

WFOT Congress 2018



AN EXPLORATION OF THE EXPERIENCES AND PERCEPTIONS OF CAREGIVERS OF CHILDREN WITH DISABILITIES REGARDING COMMUNITY-BASED REHABILITATION SERVICES IN A RURAL SETTING IN SOUTH AFRICA.

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Intro

- ▶ A global *shift in views of disability over the past 20 years.*
- ▶ *Governmental law reforms: UNCRC, African Charter, UNCPD, (Philpott & McLean, 2011).*
- ▶ SA facing increasing childhood disability prevalence.
- ▶ General Household Survey (2012) classified nearly 2.1 million children, 11.2% of the country's child population as disabled (DOSD, DWCPW, and UNICEF, 2012).
- ▶ Great emphasis on the importance of early detection, continuous and relevant rehabilitation services.
- ▶ thus narrowing the gap between government legislations and grassroots implementation.

Intro

- ▶ Rural communities in South Africa faced with greater difficulties than its urban counterparts
- ▶ *38% of the country's population marginalised.*
- ▶ *Furthermore, limited research exploring experiences and perceptions of the receivers of rehabilitation services.*

Community-Based Rehabilitation

The lens of Community-Based Rehabilitation (CBR) Framework:

defines CBR as A strategy within community development for the rehabilitation, poverty reduction, equalisation of opportunities and social inclusion of all people with disabilities WHO(2010).

Importance of human rights and equal opportunities for people with disabilities (Ned-Matiwane, 2013).

4 Components:

health -> education -> social -> empowerment.

Community-Based Rehabilitation should...

- ▶ Enable independence, social integration, economic self-sufficiency, improved quality of life and self-actualisation (WHO, 2007).
- ▶ Include concepts such as intersectoral collaboration, *active participation*, *empowerment and social inclusion* - initially foreign, in the *rehabilitation* world.

Aims

Describe caregivers' experiences of the rehabilitation services.

ID perceptions regarding the health needs

ID perceptions regarding educational and social needs

ID perceptions regarding empowerment.

Methodology

- ▶ 3 focus groups
- ▶ 5 semi-structured interviews
- ▶ 3 key informant interviews

- ▶ Analysis
 - ▶ Thematic analysis.
 - ▶ 4 provisional themes

Emerging statements

Health: Improving health outcomes over contextual barriers

“I see a huge difference. At first, he could not move. Now you cant leave him alone.. Otherwise you will find he has fallen off the bed – P4FG 1”

“They even showed us pictures of how a child with CP looks like. That’s how I found out. when we went for training on CP as 3 mothers and our children. We stayed there a full week. They showed us how to handle a child to assist them with their disability - FG1P3”

“We worked a lot there... to a point where she started learning how to crawl on her own. That’s where I started seeing a difference and I got hope that my child going somewhere and will be like other children – P4FG 2”.

- ▶ *“You know we used to do home visits. Those were nice because we could provide therapy in the person’s home.... Now we don’t do that anymore. Key Informant 1”*
- ▶ *“You know, it does get a little complicated now. It is only the urgent cases, we do home visits for - Key Informant 2.”*

“No one comes to me anymore. They would say that they will come at a certain time. But then not come. I cant walk with her to the clinic... It is not safe – PI 1”.

Emerging statements

▶ Education: Building healthier school communities

*“I took her out of school because they called me sll the time.. Saying they cant feed her.
So I always got scared.– PI 4”*

*“I don't feel like I could ever take him to school. They wont understand him. I understand
him P5FG 1”.*

“Her school friends don't treat her as though she cannot walk, you see - PI 1”.

*“We do outreaches at schools as well. That's how we get to some of the kids – Key
Informant 1”.*

Emerging statements

Social: Breaking Social barriers

"I cant do anything else besides look after him. I don't have any other life besides him –P2FG 2".

"Its not enough to do outreach. We need to be visible in the communities, see what resources our mothers can tap into in their own communities – Key Informant 1".

"She cant even play outside because where we live is horrible – PI 5".

▶ Empowerment: Changing our thinking

"I think we as therapists are not used to advocating for our patients. We get taught that we need to advocate, but we never ask, or challenge the municipality and say 'where are the parks for children to play – Key Informant 1"

"We've had so many new developments over the past few years and there's still no public space for children to play - Key Informant 2"

"We used to have a support group for us mothers at the clinic... We shared knowledge and wisdom. How do you feel when such a thing happens. They also don't happen anymore PI 1".

My experience has been very motivating for me on how to treat my child you see. Like, even when I meet other parents of children with disabilities, I always feel like helping and raising that child because I now know how to raise a child with a disability – PI 3".

What next...

While there's an appreciation for rehabilitation services, effective CBR interventions are still hampered by governmental challenges.

Rehabilitation professionals working in silos in different sectors.

Health and education components of CBR are showing more collaborative

More focus on social and empowerment components required to encourage self-sufficiency and community participation.

Thank you 😊

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