

The background of the cover page features a close-up, low-angle shot of two large, dark tree trunks on either side, with a patch of green grass in the center. Below the ground line, a dense network of brown tree roots is visible, extending across the bottom half of the page. A large, faint, diagonal watermark with the word 'Town' is visible across the right side of the image.

**A case study of factors influencing primary
healthcare “Continuity of Care” for persons with
disabilities**

THESANDREE PADAYACHEE

(PDYTHE001)

Thesis presented for the Degree of

Doctor of Philosophy

Disability Studies

Department of Health and Rehabilitation Sciences

University of Cape Town

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**Supervisor
Professor Harsha Kathard**

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Plagiarism declaration

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Name: Thesandree Padayachee

Student Number: PDYTHE001

Date: 09 February 2024

Signature: _____

Dedication

To Aiya:

I hope I've made you proud.

Rest well and know I carry you in my heart.

To my husband, Velan Marimuthu:

I couldn't have done this without you.

Thank you for believing in me.

To my beautiful sons, Kai and Ayan:

Thank you for bringing endless joy to my life.

Understand your privilege and responsibility to make the world a better place.

.

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In closing, and most importantly, I express my gratitude to the participants in this study. Despite their hardship, they shared so openly, authentically and honestly. Thank you for allowing me into your lives and giving me the opportunity and privilege to elevate your voices and shine a light on your needs.

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Glossary of terms

Community Health Worker: The South African (SA) definition is used which “refers to any worker who is selected, trained and works in the community. They are the first line of support between the community and various health and social development services. They empower community members to make informed choices about their health and psychosocial wellbeing and provide ongoing care and support to individuals and families who are vulnerable due to chronic illness and indigent living circumstances”. (Department of Health, 2018, p. 7)

Continuity of Care: The definition put forward by the World Health organization is used as the “the degree to which a series of discrete health care events is experienced by people as coherent and interconnected over time and consistent with their health needs and preference”. (World Health Organization, 2018a, p. 8)

Disability: The definition of disability used in this study is the one offered by the United Nations Convention for the Rights of persons with disabilities as “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder the full and effective participation in society of people with impairments on an equal basis with others”. (United Nations General Assembly, 24 January 2007, p. 4)

Health: The definition of health proposed by WHO is used and debated in this study, i.e. that “Health is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity.” (World Health Organization, 1946, p. 1).

Noncommunicable diseases: Diseases of long duration and the result of a combination of genetic, physiological, environmental and behavioural factors (e.g. cardiovascular diseases (such as heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and diabetes. (World Health Organization, 2023a).

Non-Profit Organisation: these organisations include non-government organisations (NGOs) and community-based organisations (CBOs) that are formally registered with the Directorate: Non-profit Organisations located at the national Department of Social Development. Registered NPOs receive a certificate of registration with a registration number and may apply for funding to employ CHWs (Department of Health, 2018).

Person-centred care: The WHO definition is used as it is also referenced in health policies in SA. “An approach to care that consciously adopts the perspectives of individuals, carers, families and communities as participants in, and beneficiaries of, trusted health systems that respond to their needs and preferences in humane and holistic ways. Person-centred care also requires that people have the education and support they need to make decisions and participate in their own care”. (World Health Organization, 2018a, p. 8).

Primary Health Care (PHC): The WHO definition is used as a “whole-of-society approach to health that aims to maximize the level and distribution of health and well-being through three components: (a) primary care and essential public health functions as the core of integrated health services; (b) multisectoral policy and action; and (c) empowered people and communities.” (World Health Organization, 2018c, p. 1)

SA Primary Health Care: Primary healthcare in SA is delivered through three streams, “1) ward based PHC outreach team for each electoral ward; 2) school health services; and 3) district based clinical specialist teams with an initial focus on improving maternal and child health.” (Department of Health, 2011c, p. 1).

Ward: geopolitical subdivisions of municipalities used for electoral purposes in SA.

Ward-based PHC outreach teams (WBPHCOT): The South African name given to teams based in PHC facilities, offering integrated services to households and individuals within its catchment area. The teams provide primary healthcare to families/households; community outreach services; preventative, promotive, curative, rehabilitative and palliative services. (Department of Health, 2018)

Universal Health Coverage (UHC): The definition proposed by WHO where “all people have access to the full range of quality health services they need, when and where they need them, without financial hardship. It covers the full continuum of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course.” (World Health Organization, 2023c)

Abbreviations

CBO:	Community Based Organisations
CCMDD:	Central Chronic Medicines Dispensing and Distribution
CRPD:	Convention for the Rights of persons with disabilities
DCST:	District Clinical Specialist Team
DHS:	District Health System
HST:	Health Systems Trust
HPSR:	Health Policy and Systems Research
KZN:	KwaZulu Natal
LMIC:	Low-and Middle-Income Countries
NGO:	Non-Governmental Organisation
NHI:	National Health Insurance
OHSC:	Office of Health Standards Compliance
PHC:	Primary Health Care
PuP:	Pick up Point.
SA:	South Africa
SDGs:	Sustainable Development Goals
THP:	Traditional Health Practitioners
UHC:	Universal Health Coverage
UNAIDS:	Joint United Nations Programme on HIV/AIDS
UK:	United Kingdom
WHO:	World Health Organization

Abstract

Background: “Continuity of Care” refers to how a patient experiences care over time and is considered to be a central pillar in the delivery of high-quality person-centred healthcare. In South Africa (SA), persons with disabilities experience a range of structural barriers to health services and even when access to health services is realised, poorly integrated health systems and services, limited human resources and poor awareness of the needs of persons with disabilities result in unmet healthcare needs. Given the rapidly transforming healthcare context of SA and the adoption of policies towards the realisation of universal health coverage, an understanding of how the health system is responding to the “Continuity of Care” needs of persons with disabilities through policy and practice is a valuable step towards realising the goal of integrated people-centred health systems; particularly in the delivery of primary healthcare (PHC).

Objectives: The study aimed to explore factors influencing “Continuity of Care” for persons with disabilities within the PHC context. Experiences and expectations of persons with disabilities were explored, relevant policies governing PHC and “Continuity of Care” were analysed and health systems responsiveness was explored to understand what influences “Continuity of Care” for persons with disabilities.

Method: This exploratory case study used a critical social theory and a health policy and systems approach to better understand how primary healthcare “Continuity of Care” for persons with disabilities can be strengthened. The Conceptual Framework for Health Systems Responsiveness (Mirzoev & Kane, 2017) informed the case study design by exploring how persons with disabilities experienced “Continuity of Care” and supported a deeper understanding of health systems gaps through perspectives of service providers in responding to the “Continuity of Care” needs of persons with disabilities. The study was conducted within the context of the SA primary healthcare policy and implementation in an urban suburb in the city of Durban, KwaZulu Natal in South Africa. The study included multiple data collection methods including interviews, focus group discussions, document reviews and analysis of relevant policies using an adapted EquiFrame (Amin, 2011). Qualitative data was analysed thematically using inductive and deductive analysis.

Results: Participants with disabilities were found to experience primary healthcare discontinuity resulting from known factors such as lack of reliable and accessible transport, negative attitudes of health facility staff and sub-optimal management of clinic and outreach services. New insights that were found to negatively affect “Continuity of Care” for persons with disabilities included the combined influences of institutional distrust; the medical model as a legacy of apartheid; incoherence in policies supporting “Continuity of care” and poor user-centred design practices in the delivery of new innovations that were unresponsive to the needs of persons with disabilities. Positive influences on “Continuity of Care” included emergent community leadership, family resilience to navigate through treatment uncertainty and supportive servant leadership styles of healthcare providers.

Conclusion: The study points to the need for an expanded understanding of “Continuity of Care” for persons with disabilities within an African paradigm where care continuity extends beyond the health facility and with a stronger emphasis on community driven models of care that respect the role and influence of traditional health practitioners and cultural practices. More research is needed to better understand institutional distrust and how traditional western models of healthcare can be re-shaped to deliver services.

Prologue

I was born into a family of educators; critical thinkers and nurturers of talent, where education was of paramount importance. From my earliest childhood memories, education and the search for deeper meaning in the world was encouraged by the adults around me. This is perhaps the foundation of my professional rebelliousness and attraction to understanding of life outside of the norm. Over the years, as I've moved through the corridors of knowledge, my worldview has become more complex and the questions I ponder hit closer to home; sometimes shaking my foundations of "self".

This PhD journey has allowed me to explore and question constructs of my reality shaped largely by my Indian South African (SA) heritage and being a healthcare professional. I am a fifth generation SA Indian, who was born into a divided society, crafted by an Apartheid government. Experiencing the realities of an evolving democratic country and having had to navigate the political and societal shifts, was both a privilege and a burden. While my grandparents and parents experienced the full brunt of Apartheid, I was somewhat shielded as a child, but as an adult am able to see and appreciate the full impact of the horrendous law that non-whites had to abide by. By virtue of being born into this unique context and now living as an adult through the country's democratic evolution, my understanding of the complex issues such as race relations, coloniality and diversity is more a lived experience than an academic exercise. In this prologue, I share critical points in my academic and professional career that led me to this PhD journey.

Disability rights captured my attention from a young age, partly due to my personality and partly due to strong personal experiences of disability. Like most Indian SAs, chronic disease is common and resulting acquired disabilities are a reality in many families. I also grew up with an

uncle who was born with congenital profound hearing loss, and much later had two cousins who were also born with hearing impairments. I observed as each achieved varying levels of participation in society but also recall the helplessness of their families, particularly around access to healthcare that met their needs.

I trained as a Speech and Language Therapist and my clinical work experience at the Chris Hani Baragwanath Hospital was likely where I unknowingly cut my teeth in the field of health systems research. Working in such a context, where levels of poverty in the surrounding community were unimaginably high and in a health system with glaring systemic challenges, was overwhelming. Like the year of mandatory community service I served at the Groote Schuur Hospital, I expected to see extremely high levels of client absenteeism and poor compliance at The Chris Hani Baragwanath Hospital. Yet strangely, in this less resourced hospital serving a much larger and poorer community, this was not the case. It is hard to explain the difference, but I believe the change could be attributed to the manner in which therapy was delivered, through deep and meaningful partnerships with clients and their families.

The reality, however, was that even though I was dedicated, worked hard and was a good clinician, my efforts were pitted against a crumbling health system. I quickly realised that my professional training had not equipped me to navigate the challenges of a failing health system. It struck me one morning in the cleft palate clinic I co-ordinated, that the system was failing the patients and, in many ways, “I was part of the system”. A mother of a cleft palate baby would have to visit the hospital three times in a week because she would have appointments at three different clinics, one with the surgeon, one with the nutritionist and one at the language clinic. She did so diligently, never complaining about the two-hour commute for each visit or the fact that her baby’s milk would spoil in the heat of summer sun as she sat waiting patiently to be seen.

It disturbed me that a better way could not be found. I began contemplating not just the therapeutic benefits of our feeding clinic, but also how I could ease her load and gain her trust. I began keeping accurate statistics, asking more questions about her challenges as a mother and reflecting on what could be done to help her. I lobbied with fellow therapists, doctors and nurses and using all the information gathered, began my bid for a new process of managing the cleft palate clinic. A simple modification of my time, a reshuffling of clinic rosters and additional effort on the part of doctors and therapists to shift their focus from themselves to the patient, meant that this mother and many others like her would only need to visit the hospital once in the week. It would mean a full day at the hospital, but this was acceptable to her, more cost effective and less physically taxing for her child. Unknowingly, I had entered the world of health systems strengthening, but there still remained a lingering uneasiness about whether Speech Therapy actually worked in addressing speech and language difficulties.

In pursuit of evidence and justification for what I was delivering to my clients, I applied for a Masters in Evidence-based Healthcare and was lucky enough to be awarded the Nelson Mandela Scholarship to undertake studies at a university in the United Kingdom (UK). The course reduced life's questions to numbers and confidence intervals. Studying epidemiology, systematic reviews, critical reviews, health economics and clinical trials, left me feeling even more bewildered about the effectiveness of my profession. Everything I reviewed left question marks against therapeutic effectiveness until I started reflecting on other professions and realised that there were no definite answers to many questions and speech therapy was no exception. It was during my postgraduate studies that I also came to experience and understand the health system in the UK. I was intrigued by how people complained bitterly about services despite having a relatively well-resourced and comparatively well-functioning health system to SA. I was

impressed by the approach to decision- and policy making and wondered what it would take to apply that level of analysis to the problems faced in SA. Could a structure like the National Institute of Clinical Excellence (NICE) be possible in SA, or would we be reliant on these western models of decision making. It was an academically turbulent time for me, generating more questions about the relevance of the course to the SA context and what I could apply when I returned home.

I was fortunate to join a leading NGO as a health systems researcher where I was exposed to the realities of health systems research and interwoven politics of healthcare. It was here that the misalignments between public health and rehabilitation was glaringly obvious to me and perhaps critical to my realisation that education, and the way that health professionals were trained, was not conducive to collaboration and seamless service delivery. In SA rehabilitation therapists include occupational therapists, audiologists, speech-language therapists, orthotists, prosthetists, physiotherapists, and mid-level workers (Louw *et al.*, 2023), many of which are in short supply and who have limited exposure to health systems research and strengthening approaches. Throughout my training as a Speech Therapist, there was limited exposure to the broad agenda of public health and global health priorities. The focus was largely on rehabilitation models of care and support. It later also became abundantly obvious that disability was not high on the agenda of health systems research in SA and that shifting the tide towards inclusive health systems would require more than just strong will, it required political will.

I recalled the times when I felt like the lone voice: the only hand raised at Health Systems Trust (HST) to lobby for the rights of persons with disabilities. One instance that I remember quite vividly was an occasion when I was part of a well-known journal club and after introducing myself, was asked by the convenor:

“...so, why are you attending this journal club – I mean rehabilitation is not a population-based intervention like public health. You people work at an individual level, right?”

This question brought into focus the broader issue of how professionals viewed each other and the relevance of rehabilitation within public health from the perspective of traditional public health practitioners. It brought several other questions to mind; were we all not working in the best interest of the individual? Could we not have a population view but still care enough to make a difference at an individual level? What emerged was a new resolve to be an advocate for persons with disabilities; and with that, my journey began.

I am now armed with 16 years of experience conducting and managing projects within the public health sector, at both national and international levels, and while I have in depth and nuanced understanding of the health system and now understand the complexity of health systems, I still have a long way to go in making a difference. I consider myself an advocate for the rights of persons with disabilities and want to contribute to facilitating better understanding of and appreciation for the role of not just the rehabilitation professional but all healthcare professions at the primary healthcare level in addressing the needs of persons with disabilities.

After 9 years at HST, I began working at a global health level and now have the ability to reflect on health from a different perspective. The disconnect between the aspirations of the political elite and the boots on the ground is something I have observed alongside different power dynamics. My step into this PhD journey was taken so that I could keep my boots on the ground and build on previous studies I conducted in the field where poor “Continuity of Care” in persons with disabilities was identified as a challenge. Whilst conducting a study investigating the state of readiness of SA to implement the Framework and Strategy for Disability and Rehabilitation

(Padayachee, 2017), I found that the voices of persons with disabilities were drowned out in the world of public health and I needed to find a way to elevate their lived reality. Through this PhD I wished to help policy makers and health implementers better understand the lived experiences and health needs of persons with disabilities so that they can be better supported towards achieving a state of optimum health and well-being. To this end, **I have privileged the voices of persons with disabilities and families** so that their experience is foundational to understanding their challenges in attaining “Continuity of Care”.

At the time of writing my PhD proposal, I had consolidated my understanding of health systems and having conducted many studies, I chose to use my skills and knowledge to uncover health systems weaknesses that further marginalise persons with disabilities, preventing them from enjoying their right to good quality healthcare and becoming active and engaged citizens in full control of their own health.

When I first decided to explore the community of Ward X, my intentions as a researcher were to explore whether PHC services were meeting the needs of persons with disabilities. It was borne out of the mind of a researcher with a pragmatic real-life question informed by a professional career in health systems research. I also had a personal link to the site; in that I had lived in this “community” for about 20 years of my life and with that came assumptions about how well I knew the community. However, what emerged during the course of the study, was that community systems like health systems are complex and dynamic. My time in this community was a vivid reminder of the need for research to be conducted in obscure and vulnerable settings like ward X because this is where health policies must be designed to work at its best not worst.

The study site chosen took me back to the community into which I was born, and through this journey I’ve reached a critical point in my world view of the relative value of “health,” what

privilege provides in attaining health in the sense of being disease-free, and the realities I have been shielded from in my professional career by virtue of having a myopic view of what it takes to achieve the goal of health. As I worked through these scholarly years investigating this concept of “Continuity of Care” in my childhood community, I have been afforded the opportunity to re-examine the world I grew up in, allowing deeper appreciation of the significance of the political and social factors at play in communities like the one in which I grew up. There is a deep acknowledgement that this study can only be described as a journey of discovery; as a person, a researcher and an advocate for the rights of persons with disabilities. In this study I see myself as an in-betweeners, close enough to see the big picture but far enough to appreciate and be critical of the many new learnings.

An important learning of this study is that “Continuity of Care” is both a highly complex and misunderstood concept, but at its core is the simple value of human connectedness and the ability of the health system to engage and understand the needs of all people.

Chapter 1: Background and rationale

1.1 Introduction

This chapter provides the background and rationale for the study and addresses its significance in relation to persons with disabilities.

1.2 The pursuit of health

All people, including persons with disabilities, are in search of good health and as such health systems across the world are obligated to ensure that healthcare is not just accessible, and of good quality, but also attainable (United Nations General Assembly, 21 October 2015). The Global Report on Health Equity for persons with disabilities (World Health Organization, 2022a) estimates that approximately 1,3 billion people globally have a disability and even though their right to health is enshrined in international human rights policy (United Nations General Assembly, 10 December 1948, 24 January 2007), this right remains largely unfulfilled (World Health Organization, 2022a)

Disability prevalence is also projected to rise due to an unprecedented rise in non-communicable diseases (Institute for Health Metrics and Evaluation, 2016), and the shift away from infectious diseases where people will reach longer life expectancies, with non-fatal impacts such as disability becoming a concern (Cieza, Sabariego, Bickenbach, & Chatterji, 2018). For persons with disabilities with chronic diseases, the cyclical interplay between disability and increasing levels of inequity and poverty (Yeo, 2001), wars and conflict, health emergencies and

poor access to health services compound the challenge of achieving good health, and heightens the need for prioritising disability inclusive health systems (Kuper & Heydt, 2019).

Our understanding of health has been largely shaped by the definition proposed by the World Health Organization (WHO) and adopted by most health systems across the world as a fundamental human right.

Health is a fundamental human right, defined as a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity.

[The right entitles] all people to a system of health protection that gives everyone an equal opportunity to enjoy the highest attainable level of health.

(World Health Organization, 1946, p. 1)

In the context of the 21st century, this definition requires careful consideration as it underpins how we understand and contribute to creating health for all. While this definition of health has played a crucial role in emphasizing the holistic nature of well-being, it has come under some criticism. The definition is considered by some to place inordinate emphasis on disease (Tinetti & Fried, 2004) and unintentionally render “*most people as unhealthy*” due to the inclusion of the word “complete” (Huber *et al.*, 2011). Huber *et al* (2011) argues that the absoluteness of the definition reinforces the medicalisation of society where something external such as medication and medical technologies are required to facilitate a state of complete health (Huber *et al.*, 2011). Perhaps the allure of the definition lies in its alignment with the dominant ethos of medicine and the medical model, where social models of disability are less accepted with preference for ill-health to be viewed as a condition, to be addressed symptomatically, in endless pursuit of a disease and symptom free existence (Hogan, 2019).

Understandably, this definition proposed just after World War 2 mirrors the context of the time; a vastly different public health picture than the one we currently face. While infectious diseases treatable by antibiotics dominated the post-war era (Adedeji, 2016), decades later we now see unprecedented levels of non-communicable diseases, where treatment is often long term with many people continuing to live productively despite having to cope with lifestyle changes and a high probability of experiencing some form of disability (Cieza *et al.*, 2018). Against this backdrop, the question of what it means to be a healthy Person with a Disability must be carefully considered. Can someone with a disability and a chronic condition ever hope to achieve a state of “health” or are they destined to live a life of disease and ill health? Critics argue for a more realistic and inclusive approach to health that considers the dynamic nature of health, diverse cultural perspectives, and the broader social determinants that influence individual and population health (Huber *et al.*, 2011). Krahn, Robinson, Murray *et al.* (2021) contend that the definition of health has the potential to impact research, policy and practice as it drives how we understand and address healthcare access, which is a particularly important issue for persons with disabilities (Krahn *et al.*, 2021). A few alternative definitions have been proposed since the 1946 definition as tabulated by Krahn *et al.* (2021) in Fig 1 below:

Table 1
Evolving views on defining health.

WHO	1948	Health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”
WHO	1986	“Health is a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities.”
WHO	2001	Health is considered distinct from function and disability. Health conditions, environmental factors, and personal factors influence disability. Disability is an umbrella term that refers to impairments, activity limitations, and participation restrictions.
Sartorius	2006	Health is a state of balance whereby individuals with disease or impairment are considered healthy by their ability to establish an internal equilibrium that allows them to get the most they can from their life despite the presence of disease or infirmity.
The Lancet	2009	Health is dynamic adaptation to stressors akin to resilience (Schulkin, 2004) and sense of coherence (Antonovsky, 1979).
Huber et al.	2011, 2016	Health is dynamic based on one's “ability to adapt and to self-manage” to maintain and restore one's sense of integrity, equilibrium and sense of well-being. Six proposed dimensions of positive health are: bodily functions, mental functions and perception, existential, quality of life, social and societal participation, and daily functioning
Halfon et al.	2014	Health as “creating capacities to achieve goals, satisfy needs, fortify reserves”
Authors	2020	“Health is the dynamic balance of physical, mental, social, and existential well-being in adapting to conditions of life and the environment.”

Figure 1. Evolving views on defining health (Source Krahn *et al* 2021, p3)

The definition proposed by Krahn et al. (2021) represents an interesting contribution to the re-definition of health i.e. “*Health is the dynamic balance of physical, mental, social, and existential well-being in adapting to conditions of life and the environment*” (p.2). It adopts a more human-centred, whole-of-life approach to understanding health along a “continuum”, acknowledging the dynamic nature of creating balance across multiple areas of what it is to be human and recognising the adaptations that may be required without the exclusionary frame of reference (Krahn *et al.*, 2021), where health and disease are pitted against each other. It creates room for any person to see health as an attainable goal regardless of their current circumstances and resonates particularly well with the aspirations of marginalised groups, including persons with disabilities. The need for contextually specific definitions of health has also been proposed by van der Linden (van der Linden & Schermer, 2022) which aligns with the dynamic nature of health proposed by Krahn *et al* (2021).

Despite the debate and critical posturing, no consensus on the way forward has yet been reached (Huber *et al.*, 2011). What we do know with some certainty is that access to good quality healthcare is a key element to achieving health and rightly features prominently as a global public health goals (United Nations General Assembly, 21 October 2015). Universal Health Coverage (UHC) is an approach to the provision of equitable healthcare where all people have access to the full range of quality health services they need, when and where they need them, without financial hardship (World Health Organization, 2023c). It is positioned to cover the full continuum of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course (World Health Organization, 2023b). It is also argued that the attainment of UHC could be facilitated across the whole population, including other marginalised groups such as the elderly, if health systems were to become more disability-inclusive (Kuper &

Hanefeld, 2018). However, health inequity remains the order of the day with persistent challenges faced by persons with disabilities having negative effects on their ability to achieve health (Greaux *et al.*, 2023).

All people are entitled to and benefit from healthcare services that are of high quality, person-centred, continuous and coordinated (World Health Organization, 2018a). These four features are of particular importance to persons with disabilities with other health conditions where careful supervision of treatment plans is required. In the design and delivery of health services, WHO promotes the concept of *continuous and coordinated care* and envisions a future in healthcare in which:

All people have equal access to quality health services that are co-produced in a way that meets their life course needs, are coordinated across the continuum of care and are comprehensive, safe, effective, timely, efficient and acceptable; and all carers are motivated, skilled and operate in a supportive environment. (*World Health Organization, 2018a, p. 12*).

While continuous and coordinated care is deemed important for persons with disabilities diagnosed with chronic diseases (Cabana, 2004), the reality is that unless the vision is achievable in all healthcare contexts, it will remain an idealistic, aspirational and decontextualised goal. In the battle between idealism versus reality, the tension is often felt most dramatically by the most vulnerable health service users. There is therefore a need for the concept of “Continuity of Care” to be deconstructed and better understood so that services can be tailored to meet the needs of persons with disabilities.

The purpose of this study therefore was to investigate the influences on “Continuity of Care” as a construct of healthcare quality in the delivery of care to persons with disabilities within the SA PHC context.

1.3 “Continuity of Care and its relevance to persons with disabilities in SA

“Continuity of Care” is a fundamental element of healthcare quality and a core value of PHC (Alazri, Heywood, Neal, & Leese, 2007; World Health Organization, 2018a). “Continuity of Care” is a complex concept, defined in many ways and is the basis of some confusion (Reid, 2002), but generally refers to how a person experiences care over time as coherent and linked, and is associated with increased up-take of health promotion, greater adherence to medical advice and decreased use of hospital services (Baker & Jeffers, 2016). When practiced, “Continuity of Care” is cited as being positively associated with improved patient satisfaction and improved health outcomes particularly for vulnerable populations (Al-Azri, 2008; Alazri *et al.*, 2007; Coleman, 2003; Crawford & Thornton, 2017; Pinto, Witte, Filippone, Baird, & Whitman, 2017) and those with complex or chronic medical conditions (Coleman, 2003). A reality of modern day healthcare, however, is that increasingly patients are seen by a spectrum of healthcare providers in a variety settings, raising concerns about fragmentation of care (Haggerty *et al.*, 2003). When patients receive care from a variety of sources the attainment of coordinated and continuous care becomes increasingly difficult (Reid, 2002)

persons with disabilities may have continuous and complex healthcare needs requiring care in multiple healthcare settings (Kuper & Heydt, 2019) but they also have preventative and curative healthcare needs much like persons without disabilities (Sutton & DeJong, 1998). They may also carry additional vulnerability due to persistent discrimination and exclusion, particularly their risk

for certain diseases such as HIV (Kuper & Hanefeld, 2018; UNAIDS Joint United Nations Programme on HIV/AIDS, 2017). This necessitates a comprehensive and coordinated approach to the provision of specific disability related and general healthcare services across the life course and at all levels of the health system, but especially at the primary care level (Sullivan, Heng, Salvador-Carulla, Lukersmith, & Casson, 2018).

There are presently international efforts to reduce fragmentation and enhance quality, continuity and coordination of care are relevant for persons with disabilities, (Casson, 2018; Kristensen, Solvhoj, Kusier, & Folker, 2019; Reid, 2002; World Health Organization, 2018a) who remain a significantly marginalised and under-prioritised group globally, and are at higher risk for poor health outcomes than their non-disabled counterparts (Kuper & Heydt, 2019; Lishner, Richardson, Levine, & Patrick, 1996). persons with disabilities experience a range of structural barriers to health services and even when access to health services is realised, poorly integrated health systems and services result in poor “Continuity of Care” and unmet healthcare needs (Department of Health, 2015; McKinney EL, 2021; Sherry, 2015). Within the SA context, the need for well-coordinated, high quality care for persons with disabilities is acknowledged and cited in policy (Department of Health, 2015) however, there exist many challenges to the realisation of this vision specifically as it relates to “Continuity of Care” for persons with disabilities.

Primary health care (PHC) as defined by the WHO is considered a global priority and central to achieving strong, effective and equitable health systems towards achieving UHC and the Sustainable Development Goals (SDGs) (Barkley *et al.*, 2020). The WHO describes PHC as a critical platform within the healthcare system which “*brings promotion and prevention, cure and care together in a safe, effective and socially productive way and is the interface between the population and the health system*” (World Health Organisation, 2008, p. 1).

In SA primary healthcare has been re-engineered, borrowing aspects of the Brazilian model of primary healthcare where the role of multidisciplinary teams and community agents support health professionals in designated catchment areas (OECD, 2021). The approach to primary healthcare in SA still pivots off a district health system which is the institutional vehicle for the delivery of PHC and district hospital services (Department of Health, 2018) and the central pillar for transforming the SA health system and achieving UHC (Fusheini & Eyles, 2016). The district health system uses district management, sub-district management as well as management of all facilities within the district to manage primary healthcare through district health plans and careful monitoring of health indicators through the District Health Information System (DHIS) (Department of Health, 2018). Against this management backdrop, primary healthcare is delivered in three streams (as shown in Figure 2 below) , namely, a ward based PHC outreach team for each electoral ward; (b) strengthening school health services; and (c) district based clinical specialist teams with an initial focus on improving maternal and child health (Department of Health, 2018).

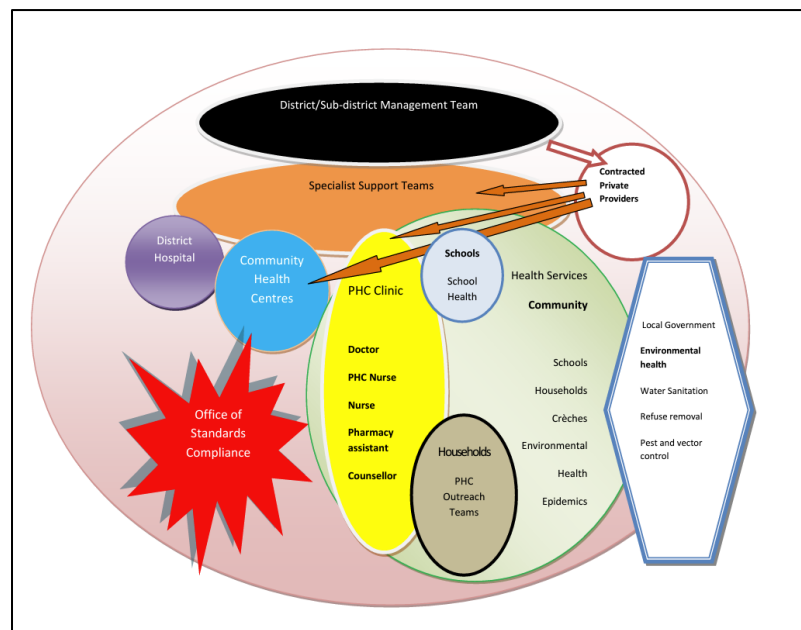


Figure 2. PHC model in SA

More recently, a fourth stream for the contracting-in of General Practitioners (GPs) was introduced in readiness for the planned implementation of the National Health Insurance (NHI) to support the delivery of Universal Health Coverage (UHC) (Department of Health, 2017b; Mureithi, Burnett, Bertscher, & English, 2018), making access to PHC a broad and diverse mix of services that relies heavily on a functional district and sub-district management team. An important feature of SA primary healthcare is that remains curative in nature and driven by a global health agenda for which it does not necessarily have the resources to deliver on (Fusheini & Eyles, 2016).

The Ward Based Primary Healthcare Outreach Team (WBPHCOT) Policy Framework launched in December 2017 (Department of Health, 2018) was positioned to drive an agenda where community health workers within the WBPHCOTs, supported by different categories of health professionals, form the bridge between communities and healthcare service provision within health facilities. The (WBPHCOT)) form a part of NGO networks and are made up of generalist community health workers, supported by nurse team leaders linked to local primary healthcare facilities (Schneider H., 2018). The vision of the policy makers through this policy was to develop a sense of ownership in the public health system through active community participation (Department of Health, 2018)

Studying “Continuity of Care” in such a context has not been broadly researched. “Continuity of Care” has been studied in a variety of settings, particularly within general practice, hospital and frail/long term care settings (Baker & Jeffers, 2016), but few studies have focussed on how it is realised in PHC settings within low-middle income countries (LMIC) and with a focus on an ever growing population of persons with disabilities. Research tends to focus on private general practice settings (Baker & Jeffers, 2016; Freeman & Hughes, 2010) in high-income countries (Heutmekeers *et al.*, 2019; Sullivan *et al.*, 2018) with particular attention being paid to

longitudinal continuity or relational continuity between the doctor and patient. These types of studies assume that patients will have a single primary care physician over a substantial part of their lifetime which may or may not be the case in many public sector PHC settings. Finding effective ways to understand “Continuity of Care” for persons with disabilities within the SA PHC setting is an important contribution to further refining the role of WBPHCOT in the delivery of health services for persons with disabilities especially in light of current health system challenges.

Within the SA context, the shortages and unequal distribution of health professionals in SA are a public health concern which has major consequences for access to primary care physicians, nurses, community health workers and rehabilitation therapists (Kautzky, 2008; Padayachee, 2017; Tiwari, 2020). Given that current definitions of “Continuity of Care” and its measurement are mostly related to patient-provider interactions, those shortages will impact health outcomes and healthcare quality, including “Continuity of Care”. The healthcare worker “brain drain” in SA is a significant contributor to these challenges with around 11% of new graduates indicating their intention to leave for greener pastures (Govender, 2024). In light of these challenges, exploring how “Continuity of Care” is currently experienced by persons with disabilities within the PHC context (as discussed above) is important for disability inclusive health system planning. This study aims to investigate “Continuity of Care” in a healthcare context that is known for its inequity, where health services are delivered through a dual system of private and public health systems, the latter servicing the majority of the population. While PHC in the public health system is the focus of the study, the evolving and complex nature of the SA healthcare landscape necessitates a broad lens for the investigation of “Continuity of Care.”

A study investigating “Continuity of Care” for persons with disabilities cannot therefore be limited to services delivered within a health facility as important drivers of healthcare access,

quality and care continuity may be observed beyond its doors. The expanded service delivery platform, the policy context and community networks through NGOs and community-based services provides a guiding framework for the manner in which services can be understood. If the goal is to enhance “Continuity of Care” for persons with disabilities, then factors within this complex policy-implementation eco-system must be explored and understood.

This study builds on findings of a previous study by the researcher (Padayachee, 2017) which found that despite the adoption of national policies to advance the rights of persons with disabilities, very little momentum had been created to realise these rights within the public health system, due to poor integration at policy and programmatic levels, especially within the context of PHC service delivery. This study therefore seeks to critically review SA PHC policies and the implementation landscape to investigate “Continuity of Care” among persons with disabilities in an attempt to better understand the extent to which services delivered promote or inhibit “Continuity of Care” within this population.

1.4 Rationale

The prevalence of disability is rising globally and its prominence as a global public health concern and human rights issue is viewed as an international development priority (United Nations, 2008; World Health Organization, 2011). Global estimates indicate that around 15% of the world’s population live with some form of disability with about 2-4% experiencing significant difficulties in functioning (World Health Organization, 2011). The WHO links the increase in the prevalence of disability to ageing populations and the global increase in the prevalence of non-communicable diseases/chronic health conditions such as diabetes, cardiovascular disease, cancer and mental health disorders (World Health Organization, 2011). Rising health inequity and poverty

across the world, combined with the additional vulnerability of persons with disabilities in the face of global health emergencies, wars and conflict mean that disability prevalence is likely to continue its upward trend (Banks, Kuper, & Polack, 2017).

Despite this rising trend in prevalence, persons with disabilities, particularly those living in LMIC countries, continue to experience significant barriers to accessing healthcare, much of which have been comprehensively studied and documented (Dune, 2012; Lishner, Richardson, Levine & Patrick, 1996; McKinney, 2021). In SA these barriers have been documented to include transport and cost challenges, health system weaknesses, lack of health worker knowledge and skills in working with disability (Sherry, 2015) and more recently inadequate protection during health emergencies (McKinney EL, 2021).

The United Nations Convention on the Rights of persons with disabilities (CRPD) is an international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities (United Nations, 2008). The CRPD adopts a social model of disability which explains it as “an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (United Nations General Assembly, 24 January 2007, p. 4).

Article one of the CRDP further offers that “*persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others*” (United Nations General Assembly, 24 January 2007, p. 4).

In addition to general health needs unrelated to their impairments, persons with disabilities may also have fluctuating, long-term or short-term impairments and may require care in multiple healthcare settings (Coleman, 2003), and from a variety of healthcare providers. During transitions between settings and healthcare providers, this population is particularly vulnerable to experiencing poor “Continuity of Care” due to fragmented healthcare services. The World Disability Report further suggests that many persons with disabilities have unequal access to health services and therefore have unmet healthcare needs compared with the general population making them more vulnerable to poor health (World Health Organization, 2011).

In response to this, Article 25 of the CRPD focuses specifically on the rights of persons with disabilities in relation to access to healthcare and recognizes that “*persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability*” (United Nations, 2008, p. 18). This is a powerful commitment that Member States make to up-holding the rights of persons with disabilities and in so doing must “*take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation*” (United Nations, 2008, p. 18).

In particular clause (b) under Article 25 states that signatories to the Convention shall:

Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons (United Nations, 2008, p. 19).

Ensuring “Continuity of Care” may be one way of facilitating access to health services for persons with disabilities. Studies have demonstrated that it is strongly influenced by demographic

factors, patient-healthcare professional relationship, inter-professional factors and organisational factors (Alazri et al., 2007; Guthrie, Saultz, Freeman & Haggerty, 2008). “Continuity of Care” may therefore be closely linked to the healthcare professionals that patients interact with, the service delivery platform from which they receive services and how healthcare professionals interact and respond to the patient’s individual needs (Wringe & Ondenge, 2017).

In addition to services received from healthcare providers, persons with disabilities may also require additional support services beyond those provided by the health system. There is a view that persons with disabilities are a distinct group of healthcare consumers creating an imperative for healthcare policy makers, planners and providers to address their specific needs (Drainoni *et al.*, 2016). This may be easier said than done as needs vary and are closely tied to the individual, their disability characteristics and associated health needs. Specific needs of persons with disabilities can also vary widely based on the social and political context as well as the economic means of the Person with a Disability. Some key areas of support that persons with disabilities may need to maintain their health include rehabilitation services, access to assistive devices, personal assistance, access to municipal services like public transport, mental health support and inclusive health promotion practices (Department of Health, 2000). Goldson (2016) proposes that persons with disabilities may require medical, psychological, economic, social education and emergency supports in order to thrive (Goldson, 2016).

Because of the strong inter-relationship between disability, poverty and poor health outcomes, attention must be paid to understanding the unique health needs of persons with disabilities and the mechanisms by which tailored support can be provided. Principally, disability is considered as a universal human experience, is aetiologically neutral and lies on a continuum (Cieza *et al.*, 2018). This implies that disability is more generalisable to the entire population and

amenable to a life course perspective where there is an appreciation of the fact that one may experience a disability at stage of one's life. The perceived challenge with such a model is the operationalisation and costs associated with ensuring coverage and access to required support. Despite this, there evidence suggests that mechanisms such as individualized funding to support such needs are perceived as beneficial with respect to quality of life, client satisfaction and safety (Fleming *et al.*, 2019).

Within the SA public health sector, there are a plethora of challenges in providing a seamless continuum of appropriate care for persons with disabilities. These include human resource constraints, fragmented and under-resourced rehabilitation services, lack of appropriate assistive devices and the adoption of a medical approach to disability, all of which translates into poor availability, affordability and access to health services for persons with disabilities (Padayachee, 2017). Stigma and discrimination from healthcare workers and broader society compound the challenges faced by persons with disabilities compromising their ability to access appropriate care and live full and productive lives. Trani et al (2020) found that stigma also gives rise to higher levels of depression and by association, lower self-esteem in persons with disabilities where psycho-social support and anti-stigma policies developed with sensitivity to cultural values, are required to break the cycle (Trani, Moodley, Anand, Graham, & Thu Maw, 2020). The care and support required to coordinate health services and the acknowledgement that disability results from and is influenced by attitudes and the environment, dictates that health service provision for persons with disabilities must be carefully studied in order to understand how their “Continuity of Care” can be strengthened for better health outcomes.

Despite the knowledge that “Continuity of Care” is important in the management of persons with disabilities, very little is known about how it is practiced and realised within the PHC

context of SA. Over the past decade, SA has placed much emphasis on the improvement of health service quality within public health facilities; partially in an effort to improve access and remedy inequities of the past but also as a means towards laying firm foundations for the implementation of the National Health Insurance (NHI) (Department of Health, 2017; Whittaker, Shaw, Spieker, & Linegari, 2011). The White Paper lays the foundation for moving SA towards UHC through the implementation of NHI and establishment of a unified and inclusive health system that promises to extend population coverage, improve the quality and quantity of services that the population will be entitled to, as well as provide financial risk protection to individuals and households whilst reducing the direct costs that the population will be exposed to when accessing healthcare.

As an interim step towards supporting improved healthcare standards, the Office of Health Standards Compliance (OHSC) serves as an independent body established in terms of the National Health Amendment Act of 2013 to ensure that both public and private health establishments in SA comply with the required health standards. Health system strengthening efforts have therefore been dominated by quality improvement initiatives guided by the establishment of the OHSC in 2015 and the promulgation of the White Paper on the National Health Insurance in 2017 (Department of Health, 2017). These high-level commitments have catapulted the SA health system towards the vision of improved standards in healthcare service delivery (Department of Health, 2011b).

However, how persons with disabilities are catered for within the context of a transforming and evolving healthcare context has not been fully explored, perhaps as a consequence of shifting priorities in a country marred with a high burden of disease or that of a deeply medicalised model where disability as a state of being is not considered (Whitehead, Kathard, & Lorenzo, 2019). Whitehead's study highlights the dominance of the medical model in undergraduate medical

training and her findings reinforce the important role the attitude of a medical doctor towards persons with disabilities can have in influencing the quality of the interaction between them. In terms of under-prioritisation, Padayachee (2017) found that technocrats and health programme staff indicated that there was not enough political will to push the agenda of persons with disabilities as programmes such as HIV and TB were seen as higher priorities (Padayachee, 2017). This highlighted the attitudinal barriers imposed by policy makers and health programme leadership which translate into structural barriers in health service delivery.

People-centred as defined by WHO is defined as an approach to care that:

consciously adopts the perspectives of individuals, carers, families and communities as participants in, and beneficiaries of, trusted health systems that respond to their needs and preferences in humane and holistic ways. Person-centred care also requires that people have the education and support they need to make decisions and participate in their own care (*World Health Organization, 2018a, p. 8*).

As opposed to people-centred care where there is a broader focus, person-centred care is focused on the individuals needs as determined by their own social determinants of health (World Health Organization, 2018a). It is noteworthy that the terms are often used interchangeably, and person-centred care is the term most often used in SA policies. While both terms are worthy ideals, it is challenging to achieve because potential outcomes are highly dependent on interpersonal interactions, which may vary widely. By virtue of the fact that people carry their own subjective biases, there is the possibility that person-centred care may achieve less than ideal conditions due to impartiality and favouritism shown to some patients over others or by variation in the level of person-centredness demonstrated. The time taken to provide the level of attention required by

some patients versus others may additionally result in disparities in workloads and potential for compassion fatigue (Summer Meranius, 2020).

Despite these issues and potential drawbacks, person-centred care is generally accepted as the appropriate path towards ensuring that patients are placed at the centre of the health decision-making process regarding their own health. Research has shown that it is associated with multiple potentially positive outcomes such as improved health and well-being, improved mutual interaction in relationships, improved cost-effectiveness in terms of hospital costs, length of hospital stays, discharge processes and time efficiency (Bensbih, Souadka, Diez, & Bouksour, 2020). The approach is valuable but needs careful consideration particularly in high disease burden and low resourced healthcare contexts like SA where its implementation is limited due to a complex health system structure (private and public), sub-optimal training and education that maintains a bio-medical approach in addition to factors such as difficult socio-cultural environments where power imbalances and limited resources restrict the shift towards new ways of working and interacting with patients (De Man *et al.*, 2016).

Nonetheless, SA aspires towards setting the bar high and has coined the term “Ideal Clinic” used to describe a PHC clinic that has attained a desired quality accreditation score (Republic of South Africa, 2015). In October 2014 as part of Operation Phakisa, a plan was developed to scale up the “Ideal Clinic” Realisation and Maintenance countrywide (Department of Health, 2016). Operation Phakisa proposed that the PHC package of services should evolve to a “continuum of care” from health promotion to palliative care and integrated clinical services should provide the platform for service delivery. To this end, service delivery configurations have been modified to incorporate “Integrated Clinical Services Management” (ICSM) which will see health facilities transformed to promote health and to prevent illness and further complications through early

detection, treatment and appropriate referral that is delivered in an integrated and coordinated service delivery platform.

The current SA public health system is ripe for the exploration of “Continuity of Care” as it offers a rare opportunity for one to understand this nexus between policy and practice and how the health system has organised itself to respond to the expectations of persons with disabilities. This study takes advantage of this opportunity and addresses a gap in knowledge by aiming to investigate factors influencing “Continuity of Care” for persons with disabilities within the PHC context and develop a framework to inform and strengthen its implementation. This study therefore asks the following question: ***How can “Continuity of Care” for persons with disabilities be strengthened within the primary healthcare context of South Africa?***

The study was guided by the following objectives:

1. To explore the *experiences* and *expectations* of persons with disabilities regarding “Continuity of Care”;
2. To conduct an analysis of relevant policies governing PHC in SA in terms of its influence on disability inclusion and “Continuity of Care” for persons with disabilities;
3. To explore health systems responsiveness to the expectations of persons with disabilities as it relates to their PHC “Continuity of Care”.

The findings of the study contribute to a deeper understanding of what persons with disabilities experience and expect from health services in relation to “Continuity of Care” and attempt to uncover how well the health system and relevant policies facilitate its implementation. The study used a community in the eThekweni municipality in the province of KwaZulu Natal (KZN) as the lens through which these insights can be obtained. While case study designs are

traditionally limited in transferability of results, the researcher proposes that a high level of transferability is possible due to the fact that the key findings are universally applicable in implementable and is further discussed in Chapter 8. Within the bounds of provincial variations in provincial legislation and implementation of health services, aspects of the study relating to the analysis of policies may be more broadly applicable across SA. It is important to state clearly that the purpose of this study was not primarily to create transferable findings but rather critically understand the issue of “Continuity of Care” as it relates to persons with disabilities delving deeply into the underlying factors that influence or inhibit its implementation. The study sought to uncover the realities of the most marginalised in society and employed a critical lens throughout the study so that the concept can be better framed for more meaningful future investigations.

1.5 The study context

The study was conducted in SA which has a population of just over 62 million people (Statistics South Africa, 2022). The most recent published statistics indicate that about 2.9 million of the population have some form of disability (Statistics South Africa, 2011b). SA has a dual structure of private and public health systems, each functioning independently. Significant disparities in financial and human resources exist between the two sectors, with many trained health professionals opting to work within the private sector rather than the public sector (van Rensburg, 2014). Some of the major barriers to achieving quality healthcare for persons with disabilities include acute shortage and maldistribution of healthcare workers, including the availability of rehabilitation teams, a high demand for health services and public services that fail to meet the demand (Sherry, 2015). In recent years SA has seen a dramatic shortage of funded positions within public sector health facilities which has exacerbated the human resource shortage (Tiwari, 2020). It is the intention of this study to focus on the public health sector, however; a

pragmatic approach is also adopted as the intersections between public and private health sectors are blurry.

South Africa's public health system struggles to overcome deep seated inequities and rectifying the injustice of the past appears to be unattainable and is now reaching a tipping point. In SA, the kind of healthcare that a person receives is largely dependent on race, class, and place of residence (Buch, 1989). Good and ill health are concentrated in the socioeconomically privileged and disadvantaged, respectively, with regard to healthcare needs (Gordon, Booysen, & Mbonigaba, 2020). Gordon *et al.*'s (2020) study, found that wealth was linked to increased health seeking behaviours and in comparison the socioeconomically disadvantaged were more likely to delay seeking care, have unmet needs, and struggle with the cost of healthcare (Gordon *et al.*, 2020). The persistent socioeconomic difference in the use of public and private healthcare services, inaccessibility and financial capacity were all found to primary causes of disparities in the use of healthcare (Gordon *et al.*, 2020).

The persistent and continuous deprivation experienced by the poor and vulnerable, who in SA are disproportionately represented by black South Africans, represents a major obstacle to many health strengthening transformations such as the NHI. With a comparable disease burden, weak systemic cohesion and infrastructure, and socioeconomic disparities, South Africa's health care system may be seen as mostly reflective of problems plaguing other Southern African nations (de Villiers, 2021). South Africa is far from adhering to all five PHC principles as 40% of the population resides in homelands, although only 12% of the health budget is allocated to them, demonstrating the unequal distribution of health care resources and the lack of appropriate, high-quality healthcare for everybody.

The dominance of the private sector, competing governmental agendas, fiscal restrictions, ideas, values, and ideologies have all played a significant role in stifling—and occasionally igniting—efforts to reform the health system in South Africa (Whyle & Olivier, 2023). In the province of KwaZulu Natal these challenges are particularly challenging and have resulted in civil unrest, crime and corruption of high proportions (Kalina, 2021).

The study site was based in a single Ward¹ in the eThekweni metropolitan area situated on the east coast of SA in the province of KwaZulu Natal (See Fig. 3) which is considered the birthplace of Community Oriented Primary Care (COPC) with the establishment of the Pholela Community Health Centre in 1940 (KwaZulu-Natal Department of Health, 2001). In this model, PHC services to the community were informed by defining and characterising the community, describing healthcare problems and modifying programmes to address priority needs, supported by effective monitoring of all activities. Although the Pholela Community Health Centre no longer shows evidence of the original activities, this model is strongly linked to the conceptualisation of PHC worldwide (Padayachee, 2012).

¹ Geopolitical subdivisions of municipalities used for electoral purposes in SA

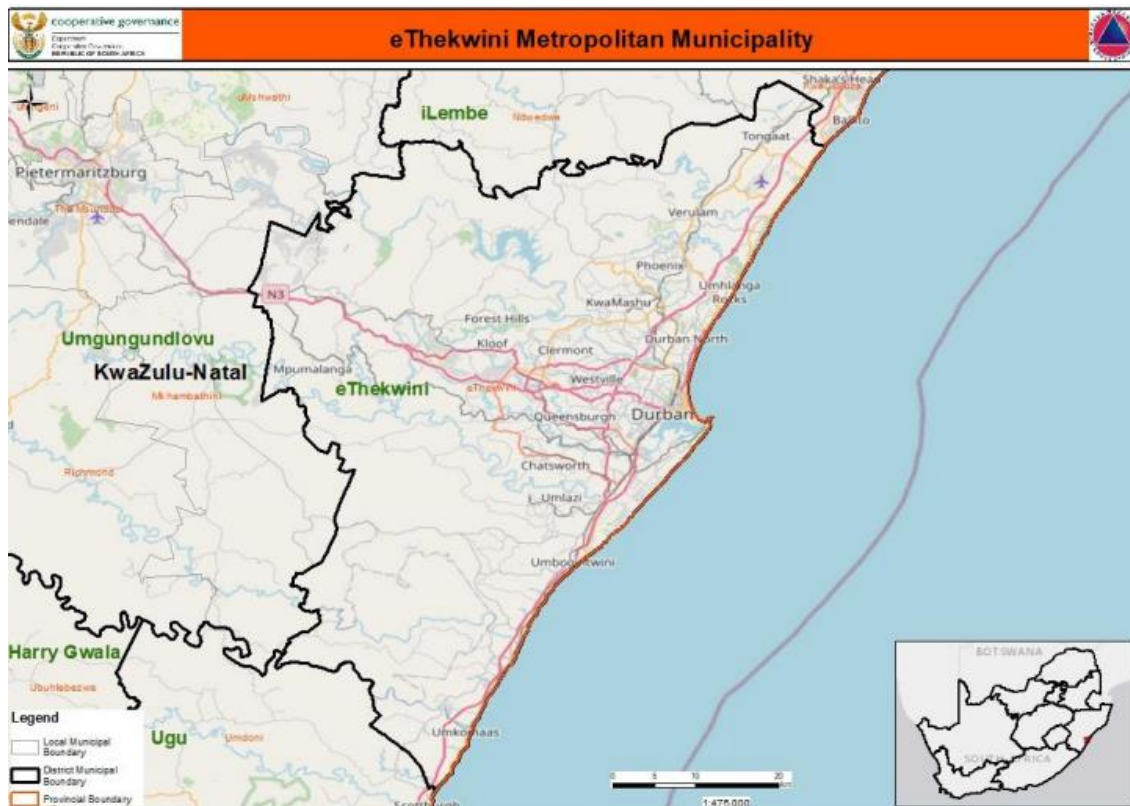


Figure 3. Map of eThekweni (Department of Cooperative Governance and Traditional Affairs, 2020)

Figure 3 above shows a map of eThekweni which is a coastal area and represents the third largest metropolitan municipality in the country. It is ranked as the third largest metro in SA with a population of 4,239 901 million people and accounts just over 30% of the population of the province of KZN (Statistics South Africa, 2022).

The latest census conducted in 2022 showed that eThekweni has a diverse population with the majority (71,6%) of the population being black African(Statistics South Africa, 2022). It is home to the largest population of Indian/Asian SA, representing 19,7% of the population (Statistics South Africa, 2022)About 6% of the population are White and 2,5% are Coloured. In terms of gender, the population is almost equally represented with 48.9% being male, and 51,1% female

(Statistics South Africa, 2022). It has an average household size of 3.3 persons, which is lower than the provincial average of 3.8 (Statistics South Africa, 2022).

Approximately 21% of the population is under the age of 15 years and 69% of the population are considered to be working age of between 15 and 64 years of age (Statistics South Africa, 2022). The overarching issues facing most people in KZN is poverty and unemployment, where 2.1 million of eThekweni's residents live below the upper bound poverty line of R1 227 per person per month, and 17.1% of the population reported having no income (Statistics SA Community Survey, 2016). 16.8% of the population has no education while 5.8% have a higher education qualification (Department of Cooperative Governance and Traditional Affairs, 2020). This pattern of poverty and deprivation are characteristic of health and social systems post-apartheid discussed earlier.

1.6 Significance of the study

“Continuity of Care” is considered a cornerstone of PHC and a core element in the delivery of quality health services. It has been consistently identified as a defining feature, and an assumed strength of PHC and has also been adopted as part of PHC approaches around the world. It is defined in many different ways; but the latest proposed definition demonstrates the relative importance of the concept of “Continuity of Care” and the need for individualised person-centred care:

PHC is a whole-of-society approach to health that aims equitably to maximize the level and distribution of health and well-being by focusing on people's needs and preferences (both as individuals and communities) as early as possible along the continuum from health promotion and disease prevention to treatment,

rehabilitation and palliative care, and as close as feasible to people's everyday environment (World Health Organization, 2018c, p. 1).

Uncovering factors that influence “Continuity of Care” for persons with disabilities has coherence with international efforts to promote inclusive health systems to ensure that persons with disabilities do not remain excluded from their right to attain the highest level of health possible. This study aims to explore the factors that influence “Continuity of Care” from the perspective of persons with disabilities, their families, community structures and that of the health system so that information generated can be used to improve PHC services for persons with disabilities. This study supports the generation of evidence and understanding to realise inclusive and equitable healthcare for persons with disabilities.

1.7 Researcher positionality

A health policy and systems researcher embarking on this study focused on “Continuity of Care” in a community that I am familiar with and marked with high levels of inequity and poverty, my positionality represents an important aspect that guides my approach to understanding this phenomenon within this context. I am aware of the power dynamics within research and have been committed to holding a reflexive stance throughout the research journey. This involved being aware at all times of my perceived position of power and privilege by my research participants, particularly persons with disabilities and their families who live in abject poverty and my research assistant, who is also part of the community. I have ensured that I maintained a high level of awareness of my own biases, assumptions and the potential impacts that it could have on the research process. Reflective conversations with colleague and my supervisor have been important mechanisms to support this journey.

My academic background and professional experience as a Speech and Language Therapist and health policy and systems researcher with a special interest in disability inclusion, positions me as an experienced researcher adequately equipped to conduct a study of this nature. I draw on over 15 years of experience in health systems research where I have been involved in about 30 research projects in various capacities while working for a SA NGO and other international development organizations. My varied professional training and career experience allows me to view the world of health systems through multiple lenses. Due to my training as a Speech and Language Therapist, I hold views on the daily challenges and experiences of persons with disabilities and their families on the road to recovery after a dramatic life changing health event and understand the path they traverse to regain independence and adapt to a new way of life. Having transitioned to a career in health systems research, I also hold views and have extensive experience on how the health system operates in SA and the challenges faced by policy makers and implementers in delivering basic health services with limited resources. Now working at a global health level at WHO, I have gained a broader view of the politics and dynamics at play in global health issues and therefore can appreciate the challenges to realising inclusive health systems at all levels of the health system.

My experience can be categorised into four distinct areas, 1) clinical experience mostly in adult neurologically acquired speech and language disorders and dysphagia; 2) research and evaluation experience in primary healthcare implementation models and the documenting of good primary health care practices (Padayachee, 2012, 2013); Padayachee and Zide (2013); 3) using routine health information to direct health systems strengthening efforts (Day, Gray, Padayachee, & Cois, 2020) and 4) advocating for greater visibility of disability inclusion in mainstream public health policy and practice (Health Systems Trust, 2020; Padayachee, 2017). The majority of my

experience is based on work done in SA, however some of my work has focused on other countries on the African continent (Leonard Cheshire, 2021a, 2021b). Throughout my research career, I frequently found myself at odds with what the results of studies meant for persons with disabilities and whether the recommendations were serving to further marginalise this population or promote inclusion. My perspective was one of an “outsider”, as my perspective was atypical yet I was technically an “insider” working closer with key players with the health system of SA. The constant tension fuelled critical debate amongst my colleagues who often could not relate to the issues I raised about disability inclusion. With this in mind, my positionality can be best described as an in-between/inside-outsider, close enough to the health system to understand its nuances, yet distant enough through my professional training to observe the weaknesses in relation to persons with disabilities. The variety of firsthand experiences accumulated over the course of 16 years therefore allowed me to apply a critical perspective of health services and how they are designed and delivered for persons with disabilities.

My intention to pursue a PhD was based on professional requirements and personal aspirations. In my position as the Programme Manager of a health systems research unit, I had the responsibility of supporting fundraising and sustainability efforts which often required a doctoral degree to hold the position of Principal Investigator. In addition to this requirement, I also held a personal desire to pursue a PhD in a topic that resonated with my interest in disability rights and inclusive health systems. The interest in “Continuity of Care” emerged organically out of a previous study I conducted which evaluated the readiness to implementation of the Framework and Strategy for Disability and Rehabilitation in South Africa (Padayachee, 2017).

My clinical background has continued to shape the research I have undertaken as part of my PhD. Specifically, it has informed the adoption of a critical social theory lens which seeks to

understand social justice and the human experience as a means to promote transformational measures for change. My qualitative interview topic guide, interview technique and data analysis, have largely been shaped by this philosophical position and are further enriched by my in-depth personal understanding of the contextual elements mentioned by participants. The inclusion of the policy analysis was an important consideration in developing the methodology of the study. I saw it as the language of policy makers. Through this study, I was not only looking to understand context and experiences of “Continuity of Care” within a system; I was also looking to evaluate the levers for change - that being policies and health systems strengthening activities that may need deeper consideration in relation to persons with disabilities.

As proposed by Sheikh, George and Gilson (2014), the seeds of transformative practice in HPSR lie in amplifying the breadth and depth of dialogue across health system actors in the conduct of research – recognizing that these actors are all generators, sources, and users of knowledge about the system (Sheikh, George, & Gilson, 2014). In my position as an actor in the health system where marginalisation of persons with disabilities is common-practice, I chose to use my in-betweener/insider-outsider position, to amplify the voices of persons with disabilities through the “Continuity of Care” journeys documented as part of the study. As a trained Speech Therapist, I appreciate the value of hearing the details of the story, so that the full picture of challenges and opportunities can be established. My positionality as an in-betweener/insider-outside provides me with the depth of understanding from health service user and provider.

My in-betweener/insider-outside positionality meant I was familiar with stakeholders within the health system but was also deeply rooted in the disability inclusion community. The same could be said for the study site which was also the community where I was born, but as I found out, saw me only as partially belonging. This in-betweener standpoint has allowed me to see

the problem of “Continuity of Care” through a wider critical lens and one that can hopefully better inform an agenda for change. Without this positionality, I might not have adopted this study design which demands criticality and active reflection and may have limited myself to a narrow and more detached perspective. Adopting a health systems lens as an in-betweeners is a rare position to assume in the space of health systems researcher and one that I feel strongly needs to be pursued in an effort to push the system to accept a different perspective on issues of marginalisation which affect a growing but persistently forgotten group – persons with disabilities.

My thoughts as I began this PhD journey in terms of knowledge generation, was to achieve a deeper understanding of “Continuity of Care” in relation to persons with disabilities. Based on my previous work, care continuity for persons with Disability was found to be sub-optimum and this study was structured in a way that would interrogate the issue for deep and nuanced understanding of what influences it; with purposeful privilege given to the voices of persons with disabilities and their families.

In summary, my positionality as a health policy and systems researcher, coupled with my personal experiences, values, and commitment to reflexivity, uniquely situates me to undertake this qualitative study on “Continuity of Care” for persons with disabilities.

1.8 Outline of chapters

This study is divided into **8 Chapters**.

Chapter 1: Background and Rationale provides the background to the study including important terminology and outlines the rationale and scope of the study.

Chapter 2: Literature Review and Conceptual Framework is written in three sections. Section A: Describes disability and how definitions have evolved over time, how it is viewed in an African context and what the prevalence estimates are both globally and in SA. Section B: describes key aspects of the SA healthcare landscape with emphasis on disability and issues of inequity, social inclusion and heightened vulnerability of persons with disabilities. The experiences of persons with disabilities in accessing healthcare are explored, including efforts to improve access, equity and quality of services in SA. Primary healthcare and universal healthcare are discussed in relation to the issue of “Continuity of Care”. Section C: Focuses on the concept of “Continuity of Care,” it’s link to PHC, trends in research and tools and measures of the concept. It outlines the Health Systems Responsiveness Framework (Mirzoev & Kane, 2017) used in the study and provides the rationale for its use.

Chapter 3 outlines the study methodology. The key research question, aim and objectives are clearly described, as well as the rationale for the selected research design. A description of the participants and setting, the participant selection criteria, data collection procedures, recruitment materials, general procedures, scientific rigor and ethical considerations is presented.

Chapter 4: presents the results of the qualitative research component of the study. It is presented as four sections which provides an account of the findings from distinct but interrelated perspectives: researcher observations of the context, the person with a disability, their family and their community.

Chapter 5: presents the main findings of the policy analysis on two levels. The first explores the extent to which the policy includes persons with disabilities in accordance with the EquiFrame approach, and the second presents the extent to which the policy addresses “Continuity of Care” for persons with disabilities with perspectives from health system actors.

Chapter 6: is the main thesis building chapter of the study, providing a deeper analysis of the 5 key findings relating to what influences “Continuity of Care” for persons with disabilities in the SA KZN context. It provides an approach to health systems strengthening that will address these influences and discusses how public health policy can be strengthened to shift the public health landscape towards greater levels of inclusion and “Continuity of Care”.

Chapter 7 presents a summary of the research that was conducted. This is followed by an evaluation of the study, its implications for policy makers and research into Continuity of Care. A framework for understanding “Continuity of Care” in context is proposed.

1.9 Summary and scope of the study

This chapter presented the background and rationale for the study within the current context of a transforming SA public health system. The chapter broadly highlighted the need for a study investigating “Continuity of Care” for persons with disabilities as it is pivotal to global commitments to develop health systems that are more inclusive of persons with disabilities. The case has been made for why the study focuses on the public PHC system as the gateway to healthcare, with emphasis on the important opportunity that the current changing SA landscape provides for the exploration of “Continuity of Care” for persons with disabilities.

Chapter 2: Literature review and conceptual framework

2.1 Introduction

“Continuity of Care” is a complex concept, variously defined depending on factors related to healthcare setting and context, healthcare conditions and type of healthcare being accessed. Nuanced understanding of the concept is gaining traction not only in an attempt to improve the quality of health services broadly, (Iyafei A, 2020), but also in relation to understanding how it can be achieved in populations with complex chronic health conditions (Ljungholm, Edin-Liljegren, Ekstedt, & Klinga, 2022). It is often referenced as an important component of international efforts to deliver person-centred care (World Health Organization, 2018a) and efforts to address the quality healthcare needs of vulnerable and marginalised populations, such as persons with disabilities (Lawthers, Pransky, Peterson, & Himmelstein, 2003). Similarly, the concept of disability is complex, multidimensional and dynamic with a high level of diversity and unique considerations for healthcare planners and implementers. The study of “Continuity of Care” for persons with disabilities within the PHC setting in SA, (by virtue of it being the gateway to the health system) demands careful consideration of key drivers for its successful implementation. Healthcare equity, the rights of persons with disabilities in relation to healthcare access, the policy landscape and transformations within the SA healthcare system all have influence over how “Continuity of Care” is planned and implemented for persons with disabilities.

This chapter explores literature relevant to this study which is discussed thematically to develop a construct of factors that influence “Continuity of Care” for persons with disabilities and reviews research conducted in this area. It also introduces the conceptual framework used in the study and is presented in four sections as summarised below.

Section A: Understanding disability within the context of health care: Describes disability and how definitions have evolved over time, how it is viewed in an African context and what the prevalence estimates are both globally and in SA.

Section B: The South African Health System: Structural reforms and its impact on persons with disabilities describes key aspects of the SA healthcare landscape with emphasis on disability and issues of inequity, social inclusion and heightened vulnerability of persons with disabilities. The experiences of persons with disabilities in accessing healthcare are explored, including efforts to improve access, equity and quality of services in SA. Primary healthcare and universal healthcare are discussed in relation to the issue of “Continuity of Care”.

Section C: “Continuity of Care” and why it matters to persons with disabilities focuses on the concept of “Continuity of Care” it’s link to PHC, trends in research and tools and measures of the concept. It unpacks the **Conceptual Framework** of the study and provides rationale for its use.

2.2 Section A: Understanding disability within the context of health

2.2.1 How disability has been defined and conceptualised over time

Disability is viewed as complex, multidimensional and a reality of the human condition. Several models of disability have been developed to facilitate our understanding of disability and have particular significance in how persons with disabilities have been catered for within the public policy (Lawson & Beckett, 2020). In many ways, the evolution in society’s understanding of disability and the increasing importance of addressing the needs of persons with disabilities within the healthcare setting, parallel the changing landscape of health systems globally. Over the past six decades, our knowledge of disability has evolved, with medical and societal viewpoints

significantly influencing how persons with impairments are perceived and valued (Hogan, 2019; World Health Organization, 2011). Models of disability provide important points of reference as programs, services, laws, regulations and structures are developed to address the needs of persons with disabilities (Lawson & Beckett, 2020).

Historically, society's early understanding of disability has been shaped by its moral and religious beliefs (Retief & Letšosa, 2018). The "moral and /or religious model" of disability views disability as an "Act of God" and punishment for the sin/s committed by the person with a disability (Retief & Letšosa, 2018). It represents one of the oldest models of disability and is important for understanding how disability is positioned within societies and across many cultures. While this model of disability may not have risen in prominence politically in shaping healthcare policies and programmes, it remains a valuable perspective for healthcare providers to be aware of, as religion and culture give meaning to the life of people (Kaur & Arora, 2019) and has bearing on the lived experience of persons with disabilities and decisions affecting their health.

From the mid-1800s onwards, the medical model of disability began to gradually replace the moral and/or religious model in lieu of significant advances in the field of medical science (Retief & Letšosa, 2018). The medical model views disability as a defect and as a comparator to what is perceived as normal functional traits (Petasis, 2019). This model describes disability as a consequence of a health condition or disease or caused by a trauma that can disrupt the functioning of a person in a physiological or cognitive way (Hogan, 2019) seeing disability as a condition.

The dominant models of disability have merged over time and currently are the Medical Model, Functional Model and Social Model (Retief & Letšosa, 2018). The terms "medical model" and "social model" of disability have dominated much of the debate around how disability is defined and understood. The medical model of disability views disability as an individual medical

problem that requires medical intervention to cure or manage. It focuses on the diagnosis, treatment, and rehabilitation of individual disabled people, and tends to view disability as a personal tragedy or a problem to be fixed (Hogan, 2019). In contrast, the social model of disability views disability as a social phenomenon that is created by social and environmental barriers. It recognizes that disabled people are not inherently "deficient," but are disabled by the physical, attitudinal, and institutional barriers that exist in society (Hogan, 2019). It emphasizes the importance of removing these barriers and creating a more inclusive and accessible society (World Health Organization, 2011).

It is important to note that these two models are not mutually exclusive, and many disability scholars and activists argue that a more holistic and integrated approach is needed that considers both the individual and social dimensions of disability (Retief & Letšosa, 2018). This approach is often referred to as the biopsychosocial model of disability, which recognizes that disability is influenced by biological, psychological, and social factors indicating that a comprehensive approach is needed to address the needs of disabled people (Petasis, 2019).

Our understanding of disability has also been shaped by shifts in public policy giving rise to the importance of the human rights model of disability (Lawson & Beckett, 2020). The human rights approach to disability recognises that persons with disabilities have the same human rights as everyone else, and that they must be respected, protected and fulfilled (Petasis, 2019). This approach is grounded in the principles of dignity, autonomy, non-discrimination, participation, and inclusion which now dominates the advocacy narrative for disability inclusion and equal rights (Lawson & Beckett, 2020). In this model, persons with disabilities are seen as rights holders, rather than passive recipients of medical care (Lawson & Beckett, 2020) and the focus is on promoting

and protecting the rights of persons with disabilities and ensuring that they are able to participate fully in society.

The human rights approach to disability is supported by a number of international legal instruments, including the United Nations Convention on the Rights of persons with disabilities (CRPD) (United Nations General Assembly, 24 January 2007). The CRPD is a human rights treaty that recognizes the rights of disabled people and outlines the obligations of states' parties to promote and protect these rights. Overall, the human rights approach to disability recognizes the inherent dignity and worth of every person and seeks to ensure that disabled people are able to enjoy their human rights on an equal basis with others (Degener, 2017).

Katsui (2008), recognising the obvious advantages of the human rights based approach, argued downsides of the human rights model in three ways: 1) its origin, 2) problems in its operationalisation, and 3) negative consequences of its operationalisation (Katsui, 2008). It's Eurocentric origins post-World War 2 give it a bias towards policy and economic emancipation rather than development, a form of cultural imperialism, in that the focus was on policies prioritising economic ideals for the East and West. It was only after the United Nations Development Programme's "2000 Report on Human Rights and Development" that human rights became a development objective. In terms of its operationalisation, the language of absoluteness of the human rights based approach has been criticised due to its lack of sensitivity to context and culture (Katsui, 2008), and with that comes the additional possible risk of imperialistic harms (Muyskens, 2022). Giving absolute priority to one group is also seen as a contradiction to the "all rights are equally important" narrative. In resource constrained settings prioritisation is a necessity and while all rights may be equal, not all rights may be fulfilled at the same time. The vagueness

and silence on how the rights are to be operationalised can result in negative consequences. This flaw is similar to the public health policy implementation gap.

African models of disability have begun to emerge in response to the view that the experience of persons with disabilities in the Global South is different from the Global North where many of the disability models have been conceptualised.

2.2.2 Disability in an African context

The emergence of scholarly debate around the need to deconstruct western based models of disability has led to proposals for African approaches to understanding disability in a manner that considers cultural, social, and historical contexts found throughout the continent (Ned, Dube, & Swartz, 2022). Although acknowledging the diversity of perspectives and customs is crucial, there are certain recurring patterns when analysing disability in African contexts. The African idea of *ubuntu* is emphasised by scholars as an African societal way of being that emphasizes community and interdependence and influences how people view disabilities (Lorenzo, 2005; Ned *et al.*, 2022). Disability as viewed through an Ubuntu lens, is seen as a collective issue as much as an individual one and the importance of group accountability and assistance for people with impairments is emphasized.

In African discourse, the social model of disability is becoming more widely acknowledged than the medical model, which concentrates on impairments. Africa is a very diverse continent with a wide range of ethnicities, languages, and customs. Regarding disabilities, each group may have its own distinct customs, beliefs and coping mechanisms (Ani, Batisai, Ntoimo, & Isiugo-Abanihe, 2023). While some cultures may struggle with stigma and discrimination, others may find it easy to include persons with disabilities into daily life (Sefotho, 2021). Historically

disability in Africa was inextricably linked with spiritualism and was glorified whereas modern day culture often sees disability as an anomaly resulting in persons with disabilities being objectified and abused because of ignorance and harsh economic conditions (Ojok & Musenze, 2019). Ojok and Musenze (2019) in their interrogation of philosophy and Western religion in comparison to ancient African cultures contend that contemporary mistreatment of persons with disabilities does not reflect a true African culture but is a symptom and a consequence of the material and economic injustice that persons with disabilities encounter (Ojok & Musenze, 2019).

In South Africa, there is evidence that disability is strongly intertwined with African spiritual and traditional beliefs which necessitates an understanding of cultural beliefs and coping mechanisms such as seeking spiritual support through traditional healers and or performing rituals (Zuma, Wight, Rochat, & Moshabela, 2016). It is estimated that close to 70% of patients opt to see a traditional healer as their first choice and that Sangomas were the most popular choice (Puckree, Mkhise, Mgohazi, & Lin, 2002). In SA, Traditional Healers are provided with a regulatory framework to ensure the efficacy, safety and quality of traditional health care services through the Traditional Health Practitioners Act of 2007 (Republic of South Africa, 2007). The act provides for the management and control over the registration, training and conduct of practitioners, students and specified categories in the traditional health practitioners' profession; and all matters connected to traditional health practitioners. Traditional healers in KZN are frequently consulted for treating health problems, including impairments. Certain communities resort to conventional healing methods that integrate herbal and spiritual therapies with contemporary medical treatments (Puckree *et al.*, 2002).

The reality; however, is that despite efforts to address it, stigma, discrimination, and lack of accessibility persist in various forms, hindering the realization of the rights and potential of persons with disabilities (Trani *et al.*, 2020). There is a growing awareness of the rights of persons with disabilities, and efforts to promote inclusive policies, accessible infrastructure, and social attitudes that foster greater inclusion increasing taking root (Sefotho, 2021).

2.2.3 Global estimates of the prevalence of disability

The World Health Survey and the Global Burden of Disease (GBD) study are the two major sources of disability prevalence estimates. The Global Report on Health Equity for persons with disabilities which draws from these two sources, indicated that as of 2021, there were approximately 1,3 Billion people with some experience of disability and that 80% of those live in the global south (World Health Organization, 2022a). The earlier World Report on Disability (World Health Organization, 2011) also provides a comprehensive overview of disability worldwide and puts forth an estimate that over 1 billion people or roughly 15% of the world's population experiences some form of disability. What is clear from these statistics is that the prevalence of disability is on the rise with the GBD study (2019) showing that the global prevalence of disability increased by 19.4% between 1990 and 2019 (Diseases & Injuries, 2020). The GBD study also demonstrated a rise in life expectancy globally, especially in high income countries (Diseases & Injuries, 2020) and with the marked increases in disability, increasing prevalence in non-communicable diseases and global disasters, the global picture of disability is worrying.

The rise in disability prevalence over the past decade is reportedly due to demographic and epidemiological changes and the increase in the number of people with noncommunicable

diseases(World Health Organization, 2022a). With people living longer with the debilitating effects of aging and the high levels of non-communicable disease, particularly diabetes and hypertension makes a compelling case for the prioritisation of disability in health systems. (World Health Organization, 2022a).

Added to this is the increased vulnerability that persons with disabilities face in the context of disasters and conflict and associated forced displacement (UN Office for Disaster Risk Reduction, 2023)as they are often most affected by natural hazards, climate-induced disasters, and global health emergencies (UN Office for Disaster Risk Reduction, 2023).

While leading authorities understand that disability is on the rise and needs to be prioritised (World Health Organization, 2022a), persistent challenges in collecting accurate and disaggregated data on disability to fully understand the patterns of disability and what we can expect in the future remains problematic.

2.2.4 Latest efforts to improve equity, access and quality

In 2021, a new landmark Resolution EB148.R6 “The highest attainable standard of health for persons with disabilities” (World Health Organization, 2021) was adopted by the 74th World Health Assembly. The resolution is squarely directed towards the creating a health sector that is more inclusive and one that is responsive to the health service needs of persons with disabilities. Some of the efforts outlined in the resolution include access to effective health services, protection during health emergencies and access to public health interventions across different sectors:

The Resolution EB 148.R6 also aims to improve collection and disaggregation of reliable data on disability to inform health policies and programmes. Resolution EB 148.R6 (World Health Organization, 2021) lists a range of actions to be taken by the WHO Secretariat including

developing a report on the highest attainable standard of health for persons with disabilities by the end of 2022; implementing the United Nations disability inclusion strategy across all levels of the organization; supporting the creation of a global research agenda on health and disability; as well as providing Member States with technical knowledge and capacity-building support necessary to incorporate a disability- inclusive approach in the health sector (World Health Organization, 2022b).

2.3 Section B: The South African health system: Structural reforms and how it impacts persons with disabilities

The South African health system is two-tiered and highly fragmented with the least advantaged heavily dependent on the under-resourced public sector, while the wealthy use the private sector (McIntyre *et al.*, 2008). The public health system is the main provider of healthcare services in the country, with about 71% of the population relying on it (Statistics South Africa, 2018). The public health system includes PHC clinics, district hospitals, regional hospitals, and tertiary hospitals, relying heavily on a functional district health system and well-orchestrated delivery of primary healthcare (Dookie & Singh, 2012). While the service is considered fundamental to the provision of healthcare services, it is plagued by several challenges, including inadequate funding, shortages of healthcare workers, outdated infrastructure and fragmentation. The public health system is also funded through general taxation and is overseen by the Department of Health.

In contrast, 27% of the population rely on health services from the private health sector (Statistics South Africa, 2018) paid for through individual contributions to private health insurance or medical assistance programs (McIntyre *et al.*, 2008) with out-of-pocket payments (Ramjee,

2014). The private health sector is generally better resourced, with modern facilities, advanced technology, and well-trained healthcare professionals (Maphumulo & Bhengu, 2019). However, it is also criticized for contributing to healthcare inequities by diverting resources away from the public system and charging high fees that are unaffordable for many.

The National Health Insurance was proposed by the South African government to create a funding mechanism to support the realisation of UHC and greater equity within the health system and is based on the constitutional rights of citizens to have access to quality healthcare services that are delivered equitable, affordably, efficiently, effectively and appropriately based on social solidarity, progressive universalism (Department of Health, 2017b). Through the NHI, citizens would be able to purchase healthcare services from medical experts in order to give universal access to healthcare at both private and public health facilities (Blecher, 2019). Then, these services would be provided at both public and private locations. However, there are a lot of unsolved issues and doubts regarding the specifics of how this plan will operate.

Despite the efforts of the SA government to remedy past injustices, Rispel (2016) argues that three fault lines namely, tolerance of ineptitude as well as leadership, management and governance failures; lack of a fully functional district health system, which is the main vehicle for the delivery of primary health care; and inability or failure to deal decisively with the health workforce crisis will place these efforts in jeopardy (Rispel, 2016).

2.3.1 Disability and health inequity

Social justice in health is referred to as "health equity," meaning that no one should be denied the chance to be healthy because they are a member of a group that has historically experienced economic or social disadvantage (Braveman, 2014). In order to achieve equitable

universal health coverage, all members of the population must have access to essential services without facing exorbitant costs (Harris *et al.*, 2011). Inequity within the SA health system refers to the unequal distribution of healthcare resources and access to healthcare services among different population groups and equates to differences in healthcare outcomes, healthcare infrastructure, healthcare personnel and healthcare services (Gordon *et al.*, 2020).

Padarath *et al* (2018) discuss the maldistribution of health personnel within SA and its impact on healthcare access and outcomes. They argue that the shortage of health personnel in rural and underserved areas is a key factor contributing to inequities in the SA health system. Mayosi *et al.* (2012) additionally identify significant financial barriers to accessing healthcare experienced by rural households, despite the availability of free public PHC.

Despite the strong evidence that equity in healthcare is needed to fulfil the human right to health, people with disabilities and their families still remain at higher health risks and consistently inferior access to care (MacLachlan *et al.*, 2012). The environment, transportation, and financial issues are among the obstacles to access, but there are also significant systemic constraints, such as program design, the incompetence of health workers in dealing with disabilities, and the general lack of planning and funding for rehabilitation (Greux *et al.*, 2023).

2.3.2 Experiences of persons with disabilities in accessing health services

persons with disabilities often face challenges in accessing quality health care services due to a lack of trained health care providers, inadequate infrastructure, discrimination, poverty, and other social determinants of health. As repeatedly acknowledged, persons with disabilities often face barriers to accessing health care services (Lagu, Griffin, & Lindenauer, 2015; McKinney EL, 2021; Sherry, 2015), including lack of access to appropriate care and equipment, lack of trained

health care providers, and inadequate infrastructure. They also encounter discrimination, stigma, and negative attitudes from health care providers and the wider society, which can lead to exclusion from health care services (Sherry, 2015). According to the WHO, persons with disabilities are more likely to experience unmet health needs and are at a higher risk of preventable diseases and premature death compared to persons without disabilities (World Health Organization, 2011).

Physical, cognitive and / or mental disability represents a major challenge in accessing healthcare (Sutton & DeJong, 1998). These access barriers manifest in many ways most notably as poor health outcomes and generally poor satisfaction with the healthcare received. A 2003 study reviewed health services literature related to quality of care for persons with disabilities in order to highlight the need for a unique framework for conceptualising quality and patient safety issues in this population (Lawthers *et al.*, 2003). The review illustrated several problems in the area of clinical quality, access, client experience and coordination (Lawthers *et al.*, 2003). Understanding what quality healthcare means for a person with a disability may be one way to address poor levels of satisfaction in this population but few studies have been found that focus on defining and measuring quality of care for persons with disabilities.

Padayachee (2017) found that persons with disabilities in KZN were not adequately prioritised in health systems policies and planning, and the silo approach to health service implementation was a major challenge for persons with disabilities in terms of ensuring their “Continuity of Care” (Padayachee, 2017).

2.3.3 Universal health coverage

PHC and UHC are vital components of the World Health Organization’s (WHO) strategy to achieve health equity and sustainable development (Hogan, Stevens, Hosseinpoor, & Boerma,

2018). UHC is a concept that aims to ensure that all individuals and communities have access to quality health services without suffering financial hardship (World Health Organization, 2018c). This includes a range of health services, from health promotion to prevention, treatment, rehabilitation, and palliative care, that are comprehensive, integrated, and person-centred (World Health Organization, 2018c).

UHC and PHC are crucial approaches to health service delivery for the improvement of health outcomes and quality of life of persons with disabilities in developing countries (Kuper & Hanefeld, 2018). The WHO's advice to countries for its successful implementation promotes robust, just, and equitable health systems that are integrated in the communities they serve (World Health Organization, 2023c). PHC is considered the efficient and economical option for the delivery of UHC; however, countries are different in its constitution, history and characteristics and tailoring to the approach is necessary with consideration for the requirements of its people and available resources (World Health Organization, 2023c).

Several challenges exist in the implementation of UHC globally; including those related to stewardship particularly as it relates to intersectoral collaboration; the creation of resources primarily human resources and infrastructure; financing where revenue collection is inadequate and service delivery challenges due to fragmentation and unregulated delivery systems (Darrudi, Ketabchi Khoonsari, & Tajvar, 2022).

Monitoring the implementation of UHC is also cross cutting challenge for which partial or incomplete data collected in non-standardised ways across countries threaten its success. It is also postulated that the obstacles to UHC measurement lies in the lack of consensus about how best to monitor it (Fullman & Lozano, 2018) with the proposal for an index of essential health services being the closest contender of the measurement of SDG3.8.1 using routinely available in-country

data. persons with disabilities; however, are not represented in this proposed index and highlights the challenge of monitoring inclusion of this population a global level.

2.3.4 Universal health coverage for persons with disabilities:

UHC is an important strategy for achieving health equity and ensuring that all individuals have access to quality health care services without suffering financial hardship. UHC provides a framework for ensuring that health care services are comprehensive, integrated, and person-centred. This includes ensuring that health care services are accessible, affordable, of high quality, and that financial barriers to accessing health care are removed.

persons with disabilities often face significant financial barriers to accessing health care services, including out-of-pocket expenses for assistive devices, transportation costs, and costs associated with specialized care(World Health Organization, 2018b). UHC can help to address these financial barriers and ensure that persons with disabilities have access to the health care services they need without suffering financial hardship.

In addition, UHC can help to address the social determinants of health that affect persons with disabilities, such as poverty, unemployment, and inadequate housing. UHC can help to promote social inclusion and reduce the economic burden of disability on individuals and families.

2.3.5 Primary healthcare for persons with disabilities:

Good quality PHC is an essential strategy for promoting health equity and addressing health inequalities. According to WHO it represents the first level of contact of individuals, the family, and the community with the national health system, bringing health care as close as possible to where people live and work (World Health Organization., 2018). PHC aims to provide

comprehensive and accessible health care services, including preventive care, treatment, and rehabilitation, that are tailored to the needs of individuals and communities (World health Organisation, 2018)

At a time in history, where we are faced with high levels of inequity and a rapidly changing world, there is a renewed emphasis on PHC using a people-centred approach. The WHO has reframed PHC in recent years, to position it as a whole of society approach to health where the needs and preferences of people are prioritised both an individual and community level, positioning the range of services offered along a continuum, from health promotion and disease prevention to treatment, rehabilitation and palliative care as close to people's everyday environment (World Health Organization and the United Nations Children's Fund (UNICEF), 2018).

This approach is especially important for persons with disabilities who require specific health care services that are often not available in traditional health care settings. The inclusion of people-centred care and focus on bring services closer to their everyday environment is critical for ensuring that persons with disabilities have access to PHC services but also more specialised care and equipment, such as assistive devices, prosthetics, and mobility aids. According to a study by the WHO (World Health Organization, 2018b), PHC can reduce health care costs and improve the quality of health care for persons with disabilities. The study found that PHC-based interventions for persons with disabilities resulted in improved health outcomes, reduced hospitalizations, and decreased health care costs. Good PHC "Continuity of Care" is therefore an essential part of delivering care that meets the needs of persons with disabilities"

2.3.6 Community-based rehabilitation

Community Based Rehabilitation (CBR) is a community development strategy that aims at enhancing the lives of persons with disabilities within their community (World Health Organisation, 1994). CBR was initiated by WHO following the Declaration of Alma-Ata in 1978 in an effort to enhance the quality of life for persons with disabilities and their families; meet their basic needs; and ensure their inclusion and participation. While initially a strategy to increase access to rehabilitation services in resource-constrained settings, CBR is now a multi-sectoral approach working to improve the equalization of opportunities and social inclusion of persons with disabilities while combating the perpetual cycle of poverty and disability. CBR is implemented through the combined efforts of persons with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services (World Health Organisation, 1994).

It emphasizes utilization of locally available resources including beneficiaries, the families of persons with disabilities and the community. According to the UN Convention on the Rights of persons with disabilities, comprehensive rehabilitation services focusing on health, employment, education and social services are needed to enable persons with disabilities attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life (United Nations General Assembly, 24 January 2007)

2.3.7 Disability data in South Africa as a means to plan for health services

According to Article 31 of the United Nations Convention for the Rights of persons with disabilities (UNCRPD), routine health information systems should allow for disaggregation of data to track the health status of persons with disabilities, the extent to which they receive the services

they need, and the extent to which budgets, human resource planning and plans enable such service coverage (United Nations General Assembly, 24 January 2007). However, in SA routine health information systems lag behind and are not yet structured to provide discrete and disaggregated data to monitor access to health services for persons with disabilities (Day *et al.*, 2020). While disability has been an indicator component in National Census and General Household Survey data since 1996, the use of differing definitions and screening tools had made it difficult to compare information sources.

Currently there is a lack of data on the nature and prevalence of disability in SA. Previously this was due to disability being viewed solely within a health and welfare framework which led to the failure to integrate disability into mainstream governmental statistical processes. Furthermore, it is noted that the Census Profile of persons with Disability (2011) is not comparable with previous data as the definition of disability differs to that which was formerly adopted (Statistics South Africa, 2011b). The challenge centres on how people with disabilities are identified as well as the identification of persons that require rehabilitation. The survey adopted a short set of questions from Washington Group on Disability Statistics which limit disability to r domains of “seeing, hearing, learning, self-care, participation and walking”, and not including persons with other disabilities, as well as children under the age of five. These questions do not capture the diversity of the disability with regards to types, degree and environmental factors placing limitations on the statistics available for research.

Sources of data that can be used to extrapolate disability data range from national surveys to some routine data though methodological differences make aggregation and comparisons difficult. Statistics South Africa (Statistics South Africa, 2011b) has applied three measures in reporting the data from the 2016 Community Survey:

- a broad measure, which includes every person who reported “some difficulty”, “a lot of difficulty” or “unable to do” in any of the six domains;
- a United Nations (UN) measure, which includes persons with at least “some difficulty” in any two of the six domains, and persons who reported “a lot of difficulty” or “unable to do” in any of the six domains;
- and a restrictive (or severe) measure, which includes persons who reported “a lot of difficulty” or “unable to do” in any of the six domains.

There remains untapped potential for data on patient experience and levels of satisfaction through routine patient satisfaction surveys conducted in health facilities as part of the Ideal Clinic initiatives (Department of Health, 2017a) for improved quality of care. In a section of the survey dedicated to patient safety, patients visiting health facilities as out-patients are asked if they have a form of disability for which they require assistance. While it is promising that surveys like this include questions on disability and accessibility, there is a missed opportunity to engage with persons with disabilities about their expectations and unmet needs. This is particularly important in light of generally positive levels of satisfaction found in population level surveys of patient satisfaction (Jacobsen & Hasumi, 2014) which do little to provide meaningful determinations of whether services are in fact of good quality and responding to the needs of service users.

2.4 Section C: “Continuity of Care” and why it matters to persons with disabilities

Interest in the term “*Continuity of Care*”, is fast gaining attention within the field of health systems research. It is cited as a powerful dimension in the delivery of patient-centred care and is especially beneficial to patients with complex healthcare needs (Alazri *et al.*, 2007) as well as

persons with disabilities. “Continuity of Care” is often expressed as the development of a “*trusting relationship*” between the healthcare practitioner and patient (Forbes A *et al.*, 2001) with research demonstrating its influence on patient-focussed outcomes (Guthrie, Saultz, Freeman, & Haggerty, 2008; Haggerty *et al.*, 2003; Sturmberg, 2003; Sudhakar-Krishnan & Rudolf, 2007; While *et al.*, 2004).

The term generally refers to the management and treatment of health conditions over time (Sudhakar-Krishnan & Rudolf, 2007; Sweeney, 2016; Ware, Tugenberg, Dickey, & McHorney, 1999) with the emphasis placed on the longitudinal and consistent caring relationship of an individual with his/her healthcare provider or team of healthcare providers. When practiced, “Continuity of Care” is cited as being positively associated with improved patient satisfaction and improved health outcomes particularly for vulnerable populations (Al-Azri, 2008; Alazri *et al.*, 2007; Coleman, 2003; Crawford & Thornton, 2017; Pinto *et al.*, 2017) and those with complex or chronic medical conditions (Coleman, 2003).

“Continuity of Care” is also defined as the coordination and delivery of services by different providers in a coherent, logical, and timely fashion where the emphasises is on the content of care protocols or management strategies, with relatively less attention paid to the “trust” relationship between the health service provider and patient (Haggerty, Roberge, Freeman, & Beaulieu, 2013). Schultz (2012) found similar patterns, but also found that there was a positive relationship between interpersonal continuity of care and patient satisfaction (Schultz, Delva, & Kerr, 2012) meaning that people tend to maintain their treatment programmes when they find a comfortable fit with a healthcare provider who understands their needs.

There are a variety of definitions for “Continuity of Care” which range from the basic availability of information about a patients past medical history to the complex interpersonal

relationship between the health professional and the patient, characterised by trust and a sense of mutual responsibility (Hill, House, & Hewison, 2008). There appears to be some agreement around how “Continuity of Care” should be defined. In general, the definition should capture the longitudinal element of care, should refer to patients and should incorporate the context of care provided (i.e. acute versus primary or across different providers).

The literature mostly refers to three basic types of continuity; 1) *Informational continuity*, 2) *Management continuity* and 3) *Relational continuity* (Guthrie *et al.*, 2008). According to Guthrie *et al* (2008), they can be defined as follows:

1. **Informational continuity**: when formally recorded information is complemented by tacit knowledge of patient preferences, values, and context that is usually held in the memory of clinicians with whom the patient has an established relationship.
2. **Management continuity**: described as the shared management plans or care protocols, and explicit responsibility for follow-up and coordination that provide a sense of predictability and security in future care for both patients and providers.
3. **Relational continuity**: which is built on accumulated knowledge of patient preferences and circumstances that is rarely recorded in formal records and interpersonal trust based on experience of past care and positive expectations of future competence and care. It is the therapeutic relationship between a patient and 1 or more clinicians that “bridges episodes of care and provides coherence through clinicians growing comprehensive knowledge of the patient and is most valuable at primary care” (Haggerty *et al.*, 2013).

Experts in the field (Schang, 2013) describe five distinct themes that can facilitate the understanding of the concept. The first theme describes “Continuity of Care” at the level of **individual**, which is care received and experienced by individuals over time. The second describes

“Continuity of Care” as **longitudinal** or care delivered to an individual over time. **Sustained and consistent** care is used to explain discrete service elements that complement each other within a coherent management plan and finally **information and information transfer** which refers to accumulated knowledge of the patient as well as transfer of patient information from one provider to another. All three have direct relevance to the provision of adequate and continuous healthcare for persons with disabilities but there are also “break points” that have been defined (Haggerty, 2001) which may occur for the patient (e.g. life cycle transition), for the provider (e.g. informal to formal care); and within the system (e.g. restructuring).

2.4.1 Primary healthcare and “Continuity of Care”

PHC and “Continuity of Care” are inextricably linked. As a gateway to healthcare, PHC principles represent an important pathway for people to access the range of preventative, promotive, curative, rehabilitative and palliative care services they may require across a lifespan. It is a complex level of the health system, with multiple providers and expansion of care into communities, and to higher levels of more specialised care through referral networks. This dynamic setting requires a range of operational and clinical mechanisms to ensure that service delivery is both seamless and coordinated for effective therapeutic outcomes. As mentioned in section 2.3.5, there is renewed focus on the delivery of people-centred PHC services that are sensitive to the needs of people and made available as close to where they live (World Health Organization, 2018c). Without good “Continuity of Care” many people accessing services through the primary healthcare system will experience fragmented and poorly integrated care.

For people such as persons with disabilities and those with chronic conditions, PHC “Continuity of Care” is vital to ensure that risks of harm due to poor relational, informational and

management continuity are minimised (World Health Organization, 2018a). There are seven shared principles of primary care which consist of care that is: (1) person and family centred, (2) continuous, (3) comprehensive and equitable, (4) team based and collaborative, (5) coordinated and integrated, (6) accessible, and (7) high value. When used together, these shared principles provide a solid platform on which to build all further health care reform (Epperly, 2019).

Starfield further describes four key functions of PHC which each consists of a structural aspect and a behavioural manifestation. Person-focused care involves the definition of a practice population and manifestations of interpersonal relationships that indicate a person focus (Starfield & Horder, 2007). The other three features are first-contact use, which involves accessibility and use by the population of services at the first realisation that care is needed; comprehensiveness, which requires the structural component of availability of resources to meet all common health-related needs of the population, and the provision of services to meet those needs without referral; and coordination, which requires a mechanism that facilitates information transfer about patients' health needs, and health care as well as the recognition of that information in the care of the patient over time (Starfield, 2011).

2.4.2 Trends and gaps in research on “Continuity of Care”

“Continuity of Care” is a fairly new but rapidly developing area of health services research. A basic scoping search using the following MESH terms on the PubMed database "Continuity of care" OR "longitudinal continuity" OR "relational continuity" OR "management continuity" OR "information continuity" AND "disability" AND "adults" limited to the past 10 years (2014-2024) produced 36 studies of which 9 were found to have appropriate relevance to continuity of care outcomes for persons with disabilities. Further refined searches targeting specific health conditions

revealed additional studies focused on various aspects of “Continuity of Care” and related outcomes. Only two studies were found to have been conducted in SA. The trend in research in this area appears to be focused on transitional care from youth to adult services for specific disabilities, and scoping reviews with an aim to establish model of care or best practices in care coordination for persons with complex healthcare needs.

2.4.3 Research on transitional care

In an evaluation of healthcare outcomes (“Continuity of Care” and healthcare utilization) for clients enrolled in LIFEspan (“Living Independently and Fully Engaged”), participants demonstrated significantly greater “Continuity of Care” (45% had engagement with adult services in the year following discharge at 18 years), compared to the prospective SB group (14%) (Kingsnorth *et al.*, 2021). The LIFEspan is a linked transition service model for youth and young adults with childhood-onset disabilities offered via an inter-agency partnership between two rehabilitation hospitals (one paediatric and one adult) in Toronto, Canada.

Hewner *et al.*’s (2021) study found that care coordination and case management were the primary strategies used to address the care needs of High Need, High Cost (HNHC) adult patients. Their recommendations were to efficiently identify and direct HNHC patients to the most appropriate resources given that technology support for coordination of care in this group was suboptimal. It was further recommended that care management interventions evolve to bridge multiple health care settings and community-based organizations through communication and collaboration. Continuity of care was seen to be vital during the immediate post discharge period, however, tracking of continuity was not adequate for the need.

Sharma and colleagues (2014), in their assessment of Transition Care, proposed the need for research to be integrated into transition curricula at the undergraduate, graduate, and postgraduate levels, as well as financial incentives offered for and piloting of the Accountable Care Organizations ACO model in centres providing care to youth during transition. Defined outcome measures for transition research and the need to study effectiveness of current transition tools on improving these outcomes were also recommended (Sharma, O'Hare, Antonelli, & Sawicki, 2014).

2.4.4 Research on primary healthcare and “Continuity of Care”

Most of the research in the field of “Continuity of Care” has been conducted in the United Kingdom, the United States of America and Canada (Haggerty *et al.*, 2013). There were few studies conducted in developing countries, although a more comprehensive search may be required as the finding may be due to publication and language bias. Most of the current published literature focusses on patients with chronic care conditions, stroke patients, patients with mental health conditions or intellectual disabilities and those who are receiving cancer therapy.

Twelve studies researched “Continuity of Care” in the context of PHC or the family physician. An evaluation conducted in Canada examined the relationship between the level of continuity and subsequent emergency department (ED) visits for adults with and without intellectual and developmental disabilities (IDD). The population-based cohort study found that individuals with IDD were more likely than individuals with no IDD to visit the ED (33.96% versus 20.28%, $p < 0.0001$). For both groups receiving greater continuity of primary care was associated with less ED use, but this relationship was more marked for adults with IDD (Durbin, Balogh, Lin, Wilton, & Lunskey, 2018). The authors concluded that “Continuity of Care” was a

higher priority for individuals with IDD whose cognitive and adaptive impairments may complicate help-seeking, diagnosis, and treatment. This study provided strong evidence for the role that primary care “Continuity of Care” can have in complex populations.

Information continuity and adaptations to how patient histories are taken was found to be important for patients with IDD. A study focusing on the factors inherent in caring for patients with IDD found that initial assessments that identified genetic or neurologic conditions to guide anticipatory care and isolate unique barriers to health promotion and chronic disease management was required. Clinicians needed to adapt history taking in light of cognitive deficits, overcome challenges to performing physical examinations and certain investigations, as well as uncertainty in the formulation of hypotheses to establish an appropriate diagnosis. It was also recommended that resources of the developmental services sector be provided as part of a management plan as well as an adapted empathetic approach in order to integrate the patient’s illness experience (Grazier, Smith, Song, & Smiley, 2014). Similar findings were reported by Birnkant and Chambers when researching the assessment and management of Duchenne muscular dystrophy in various healthcare settings, including primary care, where the issue of transitions of care was found to be important but required substantially more research and the allocation of more medical, psychosocial, and societal resources (Birnkrant & Street, 2018).

Only one study (McNeil *et al.*, 2018) was found to focus on health information and its impact on “Continuity of Care”. McNeil, Gemill, Abells *et al.* (2018) investigated health information exchange (HIE) processes that affect the health of people with IDD with a view to proposing practical tips and strategies for communicating, collaborating, and coordinating in the primary care setting. Disparities were found to exist between the provision of health care for the general population and that for people with IDD (McNeil *et al.*, 2018). These disparities were due

in part to gaps in HIE. They proposed the framework of the Patient's Medical Home to facilitate improvements in communicating, collaborating, and coordinating health care that can be implemented by family physicians in order to narrow the gaps in care that exist for people with IDD (McNeil *et al.*, 2018).

Relational continuity is an aspect of "Continuity of Care" which pivots off continuous and trusting relationships. In many contexts primary healthcare is often associated with nurse led delivery of care. An Australian-led systematic review of the effectiveness of nurse-led services for people with chronic disease found that hospitalizations were reduced by 2-8.9% and re-admissions by 14.8-51% (n=886) (Davis *et al.*, 2021). This demonstrates the effectiveness of nurse-led services in the "Continuity of Care" at the primary-secondary healthcare interface. Additional outcomes of nurse led services were positive patient experiences as well as improvement in symptoms and lifestyle (Davis *et al.*, 2021).

Sullivan and Heng's (2018) literature review also highlighted the important role of good relational continuity of care. The review focused on the issue of supporting adults with intellectual and developmental disabilities to participate in healthcare decision making. Their key findings were that person-centred health care of adults with IDD should include all possible contributions from the patient in decision making with acknowledgement that legal criteria do not address the relational aspects of decision making that are important for adults with IDD (Sullivan & Heng, 2018). The 2018 "Canadian consensus guidelines" on decision-making capacity, and how to implement the recommendations was found to incorporate decision making as a collaborative exercise in which the patient, trusted caregivers, and the family physician all are involved in deciding on medically appropriate interventions that promote the patient's goals or values (Sullivan & Heng, 2018). Their findings contributed to the revised guideline 3 of the "Primary care

of adults with intellectual and developmental disabilities (IDD)” (Sullivan, Heng, Salvador-Carulla, Lukersmith & Casson (2018).

Two studies conducted in SA were found. The first, conducted in the Western and Eastern Cape provinces, assessed access to health care for people with stroke in SA qualitatively through community perspectives (Smythe *et al.*, 2022). Complex care pathways, stroke-related physical mobility issues, large travel distances and few transportation options, lengthy wait periods, and out-of-pocket costs were found to be obstacles to receiving stroke care. Attitudinal and information barriers, and cultural beliefs all affected how well services were viewed (Smythe *et al.*, 2022). Even though there were records of positive staff attitudes, various technical and interpersonal deficiencies, such as lengthy waiting times and unfavourable staff attitudes, were linked to perceived competence and trustworthiness, which in turn led to low satisfaction and supposedly bad outcomes in this population. (Smythe *et al.*, 2022).

The second was a qualitative study following a four-month randomised controlled trial of a Home-Based Rehabilitation (HBR) intervention designed specifically for Person living with HIV in KwaZulu-Natal (Cobbing, Chetty, Hanass-Hancock, & Myezwa, 2017). Four Community Care Workers (CCW) were interviewed to obtain their experiences of being involved in carrying out this intervention. The findings highlighted the potentially important roles that HBR provided by CCW play in ensuring access to HIV patients who are also known to be at high risk for disabilities (Cobbing *et al.*, 2017). The issue of task shifting was a key finding and one that was particularly important for the SA as its practical implementation held value in alleviating resource constraints associated rehabilitation service delivery.

2.4.5 Tools and measures of “Continuity of Care”

A number of tools exist to measure “Continuity of Care” and most measures focus on a single type of continuity. Very few tools exist that aim to assess how patients transition between healthcare settings or how continuity is managed when patients move from one professional in a particular discipline to another (Reid, 2002). According to Reid (2002) while there are a number of tools that measure the various aspects of “Continuity of Care”, there does not appear to be just one single measure that captures the concept of continuity and their role in maintaining “Continuity of Care”(Reid, 2002).

In a study by Schultz (2012) patient satisfaction surveys were found to be the primary tool for measuring interpersonal or relational continuity, however; no tool exists to capture the connection between physician and patient. Measures of informational continuity include evidence of information transfer where patient transfers are compared to medical records (Schultz *et al.*, 2012).

In South Africa, Patient Satisfaction Surveys (Department of Health, 2020a) are routinely used to gather information on experiences of care at health facilities across the health system. Questions on disability have recently been included in the questionnaire however, measures of “Continuity of Care” do not appear to be included. How these surveys are administered particularly to persons with disabilities is uncertain.

2.4.6 Conceptual framework used in the study

The Human Rights Model for disability, was adopted for the study with acknowledgement of some of the weaknesses and critiques it encounters. The Human Right to Health is protected in:

- Article 25 of the Universal Declaration of Human Rights
- Article 12 of the International Covenant on Economic, Social and Cultural Rights
- Article 24 of the Convention on the Rights of the Child
- Article 5 of the Convention on the Elimination of All Forms of Racial Discrimination
- Articles 12 & 14 of the Convention on the Elimination of All Forms of Discrimination Against Women
- Article 25 of the Convention on the Rights of persons with disabilities

Human rights are fundamental rights. They cannot be gained or taken away from an individual or a group. They are acquired qua birth and are universal, i.e., every human being is a human rights subject. Neither social status, nor identity category, nor national origin or any other status can prevent a person from being a human rights subject. Therefore, human rights can be called unconditional rights. (United Nations General Assembly, 10 December 1948, p. 15)

In a colonially influenced world, one critique of the human rights model relates to the notion that all people are considered or treated as human is not the reality and that systemic structures built into society preclude the attainment of human rights. This is particularly true of the Apartheid era in South Africa where dominance of White South Africans in positions of power proceeded to limit the rights of Black, Indian and Coloured race groups. The need to constantly reflect on the historical context and the legacy of the apartheid regime on access to health services and the ability to achieve health in a post-apartheid context, forms an important aspect in decisions about the research paradigm and methodology.

In democratic SA, Section 27 of Bill of Rights in the South African Constitution (Republic of South Africa, 1996) states that

(1) Everyone has the right to have access to— (a) health care services, including reproductive health care; (b) sufficient food and water; and (c) social security, including, if they are unable to support themselves and their dependents,(d) appropriate social assistance.

(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.

(3) No one may be refused emergency medical treatment. (Republic of South Africa, 1996)

Achieving health equity and fulfilling the UN's mandate for "Health for All" require that health policies respect fundamental principles of human rights and include disadvantaged populations (Amin, 2011). This study's investigation of "Continuity of Care" as concept of healthcare quality and person-centred care can also be framed against this basic human right to health (Amin, 2011) as it involved understanding the concept in relation to a vulnerable group, namely, persons with disabilities.

Being able to critically reflect on the past and the historical roots of inequity and how these are addressed post democracy is another feature that underpins this study conceptually and forms the backdrop of the study context. This policy-practice lens is central to ensuring that context, policy and practice are given consideration and viewpoints at the nexus between service provider and service user (Walt *et al.*, 2008). Reflecting on healthcare policies reveals how they influence how we see the overall, value-laden path of a health system, but an examination of their

implementation sheds light on which values are prioritised over others. How persons with disabilities are included in the development and implementation of various policies shape their experience within the health system and therefore it is important to use policy analysis constructively to course correct and plan appropriately (Walt *et al.*, 2008).

Practice in the context of this study, relates to what health care providers think about the needs of persons with disabilities and what they do (or not do) to address these needs. How this plays out within a PHC setting would have direct relevance to understanding some of the opportunities and challenges to improving the management of persons with disabilities. In investigating PHC practice and its influence on “Continuity of Care” for persons with disabilities a broader ecological health systems approach was considered. “Continuity of Care” relates to how a person experiences care over time and depends largely on a dynamic interplay between service user and service provider in order to ensure coherent and linked care over time.

The successful implementation of “Continuity of Care” is linked to aspects of healthcare quality (World Health Organisation, 2018), key of which is the issue of Person-centered care (World Health Organization, 2018a) which is the ability of a responsive health system to demonstrate responsiveness. It serves to reason that a genuine understanding of “Continuity of Care” would require a broad enough conceptual lens to capture the interplay between actors involved in the process of service design and delivery and those and recipients of these services.

With this in mind, the Mirzoev & Kane (2017) model was found to be appropriate for this study (Mirzoev & Kane, 2017). Rooted in concept of responsiveness, Mirzoev and Kane’s 2017 model postulates that responsive health systems anticipate and adapt to existing and future health needs, thus contributing to better health outcomes. The model was adopted for this study as it provided a valuable lens through which the following perspectives could be explored:

1) It interrogates the experience of people's interaction with their health system, which confirms or disconfirms their expectations of the system.

2) It allows for the investigation of how the experience of interaction is shaped by both the people and the health systems sides of this interaction.

3) It provides for a third dimension to be explored; i.e. different influences that shape people's interaction with their health system, and ultimately affecting their resultant experiences.

Therefore, recognition of the ecological components of the service users and providers including their key determinants would enhance the conceptualisations of responsiveness. As illustrated in Figure 4, their framework builds on, and advances, the core frameworks in the health systems literature, positions the experience of interaction between people and health system as the centrepiece, and recognises the determinants of responsiveness experience both from the health provider (e.g., actors, processes) and service user perspectives (e.g., initial expectations) sides (Mirzoev & Kane, 2017).

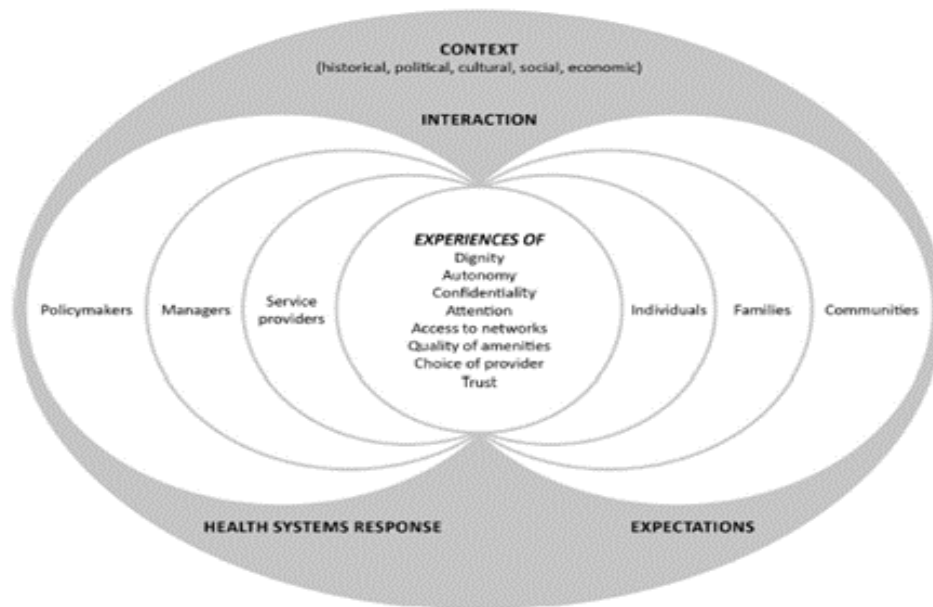


Figure 4. Health Systems Responsiveness Framework (Mirzoev & Kane, 2017)

“Continuity of Care” is a result of complex interactions based on responsiveness of anticipated needs of a population and is considered as an important objective of health systems. The conceptual framework offered by Mirzoev and Kane provides three perspectives of health systems responsiveness. First of all, being responsive means that individuals must actually interact with their health system in order for their experiences to validate or invalidate their preconceived notions about it. Second, the individuals involved in the interaction as well as the health system both influence the experience of the interaction. Third, a variety of factors determine how people engage with their health system, which in turn influences the experiences they have as a result (Mirzoev & Kane, 2017)

Mirzoev and Kane’s (2017) conceptual framework was adopted for this study as it enables an exploratory approach for systematic and in-depth analysis of a variety of perspectives in an attempt to uncover how the health system and policies shape PHC practice and respond to the perceived and real healthcare needs of persons with disabilities. This Framework underpins the

methodological considerations and decisions taken in this study which are further described in the next chapter. It is important to note that the framework was used with flexibility in order to facilitate appropriate application of this framework in a context of SA which is vastly different from the western concepts of a health system and with due consideration for the unexpected. Principally, the Mirzoev and Kane Framework was used to ensure that as the phenomenon of “Continuity of Care” was researched in a holistic and comprehensive way with due consideration policy, context and the nature of the exchange between healthcare provider within the South African primary healthcare system.

2.5 Summary of chapter

In conclusion, thus chapter provided the reader with aspects of “Continuity of Care” literature relevant to this study. It provides an argument for the significance of “Continuity of Care” in the delivery of Primary healthcare and its relevance to persons with disabilities who also have chronic conditions. These issues have been contextualised within planned health system reforms for South Africa. The dominance of research conducted in developed and well resources countries is highlighted as the conceptual framework proposed by Mirzoev and Kane (2017) which is adopted in this study was introduced.

Chapter 3: Methodology

3.1 Introduction

This chapter discusses the study methodology, beginning with the primary research question and a presentation of the main aim and objectives. This is followed by a description of the research paradigm, the ontological and epistemological approach, the study design, study methods, analytical techniques and scientific rigor that was applied to the study. The chapter concludes with a summary of the ethical procedures that were followed throughout the conduct of the study and reflections of the researcher's personal journey during the design and conduct of the study.

3.2 Research question

How can “Continuity of Care” for persons with disabilities be strengthened within the PHC context in South Africa?

3.2.1 Aim

To explore factors influencing “Continuity of Care” for persons with disabilities within the PHC context and develop a conceptual framework to inform and strengthen its implementation.

3.2.2 Objectives

1. To explore the *experiences* and *expectations* of persons with disabilities regarding “Continuity of Care”;
2. To conduct an analysis of relevant policies governing PHC in SA in terms of its influence on disability inclusion and “Continuity of Care” for persons with disabilities;

3. To explore health systems responsiveness to the expectations of persons with disabilities as it related to their PHC “Continuity of Care”.

3.3 Research paradigm

“For the master’s tools will never dismantle the master’s house.” (Laude, 1984)

A research philosophy represents the researcher's world view and understanding of truth, reality, and knowledge (Guba & Lincoln, 2005). It delineates the principles and values that influence the planning, data collection, and analysis in a research study, aligning with overarching philosophical principles (Ryan, 2018). With a natural affinity towards unearthing deeper meaning, injustice and power imbalances, the value of the **critical paradigm** became apparent to the researcher in its alignment with what the study sought to achieve. This study was conducted in a post-apartheid context which required careful unpacking of political influences to the phenomenon under investigation such as marginalisation, power imbalances and complex legacies of colonialism (Todic *et al.*, 2022). The true appreciation of the critical paradigm and its theory of transformation and emancipation came together during fieldwork where it became obvious that

Item	Positivism	Postpositivism	Critical Theory <i>et al.</i>	Constructivism
Ontology	Naïve realism—“real” reality but apprehensible	Critical realism—“real” reality but only imperfectly and probabilistically apprehensible	Historical realism—virtual reality shaped by social, political, cultural, economic, ethnic, and gender values; crystallized over time	Relativism—local and specific constructed and co-constructed realities
Epistemology	Dualist/objectivist; findings true	Modified dualist/objectivist; critical tradition/community; findings probably true	Transactional/subjectivist; value-mediated findings	Transactional/subjectivist; created findings
Methodology	Experimental/manipulative; verification of hypotheses; chiefly quantitative methods	Modified experimental/manipulative; critical multiplism; falsification of hypotheses; may include qualitative methods	Dialogic/dialectical	Hermeneutical/dialectical

Figure 5. Basic beliefs (metaphysics) of Alternative Inquiry Paradigms (Guba & Lincoln (2005))

Paradigms of knowledge and its generation can be viewed as an important axis of power and is made up of ontology, epistemology, methodology and methods (Scotland, 2012). The characteristic trait of the critical paradigm is its ability to disrupt the status quo (Kincheloe & McLaren, 2011), which was felt to be the appropriate path to take for this study as the aim was to focus on a persons with disabilities in relation to the poorly understood concept (“Continuity of Care”) with a view to elevate voices of the marginalised in an emancipatory way. Critical theorists challenge established ideas of democracy, freedom, opportunity, and social justice in order to expose oppressive power structures, such as political institutions that uphold them (Kincheloe, McLaren, Steinberg, & Monzó, 2018).

The researcher aligns with Todic *et al.*’s (2022) proposition that actors within a health system must develop the capacity to recognise manifestations for historical legacies of apartheid and reflect on the factors that serve to exacerbate health inequities (Todic *et al.*, 2022). As an actor in the health system, the researcher felt the need to use the study to achieve this goal, creating an explicit lens through which “Continuity of Care’ could be investigated in a manner that illuminated power imbalances and social structures. This was viewed as an important component of addressing inequity and highlighting Todic *et al.*’s (2022) view that healthcare interventions often ignore structural dynamic which are structural, economic and political, social and cultural which lead to deeper inequity.

This study, also falls within the social science domain and supports the objectives of the newly formed field of health policy and systems research (HPSR), which aims to comprehend and enhance the ways in which societies organize themselves to achieve collective health goals and the ways in which various actors interact during the policy-making and implementation processes to influence policy outcomes. (Gilson, 2012). The focus of this study falls within the scope of

HPSR where the phenomenon under exploration, in this case “Continuity of Care”, would benefit from a broad analytical lens beyond that of a specific health programme allowing for inclusion of the complexity of systems thinking (Martínez-García & Hernández-Lemus, 2013; World Health Organization, 2007).

The epistemological approach adopted is that of *critical social theory* as it plays a crucial role in shaping HPSR by providing a framework that goes beyond traditional analyses, encouraging a deeper understanding of the social, political, and economic factors that influence health (Gilson, 2012). *Critical social theory* recognises the influences of power dynamics, marginalisation and innovation (Weaver & Olson, 2006) prevalent when dealing with vulnerable populations like persons with disabilities and the different categories of healthcare providers. *Critical social theory* is a perspective that challenges existing social structures, aiming to uncover and address power imbalances and promote social justice and transformation. It encourages a critical examination of the assumptions underlying social phenomena and seeks to empower individuals and marginalized groups (Kincheloe *et al.*, 2018).

An approach to changing society for the better, Cuellar (2022) defines *Critical social theory* as an approach that can impact laws and policies, communities, and countries as it compels one to view an issue from a different perspective and in a manner that may lead to a shift in thinking and understanding (Cuellar, 2022). *Critical social theory* takes into consideration the political, social, historical and cultural factors influencing practice and provides an opportunity to take emancipatory action towards change. In relation to “Continuity of Care” Social critical theory as described by Todici aligns well with the concept of responsive health systems (Todici *et al.*, 2022). Starfield (2009) acknowledged the importance of person-centered responsiveness to the delivery of comprehensive and coordinated primary care services and postulated that primary care, is the

place where needs are best recognized and also where equity in health services is attained (Starfield, 2009).

“Continuity of Care” as the phenomenon of interest is conceptually bounded to person-centeredness and responsiveness. In light of this, Mirzoev and Kane’s Framework for Health Systems Responsiveness (Mirzoev & Kane, 2017) was aptly chosen as the conceptual framework for this study allowing for 1) for the creation of knowledge within a critical social paradigm, and 2) the interplay between the subject and the object as illustrated in Figure 6. In this regard, “Continuity of Care” is investigated through the lived realities of persons with disabilities, but also uses critical social theory to unpack these experiences against a transforming healthcare context.

The Mirzoev and Kane’s Health Systems Responsiveness Framework (Mirzoev & Kane, 2017) adopts a health systems framework which was deemed appropriate for this as it guides the layering of insights across multiple dimensions of reality and lived experiences aiming to make sense of the observable reality and uncover the underlying issues within the parameters of a system. Table 2 below, provides a high-level summary of the ontology, epistemology, methodology and methods adopted in this study which are further expanded in the sections to follow. Fig 6 below illustrates how critical theory (Guba & Lincoln, 1994) underpins the conceptual framework which guides the methodological considerations in the study.

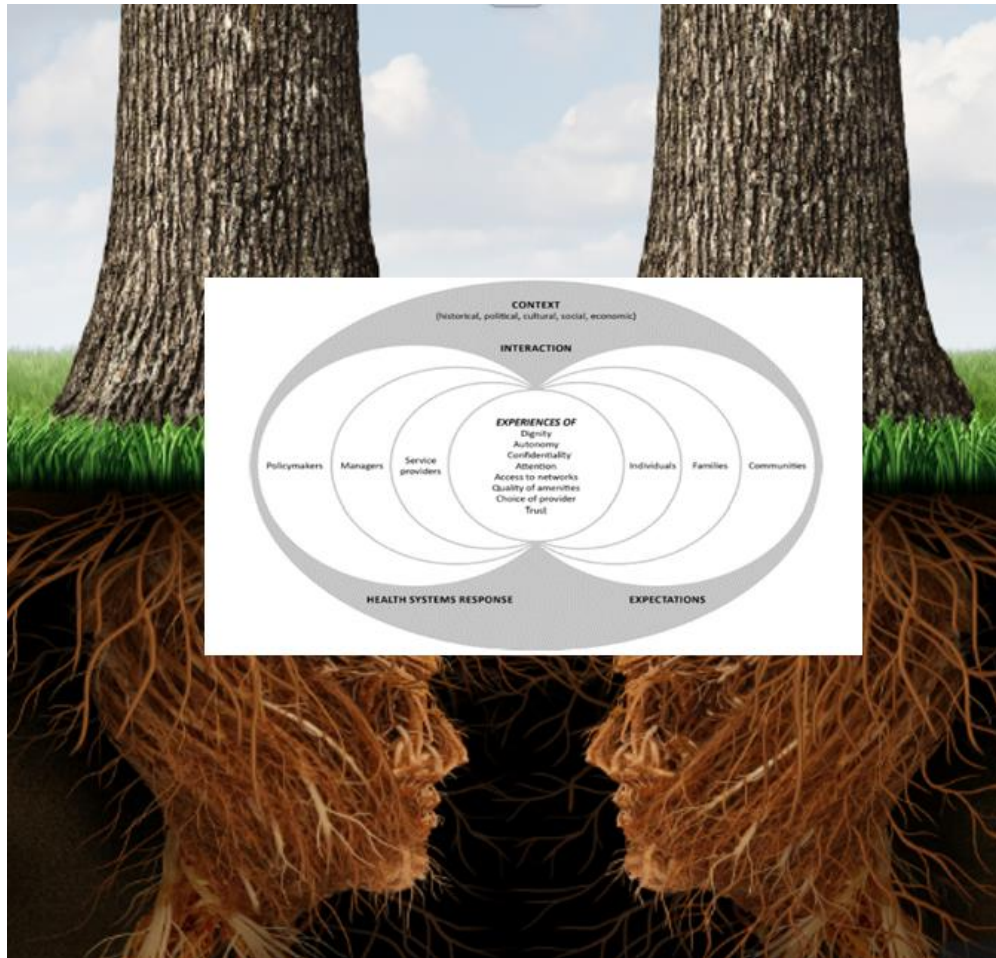


Figure 6. Illustration of critical social theory underpinning the conceptual framework and study design

Finally, an element of pragmatism was warranted in this study as many factors were not known and the context was dramatically shifting during the course of the study due to natural disasters, political unrest and the global COVID 19 pandemic, the effects of which are detailed in Chapter 5.

3.4 Research design

A qualitative exploratory case study approach (Baxter & Jack, 2015; Yin, 2012) using a Health Systems Responsiveness Framework (Mirzoev & Kane, 2017), and underpinned by critical social theory (Kincheloe & McLaren, 2011; Weaver & Olson, 2006) was adopted for this study. Yin (2012) proposes that this kind of study be undertaken to explore situations where the intervention being evaluated has no clear, single set of outcomes. Given that outcomes for “Continuity of Care” were assumed to be diverse and non-linear, an exploratory case study designed was appropriate. In this way the case study could achieve in-depth understanding of factors that influence “Continuity of Care” for persons with disabilities, with the required depth and critical reflection within a real-world context. Table 1 below provides a breakdown of the ontology, epistemology, methodology and methods of the study at a high level.

Table 1. Study ontology, epistemology, methodology and methods

	Ontology	Epistemology	Methodology	Methods
A case study of factors influencing primary healthcare “Continuity of Care” for persons with disabilities	Critical Theory (Guba & Lincoln, 1994; Guba & Lincoln, 2005)	Critical social theory	Exploratory case study	Various methods including document and policy reviews, key informant interviews, FGD, observations and reflective journals

Creswell (2009) asserts that the research design is informed by the conceptual framework and outlines the plan for the collection, measurement and analysis of data (Creswell, 2009) Studies that are qualitative in nature should adhere to systematic and deliberate sets of processes to guide

the research process (Grover, 2015). In contrast to quantitative research designs where “factual” data is required to answer a research question, qualitative designs are used to answer questions about experience, meaning and perspective. The use of qualitative designs in health policy and systems research is popular as it allows for nuanced understanding of phenomena within complex systems (Gilson, 2012).

The value of qualitative research has been gaining traction and popularity. The debate no longer revolves around whether it adds value, but rather about how value can be assured by enhancing rigour (Barbour, 2001). The Cochrane Qualitative Research Methods Group acknowledges the important role of qualitative research in adding value to systematic reviews for policy, practice and consumer decision-making (Noyes, Popay, Pearson, Hannes, & Booth, 2008).

To this end qualitative research in health policy and systems research is valuable as it is positioned to penetrate to the deeper significance of the research subject (Hammarberg, Kirkman, & de Lacey, 2016). In a recent commentary in The Lancet Regional Health-Western Pacific journal, qualitative research was highlighted for its utility in health system strengthening and highlighted its appropriateness as a method to *“understand “how” norms and stakeholders influence the design and function of health systems, “why” intended outcomes are achieved or are not achieved, and “what” the unintended outcomes are”* (Long & Jiang, 2023, p. 1).

Qualitative research designs involve complex theoretical and philosophical frameworks (Hammarberg *et al.*, 2016) that interrogate multiple perspectives. In adopting a Health Systems Responsiveness Framework (Mirzoev & Kane, 2017), the study was deemed to be amenable to qualitative research enquiry as experiences and perspectives of healthcare providers and recipients of healthcare were the focus of the study.

Yin (2009) defines a case study as “*an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident*”. (Yin, 2009, p. 4). Case studies is viewed by Creswell (2013) as a valuable method for providing an in-depth understanding of complex phenomena (Creswell, 2013). He argues that case studies are especially appropriate when researchers need to answer "how" and "why" questions and when the focus is on a contemporary phenomenon within its real-world context (Creswell, 2013). Similarly, Flyvbjerg, emphasizes the importance of using case studies for understanding social phenomena in their natural context, particularly when the research goal is to explore the deeper meanings and complexities of human behaviour. Flyvbjerg argues that case studies allow researchers to delve into the richness and complexity of a particular situation and highlights the value of thick descriptions and detailed analyses, asserting that case studies are particularly effective when dealing with intricate, context-dependent social issues (Flyvbjerg, 2011). Yin emphasizes the utility of case studies in explaining complex social phenomena and generating rich, context-specific insights all of which are particularly suitable for exploratory research and when researchers have little control over the events.

There is debate about whether a case study is considered a method or a method of data collection but Yin (2009) proposes that is a research strategy or design to study a social unit (Yin, 2009). In case study research, multiple methods of data collection are used, as it involves in-depth investigation of a phenomenon. Yin (2009).

An exploratory case study approach (Yin, 2012) was used for this study as it was found to align well with Mirzoev & Kane’s (2017) conceptual framework of health systems responsiveness and provided the flexibility to use a variety of methods to obtain deeper insights about “Continuity of Care” from a variety of perspectives. The case study approach also allowed for such an

investigation to be conducted in a natural real-life context where the boundaries between phenomenon and context are not clearly evident” (Yin, 2012).

Defining the boundary of a case study is an important aspect of case studies (Yin, 2009). The case study boundary for this study was defined as the smallest function unit of PHC implementation in SA – **a ward**. In the context of SA, the term "ward" can have different meanings depending on the context in which it is used. Within a municipality, a ward is a defined region or subdivision used for administrative purposes (Department of Cooperative Governance and Traditional Affairs, 2020). It is an administrative division inside a municipality that is in charge of offering residents with a variety of services, including health care.

Health facilities and services within a municipality may be organized or distributed based on the ward structure (Khuzwayo & Moshabela, 2017). The re-engineering of PHC plays a crucial role in the NHI framework as the implementation pivots of a ward structure PHC outreach teams at the ward level. Municipalities through ward committees often engage with communities at the ward level to understand local needs and concerns (Thornhill, 2011). This engagement may include discussions about health priorities and services required within the community (Khuzwayo & Moshabela, 2017). Primary healthcare is administered through the primary healthcare platforms of community health clinics (CHCs) and primary healthcare facilities also known as clinics (Department of Health, 2018). These clinics serve the community of a particular ward and as such has a clearly demarcated population allowing for planned services. The study boundary being the ward allowed for a functional analysis which incorporated the facilities, the community and the resources within it.

The exploratory design of the study was conceptualised within a health systems framework (Mirzoev & Kane, 2017) which was deemed appropriate to answer the research question about a

contemporary concept (“Continuity of Care”), still fairly under-researched and poorly understood, within a marginalised and under-represented group in a fairly unpredictable, dramatically changing real-life context (Yin, 2009). This qualitative exploratory case study focused on examining “Continuity of Care” for persons with disabilities within Ward X, where the pattern of inequity, poverty, inequality and political instability is understood to be similar to other wards in the greater Durban area.

The backdrop of the study was a healthcare context poised for major transformation to achieve universal health coverage and the interest was a particular population group and their experiences of the phenomenon under investigation, i.e. “Continuity of Care”. The parameter of the case is the primary healthcare journey taken by the Person with a Disability with a critical reflection on what path deviates relevant policies and what the underlying factors are that influence the journey. Figure 7 below provides a broad overview of the research design in terms of the components of the Conceptual Framework, the data collection methods and analytical approach.

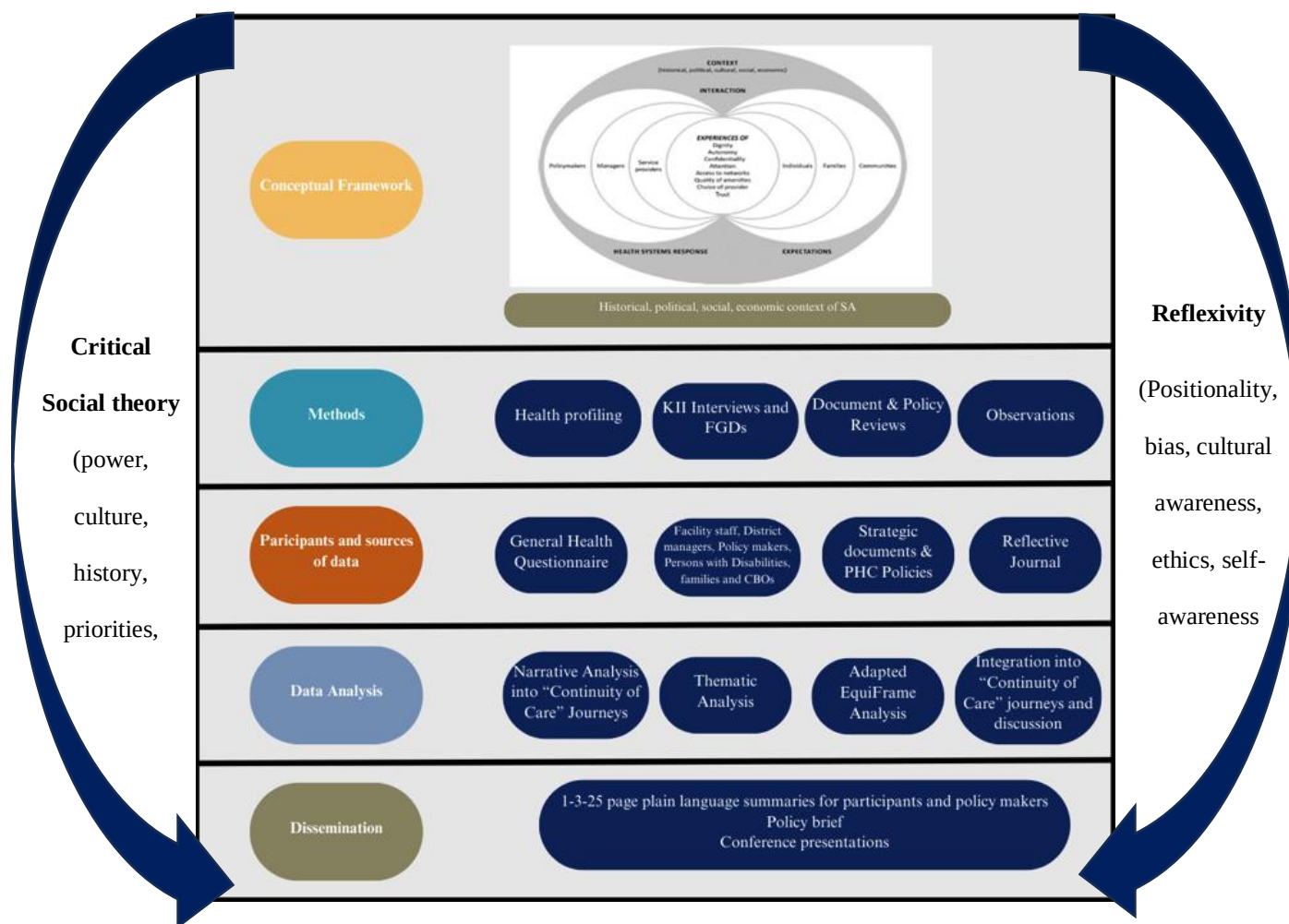


Figure 7. Overview of the study design

3.4.1 The study context

The case study site chosen was a ward in eThekweni (referred to as Ward X. See Fig. 8) in order to focus on how health services meet the PHC expectations and needs of persons with disabilities.

The health systems responsiveness model (Mirzoev & Kane, 2017) mirrored the study context of the public health system in SA well enough, though there were some limitations in terms of congruence with outreach services and other efforts that take place outside of the health facility.

One cannot compartmentalize the health facility away from the community as PHC by definition includes outreach services and linkages to community support structures. Ward X was chosen for the following reasons:

- a) It is a diverse community resembling many urban communities in the greater Durban area, with high levels of inequity along racial lines.
- b) It is a ward that services a large informal settlement and is in close proximity to a broad range of health services, outreach teams, tertiary hospital and healthcare services offered by district support partners through international donors also referred to as development partners.
- c) It is identified as a best practice site for Operation Sukuma Sakhe which is the Premier's flagship programme which represents a continuous interaction between Government and the community to come together to achieve the 12 National Outcomes through social mobilisation and the delivery of more integrated government services (UNAIDS Country Office South Africa & KwaZulu-Natal Office of the Premier, 2016). persons with disabilities are considered to be key target population in the programme.
- d) It is a ward with a high level of community engagement offering a unique lens through which "Continuity of Care" can be investigated.

Ward X shown in Figure 8 below, contains 2 suburbs and is home to approximately 28 697 people with a median age of 28 years, about 25% higher than the median age for KZN. About 27% of the population in this area are between 20-29 years old and about 73% of the population are within working age of 18-64 years (Statistics South Africa, 2022). About 48% of the population are Black SA and another 48% are Indian SA. Current statistics on the number of persons with

disabilities living in the area is not well documented at ward level, using Census 2011 or 2022 data as disability data is not disaggregated to ward level.

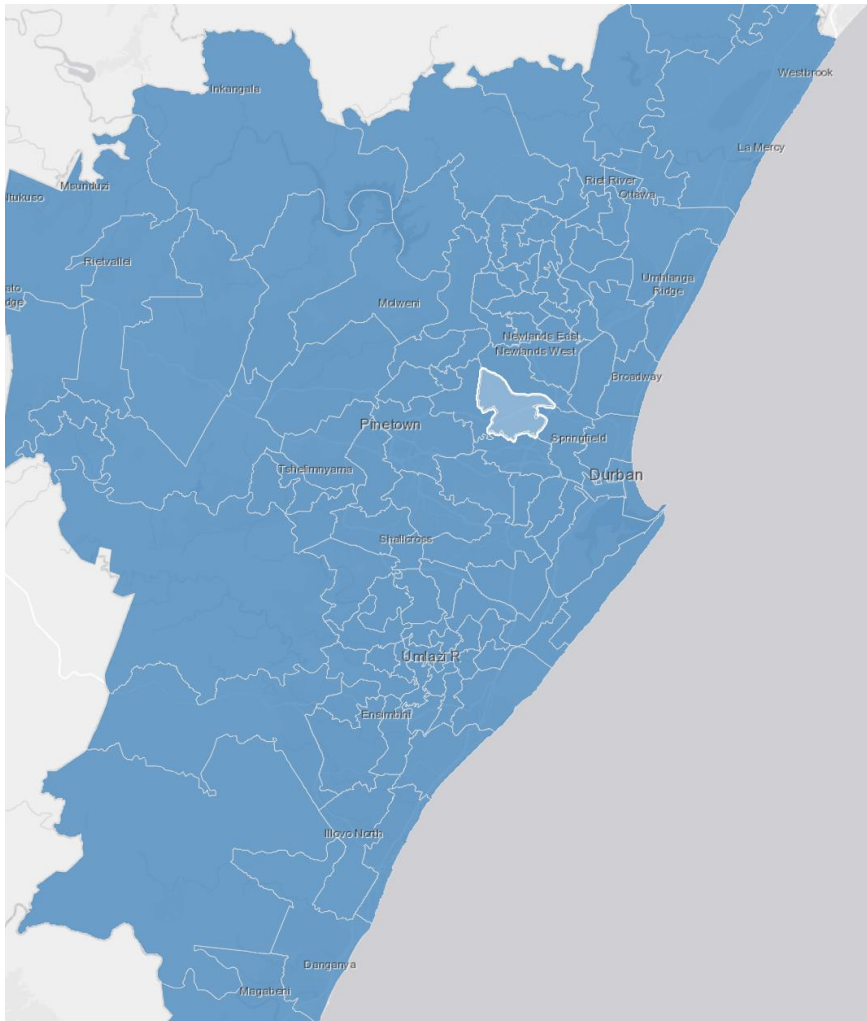


Figure 8: Map of Ward X

(Source: eThekweni Open GIS Data (Open Data, 2022))

The equal percentage of African and Indians within the ward can be explained by the history of the area. In 1966, the Group Areas Act No 41 (1950) commenced, dividing urban areas

into racially segregated zones “*where members of one specific race alone could live and work*”. (Republic of South Africa, 1950) Group areas were created “for the exclusive ownership and occupation of a designated group”. It further became "a criminal offence for a member of one racial group to reside on or own land in an area set aside by proclamation for another race”. Under the apartheid regime, Ward X would have been designated as an area for Indians only. The law was repealed in 1991.

Due to the convenient location close to the city centre, access to good quality education and other amenities, Ward X became home to more and more black African families who wanted to be closer to better resources.

Figures 9 and 10 show population and household statistics for Ward X. About 53% of people living in Ward X speak English as a first language and about 24% of people speak isiZulu as a first language which is the dominant language spoken by black Africans in eThekweni. Most residents of Ward X are SA citizens (90%) but there is an upward trend in migrant workers from the Eastern Cape and other African countries (Statistics South Africa, 2011a).

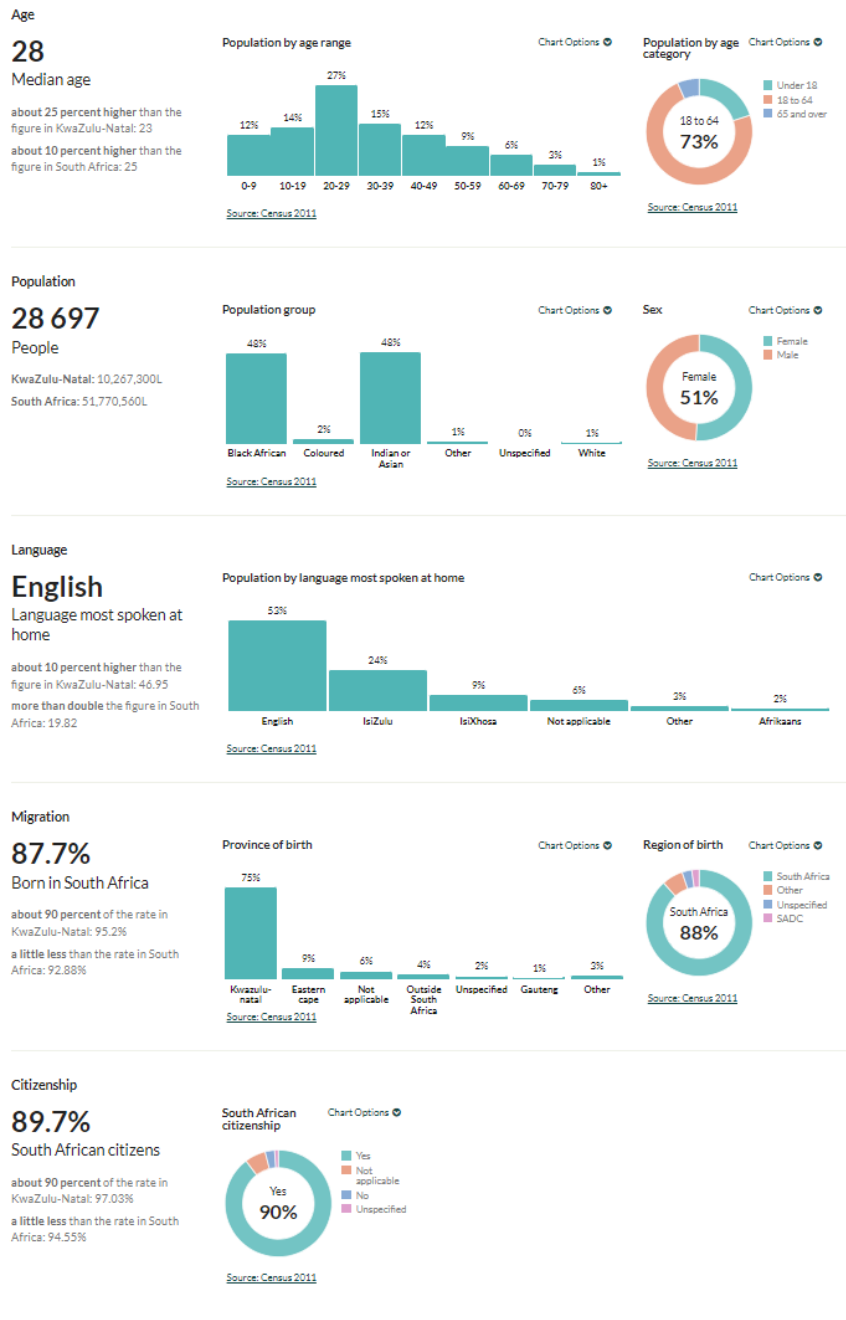


Figure 9. Population statistics of Ward X Source: (Statistics South Africa, 2011a)

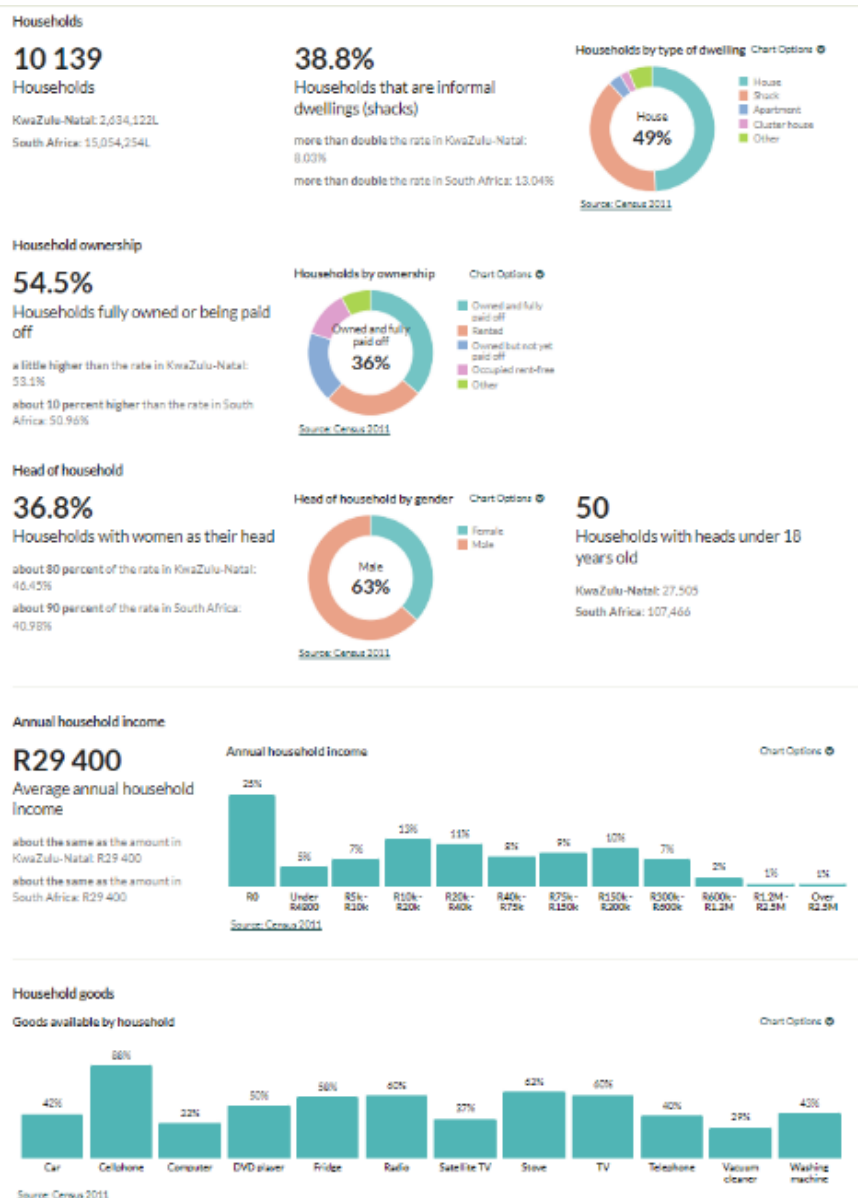


Figure 10. Household data for Ward X Source: (Statistics South Africa, 2011a)

According to the 2011 census data 10 139 households were registered in Ward X with about 38% of households being informal dwellings (shacks) and about 49% of households being described as houses (Statistics South Africa, 2011a). Only 47% reported being in employment - an alarming statistic of social inequity and an indication that poverty is a reality for more than a third of the population in Ward X (Statistics South Africa, 2011a). Census 2011 additionally found that

there were 50 households where the head of the household was under 18 years old, an indication of high levels of social vulnerability (Statistics South Africa, 2011a).

3.4.2 Study timeline

Understanding the study timeline is crucial to this study in light of the three high impact events that took place in the province of KwaZulu Natal prior to the conduct of fieldwork. All three events had significant and compounding impacts on Ward X. Figure 11 below provides an illustration of the study milestones and occurrences of the Covid 19 pandemic, the violent protests and looting and the destructive floods which are described in more detail in Chapter 4 as part of the findings.

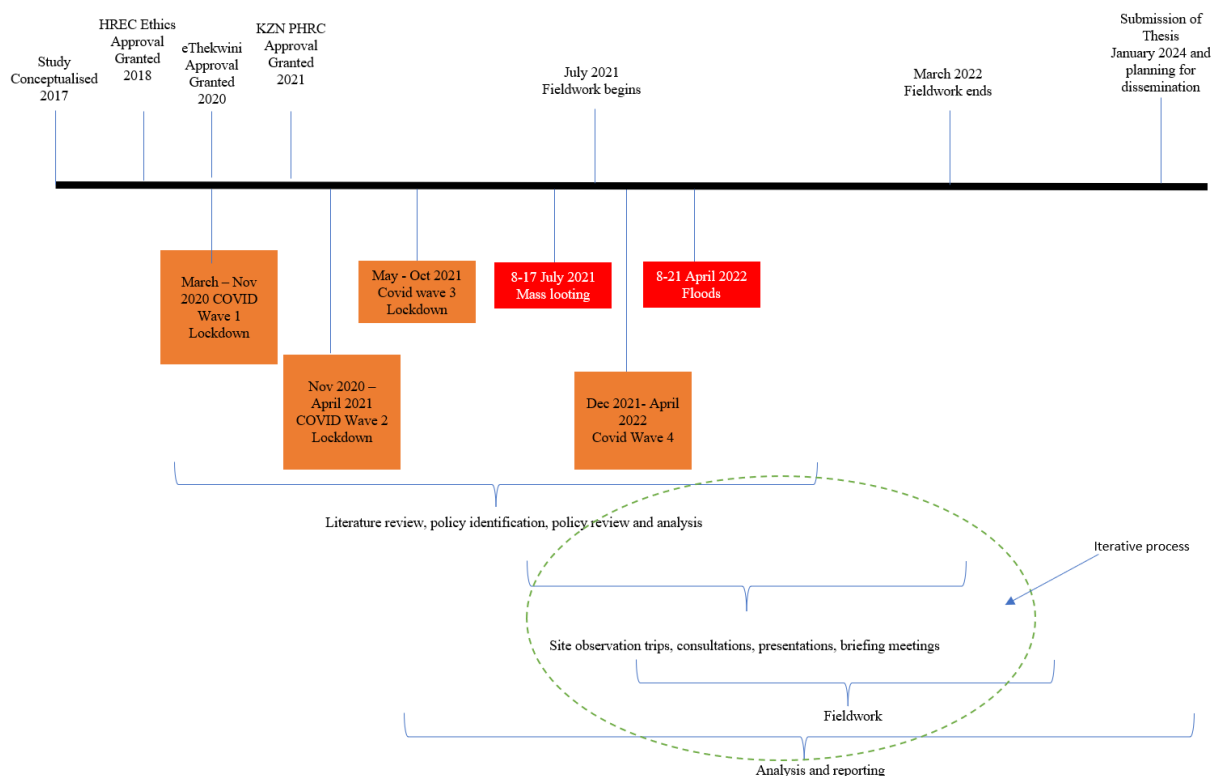


Figure 11. Study timeline and key events in eThekweni

Once ethics approval was obtained from UCT's HREC (Appendix A). It is noteworthy that the duration required to obtain access approvals from the KZN Provincial Health Research Committee (PHRC) (Appendix B), and the eThekweni Municipal Health Department (Appendix C) took about 3 years, barring COVID restrictions. This is a significant finding but not uncommon in SA as research conducted in public health facilities are highly regulated through national, provincial and district gatekeeping. There were periods in the study when the researcher reflected on whether a change in methodology was required to eliminate the inclusion of the health facility, however, this avenue was not considered as a solution as a holistic and comprehensive understanding of "Continuity of Care" was being sought.

Adaptations were therefore made to accommodate an **iterative process** of data generation where policy reviews, observations, pre-fieldwork telephonic consultations with key stakeholders and community visits were conducted while waiting for the appropriate time to interview persons with disabilities and families. It was important to conduct interviews in the natural settings and therefore, this iterative process, was worthwhile and contributed to richness and deepened understanding of the context and realities of persons with disabilities regarding "Continuity of Care". Had these interviews been conducted telephonically, the generation of rich contextual data would have been markedly reduced.

3.4.3 Research methods

The study included a **variety of methods** as prescribed by proponents of case study research (Stake, 1995; Yin, 2012) to address the research question and comprised of a health profiling, key informant interviews, focus group discussion, policy review and researcher observations. These methods are tabulated in relation to the study objectives in Table 2 with

relevant comments included on its alignment to the conceptual framework. Criticality underpinned all phases of the study as did reflexivity the data collection design and implementation as this was an important component of the philosophical paradigm of the study. The research method was guided by ethical principles and the act of informed consent (See Appendix D,E,F,G, H, I, J, K).

Table 2. Alignment of objectives and methods to conceptual framework

Study Objective	Methods	Alignment to Theoretical Framework elements
To explore the experiences and expectations of persons with disabilities regarding “Continuity of Care”	Observations (Appendix L) and photos of the environment Health profiling (Appendix D) to identify appropriate participants for the study. KII interviews with persons with disabilities (older than 18 years) (Appendix J). KII interviews with their families/caregivers (Appendix K) FGDs with community-based organisations / community support groups (Appendix L)	Uncover existing health conditions, how persons with disabilities experienced “Continuity of Care” and what their expectation were in terms of PHC services with reference to Mirzoev and Kane (2017) Conceptual Framework for Health Systems Responsiveness Uncover the role that families play in supporting “Continuity of Care” for persons with disabilities.
To conduct an analysis of relevant policies governing PHC in SA in terms of its influence on “Continuity of Care” for persons with disabilities	Policy Review: Relevant international, and local policies that guide and shape “Continuity of Care” at PHC level in SA were identified and reviewed. A selection of policies with potential to influence “Continuity of Care” within the PHC context were identified and assessed using the EquiFrame approach to policy analysis. The EquiFrame method was also used to systematically analyse policies in terms of the degree to which the policy catered selected core human rights concepts relevant to persons with disabilities and “Continuity of Care”.	A review and analysis of policies relevant to “Continuity of Care” for persons with disabilities also relates to the dimension of context as part of Mirzoev and Kane (2017) Conceptual Framework for Health Systems Responsiveness. Provides insights into influences of “Continuity of Care” for persons with disabilities from the perspective of policy makers.

Study Objective	Methods	Alignment to Theoretical Framework elements
	KII with policy makers (Appendix M) were used to further explore policy gaps and investigate the perceptions of policy makers in relation to why these gaps exist and how they could be addressed.	
To explore health systems responsiveness to the expectations of persons with disabilities as it related to their PHC “Continuity of Care”.	KII with healthcare managers (Appendix N), Primary healthcare managers (Appendix N) service providers, and community healthcare workers (Appendix P)	Uncovers the health system and provider factors that influence “Continuity of Care” for persons with disabilities and relates directly to the health system responsiveness component of Mirzoev and Kane’s (2017) Conceptual Framework for Health Systems Responsiveness.

Researcher observations and photos of the environment: Observations are a valuable tool especially when research questions require an in-depth understanding of current practices in highly complex settings. (Weston, Krein, & Harrod, 2021). This study was conducted in the midst of complexity, and uncertainty which required careful navigation during each step of its conduct. From uncertainty about when the study would begin, due to COVID 19 restrictions, to complexities in obtaining access and not being sure about safety in the field; these all contributed to an enhanced need to journal and reflect critically on what the challenges were and how they could be overcome.

Observations played a crucial role during the course of the study and took the form of unstructured observations (Harvey, 2018) where the researcher and research assistant would observe aspects of the participants home environment and living conditions, his/her general appearance and health and critically evaluate the circumstances of the individual in relation to “Continuity of Care”. Weston, Krein & Harrod (2021) describe observation as a qualitative data collection method comprised of viewing and documenting phenomena in the usual environment (Harvey, 2018; Weston *et al.*, 2021). As an example, when interviewing a Person with a Disability,

observations of mobility and levels of independence, access to amenities such as ablution facilities and food were carefully documented using a semi structured observation schedule (Appendix I). During the course of the interview observations were made in terms of the participants body language, level of effort and ability to answer the question. Astute observation made it possible to adapt questions (e.g. make them shorter, skip questions that may not apply and repeat questions if required).

Observations and personal notes in a researcher journal were used as the basis for reflective journaling which were integrated into the results of the study, in particular the “Continuity of Care” journeys. In this case study where the context was unknown, observations played a valuable role in understanding and interpreting what was being said about “Continuity of Care” by those interviewed. While the focus was intended to be the participant, the scope of the observations was multifaceted and sometimes included observations of the community layout, the characteristics of the homes and basic infrastructure (Weston *et al.*, 2021). Through rich descriptions of the context the researcher was able to interpret the results in context. Observations during the course of the study were also instrumental in triangulation of data as proposed by and thesis building, particularly in relation to policy analysis findings in relation to what was observed when interviewing participants.

Capturing the environment was also an important part of the observation exercise and involved taking photos of the environment and the study site. Photos were taken with permission; however, no pictures were taken of participants, but were restricted to those without people where it was important to capture the context and environmental challenges to health and wellbeing.

Key informant interviews (KII): Key informant interviews formed the main data collection method and were conducted with persons with disabilities, their families and health facility staff and policy makers. Across all these groups the application of KII is important as it allows for an in depth understanding of lived experiences. Creswell (2009) indicates that key informant interviews allow researchers to delve deeply into the lived experiences of individuals and allow them to share their personal narratives, perceptions, and challenges in their own words (Creswell, 2009). While this is of relevance to all participants in this study, it is crucial for persons with disabilities interviewed as they 1) often do not have the opportunity to express their views due to them being excluded as research participants and 2) because they may require additional supports and time to be able to express themselves in the way that works best for them.

Key informants, such as caregivers, advocates, or professionals working in the field, offer unique perspectives that complement the experiences of persons with disabilities. This diversity of viewpoints enriches the research by capturing a more comprehensive picture (Morse, 2015). This was the case when interviewing families of persons with disabilities, even more so because they needed to be heard and had a great deal of insight to share regarding “Continuity of Care.”

Certain aspects of KII interviews with policy makers supported the policy review process and was used to establish their interest, ideas and institutional influence (Collier 2011; Gerring 2004; Yin 2009) in relation to the policy being discussed. This design approach allowed the researcher to contextualise policy analysis findings with real life perspectives that shed light on how policy makers’ interests, ideas and institutions impact on how policies are prioritised and implemented in relation to persons with disabilities.

Focus group discussions. Focus group discussions are used widely in health research and fuse principles of qualitative research and group process theory (Jackson, 1998). It is described by

Kitzinger (1995) as a form of group interview that capitalises in group dynamics (Kitzinger, 1994). Focus groups were conducted with community-based organisations and NGOs identified for inclusion in the study. The researcher assumed that there would be many NGOs working with persons with disabilities in Ward X as the community was also serviced by a number of NGOs who provided HIV services as part of government led initiative to improve retention in care. Focus group discussions with this group of participants was deemed an appropriate method due to their busy schedules and the need to be time and cost effective in collecting data. While FGDs can generate rich and diverse data by capitalizing on group dynamic and stimulate a wide range of perspectives, experiences, and opinions, care must be taken to ensure that the method does not limit participation of others due to the dominance of one group (Kitzinger, 1994). Two focus groups were conducted, and the rest were adapted as KII due to the lack of availability of staff. Group dynamics in one group had to be managed carefully as it included the chief of the facility and a junior who deferred to her senior. Managing the power dynamics in these sessions was critical to be able to get a balanced and true account of what was the organisations' experience of "Continuity of Care". The researcher used strategies to try and normalise power dynamics at the start of the session by ensuring that participants felt safe and that the purpose of the study was clear. When the chief of the facility answered a question, the researcher probed an answer from the junior staff member, and this yielded more participation. Questions asking for examples was also useful as these encouraged responses from the junior staff member who had more close engagements with families and could contribute with more authority. The researcher also used positive feedback and invited elaboration when the junior staff member answered. It is acknowledged that this kind of interaction may have an impact on validity, however, under the

circumstances of limited time and opportunities to engage with the staff, it was considered more valuable to have an interaction rather than none.

Policy Review: Relevant PHC policies were searched for using the University of Cape Town's SA Government Policy: Library Guide, the website of the National Department of Health and the KZN provincial department of health website. Walt and Gilson (1999) claims that a large portion of health policy research incorrectly concentrates attention on the policy content while ignoring the actors involved in the process, the procedures necessary for creating and implementing change, and the context in which policy is developed (Walt & Gilson, 1994). The analysis of policies was therefore considered important to the study design because it provided an institutional lens through which "Continuity of Care" could be better understood. Theoretically policy analysis provides an important part of health policy and systems research and allows for the generation of data relating to health system priorities and the influence of actors through their ideas and interest, manifestations of power through institutions and overarching political agendas at play (Ghaffar, Gilson, Tomson, Viergever, & Rottingen, 2016).

For the purpose of this study, a policy was defined as actions which contain goal(s) and the means to achieve them, however well or poorly identified, justified, articulated and formulated (Howlett & Cashore, 2014). This definition allows for a broad initial search, and this was further narrowed using the developed criteria described below.

From the list of identified PHC policies, a sub-group of policies were identified as having objectives that align with three core areas of "Continuity of Care", namely, management continuity, relational continuity and informational continuity. Only policies developed after SA ratified CRPD in 2007 were considered and can be seen within the broader policy context in Figure 12. The selection of these policies was guided by the following criteria:

- The policy must be applicable to SA
- The policy must have quality of care as a central feature
- The policy must have contained references to quality of care or a “Continuity of Care” concept (i.e. informational continuity, management continuity or relational continuity)
- The policy should be the most recent policy available
- The policy should not be narrowly focused on a specific health programme but rather be an over-arching policy applicable to all health programmes. This was done to create a narrower focus on policies applicable to all health programmes instead of a particular health condition.

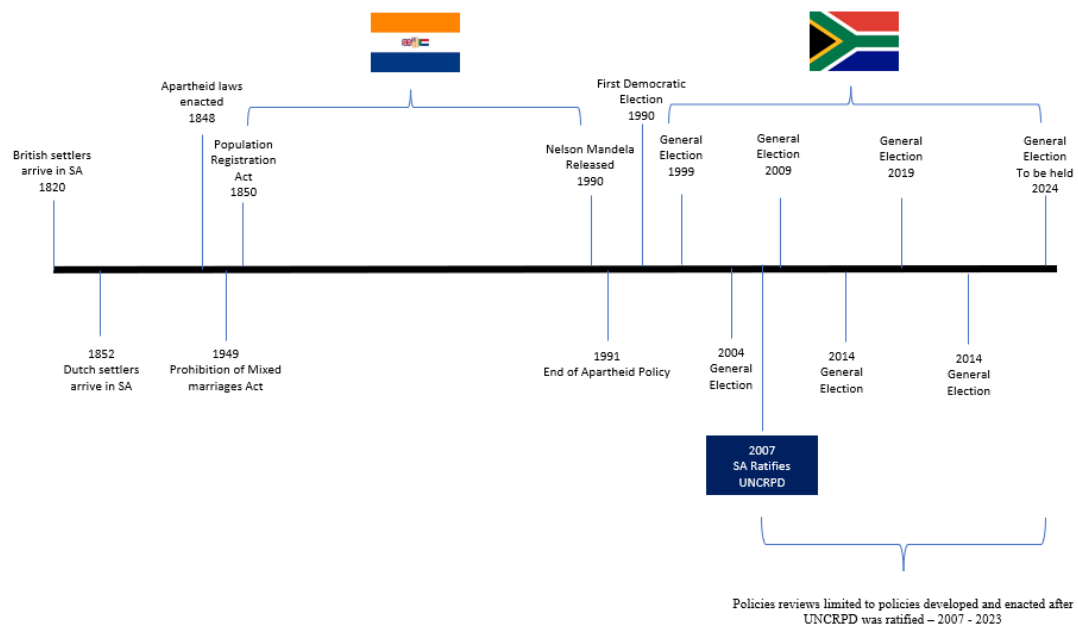


Figure 12. SA political timeline and period of policies included

3.4.4 Participants

Health service user perspectives were sought from adults (over 18 years) with a disability, families / caregivers as well as representatives from community-based organisations that support persons with disabilities were approached to participate in the study. An attempt was made to select a diverse group of participants with disabilities to represent the range of disabilities including physical disabilities, sensory impairments as well as people with mental health challenges. It should be noted however that the number of potential participants could not be determined beforehand and representation of all types of disabilities was not possible and was not the intention of the study. Table 2 provides a breakdown of the inclusion and exclusion criteria for each category of participant included in the study.

Health system perspectives were sought from facility staff, district management, provincial health managers and national policy makers. Responses were received from facility staff, district managers and provincial managers with no response from national stakeholders. This was a critical reflective point as the absence of a national perspective was not ideal. However, the data obtained from healthcare managers at district and provincial level provided adequate information regarding responsiveness and understanding of “Continuity of Care.”

Failure of policy makers to respond to requests for participation, while disappointing, was not surprising due to the nature of the emergencies that they had to deal with during the study period. However, this is a critical issue in terms of representation in health systems research where perspectives matter when issues of power and interests are at play. Sheikh, George and Gilson (2014) make the argument that change within a health system is brought about by people who work in the system and is shaped by a variety of factors including social, political, and economic (Sheikh *et al.*, 2014). With this in mind, consideration needs to be given to who is at the helm of

research and whether they are sufficient invested in and equipped to deliver change through research.

Access to Participants and recruitment . Once the relevant approvals were obtained from the UCT Health Research ethics Committee, the KZN Provincial Health Research Committee and the eThekweni Municipality, two separate processes were followed to access participants. Contact was made with organisations of persons with disabilities (provincial branched) to find circulate information about the study and find interested participants. In parallel, the local deputy counsellor was contacted to gain access to the community. Contact was also made with the health facility informing them of the study which led to referrals being made to local NGOs who could assist in finding persons with disabilities in the community of Ward X. Further to this, posters were placed on light poles in the community in both English and the local Zulu language with details of the study and how to participate.

Access to health facility staff and policy makers was done by contacting the eThekweni municipal office and making an appointment to present the study and implementation plan. An initial meeting was scheduled with the facility manager who provided access to staff and herself.

For objective 1 and 3 all potential participants were contacted via email (where possible) / SMS to determine if they would potentially be interested in taking part in the study. If interested, a suitable date and time was arranged to further discuss participation in the study.

For objective 1, persons with disabilities were intended to be identified through 2 main channels:

- a) Channel 1: Through a pre-study General Health Questionnaire administered via a provincial disability forum identified with support from the Department of Social

Development. The researcher hoped to invite 10 persons with disabilities to participate in the study via this survey. This channel proved unsuccessful and channel 2 was then initiated.

- b) Channel 2: Community-based organisations working with and providing services to persons with disabilities in Ward X were contacted. Consultations with the ward counsellor assisted us in identifying relevant local NGOs. These NGOs reaches out to the families and informed us of their willingness to meet with the researchers, persons with disabilities. Those interested in participating communicated directly with the community-based organisation who then shared details of the potential participant with the researcher. The researcher then contacted the potential participants with the help of the research assistant who resided in the community.
- c) Details about the study were also placed on social media platforms such as Facebook and community WhatsApp groups with relevant permissions from the administrators of these groups. The posts made on these social media groups provided details about the study as well as the contact details of the researcher. It was interesting to note that there were several responses from people who received the WhatsApp message, but many of them did not necessarily have a disability but had chronic medical conditions which they were struggling to manage.

Table 3. Summary of methods, tools and analysis of data

Study Objective	Methods	Tools	Analysis of Data
To explore the experiences and expectations of persons with disabilities regarding “Continuity of Care”	Health profile Participant Accounts: KII with persons with disabilities and KII with their families and community support groups to explore their experiences and expectations of “Continuity of Care” Observations and photos	General health questionnaire (Appendix D) KII schedule of questions (Appendix E, F, G, M, L, M) KII schedule for family and caregivers (Appendix L) FGD with community-based organisations – facilitator guide	Used to provide a description of the health of the participant which precedes each participant account. Thematic analysis Thematic analysis Thematic analysis
To conduct an analysis of relevant policies governing PHC in SA in terms of its influence on “Continuity of Care” for persons with disabilities.	Systematic searches for relevant documents, policies papers, meeting minutes etc... KII with relevant policy makers	Online searches KII Interview schedule (Appendix H)	Data was analysed in terms Policy implementation which entails exploring factors that influence the implementation of the policy content through various strategies and by various structures and people, including the adaptation or non-implementation of the policy by these policy actors.
To explore health systems responsiveness to the expectations of persons with disabilities as it related to their PHC “Continuity of Care”	KIIs with service providers, healthcare managers and specific PHC programme and policy makers	KII schedules (Appendix H, I, J)	Thematic analysis

3.4.5 Sampling

Given that the goal of the study was to obtain insights into a particular phenomenon and not necessarily to generalise, purposive sampling was chosen (Onwuegbuzie, 2007). Purposive

sampling ensured that key informants were selected in accordance with the criteria set out for the study. This sampling approach supported the conceptual framework adopted in the study as it was important to ensure that provider and user insights were obtained to understand it within a health systems context.

Snowball sampling is acknowledged as an effective sampling technique for identifying individuals who share common characteristics and are not easy to reach using other sampling techniques (Valerio *et al.*, 2016). In this study health service providers were identified using snowball sampling by inviting provincial managers initially interviewed to refer the researcher to others who may be able to support a better understanding of “Continuity of Care.” These participants were then asked to help identify other relevant participants.

The identification of health services users used snowballing sampling guided by the local NGOs and the community leadership. Accessing persons with disabilities and families with persons with disabilities using this sampling technique proved invaluable as they were closest to the community and were aware of the challenges faced by people who lived there.

Selection criteria. A description of the inclusion and exclusion criteria is provided in Table 4 below. Every attempt was made to ensure that representation from all levels of the conceptual framework was included, however, national level representation was absent due to no response having been received from national gatekeepers. In SA, access to national stakeholders is controlled through the National Health Research Database whereby approval is granted through the database.

3.4.6 Role of the research assistant

The methods used in this study was supported by a Research Assistant who was also a resident in the community of Ward X. His role was to primarily to support the fieldwork specifically in relation to navigating the challenges and linking the researcher to leadership in the community. His resourcefulness as a knowledgeable local was invaluable as he was able to direct activities at the opportune moments and communicate caution in there were episodes of violence or crime in the area. The Research Assistant was also instrumental during interviews as he was a Fluent English speaker and spoke the local Zulu language. His intimate knowledge of the community was valuable during the recruitment phase as he was able to provide feedback on the posters and what language would be best suited for the residents.

Training on the purpose of the study and its aims and objective were provided along with training on research ethics with a focus on confidentiality. A written agreement was signed between the researcher and the research assistant (Appendix Q). The research assist provided translation support in two KIIs where Zulu was the preferred language.

Table 4. Description of participants and inclusion and exclusion criteria

Participants	Description	Inclusion criteria	Exclusion criteria	Number
persons with disabilities	A person who defines him/herself as having a disability as per definition outlined in the UN CRPD	- The participant must perceive themselves as having a disability - The participant must be accessing PHC services at one of the selected healthcare facilities in Ward X. - Must have visited the selected PHC facility at least 3 times a year. - The participant must have a disability and one chronic condition for which he/she seeks regular healthcare support from the selected healthcare facility (e.g. Hypertension, HIV TB)	Not receiving PHC services at a PHC facility. Severe intellectual disability which may prevent active participation in the study unless primary caregiver is able to provide insight on behalf of person with disability.	5
Family of a Person with a disability	Parent or legal guardian / care giver	Must currently live with the person with a disability and be able to provide insights into services accessed by the person with a disability	Not a family member or legal guardian of a person with a disability Not a caregiver of a person with a disability	3

Participants	Description	Inclusion criteria	Exclusion criteria	Number
Community where Person with Disability lives	Community based organisations (CBO)	CBOs with direct links to public health facilities and those who work closely with persons with disabilities	Community based organisations who do not provide services to persons with disabilities.	5
Policy Makers: National and Provincial Departments of Health	Priority Programmes (defined within the National Development plan and the National Department of Health's Strategic Plan)	Must have been in the position for at least 6 months	New to the portfolio (<3 months)	No response
Policy Makers: Provincial Department of Health	Priority Programmes (defined within the National Development plan and the National Department of Health's Strategic Plan)	Must have been in the position for at least 6 months	New to the portfolio (<3 months)	3
	Rehabilitation Programme	Must have been in the position for at least 6 months	New to the portfolio (<3 months)	1
	PHC	Must have been in the position for at least 6 months	New to the portfolio (<3 months)	0
	Local governance	Must have been in the position for at least 6 months		2
PHC Facility Manager/s	The manager of the facility chosen as the case for investigation	Must be the manager of the health facility or a person duly authorised as the most senior person in the facility at the time of the study	None	1

Participants	Description	Inclusion criteria	Exclusion criteria	Number
PHC Nurse/Doctor	The PHC nurse or doctor providing healthcare services within the facilities.	Must have worked in the facility at least 6 months	New to the portfolio (<6 months	1
Rehabilitation team	Physiotherapist, Occupational Therapist, Speech Therapist (or as detailed in the Ideal Clinic manual)	Must have worked in the facility at least two years	Community service therapist newly allocated within the last year	0 No rehabilitation team attached to the facility
PHC Outreach team	Outreach Team leader	Must have worked in the facility for at least 1 year.	New to the portfolio (<1 year)	Was not given permission to access staff
Community Health Workers	A member of the community in which she/he works and who serves and responds to the health needs of the community	Must have been residing in and providing services in the community for at least 1 year	New community health worker <1 year.	Was not given permission to access staff

3.5 Data generation and analysis

Data generation began in July 2021 and continued till March 2022 and was iterative and concurrent, a characteristic that is typical of qualitative research (Baxter & Jack, 2015). Given that the researcher needed to be responsive and adaptable to a dynamic context and ready to interview at short notice, this approach worked effectively without dramatic negative effects on achieving the aim of the study. Effort was made to build relationships with community NGOs and leadership so that access to the community was smooth. Two site visits were made prior to fieldwork both to understand the context and meet with community NGOs and be better orientated to the community and the dynamics at play. Even though I was a resident of Ward X, I was not familiar with the layout of the informal settlements and required orientation to how the community was laid out.

Observations made during this time were important in preparation for the fieldwork as clean running water and sanitation were not easily accessible. The researcher was told to always enter the community with a member of the community so that safety could be assured. The role of the research assistant in this regard was critical as he lived in one of the informal settlements in Ward X. His knowledge of the local language and community dynamics were critical to being well prepared and responsive to dangers.

Table 5 below provides an account of the various methods used in the study, the data sources and the methods of analysis used for each. In case study research designs the use of various methods is encouraged because the boundaries between a phenomenon and its context are not always clear (Yin, 2012).

Table 5. Summary of methods data sources and analysis

Study Objective	Methods	Data Source	Analysis
To explore experiences and expectations of persons with disabilities, their family and the community within which they reside.	General health questionnaire with persons with disabilities KII with persons with disabilities (Appendix K,L,M)	General health questionnaire (Appendix A) Transcribed interviews	Health profiles Individual Narrative Analysis “Continuity of Care” Journeys Thematic analysis using inductive coding
	Observations and photos	Researcher diary and field notes	Integrated into reporting
	KII with families	Transcribed interviews	Thematic analysis using inductive coding
	FGDs with NGOs	Transcribed interviews	Thematic analysis using inductive coding
To conduct an analysis of relevant policies governing PHC in SA in terms of its influence on “Continuity of Care” for persons with disabilities.	Policy review	Policies, Strategic documents, meeting reports	Modified EquiFrame method of analysis
	Observations of policy implementation gaps during fieldwork	Researcher diary and field notes	Integrated into reporting
	KII with relevant policy makers	Transcribed interviews	Thematic Analysis
To explore health systems responsiveness to the expectations of persons with disabilities as it related to their PHC “Continuity of Care”	KIIs with service providers, healthcare managers and specific PHC programme and policy makers	Transcribed interviews	Thematic analysis

Broadly, data generated in the study was analysed in accordance with Alvesson and Sköldberg’s (2009) levels of reflexive interpretation which draws on critical theory (Alvesson & Sköldberg, 2009) as outlined in Fig 13 on the next page.

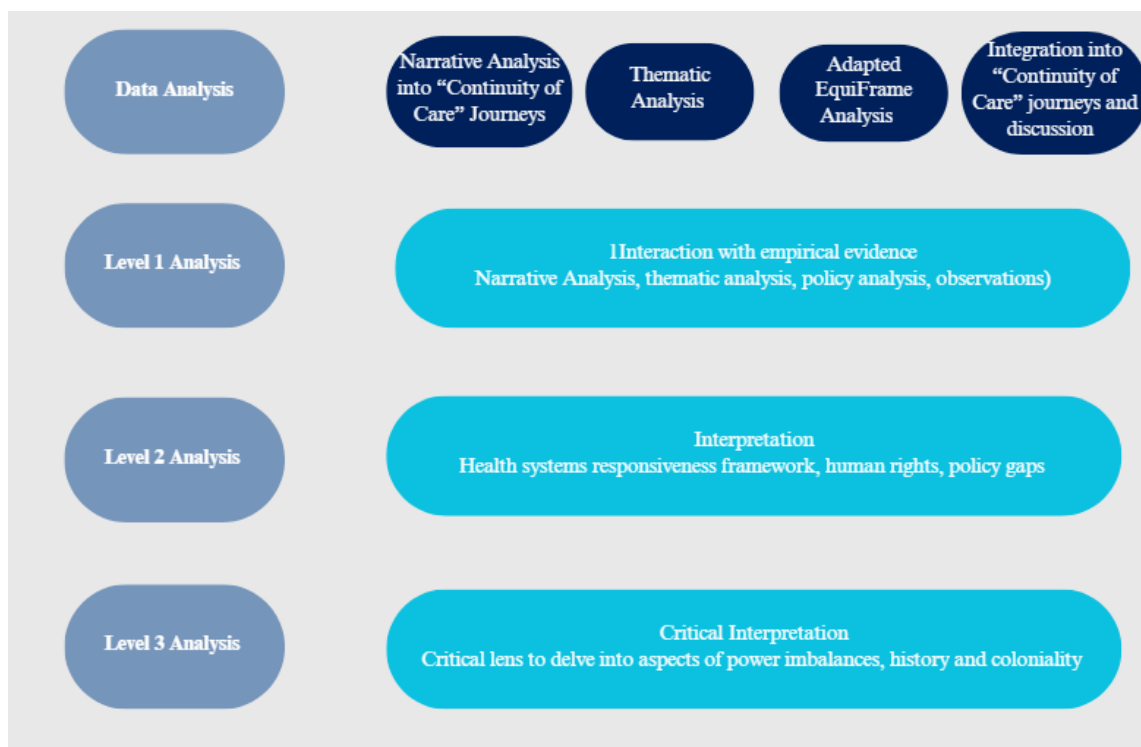


Figure 13. Data Analysis Framework

Level one analysis involved the analysis of individual components of the methodology described in the procedures below. Level two analysis attempted to bring together the different data generated from the various methods and is represented by the discussion section of Chapter 6 which includes critical interpretation in an iterative manner.

3.5.1 Observations

Data from observations were integrated into the results and reporting of the study. Due to the non-standardised way that these notes were developed between, it was more feasible and intuitive to discuss and include relevant observations in aspects of the study report where they added critical and contextual value. An example of this was in relation to understanding the challenges that participants faced in terms of mobility and access to basic facilities like the toilet. These issues are integrated into the results to highlight critical issues that affected "Continuity of Care"

3.5.2 “Continuity of Care” journeys

Data generated from KII with persons with disabilities were analysed using Individual Narrative analysis which is a qualitative analysis method directed at understanding human experience through their stories and concerned with the structure, content and function of the stories (Bamberg, 2021; Demuth & Mey, 2015). The creation of “Continuity of Care” Journeys began with a summary of data collected from the General Health Questionnaire (GHQ) (developed by the researcher) and a description of their interaction with the health system and local clinic. The GHQ was designed to collect information on persons with disabilities’ basic biographical information (age, sex, gender, language, self-reported disability and living conditions), general health conditions, number of times they visited the clinic in a year, who they saw at the clinic most often and how they felt when they visited they clinic in relation to aspects of “Continuity of Care” (i.e. longitudinal continuity, relational continuity and management continuity).

The intention was to have the questionnaire circulated through organisations of persons with disabilities in KwaZulu Natal using an online form in an attempt to find participants who lived in Ward X and met the criteria to join the study. However; no responses were received using this approach as the bigger provincial organisations indicated that they did not have on record any persons with disabilities who lived in Ward X. The researcher then contacted local leaders and NGOs in Ward X who were able to link the researcher to potential participants. Due to the fact that many did not have access to mobile, phones or computers, the GHQ was then used as a pre-interview questionnaire to ensure that the prospective participant met the criteria for the study. All questions in the GHQ were asked to the potential participant allowing the researcher to establish basic information about the participant in relation to their medical history and experience of “Continuity of Care” broadly. All participants referred to us by the Ward X NGOs met the criteria for inclusion and the success of these referrals may be attributed

to the detailed brief provided to the local leaders and NGOs which comprehensively outlined the inclusion criteria.

Buschle, Reiter, & Bethmann, (2021) have supported the use of pre-study questionnaires indicating that the good survey research depends on asking the right question postulating that such an approach ensures that suitable information is collected from respondents (Buschle, Reiter, & Bethmann, 2021). The use of the General health Questionnaire proved useful and led to richness in the development of the “Continuity of Care” journeys. It also provided the researcher with a clear focus at the beginning of the study, so that appropriate probing questions could be asked based on the situation of the participant.

A standard format was attempted to be used in describing the “Continuity of Care” journeys as follows:

- Title which summarised a key finding from the journey
- A summary of the medical and general health condition of the participant
- A tabulated summary of the participant’s responses to the five questions on their experience of care obtained from the General Health Questionnaire
- A consolidated description of the interview and their accounts of “Continuity of Care”
- A “Continuity of Care” map illustrating the journey visually
- Strategies used by the Person with a disability and their family that influenced “Continuity of Care”
- A summary of their experiences of “Continuity of Care”
- A summary of their expectations of the health system
- Policy and practice observations of the researcher
- A brief discussion of the main policy gap observed

In some cases, modifications to the format were made to highlight a certain aspect or where data was not available. An important component of the “Continuity of Care Journeys” was the critical reflections by the researcher about policy implementation gaps. In the section of timelines, the iterative nature of the policy analysis, data collection and analysis steps were illustrated. In this way, the researcher was able to draw on policy review information against what was being observed and heard in the interviews. This approach was both dynamic and extremely valuable in evaluating policy implementation from the bottom up.

3.5.3 Thematic analysis

Inductive coding was used in analysing interviews and FGDs. Inductive coding involved identifying patterns, themes, and categories in the data without preconceived notions or predefined categories (Ryan, 2000). The participants’ responses were inductively coded to minimise and manage researcher bias. Managing bias in inductive coding of qualitative data is crucial to ensure the credibility and rigor of the research. The researcher used reflexivity by constantly reflecting on potential biases during the course of the study. This was further enhanced through discussions during supervision discussions and post analysis discussions. Regular discussions between the research assistant and the researcher were valuable in maintaining awareness of potential bias.

Regularly engaging in critical reflection during the coding process meant questioning assumptions, considering alternative interpretations, and being open to re-evaluating coding decisions in light of new insights. While observations were also a source of data to be coded, this was rather integrated in an **iterative manner** into the results of the study as part of critical reflection and context framing.

Codes were then grouped into axial codes, selective Codes and themes. The following steps were adopted to ensure that data was prepared appropriately for analysis:

- The data was inductively coded by one researcher and categorized into emergent themes using NVivo to manage the data.
- These themes were generated from different participant group perspectives and the researcher's observations.
- Dominant and sub-dominant themes were identified and those not directly linked to experience of "Continuity of Care", were excluded from the ongoing analysis as appropriate. This was done mainly to reduce the volume of data and to allow more in-depth analyses of the remaining themes.
- While it was originally planned to have another researcher independently review the transcripts to confirm themes and consistency in data analyses, this was not possible.
- The PI (PhD Supervisor) oversaw the approach being used to analyse the data, checked the researcher's interpretation and whether the findings were coherent and linked to the overall objective of the study.
- Data was integrated using methods of triangulation. The latter involved an iterative or cyclical approach to analysis described by O' Cathin *et al.* (2010).

3.5.4 Policy Review

Identified policies were analysed using an adapted EquiFrame method of analysis to systematically assess the degree to which twenty-one core concepts of human rights as it relates to persons with disabilities are included. **Ten** of the twenty-one concepts were identified as being closely tied to concepts of "Continuity of Care" (see green highlighted cells in Table 5 below) based on literature and experiences of persons with disabilities.

Table 5. EquiFrame Core Concepts and sub-group of “Continuity of Care” concepts

KEY	Equiframe Core concepts	1-21
	Sub-group of “Continuity of Care” core concepts	2,5,6,11,13, 15,16,19,20,21

Core Concept Number	Core Concept	Key Question	Key Language
1	Non-discrimination	Does the policy support the rights of persons with disabilities with equal opportunity in receiving health care?	Vulnerable groups are not discriminated against on the basis of their distinguishing characteristics (i.e. Living away from services; persons with disabilities; Ethnic minority or Aged).
2	Individualized Services	Does the policy support the rights of persons with disabilities with individuality in choices of health services?	Vulnerable groups receive appropriate, effective, and understandable services.
3	Entitlement	Does the policy indicate how persons with disabilities may qualify for specific benefits relevant to them?	People with limited resources are entitled to some services free of charge or persons with disabilities may be entitled to respite grant
4	Capability-based Services	Does the policy recognize the capabilities existing within the population of persons with disabilities?	For instance, peer to peer support among women-headed households or shared cultural values among ethnic minorities.
5	Participation	Does the policy support the right of persons with disabilities to participate in the decisions that affect their lives and enhance their empowerment?	Vulnerable groups can exercise choices and influence decisions affecting their life. Such consultation may include planning, development, implementation, and evaluation and evaluation.
6	Coordination of Services	Does the policy support assistance of persons with disabilities in accessing services from within a single provider system (interagency) or more than one provider system (inter-agency) or more than one sector (inter-sectoral)? Any reference made to “Continuity of Care” (Information, Management and Relational continuity)	Vulnerable groups know how services should interact where inter-agency, intra-agency, and inter-sectoral collaboration is required.

Core Concept Number	Core Concept	Key Question	Key Language
7	Protection from Harm	persons with disabilities are protected from harm during their interaction with health and related systems	Vulnerable groups are protected from harm during their interaction with health and related systems
8	Liberty	Does the policy support the right of persons with disabilities to be free from unwarranted physical or other confinement?	Vulnerable groups are protected from unwarranted physical or other unwarranted physical or other confinement while in the custody of the service system/provider.
9	Autonomy	Does the policy support the right of persons with disabilities to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to him or her?	Vulnerable groups can express “independence” or “self-determination”. For instance, person with an intellectual disability will have recourse to an independent third-party regarding issues of consent and choice.
10	Privacy	Does the policy address the need for information regarding persons with disabilities to be kept private and confidential?	Information regarding vulnerable groups need not be shared among others.
11	Integration	Does the policy promote the use of mainstream services by persons with disabilities?	Vulnerable groups are not barred from participation in services that are provided for general population.
12	Contribution	Does the policy recognize that persons with disabilities can be productive contributors to society?	Vulnerable groups make a meaningful contribution to society.
13	Family Resource	Does the policy recognize the value of the family members of persons with disabilities in addressing health needs?	The policy recognizes the value of family See Annex XIII members of vulnerable groups as a resource for addressing health needs.
14	Family Support	Does the policy recognize individual persons with disabilities may have an impact on the family members requiring additional support from health services?	persons with chronic illness may have mental health effects on other family members, such that these family members themselves require support.
15	Cultural Responsiveness	Does the policy ensure that services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic, or linguistic, aspects of the person?	i) Vulnerable groups are consulted on the acceptability of the service provided. ii) Health facilities, goods and services must be respectful of ethical principles and culturally appropriate, i.e. respectful of the culture of vulnerable groups
16	Accountability	Does the policy specify to whom, and for what, services providers are accountable?	Vulnerable groups have access to internal and independent professional evaluation or procedural safeguard

Core Concept Number	Core Concept	Key Question	Key Language
17	Prevention	Does the policy support persons with disabilities in seeking primary, secondary, and tertiary prevention of health conditions?	
18	Capacity Building	Does the policy support the capacity building of health workers and of the system that they work in addressing health needs of vulnerable groups?	
19	Access	Does the policy support persons with disabilities –physical, economic, and groups –physical, economic, and information access to health services?	Vulnerable groups have accessible health facilities (i.e., transportation; physical structure of the facilities; affordability and understandable information in appropriate format).
20	Quality	Does the policy support quality services to vulnerable groups through highlighting the need for evidence based and professionally skilled practice?	Vulnerable groups are assured of the quality of the clinically appropriate services.
21	Efficiency	Does the policy support efficiency by providing a structured way of matching health system resources with service demands in addressing health needs of vulnerable groups?	

Particular attention was paid to assessing the value of the selected policies in relation to the 10 “Continuity of Care” concepts (highlighted in green). In this way policies under analysis were simultaneously assessed for its level of inclusion of persons with disabilities and relevance to promoting “Continuity of Care” using a single analytical framework. Content from policies were extracted when a particularly important aspect of “Continuity of Care” was identified in a policy.

Adaptations to the EquiFrame methodology

The EquiFrame methodology follows a structured analysis of policies using 21 Core Concepts relevant for disability inclusion. The approach outlines a set of criteria, scoring

procedures and indices to rank a group of policies according to their level of inclusion of vulnerable groups. For the purpose of this study the approach was adapted as follows:

- a) The analysis was limited to one vulnerable group i.e. persons with disabilities.
- b) Scoring was adapted due to only one vulnerable group being included.
- c) The **vulnerability group coverage** was adapted to include a count of the number of times disability was mentioned in the policy as a proxy for determining the “sensitivity” of a policy to persons with disabilities.
- d) Two sets of **summary rankings** were used; the first to determine the relative disability inclusion rankings and the second to determine policy alignment to “Continuity of Care” principles.

Adapted Criteria: The EquiFrame (Mannan, 2011) framework (a) defines Core Concepts, (b) identifies the key questions and key language on which the concept is based, (c) identifies Vulnerable Groups, and (d) provides a data extraction matrix to chart the analysed documents. The EquiFrame Matrix lists the 21 Core Concepts along the vertical axis, and 12 Vulnerable Groups along the horizontal axis. For the purpose of this analysis, **only 1 vulnerable group was included for analysis.**

Adapted Scoring: A data extraction matrix (checklist) was developed to measure the quality of the analysed policy documents. The EquiFrame Matrix was constructed with the vertical axis listing the 21 Core Concepts and the horizontal axis used for one vulnerable group, i.e. persons with disabilities

Each Core Concept received a score on a continuum from 1 to 4. This was a rating of the quality of commitment to the Core Concept within the policy document:

1 = Concept only mentioned.

2 = Concept mentioned and explained.

3 = Specific policy actions identified to address the concept.

4 = Intention to monitor concept was expressed.

If a Core Concept was not relevant to the document context, it was stated as not applicable (N/A). If a concept was universally applicable i.e. applicable for all people, it was scored as Universal.

Adapted Summary Indices:

Core concept coverage: A policy was examined with respect to the number of Core Concepts mentioned out of the 21 Core Concepts identified; and this ratio was expressed as a rounded-up percentage. In addition, the actual terminologies used to explain the Core Concepts, within each document, were extracted to allow for future qualitative analysis.

“Continuity of Care” (CoC) Core Concept Coverage: An additional analysis was conducted on a subset of 14 core concepts that were interpreted as being closely linked to “Continuity of Care”. The ratio of the number of CoC Core Concepts identified out of the 14 concepts was then represented as a percentage.

Core concept Quality: A policy was examined with respect to the number of Core Concepts within it that were rated as 3 or 4; that is, as either stating a specific policy action or intention to monitor that action. When several references to a Core Concept were found to be present, the top-quality score received was recorded as the final quality scoring for the respective Core Concept

“Continuity of Care” Core Concept Quality: A policy was examined with respect to the number of “Continuity of Care” Core Concepts within it that were rated as 3 or 4; that is, as either stating a specific policy action or intention to monitor that action. When several

references to a Core Concept were found to be present, the top-quality score received was recorded as the final quality scoring for the respective “Continuity of Care” Core Concept.

Vulnerability Group Coverage: A policy was examined with respect to the number of persons with disabilities mentioned. Since only one vulnerable group was under investigation, this number was used as a qualitative indicator of the how extensively specific mention of persons with disabilities was referenced in the policy. Extracts of the types of terms used to describe persons with disabilities was also included.

Overall Summary Ranking Scores: Each document was given 2 Summary Ranking scores – one for Inclusion of persons with Disability and one for Inclusion of “Continuity of Care” in terms of it being of High, Moderate or Low standing according to the following criteria as shown in Table 6:

Table 6: Description of Overall Summary Scores

Inclusion of persons with Disability		Inclusion of “Continuity of Care” Concepts”		Qualitative Assessment of Coverage
High	If the policy achieved $\geq 50\%$ on both Core Concept Coverage, Core Concept Quality and made specific mention of persons with disabilities.	High	If the policy achieved $\geq 50\%$ on “Continuity of Care” Core Concept Coverage, “Continuity of Care” Core Concept Quality and made specific mention of persons with disabilities.	Number of times persons with disability mentioned and extracts of relevant clauses
Moderate	If the policy achieved $\geq 50\%$ on either Core concept coverage or Core Concept Quality	Moderate	If the policy achieved $\geq 50\%$ on either “Continuity of Care” Core concept coverage or “Continuity of Care” Core Concept Quality	Number of times persons with disability mentioned and extracts of relevant clauses
Low	If the policy achieved $< 50\%$ on Core Concept Coverage and Core Concept Quality	Low	If the policy achieved $< 50\%$ on “Continuity of Care” Core Concept Coverage and “Continuity of Care” Core Concept Quality	Number of times persons with disability mentioned and extracts of relevant clauses

3.6 Reflexivity statement

As a researcher with a background in health policy and systems research, I was constantly aware of the potential influence my experience may have on the research process. Having done research in many different contexts and having to deal with a variety of challenges I was comfortable with the level of uncertainty connected with this study, but uncomfortable with the lack of resources available to overcome some of the obstacles. In the past, having been part of a research unit, with close working relationships with stakeholders meant that securing interviews with key informants within the health systems was rarely a challenge. I was alarmed by the poor response of national stakeholders who had participated in studies they had funded in the past. This highlighted the influence of power in the generation of knowledge which I used to ensure that interviews conducted with policy makers were comprehensive and thorough.

My cultural background as an Indian SA who grew up in the community where the study was conducted was something that I was aware of during the course of the study as I knew that it had the potential to shape my interpretations of the data. I was also aware that my experiences may influence the questions I ask and the way I engage with participants. To combat this, I engaged in pre-interview mindfulness, where I contemplated where I was going, who I was interviewing and what factors I needed to be conscious of in my interactions with participants that could influence how they responded.

I maintained heightened awareness about my positionality in relation to the power dynamics within the research context and was acutely aware that my positionality as a researcher and Indian SA female conducting work independently in a high-risk environment could impact my approach to interviewing. I ensured that I maintained sensitivity to the potential for cultural biases in my interpretations and continuously reflected on my assumptions

and preconceptions, striving to maintain an open mind throughout the data collection and analysis phases.

To mitigate potential bias, I engaged in ongoing discussions with a diverse team of colleagues, including my supervisor, to gain insights from different perspectives. Additionally, I used my researcher journal to document the challenges that were noteworthy in order to find ways to overcome them in subsequent interviews. Having a research assistant allowed for debriefing and discussion of challenges. I was able to bring him into the decision-making process to ensure that an intellectual audit trail was available to validate the accuracy of my interpretations.

3.7 Study procedure

3.7.1 Study preparation and planning

It is important to note that the study was conducted during a period of extreme instability in the province of KZN. However, due to a range of challenges (COVID-19, flooding and mass unrest) the sequence of activities had to be shifted. When the proposal was conceptualised in 2017 there was no way of anticipating these events and so a variety of adaptations in terms of timing of fieldwork needed to be made. The context during the conduct of the study was also tense and bureaucratic in terms of access to health facilities and policy makers.

The initial planning phase included obtaining approval from:

- Human Research Ethics Committee to conduct the research;
- National Department of Health (NdoH) to access national policy makers, to which no response was received
- KZN Provincial Department of Health (KZN DoH)

- The eThekweni Municipality Health Department

The process of regulatory and gatekeeper approvals represented the main delays to the study, followed by the lockdowns due to COVID-19, then the July 2021 unrest and the April 2022 flooding.

Contact was made with Disabled People's Organisations umbrella bodies to seek access to persons with disabilities residing in Ward X. None of the organisations had active records of people meeting the criteria of the study. The researcher then brought the search closer to the community of Ward X using NGOs and the acting Ward Counsellor to assist with the identification of persons with disabilities. The researcher was not given access to support from the facility staff for the conduct of the study and therefore neither health facility records nor referral documents from WBPHCOTs were possibilities.

During this period the policy analysis framework was designed. The data extraction templates were developed using the EquiFrame and modifications to the tool were conceptualised. Initially a large number of policies were identified and assessed. However, a decision was made to reduce the number substantially and focus on policies that were closely related to "Continuity of Care".

Information sheets and informed consent were translated into the relevant local language. The researcher also began inception activities to sensitise the facility and department of health to the study objectives so that approvals were facilitated, and the department of health was familiarised with the purpose of the study. Letters to the Department of Health, Disabled People's Organisations and social media posts were developed.

A general health questionnaire was refined to establish the health condition of the participant and what their experience of Continuity of Care was like in terms of Management,

Information and Relational Continuity. This general health questionnaire was planned to be conducted at the beginning of each interview with a Person with a Disability.

3.7.2 Fieldwork

Requirements for fieldwork: Two separate consultation meetings took place off-site over telephone with two NGOs who had a presence in the area. A risk assessment was conducted regarding when the best time would be to visit and what would be required. The NGOs made the following recommendations:

1. persons with disabilities needed to be visited during the day and preferably on a day when there was no rain scheduled as some areas were prone to flooding.
2. Interviews could not be done over telephone as most of identified participants did not have access to telephones and telephonic interviews were not possible. In situations where they did have phone, they would not have enough airtime to complete an interview over the phone.
3. The NGO would escort the researcher and the assistant to each household.
4. Time at each community would be limited as communities were suspicious of strangers due to the unrest and looting. Many of the communities we were visiting participated in the mass looting and some of the stolen goods were in the homes of community members.
5. We were advised to wear masks at all times
6. Escorts for follow-up visits were unlikely to be possible as the NGO was on their last month of funding to support outreach work in the ward.

In order to enhance our search, posters were developed in English and translated to Zulu. However, the local feedback from the NGOs was that English posters were preferred as

literacy in Zulu was problematic for some people and most people preferred to read in English but speak in Zulu.

Adaptations to sequencing: While it was initially intended to have persons with disabilities interviewed first, priority had to be shifted to analyse policies first to accommodate Covid 19 restrictions and delays in participant identification. Interviews with policy makers were therefore planned before conducting interviews with facility staff, persons with disabilities, families and community organisations. Access to health facilities was restricted to only one community health centre due to capacity constraints at the main health facility and no access was granted to the District Hospital. During this phase key documents and policies were sourced, studied and organised for data extraction. The implication of this change in sequencing may have had some effect on the study in that questions related to policy makers understanding of expectations of persons with disabilities had to be modified as these were not yet obtained through the interviews with persons with disabilities.

Interviews: The development of research questions is an important component and a pre-requisite to defining the aims and objectives a study (Barroga & Matanguihan, 2022). The aim of this study and its objectives were underpinned by a Health Systems Responsiveness Framework (Mirzoev & Kane, 2017) that design of tools. The tools used for data collection were also derived from the theoretical constructs of Continuity of Care, specifically, relational continuity, management continuity and information continuity.

Semi-structured interviews: For objectives 1 and 3, The Health Systems Responsiveness Framework served as a map of groups of participants whose voices needed to be included in order to adequately answer the overarching research question. Semi-structured interview schedules were developed for all participant groups. In-depth interviews were chosen as the appropriate type of interview for persons with disabilities and policy makers as it

provided flexibility and the ability to probe certain responses. Focus group discussions with NGOs and health facility staff focused on how services were rendered to enhance Continuity of Care.

Interviews with persons with disabilities and families took place in their homes. All the Black African persons with disabilities live in informal settlements, some of which were deemed uninhabitable. These homes were makeshift structures of wood and iron with basic amenities such as a bed and a table. Interviewing in the informal settlements was challenging as the homes were precariously positioned and difficult to reach. The Indian and Coloured persons with disabilities lived in modest homes, made of brick.

Interviews were conducted with the help of a research assistant, and in some cases the NGO escort where this was more feasible.

Policy analysis data extraction: For Objective 2, the EquiFrame method was adapted as outlined earlier. While it was important to assess policies in relation to all 21 core concepts, it was deemed more in line with the study objectives to uncover the values that resonated with concepts of “Continuity of Care.” The 10 core Continuity of Care concepts emerged through analysis of each of the 21 core concepts. Once the 10 core Continuity of Care concepts were derived, these terms were searched for in policies. The text relating to the term was extracted and inserted into the data extraction tool for thematic analysis and broader policy analysis.

Researcher observations and field notes: In qualitative research, researcher observations refer to the firsthand, subjective accounts of the researcher based on their direct engagement with the study participants or the research context (Creswell, 2009). Emphasis is placed on researcher’s active involvement in the data collection process and the need for an in-depth understanding of the social and cultural context under investigation (Mantzoukas, 2016). This involves researchers immersing themselves in the natural settings of the participants,

observing their behaviours, interactions, and experiences. Academic leaders stress the importance of being an active participant while also maintaining a critical and reflective stance.

In this study observations were a key part of post fieldwork reflections between the researcher and the assistant. These conversations were particularly important because the assistant was more familiar with the community than I was as he lived in an adjacent informal settlement. It was an important process to ensure comprehensive understanding of what the researcher was observing versus what the research assistant was observing. A good example of difference in what we were observing was a group of men stood at the side of the car we were in. My instinct based on my observation was to move the vehicle as it felt unsafe. However, the research assistant was quick to point out that that they were actually protecting the car while we were conducting the study. This represented my own world view bias. Another example was a discussion about ablution facilities where I assumed it was outside the home of one of the participants, but it was actually a bucket under the bed. As part of the participant accounts of “Continuity of Care”, care was taken to provide vivid descriptions of the context and the living conditions of the participants. It was important to capture some of the nuances and the complexity of the situation that people described. Researcher notes provided the bases for being able to consolidate interview data and context into a coherent account of their Continuity of Care journey. Similarly, having done the policy analysis prior to conducting interviews with persons with disabilities, the researcher was afforded an opportunity to observe and assess intended policy outcome against a real-life situation. Observations made way for iterative thinking and adaptations when necessary. In the field and off the field, observing and reflecting were key to ensuring that the study remained in focus despite the challenges.

Building rapport and trust, especially when investigating issues of personal health, is often an important step in the research process, but the reality of this context presented

constraints. . Making good use of resources within the community was a strategy that assisted in overcoming some of the challenges of building rapport.

Interview guide: Several interview schedules were developed to guide the process of interviews for the various participant groups.

Interviews with persons with disabilities, and their families focused on understanding their health condition and exploring their Continuity of Care journeys in as much depth as possible. In some cases, not all questions could be posed due to time constraints or based on the researcher's observations of the ability of the participant to progress. Interviews ranged from between 15min – 90min. However, all persons with disabilities completed the general health questionnaire (Appendix D) and a baseline of their experience in health facilities could be established using this tool.

Interviews with policy makers focused on their understanding of Continuity of Care, the barriers to implementing it and what policies they thought had the potential to support Continuity of Care.

A discussion guide was used in focus group discussions with NGOs and health facility staff. The main areas included in the guide were their understanding Continuity of care and their role in the community, as well as services they provided to persons with disabilities.

Recording of data: Digital voice recorders were used to audio record interviews and FGDs. Both the researcher and the assistant had separate recorders to ensure that data was captured. Informed consent was obtained from all participants. Participants interviewed were assured of their right to privacy, fair treatment, anonymity, confidentiality, and protection from discomfort and harm. In the case of FGDs the issue confidentiality was emphasised. Audio recordings were transcribed and coded for further analysis.

Language of interviews: A combination of Zulu and English was used depending on the preference of the participant. In situations where English was preferred, the researcher took the lead and where Zulu was preferred the research assistant translated the questions verbatim. At some stages, code switching occurred where a participant who wished to speak in Zulu, said a few words in English. The participants were encouraged to speak in their vernacular language. Interviews in Zulu were translated by the research assistant who was a native Zulu speaker and fluent in English.

Data management: All the audio recordings and copies of data were saved on a laptop, with a back-up, to which only the researcher had access and was password restricted. Hard copies were kept in a locked cabinet where other documents related to the study were kept. A back up of the data was also made and kept on a local storage device that was also password protected. A study implementation plan was used to keep track of processing of data and supported good research process as well as document management.

3.7.3 Analysis and integration of Results

This study gave rise to a great deal of data necessitating the triangulation of data. Analysis was done in stages. The first stage was consolidation of streams of data. Thereafter data from interviews and FGDs were coded and analysed using inductive thematic analysis, followed by the integration of observations and fieldnotes. Data from the pre-study survey and policy analysis was reviewed in combination with KIIs and FGDs, and where possible, validation activities were initiated to ensure that the data was accurate, as outlined above under the section on Data Analysis and are further elaborated under scientific rigor.

3.7.4 Coding

A key step in processing the research data was to become familiar with the data. This was accomplished by listening to audio recordings of interviews while reading the interview transcripts and at other times reading and re-reading the transcripts. Having been involved in each interview and FGD allowed for a seamless research journey conceptually. Visual images taken of roads to and from the community being researched brought back certain memories which I included as notes and observations.

The process of coding involved the allocation of meaningful labels and categorisation of these labels into meaningful chunks. The research assistant supported the process and where there were discrepancies, discussions were had to come up with codes that were more appropriate. Recurring ideas along a similar subject was deemed as a sub-themes and themes. A sub-theme is a specific idea that is under the main theme. In this way large quantities of data are analysed in order to create overarching findings. In the same way that codes were built and discussed, so to were themes discussed and workshopped with the research assistant and PI. Once themes were finalised, the write up began with careful attention paid to ensuring that the theme name was appropriate for the story being told. The results of the study were concisely documented in a dissertation in formats that facilitate access to information (i.e. audio file/podcast).

3.7.5 Dissemination

The researcher committed to share the report with the KZN Department of Health (KZN) and the Department of Social Development. Results will also be presented at appropriate local/international conferences.

3.8 Scientific rigor and trustworthiness

The researcher followed guidelines offered by Guba (1981), to ensure trustworthiness transferability, credibility, dependability and confirmability of the qualitative data. The strategies offered by Baxter & Jack (2008) were followed to achieve trustworthiness when using a case study methodology. These include spending time in the study context prior to the start of data collection, use of triangulation and reflective journaling, and ensuring that the participants were appropriately selected and represented the population of interest.

Credibility can be achieved when the findings of a study are linked to the reality to demonstrate that findings show the phenomenon that was studied in the field. Having participants validate findings is common practice, however, in this study it was not possible to return to all of the participants as some participants had moved away or passed on. This was the case for Mrs R and Mr N. The research assistant was instrumental in accessing participants in the community and clarifying issues that were not clear during the interview. As regards policy makers and health facility staff, efforts were made to have them review the transcript. The use of reflexivity was relied upon in this study as it allowed for the careful examination of the researcher's feelings and critical thoughts throughout the research process. I also phoned the participants who had access to phones to get further clarification about the transcribed data.

Credibility was also enhanced by ensuring that the data collected mirrored the Health Systems Responsiveness Framework where all categories of participants were represented in some way. Adding a layer of policy analysis extended the investigation of context into the issue of Continuity of Care in a way that both enhanced findings but also contextualised the policy failings when interpreted with participant accounts.

The use of triangulation was a key feature in strengthening credibility of the study. Analysis from participant interviews and FGDs, policy analysis and observations enabled

consolidation in a practical and meaningful way. This was initially envisaged to be a challenge due to the amount of data. However, the rich participant accounts created images of policy failure in the mind of the researcher, making triangulation more intuitive and reasonable.

Dependability: Dependability was obtained through an explicit and detailed report of the research process. In this study, an unambiguous, step-by-step description of the research design and methodology, including data-collection and analysis procedures, was discussed and was followed to ensure trustworthiness of the research (Jozkowski, 2017).

Reliability: Reliability in qualitative research indicates that the researcher's approach is coherent across different research settings and different participants (Creswell, 2009). Member checking though not possible in many of the interviews conducted in Ward X, was implemented with health systems actors to confirm that what was captured was accurate. By using a research assist that was part of Ward X, it was possible to use his insight to clarify contextual issues that the researcher may have had.

3.9 Ethical considerations

An information sheet and informed consent for each participant group was included in the participant leaflet. All participants were required to provide informed consent before participating in the study. The informed consent forms have been added as Appendix A, B, C, D, E, F, G, H, I, J and K. Pictures were taken of the environment only and if it was a homestead it was taken with permission from the participant.

In addition the following ethical principles (World Medical Association, 2013) was taken into consideration throughout the research process as the dignity and the well-being of the respondents were of greater importance than the outcomes of the research (Durrheim & Painter, 2006).

3.9.1 Autonomy and respect for the dignity of participants

Participation of individuals in the study was voluntary. No participant was forced to take part in the research. Information letters were provided to each participant describing the nature of the study and the expectations for research participants. Participants were respected as human beings who were capable of making their own decisions. All participants were informed of their right to withdraw from the study at any time, without any explanation or repercussions. Confidentiality was maintained. Participants contact details were taken for member check. Once verified, all identifying information was removed. Codes were used to ensure confidentiality. Participants were not identified in any publication. Confidentiality was also protected by not revealing anything learned to other participants or community members. Complete privacy and confidentiality could not be ensured. Through reading the findings of the study, participants might have been identifiable through contextual information, such as the description of the program. The research assistant supporting the study was briefed on the importance of maintaining confidentiality and signed a code of conduct and confidentiality agreement. In terms of data collection strategies that required group participation, it was acknowledged that the researcher could not guarantee that confidentiality would be maintained, as other participants might disclose information. The researcher, therefore, requested that everyone in the group respected the confidentiality of others and did not speak about what was discussed. If participants were not first language English speakers, they were provided with information letters and consent forms in their preferred language. They were also afforded the opportunity to have an interpreter.

3.9.2 Beneficence

There was no direct benefit for the participants of the study. However, through their involvement in the study, participants assisted in deepening the profession's understanding of

an emerging practice. Additionally, participants learned more about themselves and the health system that they relied on. In some situations, the research team introduced the participants to aspects of health services of which they were aware.

3.9.3 Non-maleficence

It was foreseen that no participants would be exposed to harm (direct or indirect) as they provided opinions and reflected on their experiences. Participants were informed that the study would have no impact on their health outcomes and that they would not be placed at a disadvantage by providing feedback about their experience of care at the health facility. To ensure this, the following was discussed with the participants: i) the data collection would be conducted by the researcher, and therefore, the facility supervisors would not have access to the data; ii) the FGD would take place outside the facility; and iii) all data would not be able to be linked to the service user. Participants who were service providers at the facility were asked if they had any concerns related to taking part in the study, and any perceived risks were considered, with steps taken to reduce risk. In addition, names and specific details (e.g., dates, specific activities carried out, demographic information such as race, gender) that could identify the healthcare provider were anonymized so that no participants would be identifiable. All participants were informed of the research process, and no deception was used.

3.9.4 Justice

All participants were to be treated fairly and equitably. The researcher guaranteed that all results would be reported accurately in the final document. While it was intended to have participants verify their responses by providing access to the transcripts, this was not possible in some situations. In the information letter, participants are informed that their contact details were required for verification of transcripts. Once verification was completed, all identifying information was removed. It is intended that a copy of the report would be made to all

participants, if they so wish. Contact details were kept if participants indicated that they wanted access to the results.

3.10 Summary of chapter

The chapter detailed the methodology used in the study, including the primary research question and main aim and objectives. This study was designed to be exploratory in nature as flexibility and agility was needed to understand a poorly understood concept in a real-life setting with many uncertainties. In the following chapters, the findings are presented with critical discussion on its implications.

Chapter 4: Factors influencing “Continuity of Care” for persons with disabilities: Three tiers of experiences and expectations of the health system

4.1 Introduction

This chapter is dedicated to synthesizing the multi-layered findings from key informant interviews and health questionnaires which aimed to uncover general self-reported health status of participants and their experiences and expectations of the services received in PHC facilities. The chapter has four sections which provides an account of the findings from distinct but interrelated perspectives: researcher observations of the context, the person with a disability, their family and community.

Section 1 describes the **case study site and the context within which this study was conducted**. It provides detailed descriptions of the living conditions of participants residing in Ward X and unearths the social, environmental and economic realities faced by members of this community. The description is important to fully understand the additional burden these environmental and economic conditions create for persons with disabilities in attaining good health. This is gleaned through researcher observations and analysis of reports and statistics supported by photos taken during the course of the study.

Section 2 delves into the **actual experiences and expectations of persons with disabilities, families and communities as it relates to “Continuity of Care”**. The section uses participant accounts to describe the experiences of persons with disabilities in relation to the challenges faced in the management of their healthcare needs and disabilities. Each of the six participant accounts uncovered unique healthcare journeys, which when analysed aided in

the identification of specific limitations and/or weaknesses of PHC policies and practices. This information forms the background for the policy analysis chapter (Chapter 6) which explores policy and practice weaknesses and health systems responsiveness to persons with disabilities. The perspectives of family members of persons with disabilities and of community members in Ward X are also presented as part of this section.

Section 3 and 4 presents an analysis of family and community experiences respectively.

Section 5 triangulates findings from the previous four sections and unpacks the layers of factors influencing “Continuity of Care” for persons with disabilities. Key themes are explained and will be further discussed in the Discussion Section in Chapter 6. The chapter concludes with a summary of findings and reflections from the researcher.

The chapter is written in alignment with the Health Systems Responsiveness Framework shown in Figure 14 (Mirzoev & Kane, 2017), introduced in Chapter 2.

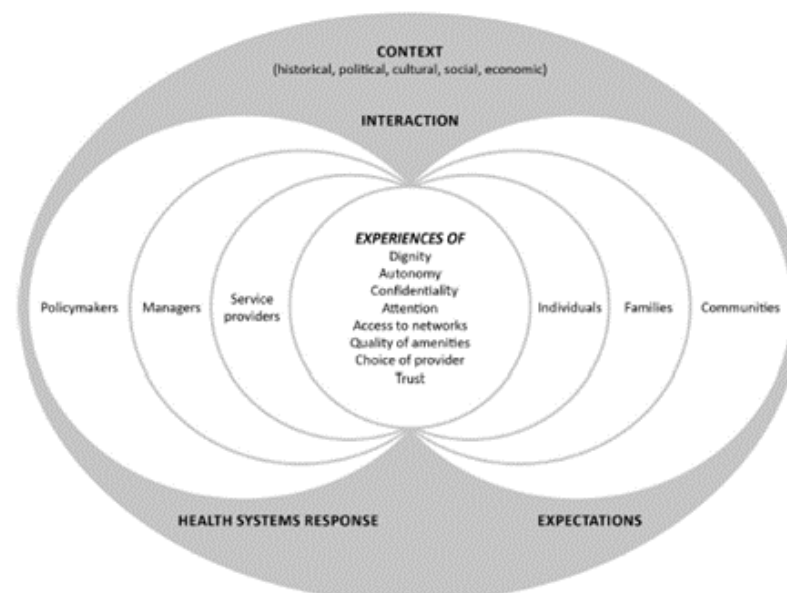


Figure 14. Health Systems Responsiveness Framework (Mirzoev & Kane, 2017)

4.2 Section 1: Catastrophic events impacting Ward X

Ward X in the last decade has been plagued with protests and civil unrest due to political turmoil and poor service delivery. As a resident of Ward X, violent protests, shootings and crimes were common experiences. However, during the conduct of the study there were three **major events** in KZN that impacted residents of Ward X. The first was COVID 19, the second was mass looting and civil unrest (of epic proportions), and the third was catastrophic flooding from storm Issa. All three of these events caused incremental and compounding negative effects on the community of Ward X, the impact of which will remain for decades to come.

4.2.1 Covid-19 (March 2021 – May 2023)

On March 2020, the first patient infected with COVID-19 was recorded in SA. On 23 March 2020 the president of the country, Mr Cyril Ramaphosa announced a 21-day lockdown to begin on 27 March 2020 – 16 April 2020. It was the first announcement of many which brought about varying degrees of lockdown restrictions affecting every facet of life. The country experienced four major waves of infection as follows:

- First wave: March 2020 – November 2020
- Second Wave: December 2020 – April 2021
- Third wave: May 2021 – October 2021
- Fourth wave: December 2021 – April 2022

Ward X residents were severely impacted in that many residents worked in the informal sector as gardeners and domestic workers and could not generate an income. According to OXFAM, when SAs went into hard lockdown on 26 March 2020, many informal workers and precarious workers found themselves without any means of generating income. The National

Income Dynamics Coronavirus Rapid Mobile Survey estimated that nearly three million people lost their jobs as a result of COVID-19 restrictions. In Durban, unemployment in the eThekwin Municipality increased to 22% with more than one million people reportedly looking for work in January 2021.

4.2.2 KwaZulu Natal's violent insurrection and mass looting

From 8 – 17 July 2021 the provinces of KZN and Gauteng experienced violence and civil unrest, the worst since the end of the apartheid, that included looting and vandalism. Analysis of the violence included “

tensions and factionalism within the governing African National Congress (ANC); stereotypical Zulu nationalism; frustration of hungry and cold people whose prospects were already constrained by the pandemic; racial tensions in the country; and the inequality between the rich and poor in SA” (Patel & Everatt, 2021, p. 1).

The unrest was thought to have begun by supporters of former President Jacob Zuma in protest against him having to serve a 15-month prison sentence for contempt of court (Makonye, 2022). Supporters in his home province of KZN set up roadblocks on major highways and burned trucks.

The unrest spread within KZN, where shopping malls and centres were ransacked by crowds of people that stole food, electronics, clothes and liquor. In Durban and Pietermaritzburg, crowds attacked the warehouses of major retailers and factories, setting them alight.

Ward X sits on at the edge of two major industrial zones. The first is the Springfield Industrial Park and the second is Pinetown. Both have large warehouses and storage facilities,

and function as the main distribution centre for stores like Makro and Game. The unrest lasted for a week until 25,000 army troops were deployed to the area under the instruction of the president.

Extensive damage was done to 161 malls and shopping centres, 11 warehouses, eight factories and 161 liquor stores and distributors, according to the government. An estimated 10 billion rand (\$680 million) was lost in stolen goods, burned trucks and destroyed property (The South African Government, 2021).

Many of the residents of Ward X who participated in the looting are employed in these warehouses and factories. The loot was carried into informal settlements in many cases and stored in fields within adjacent communities. Figures 15 and 16 below show pictures of dramatic scenes from this event.



Figure 15. Media coverage by Mail and Guardian of July 2021 unrest



Figure 16. July 2021 unrest - chaos on roads (Mail and Guardian)

4.2.3 Catastrophic Flooding: Storm Issa

Between 8 and 21 April 2022, the province of KZN was severely impacted by storm Issa. It caused flooding and mudslides across the province affecting over 40 000 people. Several thousand homes were damaged or destroyed. Critical infrastructure, including major roads, transportation, communication, and electrical systems, were damaged, and many communities living in Ward X were severely afflicted as their homes were built on open, unsafe and low-lying areas. Health services were disrupted, and people could not access food and water for days. Figures 17 shows a picture of the flood disaster in Ward X.



Figure 17. Photos of flood damage

4.2.4 Community Resources in Ward X

Pre-study activities involved collecting information about the organisations in the area working with persons with disabilities and exploring the resources available in the community. Figures 10-20 are aerial pictures of 2 informal settlements. Photos were taken of the surrounding areas to capture the overall environmental conditions of Ward X. There were also attempts to reach out to the ward councillors and political party representatives. Some of the larger organizations of persons with disabilities were open to assisting the researcher but did not have persons with disabilities registered in Ward X to whom they could connect me. The search continued through the public health facility, and the researcher was referred to a new NGO (Bridging the Gap) funded by the Centre for Disease Control through the HST who had some documentation regarding persons with disabilities. As part of their own outreach programme, they were able to assist us in accessing four families in the most remote areas in Ward X. Another 2 participants were found by the researcher visiting communities on foot and seeking assistance from local residents. In this way we were able to find six persons with disabilities who were open to participating in the study.

Infrastructure in this community was observed to be very poor and had been worsened by the impact of the disasters described earlier in this section. It was not uncommon to see sewage overflowing onto the street, abandoned houses overrun by prostitution and drug trafficking, poor quality roads and garbage not collected for weeks. Theft of electricity, poor access to water and sanitation seemed commonplace and based on the lack of response from the ward counsellor and the general environmental decay observed, the area seemed to lack political prioritisation. The researcher had attempted to contact the ward counsellor as this was recommended as the first port of call in accessing the community. After several calls and e-mails, it became clear that he was not a functional counsellor, and this was confirmed when the

community was consulted. It was reported that due to his lack of service delivery, he was driven out of the community and was unable to resume his function for fear of his safety.



Figure 18. Informal settlement in Ward X



Figure 19. Informal settlement 2 in Ward 2 -



Figure 20. Informal settlement 3 in Ward X



Figure 21. Sewerage leaks in Ward X

Figure 21 above was a picture of the road the researcher travelled on to access the site. There are 2 clinics that serve Ward X, the Clare Estate Clinic and the Reservoir Hills Clinic about 8 km away from each other. The researcher was only given permission to access the Reservoir Hills clinic as there were many activities taking place at the Clare Estate Clinic. The Clare Estate clinic was established before the 1980s and is located on the edge of one of the largest dump sites in the southern hemisphere. The Kennedy Road informal settlement is home to thousands of people. The Reservoir Hills clinic on the other hand is newly built and services a much smaller population than the Clare Estate Clinic, pictured in Figure 22-24.



Figure 22. Clare Estate Clinic

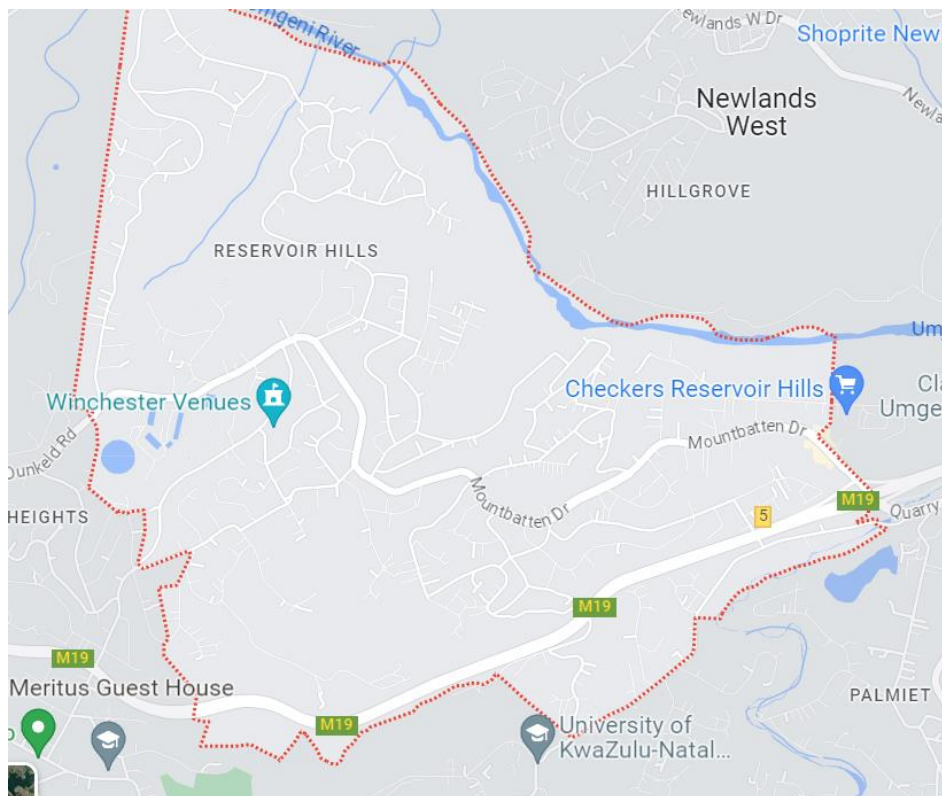


Figure 23. Municipal demarcation of Ward X



Figure 24. Reservoir Hills Clinic

The following organizations outlined in Table 7 on the next page were identified as having a strong presence in the community:

Table 7: CBO supporting persons with disabilities in Ward X

Name of Organisation	Description of services	Role in supporting persons with disabilities
NGO 1	To build the capacity of young people in the community by engaging them in innovative, productive, constructive, exhilarating pro social interventions within their Circles of Belonging in communities, schools, organizations, peer groups, and families. Their approach recognizes, builds and enhances young people's strengths and provides opportunities, fostering positive relationships, and supplying the support needed to build on their leadership strengths. They provide training to clients for effective program implementation in line with NDOH policies, render quality services and deliver on time using effective measures. They also provide gender sensitive HIV prevention services in order to increase uptake of rendered services.	Disability is not a core focus of their work. However, as part of their mainstream services, they identify vulnerable households.
NGO 2	A newly established community-based organisation whose leadership live in the community of Rainbow Ridge.	General home-based support to vulnerable residents at Rainbow Ridge.
NGO 3	Provides support to elderly residents and organises and cultural and recreational activities for the community of Ward X.	Provides transport to vulnerable people in order for them to access health and social services.
NGO 4	A non-profit frail care facility providing services to elderly and persons with disabilities.	Provides support to residents of centre to access medication. Provides guidance and support to families of residents of the centre.
NGO 5	A disaster response NGO.	persons with disabilities are beneficiaries as part of the broader provision of services during times of crisis.

The interviews analysed for this chapter were conducted in participants' homes in Ward X. The support provided by community leaders and representatives to locate persons with disabilities living in the area proved invaluable in enabling the variety of individual and family voices to describe their health journey and experience of care. This chapter additionally explores the perspectives of the community and the health system actors as represented in the conceptual framework used in this study.

4.3 Section 2: Tier 1 - Experiences and expectations of persons with disabilities

In this section, the experiences and expectations of participants with disabilities, family members of persons with disabilities and community members are presented. “Continuity of Care” journeys” are used to describe the lived experiences of participants with disabilities and rich detailed descriptions of families’ experiences are used to elevate the experiences of persons with disabilities through the eyes of their families. Interviews with members of the community are used to explore broader issues related to “Continuity of Care” for persons with disabilities. The study included six persons with disabilities, one of whom was not interviewed due to the severity of his disability, but due to the uniqueness of his case an interview was conducted with his mother.

The description of the participants with disabilities are outlined in Table 8 below and each participant journey includes introductory information obtained from the health questionnaire. The health questionnaire was an important component of the study methodology as it highlighted medical conditions experienced by each participant with a disability. The data from the health survey formed a solid foundation from which probing questions could be crafted to understand the journey in more depth. Each participant “Continuity of Care” journey” culminates in policy and practice observations, thereby illustrating policy and health system strengths and/or weaknesses. Each participant interview was broadly guided by the interview schedule, however, in certain instances as was the case with participant IDI07, an interview was not possible, and the family member was interviewed.

Table 8: Biographical details of individuals with disabilities included in the study

Identifier	Age	Sex	Language	Population Group	Disability/Health condition and consequence	Self-description of disability	Nationality	Living Situation
IDI001	84	F	English	Indian	Severe Arthritis and depression. Unable to walk without assistance	Acquired as a result of medical condition	SA	Granny cottage / shared room in a house
IDI002	65	M	Zulu	Black African	Bilateral lower limb amputee	Acquired as a result of severe sepsis	SA	Informal dwelling / shack in an informal settlement
IDI003	76	F	Zulu	Black African	Lower limb dysfunction due to congenital spinal deformity	Congenital	SA	Informal dwelling / shack in an informal settlement
IDI004	41	M	Zulu	Black African	Cerebral Palsy	Congenital	SA	Informal dwelling / shack in an informal settlement
IDI005	54	M	Zulu	Black African	Bilateral Upper limb amputee	Acquired as a result of injury by electrocution	SA	Informal dwelling / shack in an informal settlement
IDI006	58	M	English	Indian	Yes, Paraplegia	Acquired as a result of a stroke	SA	Stand-alone brick house

The “Continuity of Care” journeys that follow provide detailed narratives of how persons with disabilities interviewed experienced care over time. Each journey has been given a title based on the most significant issue noted in their story.

4.3.1 Mrs R’s “Continuity of Care” Journey: Who is my care provider when private and public health journeys intersect?

Age: 87

Sex: Female

Language spoken: English

Population group: Indian

Disability (Self-Reported): Yes, result of a medical condition

Nationality: SA

Medication: Taken daily for hypertension, kidney disease, depression and gout

Access to basic healthcare: Public clinic and private general practitioner (GP) and psychiatrist

GP / Dr visits: Every 6 months to the local for clinic and every three / four months to the private psychiatrist / GP

Professionals usually seen: Nurse and GP

Table 9: Mrs R's experience of "Continuity of Care"

	I Agree 1	I Disagree 2	I don't know 3
I see the same doctor every time			
My medical history is well documented			
I understand everything that is said to me			
My healthcare team shares information between them, so I don't have to repeat myself			
My healthcare team knows me very well and understands my challenges			

Mrs R is an 87-year-old female diagnosed heart disease, chronic depression and hypertension with associated kidney disease and significant mobility restricting oedema in both feet (Gout) which prevents her from walking even a few meters. She reported having depression since her mid-thirties, and most of her other medical conditions started in her fifties. She was observed to have mild hearing difficulties which could possibly have been age related, requiring some questions to be repeated. Mrs. R was interviewed in her home in Ward X. She lived alone in the basement of her niece's home almost all her life. Her house was observed to be below road level and accessed only by walking down a very steep tarred driveway. My observations as I walked into her home was that it was small and neat with a single bedroom, a small kitchenette and a small living room. There was an indoor bathroom and while it is small, she was proud to have a place of her own, though it was becoming increasing difficult for her to manage with household chores.

Mrs R was well enough to hold a conversation and besides her discomfort from her swollen feet, she appeared in good spirits at the start of the interview. When asked about her general health she responded:

"I got circulation problems. It is not that bad, I get the swelling, it's very stiff and tight and all and I can't walk now. Now both the knees are affected ... I find it difficult to go outside and to hang cloths and sweep the yard because I can't balance on both my knees"...

“I take tablets for the angina, depression, high blood pressure, water tablets for the kidneys and medication for gout”

Medical History: Mrs R recounted her early years and spent her entire life working to support her family. She recalled having good health in earlier days but started experiencing problems in her 50s when she began to find it difficult to climb up stairs and had shortness of breath. She had also experienced bouts of depression shortly after her marriage due to a physically abusive husband but was able to continue working and successfully raised her two children despite the fact that her husband died when her children were still young. At 84 years old, she reported significant mobility challenges, but was determined to maintain her independence for as long as she could. She explained that she was very frustrated being unable to get up easily off the chair and walk for long distances, so spends most of her time sitting in her home and watching TV to pass the time.

Experiences of health services: Mrs R explained that she was a pensioner and reliant on public health system, however due to challenges she experienced at the clinic, she also had to access services from the private health sector. She visited the local clinic every month to collect her medication and was seen by the clinic doctor every 6 months to renew her medication for her hypertension and gout. On these occasions, she reported waiting times of about 2 hours in a queue despite her mobility challenges and being elderly.

“...the doctor herself told the nurse, this patient is old and must not follow the queue and the doctor said the younger one’s must wait for the elderly to finish first. Naa, the nurse didn’t, she said I must go and have blood test and I must go follow the queue.”

Mrs R was prescribed - antidepressants; however, she could not receive these from the clinic and was told to collect them separately from the King Dinguzulu Hospital Complex, about 4 kms away from the clinic. Due to her swollen legs, Mrs R was unable to wait in the

long queues at the hospital. She attempted to follow the referral pathway and receive her care from the King Dinguzulu Hospital Complex on several occasions, but due to the long waiting times which sometimes exceeded 4 hours, she decided it was better to go to a private psychiatrist instead and get her medication at the pharmacy where she was also able to access her other medication as part of the Chronic Care Medicines Dispensing and Distribution (CCMDD) programme. Additionally, if she fell ill between clinic visits, she would ask her niece's husband to take her to a private GP who would provide medication for her swollen feet. When asked about where she received her care for her kidney problems, she indicated that she also received regular check-ups for her kidney function at the private GP when she could afford to, as the health facility did not do such checks. She explained that in addition to public clinic visits twice a year, she visited the private GP about once a month to seek care for swollen feet from what she described as her failing kidneys, resulting in general swelling, inability to urinate and general discomfort.

Her major challenge was her inability to receive all her medication through the public Chronic Care Medicines Dispensing and Distribution (CCMDD) programme which meant that she had to incur substantial out-of-pocket expenses, paid for by her children.

According to the department of Health, the CCMDD programme provides an alternative mechanism to facilitate access to medicine for stable patients. External pick-up points (PuPs) provide the patient with a more convenient option for the collection of their repeat medicine which has been dispensed and distributed via the programme. The PuP may be closer to their homes or workplace and can result in reduced transport costs.

Judgement of quality:

Despite her challenges Mrs R still reported quality of care as “*not that bad.*” She explained that since being on the CCMDD programme she did not need to go into the clinic

but picks up her medication from the pharmacy. Prior to the CCMDD programme, she would pick up her medication monthly from the clinic and would call the nurse who knew her well and would have her medication ready as soon as she arrived. The nurse however, had since died and this had an impact on Mrs R as she missed the trusting relationship that she had found in the nurse.

“...she was coloured and she was very, very helpful and you will never find her angry...she was humble, she was pretty and a caring person”

“Just last month I went, and I had problems because the new person didn't know I went to pick up the medication, they telling me to go for blood tests and urine tests and follow the queue and I had to wait for little while then they came and knew I came up to pick up my medication only; and then they gave it to me”

“I would say they not that bad. They, you know, had problems to find my file because new workers was there ... like you know they had to look for my file and it took long.”

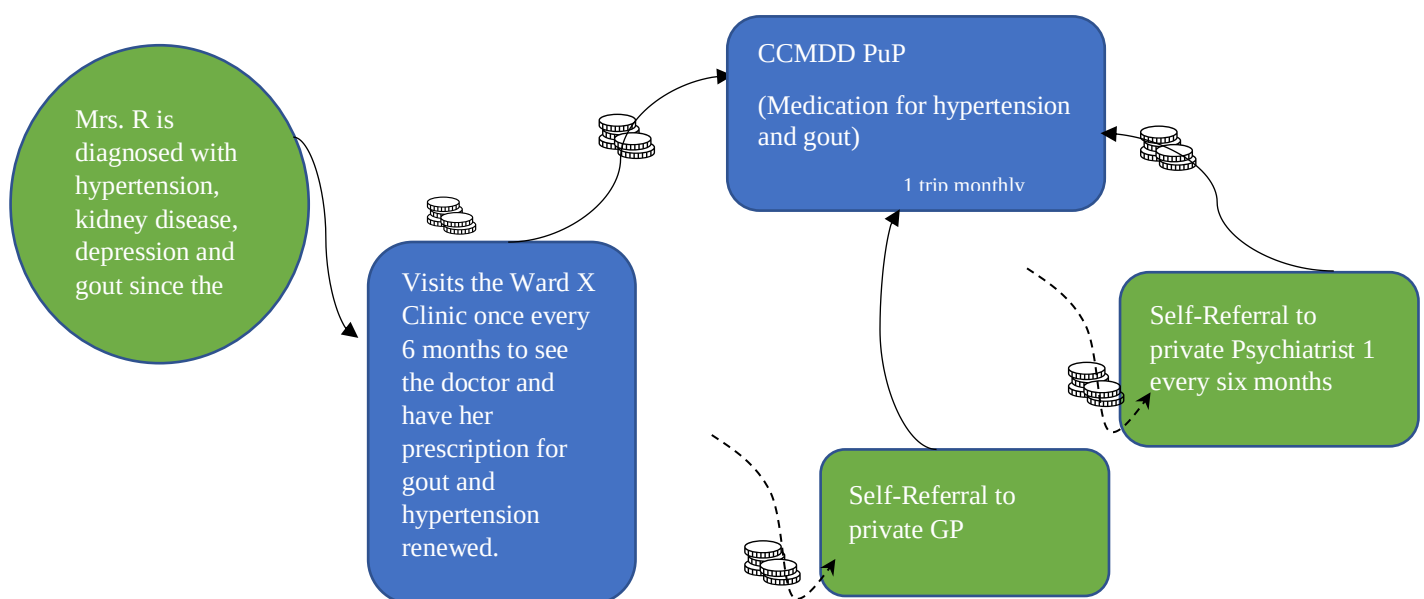


Figure 25. Mrs. R's "Continuity of Care" Journey

Strategies used by Mrs R that impacted her “Continuity of Care”:

- In the past the trusting relationship between the nurse and Mrs R made her experience at the health facility less burdensome as the nurse anticipated her needs and had her medication ready ahead of her arrival.
- Borrowing money from her family to pay for GP visits and specialist psychiatric services so that she could access care when necessary.
- Having generally low expectations of both private and public health systems assisted her by strengthening her resilience to endure the process.
- Having strong community networks to assist her with transport to the clinic.

“For the old people who stay at home they have a taxi service. When it’s clinic day they bring them in a taxi and take them home. I think they pay. Somebody takes me, but now she is sick, I ask the uncle upstairs to take me sometimes. I must make my own arrangements to go but if I have nobody then I have nobody I have to go myself.”

Expectations of the health system

Mrs R’s expectations of the health system were simple and clear. She wanted the persons with disabilities and the elderly to be acknowledged and given priority at health facilities.

“I will tell that people over 70, they are elderly people they must not let them follow the queue they must have separate queue.”

When asked about how she will continue to maintain her healthcare she replied:

“I don't want to think beyond, I just want God must take me away while my hands and legs are working, and I can still move. I don't want to think beyond that.”

Policy-practice observations

Mrs R's case in Chapter 4 serves to highlight **sub-optimal implementation of the Referral Policy for South African Health Services and Implementation Guidelines 2020**.

While the policy aims to create a health system that is interlinked to safeguard users of the health system, Mrs R's experience demonstrated that the policy was not being implemented appropriately. Referral is defined in this policy as "processes of how professionals and institutions communicate and work together to protect, promote and restore the health of an individual. This movement of a patient to another level of care could be internal, upward, downward or lateral for "Continuity of Care".

The policy states that a "*well-functioning referral system that allows for "Continuity of Care" across different tiers of care is central to the delivery of efficient and effective healthcare towards achieving universal health coverage*"(Department of Health, 2020b, p. 5).

Furthermore, Mrs R's "Continuity of Care" journey was negatively impacted by poor implementation of the guiding principles of **accessibility, continuity coordination, person-centredness and quality**, previously outlined. Her dependence on both private and public health services was due to weaknesses at the PHC facility and the hospital complex, which in turn resulted in her having to pay out of pocket to bridge the service coordination gap. The coordinating responsibility according to the Referral Policy is the patient's primary care provider, which in this case, is unclear. Is it the private GP who sees her more regularly or the clinic doctors consulted twice yearly who should negotiate her care within the public health system?

It is unsurprising therefore that in the absence of adequate coordination and communication between the GP and the clinic doctor, Mrs R's care began to deteriorate into a

patient-directed course of care which quickly became un-coordinated, inefficient and costly. It became necessary for her to visit a private facility because her needs were not correctly identified at both primary and secondary levels of care, by her primary care provider, demonstrating the poor informational and management continuity that exists between private and public facilities. Services were also not organised around Mrs R who had multiple and very complex health needs, including mounting challenges associated with her disability. If she had been identified as a patient with multiple and severe co-morbidities with mobility and financial difficulties, the primary care provider would be in an ideal position to support her “Continuity of Care”. If the primary care provider had applied the principles of person-centred care, a call to King George Hospital to arrange transport, a shorter waiting time or a wheelchair to facilitate a more appropriate level of care fit for her needs, which is possible under the current system of legislated responsibilities.

There are also potential limitations of newly implemented programmes, which are designed with good intentions, but in the absence of flexibility to apply person-centred care, many people will be trapped in a new web of challenges they may not have encountered if the programme did not exist. In Mrs R’s case, had the CCDMM programme been able to support her access to her anti-depressants, she would have been able to pick up all her medication at the pharmacy. In addition, she incurred out of pocket expenses to pay for services from a private sector psychiatrist who provided her with a script for her anti-depressants which she then collected from a local private pharmacy. While Mrs R found a practical solution to a challenge borne out of a newly implemented programme, her out of pocket expenses were not justifiable. Her “Continuity of Care” story is one that demonstrates the challenges of a dual healthcare system in SA, and lack of adherence to important health service quality standards such as coordination and person-centred care in the context of persons with disabilities. It also

highlights significant breakdown in the implementation of the Referral Policy in SA which is meant to facilitate ease of navigation between levels of the healthcare system.

4.3.2 Mr N's "Continuity of Care" Journey: Traditional healers hold a key through their powerful "trusting relationship" with people

Age: 65

Sex: Male

Language spoken: Zulu

Population group: Black African

Disability: Yes, Bilateral lower limb amputations as a result of infection after injury

Nationality: SA

Dwelling: Shack in an informal settlement

Health condition: Hypertension – diagnosed shortly after infection began

Medication: Short course, taken daily for hypertension after injury when it was diagnosed

Access to basic healthcare: Public health services

GP / Dr visits: None prior to the injury

Professionals usually seen: Clinic nurse.

Table 10: Mr N's experience of "Continuity of Care"

	I Agree 1	I Disagree 2	I don't know 3
I see the same doctor every time			
My medical history is well documented			
I understand everything that is said to me			
My healthcare team shares information between them, so I don't have to repeat myself			
My healthcare team knows me very well and understands my challenges			

Mr. N was identified by an NGO that assisted with locating persons with disabilities in Ward X. The participant lives in a shack dwelling made of wood and old rusting tin, in an informal settlement. The settlement mushroomed in the early 2000s as more black Africans migrated towards city centres. His home is at the end of a cul-de-sac and across from the settlement's ablutions facilities, which he is unable to access easily due to his disability. He was seated in a wheelchair when we met him outside his home. The wheelchair looked old and rusty, and it was clear that it was not well suited for the terrain or his body. The wheels were rusty and bent and it did not appear to be a comfortable fit. He's general condition was poor as he looked very thin, and he appeared to be in some pain, though he indicated that he was well and could participate in the interview. His home was a single room, and it was evident by the multiple holes in the roof that this was not a healthy place to live. The interview was conducted just outside the entrance of his home and the research assistant, and the CCG from the NGO assisted with translation.

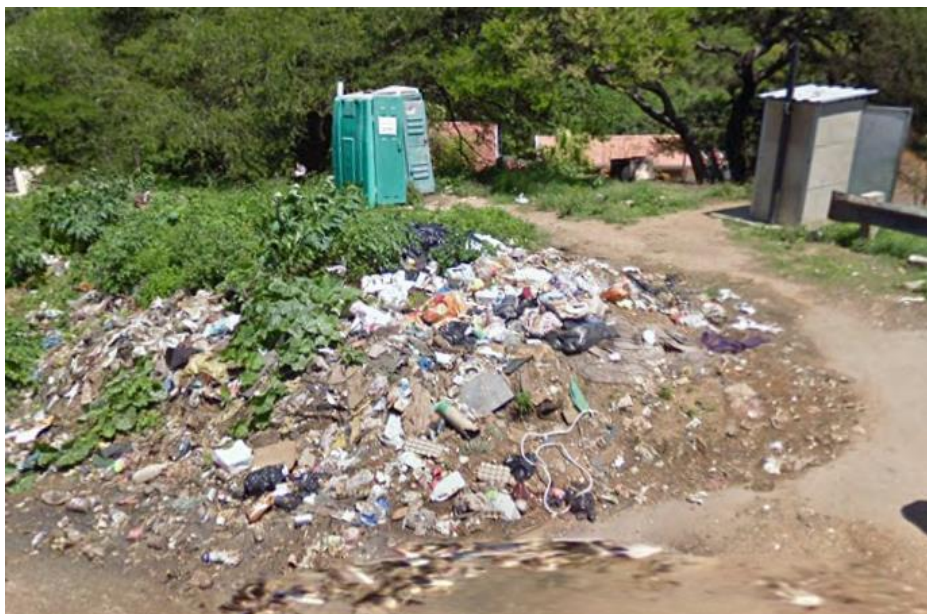


Figure 26. Toilet facilities used by Mr. N.

He was willing to participate in the study and understood why he was approached to participate. The interview took place outside his dwelling, on rough, uneven terrain. He was able to provide informed consent. The participant looked tired but denied feeling unwell. The researcher kept the interview short based on observations and obtained only the most critical aspects needed for the interview. His story was a startling journey of poor “Continuity of Care”.

Mr. N described himself a hustler who sold steel and metal to the scrapyard and fisherman at the local river. In 2018 he was injured by stepping on rusty metal pieces. He described loss of feeling in his feet due to inflammation and as the infection progressed, he knew he needed help. His instinct was to access care for his badly infected foot from the local traditional healer instead of the public health facility located about 3,5 km up the road. He explained that the traditional healer proceeded to make multiple cuts on his foot with a razor resulting in gross sepsis. His sepsis progressed despite his attempts to try and keep it clean by washing regularly. On one particular day, whilst attempting to bandage his foot, he felt an itch which his wife investigated further. The sepsis had progressed to such a degree that maggots had infested the wounds and were crawling inside his foot, resulting in the itchy sensation.

“I decided to remove the maggots with a matchstick and put the maggots in a bowl like thing, because I had this belief if something like this happened, it means you are needed home in the farm.”

Mr N’s cultural belief led him to return to his home in Nkandla as he felt that the injury and infection was a sign from the ancestors that he was needed there. The infection and maggot infestation prompted him to return home where the infection got even worse. He was taken to a clinic in his hometown and was then transferred to a hospital in Nkandla. From there he was transferred to Ngwelazane Hospital where he was advised of the need to amputate both legs.

During his time at the hospital, he was diagnosed with hypertension and given a short course of medication. He was provided with a referral note to the nearest clinic to his home in Ward X, where he was further managed by the clinic staff and the Community Care Giver (CCG) allocated to Ward X.

“They gave me the card with squares, and I collected medication, and they said after completing all of these squares in this card you won’t need to take medication anymore. I completed all the squares in the card and that was the end of me taking medication”

Having a CCG visit him as opposed to him travelling to the clinic was something that he appreciated as travelling to the clinic would have meant hiring someone to push him to the clinic in his wheelchair or hiring someone to take him by car. However, Mr N did not seem to have a good grasp of what hypertension was, nor did he appear to understand the reasoning behind his short course of medication.

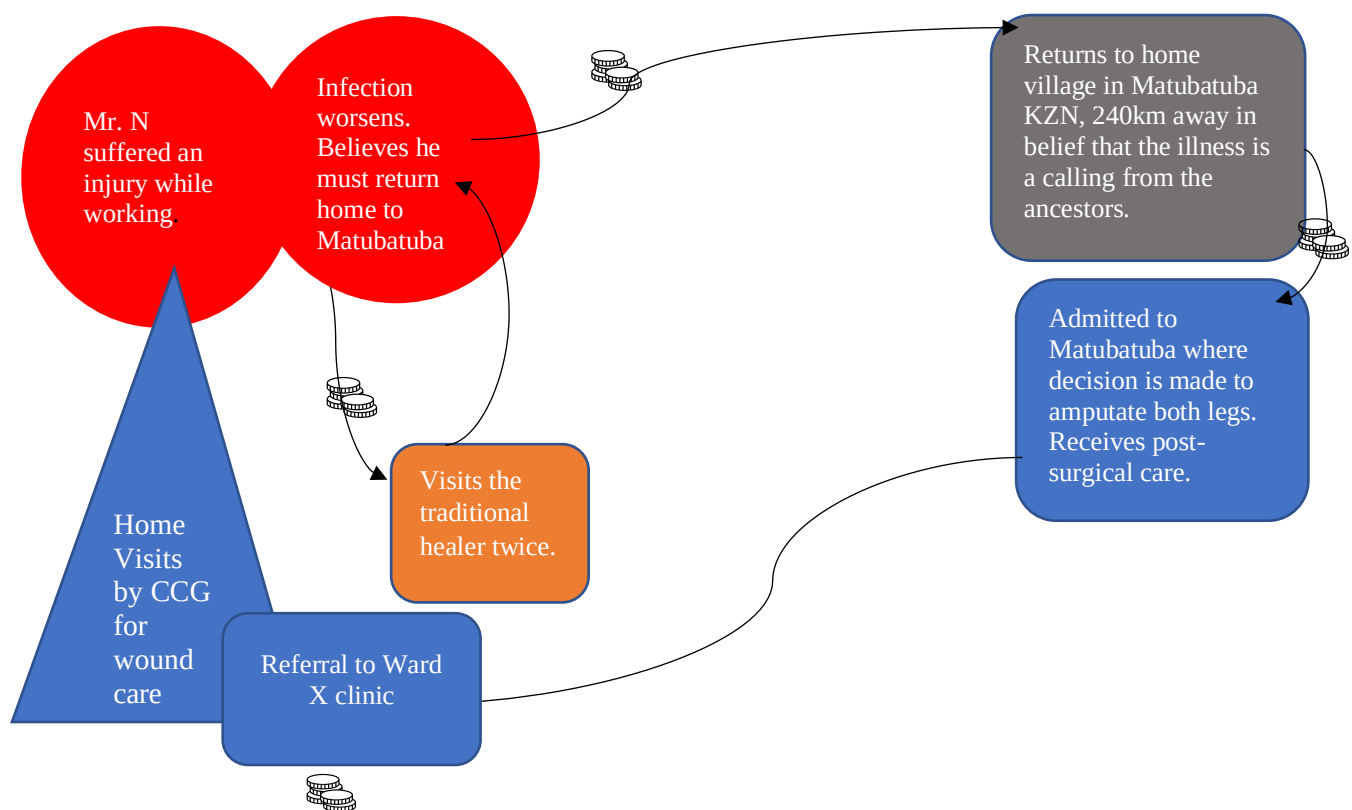


Figure 27. Mr N's "Continuity of Care" Journey

Mr N's health seeking decisions influencing his continuity or care journey

- Mr N's first port of call for assistance was the local traditional healer. His trust in traditional support and treatment seemed to outweigh trust in the public health clinic.
- When his symptoms progressed after treatment from the traditional healer his trust in his cultural practices and traditional beliefs outweighed his belief in accessing care from the clinic.
- His decision to abandon his traditional practices and seek care from a hospital in his hometown was taken as a last resort after he had exhausted all other traditional support.
- He accepted the medical diagnosis and decision to amputate his limbs and followed the referral pathway back to the local clinic in Ward X after surgery and post-surgical care.
- Once back in his home in Ward X, Mr N relied on CCGs to provide wound care support.

Experience of healthcare: Despite his initial reluctance to access care at the clinic first, Mr N felt that he was treated well at the local clinic post-surgery as he did not need to follow the queue like other people. He also felt that his medical information was well documented and that everyone at the clinic knew his condition. He did not need to repeat his background information each time and reported being fully satisfied with the services provided at the clinic.

Mr N's Expectations of the health system

At the time of the interview, Mr. N was not attending the clinic regularly but his message for those governing health services was as follows:

“The thing that I wish most from government as I live here and I don't have a toilet firstly, and I don't get tissues you see and most of the thing that the community get I don't get it and because I don't work. And this house I'm living in, it has holes in the roof, so if it's

raining, I have problem because I'm disabled, and my bed gets wet. My wife faces all the hardships because she does everything and the other thing I always over think is that when the shacks burn because most of the time incidents happen, how will I survive because I can't escape because I'm disabled."

He also requested access to a new wheelchair as he was having to repair the chair by himself.

"y'all can't help me with a new wheelchair? ... because this one is old, and you see here I have even sewed it myself."

Policy-practice observations: Mr. N's case is an example of how traditional practices if not fully integrated into the health system can lead to poor "Continuity of Care". At the level of the community, Mr N's story highlights two important issues; the first relates to traditional healers and their impact on "Continuity of Care", the second relates to PHC outreach services delivered by CHWs and CCGs and their relevance in bridging the gap between communities and the health system. These two issues are unpacked in relation to Mr N's "Continuity of Care" story.

The role of Traditional healers in advancing health, preventing disease and facilitating access to care: Mr N's "Continuity of Care" journey highlights the importance of incorporating traditional health practitioners into the health system, particularly within the PHC context where appropriate linkages to care can be made. The significance of partnerships with traditional health practitioners was internationally acknowledged in 2003 when WHO officially called on African governments *"to accord formal recognition to traditional medicine, create an enabling environment for its practice, and integrate the time-honoured system of medicine into their national health systems"*. Underpinning this call was the undeniable role that traditional medicine played in the *"combating multiple and complex conditions affecting*

Africans, and that because of its popularity, accessibility and affordability, more than 80% of the people in the Region continued to rely on it for their health care needs” WHO (2003)

called for the following measures to be taken by African countries (World Health Organisation, 31 August 2003, p. 1):

- Investment in research and development to validate claims on the safety, efficacy and quality of traditional medicines;
- Documentation of inventories of effective traditional medicine practices;
- The development of national formularies on traditional medicines with evidence of safety, efficacy and quality;
- Large-scale cultivation and conservation of medicinal plants, development of local production of traditional medicines, and the protection of intellectual property rights.

The focus of WHO’s call to action emphasised the need to enhance scientific merits of traditional medicine and focused less on healthcare delivery systems that support integration of traditional health practitioners into national health systems. However, at its Sixty-Seventh World Health Assembly, a notable shift in approach was recorded where WHO called on member states to:

(1) adapt, adopt and implement, where appropriate, the WHO traditional medicine strategy: 2014–2023 as a basis for national traditional and complementary medicine programmes or work plans;

*(2) develop and implement, as appropriate, working plans to **integrate traditional medicine into health services particularly primary health care services**;*

(3) report to WHO, as appropriate, on progress in implementing the WHO traditional medicine strategy 2014–2023.

A recent review of legislation around traditional health practitioners in Southern Africa found that SA is one of four countries with legislation relating to Traditional Health Practitioners (THP) (Abrams *et al.*, 2020). In addition to Namibia and Zimbabwe, it has also acknowledged the roles and importance of THPs in healthcare delivery by creating a council to register and formalise practices, although they have not operationalised nor registered and defined THPs. Additionally, power is allocated to the council to decide or recognise who a THP is; and can prescribe procedures to be followed for the registration of a THP (Abrams *et al.*, 2020). While there are pockets of success in integrating and involving traditional health practitioners into the health system, there remain important unresolved debates around how best to incorporate them into health service delivery, whether traditional healers want to be included into the health system, whether health professionals want to engage with traditional health practitioners and how to best regulate the profession of traditional health practitioners (Mokgobi, 2013).

Mr N's case underscores the need for the operationalisation of legislation and regulation of traditional health practitioners with specific relevance to improving linkage to care and "Continuity of Care". However, it is important to note that certain approaches legislatively are also designed for control and authority. Just as apartheid has subjugated certain groups, so too does the health system appropriate that kind of thinking into its mechanisms for control. The shortage of health professional versus the abundance of traditional healers in community settings and the reality that most people have strong cultural links and established relationships based on trust makes for a strong argument for traditional health practitioners to be integrated into the health system. A strong argument can also be made for regulation, training and cross disciplinary understanding between traditional health practitioners and western trained health professionals. Establishing parameters for engagement could help avoid complications such as those experienced by Mr N. The combined effort of traditional and complementary support

from THP with timeous and appropriate referral to a healthcare facility may result in positive outcomes such as not having to undergo amputation.

4.3.3 Mrs M's "Continuity of Care" Journey: Community networks of support work at the worst of times.

Age: 69

Sex: Female

Language spoken: Zulu

Population group: Black African

Disability: Yes, congenital back deformity resulting in paraplegia

Nationality: SA

Dwelling: Shack in an informal settlement

Health condition: Hypertension and diabetes

Medication: Chronic medication taken daily

Access to basic healthcare: Public health services

GP / Dr visits: She visits the clinic monthly to collect her medication

Professionals usually seen: Clinic nurse

Table 11: Mrs M's experience of "Continuity of Care"

	I Agree 1	I Disagree 2	I don't know 3
I see the same doctor every time			
My medical history is well documented			
I understand everything that is said to me			
My healthcare team shares information between them, so I don't have to repeat myself			
My healthcare team knows me very well and understands my challenges			

Mrs. M was identified through Bridging the Gap as she was part of the population covered by their outreach services. It was treacherous journey trying to find her home as it lay deep in the valley along the banks of the Palmiet River. Getting into the settlement required the

vehicles to travel in convoy on the bank of a river to access the home. The CCG who services this community, was unable to locate the settlement. However, after several calls to community members we made our way on foot along the riverbank, then across a precarious makeshift bridge, up a large rock upon which Mrs. M's shack was built. .

Inside her small shack, Mrs M sat with a broad smile. Her daughter and three grandchildren were present. Her daughter and children stay in a 3mX3m room, not far away. However, all the family activities occur in Mrs M's home. She is the only one who has a bed. Her home was made of badly rusted tin, riddled with holes and gaps in the roof. Unlike Mr N's, this one seems more organised and cleaner, though dangerously situated on the top of a large rock overlooking the river. It was very evident that the room was not weatherproof.



Figure 28. Informal settlement where Mrs. M resides



Figure 29. Makeshift bridge used to carry Mrs. M over the river to

The daughter preferred to speak on behalf of her mother as she indicated that her mother probably would not be able to answer all the questions. Mrs M was able to provide consent and was satisfied that her daughter would assist with the interview and translate questions so that she could understand it better.

The interview was conducted shortly after the unrest and the general atmosphere was cautious. Many people in the community looked suspiciously at our team as we entered the informal settlement. It was clear that the interview needed to be done quickly given the potential security risk, assessed by the CCG accompanying us. All COVID 19 precautions were followed; gloves, masks and hand sanitizer were used by all involved.

Mrs M smiled throughout the interview and seemed glad to have people visit her. Much of the basic information was gleaned from her daughter.

Mrs M was born with a congenital malformation of her spine. She was hospitalised several times before the age of 5 years old. The spinal deformity resulted in her growth being impacted and her daughter explained that her mother was shorter than what she would consider

as normal. Her daughter reported that her mother was diagnosed with diabetes and hypertension later in life and at present it was uncontrolled and according to her, was linked to community members “stressing her out”.

“she was born like that, because she told me when I was small, she’s been in hospital more than five years. Like she was going to have a lump on her back, so at the hospital they tried to stretch her, so now she is not normal, she is shorter than a normal person, so that’s what I know”. (Daughter of Mrs M)

“yeah , she has B.P [hypertension] , SUGAR [diabetes] , so and her B.P is worrying her too much. I think it because of the place we staying in, because the people they always making noise, they fighting ... She is trying to separate them, trying to talk to them and that is the thing that's makes the B.P go high every time”. (Daughter of Mrs M)

Mrs M’s living conditions were reported to be poor as her shack was run down, cooking, sleeping, bathing and toilet facilities all occurred in her single room. This was due to the impossibility of moving her without the assistance of a few people.

“The place that we live, it not good for her because she can’t move, she can’t go to toilet freely because the toilets are too far, so every time she needs to go to toilet, she must make it here and we must take it and throw it and then when she wants to pee, she must make it in a bucket, then we must take it and throw it for her. It is very difficult because everything she must do it here and as you see it’s a one room house, we even cook here.”

Despite the fact that Mrs M is unable to move her legs, she was reported to still play an important role in the family in that she helped with the cooking and her grandchildren were very much a part of her life. Her daughter reported that she had 5 children, and she did not work. Mrs M explained that the only income she received was R1800 in pension money that is used for the entire family as well as cover her monthly transport costs.

“Yes, there are 5, they just like all other children, they don't worry her too much but as a granny, they ask her for somethings, they don't fight with her, they just respect her as a granny, but if they want something, they will just ask her granny please do this for us; this and that because I'm not working.”

Mrs M's monthly visits to the clinic requires that they hire a few people to assist with moving her out of her house, down a precariously built bridge and down the gravel path alongside the river. They then hire a car for R150 which takes Mrs M and her daughter to the clinic about 6 km away. At the clinic, the nurses provide her with a wheelchair and attend to her first, before anyone else. The facility staff know her well.

“For her medication, we hire a car, so the car charges R150, so as you see the places like this, we have to hire the boys just to hold her and pick her up so she can go on the passage, it's very, very difficult for her to walk and she's like this and she got a sore on her leg and that sore is for years and years.”

“At the clinic she doesn't join the queue because they said all the old people, they must not join the queue and when she goes to clinic, we give them the card, she will call out the file, she goes straight to the nurse to check her sugar, check her B.P and then they just call her to the nurses.

The return journey is not always guaranteed as they often have to hustle their way back and make friendly arrangements with the driver.

“She don't join the queue, it's not taking long, not even 30 minutes because all the time we hire somebody and we tell him we not going to take long, even if you the person that we hire, he goes to work but we tell him we going to be very, very quick, yes like that.”

The nursing staff also know the pressures they face and try their best to see Mrs M as fast as they can so that they are able to get back home using the same hired car they used to get

there. Her daughter reported that they have been paying for rental vehicles and assistance for almost 30 years.

Strategies used by Mrs M and her family that impacted her continuity of care journey

- Living within close proximity to each other ensures that help is nearby should Mrs M need assistance with taking her medication and general activities of daily living.
- Strong community networks ensure that Mrs M always has someone who would be able to assist her so that she is able to attend clinic appointments.
- Hiring a car and communicating with staff about her transport challenges so that she is given priority.
- Relying on human kindness and community support.

Mrs M's experience of the health system

In describing the quality of healthcare received at the clinic, Mrs M's daughter indicated that she thought the care offered was good for her mother because she did not need to follow the regular queue. Another important aspect was that Mrs M saw the same nurse every time she visited the clinic. It was a critical factor to her being able to come to the clinic and receive care each month. Her daughter felt that it was also the reason they could be seen quickly. If she was seen by a different nurse each time, the time taken to assess her condition would be longer and she may not be able to secure transport back home. She explained that overall, even if she had to see the doctor, the wait is not long and that was most important to her.

Expectations of the health system

Mrs M's daughter's expectations of government in providing services for persons with disabilities was for her mother not to have to go to the clinic each month, but for someone to

come home to check her diabetes and hypertension and for her medication to be delivered to her doorstep rather than having to go to the clinic every month, incurring costs for each visit.

“...up and down is very stressful for me because all the time I have to try to get somebody to help me carry my mom, so if he can get somebody who can come here and check here sugar check her B.P, bring her medication that will be very nice.”

Policy-practice observations

The importance of fully functional Ward Based PHC Outreach Teams. Mrs M's case illustrates weaknesses in the implementation of the Policy Framework and Strategy for Ward-Based PHC Outreach Teams (WBPHCOT). This policy envisages visible improvements, not only in equity and access to care, but also in managing the quadruple burden of disease with a strong focus on fostering the well-being of mothers, children and other vulnerable groups.

In Mrs M's case, there was a clear weakness observed in terms of the implementation of the Policy Framework and Strategy for Ward-Based PHC Outreach Teams (WBPHCOT). As a pensioner with a disability and chronic conditions, she was inadequately managed by outreach services through WBPHCOTs. These teams were absent and represents a clear example of the dire need for outreach services to be strengthened and tailored to the needs of persons with disabilities in particular.

In the case of Mrs M, evidence of community health workers (CHWs) and community care givers (CCG) bridging the gap between the health facility and the community was not evident. It did not appear to be a capacity issue as there were CHWs and CCGs allocated to the ward, but the frequency of their visitation and their ability to respond to the needs of the most vulnerable appeared to be lacking.

Out of pocket costs associated with having to hire people to assist Mrs M out of her home and cars to transport her to the clinic were beyond her means. Mrs M was burdened with out-of-pocket expenses for more than 30 years, and throughout this period, no attempt was made by the health facility or the local ward counsellor to support her plight and alleviate her financial burden associated with maintaining good health.

4.3.4 Mr P's "Continuity of Care" Journey: Alone on the road to recovery

Age: 60

Sex: Male

Language spoken: English and Afrikaans

Population group: Coloured

Disability: Hemiplegia as a result of stroke

Nationality: SA

Dwelling: House in Ward X in Rainbow Ridge. He has lived in Rainbow Ridge all his life but has been living in the current house for 18 years

Health condition: Hypertension

Medication: Chronic hypertension medication taken daily twice a day

Access to basic healthcare: Public health services

GP / Dr visits: Monthly visits to the clinic to collect medication, private rehabilitation

Professionals usually seen: Clinic nurse

Table 12: Mr P's experience of "Continuity of Care"

	I Agree 1	I Disagree 2	I don't know 3
I see the same doctor every time			
My medical history is well documented			
I understand everything that is said to me			
My healthcare team shares information between them, so I don't have to repeat myself			
My healthcare team knows me very well and understands my challenges			

Mr P is a 60-year-old man who experienced a stroke in 2020. He identified as a person with a disability and described having difficulty walking and felt that he did not have power on the right half of his body. His speech was slurred but audible and coherent during the interview. After his stroke he was completely bed bound as he was unable to walk, but as time went on, he was able to walk with assistance and slowly regained some independence. His general demeanour was one of someone who was defeated and in low spirits, deeply reflective about his journey to recovery after his stroke. The loss of his independence seemed to have made a significant impact on his life and on his perception of self-worth.

“You see my first problem is I can’t even walk properly because of this leg here and this stroke actually hit me all on the right-hand side”.

Mr P reported that he did not have medical cover but consulted a private doctor which he paid for out of pocket. As the management of his hypertension deteriorated, his private doctor referred him to King George Hospital. Mr P recalled how he arrived at the hospital, filled out the relevant forms and was then told to come back the next day to fetch his medication. He did not drive himself to the hospital that day, so managed to get a ride back home with a friend and it was then that he began to feel ill. His wife had gone to town that day and there was nobody at home to assist him. He suffered a stroke and was found lying on the floor by his wife when she returned home at the end of the day. He was admitted to King George Hospital and upon discharge was given rehabilitation sessions once a month as an outpatient. He did not feel comfortable with the monthly rehabilitation as he did not feel it made any difference and began self-directed rehabilitation at home. His rehabilitation was long and frustrating, but he was determined to walk again. His son eventually booked him sessions at a private rehabilitation facility called Headway, where he received individual rehabilitation every Monday from 12h00 to 13h00 and attributes his progress to the consistent treatment he receives

there. His son was instrumental in getting him into rehabilitation sessions at Headway programme as they had initially told him that there was a waiting list and could not assist.

“he (my son) phoned around last year, they told him that the place is full ... but he kept on phoning and he met up with one/ two people that work there and the lady told him how exactly how I can get in, and my first appointment was in January this year because now I only been to them four times”.

Despite the fact that Mr P has two old cars parked in his driveway, he is unable to maintain them or drive himself to therapy and must rely on others to get him to his appointments.

“the only problem for me is to get there as you can see, I got two cars parked at the front and this is my 2nd car and at the moment I can't even work on it to get the car 100% for transport. It is the only problem I'm facing right now, I got to phone around for transport every Monday to pick me up from home and take me there and bring me back”.

His medical care is still accessed from the Clare Estate Clinic as he was eventually given a referral from King George Hospital. While the clinic was a lot closer, he was still unable to independently visit the clinic and had to rely on others to get him there and paid out of pocket for these trips. He was placed on the CCMDD programme which allowed him to pick up his medication at a pharmacy of his choice and attend the clinic every six months for health monitoring by the clinic doctor. While this assisted with not having to attend the clinic each month, he was still faced with the transport challenge to and from the pharmacy. The CCMDD programme was proposed to Mr P without fully understanding his needs as a person and appeared to be based on health facility operational needs. It did not address his main problems which were transport and associated costs.

“Every 2nd Monday, they will send me a [text] message to tell me my medication is ready, but now the problem is, every time I have to send someone, I need to pay them bus fare to get my medication and sometimes when they get there the medication is not ready or there is a mistake. Then they sent back the medication to hospital, and they have to make arrangements for the hospital to bring it back to them and I need to wait like maybe be a week or so before I get my medication. But now since I joined this the hospital transferred me to this clinic here”.

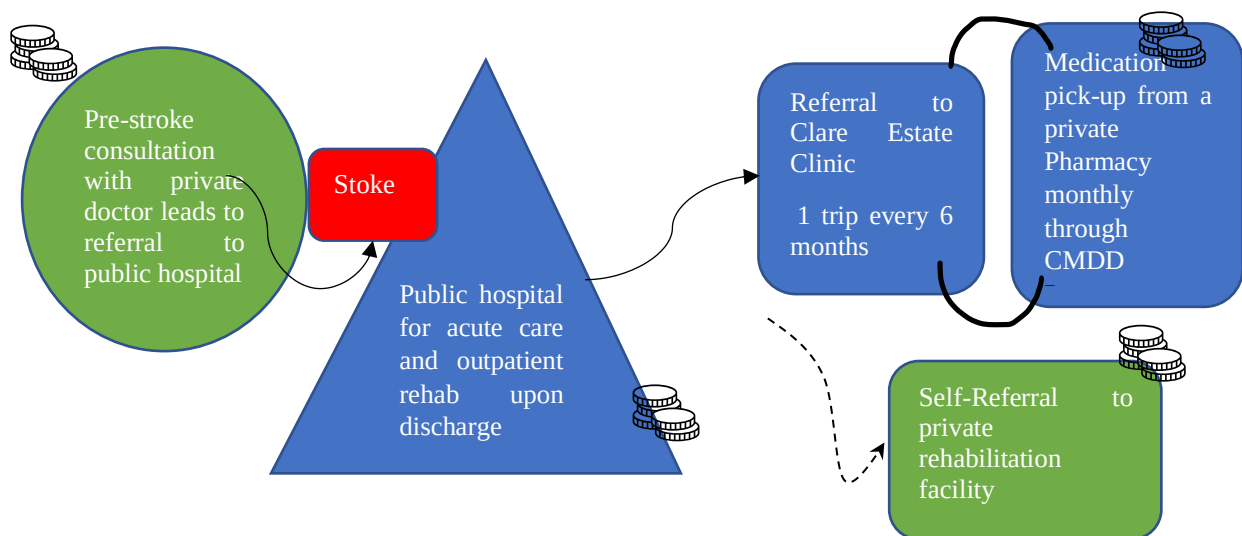


Figure 30. Mr. P's "Continuity of Care" Journey

Health seeking decisions influencing Mr P's “continuity or care”

- Reliance on self and family to navigate the changing path of care.
- Self-referral to public rehabilitation facility.
- Dependence on community support and friends for assistance with transport.
- Requesting support from family for out-of-pocket expenses to attend rehabilitation and pick up medication from pharmacy as part of CCMDD.

Experience of the health system

Mr Ps’ judgement of care provided at the hospital and clinic was generally negative for the following reasons:

- He did not feel that his needs were being met as a patient;
- He did not feel that they had consulted him about his challenges and what would work best for him;
- He was seen by a new person at the hospital each time he visited;
- He had to wait in queues which he felt he should not have to do given his age and disability;
- He did not feel that he was making progress at rehabilitation at the hospital as he was only provided with one session a month.

“she tells me that I must go back to the line and I must wait to see a doctor, if it’s not time for me to see a doctor they just give me my normal medicine but then I have to go the doctor”

“in fact a lot of people especially with the nurses at the hospital like every time it’s a different person there when you try to talk to them, they actually don’t respect you, and then some of them don’t even respect how old are you and if you tell them something, they will tell you no it’s not like that ... and every time you hear a different story, that why actually I prefer picking my medication up at the pharmacy because I just go by car, they check my card, they tell me now my medication is ready and I go pick the medication up and come home, like with the hospital it like chaos at the hospital”.

Mr P reported that the team at King George did not pay attention to his rehabilitation plan and no referral was made or attempt made to find out why he did not continue with therapy at the hospital.

“nothing , they told me nothing , it’s like they were not even interested because I used to go to King George at least every second month I had an appointment with them for rehab, yeah but then there was no care for me at King George anymore and the nurse that transferred me to Clare Estate clinic just told me, no, I will have to do this and do that and she gave a letter

to go to Clare Estate, it was like they were trying to get rid of me, you understand what I'm saying?"

In contrast, his judgement of the rehabilitation services provided at Headway was better than the public health facilities as he felt that he was able to build a rapport with the professionals there and they knew him well. He felt comfortable and could see improvements over time because he was able to receive therapy weekly. However, he still incurs expenses as he needs someone to drive him to a private Rehabilitation centre each week; a cost he might not be able to sustain for much longer.

"In fact, I would feel better if I did not go to King George or anywhere, now every time I must go there, there is a different person that's there and I don't know this person. I used to have problems lots of times with the doctors there at King George, every time you go it's a different person you see, not all of them were nice, especially with the doctors and all, they were not nice at all ... whereas if I go to Headway, I deal with one person that checks on me".

Expectations of the health system

Mr P felt that more options needed to be made available for persons with disabilities who wanted to attend therapy but did not have access to transport.

"Transport is the main problem, like for me to get to [private rehabilitation] I have to go there every Monday which is normally like four times a month, I have to be there at 12:00, every time I have to go there, I have to look for transport to actually get there. Whereas if I had someone to pick me up from home and take me there and bring me back home every Monday, that will be like, what word can I use, I even forgot this most of these words" (struggles to find the appropriate word).

Generally, his overall perspective of public health facilities was negative, and he harboured a great deal of frustration in the system.

“I am tired of this government – we make our own plans. My son drives all the way to get me, and he takes me to a private facility.”

Policy-practice observations

The role of the General Practitioner: Mr P’s case illustrates the challenges associated with the dual nature of the health system in SA at present and highlights the role played by GPs in supporting access to appropriate and cost-effective care to vulnerable groups such as persons with disabilities and the elderly. It is interesting to note that Mr P’s referral to a public hospital was made after receiving long-term care under a private GP for which he paid out-of-pocket. Mr P’s referral to King George Hospital was made (presumably) based on the GPs clinical judgment that he was on the verge of a medical emergency that would require hospitalisation and would see the patient incur catastrophic health expenses if he was admitted to a private hospital.

Several questions come to mind; why did Mr P choose to access care from the GP for so many years rather than access care, free of charge from the public health facility? From his negative accounts of his experience at public health facilities, his decision may be based on personal preference and appreciation for a long-term relationship with a one-care provider who understood his needs. The out-of-pocket expense for such services appeared to be a cost he was willing to bare, even though it may not have been one that he could fully afford without financial assistance from family.

An alternative question would be, why did the GP choose to continue treating a pensioner for a fee for so many years when he could have benefitted from free public health

services? Was the GP responding to the preference of the patient or driving a successful business practice model? What is the role of the GP in ensuring access to good quality, appropriate and affordable healthcare care within a system that is poorly integrated and sub-optimal for achieving “Continuity of Care”? The answer to some of these questions may lie in SA’s plan to implement UHC through the vehicle of a National Health Insurance (NHI).

The NHI aims to restructure and improve the healthcare system and provide universal access to quality healthcare services to all citizens. A component of ensuring access to appropriate resources is the contracting in of GPs, forming a fourth stream of the PHC, who could be utilized in the following ways:

1. Primary Care Providers: GPs will be the primary point of contact for patients seeking care and will continue providing healthcare services, such as preventative care, diagnosis, treatment, and referrals to specialists.

2. Gatekeepers: Within the healthcare system, GPs will assume the role of gatekeepers. This means that for initial evaluation and care, patients would likely need to see a GP first, who can then refer the patient to the appropriate experts if more specialized care is needed.

3. Health Promotion and Prevention: GPs will be key players in preventive care and health promotion and will provide guidance on healthy lifestyles, offer vaccinations, conduct routine screenings, and manage chronic conditions through regular check-ups.

4. Early Detection and Management: GPs will be responsible for the early identification and management of health problems in an effort to prevent complications and the need for referrals for more specialised care.

5. Coordination of Care: GPs will be part of a team managing the treatment of patients with complicated medical requirements, thereby facilitating patients receiving thorough and integrated care, across disciplines and professions.

6. Community Engagement: Local GPs can interact directly with patients and their families and will be able to promote culturally sensitive care that is person-centred.

7. Telehealth and Digital Platforms: The NHI implementation may include telehealth and digital platforms, enabling GPs to communicate with patients remotely and conduct virtual consultations. Particularly in remote and under-developed locations, this can increase access to healthcare.

8. Quality Assurance and Standardization: The NHI system will provide standardized guidelines and quality assurance standards for GPs to provide consistent and high-quality care across the nation.

9. Training and capacity building: As part of the NHI implementation, there may be measures to improve the knowledge and training of GPs order to meet the population's changing healthcare demands.

An obvious benefit of the NHI for people like Mr P is that it would alleviate the burden of out-of-pocket payments for services delivered by the GP and will facilitate “Continuity of Care” in the delivery of promotive, preventative and curative care. As a gatekeeper of the health system, GPs will have significant influence over how “Continuity of Care” is realised. In other words, information continuity, relational continuity and management continuity will begin and end at the GP as they will coordinate patients transferring between the various levels of care. This model closely resembles those in many developed countries where the GP or family physician is the locus of care. In SA, this represents a dramatic shift from the delivery of isolated private sector GP services to one that offers more equitable, cost effective and integrated care for all.

The NHI and rehabilitation services: A crucial aspect of Mr P’s “Continuity of Care” journey was the challenge he faced in receiving rehabilitation services. Faced with a newly

acquired disability, he did not feel supported by the health system and felt he was an additional burden to the healthcare and rehabilitation teams. His loss of independence was not fully appreciated by the rehabilitation team and Mr P felt that his progress was impeded by low quality services that were not responding to his personal needs and plans for recovery. His only option was to access rehabilitation from a private facility on a weekly basis, enabling him to build a good rapport with his therapist and attain a degree of independence.

Challenges faced in the delivery of rehabilitation services have been documented and include limited access due to geographic restrictions and lack of rehabilitation infrastructure, particularly for people living in rural and under-served areas. Severe shortages in the rehabilitation workforce and gross shortages of essential rehabilitation equipment, including assistive devices, impedes the delivery of effective rehabilitation services.

While the NHI policy was intended to address a range of healthcare challenges in SA, including those related to rehabilitation services, its exact approach and impact on these challenges is not clear. Disability- and mental health services will be fully integrated into PHC, but the details of how this will be accomplished are unclear. Contracting-in rehabilitation services may provide a potential window of opportunity to expand the network of services available to citizens, but it does not address the fundamental issues of transport and associated costs incurred by persons with disabilities in order for them to access rehabilitation services.

4.3.5 Mr X's "Continuity of Care" Journey: Professional denial of personal preference and the power of human resilience and community bonds

Age: 42

Sex: M

Language spoken: Zulu

Population group: Black African

Disability: Bilateral upper limb amputee

Nationality: SA

Dwelling: Informal dwelling in an informal settlement

Health condition: Hypertension and diabetes

Medication: Prescribed medication for hypertension but non-compliant.

Access to basic healthcare: Public health system. He also visits the traditional healer.

GP / Dr visits: 3 or 4 times a year

Professionals usually seen: Nurses

Table 13: Mr X's experience of "Continuity of Care"

	I Agree 1	I Disagree 2	I don't know 3
I see the same doctor every time			
My medical history is well documented			
I understand everything that is said to me			
My healthcare team shares information between them, so I don't have to repeat myself			
My healthcare team knows me very well and understands my challenges			

Mr X is a 43-year-old man who lives in an informal settlement in Ward X. He lives alone and is a bilateral upper limb amputee as a result of an injury. On 18 January 2012, Mr X was assisting community members to access electricity through means of an illegal connection. He was electrocuted and rushed to hospital where it was determined that he would require amputation of both arms from the shoulder. Upper limb amputation is exceptionally

challenging and is known to be a rare occurrence, however, bilateral upper limb amputation rarely occurs, and requires a great deal of support to adapt to a life without arms. The loss or absence of both hands or arms places an individual in a very difficult predicament and regaining independence is often a long and arduous journey. It is reported that “prosthetic rehabilitation seems promising especially for upper extremity amputees” (Soyer, Unver, Tamer, & Ulger, 2016, p. 1319) and support from family and the delivery of care using a multidisciplinary team are also important factors for better outcomes (Roşca, Baciuc, Burtăverde, & Mateizer, 2021). When one is faced with a situation where they are alone and without family, living in poverty and without access to state-of-the-art rehabilitation and support, what are the possibilities for such an individual to attain good health and regain a sense of independence and self-worth? Including Mr X’s story, provided an important lens to view “Continuity of Care” and his story of resilience and positivity was remarkable to document. Despite the odds stacked against him, he still manages to live a full life.

Before the incident Mr X was the community maintenance man who assisted with odd jobs such as fixing roofs, doors and helping build shack dwellings for new families in the settlement. Mr X was observed to have extremely strong ties to the community, and this was evidenced by the warm greetings he received from people in the settlement as we made our way down the precarious gravel pathways to the location he had selected for us to have his interview.

His “Continuity of Care” journey” began at the specialist tertiary hospital in KZN, where the amputation of both his arms was conducted. He spent a few months in hospital and described the care he received as “very good”. He was then discharged into a long-term care facility which may have also been a care home for the terminally ill, where he was provided with in-house occupational therapy and physiotherapy. Here the healthcare team taught him self-care techniques to support his journey to independence and according to Mr X, the team

at the facility were fully expecting him to stay at the facility permanently. His time at the home was reported to be good; he was grateful for the meals and assistance he received with bathing and other activities of daily living. However, after a few months at the facility, he decided to run away and returned to his home in the informal settlement. His reasons for leaving the facility were not due to the quality of the services offered, but to the fact that he witnessed many people die during his stay as it was a home for terminally ill. He recalled how each day there would be a death of one of the residents at the facility and his greatest fear was that one day it would be his turn.

“I won’t lie I will tell you the truth it was nice, eating in time, bathing in time, but the way the people were dying every time and next to your bed and the next day another person next to your bed, but it was not nice.”

He explained how he longed for his friends at the settlement and felt confident that even though he no longer had arms, he would be able to adapt to his new life because he had friends there who would take good care of him. In particular, his friend Mr C who accompanied him during his interview and assisted with translation, was reported to be the reason that he felt confident about going home. Mr X teared up during the interview as he spoke about his friend.

“You see this man, he’s the one who make me happy yeah, because I can do little things, but sometimes other things, I can’t do myself, so not from now, not from today, he [Mr C] is always with me. Yeah, and I’m happy about it and some other people. Yeah, but not like [Mr C]...yeah.”

“I wanted to go home because I know [Mr C] is here!”

Mr X’s sense of community connection appeared to form a strong part of his plan to rebuild his life with a disability, despite being in an extremely vulnerable phase of recovery from his amputation. He was living in poverty and had access to a home that did not offer any special

adaptations for a bilateral upper limb amputee, but it was his home. The challenges seemed inconsequential to him in the context of a caring environment where he was among people he trusted.

Upon his return home, the reality of life without arms slowly began to settle in. Regular activities like bathing and changing required support and assistance from his friends. Living alone compounded the issue but he began using some of the techniques taught at the facility. He was able to change and feed himself which was a major achievement and one he did not take for granted. In terms of preparation for a more independence, the facility had provided him with prosthetic arms with a hook at the end which he did not use as he felt even more disabled when he wore it. The fact that he was provided with a prosthetic arm that he would not use was an indication that the assessment of his needs was not person-centred. It could also reflect the limitations of the health system to be able to deliver assistive devices that truly met the needs of the user.

“He’s got one - the prosthetic arm...it’s got a hook so it’s not the one with a hand, it’s just the arm with a hook, but he hates it! He absolutely wants nothing to do with it and he doesn’t want to see it and he doesn’t want to touch it and he doesn’t want to hear about it! If we ask him the same question, why don’t you use it, he says - it makes him more disabled than his disability.... he would much rather show humans that he is still able to do certain things, without the use of that hand.” (Mr C, friend of Mr X)

Mr X was diagnosed with hypertension requiring prescribed medication. According to his friend, he was non-complaint and did not take his medication as required. He explained that he only visited the clinic if absolutely necessary, though his friend Mr C, indicated that Mr X often experienced pain in his shoulder and the community would urge him to go to the clinic. Mr X explained how the staff at the hospital would be protective of him and force him to the

front of the queue so that he did not have to wait too long. Interestingly, Mr X did not want to be treated differently and explained how he felt ashamed to be placed at the front of the queue when there were elderly patients were already seated and preferred to allow them to go ahead of him. Mr X went further to explain how he often helped others at the clinic to get correctly registered at the health facility when they did not have an appropriate referral address. This sense of community and camaraderie was fascinating to hear, and I found it difficult to reconcile his selflessness in the face of the immense personal challenges he faced.

Expectations of the health system

When asked about what he thought of public health services and whether they met his expectations, he again deflected the question and reflected on the desires of others and not his own. His call was for health services to be made more accessible especially for people in wheelchairs and he highlighted the need for outreach teams to deliver medication to their doorstep. He paused momentarily and then mentioned a personal need for assistance twice a week to help with deep cleaning his home. An important observation during the interview was Mr X's incredible sense of humour which his friend explained was his way of adapting to the awkwardness that his disability sometimes evoked in others. Mr C explained that he named himself "Mr No-Hands" so that people could laugh and feel at ease around him.

Mr X wanted the researcher to see his living conditions and the interview was followed by a visit to Mr X's home (See Figures 31 & 32). His home was a makeshift shelter made from a few scrap pieces of metal and plastic sheets. It was built precariously between the wall of another home and adjacent to another.



Figure 31. Mr. X's home



Figure 32. Damage to Mr. X's home after the floods

Policy-practice observations

There are three important observations that can be drawn from Mr X's "Continuity of Care" journey. These are **appropriateness of acute and post-acute care, decision making regarding prosthetic restoration and rehabilitation, incongruence and discontinuity of**

services between post-acute care and community-based rehabilitation services and community networks of support.

Appropriateness of acute and post-acute care: While care during his acute phase was judged by Mr X as appropriate and of good quality, the reported delivery of services during the post-acute stage may have had both positive and negative impacts on his “Continuity of Care”. In his post-acute phase, Mr X needed rehabilitation and psychological support. While he received the rehabilitation support to facilitate his adaptation to a life without arms, there remain questions about the level of psychological support that was offered to Mr X at this stage of his journey. The fact that Mr X held a perception that he was to remain at the facility “forever” may point to a lack of understanding of the long-term plan for his rehabilitation and reintegration into society or alternatively, that a plan for reintegration did not exist and it was indeed true that he was positioned as a long-term resident at the care home. Regardless of what the plan may have been, being in an environment as described by Mr X, where people were dying each day may have had a detrimental effect on his overall mental health and ability to envision a life outside of the facility. Maintaining a positive outlook on life may not have been possible when he was faced with the reality of death and reminded of his mortality on a daily basis. His “escape” as he called it, from the facility meant that he valued reintegration into society and made his own decision to leave when he felt prepared enough to return to his community and friends. He was not prepared to stay until this decision was made by the staff of the facility. An obvious shortcoming in the post-acute stage of his care was that it lacked the relational aspects of “Continuity of Care”, which had an impact on his mental health and ability to cope with his loss.

Decision making regarding prosthetic restoration and rehabilitation. Mr X made it clear during the interview that his prosthesis was not acceptable to him and he preferred not to use it. His strong feelings against the use of a prosthesis after almost a year in rehabilitation is

a significant finding at an individual and systemic level. According to O’Keeffe (2011), the appropriateness of the prosthetic rehabilitation for a patient is an important consideration (O’Keeffe, 2011). While prosthetic rehabilitation has been shown to be valuable for upper limb amputees (Soyer *et al.*, 2016) there are cases where “*no attempt at rehabilitation may be a valid choice where either functional restoration is prevented, service access is limited, or cosmetic restoration not valued*”. (O’Keeffe, 2011, p. 2). While it is uncertain what influenced his extreme feelings towards the prosthesis provided to him, what can be deduced perhaps is that firstly, he had limited understanding of what the prosthesis offered in its utility and secondly, his care team had limited appreciation of his value of form over function. In Mr X’s case he saw the hook at the end of the prosthesis as something that accentuates his difference from others while not using it allowed him to embrace his uniqueness and strengthened his human connection with community and friends. It has been reported that up to 20% of adult amputees choose not to use a prosthesis citing reasons such as poor solutions to basic needs (Brack & Amalu, 2021). Abandonment of prosthetic devices by upper limb amputees has also been linked to issues relating to functional reliability, appearance, comfort and usability, as well as the fact that they lack warmth and humanness which has negative appeal to users (Brack & Amalu, 2021). This highlights the inappropriateness of the one size fits all approach to the allocation of assistive devices and prosthetic rehabilitation, and points to the need for person-centeredness and joint decision making for successful adoption of the assistive device.

The significance and potential impact of poor relational continuity is highlighted by Mr X’s experience. The lack of professional proactiveness to understand the patient in context may have resulted **in incongruence and discontinuity of services between post-acute care and community-based rehabilitation services**. The WHO recently released “The Package of interventions for rehabilitation” (World Health Organization, 2023b) which outlines the most essential interventions for rehabilitation for 20 health conditions. The Package of care for

rehabilitation includes a list of the necessary assistive items, tools, and supplies, as well as the labour force that is typically qualified to carry out these interventions. In order to achieve outpatient rehabilitation at service level A as shown in Figure 33 below, a number of assessments are advised for individuals undergoing amputation at different levels of the health system (World Health Organization, 2023b). Two recommendations focus on community, social life, career and family support. They are packaged as the most essential rehabilitation interventions for 20 health conditions and are valuable to professionals who seek technical support to guide their treatment plan (World Health Organization, 2023b). The comprehensiveness of the outlined clinical package of care for amputees is notable, yet recommendations for people living in contexts of poverty add a different dimension to professional concepts of care and may be a potential professional blind spot. The lack of detail about how rehabilitation professionals can navigate community contexts creates a gap between the service delivery platforms and community-based care. In Mr X's case his context could never have been understood without a home visit. Had this been done, the dire situation he faced would have been apparent and the practical application of community-based rehabilitation would have been brought to the fore. The need for linkages to sectors outside of health would have been apparent and the rehabilitation professional will have had the responsibility to drive the process of Mr X's reintegration into his home and society, based not on the preference of the healthcare team, but based on Mr X's needs and preference. Keeping Mr X indefinitely in a facility may have been perceived by his healthcare team as an easier and safer route, but it did not take into consideration his personal desire to be re-united with his community. This represents an imposed professional perception that disregarded the power of community cohesion and its positive influence over health, particularly in impoverished and under-served communities.

“...I am alive because of Chris... you see Chris, he takes care of all of us. I ran away from that place – when people go there they die....no, no, I want to stay here. Chris and the community takes care of me now”. (Mr X - Bilateral upper limb amputee)

The National Rehabilitation Policy describes CBR as “*A healthy balance between institution-based services and community-based rehabilitation services.*” (Department of Health, 2000, p. 8). CBR according to this policy calls for proper training and empowerment of communities (Department of Health, 2000).

Discharging Mr X from the hospital and into a home served an important function in that it provided him with access to rehabilitation and a sense of independence. However, permanent residence at the facility was an assumed goal not shared by Mr X. If the team truly understood the personal circumstances of Mr X, they may have created a different therapy programme. Did they truly practice person-centred care, and would he have left if anyone understood what his personal goals were? Did they understand his psychological state of mind and what death meant to him after his incident. Having to deal with the death of others may have been an inappropriate and painful exposure.

Box 7. Rehabilitation at service delivery levels		
Service delivery level	Relevant description	Examples for rehabilitation
A. General outpatient services (clinic setting or outreach)	General outpatient services in clinic setting	• Outpatient physiotherapy, occupational therapy or speech and language therapy clinics
	Periodic schedulable services delivered by skilled health worker in home, schools, workplace, or public space	• Occupational therapy service integrated into e.g. general practitioner facility
B. First referral level (district hospital)	Outpatient services at first referral level	• Physiotherapy services integrated in acute cardiac in-patient clinic
	Emergency unit services at first referral level	• Outpatient prosthetic workshop available at district hospital
	Inpatient services at first referral level	
C. Second referral level and above (regional and national hospitals)	Advanced outpatient services at second referral level and above	• Specialized multiprofessional inpatient rehabilitation clinics for complex conditions
	Advanced emergency unit services at second referral level and above	• Specialized multiprofessional outpatient rehabilitation day clinic
	Advanced inpatient services at second referral level and above	

Figure 33. WHO rehabilitation service delivery levels

4.3.6 Mr K's "Continuity of Care" Journey: I'm no different

Age: 42

Sex: Male

Language spoken: English and Zulu

Population group: Black African

Disability: Cerebral Palsy

Nationality: SA

Dwelling: Shack in an informal settlement

Health condition: No chronic diseases

Medication: None

Access to basic healthcare: Public health

GP / Dr visits: None

Professionals usually seen: Nurses at the clinic

Table 14: Mr K's experience of "Continuity of Care"

	I Agree 1	I Disagree 2	I don't know 3
I see the same doctor every time			
My medical history is well documented			
I understand everything that is said to me			
My healthcare team shares information between them, so I don't have to repeat myself			
My healthcare team knows me very well and understands my challenges			

Mr K is a 42-year-old man living in a shack in an informal settlement. His case was documented because it portrayed an interesting perspective on "Continuity of Care". He was referred to the researcher by the community liaison who informed us about a person with a disability who lived by himself in an informal dwelling. We were driven to his home and found him seated inside on a couch. His bed stood behind the couch and across from him was another

seat with a fridge to the left and a small table to the right. He was unable to move easily and was accompanied by his mother who also assisted with the interview. His mother reported that she did not stay there but visited him once a week. She mentioned that there was a community member who came in daily to assist him if needed, but that for the most part, her son was as independent as he wanted to be. His speech was marked with severe dysarthria, but he was eager and determined to communicate and speak for himself. His mother sat across from him and only assisted with clarifying what he had said.

Mr K explained that he attended Open Air school for the physically challenged. He reported no hearing or visual difficulties and appeared to have adequate comprehension of the questions posed to him. When asked to describe his time at Open Air, he reported that he only experienced physical limitations, but used a typewriter at school to communicate sometimes. He had been living in Ward X since 1999 and when asked about his health, he enthusiastically reported that he was not a sick person. He knew where he could access health services and was confident that he would not need to attend a clinic because his health was good. His health survey results indicated that he did not see the same health professional each time he visited the clinic and that he did not understand everything that was said to him.

His perspective was quite different from the other participants in that despite the severity of his disability he maintained a positive self-image. This may be due to the education he received at Open Air school as he exuded confidence and eagerness to participate and speak for himself. His experience of the health system was an interesting perspective and one that was in contrast with the other participants.

Expectations of the health system

When asked about his expectations of health service providers at the local clinic, he mentioned that all he expected was for the “nurses to be kind and nice to him”. When probed about what he meant by “nice”, he reported that he wanted them to ask him about his condition

in a nice manner. He indicated that he did not mind sitting in queues to see the nurses as he did not see himself as “different” from everyone else.

Mr K: “yes, I don't mind because although I'm disabled but I'm just like you, if you can go into the clinic (inaudible).....

Interviewer (attempting to confirm what she had heard): “do you mean, you believe that you don't need special treatment because you are a human being like everyone”

Mr K: yes

Policy-practice observations

Mr K's case was a striking example of the diversity of needs and expectations found among persons with disabilities in relation to healthcare. Mr K's interview, though short, represented an important perspective on how persons with disabilities view themselves in relation to other vulnerable populations. In this case Mr K did not see aging or disability as any different and felt that neither group should be offered special treatment. He felt that nobody should be given special treatment at the clinic.

Mr K: “I don't believe that older people can't sit and wait, if I can wait then they can...”

His mother reported that they would take a normal taxi to the clinic if needed. She explained that the trip would be fine, but that the passengers sometimes would whisper to each other because they did not understand Mr K's disability. They ignored any negative remarks from other travellers.

Mr K's contrasting interview provided a reminder that persons with disabilities can also live healthy lives and may not need to access healthcare facilities regularly; that they may hold the view that they are no different from other people and as such feel that they do not need to be prioritised or given special care and attention.

The experiences and expectations of persons with disabilities inductively coded and thematically analysed (See Appendix U) using data generated from all five "Continuity of Care Journeys. As an additional layer of analysis these themes were mapped against the three pillars of "Continuity of Care" (Table 15) and are synthesised and analysed in Section 4 of this chapter.

Table 15: Code mapping of experiences of persons with disabilities

	Information Continuity	Relational continuity	Management Continuity	Other observations
Individual Experiences	Filing practices: Lost files, delayed retrieval, inaccurate data captured. Information about priority groups: Inconsistent application of priority for persons with disabilities and elderly. Confusion about which line to follow Limited information about new programmes, referrals for rehabilitation and options for care CCMDD, rehabilitation options, loss of information between private and public sector Burden of self-referral, private health facilities, long term care, rehabilitation.	Differences in staff attitudes towards persons with disabilities: Tailored support, telephonic support, side arrangements for medication pick up, stigma and discrimination In-consistent continuity: different health professional at each visit, same health professional, personalised service, Apprehension about visiting health facilities Stigma, long waiting times, uncertainty, attitude of staff.	Coordination of services: inclusion of persons with disabilities in CCMDD, Service delivery gaps, Visible absence of government's intersectoral programme Sukuma Sakhe.	Community self-organization: lack of trust in government support, extensive support networks, trusting relationships, guidance and support Trusting relationships beyond the health system: Traditional Health Practitioners (spirituality, delayed medical care, complications, poor integration of traditional health practitioners into health system). Friends and family: (sense of security, love, transport, meeting needs, support Out of pocket expenses: Private transport costs Out of pocket payments with activities of daily living
Individual Expectations	Continuity of personal medical information: Accuracy of documented medical history, Repeating medical history, lost files, lack of coherence between private and public health system.	Be treated with dignity Courtesy Non-racism Equality Access to resources and information Transport Support Help me help myself	Priority attention: Waiting times, queues, sequence of procedures. Home delivery of medication Appropriate provision of assistive devices Assistance with activities of daily living	I'm no different

4.4 Section 3: Tier 2 - Family perspectives on “Continuity of Care”

The study aimed to uncover perspectives of families who had lived experiences of disability. It was the intention to interview the families of the persons with disabilities who were study participants. However, the majority lived alone, did not wish their families to be interviewed or had family living in rural KZN. Three additional families were identified as having a family member with a disability. Their profiles are presented in Table 16.

Table 16: Characteristics of families interviewed

Participant	Sex	Language	Race	Family member with disability	Age of family member with a disability	Nationality	Living condition of family member
IDI007- Mrs G	F	English	Indian	Adult child with Cerebral Palsy	29	SA	Granny cottage / shared room in a house
IDI008 – Mrs K	F	English	Indian	Mother diagnosed with Parkinsons Disease with diabetes and hypertension.	87	SA	Her mother lives in a home for the elderly (Eagle’s Wings)
IDI009 – Mrs J	F	English	Coloured	Mother who experienced a stroke 2 years ago, diabetic and hypertensive. Passed on a year ago	70	SA	Her mother lived with her in their family home in Rainbow Ridge

The stories of the women interviewed are related as individual stories so that their unique contexts are illustrated, and their challenges highlighted. The analysis of their interviews and the key themes found are summarised at the end of the section and are further elaborated in the Synthesis and Discussion section.

4.4.1 Family Story 1: Mrs G – “You have to pay to be treated like a human being, but in the public health system, you are treated like an animal.”

Her story represents a perspective of a family who initially sought care from private health facilities and moved to public healthcare due to financial burdens.

Mrs G is a mother of a 29-year-old son who was diagnosed with cerebral palsy. Mrs G had a medically induced labour which was further complicated by a long and difficult delivery. Her son presented with delayed milestones and at 10 months he fell and was taken to hospital where he was later diagnosed with epilepsy. At that stage, Mrs G lived in Port Shepstone, a small town on the south coast of KZN. Her son’s epilepsy became progressively worse, and doctors were unable to find a way to manage the seizure adequately. He became photosensitive and eventually was diagnosed with cerebral palsy. Later he was also diagnosed with Autism and Attention Deficit Hyperactivity Disorder (ADHD). At that stage, the family was covered by private medical insurance, and they were seen by private doctors at the Port Shepstone Hospital. Her son spent a considerable amount of time in hospital but costs at that stage were covered by private health insurance.

The family began accessing public health care five years ago after Mrs G divorced her husband. She could no longer afford the high cost of private medical cover. She began accessing specialist services through Port Shepstone Hospital and attended the public health clinic monthly for collection of medication and routine monitoring of her son’s condition.

Mrs G reported very poor care and felt that the clinic staff were racist and reported how black African nurses would discriminate against Indian patients by pushing black African patients to the front of the queue. She felt frustrated as a mother of a child with a disability as he should have been prioritised but was overlooked. When Mrs G moved to Reservoir Hills in Durban a year ago, she began accessing care for her son from King George Hospital. The

transfer from Port Shepstone to King George hospital was administratively executed through patient file exchange between the two facilities.

Mrs G's experience of care at King George hospital was again described as "racist." She explained that her son was extremely difficult to manage both physically and behaviourally when in public and her requests to have someone see him in the car were denied. She felt that this was a racist act and described the care as very poor.

Her expectations of health professionals dealing with persons with disabilities were as follows:

"You know as nurses, you're a healthcare worker. As nurses you take an oath to do your best for everyone, uhm...but the oath is a lie because I have to question whether they are being trained properly in a proper institution. And also morally, how are they trained morally? Do they come from backgrounds where they are taught to be racist? So, when they come into a public workplace do they bring it to their workplace and sort of pass it on and express how they feel, you know whether it is an old Indian person or a person with a disability. I have nothing positive to say about our public services."

"My expectation is that people should have compassion – especially nurses and doctors – should have compassion and understanding – being in the profession and the training and writing of long essays about being altruistic. It is very disappointing and saddening that these so-called professionals have so little compassion and love or even care for another human being – you know for people like my son with disabilities."

"You have to pay to be treated like a human being, but in the public health system, you are treated like an animal."

She reported seeing new health professionals at every visit and being requested to relay her son's medical history at each visit despite all the information being documented in the file.

She reported that her son's file was sent to King George from Port Shepstone Hospital and the nurses and doctors should have access to his full medical history.

"The doctors change all the time. There are so many of them. Nobody knows Dharshan ... It's very stressful because you have to relay the whole history each time".

She also indicated that her son was not receiving any rehabilitation services at King George, but that this was also due to the fact that she had a full-time job and could not entrust her son to anyone else.

In terms of recommendations for government, Mrs G had this to say:

"I think there should be separate hospitals created for people like [my son]. Properly trained people who know how to treat persons with disabilities. They should have specially trained nurses and doctors because dealing with people who cannot express themselves takes a lot of time and patience and understanding."

Mrs G was not aware of the CCMDD programme or the Reservoir Hills Clinic. She reported no access to community support and felt quite isolated. She felt that she could not rely on anyone. Her elderly mother was her main source of support in caring for her son.

4.4.2 Family story 2: Mrs K– “The conditions and how badly they were treated – no care whatsoever”

Her story represents a perspective of a family that initially sought care from public health facilities and then moved to private healthcare due to access barriers and concerns about quality of care in public facilities.

Mrs K is the daughter of a woman diagnosed with Parkinsons disease about 15 years ago. In the first ten years after her diagnosis, she remained stable and could function independently. She maintained a good quality of life and was able to access care from public health facilities. However, as her disease progressed, she began experiencing more severe symptoms including frequent falls and general instability as well as memory loss. As her condition began to progress, the family feared for her safety as they were not sure how well she would be cared for at public health facilities and took a decision to pay for private medical cover so that she would not have to be hospitalised in a public health facility. The decision to move her to private health cover was based on fear of the quality of care and the ability of the public health facilities to provide personalised care.

*“No, no I had to put my mom on medical aid ..., for the simple reason was that she is in no position to go and wait at any of the public hospitals ..., so when she wasn't living with me one day she was not on medical aid and she got sick you know, that was the when she started getting sick, and she was living in Chatsworth. She was admitted to R.K. Khans hospital, and I had to leave school that day and be with her at hospital and I saw the treatment there. **The conditions and how badly there were treated - no care whatsoever**, I was so disappointed. The next day I came back from school and contacted GEMS and I put my mum on medical aid. Because she's on chronic medication, it helps so much that all her medication comes home, so*

once a month they can deliver her medication promptly without any problems. So, the medical aid has assisted greatly in that way and obviously it's very efficient."

Mrs K had the capacity to support her mum to a certain point. She was able to create additional living quarters and access 24-hour private home-based care for her mother during the week. She and her husband assisted with bathing her mother over the weekends and were happy to do so. Physically, however, it was challenging. Both she and her husband injured their lower backs which began to limit their ability to provide the kind of care her mother needed. As her mother's disease progressed, she experienced more frequent falls and disorientation making it more difficult to provide for her needs. The care plan needed to change as her general health was deteriorating. The initial plan of 24-hour home support during weekdays became financially unfeasible, and Mrs K began the search for a frail care facility. Information about options available in Ward X was not easily available. She ventured out as far as Verulam (about 60kms) outside of Durban and eventually through word of mouth, obtained information about Eagle's Wings in Clare Estate. The decision was not easy for Mrs K but one that she felt she needed to make in the best interest of her mother's health. She was unable to carry her mother to the bathroom any longer and she needed 24-hour medical supervision.

After a few visits to Eagles Wings she felt that the care they provided was of an adequate standard. Her mum was well cared for by the facility nursing staff. The costs were high. However, Mrs K made sacrifices in other areas of her life and saw it as a worthwhile investment as the care her mother would be receiving was tailored to her needs and comprehensive. She was able to maintain open communication with the nursing staff and they would keep her informed of any change in her condition. She was allowed to visit as often as she wanted and generally her mother seemed to be comfortable and well cared for.

Mrs K felt that if she hadn't taken the decision to move her mother to private healthcare, she would not have had good quality of care. She was not aware of any public facilities providing long-term care of an adequate standard in Durban. She was unaware of the CCMDD programme which allows patients to pick up medication at a central point, but felt that even if that were an option, her mother would still have to visit the public health clinic once a month and she was not willing to take that risk.

4.4.3 Family story 3: Mrs J “Too many chefs in the kitchen...something is going to go wrong”

Her story represents a perspective of a family accessing care solely from public health facilities and the resulting experience of “Continuity of Care”.

Mrs J was identified as someone who could provide a unique perspective on experiences of persons with disabilities accessing health services in Rainbow Ridge. Her mother was a woman with an acquired disability after she received medical care which resulted in complications and a severe contracture of her dominant hand. Her mother passed on a few months before the interview. Her mother was a machinist at a clothing factory and after the surgery, lost her job due to her disability.

“She was disabled because of her incident she had couple of years ago. She got injured and because she was diabetic, her whole hand started to swell up and she went to Addington Hospital for an operation and they said they going to cut from here to here and they going to take all the puss out and apparently they gave her doctors that were training and they took out her skin from here and they went past her wrist and so when the thing healed and her skin healed, it made her hand like this [demonstrated a twisted wrist] and she could no longer use her hand. It was her right hand, and she was a machinist that time, so she lost her job, she

couldn't manage anymore. They said in order to fix her they will have to break her wrist and recut, and she said no."

The family lived in Rainbow Ridge in Ward X all their lives. Her mother also received treatment for diabetes, hypertension and asthma from the local public clinic and requested to be referred to Addington Hospital instead of King George Hospital as it was more convenient in terms of physical access and less walking required from the taxi to the facility. A few years prior to her passing, her health took a turn for the worse. She experienced a heart attack and was diagnosed with kidney failure. Her medical condition progressed in severity, and she was frequently admitted to hospital.

"My mom was always a sickly person she had diabetes, blood pressure and asthma as well and then few years down the line, one day she said she got chest pain and when we went to hospital they said now she has a heart attack and she had kidney failure. So, from that time her body started swelling and she got so huge that we couldn't carry her ... she was bedridden. She got better for a while, same thing happened, every time we took her to the hospital she will be hospitalized for once a week, and we had a problem with the medication. They kept giving her medication and wrong medication, they changed it to something else, they kept her for couple of weeks to see if it's helping, she came out and we were back in hospital and we carried on and carried on."

Her experience of her mother's care in the last few years of her life were described as traumatic as they were unable to transport her to hospital and the emergency services would refuse to assist with transferring her from her house to the ambulance due to "security reasons" as many paramedics had been robbed or hijacked, so the rule was that families have to bring their sick family member to the ambulance. Due to her mother's size, it took five people to carry her to the roadside where the ambulance was parked, so that she could be transported to

hospital. They were given a broken wheelchair by someone in the community in which they carried her mother. The family did not have the resources for private care or hiring cars to transport her mother to hospital.

“She got to a point where she didn't want to go to hospital, and we couldn't transport her. Her body was so swollen she couldn't walk couldn't do nothing, she couldn't even speak, and we couldn't even take her anywhere because for us we didn't have money to be hiring cars and taxis. We would phone the paramedics sometimes they say they can't take her, and we must wait for couple of hours. We keep phoning saying must they come, and we say yes, we still need it, they end up not coming and say they can't make it and if they do, they expect us to take her to the road and we can't. It was hard, so I think the last time they came was when my mom passed.”

When asked about her experience accessing care from public health facilities in Ward X, she indicated that they initially sought care from the local clinic but when her condition worsened, she was referred to a hospital. She received care from King George or Addington Hospital but preferred Addington because there was better direct access to the facility from the taxi rank compared to King George which involved a longer walk. She indicated that there were some people at the facility in Addington who were helpful but most just treated her mum like a number. There was no priority given to her and she would have to wait in-line like everyone else.

“I know my mom didn't want to be there, but when I went to King George, no, it was Addington the last time, they were quite helpful, you get one or two people like the nurses, some don't pay attention because you are just another number, and you follow the line no matter.”

She recalled one instance of kindness shown by one of the doctors which was an exceptional experience. She appreciated the fact that he took the time to find out more about her mother and understand what her main complaints were.

“Normally when you go the doctor’s office most of the time, they would look at the patient’s face and look at the file and they don’t ask you anything else. They just busy writing, ok we done you need to go there and there and there. This doctor asked what happened and what medication she was on. I took all her medication that she would get from the pharmacy and he said some of this medication it’s wrong...I’m grateful for that doctor being there and he asked my mom one or two questions and was genuinely concerned about how she was feeling, if she takes her medication, has she eaten, things that someone don’t really ask you, especially at a public hospital.”

While it was a good experience, she did not see that doctor again and felt that had he been allocated to her mum, things may have been a little easier. She felt that not having a consistent healthcare provider was a major contributing factor to her mother’s deteriorating health condition, as everyone they saw had a different perspective on how she should be managed and what medication she should be on.

“I think he could have understood her. We met him the first time and if you actually take the time to speak to that person and understand them and you will remember them the next time. So, he would have the ideas about what is going on, where he can help her, maybe the medications she was using he said some of it is not right ... and try to help her or figure out what is actually wrong. Every time we saw a doctor it was ‘this is the wrong medication then they will change it’ ... and I think that was also contributing to her kidney failure.”

“you know when you put too many people to cook one food or something, too many chefs or something ...something is going to go wrong ...one doctor that is assigned to that one person ... he will know what to do, he will just see you and know what medication.”

Mrs J reported that her mother was very frustrated with her medical management and defaulted on her appointments. In the last year of her life, she opted not to take any medication and did not wish to attend any appointments. When asked to reflect on what her mother’s expectations of the health system would have been, Mrs J indicated that her mother would want better health services for persons with disabilities and many illnesses. She would want persons with disabilities to be prioritised and put at the front of the queue. She also reflected on the need for mobile health services to be closer to the people who need the services. She felt that these kinds of services would have made a difference for her mother.

“I don't know if they do it, but you know they get those mobile clinics. Where you come into the area, you have your own taxi, everything is set up in the area you know. Where transport is hard you have to wait for taxis and buses and all of that those mobile clinics where it's so close in the road ... makes it easy for the people to access it. With us here although the clinic is there, sometimes to get transport to and from it it's hard. You have to go in the heat, imagine someone with blood pressure and sugar standing in the heat for hours to wait for the bus and then when you jumping-off you have to walk to the bus stop and take the bus ... All that too plays a big important role.”

She felt that in emergency situations she could not rely on paramedics as they had demonstrated that they did not care about assisting her mother. Her recommendations for government included ensuring that emergency services personnel understand the unique situations for persons with disabilities, the elderly and those with chronic conditions. Her

feeling was that her mum might have survived if they had provided the kind of service that was required.

“With the ambulance it was hard. At least if they could understand special needs cases, at least to try and help the people, because if they came down [to the house] or tried to help us earlier on, I think she would have managed to survive. In hospital, try to prioritize the patient that needs it [care], if you young and fit I’m sure people will understand. Try help the old people out and try to be understanding. Nurses in public service, they are there to help. If you don’t want to do that, don’t get into the field even if there is the minister. He is supposed to be helping people finding out what is the problem in hospitals and the situations and try to help them out and I think they not bothered as long as they are getting their money, they are satisfied and then they just leave us to suffer. It’s been hard for my mother. Just the attitude of the nurses and the lines and the procedure of files and this and that and getting from one to the next place especially when she was sick, to get from one part of the hospital to the next part, which is on another end and from there they say you need to go somewhere else, instead of having things in order.

Mrs J also reflected on the important role that the community played in supporting her mother’s “Continuity of Care”. Chris who is the designated community leader, was reported to play a critical role in facilitating access to support and helping families when they were in crisis situations. Mrs J felt that if he was given more resources, he would be able to do much more to provide support to the community.

“... if Chris had better resources, he could help the people more efficiently ... You know his brother bought a pressure machine, sugar machine for his granny, he will actually bring that and come and help me and test here. So, if he had better resources, he will be able to help

the people more and he knows almost everyone in this community because he is always up and down.”

She reflected on how well Chris knew the community and how attuned he was to their specific needs.

“even if you get someone that is sick or disabled , you don't know the background of the situation that person has at home, so for that knowing a person like Chris when you've got nobody you know there is somebody you go to and will make a plan to help you, that's how most of them came and most of them see Chris as like a saviour - kind off, now those are the kind of people that are really, really are respected because there are quite of bit of people here that have problems and disabilities and other issues at home. They have nobody to turn to.

She commented on the fact that Chris was part of the community and was able to appreciate the context in which people lived. The fact that he spoke Zulu, English and Afrikaans was seen as a benefit to the community because he could easily converse with neighbours and community members. Another trait that she commented on was the fact that he was able to overcome racial barriers.

“he gets along with anyone, we Coloured, we Indian, we black and we even got a white now [in Rainbow Ridge] ... Chris gets along with everyone. He is really a soft touched person, very intelligent, he knows from right to wrong, you know a lot of people in this place who also have come to support and to help the community and do certain things but there is always a “but” with Chris you don't find a “but”.

Mrs J felt that although there were community health workers that visited the community a long time ago and some efforts by the community liaison to support people in the community, most of them did not live in the community and did not fully understand the unique

needs of the persons with disabilities and the elderly. Having Chris was seen as a strength for the entire community.

The findings are synthesised in Table 17 and show that challenges were distributed across all three “Continuity of Care” pillars, i.e., informational, relational and management continuity. Additional findings were placed into the ‘Other’ category.

Table 17: Open-code mapping of experiences and expectations of families

	Informational Continuity	Relational Continuity	Management Continuity	Other
Family experiences	Lack of information about support for people with disabilities - Having to repeat information - Discontinuity between facilities and within a facility - Poor administrative processes that are confusing	Changes in care provider Perceived racism Lack of empathy shown by staff Treated like just a number Hostile attitudes towards people who demand better quality services Health facility staff have poor understanding of disability and the needs of families No help from paramedics Lack of accountability of health professionals	Unwilling to adapt or be flexible Difficulty finding good quality long-term care Access challenges to health facilities Perceived quality difference between public versus private facilities Long waiting times	Demands and pressure on family Helplessness Resources for community support structures Fear of public health system Financial constraints Transport costs Preference for private facilities for persons with disabilities
Family Expectations	Accurate records shared appropriately	Preference for receiving treatment from one healthcare provider Dignity Nonracialism Emotional support Understanding Flexibility Genuine care	Mobile services Transport to facilities Assistive devices	Community support Resources for community

4.5 Section 4: Tier 3 - Community experiences of “Continuity of Care”

Telephonic interviews were conducted with four community members active in Ward X as outlined in Table 18.

Table 18: Community leaders interviewed

	Sex	Language	Race	Role in community	Nationality	Community represented	Interview method
ID1010	M	English, Afrikaans, Zulu	Coloured	Community member and head of community-based NGO	South African	Rainbow Ridge informal settlement	Telephonic
ID1011	F	English	Indian	Matron at private residential facility	South African	Private Residential Frail care facility	Telephonic
ID1012	M	English	Black African	Community liaison	South African	Ward X	Telephonic
ID1013	M	English	Indian	Community activist	South African	Ward X	Telephonic

All four community leaders interviewed were active members of the Ward X community and were able to provide nuanced feedback on Ward X and what they felt influenced “Continuity of Care” for persons with disabilities.

Rainbow Ridge through the eyes of “Lasting Legacies”: Pre-democracy (pre-1994), Ward X was seen to be a more affluent Indian area than others. Large tracks of private land owned by Indian families, passed on generationally, were the target of early land invasions that took place post-1994. The area was seen to be advantageous due to its easy access to the city centre, good schools, close access to the University of KZN and employment opportunities through new developments in the Springfield commercial zone.

“Reservoir Hills and Clare Estate were known as the “Umhlanga” of that place because it was mainly the Asian community was mainly people who wanted to stay in their*

family homesteads. I think from 1993 moving onwards is what they called the “influx or invasion of urban areas”. It was when informal settlements started popping like mushrooms all over the suburb. It was in 2003 that we realized that there were large tracks of land that people owned that nobody was doing anything with. We were saying, as a fellow SA, I need a place to stay. Can you not find it in your heart to at least allow me to place this little table here, so I can put down my head and rest? It wasn’t easy. We had to go through a lot of challenges, we had to sit in a lot of meetings”.

As time passed, the community of Rainbow Ridge became more and more impatient at the lack of service delivery. It became the hub of violent protests due to deteriorating conditions of living for its residents.

We have fought with a lot of people. First of all, to get Rainbow Ridge to be recognized as a community, to get access to water and for buses and taxis to come up the road, because they used to turn at the bottom. And electricity, that was one of the biggest issues. We had literally a physical altercation with these companies that would come and take it out [the illegal cables] and we understand what we were doing was wrong - we were stealing electricity, so we literally had to fight. I can show you scars; I got rubber bullets still stuck in my body”.

The community of Rainbow Ridge was reported to be a close-knit community who grew tired of empty promises of political parties lobbying for support before each election. Young leadership within the community drifted away from political affiliation and started to mobilise their own resources and ideologies that resonated with the needs of their community. Chris from Lasting Legacies was instrumental in making an impact within his community.

“We have been very, very vocal in protecting our people and not allowing outside parties [political] to come in and give them these beautiful ideologies and just leave. Because they raise someone’s hope and then just leave it as hope. I think that’s damaging. You should

rather leave them than giving them hope in the first place. Some of the initiatives that I that have taken part in myself personally, the development projects amongst youth, I have taken part in awareness programs for females, letting them know that guys he might be your husband but not your guard and you need to stand up and realize your own strength as a female you know. I have taken part in vaccination drives, we actually brought the clinic to the area at the time there was, what they call this, scabies it was a scabies outbreak, so I called the clinic, and I literally went and called them and sorted people out. In informal settlements there is a lot of stray animals, and those strange animals bring in illnesses into the houses.

As an overarching theme, the issue of **failed leadership** in the community of Ward X was evident from all participants. One young leader in the community whose influence galvanised over time because of the trusting relationship he developed with the impoverished community, said that he was seen as someone who knew what the community needed and was willing to fight alongside them. He was a community bred leader who was deeply connected to the community of Rainbow Ridge. He felt that persons with disabilities had been short-changed by government.

“I understand why SA are so angry at the moment. Because our leaders are selfish ... they sit in the offices, and they make decisions, and they create these policies and without even thinking and how that does affect people like [Mr K] ... Ok, so they say there is this disability grant. Must Nkululeko now get up with his disability and no access to transport, can't take care of himself properly and he must still go there and take transport and still walk from where the buses will drop him off to the offices of SASA and wait on the queue with his crutches, and there is nobody there who's going to offer them water? I think, the leaders that we got in our area they will be more than willing to assist our people, because we want to see our people grow and prosper. The ideology that we had in SA post 1994 was beautiful and it is a shame we haven't reached it yet.”

The progressive worsening of basic municipal services by government was also highlighted, as was the impact that the lack of services had on persons with disabilities. The sense that persons with disabilities have been largely ignored by government was evident

“There are no changes that’s why we trying to fight and trying by all means but there are no changes at moment - you know how our government is. We trying by all means to get proper place for them [persons with disabilities] because some of them, they can’t even walk, they don’t have proper places where they can use wheelchairs, so we have to organize a place where the wheelchair will be on a proper space to work and a place to bath, and toilets and where they staying there is no proper places for them - there is no space.”

For residential care facilities like Eagles Wings, the silence of government in supporting them was seen as a major challenge.

“I do think the government should play a much more important role in helping these non-profit organisations achieving their goals and see that you know I’m speaking for Eagles Wings. We get no funding from the government. If we did have funding, we could have done so much more because we are in need of so many things that would make the lives of our seniors and persons with disabilities so much better”.

Experiences of persons with disabilities regarding their “Continuity of Care”: One of the participants reflected on two persons with disabilities that touched his heart.

“I know about 50 persons with disabilities in Ward X. You know for [Mr K], we were happy with that the hospital organised care for him, and that people will be taking care of him...and only for him to pop up in the community 3 months later! We said, Mr X what you are doing here?”

[He replied] – “I don’t like that place; they treat us as if we are children. They treat us like we don’t have brains. I know that I’m disabled because of the mistake that I made, is my

disability not a punishment enough, why must another human being who has been paid to try to make my life easier and they make my life even worst and make it harder?” [Mr K’s response and relayed by one of the community members]

Conditions of persons with disabilities living in Ward X: the conditions of persons with disabilities living in Ward X were described by participants as very poor. Despite efforts to try and provide support, they were still observed as a vulnerable group that was not fully prioritised, especially in emergency situations, such as flooding and fires.

“I’m basically working with people staying in the informal settlement, we are looking after those persons with disabilities, they are not safe staying in the informal settlement. We are trying every day to get out government to please build proper houses for them because they scared. They get burnt whenever there is burning shacks in the area because nobody is taking care of them. I’m trying to make sure that they got a place to live in; electricity, water and other basic needs. And some can’t talk, they use sign language, and I don’t understand the sign language it becomes difficult. [Community Liaison – Ward X]

“Their experience with the health care is, first of all they were looked at as if they were not relevant, they were looked at like pieces of chess that you can just move around. It’s really emotional, it is really, really emotional” [Representative of Lasting Legacies]

The quality of care provided to persons with disabilities was reported as unacceptable and poor where persons with disabilities were made to feel ashamed for not being able to care for themselves. They were robbed of their SASSA grant money because they did not have access to transport to access their grants in person.

“About 6 or 7 years ago, we will call him MR X, he had an accident that burnt his entire body, because he was burnt his inner thighs was stuck together, so it was difficult for him to

walk and because of that it wasn't easy for him to go to the toilet, it wasn't easy to walk, it wasn't easy for him to go collect his grant. So, CCG's were the members of the health care centre and they were supposed to look after him, instead of making him more comfortable and say listen here we understand your problem and we got your back. But the minute they entered his house they were like "mmmmmmhhhhh, what's that smell!" Now you coming to make me feel better, but you telling me there's a smell in my house and they would clean him, but they would shout while they doing it and then you ask; what are you doing here? Are you here to make him feel worst or are you here to make his day seem brighter - even if it's for one hour."

"On days of his grant because he wasn't able to go, he will send people and they will rob him as if it was nobody's business you know, and they use to go to the clinic but they go to the hospital now to go fetch medication and for check-ups and they get charged exorbitant amounts for transport".

Transport: Transport to clinics and hospitals were seen as a major stumbling block for persons with disabilities who wanted to access health services. For many persons with disabilities, they were referred to hospitals rather than clinics because their chronic conditions were more severe. A round trip to the nearest hospital was reported to be around R300. There was an initiative to address the transport issue, but the community had to intervene and advocate for persons with disabilities in order for them not to be charged such high rates. They used their community support as leverage to negotiate better deals for persons with disabilities, but the service is private and to date there are no public transport options for persons with disabilities to access healthcare facilities.

"It is still existing, but we have spoken to them, and we have cut a deal with them, even if you are assisting, it a source of income for you and you cannot be charging R300 to an elderly disabled person. Also, someone who needs help and cannot be charged exorbitant

amounts, and I won't lie to you, we have threatened them a bit, and say that if you continue to charge those amounts, when you need assistance from us as leaders, we not going to be there to assist you".

Community initiatives and resources to support persons with disabilities in Ward

X: The community of Rainbow Ridge leads a number of initiatives to care for persons with disabilities by themselves. Three NGOs active in Ward X provided insights into their initiatives to support persons with disabilities. Lasting Legacies described a range of community outreach activities within Rainbow Ridge, including soup kitchens and individual support to persons with disabilities. Their support was tailored to the needs of persons with disabilities and other vulnerable households and aimed to build community cohesion and sustainability in the support provided. Eagles Wings, an NGO in Ward X, described their support to elderly people many of whom have acquired disabilities due to strokes and degenerative neurological disorders. They have established male and female residences in Ward X and provide full residential care. Bridging the Gap was the third NGO identified, which provided outreach support to health facilities in order to strengthen the community-based HIV response in the area. Their structures match that of government and their responses were therefore captured under the health systems responsiveness results in Chapter 6.

"When that soup kitchen first came, we looked after the elderly and people with the disabilities mainly. With those with disabilities we would go, and we will literally feed them ... and we would have conversation like we have conversation now. While we feed you, we will look at your surroundings and say maybe I can help you here and help you there. We will organise 2 people to come and assist to come clean the house, maybe someone who's got a washing machine and take the cloths to do the washing there". [Participant from Lasting Legacies]

There are also efforts to link people in the community who support the needs of persons with disabilities, to economic opportunities so that their assistance is recognised and rewarded.

“If you are able to cook food for that night, then for that person who is trying to assist, we take your records and we keep your records and every time an opportunity pops up and because you assisted, this is our way to say thank you to you. We would give you an opportunity maybe like go and grab that 2-month contract because you assisted”. [Participant from Lasting Legacies]

The plight of persons with disabilities was highlighted at community activities organised on special days like Mandela Day where persons with disabilities are fetched and taken to a central location and provided with fun activities and given some attention. Many persons with disabilities were relocated to new housing facilities in an area called Cornubia. The intention was to try and get persons with disabilities out of informal settlements and into formal housing. However, in relation to access to transport, it was unclear how relocation would benefit them or how they would cope being away from the network of support they enjoyed in Ward X.

There are some problems with this approach to interacting with persons with disabilities in that giving attention to this population only on specific days is superficial and akin to the old charitable model of disability. In contexts like this, there is a danger of creating a cycle of low expectation whereby people do not dare ask for more than they are given, and, in this way, they are appreciative of what they are given and not demanding of greater participation in decision making. In the same way, moving persons with disabilities to a location far away from their network of support and access to health facilities must be viewed critically. It is understandable that government has prioritised persons with disabilities for improved housing options, however, the level of engagement between government and persons with disabilities in Ward

X is questionable. Did they really want to move and are they aware of the full implications of the move in relation to healthcare access and the absence of a supportive network?

“Some we tried to give them a proper place to live in CORNUBLA and we moved some of them last year then here in PALMIET ROAD we currently have two people who we got a project coming around we trying to take them out of the informal settlement”. [Community Liaison – Ward X]

The challenges experiences by residents at Eagles Wings as reported by the participant were access to wheelchairs, therapies and transport to clinics. These factors limited “Continuity of Care” and impacted the well-being of their residents.

“We have challenges with resources for example wheelchairs and equipment for them. Things like physiotherapy and transport to the clinic – those kinds of challenges”. [Participant from Eagle’s Wings]

The nursing staff at the Eagles Wings facility do not support access to medication. Family members are responsible for ensuring access to their prescribed medication. This was reported to be difficult for some family members.

“They get their chronic medication from the hospital and their family members are responsible for picking up their medication and bringing them to us. Although it can be challenging sometimes because you know family members are busy, they are not able to pick it up on time”. [Participant from Eagle’s Wings]

The “Continuity of Care” concerns for residents living at Eagles Wings as reported by one of the nursing staff were focused more on access to therapies such as physiotherapy and speech therapy. The lack of community-based rehabilitation was highlighted especially for residents who relied on public healthcare.

“We have problems where they would require you know like physiotherapy and speech therapy for example and there’s no persons like that in the public sector that is able to continue their care at the home. So, our patients have to be taken to them for rehabilitation and this becomes a challenge because family members cannot keep up to these appointments because of their own commitments”.

The Eagles Wings staff reported knowledge of the CCMDD programme, however, the programme did present challenges when the facility went to collect the medication, as described below:

“Yes, we do have some of our patients you know who are presently collecting their medication through you know Clicks and Dischem [private pharmacy affiliated to the CCMDD programme as a Pickup Point]. But we also have challenges that when we get there sometimes the medication is not there when we go to collect it - so there's also a challenge”

Expectations of Communities relating to persons with disabilities

There was a much broader call for persons with disabilities to be given priority and access to basic services by Rainbow Ridge participants. Healthcare seemed to feature as lower priority due to the immediate dangers of their current living conditions. Better transport options for the elderly and persons with Disability was strong expectations at the community level. They highlighted the negative impacts of the high costs of private transport on persons with disabilities both in terms of their economic freedom as well as access to health and social services.

“I think our government must try and organize proper places that will look after the elders who are disabled. Build them proper houses and there must be someone who is going to look after them because they can’t clean, and it becomes dirty. Treat them equally whether they

are mentally or physically disabled. They must feel comfortable at their place, give them love because they are human beings and God created them like that”. [Community Liaison – Ward X]

The participant from Eagles Wings indicated that community-based rehabilitation was necessary for persons with disabilities as it was not feasible to transport them in wheelchairs using transport that was not comfortable for them. One of the suggestions was special allocated times for persons with disabilities to be seen at local clinics so that transport can be arranged.

“We should have a facility even if you know the doctor's or the community workers cannot come through to the centre, I realise that they are busy, but have like an allocated time you know where we can arrange transport and bring our patients to the community centres where they can be seen and taken back immediately so that they are not waiting in long queues. I would say providing equipment to the non-profit organisations like wheelchairs and their medical appliances like glucometers will be very helpful.

Table 19: Mapping of experiences of care as described by community members

	Informational Continuity	Relational Continuity	Management Continuity	Other
Community Experiences	Good relationship with private hospitals when patients are transferred Inaccurate alerts for CCMDD	Poor attitude of CCGs Community playing a facilitating role to maintain “Continuity of Care”	Poor management of outreach teams Community-based rehabilitation absent Importance of family partnerships Long waiting times at facilities	Lack of appropriate transport Lobbying for private services Community-driven support Economic opportunities for community members who assist persons with disabilities Poor housing Families are stretched too thin
Community Expectations		Appropriate public transport for persons with disabilities To be treated with dignity and care Appropriate housing and space for assistive devices Prioritisation during emergencies	Support from government for NGO and community-based organisations Better coordination with local clinics Special days for persons with disabilities and the elderly	

4.6 Section 5: Analysis of factors influencing “Continuity of Care” for persons with disabilities: Insights from individuals, families and communities

The previous sections of this chapter presented the “Continuity of Care” journeys” of persons with disabilities, as well as family experiences and community perspectives. The richness of the unique perspectives was elaborated in much detail and provided the basis for the thematic analysis presented in this section, focusing on factors influencing “Continuity of

Care” for persons with disabilities. Inductive coding and deductive thematic mapping allowed for the discovery of common threads within and across these three groups with the aim of addressing the research question. The common and diverse experiences of each group when analysed collectively allow for interesting discoveries in the data as presented in Appendix U.

4.6.1 Factors influencing “Continuity of Care”: User, family and community perspectives

Nine major factors were identified:

4.6.1.1 Burden of healthcare access: Transport

A common thread across the interviews with persons with disabilities and their families related to the issue of accessing healthcare facilities, specifically with regard to transport. Transport challenges have been a commonly reported challenge for persons with disabilities. Like many other areas of community planning, apartheid planning saw many non-white areas less resourced than areas designated for whites. Transport issues in a post-apartheid SA reveals remnants of that system with modern twists in a thriving taxi industry that is insensitive to the needs of persons with disabilities. The theme of transport in this study is slanted more towards the issue of who bears the economic brunt of addressing transport issues and the persistent challenge of a lack of reliable and accessible public transport network in SA.

Inaccessibility of public transport

Public transport to access health services was a challenge for all individuals, and for most, was not feasible. Two of the six participants reported that taxis did not come close enough to their homes and due to their mobility challenges, were unable to walk to the nearest taxi rank. One of the participants who did access public transport experienced negative reactions to his disability and generally only used it if absolutely necessary. For the remaining

three participants with disabilities, their only options were to solicit help from community members or hire private transport.

Costs of hiring private transport

Costs of private transport was prohibitive for almost all participants. Four of the six participants were pensioners relying on a state pensioner grant, while the other two were middle-aged with a disability, presumably collecting a government disability grant. Participants who needed to arrange private transport paid at least R300 per trip to the health facility and if they were to pick up medication from multiple locations, the costs were higher. Community members interviewed were also vocal about the rate charged by private transport companies and some even attempted to take on the cause by putting pressure on them to reduce their rates for persons with disabilities and the elderly. The burden of healthcare access falls not only on the individual but also on the family and community; due to their vulnerability and limited means, they are exposed to a high level of exploitation from private transport companies.

Additional mobility support costs

Direct transport costs were not the only consideration for persons with disabilities. For two participants, mobility meant requesting community members to support them out of their homes and into hired transport. For one of the participants this was achieved by appealing to the goodwill of family and people in the community but for others, the effort required paying people to assist them out of their homes. Through a western lens, this may be seen as indignity and the need to constantly rely on others may be viewed as humiliating, as it speaks to a lack of independence and free will. However, through an African lens, this is characteristic of the Ubuntu model of disability, where community is seen as an important pillar of support. In the context of this study, there appeared to be a sense of camaraderie among the community to the

extent possible, though there may also be a level of exploitation at play where compensation for assistance was required.

4.6.1.2 Compliance to PHC administration standards

In the delivery of healthcare, information continuity is the process by which information relevant to the patient's care is made available to both the patient and the provider at the right place and time in order to facilitate good "Continuity of Care". Information continuity in a private GP's room may be different from that observed in a busy public healthcare facility. In SA, the administration practices of PHC facilities and community health centres are prescribed in the Ideal Clinic Manual in order to configure and deliver services efficiently and enable patients to easily navigate through the facility to access appropriate care. . at Poorly coordinated services, including poor administrative practices, have a negative effect on the overall patient experience. In terms of the Ideal Clinic Manual, every clinic and community health centre should have a designated helpdesk, patient registration desk and patient records storage room. Standards on how patient records are filed and retrieved are prescribed in the health information policy and should be executed to the fullest degree possible.

Findings indicated that across all three categories of participants, there were negative reports of patient record-keeping which impacted on the patient's experience of care. For persons with disabilities and families there were particular challenges reported around poor filing and health information management practices. Participants, particularly those from the Indian race group complained about the need to repeat information and endure long waiting times due to lack of information of what process or queue should be followed. An interesting finding was that Indian persons with disabilities seemed to report administrative challenges to a greater extent than black African persons with disabilities.

Inconsistencies were also reported regarding patient rights to priority services. Three of the participants reported feeling confused about who needed to be given priority inside the health facility. One participant, a mother of adult man with cerebral palsy, indicated that she was not given priority and felt discriminated against, resulting in her having to wait with her son in long queues. Similarly, only the Indian participants were noted to report challenges in terms inconsistent prioritisation of persons, delays in the retrieval of files and the need to constantly repeat information.

4.6.1.3 User-centred design practices

The patient experience in public health facilities in SA is often one of long waiting times and, sometimes, repeat visits to facilities to collect medicines that were not available at the routine visit. This situation poses potential adherence barriers which may lead to poor health outcomes, and places strain on the patient in terms of transport costs as well as loss of income.

The CCMDD programme was developed by the national Department of Health to provide an alternative mechanism to facilitate access to medicine for stable patients. External pick-up points (PuPs) provide the patient with a more convenient option for the collection of their repeat medicine which has been dispensed and distributed via the programme. The PuP may be closer to their homes or workplace and can result in reduced transport costs.

Exclusion of persons with disabilities in the design of new innovations

A key finding was that the CCMDD programme was shown to have limited impact on the participants in terms of the intended convenience promised by the programme. Three individuals with disabilities noted that while they were able to avoid attending the health facility on a monthly basis, they still encountered the challenge of being unable to access some

medications through the programme, resulting in trips to a health facility, a hospital and a pharmacy. Given the associated travel costs mentioned above, the intended benefits of the CCMDD programme were not realised.

Criteria for enrolment in new innovations

One of the criteria for being able to register with the CCMDD programme is that a patient must be assessed as being in a relatively stable condition in terms of the management of their chronic condition. Two of the six individuals with disabilities met these criteria, and were enrolled in the CCMDD programme, but due to the complexity of their healthcare conditions, had to endure multiple trips to the health facility; and consequently, chose to access care from private service providers.

An interesting dilemma for persons with disabilities is achieving good health outcomes to the degree to which they are deemed to be in stable condition. For those interviewed, this goal may be unattainable when faced with multiple chronic diseases, poverty and other socio-economic vulnerabilities. The CCMDD programme while well designed for stable patients, creates further inequities in the health system and drives the most vulnerable groups into further marginalisation and deprivation in terms of achieving good health. At a time when new health innovations are the order of the day, a careful assessment of whether they have been designed with the full spectrum of users in mind is necessary.

In the case of the CCMDD, there is evidence that its design was not meant to be universally accessible but was rather based on alleviating congestion in the health facility and reducing waiting times for the stable patient, and not on pursuing the “Health for All” ideology and addressing gross inequities in the health system.

Inaccessible information

An interesting finding was that many of the participants were not aware of the CCMDD programme. All three families interviewed, regardless of whether their family members qualified for enrolment, were not aware of the programme. For the mother of a son with cerebral palsy, being able to access medication from a pharmacy as opposed to having to visit the hospital each month, would have been less stressful.

Lack of patient centeredness

Patient-centeredness is critically important when dealing with persons with disabilities because it acknowledges the unique needs, preferences, and experiences of individuals with disabilities, empowering them to actively participate in their healthcare decisions and ensuring that their care is tailored to their specific circumstances. This approach not only respects their autonomy but also contributes to better health outcomes and improved overall well-being.

For almost all persons with disabilities and families interviewed, the call for chronic medicines to be delivered to their homes was strong and based on compelling mobility and financial challenges. There was also a need expressed by many participants for health services to be closer to the community so that vulnerable groups with mobility challenges and poor health do not need to be further marginalised and excluded from accessing care.

4.6.1.4 Servant Leadership

Leadership styles are strongly correlated with quality care and associated measures, of which patient- centredness is an important component (Sfantou *et al.*, 2017). Fostering respect and civility (i.e. the pillars of empowerment and servant leadership) are foundations of creating healthcare systems that revolve around the true needs of patients (Smith & Bhavsar, 2021).

Insights from persons with disabilities and families showed that there was a deep appreciation for health professionals who demonstrated a focus on their needs and were empathetic to their unique situations. There were two factors identified that were particularly valued by participants and inadvertently had positive effects on their “Continuity of Care”: personalised care and proactiveness.

Personalised care

Participants with disabilities relied on relationships developed over time with clinic staff. One participant was able to make special arrangements by telephone to alert the nursing staff of her appointment for the day. They understood that she was unable to stand for long periods of time and would have her medication ready for her to reduce time at the facility. Another participant valued empathy and genuine interest shown in her mother’s condition, making her more hopeful about her mother’s care. When participants’ needs were well understood by the health professional treating them, or were tailored to the patient’s need, the adaptability and responsiveness displayed are a hallmark of servant leadership.

Proactiveness

Participants who provided positive descriptions of their “Continuity of Care” also expressed gratitude for nursing and medical staff who showed them respect and were proactive in their approach to health service provision. One family member was pleased to meet a doctor who asked probing questions not just about her mother’s health but also about whether she had eaten and made provisions for her to stay seated with her mother. Community and family members also reported lack of proactiveness where health professionals stuck rigidly to rules and did not wish to respond to the unique situation of the person they were treating. This was the case with emergency personnel who were not willing to assist the family with transferring the patient with a disability to the ambulance.

4.6.1.5 Othering

Othering as a powerful process that goes beyond concepts of discrimination and has the ability to capture knowledge structures, power relations, and categorization processes in their interconnectedness and to identify their effects on different levels (Akbulut & Razum, 2022). Othering is a sociocultural concept that refers to the process of perceiving and treating individuals or groups as fundamentally different from one's own group (Racine, Di Pietro, Zizzo, & Aspler, 2018). Research by Akbulut & Medele (2022) indicates that othering is an important aspect of research on health inequality (Akbulut & Razum, 2022). Othering in the context of health has shown that othering of persons with disabilities can manifest in various ways including stereotyping, exclusion and power dynamics and are compounded by the presence of ableism in the health system (Janz, 2019).

Othering was more commonly reported by Indian and Coloured than black African participants. All Indian participants mentioned some form of othering, with exclusion and discrimination being most often described. Power dynamics were also reported as a challenge amongst the Indian participants though it was not clear whether the experience of othering was linked to the disability or the race of the participant.

This observation caught the attention of the researcher and the interplay between race, disability and the historical legacies of apartheid forms part of Chapter 8.

4.6.1.6 Colonial Legacies

The impact of colonialism on healthcare in SA has been profound and has shaped the way healthcare is provided, accessed and understood. The apartheid policies entrenched the marginalisation of traditional practices and had a significant effect on the healthcare system,

including that of traditional health practices and how they are valued. While the aim of the study was not to assess the significance of traditional health practices, what was clear through one participant interview was that traditional healers and cultural norms do play a part in achieving “Continuity of Care” and when excluded, can result in negative consequences for “Continuity of Care”.

Medical Model

The medical model, also known as the biomedical model, is a perspective on healthcare that primarily focuses on the biological and physiological aspects of illness and disease. It emphasizes diagnosing and treating medical conditions through medical interventions, such as drugs, surgeries, and other medical procedures. While the medical model has made significant advancements in understanding and treating various health conditions, its exclusive focus on the biological aspects can have implications for how culture and traditional health practices are devalued.

In the case of one participant, the impact of colonialism was real and tangible. The exclusion of traditional healers and the devaluing of their role in communities (Cultural Imperialism) had life changing impacts on the person and ultimately led to poorer health outcomes and a permanent disability. The standardised approach that has been entrenched in the system means that any deviations from that standard will result in clashes between the medical model and cultural healing methods. This “worst of two worlds” approach must be contested as ultimately, the tension results in the worst possible outcomes for the person seeking care.

The story of Mr N demonstrated that traditional healers were a clear lever in the chain of care. However, the current western model of healthcare in SA has been designed to suppress cultures and practices in a punitive manner, whereby people who do not seek help from western

medical structures are left to fend for themselves. This is akin to Cultural Imperialism but further demonstrates the limits of the human rights model in respect to accessing health support through traditional practices and the ways that health intersects with culture (Muyskens, 2022). While there are obvious scientifically proven benefits of western medicine, the marginalisation of traditional practices and beliefs is not sustainable if good health is ultimately the goal. Better understanding of traditional health practices and collaboration with traditional healers may be worth the investment especially for persons with disabilities where the role of traditional healers may be even more significant.

4.6.1.7 Political and Institutional Distrust

Interviews with families and community leaders painted a clear picture of weak health system governance. Good governance in health systems is crucial for the delivery of quality health services. The theme of good governance was broken down into two sub-themes: political and leadership factors. The impact of political and institutional distrust have been found to be most dramatic in marginalised populations who experience political exclusion and who live in poverty (Hermesh, Rosenthal, & Davidovitch, 2020) with significant impact on the successful implementation of health programmes.

Political Factors

In the context of Ward X, which is a highly contested ward politically, there was a sense from participants that they could no longer rely on government. There were several mentions of political preying on the community during election campaigns where communities are wooed by political parties to secure votes and political control. There was mention of the fact that people were angry and that they were tired of being “used” as pawns in political battles of power. It was also the sense that persons with disabilities have been forgotten by government. The fact that key challenges faced by persons with disabilities in the community were ignored

and not addressed decade after decade, meant that persons with disabilities, were alienated and powerless.

At a macro level, the political economy of health as a social determinant of health is evident. The high levels of unemployment and limited means of the large majority of residents in Ward X point not just to inequity, but of policies that perpetuate poor living conditions and an inability to escape the cycle of poverty. The division of the private and public health sector in SA represents a high-level macro policy framework that has a direct impact on health equity. In relation to this study, it was also shown to have a significant impact on an individual's ability to achieve "Continuity of Care". While the public health sector provides free services, participants accessing care were faced with health services that were not tailored to their needs, requiring them to develop strategies of their own to overcome the obstacles to "Continuity of Care". A significant finding was the impact that the overarching division between public and private healthcare had on persons with disabilities. When a person with a disability cannot access the appropriate care, the knee jerk reaction is to seek care elsewhere. What was clear from the findings was the inequity in the health system, where those with financial resources could access care from both public and private health systems to compensate for the resource constraints of the former, whereas financially destitute patients were entirely dependent on whatever services were available or could 'choose' not to access them. Distrust in governments and health systems have recently been the focus of much concern due to the COVID 19 pandemic.

Governance weaknesses were evident at a micro level as well. The Sukuma Sakhe Programme developed as the Premier's Flagship programme aims to address the gaps in service provision by bringing sectors together and promoting collaboration with communities and relevant government structures, including health and social services. Through its implementation, persons with disabilities would be prioritised and weaknesses in issues such

as “Continuity of Care” would be addressed efficiently. In the spirit of Sukuma Sakhe, the issue would have been identified within a war room, where community issues are raised, discussed and solved. The fact that persons with disabilities who have lived there for decades still experience this persistent issue, is evidence of the lack of effectiveness of this programme. A tangible example would have been the transport challenges faced by persons with disabilities. Despite the fact that the programme had been lauded as the ideal model for fostering greater intersectoral collaboration and more efficient delivery of services, there was no evidence of its implementation in Ward X. Efforts to access the ward counsellor and the coordinator of Sukuma Sakhe were unsuccessful, demonstrating that lack of visibility of governance structures closest to the community. On some level, this speaks to the issue raised by a community member, who felt contempt for political parties who enter their communities with idealistic models and new ideas, which seek only to promote their own agenda and leaves the community even more broken than they were before.

4.6.1.8 Leadership Factors

During interviews with community members issues of weaknesses in health service implementation were raised. The inconsistency and perceived lack of coordination of out-reach services serves to highlight leadership weaknesses in the management and quality assurance of health services rendered to persons with disabilities. One of the community members recalled a humiliating experience of a person with a disability at the hands of a CCG, where he was belittled and humiliated because he had soiled himself. Another participant with a family member with a disability mentioned how poor attitudes of healthcare workers made her feel frustrated and discriminated against. The lack of care left both of them wondering if healthcare providers were adequately trained to work with persons with disabilities. From the researcher’s perspective the question to be asked based of these experiences, is firstly, whether the

prioritisation of persons with disabilities as outlined in the Framework and Strategy for Disability and Rehabilitation had been communicated through the leadership and management levels of the health system? Hussein El Kout, Pilusa, & Masuku's 2022 evaluation of the FSDR showed that some of the factors that influenced the implementation of the framework included actor dynamics, inappropriate leadership and negative attitudes of staff impeded the successful implementation of the framework (Hussein El Kout, Pilusa, & Masuku, 2022). And secondly, whether government sees policy design as the end point or whether implementation plans combined with accurate monitoring is valued in the SA health landscape for disability and rehabilitation? Insufficient implementation not only impacts access to services for persons with disabilities, but it also defines the health systems responsiveness to the expectations of persons with disabilities.

Emergent Community Leadership

Emergent Leadership was found to be powerful factor in supporting the "Continuity of Care" for persons with disabilities. It refers to a leadership style that naturally arises within a group based on the qualities, skills and contributions of individuals rather than being formally designated or designed. In this study there was a strong community identity and convergence in terms of their understanding of their lived reality and what needed to be addressed by the ward counsellor and what they could achieve by themselves.

Community self-organisation

Within the community of Ward X, family and community members interviewed spoken gallantly about how their community took back their power in an effort to protect themselves against those who proved not have their best interests at heart. Holding CCGs to account and questioning the ward counsellor about the need for public transport for persons with disabilities were some examples of how the community organised their responses to marginalisation and

discrimination against persons with disabilities witnessed by the community. Community-self organisation was propelled by individuals in the community who were bold enough to act against the injustices they witnessed.

Social Cohesion and human connectedness

Lasting Legacies represented a strong form of emergent leadership that was a product of organically designed community self-organisation. In the depths of poverty and in the face of constant marginalisation, the community over time worked together using resources available to them to alleviate some of the sufferings of the most vulnerable living among them. The interviews with individuals with disabilities in the Rainbow Ridge informal settlement showed how important emergent leadership was in developing and organising community-led strategies to support persons with disabilities.

There were two participants living in Ward X who exemplify the importance of community self-organisation. The first was the case of the person with a bilateral upper limb amputation living in Rainbow Ridge and the second case was a person with a bilateral lower limb amputation who lived in another informal settlement a few kilometres away. Interviews with both men, who shared many similarities in terms of socio-economic status and living conditions, painted very different pictures of recovery and resilience. The person with the upper limb amputation revealed a deep bond between himself and the community. He made specific reference to his friend who assumed a leadership role in the community for his recovery, ability to live a dignified life and be as healthy as he could be. Despite his desperately poor living circumstances, he still managed to keep a positive outlook on life and his health. In some ways, he could be considered a beneficiary of community self-organisation in that the community mobilised around his needs and provided him support and encouragement. Their connection was not superficial and was built on many years of community camaraderie. When he needed

assistance, resources within the community were leveraged to support his activities of daily living, like eating and bathing. They monitored his health and encouraged him to seek medical care for his hypertension and referred pain from his amputation site. They respected his decision not to use his prosthesis and allowed him the space to maintain his independence and dignity. In general, there was a strong sense from the participant that he could rely on his community and that his community was part of his road to health and well-being.

For the participant with bilateral lower limb amputation, the situation was very different. He described his living conditions as very poor, and he did not seem to have any close connections with people in his community. People knew of him but did not know him personally. Without strong links to the community, he maintained an isolated life solely dependent on the CCG who visited him periodically, and his wife who worked during the day. His recovery and health outcomes were very different, and one could sense that he felt abandoned by his family, his community, the ward counsellor and government in general. While a direct association between the community dynamics and his overall health outcomes cannot be made, there seems to be a possible positive association between communities who are highly organised by virtue of their connectedness and the quality of life that is experienced by persons with disabilities.

4.6.1.9 Family Resilience

The key influential factor that emerged from family interviews was “**Family Resilience**” (See Appendix R). In all interviews with family members there was sense of urgency and agency in their voices and an unrelenting pressure to be “on guard” and ensure the wellbeing of their family members. The theme of “**Family Resilience**” was deconstructed into two sub-themes. The first being the **Tenacity to advocate** and the second being the **Burdens**

of the carer. These two sub-themes capture the two overarching roles that family members pivoted between to ensure that they carefully navigated safe passage to good quality care for their family members with a disability.

Tenacity to advocate

The sub-theme of “**Tenacity to advocate**” relates the role taken on by the women interviewed on behalf of their family members with a disability. As primary caregivers they assumed the role of advocate for the needs of their family members with a disability and while this was a self-imposed responsibility, it was one that crucially made the difference to how their family experienced care over time. Two of the participants saw their role shift from being daughters of mothers who were dominant maternal figures in the family, to being primary caregivers and the voice for their mothers. They were now responsible for acting on their mothers’ behalf throughout their journey of care, which was a dramatic shift for them, psychologically, economically, emotionally and physically. In the face of many health systems challenges, their tenacity and persistence ensured that their family were able to access care. This was observed as a key factor influencing informational, relational and management “Continuity of Care”.

Two of the women interviewed expressed how constant *changes in healthcare professionals* treating their family member made the journey more challenging and complicated. For Mrs J, as the only voice for her son, felt burdened and stressed by the need to repeat information about her son’s medical history each time she visited the healthcare facility but did so in an attempt to make sure that decisions were made based on accurate information.

The women interviewed were important drivers of ensuring informational continuity as they filled the information gap created when they met new doctors and nurses at each visit. They felt that having different healthcare providers at each visit impacted the health of their

family members negatively, but also felt the obligation to make sure that the health care providers were well informed. With each visit there was always the possibility that each provider would see things differently and would adjust treatment without a full appreciation of the number of previous times the medication was changed. The women interviewed were a critical link to ensuring that the healthcare providers were well informed of the patients' medical histories. Keeping track of the changes seemed to frustrate them but in spite of the challenge they continued to pursue care for their family members in the hope that something would make a difference.

In navigating the changing needs of their family members, all three women described *access to information about resources* as a challenge. Beyond healthcare services offered at the health facility, all three woman needed access to home-based support services and were hard-pressed to access information.

The women interviewed lamented the *poor attitude of health facility staff* as a disappointing and concerning issue that they observed and experienced each time they visited the health facility. In some instances, they tried to shield their family from negative attitudes, and in others they had to exercise patience and put up with discriminatory or hurtful behaviour. Mrs G was particularly vocal about this issue describing healthcare workers as racist who only prioritised black African patients.

4.7 Summary of chapter

This chapter focused on unpacking factors influencing “Continuity of Care” from the perspective of persons with disabilities, their families and community members. Experiences were explored in rich detail, culminating in the identification of ten key factors that influenced

how care was received over time. Facility factors negatively impacting “Continuity of Care” included **lack of compliance with PHC standards**, especially regarding how patient records are managed and the rights of persons with disabilities are upheld in relation to prioritisation and access to process-related information. The **lack of user-centred design** in the conceptualisation and roll-out of new innovations resulted in persons with disabilities being further marginalised and inconvenienced in terms of access to medication. The phenomenon of **othering** was found to be present both at a community level and within facilities, negatively impacting the experience of care of persons with disabilities. **Servant leadership** traits demonstrated by health facility staff were appreciated by participants enhancing their hope in a crumbling system.

Broader health systems factors negatively impacting “Continuity of Care” included **institutional distrust** manifesting as a result political and leadership weaknesses. Factors negatively influencing “Continuity of Care”, originating outside the health facility included **lack of appropriate transport** and the exorbitant car hire costs incurred by persons with disabilities and their families.

Significantly, these poor governance factors precipitated the development of **emergent leadership** within communities whereby individuals within communities began to self-organise resources to support persons with disabilities to access healthcare that is appropriate, and person-centred. Two important themes that can be considered influential to “Continuity of Care” were **colonialism** and **human connectedness and social cohesion**.

Users of the health facilities, their families and community have portrayed a picture of multiple layers of limitations and challenges when seeking “Continuity of Care” in Ward X. In doing so, they have contributed to our understanding of influences on the “Continuity of Care” in low-resource settings similar to that of Ward X.

Chapter 5. Health systems responsiveness – Policy and practice influences on “Continuity of Care” for persons with disabilities

5.1 Introduction

In chapter 4, factors influencing “Continuity of Care” as experienced by persons with disabilities were presented as “Continuity of Care” journeys”, family stories and community perspectives. Several common themes were identified as influencing factors, including the importance of ward-based outreach teams, CCGs and home-based carers (HBC) as they expanded health care services within community. In several “Continuity of Care” stories, the costs of transport to access healthcare, poor referral and coordination practices between public and private health sectors were found to be significant barriers. Experiences of some of the persons with disabilities participants illustrated the importance of traditional beliefs and cultural practices as facilitators and disruptors of “Continuity of Care”.

The application of human-centred design in the conceptualisation and implementation of new innovations was also observed to be a relevant factor as persons with disabilities are often not considered in the development of new innovations within the health sector. An example of this was the CCMDD programme where PUPs were experienced as an additional burden or inconvenience for some participants, particularly those with mobility challenges and mental health conditions. Participants with disabilities and mental health conditions were unable to pick up all their medication at the designated PUP and therefore incurred costs and inconvenience due to additional trips to the pharmacy and the hospital/clinic as psychiatric medication was only available for pick up at a hospital. This is part of the CCMDD programme design as an intervention for stable chronic patients, however; stability considerations are done in isolation and often disregard the complexity of multiple co-morbidities and its impact on the

patient. What was clear from the interactions with participants was that participants with complex healthcare needs in vulnerable social situations were being further marginalised by the health system and efforts to create more efficiency for the masses of stable patients.

In this chapter, PHC policies, practices and their influence on “Continuity of Care” for persons with disabilities are analysed. The chapter includes results of a review of PHC policies and in-depth analysis of a four policies to determine whether they support “Continuity of Care” and include persons with disabilities. The chapter includes key themes from interviews with policy makers and health facility managers of the Reservoir Hills Clinic.

5.2 PHC policies support “Continuity of Care” for persons with disabilities

The Constitution of SA enshrines the right to health for all its citizen. Section 9 of the Constitution of SA protects citizens against unfair discrimination on the basis of race, gender, colour, age or disability. It places a duty on the State to respect, promote, protect and fulfil the rights in the Bill of Rights, including the rights of persons with disabilities. SA is also party to international laws and agreements such as the United Nations Convention on the Rights of persons with disabilities (CRPD) of 2006, which SA ratified in 2007, signalling that the country accepts all the obligations imposed by this instrument.

Disability inclusion policy commitments should find expression in local policies in order to ensure coherence and continuity between international and local instruments for change. Analysis of these policies entails bringing into view the sources of disadvantage that result in unequal opportunities and outcomes for persons with disabilities, and of using the tools of public policy to overcome these disadvantages. A similar approach has been adopted by Kuper and Heydt (2019) where experiences of persons with disabilities were used to guide and direct the analysis of policy gaps and limitations relevant to the attainment of the Sustainable Development Goals. The purpose of this section is to expand the exploration of

policy-practice observations made in chapter four and analyse a group of PHC policies in order to identify the extent to which they include persons with disabilities and promote the concept of “Continuity of Care”. While observations presented in chapter four were closely linked to the “Continuity of Care” journeys, this chapter delves deeper into these observations using a disability and inclusion-based approach to policy analyses.

5.2.1 PHC policy landscape

A total of 32 policies relating to PHC were identified as tabulated in Appendix S. In an effort to organise policies in a meaningful way, they were grouped thematically as disability specific policies and international, transformational, national programmatic and provincial policies. This provided a framework which aided in the selection of the policies for more in-depth disability inclusion and “Continuity of Care” analyses.

From the list of identified policies (Appendix S), 6 were identified as having potential relevance to “Continuity of Care” in line with the stated criteria and underwent systematic analysis using an adapted EquiFrame approach:

- A Policy on Quality in Health Care for South Africa 2007
- Policy Framework and Strategy for ward-based PHC teams 2018/19 – 2023/24
- Patient Waiting Time policy
- Referral Policy for South African Health Services and Referral Implementation Guidelines
- District Health Management Information System (DHMIS) Policy - A Long and Healthy Life for All South Africans 2011
- Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020

It is important to note that the above selection of policies do not represent all policies with relevance to “Continuity of Care” but rather reflect high potential policies relevant to the topic and congruent with the policy-practice observations reported in Chapter 4. For the purpose of the study, these policies were an approach for in-depth analysis to identify some of the technical limitations regarding disability inclusion and their “Continuity of Care”.

5.2.3 Policy on quality in health care for South Africa 2007

According to WHO, PHC is underpinned by principles of quality and high performance sharing domains related to “Continuity of Care” such as people-centred, equitable, efficient, timely and integrated, co-ordinated, continuous and accessible health services (World health Organisation, 2018). Given that “Continuity of Care” has been cited as being an embedded principle of quality of care (Al-Azri, 2008) and a foundational pillar of person-centred care, it is reasonable to expect that it should be articulated in policies relating to the delivery of quality healthcare. The **Policy on Quality in Healthcare for South Africa**, released in 2007, is designed with an overarching aim of directing health systems initiatives to improve quality of healthcare services. This policy provides public health officials in both private and public health facilities with the strategic direction they need to follow to assure quality and continuous improvement in the healthcare provided. It sets out the objectives of government to assure quality and ensure a culture of continuous improvement.

The Policy on Quality in Healthcare for South Africa aims to improve quality of care by addressing *access* to health care; increasing patients' participation; reducing underlying causes of illness, injury, and disability through preventive and health promotion activities; expanding research on evidence of effectiveness; ensuring the appropriate use of health care services; and reducing health care errors (adverse events). The stated objectives draw parallels with some aspect of “Continuity of Care”, though, it is not an explicit objective.

The Policy on Quality in Healthcare for South Africa is defined as universal and applicable to both the private and public health sectors in SA and prioritises the following:

- Conditions where most improvement can occur, and which have the greatest impact on reducing the burden of disease, mortality and improving patients' quality of life and their ability to function;
- Conditions where there is wide variation in service, indicating that many health care practices may be inappropriate and not in line with current knowledge about effective health care; and
- Conditions that are common and/or costly, where improvements will most broadly result in better health of the population and more appropriate use of health resources.

The policy mentions primary health care as the vehicle for achieving the long-term ambition of achieving quality healthcare for all people to a standard set by government. Norms and standards for primary health care standards have been created by the Office of Health Standards Compliance which provides detailed expectations and measures for compliance.

5.2.3.1 Policy sensitivity to disability and “Continuity of Care”

Disability was mentioned 7 times in this policy, primarily in relation to equity. Based on the Batho Pele principals, this policy demonstrated a high degree of alignment to principles of non-discrimination, in the universal sense but does show sensitivity to vulnerable groups such as under-served population and persons with disabilities as shown in the extract below.

Equity means ensuring that the whole population has access to quality health care. This means addressing the uneven distribution of health care resources across the country, as well as the wide variation in the quality of care throughout the health care system. In particular, there is a need to focus on the needs of historically disadvantaged individuals and communities and the

most vulnerable sectors of society, i.e. women, children, older people and persons with disabilities.

Norms and standards for PHC were referenced as key to the delivery of quality PHC services with specific mention of improvement initiatives within structures of the public health system. Packages of care and associated norms and standards were specified as necessary developments for all levels of care, which impacts the private sector and related issues of over-supply of health services.

The **Policy on Quality in Healthcare for South Africa** makes mention of “under-served populations” and the potential for resulting disability if their needs are not attended to:

“... major gaps in health status among racial, socio-economic, and under-served populations need to be targeted to reduce the underlying causes of illness, injury, and disability. For example, individuals living in poverty are more likely to experience delays in receiving appropriate treatment, or to lack access to water and sanitation within their dwelling. Lack of transport is also a problem.”

Sensitivity to “Continuity of Care” concepts

Theoretically, the Policy on Quality in Healthcare for South Africa should have considerable potential to influence “*Continuity of Care*” for persons with disabilities. Analysis showed strong alignment to management- and information continuity, identifying the need for more rigorous efforts to improve quality of care through systems designed to improve access to information about quality of care. However, only one of the 10 “Continuity of Care” concepts was referred to in the policy, i.e. individualised care, though the absence of details around how this would be achieved was absent.

The aims of the Policy on Quality in Healthcare for South Africa include considerations for “Continuity of Care” through the inclusion of terms such as “access” and “participation.”

Problems in the delivery of quality healthcare included aspects relating to informational continuity in the form of poor record-keeping and poor information. Government, the national health system, labour and healthcare professionals are to be held accountable for the delivery of improved services. Increasing patient participation was an area that the policy aimed to specifically address. Areas of “Continuity of Care” that seemed less well outlined were relational continuity and coordination of services.

The Policy on Quality in Healthcare for South Africa was found to address one “Continuity of Care” concept out of the 10, resulting in a “Continuity of Care” core concept coverage of 10%, and a “Continuity of Care” core concept quality score of 0%.

Table 20: “Continuity of Care” core concept ranking

Name of Policy	Core Concept Coverage	Core Concept Quality	“Continuity of Care” Core Concept Coverage	“Continuity of Care” Core Concept Quality	Number of times disability mentioned	CoC Summary ranking	Comments
Policy on Quality in Health Care for SA 2007	5%	10%	0%	0%	7	LOW	Detailed in quality improvement but “Continuity of Care” remains hidden as a concept.

5.2.4 Policy framework and strategy for ward-based PHC outreach teams

SA has held a strong stance in support of universal healthcare since the dawn of democracy in 1994, through its PHC Reengineering Strategy (Department of Health, 2011a), and more recently the White Paper on National Health Insurance (Department of Health, 2017b). The approach adopted SA has been one of decentralised services led by the district

health system (DHS) as the unit of implementation of PHC. The DHS was designed to address an inherently fragmented healthcare delivery system and is managed by District Management Teams (DMT)(Schneider H., 2018). PHC is the mechanism of ‘strengthening the effectiveness of the health system’ towards one that promotes cost-effective PHC services delivered as close to communities and households as possible, and is centred around health promotion, prevention and community involvement. The PHC reengineering strategy has four priority streams of implementation (Naledi, 2011):

- ward-based PHC outreach teams consisting of community health workers and a professional nurse as team leader;
- maternal, child, neonatal and women’s health district clinical specialist teams;
- an integrated school health programme; and
- contracting of private general practitioners to work in public facilities.

PHC is provided through a nurse-based, doctor supported, public PHC infrastructure of around 3500 clinics and health centres, available within 5 kilometres to more than 90% of the population, and free at the point of use (World Health Organization, 2017). The basic package of services offered is maternal, child and reproductive health, HIV and tuberculosis (TB) testing and treatment, screening and care for non-communicable diseases and treatment of common ailments. Services are offered through a network of health facility-based staff supported by NGOs which have had a prominent role in the delivery of health services in light of the HIV and TB epidemics (Naledi, 2011; World Health Organization, 2017).

The **Policy Framework and Strategy for Ward-Based PHC Outreach Teams (WBPHCOT)** (Department of Health, 2018) aims to provide a guiding framework for the implementation for health services provided in communities, closest to families and individuals

to facilitate improved health outcomes. It is cited as a “key element of primary health care in the future National Health Insurance system” which will drive major transformations within the health system in SA (Schneider H., 2018). The programme of ward-based PHC services has undergone much critique and evaluation; however, there remain persistent challenges to its successful implementation. Its significance to persons with disabilities is paramount as it has direct impact on how persons with disabilities access health services and remain under care.

The Policy Framework and Strategy for Ward-Based PHC Outreach Teams and its associated strategies are designed to ensure that Ward Based Primary Healthcare Outreach Teams (WBPHCOT) services delivered by CHWs and supported by other categories of teams such as CCGs and community rehabilitation teams, form the bridge between communities and healthcare service provision within health facilities. WBPHCOTs are supposed to bring healthcare closer to communities, families and individuals, even in the most rural and underserved areas. The intended beneficiaries of this policy are families and individuals who are most in need of support.

5.2.4.1 Policy sensitivity to disability and “Continuity of Care”

As reported in Chapter 4, many study participants with disabilities reported challenges in accessing health services closer to their homes, resulting in negative effects on their financial security and ability to manage their chronic health conditions.

A concerning finding was that persons with disabilities are not mentioned in the Policy Framework and Strategy for Ward-Based PHC Outreach Teams. Vulnerable groups are used as an umbrella term; however, the term vulnerable group is not defined and therefore an assumption is made that persons with disabilities are included under this term. It brings into question who is considered as part of vulnerable groups and who is included and excluded. The broad goal and objectives of the policy are geared towards creating efficient and effective

management and leadership capacity to support the delivery of PHC services in SA. The objectives of the policy are heavily slanted towards addressing persistent shortfalls in working conditions, human resources, the scope of work of OTs and the standardisation of monitoring systems. The strategy can be viewed as top heavy and vague, with little detail on the role of WBPHCOT in facilitating active participation of communities and individuals, and in some ways appears to entrench the hospi-centric approach to the delivery of services.

A closer look at the province of KZN context is needed to understand the implementation gaps reported by study participants. According to the KZN Department of Health's 2022 Annual Report, non-acute community-based services are provided at community and household level through Ward-Based PHC Outreach teams, School Health Teams, TB Surveillance and Multi Drug Resistant Tuberculosis (MDR-TB) Teams and Community Health Workers (CHWs) (KwaZulu Natal Department fo Health, 2022). Services provided include health promotion/ education; screening for health conditions; appropriate referral to health facilities; follow-up and support of patients on treatment; home-based care; school health services including implementation of health promoting schools; the management of MDRTB patients at household level; mental health and chronic care. Evidence of this in the community of Ward X as reported by the participants is not strong as many experienced absences of CHWs attached to the Reservoir Hills and Clare Estate Clinics.

A special programme implemented in KZN, Operation Sukuma Sakhe (OSS), is reported to be used as a vehicle for inter-government service integration at community level, including addressing the social determinants of health e.g. poverty eradication, provision of sanitation, water, electricity and waste removal. It is a government-led initiative in the province, led by the Office of the Premiere, offering enhanced service delivery, community development, and citizen engagement by fostering partnerships between government officials, local communities, and various stakeholders. The programme outlines the following goals:

1. **Community Engagement:** Sukuma Sakhe encourages active participation and involvement of local communities in identifying their own needs and priorities. This helps in tailoring government services and interventions to the specific requirements of each community.
2. **Service Delivery:** The program seeks to improve the delivery of essential services such as healthcare, education, housing, water, and sanitation. By involving local residents and leaders in decision-making, the aim is to ensure that services are effectively provided where they are most needed.
3. **Partnerships:** It emphasizes collaboration between government officials, civil society organizations, businesses, and community members. This collaborative approach is intended to pool resources, expertise, and efforts to address challenges more comprehensively.
4. **Empowerment:** The initiative aims to empower communities to take ownership of their development. By involving citizens in decision-making processes, Sukuma Sakhe promotes a sense of responsibility and agency among local residents.
5. **Job Creation and Economic Development:** It also seeks to promote economic growth and job creation at the community level. This includes supporting local entrepreneurship, skills development, and small-scale projects that can contribute to the economic well-being of the region.
6. **Infrastructure Development:** Improving infrastructure, particularly in areas with limited access to basic amenities, is a central focus. This includes projects related to road construction, electricity, and other critical infrastructure.
7. **Transparency and Accountability:** The initiative encourages transparency in governance and accountability to the community. Regular communication and feedback mechanisms help ensure that government actions are aligned with community needs.

Figure 34. Goals of Sukuma Sakhe

While the approach proposed by Sukuma Sakhe, if implemented successfully, holds great promise in addressing the needs of persons with disabilities, there appear to be overlaps between the CHW approach and that of the Sukuma Sakhe programme in so far as community outreach is concerned. With millions of rands being leveraged in support of community vulnerabilities, the lack of measurable change in communities like Ward X, brings into question issues of oversight, accountability and appropriate use of limited resources. Despite being identified as a good practice site for the Sukuma Sakhe programme there appears to be little evidence of its success in supporting vulnerable people like Mrs M living in Ward X.

Another novel programme conceptualised and implemented in KZN is the Centralised Chronic Medication Dispensing and Distribution (CCMDD) Programme. It makes chronic medication available to *stable* patients at community level, close to where they reside. It is reported as a programme that decongests facilities, saves cost and travelling times to facilities and decreases waiting times at health facilities. Other outreach services are reportedly delivered

at truck stops, taxi ranks, and other high-risk areas to increase access to basic and essential services e.g. testing for HIV, TB and other chronic conditions. The province reports that services offered at these easily accessible sites increases the possibility of timeous referral for appropriate clinical management of conditions at fixed facilities. This was however not the experience of the participants of this study who felt disenfranchised and far removed from outreach services.

The Policy Framework and Strategy for Ward Based PHC Outreach Teams did not address any of the Core concepts and resulted in a low Continuity of Care summary ranking.

Table 21: "Continuity of care" core concept ranking

Name of Policy	Core Concept Coverage	Core Concept Quality	"Continuity of Care" Core Concept Coverage	"Continuity of Care" Core Concept Quality	Number of times disability mentioned	CoC Summary Ranking	Comments
Policy Framework and Strategy for Ward-Based PHC Outreach Teams	0%	0%	0%	0%	0	LOW	Significant policy as it details high-level plans for ward-based outreach teams.

5.2.5 Referral policy for South African health services

The Referral Policy for South African Health Services aims to provide all healthcare practitioners involved in the delivery of clinical services and those undertaking the coordination of referral management with a consistent and structured approach to the referral of patients to the appropriate health service. The policy applies to all levels of stakeholders in the health delivery system including both private and public sectors. The objectives of the policy are as follows:

- Ensure that clients receive optimal care at the appropriate level.
- Strengthen coordination and complementation between levels of care, units and institutions in caring for clients.
- Facilitate optimal and cost-effective use of high specialist facilities such as hospitals by patients within and across provincial borders.
- Strengthen peripheral health facilities through feedback that will enhance the skills of the referring doctors by confirming or not confirming diagnoses.
- Enhance utilisation of services at the PHC level by those in need of care.
- Progressively reduce any unnecessary burden on tertiary and specialist hospitals.
- Define governance and other arrangements for referrals between public and private sectors.

5.2.5.1 Policy sensitivity to “Continuity of Care” and persons with disabilities

Persons with disabilities are mentioned three times in relation to person-centred care, planned patient transport and community-based services showing a high degree of responsiveness to the experiences of persons with disabilities outlined in Chapter 4.

The guiding principles of the Referral Policy for South African Health Services (listed below) show strong alignment with the 10 “Continuity of Care” core concepts, with **continuity** listed as a stand-alone principle. They are informed by Constitutional, international, regional, national imperatives and are outlined as shown in Fig 34 below.

The Referral Policy for South African Health Services, while comprehensive and detailed in its approach to addressing current referral system challenges, appears to embrace a universal approach to inclusion of vulnerable groups and is not specific around core concepts such as protection from harm, privacy, integration of services, cultural responsiveness.

Accountability: Healthcare managers have the necessary authority to achieve planned objectives and are accountable for overall performance and results.

Accessibility: Services are directly and permanently accessible without undue barriers of cost, language, culture or geography. Health services are close to the people, with a routine point of entry to the service network at primary care level (not at the specialist or hospital level).

Comprehensiveness: A comprehensive range of health services is provided, appropriate to the needs of the target population, including preventative, curative, palliative and rehabilitative services and health promotion activities.

Continuity: Service delivery is organised to provide an individual with “Continuity of Care” across the network of services, health conditions, levels of care and over the life cycle.

Coverage: Service delivery is designed so that all people in a defined target population are covered, i.e. the sick and the healthy, all income groups and all social groups.

Coordination: The patient’s primary care provider facilitates the route through the needed services and works in collaboration with other levels and types of providers. Coordination also takes place with other sectors (e.g. social services) and partners (e.g. community organisations).

Efficiency: There is minimal wastage of resources in the achievement of the objectives.

Equity: There is a fair distribution of health facilities, and no person will be unfairly discriminated in terms of access to services.

Person-centeredness: Services are organised around the person, not the disease or the financing of health services. They instead recognise and respond to the unique requirements of identified groups (e.g. Persons with Disabilities and older persons). Users perceive health services to be responsive and acceptable to them. There is participation from the target population in service delivery design and assessment. People are partners in their own healthcare.

Quality: Health services are of high quality, i.e. they are effective, safe, centred on the patient’s needs and given in a timely fashion.

Figure 35. Principles of the Referral Policy for South African Health Services

Person-centred care is a strong thread that runs through the policy. It embraces patient participation and promotes recognition of the patient before the disease. In this regard persons with disabilities are specifically identified for their unique requirements and needs. The policy promotes participation of the target population in service delivery design and assessment where people are viewed as partners in their own healthcare. Rehabilitation and palliative care are services included in the policy indicating the need for continued management and alludes to the needs for improved relational continuity.

Chronic disease support and care including home-based care within the community is outlined in the policy. This is an important indicator of the policy being relevant and informed by realities on the ground. While “Continuity of Care” is seen as a central tenet of the policy, details on how it will be achieved is lacking. The policy attempts to make a clear call for referral mechanisms between the different tiers of the healthcare system to be well defined, however, it ignores addressing some of the structural and human resources constraints that plague the health system.

No explicit link to informational, relational or management continuity is made in the policy, though there is evidence that monitoring and evaluation the policy is important and is intended. Family is not mentioned as a resource, though NGOs and CBOs are described as an important link in the referral chain. Family is mentioned in relation to top-down communication but is not referred to in the sense of being partners especially in relation to persons with disabilities. The absence of a significant role being given to family can be viewed as a weakness especially when their importance was well represented in the results of chapter four and other studies (Lorenzo, 2005). There is also the danger of inordinate amount of responsibility being transferred to the family.

The policy emphasises critical issues in the “Continuity of Care” chain such as accessibility and the need for barrier-free access to health services. It promotes health services being delivered close to people, with a routine point of entry to the service network at primary care level. In other words, the policy works to promote PHC and elevate the role of outreach teams and community-based services. Their role is further emphasised in relation to addressing population health issues with specific reference to patients with chronic conditions and identifying neglected persons with disabilities and older persons.

The policy attempts to increase accountability within the health system by stating that healthcare managers have the necessary authority to achieve planned objectives and are accountable for overall performance and results. The National Department of Health is mandated to:

- Formulate the overall **Referral Policy for South African Health services and Referral Implementation Guidelines.**

- Support the dissemination and **training of health workers on the Referral Policy** for South African Health services **Referral Implementation Guidelines**: Design and disseminate standard referral tools including referral forms and registers.
- Provide **technical assistance** and build capacity to strengthen the referral system at the provincial level.
- Coordinate the **development, review and implementation** of the Standard Treatment Guidelines and Essential **Medicines List** to inform formularies.
- Undertake overall **performance monitoring** of the referral system in SA.

Access (mentioned 27 times) features strongly in this policy in regard to Planned Patient Transport Services (PPTS):

- Each province should have a Standard Operating Procedure (SOP) for PPTS that considers the healthcare provision available within the sub-district, district and tertiary facility/ies. The SOP may also include a provision for inter provincial PPTS.
- Each district should have access to PPTS vehicles for transporting patients to higher levels of care.
- The vehicles should be appropriately equipped to transport patients, including stretcher and persons with disabilities.
- A daily/monthly schedule should be available within designated areas at the hospital.

Reference is made to how the referral policy will facilitate access to quality healthcare universally, and the issue is not contextualised within the experiences of persons with disabilities.

Table 22: Referral Policy for South African Health Services and Referral Implementation Guidelines: EquiFrame analysis results

Name of Policy	Core Concept Coverage	Core Concept Quality	“Continuity of Care” Core Concept Coverage	“Continuity of Care” Core Concept Quality	Number of times disability mentioned	CoC Summary Ranking	Comments
Policy Framework and Strategy for Ward-Based PHC Outreach Teams	24%	0%	90%	0%	3	LOW	Low core and “Continuity of Care” concept quality due to the fact that none of the concepts could be rated above 2.

5.2.6 Framework and strategy for disability and rehabilitation (FSDR)

The FSDR aims to outline comprehensive and integrated disability and rehabilitation services within the broader health and developmental context to facilitate improved access at all levels of health care (Department of Health, 2015). The policy’s preamble recognises the role of rehabilitation in the continuum of care as essential to achieving quality of life.

The FSDR relates specifically to the issue of increased longevity, chronic diseases and the higher levels of disability that is expected in the population. The FSDR identifies the limitations of the health system in preventing disability and acknowledges that broad scale government approaches are required in addressing the social determinants of health. The scope of the FSDR therefore focuses on health interventions with rehabilitation cutting across the

promotive, preventive, curative, rehabilitative and palliative continuum of care. It embeds the approach with the philosophy of community-based rehabilitation (CBR) and recognises that coordination is required from multiple sectors for the successful implementation of the policy.

The guiding principles of the FSDR include:

- Ensuring *appropriate disability and rehabilitation services* through the participation and inclusion of persons with disability, based on the principles of CBR and using a disability-inclusive developmental approach and evidence-based practice.
- Ensuring *quality services* through the adoption of norms and standards within the public health sector that are aimed at promotion, preventive, curative, rehabilitative and palliative care measures using the principle of continuum of care across the lifespan.
- Ensuring *accessibility to disability and rehabilitation services* through an integrated approach, that is cutting across all health programmes throughout the continuum of care to implement PHC-R, as well as the integration of rehabilitation services by the rehabilitation professional groups.
- Ensuring *affordable services* through evidence-based rehabilitation interventions and provision of rehabilitation services at all levels of health care, especially providing services as close as possible to where children and adults with disability and those at risk live, thus reducing “out-of-pocket” expenditure and the burden on the district hospital.

5.2.6.1 Policy sensitivity to “Continuity of Care” and persons with disabilities

The goals of the FSDR are to:

- **Integrate** comprehensive disability and rehabilitation services including within priority health programmes from primary to tertiary and specialized health care levels as guided by the document on Integrated Disability Management and Rehabilitation Pathways of Care.
- Develop an appropriate, effective and efficient **referral system** between all levels of care including the expansion of services to improve access to rehabilitation units and specialized rehabilitation centers.
- Foster **inter-sectoral collaboration** to address social determinants.
- Implement **accessibility standards** for infrastructure, communication, signage and information.
- Increase awareness and knowledge of health care workers to **change their attitudes toward children and adults with disabilities** and their families.
- **Improve monitoring and evaluation** of disability and rehabilitation services.
- **Improve Human Resources** for disability and rehabilitation services.
- **Improve access to appropriate assistive/technology** and accessories.

“Continuity of Care” does not appear to be a distinct goal of the policy but issues relevant to the promotion of management and information continuity are evidently part of the strategy. “Continuity of Care” therefore appears to be addressed through integration of rehabilitation services with other health services across the health system and not necessarily enhancing the relationship between the client and the service provider. This was an interesting finding in that rehabilitation by its very nature of being long-term is often best placed to

promote relational continuity, an intrinsic strength of the profession. The policy in some way can be viewed as an attempt to reposition rehabilitation as part of broader public health programming and in so doing may have the unintended consequence of devaluing the important role that rehabilitation therapists play in maintaining “Continuity of Care”.

persons with disabilities as the focus of the policy are specifically mentioned nine times in relation to referral pathways, CBR and general contextual arguments for why the policy was necessary. However, one of the challenges of this policy lies in its universality which attempts to address life course disability and rehabilitation needs in a single policy, risking possible dilution of the needs of specific groups such as the elderly with chronic conditions and associated disabilities. Given the complexity of designing a policy that addresses disability, rehabilitation and its integration into broader health programming across the health system, this approach leaves little room for addressing “Continuity of Care” issues specifically related to adults.

The approach adopted in the policy is for disability and rehabilitation services to span across an individual's life course, be comprehensively provided at all levels of the health system and be grounded within the philosophy of CBR which is a coordinated approach across multiple sectors to realize the inclusion of and equal opportunities for persons with disabilities. It recognizes that coordinated action is required from role-players in health, social development, education, public works, human settlements, transport and other sectors, if independent functioning is to be realized.

Analysis of the policy against the “Continuity of Care” core concepts revealed the following:

- **Participation:** The policy states the importance of participation as a central principle in the design of disability inclusive services and an important target in the FSDR. It

acknowledges the challenge of ensuring optimal levels of participation and integrates it as part of the values of the policy. It defines participation in relation to CBR, participation restrictions and rehabilitation service delivery. It, however, falls short of having participation as part of the plan or how this is to be monitored.

- **Co-ordination:** Coordination is only referenced as part of the definition of CBR which is the approach adopted in the policy. However, details of how services will be coordinated and monitored are lacking.
- **Integration:** The policy positions integration of rehabilitation and disability services as the mission of the policy indicating the provision of integrated, comprehensive, appropriate disability and rehabilitation services through effective and equitable resource allocation and inter-sectoral collaboration. It also prioritises the integration of disability and rehabilitation into priority health programmes across the care pathway from primary to tertiary and specialized health care levels.
- **Family as a resource:** Family as a resource and source of support is mentioned in the context of early childhood interventions but not in the context of adult disability and rehabilitation interventions. It may be an assumed part of the CBR approach.
- **Cultural responsiveness:** Is mentioned as a challenge whereby rehabilitation services are identified as not being culturally sensitive. And the need for health promotion and prevention of disability campaigns in collaboration with other stakeholders beyond the health system, highlighting the policy intention towards culturally responsive services.
- **Accountability:** The strategic plan includes objectives, indicators, targets and timeframes but does not include details on who is responsible and accountable for its implementation.
- **Access:** Access is defined within the context of UNCRPD and is addressed as Goal 8 for the provision of appropriate assistive/technology and accessories with specific targets.

- **Quality:** The vision of the policy is to provide accessible, affordable, appropriate and quality disability and rehabilitation services throughout the life course. However, specific focus on what is defined as quality health and rehabilitation services is absent. One is left to assume that quality disability and rehabilitation services will be the outcome if the FSDR is implemented successfully.
- **Efficiency:** Is not mentioned in relation to the delivery of services for persons with disabilities.

While the following two core concepts are not part of the ten continuity of care concepts, they are worthy of being mentioned as they are well represented in terms of promoting disability inclusion and promoting mainstreaming.

Prevention is a strong theme across the policy with expanded definitions of what is meant by the concept in the context of health and rehabilitation services. Prevention efforts at community level is articulated as ensuring quality services through the adoption of norms and standards within the public health sector that are aimed at promotion, preventive, curative, rehabilitative and palliative care measures using the principle of continuum of care across the lifespan. However, this is not expanded or explained in the context of PHC outreach structures which form an essential delivery mechanism for preventative efforts. At the primary health facility level prevention is portrayed as the conduct of integrated health promotion and prevention of disability campaigns in collaboration with all stakeholders. Details on what is meant by this are not provided.

Capacity Building is mentioned as part of sensitization workshops for health workers in all provinces, as well as the engagement of the Health Professional Council of SA and other authorities presiding over health professionals in SA. Emphasis is placed on the inclusion of

awareness of disability and rehabilitation in undergraduate training programmes. An additional goal is the auditing of disability-related complaints registers at health facilities. How this is implemented is questionable considering the findings related to the implementation of the FSDR and the preparedness of healthcare providers to engage meaningfully with persons with disabilities.

Table 23: FSDR: EquiFrame analysis results

Name of Policy	Core Concept Coverage	Core Concept Quality	“Continuity of Care” Core Concept Coverage	“Continuity of Care” Core Concept Quality	Number of times disability mentioned	CoC Summary Ranking	Comments
Policy Framework and Strategy for Ward-Based PHC Outreach Teams	48%	19%	70%	20%	3	MODERATE	While the CoC ranking is moderate, core concept quality and “Continuity of Care” core concept quality is still low, as none of the concepts could be rated above 2.

The FSDR at the time of writing, was beyond its targeted implementation period (2015-2020), though it was understood to still be a valid policy in active implementation. Findings from a previous study conducted by the researcher (Padayachee, 2017) were that a fundamental barrier to the successful implementation of the FSDR was the fact that rehabilitation services were delivered primarily through an institution-based design that had been informed by the

medical model. Efforts toward implementing the CBR model were also found to be fragmented. The following barriers were found to impact the successful implementation of the FSDR:

- Limited intersectoral collaboration.
- Health promotion and stigma reduction through increasing awareness and knowledge of disabilities in communities were not prioritised.
- Human resources and budget allocations were inadequate.
- The supply of appropriate assistive devices needed improvement (Padayachee, 2017).

The timeframe for the FSDR goals and objectives related to the development and expansion of a referral system to include rehabilitation units and specialised rehabilitation centers, as well as the development and implementation of a monitoring and evaluation (M&E) framework, had lapsed by January 2017. It was found that referral policies were still lacking, and facilities functioned without appropriate, effective and efficient referral systems between all levels of care. Moreover M&E of disability and rehabilitation services was viewed by rehabilitation staff as a limited function (Padayachee, 2017).

Some objectives that related to the goals on integration of disability services, accessibility standards at public sector facilities, as well as knowledge and attitudes of health care workers that had lapsed, included:

- Accessibility standards for infrastructure, communication signage and information in public sector facilities for persons with disabilities were not in place and not reviewed and existing standards were not reviewed specifically for persons with disabilities. There was an overall lack of disability access audits for PHC services and facilities. Reviews of accessibility standards focused on all patients attending the facilities and included, for example, a review of the elements in the Ideal Clinic Dashboard.

- Specific timeline targets for increasing knowledge and attitudes of health care workers had passed. Engagements with regulatory bodies and undergraduate training programmes were limited.
- Audits for facility-based complaints registers did not focus specifically on complaints about disability and rehabilitation services. This suggests that the level of sensitivity around reports of negative attitudes of health care workers, abuse, neglect, stigma and discrimination was low. Reports of patients experiencing verbal abuse and discrimination have been raised at provincial committee meetings and parliament, led by The Presidency.

In real life, these challenges were exemplified in all the “Continuity of Care” journeys documented in this study. The FSDR additionally fails to address the issue of the parallel health systems in SA. Many people who require rehabilitation seek care from private services but receive medical care from public health facilities. The Policy demonstrates weaknesses in, and how referral pathways can be strengthened between private and public service providers, to address the human resource shortages that plague the public health system. In the case of Mr. P, this weakness is particularly evident as he was not able to receive any support and information from public health rehabilitation therapists about private facilities. In the same way that private GP contracting is being proposed as a measure to expand general practitioner services available to the population, the contracting in of rehabilitation services could also be expanded.

The FSDR aims to support the implementation of disability and rehabilitation services using the principles of CBR where multiple stakeholders are involved addressing the needs of persons with disabilities. From the point of view of “Continuity of Care” the major challenge

in adopting this approach is the lack of accountability that exists which severely impedes linkages to care and support, and limits coordination of efforts to address the social determinants of health. In Mr. X's case, no effort was made by the rehabilitation team to assess his living circumstances and even if that was achieved, who then would be held accountable for addressing his broader needs in terms of living conditions that impact his ability to achieve and maintain good health and independence.

The one-dimensional approach to CBR therefore needs to be reviewed so that responsibility and accountability can be attributed to a particular stakeholder group. This study highlighted the importance of families and communities in playing a coordinating role. We documented cases where families were able to leverage off community resources to support their family members with disabilities. We also documented cases where leadership capacity within the community blossomed in response to weaknesses in the health system.

The FSDR shows direct relevance to management and information continuity as there are specific goals of the strategy that aim to address coordination of services and strengthen the collection of information about disability and rehabilitation services. The one aspect of Continuity of Care that appears absent are goals related to relational continuity.

An interesting aspect of the FSDR is that it seeks to address a health system responsiveness challenge of being able to assess complaints related to persons with disabilities. The Ideal Clinic adopts two aspects that are relevant to achieving this. The first is the assessment of waiting times and the second is the assessment of patient waiting times. Currently, there appears to be no framework for analysing complaints from persons with

disabilities. Figure 36 below shows Annex 56 of the Ideal Clinic Manual represents how the results of these two assessments should be displayed.

Annexure 56: Checklist for element 88 - Results of the annual patient experience of care survey are visibly displayed at the main waiting area

Use the checklist below to check whether the results of the patient experience of care survey are displayed at the main waiting area

Scoring - In column for score mark as follows:

Y (Yes) = compliant, **N** (No) = not compliant.

Item	Score
Access to services - Level of user experience with accessibility of health care services	
Availability and use of medicines - Level of user experience with availability and use of medicines	
User safety - Level of user experience with physical safety while in the health establishment	
Cleanliness and infection prevention and control - Level of user experience with cleanliness of a health establishment and infection prevention and control practices in the health establishment	
Values and attitudes - Level of user experience of personnel values and attitudes	
User waiting time - Level of user experience with waiting time for services in the health establishment	
Total	
Score (Total ÷ 6)	

Figure 36. Ideal Clinic template: "Patient Experience of Care Survey" including waiting time

These assessments represent an important and powerful tool for enhancing the participation of persons with disabilities and entrenching higher levels of engagement about health services standards and their right to insist that service standards be met. Implementation failure of the FSDR has had serious impacts on the lives of persons with disabilities, not just in the tangible sense. Continued loss of trust and faith in the system has potentially resulted in

a psychological shift in the psyche of the most vulnerable populations. Findings of the study have shown hints of what has been described as the cycle of low expectations and poor-quality care (Roder-DeWan *et al.*, 2019).

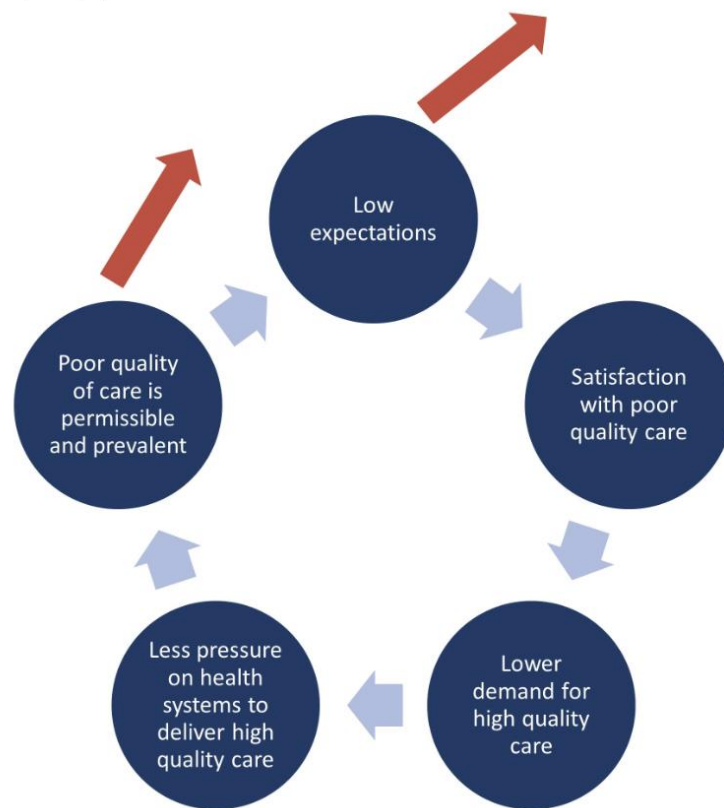


Figure 37. The cycle of low expectations (Roder-Dewan *et al.*, 2019)

They found that populations with low expectations are more likely to be satisfied with inferior quality care which in turn leads to a reduction in demand-side pressure to improve services. In many of our documented “Continuity of Care” journeys, persons with disabilities who lived in the most desperate social conditions and whose health and rehabilitation needs were not being met, did not voice their dissatisfaction. This was evident in Mr. N’s case where his request for a wheelchair was voiced as an extraordinary request when in fact that was his right. Mrs. R also appeared to resign herself to accepting low quality care, long waiting times and poor attitudes of nursing staff towards the elderly with disabilities.

A key recommendation for policy makers involved in the design of patient satisfaction surveys would be to ensure active participation of persons with disabilities while also ensuring that they are informed about service standards and their right to speak out when these are not met. Policies and interventions to raise peoples' expectations of the quality of healthcare they receive should be considered in health system quality reforms (Roder-DeWan *et al.*, 2019).

Table 24: Summary ranking scores for policies analysed for disability inclusion and “Continuity of Care” core concepts

Name of Policy	Core Concept Coverage	Core Concept Quality	“Continuity of Care” Core Concept Coverage	“Continuity of Care” Core Concept Coverage	Number of times disability mentioned	Comments
Policy on Quality in Health Care for South Africa (2007)	14%	5%	10%	0%	7	Significant policy for “Continuity of Care” as it is directly related to quality of care. While the policy is comprehensive in outlining the main areas of focus for quality improvement, “Continuity of Care” remains hidden as a concept in the policy. Some sensitivity to persons with disabilities in relation to issues of equity.
Policy Framework and Strategy for Ward-Based PHC teams 2018/19 – 2023/24	0%	0%	0%	0%	0	persons with disability not mentioned but assumed to be included under the umbrella term of “vulnerable populations”. No observable or explicit goal related to “Continuity of Care” concepts or delivery of quality health services. The policy is crafted to address persistent resource constraints, standardisation of monitoring processes and appears to be more of a response to dissatisfaction from CHWs and much less a person-centred response to the needs of people in communities including persons with disabilities.
Referral Policy for South African Health Services and Referral Implementation Guidelines (August 2020)	24%	0%	90%	0%	3	This policy is highly significant for the promotion of “Continuity of Care”. It, however, has a low core and “Continuity of Care” concept quality due to the fact that none of the concepts could be rated above 2
Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020	48	19	70	20	110	The FSDR has relevance to the realisation of continuity of care but does not include “Continuity of Care” as a discrete goal of the policy. Several Continuity of Care core concepts have been found within the policy, though details regarding how many of the concepts are implemented and monitored are missing.

5.3. Policy makers and implementers perspective on factors influencing “Continuity of Care” for persons with disabilities

In this section, perspectives of policy makers and implementers are presented in relation to PHC policies and practices that influence “Continuity of Care” for persons with disabilities. Five policy makes were interviewed, and one focus group discussion was held with health facility staff. All five policy makers were from the KZN provincial department of health. Attempts to obtain interviews with national policy makers were unsuccessful despite numerous attempts.

The findings were thematically analysed (See Appendix X). The interview tool for policy makers was designed to align with the health systems responsiveness component of the framework adopted in the study, which proposes that health systems responsiveness is a key objective of a health system and a measure of how the health system addresses legitimate concerns of individuals (Mirzoev & Kane, 2017).

The participants’ responses were inductively coded.

Table 25 below provides a description of policy makers and health facility staff included in the study. Attempts were made to obtain interviews with leadership from other health programmes, however, these were unsuccessful.

Table 25: List of policy makers and health facility staff interviewed

Participant	Male/Female	Type of engagement	Role	Number of years as a policy maker or implementer
1. Mr D	Male	KII	Disability and Rehabilitation Programme (ex-officio), Provincial Department of Health	>10years
2. Mr S	Male	KII	Disability and rehabilitation Programme	>8 years
3. Mr M	Male	KII	Manager Disability and Rehabilitation	>5 years
4. Mr C	Male	KII	Oversight of the Sukuma Sake Programme (Camperdown)	>5 years
5. Mr L	Male	KII	Acting Ward Counsellor and community leader	>3 years
6. Facility staff	2X females	FGD	Facility manager and District Manager	Both > 5 years

5.3.1 Perspectives of policy makers, health facility staff and NGOs regarding policies that influence “continuity” of care for persons with disabilities

Policy makers interviewed felt that the FSDR was an important policy for “Continuity of Care” for persons with disabilities. The results indicate that although KZN has been active in trying to implement the FSDR, the challenge faced by policy makers “in charge” of the disability programme was the deeply entrenched culture of seeing disability as “their problem” and not the concern of policy makers and implementers of other health programmes (e.g. TB / HIV). These challenges were felt to be too large and deeply entrenched to be overcome by the disability and rehabilitation team alone. This is an important finding as it relates to power imbalances which preclude the effective implementation of disability inclusion. Strong leadership is often touted as a necessary ingredient for the realisation of disability inclusive health systems (Khan *et al.*, 2018). However, less is written about the politics of health implementation where those who are medically trained are seen as more valuable in the health

system than those trained in the health and rehabilitation professions. This power differential may be a key driver of why certain health programmes reach maturity and success and others are constantly challenged. It is also a sobering reminder of the medical model at play within the health system, and its impact on disability inclusion as well as integrated services for the benefit of persons with disabilities.

Rehabilitation services were being offered to varying degrees within the districts, but were impacted by staff shortages, budget constraints and inadequate supply of medical equipment. Policy makers were complimentary of efforts made by the department during the COVID 19 pandemic where SMSs were used to contact patients. There was, however, acknowledgement that certain programmes, while exemplary in their attempt to decongest health facilities, still had a way to go in terms of being fully disability inclusive. An example of such an initiative was the CCMDD programme where disability inclusion was an afterthought not part of the programme design.

Health facility staff interviewed felt that the ward based PHC teams, and the NGOs were the most important structures in ensuring Continuity of Care for persons with disabilities. They believed that decentralised services were important as many persons with disabilities were unable to access the health facility physically and needed to be supported in the community. For the health facility in Ward X, the additional support through NGOs played a crucial role in coordinating services for persons with disabilities. They were able to connect directly with families and had begun a special programme within the facility on specific days that catered to raising awareness about disability and rehabilitation. The lack of rehabilitation teams as part of outreach services was identified as a weakness, as was the lack of outreach team kits and other medical supplies. The team acknowledged that many persons with disabilities fall through the cracks of the weak health system, but that that all they could do was work within their span of control. They were not aware of the FSDR and did not have access to the policy.

NGOs interviewed showed deep commitment to improving service delivery and support for persons with disabilities but felt that their support was contingent upon involvement of caregivers, support from health facilities and adequate resources from the relevant government departments. They felt that greater collaboration is required to achieve this and to ensure all partners are working together to achieve the mutual goal. NGOs in Ward X are directly funded through development partners who are themselves funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), which is essential for resourcing community-based efforts. The NGO interviewed acknowledged that the situation for persons with disabilities in Ward X was dire and that their activities in the area helped coordinate efforts between community structures and the health facility. One of the major challenges faced by the NGO interviewed was sustainability, in that during the COVID 19 emergency, their support to vulnerable groups through community outreach was the first to be cut. At the time of the interview, the NGO was preparing to pull out of the area due to funding cuts.

The full list of themes and supporting quotations is found in Appendix X.

5.4 Summary of chapter

This chapter critically analysed PHC policies and practices, as well as their influence on “Continuity of Care” for persons with disabilities. It addressed objectives two and three of this study which was to conduct an analysis of relevant policies governing PHC in SA in terms of its influence on disability inclusion and “Continuity of Care” for persons with disabilities and explore health systems responsiveness to the expectations of persons with disabilities as it related to their PHC “Continuity of Care”.

Results presented were guided by policy and practice observations outlined in chapter 4 and two sets of primary data: i) the analyses of PHC policies identified as being potentially relevant to “Continuity of Care” for persons with disabilities; and ii) interviews and focus group discussions with policy makers and implementers.

A review of the PHC policies while not exhaustive, highlighted the complexity of achieving PHC policy coherence and implementation. From international policy instruments to local implementation policies, the policy landscape is scattered with a range of imperatives for health implementers, leaving a high level of uncertainty about whether and how persons with disabilities are catered for. Four policies were analysed in-depth using the EquiFrame approach to policy analysis. These were:

- Policy on Quality in Health Care for South Africa (2007)
- Policy Framework and Strategy for Ward-Based PHC teams 2018/19 – 2023/24
- Referral Policy for South African Health Services and Referral Implementation Guidelines (August 2020)
- Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020.

All four policies were assessed to have close alignment to the pillars of “Continuity of Care” in terms of their goals. However, the EquiFrame analysis method unveiled low levels of core concept coverage (<50%), low

core concept quality (<50%), and low Continuity of Care core concept quality (50%). The only policy showing moderate alignment to Continuity of Care core concept quality was the FSDR which scored 70%. It was evident in all four policies that “Continuity of Care”, while mentioned as a critical outcome of the policy, did not cover the fundamentals of “Continuity of Care” such as information continuity, relational continuity and management continuity. It is uncertain why these concepts remain hidden in policies especially since “Continuity of Care” is referenced as the cornerstone of PHC (Agency for Healthcare Research and Quality, 2016; Alazri *et al.*, 2007).

The representation of the relative importance of family in maintaining good continuity of care for persons with disability was found to be low. Interviews with persons discussed in Chapter 4 revealed the significance of strong family bonds in supporting the “Continuity of Care” and navigating the challenges of a weak health system. Similarly, the role of NGOs and community-based organisations were relatively under-represented in policies with respect to maintaining the continuum of care.

A worrying finding that must be addressed is the fact that the Policy Framework and Strategy for Ward- Based PHC teams 2018/19 – 2023/24 does not mention persons with disabilities. As a core policy determining the implementation of PHC, the absence of persons with disabilities is significant. While some may argue that other policies such as the FSDR are better placed to address the general healthcare needs of persons with disabilities, the FSDR was found to focus on upstream challenges of disability inclusion and lacked detail in how service integration and coordination would be achieved. Lack of detail around accountability for its roll out was also an important finding.

Policy makers, health facility managers and NGOs who support the roll out of PHCORT, are limited in their capacity to address the “Continuity of Care” needs of persons with disabilities. Sustainability of services are negatively affected by funding cuts owing to the fact that NGOs interviewed received funding from development partners and not through government budgets. Their support to health facilities in support Continuity of Care for persons with disabilities is critical, and their lack of sustainability as a

permanent structure in the delivery of outreach services leads to unreliable services. CBR was found to have a narrow focus on early childhood interventions and did not have the capacity to address the needs of adults with disabilities to the extent required. This speaks to a critical gap in the delivery of rehabilitation services for adults with disabilities who need close monitoring.

Chapter 6: The importance of relational continuity - Thesis building

6.1 Introduction

This case study aimed to understand how “Continuity of Care” for persons with disabilities can be strengthened within the PHC context, and what factors influenced their “Continuity of Care” in the eThekweni community of Ward X. It is characterised by a high level of inequity, due to legacy of previous apartheid laws, and was also affected by a trio of disasters including COVID 19, a political insurrection and disastrous flooding during the course of the study.

The underlying premise is that all people deserve the right to good health including persons with disabilities, and that “Continuity of Care” and PHC are critical elements in the attainment of good health. However, the attainment of this right remains out of reach for many people, particularly for persons with disabilities.

While issues related to the marginalisation of persons with disabilities are multi-dimensional and fairly well documented, there is general agreement that access to good quality PHC remains a critical gateway to healthcare for persons with disabilities. PHC is firmly entrenched as the dominant approach to addressing inequities and promoting good health outcomes in SA, yet its implementation is intricate and persistently challenged by systemic breakdowns in its delivery, and to some extent the lack of implementation capacity and political will. Inadequate human resources and financial capacity, poor leadership and governance as well as inefficient use of limited resources, are known factors that negatively impact the delivery of health services to all citizens, but particularly the most vulnerable populations, including persons with disabilities.

Despite the myriad challenges faced by the health system, the vast majority of SA people are dependent on the public health sector for access to healthcare, and persons with disabilities are no exception. A critical assessment of how resource constrained health systems can achieve acceptable levels of healthcare service delivery to persons with disabilities is

essential in the context of a significant increase in the prevalence of non-communicable diseases, their additional healthcare burdens and consequent complications in accessing health care. Their unique needs require focused and prioritised attention in order to ensure that they are not “left behind”. Given that “Continuity of Care” is said to be a cornerstone of PHC and a core element in the delivery of quality health services (Alazri *et al.*, 2007; World Health Organization, 2018a), and that it has been consistently identified as a defining feature and assumed strength of primary care, it represents an important factor in the attainment of good health for persons with disabilities.

Studying “Continuity of Care” in under-resourced contexts where vulnerability and inequity are at its peak, provides a nuanced perspective of what impacts individuals with disabilities along their pathway to better health. This study aimed to explore factors that influence “Continuity of Care” from the perspective of persons with disabilities, their families, community structures and that of the health system. It is hoped that findings can be used to improve PHC services for persons with disabilities. As far as the researcher is aware, this is the first study that explored “Continuity of

Care” for persons with disabilities and chronic conditions in the South African context.

The health systems responsiveness framework was adopted as it enables exploring experiences, expectations and responsiveness of the health systems. The inclusion of the policy analysis added a further layer of analysis into health system responsiveness and makes for a rich description of what factors are integral to promoting “Continuity of Care”. These findings have been presented in chapters 4 and 5 with a concise summary of 11 factors that need to be considered when aiming to achieve better “Continuity of Care” for persons with disabilities (see Fig 33 below)

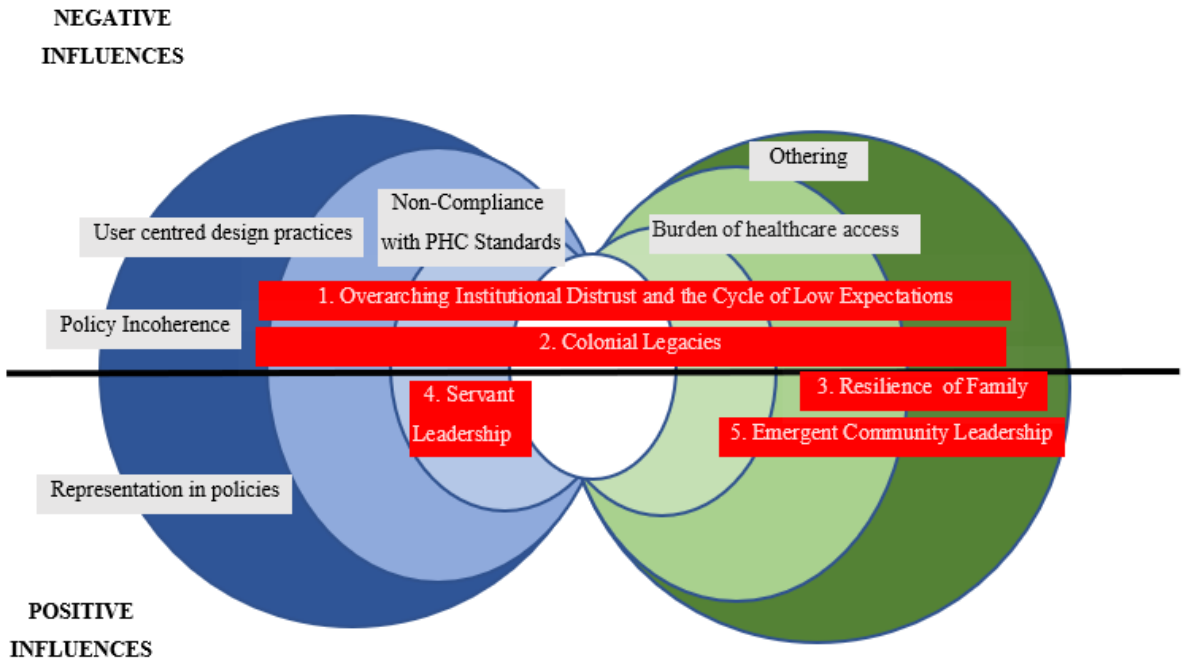


Figure 38. Factors influencing "Continuity of Care" for persons with disabilities

This chapter begins with an in-depth discussion of five selected factors found to influence “Continuity of Care” for persons with disabilities. Two negative influences (Numbers 1 and 2) and three positive influences (labelled 3,4 and 5) outlined in red highlight in Fig 38 above are discussed as

important and nuanced influences of “Continuity of Care” for persons with disabilities. These are:

1. Overarching institutional distrust and the cycle of low expectations
2. Colonial legacies
3. Resilience of family
4. Servant leadership
5. Emergent community leadership

The common thread across all five of these factors is **relational continuity** and collectively points to the importance of human connectedness and the particularly powerful impact it has on the “Continuity of Care” of vulnerable populations, such as persons with disabilities. The interesting aspect about these factors is that they fall outside of the traditional understanding of relational continuity, that is, the trusting relationship between a healthcare provider and the patient. What this study has shown is that factors outside of the health system have bearing on whether or not persons with disabilities access care and stay in care. The trusting relationship

between a healthcare provider and the patient is just one of several trusting relationships that propel relational continuity and when these are placed in jeopardy, there are important impacts on “Continuity of Care”.

Critical social theory (Kincheloe & McLaren, 2011) informs the discussion of the five influential factors that address the research question of how “Continuity of Care” for persons with disabilities can be strengthened within the PHC context in SA. This discussion is used as the basis for the central thesis of this study in response to the research question: “How can “Continuity of Care” for persons with disabilities be strengthened within the PHC context in South Africa?” I propose that a shift in health systems strengthening is required which prioritises efforts towards rebuilding trust in the health system and dismantling underlying historical legacies that serve to impede these rebuilding activities. The chapter culminates in five recommendations for policy makers on how to target relational continuity and enhance trustworthiness within the health system. the reader is also directed to Appendix Y, which details some reflections as part of the research journaling process.

6.2 Negative influences of “Continuity of Care” for persons with disabilities

Studies into “Continuity of Care” have documented several factors that hinder its successful realisation, such as poor interpersonal and communication skills, health systems weaknesses and attitudes of healthcare staff (Biringir, Hartveit, Sundfor, Ruud, & Borg, 2017; lyafei A, 2020). These are important access issues which have also been found in this study, supporting the argument that persons with disabilities continue to be marginalised and excluded from the SA health system.

Applying the ontological lens of critical social theory, where meaning is generated from critical examination (Gilson, 2012), requires a deeper analysis of the factors impacting “Continuity of Care” drawn from KII, FGDs and policy analysis (Stutchbury, 2021, p. 114). Thus, the negative influences of burden of healthcare access and transport costs, non-compliance with PHC standards, poor user-centred design practices such as the CCMDD programme, othering and policy incoherence, are metaphorically the “tip of

the iceberg” (Stutchbury, 2021, p. 114). Their underlying causes pertain to structural issues which were identified as the overarching political and institutional distrust as well as the legacy of colonialism. These are the phenomena that need addressing to provide a nuanced answer to the research question that can make a difference to the “Continuity of Care” journey” of persons with disabilities, their families and community.

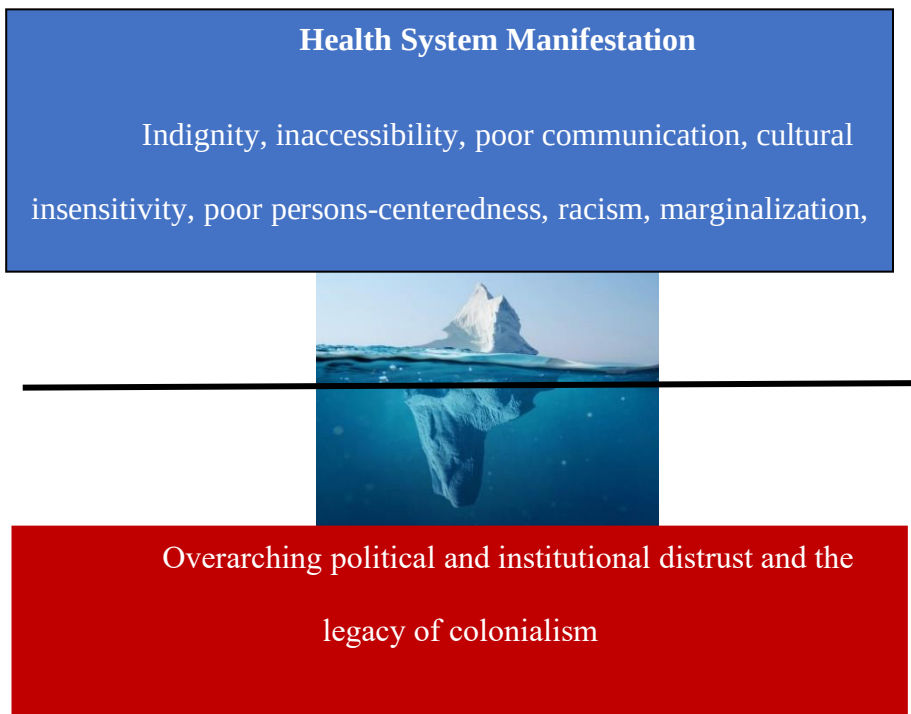


Figure 39. Root causes and associated health systems manifestations

6.2.1 Overarching political and institutional distrust

In the context of “Continuity of Care”, trust is traditionally represented by relational continuity which is the trusting and long-term relationship between a healthcare provider and a patient, generally within the context of GP. Even with the most recent proposals to better understand “Continuity of Care”, the GP is still the primary reference in understanding the “Continuity of Care” journey (Ladds & Greenhalgh, 2023). The results of this study point to a need for a broader understanding of this concept in poor and under- resourced settings where the model of PHC is decentralised, and nurse led. Chronic failures in the delivery of health services have led to deep and lasting negative effects on the trust that individuals with disabilities, families and communities have in the health system as a whole and by extension, those who work within it. Trust is a precious value in relationships and can have detrimental impacts on healthcare decisions taken by persons with disabilities when it is broken or compromised.

Two pillars of distrust have been found to have an effect on “Continuity of Care;” the first being **Political distrust** and the second, **Institutional distrust**.

Political distrust may not be an obvious threat to “Continuity of Care,” however in context of great political instability and unresponsive political leadership, it can have profound effects on the social determinants of health; more dramatically so in communities like Ward X. In Ward X persistent incompetence over decades, manifesting in the present day as an unresponsive ward counsellor, equates to no service delivery. Political distrust is rife in SA and when communities feel persistently sidelined and unheard, they develop increasing agency which can easily be manipulated by unscrupulous groups with their own political agendas as seen in the 2021 civil unrest and looting. While the target of people’s disgruntlement was government in 2021, the scene in KZN is set for future potential unrest unless political trust can be restored. Health is a highly politicized issue in any country but more so in SA where high levels of health inequality is fuelled by high levels of unemployment and poverty. The changing dynamics in SA leaves

little to be hopeful for, as dismantling a divided health system could prove more challenging than attempts to fix a broken system. It is therefore an important issue to consider when one attempts to understand how “Continuity of Care” can be improved in a SA context.

Institutional trust can be considered as fundamental to ensuring that people seek medical care when needed, follow their treatment plans and adopt health promotion advice. The “Continuity of Care” stories from individuals with disabilities and families of persons with disabilities show that institutional trust has been severely eroded through systemic failures in the health system’s understanding of the nuanced needs of persons with disabilities. There is evidence that the discrimination bias against persons with disabilities and the elderly, manifests in public health policies, health systems strengthening activities and new innovations which have direct impact on persons with disabilities and their families. This systemic discrimination has been documented as poor communication practices, lack of thought about the impact of new health services and innovations on persons with disabilities, lack of empathy towards families experiencing challenges

with accessing health services and additional financial burdens imposed on persons with disabilities who also have chronic conditions.

An example of this from this study was found in the implementation of the CCMDD programme which was inconsistently accessible to persons with disabilities with acknowledgement from policy makers that the programme was not ideal and not fully tailored to the needs of the most vulnerable, such as persons with disabilities. When this programme was accessed by persons with disabilities, their adherence was negatively impacted because only some of their chronic conditions were covered by the programme. Moreover, they often faced additional logistical challenges including more trips to health facilities and PuPs, as well as higher travel costs. Health system innovation and progress towards creating efficiencies in healthcare delivery was in this case, at odds with the goals of person-centred care in relation to persons with disabilities with chronic conditions, where the intended outcome of convenience resulted in a higher level of frustration, helplessness and distrust in the health system. If health system innovation and programme design continue to sidestep the healthcare needs of persons with

disabilities, who are a rapidly growing population in SA, there is a real risk of entrenching discrimination and marginalisation well into the 21st century.

Innovation in health system strengthening and the lack of inclusion of persons with disabilities in the design of new technologies and programmes represent a new arena of discriminatory practice that is fully perpetuated and entrenched by the current status quo. This study highlighted how a health system, steam rolling towards the future, is at risk of alienating the populations who require the most support. For elderly persons with disabilities, the implementation of new health systems interventions must be considered carefully, using a lens that takes their unique needs into account. Designing new health systems innovations must therefore be conceptualised with elements of person-centredness and social justice in mind to ensure that efforts to move the system forward do not have unintended negative consequences for the most vulnerable.

Institutional distrust in the health system can have significant impact on “Continuity of Care” as it creates barriers to health seeking behaviours. As a foundational principle of relational continuity, the results of

the study show that it strongly determines the decisions taken by persons with disabilities regarding what kind of healthcare and support is sought, where it is sought and whether they chose to adhere to the treatment plan. As evidenced by Mr X who rather chose to leave his rehabilitation treatment plan pre-maturely and risk surviving on his own, as a bilateral amputee in desperately poor social circumstances. It highlights the need for healthcare workers to begin with an assumption of distrust and work intentionally to re-establish trust as a fundamental pillar of care and support.

In the context of this study, institutional distrust was also exacerbated by the dual nature of the health system in SA, where persons with disabilities and chronic conditions, who had the financial means, reported seeking care from private health providers in addition to those offered by the public health sector as they perceived the former to be superior. However, their “Continuity of Care” pathway was complicated by multiple approaches to treatment, in addition to being expensive and incoherent. Fragmented care for people with chronic conditions is the least favourable outcome of any health

system, where the goal is to ensure treatment adherence through close and consistent health monitoring.

Community members and NGOs at the coalface of addressing community needs were also found to have lost trust in the health system in that services did not reach those who needed them most. Community based organisations are witness to the desperation of families who want to ensure that their family members with disabilities are given the best opportunity to access care, often to the detriment of the financial welfare of the family. NGOs have also fallen victim to an untenable funding landscape where funding received from larger organisations for the delivery of services to persons with disabilities are considered “nice to haves” and are often the first to be cut in time of funding distress. Furthermore, the dominance of development partners in KZN who perpetuate siloed approaches to healthcare service delivery endanger efforts to integrate and mainstream disability inclusion.

Feelings of distrust in the health system were not limited to services users, families and communities. Distrust in the health system appeared to

permeate through the health system itself where health facility staff revealed that they were largely unsupported in securing human resources to expand services into the community and felt helpless when resources were removed abruptly. Policy makers also felt a sense of distrust in fellow policy makers and health programme staff who did not see disability inclusion as a shared responsibility. This ultimately resulted in policy development practices that deprived policy makers responsible for disability and rehabilitation from supporting the mainstreaming of disability inclusion. The analysis of PHC policies showed an alarming disconnect between for instance, the FSDR and the Policy Framework and Strategy for Ward-Based PHC teams 2018/19 – 2023/24, as it related to disability inclusion standards and the need to ensure “Continuity of Care”. This might be explained in part by the disconnect reported between health programmes within the KZN provincial department of health. Each programmatic level deflected accountability to the level above ultimately pointing to deep seated political distrust.

In chapter 5 we alluded to the fact that the health system has reached a point of no return in terms of regaining the public’s trust. While the health

system in SA struggles to deal with its political, strategic and operational inefficiencies with renewed focus on efforts to improve service standards, the irony is that many if not all of these efforts disregard the importance of **trust and human connection** which is core to the Batho Pele principles underpinning public services in SA. Person-centredness is a term that is used in almost all policies, but without providing tangible insights into what is meant by the term and how it should be implemented.

Health systems across the world struggle with various challenges but the striking feature of health systems challenges in LMIC is that of shortages in human resource capacity (Roncarolo, Boivin, Denis, Hebert, & Lehoux, 2017). In SA, resource constraints are well documented with more recent challenges being government's inability to employ new graduates due to budgetary constraints. The brain drain in SA represents a significant issue in the delivery of quality healthcare. It has direct relevance to the study findings where trust and human connection is what matters most to persons with disabilities. Given that human resource challenges are likely to continue in the SA health system, there is a need to think more broadly and dynamically

about our conceptualisation of the health system. For instance, can the WHO 6 building blocks of a health system (World Health Organization, 2007) still provide the kind of nuanced understanding of a health system to address health challenges of the 21st century? Should we be working to appreciate and integrate additional elements into our understanding of the health system, for example, inclusion of community, family and traditional/ political leaders as they all have been found to play a role in influencing the health of people.

In summary, institutional distrust is a chronic condition of the health system in SA that negatively influences “Continuity of Care” and threatens appropriate health system responses to the needs of persons with disabilities. Addressing power imbalances is essential. Re-establishing institutional trust falls disproportionately on the shoulders of those service providers at the coalface of service delivery and health system efforts must focus on responding to the needs of persons with disabilities.

6.2.2 Colonial legacies

Findings of the study support the argument that apartheid's colonial legacy had a significant and long-lasting effect on SA healthcare. Apartheid era policies impacted healthcare services leading to glaring racial inequities in access to care, healthcare infrastructure, and health outcomes. The colonial aspects of apartheid on SA healthcare included racial segregation, inadequate healthcare infrastructure and deep psychological effects on people of colour (Indian, Coloured and Black South Africans) and how they valued themselves and their health. As a result, the apartheid era left a legacy of distrust between people of colour and the health system. This study showed that deep-seated distrust born in the apartheid era is still pervasive. Two important consequences of the apartheid era policies are the medical model and cycle of low expectations.

The **medical model** in the context of this study can be viewed as an influential artifact of colonialism having a strong negative influence on “Continuity of Care”. Its association with western based ideologies about health and wellbeing has lasted generations but has come under heavy

criticism for its lack of sensitivity to traditional healers and cultural practices. One particular “Continuity of Care” story (Mr N) illustrated how the medical model and its lack of sensitivity to cultural and traditional health practices resulted in disastrous impacts on health outcomes. The medical model is well represented in current concepts of “Continuity of Care.” As a western derived concept, “Continuity of Care” literature and focus is almost always related to care delivered by a GP or in hospital settings. The traditional definitions of “Continuity of Care” are derived within the walls of the clinical setting, from the relationship with the doctor (relational continuity), to the data collected (informational continuity) to how healthcare is managed and administered (management continuity). The medical model dominates our current understanding of “Continuity of Care”, and in so doing, the system runs the risk of having to deal with a multitude of additional complications as was the case with Mr N. Had the health system fully integrated traditional healers as part of PHC and community support, perhaps Mr N may have been saved the trauma of having both his legs amputated. In other ways, the medical model fails to acknowledge family as a trusted source of coherent medical

information. Partnerships of trust exist in many forms in and outside of the health systems and this needs to be represented in our construct of “Continuity of Care.”

SA is however making strides towards integrating traditional healers into the health system (Pinkoane, Greeff, & Koen, 2012). The traditional Health Practitioners Act of 2007 recognizes traditional healers and provides guidelines for their practice within the health system (Zuma *et al.*, 2016). However, their integration requires careful navigation due to the legal requirements on a cultural practice (Sidley, 2004). The health system needs to pay careful attention to the cultural preferences of communities in order to respond in a manner that leverages off what is acceptable to the community. Trust building between western trained health professionals and traditional healers represents another important health systems strengthening effort with high potential to influence “Continuity of Care”.

Another important effect of a colonial past and present is the long-term effect that it has had on people’s psyche and the standards of care of which they are worthy. Apartheid was not just a policy; it was a psychological

weapon used to make people of colour feel less valued and demanding of lower standards. High quality healthcare was not an expectation for many Black African families because apartheid framed their expectations by delivering sub-standard care. In current day SA, even though apartheid is no longer a policy, poor communities and vulnerable populations are still shackled to this dangerous logic which is further entrenched by new health systems challenges and their persistent marginalization. When people are constantly made to believe that they are not worthy of better, and the reality that they face reinforces this, it creates a cycle of low expectation that drives down demand for improved services.

This is well aligned to Roder-Dewan *et al.*'s (2019) proposition that populations with low expectations are more likely to be satisfied with poor quality care which in turn leads to a reduction in demand side pressure to improve services (Roder-DeWan *et al.*, 2019). In many of our documented "Continuity of Care" journeys, persons with disabilities who lived in the most desperate social conditions and whose health and rehabilitation needs were not being met, did not voice their dissatisfaction. This was evident in Mr. N's

case where his request for a wheelchair was voiced as an extraordinary request when in fact that was his right. Mrs. R also appeared to resign herself to accepting low quality care, long waiting times and poor attitudes of nursing staff towards the elderly with disabilities. A key recommendation for policy makers involved in the design of patient satisfaction surveys would be to ensure active participation of persons with disabilities, while also ensuring that they are informed about service standards and their right to speak out when these are not met. Policies and interventions to raise people's expectations of the quality of healthcare they receive should be considered in health system quality reforms (Roder-DeWan *et al.*, 2019). This represents low hanging fruits as structures and systems are already in place for these measures to be monitored consistently.

Reconstructing the medical model requires shifting the locus of control of healthcare from the health facility and health professionals towards a more broadened and inclusive model of control. The seven shared principles of primary care have been shown to have close ties with “Continuity of Care”,

and by virtue of it being closely linked with quality of care, are essential to the delivery of PHC (Al-Azri, 2008).

The findings of this study align somewhat with Starfield's functional description of PHC in that "Continuity of Care" is promoted when it is person-focused (Starfield & Horder, 2007). The study found that her first contact functional description is also valuable if the goal is to ensure access at first realisation of need. However, the mechanism of first contact may be slightly different in a SA context and services may be delivered differently.

6.3 Positive influences on "Continuity of Care"

6.3.1 Family resilience

The theme of Family Resilience was used to describe two important and interrelated concepts; namely 'tenacity to advocate' and the 'burden of care'. Resilience is ability to withstand and rebound in the face of adversity, trauma or stress (Walsh, 2003). Resilience literature indicates some conceptual understanding of what makes some families resilient but

broadly, research on protective and risk factors are lacking (Herdiana, Handoyo, & Handoyo, 2017) The focus on persons with disabilities tends to overshadow families' experiences, who are also impacted by the stressors of a weak health system which they jointly experience with their loved ones (i.e. delivery of sub-standard services, having to endure disrespectful behaviour of health professionals and observe first-hand the marginalisation of their loved ones).

The level of resilience of family members and their ability to withstand these episodes of deep frustration over a long period of time, is an important consideration for health professionals who want to keep their patients with disabilities in care. It is as important for health professionals to build strong trusting relationships with families as with their patients, given the pivotal role they can play in ensuring the health and wellbeing of their loved one with a disability. Family support structures were found to be important in maintaining good "Continuity of Care" for persons with disabilities and there was a distinct difference between the "Continuity of Care" journeys of persons with disabilities who lived with family members

and those who lived alone or did not have strong family support structures. An observable trait of family members involved in the provision of care and support was their resilience and tenacity to advocate for the rights of their loved ones.

‘Tenacity to advocate’ relates to the role taken on by the women interviewed on behalf of their family members with a disability. It refers to a determined and persistent approach to promoting a cause or advocating for a particular issue or group of people. It involves a strong commitment to achieving a desired outcome despite facing challenges, setbacks, or obstacles. In contexts of poverty and limited resources, the role of family is exceptionally important. The SA health landscape is often not conducive for persons with disabilities to achieve full independence and therefore necessitates strong support structures and family involvement. It may therefore be necessary to expand the commonly used definitions of “Continuity of Care” care to include families and communities as they represent an expansion of the health system into the home of the patient.

On the flip side, the burden placed on family members in ensuring “Continuity of Care” is significant and warrants more in-depth investigation. Being the critical link for continued health services was an assumed responsibility by the women interviewed. Ensuring that families are well supported so that they can continue to provide the support needed is an important consideration for health professionals. There is evidence from the interviews with family members that little consideration is given to the role that they play, and the expectation of the health system is that they will continue to support and navigate their loved ones through the myriad of challenges imposed by the health system.

6.3.2 Servant leadership

The theme of servant leadership was used to describe the type of interpersonal relationships most appreciated by persons with disabilities. Servant leadership is used in the context of this study to represent characteristics of service providers which instilled renewed hope and belief in the health system. When people were treated consistently by the same

healthcare professional, with personalised care and deep understanding of their needs, they felt valued and seen. This compares well with the traditional understanding of relational continuity and the results of the study show that even in resource- constrained contexts, simple efforts made by healthcare providers can make a difference. The challenge in the SA is that these types of experiences are seen as an exception rather than the norm. This study has shown that for vulnerable people such as persons with disabilities, these efforts make the most difference and promote adherence to treatment and have a positive bearing on “Continuity of Care” as a whole. When persons with disabilities know that their individual challenges are well understood and that the system is flexible enough to accommodate them, they are more likely to keep their appointments and maintain good adherence to treatment guidelines. We saw this clearly with Mrs R’s story, where she had built trust in one particular nurse at the facility who understood her mobility challenges and supported her by making sure that her medication was available and ready for pick up when she arrived at the health facility.

Interestingly the principle of servant leadership is not new to the health system and is an embedded principle in the Batho Pele principles which guide public health service in SA. They were developed as a set of guiding principles to enhance the provision of public services and encourage good administration. It stands for "People First," and was intended to make public services easily accessible, effective, and sensitive to the interests of the people. The Ideal Clinic adopts the Batho Pele principles; however, evidence of the health system putting persons with disabilities first was absent. There is therefore a need for greater intentionality around what servant leadership means and how it can be achieved.

6.3.3 Emergent community leadership

There was evidence of emergent community leadership in Ward X, particularly in communities with chronically high levels of poverty which were associated with positive "Continuity of Care" journeys. The importance of community leadership in driving "Continuity of Care" was most evident where desperation pushed the organic emergence of leaders in the

community. It was found to have developed naturally, driven by particular traits found in a few members of the community who saw themselves as custodians of creating a better future for their families and community members. Despite not holding any formal political titles they acted in the best interests of the most vulnerable. Their efforts to address transport challenges and call out private companies over- charging persons with disabilities had direct bearing on their ability to attend the clinic regularly and served to support their “Continuity of Care” journey. In the absence of political will to raise the community out of poverty, these leaders rose to prominence with the community because of their actions, authenticity and consistency. It again relates to the establishment of trusting relationships which was not apparent amongst study participants and appears to also be absent from health systems. Their leadership qualities arise as a result of their influence, knowledge, and peer esteem. Community leaders often do not have formal authority which creates challenges in developing agency and change and need this to be able to contribute to decision-making around the needs of their community (Hove *et al.*, 2022). Smith and Bhavsar (2021) propose that encouraging leadership

styles that promote community participation may also be valuable in creating resilience in communities during times of crises as proposed by (Smith & Bhavsar, 2021)

6.4 Summary of chapter

This chapter has provided the reader with critical discussion of two negative influences of “Continuity of Care” namely; political and institutional distrust. These issues are deeply entrenched at all levels of the health system and have important effects on “Continuity of Care”. It highlights the damaging legacy of apartheid in South Africa and the need for these issues to be addressed as the country embarks on planned health system reforms. Three positive influences namely; family resilience, servant leadership and emergent community leadership are presented as important leverage points for enhancing “Continuity of Care”. It serves to acknowledge the significant role played by families and communities in overcoming limitations of the health system and illustrates the importance of investing in communities to expand social support for persons with disabilities. It also highlighted how

“Continuity of care” can be enhanced through simple measures like improving how service providers engage with persons with disabilities.

Chapter 7: Research implications and recommendations for policymakers

7.1 Introduction

This chapter outlines implications for research into “Continuity of Care” specifically as it relates to persons with disabilities with chronic conditions and provides recommendations for policy makers and health implementers to consider when attempting to address this issue.

7.2 Recommendations for policymakers

Based on the findings of the study, the following recommendations are made to policy makers to target “Continuity of Care” improvements. These are discussed in three themes: 1) Address Policy-practice gaps in implementing “Continuity of Care”; 2) Promote family and community guided linkage to care; and 3) Identify the needs and expectations of persons with disabilities as part of responsiveness.

7.2.1 Address policy-practice gaps in implementing “Continuity of Care”

1. PHC pivots off a highly coordinated and integrated flow of services within the health facilities and beyond. These services are implemented in accordance with relevant policies. References to “Continuity of Care” and person-centered care across policies need to be standardised to facilitate both the understanding of the concepts and how it needs to be implemented.
2. “Continuity of Care” needs to be a core part of any policy that aims to improve Quality of Care and persons with disabilities must feature strongly as a population requiring tailored services. The FSDR is a policy that holds value in realising the ideals of disability and rehabilitation services, but it is also holds utility in promoting “Continuity of Care” and quality health services for persons with disabilities.
3. Power imbalances exist between medically trained policy makers and those who are trained as Health and Rehabilitation professionals. The

imbalance represents a hidden barrier to the implementation of disability inclusion within the health system as it is seen as a problem that must be addressed by rehabilitation professionals or those leading the disability and rehabilitation programme. This siloed approach does not suit the needs of persons with disabilities with chronic conditions who must be incorporated into an inclusive and universal approach to improve “Continuity of Care”.

4. Prioritise disability and rehabilitation services at political, policy, planning and implementation levels with accountability frameworks.
5. Interrogate policies using a human rights framework but ensure that the ideals created in policies are achievable and represent the values of the communities that the policy intends to serve.
6. Ensure that new technologies are fit for purpose and designed with the needs of persons with disabilities. The CCMDD programme is an important initiative, but due to its lack of sensitivity to persons with disabilities, the programme negatively impacts “Continuity of Care”.

7. Develop and revise Human Resource plans to address the shortage of therapists and specialists required to provide rehabilitation and disability services, including CBR.
8. Record-keeping and sharing of information across the levels of the healthcare system is as important as information collected within a health facility. Improvements in this regard will make for more seamless transitional care.

7.2.2 Family and community directed “Continuity of Care”

1. Families and community structures play a crucial role in supporting the “Continuity of Care” needs of persons with disabilities. PHC outreach teams and CCGs need to be better trained and equipped to work with these important support structures as they are often the “glue” that holds the care coordination journey together.
2. Traditional Healers are an important link in “Continuity of Care” as they hold a trusting relationship which is sought after in times of health crises. Their integration into the health system needs to include

their role in supporting “Continuity of Care” and the impacts of delayed referral to a health facility.

3. Training of health professionals on what “Continuity of Care” means and how it can be achieved in everyday practice is key to addressing the needs of persons with disabilities. Relational continuity was found to be most valued by persons with disabilities and does not take too much to implement even with limited resources.
4. Implement a referral guideline that informs efficient referrals of persons with disabilities and strengthens referral pathways and processes.

7.2.3 Identifying the needs and expectations of persons with disabilities as part of responsiveness

1. The creating of a health system that is responsive to the needs of persons with disabilities starts with knowing what they expect. Mechanisms to routinely gather this information and monitor health service standards in relation to it is necessary.

2. When services meet the standards expected, acknowledge it as a means of modelling the desired Servant leadership that is linked to positive experiences of “Continuity of Care” for persons with disabilities.

7.3 Research implications

Research into “Continuity of Care” show a pattern of wanting to know what works best for which population in which context. While this is a worthy approach, it runs the risk of being too narrowly focused lacking depth of understanding of the context. There needs to be a move away from disease specific enquiry towards research that takes a broader view of the issue. The following are some suggestions for researchers wishing to explore the important concept of “Continuity of Care:

1. It needs to be redefined for an African context which may require the inclusion of an important axis of influence which includes THP, community structures and family.

2. “Continuity of Care” cannot be improved within a South African context without full appreciation of the rights of “persons with disabilities”, their expectations of the health system and those who deliver services within them.
3. Traditional Health Practitioners must be part of the any enquiry into “Continuity of Care”, using appropriate participatory approaches, that shifts thinking away from the medical model towards inclusion, as well as cultural inclusion.
4. Tools for the measurement and assessment of “Continuity of care” must include service expectations of persons with disabilities specifically as their lived realities and needs may be different.
5. Patient journey mapping is valuable in understanding “Continuity of Care” as weaknesses in policies become more evident.
6. Research is needed to redefine what we mean by person-centred care and its relevance to an African context where persons with disabilities are often seen as part of a family unit. The dimension of family and community networks for support deserves further interrogation. There

needs to be a conceptual shift towards people-centered care, defined within an African context.

7.4 Study limitations

7.4.1 The dominance of the positivist paradigm

As a researcher trained mostly in the positivist paradigm, this transition to a critical paradigm has revealed how deeply ingrained positivist approaches can be in the minds of researchers. The majority of the work conducted by the researcher has been of mixed methods where the use of qualitative research was included as a superficial adjunct to quantitative results. In some ways I have felt this tension throughout the research journey and have had find ways to consciously shift my thinking and see the value in the rich qualitative data that I was generating. In adopting a critical paradigm, I was able to reverse this default position in my thinking and place emphasis on the voices of persons with disabilities.

7.4.2 Transferability

The study adopted a case study methodology which is often criticised for its limited ability to transfer findings to a broader population. The results of the study are limited in transferability to the whole of SA, but for communities who are determined to have similar characteristics in KZN, a level of transferability is perhaps possible as communities such as Ward X common place in KwaZulu Natal. Case studies typically focus on a specific context or a small number of cases, making it challenging to apply the results to a larger population.

7.4.3 Limitations of the Health Systems Responsiveness Framework

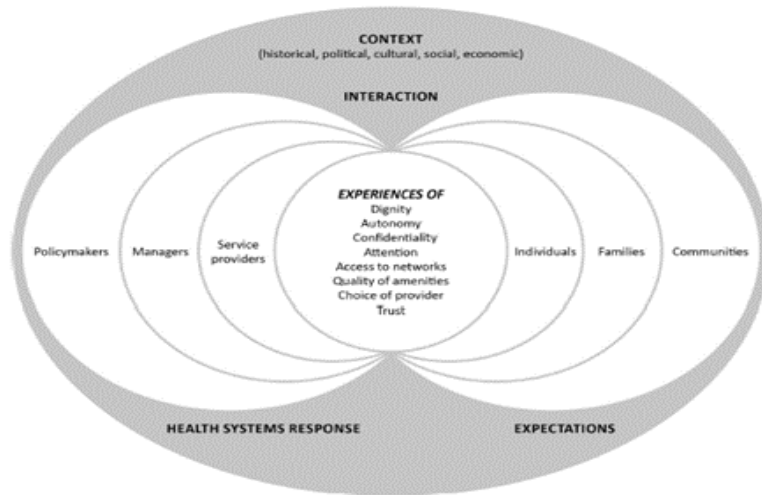


Figure 40. Health Systems Responsiveness Framework (Mirzoev and Kane, 2017)

The tool provided advantages in that it supported the exploration of perspectives about the concept of “Continuity of Care” using a health systems lens. A strength of this framework is its focus on individual-level experiences with health systems. The framework recognises that the patient's perspective is essential to evaluating the aspects of responsiveness of a health system, as the quality of the patient experience is a crucial aspect of healthcare delivery.

Using this framework allowed for the voices of persons with disabilities to be comprehensively investigated. Furthermore, the framework provided a systematic approach to evaluating the responsiveness of health systems, ensuring that all essential domains are considered.

However, there are several limitations to the framework. First, the seven domains are primarily focused on the patient experience in healthcare facilities and did not consider the wider social determinants of health that may impact patients' experiences. For example, factors such as income, education, and social support networks may influence an individuals' ability to access healthcare services, but these factors are not explicitly included in the framework.

Second, its reliance on self-reported data. Patients' perceptions of healthcare experiences can be influenced by a range of factors, including cultural beliefs, expectations, and previous experiences, which may not necessarily reflect the quality of healthcare delivery accurately. Moreover, the framework does not provide clear guidance on how to validate or verify self-reported data.

Overall, the Health Systems Responsiveness Framework by Mirzoev and Kane (2017) is a valuable tool for evaluating the responsiveness of health systems from the perspective of individual patients. However, to enhance the framework's usefulness, it may be necessary to address the limitations identified, such as incorporating social determinants of health, validating self-reported data, and considering equity issues in healthcare access. This study has demonstrated the significant role that determinants of health play in relation to “Continuity of Care” as we have seen how economic means, physical living conditions and cultural practices impact on the ability to access and maintain health. To this end I propose an integrated framework for identifying factors that influence “Continuity of Care” for persons with disabilities as shown in Fig 40 below.

7.4.4 A reimagined Policy-Practice Framework for understanding influences on "Continuity of Care"

Upon reflection of the potential limitations of Mirzoev and Kanes’ (2017) Framework of health systems responsiveness, a reimagined

framework entitled “**An integrated health systems framework for understanding "Continuity of Care"**” was conceptualised with the research approach in mind, i.e. critical social theory (Kincheloe & McLaren, 2011) using a health systems lens. Mirzoev and Kanes’ (2017) Framework of health systems responsiveness aims to understand responsiveness but is limited when applied to the concept of “Continuity of Care” as the realities of policy and practice appear far removed from the realities of people who use the health system. In this integrated framework, I proposed bringing policy and practice closer to the lived experiences of people so that there is a broader and more meaningful nexus between the community, policy and practice. What this study has demonstrated is that policy design can be informed and improved on if there are more opportunities to investigate implementation barriers in the real world.

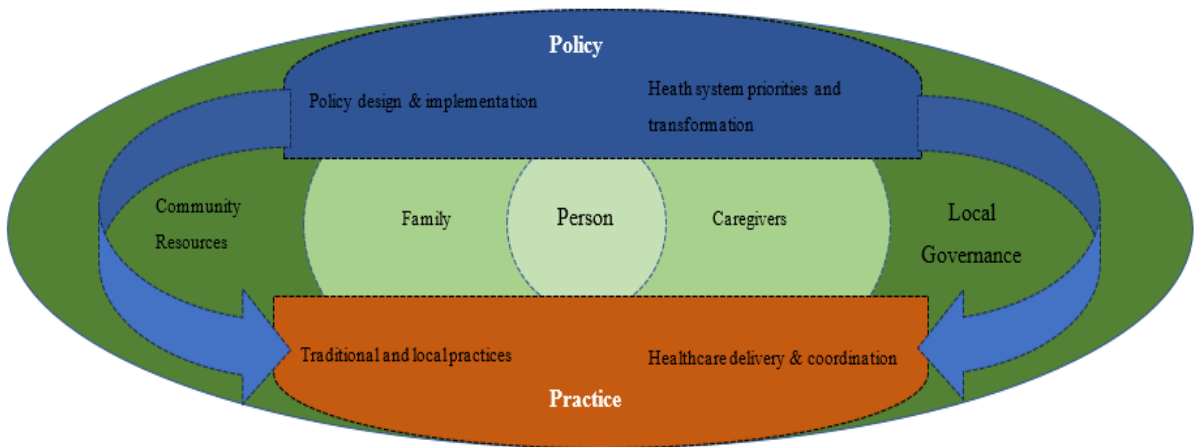


Figure 41. A Policy-Practice Framework for Understanding Influences on "Continuity of Care"

The **Integrated health systems framework for understanding "Continuity of Care"** places people and families at the centre of the policy-practice continuum with community resources and local governance representing important supportive components. The policy component of this framework acknowledges two important aspects i.e. policy design and implementation and health system priorities and transformations. In a country like South Africa, both components are important in creating policies that are

progressive. Practice relates to how policies are implemented and includes traditional and local practices and healthcare delivery and coordination. These three areas form the foundation for reimagining how people, policies and systems can be brought together to support "Continuity of Care.

The re-invigoration and strengthening of community-based organizations and more intentional efforts to engage traditional health practitioners and more importantly, families and people with lived experience of disabilities are examples of how this model can be implemented.

This offering is a first step towards creating a more nuanced understanding of “Continuity of Care” not just for persons with disabilities but for a broader population that could also benefit from such a shift in thinking. This represents a work in progress and will undergo further refinement with the aim of creating a more contextually sensitive conceptual model. As an interim offering, this model may be of use to researchers, policy makers and communities who seek to develop agency and push the system towards greater responsiveness.

7.5 Conclusion

The study findings point to the need for an expanded understanding of “Continuity of Care” within an African paradigm where care continuity extends beyond the health facility and with a stronger emphasis on community driven models of care that respect the role and influence of traditional health practitioners and cultural practices. More research is needed to better understand institutional distrust and how traditional western models of healthcare can be re-shaped to deliver services

The pursuit of health is demonstrated through this study as a turbulent journey for persons with disabilities. The critical health systems approach has revealed deeply entrenched influences on “Continuity of Care” and highlighted the disconnect between policy and practice. Some of these factors have historical roots and will need further research to discover effective ways to dismantle them. More importantly, though, the approach has allowed persons with disabilities to take centre stage in relaying their expectations of the health system to ensure good “Continuity of Care.”

Their expectations are simple, in stark contrast to the complexity imposed by researchers and health systems actors. “Continuity of Care” need not be an unattainable goal in the absence of resources. It requires responsiveness and a reset in the minds of healthcare workers around human connectedness, context and culture to ensure that no-one is left behind.

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Appendices

Appendix A: UCT Health Research Ethics Committee (HREC) Approval



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room 650 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone (021) 650 1236
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

20th October 2020

HREC REF:055/2020

Prof H Kathard
Division of disability Studies
H-45, OMB
Email: Harsha.kathard@uct.ac.za

Dear Prof Kathard

PROJECT TITLE: AN INVESTIGATION OF PRIMARY HEALTHCARE POLICIES AND PRACTICES INFLUENCING "CONTINUITY OF CARE" FOR PERSONS WITH DISABILITIES IN SOUTH AFRICA (PhD candidate Ms Thesandree Padayachee)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study subject to:

- Face-Face interviews or focus groups discussions with any disabled person may only be conducted once all lockdown restrictions have been lifted.
- If the restrictions are still in place at the time of the data collection, then the interviews should be conducted remotely using digital or telephonic communication.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID-19, dated 17 March 2020 and 6 July 2020.

Approval is granted for one year until the 30 October 2021.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledges that the Student: Ms Thesandree Padayachee will also be involved in this study.

HREC REF 055/2020 SC

Appendix B: KZN (PHRC) Ethics Approval



KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:

Postal Address: Private Bag X9050

Health Research & Knowledge Management Unit

Physical Address: 330 Langalibalele Str, PM Burg, 3201

Tel: 033-3953189/3123/2805 Fax: 033-3943792

Email address: hrkm@kznhealth.gov.za

www.kznhealth.gov.za

NHRD Ref: KZ_202102_011

Dear Ms T Padayachee
(UCT)

Approval of research

1. The research proposal titled 'An investigation of primary healthcare policies and practices influencing "continuity of care" for persons with disabilities in South Africa' was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

The proposal is hereby approved for research to be undertaken at Reservoir Hills Clinic

2. You are requested to take note of the following:

- a. All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.
- b. Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.
- c. Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.
- d. Provide an interim progress report and final report (electronic and hard copies) when your research is complete to HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200 and e-mail an electronic copy to hrkm@kznhealth.gov.za
- e. Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.

For any additional information please contact Ms G Khumalo on 033-395 3189.

Yours Sincerely

Signed by candidate

Dr E Lutge

Chairperson, Health Research Committee

Date: 11/07/2021

GROWING KWAZULU-NATAL TOGETHER

Appendix C: eThekweni Municipality Health Department

Approval

ETHEKWINI MUNICIPALITY
Community & Emergency Services Cluster
Health Unit

9 Archie Gumede Place
Durban 4001
P O Box 2443
Durban 4000
Tel: (031) 311 3505
Fax: (031) 311 3710
Website:
<http://www.durban.org.za>



19 November 2020

Dear Researcher,

Subject: Approval of a Research Proposal

The Research Proposal Titled: "An investigation of primary healthcare policies and practices influencing *"continuity of care"* for persons with disabilities in South Africa." was reviewed by the eThekweni Municipal Health Unit Research Committee. The study is hereby **approved to be conducted at Reservoir Hills Clinic and is valid for one year until 31 October 2021.**

The following conditions need to be noted:

- Submission of the indemnity form obtainable from the eThekweni Municipality Health Unit before commencement of the study.
- Prior arrangements to be made with the facility and an assurance that clinic services will not be disrupted.
- No staff member should be used for collecting data for the researchers.
- **Progress reports to be provided and the final report of the study to the eThekweni Municipality Health Unit or emailed to: Bongi.Ntombela@durban.gov.za**
- Obtain permission from the eThekweni municipality health department for press releases and release of results to communities/stakeholders.
- The department has to receive recognition for the assistance given.
- Any amendment to the study must be communicated with the eThekweni Municipality Health Unit and the relevant amendment form obtainable from the unit to be submitted.
- Withdrawal of permission to conduct research will be left to the discretion of the eThekweni Municipality Health Unit.
- **Please take note of the duration of the study approval.**
- **An extension may be applied for if required. The Committee will review such a request and provide feedback accordingly.**

Yours sincerely

Signed by candidate

Dr N.I Gxagxisa: Head of Health



Appendix D: Information Leaflet: General Health

Questionnaire

Dear Sir/Madam,

RE: Request for your participation in a questionnaire

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I want to kindly request your participation in a questionnaire that aims to explore how you experience care at your clinic. This questionnaire is a simple questionnaire which should take no more than 10 minutes of your time. The participation of persons with disabilities is often hindered because of challenges in identifying and accessing people. We are therefore using this questionnaire to invite you participate in a study to understand your experience when you visit the clinic.

Your participation in this questionnaire is voluntary. You will receive no direct benefits from participating in this questionnaire. However, your responses may help the research team understand your experiences at your clinic. There are no risks or discomforts in participating in this questionnaire. Your questionnaire answers will be sent to a link at [QuestionnaireMonkey.com](https://www.questionnairemonkey.com) where data will be stored in a password protected electronic format. Confidentiality of questionnaire answers is assured as your name, email address, or IP address will not be stored nor personal identifiers be traceable.

At the end of the questionnaire, you will be asked if you are interested in participating in an additional interview [by phone, or email]. Please feel free

to contact the researcher if you would like more information. Your personal contact information will not be shared with anyone.

If you have questions at any time about the study or the procedures, you may contact Ms Thesandree Padayachee 0725668740 thesandree.padayachee@hst.org.za.

If you feel you have not been treated according to the descriptions in this form, or that your rights as a participant in research have not been honoured during the course of this questionnaire, or you have any questions, concerns, or complaints that you wish to address to someone other than the investigator, you may contact the Principal Investigator and my supervisor Professor Harsha Kathard: harsha.kathard@uct.ac.za (w) 021 406 6401.

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

To indicate that you are happy to continue with the questionnaire please select your choice below. You may print a copy of this consent form for your records. Clicking on the “Agree” button indicates that

- You have read the above information
- You voluntarily agree to participate
- You are 18 years of age or older

Yours faithfully,

Thesandree Padayachee,

(thesandree.padayachee@hst.org.za)

Contact Number: 0725668740)

General Health Questionnaire

Demographics			Code		Code
Q1	How old are you?				
	18 – 20		1	56 - 65	5
	21 – 35		2	>65	6
	36 – 45		3		
	46 – 55		4		
Q2	Are you male or female?				
		Male	1	Female	2
		Intersex	3		
Q3	What Language/s do you speak?				
		English	1	Xhosa	7
		Zulu	2	Swati	8
		Afrikaans	3	Ndebele	9
		Venda	4	Pedi	10
		Northern Sotho	5	South African Sign Language	11
		Southern Sotho	6	Other, please specify	12
Q4	Which population group do you identify with?				
		African	1	Coloured	5
		White	2	Other	6
		Indian	3		

		Asian	4		
Q5	Do you have a disability?				
		Yes	1		
		No	2		
Q6	Please tick which most describes your disability				
		I was born with my disability	1	My disability resulted from a medical condition	3
		My disability was as a result of an injury	2	Other, please specify	4
Q7	In which province do you live?				
		Western Cape	1	Gauteng	6
		KwaZulu-Natal	2	Limpopo	7
		North West	3	Free State	8
		Mpumalanga	4	Northern Cape	9
		Eastern Cape	5		
Q8	State your nationality				
	South African		1		
	Other, please specify		2		
Q9	Where do you stay, <u>mostly</u>?				
		Stand-alone brick house	1	Informal dwelling / shack in a back yard	5

		Traditional dwelling	2	Granny cottage / shared room in a house	6
		Flat or apartment in a block of flats	3	Other _____, specify_____	7
		House in a complex	4		
		Informal dwelling / shack in an informal settlement			
Health Questionnaire					
Q10	Do you take any medication regularly for any health condition? (If no go to Q11)				
		Yes	1		
		No	2		
		Unsure	3		
Q11	If yes, how often do you take medication?				
		Everyday		Once a month	
		Weekly			
Q12	What health conditions do you have? <i>You may select more than 1 option.</i>				
		Diabetes	1	Sickle Cell disease	8
		High blood pressure	2	Obesity	9
		Cancer	3	Serious Heart condition	10
		Kidney disease	4	Autoimmune condition (E.g. Arthritis, Lupus)	11

		HIV/AIDS	5	Dementia	12
		Tuberculosis	6	Depression	13
		Asthma	7	None	14
Q13	Where do you get most of your basic healthcare from? You may tick more than one option.				
		Public clinic	1	Mobile clinic	6
		Private doctor	2	Other (Specify)	7
		Public hospital	3	I do not need any medical care	8
		Private hospital	4		
		Non-governmental Organisation (NGO)	5		
Q14	How many times do you go to visit the clinic or doctor in a year?				
		Zero	1	Four	5
		One	2	Five	6
		Two	3	Six	7
		Three	4	More than 6 times	
Q15	When you visit the clinic or doctor, which of the following people do you generally have appointments with? (you may tick more than one option)				
		Doctor	1	Occupational Therapist	5
		Nurse	2	Podiatrist	6
		Physiotherapist	3	None	8

		Dentist	4	Other (specify)	7
		Speech Therapist	5	I don't know	8
Q16	Please tell us what best describes the way you feel when you visit the clinic or doctor?				
			1	2	3
		I see the same doctor every time	I Agree	I Disagree	I don't know
		My medical history is well documented			
		I understand everything that is said to me			
		My healthcare team shares information between them so I don't have to repeat myself			
		My healthcare team knows me very well and understands my challenges			
Q17	We would like to hear more about your experiences when you are visiting a healthcare facility. If you attend a public clinic more than 3 times a year to get healthcare, we would like to invite you into the next phase of our study. Please				

	indicate if you would like to be contacted by a researcher so that we can hear about your experiences?				
		Yes, please contact me	1		
		No, I would not like to be contacted	2		
		Not sure, I need more information	3		
Q18	If yes, or you would like more information, please fill in the following details and the researcher will be in contact with you. Your information will only be accessible to the researcher and will not be shared with anyone else. Name: Contact Number: E-mail address				
Q19	If you are interested in registering to be part of a research network dedicated to ensuring that persons with disabilities are given equal opportunity to participate in research that promotes the inclusion of persons with disabilities, please contact the lead researcher Ms Thesandree Padayachee thesandree@gmail.com.				

Thank you for participating in the first phase of our study. We look forward to sharing our results with you.

Appendix D: Information Leaflet and Informed Consent: KII with National and Provincial Key Informants



UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD
HEALTH SCIENCES



Divisions of Communication Sciences & Disorders • Disability Studies •
Nursing & Midwifery • Occupational Therapy • Physiotherapy

F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 405 6401
Website: www.dhrs.uct.ac.za

Date: (day/month/year)

Dear Sir/Madam,

RE: Request for your participation as a key informant in a study exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I want to kindly request your participation in the aforementioned study.

Why is the research being done?

The World Health Organisation (WHO) describes primary healthcare as very important level of the healthcare system which “brings promotion and prevention, cure and care together in a safe, effective and socially productive way. “*Continuity of care*” is a powerful concept in delivering quality primary healthcare which is especially beneficial to patients with complex or multiple health problems and well as patients who have unique healthcare needs such as persons with disabilities. persons with disabilities have healthcare needs just like people without disabilities however; in South Africa, they experience many barriers in accessing primary healthcare services even when access is

realised, poorly integrated health systems and services may result in poor “Continuity of Care” and unmet healthcare needs.

This study aims to investigate the factors that facilitate “*continuity of care*” for persons with disabilities so that information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively.

What is the purpose of the research?

The purpose of this research is to explore primary healthcare “continuity of *care*” for persons with disabilities. “*Continuity of care*” is how a patient experiences care over time and across multiple healthcare providers and also refers to the trust relationship that develops between the patient and healthcare provider over time, which leads to better levels of satisfaction and adherence to treatment. Very few studies have investigated this very important concept and a deeper understanding of “Continuity of Care” and the factors that influence it is therefore important.

In addition, given the rapidly transforming primary healthcare context of SA towards the of universal health coverage, the adoption of progressive healthcare policies and the introduction of new healthcare standards through the establishment of the Office of Health Standards Compliance, a study like this will provide much needed information about whether these new efforts have an impact on “Continuity of Care” for one of the most vulnerable and marginalised groups of people in society. If we are to realising the goal of a truly inclusive, person-centred health system, we will need investigate the unique needs of the most marginalised in our society and put systems in place to ensure that we meet them.

Why are you being invited? What is expected of you?

As an individual with experience of primary healthcare policies and implementation plans, we hereby request your participation in this study as a key informant. You have been chosen to participate in this study because of your knowledge, and experience of government plans to transform the South African public health system towards a more inclusive and person-centred health system.

We are inviting you to take part in an interview which will last approximately 90min. This may take the form of a face to face or telephonic interview according to your preference. The questions we will ask you are related to your knowledge regarding primary healthcare policies and “Continuity of Care” specifically in relation to persons with disabilities. If you decide to participate, you will be interviewed by me, and I will also continue to engage with you on an ongoing basis until the release of the findings. You may also be asked to participate in a final validation exercise before the results or the study are finalised. The interview will be recorded and will be transcribed for analysis and interpretation. All information including transcripts and recordings will be kept confidential, accessible only to the researcher. All personal identifiers will be removed from the recordings, transcripts and other materials before analysis in order to ensure anonymity. Access to research material will be limited to research team and be kept under the management of the Principle Investigator who will ensure safety of the data.

My research proposal has been approved by the Faculty of Health Sciences, Human Research Ethics Committee - study approval number is 055/2020

Risks and benefits...

Participation in this study will not benefit you directly nor cause you discomfort or harm in any way. Through your involvement in the study, it may assist the policy makers to better understand the needs of persons with disabilities and help you design primary healthcare services that promote “Continuity of Care” and improved health for those at highest risk for poor health outcomes. Your insights on key primary healthcare policies that relate to “Continuity of Care” will be requested and we will be particularly interested in your opinions regarding the factors that impact the successful implementation of these policies.

Privacy and confidentiality...

The information that you provide will be strictly used for the aim of this study. Your details and study information will be kept confidential and will not appear in the report or publications of this study. All identifying information will be removed from any document generated from this interview and therefore your confidentiality will be maintained. Codes and unique identifiers will be used to ensure confidentiality. Audio recordings will be maintained on the researcher’s computer which is password protected.

The audio files will be used to verify the accuracy of the data collected during the interview. All data will be destroyed after five years.

While the researcher is committed to maintaining confidentiality and privacy, it does recognize that information breaching is a risk. Complete privacy and confidentiality cannot therefore be guaranteed. Through reading the findings of the study, participants may be identifiable through contextual information such as the description of a programme or site of the practice but all attempts will be made to ensure that this risk is minimised. You also do not have to answer any question or take part in the interview if you feel the question(s) make you uncomfortable.

What are your rights as a participant?

Your participation is entirely voluntary. Your participation will have no bearing on your job or on work-related evaluations or reports. You are free to stop at any time of the interview or decline responding to questions you are not comfortable to answer. You may change your mind later and stop participating even if you agreed to earlier without any consequences. You may withdraw from this study at any time, without penalty and without having to give a reason for doing so. If you would like to withdraw from the study, you can contact me directly, documents used will be discarded from the analysis. If you would like to receive a copy of the results of the study, your contact details will be kept to inform you of the results.

We thank you for your time and consideration.

Yours faithfully,

Thesandree Padayachee,
Number: 0725668740)

(thesandree.padayachee@hst.org.za)

Contact

Should you have any questions, please do not hesitate to contact me at the above details or my supervisor Professor Harsha Kathard: harsha.kathard@uct.ac.za (w) 021 406 6401

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Please sign the consent form indicating your wish to participate in the study.

Consent form

I, _____ (*full name in print*) have been invited to participate in research exploring primary healthcare policies and practices influencing “Continuity of Care” for persons with disabilities in South Africa. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and these have been answered to my satisfaction. I give consent voluntarily to be interviewed as a participant in this study and am fully aware of my rights as a research participant. I do not have any further questions. I am aware that I may withdraw from the study at any time if I so wish, without having to provide an explanation. I understand that I can contact the researcher to inform her of my withdrawal from the study. Withdrawal from the study will have no negative implications for me. I voluntarily consent to participate in this study.

Participant’s Signature: _____ Date: _____

Researcher’s Signature: _____ Date: _____

Would you like to be informed of the results of the study? Circle. YES/NO

If _____ yes, _____ provide _____ email _____ address: _____

Should you have any questions please do not hesitate to contact me or my supervisor:

Thesandree Padayachee: (thesandree.padayachee@hst.org) Contact Number: 0725668740 / 031 2669090

Professor Harsha Kathard: harsha.kathard@uct.ac.za (w): (021) 406 6401

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

Appendix C: Information Leaflet and Informed Consent: KII Primary Healthcare Facility Manager



UNIVERSITY OF CAPE TOWN
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HEALTH SCIENCES



Divisions of Communication Sciences & Disorders • Disability Studies •
Nursing & Midwifery • Occupational Therapy • Physiotherapy

F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 405 6401
Website: www.dhrs.uct.ac.za

Date: (day/month/year)

Dear Sir/Madam,

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I want to kindly request your participation in the aforementioned study.

Why is the research being done?

The World Health Organisation (WHO) describes primary healthcare as very important level of the healthcare system which “brings promotion and prevention, cure and care together in a safe, effective and socially productive way. “*Continuity of care*” is a powerful concept in delivering quality primary healthcare which is especially beneficial to patients with complex or multiple health problems and well as patients who have unique healthcare needs such as persons with disabilities. persons with disabilities have healthcare needs just like people without disabilities however; in South Africa, they experience many barriers in accessing primary healthcare services even when access is realised, poorly integrated health systems and services may result in poor “continuity of care” and unmet healthcare needs.

This study aims to investigate the factors that facilitate “*continuity of care*” for persons with disabilities so that information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively.

What is the purpose of the research?

The purpose of this research is to explore primary healthcare “continuity of *care*” for persons with disabilities. “*Continuity of care*” is how a patient experiences care over time and across multiple healthcare providers and also refers to the trust relationship that develops between the patient and healthcare provider over time, which leads to better levels of satisfaction and adherence to treatment. Very few studies have investigated this very important concept and a deeper understanding of “continuity of care” and the factors that influence it is therefore important.

In addition, given the rapidly transforming primary healthcare context of SA towards the of universal health coverage, the adoption of progressive healthcare policies and the introduction of new healthcare standards through the establishment of the Office of Health Standards Compliance, a study like this will provide much needed information about whether these new efforts have an impact on “continuity of care” for one of the most vulnerable and marginalised groups of people in society. If we are to realising the goal of a truly inclusive, person-centred health system, we will need investigate the unique needs of the most marginalised in our society and put systems in place to ensure that we meet them.

Why are you being invited? What is expected of you?

As an individual with experience of primary healthcare policies and implementation plans, we hereby request your participation in this study as a key informant. You have been chosen to participate in this study because of your knowledge, and experience of government plans to transform the South African public health system towards a more inclusive and person-centred health system.

We are inviting you to take part in in an interview which will last approximate 90min. This may take the form of a face to face or telephonic interview according to your preference. The questions we will ask you are related to your knowledge regarding primary healthcare policies and “continuity of *care*” specifically in relation to persons with disabilities. If you decide to participate, you will be interviewed by me and I will also continue to engage with you on an ongoing basis until the release of the findings. You may also be asked to participate in a final validation exercise before the results or the study are finalised. The interview will be recorded and will be transcribed for analysis and interpretation. All information including transcripts and recordings will be kept confidential, accessible only to the researcher. All personal identifiers will be removed from the recordings, transcripts and other materials before analysis in order to ensure anonymity. Access to research material will be limited to research team and be kept under the management of the Principle Investigator who will ensure safety of the data.

My research proposal has been approved by the Faculty of Health Sciences, Human Research Ethics Committee - study approval number is 055/2020.

Risks and benefits...

Participation in this study will not benefit you directly nor cause you discomfort or harm in any way. Through your involvement in the study, it may assist the policy makers to better understand the needs of persons with disabilities and help you design primary healthcare services that promote continuity of care and improved health for those at highest risk for poor health outcomes. Your insights on key primary healthcare policies that relate to continuity of care will be requested and we will be particularly interested in your opinions regarding the factors that impact the successful implementation of these policies.

Privacy and confidentiality...

The information that you provide will be strictly used for the aim of this study. Your details and study information will be kept confidential and will not appear in the report or publications of this study. All identifying information will be removed from any document generated from this interview and therefore your confidentiality will be maintained. Codes and unique identifiers will be used to ensure confidentiality. Audio recordings will be maintained on the researcher's computer which is password protected. The audio files will be used to verify the accuracy of the data collected during the interview. All data will be destroyed after five years.

While the researcher is committed to maintaining confidentiality and privacy, it does recognize that information breaching is a risk. Complete privacy and confidentiality cannot therefore be guaranteed. Through reading the findings of the study, participants may be identifiable through contextual information such as the description of a programme or site of the practice but all attempts will be made to ensure that this risk is minimised. You also do not have to answer any question or take part in the interview if you feel the question(s) make you uncomfortable.

What are your rights as a participant?

Your participation is entirely voluntary. Your participation will have no bearing on your job or on work-related evaluations or reports. You are free to stop at any time of the interview or decline responding to questions you are not comfortable to answer. You may change your mind later and stop participating even if you agreed to earlier without any consequences. You may withdraw from this study at any time, without penalty and without having to give a reason for doing so. If you would like to withdraw from the study, you can contact me directly, documents used will be discarded from the analysis. If you would like to receive a copy of the results of the study, your contact details will be kept to inform you of the results.

We thank you for your time and consideration.

Yours faithfully,

Thesandree Padayachee, (thesandree.padayachee@hst.org.za Contact Number:
0725668740)

Should you have any questions, please do not hesitate to contact me at the above details or my supervisor Professor Harsha Kathard: harsha.kathard@uct.ac.za (w) 021 406 6401

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Please sign the consent form indicating your wish to participate in the study.

Consent form

I, _____ (*full name in print*) have been invited to participate in research exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and these have been answered to my satisfaction. I give consent voluntarily to be interviewed as a participant in this study and am fully aware of my rights as a research participant. I do not have any further questions. I am aware that I may withdraw from the study at any time if I so wish, without having to provide an explanation. I understand that I can contact the researcher to inform her of my withdrawal from the study. Withdrawal from the study will have no negative implications for me. I voluntarily consent to participate in this study.

Participant’s Signature: _____ Date: _____

Researcher’s Signature: _____ Date: _____

Would you like to be informed of the results of the study? Circle. YES/NO

If _____ yes, _____ provide _____ email _____ address: _____

Should you have any questions please do not hesitate to contact me or my supervisor:

Thesandree Padayachee: (thesandree.padayachee@hst.org) Contact Number: 0725668740 / 031 2669090

Professor Harsha Kathard: harsha.kathard@uct.ac.za (w): (021) 406 6401

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

Appendix D: Information Leaflet and Informed Consent: KII with Health Facility Staff



UNIVERSITY OF CAPE TOWN
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HEALTH SCIENCES



Divisions of Communication Sciences & Disorders • Disability Studies •
Nursing & Midwifery • Occupational Therapy • Physiotherapy

F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 405 6401
Website: www.dhrs.uct.ac.za

Date: (day/month/year)

Dear Sir/Madam,

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I want to kindly request your participation in the aforementioned study.

Why is the research being done?

The World Health Organisation (WHO) describes primary healthcare as very important level of the healthcare system which “brings promotion and prevention, cure and care together in a safe, effective and socially productive way. “*Continuity of care*” is a powerful concept in delivering quality primary healthcare which is especially beneficial to patients with complex or multiple health problems and well as patients who have unique healthcare needs such as persons with disabilities. persons with disabilities have healthcare needs just like people without disabilities; however, in South Africa, they experience many barriers in accessing primary healthcare services even when access is realised, poorly integrated health systems and services may result in poor “continuity of care” and unmet healthcare needs.

This study aims to investigate the factors that facilitate “*continuity of care*” for persons with disabilities so that information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively.

What is the purpose of the research?

The purpose of this research is to explore primary healthcare “*continuity of care*” for persons with disabilities. “*Continuity of care*” is how a patient experiences care over time and across multiple healthcare providers and also refers to the trust relationship that develops between the patient and healthcare provider over time, which leads to better levels of satisfaction and adherence to treatment. Very few studies have investigated this very important concept and a deeper understanding of “*continuity of care*” and the factors that influence it is therefore important.

In addition, given the rapidly transforming primary healthcare context of SA towards the of universal health coverage, the adoption of progressive healthcare policies and the introduction of new healthcare standards through the establishment of the Office of Health Standards Compliance, a study like this will provide much needed information about whether these new efforts have an impact on “*continuity of care*” for one of the most vulnerable and marginalised groups of people in society. If we are to realising the goal of a truly inclusive, person-centred health system, we will need investigate the unique needs of the most marginalised in our society and put systems in place to ensure that we meet them.

Why are you being invited? What is expected of you?

As an individual with experience of primary healthcare service delivery, we hereby request your participation in this study as a key informant. You have been chosen to participate in this study because of your knowledge, and experience of primary healthcare services in this ward and in the South African public health system, towards a more inclusive and person-centred health system.

We are inviting you to take part in in an interview which will last approximate 90min. This may take the form of a face to face or telephonic interview according to your preference. The questions we will ask you are related to your knowledge regarding

primary healthcare policies and “continuity of *care*” specifically in relation to persons with disabilities. If you decide to participate, you will be interviewed by me, and I will also continue to engage with you on an ongoing basis until the release of the findings. You may also be asked to participate in a final validation exercise before the results or the study are finalised. The interview will be recorded and will be transcribed for analysis and interpretation. All information including transcripts and recordings will be kept confidential, accessible only to the researcher. All personal identifiers will be removed from the recordings, transcripts and other materials before analysis in order to ensure anonymity. Access to research material will be limited to research team and be kept under the management of the Principle Investigator who will ensure safety of the data.

My research proposal has been approved by the Faculty of Health Sciences, Human Research Ethics Committee - study approval number is 055/2020.

Risks and benefits...

Participation in this study will not benefit you directly nor cause you discomfort or harm in any way. Through your involvement in the study, it may assist the policy makers to better understand the needs of persons with disabilities and help you design primary healthcare services that promote continuity of care and improved health for those at highest risk for poor health outcomes. Your insights on key primary healthcare policies that relate to continuity of care will be requested and we will be particularly interested in your opinions regarding the factors that impact the successful implementation of these policies.

Privacy and confidentiality...

The information that you provide will be strictly used for the aim of this study. Your details and study information will be kept confidential and will not appear in the report or publications of this study. All identifying information will be removed from any document generated from this interview and therefore your confidentiality will be maintained. Codes and unique identifiers will be used to ensure confidentiality. Audio recordings will be maintained on the researcher’s computer which is password protected. The audio files will be used to verify the accuracy of the data collected during the interview. All data will be destroyed after five years.

While the researcher is committed to maintaining confidentiality and privacy, it does recognize that information breaching is a risk. Complete privacy and confidentiality

cannot therefore be guaranteed. Through reading the findings of the study, participants may be identifiable through contextual information such as the description of a programme or site of the practice, but all attempts will be made to ensure that this risk is minimised. You also do not have to answer any question or take part in the interview if you feel the question(s) make you uncomfortable.

What are your rights as a participant?

Your participation is entirely voluntary. Your participation will have no bearing on your job or on work-related evaluations or reports. You are free to stop at any time of the interview or decline responding to questions you are not comfortable to answer. You may change your mind later and stop participating even if you agreed to earlier without any consequences. You may withdraw from this study at any time, without penalty and without having to give a reason for doing so. If you would like to withdraw from the study, you can contact me directly, documents used will be discarded from the analysis. If you would like to receive a copy of the results of the study, your contact details will be kept to inform you of the results.

We thank you for your time and consideration.

Yours faithfully,

Thesandree Padayachee, (thesandree.padayachee@hst.org.za) Contact
Number: 0725668740)

Should you have any questions, please do not hesitate to contact me at the above details or my supervisor Professor Harsha Kathard: harsha.kathard@uct.ac.za (w) 021 406 6401

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Please sign the consent form indicating your wish to participate in the study

Consent form

I, _____ (*full name in print*) have been invited to participate in research exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and these have been answered to my satisfaction. I give consent voluntarily to be interviewed as a participant in this study and am fully aware of my rights as a research participant. I do not have any further questions. I am aware that I may withdraw from the study at any time if I so wish, without having to provide an explanation. I understand that I can contact the researcher to inform her of my withdrawal from the study. Withdrawal from the study will have no negative implications for me. I voluntarily consent to participate in this study.

Participant’s Signature: _____ Date: _____

Researcher’s Signature: _____ Date: _____

Would you like to be informed of the results of the study? Circle. YES/NO

If _____ yes, _____ provide _____ email _____ address: _____

Should you have any questions please do not hesitate to contact me or my supervisor:

Thesandree Padayachee: (thesandree.padayachee@hst.org) Contact Number: 0725668740 / 031 2669090

Professor Harsha Kathard: harsha.kathard@uct.ac.za (w): (021) 406 6401

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

Appendix E: Information Leaflet and Informed Consent: KII with Person with a Disability



UNIVERSITY OF CAPE TOWN
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HEALTH SCIENCES



Divisions of Communication Sciences & Disorders • Disability Studies •
Nursing & Midwifery • Occupational Therapy • Physiotherapy
F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

Date: (day/month/year)

Dear Sir/Madam,

RE: Request for your participation in a study exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I would like to kindly request your participation in this study which aims understand how you are cared for as a person accessing public health services within your community.

Why is the research being done?

Primary healthcare as very important level in the health system as it provides people with a range of services to ensure that they are prevented from getting ill and receive proper health services to cure them from illnesses and diseases they may be suffering from. Sometimes people receiving care at this level have many healthcare problems that require management from more than one healthcare providers. When this happens the quality of healthcare depends on how well the healthcare providers coordinate care so that healthcare is continuous and allows for important information to be passed on from one

healthcare provider to another. This is called “*Continuity of care*” and it is considered to be a very effective way to improve quality of care particularly for persons with disabilities. persons with disabilities have healthcare needs just like people without disabilities however; in South Africa, they experience many barriers in accessing primary healthcare services even when access is good, poor “continuity of care” results in poor experience of care.

This study aims to investigate the factors that influence “*continuity of care*” for persons with disabilities so that we can try to improve how persons with disabilities are cared for within the health system.

What is the purpose of the research?

South African healthcare is changing very fast to try to make services more accessible and of better quality. We need to understand if the new policies are making a difference in terms of how persons with disabilities are managed so that we can provide the policy makers with feedback in terms of what can be done to meet the expectations of persons with disabilities.

Why are you being invited? What is expected of you?

As an adult with a disability, you have first-hand information on the quality of healthcare services provided by the government. You are best placed to provide the researcher with first-hand information about your experiences and expectations of primary healthcare. We want you to tell us about how your healthcare providers respond to your unique needs and how you feel about the care you receive between the many service providers you may have to see. You have been chosen to participate in this study because of we wish to understand how persons with disabilities are cared for within primary health facilities, specifically in terms of how your care is coordinated to ensure good “*continuity of care*”.

We are inviting you to take part in in an interview so that we can discuss what happens when you access care at the clinic. We want to know about who the main person is who cares for your health, how you feel about how communication about your health condition is managed between different healthcare professionals and what you have to do to make sure that your healthcare needs are understood by the various healthcare providers you may see. The interview will last approximate 90min. We would like to

interview you in person and will be willing to meet with you at a convenient place close to your home or at your home. We will have to be guided by local policy regarding COVID 19 restrictions so we may have to conduct this interview via the phone.

If you decide to participate, you will be interviewed by me and I will also continue to engage with you on an ongoing basis until the study is completed. You may also be asked to participate in a final validation exercise before the results or the study are finalised. The interview will be recorded and will be transcribed for analysis and interpretation. All information including transcripts and recordings will be kept confidential, accessible only to the researcher. All personal identifiers will be removed from the recordings, transcripts and other materials before analysis in order to ensure anonymity. Access to research material will be limited to research team and be kept under the management of the Principle Investigator who will ensure safety of the data.

My research proposal has been approved by the Faculty of Health Sciences, Human Research Ethics Committee - study approval number is 055/2020.

Risks and benefits...

Participation in this study will not benefit you directly nor cause you discomfort or harm in any way. Through your involvement in the study, it may assist the policy makers to better understand the needs of persons with disabilities and help design primary healthcare services that promote continuity of care and improved health for those at highest risk for poor health outcomes. persons with disabilities. I am interested in your experiences and expectations of primary healthcare specifically in terms of how you are managed if you have to be seen by more than one healthcare provider.

Privacy and confidentiality...

The information that you provide will be strictly used for the aim of this study. Your details and study information will be kept confidential and will not appear in the report or publications of this study. All identifying information will be removed from any document generated from this interview and therefore your confidentiality will be maintained. Codes and unique identifiers will be used to ensure confidentiality. Audio recordings will be maintained on the researcher's computer which is password protected.

The audio files will be used to verify the accuracy of the data collected during the interview. All data will be destroyed after five years.

While the researcher is committed to maintaining confidentiality and privacy, it does recognize that information breaching is a risk. Complete privacy and confidentiality cannot therefore be guaranteed. Through reading the findings of the study, participants may be identifiable but all attempts will be made to ensure that this risk is minimised. You also do not have to answer any question or take part in the interview if you feel the question(s) make you uncomfortable.

What are your rights as a participant?

Your participation is entirely voluntary. Your participation will have no bearing on your job or on work-related evaluations or reports. You are free to stop at any time of the interview or decline responding to questions you are not comfortable to answer. You may change your mind later and stop participating even if you agreed to earlier without any consequences. You may withdraw from this study at any time, without penalty and without having to give a reason for doing so. If you would like to withdraw from the study, you can contact me directly, documents used will be discarded from the analysis. If you would like to receive a copy of the results of the study, your contact details will be kept to inform you of the results.

If you have specific requirements to participate in the study e.g. you need an interpreter or need assistance from a caregiver, you are more than welcome to let me know and I will try my best to ensure that your specific needs are accommodated.

We thank you for your time and consideration.

Yours faithfully,

Thesandree Padayachee, (thesandree.padayachee@hst.org.za Contact Number: 0725668740)

Should you have any questions, please do not hesitate to contact me at the above details or my supervisor Professor Harsha Kathard: harsha.kathard@uct.ac.za (w) 021 406 6401. If you have any concerns about the ethics of the study, please contact Professor Marc

Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Should you feel sad or depressed please do contact the research team. We would also like to provide you with the contact details for Durban and Coastal Mental Health who will be able to provide additional psychosocial support. (3 Hatton Avenue, Sherwood, Durban, 4091, dcmhmail@dcmh.org.za, 031 207 2717)

Please sign the consent form indicating your wish to participate in the study.

Consent form

I, _____ (*full name in print*) have been invited to participate in research exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and these have been answered to my satisfaction. I give consent voluntarily to be interviewed as a participant in this study and am fully aware of my rights as a research participant. I do not have any further questions. I am aware that I may withdraw from the study at any time if I so wish, without having to provide an explanation. I understand that I can contact the researcher to inform her of my withdrawal from the study. Withdrawal from the study will have no negative implications for me. I voluntarily consent to participate in this study.

Participant’s Signature: _____ Date: _____

Researcher’s Signature: _____ Date: _____

Would you like to be informed of the results of the study? Circle. YES/NO

If _____ yes, _____ provide _____ email _____ address: _____

Should you have any questions please do not hesitate to contact me or my supervisor:

Thesandree Padayachee: (thesandree.padayachee@hst.org Contact Number: 0725668740 / 031 2669090. Supervisor: Professor Harsha Kathard: harsha.kathard@uct.ac.za (w): (021) 406 6401

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

Appendix F: Information Leaflet and Informed Consent: KII with Families of Person with Disability



UNIVERSITY OF CAPE TOWN
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HEALTH SCIENCES



Divisions of Communication Sciences & Disorders • Disability Studies •
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F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

Date: (day/month/year)

Dear Sir/Madam,

RE: Request for your participation in a study exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I would like to kindly request your participation in the aforementioned study.

Why is the research being done?

Primary healthcare as very important level in the health system as it provides people with a range of services to ensure that people are prevented from getting ill and receive proper health services to cure them from illnesses and diseases they may be suffering from. Sometimes people receiving care at this level have many healthcare problems that require management from more than one healthcare provider. persons with disabilities for instance may have more healthcare needs that people without disabilities. When this happens the quality of healthcare depends on how well the healthcare providers coordinate care so that it is continuous and allows for important information to be passed

on from one healthcare provider to another. This is called “Continuity of care” and it is considered to be a very effective way to improve quality of care particularly for persons with disabilities. persons with disabilities have healthcare needs just like people without disabilities however; in South Africa, they experience many barriers in accessing primary healthcare services even when access is good, poorly “continuity of care” results in poor experience of care.

This study aims to investigate the factors that influence “continuity of care” for persons with disabilities so that we can try to improve how persons with disabilities are cared for within the health system.

What is the purpose of the research?

The South African healthcare system is changing very fast to try to make services more accessible and of better quality. We need to understand if the new policies are making a difference in terms of how persons with disabilities are managed so that we can provide the policy makers with feedback in terms of what can be done to meet the expectations of persons with disabilities.

Why are you being invited? What is expected of you?

As a family member / caregiver to a person with a disability you have first-hand information on the quality of healthcare services provided by the government. You are best placed to provide the researcher with first-hand information about your experiences and your expectations of primary healthcare in your role as family member / caregiver. We want you to tell us about aspects relating to how healthcare providers respond to the unique needs of your family member with a disability and how you feel about the care they receive between the many service providers they may have to see. You have been chosen to participate in this study because we wish to understand your perspective as an immediate source of support to your family member with a disability. specifically in terms of what you do to make sure that advice of healthcare providers is followed and what you do to ensure good “continuity of care”.

We are inviting you to take part in an interview so that we can discuss what happens when your family member accesses care at a public clinic. We want to know about who the main person is who cares for their health, how you feel about how communication about their health condition is managed between different healthcare professionals and what you have to do to make sure that their healthcare needs are understood by the

various healthcare providers you may see. The interview will last approximate 90min. We would like to interview you in person and will be willing to meet with you at a convenient place close to your home or at your home. If you prefer a telephonic interview, this can also be accommodated.

If you decide to participate, you will be interviewed by me and I will also continue to engage with you on an ongoing basis until the study is completed. You may also be asked to participate in a final validation exercise before the results or the study are finalised. The interview will be recorded and will be transcribed for analysis and interpretation. All information including transcripts and recordings will be kept confidential, accessible only to the researcher. All personal identifiers will be removed from the recordings, transcripts and other materials before analysis in order to ensure anonymity. Access to research material will be limited to research team and be kept under the management of the Principle Investigator who will ensure safety of the data.

My research proposal has been approved by the Faculty of Health Sciences, Human Research Ethics Committee - study approval number is 055/2020.

Risks and benefits...

Participation in this study will not benefit you directly nor cause you discomfort or harm in any way. Through your involvement in the study, it may assist the policy makers to better understand the needs of persons with disabilities and help design primary healthcare services that promote continuity of care and improved health for those at highest risk for poor health outcomes. persons with disabilities. I am interested in your experiences and expectations of primary healthcare specifically in terms of how you are managed if you have to be seen by more than one healthcare provider.

Privacy and confidentiality...

The information that you provide will be strictly used for the aim of this study. Your details and study information will be kept confidential and will not appear in the report or publications of this study. All identifying information will be removed from any document generated from this interview and therefore your confidentiality will be maintained. Codes and unique identifiers will be used to ensure confidentiality. Audio recordings will be maintained on the researcher's computer which is password protected. The audio files will be used to verify the accuracy of the data collected during the interview. All data will be destroyed after five years.

While the researcher is committed to maintaining confidentiality and privacy, it does recognize that information breaching is a risk. Complete privacy and confidentiality cannot therefore be guaranteed. Through reading the findings of the study, participants may be identifiable but all attempts will be made to ensure that this risk is minimised. You also do not have to answer any question or take part in the interview if you feel the question(s) make you uncomfortable.

What are your rights as a participant?

Your participation is entirely voluntary. Your participation will have no bearing on your job or on work-related evaluations or reports. You are free to stop at any time of the interview or decline responding to questions you are not comfortable to answer. You may change your mind later and stop participating even if you agreed to earlier without any consequences. You may withdraw from this study at any time, without penalty and without having to give a reason for doing so. If you would like to withdraw from the study, you can contact me directly, documents used will be discarded from the analysis. If you would like to receive a copy of the results of the study, your contact details will be kept to inform you of the results.

If you have specific requirements to participate in the study e.g. you need an interpreter or need assistance from a caregiver, you are more than welcome to let me know and I will try my best to ensure that your specific needs are accommodated.

We thank you for your time and consideration.

We thank you for your time and consideration.

Yours faithfully,

Thesandree Padayachee,

(thesandree.padayachee@hst.org.za)

Contact Number: 0725668740)

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Should you feel sad or depressed please do contact the research team. We would also like to provide you with the contact details for Durban and Coastal Mental Health who will be able to provide additional psychosocial support. (3 Hatton Avenue, Sherwood, Durban, 4091, dcmhmail@dcmh.org.za, 031 207 2717)

Please sign the consent form indicating your wish to participate in the study.

Consent form

I, _____ (*full name in print*) have been invited to participate in research exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and these have been answered to my satisfaction. I give consent voluntarily to be interviewed as a participant in this study and am fully aware of my rights as a research participant. I do not have any further questions. I am aware that I may withdraw from the study at any time if I so wish, without having to provide an explanation. I understand that I can contact the researcher to inform her of my withdrawal from the study. Withdrawal from the study will have no negative implications for me. I voluntarily consent to participate in this study.

Participant’s Signature: _____ Date: _____

Researcher’s Signature: _____ Date: _____

Would you like to be informed of the results of the study? Circle. YES/NO

If _____ yes, _____ provide _____ email _____ address: _____

Should you have any questions please do not hesitate to contact me or my supervisor:

Thesandree Padayachee: (thesandree.padayachee@hst.org Contact Number: 0725668740 / 031 2669090

Professor Harsha Kathard: harsha.kathard@uct.ac.za (w): (021) 406 6401

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Appendix G: Information Leaflet and Informed Consent: FGD with Community-Based Organisations



UNIVERSITY OF CAPE TOWN
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HEALTH SCIENCES



Divisions of Communication Sciences & Disorders • Disability Studies •
Nursing & Midwifery • Occupational Therapy • Physiotherapy
F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

Date: (day/month/year)

Dear Sir/Madam,

RE: Request for your participation in a study exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I wish to kindly request your participation in the aforementioned study.

Why is the research being done?

Primary healthcare as very important level in the health system as it provides people with a range of services to ensure that people are prevented from getting ill and receive proper health services to cure them from illnesses and diseases they may be suffering from. Sometimes people receiving care at this level have many healthcare problems that require management from more than one healthcare provider. persons with disabilities for instance may have more healthcare needs that people without disabilities. When this happens the quality of healthcare depends on how the health system arranges services so that care is continuous in terms of aspects like patient information about their treatment

plan as well as general management of the patient in terms of specific healthcare needs associated with his/her disability. This is called “*continuity of care*” and it is considered a powerful aspect of quality primary healthcare which is especially beneficial to patients with complex or multiple health problems and well as patients who have unique needs such as persons with disabilities. persons with disabilities have healthcare needs just like people without disabilities however; in South Africa, they experience many barriers in accessing primary healthcare services even when access is good, poorly “*continuity of care*” results in poor experience of care and unmet healthcare needs.

This study aims to explore the factors that influence “*continuity of care*” for persons with disabilities so that information generated can be used in health systems strengthening effort strengthen health care services, particularly for persons with disabilities.

What is the purpose of the research?

Very few studies have investigated this very important concept and a deeper understanding of “*continuity of care*” and the factors that influence it is therefore important. In addition, the South African health system is changing very fast to try to make services more accessible and of better quality. We need to understand if the new policies are making a difference in terms of how persons with disabilities are managed so that we can provide the policy makers with feedback in terms of what can be done to meet the expectations of persons with disabilities.

Why are you being invited? What is expected of you?

As a support structure and community resource for persons with disabilities, you are ideally placed to provide the researcher with information about the factors that influence continuity of care for persons with disabilities. You will have comprehensive knowledge of what does and does not work for persons with disabilities who access primary healthcare services and you will also be able to provide us with information about the impact that poor “*continuity of care*” has on the person with a disability persons with disabilities and their families. We want to explore what you think needs to be done to improve “*continuity of care*” for persons with disabilities so that we can discuss these expectations with policy makers and health service providers.

We are inviting you to take part in a focus group discussion so that we can discuss what the issue of “continuity of care” with you. We want to about what links you have with the primary healthcare facility and if you have a role to play in facilitating “continuity of care” for persons with disabilities. We also would like to know what services you offer to persons with disabilities and what information about your care and support may be valuable to the healthcare professionals at the clinic. The discussion will last approximate 90min. We would like to interview you in person and will arrange for the discussion to take place at a central location near your office.

If you decide to participate, I will be the main facilitator and I may be assisted by a translator if one is required. I will also continue to engage with you on an ongoing basis until the study is completed. You may also be asked to participate in a final validation exercise before the results or the study are finalised. The interview will be recorded and will be transcribed for analysis and interpretation. All information including transcripts and recordings will be kept confidential, accessible only to the researcher. All personal identifiers will be removed from the recordings, transcripts and other materials before analysis in order to ensure anonymity. Access to research material will be limited to research team and be kept under the management of the Principle Investigator who will ensure safety of the data.

My research proposal has been approved by the Faculty of Health Sciences, Human Research Ethics Committee - study approval number is 055/2020.

Risks and benefits...

Participation in this study will not benefit you directly nor cause you discomfort or harm in any way. You will be reimbursed for your time and transport costs. Through your involvement in the study, policymakers will be able to better understand the needs of persons with disabilities and may have the information necessary to design primary healthcare services that promote continuity of care and improved health for those at highest risk for poor health outcomes. I am interested in your experiences and expectations of primary healthcare specifically in terms of how you are managed if you have to be seen by more than one healthcare provider.

Privacy and confidentiality...

The information that you provide will be strictly used for the aim of this study. You will be participating in a group discussion with other community-based organisations that provide services to persons with disabilities. Your anonymity and confidentiality cannot therefore be guaranteed. The researcher will ensure though that your details and study information will not appear in the report or publications of this study. All identifying information will be removed from any document generated from this interview group discussion and therefore your anonymity will be maintained on our study records. Codes and unique identifiers will be used to ensure confidentiality. Audio recordings will be maintained on the researcher's computer which is password protected. The audio files will be used to verify the accuracy of the data collected during the interview. All data will be destroyed after five years.

While the researcher is committed to maintaining confidentiality and privacy, it does recognize that information breaching is a risk especially in a group discussion. Complete privacy and confidentiality cannot therefore be guaranteed. Through reading the findings of the study, participants may be identifiable through contextual information such as the description of a programme or site of the practice but all attempts will be made to ensure that this risk is minimised. You also do not have to answer any question or take part in the interview if you feel the question(s) make you uncomfortable.

What are your rights as a participant?

Your participation is entirely voluntary. Your participation will have no bearing on your job or on work-related evaluations or reports. You are free to stop at any time of the interview or decline responding to questions you are not comfortable to answer. You may change your mind later and stop participating even if you agreed to earlier without any consequences. You may withdraw from this study at any time, without penalty and without having to give a reason for doing so. If you would like to withdraw from the study, you can contact me directly, documents used will be discarded from the analysis. If you would like to receive a copy of the results of the study, your contact details will be kept to inform you of the results.

If you have specific requirements to participate in the study e.g. you need an interpreter you are more than welcome to let me know and I will try my best to ensure that your specific needs are accommodated.

We thank you for your time and consideration.

Yours faithfully,

Thesandree Padayachee,
Number: 0725668740)

(thesandree.padayachee@hst.org.za)

Contact

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Should you feel sad or depressed please do contact the research team. We would also like to provide you with the contact details for Durban and Coastal Mental Health who will be able to provide additional psychosocial support. (3 Hatton Avenue, Sherwood, Durban, 4091, dcmhmail@dcmh.org.za, 031 207 2717)

Please sign the consent form indicating your wish to participate in the study.

Consent form

I, _____ (*full name in print*) have been invited to participate in research exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and these have been answered to my satisfaction. I give consent voluntarily to be interviewed as a participant in this study and am fully aware of my rights as a research participant. I do not have any further questions. I am aware that I may withdraw from the study at any time if I so wish, without having to provide an explanation. I understand that I can contact the researcher to inform her of my withdrawal from the study. Withdrawal from the study will have no negative implications for me. I voluntarily consent to participate in this study.

Participant’s Signature: _____ Date: _____

Researcher’s Signature: _____ Date: _____

Would you like to be informed of the results of the study? Circle. YES/NO

If _____ yes, _____ provide _____ email _____ address: _____

Should you have any questions please do not hesitate to contact me or my supervisor:

Thesandree Padayachee: (thesandree.padayachee@hst.org) Contact Number: 0725668740 / 031 2669090

Professor Harsha Kathard: harsha.kathard@uct.ac.za (w): (021) 406 6401

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

Appendix H: Information Leaflet and Informed Consent: KII with National and Provincial Key Informants



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HEALTH SCIENCES



Divisions of Communication Sciences & Disorders • Disability Studies •
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F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

Date: (day/month/year)

Dear Sir/Madam,

RE: Request for your participation as a key informant in a study exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I want to kindly request your participation in the aforementioned study.

Why is the research being done?

The World Health Organisation (WHO) describes primary healthcare as very important level of the healthcare system which “brings promotion and prevention, cure and care together in a safe, effective and socially productive way. “*Continuity of care*” is a powerful concept in delivering quality primary healthcare which is especially beneficial to patients with complex or multiple health problems and well as patients who have unique healthcare needs such as persons with disabilities. persons with disabilities have

healthcare needs just like people without disabilities however; in South Africa, they experience many barriers in accessing primary healthcare services even when access is realised, poorly integrated health systems and services may result in poor “continuity of care” and unmet healthcare needs.

This study aims to investigate the factors that facilitate “*continuity of care*” for persons with disabilities so that information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively.

What is the purpose of the research?

The purpose of this research is to explore primary healthcare “continuity of *care*” for persons with disabilities. “*Continuity of care*” is how a patient experiences care over time and across multiple healthcare providers and also refers to the trust relationship that develops between the patient and healthcare provider over time, which leads to better levels of satisfaction and adherence to treatment. Very few studies have investigated this very important concept and a deeper understanding of “continuity of care” and the factors that influence it is therefore important.

In addition, given the rapidly transforming primary healthcare context of SA towards the of universal health coverage, the adoption of progressive healthcare policies and the introduction of new healthcare standards through the establishment of the Office of Health Standards Compliance, a study like this will provide much needed information about whether these new efforts have an impact on “continuity of care” for one of the most vulnerable and marginalised groups of people in society. If we are to realising the goal of a truly inclusive, person-centred health system, we will need investigate the unique needs of the most marginalised in our society and put systems in place to ensure that we meet them.

Why are you being invited? What is expected of you?

As an individual with experience of primary healthcare policies and implementation plans, we hereby request your participation in this study as a key informant. You have been chosen to participate in this study because of your knowledge, and experience of government plans to transform the South African public health system towards a more inclusive and person-centred health system.

We are inviting you to take part in an interview which will last approximately 90min. This may take the form of a face to face or telephonic interview according to your preference. The questions we will ask you are related to your knowledge regarding primary healthcare policies and “continuity of care” specifically in relation to persons with disabilities. If you decide to participate, you will be interviewed by me and I will also continue to engage with you on an ongoing basis until the release of the findings. You may also be asked to participate in a final validation exercise before the results or the study are finalised. The interview will be recorded and will be transcribed for analysis and interpretation. All information including transcripts and recordings will be kept confidential, accessible only to the researcher. All personal identifiers will be removed from the recordings, transcripts and other materials before analysis in order to ensure anonymity. Access to research material will be limited to research team and be kept under the management of the Principle Investigator who will ensure safety of the data.

My research proposal has been approved by the Faculty of Health Sciences, Human Research Ethics Committee - study approval number is 055/2020.

Risks and benefits...

Participation in this study will not benefit you directly nor cause you discomfort or harm in any way. Through your involvement in the study, it may assist the policy makers to better understand the needs of persons with disabilities and help you design primary healthcare services that promote continuity of care and improved health for those at highest risk for poor health outcomes. Your insights on key primary healthcare policies that relate to continuity of care will be requested and we will be particularly interested in your opinions regarding the factors that impact the successful implementation of these policies.

Privacy and confidentiality...

The information that you provide will be strictly used for the aim of this study. Your details and study information will be kept confidential and will not appear in the report or publications of this study. All identifying information will be removed from any document generated from this interview and therefore your confidentiality will be maintained. Codes and unique identifiers will be used to ensure confidentiality. Audio recordings will be maintained on the researcher’s computer which is password protected.

The audio files will be used to verify the accuracy of the data collected during the interview. All data will be destroyed after five years.

While the researcher is committed to maintaining confidentiality and privacy, it does recognize that information breaching is a risk. Complete privacy and confidentiality cannot therefore be guaranteed. Through reading the findings of the study, participants may be identifiable through contextual information such as the description of a programme or site of the practice but all attempts will be made to ensure that this risk is minimised. You also do not have to answer any question or take part in the interview if you feel the question(s) make you uncomfortable.

What are your rights as a participant?

Your participation is entirely voluntary. Your participation will have no bearing on your job or on work-related evaluations or reports. You are free to stop at any time of the interview or decline responding to questions you are not comfortable to answer. You may change your mind later and stop participating even if you agreed to earlier without any consequences. You may withdraw from this study at any time, without penalty and without having to give a reason for doing so. If you would like to withdraw from the study, you can contact me directly, documents used will be discarded from the analysis. If you would like to receive a copy of the results of the study, your contact details will be kept to inform you of the results.

We thank you for your time and consideration.

Yours faithfully,

Thesandree Padayachee,
Number: 0725668740)

(thesandree.padayachee@hst.org.za)

Contact

Should you have any questions, please do not hesitate to contact me at the above details or my supervisor Professor Harsha Kathard: harsha.kathard@uct.ac.za (w) 021 406 6401

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Please sign the consent form indicating your wish to participate in the study.

Consent form

I, _____ (*full name in print*) have been invited to participate in research exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and these have been answered to my satisfaction. I give consent voluntarily to be interviewed as a participant in this study and am fully aware of my rights as a research participant. I do not have any further questions. I am aware that I may withdraw from the study at any time if I so wish, without having to provide an explanation. I understand that I can contact the researcher to inform her of my withdrawal from the study. Withdrawal from the study will have no negative implications for me. I voluntarily consent to participate in this study.

Participant’s Signature: _____ Date: _____

Researcher’s Signature: _____ Date: _____

Would you like to be informed of the results of the study? Circle. YES/NO

If yes, provide email address:

Should you have any questions please do not hesitate to contact me or my supervisor:

Thesandree Padayachee: (thesandree.padayachee@hst.org) Contact Number: 0725668740 / 031 2669090

Professor Harsha Kathard: harsha.kathard@uct.ac.za (w): (021) 406 6401

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

Appendix I: Information Leaflet and Informed Consent: KII Primary Healthcare Facility Manager



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HEALTH SCIENCES



Divisions of Communication Sciences & Disorders • Disability Studies •
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F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

Date: (day/month/year)

Dear Sir/Madam,

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I want to kindly request your participation in the aforementioned study.

Why is the research being done?

The World Health Organisation (WHO) describes primary healthcare as very important level of the healthcare system which “brings promotion and prevention, cure and care together in a safe, effective and socially productive way. “*Continuity of care*” is a powerful concept in delivering quality primary healthcare which is especially beneficial to patients with complex or multiple health problems and well as patients who have unique healthcare needs such as persons with disabilities. persons with disabilities have healthcare needs just like people without disabilities however; in South Africa, they experience many barriers in accessing primary healthcare services even when access is realised, poorly integrated health systems and services may result in poor “continuity of care” and unmet healthcare needs.

This study aims to investigate the factors that facilitate “*continuity of care*” for persons with disabilities so that information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively.

What is the purpose of the research?

The purpose of this research is to explore primary healthcare “*continuity of care*” for persons with disabilities. “*Continuity of care*” is how a patient experiences care over time and across multiple healthcare providers and also refers to the trust relationship that develops between the patient and healthcare provider over time, which leads to better levels of satisfaction and adherence to treatment. Very few studies have investigated this very important concept and a deeper understanding of “*continuity of care*” and the factors that influence it is therefore important.

In addition, given the rapidly transforming primary healthcare context of SA towards the of universal health coverage, the adoption of progressive healthcare policies and the introduction of new healthcare standards through the establishment of the Office of Health Standards Compliance, a study like this will provide much needed information about whether these new efforts have an impact on “*continuity of care*” for one of the most vulnerable and marginalised groups of people in society. If we are to realising the goal of a truly inclusive, person-centred health system, we will need investigate the unique needs of the most marginalised in our society and put systems in place to ensure that we meet them.

Why are you being invited? What is expected of you?

As an individual with experience of primary healthcare policies and implementation plans, we hereby request your participation in this study as a key informant. You have been chosen to participate in this study because of your knowledge, and experience of government plans to transform the South African public health system towards a more inclusive and person-centred health system.

We are inviting you to take part in in an interview which will last approximate 90min. This may take the form of a face to face or telephonic interview according to your preference. The questions we will ask you are related to your knowledge regarding

primary healthcare policies and “continuity of *care*” specifically in relation to persons with disabilities. If you decide to participate, you will be interviewed by me and I will also continue to engage with you on an ongoing basis until the release of the findings. You may also be asked to participate in a final validation exercise before the results or the study are finalised. The interview will be recorded and will be transcribed for analysis and interpretation. All information including transcripts and recordings will be kept confidential, accessible only to the researcher. All personal identifiers will be removed from the recordings, transcripts and other materials before analysis in order to ensure anonymity. Access to research material will be limited to research team and be kept under the management of the Principle Investigator who will ensure safety of the data.

My research proposal has been approved by the Faculty of Health Sciences, Human Research Ethics Committee - study approval number is 055/2020.

Risks and benefits...

Participation in this study will not benefit you directly nor cause you discomfort or harm in any way. Through your involvement in the study, it may assist the policy makers to better understand the needs of persons with disabilities and help you design primary healthcare services that promote continuity of care and improved health for those at highest risk for poor health outcomes. Your insights on key primary healthcare policies that relate to continuity of care will be requested and we will be particularly interested in your opinions regarding the factors that impact the successful implementation of these policies.

Privacy and confidentiality...

The information that you provide will be strictly used for the aim of this study. Your details and study information will be kept confidential and will not appear in the report or publications of this study. All identifying information will be removed from any document generated from this interview and therefore your confidentiality will be maintained. Codes and unique identifiers will be used to ensure confidentiality. Audio recordings will be maintained on the researcher’s computer which is password protected. The audio files will be used to verify the accuracy of the data collected during the interview. All data will be destroyed after five years.

While the researcher is committed to maintaining confidentiality and privacy, it does recognize that information breaching is a risk. Complete privacy and confidentiality

cannot therefore be guaranteed. Through reading the findings of the study, participants may be identifiable through contextual information such as the description of a programme or site of the practice but all attempts will be made to ensure that this risk is minimised. You also do not have to answer any question or take part in the interview if you feel the question(s) make you uncomfortable.

What are your rights as a participant?

Your participation is entirely voluntary. Your participation will have no bearing on your job or on work-related evaluations or reports. You are free to stop at any time of the interview or decline responding to questions you are not comfortable to answer. You may change your mind later and stop participating even if you agreed to earlier without any consequences. You may withdraw from this study at any time, without penalty and without having to give a reason for doing so. If you would like to withdraw from the study, you can contact me directly, documents used will be discarded from the analysis. If you would like to receive a copy of the results of the study, your contact details will be kept to inform you of the results.

We thank you for your time and consideration.

Yours faithfully,

Thesandree Padayachee, (thesandree.padayachee@hst.org.za) Contact
Number: 0725668740)

Should you have any questions, please do not hesitate to contact me at the above details or my supervisor Professor Harsha Kathard: harsha.kathard@uct.ac.za (w) 021 406 6401

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Please sign the consent form indicating your wish to participate in the study.

Consent form

I, _____ (*full name in print*) have been invited to participate in research exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and these have been answered to my satisfaction. I give consent voluntarily to be interviewed as a participant in this study and am fully aware of my rights as a research participant. I do not have any further questions. I am aware that I may withdraw from the study at any time if I so wish, without having to provide an explanation. I understand that I can contact the researcher to inform her of my withdrawal from the study. Withdrawal from the study will have no negative implications for me. I voluntarily consent to participate in this study.

Participant’s Signature: _____ Date: _____

Researcher’s Signature: _____ Date: _____

Would you like to be informed of the results of the study? Circle. YES/NO

If _____ yes, _____ provide _____ email _____ address: _____

Should you have any questions please do not hesitate to contact me or my supervisor:

Thesandree Padayachee: (thesandree.padayachee@hst.org) Contact Number: 0725668740 / 031 2669090

Professor Harsha Kathard: harsha.kathard@uct.ac.za (w): (021) 406 6401

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

Appendix J: Information Leaflet and Informed Consent: KII with Health Facility Staff



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HEALTH SCIENCES



Divisions of Communication Sciences & Disorders • Disability Studies •
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F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

Date: (day/month/year)

Dear Sir/Madam,

RE: Request for your participation as a key informant in a study exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I want to kindly request your participation in the aforementioned study.

Why is the research being done?

The World Health Organisation (WHO) describes primary healthcare as very important level of the healthcare system which “brings promotion and prevention, cure and care together in a safe, effective and socially productive way. “*Continuity of care*” is a powerful concept in delivering quality primary healthcare which is especially beneficial to patients with complex or multiple health problems and well as patients who have unique healthcare needs such as persons with disabilities. persons with disabilities have healthcare needs just like people without disabilities however; in South Africa, they experience many barriers in accessing primary healthcare services even when access is realised, poorly integrated health systems and services may result in poor “continuity of care” and unmet healthcare needs.

This study aims to investigate the factors that facilitate “*continuity of care*” for persons with disabilities so that information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively.

What is the purpose of the research?

The purpose of this research is to explore primary healthcare “*continuity of care*” for persons with disabilities. “*Continuity of care*” is how a patient experiences care over time and across multiple healthcare providers and also refers to the trust relationship that develops between the patient and healthcare provider over time, which leads to better levels of satisfaction and adherence to treatment. Very few studies have investigated this very important concept and a deeper understanding of “*continuity of care*” and the factors that influence it is therefore important.

In addition, given the rapidly transforming primary healthcare context of SA towards the of universal health coverage, the adoption of progressive healthcare policies and the introduction of new healthcare standards through the establishment of the Office of Health Standards Compliance, a study like this will provide much needed information about whether these new efforts have an impact on “*continuity of care*” for one of the most vulnerable and marginalised groups of people in society. If we are to realising the goal of a truly inclusive, person-centred health system, we will need investigate the unique needs of the most marginalised in our society and put systems in place to ensure that we meet them.

Why are you being invited? What is expected of you?

As an individual with experience of primary healthcare service delivery, we hereby request your participation in this study as a key informant. You have been chosen to participate in this study because of your knowledge, and experience of primary healthcare services in this ward and in the South African public health system, towards a more inclusive and person-centred health system.

We are inviting you to take part in in an interview which will last approximate 90min. This may take the form of a face to face or telephonic interview according to your preference. The questions we will ask you are related to your knowledge regarding primary healthcare policies and “*continuity of care*” specifically in relation to persons with disabilities. If you decide to participate, you will be interviewed by me and I will also continue to engage with you on an ongoing basis until the release of the findings. You may also be asked to participate in a final validation exercise before the results or the study are finalised. The interview will be recorded

and will be transcribed for analysis and interpretation. All information including transcripts and recordings will be kept confidential, accessible only to the researcher. All personal identifiers will be removed from the recordings, transcripts and other materials before analysis in order to ensure anonymity. Access to research material will be limited to research team and be kept under the management of the Principle Investigator who will ensure safety of the data.

My research proposal has been approved by the Faculty of Health Sciences, Human Research Ethics Committee - study approval number is 055/2020.

Risks and benefits...

Participation in this study will not benefit you directly nor cause you discomfort or harm in any way. Through your involvement in the study, it may assist the policy makers to better understand the needs of persons with disabilities and help you design primary healthcare services that promote continuity of care and improved health for those at highest risk for poor health outcomes. Your insights on key primary healthcare policies that relate to continuity of care will be requested and we will be particularly interested in your opinions regarding the factors that impact the successful implementation of these policies.

Privacy and confidentiality...

The information that you provide will be strictly used for the aim of this study. Your details and study information will be kept confidential and will not appear in the report or publications of this study. All identifying information will be removed from any document generated from this interview and therefore your confidentiality will be maintained. Codes and unique identifiers will be used to ensure confidentiality. Audio recordings will be maintained on the researcher's computer which is password protected. The audio files will be used to verify the accuracy of the data collected during the interview. All data will be destroyed after five years.

While the researcher is committed to maintaining confidentiality and privacy, it does recognize that information breaching is a risk. Complete privacy and confidentiality cannot therefore be guaranteed. Through reading the findings of the study, participants may be identifiable through contextual information such as the description of a programme or site of the practice but all attempts will be made to ensure that this risk is minimised. You also do not have to answer any question or take part in the interview if you feel the question(s) make you uncomfortable.

What are your rights as a participant?

Your participation is entirely voluntary. Your participation will have no bearing on your job or on work-related evaluations or reports. You are free to stop at any time of the interview or decline responding to questions you are not comfortable to answer. You may change your mind later and

stop participating even if you agreed to earlier without any consequences. You may withdraw from this study at any time, without penalty and without having to give a reason for doing so. If you would like to withdraw from the study, you can contact me directly, documents used will be discarded from the analysis. If you would like to receive a copy of the results of the study, your contact details will be kept to inform you of the results.

We thank you for your time and consideration.

Yours faithfully,

Thesandree Padayachee, (thesandree.padayachee@hst.org.za Contact Number:
0725668740)

Should you have any questions, please do not hesitate to contact me at the above details or my supervisor Professor Harsha Kathard: harsha.kathard@uct.ac.za (w) 021 406 6401

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Please sign the consent form indicating your wish to participate in the study

Consent form

I, _____ (*full name in print*) have been invited to participate in research exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and these have been answered to my satisfaction. I give consent voluntarily to be interviewed as a participant in this study and am fully aware of my rights as a research participant. I do not have any further questions. I am aware that I may withdraw from the study at any time if I so wish, without having to provide an explanation. I understand that I can contact the researcher to inform her of my withdrawal from the study. Withdrawal from the study will have no negative implications for me. I voluntarily consent to participate in this study.

Participant’s Signature: _____ Date: _____

Researcher’s Signature: _____ Date: _____

Would you like to be informed of the results of the study? Circle. YES/NO

If yes, provide email address:

Should you have any questions please do not hesitate to contact me or my supervisor:

Thesandree Padayachee: (thesandree.padayachee@hst.org) Contact Number: 0725668740 / 031 2669090

Professor Harsha Kathard: harsha.kathard@uct.ac.za (w): (021) 406 6401

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

Appendix K: Information Leaflet and Informed Consent: KII with Community Healthcare Workers



UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD
HEALTH SCIENCES



Divisions of Communication Sciences & Disorders • Disability Studies •
Nursing & Midwifery • Occupational Therapy • Physiotherapy
F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

Date: (day/month/year)

Dear Sir/Madam,

RE: Request for your participation in a study exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa

I am a PhD student conducting research in the Division of Disability Studies at the University of Cape Town. I wish to kindly request your participation in the aforementioned study.

Why is the research being done?

Primary healthcare as very important level in the health system as it provides people with a range of services to ensure that people are prevented from getting ill and receive proper health services to cure them from illnesses and diseases they may be suffering from. Sometimes people receiving care at this level have many healthcare problems that require management from more than one healthcare provider. persons with disabilities for instance may have more healthcare needs that people without disabilities. When this happens the quality of healthcare depends on how the health system arranges services so that care is continuous in terms of aspects like patient information about their treatment plan as well as general management of the patient in terms of specific healthcare needs associated with his/her disability. This is called “*continuity of care*” and it is considered

a powerful aspect of quality primary healthcare which is especially beneficial to patients with complex or multiple health problems and well as patients who have unique needs such as persons with disabilities. persons with disabilities have healthcare needs just like people without disabilities however; in South Africa, they experience many barriers in accessing primary healthcare services even when access is good, poorly “continuity of care” results in poor experience of care and unmet healthcare needs.

This study aims to explore the factors that influence “*continuity of care*” for persons with disabilities so that information generated can be used in health systems strengthening effort strengthen health care services, particularly for persons with disabilities.

What is the purpose of the research?

Very few studies have investigated this very important concept and a deeper understanding of “continuity of care” and the factors that influence it is therefore important. In addition, the South African health system is changing very fast to try to make services more accessible and of better quality. We need to understand if the new policies are making a difference in terms of how persons with disabilities are managed so that we can provide the policy makers with feedback in terms of what can be done to meet the expectations of persons with disabilities.

Why are you being invited? What is expected of you?

As a support structure and community resource for persons with disabilities, you are ideally placed to provide the researcher with information about the factors that influence continuity of care for persons with disabilities. You will have comprehensive knowledge of what does and does not work for persons with disabilities who access primary healthcare services and you will also be able to provide us with information about the impact that poor “*continuity of care*” has on persons with disabilities and their families. We want to explore what you think needs to be done to improve “*continuity of care*” for persons with disabilities so that we can discuss these expectations with policy makers and health service providers.

We are inviting you to take part in an interview so that we can discuss what the issue of “continuity of care” with you. We want to know about what links you have with the primary healthcare facility and if you have a role to play in facilitating “continuity of care” for persons with disabilities. We also would like to know what services you offer to persons with disabilities and what information about your care and support may be valuable to

the healthcare professionals at the clinic. The discussion will last approximate 90min. We would like to telephonically at a time that is suitable for you.

If you decide to participate, I will be the main interviewer and I may be assisted by a translator if one is required. I will also continue to engage with you on an ongoing basis until the study is completed. You may also be asked to participate in a final validation exercise before the results or the study are finalised. The interview will be recorded and will be transcribed for analysis and interpretation. All information including transcripts and recordings will be kept confidential, accessible only to the researcher. All personal identifiers will be removed from the recordings, transcripts and other materials before analysis in order to ensure anonymity. Access to research material will be limited to research team and be kept under the management of the Principle Investigator who will ensure safety of the data.

My research proposal has been approved by the Faculty of Health Sciences, Human Research Ethics Committee - study approval number is 055/2020.

Risks and benefits...

Participation in this study will not benefit you directly nor cause you discomfort or harm in any way. You will be reimbursed for your time and transport costs. Through your involvement in the study, policymakers will be able to better understand the needs of persons with disabilities and may have the information necessary to design primary healthcare services that promote continuity of care and improved health for those at highest risk for poor health outcomes. I am interested in your experiences and expectations of primary healthcare specifically in terms of how you are managed if you have to be seen by more than one healthcare provider.

Privacy and confidentiality...

The information that you provide will be strictly used for the aim of this study. You will be participating in a group discussion with other community-based organisations that provide services to persons with disabilities. Your anonymity and confidentiality cannot therefore be guaranteed. The researcher will ensure though that your details and study information will not appear in the report or publications of this study. All identifying information will be removed from any document generated from this interview group

discussion and therefore your anonymity will be maintained on our study records. Codes and unique identifiers will be used to ensure confidentiality. Audio recordings will be maintained on the researcher's computer which is password protected. The audio files will be used to verify the accuracy of the data collected during the interview. All data will be destroyed after five years.

While the researcher is committed to maintaining confidentiality and privacy, it does recognize that information breaching is a risk especially in a group discussion. Complete privacy and confidentiality cannot therefore be guaranteed. Through reading the findings of the study, participants may be identifiable through contextual information such as the description of a programme or site of the practice but all attempts will be made to ensure that this risk is minimised. You also do not have to answer any question or take part in the interview if you feel the question(s) make you uncomfortable.

What are your rights as a participant?

Your participation is entirely voluntary. Your participation will have no bearing on your job or on work-related evaluations or reports. You are free to stop at any time of the interview or decline responding to questions you are not comfortable to answer. You may change your mind later and stop participating even if you agreed to earlier without any consequences. You may withdraw from this study at any time, without penalty and without having to give a reason for doing so. If you would like to withdraw from the study, you can contact me directly, documents used will be discarded from the analysis. If you would like to receive a copy of the results of the study, your contact details will be kept to inform you of the results.

If you have specific requirements to participate in the study e.g. you need an interpreter, you are more than welcome to let me know and I will try my best to ensure that your specific needs are accommodated.

We thank you for your time and consideration.

Yours faithfully,

Thesandree Padayachee,
Number: 0725668740)

(thesandree.padayachee@hst.org.za)

Contact

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Please sign the consent form indicating your wish to participate in the study.

Consent form

I, _____ (*full name in print*) have been invited to participate in research exploring primary healthcare policies and practices influencing “continuity of care” for persons with disabilities in South Africa. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and these have been answered to my satisfaction. I give consent voluntarily to be interviewed as a participant in this study and am fully aware of my rights as a research participant. I do not have any further questions. I am aware that I may withdraw from the study at any time if I so wish, without having to provide an explanation. I understand that I can contact the researcher to inform her of my withdrawal from the study. Withdrawal from the study will have no negative implications for me. I voluntarily consent to participate in this study.

Participant’s Signature: _____

Date:

Researcher’s Signature: _____

Date:

Would you like to be informed of the results of the study? Circle. YES/NO

If _____ yes, _____ provide _____ email _____ address:

Should you have any questions please do not hesitate to contact me or my supervisor:

Thesandree Padayachee: (thesandree.padayachee@hst.org) Contact Number:
0725668740 / 031 2669090

Professor Harsha Kathard: harsha.kathard@uct.ac.za (w): (021) 406 6401

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

If you have any concerns about the ethics of the study, please contact Professor Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 406 6496 or at marc.blockman@uct.ac.za

Appendix L: Interview Notes/Observation Template

Date: Interview-Start [hh:mm] Interview-End [hh:mm] Duration [in minutes] Name of Interviewer / Researcher Name of assistant / note taker Additional Remarks of the interviewer Access requirements:	
In the left-hand column, the following will be discussed: a) Setting (i.e., what does it look like, layout, set up etc.) b) Person interviewed c) Outline of interview process	In the right-hand column, the following will be discussed: a) Insights b) Body language c) Non-verbal exchanges d) Commentary

Appendix M: Interview Schedule: KII with Person with a Disability

INTRODUCTION TEXT

The purpose of this interview is to explore factors that influence “continuity of care” for persons with disabilities so that information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively. The interview will focus on three main areas:

1. Your experiences of care at the primary healthcare clinic you visit and your expectations of care in terms of

a) your relationship with your healthcare providers,

b) how your personal health information is managed and

c) how your care is coordinated and managed by the primary healthcare team.

We will be audio recording this interview for validation and analysis purposes as mentioned in the informed consent you have signed. Are you ready to begin?

Date of interview	
Type of disability	
Age	
Use of interpreter / assistant?	
Interview-Start [hh:mm]	
Interview-End [hh:mm]	
Duration [in minutes]	
Name of Interviewer / Researcher	
Name of note taker	
Additional remarks	

Tell me a little about yourself?

Why do you need to visit the clinic?

How often do you have to go to the clinic?

Please describe a typical visit to the clinic?

How many healthcare professionals do you usually see during a visit to the clinic?

Tell me about the quality of care that you receive at the clinic in terms of how healthcare providers communicate with each other about your condition and how information is recorded and shared between healthcare providers?

How satisfied with how your information is managed between visits and between healthcare providers?

Who do you think knows you best at the clinic? Why?

What are the things that you are not happy about in terms of how your care is managed at the clinic?

What are some of the things that you are happy with at the clinic?

What are some of the things that you are not happy about at the clinic?

What would you like to recommend to the Department of Health in terms of your care coordination and management?

Thank you for your interest and participation in this interview

Appendix N: KII with Families of persons with disabilities

INTRODUCTION TEXT

The purpose of this discussion is to explore factors that influence “continuity of care” for persons with disabilities so that information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively.

The discussion will focus on your insights and experiences of your family member’s care at the primary healthcare clinic and your expectations of primary healthcare coordination in terms of

- a) the trust relationship with healthcare providers,*
- b) how clinical health information is managed and communicated between healthcare providers and*
- c) how your family members’ care is coordinated and managed by the primary healthcare team.*

We will be audio recording this discussion for validation and analysis purposes as mentioned in the informed consent you have signed. Are you ready to begin?

Date of KII	
Ages of participants	
Use of interpreter / assistant?	
KII-Start [hh:mm]	
KII-End [hh:mm]	
Duration [in minutes]	
Name of facilitator	
Name of note taker	
Additional Remarks	

Tell me little bit about your family member with a disability?

Please tell me about his/her medical history and what he/she visits the clinic for?

How satisfied are you with the care that your family member receives at the clinic? Please explain your answer.

What are your expectations of the people who provide healthcare services to you at the clinic?

Who do you think understands your family member best at the clinic?

What has been your experience in terms of how care is coordinated for your family member with a disability? (Probe how many healthcare providers see the family member, how information is recoded and transferred from one healthcare provider to another, how clinical records are maintained from one visit to another, how care for their family member is generally managed by the primary healthcare team)

Who do you trust most at the clinic in terms of providing care that is what you are expecting and why do you trust this person.

(Probe reasons for their answers, if they think trust is an important part of primary healthcare, who in the primary healthcare team they trust the most and why)

What are your recommendations in terms of how the Department of health can improve primary healthcare services for persons with disabilities?

Thank you for your interest and participation in this interview

Appendix O: FGD with community-based organisations

INTRODUCTION TEXT

The purpose of this discussion is to explore factors that influence “continuity of care” for persons with disabilities. Information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively.

The FGD will focus on three main areas: 1. Your insights into whether current primary healthcare services meet the expectations of persons with disabilities in terms of “continuity of care” and your recommendations on how “continuity of care” for persons with disabilities can be improved. We will be audio recording this discussion for validation and analysis purposes as mentioned in the informed consent you have signed. Are you ready to begin?

Date of FGD	
Ages of participants	
Use of interpreter / assistant?	
FGD-Start [hh:mm]	
FGD-End [hh:mm]	
Duration [in minutes]	
Name of facilitator	
Name of note taker	
Additional Remarks of the facilitator ²	

² Additional remarks can concern any impressions the interviewer had of the circumstances of the interview, of the place (e.g. if the interview took place at the site of the project) of the interview partners, etc.

Let's do a round of introductions – facilitator introduces herself and the participants

The facilitator explains the definition of “continuity of care” including the three main aspects of the concept; relational continuity, information continuity and management continuity. This sets the scene for the discussion questions and probes.

Let's begin the discussion by talking about the kinds of support that you offer to persons with disabilities in the community and if these services are in any way aligned or integrated to primary health care services? (Probe the type of support offered, how it is delivered, how they interact with the primary healthcare clinic).

What do you think are some of the main factors that influence the continuity of care for persons with disabilities? (probe all three aspects of continuity of care)

What have been some of the main changes that you have witnessed over the past 10 years in terms of how persons with disabilities are cared for in primary healthcare clinics?(probe key policies, ideal clinic, office of health standards compliance, ICSM, whether these changes have been good or bad)

What do you think persons with disabilities expect when they visit the clinic and do you think current primary healthcare services meet these expectations? (Probe which services meet the needs of persons with disabilities and which don't.)

What are your top five recommendations in terms of how “continuity of care” can be improved for persons with disabilities? (probe in terms of relational, informational and management continuity)

Thank you for your interest and participation in this interview

Appendix P: Interview schedule: KII with National, Provincial and District key informant interviews

INTRODUCTION TEXT

The purpose of this interview is to explore factors that influence “continuity of care” for persons with disabilities so that information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively. Key policies and primary healthcare practices will be explored as we seek to understand the expectations of persons with disabilities in terms of “continuity of care” and how the health system particularly at primary healthcare level responds to them.

The interview is semi-structured but will focus on three main areas:

- 1. Your insights and opinions on how current policies impact on “continuity of care” for persons with disabilities (i.t.o interests, ideas and institutions),*
- 2. Your understanding of the expectations of persons with disabilities when it comes to primary healthcare and*
- 3. What can be done at a primary healthcare level to facilitate “continuity of care” for persons with disabilities?*

We will be audio recording this interview for validation and analysis purposes as mentioned in the informed consent you have signed.

<i>Date of interview</i>	
<i>Position and number of years in the position</i>	
<i>Interview-Start [hh:mm]</i>	
<i>Interview-End [hh:mm]</i>	
<i>Duration [in minutes]</i>	
<i>Name of Interviewer / Researcher</i>	
<i>Name of assistant / note taker</i>	

SECTION A: PRIMARY HEALTHCARE POLICIES

Tell me about your role within the department of health? (*Probe involvement in policy making for primary healthcare and any involvement with planning services for persons with disabilities*)

Continuity of care is concerned with how a patient's care is connected over time and is an important aspect of delivering high quality care and improving patient satisfaction. Continuity of care often relates to the caring long-term relationship between the patient and the healthcare professional and also includes organizational aspects related to how information about a patient is shared between different healthcare professionals and how care is coordinated between them. What are your thoughts about this concept in relation to persons with disabilities accessing primary healthcare services in SA and do you think we are able to achieve "continuity of care" to persons with disabilities?

In the last 10 years, what do you think have been the most significant strides made in terms of policies that impact "continuity of care" for persons with disabilities?

Tell me about the background to these policies, in other words, tell me about how these policies come to be developed? (probe key people who may have advanced the policy agenda, what ideas of the time shaped the content and what structural factors e.g. international imperatives, influenced the development of the policies)

Of these policies, which three policies have the most potential to impact the "continuity of care" for persons with disabilities at a primary healthcare level and why?

What do you think are the key factors that impact/influence the implementation of these policies? (Probe interests, ideas, and institutions)

What are your thoughts on the current status of implementation of these policies? (Probe challenges, successes and plans for the immediate and distant future and who is responsible for its implementation)

SECTION B: RESPONDING TO EXPECTATIONS OF PERSONS WITH DISABILITIES

What do you think persons with disabilities want in terms of primary healthcare service delivery and particularly in terms of their “continuity of care” (i.e. in terms of relational, informational and management continuity)?

Do you think current day policies respond to the expectations of persons with disabilities? (Probe how and why they feel the way they do)?

Do you think persons with disabilities require more effort in terms of care coordination at primary healthcare level? Why and in what ways?

SECTION C: WHAT CAN BE DONE TO IMPROVE CONTINUITY OF CARE FOR PERSONS WITH DISABILITIES

Can you outline the most significant challenges experienced by the department of health in terms of caring for and managing persons with disabilities within the primary healthcare context?

What are some of the proposed solutions to these challenges?

Who do you think bears the responsibility for ensuring that information about a patient is accurately transferred from one healthcare professional to another?

Do you think there is a need for a care coordinator who manages the flow of information and coordination of services when a patient has to be seen by more than one service provider? Why?

Who within the primary healthcare context is best placed to play this care coordination role for persons with disabilities considering their potentially unique needs? Please give reasons for your answer?

We have reached the end of the interview, do you have any additional comments?

Thank you for your interest and participation in this interview

Appendix Q: Interview Schedule: KII with Healthcare Managers

INTRODUCTION TEXT

The purpose of this interview is to explore factors that influence “continuity of care” for persons with disabilities. The information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively. Key policies and primary healthcare practices will be explored as we seek to understand the expectations of persons with disabilities in terms of “continuity of care” and how the health system particularly at primary healthcare level responds to them.

The interview is semi-structured but will focus on three main areas:

- 1. your insights and opinions on how current policies impact on “continuity of care” for persons with disabilities (i.t.o interests, ideas and institutions),*
- 2. Your understanding of the expectations of persons with disabilities when it comes to primary healthcare and*
- 3. What can be done at a primary healthcare level to facilitate “continuity of care” for persons with disabilities?*

We will be audio recording this interview for validation and analysis purposes as mentioned in the informed consent you have signed.

<i>Date of interview</i>	
<i>Position and designation</i>	
<i>Number of years in position?</i>	
<i>Interview-Start [hh:mm]</i>	
<i>Interview-End [hh:mm]</i>	
<i>Duration [in minutes]</i>	
<i>Name of Interviewer / Researcher</i>	
<i>Name of assistant / note taker</i>	

SECTION A: PRIMARY HEALTHCARE POLICIES

Tell me about your role within the department of health? (*Probe involvement in policy making for primary healthcare and any involvement with planning services for persons with disabilities*)

Continuity of care is concerned with how a patient's care is connected over time and is an important aspect of delivering high quality care and improving patient satisfaction. Continuity of care often relates to the caring long-term relationship between the patient and the healthcare professional and includes organizational aspects related to how information about a patient is shared between different healthcare professionals and how care is coordinated between them. What are your thoughts about this concept in relation to persons with disabilities accessing primary healthcare services in SA and do you think we are able to achieve "continuity of care" to persons with disabilities?

In the last 10 years, what do you think have been the most significant strides made in terms of policies that impact "continuity of care" for persons with disabilities?

Tell me about the background to these policies, in other words, tell me about how these policies come to be developed? (probe key people who may have advanced the policy agenda, what ideas of the time shaped the content and what structural factors e.g. international imperatives, influenced the development of the policies)

Of these policies, which three policies have the most potential to impact the "*continuity of care*" for persons with disabilities at a primary healthcare level and why?

What do you think are the key factors that impact/influence the implementation of these policies? (Probe interests, ideas, and institutions)

What are your thoughts on the status of implementation of these policies? (Probe challenges, successes and plans for the immediate and distant future and who is responsible for its implementation)

SECTION B: RESPONDING TO EXPECTATIONS OF PERSONS WITH DISABILITIES

What do you think persons with disabilities want in terms of primary healthcare service delivery and particularly in terms of their “continuity of care” (i.e. in terms of relational, informational and management continuity)?

Do you think current day policies respond to the expectations of persons with disabilities? (Probe how and why they feel the way they do)?

Do you think persons with disabilities require more effort in terms of care coordination at primary healthcare level? Why?

SECTION C: WHAT CAN BE DONE TO IMPROVE CONTINUITY OF CARE FOR PERSONS WITH DISABILITIES

Can you outline the most significant challenges experienced by the department of health in terms of caring for and managing persons with disabilities within the primary healthcare context?

What are some of the proposed solutions to these challenges?

Who do you think bears the responsibility for ensuring that information about a patient is accurately transferred from one healthcare professional to another?

Do you think there is a need for a care coordinator who manages the flow of information and coordination of services when a patient has to be seen by more than one service provider? Why do you feel this way?

Who within the primary healthcare context is best placed to play this care coordination role for persons with disabilities considering their potentially unique needs? Please give reasons for your answer?

We have reached the end of the interview, do you have any additional comments?

Thank you for your interest and participation in this interview

Appendix R: Interview Schedule: KII with Primary Healthcare Manager

INTRODUCTION TEXT

The purpose of this discussion is to explore factors that influence “continuity of care” for persons with disabilities so that information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively.

The KII will focus on three main areas:

Your insights and experiences of managing a person with disabilities with more than one healthcare problem,

your understanding of what persons with disabilities want in terms of their primary healthcare team and

your recommendations on how continuity of care for persons with disabilities can be improved.

We will be audio recording this discussion for validation and analysis purposes as mentioned in the informed consent you have signed. Are you ready to begin?

<i>Date of KII</i>	
<i>Ages of participants</i>	
<i>Use of interpreter / assistant?</i>	
<i>FGD-Start [hh:mm]</i>	
<i>FGD-End [hh:mm]</i>	
<i>Duration [in minutes]</i>	
<i>Name of facilitator</i>	
<i>Name of note taker</i>	

The interviewer explains the definition of “continuity of care” including the three main aspects of the concept; relational continuity, information continuity and management continuity. This sets the scene for the discussion questions and probes.

Let's begin the discussion by talking about your experiences of delivering services to persons with disabilities who need care from multiple healthcare professionals. Please describe how primary healthcare is currently delivered to persons with disabilities in this clinic? (probe how care is coordinated, how clinical information is recorded and who in the primary healthcare team takes the management role in coordinating high risk patients)

What have been some of the main policy and practice changes over the past 10 years in terms of how persons with disabilities are cared for in primary healthcare clinics?(probe key policies, ideal clinic, office of health standards compliance, ICSM)

What do you think persons with disabilities expect when they visit the clinic and do you think these policies and practices meet their expectations? (probe their understanding of needs and expectations of people with disability i.t.o access, coordination of services and trust in healthcare team)

What are your thoughts on how your facility meets the expectations of persons with disabilities in terms of their continuity of care and where can you do better?

What are your recommendations in terms of how "continuity of care" can be improved for persons with disabilities? (probe in terms of relational, informational and management continuity)

Thank you for your interest and participation in this interview

Appendix S: KII Community Healthcare Workers

INTRODUCTION TEXT

The purpose of this discussion is to explore factors that influence “continuity of care” for persons with disabilities. Information generated can be used in health systems strengthening efforts, particularly at primary healthcare level, so that persons with disabilities can be managed more effectively.

The interview will focus on three main areas: 1. Your insights into whether current primary healthcare services meet the expectations of persons with disabilities in terms of “continuity of care” and your recommendations on how “continuity of care” for persons with disabilities can be improved. We will be audio recording this discussion for validation and analysis purposes as mentioned in the informed consent you have signed. Are you ready to begin?

Date of KII	
Ages of participants	
Use of interpreter / assistant?	
FGD-Start [hh:mm]	
FGD-End [hh:mm]	
Duration [in minutes]	
Name of facilitator	
Name of note taker	
Additional Remarks of the facilitator ³	

³ Additional remarks can concern any impressions the interviewer had of the circumstances of the interview, of the place (e.g. if the interview took place at the site of the project) of the interview partners, etc.

The interviewer explains the definition of “continuity of care” including the three main aspects of the concept; relational continuity, information continuity and management continuity. This sets the scene for the discussion questions and probes.

Let’s begin the discussion by talking about the kinds of support that you offer to persons with disabilities in the community and if these services are in any way aligned or integrated to primary health care services? (Probe the type of support offered, how it is delivered, how they interact with the primary healthcare clinic).

What do you think are some of the main factors that influence the continuity of care for persons with disabilities? (probe all three aspects of continuity of care)

What have been some of the main changes that you have witnessed over your career in terms of how persons with disabilities are cared for in primary healthcare clinics?(probe key policies, ideal clinic, office of health standards compliance, ICSM, whether these changes have been good or bad)

What do you think persons with disabilities expect when they visit the clinic and do you think current primary healthcare services meet these expectations? (Probe which services meet the needs of persons with disabilities and which don’t.)

What are your top five recommendations in terms of how “continuity of care” can be improved for persons with disabilities? (probe in terms of relational, informational and management continuity)

Thank you for your interest and participation in this interview

Appendix T: Research Assistant Confidentiality Agreement

A. INSTRUCTIONS

Please read through the entirety of this form carefully before signing.

Electronic signatures are not valid for this form. After completing the required fields, please print and sign this form in blue or black ink. After this form has been signed by the research assistant, it should be given to the investigator of the research study for submission.

The research assistant should keep a copy of the *Research Assistant Confidentiality Agreement* for their records.

B. CONFIDENTIALITY OF A RESEARCH STUDY:

Confidentiality is the treatment and maintenance of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure (the consent form) without permission. Confidential information relating to human subjects in a research study may include, but is not limited to:

Name, date of birth, age, sex, address, and contact information;

Current contact details of family, guardian etc.;

Medical or educational history and/or records;

Sexual lifestyle;

Personal care issues;

Service records and progress notes;

Assessments or reports;

Ethnic or racial origin;

Political opinions, religious or philosophical beliefs.

As a research assistant you will have access to confidential information pertaining to the research study. Many participants have only revealed information to investigators because principal investigators have assured participants that every effort will be made to maintain confidentiality. That is why it is of the utmost importance to maintain full confidentiality when conducting a research study. *Below is a list of expectations you will be required to adhere to as a research assistant. Please carefully review these expectations before signing this form.*

C. EXPECTATIONS FOR A RESEARCH ASSISTANT

In order to maintain confidentiality, I agree to:

1. Keep all research information that is shared with me (e.g. flash drives, notes, transcripts, data, etc.) confidential by not discussing or sharing this information verbally or in any format with anyone other than the principal investigator of this study;

2. Ensure the security of research information while it is in my possession. This may include:

Keeping all documents and/or data related to the research study on a password protected computer with password protected files;

Closing any programs, documents, or data files related to the research study when away from the computer;

Keeping any printed documents and/or data related to the research study in a secure location such as a locked filing cabinet;

Permanently deleting any digital communication containing documents and/or data related to the research study.

3. Not make copies of documents and/or data related to the research study unless specifically instructed to do so by the principal investigator;

4. Give all research information/data and research participant information/data back to the principal investigator upon completion of my duties as a research assistant;

5. After discussing it with the principal investigator, erase or destroy all research information that cannot be returned to the principal investigator upon completion of my duties as a research assistant.

Name of Research Assistant:

Title of Research Study:

By signing this form, I acknowledge that I have reviewed, understand, and agree to adhere to the expectations for a research assistant described above. I agree to maintain confidentiality while performing my duties as a research assistant and recognize that failure to comply with these expectations may result in disciplinary action.

Signature of Research Assistant

Date

Print Name

Appendix U: Key Cross-Cutting Themes

Table 26: Key cross-cutting themes identified using open inductive coding

Open codes	Axial Coding	Selective Coding	Theme
Delayed retrieval of files Inaccurate data captured on file SMS alerts inaccurate Need to repeat information Inconsistent prioritisation Confusion Queues No information on next steps Doubt about rights and prioritisation for persons with disabilities and the elderly.	Poor filing and health information management practices Information about patient rights	 Administration Factors	NON-COMPLIANCE WITH PHC STANDARDS
Candidacy for new programmes (CCMDD) Lack of information about rehabilitation services Referral options to private health facilities Long term care options Rehabilitation options Medication delivery options Emergency care unhelpful Lack of assistive devices e.g., wheelchairs	Exclusion of persons with disabilities in new innovations Inaccessible information and resources	Universal design factors Lack of patient centeredness	DESIGNING FOR SOCIAL JUSTICE

Open codes	Axial Coding	Selective Coding	Theme
	Unwillingness to adapt and respond to needs		
Travel costs Out-of-pocket payments Unexpected costs Multiple trips Car hire Assistance for mobility Exploitation	Making difficult choices Cost of access to health	Access Factors	BURDEN OF HEALTHCARE ACCESS: TRANSPORT
Pre-emptive service Same health professional Flexibility of service providers Going the extra mile Tailored support Telephonic support Adapted arrangements for medication pick up	Personalised care Proactiveness	Interpersonal Factors	SERVANT LEADERSHIP
Stigma Indifference Avoidance Inconsistency	Attitudes to persons with disabilities Ignorance	Social Factors	OTHERING
Traditional healers Delay in care Infection Complication Faith in God God fearing	Unintended consequences Exclusion of traditional healers	Medical Model Exclusion of Community Needs and Values	COLONIAL LEGACIES

Open codes	Axial Coding	Selective Coding	Theme
CHW and CCG gaps Low priority for home-based care	Weakened community links		
Absence of Sukuma Sakhe Absence of ward counsellor Poor housing conditions Crime Poverty No faith in government support Distrust in quality of care offered to persons with disabilities Fear of public health institutions Outreach team resource constraints No mobile clinics No delivery of medication Insufficient linkage between facility and community	Lack of accountability Distrust in government Lack of coordination of outreach services	Political-economic factors Leadership factors	POLITICAL AND INSTITUTIONAL DISTRUST
Government has forgotten us Nobody cares Make my own plan We have to help ourselves Community support networks Leadership	Sense of alienation by government Community activism	Community self-organization	

Open codes	Axial Coding	Selective Coding	Theme
Trust and friendship Empathy Love Friends Family Sense of security Transport Knowing needs Support in crisis Genuine care Relationships built over time	Trusting relationships beyond the health system Seeing person in context Mobilisation of resources	Social Cohesion Human Connectedness	EMERGENT COMMUNITY LEADERSHIP
Filling in information gaps due to different care providers Looking for resources by themselves Shielding from poor attitude of health facility staff Accommodations for long waiting times Addressing lack of accountability and poor service Asking critical questions Pushing against access challenges		Tenacity to advocate	RESILIENCE OF FAMILIES
Concern about whether they are doing what is best Care at home Physical and emotional impact on carer Balancing competing priorities Fear of public health facilities Financial considerations Relinquishing control Helplessness		Burdens of the Carer	

Open codes	Axial Coding	Selective Coding	Theme
Accepting support			
PERSONS WITH DISABILITIES' EXPECTATIONS FOR THEIR "Continuity of Care"			
Keep accurate records I don't want to repeat my medical history Don't lose my file I access care from public and private systems – records should keep track of my journey	I want my information to be accurate and shared appropriately	My personal medical information is my story – keep it safe	
Courtesy Non-racism Equality Access to resources and information Transport Support Involvement in decisions	I have rights I am human I deserve the same as everyone else	Treat me with dignity and respect	
Waiting times, queues, sequence of procedures. Home delivery of medication Appropriate provision of assistive devices Assistance with activities of daily living	Ask me what I prefer Involve me in decisions about my care I need flexibility		
FAMILY AND COMMUNITY EXPECTATIONS OF "Continuity of Care" FOR PERSONS WITH DISABILITIES			
persons with disabilities and the elderly cannot wait in queues Mobile services are needed in underserved areas Transport to health facilities must be prioritised Provide training for healthcare providers so that they understand the needs for persons with disabilities Don't discriminate against people based on their race			

Open codes	Axial Coding	Selective Coding	Theme
Be empathetic Be true to your oath of service Do not keep changing healthcare providers Create special clinics and hospitals for persons with disabilities People in the area can do a better job of supporting persons with disabilities and the elderly if they are better resourced			

Appendix V: Identified Healthcare Policies

Table 27: List of identified healthcare policies related to PHC organised by categories

Policy category	Description	Polices identified	Analysis		Justification
			Thematic	EquiFrame	
International commitments	These are international strategies or commitments which SA is signatory to with relevance to how PHC is delivered.	United Nations Convention on the Rights of persons with disabilities (United Nations General Assembly, 24 January 2007)			Included as it is the overarching disability inclusion call to action to and has been ratified and adopted by SA.
		Sustainable Development Goals 2030 (United Nations General Assembly, 21 October 2015)			The Sustainable Development Goals is the international blueprint to achieve a sustainable future for all and includes health related targets as part of Goal 3: “Good Health and Well-being.”
		Africa Health Strategy (AHS) (2016 – 2030)			AHS 2016 - 2030 provides strategic direction to Africa’s Member States in their efforts in creating better performing health sectors.
Transformational Policies	These are recent polices delivered by the national department of health in SA which aims to transform how health is delivered in the country.	National Health Act (Republic of South Africa, 2003)			The overarching legislative framework governing the health sector in SA. Not included in the analysis as it falls outside the ten-year period.

Policy category	Description	Policies identified	Analysis	EquiFrame	Justification
			Thematic		
		White paper on the Transformation of the health system 1997			
		National Health Insurance Bill			SA's National Health Insurance (NHI) bill is a major transformational policy which was passed into law in 2022 bringing the country closer to its vision of achieving universal access to healthcare.
		National Health Insurance Policy - Towards Universal National Health Insurance Policy health Coverage 2017			The NHI bill is a tool to achieve universal health coverage. It aims to ensure that all SAs have access to quality healthcare services
		Presidential Health Compact			The Compact lays down a five-year roadmap for health systems strengthening reforms under the '9 pillars' towards accelerating Universal Health Coverage (UHC) in SA.
		National Development Plan 2030			The NDP is a plan for SA where government will engage with all sectors to understand how they are contributing to implementation, and particularly to identify any obstacles to them fulfilling their role effectively. The Plan identifies the improvement of the quality of public services as

Policy category	Description	Polices identified	Analysis Thematic	EquiFrame	Justification
					critical to achieving transformation, of which health and achieving universal healthcare, is an important objective.
National Programmatic Policies	These are a set of national policies directing how particular health programmes and aspects of healthcare are delivered.	National Core Standards for Health Establishments in SA 2011			Used to develop a common definition of quality care which should be found in all health establishments in SA, as a guide to the public, managers and staff at all levels. It establishes a benchmark against which health establishments can be assessed, gaps identified, and strengths appraised; and provides for the national certification of compliance of health establishments with mandatory standards.
		Policy Framework and Strategy for Ward-based PHC teams 2018/19 – 2023/24			Outlines comprehensive and integrated disability and rehabilitation services within the broader health and developmental context to facilitate improved access at all levels of health care
		South African Maternal, Perinatal and Neonatal health policy 2021			Excluded

Policy category	Description	Policies identified	Analysis	EquiFrame	Justification
			Thematic		
		SA's National Strategic Plan for HIV, TB and STIs 2017 – 2022			Excluded
		National HIV testing services policy 2016			Excluded
		Antiretroviral Treatment Clinical Guidelines for the Management of HIV in Adults, Pregnancy, Adolescents, Children, Infants and Neonates (2019)			Excluded
		Patient Waiting time policy			Included
		DoH Policy on Sexual and Reproductive Health and Rights: Fulfilling our Commitments 2011- 2021 and beyond. (Final Draft 2011)			Excluded as it provided a specific focus on sexual and reproductive health and rights

Policy category	Description	Polices identified	Analysis Thematic	EquiFrame	Justification
		A Policy on Quality in Health Care for SA 2007			Included
		Referral Policy for South African Health Services and Referral Implementation Guidelines			Included
		District Health Management Information System (DHMIS) Policy - A Long and Healthy Life for All South Africans 2011			Included
		National Health Promotion Policy and Strategy 2015-2019			Excluded
		National Digital Health Strategy for SA			Excluded
		Mental Health Policy 2021			Excluded

Policy category	Description	Polices identified	Analysis Thematic	EquiFrame	Justification
KZN Programmatic Policies	These are a set of policies relevant only in KZN directing how particular health programmes and health services are delivered.	KwaZulu-Natal Provincial Health Act of 2000;			
		KZN DoH Strategic plan 2020/2021 – 2024/25			
		Clinic Committees			
Disability specific polices (Analysed only in terms of “Continuity of Care” core concepts)	These are international, African continental and South African policies designed to pursue disability inclusion in health systems and programmes.	African Union Commission: Department of Social Affairs. Continental Plan of Action for the African Decade of persons with disabilities 2010-2019			
		Framework and Strategy for Disability and Rehabilitation Services in SA 2015-2020			
		National Rehabilitation Policy			
		White Paper on the Rights of persons with disabilities 2015			
		National Disability Policy			
		Policy Guidelines for The Licensing for the Residential and or Day Care Facilities for persons with Mental Illness and or Severe or Profound Intellectual Disability			

Appendix X: Themes from Interviews with Policymakers and Implementers

Table 28. Themes from policymaker and implementer interviews

Themes	Sub-themes	Quotations by participants
Theme 1: Influences on “Continuity of Care” for persons with disabilities	1. Limited resources	<i>“during COVID 19, we lost a lot of our staff and with budget cuts many of the NGOs closed and we were again impacted”.</i>
	2. Security concerns for outreach teams	<i>“The challenges that we are experiencing as a department, besides limited resources, is crime in our community. Because of high levels of crime some of our outreach teams have been hijacked, some have had their cell phones stolen, and some of them being held on gun point”.</i>
	3. Siloed health programming	<i>“Generally, you will find that if you [are] within a different department or unit, the ones who have to deal with HIV, TB and so on, those units, to develop their policies, if you are lucky you will be invited to participate in the development t of those policies”.</i> <i>“There are no prescripts that say if you are developing policy, you should involve all district internal stakeholders – it is just an ideal thing depends on how people think in their particular sections”.</i>

Themes	Sub-themes	Quotations by participants
	4. Faking disability to continue therapy	<i>“Those policies don't fall under my program, they are managed by another business managing chronic diseases, so I'm unfortunately not able to give information of that”.</i> <i>“ideally, we should be involved, in fact, in all departmental policy development, ideally, but what is happening, we're only involved in policies that relate specifically to disability and rehabilitation”.</i> <i>The challenge that we are having is where people, withhold the information for disability grants. Family members, they hide that there've got disabilities, and others they do not bring their families for health services or for rehab especially why because they are afraid to say it. In case the relative is fully rehabilitated and functional independent and they lose their disability grant”.</i>
Theme 2: “Continuity of Care” promoting policies	1. FSDR 2. Community-Based Rehabilitation 3. WBPHC 4. Referral Policy	<i>“For me, the CBR, is the one that has been the foundation for continuum of care. Why do I say so? Because remember the people generally access rehabilitation at a hospital not as the primary health care in most districts. But because they're these traders in the middle that assists the medical community level, it makes them to work with them, not only with rehabilitation and other health services that they require, maybe at the clinic or anywhere else. But the fact that the system of rehabilitation is operating at the community level. It makes persons with disabilities their life of disability, much easier”. (Coordinator Disability and Rehabilitation)</i>

Themes	Sub-themes	Quotations by participants
		<i>"we found that there are many people who have been defaulting because of the troubles of transport and some because they are blind nobody is helping them to go to the clinic. The CBR teams provided them with information, that is relevant to them besides the rehabilitation and other health needs that they will require(".</i>
Theme 3: Initiatives to improve "Continuity of Care"	Expanding community outreach through community rehabilitation facilitators Expanding NGO and donor support	<i>"we have decided to expand community-based rehabilitation services in about 14 areas and these are for the poorest of the poor people the less privileged people that we have targeted. We have recruited community-based rehabilitation facilitators that are going from door to door to identify persons with disabilities especially those not able to come out of their houses or that have been moved by their families because they cannot afford transport to take them to the clinic".</i> <i>"We have looked at asking other donors or other partners to assist in covering up those [services] that no longer work very perfectly but for disabilities and rehab there are very few that continued because of financial constraints, but other some of the big partners or NGOs have continued their support with the department and they in fact expanded their response in terms of bringing resources to support person with disabilities in KZN".</i> <i>"with the social media I think it's helping in terms of coordinating the appointments for our clients that we were not able to reach. Especially those who are able to afford smart phones; unfortunately, it's not everyone especially persons with disability who are coming from poorer families that can't afford a smart phone or their family members can afford. Those who are able to afford smart phones we are able to reach out to them to inform them if their assistive devices there are available for them to them to collect".</i>

Themes	Sub-themes	Quotations by participants
	Using acceptable communication channels	<i>“People like to be informed. We use SMS to confirm an appointment or when delivering an assistive device to them”.</i> <i>“We sometimes use SMS for coordination for support groups with disabilities and we use the social media especially those who have zoom, WhatsApp, and we are able to reach out to them and we are able to get some messages through”.</i>
Theme 4: We know what persons with disabilities want		<i>“Most of them want it [services] to be made available all the time and the services must be in a proper format - information about the services must be in a proper format in terms of their understanding. Like visual impaired persons they will want their information that is available in easy format for them to read the information and understand it and then for the people who are deaf they will also want to have information available to them through they interpreter”.</i>

Appendix Y: Researcher reflections

I was the primary researcher in this study and while I am aware of the subjective bias that is inherent in qualitative research, I chose this approach as I felt it was important to investigate the concept of “Continuity of Care” deeply and broadly to elucidate the realities faced by persons with disabilities in a SA context. The conceptual construct of the Health Systems Responsiveness Framework was one of the first steps towards searching for a wider understanding of “Continuity of Care” beyond the realm of the clinical setting. I believe that this positioned the study from the outset to be inclusive and deep in its investigative approach. It was important to me, based on my clinical work and experience of the barriers to disability inclusion, to ensure that the voices of persons with disabilities were adequately reflected in my study.

I had alluded to the need for pragmatism in the conduct of this study. I found myself having to adapt more frequently than I ordinarily would, and I believe that this was necessary. Having a certain level of familiarity with the community, helped me navigate challenges better and supported good decision-making in times of uncertainty. Due to the triple disasters experienced by the community, we were acutely aware of the desperation of the community and the potential for us to be seen as easy targets for criminals. We had to trust the community and families to keep us safe and during the conduct of some of the interviews we needed to stay informed by the community and followed their lead. We also needed to travel with back up mobile phones and ensure that our families and teams were informed about our filed work plans at all times.

A second layer of learning was in relation to interviews with persons with disabilities. In this study there were no opportunities for preparation for the situations we would enter. I went into the field blind, not knowing who I would be interviewing and the type of disability that they would have. This was disconcerting at first, but research acumen was critical in these situations, and I found myself drawing on my clinical skills supported by my research skills to make the relevant decisions. At times I had to resign myself to the fact that a full-scale interview would not be possible or that we would need to cut an interview short to ensure our safety. These were all important moments in the study, which upon reflection, makes me proud of what I was able to achieve despite the challenges.

Throughout this study I was constantly reminded of the importance of conducting research in less-than-ideal conditions with the most marginalised populations. As health systems researchers we are taught to apply additional protections to vulnerable groups, but I now contend that within the reasonable limits, these constructs be challenged as protections serve only to further marginalise persons with disabilities. This study has allowed me to appreciate the need for researcher to dare to explore uncharted territory when attempting to understand lived experiences of persons with disabilities.