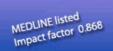
# **Rural and Remote Health**





he International Electronic Journal of Rural and Remote Health Research, Education, Practice and Policy

#### ORIGINAL RESEARCH

# Determining the competences of community based workers for disability-inclusive development in rural areas of South Africa, Botswana and Malawi

#### T Lorenzo, E van Pletzen, M Booyens

University of Cape Town, Cape Town, Western Cape, South Africa

Submitted: 18 November 2013; Revised: 15 October 2014; Accepted: 15 October 2014; Published: 5 June 2015

Lorenzo T, van Pletzen E, Booyens M

Determining the competences of community based workers for disability-inclusive development in rural areas of South Africa, Botswana and Malawi

\*Rural and Remote Health 15: 2919. (Online) 2015

Available: http://www.rrh.org.au

#### ABSTRACT

Introduction: Persons with disabilities and their families still live with stigma and a high degree of social exclusion especially in rural areas, which are often poorly resourced and serviced. Community-based workers in health and social development are in an ideal position to assist in providing critical support for some of those most at risk of neglect in these areas. This article analyses the work of community disability workers (CDWs) in three southern African countries to demonstrate the competencies that these workers acquired to make a contribution to social justice for persons with disabilities and their families. It points to some gaps and then argues that these competencies should be consolidated and strengthened in curricula, training and policy. The article explores local experiences and practices of CDWs so as to understand and demonstrate their professional competencies and capacity to deliver disability-inclusive services in rural areas, ways that make all information, activities and programs offered accessible and available to persons with disabilities.

**Methods:** A qualitative interpretive approach was adopted, informed by a life history approach. Purposive sampling was used to select 16 CDWs who had at least 5 years experience of disability-related work in a rural area. In-depth interviews with CDWs were conducted by postgraduate students in Disability Studies. An inductive and interpretative phenomenological approach was used to analyse data.

**Results:** Three main themes with sub-categories emerged demonstrating the competencies of CDWs. First, integrated management of health conditions and impairments within a family focus comprised 'focus on the functional abilities' and 'communication, information gathering and sharing'. Second, negotiating for disability-inclusive community development included four sub-categories, namely 'mobilising families and community leaders', 'finding local solutions with local resources', 'negotiating



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

retention and transitions through the education system' and 'promoting participation in economic activities'. Third, coordinated and efficient intersectoral management systems involved 'gaining community and professional recognition' and the ability to coordinate efforts ('it's not a one-man show'). The CDWs spoke of their commitment to fighting the inequities and social injustices that persons with disabilities experienced. They facilitate change and manage the multiple transitions experienced by the families at different stages of the disabled person's development.

Conclusions: Disability-inclusive development embraces a philosophy of social inclusion and a set of values that seeks to protect the human dignity and rights of persons with disabilities. It requires a workforce equipped with skills to work intersectorally and in a cross-disciplinary manner in order to operationalise the community-based rehabilitation guidelines that are designed to promote delivery of services in remote and rural areas. CDWs potentially have a unique set of competencies that enables them to facilitate disability-inclusive community development in rural areas. The themes reveal how the CDWs contribute to building relationships that restore the humanity and dignity of persons with disabilities in their family and community. These competencies draw from different disciplines which necessitates recognition of the CDWs as a cross-disciplinary profession.

**Key words:** audiology, community health workers, community-based rehabilitation, development workers, disability, occupational therapy, physiotherapy, primary health care, social work, southern Africa, speech therapy.

#### Introduction

Persons with disabilities across the lifespan are a neglected and vulnerable group, particularly in rural areas on the African continent. These areas are under-resourced as they have few if any public services, and vast distances to cover. Services provided by non-governmental organisations (NGOs) are dependent on donor funding so they struggle to sustain their programs and to retain health and rehabilitation professionals<sup>1</sup>. Rural areas have remained underdeveloped due to urban bias of government policies and programs<sup>1-4</sup>. Duncan et al. expand the meaning of the term 'rurality' to be more than geographical location because this includes 'the structure, state and quality of life of people living in sparsely settled places away from the direct influence of large cities and towns'5(p. 30). Opportunities for continuing professional development and support are limited. Information and communication systems are needed to generate and disseminate knowledge on disability-inclusive community development in order to equalise opportunities for persons with disabilities<sup>6</sup>. Current research exploring the livelihoods of disabled youth in rural and peri-urban areas in South Africa found there was poor access to information on disability inclusion, particularly poverty alleviation programs and economic development<sup>4</sup>. Many studies have identified a major challenge to be the inaccessible transport systems caused by physical, attitudinal and financial barriers, which limit participation of persons with disabilities in accessing services and opportunities for development<sup>1,7-10</sup>.

While disability has traditionally been regarded as the domain of medical and charitable interventions, the Convention on the Rights of Persons with Disabilities<sup>11</sup> and the Community Based Rehabilitation Guidelines<sup>12</sup> and literature demonstrate that professionals and service providers across sectors have a responsibility to develop programs that are inclusive of persons with disabilities<sup>6,13-16</sup>.

Despite legislation and institutional structures that are in place to support and facilitate the implementation of policies, insufficient human capacity and resources create a barrier to the inclusion of persons with disabilities and their families in the community at large<sup>5</sup>. Relevant primary role players in this quest are community health and rehabilitation workers and community development workers, who are well positioned to integrate disability issues into existing programs. The inclusive term used in this article to refer to such workers is 'community disability workers' (CDWs) (see details in the



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

methods section). This article is based on research conducted among experienced CDWs in Botswana, Malawi and South Africa so as to demonstrate their professional competencies, which enable them to make a valuable contribution to developing disability-inclusive community services in rural areas. Rehabilitation and disability services fall under the Ministries of Health and Social Development in the three countries. The burden of service provision falls largely on community-based workers and NGOs. Minimal research has been done on determining the competencies of CDWs. Cross-disciplinary research in this area is necessary to determine the necessary capacity to function as a CDW. Such research will inform further curriculum development for their continuing professional development, to ensure that they are equipped with the competencies needed in the field.

#### Methods

The study sought to identify the professional competencies of CDWs by exploring their local experiences and practices in rural areas in three countries: South Africa, Botswana and Malawi. These countries were chosen as four postgraduate students were interested in researching this topic for their course unit 'Developing critical research literacy'. A qualitative, interpretive approach was adopted, informed by a life history approach and phenomenology<sup>17</sup>. This article focuses on CDWs' descriptions of their work in order to identify key professional competencies that they already display and to determine further capacity necessary to deliver disability-inclusive services.

#### **Participants**

Purposive sampling<sup>17</sup> was used to select CDWs who had at least 5 years experience in doing disability-related work in a rural area. A total of 16 CDWs participated in this study with eight participants from Botswana, four from Malawi and four from South Africa (Table 1). There were nine women and seven men, with an age range of 26–54 years. Four participants were disabled and eight participants had a family member with a disability. Their length of training in community-based rehabilitation (CBR) varied, ranging from 6 months to 4 years. The majority of participants

were employed within the Department of Health and Social Development in different job categories; four participants worked for NGOs. They had extensive experience in disability-related work, ranging from 5 to 27 years with an average of 14 years.

#### Data collection

The research team consisted of six academics from the disciplines of Disability Studies, Higher Education, Public Health and Social Development, and five postgraduate students in Disability Studies, who were from different disciplinary backgrounds, namely a physiotherapist, an occupational therapist, an occupational therapy technician, and a medical prosthetist and orthotist. Two students did the fieldwork in Botswana, one in Malawi and one in South Africa. The training of the students to undertake data collection is described in Figure 1. The students were from the countries where data was collected and therefore had first-hand experience of the health, rehabilitation and social development services as well as the contribution of NGOs. The training they received was part of a critical research literacy course which they had to do as a requirement of the postgraduate diploma. They received feedback from the lecturers as well as the research team, which kept their experience grounded.

In-depth interviews were conducted between September 2011 and January 2012 at places and times convenient to the participants, which included the workplace, coffee shops or participants' homes. An initial interview was conducted with each CDW which ranged from 45 minutes to 1.5 hours. Key questions covered the demographics of participants, their childhood experiences of growing up in rural areas and schooling, the transition to work and influences on choice of careers 18. They shared both high and low points in their work experiences that in retrospect they identified as turning points. Permission was obtained to digitally record the interviews, which were transcribed verbatim for data analysis. Follow-up interviews or phone calls of about 1 hour were done to fill any gaps or seek clarity where needed as a means of member-checking with participants. A limitation of the study is that data was not sufficient to develop full life histories due to time constraints and the limited research experience of the postgraduate students at the time of fieldwork.



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

Table 1: Background and experience of study participants<sup>†</sup>

Country	Sex	Profession	Length of training (years)	Years of experience	Disability in family
Botswana	F	Social worker (1)	3	7	No
	F	Rehabilitation officer (2)	4	13 and 17	1 child, sister daughter, cousin,
	M	Rehabilitation technician (1)	2	12	Father
	3 F, 1 M	Family educator (4)	6	10, 11, 22, 27	1 child, 1 nephew and 1 grandchild
Malawi	M	Rehabilitation technician (4)	1 x 2 3 x 3	17 5, 10, 17	Cousin, father, relative
South Africa	3 M, 1 F	3 OT technician (3)	1 x 2 2 x 3	10 17 and& 20	2 brothers
	F	Community development worker (1)	1	5	self

<sup>†</sup> For the purpose of this study a generic term, CDW, was used to include the different categories of community rehabilitation workers, community rehabilitation facilitators, rehabilitation technicians, occupational therapy technician, disability consultants, community development workers and community health workers. F, female. M, male. OT, occupational therapy.

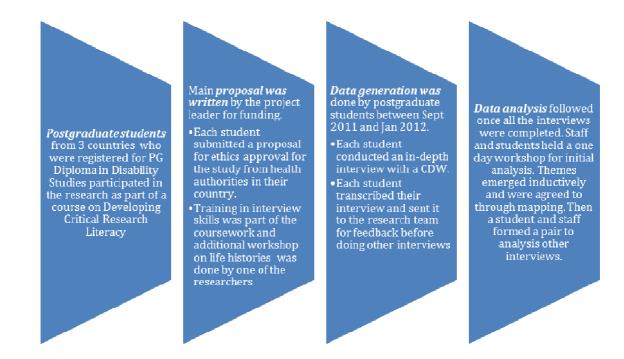


Figure 1: Overview of the data-gathering process.



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

#### Data analysis

The research team used an inductive process with interpretative phenomenological analysis<sup>19</sup>. This process enabled the researchers to identify the deeper meanings underlying the experiences of the CDWs. There was a first-level analysis of one transcript by each member of the research team, followed by a second-level analysis of emerging themes and patterns across the CDW transcripts from different countries.

Rigour was ensured through the group process and multiple levels of analysis. All team members read all the transcripts before an analysis workshop. In the workshop the researchers divided into two groups and decided on the most informative transcript. Each group identified and grouped themes and categories. They then worked in pairs to analyse another transcript using existing themes as well as identifying any new themes that emerged. Two team members then used Dedoose (http://www.dedoose.com) qualitative data analysis software to create an electronic database of all transcripts, themes and categories. The data analysis process addressed confirmability, as the themes identified were verified by the two groups. The students did member-checking with the participants. Thick description of contextual factors and experiences of CDWs was provided through verbatim quotes.

#### Ethics approval

This study was a sub-study of a larger study on Disabled Youth in Rural Areas which obtained ethical approval from the Faculty of Health Sciences Human Research Ethics Committee at the University of Cape Town (HREC REF: 428/2011). Informed consent was obtained from each participant at the beginning of the study. Confidentiality and the identities of the participants were assured by using pseudonyms in reporting the findings.

#### Results

Three competencies of CDWs in rural areas emerged as three core themes: integrated management of health conditions and impairments, negotiating for disability-inclusive community development, and facilitating coordinated and efficient intersectoral management systems. Each theme and its further sub-categories are illustrated by quoting CDWs directly (see Table 2 for summary).

## Theme 1. Integrated management of health conditions and impairments

CDWs' competence in adopting an integrated approach to managing health conditions and impairments at a community level was reflected in two sub-categories: ability to focus on the functional abilities of the disabled person and communicative competence, involving information gathering and sharing with the family.

Focus on functional abilities: CDWs saw as one of their primary competencies the ability to do early identification and screening of persons with impairments in the community to prevent functional limitations, whether physical, mental or psycho-social in nature. Common health conditions resulting in impairments identified by the CDWs included cerebral palsy, epilepsy, learning difficulties, spinal cord injuries, strokes and mental illness. The CDWs explained that they often work alone in contexts where there are no clinicians, so they need good clinical skills to assess and improve the functional ability of the person with impairment. There were many examples of CDWs making a difference in the lives of individuals, as illustrated in how a CDW helped a person who had had a stroke:

I managed to assist the client in dressing, eating, bathing, toileting and walking. So the client was able to do the daily living activities. So I became confident that I can do it alone. (Jeffrey, Malawi)

In many instances they themselves made devices from appropriate paper technology or ensured that individuals accessed their medication. The CDWs felt they fulfilled a critical role in intersectoral referrals and the provision of assistive devices:

I tried to talk with the mother [to find out if] they really want the child to go to school and the mother agreed. Then I



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

went to the closest school to request if they can admit the child which was successful. The child did not have wheelchair so I went to the hospital where the child was issued a wheelchair. (Mpho, South Africa)

Intervention often involved the ability to build and restore relationships through informing neighbours and family about conditions. Another success story involved a mother who had a psycho-social impairment. She was not taking her medication and was argumentative with neighbours who intended to report the matter to the police. The CDW managed the tensions by brokering relationships and providing support for compliance in accessing treatment:

So she is no longer fighting and has good relationship with the family members and neighbours. I also advised the family members to make sure she is taking treatment. (Londi, South Africa)

CDWs addressed exclusion from family relationships due to difficulties with communication. A CDW taught herself rudimentary skills in sign language so she could work with a young boy. His condition improved, which was appreciated by the family:

I made friends with this boy because I knew a few sign language signs that I had read from a book ... he mastered [the signs] within a short period of time. His parents and other members ... admired the relationship that I had built with the boy because, somehow, his condition had improved although I was not a speech therapist. (Mpho, South Africa)

#### Communication, information gathering and sharing: A

CDW in Botswana illuminated the importance of being able to gather and record accurate information together with good interpersonal skills and sensitivity in educating family members about medical and rehabilitative intervention:

I had to learn to explain everything in detail if I identified a child who needed to be operated for a correction or a rehabilitative measure. Sometimes I had to go back and research a bit more about that condition so that when I explain to parents I know fully exactly what I am talking about. (Kgomotso, Botswana)

There was a similar situation in South Africa involving a young man who had suffered a spinal cord injury in a cycling accident with a car:

He did not like himself until the family come to ask me if I can help... so I went to discuss with him until he understood; now he is working at the offices. (Noname, South Africa)

The CDWs are competent in interpreting professional language for families and enable continuity of care by ensuring access to professional services and resources:

... there is one grandmother from the other ward came with a letter from SASSA [South African Social Security Agency]. So she wanted to understand what was in the letter. (Noname, South Africa)

A CDW related how he 'works like a social worker' in situations where the primary need is the financial problems experienced by families. His efforts help prevent developmental delays and further impairments of the child by addressing malnutrition. In many instances, CDWs provide from their own resources:

... ok mother, if you can have some groundnuts and flour, and you make phala [porridge] for the child... sometimes I use my personal resources, but I am not rich. But I give you this packet of sugar as a start-up, go there and work 'ganyu' [casual work] please for the sake of this child. (Nick, Malawi)

# Theme 2. Negotiating for disability-inclusive community development

One of the CDWs' central concerns is to ensure that a disabled person becomes part of their family and community again. They showed the ability to tackle development issues across a wide front, ranging from participation in inclusive education and skills development to supporting employment and entrepreneurship. Sub-categories of this theme were mobilising families, communities and community leaders, finding local solutions with local resources, negotiating transitions through the education system, and promoting participation in economic activities.



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

Table 2: Summary of themes and categories demonstrating competencies of community disability workers

The	eme	Category		
1.	Integrated management of health conditions and impairments	Focus on the functional abilities		
		Communication, information gathering and sharing		
2.	Negotiating for disability-inclusive community development	Mobilising families and community leaders		
		Finding local solutions with local resources		
		Negotiating retention and transitions through the education system		
		Promoting participation in economic activities		
3.	Facilitating coordinated and efficient intersectoral	Gaining community and professional recognition		
	management systems	Ability to coordinate efforts		

#### Mobilising families, communities and community

**leaders:** In order to raise awareness of disability issues, CDWs need to be competent in undertaking a situational analysis of both home and community contexts. This aspect includes the social dynamics generated by attitudes towards disability. They educate families and communities about different health conditions, offer counselling and attempt to establish realistic expectations:

So when you go to the village you have to assess the village, the home situation, how people are relating with the person [with a disability]; if there are misunderstandings, you go there and try to solve them. (Emak, Malawi)

CDWs were also dynamic in developing messages to facilitate changes in the way the individual, family and neighbours see and think about disability. Their beliefs about change seem to have a strong spiritual basis — that disability is a gift from God, and that the disabled child still has potential and abilities. They were able to shared strong messages about the constructive roles that family and community members play, helping the parents to recognise that their child with a disability needs them:

[I encouraged the family] to understand that this is not your fault ... even 'wazungu' [white person] do have disabled child ... But you see God gives them something ... No matter how severely disabled the child is, something positive can come

out of the child ... the child sees you as father and mother. (Nick, Malawi)

CDWs also bring parents together in support groups:

Mothers were happy also to find out that they were not the only ones having a child with disabilities. When they come to our place, they meet together with people from different places. So they share experiences. Sometimes they see that their child is better than other children and they also got encouraged. (Chisomo, Malawi)

A CDW-facilitated interaction occurred between a village headman and mothers of disabled children to form a supportive network:

So [village headman] said 'this is good news'. Now he started asking the ladies, 'why is [it] that you people were hiding?' They said that, 'we face discrimination, that's why, you don't know about these things. We tend to hide them because people mock us, they spit. It's quite a nasty situation.' (Nick, Malawi)

Finding local solutions with local resources: A CDW pointed to how mapping villages to identify resources that a disabled person needs is usually a good starting point, as the needs identified are then prioritised by community members themselves:



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

I treated a certain child who had TB of the spine who was rejected by the parents ... After the child was picking up, the whole community came up and we were working together trying to find a way. They were able to contribute for the production of walking aids until the child was fully cured. (Emak, Malawi)

A focus on advocating safe motherhood and delivery by the CDWs occurred in Botswana. It illustrated the CDWs' ability to educate mothers on early warning signs, screen for impairments and contribute to disability prevention in childhood. But despite some successes, the tension between local traditional practices and formal health service practice became evident:

The incident gave me some momentum to mobilise the community and educate it on issues of safe delivery. With the help of community leaders, I began to advocate for hospital or clinical delivery so as to do away with home delivery. The idea got a lot of support from many community members, some of whom had the terrible experiences of losing both baby and mother. (Karabo, Botswana)

Advocacy requires practical skills to facilitate a change in attitudes that enables greater access for participation. CDWs in South Africa demonstrated the competence to do simulation activities such as getting taxi drivers to be passengers to raise their awareness of disability:

So we made sure that if they want to step out in the street like e.g. hospital gate, we just pass for a little distance because we wanted them to feel the pain. Also how do blind people feel if you don't drop them where requested. So it did have an impact because the taxi drivers realised they were doing mistakes. (Londi, South Africa)

Fostering disability-inclusive community development also necessitates competencies in negotiating transitions through the education system and inclusion in livelihood opportunities.

Negotiating retention and transitions through the education system: The CDWs shared how they played a crucial role in ensuring children's retention in the education

system from primary through to tertiary levels. Together with disabled people's organisations, CDWs have a strong focus on advocacy in education, specifically targeting school teachers, principals and school governing bodies about children's abilities to ensure their retention in school. This included the need for career guidance:

The child who had epilepsy was taken out of the school as he was [having many fits and] not performing well. I went to discuss the matter with the principal. So I educated him about epilepsy and ... they readmitted the child. The child was happy to be back to school. (Mpho, South Africa)

The [child with a disability] graduated at the university ... that boy basically grew up in my hands ... going to school and eventually graduating. They had a party and I could see even the family were so happy [and] attributed that success to us. (Gil, Botswana)

CDWs expressed how they were able to work across health and education sectors to promote inclusion and reduce dropouts. This ability ensured that disabled children were able to succeed despite their health condition and achieve the highest standard of education possible:

Those who are having difficulty learning were referred to hospitals for assessment so they would be placed in special schools. We insisted that if a person fails, it doesn't mean that they cannot do anything ... I also targeted schools during exams to talk to scholars on how to manage exam stress. (Mpho, South Africa)

In one country the CDWs engaged directly with funders and promoted the possibility of inclusive education:

I talked [with the school leadership] about the inclusive education project that was funded by UNICEF that focuses on the inclusiveness of human rights in education. We have projects in [urban areas and rural villages]. (Nick, Malawi)

**Promoting participation in economic activities:** The experiences of CDWs revealed that many adults with



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

disabilities were only able to obtain a primary school education, after which they went back to live in their rural community, finding themselves trapped in a life of unemployment and poverty. CDWs thus identified opportunities for persons with disabilities to develop economically marketable skills, preparing them to take up opportunities to establish local entrepreneurial ventures:

At that time if you sent someone to read about leatherworks, you knew that someone was going to benefit from that course and earn a living. (Kgomotso, Botswana)

I assisted him by motivating a further education and technical college to admit him to do hand activities. So he did engineering and is fixing cars now. He is the owner of the workshop. So the community sees now that he can do something. (Londi, South Africa)

As part of efforts to promote participation in the economy, the CDWs' work involves organising people to work together to write proposals for funding, seed money or equipment needed for a business venture, to write advertisements for local newspapers and to market to potential customers. A CDW felt that the effort put into mobilising these resources was worthwhile as the persons with disabilities became economically independent:

I wanted [a person with a psycho-social impairment] to work with person with a physical disability starting a car wash because the grant is little for them ... I also motivated for the local game lodges to bring their cars ... even in the schools I asked all teachers to bring their cars. So [persons with disabilities] started to realise that they can work for themselves. Even the community started to respect and loves them. They are not going around begging money from people but they work for themselves. (Londi, South Africa)

# Theme 3: Facilitating coordinated and efficient intersectoral management systems

This competence is needed to bring together the two preceding themes. Two sub-categories emerged under this theme: gaining community and professional recognition, and the ability to coordinate efforts.

#### Gaining community and professional recognition:

The CDWs in the study work across so many sectors, making it hard for them to gain community and professional recognition. Their stories spoke of their humility and gratification when their achievements and successes were recognised by families. Many expressed how their work was fulfilling, that they witnessed changes and that individuals and families expressed their appreciation:

With this job, you really see the results. ... It motivates you even more than the salary! You walk up tall, you show people, this guy got prosthesis and is walking. (Gil, Botswana)

Reciprocal capacity development seems to occur in the process of raising awareness and creating opportunities for participation of persons with disabilities, which leads to the recruitment of community members to become rehabilitation therapists as well:

When I was training as an occupational therapy assistant, I also did CBR ... Then it was easier for me to stand before school children and tell them about speech, physio and OT [occupational therapy] ... Some of the kids that I motivated, they are now my supervisors as they are back now working with me. (Londi, South Africa)

There were also challenges, however. CDWs expressed that a major impediment in their work was their level of academic qualification. This gap highlighted the need for a career pathway that would strengthen professional recognition in their 'work with other highly qualified professionals' (Nick). In this respect, they expressed their commitment to lifelong learning to equip themselves with the necessary skills and knowledge in this field:

I need to improve or upgrade my educational and professional qualifications so as to improve my knowledge and skills in my field of work as a disability worker. It would improve my



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

performance at work but also the lives of the people with disabilities (Mothusi, Botswana).

All CDWs in the study spoke of the intersectoral nature of disability and development and the importance of coordination between service providers.

**Ability to coordinate efforts ('it's not a one-man show'):** CDWs displayed the ability to work in a coordinated fashion, across a number of sectors. They explained that they gave technical assistance on rehabilitation and disability, as well as on project development and fundraising, to a range of different service providers:

We have been working mostly with schools ... they refer to me to assess the child and I write how they could solve that problem. There was good relationship with the hospital and clinics, who we were working hand in hand .... We had to go to nursery schools, or NGOs, and the orphanages and tell them how they can identify the children at an early age who may need our help. (Emak, Malawi)

CDWs see themselves as multi-skilled community workers and disability as a cross cutting issue, which inevitably means that they work across sectors in government:

We say that we mainstream disability in development activities. Before [persons with disabilities] could not stand and fight, but now they can stand and fight for their rights ... I need to mainstream disability issues into the District Education Management (DEM), District Agricultural Development Office (DADO), the District Health Director. (Jimu, Malawi)

At the same time, CDWs often work alone, with little human resource support, which they find difficult. Across all three countries, competencies in developing and implementing management systems were needed in terms of supervisory capacity and project management. Although only one of the four CDW participants in Botswana seems to have been a supervisor – 'I used to supervise [social work undergraduate] students' (Gil, Botswana) – this responsibility may be a

competence that needs to be developed in others in future if their role is recognised and becomes a profession in its own right.

Some of the CDWs have had opportunities to travel across continents to attend relevant skills development courses related to rehabilitation as well as to management:

I have been in and out of several courses. I have been to management course at Institute of Management, a Financial Accounting Course. ... I went [to] Bobath, in South Africa. So that gave me an opportunity to interact with people. (Nick, Malawi)

The three themes illustrate the valuable contribution that CDWs make to building relationships and collaborative services to address inequities related to scarce resources in underserviced rural and remote areas. These competencies are considered further in the next section.

#### Discussion

The CDWs in this study demonstrate the ability to provide a relevant response to managing the needs of children, youth, adults and elderly living in rural areas who have various impairments, which cause them to face many barriers to participation in everyday life. Coleridge<sup>20</sup> has recognised that those with multiple and severe impairments are often most neglected in rural communities. CBR is not an alternative system separate from primary health care but is envisioned as an integral component of the Alma Ata Declaration<sup>21</sup>, which ensures the particular needs of persons with disabilities are addressed through capacitating community-based workers with competencies in alleviating consequences of impairments.

Theme 1 addressed impairment-related needs, which have to be matched with a focus on environmental factors that affect participation in community, social and economic development, as illustrated in themes 2 and 3. The three themes confirm the relevance of the two-pronged approach



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

advocated in CBR to ensure equal opportunities are created for persons with disabilities<sup>12</sup>. Underpinning the themes is the critical role that CDWs play in building relationships that restore the dignity and respect of persons with disabilities within their families and wider community. Three essential competency strands emerged from the themes, which arguably are applicable internationally.

# 1. Integrated management of health conditions and impairments with a strong family focus

A family-focused approach is advocated as so much of the work of the CDWs has a strong maternal and child health focus to ensure early detection and referral of disabled children to relevant professional expertise. Their core competencies related to managing health conditions and impairments are early identification and screening of functional abilities, educating the individual and/or family members about mobility, self-care, language development and communication; compliance with medication; the making of assistive devices; and referrals to relevant professional services. The CDWs provide information on different health conditions that helps families make informed decisions about the services and opportunities that exist for promoting the person's wellbeing. This role extends to persons and groups with chronic diseases of lifestyle to ensure maximum health promotion and prevention of further impairment. CDWs need to know the referral and care pathways for matters that are beyond their level of competence. So it is essential for health planners to ensure that the generalist knowledge of CDWs is integrated with the specialist knowledge of rehabilitation professionals by recognising CDWs as equal members of the primary health care team at district level.

# 2. Negotiating disability-inclusive community development

The experiences of the CDWs in the study reveal that opportunities exist for social inclusion and awareness raising, beyond what rehabilitation therapists traditionally do, and that this is essential in the quest for greater social inclusion of persons with disabilities. The CDWs are effective in

educating colleagues in primary healthcare services, social development and the education system about disability inclusion. They have assisted their families to advocate, negotiate and manage the numerous transitions they go through as children or youth with a disability progress through different life stages.

CDWs act as advocates and facilitate the access of persons with disabilities to local services and resources that are available to the wider community. Facilitating and capacity building for promoting participation in the economy and entrepreneurship were identified as significant competencies of CDWs in order to address poverty. Persons with disabilities need opportunities for business development in their local communities.

The CDWs in the study clearly have empathy and insights for the struggles faced by persons with disabilities growing up in rural areas<sup>18</sup>. The combined efforts of government sectors, alongside disabled people's organisations and other local civil society organisations, are needed to make services, activities, information and other resources accessible to persons with disabilities. The CDWs' competencies need to extend into influencing the curricula of professional programs in higher education institutions so that the WHO's vision for CBR as part of the primary healthcare approach that addresses poverty and social inclusion alongside rehabilitation can be realised<sup>12</sup>. The approach is aligned with the goals and principles of the UN Convention on Rights of Persons with Disabilities (UNCRPD) and will contribute to the achievement of disability inclusion in the UN Millennium Development Goals<sup>22</sup>. In this way, persons with disabilities are able to participate equally and contribute to community life.

# 3. Coordinated and efficient intersectoral management systems for disability inclusion

CDWs often work in rural settings where there are no professional-led services to ensure standards of good practice. This absence necessitates recognition by those in leadership positions in public services and higher education that CDWs



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

make a meaningful contribution to the families of persons with disabilities and the communities in which they live, not just the individual. Across all three themes, it is evident that the work of the CDW is often cross-disciplinary in nature, which raises the challenge of providing continuing professional development for CDWs as well as good support and supervisory structures. Rehabilitation therapists are needed for supervision related to functional abilities at the individual level and support groups for health promotion and skills development. Social workers or development practitioners would provide support and supervision on aspects related to counselling, group work and community development. Competence in project management is critical as fundraising and proposal writing were identified as essential skills for sustainability of projects and initiatives at a community level.

A recurring weakness of CBR programs evident in the findings is the tendency of disability programs to be developed in silos by different ministries, that is, vertical programs without the horizontal coordination needed for inclusion<sup>5,13,14,16</sup>. Another major barrier is inadequate access to information about available services and activities<sup>1-3,5,7,12</sup>. When information is available, it is often not accessible to those with sensory impairments related to vision and hearing.

The sentiment that inclusive development 'is not a one-man show' requires deep reflection by many managers and leaders in human resource development and information systems as to how to include the social and environmental aspects of disability. Human resource managers and planners need to consider how career pathways are developed across the different sectors for such specialised practitioners to gain the necessary professional recognition.

Government departments need to focus on how to improve service delivery to persons with disabilities by bridging the gap in coordination of services and programs across sectors that are most commonly tasked with service provision responsibilities, namely health, education and social development. The findings of this study also imply that departments of labour and transport have taken very little

cognisance of their responsibilities to promote access to participation and to information on services and resources. It is here that CDWs have demonstrated the competence to build partnerships for disability-inclusive community development across multiple levels of government, NGOs, and international development organisations and donors.

The lasting impact of CDWs is felt when all service providers are supportive of their work and facilitate the meeting of needs in an inclusive way. The contextual barriers that CDWs experience is the focus of another article providing further evidence of the competencies they need to acquire<sup>23</sup>.

#### Conclusions

The findings in this article have focused on the current competencies of the CDWs in this study, which illustrate how the CDW is a unique worker who is responsible to the individual disabled persons and their families, as well as for coordinating services across different sectors to facilitate their inclusion in local communities. The removal of barriers to ensure equal participation of persons with disabilities in development opportunities contributes to achieving primary healthcare aims and the Millennium Development Goals.

This article has demonstrated the competencies of CDWs to deliver inclusive services in rural areas. They are faced with the challenge of building a robust system for the individual and their family to manage transitions associated with disablement as part of a complex system of change. Community disability work needs to be recognised as a cross-disciplinary profession. This attempt to present a strong case to replicate the deployment of CDWs, particularly in underresourced rural areas, to achieve the vision for disability-inclusive community development, is made with a hopeful heart that it will be heeded. Further research on the specific training of the different categories of CDWs — with particular attention to competency development — would yield interesting insights and relevant outcomes.



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

## Acknowledgements

Funding and intellectual support was provided from the Programme for Enhancing Research Capacity (PERC), Research Office, University of Cape Town and the National Research Foundation Community Engagement Strategy. Thank you to the CDWs who were willing to be participants in the study. Thank you to members of the research team: Sylvester Butao, Bryson Kabaso, Zelda Mbu and Khadija Mashuke (postgraduate diploma students, data gathering and data analysis workshop); Callista Kahonde (PhD candidate, data analysis workshop); Dr Sarah Rule (honorary senior lecturer, co-supervisor, interview training, data analysis workshop); Professor Roy McConkey (visiting professor, guidance throughout project); Ikechukwu Nwanse (project manager); Dr Ermien van Pletzen (co-supervisor, data analysis, co-author); Dr Margaret Booyens (data analysis, coauthor); and Associate Professor Theresa Lorenzo (project leader, lead author, supervisor). The authors appreciate the insightful comments from the reviewers that improved the coherence of the article.

### References

- 1. Lorenzo T, Cramm JM. Access to livelihood assets among youth with and without disabilities in South Africa: implications for health professional education. *South African Medical Journal* June 2012; 102(6): 581.
- 2. Office of Deputy President. White paper on an Integrated National Disability Strategy. Pretoria: Government Press, 1997.
- **3**. Hartley S, Okune J. *CBR policy development and implementation*. Norwich, University of East Anglia, 2007.
- 4. Chappell P, Lorenzo T. Exploring capacity for disability-inclusive development. In T. Lorenzo (Ed.). *Marrying community development and rehabilitation: reality or aspiration for disabled people.* Disability Catalyst Africa series 2. Cape Town: Disability Innovations Africa, 2012; 5-35.

- **5**. Duncan M, Sherry K, Watson R. 2011 Disability and rurality. In T Lorenzo (Ed.). *Intentions, pillars and players*. Disability Catalyst Africa series 1. Cape Town: Disability Innovations Africa, 2011.
- 6. Lorenzo T, Cloete L. Promoting occupations in rural communities. In R Watson, L Swartz (Eds). *Transformation through occupation*. London and Philadelphia: Whurr Publishers, 2004; 268-286.
- 7. Lorenzo T. We are also travellers: an action story about disabled women mobilizing for an accessible public transport system in Khayelitsha and Nyanga, Cape Metropole, South Africa. *South African Journal of Occupational Therapy* 2008; **39(1):** 32-40.
- 8. Loeb M, Eide AH, Jelsma J, Ka'Toni M, Maart S. Poverty and disability in Eastern and Western Cape Provinces, South Africa. *Disability and Society* 2008; **23(4)**: 311-321.
- 9. Maart S, Eide AH, Jelsma J, Loeb M, Ka'Toni M. Environmental barriers experienced by urban and rural disabled people in South Africa. *Disability and Society* 2007; **22(4):** 357-369.
- **10**. Kahonde C, Rhoda A, Mlenzana N. Persons with physical disabilities' experiences of rehabilitation services at community health centres in Cape Town. *South African Journal of Physiotherapy* 2010; **66(3):** 2-7.
- **11**. United Nations. UN Convention on Rights of Persons with Disabilities. UN: New York, 2006.
- **12**. World Health Organization. *Community-based rehabilitation guidelines*. Geneva: WHO, 2010.
- **13**. Finkenflügel H, Rule S. Integrating community-based rehabilitation and leprosy rehabilitation services into an inclusive development approach. *Leprosy Review* 2008; **79**: 83-91.
- 14. Rule S, Lorenzo T, Wolmarans M. Community based rehabilitation: new challenges. In: B Watermeyer, L Swartz, T Lorenzo, M Schneider, M Priestley (Eds). *Disability and social change: a South African agenda*. Cape Town: HSRC Press, 2006.



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

- **15**. Lorenzo T, Toni M, Priestley M. Disability studies: engaging activism and academia for social change. In: B Watermeyer, L Swartz, T Lorenzo, M Schneider, M Priestley (Eds). *Disability and social change: a South African agenda*. Cape Town: HSRC Press, 2006.
- **16**. Lorenzo T. Equalising opportunities for occupational engagement: disabled women's stories. In: R Watson, L Swartz (Eds). *Transformation through occupation*. London and Philadelphia: Whurr Publishers, 2004; 85-102.
- 17. Plummer K. Documents of life. London: Sage Publications, 2001.
- **18**. Rule S, Kahonde C, Lorenzo, T (under review). 'When I grow up I would like to be ...' Factors affecting career choice of community disability workers in southern Africa *IJDDE* 14 May (Online) 2015. doi: 10.1080/1034912X.2015.1035699.
- **19**. Holloway I, Freshwater D. *Narrative research in nursing*. Oxford: Blackwell Publishing, 2007.

- **20**. Coleridge P. Making the UN Convention on the Rights of Persons with Disabilities a reality through Community Based Rehabilitation (CBR): a tale of two triangles. Paper presented at Disability Studies Seminar Series, University of Cape Town, July 2011.
- 21. World Health Organization. Alma Alta Declaration. Geneva: WHO, 1978.
- 22. United Nations. Millennium Development Goals. UN: New York, 2000.
- 23. van Pletzen E, Booyens M, Lorenzo T. An exploratory analysis of community-based disability workers' potential to alleviate poverty and promote social inclusion of people with disabilities in three Southern African countries. *Disability and Society* (Online) 2014; doi:10.1080/09687599.2014.958131.