



Understanding **Community Based Rehabilitation** in South Africa



REPORT ON A STUDY CONDUCTED BY



2015

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ABBREVIATIONS

CBO	Community based organisation
CBR	Community Based Rehabilitation
CORRE	Community Rehabilitation Research and Education Programme
CP	Cerebral palsy
CREATE	CBR Education and Training for Empowerment
CRF	Community rehabilitation facilitator
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CRW	Community rehabilitation worker
DPO	Disabled people's organisation
DPSA	Disabled People South Africa
ECD	Early childhood development
FELM	Finnish Evangelical Lutheran Mission
ILO	International Labour Organisation
IUPHC	Institute of Urban Primary Health Care
NGO	Non-government organisation
NPO	Non-profit organisation
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination Act
PGC	Parent Guidance Centre
SABWO	South African Blind Workers' Organisation
SACLA	South African Catholic Leadership Assembly
SADA	South African Disability Alliance
SASSA	South African Social Security Agency
SETA	Sector Education and Training Authority
UNESCO	United Nations Education, Scientific and Cultural Organisation
WHO	World Health Organisation



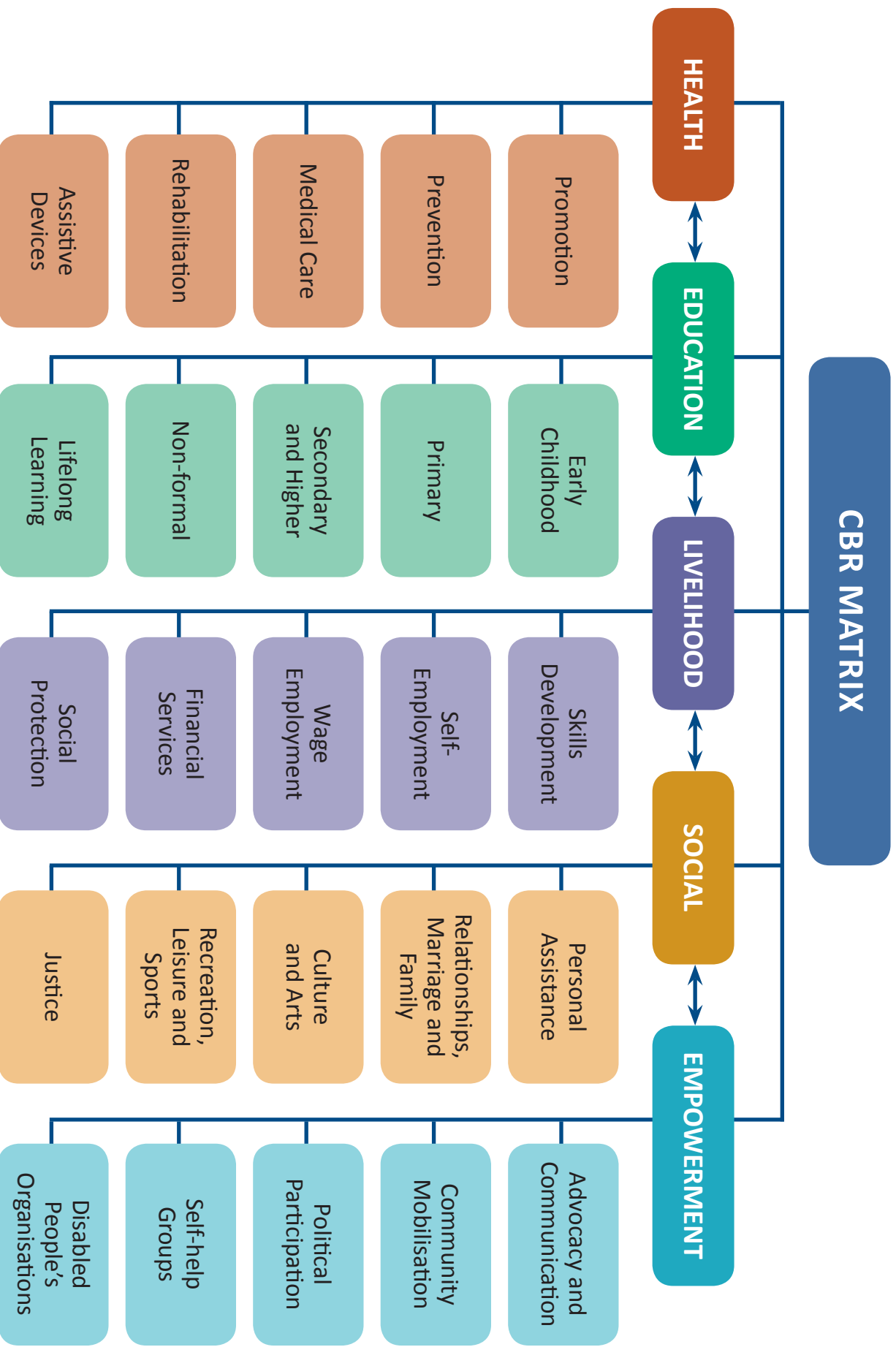
INTRODUCTION

TO COMMUNITY BASED REHABILITATION

Community Based Rehabilitation (CBR) has been promoted internationally for more than 30 years as a core strategy for improvement in the quality of life and services for people with disabilities: “Community Based Rehabilitation is a strategy within community development for the rehabilitation, equalisation of opportunities and social inclusion of all adults and children with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education, vocational and social services.” *(ILO, UNESCO, WHO Joint Position Paper 2004).*

Unlike other conventional rehabilitation programmes, which tend to be mainly medical and institutional, CBR is categorically based within a community development framework. The strategy of CBR places equal emphasis on inclusion, equality and socio-economic development as well as rehabilitation of all people with disabilities.

More recently, in 2010, the World Health Organisation (in the CBR Guidelines) has captured the nature of CBR in the form of a matrix which is illustrated on the following page. This matrix is based on the idea that community based rehabilitation is a strategy for disability-inclusive development and the underlying principles are participation, inclusion, sustainability and empowerment through



self-advocacy. The CBR matrix consists of 5 components: health, education, livelihoods, social and empowerment with each of the components being made up of 5 elements. Although there are many different elements of CBR, no one organisation or CBR programme is expected to deal with all elements.

The CBR Guidelines (WHO, UNESCO, ILO & IDDC, 2010) align CBR and community based inclusive development (CBID) to the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Thus CBR is seen as a practical strategy to facilitate the implementation and respect of human rights of persons with disabilities, particularly at community level. CBR activities are aimed at reducing poverty amongst persons with disabilities and meeting their needs related to health, education, livelihoods and social concerns.

Background to Community Based Rehabilitation in South Africa

Community based rehabilitation was initially discussed by rehabilitation professionals and persons with disabilities when the Rural Disability Action Group (RURACT) was formed in 1985. In 1986 the professional associations of occupational therapy, physiotherapy and speech therapy proposed the training of community rehabilitation workers (CRWs) to the then South African Medical and Dental Council. Three pilot sites were identified and training programmes were set up for CBR personnel in Khayelitsha in Cape Town (SACLA¹), Alexandra Township in Johannesburg (IUPHC²) and in Acornhoek in rural Limpopo Province (CORRE³). The CBR programmes in Acornhoek and Alexandra trained mid-level CBR personnel known as community rehabilitation facilitators or community rehabilitation workers over a two year period. The majority of CBR personnel trained in these programmes were able-bodied with a number having relatives who were disabled. The community rehabilitation facilitators/workers were employed in both NGOs and government in many areas of South Africa, including the Free State, North West, Gauteng, Mpumalanga, Limpopo and KwaZulu Natal. In Khayelitsha mothers of children with disabilities were trained as grassroots community rehabilitation workers over a six week period. Each of these training programmes had somewhat different emphases in their content thus gearing the CBR personnel to work in slightly different ways. As can be seen, even from the beginning of CBR in South Africa there have been differences in the way CBR programmes and training have been conceptualised and implemented.

In 1998 another model of CBR was developed in Mpumalanga Province. Disabled People South Africa (DPSA) was contracted by the provincial Department of Health to provide CBR services. These services include peer counselling, referral to other services and resources and work on livelihoods being provided by persons with disabilities themselves who have had a minimal amount of training.

CBR has been included in the National Rehabilitation Policy of the Department of Health as a philosophy that underpins rehabilitation services. More recently the Department of Social Development also developed a policy focusing on social rehabilitation in the community. In spite of

1 South African Catholic Leadership Assembly

2 Institute of Urban Primary Health Care

3 Community Rehabilitation Research and Education Programme

these national policies, there is no one strategy or method of implementation of CBR in South Africa. It is to some extent a contested strategy although it is accepted that CBR has something to offer persons with disabilities in South Africa.

MOTIVATION FOR THE STUDY

CREATE is an organisation that has been active in the field of CBR since 1998. Initially we trained community rehabilitation facilitators but the training was stopped in 2006 due to the Health Professions Council of South Africa requiring profession-specific mid-level workers rather than multi-skilled CBR personnel. This led to the evolution of CREATE into an organisation that focuses on inclusive development and human rights and that implements CBR across all the components and a number of elements of the CBR matrix. Through our work with a number of government departments, including the Department of Health, the Department of Social Development, the Department of Education and the KwaZulu Natal Provincial Legislature as well as non-government organisations and disabled people's organisations, we have come to realise that the lack of a coherent, up-to-date and common understanding of CBR in South Africa has led to a situation where the value of CBR as a strategy for implementing the CRPD and bringing services to persons with disabilities at community level is not fully recognised.

In 2014 CREATE received funding from the Finnish Evangelical Lutheran Mission (FELM) for a project entitled: "Inclusive development for people with disabilities: Supporting the Development of Community Based Rehabilitation in South Africa". In order to ensure this project is targeted at appropriate stakeholders and that it addresses the real needs of these stakeholders, it was important to gather baseline data on the understanding and implementation of CBR in South Africa. Thus the study reported on in this document was conceptualised to gather the baseline information. Although the research was specifically designed to meet CREATE's need for a baseline, the timing of the whole project funded by FELM is apposite as current developments in South Africa, such as the Framework and Strategy for Disability and Rehabilitation in South Africa 2015 being developed by the national Department of Health, would benefit from a coherent, up-to-date conceptualisation of CBR.

AIM OF THE STUDY

The aims of the study were therefore as follows:

1. To explore the current understandings of community based rehabilitation in South Africa
2. To describe the implementation of community based rehabilitation throughout South Africa based on five exemplars of CBR projects or programmes.



METHODOLOGY

CREATE used a mixed methods approach to the research into CBR in South Africa. A survey, eliciting mainly quantitative data was used in the initial phase of the research. This was followed by five case studies of organisations implementing CBR. The survey enabled us to get a broad picture of the understanding of CBR across the country while the case studies involved a more in-depth qualitative look at the practice of CBR in South Africa.

Data collection methods

Survey

A pilot survey was conducted whereby a draft questionnaire was designed and sent to 11 people for comment (eight responses were received (73%). Based on these comments the questionnaire was revised. The questionnaire, together with an introductory letter, was uploaded electronically to SurveyMonkey and emailed to a database, drawn from a national network of various electronic listserves. When analysing the initial summary data, collated by SurveyMonkey, the responses were positively skewed towards therapists and negatively skewed towards community rehabilitation facilitators or workers (CRWs), disabled people's organisations (DPOs) and persons with disabilities. Remedial action consisted of re-emailing the DPOs and nine provincial rehabilitation co-ordinators as well as conducting telephone interviews with seven CRWs, some of whom are persons with disabilities. The questionnaire was also sent out in a Microsoft Word format to those who had problems with Internet access.



Case studies

The researchers used semi-structured interviews, focus group discussions and document analysis as well as observation to gather data at each site. In addition at Gelukspan Hospital beneficiaries of the CBR project engaged in a participatory rural appraisal timeline exercise to generate data on the history of the CBR project

Sampling

Survey

The survey was sent out to 367 potential respondents identified from existing databases for national electronic listserves. The sample included DPOs, member organisations of the South African Disability Alliance, members of Rural Rehab South Africa, CRWs, government officials from the Departments of Health, Social Development, Education and other disability focal people. There were 86 respondents from 7 provinces (no responses from Free State and Limpopo provinces).

Case studies

The sites for the case studies were purposively selected, partially based on responses to the survey and also based on the researchers' knowledge of CBR in South Africa. The CBR projects/programmes were selected to represent both urban and rural locations; government and NGO-funded programmes; projects/programmes targeted at specific age groups or all ages; one programme targeted at persons with only one type of impairment while other projects/programmes address people with a range of impairments. Two of the projects were chosen because of their base in a government health institution and a government education institution.

At each case study site, with the exception of CREATE, beneficiaries as well as staff of the organisation participated in the data gathering. Due to time constraints, only staff were interviewed at CREATE.

Data analysis methods

Survey

The research team used both quantitative and qualitative methods to analyse the survey responses. Data from questions 9 and 10 were qualitative and therefore a process of immersion, unpacking, associating, ascribing meaning, thematic analysis, patterning and temporal linking was followed. The data from SurveyMonkey was received as a summary document with percentages that highlighted frequency of response. SurveyMonkey also created a composite document of all the individual responses from respondents who completed the survey. In addition CREATE entered the data into SPSS and some cross-tabulations were performed.

Case studies

All interviews and focus group discussions were audio recorded and then translated and transcribed. Data from the case studies were analysed qualitatively using the CBR matrix and key concepts in CBR as the organising themes.

Ethical issues

The introductory letter for the survey indicated that by replying to the survey, the respondent was giving consent to participate in the research. All participants in the case studies received an explanation of the research and gave informed consent to participate. In this report all quotes from participants only indicate their broad designation so that anonymity is assured.

Limitations

There are several limitations of the study as listed below.

1. The respondents to the survey were mainly therapists. This may in part be a function of the particular email databases we used. When we realised that there was insufficient data from DPOs, additional attempts were made to contact SADA affiliates and DPOs. However only one response was received from a SADA affiliate and one from DPSA.
2. The use of an electronic survey limits the participants to those who have access to the internet and emails. To counteract this some telephone interviews were conducted with the survey instrument and this data was electronically captured.
3. The selection of five organisations for the case studies is necessarily limited and does not represent all different forms of CBR in South Africa.



SURVEY RESULTS

CREATE obtained 86 responses to the survey from respondents from seven provinces of South Africa. There were no respondents from Free State or Limpopo Province although we are aware that CBR is currently or has been implemented in both these provinces. In addition we had several respondents who are active at national level in various government departments. As mentioned in the Methodology section of the report, the majority of the respondents described themselves as therapists. In addition some were government officials, employees of non-government organisations, academics or researchers. 12.8% of the respondents were persons with a disability and the same percentage described themselves as community rehabilitation facilitators/workers. See Figure 1 below.

Although 96.5% of the respondents indicated that they had been exposed to the concept of CBR through a variety of means, including through their own work and the work of others they know, a sizeable proportion of respondents (23.3%) indicated that they were not at all familiar with the recent CBR Guidelines and CBR matrix. It appears therefore that a number of respondents may have an outdated knowledge of CBR. This may be reflected in the responses to the question about respondents' views of CBR. Most respondents (50.6%) chose the description of CBR as "a programme that facilitates social inclusion and equal opportunities for persons with disabilities". This definition of CBR is closely aligned to that found in the Joint Position Paper on CBR (WHO, ILO & UNESCO, 2004), illustrating that the respondents are knowledgeable about CBR as it has been conceptualised internationally. However, only 15 of the 85 respondents who answered the question (17.6%) selected the statement that represents the most recent conceptualisation of CBR according to the CBR Guidelines (WHO, 2010) that CBR is "a strategy for disability-inclusive development" (see Figure 2 below).

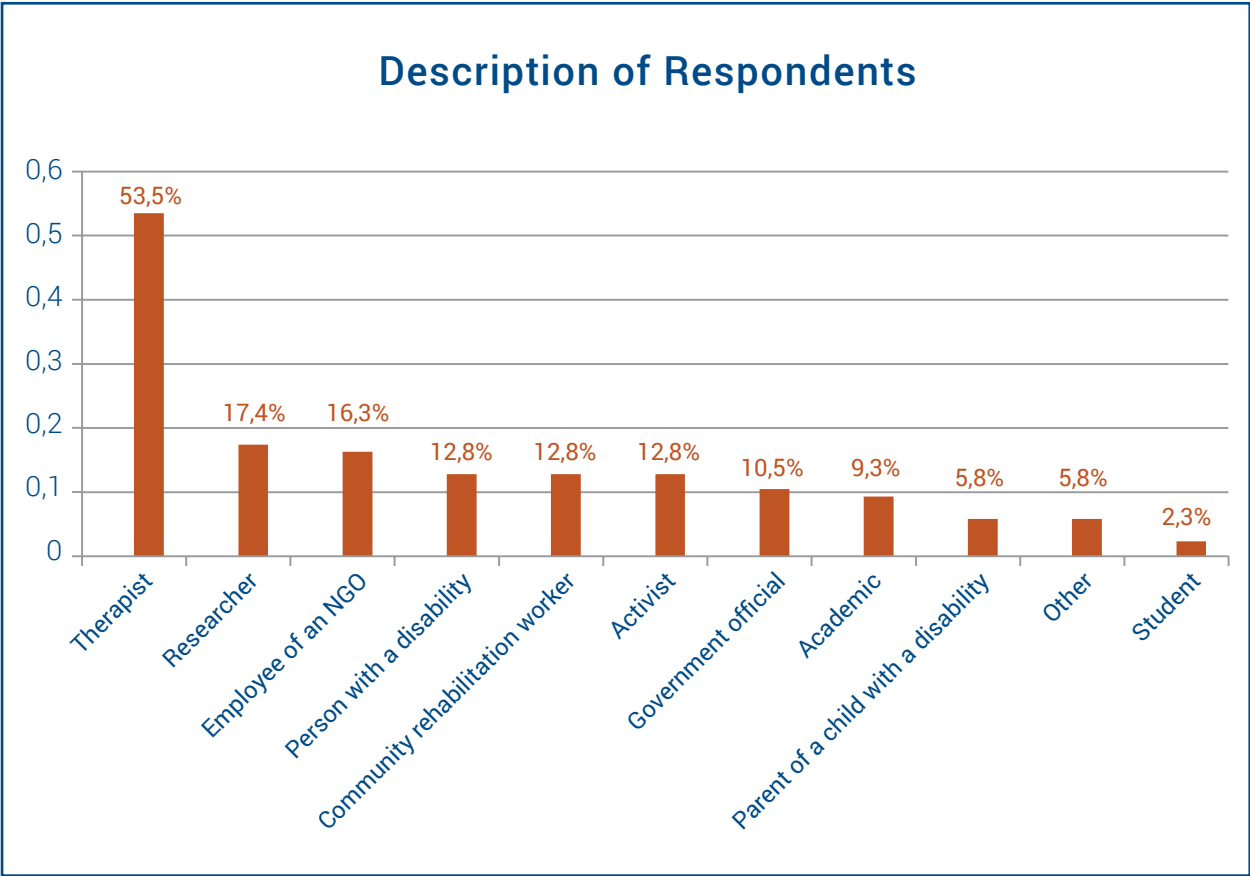


Figure 1

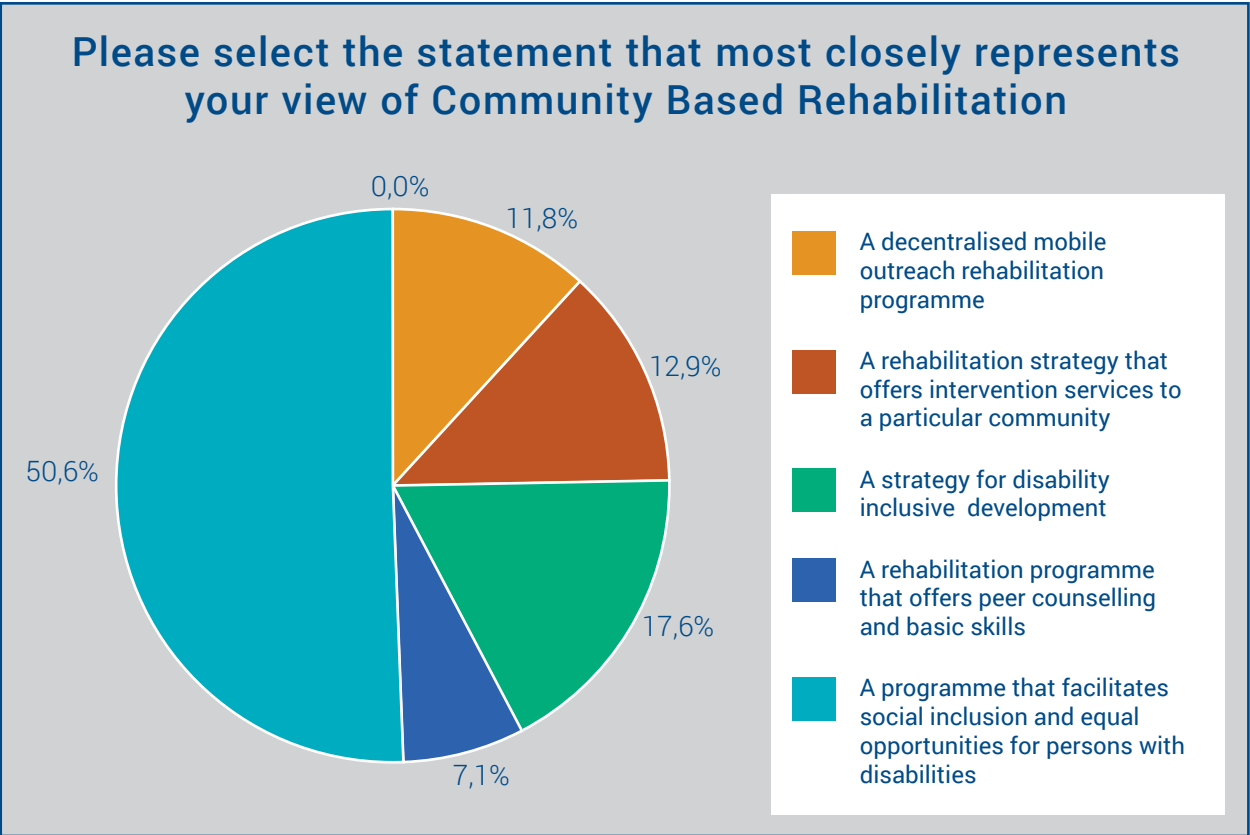


Figure 2

In the survey, respondents were asked to select the five most important aspects of CBR from a pre-determined list. The five most common responses were: involvement of people with disabilities; advocacy for disability rights; rehabilitation; inclusive development and community development work (see Table 1 below). This seems to illustrate that the majority of respondents understand CBR as being far more than just rehabilitation or health-related interventions at a community level. CBR is understood by many as linked to the broader issues of disability rights and inclusive development, which is prominent in the CBR Guidelines (WHO, 2010).

In your understanding what are/would be the 5 most important aspects of Community Based Rehabilitation?		
Answer options	Response Percent	Response Count
Involvement of people with disabilities	84.9%	73
Advocacy for disability rights	72.1%	62
Rehabilitation	60.5%	52
Inclusive development	58.1%	50
Community development work	43.0%	37
Referral to other resources	37.2%	32
Education-related interventions	36.0%	31
Outreach	32.6%	28
Health-related interventions	30.2%	26
Peer counselling	22.1%	19
Poverty reduction	16.3%	14
Other (please specify)	2.3%	2
answered questions	86	
skipped questions	0	

Table 1

In response to the question related to the beneficiaries of a CBR project/programme, the majority of respondents chose persons with disabilities of various ages from childhood through to adulthood and their parents/caregivers or family members (see Figure 3 below). While of course persons with disabilities and their caregivers and families are central to any CBR programme, if one takes the approach to CBR that it is a strategy for disability-inclusive development, then other beneficiaries also become important. In order to achieve development that is disability inclusive, a CBR programme would need to work with community leaders, community members, disabled people's organisations and community based organisations. Few respondents chose these as beneficiaries of a CBR project/programme. However, the responses to this question of the survey may reflect the way the question was phrased.

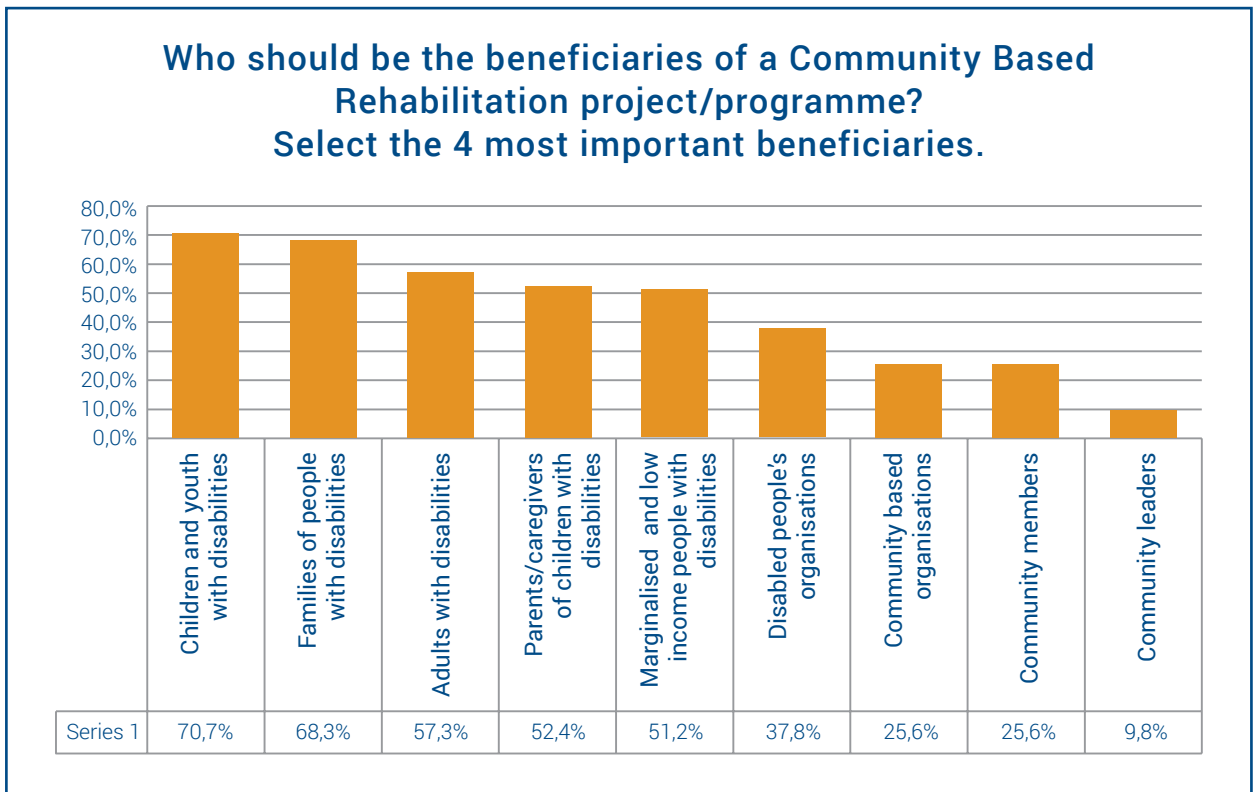


Figure 3

The survey also asked what the source of funding should be for CBR programmes in South Africa. Significantly more respondents felt that government departments such as the Departments of Health, Education and Social Development should fund CBR than that funding should come from DPOs, non-government sources or academic institutions (see Figure 4 below).

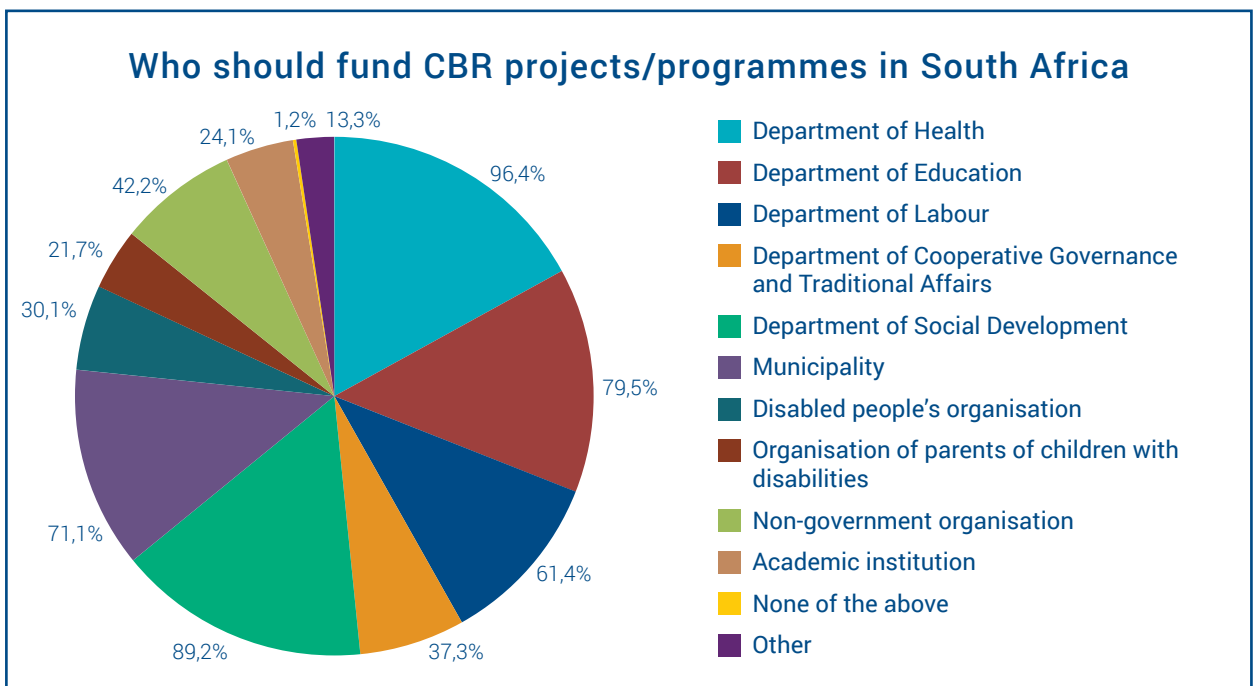


Figure 4

In addition to the quantitative data obtained in the survey, two questions also gathered qualitative data. The qualitative data was elicited from two questions concerning the role that persons with disabilities should play in CBR and a general request for comments on CBR.

Respondents identified a wide variety of roles for persons with disabilities within a CBR project or programme as well as a number of activities that they should implement within CBR. Many respondents felt that persons with disabilities have a role to play in CBR throughout the project life cycle.

They should be partners in all activities of the project, from planning, needs assessment and implementation and evaluation of projects.

Student, Western Cape

According to respondents, some of the activities that persons with disabilities should be implementing in CBR include advocacy, disability awareness, peer support, liaison with the community, needs analysis and creating livelihoods.

Advocacy roles to promote their inclusion within communities and lower discrimination and stigmatism surrounding having a disability.

Therapist, KwaZulu Natal

[Persons with disabilities should] Be employed as peer counsellors and referral points, including independent living support.

Government official, Gauteng

[Persons with disabilities] As members of each community, determining the goals and priorities for the project.

Therapist, KwaZulu Natal

They should promote and do [disability] awareness campaigns.

Person with a disability, KwaZulu Natal

Although five respondents indicated that the role of persons with disabilities is as beneficiaries of a CBR project/programme, several people felt that persons with disabilities should be employed within a CBR programme.

Where possible [a person with a disability] can be employed, for example, as a rehab worker or running an income generation project.

Therapist, Mpumalanga



One respondent particularly emphasized the role of persons with disabilities in the governance of CBR projects and programmes.

Disabled people should be recruited to serve on Governing Boards of NGO's providing such services, in order to represent disabled people and to assist with the designing of CBR programmes, as well as to oversee the implementation of the programmes.

NGO director, Eastern Cape

According to a number of respondents when persons with disabilities play these roles, this leads to sustainability of a CBR project/ programme and empowerment of persons with disabilities.



Provide valuable input and leadership where they can as the disabled people they know best what is needed. Once projects take off they should play role in sustaining the projects/ programmes. They should be part of every part of the process. It is the only way to ensure sustainability. Outside intervention only lasts so long- projects and programmes must be sustainable by the community.

Therapist, KwaZulu Natal

More than half the respondents gave general comments on CBR in South Africa. The topics of these comments ranged from the context of South Africa in which CBR is situated, to the current status of CBR in South Africa, barriers, enablers and opportunities for CBR and the value of CBR. A number of respondents also made recommendations for the way forward.

Respondents identified a number of negative aspects regarding the current status of CBR in South Africa. They commented that there is confusion about CBR, it is often not visible, there are poor rehabilitation services and in many areas CBR programmes do not exist at all. For example:

I have struggled to come across practical examples of how CBR has been implemented in South Africa. Completely underestimated and not publicized enough. People who are not in the health sector don't know about CBR.

Therapist, Eastern Cape

The debate on CBR in South Africa is derailed by a narrow definition of CBR limiting it to the cadre that should provide it and not the conceptual underpinnings of the strategy. Far too often the responsibility has been placed under Health whereas all literature is clear on the cross cutting nature of the strategy.

Government official, national

In addition to the negative comments about the status of CBR in South Africa, a number of barriers that affect CBR were also described. These include resource constraints, human resource barriers, difficulties with transport, lack of intersectoral collaboration and policies that are not implemented.

Great policies, total lack of appropriate political commitment and necessary negotiation to operationalise.... Therapists, DPO's and other implementers often lack the skills and capacity to develop CBR programmes and the structural support (e.g. staff mandate, budgets) are lacking.

Researcher & activist, Western Cape

However, a number of respondents also expressed the value of and opportunities for CBR in South Africa. For example:

I believe that the Empowerment Component of CBR can be a fantastic, cost-effective intervention. I also think that a focus on human rights literacy is essential for holding State services accountable for providing accessible and adequate services.

Activist, Gauteng

My experience of the CRFs [community rehabilitation facilitators] in Vhembe in Limpopo has been extremely positive. I feel that CBR is essential to an appropriate, meaningful and effective service for people with disabilities.

Academic & activist, Gauteng

Current re-engineering of PHC: stark neglect by DoH [Department of Health] to integrate the philosophy of CBR into the structure of the district health teams (including proposed district mental health teams). This omission is short-sighted because the addition of CRW's [community rehabilitation workers] (appropriately trained, supervised, paid etc.) to the core PHC [primary health care] teams would absorb much of the impairment/functional limitations/ participation restriction (i.e. disability related concerns) in households that arise from the quadruple burden of disease in SA. CBR as a philosophy endorses a lifespan/well-being approach...SA cannot afford a 'fix it' approach... it is high time that sectoral services go 'upstream' to address the social determinants of health.... and CBR is one such strategy.

Academic & researcher, Western Cape

The recommendations made by respondents related to human resource training, intersectoral collaboration and mainstreaming inclusion with a variety of general recommendations as well.

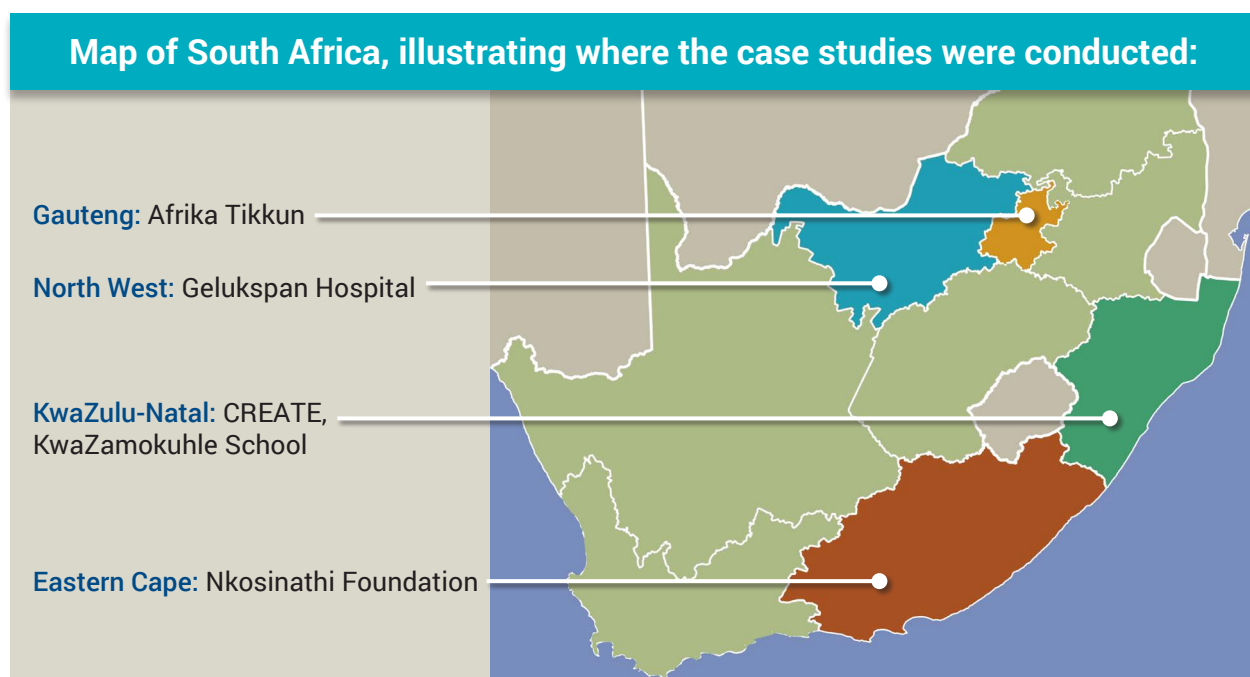
CBR implementation guidelines should be developed at government level with adequate resources. A study of the impact of the projects implemented by different agencies should be put together so as to gain some lessons.

Person with a disability, KwaZulu Natal



CASE STUDY FINDINGS

In this section of the report, we discuss the findings of case studies of five organisations around the country that consider themselves either to be CBR organisations or to have a CBR programme. The case studies are descriptive rather than evaluative and therefore the findings represent some examples of what is possible in the implementation of CBR in South Africa, without a concomitant evaluation of whether this is positive or negative.



The first part of the case study findings gives a brief summary of each organisation. Following this is a combined analysis of how the work of the five organisations fits into the CBR matrix (WHO,2010) and an exploration of the meaning of key terms in community based rehabilitation. This illustrates how five South African CBR programmes conceptualise community based rehabilitation and it offers insights into possible means of implementation of CBR in South Africa.

Afrika Tikkun Empowerment Programme: Children with Disabilities and their Families

1. Location

The Empowerment programme of Afrika Tikkun is currently operational at three sites in Gauteng: Orange Farm, Braamfontein (and inner city areas of Johannesburg) and Diepsloot.

2. History

Afrika Tikkun is an established non-government organisation working in six townships in South Africa. Their focus had been on orphans and vulnerable children and in 2010 they commissioned a baseline study and needs analysis in response to their recognition of the need to include children with disabilities in their work. Jean Elphick spent a year gathering information and meeting with parents of children with severe disabilities, culminating in a report and a further period to develop an action plan. The parents prioritised three aspects that they wished to be included in the future programme: teaching the community about inclusion of children with disabilities; developing a support group for parents and caregivers of children with disabilities and education for both the families and the children with disabilities. Over the next three years the Empowerment Programme was piloted at the Orange Farm site of Afrika Tikkun, resulting in the parents and caregivers forming their own organisation known as Sidinga Uthando. In 2014 the Empowerment Programme extended its reach to Hillbrow and Diepsloot, beginning with a launch and human rights literacy training for parents and caregivers from Hillbrow and the inner city areas of Johannesburg.



3. Target group of the Empowerment Programme

The target group for the Empowerment Programme is mainly parents and caregivers of children with disabilities. However, their advocacy activities target a range of people including government officials in various departments, police officers, others working in the field of child abuse, ECD centre staff, schools and community members.

4. Staff implementing community based rehabilitation

The staff of the Empowerment Programme includes the national manager, the programme coordinator, case administrators and advocacy officers. The majority of the staff members are themselves parents or caregivers of children with disabilities.

5. Governance

The Empowerment Programme is one of Afrika Tikkun's programmes and as such is governed by the board of directors for the whole NGO. Sidinga Uthando, as a separate organisation, has its own committee made up of parents and caregivers of children with disabilities.

6. Activities of the Empowerment Programme

Below is a list of activities of the Empowerment Programme which relate to CBR. This list has been compiled by the researchers based on observation, data from an interview and a focus group discussion and on information from reports and other documents. This list may therefore not be complete but will give the reader an idea of the main activities of the programme.

Health

- Facilitating access to wheelchairs
- Referring children with disabilities for hearing tests, eye tests, occupational therapy, speech therapy
- Arranging input and training on how to assist children with various impairments including cerebral palsy, autism, muscular dystrophy and hearing impairment

Education

- Working with Afrika Tikkun's early childhood development programme to facilitate the inclusion of children with disabilities
- Consultative meetings with the Department of Education and lobbying for a school for children with disabilities in Orange Farm
- Assisting parents and caregivers with school referrals and applications
- Running disability sensitivity workshops for ECD practitioners

Livelihoods

- Organising computer training for self-help group members
- Referring parents and caregivers and assisting them with obtaining birth certificates, ID books and social grants
- Encouraging self-help group members and building their capacity to run a charity shop to generate income

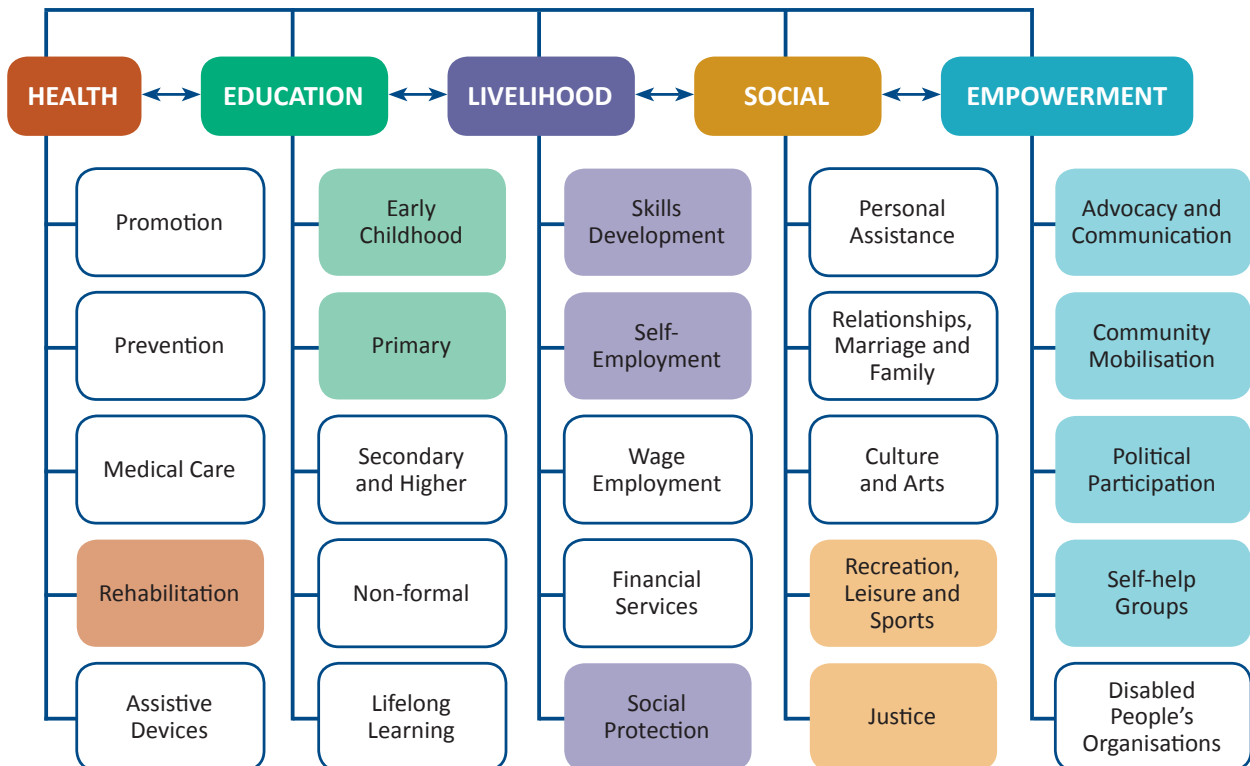
Social

- Overseeing the court case of a youth with cerebral palsy who was raped
- Supporting members of the self-help group who are attending court cases
- Obtaining the assistance of lawyers in dealing with cases involving children with disabilities
- Organising and running a race and sports event including able-bodied and disabled children in Orange Farm

Empowerment

- Educating children with disabilities and their families on their rights and responsibilities
- Presenting memoranda to relevant officials about issues such as child abuse
- Raising awareness amongst the police and various professionals of the abuse of children with disabilities
- Mobilising children with disabilities and their families to come together
- Facilitating the formation of self-help groups for parents and caregivers of children with disabilities
- Building the capacity of the self-help group
- Advocating on behalf of children and families not accessing their rights
- Running Child Protection Dialogues for professionals on including children with disabilities in child protection matters
- Presentation to the Department of Women, Children and People with Disabilities on gender-based violence and disability
- Running disability awareness training for various community groups and groups within Afrika Tikkun

7. CBR matrix reflecting the work of the Afrika Tikkun Empowerment Programme



CBR Education and Training for Empowerment – CREATE

1. Location

CREATE's offices are located in Pietermaritzburg. The organisation primarily works in all districts of KwaZulu Natal but it also implements activities throughout South Africa. In addition CREATE has worked in Nigeria, Zambia, Namibia, Botswana and Uganda.

2. History

CREATE initially started as the KwaZulu Natal branch of the Institute of Urban Primary Health Care (IUPHC) in 1998. As such, it took on the training of CBR mid-level workers known as community rehabilitation facilitators (CRFs) which had started at the IUPHC at Alexandra Health Centre. In 2001 CREATE became an independent non-profit company and a registered non-profit organisation. The mid-level CBR training continued until the end of 2006. From 2001 CREATE has engaged in a number of other activities related to CBR and disability, including the national pilot testing and roll out of inclusive education, the pilot testing of CBR for the national Department of Social Development and assisting mainstream NGOs funded by two large donors, to become disability inclusive.

3. Target group of CREATE

CREATE has a wide target group. Children, youth and adults with all types of impairments are both direct and indirect beneficiaries of CREATE's work. In addition CREATE works with parents, caregivers and other family members of persons with disabilities. CREATE also targets a variety of other stakeholders who interact with and/or provide services to persons with disabilities. This includes traditional leaders, local councillors and municipalities, government officials in a number of different departments, ECD practitioners, teachers, HIV counsellors, mainstream NGOs, DPOs and disability NGOs.

4. Staff implementing community based rehabilitation

CREATE has grown from 2 members of staff in 2001 to the current 7 members of staff of whom two have disabilities. Currently there is a managing director, an advocacy officer, three trainers, an admin officer and a driver. Two of the staff members originally trained as CRFs.

5. Governance

CREATE has a board of eight directors of whom five are persons with disabilities and one is a parent of a child with a disability.

6. Activities of CREATE

Below is a list of activities of CREATE which relate to CBR. This list has been compiled by the researchers based on observation, data from interviews and on information from reports and other documents. This list may therefore not be complete but will give the reader an idea of the main activities of the programme.



Health

- Training with children and youth with disabilities: topics - knowing your body, how the body changes in puberty, sexuality, sex, sexual health, protecting your body, how to say no, the right to say no and HIV and AIDS.
- Training with parents of children with disabilities: topics - understanding your disabled child, sexuality, rights in relation to reproductive health and HIV and AIDS
- Training with HIV and AIDS counsellors: topic - preparing counsellors to include persons with disabilities in their counselling activities
- Training adults with disabilities: topic - sexuality, rights in relation to reproductive health and HIV and AIDS

Education

- Training for ECD centres: topic - how an ECD centre can be disability inclusive
- Training for ECD practitioners: topics - how to promote the development of children with disabilities at their centres, using stimulation kits and tools and toys to use; learning disability
- Training parents: topics - inclusion, disabled children's' rights
- Facilitating physical access at an ECD centre
- Training for teachers, Department of Education officials, principals and others at mainstream primary schools and special schools on inclusive education; screening, identification, assessment & support; and curriculum adaptation

Livelihoods

- Referral to potential employers
- Income generation training and follow up

- Preparing youth for the world of work through training and follow up
- Facilitating the training of persons with disabilities as photo journalists
- Training DPOs to run savings groups

Social

- Training for traditional leaders on access to justice for persons with disabilities in the traditional courts
- Training human rights forums on the Constitution, the CRPD and the Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA) and how to take cases to the Equality Court
- Funding legal support for a case involving a person with a disability at the Labour Court

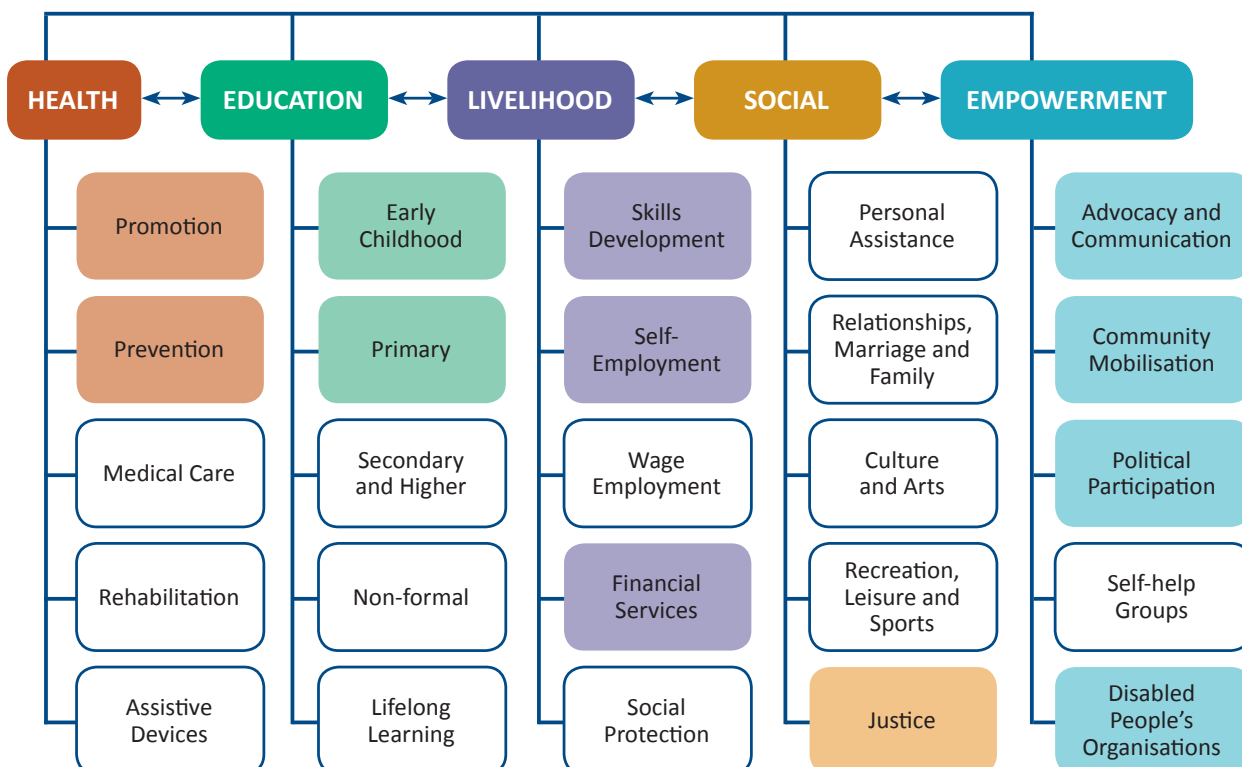
Empowerment

- Advocacy for the respect of the rights of persons with disabilities
- DPO training: topics - writing an application for NPO status, writing funding proposals, project development, project management and writing a business plan
- Organising meetings where political party candidates can speak to persons with disabilities prior to elections

Disability-inclusive development

- Identifying resources to assist NGOs to make water, sanitation and hygiene facilities disability-inclusive
- Arranging for an architect to design waterless, disability-inclusive public toilets in Ingwavuma
- Arranging sign language classes for an NGO so they can include Deaf persons in their gender-based violence prevention activities

7. CBR matrix reflecting the work of CREATE



Gelukspan Hospital CBR programme

1. Location

Gelukspan District Hospital is located in a rural community near Mahikeng in North West Province. The CBR project operates from and within the Parents Guidance Centre (PGC) Reakgona, which is part of the Hospital set up. The disability programmes include some young people with disabilities from as far away as Kuruman in the Northern Cape participating in leadership roles within different programmes.

CBR principles are implemented within the Centre-based programmes with a clear focus on transfer into the communities as well as in training programmes for disability focused community based projects (Disability Project Leadership Training) as well as in outreach programmes, which include support of the projects participating in the leadership training.

2. History

The PGC Reakgona was founded in 1984 as part of building up the physiotherapy and rehabilitation outreach services in Gelukspan Hospital. During the first years a lot of outreach activities helped to identify many children with cerebral palsy (CP) and other disabilities. During these years they were facing much neglect and ignorance. There was a great need to teach and train parents about childhood disabilities, their causes, approaches and also to render basic rehabilitation services. Onsite CP courses were designed to answer this need. The courses consisted of basic teaching and exercises for the children. From 1996 onwards a more dynamic approach and gradual growth of different aspects related to empowerment, project development and parental guidance evolved. Over the years about 10 programmes developed, adding different aspects relevant to disability services to the basic idea of parental guidance. People with disabilities had more say and influence over the development of programmes as well as the parents who mainly shaped the growth of the CP course programmes and a variety of courses offered. Today the PGC tries to share its experience by empowering community based organisations working with children with disabilities to render similar but community based programmes according to their own identified needs and answers towards those.

3. Target group of Gelukspan District Hospital CBR programme

This CBR programme focuses mainly on children with disabilities, their parents and also youth with disabilities. In addition, the Gelukspan Hospital CBR Programme works with some DPOs/ CBOs.

4. Staff implementing community based rehabilitation

5-6 Staff members from the Physiotherapy Department of the hospital implement the CBR programme. There is a young man with a disability who is employed to adapt and repair assistive devices. 3 volunteers with disabilities are contributing towards different programmes and also serve as watchdogs for quality and meeting the real needs of persons with disabilities.

Different small sub-teams implement different programmes. During outreach activities small teams consisting of 2-3 persons work together to deliver or facilitate therapeutic, empowerment and

assistive device interventions. Teaching, hands-on intervention and reflection of experiences and sometimes helping with conflict resolutions are part of project visits and in a smaller version also when meeting families during home visits.

5. Governance

Basically the staff structure and lines of responsibility within the Hospital apply. However, the PGC program is also accountable towards the District Management Team of the Ngaka Modiri Molema District, as this is allocating the budget towards the program, sharing it evenly between the sub-districts.



6. Activities of the Gelukspan Hospital CBR project

Below is a list of activities of the Gelukspan Hospital CBR project. This list has been compiled by the researchers based on data from interviews, a focus group discussion and documents. This list may therefore not be complete but will give the reader an idea of the main activities of the programme.

Health

- Teaching parents of children with disabilities about nutrition and hygiene to promote good health
- Raising awareness of disability amongst parents and community members to reduce stigma and contribute to prevention of secondary disabilities
- Providing therapy for children and youth with disabilities
- Teaching parents and caregivers how to exercise and stimulate their children
- Providing home programmes for the rehabilitation of children with disabilities
- Teaching children with disabilities and their families to use alternative and augmentative communication, including communication boards and various devices
- A customised wheelchair and assistive devices service which includes assessing the person, adjusting and modifying wheelchairs and other assistive devices and maintaining wheelchairs
- Referral of families to other health team members and relevant resources

Education

- Promoting and supporting the development of day care centres that include children with disabilities
- Implementing Montessori infancy facilitation in PGC Reakgona
- Providing non-formal training for parents and caregivers on cerebral palsy and other impairments and how to assist children with disabilities with the aim of adapting this into a formal SETA-accredited course

- Running a Disability Project Leadership course which provides training on administration, financial and human resource management, therapeutic and occupational activities

Livelihoods

- Developing skills of youth with disabilities through the Disability Project Leadership course

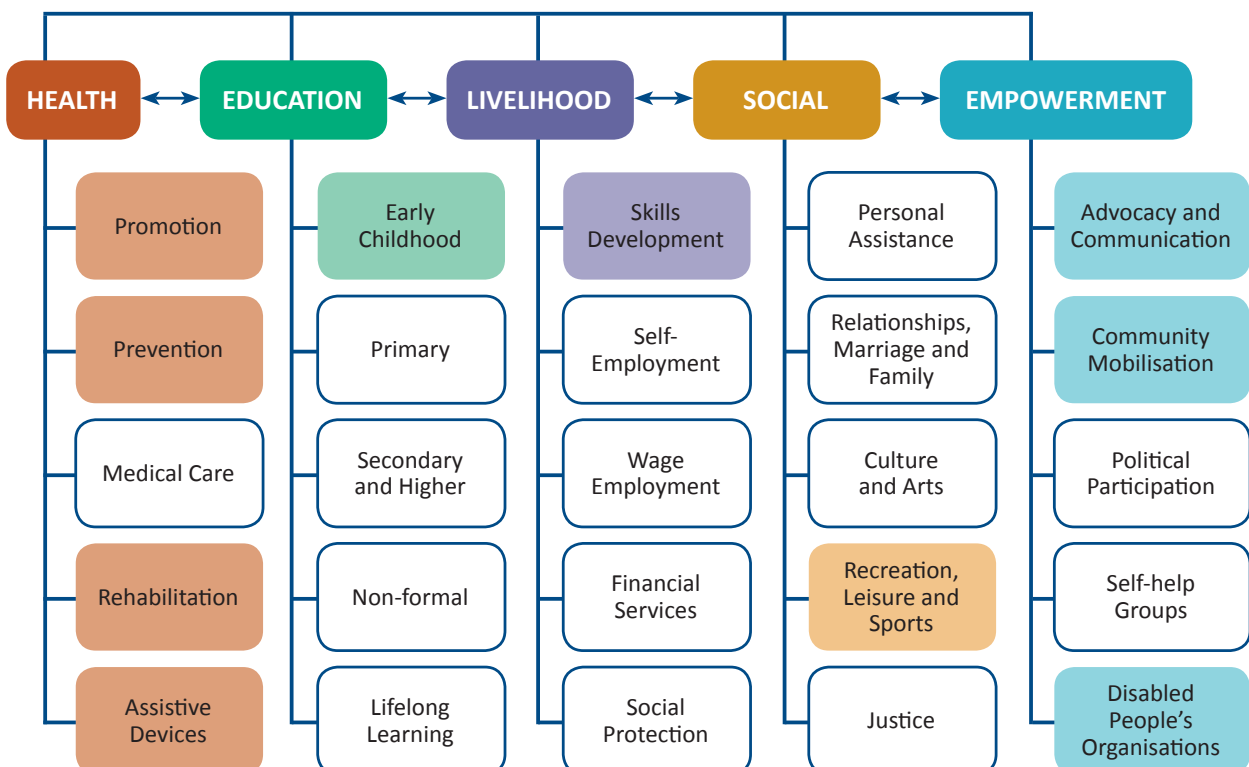
Social

- Providing social support and counselling to parents and caregivers
- Initiating and supporting the GBT Mongoose Wheelchair Basketball team which has done very well in the televised Super Sports league with 5 players from this team being selected to represent North West which were the overall winners of the National Championships in 2014.

Empowerment

- Running the Solofelang project for youth with severe impairments which follows the Dare to Dream process and empowers the youth to work towards attaining their goals and dreams
- Peer mentoring and support amongst youth with disabilities who have attended the Disability Project Leadership course
- Enabling children with disabilities to make their own choices and parents of children with disabilities to express their needs
- Supporting disability groups initiated by parents and youth with disabilities who have been linked with the CBR project

7. CBR matrix reflecting the work of the Gelukspan CBR programme



KwaZamokuhle Special School CBR Project

1. Location

KwaZamokuhle Special School is located in a rural area just outside the town of Estcourt in KwaZulu Natal. The CBR project operates in the areas of Ntabamhlophe, Loskop, and Ephangweni.

2. History

In the early 1980s the KwaZamokuhle Diaconic Centre was run by the Church of Sweden and was involved in a number of income-generating projects, including a bakery, beading, basket weaving, agriculture and a church textiles department. Several persons with disabilities worked in the various income generating projects and in 1983 the KwaZamokuhle Centre became a protective workshop for persons with disabilities over the age of 16. In addition 12 children with disabilities boarded at the centre and attended school close by. In January 1988 KwaZamokuhle School opened its doors for the first time, mainly accommodating children with physical impairments. The school's work was overseen by a school governing body (SGB) that included the school management, an occupational therapist and a volunteer physiotherapist supported by a visiting doctor who conducted assessments on a monthly basis. In response to needs identified in the community a CBR sub committee was formed under the auspices of the school governing body. The KwaZamokuhle CBR project has been a feature of the school's Constitution since the inception of the school. The functioning of the CBR project has, since 1996, largely been driven by the CRF employed by the project.

3. Target group of KwaZamokuhle CBR project

The target group of this CBR project is children and youth with disabilities, caregivers of children with disabilities, DPOs, self-help groups and day care centres for children and youth with disabilities. In addition, this project works with certain sectors in the community promoting disability awareness.

4. Staff implementing community based rehabilitation

Currently the CBR project is managed by staff of KwaZamokuhle Special School, including therapists who get salaries from the Department of Education. The CBR project has, with funding from the German Evangelical Lutheran Mission, directly employed a CRF and a driver to implement the CBR activities.

5. Governance

The CBR project is part of the school's constitution. Its functions are overseen by the school governing body together with a CBR project sub-committee. The day to day running of the project is overseen by the CBR management committee. The expenses of the CBR project are administered by school officials. The KwaZamokuhle Special School's SGB meets quarterly to ensure that funding is spent according to line items in the budget.

6. Activities of KwaZamokuhle Special School CBR project

Below is a list of activities of the KwaZamokuhle CBR project. This list has been compiled by the researchers based on data from interviews, a focus group discussion and documents. This list may therefore not be complete but will give the reader an idea of the main activities of the programme.



Health

- Prevention of disability through awareness raising
- Burns prevention education
- HIV and AIDS education, referral and counselling
- Measurement and referral for assistive devices and educating persons with disabilities and their families to care for the assistive device
- Ensuring people have access to and are taking their medication
- Home programmes for children with disabilities, including stimulation and positioning

Education

- Early childhood screening and identification
- Establishing and supporting day care centres
- Facilitating the inclusion of children with disabilities into mainstream schools
- Referring children who require high levels of support to the special school
- Facilitating the improvement of accessibility at mainstream schools either through paying directly for ramps or motivating the Department of Education to improve accessibility
- Running disability awareness training for learners in mainstream secondary schools
- Providing or facilitating access to bursaries for young people with disabilities to study at tertiary institutions

Livelihoods

- Supporting self-help groups with skills training for their chosen income generation projects, including how to open a bank account, budget and manage profits
- Providing start-up funding for small businesses/income generation projects
- Referring clients to the Department of Home Affairs for birth certificates and ID books and to the South African Social Security Agency (SASSA) for grants

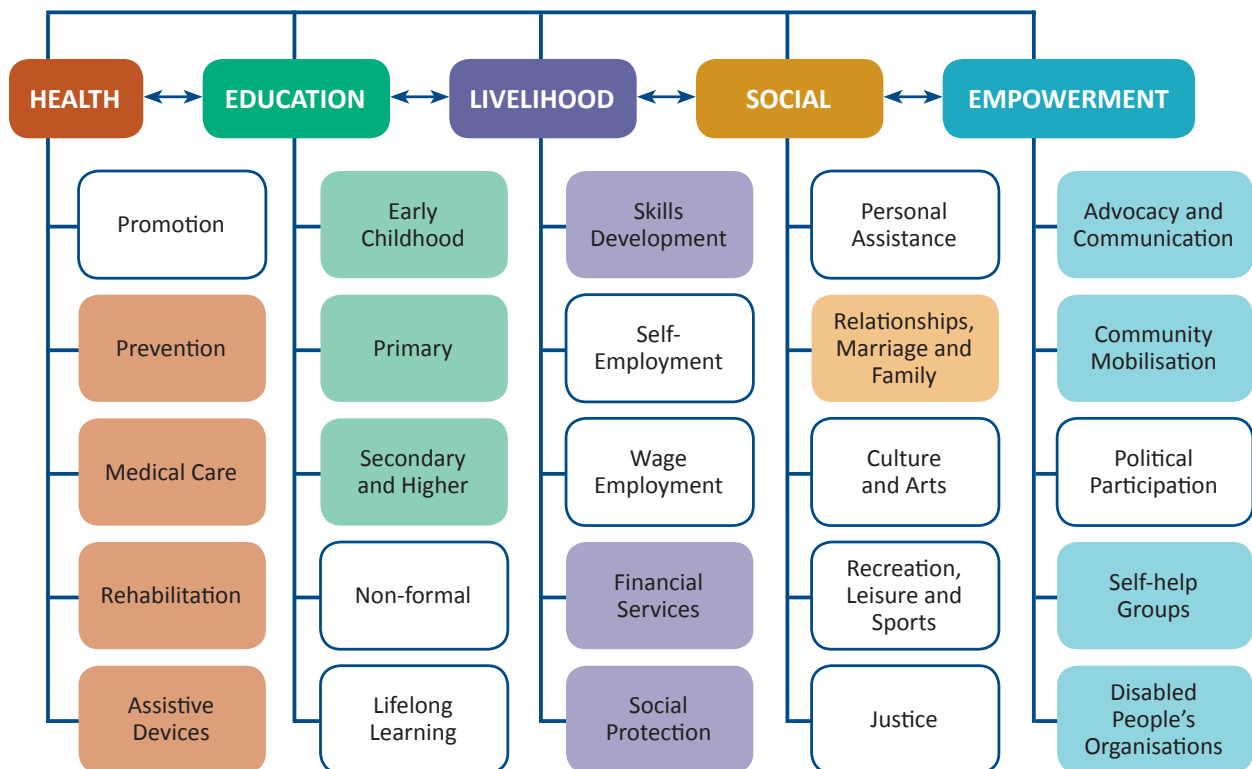
Social

- Guiding and assisting persons with intellectual impairments with regards to relationships
- Motivating persons with disabilities to participate in sport

Empowerment

- Assisting groups to become registered non-profit organisations with the Department of Social Development
- Lobbying and educating the local municipality to improve accessibility
- Training persons with disabilities on their constitutional rights
- Negotiating with the taxi association to ensure persons with disabilities are transported and not charged double fares

7. CBR matrix reflecting the work of KwaZamokuhle Special School CBR project



Nkosinathi Foundation

1. Location

Nkosinathi Foundation is located in Port Elizabeth. It provides services in the Nelson Mandela Bay metro as well as in the rural areas of Tsitsikamma, Hankey, Patensie, Addo and Paterson.

2. History

Nkosinathi Foundation started as the South African Blind Workers Organisation (SABWO) in 1948. The organisation was founded by a small group of blind people who wished to help other newly blinded adults and children in the absence of any other services for blind people. Initially SABWO involved blind volunteers doing rehabilitation with other blind people which included mobility and adapted skills of daily living. A social worker worked with SABWO providing social services and later Debby Wakeford, a sighted person who has since become the director was employed and received training from the South African National Council of the Blind to provide rehabilitation. As the rehabilitation services became more formalised, the demand grew and so the organisation has expanded. In addition, in the beginning SABWO only worked with blind people and those who had insufficient vision to cope with activities of daily living. More recently the organisation has included people with low vision as beneficiaries of their services.

3. Target group of Nkosinathi Foundation

The beneficiaries of Nkosinathi Foundation are people of all ages (from birth) who are blind or partially sighted. Nkosinathi Foundation also provides services to their families and caregivers as well as other key stakeholders such as teachers, employers, co-workers and medical staff, including ophthalmic nurses.

4. Staff implementing community based rehabilitation

Currently Nkosinathi Foundation is staffed by a director, a social worker, an orientation & mobility instructor, a low vision practitioner, an early childhood development coordinator, two early childhood development assistants, an administrator and seven rehabilitation community field workers.

5. Governance

The organisation is a registered non-profit organisation and is governed by a Management Board. According to the constitution of Nkosinathi Foundation, at least 65% of board members must be people who are blind or partially sighted.

6. Activities of Nkosinathi Foundation

Below is a list of activities of Nkosinathi Foundation which relate to CBR. This list has been compiled by the researchers based on observation, data from an interview and a focus group discussion and on information from the organisational profile document. This list may therefore not be complete but will give the reader an idea of the main activities of the programme.



Health

- Improving a blind person's mobility by training them to use a cane
- Teaching adapted skills of daily living e.g. pouring water and cooking
- Assessing clients who have low vision
- Recommending assistive devices for low vision
- Helping people access white canes
- Training ophthalmic nurses about rehabilitation
- Educating people on the prevention of blindness from diseases such as diabetes and HIV
- Promotion of healthy lifestyles

Education

- Assisting parents / caregivers to access schooling for their visually impaired children
- Running a weekly group for any blind or partially sighted children from the Foundation Phase of the local special school or the community. In this group the children learn orientation & mobility skills and receive stimulation and rehabilitation.
- Running an early childhood development group for blind or partially sighted children under the age of 4 years and their parents

Livelihoods

- Providing computer training and training in the use of Braille
- Planning to set up the first internet café for blind people in Nelson Mandela Bay metro

- Working with a group in Addo and Paterson which does vegetable gardening. Group members have been taught money identification and budgeting so they can manage their own income-generation project.
- Providing start-up capital for micro businesses
- Have provided orientation for people when newly employed at big businesses. Also have run workshops and training for company staff working with blind people to deal with their attitudes towards blind people.
- Provide the CVs of blind and partially sighted people to potential employers

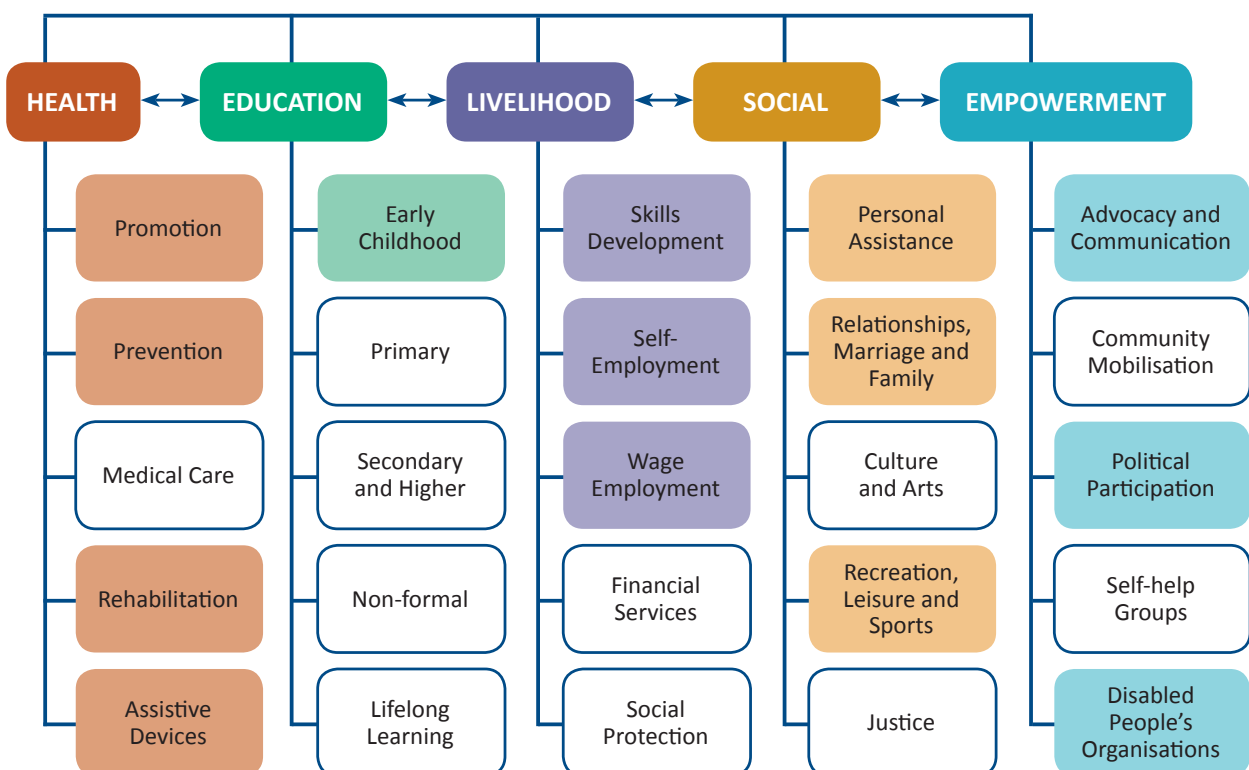
Social

- Provide counselling to family members and spouses where there are problems in the relationship because of blindness
- Social workers provide assistance to the beneficiaries for a range of personal issues – from housing matters to getting guide dogs to the vet!
- Facilitating social groups and arranging outings for the groups.

Empowerment

- Board members do voter education
- One board member helped to design the ballot paper for blind people
- Board members are quite involved in advocacy

7. CBR matrix reflecting the work of Nkosinathi Foundation





UNDERSTANDING

AND IMPLEMENTING KEY CONCEPTS IN CBR

As illustrated in the results of the survey, there are many different perspectives of CBR in South Africa. In this section of the report we share the views and practices of staff and beneficiaries of the organisations in the case studies related to key concepts in CBR. These are people who practically implement and participate in CBR and they have an understanding of CBR from their own experiences which may or may not be complemented by knowledge of the official positions on CBR from bodies such as the World Health Organisation.

Community based rehabilitation

CBR has been described as a strategy, a philosophy, a set of principles and a service by a number of stakeholders and in various official documents in South Africa and internationally. Although the CBR Guidelines and previously the Joint Position Papers on CBR offer definitions and descriptions of CBR it is understood and practised in a variety of ways.



One young man with a disability from the Gelukspan Hospital CBR project offered a concise view of CBR:

CBR looks at an individual child or adult with a disability, family members and community. CBR ensures that the needs of persons with disability like health, education are met. Barriers to disability are removed. It ensures that people are socially included, people with disabilities are empowered and people with disabilities are able to fulfil their potential.

Equal opportunities

The concept of equalisation of opportunities (and equal opportunities) has been central to CBR since its inception. It brings to the fore the need to remove barriers and the importance of respecting the rights of persons with disabilities.

A staff member of CREATE captured her understanding in the following way:

I mean for example in the traditional leaders project ...I think we are helping with equal opportunities and equalisation of opportunities by changing the attitudes of traditional leaders so that they then support the need for disabled people to be given housing alongside everybody else. But those traditional leaders understand that people with physical impairments might have special needs regarding how they might need wider doorways or ramps or whatever. So it's levelling the playing fields where the traditional leader not only works with the municipality in terms of getting housing for the able bodied people who are in his area but also for the disabled people. So there's equal opportunities to get housing whether you're able bodied or disabled.

A member of Sidinga Uthando in Orange Farm linked the idea of equal opportunities to human rights.

The name, Sidinga Uthando, speaks for itself, I think it links, everyone has a right for us to be all equal, whether disabled or not, we all get the same amount of love and have equal rights.

Rehabilitation

Although the need for provision of rehabilitation in a community setting was a driving force in the development of CBR, more recently in the CBR Guidelines, the concept is shifting to community based inclusive development. However, as seen in the results of the survey, many people in South Africa still see rehabilitation as a very important part of CBR.

Nkosinathi Foundation sees itself primarily as a rehabilitation organisation but this is not a narrow conceptualisation of rehabilitation. For example, the director pointed out that their work in ECD overlaps with and links very closely to rehabilitation for blind and partially sighted children. Similarly, providing computer training for blind and partially sighted persons is also considered an aspect of rehabilitation as it prepares these people to seek employment or attend university – learning functional skills to play their role in society.

Disability inclusive development

As mentioned above, a newer and broader view of CBR includes the concept of disability inclusive development. This concept has not been explored in detail in South Africa and it has not been incorporated into official policies as yet.

A CREATE staff member gave an example of what she feels is disability inclusive development within a CBR organisation.

CREATE getting [person's name] who is an architect to help an organisation in Ingwavuma called Fancy Stitch to design waterless toilets for public use that would be disability friendly... so that for me is a clear example of development, development of sanitation in an area where there were no public toilets or no working public toilets in Ingwavuma that are inclusive of disability.

The staff member of CREATE also indicated the importance of a twin-track approach to development.

So that you've got the municipality and the traditional leaders aware of disability needs and trying to do things on their own and then you've also got the strong disability group lobbying from the other side and advocating so I think that approach is also part of disability inclusive development.

Social inclusion

In early conceptualisations of CBR the definition included the term social integration. As CBR has evolved the terminology has changed to social inclusion which can be linked to the removal of barriers and equal opportunities.



A person with a disability linked to KwaZamokuhle CBR project explained social inclusion in this way:

People become aware that they are part of society, ja they are part of society they are socially involved in everything. As long as they are out there not being hidden at home, we can be here, we are part of people we also can do things here.

Empowerment

According to the CBR Guidelines, although empowerment is one component of the CBR matrix, it relates to all other components of CBR and therefore it is crucial to the implementation of CBR.

The CBR Programme at Afrika Tikkun has empowerment as its central organising issue. Parents and caregivers are empowered to lobby for access to services and to advocate for an end to gender-based violence that affects girls and women with disabilities. Parents and caregivers who were initially beneficiaries of the programme are now employed in the Empowerment Programme and accompany other parents on the path to self-empowerment. As one staff member of Afrika Tikkun explained:

I have been empowered by the programme now as I am working as a case administrator. I am seeing the programme empowering other women just like me who didn't have information of where to go, how to do things, how to.. force government to give you the rights ... we didn't know but empowerment has taught us how to do those things, so I am empowered and I am seeing empowerment empowering other women.





CONCLUSION

This study comes at an important time in South Africa when policies and frameworks are being developed in relation to disability and rehabilitation. It has been important to assess the current understanding of CBR in South Africa in order to determine how to move forward and bring the CBR Guidelines and matrix to the fore as we endeavour to implement the CRPD. We hope that decision-makers and implementers will learn from the examples of CBR in practice in the five case studies and that the survey results will point to gaps that need to be addressed. Finally, we hope that you will join us as we strive towards a society that respects the rights of all, using CBR as one means to achieve this.



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