Community participation and the right to health for people with disability:

A qualitative study into Health Committees' understanding and practise

of their governance role in relation to disability.

By

Theodore William John Abrahams

ABRTHE002

SUBMITTED TO THE UNIVERSITY OF CAPE TOWN

In partial fulfilment of the requirements for the degree

Masters of Public Health (Health Systems)

Faculty of Health Sciences

UNIVERSITY OF CAPE TOWN

Date of submission: 2nd July 2015

Supervisors:

Ms Hanne Haricharan

School of Public Health, University of Cape Town.

Prof. Leslie London

School of Public Health, University of Cape Town.

DEDICATION

I dedicate this work to my Creator, my Saviour and my source of strength, my Lord and God. Without His providence in times of strife, and His abundance of grace, I would most certainly not have completed this journey.
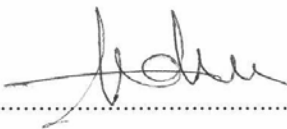
To my parents, Wilfred and Rachel, who have supported and encouraged me throughout my life journey I say thank you. Your selfless sacrifice, guidance and unconditional love will always stay within me, and inspire me to spread these virtues to all I come across.

To my wife Tamlin, your love, patience and caring nature have been precious sustenance for when I was at my lowest. I thank you for your enduring support and belief in me.

DECLARATION

I, Theodore William John Abrahams, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: ....

Date: ....2 FULY 2015........

ABSTRACT

BACKGROUND: People with disabilities encounter major barriers that prevent them realising their right to health in South Africa. Health committees are legislated structures for community participation in health at a local level. This study investigated how health committee members understand and practise their role in community participation and how this advances the right to health for persons with disability.

METHODS: A qualitative study was conducted with three health committees in the Cape Town Metropole in the Western Cape province of South Africa purposively selected for the study. Three facility managers and eight health committee members took part in focus group discussions and semi-structured interviews, supplemented by participant observations of committee meetings. Additionally, semi-structured interviews were conducted with 2 disability activists. These methods were used to gain a rich understanding of health committees' roles and practises in relation to persons with disabilities. Thematic analysis was used to analyse the data.

RESULTS: The main research findings were: (i) health committees did not prioritise disability on their respective agendas; (ii) persons with disabilities were not adequately represented on health committees; (iii) health committees exhibited poor understanding of disability barriers relating to health; (iv) lack of egalitarian values led to persons with disabilities not trusting the health committee, and distrust amongst health committee members; lastly (v) health committees augment health facility operations instead of fulfilling their governance and oversight function. These factors may have contributed to health committees not helping to advance the right to health for persons with disabilities.

CONCLUSIONS:

Health committees should include mandated representation of persons with disabilities, whilst addressing marginalisation directed toward persons with disabilities on committees. Training of health committees, as well as networking with disabled organisations, could help improve their limited understanding of disability. Health committees should consider

addressing disability a human rights issue, which critically involves community mobilisation, raising awareness around issues of disability and promoting agency amongst persons with disabilities to claim their rights.

KEYWORDS:

Health Committees, Community Participation, Disability, Right to Health, Governance, Values, Trust.

325 words (including keywords).

ACKNOWLEDGMENTS

TABLE OF CONTENTS

PART A: PROTOCOL

List of abbreviations

DWCPD - Department of Women, Children and Persons with Disabilities

FGD – Focus Group Discussions

HC – Health Committee

HPSR – Health Policy and Systems Research

ICESCR – International Covenant on Economic, Social and Cultural Rights

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

WHO - World Health Organisation

Introduction

Section 27(1) a, of the Constitution of South Africa states that "*everyone has the right to have access to health care services*" (Republic of South Africa, 1996: 1255), Section 27 also however houses other rights that are prerequisite to the right to health being enlivened, viz: the right to food and water, as well as the right to social security (Republic of South Africa, 1996). Section 9(2) of the Constitution states that "*Equality includes the full and equal enjoyment of all rights and freedoms*" for all persons, free from unfair discrimination (Republic of South Africa, 1996: 1247). This means that the right to health should be available to all persons in equal measure, irrespective of disability status. It is also important to note that human rights do not exist alone, and are co-dependent on other rights being enlivened as well.

Persons with disabilities face large-scale discrimination and inequality when accessing health care services, and worsened health outcomes as a result thereof (World Health Organisation [WHO], 2011; Worral et. al, 2007; Kleinties, Lund & Swartz, 2013). Health committees, a statutory body for community participation at clinic level, have been shown to have the potential to help improve the right to health for communities (Boulle et al., 2008).

This study explores if and how health committees improve the right to health for people with disability. Persons with disabilities warrant special attention due to the hardship ad discrimination they encounter in the health system. The study will also test whether health committees are in fact a suitable mechanism to advance community participation for persons with disabilities. The study assumes a Health Policy and Systems Research (HPSR) perspective, and will utilise the phenomenon of how and whether health committees' understanding and practises can influence persons with disabilities' access to their right to health, as an inlet to examine the HPSR variables at play, and will be expanded upon later in the proposal.

Disability defined

Disability can be defined 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 , 2007: 1).

The evolving nature of how disability is defined, is exemplified in contemporary discourse around the emerging paradigm in literature and disability circles, forming a marriage between the "*medical model*", where only the impairment dictates the resultant function, and the "*social model*" where societal barriers e.g. lack of transport access, disables the individual and not the impairment, to form the holistic "*bio-psycho-social model*" (WHO, 2011: 4). The bio-psycho-social model shows how the body impairment interacts with the physical environment, as well as the social context, and how these interactions profoundly affect how "disabled" the individual really is.

Disability barriers

Persons with disabilities experience numerous tangible barriers - the "*hardware*" in HPSR dialogue (Gilson, 2012: 25) - when accessing their right to health, examples of these barriers include: informational access barriers e.g. absence of sign language interpreters for deaf persons accessing clinic services (WHO, 2011; Haricharan et al., 2013), limited physical access barriers e.g. lack of ramps for entering facilities, limited human resources e.g. the scarcity of specialist rehabilitation professionals (Department of Women, Children and Persons with Disabilities [DWCPD], 2013), to mention a few.

In South Africa specifically, the contextual landscape has also significantly contributed to the barriers experienced by persons with disabilities today. The legacy of discrimination during Apartheid, in the form of inequitable health service delivery (Coovadia et. al, 2009) and cure-oriented care with limited health promotion and rehabilitation care

(Ntsaluba & Pillay, 1998), have all in-part contributed to the health profile the country endures today. More recent epidemics e.g. HIV and its vastly proliferative morbidity such as peripheral neuropathy (Groce et. al, 2013), and the morbidity related to injury e.g. traumatic brain injury and resultant permanent motor deficits (Adnams, 2010; Coovadia et. al, 2009), each of which considerably worsens disability outcomes due to disease related sequelae (WHO, 2011).

Additionally, the "*software*" type elements of HPSR are the interpersonal factors, norms, values and beliefs of society, that influence the interactions of people within the health system(Gilson, 2012: 26). A specifically relevant software element is "*negative attitudes*" or stigma, which is the unjust discriminatory perceptions of service providers and communities against persons with disabilities (WHO, 2011; Kleinties, Lund & Swartz, 2013). Examples of negative attitudes include the erroneous notion that persons with disabilities are sexually inactive, and omitting offering contraception to them. Another software barrier is the low-rung priority perception of disability on the health research agenda (Kleintjes, Lund & Swartz, 2013). The software elements as well as the hardware elements, and possibly more importantly the interaction between the two, have a substantial effect on the access to health care for persons with disabilities (WHO, 2011).

The barriers that persons with disabilities face are pervasive in reach and need a transversal approach to be understood adequately. Any intervention that looks to understand the context with some degree of success would thus need to understand and the hardware- elements, but importantly should not forget to understand the software elements that underpin the context of the health system (Gilson, 2012). HPSR is thus a suitable, if not ideal disciplinary approach to attempt to delve into this phenomenon and understand its composite elements in the required depth.

The right to health in South Africa

The right to health can be defined as right to "*the enjoyment of the highest attainable standard of physical and mental health*" (WHO,

Constitution, 1946). The International Covenant on Economic, Social and Cultural Rights (ICESCR) is an international human rights instrument that focuses on inter-alia socio-economic rights, of which the right to health is one (United Nations, 1976). The ICESCR mentions that rights, such as the right to health cannot exist independently, and need other complimentary rights to be enlivened adequately. South Africa's has not, as of yet ratified the ICESCR, but its Parliament has however taken a decision to do so. To date however this has not yet been done. The ICESCR also recognises the underlying determinants of health e.g. food, water, sanitation etc., which are socio-economic factors that need to be addressed to ensure the fruition of the rights mentioned in it.

The ICESCR's General Comment 14, elucidates the critical components required to evaluate the right to health, viz:

Availability – goods and services available in sufficient quantities,

Accessibility – health services need to be financially, physically and geographically accessible in an indiscriminate manner,

Acceptability – health services should be culturally and ethically acceptable as well as gender-sensitive,

and lastly health care services of a medically and scientifically good *Quality* (United Nations, 1976).

Each of these components of the right to health need to be fulfilled by the State to bring about the right to health, whilst the concomitantly addressing the underlying determinants of health, which is sorely lacking for persons with disabilities.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its relevance to South Africa

The UNCRPD is a disability specific rights document released by the United Nations to support human rights measures for persons with disabilities in the face of discrimination and inequity, but also to highlight the specific needs of persons with disabilities and accommodations that the State has to put in place to provide for these needs.

Discrimination in the form of absent or reduced participation in health care decision-making is widespread for persons with disabilities (WHO, 2011). Persons with disabilities also bear the brunt of other forms of societal discrimination e.g. sexism and racism, resulting in a form of compounded discrimination with even worsened health outcomes (O'Neill, 2005; Rademacher et. al, 2010; WHO, 2011).

South Africa ratified the UNCRPD in 2007, and is thus obliged to enact the prescriptions listed in it. There are numerous prescriptions and include some State-borne obligations to, inter-alia: promote access and equality for persons with disabilities (DWCPD, 2013). Some improvements by the State have however been observed in recent times, such as the establishment of the DWCPD as an independent ministry, recognising the specialised needs that persons with disabilities have. South Africa has however experienced detractions from the "systematic approach to the implementation of the UNCRPD" (DWCPD, 2013). Some of these euphemistic detractions are considerably extensive, which, for example, include the inadequate reporting mistreatment of persons with psycho-social disability in mental health care facilities, the unavailability of psychotropic medication, lack of accessible health information media, and are all only a few of the examples of how the State has been unable to implement the UNCRPD to the extent it desires (DWCPD, 2013).

The UNCRPD and how it relates to disability health

The UNCRPD identifies some of the rights specifically relating to persons with disabilities in the form of articles that describe the State's duty to improve equity and access to fundamental freedoms. Some of the relevant articles from the UNCRPD have been chosen and expanded upon below, to provide a framework to better understand some of the barriers faced by persons with disabilities in South Africa, as well as to identify the shortcomings of the State, in so doing emphasising the reality of impeded access to the right to health that persons with disabilities experience.

Article 5 – Equality and inequality, non-discrimination, poverty vulnerability in South Africa

Equality features very strongly in the UNCRPD, and assumes a central focus in the description of purpose within the document (United Nations, 2011). The UNCRPD states that "*all persons are equal before and under the law*" including persons with disabilities (United Nations, 2007: 8). The UNCRPD describes the term "*reasonable accommodation*", which is the execution of fair discriminatory practises by the State, in the form of policy and actions, against non-disabled persons, intended to offset prevalent inequality experienced by persons with disabilities in society (United Nations, 2007: 5). The UNCRPD even goes a step further, stating that in instances where inequality exists for persons with disabilities, that absence of reasonable accommodation practises by the State constitutes discrimination against persons with disabilities by the State (United Nations, 2011).

Apartheid's perverse practises have compounded discrimination against persons with disabilities on an even greater scale if they were non-white (Gathiram, 2008). To date, black women with disabilities still experience significantly more inequality and poverty than any other race or gender (DWCPD, 2013). There is also a very strong correlation between poverty and disability observed in South Africa (Braithewaite & Mont, 2009). The case for compounded barrier persons with disabilities being confronted by compounded barriers in South Africa, who, for example are female as well as black, further underscores the inequality observed by persons with disabilities. South Africa has however instituted affirmative action in some areas of government policy, a form of reasonable accommodation to offset some of the inequality experienced by persons with disabilities (Department of Social Development, 1997). South Africa still has not achieved its desired employment targets for disability specific affirmative action (DWCPD, 2013).

Article 9 – Accessibility

This Article describes some of the access dynamics specifically for persons with disabilities, such as the establishment of physical support

e.g. appropriate transport media and informational access in the form of Braille. South Africa's accommodations for persons with disabilities have so far been limited, an example of access accommodations is the recent changes made to its currency to make it more friendly to visually impaired persons (DWCPD, 2013). Haricharan et al. describes in some detail how a hearing impaired female encounters numerous barriers to accessing her right to health, and the severe negative health outcomes that follow (2013a). Access for persons with disabilities in South Africa on various levels and areas is often sorely lacking.

Article 20 – Personal mobility

Persons with disabilities experience significant barriers to mobility, such as the unavailability of suitable quality assistive devices e.g. wheelchairs, with of adequate specifications to achieve optimal personal mobility (WHO, 2011). This article identifies partially, how the State needs to ensure that persons with disabilities can have access to assistive devices that are appropriate for their specific disability and are adequately accessible at their health facility. Additionally, the article also describes the need for appropriate rehabilitation services with specialist human resources e.g. occupational therapists that are geographically and financially equally accessible in rural and urban centres, as well as the choice of mobility devices and at an affordable cost, whilst taking into account the resource constraints faced by the State in providing health care services.

South Africa has utilised policy to progress personal mobility for persons with bodily impairments in the form of the National Rehabilitation Policy (DOH, 2006), which provides guidelines for the provision and distribution of assistive devices. There are a range of assistive devices available at all levels of the South African health system, and full fee-exemptions do exist for health care, including assistive devices for those who are eligible for disability social assistance (DWCPD, 2013; DOH, 2011). However choice of assistive devices, limited training facilities for rehabilitation professionals, as well as poor monitoring and evaluation of assistive

device distribution are all factors amongst others that hamper the attempts to optimise personal mobility for persons with disabilities in South Africa (United Nations, 2007; DWCPD, 2013).

Articles 25 and 26 - Disability and Health, habilitation and rehabilitation

Articles 25 and 26 respectively speak about health, habilitation and rehabilitation and the State obligations that relate to these. It details inter-alia: specific care for the needs of persons with disabilities e.g. early interventions to offset exposures that result in, or worsen bodily impairments and ultimately disability.

The South African government has recognised the vulnerability of persons with disabilities by producing specialised pieces of legislation to recognise the specific needs of different vulnerable bodies. An example of this is the Mental Health Care Act of 2002, which is currently in the process of being brought in line with the UNCRPD (DWCPD, 2013).

Health committees in South Africa

The Department of Health has produced the White Paper on Transformation of the Health System in South Africa, and highlights the importance of community participation to improve bilateral communication between the facility and the community, especially for those most vulnerable e.g. persons with disabilities, and encourages communities to have a say in taking responsibility for their own health (DOH, 1997).

The National Health Act attempts to promote community participation at a primary care level in the form of health committees, and prescribes the existence of health committees in Section 47(1)c (DOH, 2003). Health committees are thus the interface between communities and Community Health Centres, and are the representatives of communities to improve participation, to help realise the right to health, as well as get communities to take responsibility for their own health (DOH, 1997).

health committees should consist of community elected representatives, the elected local ward councillor and the facility manager of the Community Health Centre in question, as stipulated in the National Health Act of 2003 (DOH, 2003). Although the National health Act mandates the existence of health committees, it importantly however does not specify the exact functional roles and powers for these health committees, and devolves this function to a Provincial level stating that "*The functions of a committee must be prescribed in the provincial legislation in question*" in Section 47(3) (DOH, 2003). Individual provinces have demonstrated an inability to fully implement the roles for health committees in their respective legislation (Padarath & Friedman, 2008). During a rapid appraisal of health committees by Haricharan, it was found that only six of the nine provinces in South Africa, have some form of role description in their provincial health acts for health committees, the Western Cape is however not one of them (2013b). The absence of provincial legislation on the roles of HC's in the Western Cape has had a dire effect on the ability of HC's to bring about community participation (Haricharan, 2012).

Meaningful community participation is a vital conduit to assist in improving health outcomes, and is seen as a basic human right (Potts, 2005), and specifically for persons with disabilities (United Nations, 2007). HC's can thus help bring about meaningful participation, which could help to realise the right to health for communities (Boulle et al., 2008) of which persons with disabilities form a part.

Community participation

Various degrees of community participation have been demonstrated over the years, with the classic work of Arnstein's famous "*participation ladder*", which ranks participation ranging from "*citizen control*" which is the ideal meaningful participation, to the opposite extent of the spectrum viz: "*manipulation*", where community participation is the façade used to exploit communities for unsavoury gain (1969).

A more elaborate description of participation is provided by Fattore and Tediosi, who have built on the work of Hood, by expanding on the four

themes of "*cultural theory*" viz: *fatalist, individualist, egalitarian* and *hierarchical* approaches, each with its own mix of participatory decision-making and management-only decision-making (2013). Their paper asserts that a body which has a role of governance (in this case the HC), is shaped by the values constitute it, specifically the affinity in which it engages in community participation and the resultant this has on decisions made on behalf of the community.

The roles of health committees

In light of the Western Cape Department of Health's inability to provide legislation around the roles and functions of health committees, the Cape Metro Health forum, the body that coordinates the functions of health committees within the Metropole district, had subsequently produced the Draft Policy Framework for Community Participation/Governance Structures for Health, to be known as the Western Cape Draft Policy.

The Western Cape Draft Policy identifies four roles of health committees, viz: to provide governance with regard to service provision, ensure the needs, concerns and complaints of patients are addressed by management, generate community support for facility programmes/initiatives and to monitor the performance, effectiveness and efficiency of health facilities. Health committees were thus toted by the Cape Metro Health Forum, to essentially have a governance role when executing their functions.

The National Department of Health has also acknowledged the inability of provinces to provide legislation around the roles of health committees, and has subsequently released the Draft Policy on Health Governance Structures (DOH, 2013a). The Draft Policy (as it will be known from now on), also situates HC's primarily as *governance* structures with the objectives to improve inter-alia: assimilation of community inputs to guide institutional policies and practises, oversight to ensure service provider accountability and to strengthen community participation of the community in facility matters (DOH, 2013a).

Governance can be defined as "*the exercise of power through institutions to steer society for the public good*" (Huss et. al, 2010: 5). Governance encompasses several meta-themes, some of these include authority/power (Huss et. al, 2010), accountability (George, 2009), decision-making, performance and organisation of inputs onto the operational agenda (Siddiqi, et. al, 2009). Governance is influenced by positive factors e.g. strong leadership as well as negative factors e.g. lack of political support, poor oversight, and affects individuals as well as the entire organisation (Huss et. al, 2010).

Governance is a broadly encompassing theme and one of the HPSR tenets. Governance arranges services and inputs in a manner to achieve good, or bad outcomes for the society. The HC similarly can do the same for persons with disabilities, through its role as being representatives for communities, it can potentially positively arrange disability inputs high on its agenda, ensure accountability of service providers to address the needs of persons with disabilities etc., so as to forward the right to health for persons with disabilities.

HC's could also conversely neglect to take up its function of being representatives for persons with disabilities, by engaging in activities that discriminate against persons with disabilities, as well as using their authority to work against interventions aimed at addressing the needs of persons with disabilities, resulting in poor health outcomes for persons with disabilities as a result of poor governance.

Importantly however, one needs to realise that contextual influences within the HC e.g. personal relationships and external influences e.g. policy environment can have a significant impact on the HC's ability to bring about good governance (Huss et. al, 2010; McCoy, Hall & Ridge, 2012). "Blame" should thus not be attributed entirely to the HC if they are unable to ensure good governance, but the ability of the HC to bring about good governance should be viewed within the context of the system that it undertakes its functions.

Primary Health Care and participation in South Africa

Primary Health Care is an approach adopted at the Alma Ata conference in 1978, which prompted the global movement for health system reform, amongst others aiming to: promote health for all persons, self-determination and self-reliance of nations to address their own health needs, whilst recognising that socio-economic factors play an immense role in making Primary Health Care work, and need to be addressed concordantly (Maciocco, 2008). The Primary Health Care movement emphasizes health care provision at a community level, with participation in health matters, by communities, being identified as a key element to actualising the goals of Primary Health Care (Maciocco, 2008).

Realising that participation emerges as being a key element in realising the right to health for communities, and that health committees are representatives for communities, health committees are thus essential to making Primary Health Care work. This study will thus take place at the primary level for two reasons. Firstly, it is the level whereby HC's are supposed to be representatives for persons with disabilities, as members of the community. Secondly, the primary level is where persons with disabilities usually enter the health system when trying to realise their right to health. The primary level therefore provides the platform to investigate the dynamics of how and whether participation takes place for persons with disabilities, and its effect on the right to health.

Health policy and systems research and the its relevance this study

HPSR can be defined as a discipline:

"*that seeks to understand and improve how societies organize themselves in achieving collective health goals, and how different actors interact in the policy and implementation processes to contribute to policy outcomes*" (Alliance for Health Policy and Systems Research, 2011).

Parts of the definition of HPSR will be broken into segments, and its relevance to this specific study explained below:

"…improve how societies organize themselves in achieving collective health goals"

HPSR comprises some of the hardware type (Building Blocks) components of the health system e.g. Finances, Governance etc. HPSR also recognises that people are the central, omnipresent element of the health system that bring all the building blocks to life as shown in Figure 1. People are central to achieving the right to health for communities (Gationde, Sheik & Saligram, 2013). In this specific instance, the people are the HC's playing a part in achieving the right to health for persons with disabilities.

It is therefore the interactions between the hardware and software elements within the HC and how they organise themselves, as well has how the HC interacts with external actors e.g. service providers, service users and policy makers that have a fundamental impact on the realisation the right to health for persons with disabilities.

Figure 1. People at the centre of the "Building Blocks" (De Savigny & Adam, 2009).

"…actors interact in the policy and implementation processes to contribute to policy outcomes."

The actors of interest in this study are the HC members, and how they articulate with the health system to help bring about, or not, their governance role to help realise the right to health for persons with disabilities. This study will be an analysis for policy, where the experience

of actors (health committees) and how they interact with the policy (Draft Policy), will have a bearing on how the right to health can be achieved for persons with disabilities (Gilson, 2012).

The selected articles of the UNCRPD and the, criteria set out in General Comment 14 to evaluate the right to health are not the sole focus of the study, but will be the "markers" to assess whether HC's are helping to realising the right to health for persons with disabilities. As representatives for communities, of which persons with disabilities form a part, HC's in their governance role will be evaluated to assess whether their understanding and practises can contribute to advancing the right to health for persons with disabilities.

Problem statement

Some of the afore-mentioned findings from literature recognise inter-alia: that persons with disabilities are especially vulnerable, experience numerous barriers, and are exposed to profound inequality and discrimination when attempting to access their right to health. The special accommodations to improve functionality of persons with disabilities, to reduce the impact of their disability as described in the UNCRPD are also not enacted on an appropriate scale in South Africa.

Meaningful community participation can be a way to realise the right to health for communities, of which persons with disabilities form a part. HC's have been shown to have the potential to contribute to realising the right to health for communities. This study will assess whether HC's are able to help realise the right to health specifically for persons with disabilities, as persons with disabilities are also community members and HC's should be their representatives as well. The study will use HC's ability to ensure the right to health for persons with disabilities specifically as an inlet to looking at the relevant HPSR issues, specifically around governance, but not exclusively.

The Constitution, in Section 27, recognises that the right to health cannot exist independently, and needs other contributory rights, as well the underlying determinants of health to be addressed to truly realise the right to health. General comment 14 of the ICESCR provides the criteria

to evaluate the right to health, and these criteria will be used to assess how and whether HC's are contributing to realise the right to health for persons with disabilities. The selected articles from the UNCRPD, which highlight the barriers endured by persons with disabilities, and the accommodations necessary to overcome these, will be used to assess whether persons with disabilities' rights are being addressed.

This study will attempt to investigate whether HC's are indeed a suitable channel to bring about meaningful participation for persons with disabilities, necessary to help realise about right to health specifically for persons with disabilities.

Not much is known about the willingness, ability, constraints of HC's when engaging in disability matters, and their understanding around disability matters and barriers, specifically persons with disabilities' access to the right to health, and other relevant articles within the UNCRPD. These issues will be further explored in this study.

Another unknown variable is whether HC's can indeed fulfil their governance roles as stated in the Draft Policy, and whether they use their governance role to bring about positive or negative outcomes on the right to health. Regarding governance, the elements (software), that make up governance will be examined to assess whether they have an impact on the HC's ability to bring about the right to health for persons with disabilities.

There is also the knowledge gap regarding the barriers that HC encounter when trying to fulfil their role to be representatives for persons with disabilities, as part of the community. These could include inter-alia: the lack of financing for HC's, resistant attitudes of health care providers to HC initiatives, friction between HC members etc., there may be other barriers not mentioned here, these too will be investigated.

HC's do not exist in a vacuum, and its influences and actors are intertwined with a myriad of actors and contextual factors. This study focuses on the HC, but realises that internal and external contextual factors do play a role in how HC's can impact on their roles, and ultimately the bearing this has on participation for communities. These

contextual factors may play a fundamental role in the ability of HC to execute their governance role as stated in the Draft Policy, to bring about meaningful community participation for persons with disabilities, and will be investigated further.

Conceptual framework

The right to health care services is decreed in the Constitution of South Africa. To enliven this right, the State has produced various documents to promote meaningful community participation, underlying its importance. One of these documents is the National Health Act of 2003, which mandates the existence of HC's but does not describe the roles of the committees (DOH, 2003). HC's are mechanism to help bring about community participation, but requires the fulfilment of certain factors to ensure their ability to function and provide meaningful community participation (McCoy, Hall & Ridge, 2012). HC's have been shown to help strengthen the right to health, and are thus an applicable mechanism to bring about community participation, and hopefully help strengthen the right to health. The lack of clearly described roles for HC's in the Western Cape, amongst others, had a negative effect on the functionality of HC's and their ability to bring about meaningful community participation (Haricharan, 2012).

Persons with disabilities face numerous barriers when accessing their right to health (WHO, 2011). Persons with disabilities are vulnerable, and encounter inequality and discrimination in various forms (WHO, 2011). Persons with disabilities' access to various rights, including the right to health is compromised greatly in many aspects, when evaluated under the criteria to access the right to health.

It is hypothesised that HC's can be the participatory link between persons with disabilities, and the facility, and can thus be the mechanism to forward the already impeded right to health for persons with disabilities through their governance role. The practises and understanding of HC's regarding human rights, specifically the right to

health, disability barriers and meaningful community participation of persons with disabilities will be investigated in this study.

Research question:

Are health committees, as governance structures, ensuring the right to health for people with disability – and if not, what are the barriers for them undertaking this role?

Sub-questions:

1. Are health committees able to help realise the right to health (availability, accessibility and acceptable and quality of services), for persons with disabilities by fulfilling their governance role.
2. Do health committees address the underlying determinants of health when attempting to realise the right to health for persons with disability?
3. Are health committees able to help realise the rights and special accommodations stated in the Convention on the Rights of Persons with Disabilities?
4. How well do health committees understand the barriers mentioned in the Convention on the Rights of Persons with Disability, relating to how persons with disability access their right to health?
5. How do HC's engage persons with disability in health related decision-making on their behalf, to help advance the right to health for persons with disabilities?
6. How do contextual factors, and the arrangement of services under the ambit of governance by health committees positively or negatively influence their capacity to realise the right to health for persons with disabilities?

Research aims/objectives:

1. To explore whether health committees understand their role as a governance structure to involve the advancement of the right to health specifically for persons with disability.

2. To assess how health committees practise, and prioritise their governance role to advance the right to health for persons with disability, including how they execute these roles to help realise the right to health for persons with disability, under the four criteria mentioned in General Comment 14, and the special accommodations for persons with disability mentioned in the Convention on the Rights of Persons with Disability.

3. To describe how health committees understand the barriers experienced by persons with disability when accessing their right to health, and how they believe these can be addressed.

4. To identify the barriers that health committees experience when trying to help realise the right to health for persons with disability.

5. To evaluate how the governance role of health committees impacts on their ability to bring about the right to health for persons with disability.

Purpose:

1. To improve knowledge – for policy makers, health committees, and health officials - of health committees' role in advancing the right to health for people with disability, including understanding and knowledge of disability and barriers.

2. To make recommendations that would enable health committees to act as representatives for persons with disabilities and advance the right to health for people with disability (including training needs).

Operational definitions

Disability:

The emerging paradigm in literature and disability circles forms a marriage between the "*medical model*" where only the impairment dictates the resultant function, and the "*social model*" where societal barriers disable the individual and not the impairment, to form the more holistic "*bio-psycho-social model*". This model shows how the body impairment interacts with the physical and social environment whilst acknowledging the profound role played by personal factors such as negative attitudes in this interaction (WHO, 2011).

Human rights:

Human rights are based on obligatory laws that bind governments and government actors to act in ways to maintain, promote and protect these rights for all human beings. These rights are based on the person's inherent humanness. All human beings are entitled enjoy human rights on an equal basis without any undue discrimination. Human rights are interrelated, interdependent and indivisible, meaning that no right can exist in separation from another, human rights thus exist in unison. (United Nations, 2013)

Right to health

The right to health can be defined as "*the right to the enjoyment of the highest attainable standard of physical and mental health", and is* based on the original WHO definition of health (WHO, 1948). This definition of the right to health should be enlivened without discrimination on the basis of race, religion, political belief, economic or social condition, and requires that provisions be made to address the "underlying determinants of health" inter-alia: access to safe drinking water, adequate housing and nutrition etc. Addressing the underlying determinants of health is essential to achieve the right to health, as the right to health cannot exist without the fulfilment of these underlying determinants, some of which are rights on their own e.g. right to gender

equality, further emphasising the interrelatedness, indivisibility and interdependence of human rights (United Nations, 2013).

Community participation:

Padarath and Friedman described community participation to be the provision of *"an opportunity for community members and health care workers to become active partners in addressing local health needs and related health service delivery requirements. Community participation also enables community members and other stakeholders to identify their own needs and how these should be addressed, fostering a sense of community ownership and responsibility"* (2008). Key to this definition is that community members, in this instance persons with disabilities should be able to identify their *own* needs, and differs importantly from other definitions such as the one in the White Paper on the Transformation of the Health System, which assumes that persons with disabilities and other community members have homogenous health needs and that these needs can be presented as a collective (DOH, 1997). This definition by Padarath and Friedman allows persons with disabilities to have input on how their health needs are addressed, due to the very specific barriers faced by them. This definition also places the self-determination of needs before the assumption of ownership and responsibility for health, recognising that it is highly difficult to assume responsibility for health without having a say in objectifying health needs. This definition allows vulnerable groups such as persons with disabilities to have a say in determining their own health needs is a vital step toward ownership of health outcomes and engaging in true meaningful participation.

STUDY METHODOLOGY

Sampling

HC's will be selected from the Klipfontein sub-district of the Metropole Geographic Service Area. Considerable variations in functionality has been observed in HC's in the Western Cape (Glattstein-Young, 2010), and this will have an effect on the feasibility of selecting certain HC's for this study.

The inclusion criteria for selecting HC's are: HC's that meet at least once every month, and reach a quorum (half of members plus one) for the minimum of six months in the calendar year. Out of this pool, three entire HC's will be randomly chosen for the study.

Every member of each respective HC chosen for the study, will be used in the data collection for participant observation and Focus Group Discussions (FGD), barring any unforeseen logistical barriers and of course the accession of informed consent by participants.

Purposive sampling will be utilised by the researcher to select two individuals per chosen health committee, for the semi-structured interviews, under the guidance of the Cape Metro Health Forum Deputy-Chairperson, who is also the chairperson of the Klipfontein Health Forum, which is the coordinating body for health committees in the sub-district. Factors to assist the selection of appropriate individuals for the semi-structured interviews would be the participant membership of the HC for at least one year, and that the participant has adequate experience to provide information on whether health committees work/deal with disability issues. It is anticipated that these selected individuals should be able to yield significant information regarding the understanding and practise on how or whether health committees can advance the right to health for persons with disabilities specifically, by virtue of them being representatives for the community, of which persons with disabilities form a part.

The main objective of purposive sampling will be to above-all, richly understand the dynamics in question by seeking those with interesting

and even opposing views to existing theoretical hypotheses (Barbour, 2001), viz, HC's ability to help realise the right to health for persons with disabilities. Purposive sampling for semi-structured interviews will take place after the FGD and participant observation, which will help guide the researcher in the semi-structure interview phase and develop a better rapport with the participants.

Study methods

This will be an exploratory study, due to the paucity of knowledge around how health committee member's understanding and practise involving disability matters can possibly advance the right to health for persons with disabilities.

The case-study methodology was chosen to examine this little-known phenomenon, hence the need for an in-depth investigation into this highly complex myriad of factors affecting health committees practises and understanding. Qualitative Case-study methodology can be defined as an: "*in-depth, multi-faceted understanding of a complex issue in its real-life context*" (2011: 1). The scarcity of existing knowledge, as well as the mix of highly complex contextual factors that influence the issue, have also contributed to selection of a case-study approach (*Mouton, 2000*).

The study will involve all of the individual health committees that satisfy the inclusion criteria as mentioned in the sampling section. The complex issues are the obvious barriers preventing persons with disabilities accessing their right to health, and whether or not health committees can facilitate this. In this case-study approach, the researcher will follow an "emic", in-depth insider perspective of understanding the experience through the participant's view, to observe how health committee member's understanding and practises can influence the right to health for persons with disabilities, and not necessarily focus on the researcher's interpretations (Babbie and Mouton, 2006).

The participant's perceptions are of specific relevance to the HPSR researcher, as in this case, these perceptions shape understanding of health committees and their practises in engaging in disability matters.

The case-study approach in HPSR is of significant value in complex real-life environments, where the researcher is aiming to establish the causes for specific policy interactions, as well as how physical, personal and contextual influences on policy development, greatly impacts on how actors implement policy, and its resultant effect on its users (Lee et. al, 1998). The policy interactions in this case would be how HC's work in their governance role described in the Draft Policy, and its effects on persons with disabilities' right to health.

The study will be entirely qualitative, as it is hoped that the information acquired will have much greater depth, as well as being of greater practical use. Multiple qualitative sources of evidence will be utilised, such as FGD, participant observations and semi-structured interviews, in order to provide the richest possible description of the data. A voice recording machine will be used to record data throughout the data collection phase and will as well be used in the analysis phase for transcription purposes.

Participant Observation: Participant observation will shed light upon the behaviours of HC member's around matters of disability and human rights. Participant observations give very good insight into the context at play, as well as lessened responder bias due to the "'natural'' setting where they execute their duties (Flick, 1998). Participant observations can also allow the researcher to observe non-verbal communication e.g. disengagement to suggest disinterest when issues of disability are raised. The participant observation can thus partly provide a guiding role for questions later on in the other data collection methodologies as well as observe dimensions not captured in the semi-structured interview and FGD phase. This dual capacity of participant observation is useful to aid the understanding and arrangement of the priority that issues around disability as well as the HC's willingness to engage with these matters. The findings are however not exhaustive and if newer, relevant information emerges it, too, will be investigated. The observation will also allow for some acclimatisation of the HC members to the researcher and to facilitate discussion and rapport formation with the participants. All the HC members selected for the study will be observed using this method.

Focus Group Discussion: FGD are an important tool in providing the researcher with a view on how participants interact in a group setting and also allows for deeper investigation of emerging information as it appears. FGD also allow for a snowball-like effect for the accumulation of information, where emergent ideas can be expanded when participants share and feel they can add to the discussion further growing information. FGD will utilise all of the members of the HC, and will take place before the semi-structured interviews. This is done do negate the effect of participants changing their responses to more socially desirable, possibly less truthful responses, owing to the communal nature of FGD and the coercive social pressures that may exist. One of the dimensions to be observed could include the aversion or conversely the degree of willingness by participants regarding issues of disability, participation and human rights.

Semi-structured interviews: Following the participant observations and FGD, the semi-structured interviews will be undertaken with two participants from each of the selected HC's. Participant observation and FGD will guide the sampling of participants needed for the semi-structured interviews. Saturation i.e. the cessation of new information to arise, will determine the need to interview more than the two participants if the information yield is insufficient.

Semi-structured interviews have an invaluable ability to get detailed information and to assess how individuals feel, think and understand the issue at hand. They also provide the researcher with an ability to pursue other, potentially more interesting information that may emerge during the interview and aid flexibility, ultimately serving the goal of illuminating the data even further to give an even richer account. Semi-structured interviews are also helpful to observe how participants respond outside a communal setting, in a one-on-one setting where responses needn't be affected by pressure to do so in a socially desirable manner and hopefully eliminate the fear of reprisal due to possibly controversial comments, the product of which is hopefully a more honest response. Semi-structured interviews allow those persons that struggle to vocalise their subjective theory i.e. knowledge scope of the issue that they can

randomly recall offhand, to express themselves better than if they were in a group, without the need to compete for talk-time especially amongst more dominant personas (Flick, 1998).

Data management

All data accrued in the study will attempt to be treated with confidentiality, this can however not be guaranteed in FGD specifically due to the communal nature of method and information shared in front of numerous persons other than the researcher. Prior to the commencement of the data collection, written consent will be completed for participants as well as a description of the management and dissemination of the data. Digital data e.g. voice recordings will be stored on a private password controlled computer and backed up on a removable hard disk which with the written notes will be locked in a cupboard only accessible by the researcher and his supervisor. Participants will be able to access their own transcripts to review at any reasonable time and if prior arrangements have been made with the researcher.

Site preparation

Participant observations will commence prior to the semi-structured interviews and the FGD respectively, but may continue once the FGD and semi-structured interviews have commenced, if its intended data yield has not yet been met. The benefit of an extended period of participant observation will hopefully allow the researcher to develop a greater level of trust with the participants and facilitate more uninhibited discussion and information accumulation. A work schedule for data collection will be forwarded to all participants to assist them in planning to be able to attend the sessions, and reduce delay in the research programme. The participant observation does not have any anticipated time impediment to the participant, and is unlikely to cause any disruption in activities of the HC due to these being undertaken at already scheduled HC meetings. The interviews and FGD will have obvious time demands and these will be ameliorated by scheduling sessions at times well in advance after agreeing on the most suitable

date and time for the participant e.g. after scheduled HC meetings. Great care will be taken to prevent interference with daily activities and the onus will be on the researcher to as best possible accommodate the HC member's availability. The HC member will determine his/her preference to hold interviews at the facility in a designated area or in another previously arranged area outside the facility. Permission will be obtained from the relevant authorities prior to commencement of research. HC members involved in the research will be reimbursed for travel if research occurs outside of scheduled HC times. Refreshments will be available to all participants engaged in research for intent to promote an atmosphere of geniality.

Data analysis

The study would find itself in the "critical realist" knowledge paradigm, which captures virtues of both the "*positivist*" biomedical, logical tradition of explaining causal relationships, and the sociological tradition of deepened understanding. The "*critical realist*" knowledge paradigm is plainly expressed as questions in research about "*what works for whom under which conditions*", making it well applicable to case-study research (Gilson, 2012). The critical realist knowledge paradigm finds great applicability in real world situations such as the current HC environment in the Metropole, where solutions to real-life problems of a relativist (inductive, sociological) and positivist (hypothesis driven) nature are being required. The knowledge paradigm of critical realism is thus hoped to help understand what could and should be done in this setting to improve health committee's understanding and practises that can contribute to enhancing the right to health for persons with disabilities.

Thematic analysis will be used to analyse the data manually. In this analytic approach, the researcher groups emergent data into themes inductively, i.e. the current premise that the researcher has derived directly from the research, through the grounded theory analytical approach (Mouton, 2001).

The researcher will conduct the analysis, but to improve rigour, the analytical approach of "crystallisation" will be utilised. Crystallisation

offers an alternative to one of the pillars of qualitative research analysis, namely triangulation, by instead looking to *comprehensively* analyse findings from various data collection methods, as opposed to finding some pseudo-uniform agreement between data collection methods, which inherently require vastly different approaches to analysis (Barbour, 2001). Crystallisation also embraces the comprehensive analysis of phenomena from various vantage points, making it more realistic due to its acknowledgement of various realities having equally relevant truth (Mays and Pope, 2000).

An initial round of member checking will be done upon preliminary collection of data. This is done to aid rigour by allowing participants do check whether the researcher captured exactly what the participant tried to convey in the data collection, which improves the process of credibility (Robson, 2002). The final round of analysis will take place after the member checking and initial analysis phase.

The researcher will need to be well immersed in the data to allow for sufficient coding to take place. Preliminary analysis of the data will take place within 48 hours of the interview, to ensure that the observations are still fresh in the memory of the interviewer. Another round of analysis will take place at a later stage.

Reflexivity – is the open presentation of the researcher's own deductions and influences that may have a bearing on the interpretation of analysis and findings (Gilson, 2012). The researcher undertaking this study has a clinical background, shaped largely by interactions with health service users, and takes a specific interest in policy and how policy affects different groupings specifically, especially vulnerable groups such as persons with disabilities.

Dependability – is the process where others can see the decisions made in the research project to ensure that it followed a logical construction of one phase leading to the next, as well as full, explicit documentation of the research process from start to finish (Robson, 2002). Firstly, this will be achieved in this project by submitting this research protocol documenting the systematic processes envisaged by the researcher

before commencing the research. Secondly, there will be consistent documentation of the process to allow an external reviewer to assess the research process undertaken.

Confirmability - the element of trustworthiness and rigour in qualitative research is to ensure the data generated by participants confirms the study's findings. Confirmability will be improved by the utilisation of multiple sources of evidence that complement each other as well as member checking where participants confirm (or not), their initial responses from the data (Yin, 2009). Mention will be made if agreement is found between participant views and findings, but confirmability will not be the absolute indicator of rigour in this instance.

Transferability – is the generalisability of research findings, when transferring findings from one context or situation to another. Not much is known about how or even whether health committee's understanding and practises can, or not, advance the right to health for persons with disabilities, which makes the transferability of the results of to another context a treacherous task. The purpose of the research is thus exploratory, largely looking to generate knowledge in situations or phenomena that are not well understood (Robson, 2002), therefore transferability to other settings is not necessarily the sole focus, but to fundamentally understand the data. As the body of knowledge improves, the goal is to allow for explanation of patterns from existing research to occur, and then to link these patterns to *explain* findings, allow for abstraction and aid then generalisability to other settings (*Gilson*, 2012). In this particular envisaged study, one has to take cognisance of the immense influence of the contextual environment on policy and health committee functioning and the subsequent effect on community participation (Mc Coy, Hall and Ridge, 2012), thus findings based solely on literature in settings outside of the Metropole, local or internationally, cannot indiscriminately be transferred into this setting without the necessary contextual adjustment. This is in fact not the purpose of the research to generalise or transfer findings, but to rather gain a deepened understanding, hence the need for a case-study

approach to allow for an intensively studied account of the phenomenon observed.

Dissemination of report

Dissemination of the research report will take place in a staged approach. The first stage will include feedback to the HC members who were the main participants in the study. This component of feedback will take two forms. The first will entail the forwarding of one hard-copy of the full report to every HC involved, this is done in recognition that electronic access documents are not always easily accessible for many persons. An electronic copy will however be offered to all participants. The second will be a discussion between the researcher and the HC members, to explain findings and provide a platform for questions for persons who struggle to comprehend the written text due to educational factors or language barriers, as well as to personally thank and the participants for their vital input.

The third stage will entail the distribution of research report briefs to accompany full text copies of the research report to the South African Learning Network for Health and Human Rights, senior managers in the DOH of the Provincial Government Western Cape, the Cape Metro Health Forum and the respective facility managers of the facilities utilised in the study. This stage will also entail engaging with the senior managers within the Provincial Government Western Cape to discuss the findings and address any other queries that may emerge.

The report will also be forwarded to UCT's school of Public Health, Health Systems Department, for grading and possible publishing in a related journal.

Expected time and space impact on the health facility and members

Participant observation

Participant observation will occur as mentioned during HC meetings and will not have any bearing on time or space needed by the services in the facility. One has to however take cognisance that the presence of the researcher may to a certain extent be an imposition on the participants,

whether expressed or not, and may influence the non-verbal behaviour and/or verbal responses of the participants.

Interviews

Interviews will take place in a designated area where HC's usually meet, unless otherwise preferred by the participant. Great care will be taken to ensure privacy in the designated area i.e. access control and ensuring non disturbance. Bookings for the area and clearance through the facility manager will be done after attaining the preference from the participant.

Interviews will last for a maximum of one hour per session. If more interesting information does emerge, further consent will be obtained by the researcher prior to more data collection with the participant. There will thus be a definite impact on the facility as space will be required to do the interviews, and this request for space will need to be sought from the necessary powers that be.

Focus Group Discussions

FGD will take place in the area where the HC usually meets. To ensure that minimal disruption and a highly efficient meeting takes place, participants will be briefed regularly prior to sessions with great care taken to not influence opinion in any way. Cordial relations with the participants will be strived for by the researcher to encourage optimal attendance and freedom of expression during data collection sessions. FGD will not exceed an hour in duration, but again, if more interesting information is obtained, arrangements will be made to have another discussion. Again, space will be required for this means of data collection and will be arranged if approved with the manager in question.

Ethics

Much dissent exists in the current policy context around HC roles, with various actor groups having differing views what the content of the policy should entail. This policy vacuum due to lack of consensus by actors results in a blunting of HC's actions (Glattstein-Young, 2010). Much care therefore needs to be taken to control as best possible the

negative effects that might emerge as actors express their views on this sensitive subject, and to mitigate the fall-out of conflicting views that may emerge as a result of the study. The study will thus make expressly clear, the intentions and the potential anticipated risks, and make an effort to modestly predict benefits. As with any discourse around sensitive issues, there may be elements of vulnerability amongst some of the HC members looking to speak out against undesirable practises by HC's and service providers relating to persons with disabilities, which may expose them to possible victimisation upon completion of the research or even during the research.

The methodology and analysis will be explained in as understandable terms as needed, and agreement will be sought after explanation to attain optimal understanding of potential risks and benefits. I, the researcher am fully proficient in English and Afrikaans and can act as a translator if any inability exists to converse in either language. Although highly unexpected, if large scale language barriers present e.g. inability to understand and/or speak English or Afrikaans, the services of an interpreter will be obtained. There will ultimately always be some responsibility on the shoulders of the researcher to provide as best possible an environment that promotes fairness throughout the research process, and make an explicit attempt not to favour one party over the other, and to limit possible encroachment on others' reflection of views, in a fair, just manner.

Ultimately research needs to be of benefit for it to be ethically credible, the research attempts to provide some important information for persons with disabilities to access their right to health through meaningful participation. This benefit may come at the cost of other undesirable encounters such as conflict between health committee members.

The participants will always have the choice throughout the study to decide whether or not they would like to continue in the study, and will not be coerced in any manner to continue against their will.

Benefits

Some of the anticipated benefits include contribution to the knowledge around health committee practises and understanding, and may even assist in the improvement of the right to health for persons with disabilities. The research also aims to inform training to be undertaken with health committees, to improve their ability to bring about community participation to help realise the right to health for persons with disabilities. There may also be a modicum of health system strengthening due to the orientation of the researcher doing HPSR.

There may well be an improved understanding of disability rights issues for health committee members which could possibly influence their future practise of disability matters. The research may also be able to inform future policy around health committee's roles, to ensure the right to health for vulnerable groups such as persons with disabilities.

The benefits are not exhaustive, and more may occur, but is imperative that the researcher describes these benefits prudently to minimize any disappointment that may occur on the part of participants due to unreal expectations.

Negative effects

As mentioned, the current policy void has resulted in some contention on various issues. The expression of unpopular views within HC's may result in certain members feeling ostracized and resultant negative fallout during or after the researcher has left the facility. Participants can thus at any time, can excuse themselves from the study, and participants will not be coerced in any form to continue in the study, or to compromise themselves in any manner. The researcher will leave all necessary contact details with the participants to voice any complaints or concerns if the need arises. As much as it is hoped that the study will outline issues around disability rights and community participation to affect training and improve knowledge on related issues for HC's, it may also not do so, which may result in, or worsen any existing disappointment, de-motivation on the part of HC members with lingering effects. This negative outcome may not be attributable to the

endeavours of the researcher, but the researcher will however always strive to be fully transparent with the objectives of the research and motives, to ensure as "true" informed consent as best possible, by ensuring the participant understands the research objectives, and consents to it without any undue influence, as well as to report back to participants in a sincere manner, in good faith.

Much care will be taken to minimize the disruption to HC's activities, but some disruption is unavoidable. This disruption may be negligible, but it is imperative that participants be fully aware of the possible ill effects. There may be unanticipated negative effects unforeseen by the researcher, experienced by the participants. Participants thus need to be fully aware and comfortable with that which is expected from them.

On completion of research, all the stakeholders involved will be informed of the findings of the research and acknowledged, albeit not in a personal capacity.

It is vital that the participants and other involved actors such as facility managers have reasonable access to the researcher throughout the course of the study. Full contact details of the researcher will be provided to the relevant parties upon starting the study.

Budget

This budget is not immutable, and pending major changes in the planned research the described quantities should suffice.

Expenditure	Total Cost (ZAR)
Translation (if required)	R500
Audio recorder	Borrow from UCT
Telecommunications: - Cell phone	 R250 x 2 = R500

- Land line	R100 x 2 = R200
- Internet for email	R150 x 2 = R300
Stationery: - Flip-charts	R100
- Paper	R540 (3x Boxes, at R180 each)
- Photocopying and printing	R200
- General office supplies	R100
-	
Wages	Nil. Researcher will be responsible for all activities and will be unpaid.
Fuel and transport	R1800 (Private vehicle)
Refreshments at interviews and FGD	R1500
Contingency	R1000
Total cost	**R6740**

Scheduling

MONTH \ ACTIVITY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	JAN
Research proposal construction			■	■				
Literature review			■	■	■			
Ethics Approval: - UCT - Provincial Government Western Cape					■			
Sampling and negotiation of access					■			
Participant Observation					■	■		
Semi-structured interview					■	■		
FGD					■	■		
Preliminary analysis and member checking					■	■	■	
Final analysis					■	■	■	

Write-up and dissemination								38
Submission of thesis								
Dissemination and feedback to actors								

Sources of funding

Financial and Contractual Information:

Is the study being sponsored or funded?	**Yes**
If yes Is the study sponsored/funded by a Pharmaceutical Company?	**No**
Who is the sponsor/funder of the study?	**NRF (National Research Fund) and The Learning Network**
What is the total budget / sponsorship for the study?	**R6740**
Conference Funding? (Travel, subsistence?)	**Not presently**
Are there any restrictions or conditions attached to publication and/or presentation of the study results?	**No**
Does the contract specifically recognize the independence of the researchers involved?	**Yes**
Will additional costs be incurred by the hospital/clinic?	**No**

References

Adnams, C. M., 2010. Perspectives of intellectual disability in South Africa: epidemiology, policy, services for children and adults. *Current Opinion in Psychiatry*, 23(5):436-40.

Alliance for Health Policy and Systems Research. 2011. *What is HPSR? Overview. Geneva, World Health Organization*. Available: http://who.int/alliance-hpsr/about/hpsr/en/index.html [2013, September 2].

Arnstein, S.R. 1969. A ladder of citizen participation. *Journal of the American Institute of Planners*. 35(4): 216–22.

Babbie, E., Mouton, J. 2001. The Practise of Social Research. South African Edition. Cape Town: Oxford University Press.

Barbour, R.S. 2001.Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *British Medical Journal (Clinical research ed.)*. 322:1115-1117.

Boulle, T., Makhamandela, N., Goremucheche, R., & Lowensen, R. 2008. *Promoting partnership between communities and frontline health workers: Strengthening community HC's in South Africa* (PRA paper No. 8). Harare: EQUINET.

Braithwaite, J. & Mont, D. 2009. Disability and poverty: A survey of World Bank Poverty Assessments and implications. *ALTER - european journal of disability research / revue européenne de recherche sur le handicap*. 3(3):219-232. Doi:10.1016/j.alter.2008.10.002.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D. & McIntyre, D. 2009. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet*. 374(9692):817-834.

Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A. & Sheikh, A. 2011. The Case Study Approach. *BMC Medical Research Methodology*. 11(1):100-109.

De Savigny D, Adam T. 2009. Systems thinking for Health systems strengthening. Geneva: World Health Organization & Alliance for Health Policy and Systems Research.

Department of Health. 1997. *White paper on transformation of the health system in South Africa.* Pretoria: Government Gazette.

Department of Health. 2003. *National Health Act*. Pretoria: Government Gazette.

Department of Health. 2006. *National Rehabilitation Policy*. Pretoria: Government Gazette.

Department of Health. 2011. *Uniform Patient Fee Schedule (Appendix H).* Pretoria: Government Gazette.

Department of Health. 2013a. *Draft Policy on Health Governance Structures*. (Unpublished).

Department of Health. 2013b. *Heatlhcare 2030. Western Cape Government Department of Health*. Available: http://www.westerncape.gov.za/dept/health [2013, August 10].

Department of Women, Children and Persons with Disabilities. 2013. *Draft first country report to the United Nations on the implementation of the Convention on the Rights of Persons with Disabilities in South Africa Final Draft (un-edited)*. Available: *www.info.gov.za/view/DownloadFileAction?id=179901* [2013, April 10].

Fattore, G., Tediosi, F. 2013. The Importance of Values in Shaping How Health Systems Governance and Management Can Support Universal Health Coverage. *Value for Money.* 16: 19-23.

Flick, U. 1998. An Introduction to Qualitative Research. Berlin: Sage Publications.

Gaitonde, R. Sheikh, K. & Saligram, P. 2013. Community Participation in Health: Global Literature Review. Delhi: Public Health Foundation of India.

Gathiram, N. 2008. A critical review of the developmental approach to disability in South Africa. *International journal of social welfare.* 17(2):146-155.

George, A. 2009. 'By papers and pens, you can only do so much': views about accountability and human resource management from Indian government health administrators and workers. *International Journal of Health Planning and Management.* 24(3):205-224. Doi: 10.1002/hpm.986.

Gilson, L. 2012. Ed. Health Policy and Systems Research: a methodology reader. Geneva: World Health Organization.

Glattstein-Young, G. 2010. Community Health Committees as a Vehicle for Community Participation in Advancing the Right to Health. D.Bibl. University of Cape Town.

Groce, N.E., Rohleder, P., Eide, A.H., MacLachlan, M., Mall, S. & Swartz, L. 2013. HIV issues and people with disabilities: A review and agenda for research. *Social science & medicine.* 77(0):31-40. Doi:10.1016/j.socscimed.2012.10.024.

Haricharan, H.J. 2012. Extending participation: Challenges of health committees as meaningful structures for community participation. Cape Town: University of Cape Town.

Haricharan H.J., Heap, M., Coomans, F., London, L. 2013a. Can we talk about the right to healthcare without language? A critique of key international human rights law, drawing on the experiences of a Deaf woman in Cape Town. *South Africa, Disability & Society.* 28(1): 54-66.

Haricharan, H.J. 2013b. Rapid appraisal of health committees. Cape Town: University of Cape Town.

Huss, R., Green, A., Sudharshan, H., Karpagam, S.S, Ramani, K.V. Tomson, G., & Gerein, N. 2010. Good governance and corruption in the health sector: lessons from the Karnataka experience. *Health Policy and Planning.*26(6): 471-484. Doi:10.1093/heapol/czq080

Kleintjes, S., Lund, C. & Swartz, L. 2013. Barriers to the participation of people with psychosocial disability in mental health policy development in South Africa: A qualitative study of perspectives of policy makers, professionals, religious leaders and academics. *BMC International Health and Human Rights.* 13(17):1-10. doi:10.1186/1472-698X-13-17.

Lee, K., Lush, L., Walt, G. & Cleland, J. 1998. Family planning policies and programmes in eight low-income countries: A comparative policy analysis. *Social science & medicine.* 47(7):949-959. doi:http://dx.doi.org.ezproxy.uct.ac.za/10.1016/S0277-9536(98)00168-3.

Mays, N., Pope, C. 2000. Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal.* 1;320(7226):50-52.

Maciocco, G. 2008. From Alma Ata to the Global Fund: The History of International Health Policy. *Social Medicine*. 3(1):36-48.

McCoy, D.C., Hall, J.A. & Ridge, M. 2012. A systematic review of the literature for evidence on health facility committees in low- and middle-income countries. *Health policy and planning.* 27(6):449-466.

Mouton, J. 2001. How to succeed in your Master's & Doctoral Studies. A South African Guide and Resource Book. Pretoria: Van Schaik.

Ntsaluba, A., Pillay, Y. 1998. Reconstructing and developing the health system – the first 1000 days. *South African Medical Journal*. 88:33-36.

O'Neill, P. 2005. Review of Community Psychology: 'In Pursuit of Liberation and Well-being'. *Canadian Psychology/Psychologie Canadienne.* 46(3):173-175. doi:10.1037/h0087024.

Padarath, A., & Friedman, I. 2008. *The status of clinic committees in primary level public health sector facilities in South Africa*. Durban: Health Systems Trust.

Potts, H. 2009. *Participation and the right to the highest attainable standard of health*. Colchester: Human Rights Centre, University of Essex. Available:
http://www.essex.ac.uk/hrc/research/projects/rth/projects.aspx [2013, September 20].

Radermacher, H., Sonn, C., Keys, C. & Duckett, P. 2010. Disability and participation: It's about us but still without us! *Journal of community and applied social psychology*. 20(5):333-346.

Robson, C. 2002. Real World Inquiry. In: *Real World Research: A resource for social scientists and Practitioner-researchers (2nd Ed)*. Oxford: Blackwell Publishing.

Republic of South Africa Constitution. 1996. Pretoria: Government Printers.

Siddiqi, S., Masud, T.I., Nishtar, S., Peters, D.,H., Sabri, B., Bile, K.M., & Jama, M.A. 2009. Framework for assessing governance of the health system in developing countries: gateway to good governance. *Health Policy*. 90(1):13-25.

United Nations. 1976. *International Covenant on Economic, Social and Cultural Rights*. Available:
http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx [2013, July 27]

United Nations. 2007. *Convention on the rights for Persons with Disabilities*. Available: http://www.un.org/disabilities/convention/conventionfull.html [2013, May 18].

United Nations. 2013. *The Right to Health Fact Sheet. No. 31.* Available:
http://www.ohchr.org/EN/PublicationsResources/Pages/FactSheets.aspx [2013, June 15].

World Health Organization. 2011. *World report on Disability.* Geneva: World Health Organization.

World Health Organisation. 1948. *Constitution*. Available: http://www.who.int/governance/eb/who_constitution_en.pdf [2013, September 20].

PART B: LITERATURE REVIEW

INTRODUCTION

Persons with disabilities encounter many barriers when accessing health care services, both internationally, [1] and in South Africa [2][3]. The voices of persons with disabilities in South Africa are often disregarded in the development of health policy, negatively influencing participatory outcomes [2]. Disability should be viewed and addressed as a rights issue, owing to the massive inequality persons with disabilities often face [4], and responses should focus on inclusive measures to improve the participation of persons with disabilities in health matters [5]. This research utilised a rights-based framework to establish whether health committees, a mechanism to bring about community participation in health governance, can help advance the right to health for persons with disabilities via their governance function.

This literature review begins with the author elaborating on the health-related barriers persons with disabilities face in the South African setting, as well as impact of societal perspectives on the extent of disablement. It then moves on to review community participation in health; factors influencing health committees' ability to bring about community participation in health; and selected human rights instruments, specifically the International Covenant on Economic, Social and Cultural Rights (ICESCR) General Comment 14 and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Lastly, the review examined governance literature, and how these may have influenced the ability of health committees to bring about community participation.

REVIEW OBJECTIVES

- **To review literature on the barriers experienced by persons with disabilities in accessing health care in South Africa.**
- **To review the literature on how community participation has been operationalised through health committees in South Africa.**
- **To describe international and national provisions for the right to health for persons with disabilities.**
- **To evaluate how governance influences the ability of health committees to bring about community participation.**

LITERATURE SEARCH STRATEGY

SEARCH TERMS:

The following search terms were used to review the relevant literature:

Disability barriers in South Africa:

The researcher focused on the health-related barriers experienced by persons with disabilities in South Africa. This was done to highlight the disproportionately greater barriers persons with disabilities experience when accessing health care services. Social perspectives on disability influence the extent to which society discriminates and excludes persons with disabilities. Societal exclusion is considered to be a barrier, and negatively influences the health of persons with disabilities. The following search terms were used:

Disability; disability barriers; disabled health; health; South Africa; bio-psychosocial; negative attitudes.

Community participation and health committee in South Africa:

Community participation can take many different forms. The researcher thus decided to focus on community participation manifested through health committees, looking at their effectiveness internationally and locally. The review also looked at how health committees were operationalised, and the factors affecting their ability to perform their

function in the South African setting. The following search terms were used:

Health committees; community health committees; clinic committees; health facility committees; community participation; South Africa.

International and national provisions for the right to health for persons with disability

The review focused on two international human rights instruments, namely the ICESCR, specifically its General Comment 14, and the UNCRPD. These rights instruments provided the framework to review the literature on the right to health for persons with disabilities locally. The following search terms were used:

United Nations Convention on the Rights of Persons with Disabilities; International Covenant on Economic, Social and Cultural Rights; right to health; General Comment 14; South Africa.

Values and trust in governance

Governance is a very broad area of research. The researcher, however, focused specifically values, as they fundamentally influence the manner in which governance is dispensed. Health committees' governance style may have a bearing on the manner in which they interact with disability issues. Trust has a bearing on governance, which may be beneficial for the advancement of the health needs of persons with disabilities. The following search terms were used:

Governance; accountability; values; egalitarian; rent-seeking behaviour; trust.

Boolean search strategy was employed, utilising only one Boolean operator namely: 'AND', to refine the search strategy and find more applicable resources.

SEARCH SOURCES:

The following search databases were used via the University of Cape Town Libraries platform: PubMed, Sciencedirect, Scopus, Cinahl, Google

Scholar, and a Health Policy and Systems Research database, namely RESYST (Resilient and Responsive Health Systems).

INCLUSION CRITERIA:

English Journal articles and books sourced from physical and electronic databases in University of Cape Town Libraries, government legislation and publications, and reports by research organisations. The researcher utilised references identified within the afore-mentioned literature sources, and were included in the literature review.

Only publications since the year 1980 were included in this review, barring two publications; one from 1969 which was fundamentally influenced discourse on community participation, and another from 1976, which was the basis for the human rights framework utilised. Publications from both developing and developed nations were utilised in this research.

DISABILITY HEALTH CARE BARRIERS IN SOUTH AFRICA

Addressing the social determinants of health, such as adequate sanitation, economic development, and education are essential to achieving the highest standard of mental and physical health [6]. Globally, persons with disabilities experience disproportionately greater health care barriers as well as socio-economic barriers [1]. These barriers have a major impact on the equitable participation of persons with disabilities in society [1][7]. The disproportionate health-related barriers that persons with disabilities are exposed to in South Africa are expanded on below.

Persons with disabilities in South Africa are over-represented amongst the poorest, least educated, and unemployed; exposed to poor sanitation [8]; and are very often excluded from participating as citizens in community affairs [9]. They also face numerous other barriers to accessing health care services such as geographically inaccessible facilities, a high cost of public transport, inaccessible vehicles for physically impaired persons [10], as well as a lack of appropriately qualified, professional interpretive services for hearing impaired health

service users that hinder quality of care [11][12][13]. Social support initiatives in the form of disability grants are often the only source of income for many persons with disabilities [13]. Persons with disabilities, in many instances, experience difficulties in accessing social support services due to them not being fully aware of their eligibility, as well as excessive bureaucracy associated with accessing these disability grants [14].

The inequitable exposure of persons with disabilities to negative socio-economic health determinants and difficulties in accessing social support confirms disability as a human rights issue. This is in direct contravention of the fundamental right to equity in the South African Constitution, and a violation of health and social security rights contained in Section 27 of the Constitution. These examples highlight the interrelatedness and indivisibility of human rights, emphasising that the right to health cannot be realised for persons with disabilities, unless other equally important rights, such as equality are realised. The promotion of an approach grounded on the realisation of human rights is fundamental to advance the needs for persons with disabilities [4][5] .

Social perspectives of disability

Environmental barriers that persons with disabilities are exposed to are, to a large extent, influenced by prevailing social perspectives on disability [7]. It is argued that social perspectives on disability actually disable the individual, and not the impairment itself [1]. The evolution of social perspectives pertaining to disability are discussed below, and their impact on the equal participation of persons with disabilities in society.

Society's prevailing perspective on disability can have a profound effect on the daily experience of persons with disabilities [1]. Societal views of disability, initially seen as a form of divine retribution in medieval times, have morphed considerably since then to include impairment-related and social aspects [15]. Societal perspectives pertaining to disability have the potential to exclude persons with disabilities from mainstream participation due to overt, or often more insidious social interactions which are fixated on normative classification of persons in terms of what

it considers normal [7]. The following contrasting societal perspectives on disability illuminate this classification.

The *"human diversity perspective"* is oriented along a view that disability should be considered as another variant of human existence, just as race, gender, or sexual orientation.

A more common, and potentially destructive view of disability is the positivist *"natural disadvantage"* perspective, where the individual is primarily defined by his/her impairment, and should be moulded through various interventions, such as limb prostheses, to fit into society's view of normalcy [7].

Employing the natural disadvantage perspective, via interventions to correct impairments of persons with disabilities to fit into the "normal" societal schema, is vital to improving participation in societal interactions, through, for example, the provision of assistive devices. The downside to solely utilising this perspective, is however, that these interventions are then prone to being perpetually perverted to exclude persons with disabilities from ever being just considered another type of human diversity [7]. The natural disadvantage perspective, by its very nature, often erroneously omits the profound impacts of the social environment on the person with a physical or mental impairment, often being the primary reason for disablement [7][15][16].

The contemporary view of disability has shifted significantly to include the social participatory element of disability at its centre, although not entirely excluding the bio-medical aspect, culminating in the '*bio-psychosocial perspective*' [1]. The bio-psychosocial disability perspective importantly acknowledges that the perspectives of "normal" society members and the power they yield, greatly determines the degree of participation in daily interactions of many persons with disabilities, and not the impairment itself [1][7][15][17]. It is therefore the perspectives of society, and the values that underpin it, that shapes the prevailing view of normality, and subsequently the extent of exclusion of persons with disabilities from various societal interactions [1][7].

COMMUNITY PARTICIPATION

The Primary Health Care approach emanated from the Alma-Ata declaration, which was adopted in 1978 at the World Health Assembly, a multinational gathering of health ministers, held in Alma-Ata, Kazakhstan, in 1978 [18]. The Alma-Ata declaration, called on nations to, inter-alia: acknowledge the profound role socio-economic determinants of health, such as adequate water, food etc. play in achieving good health outcomes; improve health outcomes for citizens for socio-economic prosperity; develop policies that look to support health promotion activities to prevent adverse health outcomes; have communities participating in all matters regarding their health, determining their own needs, and being actively involved in the planning of interventions to address these needs, to ultimately achieve equitable social and economic development for communities. The adoption of Primary Health Care by the World Health Organisation signalled a marked policy shift from existing inequitable, curative health systems, toward universally accessible health systems oriented on fundamental principles of equity and the participation of users in health-related decision-making [18][19].

Factors such as political and economic crises, extensively spreading infectious epidemics, and an exodus of skilled health workers from developing nations to developed nations have all contributed to the stagnation of the Primary Health Care movement globally, and its comprising elements, such as community participation. Watered-down versions of Primary Health Care such as selective Primary Health Care often exemplified by low-cost vertical interventions which focus on individual health programmes, and not transversal health system change as envisaged at Alma-Ata, have stifled the Primary Health Care Movement [19]. Macro-economic factors, such as the global development agenda strongly leaning toward neo-liberal financial policies, and resultant pressure placed on developing nations to under-spend on public services such as health, have also contributed to the poor implementation of Primary Health Care, and ultimately community participation [18].

Community participation is a central tenet of the Primary Health Care approach [18][19]. The community referred to in community participation in health can possibly be best understood as *"a group of people with diverse characteristics who are linked by social ties, share common perspectives and engage in joint action in geographical locations or settings"* [20]. These groups of people that make up a community are characteristically socially diverse, with differing social influences, but at the same time also (albeit to varying extents), share common values [20]. Participation, relevant to community participation in health could again be understood to involve "*genuine and voluntary partnerships between different stakeholders from communities, health services and other sectors based on shared involvement in, contribution to, ownership of, control over, responsibility for and benefit from agreed values, goals, plans, resources and actions around health*" [21]. Participation, derived from this definition, suggests that the degree of control over elements involved in a health system is an important part of participation. Community participation in its entirety could be conceptualised as social interactions orchestrated by collectives within a geographically defined society which share common needs, and take actions to implement measures based on these needs to achieve shared outcomes [22]. Community participation is largely operationalised in two sub-categories: firstly, community development, where communities organise themselves and resources along existing needs separate to activities of the state; or secondly, when decentralisation of state functions warrants the participation of citizens in governance activities. These two types of community participation are largely differentiated essentially by their proximity to the activities of the state [23].

Structures enlivening community participation take on various forms, from locally organised community meetings [23], to elected citizens serving on the boards of state institutions [24]. Community participation has been shown in literature to have numerous benefits, ranging from improving state responsiveness to the needs of communities [23], improved availability of services through community efforts to generate their own resources [24], and the promotion of equitable resource distribution by incorporating marginalised groups in decision making [25].

Disability activism in South Africa championed the mantra: 'nothing about us without us', as a rallying call for persons with disabilities to contest their exclusion from decisions involving them [26]. The refrain 'Nothing about us without us' fundamentally speaks to persons with disabilities representing themselves in various societal domains, by active participation, to allow persons with disabilities to be empowered and to determine the course of their own lives [26].

COMMUNITY PARTICIPATION AND HEALTH COMMITTTEES

Community participation structures in health can either take the form of formally legislated representative structures, or informal structures, such as those which emerge due to a prominent community need [27]. An example of informal participation includes the mobilisation of civil-society organisations in Guatemala to counter state driven oppression of social participatory movements [28]. Health facility committees are an example of formal community participation, as their existence is mandated in legislation [29].

There is much variability in the functions of health facility committees [30][31]. However, research suggests that health committees should contain the following fundamental functions: governance, which involves agenda setting and oversight [32] to make facilities aware of the health needs of the community; shared decision-making between committees and the facility; to act as levers for social equity entailing the involvement of marginalised sections of the community, for example, persons with disabilities [30]; as contributors to the planning and provision of health services [33] and acting as agents of health information diffusion within communities [34]. Community participation through health facility committees has been shown to be effective in different settings [30]. Examples substantiating the benefit of community participation in health via health facility committees include: improved community satisfaction with services in Peru [35]; improved access to health services in Zimbabwe [36]; and lastly, improved health coverage of essential interventions, for example, vaccinations in Uganda [37].

Research conducted in South Africa found that health committees were able to advance the right to health for communities [38].

However, structures intended to bring about community participation have also experienced criticism. Some examples include participatory structures often tending to recruit prominent and more educated community members over more vulnerable members; undertaking health interventions separate to community priorities, such as employment or community safety, leading to poor sustainability [39]; participatory structures relying on "preference aggregation", which is the process of decision-making in favour of the majority, over consensus-based deliberations that include all segments of the community, where vulnerable groups, however under-represented could still be included in the participatory discourse [40].

Positive indications of the effectiveness of health committees cannot however be uniformly be generalised across all settings, as community participation interventions via health facility committees are not standardized, and are highly context-sensitive [30][31]. There is a shortage in literature regarding the effectiveness of health facility committees [41]. Nonetheless, there is evidence that health facility committees can have a positive influence on the health system if certain requisites were in place, such as: role clarity, health system factors which include supportive staff attitudes, and societal factors, for example, the generation of political support for health facility committees [30]. Societal Contextual factors such as history [28][31] influence the functioning of health committees. Such examples include participatory discourse focusing on issues of socio-economic advancement in the presence of a greater political developmental agenda [42], or the influence of participatory bodies in achieving equitable health outcomes coinciding with equity-centred socio-cultural perspectives [43].

HEALTH COMMITTEES IN SOUTH AFRICA

South Africa adopted the Primary Health Care approach after the dawn of the post-apartheid democratic dispensation, to address the existing inequality of health services evident after apartheid, through community participatory reforms and engaging citizens in decision-making [44][45].

South Africa's health system, prior to democracy, was highly fragmented, with services unequally distributed along racial lines [46]. The democratic government recognised the vast disparity in health services that exists for many South Africans, and subsequently produced the White Paper for the Transformation of the Health System in South Africa. This document identified the participation of communities in health matters as a necessary component to achieve one of its key objectives, the Primary Health Care approach [47].

The government adopted the National Health Act of 2003, which, in-part aimed to unify the fragmented health service by establishing the district health system [29]. The National Health Act, in line with the country's Constitution, describes the three tiers of government - national, provincial and municipal - which are essential to the establishment of the district health system. The national department is primarily responsible for the development of policy and monitoring provincial health services through national health plans. Provincial health services in each of the nine provinces are tasked with, amongst others, implementing the district health system by demarcating geographical service areas, planning and providing health services. Local municipalities within provinces are primarily tasked with providing preventative and promotive services, including environmental health and others [29].

Community participation in health was formalised in the National Health Act through the prescription of community health committees (a form of health facility committees) referred in this review hereforth as health committees, linked to primary care facilities, or groups of primary care facilities [29]. The Act specifies that health committees must be composed of the following members: the health facility manger, the

local municipal wards councillor and community members, but delegates the prescription of roles and functions of health committees to the respective provincial health departments. However, the Act does not specifically illustrate matters critical to health committee functionality, such as elections, tenure or remuneration. Two provinces, the Eastern Cape and the Free State, have added to the basic composition described in the National Health Act, by mandating the representation of a number of stakeholders including persons with disabilities with on health committees [32].

Only five of the nine provinces have so far provided roles and functions for health committees, and the Western Cape Province is one province that has not yet done so [32]. The absence of policy detailing the roles and functions of health committees in the Western Cape Province has had a negative impact on their functionality, resulting in them being viewed by facility staff as ancillary workers augmenting the functions of the facility [48].

Within the South African setting, Glattstein-Young, looked into whether community participation via health committees helped to realise the right to health. The author categorized a health committee as 'strong' when regular meetings with regularly actionable outcomes were undertaken, a 'moderate' health committee held regular meetings, but attendance and actions resulting from these were not adequate, and 'weak' when health committees were, for all intents and purposes, non-functional [38]. The study found that the strong health committee were able to help to promote the right to health for communities when more equitable power relations between facility managers, staff and health committee members were evident. The study also highlighted the need for '*wider*' community participation to include marginalised groups, for example, persons with disabilities [38].

Health committees are the structures to bring about community participation in health in South Africa. Research suggests that community participation should include a meaningful degree of citizen control in

decision-making [25], identification, and influence in the resolution of community needs [22], agenda setting and ensuring accountability in service delivery [49]. Health committees therefore, as the mechanism to bring about community participation, are required to have a governance and oversight role to improve accountability in health services [32]. Perceived illegitimacy of health committees on the part of health department representatives, coupled with the absence of a policy for health committees, negatively influenced community participation [50] and their subsequent governance function.

However, community participation in the South African health setting has had limited success, owing in-part to the sub-optimal functioning of health committees [33][51]. Reasons for this shortcoming include: (i) discrepancies between provinces in how they conceptualise the governance and oversight role of health committees, (ii) limited administrative and political support for health committees [extending], and (iii) resource constraints due to political ambivalence impacted negatively on health committee functions [33].

THE RIGHT TO HEALTH IN INTERNATIONAL LAW

Human rights are claims based on legally protected entitlements, made by individuals or groups which aim to fulfil basic human needs [52]. Rights can be classed in two categories, socio-economic rights such as the right to food, and civil-political rights, such as freedom of association. Human rights are obligations (generally located in international or country laws), that require states to protect the most vulnerable in society to foster social justice [52].

The Vienna Declaration and Programme of Action emerged from the World Conference on Human Rights in 1993 declared human rights to be indivisible, inter-related, interdependent, and universal [53]. Central to this declaration is the fundamental tenet that rights cannot be implemented selectively or in order of priority, but instead must be implemented in its entirety [52]. States should not only commit to recognising human rights as merely an ideological platitude, but should

also work to make concrete progress on the realisation of rights, for real-life change in citizens' lives [54].

International human rights law acknowledges the reality that states have finite resources at their disposal, limiting their ability to immediately enliven the spectrum of socio-economic rights; states are thereby required to progressively realise the rights of the most vulnerable within a predetermined period [55][56]. The concept of progressive realization thus allows states to ration the delivery of services based on available resources but within a framework of progressively expanding services over time. Thus, states may deliver rights obligations over a period of time, but must progressively show observable actions to honour these rights [56].

The first framing of health as a right is contained in the World Health Organisation Constitution which defines health as: *'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'* and goes on to say that all human beings should have the right to the highest attainable standard of health [57]. The idea that health is a right was carried forward into the ICESCR, which is a rights instrument containing various rights protections, including the right to the highest attainable standard of health [58]. Subsequently, the Committee on Economic, Social and Cultural Rights developed general comments to elaborate on specific rights within the document. General comments are expert interpretations of the rights contained within the ICESCR. General comment 14 is the normative elaboration on the highest attainable standard of health, which expands on what constitutes the right, including the acknowledgment of specifically vulnerable groups of people such as persons with disabilities, and states' duties to uphold the right [6].

General Comment 14 of the ICESCR categorises the components of the right to health in the following manner:
Accessibility, with its four sub-elements: non-discrimination, physical, economic and information accessibility. Non-discrimination is a

fundamental element of improving access, as discriminatory practises especially against marginalised groups in society, can inhibit access to health care. Physical access implies the presence of health services and amenities relating to the underlying determinants of health, for example, adequate sanitation, in a reachable proximity for all sectors of society. Economic access suggests that heath care, and the costs associated with the underlying determinants of health, are equally affordable for all in society, especially disadvantaged groups. Informational access emphasises the importance of communication in health, acknowledging that all persons should be able to obtain and reciprocally give health information in a fair manner.

Availability of health services implies the rendering of functional services that include the underlying determinants of health, physical and human resources of adequate quantity. The extent of delivery will likely depend on the financial capacity of the state to deliver on these services and resources.

Acceptability of health services, speaks to whether health services are appropriate from a cultural and medico-ethical perspective, as well as whether health services honour confidentiality in health.

Lastly, health services must be of good *Quality*, importantly noting that services should abide by medical scientific standards, and measures to improve quality should include those aimed at the underlying determinants of health [6].

THE RIGHT TO HEALTH IN SOUTH AFRICAN LAW AND POLICY

 The South African Constitution was built on fundamental elements of equity, freedom and human dignity [17]. The right to health in the South African context imposes a duty on the government to progressively realise access to health care services for its citizens [52]. The Constitution contains various human rights provisions, it provides for an array of health rights, which include the right to health care services and emergency treatment, the right to equity and human dignity for all persons, rights pertaining to the social determinants of health, for example, food and water, and rights which give explicit protection to vulnerable groups such as persons with disabilities [52]. The Constitution holistically

integrated socio-economic and civil-political rights, without hierarchically ordering some rights over the other, reflecting its acknowledgement of the indivisibility of rights [59].

Section 27 of the Bill of Rights, contained within the South African Constitution of 1996, houses a set of socio-economic rights, namely, the right to have access to: '*(i) health care services, including reproductive health care; (ii) sufficient food and water; and (iii) social security* [60]. The National Health Act of 2003 is one such statutory framework to elaborate on the right to health care services contained in the Bill of Rights. Other legislative measures adopted to operationalise the right to health care services provide specific protections for vulnerable groups, such as the Mental Health Care Act of 2002 [61], and the Children's Act of 2005 [62]. Chapter 9 of the Constitution mandates the presence of independent institutions to strengthen democracy and preserve rights contained in the Constitution. Institutions specifically ordered to protect health rights include the Public Protector and the South African Human Rights Commission. An example of the work of so called Chapter 9 institutions was the South African Human Rights Commission's review of the barriers persons with disabilities face when accessing health services [54]. South Africa's parliament has ratified the ICESCR, iterating its policy-based intentions to provide human rights protections for its citizens.

THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITY

Issues affecting persons with disabilities have, for very long, been seen as an adjunct to those affecting the majority of society, often leading to fragmented interventions. Disability interventions are often hampered by a lack of political will, financial commitment and policy impotence, ultimately leading to poor sustainability, inequality and limited meaningful changes in the lives of persons with disabilities [1]. Disability is increasingly being viewed as a human rights issue both internationally [1][5][7] and locally[4]. The UNCRPD is an international human rights treaty that provides broad obligations on states, in order to promote equity and non-discrimination against persons with disabilities [63].

The UNCRPD contains various articles, which aim to give persons with disabilities, as well as specifically vulnerable groups of persons with disabilities, such as women the necessary protection against the barriers they face [63]. The following articles: Article 9, the accessibility to health services; Article 20, improvement of personal mobility for persons with disabilities; Article 25, health; and Article 26, involving the rehabilitation of persons with disabilities, are relevant to this research as they relate most prominently to the health rights for persons with disabilities.

The implementation of UNCRPD globally has however been erratic and slow, with little real-life changes in the lives of persons with disabilities [64]. It is argued that the implementation of the UNCRPD is often impaired due to states not appropriately employing monitoring and evaluation measures. Civil society should be actively involved in monitoring the implementation of the UNCRPD, not as a parallel programme, but incorporated within existing development programmes [64]. South Africa, showing its policy intent to address the associated rights exclusions that persons with disabilities often face, ratified the UNCRPD in 2007 [3].

THE RIGHT TO HEALTH FOR PERSONS WITH DISABILITY IN SOUTH AFRICA – POLICY AND PRACTICE

South Africa offers numerous rights-based protections for persons with disabilities under its various policy documents. The extensive barriers persons with disabilities are exposed to however limit them from enjoying the benefits afforded to them in policy, revealing a deep chasm between policy and the practice. Several examples of these health-related barriers are listed below, to articulate the difficulties persons with disabilities face when attempting to utilise their right to health.

ACCESS
Non-discrimination

Some of the health-related barriers persons with disabilities experience whilst accessing health care services include negative attitudes which

are a form of discrimination, and are typically prejudicial and/or exclusionary practises perpetuated against persons with disabilities [2]. Socio-cultural prejudice toward persons with disabilities is also unfortunately highly prevalent within the South African setting. Stakeholders in various psychosocial disability advocacy movements in South Africa were continuously excluded from platforms where many fundamental mental health policies were developed, as well as other general health service delivery reforms. The reasons for this include: negative attitudes and stigmatisation, where health planners often prejudicially judge persons with psychosocial disability as incompetent to participate in decisions regarding their health; poverty limiting their access to decision-making platforms; and limited community supporters to advocate for their participation [2]. Discrimination as a result of negative attitudes manifest amongst health care professionals who often do not fully understand the behavioural changes that are often present in children with disability, and then subsequently lose patience, and end up not treating children with disability with the empathy they require [54]. The reasons for the common instances of negative attitudes toward persons with disabilities in the public service are often due to poorly trained staff and ineffective redress mechanisms for persons with disabilities [3].

The relationship between HIV and disability is a bilaterally harmful one, as persons with disabilities are often at greater risk for developing HIV, and persons with HIV at a higher risk for developing physical and/or mental impairments which have the potential to disable individuals [64]. Negative attitudes within society are partly responsible for the increased risk of persons with disabilities acquiring HIV as persons with disabilities are often coerced into sexual relationships under arranged marriages, or due to a need by the individual to feel accepted [65]. Other such manifestations include discriminatory attitudes encountered by females with disabilities when accessing reproductive health care [66], and 'virgin cleansing', which is the fallacy whereby HIV infected persons imagine that sex with a virgin, in this case a person with a disability whom they presume are asexual, will reverse their HIV infection [67].

Several examples from the South African context are listed below, which explain the impact of health-related barriers on persons with disabilities' right to the highest attainable standard of health under the criteria listen in General Comment 14 of the ICESCR; as well as how barriers influence the realisation of selected articles under the UNCRPD.

Physical Access

Persons with disabilities experience considerable physical barriers when accessing health care in South Africa [1][3][17], such as: inaccessible transport [10][68], or a lack of physical infrastructure accommodations, for example, disabled-friendly toilets [3]. Barriers, and their negative effects on persons with disabilities are often experienced to a greater extent in developing countries such as South Africa, due to the abundance of detrimental socio-economic effect amplifiers, for example, high levels of poverty and a high disease burden [69]. These physical access barriers are pervasive, and affect persons with disabilities in numerous ways, in that they extend across the spectrum of disability impairments [1][11]. Manifestations of these amplified barriers include intellectually disabled children who have greater likelihood of being orphaned due to their HIV infected parents not accessing quality health care [69].

Economic Access

A lack of affordable health services is often the main reason why persons with disabilities do not receive the health care they require [1]. Unaffordable health services for persons with disabilities are often exacerbated by high out of pocket costs associated with health care [70]. Research conducted on social assistance in developing nations revealed that persons with disabilities often incur extra costs compared to non-disabled individuals, such as assistive devices and communicative aids, suggesting that it may cost more for persons with disabilities to attain the same living standards [71]. Extra costs have a direct bearing on the affordability of health services for persons with disabilities [1].

Rehabilitation services in South Africa are predominantly situated in major cities, often rendering persons with disabilities in rural areas unable to afford the transport costs associated with accessing these services [3]. Rudimentary home care is not offered free of charge throughout the country, and is often unaffordable even in the presence of social assistance [72].

Informational Access

Rohleder et al. inquired about the role that disability organisations in South Africa play in addressing HIV in South Africa, and found that persons with disabilities were often excluded from accessing health information around HIV [66]. They also found that persons with disabilities were not aware of their increased risk for developing HIV, with ramifications for their future sexual behaviour and risk of developing and/or spreading HIV.

Visually impaired South Africans are also often marginalised, as health informational resources relating to HIV are not always in accessible media, contributing to false perceptions amongst persons with disabilities around HIV/Aids [67]. Research suggested that persons with disabilities appeared to not be overly concerned about acquiring HIV as they believed their infection would be reversed by someone else, underlining the how poorly informed some persons with disabilities were regarding HIV [66].

AVAILABILITY

Swartz found that clinicians with poor African language proficiency saw the assessments of persons with disabilities for disability grants as more of a bureaucratic exercise to ensure hospital functionality, and not for its intended value of contributing to the reduction of extreme poverty associated with disabilities [12]. The lack of professional language interpreters had an adverse impact on how persons with disabilities are

perceived and the care they receive. The availability of rehabilitation professionals and physical resources influence health outcomes of persons with disabilities, for example, assistive devices in South Africa are severely limited due to budgetary constraints faced by the government [3], which needs to provide health care services to other pressing health burdens, for example, HIV [46]. A review focusing on the health outcomes of persons with intellectually disabilities reaffirmed the lack of availability of adequately skilled human resources working in the disability arena. Apartheid substantially worsened this human resource shortage, often exemplified by the lack of trained multi-disciplinary health services and in rural areas, resulting in unacceptable service gaps for persons with disabilities [69].

The UNCRPD obliges states to provide adequately trained health professionals to work with persons with disabilities [63]. Limited availability of human and physical resources have a negative impact on the provision selected rights contained in the UNCRPD, which prevents persons with disabilities from accessing health services such as rehabilitation services.

The state has however started to recognise the negative effect of unavailable health services and resources for persons with disabilities, and argues that it has started to increase the budgetary allocation for disability-specific health services, to relieve the pressure on non-governmental institutions, which currently carry a substantial cost-burden of disability health services [3].

ACCEPTABILITY

In 2009, the South African Human Rights Commission undertook an inquiry into the right to health at public facilities, and found that health centre staff often exhibited inappropriate behaviour specifically toward persons with disabilities, and did not show the necessary sensitivity to meeting the health needs of persons with disabilities, resulting in unacceptable service delivery toward persons with disabilities [54].

Persons with disabilities often require nuanced introduction to places of employment as part of their vocational rehabilitation. Persons with disabilities were often subjected to unacceptably long waiting lists, often in excess of one year, to be placed in vocational rehabilitation centres, often resulting in persons with disabilities defaulting on their attendance of rehabilitation programmes [73].

QUALITY

Poor quality health care can have dire consequences, including increased risk of mortality and morbidity [54]. Persons with intellectual disabilities utilising health care services were often treated by persons without the specialised training needed to manage their complex conditions [54], resulting in obvious quality implications of care [3]. Further examples of poor health care quality include children with disabilities who were often issued assistive devices that were inappropriate for their condition or age, in contravention of prescription standards for the fitting of assistive devices [54], as well as waiting for excessively long periods to receive assistive devices [3]. Rehabilitation services for persons with disabilities across provinces within South Africa differ greatly in quality, largely due the disparities as a result of Apartheid [3]. Some of the ramifications of the HIV epidemic are its numerous disease sequelae, such as mental health impairments, which place extra strain on already inadequate mental health services, negatively impacting on the quality of health services available for persons with disabilities [74].

A case study conducted on access to health services for persons with hearing impairments revealed that language barriers often result in impaired quality of health services, as well as other rights violations, including the right to health [11]. Another study looked into how clinicians in a hospital setting interacted with mental health users with psychosocial disability; it found that informal interpreters, a common sight in South African health facilities, were often used to augment health services where professional, experienced interpreters were not available

[12]. Communication barriers between clinicians and mental health users with psychosocial disability often resulted in inaccurate diagnoses, with resultant sub-optimal patient outcomes. Both studies called for professional interpreter services to be made available to persons with disabilities when accessing health services to improve, amongst others, quality of care.

The White Paper on Transforming the Public Service of 1997, listed the Batho Pele 'People First' Principles, in which it contains various prescripts to improve service delivery, including citizens' right to courteous treatment [75]. Persons with disabilities are however continually exposed to poor staff attitudes when accessing health services [54][75]. The contravention of service standards leads to the exposure of persons with disabilities to poor quality health services.

Another health care review of persons with disabilities found that cognitively impaired children were at an increased risk of receiving incorrect chronic medicines, with adverse effects on the quality of health care they experienced [3].

South Africa has, however, put into place numerous legislative and policy-based protections for persons with disabilities to receive services of high quality standards. An example of these protections is the National Rehabilitation Policy, which, as a guiding principle, mandates health facilities to provide assistive devices of high quality [76]. Another statutory measure to improve quality in health services is the National Core Standards, developed by the national department of health, which is a document containing normative standards that health facilities must satisfy which reflect desired standards of quality care [77]. Standards relating to persons with disabilities are specifically mentioned in the National Core Standards, although relating only to accessibility for persons with physical impairments and not other types of disability, such as sensory disability or intellectual disability [77]. The Mental Health Care Act of 2002 mandates the existence of Mental Health Review Boards within the various provinces, which are tasked with ensuring the rights of

persons accessing mental health is protected [61]. Persons with disabilities' ability to complain about poor quality health services is often hampered in South Africa due to poorly functioning, or in many cases, non-functional Mental Health Review Boards [3].

The state also aimed to improve quality outcomes for citizens accessing health services, including persons with disabilities, by commencing the National Health Facility Baseline Audit, which assessed health facilities' readiness to achieve quality standards [3]. The results however speak about serious shortcoming in quality of health services, especially in areas of patient safety and a lack of caring attitudes [78].

Numerous examples exist which outline the barriers persons with disabilities experience in accessing their right to health in South Africa [54]. South African policies provide broad ranging, inclusive policies that offer numerous protections for health rights of persons with disabilities, but policy implementation falls substantially short [3][54]. Various aforementioned factors contribute to the stasis in implementation of policy. Implementation of health policy directives relating to vulnerable groups such as persons with disabilities, and working towards achieving policy goals in practise is imperative to realising the right to health [54]. The implementation of disability health policy relating to the right to health can be achieved, in-part through: improved targeting of disability interventions which end up reaching persons with disabilities; accountability mechanisms monitored by the national department of health on deliverables relating to disability; and fast-tracking disability interventions that address barriers [3]. Efforts to strengthen health policy implementation specifically for persons with disabilities should include increasing the profile of disability health research, and engaging with health workers around perceptions that perpetuate discrimination [54].

GOVERNANCE AS THEME OF HEALTH POLICY AND SYSTEMS RESEARCH

Good governance comprises elements of accountability and responsiveness, which can potentially improve health care outcomes,

health system performance [79], and the implementation of health policies [80]. Good governance is thus critical to addressing the health needs of persons with disabilities. Another critical component of good governance is public participation in decision-making [79][81]. Health systems should thus promote good governance practises, and subsequent community participation, in order to better address the health needs of persons with disabilities.

Governance is one of the six building blocks in the health system model, and is a cross-cutting, central component to the delivery of services within the health system [82]. The World Health Organisation is currently considering adding the participation of service users as one of the core transversal elements that interplay with all the building blocks (including governance) that comprise a health system [83].

A definitive description of governance is illusive, owing to the various sub-components that it is comprised of, inter-alia: accountability, answerability, oversight [84], actor relationships, power, values, health-related policy and political factors [85], and positive and negative influences at various levels of authority [86]. One possible contributor to the hazy definition of governance is the lack of an agreed upon "fit" of contextual design of factors required to best understand governance [86]. Possibly the most inclusive, yet concise definition of governance is that of Burris, Drahos & Shearing, which describes governance as the *"management of the course of events in a social system"* [87]. This definition recognises that a central entity (the governance structure) intentionally, or not, orchestrates the dynamics - be they in an interpersonal, resource or power form - within the social system to achieve pre-set goals [88].

State governance authorities should consider promoting the involvement of civil-society and private sector to execute the functions government, and hold it accountable [23][79]. Health committees, as governance structures, should play a role in planning primary health facilities, ensuring

the needs of communities are addressed, and hold facilities accountable [32][89].

GOVERNANCE AND ACCOUNTABILITY

Good governance is the employment of governance in an egalitarian, transparent manner, grounded on morality void of self-enriching interests [81]. Good governance involves the concept of accountability at its centre [81]. Brinkerhoff [84] describes accountability as the burden to provide answers on decisions taken, and why these were taken. Failing the delivery of accountability, sanctions may be imposed to regulate the behaviour to ensure accountability. Another critical aspect of accountability is the ability of an oversight body to impose sanctions to keep governance entities answerable, yet accountability is often not employed adequately in the presence of ineffectual sanctions. However, accountability need not always be punitive, measures aiming to promote answerability could also include the availability of incentives to realise desired standards or behaviours. Importantly, accountability cannot be implemented vertically in selected areas within a health system, and in other areas corruption and poor governance run rife. All elements of accountability need to be adopted in a system-wide manner to achieve real accountability [84].

Achieving system-wide accountability is possible and has been empirically established as seen in the New Zealand healthy system [43]. In this example, community participatory bodies in the form of district health boards were established by the minister of health. These boards comprised public servants as well as members of communities to hold health service facilities accountable to the needs of communities. District health boards were equipped with considerable clout to sanction health facilities and attune the delivery of services, which proved effective in bringing about accountability. Importantly, the research highlighted the significance of shared values such as inclusivity and equity in achieving accountability and oversight [43].

GOVERNANCE AND VALUES

Governance entities' decision-making is fundamentally guided by its values. Implicit governance values determine the affinity to involve, or exclude stakeholders from decision-making [90].

Poor governance is characterised by corruption, impotent oversight bodies open to perversion, lack of accountability, and self-serving interests [90]. Similarities are observed between poor governance and rent-seeking behaviours, which are a set of governance values. Rent-seeking behaviours are typically characterised by: corruption, manipulation of rules to suit self-gain at the expense of the greater good, the centralisation of power, exclusionary practises, and a lack of accountability to citizens [23].

Egalitarian values are, however, contradictory to rent-seeking values, and are generally manifested by governance practises that: encourage a sense of unity; promote wider participation of all sectors in deliberative decision-making over economic, social, or political pedigree; oppose unjust professional hegemony or excessively hierarchical structures, ultimately generating mutually beneficial agreement in decision-making [90].

Decentralisation of power to ensure equitable enjoyment of services and resources are key manifestations of egalitarian values [90]. Good governance requires: strong state-public partnerships that have a balance in power to realise equitable service delivery, the inclusion of civil society in governance functions, and actions to stop corrupt practises and foster accountability [81]. Egalitarian values could thus be the cornerstone of actions to promote good governance.

GOVERNANCE AND TRUST

Gilson considers trust to be a relational interaction between entities, conferred upon the trustor when the trustee considers the trustor able to

advance their needs, or to at least not be working against the trustee's needs [91]. The trust relationship is largely driven by trustor perceptions of parity, as notions of partisanship corrode trust. Discrimination and inequality in decision-making and resource allocation, detracts from an organisation's legitimacy, which, in turn hampers its efforts to achieve objectives [91].

The benefits of trust within a health setting are substantial, and include, amongst others, the strengthening of social capital, essential for generating information and resource sharing networks between service providers [91]. Other benefits of trust include improvement in health outcomes for communities, and building legitimacy of health service providers, which could lead better implementation of planned service interventions. Trust also develops legitimacy, which in turn promotes ethical manifestations of governance within a respective society [91].

SUMMARY

Participation of communities in health care decision-making lies at the heart of Primary Health Care, the revolutionary health care paradigm which recognises the fundamental role that health care improvements play in achieving social and economic development.

Community participation can take various forms, which involve formal or informal mechanisms. Structured community participation in health is often realised through health committees, which represent the health needs of communities. Health committees have been shown to be effective under certain conditions, but the extent of their effectiveness as well as their ability to advance the health needs of persons with disabilities remains unclear.

Health committees were intended to be governance structures in policy. Local evidence however, shows that their governance role is hampered by a lack of policy that clarifies their roles, which inhibits health committees' ability to represent the health needs of communities. Although health committees encounter challenges relating to their governance role, it is important to note that values influence the manner

in which governance is practised. Egalitarian values greatly influence the decision-making of governance structures in being equitable and inclusive of the entire community. Egalitarian values also stimulate trust between service users and the governance entity.

The South African Constitution offers numerous health rights that provide protections for all its citizens, including persons with disabilities. It ratified both the ICESCR and the UNCRPD, signalling its strong policy intent to deliver on the right to health for its citizens, including persons with disabilities. Persons with disabilities in South Africa however still endure substantial barriers that hinder them achieving their right to health.

JUSTIFICATION FOR FURTHER RESEARCH

Persons with disabilities' right to health is greatly impeded in the South African setting, with numerous examples supporting this assertion available in research. Health committees' struggles to bring about community participation have been documented in literature. It is however not known whether health committees represent the needs of persons with disabilities, as well as other vulnerable groups, and the factors that influence them doing so. It is also not known how health committees practice their governance role in relation to persons with disabilities, as well as how governance values influence the trust that persons with disabilities in communities have in health committees. This study will look into whether health committees, as governance structures, are helping to realise the right to health for persons with disabilities – and if not, what are the barriers that deter them undertaking their role. The research will look to inform health committee practises specifically relating to disability and how this can be strengthened to help realise their right to health.

References:

1. World Health Organisation. World Bank: World report on disability. Malta: World Health Organisation; 2011.

2. Kleintjes S, Lund C, Swartz L. Barriers to the participation of people with psychosocial disability in mental health policy development in South Africa: A qualitative study of perspectives of policy makers, professionals, religious leaders and academics. BMC International Health and Human Rights. 2013;13(1).

3. Department of Women Children and People with Disability: Draft first country report to the United Nations on the implementation of the Convention on the Rights of Persons with Disabilities in South Africa Final Draft (Un-edited). http://www.gov.za/documents/first-country-report-united-nations-implementation-convention-rights-persons-disabilities (2013). Accessed 5 Jul 2014.

4. Heap M, Lorenzo T, Thomas J. 'We've moved away from disability as a health issue, it's a human rights issue': reflecting on 10 years of the right to equality in South Africa. Disability & Society. 2009;24(7):857-868.

5. Hunt P, Mesquita J. Mental Disabilities and the Human Right to the Highest Attainable Standard of Health. Hum Rights Q. 2006;28(2):332-356.

6. United Nations Economic and Social Council: International Covenant on Economic, Social and Cultural Rights: General Comment 14: The right to the highest attainable standard of health (Article 12 of the International Covenant on Economic, Social and Cultural Rights). http://www.unhchr.ch/tbs/doc.nsf/ (2000). Accessed 20 Jul 2014.

7. Diniz D, Barbosa L, dos Santos WR. Disability, Human Rights and Justice Disability, International Journal on Human Rights. 2009;6(11):61-71.

8. Coulson J, Napier M, Matsebe G. Disabiltiy and human spaces. In: Watermeyer B, Swartz L, Lorenzo T, Schneider M, Priestly M, editors. Disability and social change: a South African agenda. Cape Town: HRSC Press; 2006. p. 324-387.

9. Elwan A. Poverty and disability: A survey of the literature: Social Protection Advisory Service. Washington DC: World Bank; 1999.

10. Lorenzo T: We don't see ourselves as different: a web of possibilities for disabled women: how black disabled women in poor communities equalise opportunities for human development and social change. http/www.open.uct.ac.za/handle/11427/9982 (2005). Accessed 10 Nov 2015.

11. Haricharan HJ, Heap M, Coomans F, London L. Can we talk about the right to healthcare without language? A critique of key international human rights law, drawing on the experiences of a Deaf woman in Cape Town, South Africa. Disability & Society. 2013;28(1):54-66.

12. Swartz L. On the edge: Ward-rounds in a South African psychiatric emergency department. Soc Sci Med. 1992;35(9):1115-1122.

13. Heap M, Morgans H. Language policy and SASL interpreters in the public service. In: Watermeyer B, Swartz L, Lorenzo T, Schneider M, Priestly M, editors. Disability and social change: A South African agenda. Cape Town: HSRC Press; 2006. p.134-147.

14. Saloojee G, Phohole M, Saloojee H, Ijsselmuiden C. Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. Child: care, health and development. 2007;33(3):230-235.

15. Coleridge P. Disability, Liberation, and Development. Oxford: Oxfam; 1993.

16. Barnes C, Mercer G. Exploring disability: Competing models and approaches. Cambridge: Polity Press; 2010.

17. South African Human Rights Commission. Towards a barrier-free society. Johannesburg: South African Human Rights Commission; 2002.

18. Lawn JE, Rohde J, Rifkin S, Were M, Paul VK, Chopra M. Alma-Ata 30 years on: revolutionary, relevant, and time to revitalise. The Lancet. 2008;372(9642):917-927.

19. Gillam S. Is the declaration of Alma Ata still relevant to primary health care? BMJ. 2008;336(7643):536-538.

20. MacQueen KM, McLellan E, Metzger DS, Kegeles S, Strauss RP, Scotti R, Blanchard L, Trotter RT. What is community? An evidence-based definition for participatory public health. Am J Public Health. 2001;91(12):1929-1938.

21. EQUINET/TARSC. Report of the TARSC/EQUINET regional meeting on public participation in health, in cooperation with IDRC (Canada) and WHO (AFRO/HSSD) (Policy Series No. 5). Harare: EQUINET; 2000.

22. Rifkin SB, Muller F, Bichmann W. Primary health care: on measuring participation. Soc Sci Med. 1988;26(9):931-940.

23. Mansuri G, Rao V. Localizing development: does participation work? Washington DC: World Bank Publications; 2012.

24. Brownlea A. Participation: Myths, realities and prognosis. Soc Sci Med. 1987;25(6):605-614.

25. Arnstein SR. A ladder of citizen participation. J Am Inst Plann. 1969;35(4):216-224.

26. Rule S, Lorenzo T, Wolmarans M. Community-based rehabilitation: new challenges. In: Watermeyer B, Swartz L, Lorenzo T, Schneider M, Priestly M, editors. Disability and social change: a South African agenda. Cape Town: HRSC Press; 2006. p. 273-290.

27. Rodriguez-García R, Bonnel R, N'Jie N, Olivier J, Pascual FB, Wodon QT. Analyzing community responses to HIV and AIDS: Operational framework and typology. World Bank Policy Research Working Paper 5532. Washington DC: World Bank; 2011.

28. Flores W, Ruano AL, Funchal DP. Social participation within a context of political violence: implications for the promotion and exercise of the right to health in Guatemala. Health Hum Rights. 2009;11(1):37-48.

29. Department of Health. National Health Act. Pretoria: Government Printers; 2003.

30. McCoy DC, Hall JA, Ridge M. A systematic review of the literature for evidence on health facility committees in low- and middle-income countries. Health Policy Plan. 201; 27(6):449-466.

31. George A, Scott K, Garimella S, Mondal S, Ved R, Sheikh K. Anchoring contextual analysis in health policy and systems research: A narrative review of contextual factors influencing health committees in low and middle income countries. Soc Sci Med. 2015;133:159-167.

32. Haricharan HJ. Rapid appraisal of health committee policies in South Africa. Cape Town: University of Cape Town; 2014.

33. Padarath AP, Friedman I. The status of clinic committees in primary level clinics in three provinces in South Africa. Durban: Health Systems Trust; 2008.

34. Glattstein-Young G, London L. Community Health Committees as a vehicle for participation in advancing the right to health. Critical Health Perspectives Publication of the People's Health Movement, South Africa. 2010;2(1).

35. Iwami M, Petchey R. A CLAS act? Community-based organizations, health service decentralization and primary care development in Peru. Local Committees for Health Administration. J Public Health Med. 2002;24(4):246-251.

36. Loewenson R, Rusike I, Zulu M. Assessing the impact of health centre committees on health system performance and health resource allocation. Training and Research Support Centre, Harare: EQUINET; 2004.

37. Svensson J, Björkman M. Power to the People: Evidence from a Randomized Field Experiment of a Community-Based Monitoring Project in Uganda. Q J Econ. 2009;124(2):735-769.

38. Glattstein-Young GS: Community health committees as a vehicle for participation in advancing the right to health. http://www.uctscholar.uct.ac.za/PDF/76513_Glattstein_Young_G_ S.pdf (2010). Accessed 21 Jun 2014.

39. Askew I, Khan AR: Community participation in national family planning programs: some organizational issues. Stud Fam Plann. 1990:127-142.

40. Fung A. "Thinking about Empowered Participatory Governance Archon Fung and Erik Olin Wright". Deepening democracy:

Institutional innovations in empowered participatory governance. 2003;4:3.

41. Molyneux S, Atela M, Angwenyi V, Goodman C. Community accountability at peripheral health facilities: A review of the empirical literature and development of a conceptual framework. Health Policy Plan. 2012;27(7):541-554.

42. Pagliccia N, Spiegel J, Alegret M, Bonet M, Martinez B, Yassi A. Network analysis as a tool to assess the intersectoral management of health determinants at the local level: A report from an exploratory study of two Cuban municipalities. Soc Sci Med. 2010;71(2):394-399.

43. Barnett P, Tenbensel T, Cumming J, Clayden C, Ashton T, Pledger M, Burnette M. Implementing new modes of governance in the New Zealand health system: An empirical study. Health Policy. 2009;93(2–3):118-127.

44. Levendal E, Lapinsky S, Mametja D. Community involvement in health. South African Health Review. 1997;1997:129-135.

45. Ntsaluba A, Pillay Y. Reconstructing and developing the health system-the first 1 000 days. South African Medical Journal. 1998;88:33-35.

46. Coovadia H, Jewkes R, Barron P, Sanders D, McIntyre D. The health and health system of South Africa: historical roots of current public health challenges. The Lancet. 2009;374(9692):817-834.

47. Department of Health. White Paper for the Transformation of the Health System in South Africa. Pretoria: Government Gazette; 1997.

48. Haricharan HJ. Extending participation: challenges of health committees as meaningful structures for community participation. A study of health committees in the Cape Town Metropole. Cape Town: University of Cape Town; 2012.

49. Hunt P. Foreword. In: Potts H. "Participation and the right to the highest attainable standard of health." Colchester: Human Rights Centre, University of Essex; 2009.

50. Meier BM, Pardue C, London L. Implementing community participation through legislative reform: A study of the policy

framework for community participation in the Western Cape province of South Africa. BMC International Health and Human Rights. 2012;12:15.

51. Boulle T, Makhamandela N, Goremucheche R, Loewenson R. Promoting partnership between communities and frontline health workers: strengthening community health committees in South Africa. EQUINET PRA paper. Harare: EQUINET; 2008.

52. London L, Baldwin-Ragaven L. Human rights obligations in health care: main article. CME: Your SA Journal of CPD. 2006;24(1):20-24.

53. United Nations Human Rights Office of the High Commissioner for Human Rights. Vienna Declaration and Programme of Action. Geneva: United Nations;1993.

54. South African Human Rights Commission. Public Inquiry: Access to Health Services. Johannesburg: South African Human Rights Commission; 2009.

55. London L, Schneider H. Globalisation and health inequalities: Can a human rights paradigm create space for civil society action? Soc Sci Med. 2012;74(1):6-13.

56. World Health Organisation. 25 [Twenty five] questions and answers on health and human rights. Geneva: World Health Organisation; 2002.

57. World Health Organisation. Constitution, Preamble. Geneva: World Health Organisation; 1946.

58. United Nations: International Covenant on Economic, Social and Cultural Rights. http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx (1976). Accessed 30 Jun 2014.

59. London L. What is a human-rights based approach to health and does it matter? Health Hum Rights. 2008;10(1):65-80.

60. Republic of South Africa. Constitution of the Republic of South Africa. Pretoria: Government Gazette; 1996.

61. Department of Health. Mental Health Care Act. Pretoria: Government Printers; 2002.

62. Department of Social Development. Children's Act. Pretoria: Government Printers; 2005.

63. United Nations. General Assembly: Convention on the Rights of Persons with Disabilities and Optional Protocol. Geneva: United Nations; 2007.

64. Lang R. The United Nations Convention on the right and dignities for persons with disability: A panacea for ending disability discrimination? ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap. 2009;3(3):266-285.

65. Philander JH, Swartz L. Needs, Barriers, and Concerns Regarding HIV Prevention among South Africans with Visual Impairments: A Key Informant Study. Research Reports. Journal of Visual Impairment & Blindness. 2006;100(2):111-114.

66. Rohleder P, Swartz L, Schneider M, Groce N, Eide AH. HIV/AIDS and disability organisations in South Africa. AIDS Care. 2010;22(2):221-227.

67. Groce NE, Trasi R. Rape of individuals with disability: AIDS and the folk belief of virgin cleansing. The Lancet. 2004;363(9422):1663-1664.

68. Schneider M, Manabile E, Tikly M. Social aspects of living with rheumatoid arthritis: a qualitative descriptive study in Soweto, South Africa–a low resource context. Health Qual Life Outcomes. 2008;6:54.

69. Adnams CM. Perspectives of intellectual disability in South Africa: epidemiology, policy, services for children and adults. Current Opinion in Psychiatry 2010; 23:436-440.

70. Saxena S, Sharan P, Saraceno B. Budget and financing of mental health services: baseline information on 89 countries from WHO's Project Atlas. J Ment Health Policy Econ. 2003;6(3):135-143.

71. Mitra S. Disability Cash Transfers in the Context of Poverty and Unemployment: The Case of South Africa. World Dev. 2010;38(12):1692-1709.

72. South African Social Security Agency: You and your grants 2009/10. http://www.sassa.gov.za (2009). http://www.sassa.gov.za/applications/cms/documents/file_build.asp?id=100000081. Accessed 15 December 2015.

73. Coetzee Z, Goliath C, van der Westhuizen R. Re-conceptualising vocational rehabilitation services towards an inter-sectoral model. South African Journal of Occupational Therapy. 2011;41(2):32-37.

74. Kagee A, Remien R, Berkman A, Hoffman S, Campos L, Swartz L. Structural barriers to ART adherence in Southern Africa: challenges and potential ways forward. Global public health. 2011;6(1):83-97.

75. Mgwili M, Watermeyer B. Disability and service provision. In: Watermeyer B, Swartz L, Lorenzo T, Schneider M, Priestly M, editors. Disability and social change: a South African agenda. Cape Town: HRSC Press; 2006. p. 260-272.

76. Department of Health. National Rehabilitation Policy. Pretoria: Government Printers; 2000.

77. Department of Health. National Core Standards for Health Establishments in South Africa. Pretoria: Government Gazette; 2012.

78. Health Systems Trust. National Health Care Facilities Baseline Audit. National Summary Report. Durban: Health Systems Trust; 2012.

79. Siddiqi S, Masud TI, Nishtar S, Peters DH, Sabri B, Bile KM, Jama MA. Framework for assessing governance of the health system in developing countries: Gateway to good governance. Health Policy. 2009;90(1):13-25.

80. McCourt W, Gulrajani N. The future of development management: Introduction to the special issue. Public Administration and Development. 2010;30(2):81-90.

81. Huss R, Green A, Sudarshan H, Karpagam S, Ramani K, Tomson G, Gerein N. Good governance and corruption in the health sector: lessons from the Karnataka experience. Health Policy Plan. 2011;26(6):471-484.

82. World Health Organisation. Monitoring the building blocks of health systems: A handbook of indicators and their measurement strategies. Geneva: World Health Organisation; 2010.

83. Health Systems Global. Lazarus JV, France T: A new era for the WHO health system building blocks? http://healthsystemsglobal.org/GetInvolved/Blog/TabId/155/PostId/21/a-new-era -for-the who-health-system-building-blocks.aspx (2014). Accessed 10 February 2015.

84. Brinkerhoff DW. Accountability and health systems: toward conceptual clarity and policy relevance. Health Policy Plan. 2004;19(6):371-379.

85. George A. "By papers and pens, you can only do so much": views about accountability and human resource management from Indian government health administrators and workers. Int J Health Plann Manage. 2009;24(3):205-224.

86. Brinkerhoff DW, Bossert TJ. Health governance: principal-agent linkages and health system strengthening. Health Policy Plan. 2014;29(6):685-693.

87. Burris S, Drahos P, Shearing C: Nodal governance. Australian Journal of Legal Philosophy. 2005;30.

88. Hein W. A United Nations Global Health Panel for Global Health Governance: A commentary on Mackey. Soc Sci Med. 2013;76(0):18-20.

89. Department of Health. Draft policy on the health governance structures. Pretoria: Government Gazette; 2013.

90. Fattore G, Tediosi F. The Importance of Values in Shaping How Health Systems Governance and Management Can Support Universal Health Coverage. Value in Health. 2013;16(1, Supplement):S19-S23.

91. 23. Gilson L. Trust and the development of health care as a social institution. Soc Sci Med. 2003;56(7):1453-1468.

PART C: JOURNAL MANUSCRIPT

(BMC HEALTH SERVICES RESEARCH)

**Community participation and the right to health for people with disability:
A qualitative study into Health Committees' understanding and practise
of their governance role in relation to disability.**

Community participation and the right to health for people with disability: A qualitative study into Health Committees' understanding and practise of their governance role in relation to disability.

Theodore WJ Abrahams

ABSTRACT

BACKGROUND: Persons with disabilities encounter major barriers that prevent them realising their right to health in South Africa. Health committees are legislated structures for community participation in health at a local level. This study investigated how health committee members understand and practise their role in community participation and how this advances the right to health for persons with disability.

METHODS: A qualitative study was conducted with three health committees in the Cape Town Metropole in the Western Cape province of South Africa purposively selected for the study. Three facility managers and eight health committee members took part in focus group discussions and semi-structured interviews, supplemented by participant observations of committee meetings. Additionally, semi-structured interviews were conducted with 2 disability activists. These methods were used to gain a rich understanding of health committees' roles and practises in relation to persons with disabilities. Thematic analysis was used to analyse the data.

RESULTS: The main research findings were: (i) health committees did not prioritise disability on their respective agendas; (ii) Persons with disabilities were not adequately represented on health committees; (iii) health committees exhibited poor understanding of disability barriers relating to health; (iv) lack of egalitarian values led to persons with disabilities not trusting the health committee, and distrust amongst health committee members; lastly (v) health committees augment health facility operations instead of fulfilling their governance and oversight function. These factors may have contributed to health committees not helping to advance the right to health for persons with disabilities.

CONCLUSIONS:

Health committees should include mandated representation of persons with disabilities, whilst addressing marginalisation directed toward persons with disabilities on committees. Training of health committees, as well as networking with disabled organisations, could help improve their limited understanding of disability. Health committees should consider addressing disability a human rights issue, which critically involves community mobilisation, raising awareness around issues of disability and promoting agency amongst persons with disabilities to claim their rights.

KEYWORDS:

Health Committees, Community Participation, Disability, Right to Health, Governance, Values, Trust.

325 words (including keywords).

BACKGROUND

Persons with disabilities in South Africa experience barriers to health care access, with subsequent poor health outcomes [1][2][3]. These barriers range from inequitable access to assistive devices [4] and health facilities frequently not stocking important medications [5], to persons with disabilities experiencing discriminatory attitudinal barriers within their social environment that make them vulnerable, for example, to violations of their reproductive health rights [6]. Persons with disabilities are generally excluded from HIV related prevention education [6], and health promotion information, which, even when it eventually reaches persons with disabilities, it is often not in accessible formats [7]. Other health-related barriers include lack of access to important medications and assistive devices [5]. Discrimination against persons with disabilities also extends to the policy realm, where disability organisations are often excluded from the development of health policy [8]. Barriers in health care negatively influence health outcomes of persons with disabilities [1]. Poor health outcomes are amplified by the HIV epidemic, contributing to the high prevalence of HIV-associated disablement experienced in South Africa [4].

The Alma Ata declaration on Primary Health Care aimed to bring about global health care reforms, emphasising the need for communities to participate in health care in order to accelerate equitable health system improvements for communities [9]. The democratic government of South Africa identified the Primary Health Care Approach, which includes community participation as a means to achieving a more equitable health system [10]. The government's objective of strengthening participation in the health sector aimed to: (i) include communities in the planning, and delivery of care services, (ii) improve accountability of health services to communities, and (iii) for communities to take ownership of their health care [10].

Health facility committees, referred hereon as health committees, are mechanisms often utilised to bring about community participation in health [11]. International evidence suggests that community

participation in health undertaken through health committees can be effective in improving health care quality and health outcomes [11][12]. In South Africa, the National Health Act of 2003 mandates the establishment of health committees linked to every health facility or group of health facilities [13]. Health committees have been shown to advance the right to health for communities in a study in Cape Town, especially when power in decision-making was shared with greater parity between health committees and facility managers [14].

Community participation in the South African health environment includes community involvement in the planning and implementation of health-related services, engagement with facilities, and the improvement of health service accountability [10]. Health committees, as the mechanism to realise community participation, should therefore bring about these functions. Given that governance can be defined as "the exercise of power through institutions to steer society for the public good" [15], it is evident that the role attributed to health committees in policy renders them governance structures [2][16][17]. The following elements have been identified to be essential in community participatory governance: oversight, accountability, influence in decision-making and agenda setting, problem identification and subsequent finding of solutions [16].

Unlike the rest of South Africa, where most provinces have increasingly come to define health committee roles to include governance, the Western Cape Province of South Africa does not currently have a policy on health committees, and does not specify the roles and functions of health committees [16]. Health committees were therefore unable to realise meaningful community participation and their governance role [18]. Health committees in the Western Cape Province currently do not receive funding, resources or institutional support from provincial authorities, nor political support for their work, further obstructing their ability to bring about meaningful community participation [18].

Health committees have experienced major barriers in realising the right to health for communities in South Africa. These include, inter-alia, the failure of provinces to translate given policy roles into practice [19]; the lack of a clear mandate; poor sustainability of health committee functionality, owing to inconsistent meeting attendance by members and not completing their tenure within the health committee; and a lack of political support resulting in under resourcing of health committees [18].

Health committees' governance role in South Africa has therefore been severely limited in practise [16]. For example, health committee members were reported to undertake menial tasks such as health education, not their intended governance and oversight function [18][19].

The Constitution of the Republic of South Africa states the rights obligations of the state to promote equitable service delivery (including health care) for vulnerable sectors of society commonly subjected to discrimination [20]. This commitment to addressing the needs of the most vulnerable is one of the hallmarks of a human-rights based approach evident in documents such as the South African Constitution's Bill of Rights, the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the United Nations Convention on the Rights of People with Disabilities (UNCRPD). South Africa has ratified the ICESCR and the UNCRPD. The ICESCR contains optional protocols, called General Comments, which are elaborations of the core rights contained within the covenant. General Comment 14 provides an expert interpretation of the right to the highest attainable standard of health [21], and elaborates on the measures that constitute the right to health.

As the mechanism for community participation in health, health committees should represent the health needs of communities, including vulnerable groups [14] such as persons with disabilities, to help realise equitable health services provided for in the Constitution. Health committees, through their participatory roles and governance function should hold the state – represented by health facilities - accountable to

its rights obligations, especially towards some of the most vulnerable in society, such as persons with disabilities.

Legislation specifies that health committees must be composed of the following members: the health facility manger, the local municipal wards councillor and community members [13]. Whereas research suggests that health committees can help realise the right to health for communities [14], no evidence was found in the literature regarding health committees' ability to represent the needs of persons with disabilities or to help realise the right to health for persons with disabilities. This study investigated whether health committees help to advance the right to health for persons with disabilities, by exercising their governance function. This study aimed to: (i) explore whether health committees understood their role to include the representation of the needs of persons with disabilities; as well as (ii) explore the governance practises of health committees in relation to persons with disabilities, and the factors that contributed to these practises; (iii) and investigate whether health committees were able to help realise the right to health for persons with disabilities through their community participatory role.

METHODOLOGY

Study setting

This study formed part of work of the Learning Network for Health and Human rights, a research collaborative between local civil society organisations and local and international universities [22]. The Learning Network's goal is to empower community organisations such as health committees to realise communities' right to health. Conducting research as part of the Learning Network allowed the researcher utilise existing contacts, thus building on the trust already established by the previous research undertaken by the Learning Network, and may have facilitated for easier access to health committees.

This study took place in one of the eight sub-districts of the Cape Town Metro Health District, Western Cape Province. Three health committees (site A, site B, and site C), each linked to their respective health facility, and serving different geographical areas within the sub-district, were selected. The sub-district has a population of approximately 180 000 people, and is characterised by high levels of poverty [23], violence and a high morbidity profile [24]. Health facilities in the area were under immense service pressures from high patient loads and lack of adequate resources [24]. All of the cases selected in this research were from only one of eight sub-districts. This was, however, done due to the variability in functionality of health committees across the Province which meant that selection across a spectrum of facilities in may not have been useful. Other provinces

Study Design, Sample Data Collection

This study utilised qualitative methods, including multiple modalities such as participant observations, focus group discussions, semi-structured interviews and document reviews. The data were collected over a six-month period (March, 2014 – August, 2014).

Three health committees were purposively chosen to be a part of this study, namely site A, B and C, under advice from an experienced health committee leader who is the chairperson for the umbrella body for health committees in the Cape Metro. Some health committees in the Western Cape have been found to be unsustainable due to irregular attendance and numerous cancellations, ultimately hampering their functionality [18]. The researcher therefore chose these sites because they were deemed functional, as sufficient data could not otherwise be obtained from defunct health committees. The selected health committees' membership ranged from six to twelve respondents, which varied to sometime erratic attendance at some committee meetings. One critique of purposive sampling is that it relies heavily on the researcher, and this reliance may overly-influence the selection of the sample. For example, if the researcher has befriended certain

respondents he/she may be more inclined to select these persons over their ability to contribute to the research. The researcher addressed this influence by obtaining external assistance in selecting cases to form part of the research, as well as standardising the inclusion of some person without actively selecting them e.g. facility managers in interviews.

Participant observations were done at health committee meetings and all health committee members were approached to participate in these groups, but some health committee members were not able to make each data collection session due to personal reasons. Attendance at the participant observations and focus group discussions ranged from three to seven respondents. Respondents were issued with pseudonyms when included in the write-up of the manuscript to protect anonymity.

Participant observations were undertaken during all health committee meetings which took place at the respective health facilities during the data collection period. The researcher observed verbal data, including data such as the tone used to express frustration or apathy, as well as non-verbal data, such as body posturing or gestures suggesting disinterest in certain issues. The researcher did not only passively observe discussions, but participated in health committee meetings, giving input selectively, primarily on relevant topics relating to the subject matter. This was done to guide discussion to illicit a richer perspective and to clarify aspects that may be included as data. Participant observations were the first data collection modality undertaken at all sites. There are, however, certain limitations to using participant observation, such as the researcher's own biases overly influencing the subject matter, and resultant outcomes taken from data; as well as respondents' inputs being influenced by the presence of the researcher, artificially influencing the discussions that normally take place. The researcher, however, adopted this modality to recruit respondents for subsequent semi-structured interviews, by engaging on relevant topical issues and assessing responders' potential to yield interesting information, and to gain rapport with respondents in order for them to freely discuss matters in focus group discussion and interviews, further limiting guarded responses.

Three respective focus group discussions were conducted with each health committee (following the participant observations). All health committee members were invited to attend the focus group discussions. Attendance at focus group discussions reflected the attendance at participant observations. Generally, older persons and females were overrepresented at both focus group discussions and participant observations. Focus group discussions allow respondents to build on the ideas expressed by other respondents, in so doing, allowing for knowledge accumulation within the group, and for the researcher to investigate verbal, as well as non-verbal elements of group dynamics [25]. The researcher facilitated discussions, and focused on matters pertaining to respondents' contributions to the health-related experience of persons with disabilities, how respondents represented, or did not represent the needs of persons with disabilities, as well as factors affecting respondents' ability to practise their governance role in relation to disability.

Eleven semi-structured interviews with committee members were conducted following the focus group discussions. Each of the managers at the three facilities were interviewed because of their potentially important role in influencing health committees' ability to realise their governance role. Eight other health committee members were also selected for interviews. Selection criteria included respondents who had participated consistently in the health committee, i.e. those who have reliably attended meetings for at least one year. One respondent who took part in the interviews did not fulfil the requirement to be included in the interviews as he was not a member for an entire year. The concession was allowed because of his vast experience in community-based organisations and knowledge of disability-related experiences. Focus group discussions allowed the researcher to purposively sample respondents for subsequent interviews. All respondents selected for interviews were sourced from those present at focus group discussions, barring one facility manager who did not consistently participate in the activities of the respective health committee. Consistent attendance at

health committee meetings was used as a selection criterion, as health committees in the Western Cape Province often experience high levels of attrition [18]. Two individuals external to the health committee who were involved in disability-specific community activities were also selected to take part in the semi-structured interviews to gain a richer perspective of the role that health committees play in relation to disability. A combined total of 13 interviews were conducted throughout the study.

Lastly, reviews of committee minutes were conducted at site A and site C. The researcher requested permission to view minutes at site B, but no feedback was given after several requests. Reviews took place after interviews had been completed, which allowed the researcher to corroborate data obtained from focus group discussions and interviews. Importantly, reviews of minutes provided insights into how health committees set their agenda, the subsequent interventions they pursued, and those neglected.

Analysis

Thematic analysis (using inductive and deductive analytical methods) was used by the researcher to analyse the data. First-, and second-level inductive data analysis was done using NVIVO 10® software to develop thematic codes.

The ICESCR's General Comment 14 was used as the primary framework to structure the deductive analysis of health committees' understanding of their role and practises in relation to the right to health for persons with disabilities, using the four composite elements of the right to health.

Additionally, selected articles contained in the UNCRPD were incorporated into the elements of the right to health to generate a more substantive framework to evaluate the understanding, and practises of health committees in relation to persons with disabilities.

The elements of the General Comment 14 [21] and the UNCRPD [26] are listed in the table below.

Table 1. Framework to Evaluate the Realisation of the Right to Health	
Elements of the ICESCR General Comment 14 [21]	**Selected Elements of the UNCRPD [26]**
Access includes informational, physical, and economic access to health services, as well as the absence of discrimination.	Article 9 (Access to health services) entails the necessary reasonable accommodations for persons with disabilities to optimally participate in society.
Availability entails health services of an adequate quantity.	Three respective articles are associated availability of health services. These are: Personal Mobility, which is the availability of assistive devices; Health, which specifies the availability of equitable health services for persons with disabilities; and Rehabilitation, which includes the availability of rehabilitation professionals.
Acceptability entails health services that are acceptable to medical standards and the cultural norms of users.	The article describing Equality states that health services should be of an acceptable standard.
Quality health services are exemplified by appropriate medical and patient safety standards, implemented through audits and other regulatory measures.	

Moreover, organisational values greatly influence the affinity for the uptake of issues onto a governance agenda for an organisation

[15][27][28]. The researcher identified two value sets relating to governance in the literature to structure the deductive analysis.

(i) Egalitarian values, characterised by high degrees of equitable participation of all sectors of society, altruism, empowerment of a heterogeneous array of health service users, and keeping health providers accountable through strong civil society mobilisation [28];

(ii) On the opposite end of the value spectrum are rent-seeking values which manifest in opposition to participation and inclusive practises; and undertaking activities that promote selfish gain [27].

The literature identified the extensive vulnerability, inequality and exclusion that persons with disabilities face when accessing health services. By utilising opposing values, the researcher was able to place respondents on a values spectrum, in so doing establishing whether, or not, there was a relationship between values exhibited and the extent to which respondents represented the needs of persons with disabilities.

A study found that corresponding values oriented around equality between communities and health system authorities generates trusting relationships [29]. Importantly, citizen trust in an institution produces the by-product of caring engagement, as well as protection of the least powerful and most vulnerable [30], which could be beneficial for persons with disabilities as the focus for this study. Trust was therefore identified as a key factor that could influence health committees' governance practises and the resultant impact on persons with disabilities.

Ethical considerations
This study was approved by the University of Cape Town's Research Ethics Committee (Reference number: 725/2013).

Respondents were informed of the risks and potential benefits associated with the research, and were required to sign a consent form to continue.

Methodological rigour

Reflexivity

Researcher values greatly influence research findings, thus demanding the researcher to explicitly display reflexivity in their work [31]. The researcher has a special interest in inequality of health outcomes associated with vulnerable groups, such as persons with disabilities, and the factors that affect inequality. The researcher has a background in clinical health sciences, specifically rehabilitation, which sensitized his awareness of the substantial barriers persons with disabilities face, specifically within the health system. These influences may have contributed to the researcher's interest in matters of equity and social justice and the subsequent outcomes of the research. The researcher kept a reflective journal throughout the study to reflect on how his values may influence the findings.

Trustworthiness

Trustworthiness in research speaks to the neutrality of findings in qualitative work [32], in other words convincing the researcher and reader of the worthiness of the findings [33]. The researcher utilised the criteria set out below to articulate the measures taken to strengthen trustworthiness in research.

Confirmability refers to whether research findings indeed emanate primarily from the data and not researcher bias [33]. The researcher recorded all verbal data collection sessions and subsequently transcribed these, as well as writing notes during participant observations, and conducted field notes throughout the research process, and used these data for the analysis.

 Credibility, or the truthfulness of data, is the accuracy of the match between the respondent's intended meaning and how these are attributed to them in the research findings [33]. The researcher utilised triangulation, a technique which uses varying perspectives to draw a

conclusion, by utilising different information sources as well as data collection methodologies to draw conclusions.

Dependability refers to whether findings, if context and/or subjects were the same, or similar, are able to be reproduced [33]. Dependability can only manifest if findings are sufficiently credible [32]. The utilisation of triangulation thus assisted in the dependability of findings. Inquiry audits, conducted by an auditor, scrutinise researcher findings so as to optimise agreement between conclusions [33]. The study's findings were availed to two supervisors for critique to further strengthen dependability.

Transferability is the process whereby research findings can be adapted to different settings or individuals/groups [33]. The researcher aimed to improve transferability by using purposive sampling. This was done to apply data gathering techniques to the broadest possible spectrum of information sources.

RESULTS

There were 13 respondents of whom 11 were health committee members. Table 2 briefly describes the profile of the respondents in terms of their relationships to the health committee and their community roles.

Table 2. Profile of Study Participants	
Site A	
Pseudonym	**Description Profile**
Karen	Karen was a female community worker with over thirty years of experience in community development projects, a health committee member and was the project manager of a local community development organisation.
Patricia	Patricia was a female facility manager at Site A health facility with vast experience in various clinical environments as a professional nurse.
Lydia	Lydia was the coordinator of an informal disability organisation and a member of a faith-based organisation, but did not have any links to any formal disability organisations. She was active in the health committee since the early years of its existence.
Nandi	Nandi was the project manager of a local non-governmental organisation and the health committee chairperson.
Lindiwe	Lindiwe was the deputy secretary of the health committee and the project manager at a local community development centre.

Site B	
Alan	Alan, a male committee member, was appointed three years ago as facility manager of Site B Community Health Centre. He has several years of managerial experience and has previously interacted with health committees but not as a member.
Michael	Michael was a highly enthusiastic disability activist; he coordinated a local disability workshop. He was not a member of the health committee but was involved with numerous disability civil society organisations.
Michelle	Michelle was the secretary of the health committee and had numerous years of experience in civic committees, and a member of the Cape Metro Health Forum.
Celeste	Celeste was the longstanding chairperson of the health committee with many years of involvement in civic organisations.
Site C	
Fatima	Fatima, a female facility manager, had a background in Nursing and management, and was a health committee member.
Megan	Megan, a female, and the longest serving member on the health committee.
Anele	Anele had many years of experience in civil society activities, and was a relatively new member of the health committee. He also had extensive experience in the local community policing forum and is a member of its regional executive.
Linda	Linda is a specialist orthopaedic nurse with several years of experience and keen disability interest. She was a member of a large non-governmental disability organisation and regularly attended their meetings.

Five themes emerged from the analysis and are detailed below.

Operational Invisibility of Disability

Disability issues were not prominent in any of the health committees' operations with little engagement in disability matters across sites. Only two matters specific to disability were reported as identified and discussed by the committee since they were established.

At site A, a disabled-friendly toilet was initially closed due to vandalism, resulting in impeded access. The matter was raised at several meetings by Lydia, the disabled organisation's representative, but remained unresolved. The lack of priority was evident in how one health committee member scoffed when the disability toilet issue was raised in a meeting. Nandi, the chairperson of site A's health committee re-affirmed the lack of priority of disability issues on the health committee agenda.

> "For all of the years it has just been about the toilet, the disability toilet." (Nandi)

Site B was involved in a once-off disability awareness day over five years ago, and had not discussed or taken up any disability interventions since then. Site C's health committee members could not recall taking part in any specific disability intervention and had not discussed any disability matters.

Considering the impact of health-related disability barriers, the health committees' inertia in establishing interventions to advance disability rights matters, highlighted the lack of attention disability received from health committees.

Representivity of persons with disabilities on health committees

Only one health committee (in site A) had a representative of a disabled person's organisation (Lydia). The health committees at site B and C did

not have any representation of disability organisations in spite of the existence of vibrant disability organisations in those areas. Disability organisations therefore seemed to be under-represented on health committees.

Diminished disability voice on the health committee

Even when persons with disabilities were present on a health committee, as was the case with Lydia, disability matters were not taken seriously in meetings. Lydia's voice was often suppressed, and over-ridden during meetings. Generally, for the health committee to pursue a proposed intervention, motions needed popular endorsement by the members. The researcher observed minimal support for interventions suggested by Lydia. There appeared to be some tension between Lydia and certain health committee members, evidenced by Lydia being interrupted regularly during meetings and spoken to in an abrasive manner by some respondents. The tension directed at Lydia seemed to stem from perceptions that she unnecessarily delayed discussions, was overly-demanding, and provided less important input.

> "You know aunty Lydia...I feel that our guys [fellow health committee members] are looking down [on her], I mean she is an adult". (Nandi)

The silencing of Lydia's voice on the health committee limited her ability to advance disability issues in the health committee.

Low community awareness of health committees
In all three communities, it was noted that persons with disabilities had little knowledge of the existence of a health committee, and preferred to address issues related to health services in other ways, like complaining via disability organisations.

Michael coordinated a disability workshop in site B, and was highly regarded within the disability community as a champion of their cause, and well known in the rest of the community as well as the local health

facility. He was not aware of the existence of the health committee prior to the interview, and commented that many other persons with disabilities did not know of the health committee's existence. The following exchange between him and the researcher illustrates this.

> "Researcher: has anyone approached you to join them at the health committee?
>
> Michael: No, we never hear that. We never even hear that the health committee is existing.
>
> Researcher: So do other disabled people know about the health committee?
>
> Michael: No… we don't know anyone; we don't know the people on there (health committee). We don't know how they are operating."

Michael was not a member of the health committee yet he was the preferred contact to receive health care-related complaints from persons with disabilities in the community. He often made direct contact with the facility management to resolve complaints and liaised with complainants thereafter:

> "so that time they [persons with disabilities] come to us … because when they go the clinic they tell us they are not sure that things will change, you see?" (Michael)

Persons with disabilities could only voice their needs and complaints to health committees if they knew of their health committee and who the members were. Persons with disabilities' preference to seek assistance from Michael, instead of health committee members, reinforce this observation. Because of their obscurity, health committees may have been incapable of receiving, and addressing the complaints of persons with disabilities, as well as addressing other health-related issues of persons with disabilities.

Health Committees' understanding of disability barriers

The research found that all three respective health committees generally exhibited low levels of understanding regarding disability barriers. Numerous respondents could not elaborate on perceived disability barriers even after multiple attempts at probing by the researcher.

> "I don't think we [as the health committee] have an understanding [of disability], because we first need to be trained in that, so that we can spread [the knowledge]." (Nandi)

Individuals with better understanding of disability

There were however three individual respondents, one from each site exhibited empathy specifically toward the experience of persons with disabilities and therefore appeared to have a better understanding of disability issues. These respondents were deeply grounded in community's experience, considering their existence inextricably linked to that of their fellow community members, and interacted with all persons in the community irrespective of social standing, especially those with the greatest need.

> "I speak to people on the ground and work with the ordinary person… I live in a working class community, and I can't be something I am not... If you start losing track of the needs of the people you are supposed to help, then you are in the wrong profession." (Karen)

They were empathetic toward the needs of vulnerable persons, although no instances were mentioned where they specifically addressed the needs of persons with disabilities. This may have been due to the lack of popular support available for disability-oriented interventions from other health committee members. However, respondents with greater understanding of disability were agents of redress for other vulnerable groups, challenging service provider discrimination.

"Sometimes there is the situation where the [elderly] people want to go the toilet, there was one where that person was harassed by the cleaner because they spilled urine on the floor, because he was sitting long in the pharmacy and nobody helped him... I wanted a case against that cleaner who shouted at that guy [elderly person]." (Michelle)

These individuals' values, based on service toward the community engendered loyalty and trust from others whom they work with, a sentiment articulated in the following exchange.

'Researcher: "... Is Karen trusted within the community"

Lindiwe: "Oh yes! You can't down her"'.

Karen displayed better understanding of disability barriers which seemed to emanate from her empathetic attitude toward persons with disabilities, as she explained that one can only represent persons with disabilities if you are aware of the barriers they face when accessing health care.

"you will need to empathise with that person, to understand where they are coming from and what they are going through. If you can't empathise and think about where this person [with a disability] is coming from, then you won't know what they are going through." (Karen)

Megan, a respondent at site C, verbalised her frustration at the sub-standard service experienced by persons with disabilities. She displayed an enhanced understanding of disability through her interactions with persons with disabilities and a desire to restore equity for persons with disabilities.

"it's very unfair when you look at their experience, the people that are now waiting to come and see doctor first have to get their folders. They take very long for the disabled people...those are the people who I want to help." (Megan)

The following themes emerged from interviews with respondents with better understanding of disability, as well as persons external to the health committee with in-depth understanding of disability issues. These serve to highlight some of the difficulties persons with disabilities encounter when accessing health services and potential opportunities for health committees to advance the right to health for persons with disabilities.

Compounded disadvantage

Respondents with a better understanding of disability-related barriers were able to expand on examples of barriers experienced by persons with disabilities with some degree of insight, characterising the chasm in understanding between these individuals and other committee members. One such example was compounded disadvantage - the amplification of disablement due largely to demographic factors, for example, race or sex [2] - these ranged from negative attitudes of facility staff, to poorly accessible facilities, and a lack of sensory information resources to name a few. A respondent with better understanding of disability barriers commented on the compounded disadvantages persons with disabilities face when accessing health services below:

> "If able-bodied people are disadvantaged by poor services like that, what about wheelchair bound or the blind for example. Apart from the fact that they are confronted by safety issues, they are also affected by other issues like, are they able to navigate to the service?" (Karen)

Variable quality of services at facilities

Health committee members across facilities and other respondents have mentioned how persons with disabilities often travel considerable distances to access other facilities that they perceive to be of better quality. A reason for the difference in quality of services was the stigmatisation persons with disabilities experience. Stigmatisation was based on the individual's impairment and also related to diseases that often result in impairment (for example, HIV), and its various sequelae.

'But one afternoon, there was a person [with a disability] complaining and said, "why we don't want to go to Day Hospital [site B clinic], we want to go to [another clinic] rather, because if you go to the staff at the clinic with a chest they will always give you a Panado [aspirin]"'. (Michelle)

Even in light of this, health committees still did not address the variances in quality persons with disabilities were exposed to.

Disability not taken seriously at facility level

Linda's work entailed servicing several health facilities, including site C, and attended disability organisation advocacy meetings, repeatedly expressing her passion for disability matters.

She mentioned how a top-down audit instituted by line management in the health services were implemented with little vigour by facility managers, and in an erratic fashion across facilities. She bemoaned the omission of disability matters from the facility's operational agenda.

"I don't know whether it [disability] is my area of work, and my speciality and my passion, it seems to always be last on the [facility managers'] list." (Linda)

Linda's feelings were consistent with instances where disability issues were poorly prioritised as observed at site A and B. Wheelchair access ramps and sheltered areas for persons with disabilities respectively were implemented at the respective facilities, but merely a result of building specifications, not due to any advocacy on the part of the health committee, which was supposed to be the voice of the community.

Facility managers faced considerable resource constraints as well as challenges associated with over-burdened health facilities and the impact of highly prevalent diseases such as HIV and Tuberculosis; which may have resulted in disability not being taken seriously. Other research has found that facility managers played a substantial role in setting the agenda of the health committee [18]; it may be that a lack of disability prominence on the agenda of the health facility may have to some extent influenced the health committee to do the same.

Site A's health committee undertook issues relating to HIV and Tuberculosis with great vigour, such as a feeding scheme for indigent Tuberculosis patients, observed in their March 2014 minutes. Tuberculosis remained on the agenda of meetings, reflected by the health committee's efforts to enrol the services of a specialist infectious-disease nurse to address Tuberculosis concerns in the community. Site A's health committee also undertook health promotion on World AIDS day to raise awareness of HIV.

Disability issues, although serious thus appeared to be under-prioritised by health committees in pursuit of interventions parallel to those prioritised by the facility such as Tuberculosis and HIV.

Values and their influence on trust in governance practises

The values exhibited by respondents influenced how they practised their governance role in relation to persons with disabilities. Selected examples pertaining to these practises were categorised into egalitarian or rent-seeking values, to establish a relationship between specific values and how they influence governance practises directed at persons with disabilities.

Values

Egalitarian values

Members who exhibited greater understanding of disability barriers exhibited highly altruistic traits, often expressing their community work as an act of service. They considered their role to work toward the good of the greater community, working to offset inequality, and being agents of justice. They were more likely to be accessible and sensitive to the complaints of persons with disabilities, and have greater knowledge of barriers they experience.

However, in general, health committee members' understanding of the barriers persons with disabilities face was poor. Karen, Megan and Michelle exhibited a better understanding of disability barriers and more

egalitarian values. They however did not personally, or as a part of the health committee, undertake any interventions to address the barriers persons with disabilities face. Thus, their increased understanding did not yield any tangible changes in health outcomes for persons with disabilities. Respondents exhibiting egalitarian values were in the minority within committees, which may have contributed to the absence of interventions to address the needs of persons with disabilities.

Rent-seeking behaviour

Rent-seeking values were associated with health committee members who embodied little understanding into the experience of persons with disabilities, were highly inaccessible to marginalised groups such as persons with disabilities, and more interested in issues where there may have been personal gain. These individuals were not part of well-networked organisations with access to physical and informational resources, and battled to garner adequate support for their interventions. One such example is described below. It details how some health committee members were present at the facility only to selectively represent the needs of friends or relatives and not those of the greater community.

> "Sometimes I feel that they are coming here with their own agenda... to sort out a neighbour or a friend. When they come to pharmacy they [ostensibly] want to sort out those problems [of all sitting in the queue], so when they come in then they pretend to be looking after the guys that are there, then in the meantime they come for their own agenda [addressing needs of friends/relatives]."(Alan)

Rent seeking behaviours emerged in focus group discussions and centred on self-enrichment or addressing personal scores over the representation of the community's needs. In the lengthy discussion, after several attempts by the researcher to focus on community participation for persons with disabilities, certain respondents repeatedly reverted to lamentations around them not being appointed to posts at the facility, or having access to facility resources such as cars for personal gain

under the guise of health committee activities. Importantly, instead of selfless service, where the community's needs come first; in this example, a respondent of the site B health committee appeared to use her position as a community representative to advance her own needs. By pursuing a self-serving agenda, these respondents were not motivated to advance the needs of persons with disabilities, but rather their own interests. They therefore did not see themselves as representatives of persons with disabilities.

> "Because I thought in their [facility's] minds, capacity building is for themselves, theirs is different to ours. They think they can do whatever they want to with our community whereas we possess our people." (X1, a health committee member at site B)

The quote refers to an individual who considers their role in a health committee member as a leverage mechanism against facility management, to elicit personal gain or to pursue a personal agenda. This appears to be in directly oppositional to the view of respondents espousing egalitarian values, who consider their role as servitude to the community.

Trust

An association was observed between respondents exhibiting egalitarian values and the trust bestowed upon them by fellow health committee members and community members. An example is illustrated below, referring to a respondent's preference to trust certain health committee members, and not trust another who did not seem to share the same egalitarian values.

> "Myself, X2 and X3 I can trust. But X4, I cannot trust him. He just speaks and speaks, but he doesn't pitch up to speak to those people [management at the facility] and he doesn't pitch up [at meetings]". (Megan)

Distrust however, was not only evident between health committee members, but between health committees and facility management staff. The absence of roles and functions for health committee members,

resulted in them directly reprimanding health providers whom they believed were providing services in an undesirable manner, in an attempt to practise their governance and oversight function. This led to friction between staff, management and health committees as health committees were seen to usurp the functions of management, albeit in an attempt to improve services. The end-result seemed to be distrust between management and health committees. A health manager's account illustrates this experience below:

> "but then sometimes they [health committee members] will come to facility then they fight with the staff member, then they want me to do something to that staff member... A person can be rude to you, that doesn't mean that I must just fire that person because the person was rude to you and you are the health committee. There has to be a series of transgressions before it can get to the point whereby I can say I can dismiss you." (Alan)

Distrusting relationships between health committees and facility management seemed to impede community participation which may have in-turn hampered community participation specifically for persons with disabilities.

Augmentation of services as opposed to governance

Health committees were found to be undertaking services that augment facility operations instead of exercising their governance role. For example, Megan, along with a few other health committee members from site C clinic were often found helping with operational-oriented tasks such as queue management. In site A, health committee members also undertook similar operational tasks, such as the afore-mentioned organising of feeding schemes for indigent Tuberculosis patients.

Health committees, generally, did not act in a governance role, but at an operational level, augmented service delivery at the clinic. The health committees' augmentative role did not involve making important decisions to hold the facility accountable to the needs of the community. Their augmentative role was generally void of any of the

elements of community participation in health committee governance, such as oversight, adequate participation in decision-making and agenda setting and holding service providers accountable. Considering the substantial barriers persons with disabilities face when accessing health in South Africa, health committees were incapable of holding health services accountable to provide equitable health care for persons with disabilities, and helping to ensure facilities address the health-related barriers of persons with disabilities.

The right to health

The framework comprising the elements of the general comment 14 and selective articles in the UNCRPD was used to evaluate whether health committees helped to advance the right to health for persons with disabilities. Examples of how health committees interacted with these elements are detailed below.

The first aspect is access. The closure of the disabled-friendly toilet by facility management after Lydia's repeated attempts to revive the matter is one such example of health committees failing to improve access for persons with disabilities. Reviews of minutes revealed that the disability-friendly toilet matter was the only disability intervention undertaken by any of the three health committees under investigation.

The only barriers to access for persons with disabilities addressed by health committee members related to non-discrimination, albeit weakly. Michelle, the site B health committee member supported an HIV infected woman with a physical impairment who feared discriminatory negative attitudes and was an example of a health committee member addressing discrimination as a barrier to access.

> 'She [woman with physical impairment and HIV] says: "you know, I don't feel comfortable sitting in that wheelchair … then they must push me and everyone is looking at me and I used to walk… So for me, I am feeling very shy to face our people"…But since I have been speaking to her, and I tell her: "you know why

you are going to the clinic, you shouldn't worry about the next person, just answer them freely"'. (Michelle)

The second aspect is availability. Health committees across all three sites did not undertake any interventions to improve the availability of health services for persons with disabilities, or did not take up issues of acceptability. One explanation might be because persons with disabilities were not represented on health committees, and thus could not voice their sentiment on the acceptability of health services to health facilities. The third aspect refers to acceptability. Alternatively, it could be that health committees lacked understanding of disability, health committees across facilities thus did not represent what persons with disabilities deemed to be medically or culturally acceptable, inhibiting the right to health.

Lastly, with reference to quality, the example of health facilities' failure to prioritise disability matters had negative effects on the quality of services for persons with disabilities, as well as health committees' inability to address instances of variable quality of services.

Ultimately, under the components of the ICESCR's General comment 14, namely accessibility, availability, acceptability and quality, health committees as a collective were not able to advance the right to health for persons with disabilities.

DISCUSSION

The poor representivity of persons with disabilities on health committees may have contributed to the low prioritisation of disability-health issues on the health committee agenda. However, even when a respondent with a disability was present on a health committee, she continued to be marginalised from the committee's decision-making, and appeared to have a diminished voice, compared to her colleagues. This suggests that while representation of persons with disabilities is crucial in addressing disability issues, representation does not guarantee that disability issues will be addressed. This is in line with research, which has suggested that

mandatory representation of vulnerable groups on community participation structures may not guarantee positive participatory outcomes [27]. Other factors such as gender or social discrimination may hamper the effectiveness of quota-based representation of vulnerable groups [27]. The representation of persons with disabilities on health committees will thus not guarantee equitably optimal participation, but it is the important first step to doing so.

Democratic theory encompasses three fundamental areas, representative democracy, where elected person represent constituents, direct democracy, where decisions are taken in the presence of all citizens, and participatory democracy where citizens participate in decision-making with represented government officials [34]. Participatory democracy has roots in civic republicanism theory, which promotes the active participation of citizens in politics and acknowledgment of their duties to society [35]. Liberal rights theory is on the opposite spectrum which prioritises rights over duties and voluntary participation over active/mandatory participation [35]. The South African context political context is characterised primarily by liberal rights perspective, owing to the presence of numerous socio-economic and civil-political rights available to citizens with non-mandatory participation in political processes. Mandating representation is thus at odds with the greater political pedagogy of the country, and will not readily align to existing platforms where decisions are taken. Coupled with this is the existing high economic cost of participation which may stunt participation [18]. Mandating participation may not, therefore, assist in the empowerment of persons with disabilities on health committees and subsequently help the advancement of the rights of persons with disabilities. However, considering the impaired participation and the associated impeded power persons with disabilities have on health committees, mandating their representation could be the first step in strengthening the otherwise impotent participation that currently exists for persons with disabilities on health committees. Efforts on the part of the health committee to address marginalisation and emboldening the voice of persons with disabilities should accompany their mandatory representation. Deliberative decision making is centres on inclusivity of

those affected by decisions in an open, transparent manner where arguments should be substantiated and decisions taken thereafter [36]. Efforts to embolden the voice of persons with disabilities and improve participation could include following tenets of deliberative democracy, which have the benefit of countering rent-seeking behaviours which are can be common in forms of representative democracy [34], help to crystallise issues around a common interest [35] and provide more equitable outcomes [36]. Persons with disabilities are not a homogenous group, and have varying needs and are not immune to the adverse effects of power asymmetries [37]. The training of the health committee chairpersons and members in deliberative discourse could ensure disabled issues are understood and are addressed based on relevant needs and to pursue an overall agenda of social justice for all involved. More research is required to understand the optimal mix of representation of persons with disabilities on health committees and potential models of deliberation.

The health committees in this study, barring three individual respondents, generally had limited understanding of the sizeable barriers persons with disabilities encounter. A study aiming to establish the training requirements of health committees found that discrepancies between their envisioned role and their current role were influenced by training deficits [18]. It may be plausible that health committees did not initially envision their role to include representing the needs of persons with disabilities because of a lack of skills to do so. Furthermore, literature supports this as incapacity and a lack of training on the part of health committees was identified to be a major barrier to them being able to execute their participatory function for communities [14][18][19][39]. Health committees require extensive training on disability health-related barriers to develop their understanding. Training to improve the understanding of disability may not be enough to ensure disability issues are addressed by health committees, since the three respondents who exhibited a developed understanding of disability did not undertake any specific disability-related interventions. Training should thus be coupled with a commitment by health committees to embark on interventions to address disability barriers.

Future interventions to represent the health needs of persons with disabilities should be careful considered. Disability advocacy interventions often experience a difficult balancing act; on the one hand, they need to protect the disabled identity as they often become assimilated into other pressing social issues of inequality, for example, poverty, leading to a focus shift away from disability [40]. On the other hand, disability organisations must establish networks with other well-functioning non-disability organisations to amplify their effectiveness [40]. Health committees should aim to network extensively with disability organisations in their own areas, strengthening capacity, whilst allowing these organisations to maintain their identity to specifically advance disabled issues. Health committees should also consider expanding their disability networks beyond their respective communities in an effort to develop their understanding of disability issues.

Persons with disabilities in South Africa are often exposed to sub-optimal quality of services at primary health facilities [3][41]. Disability was not taken seriously at a facility level and respondent accounts revealed variable quality of health services for persons with disabilities at various facilities. The South African National Department of Health developed the National Core Standards, an audit tool containing baseline standards to which health facilities must adhere in order to achieve uniform quality standards across health facilities [42]. Furthermore, the National Core Standards provides a medium for authorities to hold health facilities accountable to deliver quality care for persons with disabilities, mandating amongst others the need for a disabled-friendly toilet, and ramps for wheelchair users [42]. The National Core Standards tool for primary health care facilities, however, has a limited scope regarding disability, focusing only on physical impairments, and not sensory or intellectual impairments. Research suggests that effective oversight mechanisms are critical to the improvement of poorly performing primary health facilities [43]. Health committees can potentially play an important role in improving quality of care for persons with disabilities by executing their oversight role, utilising normative statutes such as the National Core Standards to hold health facilities accountable in delivering quality services for persons with disabilities.

However, health committees were generally not involved in strategic or planning matters – fundamental to community participation in health - pertaining to the running of the facility [19]. The absence of policy detailing the roles and functions of health committees manifested in the resultant inhibition of community participation [39].Facilities should ensure that health committees are involved in quality-related interventions such as the National Core Standards, and subsequently provide oversight over activities to improve quality for persons with disabilities.

Two contrasting values sets were identified in the research, namely, egalitarian and rent-seeking. An important finding from this study suggested an association between respondents who displayed egalitarian values and trust bestowed upon them by others. Health committees can potentially generate trust amongst persons with disabilities by displaying egalitarian values. The benefits of trusting relationships between health system actors include caring citizen engagement, the protection of the most vulnerable, and providing the impetus to generate collective action around common goals [30] which may be useful in helping health committees realise the right to health for persons with disabilities. Participatory structures generally rely on preference-aggregation, a process whereby decisions are made based on the salient view of the majority of members [27]. Considering the under-representation of vulnerable groups on community participatory structures, preference-aggregation may, in-part, explain the under-prioritisation of disability issues. Although the embodiment of egalitarian values did not automatically translate to pursuit of disability-related interventions by respondents, the embodiment of egalitarian values by the majority of members may enhance the uptake of disability issues on their agenda as they strive toward equality for the most vulnerable. Persons with disabilities did not seem to be aware of health committees, and appeared in one example to trust a respondent external to the health committee with representing their needs at the health facility. Distrust was evident amongst committee members and led to fragmentation in their activities, largely due to conflicts as a result of clashing egalitarian and rent-seeking behaviours.

Research indicates corresponding values between health system actors generates trusting relationships [29]. A fundamental question emerges: how do health committees synergise their values with those of persons with disabilities in the community in order to build trust? International evidence suggests communities show greatest affinity toward health system values based on equitable access [29]. Local literature on the specific values that translate to trusting relationships within the health system is sparse. This study suggests that health committees should undertake interventions that engender egalitarian values in order to establish trusting relations with persons with disabilities. These interventions should complement the composite elements of egalitarianism, such as engaging and mobilising communities around issues of equality for persons with disabilities and holding facilities accountable to address these. Other ways to operationalise egalitarian values could include internal accountability measures such as town hall meetings where they report back on initiatives undertaken to promote disability, instituting corrective measures against members pursuing personal gain over that of the community, and aforementioned efforts to increase the capacity of persons with disabilities.

Community participatory structures can only hold facilities accountable if sufficient support is provided from the health facility they deal with [38]. In this policy environment, however, where health committees associated to a facility are not equipped with a mandate to hold facilities accountable, coupled with the numerous barriers persons with disabilities experience at the health facility, one wonders whether the health facility is indeed the appropriate place to raise disability issues. Importantly, however, health committees at a facility level can shape societal values [11]. Considering that the relationship between values and governance, health committees at a facility level may be able to influence societal values, to be more sensitive to issues of marginalised groups such as persons with disabilities, and strengthen good governance. Disability issues should therefore be raised at the level of the health facility as well as other levels within the health system

Health committees often practised augmentative service delivery, far-removed from the elements of community participation in health governance that they were intended to fulfil. Without legislation legitimising, and clarifying the roles of health committees, community participation may face serious peril [39]. There can be no community participation for vulnerable groups such as persons with disabilities in the face of meaningless participation for the greater community. This study supports findings from other research [14][18][19] calling on provincial policy makers to, inter-alia: specify the roles of health committees as mandated in the National Health Act, and to provide necessary support and recognition for health committees to bring about meaningful community participation [18]. Addressing shortcomings in policy is important, but will not assist health committees in helping realise the right to health for persons with disabilities on its own. Health committees should primarily look to prioritise disability and reorient their values toward egalitarian values in order to help realise the right to health for persons with disabilities.

Health committees across facilities did not, as a collective, advance the core elements of the right to health: access, availability, acceptability and quality of health services for persons with disabilities. The reasons for this are four-fold; firstly, disability issues were not very prominent on the agenda of the health committee and may have contributed to the low priority of disability. Secondly, health committees' poor understanding of disability barriers may have impeded their ability to adequately represent the health needs of persons with disabilities. Thirdly, there was both a lack of egalitarian values and the presence of rent-seeking values within health committees that adversely influenced their willingness to represent the health needs of persons with disabilities. Lastly, community participation may have, in itself, been undermined, due to the contextual, organisational, and policy factors, resulting in the health committee assuming roles that augment health services and not providing the intended oversight and governance.

Disability is widely regarded as a rights issue and should be addressed as such [2][40][44], by holding states accountable to honouring socio-

economic and civil-political human rights obligations for vulnerable groups [44] such as persons with disabilities [40]. Rights-based civil society movements in South Africa, like the Treatment Action Campaign successfully advocated for a large scale increase in the provision of HIV medication [44]. They did so by employing community agency, which involved abrasive efforts such as legal action through the courts; whilst empowering vulnerable groups to establish collaborations with health policy makers to ensure the state honours its rights-based obligations. The promotion of agency amongst the most vulnerable in a community is critical to the success of rights rights-based civil society approach, and can be critical in promoting equity [44]. Health committees can play an important role in addressing the various barriers that limit the right to health for persons with disabilities, by adopting a human-rights approach. The human rights approach requires strong community engagement and efforts to promote awareness on rights [45]. Health committees should aim to promote agency amongst persons with disabilities to strengthen their claim to their right to health by mobilising persons with disabilities, as well as the greater community around issues of equity. Health committees should consider working with disability organisations to conduct training with communities in order to raise awareness on the barriers persons with disabilities face.

A Rapid Appraisal on health committees in South Africa found that two Province's policies mandated the presence of persons with disabilities in health committees, reflecting their respective policy intent be more inclusive of persons with disabilities. This of course, is in stark contrast to the absence of any policy on health committees in the Western Cape Province, never-mind a policy mandating the representation of persons with disabilities. Also, the Western Cape Province Department of Health houses several Directorates, of which the Metro, (where this study took place) is one such directorate. The study was located within one of the Metro's eight sub-districts, reflecting the relatively limited geographical scope of the research. However, Health Policy and Systems Research considers the generalisability of qualitative findings to be dependent on the contextual relevance and the degree to which findings have been abstracted in theory [46]. Even though the study took place in a

relatively narrow geographical location and in a Province without a policy mandating the presence of persons with disabilities, ostensibly reflecting a poor commitment to disability issues, it is not empirically known whether mandatory representation of persons with disabilities in either Province yielded any benefits. Therefore, policy commitment cannot uniformly be equated to observable support for persons with disabilities refuting the relevance of policy commitment as a contextual factor influencing generalisability. There may, however, be other caveats to consider prior to generalising outcomes observed in this research.

CONCLUSION

Health committees did not advance the right to health for persons with disabilities due to the following four main reasons: under-prioritisation of disability; generally poor understanding of disability; lack of egalitarian values leading to distrust amongst persons with disabilities and peers; and continuing to augment operational services of the institution as opposed to their intended governance and oversight function.

Transversal recommendations include mandating the representation of persons with disabilities, whilst addressing marginalisation they experience whilst on the health committee. Health committees can improve their understanding of disability with training interventions and networking with disabled organisations, which may have the potential to strengthen disability advocacy. The research supports the call for provincial authorities to clarify the roles of health committees. Health committees should address disability as a rights issue, mobilising communities around disability equity, and raising awareness.

Abbreviations:

ICESCR – International Covenant on the Economic, Social and Cultural Rights

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

Competing interests:

The author has no competing interests.

Author's contributions:

The author was responsible for the development of the research design, data collection, management, analysis, and writing up of findings.

Author's information:

[1]Masters of Public Health (Health Systems) candidate, University of Cape Town, South Africa.

[1]Quality Assurance Manager at Alexandra Hospital, Cape Town, Western Cape Government: Department of Health, South Africa.

Acknowledgements:

London and Ms Hanne Haricharan for their comments on drafts of this study.

REFERENCES:

1. Adnams CM. Perspectives of intellectual disability in South Africa: epidemiology, policy, services for children and adults. Current Opinion in Psychiatry 2010; 23:436-440.

2. World Health Organisation. World Bank: World report on disability. Malta: World Health Organisation; 2011.

3. South African Human Rights Commission. Public Inquiry: Access to Health Services. Johannesburg: South African Human Rights Commission; 2009.

4. Coovadia H, Jewkes R, Barron P, Sanders D, McIntyre D. The health and health system of South Africa: historical roots of current public health challenges. The Lancet. 2009;374(9692):817-834.

5. Department of Women Children and People with Disability: Draft first country report to the United Nations on the implementation of the Convention on the Rights of Persons with Disabilities in South Africa Final Draft (Un-edited). http://www.gov.za/documents/first-country-report-united-nations-implementation-convention-rights-persons-disabilities (2013). Accessed 5 Jul 2014.

6. Rohleder P, Swartz L, Schneider M, Groce N, Eide AH. HIV/AIDS and disability organisations in South Africa. AIDS Care. 2010;22(2):221-227.

7. Philander JH, Swartz L. Needs, Barriers, and Concerns Regarding HIV Prevention among South Africans with Visual Impairments: A Key Informant Study. Research Reports. Journal of Visual Impairment & Blindness. 2006;100(2):111-114.

8. Kleintjes S, Lund C, Swartz L. Barriers to the participation of people with psychosocial disability in mental health policy development in South Africa: A qualitative study of perspectives of policy makers, professionals, religious leaders and academics. BMC International Health and Human Rights. 2013;13(17).

9. Lawn JE, Rohde J, Rifkin S, Were M, Paul VK, Chopra M: Alma-Ata 30 years on: revolutionary, relevant, and time to revitalise. The Lancet. 2008;372(9642):917-927.

10. Department of Health. White Paper for the Transformation of the Health System in South Africa. Pretoria: Government Gazette;1997.

11. McCoy DC, Hall JA, Ridge M. A systematic review of the literature for evidence on health facility committees in low- and middle-income countries. Health Policy Plan. 2012;27(6):449-466.

12. Loewenson R, Machingura F, Kaim B, Training and Research Support Centre (TARSC) Rusike I (CWGH). 'Health centre committees as a vehicle for social participation in health systems in east and southern Africa' EQUINET discussion paper 101, TARSC with CWGH and Medico. Harare: EQUINET; 2014.

13. Department of Health. National Health Act. Pretoria: Government Gazette; 2003.

14. Glattstein-Young GS: Community health committees as a vehicle for participation in advancing the right to health. http://uctscholar.uct.ac.za/PDF/76513_Glattstein_Young_G_S.pdf (2010). Accessed 21 Jun 2014.

15. Huss R, Green A, Sudarshan H, Karpagam S, Ramani K, Tomson G, Gerein N. Good governance and corruption in the health sector: lessons from the Karnataka experience. Health Policy Plan.2011;26(6):471-484.

16. Haricharan HJ. Rapid appraisal of health committee policies in South Africa. Cape Town: University of Cape Town; 2014.

17. Department of Health. Draft policy on the health governance structures. Pretoria: Department of Health; 2013.

18. Haricharan HJ. Extending participation: challenges of health committees as meaningful structures for community participation. A

study of health committees in the Cape Town Metropole. Cape Town: University of Cape Town; 2012.

19. Padarath A, Friedman I. The Status of Clinic Committees in Primary Level Public Health Sector Facilities in South Africa. Durban: Health Systems Trust; 2008.

20. Republic of South Africa. Constitution of the Republic of South Africa. Pretoria: Government Printers; 1996.

21. United Nations Economic and Social Council: International Covenant on Economic, Social and Cultural Rights: General Comment 14: The right to the highest attainable standard of health (Article 12 of the International Covenant on Economic, Social and Cultural Rights). http://www.unhchr.ch/tbs/doc.nsf/ (2000). Accessed 20 Jul 2014.

22. London L, Fick N, Tram KH, Stuttaford M. Filling the gap: A learning network for health and human rights in the Western Cape, South Africa. Health Hum Rights. 2012;14(1):88-105.

23. City of Cape Town: City statistics and population census: 2011 Census. https://www.capetown.gov.za/en/stats/Pages/Census2011.aspx (2011). Accessed 21 July 2014.

24. Marszalek J, De Villiers PJ. Morbidity profile of admissions to GF Jooste Hospital, Manenberg, Cape Town: original research. South African Family Practice. 2006;48(6):p.15, 15a-15e.

25. Flick U: An introduction to qualitative research: Thousand Oaks: Sage; 2009.

26. United Nations. General Assembly. Convention on the Rights of Persons with Disabilities and Optional Protocol. Geneva: United Nations; 2007.

27. Mansuri G, Rao V. Localizing development: does participation work? Washington DC: World Bank Publications; 2012.

28. Fattore G, Tediosi F. The Importance of Values in Shaping How Health Systems Governance and Management Can Support Universal Health Coverage. Value in Health. 2013;16(1, Supplement):S19-S23.

29. Abelson J, Miller FA, Giacomini M. What does it mean to trust a health system?: A qualitative study of Canadian health care values. Health Policy. 2009;91(1):63-70.

30. Gilson L. Trust and the development of health care as a social institution. Soc Sci Med. 2003;56(7):1453-1468.

31. Sheikh K, George A, Gilson L. People-centred science: strengthening the practice of health policy and systems research. Health Res Policy Syst. 2014; 12:19-4505-12-19.

32. Lincoln YS, Guba EG. Naturalistic inquiry. Sage: Newbury Park;1985.

33. Babbie E, J Mouton. The practise of social research. South African Edition. Cape Town: Oxford University Press; 2001.

34. Aragonès E, Sánchez-Pagés S. A theory of participatory democracy based on the real case of Porto Alegre. Eur Econ Rev. 2009;53(1):56-72.

35 McCowan T. Educating citizens for participatory democracy: A case study of local government education policy in Pelotas, Brazil. International Journal of Educational Development. 2006;26(5):456-470.

36 Hendriks CM. Deliberative governance in the context of power. Policy and Society. 2009;28(3):173-184.

37 McKenzie J, Müller B. Parents and therapists: dilemmas in partnership. In: Watermeyer B, Swartz L, Lorenzo T, Schneider M, Priestly M, editors. Disability and social change: a South African agenda. Cape Town: HRSC Press; 2006. p. 311-323.

38 Mogensen HO, Ngulube TJ. Whose Ownership? Which Stakes? Communities And Health Workers Participating In The Zambian Health

Reform. Urban Anthropology and Studies of Cultural Systems and World Economic Development. 2001;30(1):71-104.

39. Meier BM, Pardue C, London L. Implementing community participation through legislative reform: A study of the policy framework for community participation in the Western Cape province of South Africa. BMC International Health and Human Rights. 2012;12(1).

40. Heap M, Lorenzo T, Thomas J. 'We've moved away from disability as a health issue, it's a human rights issue': reflecting on 10 years of the right to equality in South Africa. Disability & Society. 2009;24(7):857-868.

41. South African Human Rights Commission: Towards a barrier-free society. Johannesburg: South African Human Rights Commission; 2002.

42. Department of Health. National Core Standards for Health Establishments in South Africa. Pretoria: Government Gazette; 2012.

43. Topp SM, Chipukuma JM, Hanefeld J. Understanding the dynamic interactions driving Zambian health centre performance: a case-based health systems analysis. Health Policy Plan. 2015;30(4):485-499.

44. London L. 'Issues of equity are also issues of rights': lessons from experiences in Southern Africa. BMC Public Health. 2007;7:14.

45. Geffen N. Applying human rights to the HIV/AIDS Crisis. Human Rights Dialogue. 2001;2(6):13-14.

46. Gilson L. Editor. Health Policy and Systems Research: a methodology reader. Geneva: World Health Organization; 2012.

PART D: APPENDICES

CONSENT FORM

Study title: Health Committees' understanding and practise of community participation, human rights and disability as a rights issue.

Dear sir/madam,

My name is Theodore Abrahams, I am a student at the University of Cape Town, and I am doing my Masters in Public Health degree. I am doing a research study that will try to look at the understanding and practises of persons within health committees, and how these can possibly advance the right to health for persons with disability in the Western Cape.

By now, you should have obtained the information sheet, which outlines the study in more detail. I would like you to ask you to participate in this study.

Please note that if you do not want to take part in this study, you do not have to. You also can withdraw from the study at any time during the research process, be it during the focus group discussions and participant observations, if you are chosen during to be part of the interviews, or any other time during the research. If you withdraw from the study, you will not be treated negatively in any way by me, the researcher. Also, the health care you receive will not be affected in any way if you withdraw from the study, or decide not to take part in the it.

If you do wish to participate, I may invite you to take part in the following:

1. Participant observations – during your health committee meetings
2. An interview – lasting approximately one hour
3. Focus group discussions – lasting approximately one hour

The interviews and focus group discussions can be conducted in your first language upon your request.

Any information collected by the researcher will be kept confidential. This means that only my supervisor(s) and I will have access to the researcher notes, tapes, and the notes made from these tapes. The information obtained from you, will not be shared with anyone other than the research team without your permission.

What is expressed by you in the interviews will be kept anonymous. This means that when we report on your responses, no individual names will be included, and nothing you've said in the research will be linked to you personally in any way. What is expressed by you in the focus group

discussions and participant observations, can however not be kept completely anonymous due to the presence of other persons, whom I have no control over.

You will not be paid to be a part of the research. There are minimal risks to taking part in this study, for example saying something that may be misunderstood by others, or taken in the unintended context in the focus group discussions. This however is not a major risk, as participants are in regular conversations with each other, whilst performing the duties of health committees, and there should thus be a common familiarity of participants. The researcher will however make an effort to advise all participants to not make any personal judgements based on responses made in the focus group discussions.

Confidentiality in the interviews is guaranteed.

General information

If you do feel the need for me to explain any other issues relating to the research after the interview and focus group discussions, I will be more than happy to do so and offer my contact details for you to get in touch with me.

Please note that you should only participate in this study if you feel you have a good understanding of what is expected of you as a participant. This means that you should take the time to read the information sheet carefully, and by all means, request further clarity from me if you do not understand anything relating to the study.

Contact for additional information:

Theodore Abrahams (Master student in Public Health and principal researcher)

Tel: (021)503-5037 or 0839222102

Email: theoabrahams@gmail.com

Please complete the following if applicable to you

Declaration:

I, _____(name) have read the information sheet and/or it has been explained to me. I fully understand what the study entails, as well as what is expected of me as a participant. I agree to take part in the research.

Please tick the boxes that you agree to:

I agree for notes of the meetings and focus group discussions to be taken ☐

I agree for the interview to be tape-recorded ☐

Participant: _____ _____

                   Name and Surname: **Signature**

Principal Researcher: _____
                                Signature

Date: _____

PROJECT INFORMATION

Study title: Health Committees' understanding and practise of community participation, human rights and disability as a rights issue.

You have been asked to participate in this research project, which is part of a Masters in Public Health degree, and part of the larger project of the Learning Network on Health and Human Rights South Africa, aimed at advancing the right to health. This study is hoped to help us understand how health committees' practises and understanding could advance the right to health for persons with disability.

I would like you to understand why the research is being done, as well as what is hoped will come from it, as well as what will be asked of you as a research participant.

Why is this research being done?

The Constitution of South Africa allows for numerous rights to the people of South Africa. One of these rights is the right to health. The right to health for persons with disability is greatly impeded in South Africa, due largely, to inequality and discrimination. Health committees are representatives for communities, and have been shown to have the potential to advance the right to health for communities. Health committees, as representatives of communities, including persons with disability, and could thus be a mechanism to help advance the right to health for persons with disability.

What is hoped to be achieved from this study:

6. To look into how health committees' understanding of their governance role could advance the right to health for persons with disability.
7. To look at how the practises of health committees could advance the right to health for persons with disability, as well as some of the special accommodations set out in the Convention on the Rights of Persons with Disability.
8. To identify the barriers to health committees helping to advance the right to health for persons with disability.
9. To establish ways to achieve some generalised health system improvements, using the advancement of the right to health for persons with disability as an inlet to address some of the underlying systemic issues.
10. To make recommendations to stakeholders on how to help advance the right to health for persons with disability.

Which research methods will be used?

1. Participant observations

Participant observation is a method that researchers use when they want to see how participants conduct themselves in a "real-life" setting, to be able to see how participants interact with each other, as well as what participants said, how they said it, as well as the unsaid. To see how persons within the health committee interact with disability issues, as well as to evaluate how they execute their governance role to help advance the right to health for persons with disability.

2. Focus group discussions

Focus group discussions are another research method, where the researcher asks questions to a group of participants, and wants to see how people interact in a group, as well as how ideas can start to develop from one person to another, to form a deeper understanding of the question at hand.

To look into how persons within health committees interact with each other when working advance the right to health for persons with disability, as well as how they prioritise these issues.

3. Interviews

These look at selected persons within the health committee, and look to get an in-depth understanding of the individual's understandings and practises around issues to advance the right to persons with disability at a much deeper level.

What is expected from you as a participant?

You will be expected take part in some/all of the above-stated methods, and to answer questions posed to you in an honest way.

Anticipated time commitments?

Interviews – approximately one hour

Focus group discussions- approximately one hour

Participant observations – during scheduled health committee meetings

What are the benefits of taking part in this study?

You will not be paid to take part in this study, or receive any material remuneration. Your inputs could provide interested parties e.g. facility manager, other health committee members, policy makers etc. with information on whether health committees can advance the right to

health for persons with disability. The information could lay the platform for other studies or organisations to do more work to help realise the right to health for persons with disability. Improvement in practises and understandings health committees can also possibly have other knock-on benefits to improve other areas in health committee operations.

It is vital to note that improvement of the right to health for persons with disability is **not** guaranteed following this study.

What are the risks to participating in this study?

Other participants may make judgments on you based on your responses made during the study. Much effort will be made by the researcher to try and negate this, but participants must be aware of this being a potential risk. The information gathered by the researcher will stay confidential, and if sharing is required, permission will first be obtained from you, the participant.

Consent form

You will need to complete and sign the consent form to take part in the research. The consent form is for your protection, to ensure that you fully understand what is expected of you and why the research is being done. The consent form follows after this form.

Contacts

1. Theodore Abrahams – (021)503-5037/083 922 2102

Email: theoabrahams@gmail.com

(Principal researcher – UCT Masters Student)

2. Hanne Haricharan – (021)650-2567

Email: Hanne.Haricharan@uct.ac.za

(Researcher supervisor – UCT/Learning Network South Africa)

APPENDIX C: Semi-structured interview question sheet and question list for focus group discussions.

Interview Questionnaires

Interview no:

Interviewer:

Age of participant:

Research question:

Are health committees, as governance structures, ensuring the right to health for people with disability – and if not, what are the barriers for them undertaking this role?

Sub-Questions:

Are health committees able to help realise the right to health (availability, accessibility and acceptable and quality of services), for persons with disabilities by fulfilling their governance role.

Do health committees address the underlying determinants of health when attempting to realise the right to health for persons with disability?

Are health committees able to help realise the rights and special accommodations stated in the Convention on the Rights of Persons with Disabilities?

How well do health committees understand the barriers mentioned in the Convention on the Rights of Persons with Disabilities, relating to how persons with disability access their right to health?

How do health committees engage persons with disability in health related decision-making on their behalf, to help advance the right to health for persons with disability?

How do contextual factors, and the arrangement of services under the ambit of governance by health committees positively or negatively influence their capacity to realise the right to health for persons with disabilities?

Interview and focus group discussion questions:

1. Are health committees able to help realise the right to health (availability, accessibility and acceptable and quality of services), for persons with disabilities by fulfilling their governance role.

- What do you understand human rights to be?
  - Probe for right to health understanding
  -
- What do you understand governance to be?
- Who is entitled to human rights?
- How do you understand the right to health?
- How realistic do you think the right to health really is in this setting, especially or persons with disability?

2. Do health committees address the underlying determinants of health when attempting to realise the right to health for persons with disability?

- Which factors do you think are important to address when attempting to realise the right to health?
- How important is say, water, or food, when looking at ways to realise the right to health for persons with disability?
- Comment on some of the factors involving the patient's environment that you consider when implementing interventions as a health committee for your community?

3. Are health committees able to help realise the rights and special accommodations stated in the Convention on the Rights of Persons with Disabilities?

- Has your health facility made some of the structures in the facility disability-friendly?
- How important is it to make health facilities accessible to all persons?

4. How well do health committees understand the barriers mentioned in the Convention on the Rights of Persons with

Disabilities, relating to how persons with disability access their right to health?

- What are the difficulties experienced, if any, by persons with disability when coming to health facilities?
- How does the facility address, or not, some of the difficulties that persons with disability experience when coming to health facilities?
- What is your role in working with person with disability?
- What is your understanding of human rights documents?
- Describe your relationship with any person(s) with disability you encounter in your work at the health facility.
- How easily, or not, do people with disability move through your facility?

5. How do health committees engage persons with disability in health related decision-making on their behalf, to help advance the right to health for persons with disability?

- Who makes decisions relating to health care for persons with disability?
- Describe the way resources are allocated to different projects, then describe how they are done for persons with disability, if at all?

6. How do contextual factors, and the arrangement of services under the ambit of governance by health committees positively or negatively influence their capacity to realise the right to health for persons with disabilities?

- How do you feel about the current policy environment around health committees roles and functions?
- How do your actions as a health committee influence the health care for persons with disability?
- Describe the process when deciding which interventions are undertaken to improve health for the community?
- How freely can you make decisions around resource allocation to certain projects that you feel important?
- How willingly do facility staff work with the anticipated projects of the health committee?

General questions:

How do you think health committees can improve the experience for persons with disability at health facilities?

What are your thoughts on the lack of a policy to describe the roles for health committees?

What would you like to see as roles for yourselves if new policy were to be developed for the roles of health committees?

Do you have any other questions, or concerns that we have not yet spoken of?

APPENDIX D: UCT ethics approval to conduct research

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences

Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/research/humanethics/forms

13 January 2014

HREC REF: 725/2013

Ms H Haricharan
Public Health & Family Medicine
Falmouth Building

Dear Ms Haricharan

PROJECT TITLE: HEALTH COMMITTEES' UNDERSTANDING AND PRACTISE OF COMUUNITY PARTICIPATION, HUMAN RIGHTS AND DISABILITY AS A RIGHTS ISSUE

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has formally approved the above-mentioned study. We acknowledge that the student Mr Theodore Abrahams is also involved on this project.

Approval is granted for one year until the 30th January 2015

- Please change the supervisor to be the PI. The student will be recognised on all communications.

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/research/humanethics/forms)

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC reference no in all your correspondence.

Yours sincerely

T U Burgess

pp

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN ETHICS
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical
Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50. 56 and 312.

APPENDIX E: Permission to conduct research at health facilities

Civic Centre
12 Hertzog Boulevard
Cape Town 8001
P O Box 2815, Cape Town 8000
Ask for: Dr G H Visser

Tel: 021 400-3981
Cell: 083 298 8718
Fax: 021 421-4894

Iziko loLuntu
12 Hertzog Boulevard
Cape Town 8001
Cela: Qrh G H Visser

Umnxeba: 021 400-3981
Cell: 083 298 8718
Ifeka: 021 421-4894

Burgersentrum
Hertzog-boulevard 12
Kaapstad 8001
Posbus 2815, Kaapstad 8000
Vra vir Dr G H Visser

Tel: 021 400-3981
Sel: 083 298 8718
Faks: 021 421-4894

E-mail: helena.visser@capetown.gov.za
Website: http://www.capetown.gov.za
Ref:
Filename: http://citymyalles.capetown.gov.za/personal/kjennings/Personal Documents/My Documents/City General/Research/UCT/TAbrahams 10396.docx

CITY OF CAPE TOWN | ISIXEKO SASEKAPA | STAD KAAPSTAD

CITY HEALTH — Specialised Health

2014-03-11

Re: Research Request: Health committees' understanding and practice of community participation, human rights and disability as a rights issue (ID NO: 10396)

Dear Mr Abrahams,

Permission has been granted for you to do your research in the Klipfontein Sub District.

Klipfontein Sub District: Manenberg Clinic
Contact People   Mr K Nkoko (Sub District Manager)
                                    Tel: (021) 630-1667/ 082 433 1332
                                    Mrs T Nojaholo (Head: PHC & Programmes)
                                    Tel: (021) 630-1626/ 084 220 0133

Please note the following:
1.   All information obtained must be kept confidential.
2.   Access to the clinic and its staff must be arranged with the relevant Manager such that normal activities are not disrupted.
3.   A copy of the final report must be sent to the City Health Head Office, P O Box 2815 Cape Town 8001, within 6 months of its completion and feedback must also be given to the clinics involved.
4.   Your project has been given an ID Number (10396). Please use this in any future correspondence with us.

Thank you for your co-operation and please contact me if you require any further information or assistance.

Yours sincerely

DR G H VISSER
MANAGER: SPECIALISED HEALTH

cc.   Mr Nkoko & Mrs Nojaholo
      Dr K Jennings

THIS CITY WORKS FOR YOU   ESI SIXEKO SISEBENZELA WENA   HIERDIE STAD WERK VIR JOU

STRATEGY & HEALTH SUPPORT

Health.Research@westerncape.gov.za
tel: +27 21 483 6857; fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001.
www.capegateway.gov.za)

REFERENCE: RP 019/2014
ENQUIRIES: Ms Charlene Roderick

1 Torbruk Close
Strandfontein
Cape Town
7798

For attention: **Mr Theodore Abrahams**

**Re: Health Committees' understanding and practise of community participation, human rights and
disability as a rights issue.**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased
to inform you that the department has granted you approval for your research.
Please contact the following people to assist you with any further enquiries in accessing the
following sites:

| Gugulethu CHC | L Mbanga | Contact No. 921 637 1280 |
| Heideveld CHC | A Eksteen | Contact No. 021 637 8054 |

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested
facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the
department with an electronic copy of the final report within six months of completion of
research. This can be submitted to the provincial Research Co-ordinator
(Health.Research@westerncape.gov.za).
3. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR J EVANS
ACTING DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 02/05/14
CC   P OLCKERS   DIRECTOR: MITCHELLS PLAIN / KLIPFONTEIN

143

APPENDIX F: BMC Health Services Research – Instructions to Authors

Instructions for authors

Research articles

Criteria | Submission process | Preparing main manuscript text |
Preparing illustrations and figures |Preparing tables | Preparing
additional files | Style and language

Assistance with the process of manuscript preparation and submission is
available from BioMed Central customer support team. See 'About this
journal' for information about policies and the refereeing process. We
also provide a collection of links to useful tools and resources for scientific
authors on our page.

Criteria

Research articles should report on original primary research, but may
report on systematic reviews of published research provided they adhere
to the appropriate reporting guidelines which are detailed in our Editorial
Policies. Please note that non-commissioned pooled analyses of selected
published research will not be considered.

Submission process

Manuscripts must be submitted by one of the authors of the manuscript,
and should not be submitted by anyone on their behalf. The submitting
author takes responsibility for the article during submission and peer
review.

Please note that *BMC Health Services Research* levies an article-
processing charge on all accepted Research articles; if the submitting
author's institution is a BioMed Central member the cost of the article-
processing charge may be covered by the membership (see About
page for detail). Please note that the membership is only automatically
recognised on submission if the submitting author is based at the
member institution.

To facilitate rapid publication and to minimize administrative costs, *BMC
Health Services Research*prefers online submission.

Files can be submitted as a batch, or one by one. The submission process
can be interrupted at any time; when users return to the site, they can
carry on where they left off.

See below for examples of word processor and graphics file formats that can be accepted for the main manuscript document by the online submission system. Additional files of any type, such asmovies, animations, or original data files, can also be submitted as part of the manuscript.

During submission you will be asked to provide a cover letter. Use this to explain why your manuscript should be published in the journal, to elaborate on any issues relating to our editorial policies in the 'About *BMC Health Services Research*' page, and to declare any potential competing interests. You will be also asked to provide the contact details (including email addresses) of potential peer reviewers for your manuscript. These should be experts in their field, who will be able to provide an objective assessment of the manuscript. Any suggested peer reviewers should not have published with any of the authors of the manuscript within the past five years, should not be current collaborators, and should not be members of the same research institution. Suggested reviewers will be considered alongside potential reviewers recommended by the Editorial team, Editorial Advisors, Section Editors and Associate Editors.

Assistance with the process of manuscript preparation and submission is available from BioMed Central customer support team.

We also provide a collection of links to useful tools and resources for scientific authors on our Useful Tools page.

File formats

The following word processor file formats are acceptable for the main manuscript document:

☐ Microsoft word (DOC, DOCX)

☐ Rich text format (RTF)

☐ Portable document format (PDF)

☐ TeX/LaTeX (use BioMed Central's TeX template)

☐ DeVice Independent format (DVI)

TeX/LaTeX users: Please use BioMed Central's TeX template and BibTeX stylefile if you use TeX format. During the TeX submission process, please submit your TeX file as the main manuscript file and your bib/bbl file as a

dependent file. Please also convert your TeX file into a PDF and submit this PDF as an additional file with the name 'Reference PDF'. This PDF will be used by internal staff as a reference point to check the layout of the article as the author intended. Please also note that all figures must be coded at the end of the TeX file and not inline.

If you have used another template for your manuscript, or if you do not wish to use BibTeX, then please submit your manuscript as a DVI file. We do not recommend converting to RTF.

For all TeX submissions, all relevant editable source must be submitted during the submission process. Failing to submit these source files will cause unnecessary delays in the publication procedures.

Publishing Datasets

Through a special arrangement with LabArchives, LLC, authors submitting manuscripts to BMC Health Services Research can obtain a complimentary subscription to LabArchives with an allotment of 100MB of storage. LabArchives is an Electronic Laboratory Notebook which will enable scientists to share and publish data files in situ; you can then link your paper to these data. Data files linked to published articles are assigned digital object identifiers (DOIs) and will remain available in perpetuity. Use of LabArchives or similar data publishing services does not replace preexisting data deposition requirements, such as for nucleic acid sequences, protein sequences and atomic coordinates.

Instructions on assigning DOIs to datasets, so they can be permanently linked to publications, can be found on the LabArchives website. Use of LabArchives' software has no influence on the editorial decision to accept or reject a manuscript.

Authors linking datasets to their publications should include an Availability of supporting data section in their manuscript and cite the dataset in their reference list.

Preparing main manuscript text

General guidelines of the journal's style and language are given below.

Overview of manuscript sections for Research articles

Manuscripts for Research articles submitted to *BMC Health Services Research* should be divided into the following sections (in this order):

 Title page

Abstract

  Keywords

  Background

  Methods

  Results and discussion

  Conclusions

  List of abbreviations used (if any)

  Competing interests

  Authors' contributions

  Authors' information

  Acknowledgements

  Endnotes

  References

  Illustrations and figures (if any)

  Tables and captions

  Preparing additional files

The **Accession Numbers** of any nucleic acid sequences, protein sequences or atomic coordinates cited in the manuscript should be provided, in square brackets and include the corresponding database name; for example, [EMBL:AB026295, EMBL:AC137000, DDBJ:AE000812, GenBank:U49845, PDB:1BFM, Swiss-Prot:Q96KQ7, PIR:S66116].

The databases for which we can provide direct links are: EMBL Nucleotide Sequence Database (EMBL), DNA Data Bank of Japan (DDBJ), GenBank at the NCBI (GenBank), Protein Data Bank (PDB), Protein Information Resource (PIR) and the Swiss-Prot Protein Database (Swiss-Prot).

You can download a template (Mac and Windows compatible; Microsoft Word 98/2000) for your article.

For reporting standards please see the information in the About section.

Title page

The title page should:

  provide the title of the article

  list the full names, institutional addresses and email addresses for all authors

☐ indicate the corresponding author

Please note:

☐ the title should include the study design, for example "A versus B in the treatment of C: a randomized controlled trial X is a risk factor for Y: a case control study"

☐ abbreviations within the title should be avoided

Abstract

The Abstract of the manuscript should not exceed 350 words and must be structured into separate sections: **Background,** the context and purpose of the study; **Methods**, how the study was performed and statistical tests used; **Results**, the main findings; **Conclusions**, brief summary and potential implications. Please minimize the use of abbreviations and do not cite references in the abstract. **Trial registration**, if your research article reports the results of a controlled health care intervention, please list your trial registry, along with the unique identifying number (e.g. **Trial registration**: Current Controlled Trials ISRCTN73824458). Please note that there should be no space between the letters and numbers of your trial registration number. We recommend manuscripts that report randomized controlled trials follow the CONSORT extension for abstracts.

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should be written in a way that is accessible to researchers without specialist knowledge in that area and must clearly state - and, if helpful, illustrate - the background to the research and its aims. Reports of clinical research should, where appropriate, include a summary of a search of the literature to indicate why this study was necessary and what it aimed to contribute to the field. The section should end with a brief statement of what is being reported in the article.

Methods The methods section should include the design of the study, the setting, the type of participants or materials involved, a clear description of all interventions and comparisons, and the type of analysis used,

including a power calculation if appropriate. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses in the Methods section.

For studies involving human participants a statement detailing ethical approval and consent should be included in the methods section. For further details of the journal's editorial policies and ethical guidelines see 'About this journal'.

For further details of the journal's data-release policy, see the policy section in 'About this journal'.

Results and discussion

The Results and discussion may be combined into a single section or presented separately. Results of statistical analysis should include, where appropriate, relative and absolute risks or risk reductions, and confidence intervals. The Results and discussion sections may also be broken into subsections with short, informative headings.

Conclusions

This should state clearly the main conclusions of the research and give a clear explanation of their importance and relevance. Summary illustrations may be included.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations can be provided, which should precede the competing interests and authors' contributions.

Competing interests

A competing interest exists when your interpretation of data or presentation of information may be influenced by your personal or financial relationship with other people or organizations. Authors must disclose any financial competing interests; they should also reveal any non-financial competing interests that may cause them embarrassment were they to become public after the publication of the manuscript. Authors are required to complete a declaration of competing interests. All competing interests that are declared will be listed at the end of published articles. Where an author gives no competing interests, the listing will read 'The author(s) declare that they have no competing interests'.

When completing your declaration, please consider the following questions: *Financial competing interests*

☐ In the past three years have you received reimbursements, fees, funding, or salary from an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future? Is such an organization financing this manuscript (including the article-processing charge)? If so, please specify.

☐ Do you hold any stocks or shares in an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future? If so, please specify.

☐ Do you hold or are you currently applying for any patents relating to the content of the manuscript? Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript? If so, please specify.

☐ Do you have any other financial competing interests? If so, please specify.

Non-financial competing interests

Are there any non-financial competing interests (political, personal, religious, ideological, academic, intellectual, commercial or any other) to declare in relation to this manuscript? If so, please specify.

If you are unsure as to whether you, or one your co-authors, has a competing interest please discuss it with the editorial office.

Authors' contributions

In order to give appropriate credit to each author of a paper, the individual contributions of authors to the manuscript should be specified in this section.

According to ICMJE guidelines, An 'author' is generally considered to be someone who has made substantive intellectual contributions to a published study. To qualify as an author one should 1) have made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; 2) have been involved in drafting the manuscript or revising it critically for important intellectual content; 3) have given final approval of the version to be published; and 4) agree to be accountable for all aspects of the work in ensuring that

questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. Acquisition of funding, collection of data, or general supervision of the research group, alone, does not justify authorship.

We suggest the following kind of format (please use initials to refer to each author's contribution): AB carried out the molecular genetic studies, participated in the sequence alignment and drafted the manuscript. JY carried out the immunoassays. MT participated in the sequence alignment. ES participated in the design of the study and performed the statistical analysis. FG conceived of the study, and participated in its design and coordination and helped to draft the manuscript. All authors read and approved the final manuscript.

All contributors who do not meet the criteria for authorship should be listed in an acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support.

Authors' information

You may choose to use this section to include any relevant information about the author(s) that may aid the reader's interpretation of the article, and understand the standpoint of the author(s). This may include details about the authors' qualifications, current positions they hold at institutions or societies, or any other relevant background information. Please refer to authors using their initials. Note this section should not be used to describe any competing interests.

Acknowledgements

Please acknowledge anyone who contributed towards the article by making substantial contributions to conception, design, acquisition of data, or analysis and interpretation of data, or who was involved in drafting the manuscript or revising it critically for important intellectual content, but who does not meet the criteria for authorship. Please also include the source(s) of funding for each author, and for the manuscript preparation. Authors must describe the role of the funding body, if any,

in design, in the collection, analysis, and interpretation of data; in the writing of the manuscript; and in the decision to submit the manuscript for publication. Please also acknowledge anyone who contributed materials essential for the study. If a language editor has made significant revision of the manuscript, we recommend that you acknowledge the editor by name, where possible.

The role of a scientific (medical) writer must be included in the acknowledgements section, including their source(s) of funding. We suggest wording such as 'We thank Jane Doe who provided medical writing services on behalf of XYZ Pharmaceuticals Ltd.' Authors should obtain permission to acknowledge from all those mentioned in the Acknowledgements section.

Endnotes

Endnotes should be designated within the text using a superscript lowercase letter and all notes (along with their corresponding letter) should be included in the Endnotes section. Please format this section in a paragraph rather than a list.

References

All references, including URLs, must be numbered consecutively, in square brackets, in the order in which they are cited in the text, followed by any in tables or legends. Each reference must have an individual reference number. Please avoid excessive referencing. If automatic numbering systems are used, the reference numbers must be finalized and the bibliography must be fully formatted before submission.

Only articles, clinical trial registration records and abstracts that have been published or are in press, or are available through public e-print/preprint servers, may be cited; unpublished abstracts, unpublished data and personal communications should not be included in the reference list, but may be included in the text and referred to as "unpublished observations" or "personal communications" giving the names of the involved researchers. Obtaining permission to quote personal communications and unpublished data from the cited colleagues is the responsibility of the author. Footnotes are not allowed, but endnotes are permitted. Journal abbreviations follow Index

Medicus/MEDLINE. Citations in the reference list should include all named authors, up to the first 30 before adding '*et al.*'..

Any *in press* articles cited within the references and necessary for the reviewers' assessment of the manuscript should be made available if requested by the editorial office.

An Endnote style file is available.

Examples of the *BMC Health Services Research* reference style are shown below. Please ensure that the reference style is followed precisely; if the references are not in the correct style they may have to be retyped and carefully proofread.

All web links and URLs, including links to the authors' own websites, should be given a reference number and included in the reference list rather than within the text of the manuscript. They should be provided in full, including both the title of the site and the URL, in the following format:

The Mouse Tumor Biology Database

[http://tumor.informatics.jax.org/mtbwi/index.do]. If an author or group of authors can clearly be associated with a web link, such as for weblogs, then they should be included in the reference.

Examples of the *BMC Health Services Research* reference style

Article within a journal Smith JJ. The world of science. Am J Sci. 1999;36:234-5.

Article by DOI (with page numbers) O'Mahony S, Rose SL, Chilvers AJ, Ballinger JR, Solanki CK, Barber RW. Finding an optimal method for imaging lymphatic vessels of the upper limb. Eur J Nucl Med Mol Imaging. 2004;31:555-63. doi:10.1007/s00259-003-1399-3.

Article by DOI (before issue publication and without page numbers) O'Mahony S, Rose SL, Chilvers AJ, Ballinger JR, Solanki CK, Barber RW. Finding an optimal method for imaging lymphatic vessels of the upper limb. Eur J Nucl Med Mol Imaging. 2004. doi:10.1007/s00259-003-1399-3.

Article in electronic journal by DOI (no paginated version) Slifka MK, Whitton JL. Clinical implications of dysregulated cytokine production. Dig J Mol Med. 2000. doi:10.1007/s801090000086.

Article within a journal supplement Frumin AM, Nussbaum J, Esposito M. Functional asplenia: demonstration of splenic activity by bone marrow scan. Blood 1979;59 Suppl 1:26-32.

Book chapter, or an article within a book Wyllie AH, Kerr JFR, Currie AR. Cell death: the significance of apoptosis. In: Bourne GH, Danielli JF, Jeon KW, editors. International review of cytology. London: Academic; 1980. p. 251-306.

OnlineFirst chapter in a series (without a volume designation but with a DOI) Saito Y, Hyuga H. Rate equation approaches to amplification of enantiomeric excess and chiral symmetry breaking. Top Curr Chem. 2007. doi:10.1007/128_2006_108.

Complete book, authored Blenkinsopp A, Paxton P. Symptoms in the pharmacy: a guide to the management of common illness. 3rd ed. Oxford: Blackwell Science; 1998.

Online document Doe J. Title of subordinate document. In: The dictionary of substances and their effects. Royal Society of Chemistry. 1999. http://www.rsc.org/dose/title of subordinate document. Accessed 15 Jan 1999.

Online database Healthwise Knowledgebase. US Pharmacopeia, Rockville. 1998. http://www.healthwise.org. Accessed 21 Sept 1998.

Supplementary material/private homepage Doe J. Title of supplementary material. 2000. http://www.privatehomepage.com. Accessed 22 Feb 2000.

University site Doe, J: Title of preprint. http://www.uni-heidelberg.de/mydata.html (1999). Accessed 25 Dec 1999.

FTP site Doe, J: Trivial HTTP, RFC2169. ftp://ftp.isi.edu/in-notes/rfc2169.txt (1999). Accessed 12 Nov 1999.

Organization site ISSN International Centre: The ISSN register. http://www.issn.org (2006). Accessed 20 Feb 2007.

Preparing illustrations and figures

Illustrations should be provided as separate files, not embedded in the text file. Each figure should include a single illustration and should fit on a single page in portrait format. If a figure consists of separate parts, it is important that a single composite illustration file be submitted which contains all parts of the figure. There is no charge for the use of color figures.

Please read our figure preparation guidelines for detailed instructions on maximising the quality of your figures.

Formats

The following file formats can be accepted:

☐ PDF (preferred format for diagrams)

☐ DOCX/DOC (single page only)

☐ PPTX/PPT (single slide only)

☐ EPS

☐ PNG (preferred format for photos or images)

☐ TIFF

☐ JPEG

☐ BMP

Figure legends

The legends should be included in the main manuscript text file at the end of the document, rather than being a part of the figure file. For each figure, the following information should be provided: Figure number (in sequence, using Arabic numerals - i.e. Figure 1, 2, 3 etc); short title of figure (maximum 15 words); detailed legend, up to 300 words.

Please note that it is the responsibility of the author(s) to obtain permission from the copyright holder to reproduce figures or tables that have previously been published elsewhere.

Preparing tables

Each table should be numbered and cited in sequence using Arabic numerals (i.e. Table 1, 2, 3 etc.). Tables should also have a title (above the table) that summarizes the whole table; it should be no longer than 15 words. Detailed legends may then follow, but they should be concise. Tables should always be cited in text in consecutive numerical order. Smaller tables considered to be integral to the manuscript can be pasted into the end of the document text file, in A4 portrait or landscape format. These will be typeset and displayed in the final published form of the article. Such tables should be formatted using the 'Table object' in a word processing program to ensure that columns of data are kept aligned when the file is sent electronically for review; this will not always be the case if columns are generated by simply using tabs to separate text. Columns and rows of data should be made visibly distinct by ensuring that the borders of each cell display as black lines. Commas

should not be used to indicate numerical values. Color and shading may not be used; parts of the table can be highlighted using symbols or bold text, the meaning of which should be explained in a table legend. Tables should not be embedded as figures or spreadsheet files.

Larger datasets or tables too wide for a portrait page can be uploaded separately as additional files. Additional files will not be displayed in the final, laid-out PDF of the article, but a link will be provided to the files as supplied by the author.

Tabular data provided as additional files can be uploaded as an Excel spreadsheet (.xls) or comma separated values (.csv). As with all files, please use the standard file extensions.

Preparing additional files

Although *BMC Health Services Research* does not restrict the length and quantity of data included in an article, we encourage authors to provide datasets, tables, movies, or other information as additional files.

Please note: All Additional files **will be published** along with the article.

Do not include files such as patient consent forms, certificates of language editing, or revised versions of the main manuscript document with tracked changes. Such files should be sent by email to editorial@biomedcentral.com, quoting the Manuscript ID number.

Results that would otherwise be indicated as "data not shown" can and should be included as additional files. Since many weblinks and URLs rapidly become broken, *BMC Health Services Research* requires that supporting data are included as additional files, or deposited in a recognized repository. Please do not link to data on a personal/departmental website. The maximum file size for additional files is 20 MB each, and files will be virus-scanned on submission.

Additional files can be in any format, and will be downloadable from the final published article as supplied by the author. We recommend CSV rather than PDF for tabular data.

Certain supported files formats are recognized and can be displayed to the user in the browser. These include most movie formats (for users with the Quicktime plugin), mini-websites prepared according to our guidelines, chemical structure files (MOL, PDB), geographic data files (KML).

If additional material is provided, please list the following information in a separate section of the manuscript text:

▢ File name (e.g. Additional file 1)

▢ File format including the correct file extension for example .pdf, .xls, .txt, .pptx (including name and a URL of an appropriate viewer if format is unusual)

▢ Title of data

▢ Description of data

Additional files should be named "Additional file 1" and so on and should be referenced explicitly by file name within the body of the article, e.g. 'An additional movie file shows this in more detail [see Additional file 1]'.

Additional file formats

Ideally, file formats for additional files should not be platform-specific, and should be viewable using free or widely available tools. The following are examples of suitable formats.

▢ Additional documentation

o PDF (Adode Acrobat)

▢ Animations

o SWF (Shockwave Flash)

▢ Movies

o MP4 (MPEG 4)

o MOV (Quicktime)

▢ Tabular data

o XLS, XLSX (Excel Spreadsheet)

o CSV (Comma separated values)

As with figure files, files should be given the standard file extensions.

Mini-websites

Small self-contained websites can be submitted as additional files, in such a way that they will be browsable from within the full text HTML version of the article. In order to do this, please follow these instructions:

1. Create a folder containing a starting file called index.html (or index.htm) in the root.

2. Put all files necessary for viewing the mini-website within the folder, or sub-folders.

3. Ensure that all links are relative (ie "images/picture.jpg" rather than "/images/picture.jpg" or "http://yourdomain.net/images/picture.jpg" or "C:\Documents and Settings\username\My Documents\mini-website\images\picture.jpg") and no link is longer than 255 characters.

4. Access the index.html file and browse around the mini-website, to ensure that the most commonly used browsers (Internet Explorer and Firefox) are able to view all parts of the mini-website without problems, it is ideal to check this on a different machine.

5. Compress the folder into a ZIP, check the file size is under 20 MB, ensure that index.html is in the root of the ZIP, and that the file has .zip extension, then submit as an additional file with your article.

Style and language

General

Currently, *BMC Health Services Research* can only accept manuscripts written in English. Spelling should be US English or British English, but not a mixture.

There is no explicit limit on the length of articles submitted, but authors are encouraged to be concise.

BMC Health Services Research will not edit submitted manuscripts for style or language; reviewers may advise rejection of a manuscript if it is compromised by grammatical errors. Authors are advised to write clearly and simply, and to have their article checked by colleagues before submission. In-house copyediting will be minimal. Non-native speakers of English may choose to make use of a copyediting service.

Language editing

For authors who wish to have the language in their manuscript edited by a native-English speaker with scientific expertise, BioMed Central recommends Edanz. BioMed Central has arranged a 10% discount to the fee charged to BioMed Central authors by Edanz. Use of an editing service is neither a requirement nor a guarantee of acceptance for publication. Please contact Edanz directly to make arrangements for editing, and for pricing and payment details.

Help and advice on scientific writing

The abstract is one of the most important parts of a manuscript. For guidance, please visit our page on Writing titles and abstracts for scientific articles.

Tim Albert has produced for BioMed Central a list of tips for writing a scientific manuscript. American Scientist also provides a list of resources for science writing. For more detailed guidance on preparing a manuscript and writing in English, please visit the BioMed Central author academy.

Abbreviations

Abbreviations should be used as sparingly as possible. They should be defined when first used and a list of abbreviations can be provided following the main manuscript text.

Typography

 Please use double line spacing.

 Type the text unjustified, without hyphenating words at line breaks.

 Use hard returns only to end headings and paragraphs, not to rearrange lines.

 Capitalize only the first word, and proper nouns, in the title.

 All lines and pages should be numbered. Authors are asked to ensure that line numbering is included in the main text file of their manuscript at the time of submission to facilitate peer-review. Once a manuscript has been accepted, line numbering should be removed from the manuscript before publication. For authors submitting their manuscript in Microsoft Word please do not insert page breaks in your manuscript to ensure page numbering is consistent between your text file and the PDF generated from your submission and used in the review process.

 Use the *BMC Health Services Research* reference format.

 Footnotes are not allowed, but endnotes are permitted.

 Please do not format the text in multiple columns.

 Greek and other special characters may be included. If you are unable to reproduce a particular special character, please type out the name of the symbol in full. **Please ensure that all special characters used**

are embedded in the text, otherwise they will be lost during conversion to PDF.

Units

SI units should be used throughout (liter and molar are permitted, however).