

Health-system strengthening that matters to rural persons with disabilities: lessons from the Eastern Cape

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People with disabilities are particularly vulnerable to health-system weaknesses and failures. Disability, poverty and poor access to healthcare services occur in a mutually reinforcing vicious cycle, and health system-strengthening measures are vital in interrupting this cycle. Knowing which health system aspects need to be addressed requires an understanding of how people with disabilities currently engage (or do not engage) with services. While much recent research addresses healthcare access for people with disabilities, very little of this research has explored the interaction of this vulnerable population with the health system over time, or their choices and experiences within this process.

This chapter presents research into the engagement of people with disabilities with primary health care services in a rural area of the Eastern Cape. A group of people with disabilities was followed over two years, providing qualitative longitudinal data on health system engagement, contextualised within the realities of daily life in an

impoverished rural community. Through understanding the healthcare experience from the perspective of people with disabilities, important lessons emerged on how health systems can either exclude or engage this vulnerable population.

The study describes the often-hidden temporal and spatial dimensions of healthcare engagement, which pose serious barriers to people with chronic health conditions and people with disabilities. At the same time, it reveals the pivotal role of individual interaction between healthcare worker and healthcare seeker, and the ways in which the health system can either constrain or enable this. While the findings point to large-scale health system changes needed if people with disabilities are to fully realise their right to health care, the findings also suggest the protective role of trust and positive relationships at individual level in strengthening healthcare engagement. The recommendations offer hope not only for people with disabilities, but also for the broader population.

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Introduction

A growing body of literature describes the challenges facing people with disabilities in accessing health care in low- and middle-income countries, including South Africa.¹ People with disabilities are known to experience marginalisation in both the health system and broader society, often for related reasons, such as environmental barriers, increased risk of poverty, and social exclusion. Clear trends are emerging across the data from different settings, including the barriers to access posed by transport costs, healthcare worker knowledge and attitudes, inaccessible environments, and lack of specialised services.^{2,3}

Large-scale quantitative studies cannot account for the wide variation in individual healthcare-seeking choices and responses under the same set of constraints. Questions about this variation rose when the first author [KS] was working as an occupational therapist in a rural district hospital, and led to a doctoral study aimed at understanding how people with disabilities and their households made decisions about engaging with the health system, how they experienced this engagement, and how this process unfolded over time in the context of their everyday lives. The study theorised that understanding different people's choices would shed light on what they valued in health and health care, and indicate possible health-system strengthening measures beyond simply removing barriers to access.

This chapter describes selected aspects of the research findings, using case studies to illustrate elements of healthcare engagement by people with disabilities.

Methodology

An embedded case study was done of 11 people with disabilities and their households living in a remote rural village in Alfred Nzo district, Eastern Cape. This area falls under tribal leadership of the amaBhaca people, and traditional practices remain strong.

Like many former homeland areas, Alfred Nzo district is characterised by poor infrastructure, high unemployment and deprivation levels, and considerable labour migration to the cities.⁴ In line with the Rural Health Advocacy Project's definition of rurality, healthcare access in this area is complicated by large distances between different levels of healthcare facility, topographical barriers, and inherent health-system challenges.⁵ Participants' engagement with healthcare services was studied over a two-year period, using ethnographic methods, including immersion in context, participant observation, narrative interviewing, and key informant interviews. Each 'case' was built up using additional data from family members and healthcare workers, creating a multifaceted picture of engagement.

Participants were recruited through a local research assistant and community research advisory group, and were purposively sampled for maximum variation in age, gender and type of disability. The small sample size and prolonged engagement allowed for considerable depth in each case. Data generation and analysis took place iteratively, using a combination of thematic and narrative analytical methods. Further methodological detail on the study has been published elsewhere.⁶

Ethical permission for the study was obtained from the University of Cape Town's Health Research Ethics Committee (HREC no. 569/2012) and from the Eastern Cape Department of Health.

Key findings

The findings confirmed much already known about barriers and challenges faced by rural people with disabilities in accessing health care. However, by exploring how different individuals responded to the same factors in the unfolding context of their lives, new dimensions to healthcare engagement were uncovered.

For participants experiencing chronic or long-term health needs (both disability-related and otherwise), the temporal dimension of healthcare engagement became especially important. Following the stories of individuals over time provided a view of the full cycle of healthcare seeking, from the emergence of a health need through to the outcomes of healthcare received. The following sections of this chapter unpack how participants made decisions about healthcare seeking, characteristics of their healthcare-seeking trajectories over time, and the pivotal role of individual interaction with healthcare workers in determining the perceived quality and effectiveness of health care.

Deciding to seek care

Viewing healthcare engagement from the perspective of people with disabilities and their families, it was clear that there was no simple pathway from experiencing a health need to seeking services. The decision to seek health care was a complex reasoning process, weighing up the health need experienced against the costs of seeking health care, and the perceived likelihood of receiving satisfactory help. In this cultural and socio-economic context, healthcare seeking is usually a decision taken by the household not the individual, and was therefore influenced by family relationships and values, competing demands on resources, and other contextual factors such as culture and income.

The costs of almost any healthcare visit were high, including transport money, time, and social assistance. While the nurse-run local clinic could provide basic primary care, a doctor could only be seen at the district hospital in town, and this was necessary for the majority of the health needs

reported by our participants (which included treatment for pain, fatigue, epilepsy, respiratory infections, and neurological impairments, among others). Such a visit would take an entire day, with the participant and relative catching the only taxi to town at 05h00, and returning after 17h00. Fares for a person with a disability accompanied by a relative could be up to 10% of the monthly disability grant (more if a wheelchair was also transported), before payment of user fees and other expenses. No disability-specific services existed in the community itself, and although several rehabilitation professionals were employed at the district hospital, only two of the 11 participants had ever had contact with them.

Given these dynamics, not every health problem experienced by people with disabilities led to healthcare seeking. While acute or common health conditions (e.g. a fever) might lead to a straightforward visit to the clinic for curative care, disability-related health needs (e.g. treatment for a psychiatric condition or access to assistive devices) were more complex.

Not all participants had a diagnosis for the condition leading to their impairment, or a clear idea of what kind of treatment or outcome could be hoped for. A large proportion of healthcare seeking was a search for unspecified help for a disabling condition that general healthcare services had been unable to address satisfactorily. Lack of information about disability services contributed significantly to extending this process. While cure was ‘first prize’, the participants also needed understanding of what had happened to them, and to be satisfied that they had done all they could to find help.

Hope of cure could drive massive expenditure and effort on services of negligible benefit, including public and private sector practitioners and traditional healers. One mother, whose adult son had been born with cerebral palsy, described how she had travelled the province for the first 10 years of his life, following up rumours of services for children with disabilities. For a time, she had made a three-day round trip every month to take him to physiotherapy in a city over 300 km away. Eventually, seeing no change in his condition, she had given up. She told us:

I have forgiven [those who did not help me]. I have accepted that God has given it to me to stay with my son as he is.

This acceptance was reflected by another participant, an elderly woman named Iris^a who had become paralysed for unknown reasons. She told us she had not even been to the clinic since 1975, as healthcare workers had never been able to help her with her problem. It became clear how each healthcare-seeking episode built on past experiences, either of success or failure.

a All participant names have been changed to preserve confidentiality. Pseudonyms are used for ease of reference.

The choice to disengage from the health system sometimes meant missing out on real help. One young woman named Nocawa had a hearing impairment that severely affected her schooling and relationships with her family and peers. Her mother had given up seeking help for her some years before, and was unaware of new audiology services at the district hospital. Nocawa was referred to them, and the hearing aid she was given allowed her to learn and socialise fully for the first time. Her mother told us:

Before I was worried, because I wanted to push her in school to finish Standard 10. Now she has a hearing aid she wants to be a teacher, because she understands everything.

In weighing up health needs against costs of healthcare seeking, the functional impact of a condition was often its most significant characteristic, especially where this affected household livelihoods. Sibongile was a young man who walked with crutches due to a lower-limb impairment. He supported his wife and two children by doing household repair work around the village. He explained a serious health problem he faced:

The problem is when you don't have enough [crutch] rubbers. Because you walk a long distance, you see ... and if [your crutch] doesn't have a rubber ... this iron is causing pains straight here. It pounds on you.... Now I was always lying down with the pain.... I am worried how I am going to work for my children.

Replacement crutch rubbers weren't available at the clinic, and the only solution was a costly trip to the hospital. To the healthcare workers who saw him there, this was hardly a ‘serious’ need, but the cost of not seeking care, i.e. loss of income, justified the expense for the family.

By contrast, the family of Nolufefe, a young girl with intellectual disability, chose to discontinue her epilepsy treatment because the time cost of monthly clinic visits was not justified by any change in her level of function. Her mother was widowed and extremely poor, and the little available money was spent on schooling for Nolufefe's brothers, who had the potential to earn income in future. This difficult choice brought judgement from local community health workers and clinic nurses, who accused Nolufefe's mother of “just eating the [disability] grant”.

Healthcare seeking over time: protracted trajectories

People with disabilities are known to need complex packages of care, and to be especially vulnerable to health system fragmentation.³ Following the participants' stories, it was clear how healthcare engagement could be unnecessarily protracted over time and space. Even more significant than the costs of transport or long waiting times were the factors (both within and outside the health system)

that multiplied these economic, personal and social costs across a healthcare-seeking cycle.

The first 'multiplication factor' was the entry point into the system: all healthcare seeking had to begin at the local clinic, even when the need for a doctor or other health professional was clear. At the time of the study, doctors and rehabilitation professionals did not conduct outreach to this area, and there was little communication between hospital and clinic staff. For logistical reasons, the clinic and hospital could not be visited on the same day, and even reaching the clinic could take considerable time and effort, especially for people with mobility impairments. The clinic nurses were helpful in adapting some procedures to accommodate them, e.g. allowing chronic medication to be collected by family members, but their influence was constrained by their limited clinical scope.

The second multiplication factor was the frequent need for follow-up visits to complete an intervention, for example returning to the hospital for test results. While some such visits were unavoidable, healthcare workers seemed unaware of the costs for the participants, and therefore did not factor this into their decision-making or expectations. For example, when Phindile, a young man with mental illness, was admitted to hospital, the nurse required his sister to bring him clean clothes the next day, and the doctor expected the family to visit him daily. In reality, they could barely afford to fetch him on discharge.

The difficulty of affording a second healthcare visit within a short time period often resulted in follow-up appointments being missed, and families would then need to begin again from clinic level, with the added disadvantage of being labelled 'non-compliant' by healthcare workers.

The third multiplication factor was the centralisation of disability services. A rehabilitation service, including physiotherapy, occupational therapy and audiology, was located at the district hospital and therefore only accessible via clinic referral. The clinic nurses did not seem to know about these services, and doctor referrals were limited. There were no peer supporters or mid-level rehabilitation workers in this community, and local capacity to address health-related disability needs was therefore low. Community health workers did visit the homes of the study participants, but their limited training had not yet included disability or mental health skills.

Further, some rehabilitation services required visits elsewhere too, because certain equipment was not available at the district hospital. For example, the audiologist did not have a testing booth, and Nocawa and her mother had to visit a second hospital to complete her assessment. More unreasonably, the physiotherapist did not have stock of the rubbers needed by Sibongile, and he was referred to the tertiary hospital 100 km away for these. Policy allowed only one pair to be issued at a time, and the poor quality of the

product meant that this ordeal had to be repeated every two to three months.

Rehabilitation interventions, including assistive devices, almost always require a series of visits within a reasonable time period to be effective, and this was unaffordable for residents in the study site. Nocawa, the young woman who benefitted so greatly from a hearing aid, lost use of this device after several months because she was unable to return to the hospital for new batteries. The hospital manager did not allow the rehabilitation team to do outreach, and nobody had thought to make such items available at clinic level. In Sibongile's case, the clinic nurse arranged at his request for some rubbers to be delivered to the clinic with medication stocks. This was a huge improvement, but the supply was quickly depleted and not replaced.

Such organisation of health services considerably amplified the costs of health care for people with disabilities in this area, especially those living rurally. Unfortunately, these realities were largely invisible to healthcare workers, who expressed frustration at families' lack of engagement. One doctor told us:

Some of the challenges we face: the relative brings a patient, and never comes to visit them, ever ... I have to see 35 patients, I can't sit with them, you know, one on one, and want to hear what their concerns are...

Such perceptions had a significant impact on the relationship between healthcare workers and people with disabilities, which in turn affected the quality of care received.

Clinical encounters: two modes of engagement

The high costs, complex decisions and lengthy engagements described above often came down to an encounter with a healthcare worker that might not last more than 10 minutes. As previously stated, the doctor at the district hospital played a pivotal role, being responsible for diagnosis, treatment prescription, and/or referral. Unfortunately, many of the consultations described to us were characterised by a sense of 'going through the motions' rather than a serious attempt to understand and meet a health need. We came to call this mode of (dis) engagement 'futile reproduction'.

Futile reproduction

This approach was reductive, with simplistic explanations or 'diagnoses' applied to the complex situations of people with disabilities. These responses were heavily based on assumptions about people with disabilities and their families, and were particularly evident in relation to people with mental illness. Psychiatric assessment was observed to be very limited, with nurses and doctors seeming to judge mental state largely by appearance. Speaking about Phindile, a clinic nurse told us:

My assessment was, he is defaulting from treatment. When he came back from [the hospital], he was very neat, but after he defaulted for three months, he was very dirty.... He is very clean when he is taking treatment.

When Phindile visited the hospital, his brother would first wash him, by force if necessary. This could mean an underestimation of his illness, as happened when he was assessed for renewal of his disability grant. His brother told us:

He was once getting [the grant] and it stopped, because the doctor said he is fine. He received for nine or ten months and when he went for its reactivation, the doctor said he is fine.

At the same time, if Phindile was seen to be dirty, another assumption came into play. The clinic nurse explained:

The families, they are neglecting [the people with disabilities]. They care for them one day in the month, when they take them to pension point.... After that the family just leave them in the house, not washing them, not changing their clothes....

While certainly true in some cases, this assumption placed suspicion on every family, and healthcare workers were quick to judge them for 'not caring'.

Such cursory summing-up was coupled with active silencing of the healthcare seeker and family members during the encounter, or at least failure to listen to what they had to say. Phindile's sister-in law told us:

When I was trying to answer the doctor, he was saying to me, 'Please close your mouth, I am asking Phindile not you'. After that, the doctor didn't ask me anything.

Another feature of 'futile reproduction' was the application of formulaic interventions to the perceived 'diagnosis'. One participant, Nozukile, had repeatedly sought help for a non-specific list of symptoms, including fatigue and generalised body pain. Healthcare workers had repeatedly prescribed "Panado, B-Co and Brufen", without fully examining her, clearly convinced that nothing significant was wrong. She told us:

What I think is, maybe when the doctor looks at the card and sees that the nurses have given me these pills, he thinks he must also do the same. And when the nurses look at the card and see that the doctor has given me these pills, they think they must do the same ... [but] no one has ever asked whether they are helping me or not.

Sometimes formulaic interventions involved shunting a person with disability from one service to the next. In the case of people with mental illness in this area, it was almost impossible to get transport to the hospital in case of an emergency. According to the clinic nurse:

The ambulance will not come for the psychiatric client, they say it is a police case.

At the same time, the police would not come unless a crime had been committed. While this was obviously paradoxical, none of the service providers involved seemed to see or be able to address this.

The pattern of 'futile reproduction' could result in many wasted visits, the costs of which were hidden from the healthcare workers concerned. While it was tempting to blame healthcare workers for acting in this way, their behaviour needed to be seen in the context of the health system of which they were part. High caseload and chronic shortage of staff made it necessary to ration the time and energy they spent on each patient, and 'priority conditions' such as HIV, tuberculosis and maternal and child health were placed first. Not only did these workers often lack the knowledge of disability to offer constructive help, they were also situated within a system that by its very structure and values, tended to obscure and minimise the needs of people with disabilities. Isolated in the hospital from the life context of their patients, and situated within a medical value system focused on curing disease and saving lives, healthcare workers simply weren't positioned to perceive or respond to the realities of disability in the communities they served.

A key feature of the health service that perpetuated 'futile reproduction' was lack of continuity in the relationship between healthcare worker and seeker. People were expected to see whomever was available, and this often meant needing to tell their story anew with each visit. It also meant that clinicians seldom saw the results of their interventions, and had little opportunity to learn from experience. They also had little incentive to address a problem effectively, compared with simply seeing the patient (and the rest of the day's queue) as quickly as possible.

Collaborating to heal

In spite of all of these challenges, participants did sometimes experience positive and satisfactory encounters with healthcare workers. While uncommon, their accounts of these occasions provided crucial insight into what they valued and considered to be quality in health care.

Overwhelmingly, these positive experiences were characterised by the interpersonal engagement initiated by the healthcare worker. A kind and respectful manner seemed to be considered inseparable from being a good clinician:

If I see [the doctor] in [the supermarket] I can greet him with his name, and he is going to smile. Some of them tell themselves they are the best people in our lives – I won't greet that one. The good doctor is the one who is humble, willing to greet.

It was also clear that community members took note of individual healthcare workers, and this could strongly

influence their future healthcare-seeking choices. The same key informant said:

Before you examine me, I want to know your name and your surname, so that whatever can happen, I can know who I was dealing with, know whether to go back to that doctor, if he was good. I can follow him to [another town] if he was transferred.

By contrast, another participant explained her response to a negative interaction with a doctor:

I don't want to go again to the hospital, because the doctor I met there last time was so rough.... I can go back there when I hear that that doctor is not there anymore.

Another feature of positive engagement with healthcare workers was what Mamthuli, the mother of the young man with cerebral palsy, described as “their will to help”. Among all her fruitless attempts to find treatment for her son, she expressed strong satisfaction with one hospital:

I think at [that hospital], I was treated so well and the treatment was super. The nurses were so kind.... In all the places I went to, they were the only ones who thought about performing an operation to make [my son] walk. What I liked is their will to help, even though it did not help at the end.

The staff concerned had identified with this mother’s real-life goals for her son (which again connected health outcomes with function). By contrast, she reflected thus on the poor-quality therapy her son had received in his early years:

They just stretched him.... I did not see any help in it.

Although neither intervention had achieved its goal, she judged them very differently. This was a strong reminder that clinical outcome was far from the only criterion for quality health care, and that where ‘cure’ might not be possible, good relational engagement might be even more important.

It was clear that the participants carefully observed healthcare workers and critically evaluated their practice. A proper assessment was considered vital, and the opinion of a doctor who did not pay attention to referral letters, listen to their stories or conduct a physical examination, was often disregarded. This was especially significant when no clear diagnosis might be forthcoming, as in the case of Nozukile. After several years of experiencing ‘futile reproduction’, she was seen one day by a doctor who listened carefully and conducted a full examination. Nozukile explained:

[I was helped] because of the care that I got from the doctor. Other doctors would not even examine me. They would ask me questions, write down and prescribe pills according to what I say, not according to what he spotted. But this one doctor prescribed according to her examination.

Like her colleagues before her, this doctor had found nothing clearly wrong with Nozukile, but how she was seen to reach this conclusion made all the difference:

This time I was satisfied. I think the doctor I got did her best. I am fine ever since I saw her.

A final component of these positive encounters was a sense of collaboration, and value placed on the participant’s own knowledge of his/her body. One parent explained:

You are going to help each other, patient and nurse, because you are asking a question, and the other is answering, so you are helping each other, both of you.

Together, these features added up to an approach we termed ‘collaborating to heal’, which bore a strong resemblance to person-centred care, as described in the literature.⁷ While uncommon, it was seen to occur under the same constraints and pressures as ‘futile reproduction’, indicating that healthcare workers had some choice in their mode of engagement. While they might be unaware of the significance of their behaviour, it was clear how this could make the difference for our participants between restored capability and peace of mind, and further weeks or months of costly healthcare seeking.

Conclusions

This research uncovered how apparently minor features of health system organisation could have dramatic and expensive consequences for people with disabilities and their families. At the same time, it showed the primary importance they placed on positive relational engagement with healthcare workers, and how a person-centred approach seemed to outweigh the many negatives. Trust in known individual healthcare workers also seemed to make further engagement with healthcare services more likely. While the literature primarily addresses trust at a system level and within healthcare organisations,^{8,9} the findings demonstrated how personal trust might be protective in the presence of serious health system challenges. Health system interventions that support and facilitate such relationships are discussed below.

Viewing healthcare engagement from the perspective of people with disabilities highlighted human complexities in the healthcare interface, which go unacknowledged by health systems thinking based on ‘delivery’ of set interventions for defined diagnoses.¹⁰ Our participants’ experiences were a reminder that health needs do not always arise in straightforward biomedical categories, and that a curative focus on ‘priority conditions’ can marginalise some of the most vulnerable members of society.

Although small in size, the study demonstrates the value of a person-centred, contextualised understanding of how people engage with the healthcare system. Statistical generalisability was not attempted, but the findings may be reasonably expected to reflect the situations of people with disabilities living under similar conditions of poverty, rurality and constrained access to health care (theoretical generalisability).¹¹ While more research is needed to confirm these findings at scale, what emerged was sufficient to inform recommendations at the level of healthcare workers, the health system, and future research.

Recommendations

Healthcare workers

To be effective, healthcare workers need a strongly contextualised understanding of health, illness and disability in the communities they serve. This understanding should be embedded in disability training across health professions¹² but also in ongoing learning built into clinical practice. Outreach to clinic and community settings helps bring services closer to people, but is even more valuable in giving healthcare workers insight into their patients' life context.

As the prevalence of chronic illness grows, health workers need to understand health differently: not as “a complete state of physical, mental and social wellbeing”,¹³ but more realistically, as people's capability to do the things they need and want to do.¹⁴ This perspective allows a move beyond attempting to cure (which may fail) to possibilities of promoting healthy function and participation despite impairment or illness. While the skills to achieve this may belong particularly with rehabilitation professionals, sharing this perspective across the team is essential for effective multidisciplinary (or transdisciplinary) health care.

Every healthcare worker needs to understand the practicalities of access to health care for their patients, as well as their own responsibility to ensure that care pathways are as direct and affordable as possible. Advocacy and problem-solving by healthcare workers at local level can be powerful in overcoming minor barriers with significant cost implications, but this relies on healthcare workers paying attention to the story of healthcare seeking over time, rather than simply the moment of a patient presenting to them.

Finally, healthcare workers will benefit from insight into how they are perceived by healthcare seekers, and the potential impact of relationship quality on the effectiveness of their interventions. The study presented here was one attempt to gain such insight.

Health system measures

While emphasis is placed on healthcare workers' behaviour change, it is vital that health systems are organised to support the kind of practice recommended.

Outreach by health professionals based at district hospitals should be promoted and resourced, both to make services more accessible to people with disabilities and to build the understanding of context described above.

Disability services in particular need to be brought as close as possible to where people live; this includes provision of assistive devices, repair of devices, and the availability of spares. In planning services, the full care pathway needs to be understood and the full 'package' made accessible and affordable. For rural people with disabilities, this means rehabilitation being integrated into primary health care.^{15,16} Disability knowledge and skills should be available at community level through trained community health workers, peer supporters and mid-level rehabilitation workers, supported by rehabilitation professionals at district or district hospital level. Active follow-up with households of people with disabilities would overcome many barriers to accessing care, and prevent 'falling out' of the system. Good relationships between the levels of care, and the use of communication technology (e.g. telephone follow-ups) should reduce fragmentation and some of the need for hospital visits. Where facility visits are necessary, accessible planned patient transport, fee waivers, and prioritised queueing for people with disabilities will further reduce costs.

Secondly, healthcare provision should promote longitudinality in the relationship between healthcare users and an allocated individual healthcare worker.¹⁷ Longitudinal care has been shown to improve satisfaction with health care (including for health professionals themselves), and to increase healthcare effectiveness and efficiency.¹⁸ This is of particular importance for people with long-term and complex health needs, including many people with disabilities, and could be instrumental in overcoming the service fragmentation and barriers to entry illustrated in the participants' stories.

Finally, the priorities and goals set by health officials and policy-makers need to move beyond targeting 'priority conditions' and biomedical solutions to encompass the health needs and goals of people with disabilities and chronic health conditions. This means adopting a genuinely people-centred approach to health systems and health care.¹⁹

Further research

This study was based on a small sample in a single village, and more research is needed to confirm its applicability in other settings. It did, however, demonstrate the value of in-depth, contextualised research over a period of time to understand better how people with disabilities engage with the healthcare system (or choose not to do so).

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