfriend and social workers. This disparity indicates the need for inclusive social spaces where disabled youth can interact with peers and develop relationships. Opportunities to develop inclusive sport and recreation groups as a major use of free time among youth needs to be explored. Another space where youth interact is at school. However, retention from primary to secondary education was particularly poor for disabled youth, but both groups struggled with access to higher education. This situation limited opportunities for education and employment. Support could be provided by CRWs and undergraduate students using service learning placements as a vehicle for development (Lorenzo, et.al, in progress, and van Niekerk et al, 2006).

CRWs as critical catalysts for disability inclusive development

The results indicate that CRWs are well positioned to be critical catalysts in accessing resources to mainstream livelihood opportunities of disabled youth in Winterveldt as they have initiated similar projects in the past that would provide skills development and raise awareness of their needs amongst service providers from relevant sectors. Disability inclusion depends on raising awareness among disabled people through the co-ordination of professionals across different sectors, universities and community-based workers. CRWs could be the catalyst to ensure collaboration across sectors by making information on services and resources accessible to youth and their families. Some professionals appear to misunderstand or not recognise the role of CRWs, which leads to their poor supervision and limiting their role. Hartley (2002) articulates that this may also lead to the suspicions of professional groups towards those outside their professional 'box' and their unwillingness to cooperate with them.

Skills development and employment are areas that CRWs are equipped to address with the support of occupational therapists and social workers. Lorenzo (2003; 2005) and van Niekerk et al. (2006) provide evidence of CRWs accessing entrepreneurship development opportunities for disabled youth. Their ability to negotiate partnerships between NGOs, DPOs and government services was also illustrated (Lorenzo, van Niekerk and Mdlololo, 2007). Supported employment and job coaching (Engelbrecht and Lorenzo, 2010; Van Niekerk et al, 2011) are other strategies that have been successfully implemented in an attempt to overcome these barriers and would be useful to explore for youth development generally.

The experience of using CRWs as team members in the study suggests that they are in a good position to generate evidence related to the implementation of CBR programmes and how the rights of disabled youth can be monitored to be able to report on the implementation of the UNCRPD by government and NGOs. The CRWs visit disabled youth in their homes and are able to gather information related to their participation across sectors. They are also in a good position to sensitise mainstream programmes to the needs of disabled youth and thereby facilitate their inclusion in development programmes for the general youth population.

Shipham and Meyer (2002) reflect on the success of campaigns by CRWs and students, which should be revived as a strategy for social, economic and political empowerment, so that disabled youth are seen as contributing citizens of their community and country at large. Similarly, raising awareness of relevant local government and municipal services, together with the mobilisation of the public transport sector are all functions CRWs have performed in similar contexts (Rule et al, 2006). The Empowerment component of the CBR Guidelines (WHO, 2010) recommends the formation of DPOs to facilitate their political development. Gara (2007) identified the benefits of mothers becoming policy literate to enable them to access to early childhood development (ECD) resources for their disabled children. Such networks could be extended to youth development networks as well. The CRWs could do awareness campaigns on voting rights as well as addressing barriers to youth's participation in local and national government elections.

Limitations

Data was collected during the day so we may have over-representation of unemployed youth. There were more non-disabled females which could be expected due to cultural and patriarchal roles as more non-disabled youth have intimate relationships. The CRWs reported that there were

more young men on street corners looking for casual work. CRWs were therefore unable to match for both age and sex. Disability status was self-reported. Although fieldworkers were CRWs who were trained in screening for disability, they still reported some difficulties in verifying the disability status. These difficulties were particularly evident in differentiating youth with psycho-social disabilities and intellectual disability. This could explain why mental health issues appear to be underreported. Occupational therapy students could develop programmes in conjunction with social work students to raise awareness and dispel myths of mental illness in communities. We did not ask for nature of health problems experienced by youth in completing school or in accessing employment opportunities so this could be explored in future research. The small sample and non-probability sampling meant that comparative analysis between two groups was limited.

CONCLUSION

CRWs have the skills and knowledge to be critical catalysts for disability inclusion in development opportunities at community level. Across health, education, labour and social development, it is clear that disability-awareness campaigns need to be organised so that service providers are alert to the needs of disabled youth and ways are sought to integrate them into existing development programmes.

All sectors need to recognise and value the abilities of disabled youth so that sustained, inclusive development becomes a reality, and they are able to contribute as respected citizens.

CHAPTER THREE

Stories from the Field

In a qualitative study funded by PERC, four postgraduate students in Disability Studies at UCT used a topical life history approach to gather data on the experiences of different professional groupings in South Africa, Botswana and Malawi in 2011 (see Lorenzo, von Pletzen and Booyens [in progress] for details of methodology).

Here we share some of the stories to illustrate the complexities and inter-sectoral nature of their work. It is evident that community disability practitioners (CDPs) come from different professional backgrounds and perform a vital, though often poorly recognised, and rewarding role of ameliorating the effects of stigma and disadvantage of disability. Their capacity to deliver support services to disabled people and to promote advocacy in rural areas needs to be appreciated and strengthened.

A COMMUNITY DEVELOPMENT WORKER MOBILISES RESOURCES FOR DISABLED PEOPLE

by **Zelda Mubi**

This story shares the experience of a community development worker who has integrated disability issues into her work. Her experience highlights the need for community-based workers to be appreciated for their capacity to deliver support services and to promote advocacy in rural areas. They need to be strengthened if they are to restore and protect the dignity of young disabled people who are a vulnerable and marginalised group in rural areas. In her village, CDWs are supervised by primary health care managers who have limited understanding of the work they are doing, which leads to failures in delivering rehabilitation services to people with disabilities in the community. It also affects the capacity of CDWs to make home visits. This is her story:

My mother was not educated and, while she was unemployed, she made sure that we get something to eat every day. There was a time where she slept without food but we ate something. So there was a project from government where she was appointed. They were cleaning the streets and graveyards. That small amount she received she was making sure that we are happy. But there is something that I won't forget what she did. There was a shop where we use to buy food next to school. So friends would always have pocket money to buy quarter bread and atchaar. So I told mom that I also want that food, then she went to the shop and ask for credit for the quarter and atchaar, then when she receives her salary she went and paid.

My first time to see a disabled person was when I was at primary level. I saw the child and felt sorry for her but at the same time I was very scared. She was staying close to school. Then in our class, when you make noise, our class teacher was not punishing us but she will command you to carry the child home after school. So that helped me get used to her and I was not scared anymore. I realised that she is a human being like me; just the problem is her legs are not the same like mine. She is having the artificial shoes. I just saw there is nothing to be scared of.

Other people also opened my eyes to understand disability. The owner of a supermarket here helped a man who was mentally ill. He used to sit in front of the shop. The owner of the shop requested the workers there to give him a half of bread plus king-size Coke. So I realised this

person is valued which means he is important.

In 2003 I was a volunteer at SANCA, where they trained us to be peer counsellors to people who were alcoholic and taking drugs. Sometimes the awareness was conducted with the police officers, so the SANCA gave the officers our number then they call us and go to the awareness together especially in children at schools – to educate them about danger of using drugs. They included skills on how to assist people with poverty and to help women who had been abused. So the programme itself it had an impact itself on me to love more disability people. So in my work as CDW, I want to help these people and leave them with a change as you can see that there is poverty.

Another challenge is that I assist families when I see a disabled child with no birth certificate. They are refugees so they don't meet the requirement from Department of Home Affairs for an ID. Even the mother doesn't have the ID document. So it is painful because you can see the situation is bad and there is nothing that you can do for them. So as CDWs we are documenting them so they can get IDs.

We are also helping with the participation of disabled people in community programmes. For some of them is not easy for them to accept their disability as they think that their disability is not accepted in the community. So they don't feel like exposing themselves to the community. Some disabled people are afraid to face the world. Some don't get the information. So what is happening here we use loud speakers in the streets to announce events. We organise workshops so all the people in the community need to be educated about disability. There is a disabled man I know who is not afraid of anything.

I myself have a hearing problem for six years now. It is difficult. I first tell them that I have a hearing problem. Sometimes when I speak to them they become upset because I didn't hear what they were saying. Especially in community meetings I find it difficult. I ask my friends always what they say because I am using hearing aids. Previously I had one but now I've bought another one for the left ear as well. My supervisor is supportive as she said to me if I face challenges of giving information as I don't hear people well then I must report them. To be honest with you I accepted my condition but not hundred percent. It is still hurting me. I am better because previously I was full of anger, shouting and commanding. Sometimes I question why me because in my family there is no one disabled, and I became disabled at this age.

Ms Mubi was able to refer the CDW to an occupational therapist and audiologist at the local hospital who were able to help with the necessary assistive devices.

SOCIAL WORKERS: INTEGRATING DISABILITY ISSUES

by Bryson Kabaso

This study explored the experiences of CDWs in the rural southern part of Botswana. With their main task being to coordinate disability activities in rural areas, they identify people with disabilities in the villages and coordinate the information with the Health team. CDWs are traditionally chosen from within their communities and taken for training with the understanding that they go back after the training to improve service delivery in their respective communities. Most of these disability workers have some relationship with disability, for example, have disabled children, siblings or parents.

The story reflects the influences on career choices of community disability workers and the lessons on sustainability of disability-inclusive service delivery, together with the challenges. A social worker who did rehabilitation programmes in health ministry for three years before returning to social services shares important insights into the political systems that shape the way in which we manage disability inclusive development initiatives as they often involve partnerships between government ministries, local and international NGOs as well as disabled people's organisations. Issues of human resource development and financial resources are central to sustainability of programmes. We begin her story in childhood:

As a person with disabilities I noticed at an early age that there were some differences between me and those other people who I was living with. The young kids were asking don't you have hands and stuff... Or the way I do things. I would notice that other kids would be doing things differently to how I would be do things.

When I finished school, my first choice was to be a journalist, but through cut off points I ended up doing social work. It was in the line of careers that was my second choice because when I grew up I just wanted to help people who were disadvantaged somehow, either being people with disabilities or people from minority groups.

A highlight for me was when I solicited the donation of wheelchairs for disabled children and adults in my community because some were just crawling in the village whereby the Council couldn't help. Together with my team, we solicited funding. It was overwhelming to the people that we helped.

I recognise the changes that have happened because the people would now realize that they have potential and that they can do something

... I have some people I have groomed and now they have grown and they are voicing out, they are even part of the youth who are advocating for the rights of the disabled people.

A major challenge in this work is related to people with multiple and profound impairments. For example, we do not have the means for a child who has multi-disability issues, he would not be able to walk, he would not see and not hear. In our country we don't have the institution or an organisation that can help such people. At the organisations where they help the deaf, they would say they would not enrol this person in the institution because he has other issues that they are not dealing with.

Another challenge is the absence of a visible, active, co-ordinating disability structure in the country. There are policies and there are structures, they are there, but it's just written in black and white. There isn't any law enforcement pertaining to who should do this and who should do that. We have a representative in the Office of the President. As the higher office maybe things will change now. But he seems overwhelmed, so without our help or without our assistance also he cannot make it. Maybe ... with the advice that we could give him because we have been in the field we have experienced much. Maybe something would come out because a lot of people were expecting much looking at the fact that it's in the OP. But maybe even the structure of the office should be reviewed because one person cannot hold that much responsibility alone.

There are some funds from the government but here in our country we don't have those institutions for people with disabilities provided by government, maybe we could have the government building more local schools. An NGO runs a centre that has a primary school and then they have got tertiary, they are even grooming up people. When they see that you have got potential you will be placed in local schools. There is somebody I know who is a doctor and a lot of people and even those who cannot excel academically, they even go to the vocational training institute and afterwards they even work there because there is an orchard there, there is pottery they are doing among many other work skills projects.

FAMILY WELFARE EDUCATORS EMBRACE DISABILITY

by Khadija Mashuke

The implementation of disability-inclusive development is hampered by a shortage and inequality in the distribution of professional human resources. From the interviews with four family welfare educators who work in rural Kalahari, the factors influencing their career choice included family of origin and personal experiences, interactions with persons with disability, desire to help others, professional role models, as well as the individual's assessment of his or her skills. Therefore, in developing human resources for disability-inclusive development, life experience should be considered as it forms the backbone of successful CBR implementation. Impressions are created at a young age and then recreated as we move through life through our interactions with disabled people as well as professional working in the field:

I grew up being afraid of people with disability. The time I started work I met with people with different kind of disability and then I got used to them. I then enjoyed my work as I worked hand in hand with the rehabilitation officer and physiotherapists. I learned different attitudes as we worked in the community.

Another family welfare educator felt her choice of career was a spiritual calling from a young age as she was inspired by the work of a professional in the village.

I became involved in this work – it seems I like God gave me this work. When I was young I saw what the family welfare educator was doing in the village i.e. home visits, counselling and treating patients. I said to my granny that I have already done the work of a family welfare educator, after I finish my school I will therefore become a family welfare educator or a nurse. This encouraged me to work hard so that I can be a nurse or family welfare educator.

Their work required the knowledge of local culture so that relevant activities were used in early identification and screening of impairments in the villages then following through with effective treatment interventions. Their responsibilities included creating referral and care systems that ensured outcomes of rehabilitation into schooling.

Before training as a Family Welfare Educator, I met a man in [a village] who was mute and deaf. I started working in August 1979. I was doing mobile clinics in the game reserve. I was making different sounds using local things like putting stones in the tin and making

the sound, so that the mother cannot say she did not have 'dikeleketsi' (fruit of Mokala Tree). He ended up talking even though he was slow and I referred him to the Rehabilitation Centre for further assessment. He started school when his young brother was doing Standard Seven.

Not all interventions had positive outcomes which the family welfare educators found disheartening:

This work is very difficult as it needs you to change someone, family or the community. But there are different beliefs and here in Ghanzi [this village] there are many tribes, churches, traditional beliefs and they do differ so it needs more effort. Some families have members who have disabilities and they do not really care for them but have reduced them to beggars to fend for themselves. They are a disgrace and difficult to work with at community level. Some forsaken people with disabilities roam our streets and cannot easily be accounted for in terms of community participation in disability work.

I wish all people with disability can be assisted but the shortage of transport and manpower is still a problem. I feel like my work is incomplete. I really need these problems to be solved.

RESTORING HUMANITY IN RURAL AREAS

by Sylvester Butao

Eric's father had a mental illness when Eric was a child. He remembers his father being admitted to the local mental hospital for some months and when he improved he came home to his village in Malawi. While he lives alone and makes a living selling bricks that he moulds, Eric's father is still considered "mad" by many in the community, which shows how stigma lingers. Eric describes his father as a charming man who loves him dearly.

Eric completed the two-year rehabilitation certificate course. He says that his choice of profession was unrelated to his father's experience.

Eric said that many incidents reflect the need for CDWs to be competent in managing conflictual relationships related to service delivery. He also considers it problematic - and a hindrance to CDWs trying to do their jobs - that many politicians consider vulnerable people useful in their election campaigns. When politicians came across people with disabilities what they did was bring wheelchairs and tricycles and distribute them to

people without proper assessments. So when the CDWs went there and said the equipment was not appropriate, people with disabilities and their families would say that it was the MP who gave it to them. It was difficult for the CDWs to confront the relevant MP because members of parliament are highly regarded in the community.

Despite these challenges, Eric feels he is a zealous CDW. He talks of the time he mediated the formation of a group of people with disabilities and parents of children with disabilities in the community. He gave them guidelines on how they could fight for their needs, but he was not involved in appointing their leadership and did not have regular responsibilities in the group. This group has been able to take issues to the Ministries of Persons with Disabilities and the Elderly and Health. It has also been advocating for the inclusion of children with disabilities in schools. If issues of discrimination are raised in the schools, they could go and discuss this with the teachers. If the issues were too complicated they could involve Eric to help mediate. And so inclusion was achieved.

I cannot say that I chose this career because there was an event. We go to school, we learn, [but] without any [career] guidance. After that, we just choose whatever way and we end up what we are today. Because when I was a child and even at secondary school my aspiration was to become a medical doctor. But I did not know that there is a profession in the medical rehabilitation until I finished secondary school.

In the community, I can say that I learnt about people. What people do in the community, rather than here in the city where everybody is doing his own thing. But in the community you can understand their ideologies. So the community helped me a lot, it builds. The people have trust in community workers.

The trust that the community placed in me helped me to meet the challenges.

Disability work in the community is complex – it's not like a one-man operation. In the community someone will come with a problem. Maybe you register the person and what you have to do is to go and find the place where the person is living. So in that way when you go to the village you have to assess the village, the home situation, the people – how they are relating with the person, if there are misunderstandings you go there and try to solve them. Counsel the people and explain what the condition is and what should we expect of that condition. So it's like you try to integrate the person in that community where the person is not accepted.

The incident I remember most happened when I was in [the district]

with a gentleman who was blind, and had an irrigation farm. So he could lead people who were able-bodied. When I came to him and asked why he is working more than those people who can see easily, he inspired me by asking, “If you look at me and those people who are working, who is blind?”

REFLECTIONS ON HOW TO USE DISABILITY DATA FOR SERVICE PLANNING



by **Soraya Maart**

The two chapters in this submission reflect the need for building an evidence base for disability-inclusive community services. The relevance of research capacity needs to be appreciated by all stakeholders.

The World Disability Report (2011) acknowledges that most people with disabilities have greater health care needs than other people. This could be related to the co-morbidities associated with disabilities, age-related conditions as well as their vulnerability to violence and trauma. Inaccessible health services, and lack of transport, could compound the mobility problems experienced by a person with a disability seeking health care. Specialised health care services and advanced rehabilitation opportunities should be a priority of health systems globally to fully equalise opportunities of participation for people with disabilities. The report further indicates that the percentage of people with disabilities unable to access the services that they need is higher than for those without disability in every age range, and higher in low income compared to high income countries.

CBR has been implemented in most developing countries to compensate for the absence of health care services for people with disabilities. It has always been the responsibility of enlightened family and community members to care for and prevent the exclusion of people with disabilities from society. This system of care has evolved from volunteerism to a service provision philosophy that incorporates all stakeholders to ensure that people with disabilities have an equal opportunity for development. This philosophy requires that services being implemented for people with disabilities are coordinated across different sectors, are appropriate, affordable and accessible.

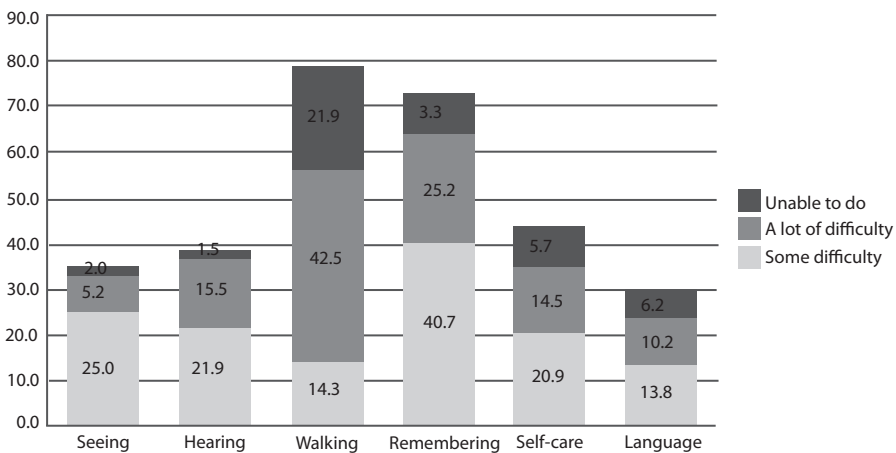
Using national disability statistics, it would be possible to identify service needs of people with disabilities. The National Census (Stats SA, 2001)

estimated the prevalence of disability to be 5% of the total population. However this was based on a simple dichotomous question related to functioning. The use of the Washington Group questions, with qualifiers, allowed for more nuanced data around disability to be gathered during the last census. The Washington Group on Disability Statistics has established a Short Set of Questions (six questions) that can be used to identify persons with disability. The questions have been endorsed by several international agencies and in several countries. They ask about functional problems at the level of activity, thereby identifying people who experience difficulties with basic tasks. The questions are:

1. Do you have difficulty seeing, even if wearing glasses?⁶
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, (for example, understanding or being understood by others)?

Each question has four response categories: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do it at all. The severity scale is used in the response categories in order to capture the full spectrum of functioning from mild to severe.

FIGURE 3: DISABILITY TYPE WITHIN THOSE INTERVIEWED
Disability type
n=192



In a cross-sectional descriptive survey recently conducted in an under-resourced community in the Western Cape, 1 000 households were visited. An aerial view map of the area was used to enumerate the area for cluster sampling. Dwelling type was used as a proxy for cluster sampling. The study was approved by the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town. Subjects included all adults and children living in the household identified. The most senior member present at the time of the visit, or the head of the household, was asked to provide information on all the other members.

Information was obtained on 3 788 individuals. The mean age of the sample was 30.5 years (SD 17.5). Females represented 54% of the sample. A 12.1% disability prevalence was identified, with most people having “some difficulty” in at least two domains explored. The most prevalent impairments identified were walking and remembering among the 192 people with disabilities who were available for the interview.

In identifying interventions for the persons with impairments who were identified, the difficulties with walking could be addressed by physical rehabilitation and the provision of assistive devices. If “remembering” can be used as a proxy for cognitive or psychological problems, the need for skills related to mental health should be included when planning services at community level. The degree of difficulty experienced by people with disabilities could also indicate the level of interventions required. A person who is “unable to do” in most of the domains might indicate a high level of disability requiring constant care and maintenance, whereas a person with “moderate to severe” difficulties could require a high level of expertise for a shorter duration to minimise difficulties experienced.

The interpretation of these cut-off points of disability prevalence was further supported by the service needed and the inability to access this service, as reported by people with disabilities. Of those needing rehabilitation services, 51% said they did not receive such services. Further to this 69% who said they needed home-based care did not receive this.

In conclusion, we must ensure that rehabilitation services are included in the continuum of care provided to all citizens, and that these are available at all levels of care. Appropriately skilled cadres of rehabilitation workers must be available to address the needs of people with disabilities at every level of service provision.

TABLE 6: ACCESS TO SERVICES NEEDED			
	Received	Did not receive	Total
Medical rehabilitation	42	45	87
	48.28%	51.72%	
Assistive devices	57	32	89
	64.04%	35.96%	
Educational services	18	14	32
	56.25%	43.75%	
Vocational training	11	11	22
	50.00%	50.00%	
Disability counselling	22	23	45
	48.89%	51.11%	
Counselling parent/ family	12	16	
	42.86%	57.14%	
Welfare service	91	22	113
	80.53%	19.47%	
Health service	91	22	113
	98.68%	1.32%	
Home-based care	10	23	33
	30.30%	69.70%	

ENDNOTES

- 1 The other articles (not included in the table) deal with definitions and monitoring processes and were not deemed relevant to the level of the community disability practitioner.
- 2 There are no CRFs working in the Western Cape. The majority of them are employed by the Department of Health and non-governmental organisations in KwaZulu-Natal, Free State, Gauteng, Limpopo, Mpumalanga and North West Province.
- 3 Assistive devices refer to any external device that has to be designed, made or adapted to assist a person with a disability to achieve independence in activities of daily living (e.g. wheelchairs, splints, crutches, Braille, assistive communication systems).
- 4 Grant in Aid is a small grant given to people with disabilities or elderly people who are unable to care for themselves and need the assistance of a full time caregiver. They must also be in receipt of other social grants. At the time of writing this report (March 2012) the Grant in Aid was R260 a month.
- 5 The Disabled Youth Enabling Sustainable Livelihoods (DYESL) Project was a collaborative study with occupational therapy departments from five other universities in South Africa: University of KwaZulu-Natal (UKZN), University of the Witwatersrand (WITS), University of Limpopo (UL) – MEDUNSA campus, University of Pretoria (UP), and University of the Free State (UFS).
- 6 The inclusion of assistive devices was considered for two domains only, seeing and hearing, as limitations in these domains can often be overcome with the use of glasses or hearing aids.

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MARRYING COMMUNITY DEVELOPMENT AND REHABILITATION

Disability Catalyst Africa intends to create spaces for dialogue, debate and action among different players in higher education institutions, civil society organisations and government, particularly local government. In this second publication in the series the reader is provided with a succinct summary of the actions that would make a real difference to all the world's citizens who are called 'disabled'; whether they be male or female, young or old, rich or poor. In common with the growing international consensus on community-based rehabilitation, the actions are grouped across five main domains – health, education, livelihoods, social inclusion and empowerment. For each domain, the authors identify the specific actions that would remove the barriers and produce better lives for upwards of 10% of citizens who live with disability. All their proposals are rooted in evidence from research and development studies undertaken mostly in Africa so they cannot be dismissed as either fanciful or unworkable.



AFFIRM

ADVOCATE

ACCOUNT