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# **CIVIL SOCIETY ACTIVISM IN ACCESSING HEALTHCARE IN SOUTH AFRICA**

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## **TECHNICAL REPORT**

*September 2013*

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## **Abbreviations**

AIDS	Acquired immuno deficiency syndrome
ARA	Association for Responsible Alcohol Use
CANSA	Cancer Association of South Africa
CODESRIA	Council for the Development of Social Science Research in Africa
DSA	Diabetes South Africa
HIV	Human immunodeficiency virus
HSF	Heart and Stroke foundation
HSRC	Human Science Research Council
NCD	Non-communicable disease
PWN	Positive Women's Network
SADAG	South Africa Depression and Anxiety group
SANCA	South African Council for Alcoholism and Drug Dependence
TAC	Treatment Action Campaign

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# CHAPTER 1 INTRODUCTION

## 1.1 Background to the study

In 2010, the Council for the Development of Social Science Research in Africa (CODESRIA) issued a call for proposals from researchers based in African universities and centres of research to constitute Comparative Research Networks (CRNs) and undertake studies on or around selected priority research themes. A proposal for a study under the theme *“Health, Politics and Society in Contemporary Africa”* was submitted by a multidisciplinary team of researchers based at the Population Health, Health Systems and Innovation programme (PHHSI) of the Human Sciences Research Council of South Africa (HSRC). These members formed the CRN for the study. This report presents the key findings of the study which was entitled.

In this study access to healthcare refers to accessing comprehensive care for people living with HIV and AIDS and those living with Non-communicable diseases (NCDs).

## 1.2 Introduction

Non-communicable diseases (NCDs)—which are defined as medical conditions or diseases that are not infectious (WHO, 201)—are the leading causes of mortality in the world, accounting for 36 million of the 53 million annual deaths globally (Cesare et al, 2013; WHO, 2013). By nature, these diseases—also known as chronic diseases—are long in duration and have generally slow progression (WHO, 2013). They include mental and neurological disorders such as dementia and Alzheimer’s diseases, autoimmune disorders such as psoriasis; bone and joint conditions such as osteoporosis and arthritis; as well as renal, oral, eye and ear diseases (NCD Alliance, n.d). However, according to the World Health Organisation, the four main types of NCDs—which account for about 80 per cent of all NCD deaths—are cardiovascular diseases (such as heart attacks and stroke); cancers; respiratory diseases (such as chronic obstructed pulmonary disease and asthma); and diabetes (WHO, 2013).

The four key risk factors of NCDs are largely driven by four preventable and modifiable behavioural risk factors: tobacco use (including exposure to second-hand smoke); unhealthy diets (those high in fats, salt and sugar); insufficient physical activity; and harmful use of alcohol (WHO, 2010; Beaglehole et al, 2011b). These behaviours, in lead to

metabolic or physiological changes that increase the risk of NCDs such as obesity, increased blood pressure, high levels of or glucose (hyperglycaemia) and high levels of cholesterol or hyperlipidaemia ((WHO, 2010; Beaglehole et al, 2011b)

Beaglehole et al (2011b) posit that underlying the main risk factors of NCDs are socio-economic factors such as poverty, inequality, unemployment, social instability, unfair trade, and global imbalances. Indeed, available evidence shows that while NCDs affected people—men, women and children—from all income groups and in almost all countries (Beaglehole et al, 2011a), low and middle countries particularly in the Americas, The Eastern Mediterranean, Europe, South-East Asia and the Western Pacific, carry a disproportionate burden of these diseases (Cesare et al, 2013; WHO, 2010; 2013). Among individuals the risk of NCDs has been shown to be highest among vulnerable people of low socio-economic status and those living in poor and marginalised communities (Cesare et al, 2013; NCD Alliance, 2013) where access to comprehensive services for the prevention and treatment of NCDs is poor because of fiscal limitations, weak health systems and/or inadequate policy and legislative frameworks to tackle NCDS (Beaglehole et al, 2011a).

NCDs exact a heavy and growing toll on the socio-economic development of affected countries through, *inter alia*, increasing individual and household impoverishment (NCD Alliance, 2013; WHO, 2010) through various pathways. As Beaglehole et al (2011a:1439) assert:

Most [NCDs] are chronic and can lead to continued expenditure that trap poor households in cycles of debt and illness, perpetuating health and economic inequalities ... NCDs diminish household earnings and a family's ability to provide for and educate children...

At the global and national macroeconomic level, NCDs adversely affect labour supply, productivity and investment (as summarised in Box 1 below), resulting in reductions in overall economic output (Beaglehole et al 2011a; NCD Alliance, 2012

**Box 1: Impact on NCDs on Economic Development**

**Foregone national income:** NCDs are estimated to cause cumulative economic losses of nearly \$500 billion USD per year, for a total of \$47 trillion USD by 2030. This loss is equivalent to approximately 75% of the 2010 global GDP.

**Lost productivity:** In many LMICs, NCDs are affecting populations at younger ages, resulting in longer periods of ill health, early death of the main income earner, and a greater loss of productivity that is vital for development

Source: adapted from NCD Alliance (2012:1)



The global epidemic of NCDs is now widely and internationally recognised as a major development challenge that needs to be addressed as a pathway to socio-economic development. One of the earliest recognition in this regard was at the 2002 *Johannesburg Declaration in Sustainable Development* where UN Member States affirmed their “pledge to ... fight against the worldwide conditions that pose severe threats to the sustainable development of our people, which include communicable and chronic diseases”<sup>1</sup>. By the same token, in 2010 the *High-level Meeting of the General Assembly on the Millennium Development Goals* called for accelerated progress to address “evolving health challenges such as the increased incidence of con-communicable diseases”<sup>2</sup>. A year later at the UN High-level meeting on NCDs (September, 2011) the *Political Declaration on the Prevention and Control of Non-Communicable Diseases* committed the UN system-wide action to combat NCDs and control their modifiable risk factors particularly in low and middle-income countries” (NCD Alliance<sup>2</sup>:2).

The NCD Alliance (nd:2) however argues that “despite this political recognition ... the global response to the NCD epidemic has been slow ...while the epidemic continues to grow, hindering progress on sustainable development”. This is particularly the case in low-and middle-income countries where within-country dimensions of NCDs have not received explicit attention in academic research and policy dialogues, thus leading to scarcity of evidence that could be used to formulate and implement interventions to reduce NCD and their inequalities (Cesare et al. 2013). This lack of attention to NCDs is been particularly evident in the civil society sector which has otherwise had, over the years, profound impacts on health policy and issues (WHO, 2001). In South Africa, for example, civil society activism is hailed for having brought the HIV and AIDS epidemic to the centre-stage of public and policy discourse and forcing the State to not only acknowledge the epidemic but to also to put in place explicit care, support and treatment interventions including the provision of free access to anti-retroviral therapy.

Much less is known, however, about civil society activism and its role in improving or ensuring access to treatment for other major diseases and health conditions that lead to mortality in South Africa. These diseases which have resulted in the loss of 65 000 lives per year (Statistics South Africa, 2006; Puone et al, 2008). include NCDs such as heart diseases stroke, hypertension, and diabetes. This study therefore aims to contribute to the closing of

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<sup>1</sup> Johannesburg Declaration on Sustainable Development. Paragraph 19. 2002

<sup>2</sup> Keeping the promise: united to achieve the Millennium Development Goals. United Nations General Assembly resolution. 19 October 2010. A/Res/65/1.

this knowledge gap by comparing strategies of HIV and AIDS civil society organisations (CSOs) with those of organisations advocating for access to healthcare with regard to NCDs in South Africa.

### **1.3 Objectives of Study**

The **specific objectives** of the study are as follows:

1. To examine the political and social context of healthcare provision for NCDs and HIV and AIDS in South Africa.
2. To explore the strategies used by HIV and AIDS civil society organisations in advocating for greater access to treatment and healthcare.
3. To explore the strategies used by civil society organisations representing NCDs in advocating for greater access to treatment and healthcare
4. To compare the strengths and weakness of the strategies used by HIV and AIDS civil society organisations with those used by NCD civil society organisation to help access treatment and healthcare.

It is envisaged that the findings of the study will contribute to greater theoretical understanding and knowledge on how civil society activism can contribute to increased access to healthcare.

### **1.4 Methodology**

#### **Approach**

To achieve the objectives the study employed the comparative research method which is inherent in social science research (Mills, van de Bunt, & de Bruijn, 2006; Ragin & Robinson, [ND]; Robinson & Ragin, 2007). The comparative approach is a method in its own right and is a fundamentally case-oriented technique (Ragin C. , 2008). Given that only a few cases are often the focus, substantive knowledge about each case is generated. Whereas the focus of research is often to document the general patterns of a phenomenon characterising large populations and then draw conclusions, comparative research works differently. The focus in comparative research is not on the relationship between variables or on the problems of inference or prediction but on making sense of a small number of cases because they are substantively and theoretically important (Ragin C. , 2008). The constitution of cases and population is a key focus in social science research. In surveys the target population is demarcated by demographic, geographic, and temporal considerations and the focus is on deriving a representative sample. In contrast, the focus of comparative

research is on cases which are viewed as being important configurations of events and structures at a macro level (Ragin & Robinson, [ND]). Cases are treated as singular entities, which are purposefully defined and selected. Comparative studies often start with simple ideas about social phenomena in like settings (such as countries, organizations, regions and cultures among other variables) can parallel each other to sufficiently allow for comparison and contrast. The unit of comparison has to have some level of similarity to be compared with similar unit; that is cases have to be alike enough to allow for comparison.

In quantitative studies, large numbers are often preferred. The larger the size of the sample the more likely it is to test underlying assumptions about the units of analyses. In comparative research the focus is on phenomena that can be considered to be rare and so the cases are few (Ragin C. , 2008). Cases are often of interest because they have some historical or cultural significance. Whereas theory-testing is a critical concern in quantitative studies it is not always possible to apply theory-testing to comparative studies because of the small number of cases that this involves. The focus in case-oriented comparative studies is on studying and gaining in-depth knowledge about each case (Ragin & Robinson, [ND]). It is often not possible to test an idea generated through in-depth analysis using another sample of cases. Comparative studies help to explain the “how” of culturally or historically significant phenomena.

Cross-national studies help to explain, interpret and understand emerging patterns, diverse outcomes, processes and their significance for phenomenon under investigation. While countries are useful comparators, the disadvantage is that within-country differences are often obscured, particularly where there is great diversity within the same country, resulting in what is referred to as ‘whole-country bias’. The units of observation in comparative studies are territorially distinct macro social units. A phenomenon can be studied at various levels of analysis. What is important is to clarify the unit of analysis and the level of analysis that the study intends to focus on. The focus in comparative research is to draw out the similarities and differences in the units of analyses.

Although comparative analysis is as old as the discipline of sociology, the approach continues to generate debate due to what are considered its problems (Mills, van de Bunt, & de Bruijn, 2006). Scholars on both sides of the divide raise important methodological issues that continue to be the subject of debate (Mills, van de Bunt, & de Bruijn, 2006; Ragin & Robinson, [ND]). Some of the problems of comparative research relate to sampling (case selection), construct equivalence, variable/ case orientation and causality (Mills et al

2006:621). Comparative methodology is used in both quantitative and qualitative research and therefore the challenges of employing the technique affect both research approaches (quantitative and qualitative). In quantitative the focus large numbers or units (representative sample) produces a range of variables that can be compared. While a representative sample from a number of countries is likely to provide statistically sound results, the risk of gaining superficial understanding of the entities or phenomena involved remains (Mills, van de Bunt, & de Bruijn, 2006). In qualitative research the focus on a small number of cases with a range of variables is also problematic. While these (few cases and more variables) provide the opportunity for in-depth understanding, the cases can be considered too few to effectively draw conclusions regarding causality (Mills, van de Bunt, & de Bruijn, 2006). Another methodological challenge that comparative studies raise is that of construct equivalence which refers to “the instance where the instrument measures the same latent trait across all groups (Mills et al, 2006:623). A typical problem in cross-national comparisons can occur when dealing with concepts such as class, race, or ethnicity in the South African context. How these are defined in one context might radically differ with their definition and description in other contexts. Such challenges presented by comparative research force analysts to debate and formulate constructs that are comprehensive enough yet which also move beyond the national or cultural specificity.

In terms of whether the focus is on variable or case orientation, it is important to understand what is involved. In the case-oriented approach, the focus is on a few cases with numerous variables. In the variable-oriented approach the focus is on numerous cases and the comparison is based on a few variables. The debate on attribution and causality in comparative methods reflects the arguments related to support for quantitative and qualitative research (Mills, van de Bunt, & de Bruijn, 2006). Analysts grounded in the quantitative tradition argue that causality can be established through statistical techniques such as correlation. However analysts grounded in qualitative or interpretivist tradition take a relativist position and postulate that causality can be attributed not to one but a range of factors.

Despite the seemingly complex challenges that comparative research methodology (CRM) presents it remains a valuable technique analysing social phenomena and it is from this position that we employ the technique in understanding civil society activism in accessing healthcare for people living with HIV and AIDS and those living with NCDs. As Mills et al (2006) notes, the goal of comparative research is to draw out the similarities and differences or variance in the entity under focus.

Whereas most comparative research seems focus on cross-national studies, the current study focuses on within-country comparisons. Our unit of analysis is organizations and we use different levels of analysis. We compare civil society activism of organizations that deal with non-communicable diseases (NCD) with the activism of organizations that focus with HIV and AIDS. The purpose is to understand how the activism of these two different types of organizations has helped communities gain greater access to healthcare for their specific conditions (NCDs) and HIV and AIDS.

### **Data sources**

The study drew from a desktop review of policy and legislative documents related to NCDs in South Africa as well as relevant national and international literature. The document and literature review was completed by primary data collected during face-to-face interviews with key informants in selected CSOs dealing with HIV and AIDS as well as NCDs.

### ***Document and literature review***

The document and literature review entailed a comprehensive and analytical desk-top review of:

1. Relevant policy and legislative documents related to NCDs in South Africa as well as, operational and other documents of all the selected civil society organisations. The purpose of this review was to obtain a deeper understanding of the country's current frameworks for commitment and the organizations' experiences of programme implementation and multi-sectoral support.
2. Relevant academic publications on NCDs, HIV and AIDS and civil society activism in South Africa. The aim of the review was to assess current knowledge about civil society activism for healthcare in South Africa.
3. Current empirical literature reflects on civil society activism for healthcare in other parts of Africa and the world. The aim of this component of the literature review was to assess the state of knowledge about civil society activism, and to document the scope and nature of "best practice" interventions in other parts of the world that could be relevant for South Africa.

### ***Key informant interviews***

Following the document and literature review, key informant interviews (face-to-face and telephonic<sup>3</sup>) were conducted with representatives of 12 selected HIV and AIDS and NCDs civil society organisations as shown in Table 1 below.

**Table 1: Organizations Interviewed**

<b>Organisation</b>	<b>Focus</b>	<b>Method of data collection</b>
<ul style="list-style-type: none"><li>• Treatment Action Campaign (TAC)</li></ul>	<ul style="list-style-type: none"><li>• HIV and AIDS</li></ul>	<ul style="list-style-type: none"><li>•</li></ul>
<ul style="list-style-type: none"><li>• The Heart and Stroke Foundation</li></ul>	<ul style="list-style-type: none"><li>• Heart and Stroke</li></ul>	<ul style="list-style-type: none"><li>•</li></ul>
<ul style="list-style-type: none"><li>• The Cancer Association of South Africa (CANSA)</li></ul>	<ul style="list-style-type: none"><li>• Cancer</li></ul>	<ul style="list-style-type: none"><li>•</li></ul>
<ul style="list-style-type: none"><li>• Diabetes South Africa (DSA)</li></ul>	<ul style="list-style-type: none"><li>• Diabetes</li></ul>	<ul style="list-style-type: none"><li>•</li></ul>
<ul style="list-style-type: none"><li>• The South African Depression and Anxiety Group (SADAG)</li><li>• SA Federation for Mental Health</li></ul>	<ul style="list-style-type: none"><li>• Mental illness/ drug abuse</li></ul>	<ul style="list-style-type: none"><li>•</li></ul>
<ul style="list-style-type: none"><li>• Positive Women's Network (PWN)</li></ul>	<ul style="list-style-type: none"><li>• HIV and AIDS</li></ul>	<ul style="list-style-type: none"><li>•</li></ul>
<ul style="list-style-type: none"><li>• CINDI</li></ul>	<ul style="list-style-type: none"><li>• HIV and AIDS</li></ul>	<ul style="list-style-type: none"><li>•</li></ul>
<ul style="list-style-type: none"><li>• South African Council on Alcoholism and Drug Dependence (SANCA)</li><li>• Industry Association for Responsible Alcohol Use (ARA)</li><li>• Alcoholics Anonymous (AA)</li></ul>	<ul style="list-style-type: none"><li>• Alcoholism</li></ul>	
<b>12</b>	<b>Total</b>	

The main purpose of these interviews was to gather stakeholders' perspectives on the strategies used by their organisations including the rationale for the strategies used; the challenges and successes made with regard to the implementation of such strategies; as well as their required support for ensuring access to health care in their domains.

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<sup>3</sup> These took place when there were time and spatial constraints

## **Selection of organisations**

The research team used the internet to identify and compile a list and contact details of potential organisations that would be relevant to the study that is focusing on HIV and AIDS or NCDs. The organisations were then contacted by phone requesting their participation in the study. This was followed by a formal invitation by e-mail. During the course of the study some key informants referred the researchers to other organisations in their activist networks. Thus both purposive and snowball sampling techniques were used to select study participants. Through this selected process a total of 12 organisations (Table 1) was eventually studied.

## **Data collection**

The interviews, done between November 2012 and March 2013, were conducted in English using a semi-structured interview guide (Appendix 1) and by a team comprising of an interviewer and a note-taker. With the consent of interviewees most of the interviews were recorded. Where participants did not wish to be recorded only notes were taken. The interviews took approximately 1 hour 45 minutes to complete.

## **Data analysis**

Given that the data collected is qualitative, the analysis entailed content analysis and constant comparative analysis method (CCM) using NVIVO software. CCM involves making systematic comparison across units of data (for example, interviews, statements or themes) to develop conceptualizations of the possible relations between various pieces of data. The idea behind the use of these two qualitative data analysis methods is to identify the key themes emerging from the data and to be able to compare the strategies of organisations involved in HIV and AIDS activism and those organisations involved in non-communicable diseases (NCD).

## **1.5 Ethical Consideration**

The study was granted ethical approval by the HSRC Research Ethics Committee (REC) (3/22/08/12 approval number).

## **1.6 Structure of the Report**

The executive summary provides a brief overview of the study with special focus on the main findings and their implications for policy, practice and further research. Chapter 1 outlines the rationale, aims and methods used for this research. Chapter 2 presents the document and literature review and outlines the current legal and policy framework that

facilitate the addressing of NCDs and HIV and AIDS in South Africa. Chapter 3 presents the findings of the key informant interviews. Then report concludes with Chapter 4 where the key findings are summarized and recommendations for practice are provided.



## **CHAPTER 2     THE POLITICAL AND SOCIAL CONTEXT OF CIVIL SOCIETY ACTIVISM FOR HEALTHCARE IN SOUTH AFRICA**

### **2.1     Introduction**

This chapter provides a brief overview of the current trends levels and patterns of non-communicable diseases (NCDs) in South Africa and the key risk factors. The current legal and policy framework for dealing with these diseases is also presented. In this chapter both HIV and AIDS and NCD civil society organizations, their vision, mission, programmes and activities are presented with a view to understanding the extent of their activism and establishing the basis for comparison. The chapter suggests that there are areas of similarities in terms of the civil society activism for access to comprehensive care for HIV and AIDS and also for the NCDs. There are also differences and we also try to understand and explain the differences.

### **2.2     Policy and legislative Framework**

The South African government has since 2000 developed many policies and programmatic responses to ensure that there is a multi-sectoral response to HIV/AIDS. This is currently driven by the National Strategic Plan (NSP) 2012 – 2016 which outlines the country's planned response to the prevention and treatment of HIV and AIDS, TB and STIs over the next five years. "It seeks to improve on the achievements of the last Plan (NSP 2007 – 2011), which massively scaled up our anti-retroviral treatment (ART) programme and sought to decrease the number of new HIV infections' (SANAC, 2013). The NSP is complemented by a variety of policies and guidelines including:

- the revised policy and guidelines for the implementation of the PMTCT programme
- the Integrated Nutrition Programme
- Infant and Young Child Feeding Policy (2008)
- A policy on quality health care for South Africa (2008)
- The School Health Policy for South Africa
- Policy guidelines for Youth and Adolescent Health
- Policy Framework for Orphans and other Children made Vulnerable by HIV & AIDS
- National Action Plan for Orphans and other Children made vulnerable by HIV and AIDS
- Home and Community-Based Care Policy Framework

With regards to NCDs, the post-apartheid government in South Africa has been pro-active in addressing concerns around NCDs and evidence suggests that since 1994, a range of legislations and measures that directly address NCDs have been passed. In 1993 the South African government passed the Tobacco Products Control Act. The enactment of the Act protected children and adolescents from the glamorisation of smoking. The Act also ensured that the rights of non-smokers were protected by ensuring smoke-free public environments. Government attempts to control smoking also evident in the annual tax increases on tobacco products and this has not only discouraged potential smoker from starting the habit but it may have discouraged existing smokers to also quit. According to Mayosi et al (2009) smoking is among the attributes included in the South African death notification form thus helping to monitor causes of death related to smoking.

In terms of alcohol control, South Africa in 2003 passed the Liquor Act (Act 59 of 2003) whose aim is to control alcohol abuse and its associated socioeconomic effects. The Liquor Act (RSA, 2004) also aims to encourage responsible and sustainable liquor industry, and prevent advertising of liquor to children. Annual increases on alcohol are meant to discourage alcohol consumption but whether this objective is being achieved is subject to debate as the price increases of branded alcoholic beverages do not stop the consumption of alcohol. Instead, consumers to seek cheaper and often more dangerous alternatives. Other measures the measures taken include reducing the amount of alcohol allowed in the blood alcohol levels of drivers, increasing taxes on alcohol and tobacco products, requiring warnings on the labels of alcohol and tobacco among other measures (Bradshaw, Steyn, Levitt, & Noliyana, 2011). The seriousness of the government in dealing with alcohol related mortality is evident in the fact that not only is there a national Liquor Act (2004) but provinces such as Eastern Cape, Gauteng and Western Cape have Liquor Acts which regulate how they deal with alcohol related issues within their regions (Western Cape Province, 2008; Gauteng Province, 2013; Eastern Cape province, 2003). Provinces such as the Eastern Cape have Liquor regulation boards which ensure compliance with the laws, legislations and regulations related to alcohol.

Since the formation of the Directorate for Chronic Diseases, disability and Geriatrics Unit in 1996, a range of national guidelines have been formulated to prevent and control NCDs in South Africa (Bradshaw et al, 2011). The promulgation of the Mental Health Care Act No 17 of 2002 (RSA, 2002) provided the guidelines for the provision of care in the public in the health system and also provided the scope for community-based care for mental health

patients. The glaring challenges of poverty, unemployment, HIV and AIDS, crime and violence all point to the mental health challenge that South Africa faces and the need to translate the good intentions of the policy into care for patients and actively address it as part of the health care system.

Currently the key driving document is the *Strategic Plan for the Prevention and Control of Non-Communicable Diseases 2013-17* which “establishes the framework for reducing morbidity and mortality from non-communicable diseases (NCDs) in the context of broad health reform in South Africa...” (Department of Health, 2012:12). South Africa is also a signatory to most key international and regional resolutions and commitments aimed at addressing NCDs. These include World Health Assembly’s Resolution WHA53.17 (2000) on the Prevention and Control of Non-Communicable Diseases; Resolution WHA61.14 (2008) on Prevention and Control of Non-Communicable disease Implementation of the Global strategy; the Brazzaville Declaration on Non-Communicable Disease Prevention and Control in the WHO Africa Region (2011). South Africa also actively participated in the First Global Ministerial Conference in Healthy Lifestyles and Non-Communicable Disease Control held in Moscow Russia in 1022 and well as the United Nations High level Meeting on NCDs also held in 2011.

While communicable, maternal, perinatal, and nutrition conditions account for the main cause of mortality in South Africa, NCDs account for about 29 per cent of deaths and out of all the NCD deaths, cardiovascular disease alone accounts for 18 per cent. As elsewhere in the world, the main NCDs in South Africa are listed as cardiovascular diseases, diabetes, Cancer and chronic respiratory diseases. The main risk factors associated with these are mainly tobacco use, physical inactivity, unhealthy diets and harmful use of alcohol (DOH: 2012). The Vision of the Strategic Plan for the Prevention of NCDs in South Africa is stated as “A Long and healthy life for all through prevention and control of non-communicable diseases”. The main components of the Strategy (DOH, 2012:26) are listed as:

1. Prevent NCDs and promote health and wellness at population, community, and individual levels
2. Improve control of NCDs through health systems strengthening and reform
3. Monitor NCDs and their main risk factors and conduct innovative research.

These strategies form the pillars of programmatic activities by both government and civil society organisations.

**Table 2: South African NCD Policies**

<b>Year</b>	<b>Act</b>
1977	Mental Health Policy Guideline
1993	Radiation Control Act: Group IV Hazardous Substances-Exclusion & Examples
1993	Tobacco Products Control Act
1997	National Policy guidelines for Mental Health
1998	National Programme for control and management of hypertension at primary level
1998	National Programme for control and management of diabetes type 2 at primary level
1999	National Guidelines on Primary Prevention and Prophylaxis of Rheumatic Fever (F) and Rheumatic Heart Disease for health professionals at primary level
1999	National Guidelines on management and control of Asthma in children at primary level
1999	Policy guidelines on primary prevention of chronic diseases of lifestyle (CDL)
1999	National guideline on prevention of falls of older persons
1999	Guideline for the promotion of active aging in older adults at primary level
1999	National Cancer control programme – Baseline Document
1999	Tobacco Products Control Amendments Act (Act 12 of 1999)
2000	Norms Manual for Severe Psychiatric Conditions
2000	National Guideline: Cervical Cancer Screening Programme
2000	National guideline on foot health at primary level
2001	National guidelines on Long Term Domiciliary Oxygen
2001	National Guideline on Osteoporosis
2001	National Guideline: Management of Asthma in Adults at primary level
2002	Information on Female Breast Cancer for Primary Level Health Care Providers
2002	National Guideline on Stroke and Transient Ischaemic Attack Management
2002	Mental Health Care Act
2003	Eastern Cape Liquor Act No 10
2003	National guideline on testing for prostate cancer at Primary hospital level
2003	National Guideline: Palliative care for adults – A guide for health professionals in South Africa
2004	National guideline: Early detection of and management of Arthritis in Adults at primary level
2003	National guideline: Prevention and management of Overweight and Obesity in South Africa

2004	The Liquor Act No 59
2004	National Health Act
2005	Mental Health Care Act No 17 of 2002 and its Regulations
2005	Child and Adolescent Mental Health Policy Guideline
2005	National Guideline: A guide for Health Care Personnel in Paediatric Palliative Care
2005	National guidelines: The Management of diabetes type 1 and type 2 in adults at hospital level
2005	Guidelines for the management of epilepsy in adults
2005	Traditional Health practitioners Act (Act 35 of 2004)
2006	National Guideline: Non-Communicable Diseases- A Strategic Vision
2006	National Guideline: Updated Management of Hypertension in Adults at Primary Care Level
2007 amended 2008	Regulations relating to health message on container labels of alcoholic beverages, Foodstuffs, Cosmetics and Disinfectant Act, 1972
2007	Mental Health Review Board Orientation Guidelines and Manual
2008	Guidelines for the management of Type 1 diabetes in children
2008	Guidelines for the management of epilepsy and seizures in children at hospital level
2008	National Guideline: Management of Substance Abuse and Misuse amongst older adults
2008	Tobacco Products Amendment Act
2008	Western Cape Liquor Act
2009	Long-term care model implementation framework
2009	Diabetes Declaration implementation strategy
2011	Promotion of Physical Activity in Older Persons
2011	Management of Foot Health at Primary Level
2011	Regulations relating to Trans at in foodstuffs
2011	Mini Drug Master Plan 2011/12-2013/14
2011	Electro-Convulsive Therapy (ECT) Guidelines
2012	National Development Plan
2013	Regulations relating to the reduction of sodium in certain foodstuffs and related matters
2013	Gauteng Liquor Act

Source: Adapted from DOH. 2013. Strategic Plan for the Prevention and Control of Non-Communicable Diseases 2013-17. Pretoria: Department of Health, and specific policies.

The targets set for the prevention and control of NCDs in South Africa not only require state intervention but the intervention of different stakeholders in society including civil society organisations. Thus the Strategic Plan is emphatic about using a multi-sectoral approach that not only includes the department of health as the key player but also includes other government departments such as Department of Finance, the Treasury, Department of Trade and Industry, Retailers, food producers and civil society.

The role of civil society is viewed as being critical in addressing the NCD risk factors as well as encouraging individuals and communities to take ownership of their behaviours and actions which lead to the development of NCDs. The Strategic Plan underscores the importance of CSOs in equipping the public with information to help the population make healthy choices, through awareness raising campaigns and community education to raise health literacy.

In addressing the prevention and control of NCDs in South Africa the Strategic Plan suggests that a multi-pronged approach that moves beyond the medical approach is required and specific interventions include:

1. Inter-sectoral collaboration for prevention of NCDs
2. Addressing the use of tobacco and tobacco products
3. Diet
4. Promoting physical activity
5. Reducing the harmful use of alcohol
6. Introduction of human papilloma virus vaccine
7. School health services
8. The role of civil society in promoting health
9. Addressing the main NCD risk factors through interventions with NCDs
10. Control of NCDs through health systems strengthening.

In terms of tobacco use, South Africa has over a period of close to 20 years developed a complex legislative and regulation framework to prevent and control the harmful effects of smoking as noted in the existing anti-tobacco legislation. In recent years the state has also shifted its focus to diet related measures to help control and prevent NCDs. The country is currently in the process of passing legislation to reduce the salt content in processed foods and the content of trans fats in food. Although all required dietary changes cannot be legislated, the Strategic Plan (DOH, 2012) recognises that there is need for the population

to reduce the in-take of salt in food, take less fast and fried foods and snacks, avoid the use of hard margarines in food, decrease the use of foods with refined sugars as well as the required increase in the intake of healthy foods such as whole grains, more fruits, vegetables and legumes. In accomplishing the required measures to achieve the vision of a healthy nation, the role of both the state civil society and all other stakeholders such as producers and retailers of food products remain critical. Our focus here is on civil society organisations and the strategies that they employ in facilitating access to healthcare for people living with HIV and AIDS and those living with NCDs.

### **2.3 Civil society activism in health care in South Africa**

Civil society is a term generally used to refer to a variety of formal and informal civic and social organisations and institutions that form the basis of a functioning society as opposed to the force-backed structures of a state, irrespective of the state's political system. The sector commonly embraces a diversity of spaces, actors and institutional forms varying in their degree of formality, autonomy and power<sup>4</sup>. Closely related to civil society organisation are “social movements” defined by Brown et al (2004:52) as “informal networks based on shared beliefs and solidarity which mobilize around conflicting issues and deploy frequent and varying forms of protest” (Brown, 2004 ). Looking at both definitions, it is evident that although these bodies are referred to by different names, they operate in the same way.

### **2.4 Types and strategies of health social movements**

It has been argued that achieving universal health coverage is not dependent on the nature of the financing scheme or the amount of health spending but on the political will of governments (Garret et al as cited by De Ceukelarie, 2009). Civil society organizations (CSOs) or health social movements (HSMs) have made it their mandate to encourage such will. Brown et al (2007) devised a typology of health social movements and came up with three categories: *health access movements*; *constituency-based health movements*; and *embodied health movements*. Health access movements fight for equitable healthcare access as well as an improved provision of health services; an example of these includes movements seeking national health coverage. Constituency-based health movements seek to address health inequality and equity based on race, ethnicity, gender, class and sexuality differences- these includes women's health movement and gay and lesbian health

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<sup>4</sup> [http://www.lse.ac.uk/collections/CCS/what\\_is\\_civil\\_society.htm](http://www.lse.ac.uk/collections/CCS/what_is_civil_society.htm)

movements. Lastly, embodied health movements address disease, disability and illness experience by challenging the medical science.

Depending on the desired outcome, health social movements employ different strategies in their activism. In their review of four health-based social movements, Keefe et al (2006:58) identified the following six:

- i. Empowering people living with the health condition to gain control of their health
- ii. Controlling the terms of discourse by shaping the words and phrases used to speak about the health and social condition
- iii. Shaping the research and federal drug approval agendas
- iv. Direct lobbying to convince elected officials to approve pilot projects providing direct services to persons with the condition
- v. Providing alternative clinical and preventive services to individuals whom are unable to get help from traditional healthcare facilities
- vi. Attempts at changing laws or their enforcements through a combination of civil disobedience, legal challenges and lobbying.

The approach adopted by the US-based group AIDS Coalition to Unleash Power (ACT UP) can be used to illustrate how these strategies are applied. ACT UP was formed due to dissatisfaction of a gay-led AIDS service-providing agency which was against the top-down approach to AIDS policy; the agency did not believe that 'experts' were the guardians of knowledge and they wanted to de-monopolise the spread of medical knowledge. One of their strategies was that of civil disobedience which involved a number of non-violent protests including; activists chaining themselves to a balcony in the New York Stock Exchange while others demonstrated outside the building to urge traders to sell stocks of a manufacturer who refused to make the drug more affordable. Prices of AZT were subsequently brought down, to the credit of ACT UP. Others efforts by the organization saw the US Federal Drug Authority speeding up its drug approval process and reversal of a policy where the government had planned to tighten its patent law so that treatment drugs would not be manufactured by other countries at lower costs.

Another example related to the emergence of feminism all over the world that shaped what women health is today. Among other things feminists movements challenged the lack of concern for women's health in the international health sphere arguing that the only time the gender lens was applied in international health was with regards to reproductive



health of women but yet again, this was when population control policies were being developed(Desai, 2004). To this end, women's organizations sought to reclaim control of female bodies and sexualities and in 1969, a group of women in Boston in the United States began to share stories about their experiences with the medical system and focused on issues of reproductive health. They realized that their stories were not so different from each other so they decided to work together and effect change. These women educated themselves about women's health and translated scientific medical discourse into a less scientific language. They called themselves the Boston Women's Health Book Collective (BWHC) and they published the book *Our Bodies, Ourselves* in 1973. The book went on to sell over four million copies and was translated into 16 languages; the publication is said to have been one of the landmark developments in women's health activism and many other similar movements addressing women's health have since emerged (Desai, 2007; Keefe et al, 2006).

Breast cancer activism became more effective with the emergence of the second wave of feminism. Previously, women diagnosed with breast cancer did not have treatment options except radical mastectomy as prescribed by the medical profession. Breast cancer activism shaped the way breast cancer is regarded today by empowering those people living with the condition by education and advocacy, removing the stigma associated with breast cancer as well as the feeling of loss of femininity; and lastly by increasing consumer awareness on the range of treatment options available, disease prevention and early detection (Keefe et al, 2007).

Although civil society organisations have been contributing to public health for many years, they have become more prominent in recent years, growing in scale and influence and having profound impacts on health policy and issues (WHO, 2001) particularly in the area of HIV and AIDS. In the early stages of the epidemic, national leadership in many African countries were downplaying the devastating effects of the pandemic if they were not quiet about it. The burden of caring for the sick was largely placed on the families of the infected people. In fact, national leaderships justified limited government support by arguing that "traditional social networks (especially the extended family) will buffer the economic and social impacts of HIV and AIDS and provide for orphaned children, widowed women and elderly caregivers" (Rau, 2006: 286). It was civil societies that were at the fore-front of the AIDS battle. Indeed, many of the most innovative and effective initiatives to address HIV and AIDS were designed and implemented by civil society organizations. These organizations have been progressive in their thinking; they saw the importance of

comprehensive responses to HIV and AIDS while international were focusing on separate components, i.e. individual behaviour change, management of sexually transmitted infection, policy development. As Peersman et al (2009) posit, in many countries affected by the epidemic it was early civil society initiatives which laid the foundations on which national HIV and AIDS responses would be built. In sum:

Civil society organisations have played a significant role in the direct provision of HIV-related services due to their presence in or connections with affected communities, especially marginalised groups. As public health hospitals became overburdened with AIDS patients in highly affected areas, for example civil society organisations have assumed responsibilities for health care provisions; in many places, they were the pioneers of counselling and of home-based care of the sick. ... Their activism also helped to create the foundation for better access to health care and more affordable treatment. Civil society remains at the forefront of HIV service provision particular among the most vulnerable and hard-to-reach populations ... and especially in places where behaviours that put people at high risk of HIV are criminalized (Peersman et al, 2009:S97).

Civil society organisations have also played an important role in the advocacy, prevention and control of NCDs, helping to mobilise public and political awareness, to shape policy responses, as well as to support and deliver prevention and treatment programmes (Mungal-Singh, 2011). (Mungal-Singh Cites, as examples of NCD civil society activism, two groups: (1) The World Health Organisation Framework Convention on Tobacco Control (WHO FCTC) which continues to pool and coordinate civil society expertise and resources to present a strong counterforce to the tobacco industry and (2) The NCD Alliance “which brought together the four international federations addressing cardiovascular diseases, diabetes, cancer, and chronic respiratory disease [to create] the platform for global collaboration and joint advocacy’ (Mungal-Singh, 2011:3). Mungal-Singh further credits these two civil society organisations with bringing about the United Nations High Level Meeting that placed NCDs on the global arena.

### **Civil society activism in South Africa**

In South Africa, however, much of the health-related civil society activism has been in the area of HIV and AIDS, notably by the Treatment Action Campaign (TAC). The TAC lobbied for access to antiretroviral treatment through a combination of protests, social mobilisation and legal actions (including against pharmaceuticals), and it continues to be cited as a model for social mobilisation (Mungal-Singh, 2011). To provide background and context, it is noteworthy that the first official AIDS case in South Africa was reported in

1982 in a homosexual man who contracted the virus while in California, USA. At first it seemed like it was only affecting homosexual men but by 1985 heterosexual infections were also reported. The apartheid regime viewed HIV and AIDS as a black or gay disease and neither were deemed a priority deserving serious attention. The pandemic barely featured on the agendas of both the White ruling party and the liberation movements. There was however a small degree of activism mostly among gay and lesbian activists and some health professionals (Mbali, 2010).

South Africa held its first National AIDS Convention in 1992. The Convention was attended by anti-apartheid political organizations, non-governmental organisations (NGOs), the government, businesses and unions (Mbali, 2010). Following the Convention, the National AIDS Plan, based on an action plan by the National AIDS Committee of South Africa (NACOSA) was drafted. According to Mbali (2010:230), the plan had six main components, which were developed by working groups concentrating on education and prevention, counselling, health care, human rights and law reform, and welfare and research. The plan was unique in its emphasis on human rights, the involvement of people living with HIV and its call for a multi-sectoral response to be implemented through all departments of government.

After the new democratic government was elected into power in 1994, the implementation of the AIDS Plan was delayed due to a number of reasons. The government prioritized state transformation and economic growth. While health reform was one of the priorities and it involved collapsing the racialised health system into one national and nine provincial departments of health (Mbali, 2010; Leclerc-Madlala, 2005). But in addition to these challenges, it is argued that there was little political will to fight the HIV and AIDS epidemic. Focus was mainly on HIV prevention and the government was not keen on providing funding for the treatment drug ARV (antiretroviral). Thus, like its predecessor, the new government's response to the HIV pandemic was not impressive (Pieterse, 2008).

In 1997 the government, under the leadership of Nelson Mandela, enacted the Medicines and Related Substances Control Amendment Act No. 90 so as to make essential medicine more affordable. The Act allowed for the manufacturing of generic HIV and AIDS treatment and it also encouraged the promotion of generic alternatives. Pharmaceutical companies argued that the Act was in breach of the government's TRIPS (Trade-related Aspects of Intellectual Property Rights) Agreement obligation, which allowed pharmaceuticals to be patented globally. TRIPS is under the authority of WTO and thus all member countries are

compelled to comply (George, 2011). Thirty-nine (39) pharmaceutical companies initiated a suit against South Africa in 1998 for the violation of TRIPS.

The government then led a global effort in requesting the suspension of TRIPS for the AIDS drug. In 2001, after a global outcry, the pharmaceutical companies withdrew its lawsuit against South Africa. This means that South Africa was left free to implement the Act but even so, it still failed to provide access to AIDS treatment (Lethbridge, 2009). By then South Africa had appointed a new president, Thabo Mbeki, who initiated and led a decade long AIDS-denialism. Amongst other things, he asserted that AIDS was a western invention and that the pharmaceutical companies invented AIDS solely for profit. Mbeki enjoyed support from within the ANC and 'dissident' scientists. One of the most controversial AIDS dissident documents was the *Castro Hlongwane, Caravans, Geese, Foot & Mouth and Statistics: HIV/AIDS and the Struggle for the Humanisation of the African*, which was published on the ANC website in 2002. The document blamed "AIDS drugs and pharmaceutical companies for the 'medicalization of poverty' and for systematically destroying the immune system of Africans" (Robins, 2004: 658). The then minister of health, Manto Tshabalala-Msimang also supported the president by claiming that the drugs were toxic and instead recommended beetroot, garlic and African potatoes as immune boosters (Pieterse, 2008; Susser, 2011). It was against this backdrop that TAC was formed in 1998 and the initial goal was to fight for access to treatment for people living with HIV and AIDS (PLWHA) but the organisation eventually focused its attention to the state's role in providing treatment for the poor. TAC was formed in December 1998 in Cape Town with a mission to "ensure that every person living with HIV has access to quality comprehensive prevention and treatment services to live a health life". The organization by 2012 had 16, 000 members, 267 branches and 72 full time staff members ([www.tac.org.za](http://www.tac.org.za)). The majority of TAC's volunteers are young African women, many of whom are HIV- positive.

The conditions in the country had forced TAC to go beyond its primary mission and attend to a wider range of issues, which includes: "tackling the global pharmaceutical industry in the media, the courts (together with the government) and the streets; fighting discrimination against HIV-positive people in schools, hospitals and at the workplace; challenging AIDS dissident science; and taking the government to court for refusing to provide MTCT (mother-to child transmission) programmes in public health facilities" (Robins, 2004: 662).

Some of the strategies employed by TAC included: staging high-profile protests and civil disobedience campaigns and these strategies were often supplemented by legal action. Pieterse (2008: 369) argues that the organisation has mostly initiated and pursued litigation based on the health-related socio-economic rights guaranteed by the 1996 Constitution and this is the reason why TAC has been able to have so much impact on the policy environment. TAC has been said to have shaped poor people's access to social services more than other social movements and is recognized internationally. One of the greatest outcomes of the legal case against South Africa was that it highlighted the challenges that TRIPS imposed, especially on developing countries, in the delivery of healthcare. Brazil and Thailand, who relied on lower-cost generic HIV treatment, were some of the developing countries that were greatly affected by the implementation of TRIPS. Brazil began to grant pharmaceutical patents in 1996 and the high prices of patented medicine took up a great proportion of the AIDS budget: at one point three of the seventeen patented drugs took up about 75% of the country's AIDS budget (Hoen, Berger, Calmy, Moon, 2011).

In November 2001, the Doha Declaration on TRIPS and Public Health and Public Health was adopted. The Doha Declaration "stands for the proposition that member governments must implement and interpret the TRIPS Agreement in such a way that it supports public health by promoting access to existing medicines and the creation of new medicines" (George, 2011: 189). The Declaration has allowed for the production of lower-cost generic versions of patented medicines on a large scale.

Another outcome of strong activism and increased commitment to AIDS treatment was the Declaration of Brasilia in 2003, of which South Africa, India and Brazil are signatories. This led to the creation of the India, Brazil, and South Africa (IBSA) Dialogue Forum whose purpose is "sharing strategies to address international issues of common concern to the countries and to promote cooperation in international trade, areas of defence, multilateral diplomacy, social development, environmental issues, and to foster greater South-South cooperation" (George, 2011: 191).

This collaboration has benefited all three countries: Brazil has won several concessions from many international pharmaceutical corporations with threats to use compulsory licensing and they have managed to reduce AIDS-related mortality by over 50% through their program of providing free, universal treatment access; India is the manufacturer of

more than fifth of the world's generic drugs and they export these generics to countries largely burdened by the epidemic, including South Africa (George, 2011).

While NCDs-related civil society organisations in South Africa such as the Cancer Association of South Africa (CANSA), the Heart and Stroke Foundation SA, Diabetes SA and the National Council Against Smoking have been described as “well-established organisations with national resources and infrastructure” (Mungal-Singh, 2011:5) much less is known, about their activism and their role in improving or ensuring access to treatment for NCDs in South Africa. The range of strategies that these organisations use in seeking to control specific NCDs in South Africa are also not clearly understood. Another question that abounds relates to how successful NCD civil society organisations have been in their activism to prevent and control NCDs. A further question relates to why when compared to organisations dealing with HIV and AIDS organisations dealing with NCDs appear less successful or even known?

## **2.5 HIV and AIDS and Non-Communicable Diseases in South Africa**

### **HIV and AIDS**

South Africa is one of the countries in the world worst affected by the HIV and AIDS epidemic. According to UNAIDS (2011), of the 34 million people living with HIV and AIDS in the world, an estimated 5.6 million live in South Africa. This represents an alarming figure of more than 16% of all people living with HIV and AIDS in the world. Many of the country's population living with HIV and AIDS are as young as 15 years old. South Africa also has an estimated number of 1 900 000 orphans resulting from AIDS (UNAIDS, 2012). The extent of the impact of HIV and AIDS in South Africa especially on young people is thus unquestionable.

An estimated 5.6 million people were living with HIV and AIDS in South Africa in 2011, the highest number of people in any country. In the same year, 270,190 South Africans died of AIDS-related causes. Although this number reflects the huge amount of lives that the country has lost to AIDS over the past three decades, it is 100,000 fewer deaths than in 2001, demonstrating the many lives that have been saved through a massive scale-up of treatment in the last few years.

## **Non-communicable diseases**

In the absence of HIV and AIDS, non-communicable diseases (NCDs) are the leading cause of mortality in South Africa as in many other African countries (Maher et al 2010; Negin et al, 2011; Schneider et al , 2009; Vorster et al ; McCarthy et al 2010; Asfaw, 2006; Harries et al 2008). Although “detailed information on NCDs in South Africa is constrained by inadequate surveillance and research” current available data suggest “the dire need for greater attention to prevention and control of NCDs than is currently the case” (Department of Health, 2012:17). Drawing from the World Health organization data, the *country’s Strategic Plan for the Prevention and Control of Non-Communicable Diseases 2013-17* reports that NCDs accounted for 29 per cent of all deaths in South Africa in 2008. Of these deaths 11 per cent were due to cardiovascular diseases; 7 per cent to cancers; 3 per cent to respiratory diseases, another 3 per cent to diabetes; and 4 per cent to other NCDs. Thus, cardiovascular diseases and cancers accounted for a total of 18 per cent of all deaths in South Africa in that year. Although the figures were much higher, the same pattern was observed when Statistics South Africa’s Death Notification data was analysed: 18 per cent of all deaths in in South Africa 2008 were due to cardiovascular diseases; 7 per cent to cancer; 4 per cent to respiratory disease; 2 per cent to diabetes; and 9 per cent to other NCDs—all showing that NCDs accounted for 40 per cent of all deaths in South Africa in 2008. This overall pattern of NCDs was affirmed by the recent results of the first ever South African Nutrition and Health and Examinations Survey (SANHANES) (2013).

In the SANHANES study in which 25 532 individuals were interviewed, some study participants underwent clinical examinations for specific NCDs (Shisana et al, 2013). Among the study participants that underwent clinical examinations, more than two thirds were found to have high blood pressure, and a similar proportion were found to be overweight or obese and less than a third consumed alcohol (Shisana et al 2013). Nationally, among the study participants that underwent clinical examinations 30.9 per cent reported having a history of high blood pressure, 20.7 per cent had a history of blood sugar, stroke 8.9 per cent and 7.6 per cent had a history of heart disease. (Shisana et al 2013). In terms of regions, NCDs were highest among urban populations in Northern Cape, Eastern Cape, Western Cape, Free State and KwaZulu-Natal.

In terms of race NCDs were reported to be highest among Indians where 46.8 per cent had high blood pressure; 20.8 per cent had heart disease and 49 per cent had high blood sugar. Coloureds have the highest rate of stroke (14.1 per cent) (Shisana et al, 2013). Africans were reported to have the lowest rate of self-reported NCDs. In terms of province, NCDs

were highest in Free State high blood pressure was reported among 45.8 per cent of participants, 14.2 per cent had heart disease, 14.5 per cent reported stroke and 26.7 per cent reported stroke (Shisana et al, 2013). In terms of gender, NCDs are highest among women among whom 20.6 per cent were found to have high blood pressure compared to 12 per cent among men. Females, 2.9 per cent compared to 1.5 per cent of males had heart disease (Shisana et al, 2013).

As with HIV and AIDS, the pattern of NCDs in South Africa is gendered with the total NCD deaths (per 100 000 population) being higher among females (98.1) than among men (92.4) in 2008 (Department of Health, 2012). Furthermore, while smoking and alcohol use are more common among South African men, obesity remains largely a woman's disease. What is more worrying in post-apartheid South Africa is that NCDs such as obesity are increasingly becoming common among children and adolescents. In the SANHANES study (2013) a higher proportion of females (25 per cent) than males (19.6 per cent) were found to be obese. More females (40.1 per cent) than males (11.6 per cent) were reported to be overweight (Shisana et al, 2013). The SANHANES study (Shisana et al 2013) reported that the body mass index (BMI) increased with age.

Mayosi et al (2009) reports that demographic changes are among the risk factors for NCDs in South Africa. In essence, in a period of about 50 years the demographic transition in South Africa has resulted in an overall increase in fat in-take among Africans from a low of 16.4% to about 26.2% of total energy and a reduction of carbohydrate intake from 69.3% to 61.7% (Mayosi et al 2009). In the same period the diet of the rural population has increasingly tended to resemble that of developed countries. Whereas the demographic transition might explain the increase in the prevalence of NCDs among Africans, genetic and ethnic factors explain the predisposition of Afrikaners to cardiovascular disease and Indians to insulin resistance resulting in their susceptibility to type 2 diabetes and ischaemic heart disease. With this background South Africa has set targets to address the risk of NCDs by 2020 (DOH, 2011) as shown in the table below.

## **2.6 Civil Society Activism for NCDs in South Africa**

Also already noted, much of the civil society activism for healthcare in South Africa has overwhelmingly been in the domain of communicable diseases such as HIV and AIDS, tuberculosis and sexually transmitted infections (STI). Although civil society organisations



that advocate for the comprehensive care of people living with NCDs exist, these are much less visible than the organisations that focus on the communicable diseases.

Civil society activism for comprehensive care among people living with diabetes needs to focus (Msollentze, Konning, & Wagenaar, 2010) on the following:

- Access to essential medicines
- Access to healthcare
- Functioning health systems

**Table 3: Targets for reduction of NCDs in SA**

<b>Condition</b>	<b>Reduction in percentage (%) by 2020</b>
Reduce the relative premature mortality (under 60 years of age) from NCDs	25%
Reduce tobacco use	20%
Reduce relative per capita consumption of alcohol	20%
Reduce mean population intake of salt to <5 grams per day	
Reduce proportion of people who are obese or overweight	10%
Reduce prevalence of people with raised blood pressure	20%
Screen all women at least every 5 years for cervical cancer	All
Screen all men over 40 years of age for prostate cancer	All
Increase the percentage of people controlled for hypertension, diabetes and asthma	30%
Increase number of people screened and treated for mental health by 2030	30%

Source: DOH (2012). South African Declaration on the Prevention and Control of Non-Communicable Diseases. Pretoria: Department of Health.

To improve the quality of life of children living with type 1 diabetes and ensure that they lead a normal life, civil society activism needs to focus on the following:

- Ensure availability of insulin in healthcare facilities
- Education- provide information on how the disease can be managed in children
- Ensure the availability of diagnostic tools
- The procurement of drugs and essential supplies should be improved
- Healthcare workers must be adequately trained to deal with the condition in children
- Ensure that the acceptable standards of care are delivered at the primary healthcare level

Evidence suggests that NCDs are indeed a serious health issue that affects both the developed and low income countries, much less is documented about activism around healthcare access for people living with NCDs. There is however evidence that Non-governmental organisations are involved in activism for the comprehensive care of people affected by NCDs. In South Africa the Organisations that are involved in civil society activism include: the Cancer Society of South Africa, the Heart and Stroke Foundation, Diabetes South Africa and the South African Depression and Anxiety Group.

### **Cancer Association of South Africa (CANSA)**

The organization was established in 1932 and its purpose is “to lead the fight against cancer in South Africa by offering a unique, integrated service to the public which involves holistic cancer care and support to all people affected by cancer” (CANSA, 2013). The mission of CANSA is “to be the most preferred non-profit leader that enables research, educates the public and provides support to all people affected by cancer” (CANSA, 2013). As a national organisation, CANSA has a range of programmes that include service delivery, research watchdog role, and the seal of recognition programme.

Under service delivery CANSA spends at least R6million annually on research aimed at applying the findings the care and treatment of the different forms of cancer. The health programme involves screening and cancer control. In addition to the CANSA care homes there is also what is referred to as hospitem, based in Polokwane for the out-of-town patients already undergoing cancer treatment. The clinics and care centres operated by the organisation provide counselling and support groups not only for the patients but also for their families. The Science and Resource centre has a toll-free number that people can call and get assistance during office hours. CANSA has developed the Cancercare coping kits (audio programmes) in different languages to assist people living with the disease and also their families.

In terms of research, CANSA has a long-standing partnership with the Medical Research Council (MRC) and the National Health Laboratory Service (NHLS). Through the Cancer Research Initiative (CARISA) about R6million is spent researching the disease in South Africa.

The watchdog role / Advocacy entails putting issues about cancer in the public domain and ensuring that policy makers address the concerns. The advocacy role also entails creating

public awareness about the causes and prevention of cancer, given that one in four people in South Africa are affected by cancer. There are about 100,000 new cases of cancer diagnosed annually and about 60 000 people lose their lives to the disease every year. The lobbying and advocacy work of CANSA is informed by research and aimed at ensuring that policy makers put in place measures and regulations which ensure that the public is protected from cancer causing agents (carcinogens).

The lobbying and advocacy of CANSA has yielded a number of outcomes and successes:

1. Formation of the Patient Health Alliance of NGOs (Phango), an umbrella group of NGOs that focus on non-communicable diseases. Phango has been instrumental in the drafting of the Patient Health Charter
2. Speeding up the treatment of cancer patients at the Johannesburg Hospital. CANSA also ran a campaign warning patients against the use of Insulin Potentiation Therapy
3. Notifying the Department of Health (Western Cape) about the closure of the oncology unit at George Hospital. This intervention resulted in the re-opening of the unit within 2 months thus providing care to patients in the surrounding areas
4. CANSA played a critical role on the anti-tobacco legislation that banned the advertising of tobacco products. In 2009 CANSA received an award of recognition from the WHO in recognition of its work in the fight against the use of tobacco in South Africa
5. In the update of the National Cancer Control Programme, CANSA recommended the mandatory registration of the disease.

CANSA has about 350 staff spread throughout the country and about 5,000 volunteers. The organisation also operates homes that care for people with the different forms of cancer.

## **Heart and Stroke Foundation**

The vision of the organization is “ A future where fewer South Africans are affected by cardiovascular disease (CVD)” The mission is stated as “To encourage prevention at all levels, empower South Africans to adopt healthy lifestyles and make healthy choices easier”

The specific objectives of the HSF are stated as to:

- Provide information and support to build healthy communities
- Advocate at all levels to minimize South Africans’ risk of developing heart disease and stroke
- Support research for improved tools and methods of CVD prevention.

While noting that about 80 per cent of deaths in South Africa are caused by heart disease, specific causes are preventable. Heart disease is biggest killer in South Africa after HIV and AIDS. While not much has been documented about the activism of the HSF, it is evident that the organization is involved in activism through specific programmes as shown in the table

**Table 4: Heart and Stroke Foundation- Activities and Programmes**

Tests and screenings
Go red for women
Think red campaign
Looking from the heart
Hearty
Heart awareness
Expectant parents' project
Tuck shop

Adapted from Heart & Stroke Foundation Website (2013)

These programmes are all aimed at raising awareness about heart disease and the measures that individuals and families can take to prevent its occurrence.

#### Diabetes South Africa (DSA)

Diabetes South Africa (DSA) is among the civil society organisations involved in activism to ensure greater access to care and treatment for people living with the disease. Although the DSA does not have an explicitly stated vision, its mission is provided as “Promoting Diabetes Care and Support for all” (Diabetes South Africa (DSA), 2013). There are a range of activities that the organization is involved in throughout the year, but the activist work is broadly categorized as follows:

Informing, encouraging and supporting all people who have diabetes and their families

Activating as an advocate for people with diabetes, lobbying for better facilities, cheaper medication and better services

Promoting public awareness of diabetes, its symptoms and risks’ (Diabetes South Africa (DSA), 2013).

The DSA has activities lined up throughout the year in the different cities and provinces. The activities are mainly aimed at creating awareness around prevention and providing education to help the newly diagnosed to manage their condition. Some of the activities include corporate functions such as the Denim for diabetes function planned for World Diabetes day on 14th November. In terms of the Denim day corporates who choose to participate allow their staff to wear a denim item. For R10 the participants get a stick reading "I've escaped my uniform for Diabetes Day and Diabetes SA". For Schools that participate in the Denim day, students are allowed to wear a Denim Item instead of their Uniform. For R2.00 students get the same Denim stick that reads. "I've escaped my uniform for Diabetes Day and Diabetes SA" (Diabetes South Africa (DSA), 2013).

Provincial chapters of the DSA hold their own events which range from lifestyle meetings (KwaZulu-Natal) to diabetes runs and walk that are convened throughout the country by the different branches. All these activities are aimed at creating awareness about the prevention and management of diabetes. Other activities include cooking demonstrations, community health days and corporate health days.

The DSA is a voluntary organization which relies on the commitment of its members and their families to ensure that its programmes and activities are implemented. The partners of DSA include University Medical Departments, State and provincial health departments, SEMDSA (Diabetes Education Society of South Africa) for specialist healthcare workers; CDE (Centres for Diabetes and Endocrinology), an association of private and medical practitioners and other diabetes related healthcare workers; NGOs worker on related primary healthcare sector and industry, including pharmaceutical companies and other companies servicing people with diabetes. What is evident from the partners of the DSA is that they are organisations that support the mission of the organization.

### **South African Depression and Anxiety Group (SADAG)**

SADAG is a non-profit section 21 company formed with the purpose of providing 'a support network for the thousands of South Africans who live with mental health problems'. SADAG estimates that 1 out of every 5 people will at one time suffer from a mental illness. In addressing the mental health challenges SADAG is involved in a variety of activities which among others include:

About 180 support and outreach groups throughout South Africa which help to address the needs of both urban and rural populations with mental illness

Telephone counselling service that operates from 8am to 8pm

Educational materials focusing on mental health elements such as depression, bipolar, anxiety, sleep disorders, schizophrenia, teen suicide and substance abuse

Information sharing through a monthly newsletter, videos, audios, books and a website with over 450,000 hits per month

Referral service and free treatment where necessary

Training provided to large corporates and schools

Although SADAG is a low-budget NGO, it has had a huge impact on both rural and urban populations. The organisation developed the Speaking Books which provide information about mental health, HIV and AIDS, Tuberculosis (TB), safe sex, Malaria, teen suicide. This book does not require one to read but rather to listen to the message and is therefore both to those who can and those who cannot read for various reasons. The organisation has won numerous international awards because of the Speaking Books. Due to its work that reaches rural communities with message on mental health, the organisation has received endorsements from the World Bank, Department of Health (DOH), Department of Education (DoE), de Beers, the US embassy in South Africa, World Federation for Mental Health, the WHO, the Global Fund, and the Department of Social Development (DSD).

Like the organisations that deal with HIV and AIDS, it is evident that the activities of the NCD organisations are targeted at accomplishing the mandate of these organisations. The NCD organisations are involved in a lot of activities which range from creating awareness about prevention and control of specific NCDs to lobbying and influencing policy positively in order to ensure that NCDs are reduced in the country. There are, however, stark differences in the activism of the HIV and AIDS organisations compared to the activism of NCD organisations. While HIV and AIDS organisations appear to have taken their work in ensuring access to treatment and comprehensive care as human rights issues and ones about social justice, the same approach does not appear to be used by the NCD activist organisations. HIV and AIDS organisations used litigation to ensure that the health rights of people living with HIV and AIDS are recognized. The NCD organisations appear to have focused on the science of why it is important to address NCDs. For example, CANSA commits research and has used this to lobby for the enactment of legislation banning the advertising of tobacco products. The organisation (CANSA) has also used research to show why the government needs to pass legislations protecting the public from carcinogenic agents which cause cancer. DSA through its programmes advocates for healthy living, supports newly diagnosed patients and their families on how to manage the disease. While CANSA might be at the forefront of advocacy and lobbying the issues it tackles have not been politicised as HIV and AIDS was before government took action. Thus it appears that

politics and mass mobilisation are the missing elements in the activism of the NCD organisations.

In reviewing the work of civil society organisations involved in activism for greater access to healthcare, it is notable that although information on the mission, vision, objectives and activities/programmes is readily available. However much less information related to annual reports and financial statements is available. A search for the financials of the different CSO financials provided information on the financials of two organisations: TAC and CANSA. Over a 5-year period the income of these CSOs (TAC & CANSA) was reported as shown in the table below.

**Example of CSO income over a period of five years**

Organisation	Year of operation and Total income in million Rands (R )				
	2012	2011	2010	2009	2008
TAC	42 201 735	51,154 076	55,630 029	51 125 537	36 699 997
CANSA	154 353	140 732	153 135	152 119	137 211

The differences in the finances are explained by the fact that CANSA has been in existence for much longer than the TAC which was only established in the late 1990s. Given the lengthy period of existence and how it conducts its work, CANSA has over the years accumulated huge assets in the form of fixed property. It is however not clear what forms the TAC assets take. CANSA's fixed property assets mainly consist of the homecare centres used for palliative care of patients. From the 5-year reports of financials, it is evident that CANSA's income far exceeds that of the TAC. We cannot however conclude that CSOs involved in NCD work have more income in the absence of further evidence.

What is evident from the financials is that although financials of both TAC and CANSA suggest a gradual annual increase, it is also evident that there was a drop in the finances of both organisations in 2011. While the main source of finances for CSOs dealing with HIV and AIDS are international organisations, governments and individual contributions, the main sources of funding for CSOs involved in NCDs are local corporates, gifts and bequests.

**Table 5: Sources of Funding for CSO**

<b>HIV and AIDS CSOs</b>	<b>Non-communicable Diseases CSOs</b>
Donors	
Aids vaccine advocacy coalition	
MAC foundation	Fees for patients
Medicine san frontiers	Investments
Open Society Frontiers - OSA	Leases
South African Development Fund	Bequests
Stephen Lewis foundation	Donations
Atlantic Foundation	Corporates and Trusts
The Atlantic Philanthropies	Government grants
The Ford Foundation	Mail appeals
General Fund	Teledonations`
The global fund to fight AIDS, TB and Malaria	
Raita Foundation	
UK Department for International Development	

## **2.7 Summary**

In this chapter we set out to present the social and political context of HIV and AIDS activism and also that of NCD activism. What emerges is that there is an abundance of legislation that is focused on the prevention, control and treatment of NCDs. The NCD civil society organizations have been in existence for much longer and have therefore accumulated both a wealth of assets and experience to run their organizations. HIV and AIDS organizations have been in existence for a much shorter period, with TAC having been formed in 1998 and others having been established in the 1990s also.

There are similarities and differences in the strategies used by both NCD and HIV and AIDS organizations in their activism to facilitate greater access to care for their members. The similarities lie in advocacy, media, empowerment, collaboration and partnerships among other issues. The differences in activism lie in how the strategies are employed. While NCD organizations might commission research into cancer, HIV and AIDS organizations do not



necessarily commission research but like cancer organizations, inform members of clinical trials so that those interested can participate as this helps members benefit from the latest treatments. While both NCD and HIV and AIDS organizations suggest that they struggle with funding, the level of struggling is different. NCD organizations seem to have donations built into their financial resources just like HIV and AIDS organizations. What is however different is that NCD organizations such as CANSA have assets in immovable properties whereas HIV and AIDS organizations do not seem to have such assets. Whereas the NCD organizations seem to be national and based in key urban centres, the HIV and AIDS organizations seem to reach to the grassroots level in terms of their operations. The grassroots reach of the HIV and AIDS organizations might be due to the set-up of their operations and the strategies they utilise some of which require mass mobilisation.

Although both HIV and AIDS organizations and also NCD organizations constantly cite the challenge of inadequate funding, the unavailability of financial statements and annual reports in the public domain makes it difficult to establish the actual financial position of most organizations. Where information is available it becomes obvious that NCD seem to have more funding available than HIV and AIDS organizations.

## **CHAPTER 3 STRATEGIES USED BY CIVIL SOCIETY ORGANIZATIONS FOR GREATER ACCESS TO HEALTHCARE**

### **3.1 Introduction**

The previous chapter explored the socio-economic and political context of NCD activism for access to healthcare for people living with HIV and AIDS and also the non-communicable diseases. In comparing the HIV and AIDS organizations and the NCD civil society organisations the chapter showed that most of the NCD organizations have been in existence for much longer than the HIV and AIDS organizations. The chapter showed that while the vision, mission, funding might differ for the various organizations, there are indeed elements which can be compared and these are discussed further in this chapter. This chapter reports the findings on interviews conducted with CSOs involved in HIV and AIDS and also NCD activism. The chapter compares the strategies used by both HIV/AIDS civil society organisations with those used by NCD civil society organisations. The chapter also compares financing and partnerships among HIV/AIDS organisations and NCD CSOs. The final section is a recapitulation of the key points emerging from the discussion.

### **3.2. Strategies**

Civil society activism has been critical to understanding issues of access, equity and human rights in the access to healthcare. In seeking greater access to healthcare it is evident from the literature that some strategies have been more successful than others. Strategies used by HIV and AIDS organisations have been very successful in ensuring that the pandemic came to the attention of the global community and that measures to deal with it became a global concern and not just a concern of the countries affected. Much as CSOs involved in activism for greater access to quality and comprehensive care for people living with NCDs, such CSOs have not achieved the success achieved by HIV and AIDS CSOs. In this study the question on strategies sought to find out which strategies were used by the selected civil society organisations and to what effect these strategies were used.

#### **3.2.1 Strategies used by NCD Civil Society Organisations to access healthcare**

It emerged from the study that the most common strategies used by NCDs civil society organisations include the use of media, public education, advocacy, participatory strategies, passive strategies, grassroots empowerment strategies, collaboration with researchers,

confrontational strategies, partnerships, influencing policies on NCDs, monitoring compliance

### ***Media***

Media as used by the NCD organisations refers to vehicles such as the internet, radio, magazines, social media (face-book & twitter) pamphlets and books. Television and newspaper adverts were also mentioned among the range of strategies related to the media that are used to bring raise awareness around NCDs. All the organisations had websites where information about their vision, mission and activities were posted. What became evident is that some had capitalized on the internet to disseminate as much information about their work as possible. Some of the information contained included journal articles about the specific NCD, information on where to get help and the contact details of the organization. The radio was also used as well as the newspapers. One organization noted that that through various media, it is able to reach about 5.9 million people per year.

The strategies used might be used by the specific organization on its own or in conjunction with partners. In terms of creating awareness, some organisations have latched onto the Department of Health awareness campaigns to disseminate prevention messages about cancer. Preventing NCDs among those that do not yet have them and those that already have them was cited as a key reason why organizations use the media to disseminate information.

### ***Public education***

Awareness campaigns also involve having exhibitions at clinics both private and public in order to disseminate information about prevention of NCDs such as alcoholism and substance abuse. Partnerships are critical in ensuring successful exhibitions and awareness campaigns that aim at p Education campaigns to create awareness around NCDs were conducted by all the seven organisations. The education campaigns were described in terms of: prevention and awareness campaigns, workshops, public education, health promotion, giving talks at schools, clinics, churches, workplaces and communities. The education messages are often about prevention of NCDs and how to deal people who already have a certain condition. Prevention was discussed in terms of substance abuse; prevention focuses on ensuring those that are not affected do not try drugs and alcohol. Prevention also aims at ensuring that those already roped into substance dependence receive treatment to get out of addiction. Essentially, prevention aims to ensure that

communities are free of substance abuse whether this relates to prescription drugs or addictive substances. In terms of mental illness the talks in schools focus on how to identify the problem, where to get help and what to do in case of emergency.

### ***Advocacy***

Advocacy strategies aimed at reducing NCDs such as drug and substance abuse, violence against children and maltreatment, emotional abuse target vulnerable populations such as children. Advocacy strategies include the convening of activities such as 'Sports against Drug Abuse', to help prevent the use of drugs and other substances. Advocacy against the violation of children's rights has also involved the use of participatory techniques such as giving children cameras and asking them to take pictures that depict the violation of their rights and publishing such pictures. Advocacy work related to children's rights has also entailed the use of indigenous techniques of engagement such as the use of imbizo's (community meetings) where local leaders are invited to discuss issues related to children. Given the power relations between the children and leaders, the strategy within the imbizos has been to ask children to write down issues that infringe of their rights and these are then directed to relevant departments such as department of health, social development, education and home affairs. Such strategies have worked to reveal the violations of children's rights and children have also been able to voice the type of communities they want to live in. The violation of children's rights affects their well-being emotionally, mentally and even physical. In terms of advocacy there are key strategies and then there are strategies within strategies. Thus educating children about their rights is a core strategy. However when in the education sessions children are equipped with cameras to take pictures of the violation of their rights, then the taking of pictures becomes a sub-strategy within the main advocacy strategy identified as education. When the pictures taken are followed up with drama by the children who then perform the violation of their rights, the drama becomes a strategy within the broader strategy of education as a form of advocacy.

Regardless of the target audience, awareness-raising aims to change behaviour. In the case of awareness campaigns by NCDs, the aim is to prevent the increase in the population of people suffering from diseases such as diabetes, heart diseases, stroke, and high blood pressure among others. Awareness raising by NCD organisations also aims at educating the target populations on what individuals living with NCDs can do to manage the condition or seek help and a condition arises. For example in the case of depression and anxiety amongst teenagers, awareness raising aims to help them identify the symptoms of the

illness, know where to get help and what to do in the case of an emergency. Awareness raising for organisations dealing with NCDs also targets industries and producers of consumer products that can either increase or decrease the incidence of NCDs such as obesity, diabetes, high blood pressure and stroke. In the case of the Heart and Stroke foundation, food producers would like to have the heart mark which suggests that their foods are cholesterol free in order to increase sales. Thus getting accredited to endorse the heart mark on food products sends the message that the particular brand sells healthy foods and such perceptions help to increase the sales and ultimately profits of food retailers.

### ***Participatory strategies***

In terms of advocating against NCDs such as substance abuse and violation of children's rights, the participation of stakeholders was cited as key. One organization noted that its advocacy and awareness included the exhibition of talents among the youth, playing indigenous games while also inviting services providers such as emergency services, nurses and clinics in the targeted areas to provide information on NCDs such as substance abuse. Advocacy for children's rights included educating them about their rights and allowing them to express the violation of these rights through photography, drama and writing of notes about issues of concern to them. Such advocacy strategies that combined education with participation by children gave them the opportunity to state which department should be involved in resolving their problems. Participatory strategies used by NCD organisations included the recruitment of volunteers to work in the prevention of substance abuse, recruiting graduates of psychology and social work to do their internships in programmes dealing with mental health issues such as teenage suicide, depression and anxiety. The use of volunteers and interns were strategies that benefitted both the organisations by ensuring service provision continued at minimal or no cost. Those recruited as volunteers or interns benefitted from gaining work experience in while also being helpful to the specific communities.

### ***Passive Strategies***

Passive strategies include writing letters to the relevant authorities such as the department of health with regard to NCDs as issues arise. Out of seven organisations dealing with NCDs, three (3) reported the use of one or more of the passive strategies. Letters are used first to draw the attention of authorities to specific issues and are useful as they represent a record of the issue and what has been communicated about it. Organisations dealing with substance abuse and alcoholism had formulated a code of conduct by which all enterprises

dealing with the production and distribution of liquor must comply. It is however not clear what happened to enterprises which failed to comply. Attending meetings and making contributions in issues related to NCDs was another strategy which ensured that NCDs were factored into decision-making. Although NCD organisations were invited to some of the meetings, there were some where they did not always get invited to. In instances where they received no invitation and they had information about a meeting, the representatives simply attended to ensure that they lobbied for their NCDs.

Organisations dealing with NCDs cited advocacy in the form of petitions, letters to government and commenting on health bills and drawing up codes of conduct as part of their strategy for raising awareness. Petitions and letters are used by organisations due to limited resources for conducting public campaigns. For organisations dealing with substance abuse it was noted that drawing up the code of conduct for the liquor industry was meant to ensure that alcohol was not sold to pregnant women and minors. Petitions and letters are useful in that these represent the record of an issue brought to the attention of stakeholders, particularly if the petition or letter is brought to government. Commenting on bills and constitutional amendments also fit in this category of documentation produced by activists as part of bringing awareness around chronic illnesses in society. Participants noted that they had participated in commenting on draft bills and constitutional amendments on NCDs.

### ***Grassroots Empowerment strategies***

Out of seven organisations dealing with NCDs three reported the use of support groups. Support groups were reported in the case of substance abuse. In such instances individuals dependent on substances are referred to support groups to assist them in the process of getting out of drugs or alcohol dependence. Support groups are also used particularly in rural areas where access to mental health services is non-existent or poor. Such groups help individuals to cope with the condition and also learn how to manage the condition without being stigmatized. Support groups are therefore grassroots organisations which help individuals with one or other form of NCDs to cope in the absence of professional help. It is however notable that support groups on their own are not a substitute for professional help but rather complement the services provided by the professionals.

### ***Collaboration with researchers***

Among the NCD organisations selected for this study, three out of seven reported that they used research as one of their activist strategies. Two of the organisations were not directly

involved in conducting the NCD research but partners with collaborators in the studies. One of the organisations conducted its own research into the NCD issues of concern. The studies from the research conducted were used in advocacy against cancer and cardiovascular diseases. In terms of cancer the idea was to show the link between smoking and the disease. In terms of cardiovascular research the idea was to conduct studies on nutrition in order to provide concrete information to the public on what foods cause or do not cause cardiovascular diseases. One of the NCD organisations used research to draw out issues affecting vulnerable children and to advocate for children's justice. The research conducted on cardio-vascular diseases had resulted in one organization being able to provide relevant information to the public on how to prevent cardiovascular diseases.

### ***Confrontational strategies***

Although most NCD organisations did not use very radical strategies in their advocacy work, they used a range of strategies that might be considered confrontational. The strategies classified as confrontational were those that were very obvious and which brought attention of the media, government and communities to the NCD organisations. Such strategies included marches, lobbying, out rightly criticizing government where it slipped in matters relating to NCDs. One of the areas where NCD organisations had come out criticizing government was in the BBBEE legislation that required their funders to show the proportion of Black people that would benefit from the funding. NCD organisations criticized this bill because it would have severely led to loss of funding as corporates seek to comply with the Broad Based Black Economic Empowerment (BBBEE) legislation. Lobbying government to recognize NCDs as critical in the country is also another strategy that has been used. The argument here was that although the proportion of individuals living with NCDs is not as high as that of people living with HIV and AIDS, the neglect by government of NCDs was leading to an NCD pandemic in South Africa. A key informant however noted the current focus by government on NCDs was not so much as a result of non-profit organisations lobbying, but rather the result of a global recognition of the importance of tackling NCDs. Investigating patient complaints was also among the confrontational strategies that ensured individuals living with NCDs received medical attention and that their rights were not violated. In instances where patient complaints were found to be valid, the health facilities were force to provide care and in some instances the NCD organization facilitated transfer to a different facility.

Marching is a confrontational strategy that was cited by at least two organisations. Non-profit organisations mobilized communities to march against drugs in communities as

these affected mainly the young people. NCD organization also mobilized children to march against the violation of their rights and the appropriation of playing spaces by businesses such as sheebens in residential areas. Such marches were accompanied by memos to the relevant authorities to seek resolution to the issues. For example children's marches included handing over memos to the mayor or a municipality as that is the authority responsible for ensuring compliance with the city bye-laws.

### ***Partnerships***

The use of partnerships in the advocacy against NCDs was mentioned by five out of the seven organisations. The discussion about the stakeholders elicited the same responses to that about partners. Thus the same names mentioned as partners also appeared in the analysis of stakeholder awareness.

Communities that work with expert NGOs are very supportive but people are suspicious of organizations that work with the liquor industry...The organization works with individuals at the primary level ... and do not focus on people who already abuse alcohol (KII\_2)

Stakeholders influence what the organisations do with the funding that they provide (Kii\_3)

When the organization recommends clients to psychologists, psychiatrists etc., and such professionals in turn do work pro bono for the organization...Organisations intervene for clients where they run out of money for treatment – this entails making deals with the service providers (KII\_5).

When we have things to which they can get involved it is there, the response is there. But we are not deliberately seeking a mandate directly from patients... (KII\_6).

From government there's basically a recognition to be doing the work in this area of prevention because they realized that economically it makes sense to prevent diseases rather than spending money on ...to treat so there is already a buy-in and there is policy being created to support ... for example... the smoking legislation, the next example is currently... the salt reduction legislation (KII\_7).

If you look at the private sector, they are starting to realize the impact they have on the health of the nation and for a number of reasons. Part of the reason has to do with social corporate responsibility requirements that they need to ... and they know they have to do their bit for community development taking care of the health of the nation...for others it is because it makes business sense (KII\_7).



The partnerships were useful in advocacy against NCDs for instances in the case of CANSA partnering with the department of health to disseminate cancer prevention messages; in helping the organisations provide services to the most vulnerable groups as in the case of SADAG partnering with professionals, in preventing NCDs such as drug abuse in communities through partnering with the police. Partnerships were also useful in ensuring the formulation of policies that help reduce the increase of cardiovascular diseases such as heart attacks, stroke, and high blood pressure. The formulation of policies such as the anti-tobacco laws and the of salt reduction bill were formulated in partnership with NCD organisations. Partnering with the local authority has ensured that the municipality is aware of how breaching city by-laws affects the well-being of children because children have been able to articulate such issue through hold marches and issuing memos to the authorizes.

### ***Influencing policies on NCDS***

Four out of the seven NCD organisations interviewed reported that they had in one way or the other influenced health policies. Some of the policies mentioned include the Children's Act, the tobacco laws and the salt legislation that is currently being debated. The NCD organisations have been involved in commenting on the bills and giving their inputs directly or indirectly to the policy makers. Thus commenting on bills and influencing the content of policies is one of the activist strategies used by organisations to create awareness, and help prevent NCDs. There are instances where the influence of NCD organisations has tended to put them on a collision course with the government. An example is the recent BBBEE draft legislation that awards BBBEE points to non-profit organisations based on the racial profile of communities that they serve. Non-profits working in predominantly Black communities would essentially get more points than those working in predominantly White areas. This presents a challenge to many NCD organisations as most of their members are White and although they might have activities in Black areas.

### ***Monitoring Compliance***

Three out of the seven NCD organisations in this study reported that monitoring compliance was one of their strategies in ensuring the prevention, treatment and care of individuals living with NCDs. An organization dealing with substance abuse noted that they were involved in monitoring compliance with the code of conduct in the marketing and distribution of alcohol. The focus was on ensuring that alcoholic beverages were not sold to under-age individuals and pregnant women. Also monitored was access to healthcare for

individuals with mental illness. In instances where individuals reported that they had been denied care, the NCD organization intervened to ensure that care was provided. In other instances, the NCD organization found an alternative healthcare provider for the affected individuals. Also monitored were patient rights to ensure that these were not violated. The patients here refer generally to individuals living with NCDs, and the focus was to ensure that their rights were not violated through discriminatory policies or practices. In fact one of the organisations had been formed as a result of the neglect of NCDs by the state in the face of the HIV and AIDS epidemic.

### ***Other Strategies***

Organisations distinguished prevention campaigns particularly where substance abuse is concerned. There are awareness campaigns that are aimed at preventing the on-set of substance abuse among those that have not started using substances. The second type of prevention is among those who have started abusing substances such as drugs and alcohol or even prescription medication. Strategies that did not fit into the broad categorisations included the use of cartoon characters in the campaign against NCDs, the use direct of direct marketing strategies that involve door-to-door awareness campaigns and the involvement of law enforcement agencies such as the police to create greater visibility. Face-book and twitter were also being used in NCD campaigns and one organization noted that it had a specific topic of discussion on face-book every week.

### ***3.2. Strategies used by HIV and AIDS organisations to access health care***

Like the NCD organisations, civil society organisations that deal with HIV and AIDS use a range of strategies to access healthcare. These strategies include the use of the media, public education, litigation, civil disobedience, advocacy, and public demonstrations among others.

#### ***Media***

The type of media mentioned by the HIV and AIDS organization here refers to the use the electronic media (internet, email etc.), radio, television, pamphlets, and books to disseminate information about the HIV and IDS.

#### ***Public education***

This was described in terms of community education, door-to-door campaigns and sessions conducted with people living with HIV and AIDS in order to help them understand their condition. Whereas public education was initially used by people living with HIV and AIDS

to educate them, it was extended to include whole communities and educate the public about the pandemic.

I asked [a sister] \*\*\*\* who was very helpful and [a doctor]\*\*\* to please allow us not to have that space...I asked that we make that learning...while people wait and also give food. With that people were now beginning to asking can we assist, can we eat, can we wash the dishes and then what is HIV, what is AIDS, when you are told you have this disease what does it mean? So that helped people to open up a bit and started talking and then we started a support group and people were supportive (KII\_9)

Public education has also been used by HIV and AIDS education help de-stigmatise the disease. As a participant noted, there is stigma which is often external and directed towards people living with HIV and AIDS. The extension of community/public education helped to educate the public as well as the people living with HIV and AIDS on how to deal with the disease, causes, prevention and later treatment and care.

It is notable that public or community education is not only done out there in communities and public spaces but also at clinics and hospitals as PLWA wait to be attended to. Activists use waiting rooms to teach PLWAs about HIV and AIDS, opportunistic infections, medication, side-effects and any other information that is relevant. The result is that PLWA are able to gain useful insights and can confidently converse with their physicians about the medication that they receive and the side effects because they already have a basis from which to begin the conversation.

The other part of our strategy that we use is what we call prevention and treatment literacy and that strategy is mainly to train our members to be treatment literate but also to be educated about their rights in relation to health rights and most of the people who train in our branches what we call them prevention and literacy practitioners. They work both in communities training our branches and community members to know their health rights but to also know the facts of HIV/AIDS prevention and treatment so that when they go to the health system they know what to expect related to the illnesses that they may have; what treatment is required and how to manage that disease. But at the same time, at the health system level we have treatment literacy practitioners placed in healthcare facilities (KII\_10).

In terms of the public/ community education, HIV activists have the prevention and treatment literacy campaigns. These focus on raising awareness of PLWAs about their rights. The treatment and literacy campaigns also focus on health promotion to ensure that

PLWA are knowledgeable about their condition so that when they visit the physicians more time is spent diagnosing and providing treatment than in trying to explain basic concepts.

### ***Support groups***

It is notable that the notion of support groups arose out of the experience of PWLAs seeking healthcare and realizing that there were many people like them, going through similar traumatic experiences yet with no support to help them deal with the trauma. Initially the support groups which were limited to people that visited the clinics focused on addressing the immediate needs of members on an impromptu basis.

So I went to the embassies in Pretoria I asked if they can donate...the wives of the ambassadors can donate some corn flakes, milk, bread, whatever or they can give or buy actually. When that came I was also partnering with another partner to come and just deliver the prayer. .. I remember there were other women also who have lost a child we donated something like R1 or 50c I can't remember but she left the clinic feeling like the world was off her shoulders (KII\_9).

Although members were not open to discussing what was happening in their lives, those who were keen enough would recognize that the need and address it. For example when members reported the loss of a family member, the support group would gather together the little money they had and support their bereaved member. Support groups initially focused on PLWAs but later changed to address the plight of orphans and caregivers affected by HIV and AIDS. The support groups dealing with HIV and AIDS not only deal with prevention now but with the provision of anti-retroviral treatment, have also changed to include treatment in their support groups. The HIV and AIDS organisations are in themselves a type of support for their members. This is particularly the case when it comes to sharing of responsibilities. As noted by a participant, when there are talks to be given on HIV and AIDS the organization mobilises members to get involved and these members are paid for giving the talks by the organization. Thus individuals who would otherwise have no income are helped by being part of a group that is required to provide information on HIV and AIDS.

### ***Engagement***

As mentioned by a key informant, engagement is often used in the initial stages when activists interact with officials in charge of healthcare. The idea is to draw attention to issues related to HIV and AIDS away from the public and to get the government to act on these issues. Engagement starts at the grassroots level where activists start engaging with the MEC for health. When engagement fails at the provincial level it is escalated to the

national level. Only when engagement with the national health structures fails, do the activists move to more radical strategies such as such as civil disobedience, and public demonstrations.

### ***Litigation and legal action***

This is a strategy that HIV and AIDS organizations have used to great effect. The activists have been able to use litigation because their members included lawyers who took up the cases on a pro bono basis. Litigation was used against government and multinationals in different ways. In terms of government the HIV and AIDS organisations used legal action to force government to make available drugs for mother-to-child transmission. Once the battle for the provision of drugs for mother-to-child transmission had been won, the organisations now made it their mission to ensure that comprehensive care for people living with AIDS was provided in public health facilities. These battles against the government were won in the South African courts which based their arguments on the constitutional provisions for access to health care.

So that was really helpful because the lawyers were activists, they knew their story, they would break it into pieces; that is why we could do civil disobedience hoping we would be arrested and that wasn't happening but we knew our rights. We would say don't talk to med, talk to them...TAC then helped by getting some funding for the activities and they put us on treatment in that time while government was still dilly-dallying/deciding when to implement the ARVs (KII\_9)

Legal battles by the HIV and AIDS organisations were also difficult for these were waged against pharmaceutical giants that had held the world hostage over their claim issue with that the insistence on patented drugs had made it very difficult for the masses of people to access health care. The patented drugs were very costly and therefore unaffordable to the masses of the poor in South Africa and Africa in general, that is still the most affected by the HIV and AIDS epidemic. The result of the litigation is that the multinational pharmaceuticals were depicted caring more about profits than people. TAC won the court cases and since then South Africa has been able to provide ARV treatment using generics.

### ***Civil Disobedience***

This is a strategy that was used to try and force government to provide treatment to people living with HIV and AIDS. For the activists it was a do or die strategy. Civil disobedience was adopted when it was realized that government was not listening and responding to calls for treatment. Among the things that led to civil disobedience was the fact that babies were dying for lack of treatment. The mortality from HIV and AIDS was rising and yet the response from the South African government was very slow. As a result, the activists

decided to declare to the world that the death rate in South Africa was about 500 people on a daily basis.

....there was a new minister and she was on our side. The second time around now when she is needed to give the drugs herself she couldn't now... So that became an issue and we had to now take her up... We had a lot of things like civil disobedience where we ask all our friends around the continent and outside to say 500 people were dying in South Africa ...ja 500 per day used to die those days... 1999, I think. In 1998 we were sitting at 3 million people infected/living with HIV/AIDS in South Africa; now we are almost at 6 or whatever, you can see that the disease is growing and we are not doing too much (KIL\_9).

Civil disobedience was not only used to draw attention of the government but of the world to the HIV and AIDS crisis in South Africa. The activists used each and every means to let the world know that people were dying in numbers yet action to prevent these deaths was very slow by governments. Pharmaceuticals too were not budging on the prices of their medicines. Thus civil disobedience was used when all avenues to communicate about the HIV and AIDS crisis had been exhausted.

### ***Public Demonstrations***

Like civil disobedience, public demonstrations are often used as a last resort when non-confrontational tactics such as engagement have been exhausted. In the case of HIV and AIDS organisations, public demonstrations were initially used to draw attention to the lack of action by government in providing treatment to expectant mothers in order to prevent mother-to-child transmission. Once this battle had been won the public demonstrations were used to draw attention to the adamant position of pharmaceuticals in refusing to allow the production and distribution of generic drugs in the face of the HIV and AIDS crisis. In addition to demonstrations against pharmaceutical giants in South Africa, public demonstrations that were relayed all over the world were held by the HIV and AIDS activists.

In recent years, after winning the battle for access to HIV and AIDS treatment, the activists have continued to use demonstrations to draw attention to the lack of drugs at health care facilities. As clarified by participants this is usually used when all other options such as engagement, letters and petitions have failed. Public demonstrations are used by HIV and AIDS organisations to get the government to listen and address the concerns raised. When HIV and AIDS organisations first began mobilizing members, public demonstrations were used to draw attention to the plight of PLWA and the failure of government to respond to

the HIV and AIDS crisis in South Africa. Demonstrations have in recent years focused on the lack of drugs in hospitals and have brought to light the specific health facilities that ran out of drugs and the fatalities that happened as a result of the lack of drugs.

Awareness-raising for HIV and AIDS organisations targets the general population and aims to prevent infection amongst the infected, prevent further re-infection amongst those already infected and provide information about treatment and the rights of people living with HIV and AIDS. Such awareness also targets the service providers to ensure that they provide healthcare with compassion and that do not stigmatise people living with HIV and AIDS.

### ***Advocacy and bottom up strategies***

Bottom-up strategies have emerged as a result of the years of social activism by HIV and AIDS organisations. The organization of HIV and AIDS organisations from the grassroots to the national level has meant that activists are trained on how to tackle issues from the community level. When this fails the issues are escalated to the provincial level. If the concerns are tackled at the provincial level then the issue does not reach the national level. Only when there is no response or solution at the grassroots and provincial levels are issues taken up at the national level. Examples of issues tackled using the bottom-up approach include the lack of drugs at health clinics. When such an issue is not solved at the grassroots and provincial level then it is escalated to the national level. At the national level it is then decided what strategy should be adopted before the activists go public with the issue.

### ***Monitoring access to healthcare***

Monitoring access to health care is not a new strategy but began with the on-set of civil society activism on HIV and AIDS. Initially monitoring was used by activists to monitor how PLWAs were treated when they sought medical help in health facilities. The activists would teach PLWAs their rights and how they should expect to be treated at health facilities by medical personnel. PLWAs were taught to monitor and report cases of stigmatization to the activist groups so that these would be brought to the public. The aim was to ensure that PLWAs are treated with dignity as humans suffering from a terminal illness just as others with terminal illnesses.

So we also depend on our branches and our treatment literacy practitioners on the ground to monitor access to services and challenge where there has been instances where access to

services there is not adequate. But then when it becomes beyond the branch and beyond the prevention and literacy practitioners we take it up as a provincial campaign and a national campaign (KII\_10).

In recent times, monitoring access has progressed to include treatment literacy. Treatment literacy is provided by treatment literacy practitioners who have been trained by the activist organization to educate PLWAs on what to expect when they visit physicians. The treatment literacy practitioners provide basic information about HIV and AIDS and the possible conditions that arise out of the illness. The purpose is to ensure that when the PLWA sees the physician, the focus by the physician is no longer on providing the patient with basic information but rather on managing the condition of the individual patient. Part of treatment literacy includes educating the PLWAs about the different medications they can expect for various conditions related to HIV and AIDS. This empowers PLWAs to monitor the type of treatment that physicians prescribe to them and they are able to challenge the physicians and ask for the correct prescriptions.

Monitoring is about ensuring that the rights of PLWAs are not violated, that they are treated with dignity and provided with appropriate care by healthcare professionals. Monitoring access to healthcare also includes monitoring the stocks of ARVs in health facilities. Through PLWAs, activist groups are able to indicate the length of period that a facility has been out of ARV. Once the activists note that the lack of stock for ARVs is not a problem confined to a specific facility, district or province then this becomes a national issue around which they mobilise. Only when no prompt action is forthcoming from the health authorities do the activists resort to litigation and public demonstrations.

### ***Partnerships***

In the process of advocating for access to treatment and the health rights of people living with HIV and AIDS the HIV and AIDS organisations ended up forging partnerships with a range of stakeholders. Some of the partnerships were about creating awareness of the concerns of children when their rights are violated. An example is the partnership between a children's network with a municipality which gave children the opportunity to express their views about the violation of their rights to play and be children in general.

Some of the partnerships were mutually beneficial in the sense that the HIV and AIDS organisations were able to educate the public while raising funds for their organisations.



The result was that the partnerships created awareness on how to deal with HIV and AIDS in the work place, the rights of PLWAs in the workplace and de-stigmatising the workplace. Some partnerships were forged with very unlikely partners. An example is a partnership forced between a pharmaceutical multinational and the HIV and AIDS activists. In this partnership the activists learnt that government had been receiving critical medication for dealing HIV and AIDS conditions yet the activists had not accessed it because they had been unaware of it. In the same partnership there was a reversal of roles. Whereas in most cases it was the HIV activists training communities and the public about HIV and AIDS, the activists now had the opportunity to learn about HIV and AIDS medication, how it works and its effects.

Another unlikely partnership was that between a group of HIV and AIDS activists with the government. The result was that although some group of activists did not accept funding from government, the second group accepted such funding and in fact it continues to pursue it in order to keep the operations of the organization running. Some partnerships are long-term and others are short-term. Some are mutually beneficial while others are one-sided. Often it is the HIV and AIDS activists seeking to draw out the benefits of treatment and health rights. Where the objectives are not the focus the partnership quickly disintegrates.

### ***Influencing Policy and Practice***

Without stating it bluntly, among the strategies that HIV and AIDS activists have used to increase access to healthcare has been through influencing policy. Through the litigations, civil disobedience and public demonstrations, HIV and AIDS activists forced the South African government to change its policy and practice on a number of issues related to HIV and AIDS:

1. The provision of drugs for the prevention of mother-to-child transmission (PMTCT)
2. The provision of treatment to PLWAs
3. The protection of the general human rights of PLWAs
4. The change in policies and practices that labelled and stigmatized PLWAs

As a result of the strategies that put all the stakeholders that played a part in saving the lives of PLWAs and children, HIV and AIDS practitioners also changed international policies and practice. Legal action together with the South African government force

pharmaceutical multinationals to change their hard-line stand against the production and distribution of generic ARVs for the treatment of PLWAs.

So we started seeing all of these patterns and we had to put our foot down, we fought with the pharmaceutical companies and we won the case; Manto was...and then there was a new minister and she was on our side. The second time around now when she is needed to give the drugs herself she couldn't now (KII\_10).

Governments and multilateral agencies began to provide funding for HIV and AIDS programmes in a way that they had not done before. By taking in women and children suffering from domestic violence as a result of HIV and AIDS the activists through their strategy of rescuing such families brought about awareness of the link between gender-based violence and HIV. Previously HIV and AIDS funding was delinked from social issues such as domestic violence and poverty as it was treated as a purely medical condition. Through highlighting the plight of PLWAs that were suffering from domestic violence and general destitution, HIV activists changed the way the pandemic was perceived globally. As a result funders began not only to fund HIV and AIDS as a disease but also allocated funding to deal with issues of domestic violence. Thus policies around funding changed to respond to the situation of PLWAs rather than being framed from the perspective the funders.

And then other issues were coming in, the same women who were HIV, some would come been crying...what is the problem? They were beaten up by their partners because they think they got HIV. So now we were forced again not just to look at HIV...just HIV as a disease, we needed to touch on the poverty part...the fact that that the woman is dependent on the man...if you are ill the child is the one...the partner is never there making sure you are gonna reach the hospital. So we started looking at it now...there is violence in...they kept saying these things and no one wanted to listen. I can see recently that they are even having funding on violence against women and HIV, they even mentioned the two (KII\_10).

By protesting directly against the minister for home affairs about being labelled in their official documents, HIV and AIDS activists changed government policy and practice in terms of how PLWAs are treated. Thus the practice and policy of identifying individuals as HIV positive was perhaps brought to a halt by the South African activists thus opening the way for other governments to stop discriminating, stigmatizing and labelling PLWAs.

Part of my consultancy at Eskom was that we started a thing called GIPA, GIPA was greater involvement of people living with HIV; it is a declaration that was signed by our heads of state in

Paris- that made many companies also...we were saying to companies that you have to employ people living with HIV not because they are living with HIV but maybe because they qualify and also they can teach the company. So I was placed at Eskom for that reason and if you could remember in 1998/9 Eskom was already getting awards for the good job because we were really their health wellness...we used to assist that, talk to workers, make sure that their things are going right (KII\_9).

Influencing policy and practice is one of the strategies that HIV and AIDS activists have helped to stop the violations of the right to human dignity of PLWAs and upheld their health rights.

In the conference that I organised minister [inaudible] was giving visas for those who needed visas to come to the country. Few visas we had to turn them back because they had a stamp that was written HIV... We had to say minister, this page you are gonna have to cover it with something. They started negotiations and AIDS Legal Network and others in those days assisted. So there were lot of stigma, there were lot of problems (KII\_9).

The direct intervention of HIV and AIDS activists and the threat of litigation forced the South African government to stop labelling people visiting the country in terms of their HIV status. The confrontational strategies, the threat of litigation and sheer boldness of the activists changed how PLWAs are treated in policy and practice.

### **3.3 Comparison of strategies used by civil society organisations dealing with NCDs and HIV and AIDS in accessing healthcare**

The range of strategies used by both organisations involved in NCD and HIV and AIDS activism points to certain strategies commonly used by both types of organisations. These include the media in its entirety (electronic, print, radio, pamphlets, direct marketing, magazines etc.). Through the media civil society organisations are able to lobby government, criticize and complain about NCDs and HIV and AIDS. Such strategies are used to bring about awareness around NCDs such as alcoholism, mental illness and NCDs in general such as diabetes, cardiovascular diseases and HIV and AIDS.

Like the HIV and AIDS organisations NCD organisations also use public campaigns, public education, imbizo public consultation, advocacy and door-to-door campaigns. The provision of public education on NCDs and HIV and AIDS involves holding talks, holding support groups for people with challenges such as alcoholism, mental illness such as anxiety and depression and HIV and AIDS. There are however challenges in the provision of public education through workshops, talks and other forums. When such strategies are

used in the poor and marginal communities, potential participants raise questions such as how attending the forum that particular day will benefit them individually. Thus participants are often heard to argue that unless they are provided with a meal they do not see the value in attending the education sessions hence public education remains a challenge although used by a range of organisations. Public awareness education programmes, it seems are used across the various organisations but the experience of different stakeholders also varies. Whereas there are those who use workshops as a strategy, others work with small classes of learners to disseminate very specific information.

Awareness-raising takes a range of forms such as public education sessions, workshops, support groups and door-to-door campaigns among others. Most organisations, both those involved in NCDs and HIV and AIDS direct their awareness programmes to the general public. However some organisations target industries and producers of goods that contribute to the increase of NCDs such as cardiovascular illnesses, diabetes, high blood pressure and stroke.

Whereas petitions were mentioned among the NCD type of organisations, the same strategy was not mentioned by the HIV and AIDS organisations. Whereas public demonstrations, sit-ins, and picketing were used by HIV and AIDS organisations, the same strategies were not cited by the NCD type of organisations. The strategy of educating the public and communities was cited by both NCD and HIV and AIDS education. Providing education represents a top-down approach where the assumption is often that knowledge rests with the educator and that the learners are 'empty vessels' read to be filled with the specific type of ideas. Teacher-centred education assumes that the learners are ignorant and need to be provided with knowledge by the educator. It is however notable that the idea of working with the communities to build capacity was cited by the HIV and AIDS organisations. Working 'with' is different from imparting education to a group of learners, i.e. educating. 'Working with' represents a partnership and equal valuing of ideas of the stakeholders. This is one of the areas where there appears to be a difference in the way the organisations operate (HIV and NCD).

The strategy of engaging with public health officials was identified by the HIV and AIDS organisations but, it is also evident that NCD organisations also use it. The difference lies in how engagement is used. HIV/AIDS organisations use it as a starting point in articulating their concerns with public health managers and if this strategy fails at the provincial level it

is escalated to the national level. If engagement fails the national level, then confrontational strategies such as public demonstrations, sit-ins, and picketing are used. For the NCD organisations, engagement is a strategy on its own, an end in itself. NCDs use engagement to draw attention to issues such as child maltreatment and abuse, children's concerns such as the location of sheebens near their schools and the delay of ambulances in responding to emergencies. For HIV and AIDS organisations, engagement one of the phases used to get the government to respond to HIV and AIDS issues such as the lack of anti-retroviral drugs in public hospitals. When engagement fails then public demonstrations are used.

Marches were also cited as one of the strategies used by civil society to draw attention to issues of concern. Marches are different from public demonstrations as the agenda is often carried in a memorandum address to a specific office. The idea of a public demonstration is to make a statement about an issue affecting the specific grouping. The purpose of demonstrations is often to express outrage, draw attention to the gravity of a situation. While demonstrators might have a memo, often people who choose to join the demonstration can choose how best to express their outrage. In marches the focal point is the memo. In public demonstrations the focal point are the messages that the demonstrators put in their posters either in pictures or words. One organization reported that it did not have any specific strategies that it used but on further probing it became clear that the organization was using imbizos to educate communities about the specific health condition.

### **3.3.1 Effect of using the various strategies**

The effect of the strategies used by both NCD and HIV and AIDS organisations have effect one way or another. These general effects of strategies used by both NCD and HIV and AIDS activists have been analysed and grouped into three broad categories: as follows:

1. Perceived positive impact
2. Cannot say, cannot quantify
3. Neutral impact

#### ***Perceived positive impact***

Organisations which felt that they had had a huge impact had the following to say:

Huge because it meant a better understanding of healthcare, it helped them understand more about healthcare; it meant they can access it anytime it suits them. It means they can take the book through to the neighbour to share them with their sister-in-law (KII\_5).

Commenting on the talking book, a participant noted that it is read by at least 27 people. Thus the distribution of 200,000 copies translates into 5.4 million people being reached with messages about mental illness, how to identify the symptoms, where to seek help and what to do in case of an emergency. A participant noted that the quantification of the publicity generated by activists involved in mental health had resulted in 5.9 million people being reached. Activism by NCD organisations appears to be changing attitudes of communities towards conditions such as mental illness. Whereas in the past a mentally ill individual would think of visiting the traditional medicine man, now there is awareness that mental illness is a treatable condition like other illnesses. Although people might also choose to visit traditional doctors, they are aware that health facilities can and do offer remedies for mental health. Providing information about NCDs has led to their de-mystification, de-stigmatisation. Greater awareness has helped people to view NCDs as the illnesses that they are not something out there. Commenting about mental illness, a participant noted that greater awareness and information, has made people realize that if they are real illnesses, there is real treatment.

Previously they went to traditional healers now they still might do that first but the second thing that they might do is to go to a Westernised source (KII\_5).

It can then be argued that greater awareness has resulted in behaviour change amongst communities. The health-seeking behaviour is not geared towards getting treatment for illnesses that might not have received attention previously, for example mental illness.

For the NCD organization dealing with cardiovascular diseases, just a single mark that on various products was helping to change people's behaviour into making healthier food choices. For example instead of going for just any brand of margarine, consumers were choosing to use what had been advertised as a healthier option; instead of purchasing any food stuff in the market, consumers were opting to choose the healthier options which carried familiar mark and in this case it was the heart mark of the heart and stroke foundation. Food producers and retailers too were making changes to provide healthier food s to qualify them for the heart mark and ultimately earn them more profits from the more healthy preferences that consumers were making.

The use mobile clinics to address alcoholism has led to partnerships with the general healthcare clinics in communities to provide services. In seeking to prevent substance abuse and addiction partnerships have also been forged with the law enforcement institutions to ensure greater support to the work that is already being conducted in communities. The fact that organisations have experienced reformed addicts returning as volunteers to assist others suggests that the interventions to some extent have a good effect.

On the policy level the NCD organisations through commenting on bills and policies are helping shape the interventions taken by government to help in the reduction of the population suffering from such illnesses. In the case of cancer, NCD organisations had worked with the government to pass the anti-smoking legislation. In the case of cardiovascular (stroke, high blood pressure and heart attack) the NCD organisations were currently working on the salt reduction legislation. The assumption is that a reduction in salt consumption would go a long way in reducing high blood pressure.

For the civil society involved in HIV and AIDS activism, engagement, putting pressure, civil disobedience, public demonstrations and suing the government had a tremendous impact:

And then they sort of agreed...the cabinet was agreeing but in the meantime AZT and Nevirapine was given to pregnant women at some point after so many children have died but even the MCC wasn't ready to issue that drug (KII\_9).

The result was the provision of drugs to prevent mother-to-child transmission of HIV and AIDS. Once this battle was won the activists pushed their agenda further. The type of public/ community education described by the HIV and AIDS civil society groups was not just about the disease it was also about getting their points across to the authorities and ensured that they (people living with HIV and AIDS) did not die without making effort to get treatment. As one activist put it:

So we started just getting into the politics while we are trying to also make people...we used to teach people on your life is politics and also with the help of TAC and Section 21 today{then it was called Aids Law Project}. So that was really helpful because the lawyers were activists, they knew their story, they would break it into pieces; that is why we could do civil disobedience hoping we would be arrested and that wasn't happening but we knew our rights. We would say don't talk to med, talk to them...(KII\_9).

Thus public engagement, public demonstrations and community education were mixed with unorthodox means to provoke arrest by the authorities. The aim was to bring attention to the HIV and AIDS epidemic in South Africa. Civil society activism for HIV and AIDS organisations resorted to using unorthodox, illegal means to make their statements. This included importing general anti-retroviral drugs from Asia and prescribing them to their members:

TAC then helped by getting some funding for the activities and they put us on treatment in that time while government was still dilly-dallying/deciding when to implement the ARVs.... The whole strategy was people wanted to be arrested then we find out that you could even apply for drugs using Section 21. People used to sit and research a lot of these so we would just deal with it at the end. Like the Competition Commission, I didn't even know there was such a body...you would end up knowing every other body on health. If a nurse treats you at the clinic and she is stigmatising you, where to report her...the health was moving to that level where certain things were not acceptable. The reason we were putting our people at the hospitals and clinics was so that our people could be there as outreach or fieldworkers, they would be there to talk to a person at that level and then assist the nurse and the doctor so that when they reach that person it is easier...it is not a person sitting there not knowing what is going on with her but can assist the doctor. That is when TAC introduced treatment literacy; we were trained and I took the things to train my organisation...everyone would have to know what is TB and what needs to happen when you have this and what needs to happen...when you have thrush you don't have to die (KII\_10).

The confrontational strategies used by the HIV and AIDS organisations resulted in more gains than they had sought. Pharmaceutical companies began to engage with them and provide information about the medicines that were available to treat conditions that PLWHA were experiencing. Thus instead of being enemies the pharmaceuticals became partners and began providing training to PLWHAs. The information provided by the pharmaceuticals resulted in greater access to the relevant medicines and people's lives were saved.

We started fighting with other pharmaceutical companies like Pfizer, Pfizer approved a drug that was killing thrush and they were giving government [drug name] for five years. We also ran around the clinic when people were turned around without the [drug name], we wanted to know because that company has donated it to the country for five years, where is it? We asked the same company to come and train our people on what does the drug do and all of that and so we were also getting that. You could see when people were taking that drug they would be okay, the thrush would go, a person would be able to eat, the thrush would be in the oesophagus and coming out...and also we were teaching people sort of the medicine in a very simple way. We used to call it media township...we break it down to the township level so even if you didn't go



to school you would be able to say if you needed a second drug so it was beginning to be interesting (KII\_9).

A key informant dealing with HIV and AIDS summarized the impact or effect of the strategies by noting that the confrontation, public demonstrations, civil disobedience and interdicting the government and multinationals had resulted in the provision of ARVs. About 2 million people in South Africa were alive because of the provision of ARVs in the public healthcare facilities.

### ***Cannot say, cannot quantify impact***

Some organisations particularly those dealing with NCDs categorically noted that they could not quantify the impact that their strategies had on reducing the specific NCDs because their focus was on ensuring that their target groups were aware of the issues and how to respond to them:

A participant noted that the strategies used had helped to mobilise ordinary people living with HIV and AIDS to access treatment and bring about change: 'It is also about how we organize and mobilise ordinary people with HIV who are perceived as patients, who were calling for change and holding [government] accountable (KII\_10).

Organisations dealing with drug and alcohol abuse note that it is difficult for individuals to admit that they have a problem and to seek help:

But with the people that have come and said you have helped us and we want to help again. You find people saying I was able to find this with your help; I want to lend a hand. A lot of people do come, a lot of schools are referring, and clinics are referring. It is a big problem and as I said, we cannot... cure everybody (KII\_3).

### ***Neutral/ little impact***

Some organisations feel like they are not having an impact due to the growing problem of NCDs. There are times when organisations feel like they are losing the battle against NCDs '*Sometimes we feel like we are fighting a losing battle*' (KII\_3). The quotation suggests that organisations dealing with NCDs at times feel as if they are not having any impact at all. It appears the problem of drug and substance abuse in communities sometimes feels so enormous that the efforts being put to address it seem like a drop in the ocean. On the other hand it is evident that efforts to address drug and alcohol abuse are having impact particularly in schools. Among those who have been rehabilitated, there are those who

return and seek to help others get out of drug and alcohol addiction. Although the organisations cannot always quantify the impact, the qualitative impact is evident when people who have been rehabilitated refer others for treatment and rehabilitation and when schools identify learners that need rehabilitation. Such gestures suggest that efforts at addressing the problems of alcohol and substance abuse are having impact.

While some organisations have expanded their mandate to cover the wider population as opposed to the past when their target was limited to a specific group, it appears the problem of NCDs is growing. Examples here include cardiovascular diseases and diabetes. The organisations have a range of activities, their publicity campaigns are receiving attention, their branding is receiving acceptance among consumers and industries, but the problem of cardiovascular diseases and diabetes continues to grow unabated. What is notable is that the organisations that target these NCDs use conventional means to bring awareness around the specific NCDs.

Commenting on access an organization noted that, *'we cannot help with access, that is the government's issue and why we fight government'* (KII\_4).

Providing access to services or treatment is viewed as the responsibility of government and not the NGOs dealing with various types of organisations.

Another organization noted that despite greater expanding their mandate to address prevention of the specific NCD in the wider population, the problem had worsened. The statistics of people affected by NCDs point to an increase rather than a decrease. It is such trends that have resulted in greater efforts being made to create greater awareness, publicity and change behaviour in the general South African population.

### **3.3.2 Challenges of using various strategies**

Out of 10 organisations interviewed nine responded to the question on challenges about using different strategies. The analysis was structured in terms of the organisations that deal with HIV and AIDS and those which deal with NCDs.

#### ***Challenges of using the various strategies among NCD organisations***

It is apparent that organisations dealing with NCDs appear to have more challenges than those dealing with HIV and AIDS. Among all the organisations dealing with NCDs, funding was cited as a key challenge. Without funding, the organisations cannot conduct their

advocacy work, recruit professionals, run their operations and provide services to their target groups. For the NCD organisations fortunate to receive donor funding, the challenge is that the funding is allocated to specific projects within the organization. If the organization has three or more programmes and only one is funded, it is not possible to distribute the available funds to the other two programmes, if the funding was provided for a specified project. This is because the donors often ask for financial statements indicating how the funds have been spent.

The lack of funding has resulted in the closure of some of the NCD organisations particularly those working in rural areas where it is difficult to access funding. Thus funding is critical to the existence of the NCD organisations and to the implementation of their prevention and care programmes. Programmes affected by the lack of funding include the rehabilitation of drug addicts, treatment of mental illness, advocacy work for the prevention of HIV and AIDS. The result is that most of the programmes designed by NCD organisations are not sustainable as these depend entirely on the availability of funds to run the programmes, pay professionals and pay for materials and office operations. The lack of certainty about the funding situation has meant that the organisations cannot afford to pay competitive salaries to their professional staff hence the high turn-over of staff in these organisations.

Lack of funding also implies that some organisations have to find innovative ways of operating. Some now link up with their members online, board membership is kept at a minimum and there are no physical offices because members meet online. For some organisations the lack of membership has meant they cannot afford offices and those that had offices have closed.

While it is clear that NCD organisations are busy with programmes on prevention, the organisations also admitted that they could not tell the impact of their work. NCD organisations dealing with drugs admitted that they could not identify where the use of specific drugs was most prevalent. Other organisations admitted that they were too busy with the prevention work that they did not have time to measure the impact of their work. Some however noted that there was data on specific programmes in their organisations to show the reach of their prevention effort although they had clearly not focused on impact assessment.

The use of letters and petitions can be considered passive types of strategies. Letters take time to reach the recipient. It also takes long to get enough signatures for a petition. Unless a letter is registered there is a chance of it not reaching the intended recipient on time. Chances are that when the contents of the letter seem to be making demands there is a possibility of an official first trying to address the concerns before responding to the letter if at all they get to that point. Thus passive strategies might be considered safe options, but they also represent the written records that can be drawn upon in cases of litigation.

Although some NCD organisations are aware of the increasing incidence of NCDs among the South African population, it is not always possible to tell where the issues are concentrated. An example is the problem of substance abuse and addiction. Organisations are aware that this is a growing problem in the society, but they also admit that it is a challenge to tell exactly what drugs are concentrated in which areas. The same case applies to the challenge of depression and anxiety, and teen suicide. The activist organisations are aware that mental illness is a growing challenge but since the organisations do not conduct research it is not clear what the magnitude of the problem is. What then emerges is that the failure to include research or monitoring and evaluation to establish where certain NCDs are most concentrated becomes a challenge in establishing the real impact of these organizations. Thus the operations seem like an attempt to simply throw a hook into any part of the river and then waiting to see how many fish will be caught. Such an approach is unlikely to yield anything. There is need for detailed planning both for the implementation of activities as well as for the monitoring and evaluation of the impact of the activities and strategies employed by NCD organizations.

### ***Challenges in using the various strategies among HIV and AIDS organisations***

Organisations dealing with HIV and AIDS face the challenge of funding which is so severe that some note that they do not have funds to meet the costs of their operations. Lack of funding has meant that organisations dealing with HIV and AIDS find innovative ways of keeping their prevention and treatment programmes in place. This has included cutting down on the scale of their activities. Unlike before when they would get involved in programmes for a full period, now they have had to cut down on the time spent on critical programmes hence the lack of their visibility on critical issues relating to the epidemic. The HIV and AIDS organisations also note that lack of funding affects their ability to meet operational costs. The lack of funding among HIV and AIDS organisations has also meant that they focus on the less costly activities. Unlike before when they would organize huge public demonstrations, now they are back to the grassroots level where they try to engage

with the political leaders to get attention in matters pertaining to HIV and AIDS. The challenge of scaling down operations impacts on the how their members view what is happening. For example, it was noted that members of HIV and AIDS felt that engaging with politicians was a waste of time.

Engagement was viewed as mild form of activism and understood by members of such organisations as a way of being co-opted. Thus although it is cheaper to engage at the grassroots level to get solutions face at that level, the more radical approach of public demonstrations is preferred as it is loud and has a reverberating impact. When the politicians do not listen the HIV and AIDS activists take to the streets to make their point which is not only heard locally but internationally.

Lack of funding is not only a function of the economic melt-down but also an artificial scarcity of funds created by the HIV/AIDS organisations. While funding might be available from governments, pharmaceuticals and multilateral agencies, some HIV and AIDS organisations had chosen not to accept funding from specific donors in order to maintain their independence and continue to actively fight for the rights of people living with HIV and AIDS without offending its funding partners. Thus on principle, organisations whose monies are not accepted include the South African government, pharmaceuticals, US government and its development agency, USAID. While some of the HIV and AIDS organisations have taken a hard-line stand on funding, the smaller organisations appear willing to accept funding from any source in order to conduct their activities. Thus it is clear that funding from the Department of Health and Social development is readily accepted.

Another challenge that HIV and AIDS organisations faced was the difficulty in showing the link between HIV and socio-economic factors such as domestic violence. Activists had to assist women and children thrown out of their homes because of HIV and AIDS; children were being raped by their fathers in the absence of their mothers; women were being inherited without consent on the death of their husbands. Such were the difficult challenges that HIV and AIDS organisations had to deal with. However in the early stages of activism, the link between HIV and poverty or domestic violence was not understood by the funders. The activists once again demonstrate this link through their work with communities.

Strategies such as litigation and public demonstrations puts HIV and AIDS organisations on a collision course with government and multi-nationals who might also be their partners. Both litigation and demonstrations can be equated to arm-twisting government to do what it is supposed to be doing not at its own pace but at the pace of the activists. Litigation and demonstrations result in hostile relations between the HIV activist audience which is mainly government and pharmaceuticals. HIV and AIDS activists were for some time viewed as very powerful and hostile to government whose intervention remains critical in ensuring of treatment and care. By Insisting on the protection patents, the pharmaceuticals too got in the way of HIV and AIDS activists. In seeking access treatment, care and health rights, it becomes easy to make enemies with groups or institutions that should be partners. There is always a need to strike a balance and ensure that the purpose of the strategy (litigation or demonstration) is to secure the treatment and health rights of PLWAs.

Whichever strategy is used there is always the concern about balancing the interests of members and interests of partners. Whereas the HIV activists would like to use a systematic approach in advancing their case of the department of health and therefore explore less confrontational strategies to the end, the members who should benefit from the resolution of challenges are often impatient with passive strategies. For example engagement might be considered less effective by members who would like to be on the streets making their point. The officials of HIV and AIDS organisations however consider engagement a better strategy as it avoids confrontation and ‘bad blood’ with the Department of health. Yet both members and officials of HIV activist groups are wary of engagement which often happens behind the scenes, away from the full view of the public, because it can easily be manipulated by the politicians. While the preference of HIV and AIDS activist organisations is public demonstrations, these create a hostile relationship with the politicians and service providers. On the other hand, engagement which might seem to be low impact ensures that good relations are maintained. Striking a balance between interests of members and interests of partners remains critical.

### **3.3.3 Comparison of the challenges**

It is clear that both organisations that deal with NCDs and HIV and AIDS are faced with the challenge of lack of funding, lack of sustainability because rely on donors to finance their activities. The lack of funding impacts on the range of activities those organisations can be involved in. The decline of funding to organisations dealing with NCDs and also HIV and AIDS organisations so serious that some report not having funds for office space, basic

operational issues such as paying for telephone services, internet etc. For some organisations the lack or decline of funding implies that organisations do not have funds for carrying out their activities

When there is no funding I call the same people and say are we not supposed to work and just be volunteers. Sometimes the lines are locked, you are writing to Eskom, some days you are coming into the offices that have put a chain for two months. If the government says they don't have money why don't they give us a public building like yours and we could just be all there where the electricity and phones are maybe is a prepaid (KII\_9).

Despite the challenges involved in the use of strategies that require funds, both NCD and HIV and AIDS organisations have found innovative ways of cutting and reducing costs to the bare minimum. One NCD organization was very thin in terms of its board. Meetings are held via Skype. Interaction with members is through the internet and email. This helps to keep costs at a minimum. An HIV and AIDS organization reported that when they had to make presentations to different organisations, they charged corporates for their time. An NCD organization reported that to deal with lack of funding which was essential to their operations, the organization used cross-subsidisation to ensure that the programmes in poor areas were funded while charging for work done in more affluent areas and organisations.

Both NCD and HIV and AIDS organisations have had to struggle to ensure that their constituencies get access to healthcare using the media, public intervention, engagement and even public demonstrations. It is evident that civil society organisations play a critical role in ensuring that their target groups' access healthcare and that they are aware of their health rights. While the NCD organisations might use similar strategies as the HIV and AIDS activists, it is clear that the HIV and AIDS activists follow a specific process in advocating for their rights and in ensuring access to treatment. For example while an NCD might use a passive strategy like writing letters to health authorities and getting a petition, the HIV and AIDS also use these too but these are just the starting steps which if not addressed by the health authorities result in more hostile active strategies such as civil disobedience and public demonstrations. Unlike the NCD organisations, HIV and AIDS activists use civil disobedience as a strategy for accessing healthcare.

Whereas the NCD organisations appear to be involved in developing innovative programmes and products for getting their messages across, the HIV and AIDS organisations mainly rely on pamphlets and the mobilization of members to get their point across. While the NCD organisations might use one strategy at a time, the HIV and AIDS

activists often combine strategies. For example while negotiating with health authorities to for the provision of ARVs, often the members are ready to demonstrate to demand for their rights. The difference in terms of how the strategies are used, i.e. single strategy versus a combination seem to depend on the availability of funding. Given the amount of funding that HIV and AIDS activists are able to attract, they are also more able to concurrently apply a range of strategies for example, issuing pamphlets, talking to the media while also having a team that is negotiating with the health authorities. Furthermore it appears that while the NCD organisations appear to have specific strategies well planned out the HIV and AIDS organisations appear to use a gradual approach that starts with the most 'harmless' strategy and builds up to the most legal type of strategy which was cited as the public demonstration. The public demonstrations are 'dangerous' because they often depict the target as merciless, cruel and unconcerned with the sick and dying masses. This is among the strategies that the AIDS activists have used to great effect

What is clear from both organisations dealing with NCDs and HIV and AIDS organisations is that the strategies used in advocating for prevention, treatment and care are largely influenced by the availability of funds. The lack of funding leads to a change of strategy and the extent to which specific strategies can be used. For example the number of days used in campaigning against various illnesses is reduced, the amount of publicity materials used is reduced and the number of staff and frequency of activities all reduce due to the lack of funding. It is notable that some organisations dealing with NCDs and HIV and AIDS have had to stop their activities and close their offices due to lack of funding. The use of various strategies is also constrained by the availability of funding. It is notable that the HIV and AIDS organisations had to drastically cut down on their activities. For example whereas in the past HIV and AIDS organisations previously conducted awareness campaigns against women abuse.

It is however notable that while the challenges faced by organisations dealing with NCDs relate to the lack of time, capacity and resources just like the organisations dealing with HIV and AIDS, there is a notable difference. The strategies used by HIV and AIDS organisations have been cited as a challenge. Specifically HIV and AIDS organisations have to deal with perceptions from their members in terms of the strategies that they use from time to time. While the strategies used by HIV and AIDS organisations include both public demonstrations and engagement, most members of these organisations seem to prefer demonstrations as these have an immediate impact. On the other hand, there is concern



from the organisations that using engagement is risky because such a strategy can be manipulated by stakeholders such as politicians.

While one of the challenges of the NCD organisations is stated variously as the lack of qualified professionals, the HIV and AIDS professionals did not cite such a challenge. The lack of professionals was cast in terms of individuals joining the NCD organisations just to gain the required experience and then leave, the challenge of HIV and AIDS organisations is to ensure quality treatment and care without discrimination and being stigmatized. Whereas the challenge of healthcare for NCD organisations such as those dealing with mental illness was to access healthcare facilities, the challenge with HIV activists was to ensure the appropriate treatment for their members

Both organisations dealing with NCDs and HIV and AIDS are cautious about receiving funding from some governments and from pharmaceutical companies. The argument advanced is that they would be compromised and not be effective in advocating the issues within their mandate effectively. Funding also comes with conditionalities and where these are involved, there is apprehension funding has the potential to silence the activism of the organisations involved. To raise funds for their activities, organisations that have declined funding from certain governments and pharmaceuticals have to write proposals to get financed based on the soundness of their ideas.

### **3.4 Financing**

The discussion on funding focused on the sources of funding, the adequacy and sustainability of the funding and the impact of funding on access to health care among both the NCD and HIV and AIDS organisations.

#### **3.4.1 Financing of NCD organisations**

Funding is often scarce and these organisations are flexible in that they write proposals to fund specific projects in their organisations. If such proposals are not considered and funds are made available for other programmes the NCD organisations also accept such funding. NCD organisations often struggle to keep their programmes running due to lack of sustained income flows. Given the low budgets that they operate with, it becomes difficult to work with the best professionals. Most of the professionals that join the NCD organisations do so for a brief period of time to gain the work experience and after that they look for better opportunities. The result is that low incomes in civil society organizations have led to high levels of staff turn-over. While funding might be adequate

for a specific programme, it is never adequate for the organisations. Thus NCD organisations always have to find innovative ways of using the available funds not only for the specific projects but for the organization as a whole.

The lack of funding profoundly impacts on the operations of NCD organisations. It means less work is done, fewer areas are covered in the awareness campaigns and often those excluded are the marginal areas. However NCD organisations have found innovative ways of dealing with the shortage of funds. Some have entered deals with professionals in such a way that both parties. One organization noted that they refer patients with medical aid to a selected group of professionals. In return such professionals provide free services to individuals referred to them by the NCD organization free of charge.

### **3.4.2 Financing of HIV and AIDS organisations**

HIV and AIDS organisations get most of their funding from external funders such as multi-lateral and bilateral organisations. HIV activists also get their funding from trusts such as the Bill and Melinda Gates and other American foundations and trusts. The funding for HIV and AIDS is used in creating awareness about the disease. Funding has also been used to address access to treatment, health rights and tackle government and multinationals to provide access to treatment through litigation. Funding for HIV and AIDS has been largely responsible for the battles won from access to treatment for prevention of mother-to-child transmission, to the universal access to PLWHAs in South Africa.

Yet even after winning the battles for access to comprehensive care, the HIV and AIDS organisations have continued to lobby to ensure for the continued flow of HIV and AIDS drugs in public healthcare facilities. Due to the availability of funding, the organisations are able to mobilise activists to ensure that state hospital procurement processes ensure the availability of drugs as the lives of people depend on treatment. Funding remains critical in the mobilization of HIV and AIDS activists from the grassroots to the national level. Funding allows HIV activists to operate at the most basic levels of the communities and the resolution of challenges starts at the most basic level of society through the support groups. What is not resolved at the grassroots level is escalated to the province and when the provincial level fails the national level gets involved. The use of the bottom-up strategy has been made possible by the availability of international funding.

The HIV and AIDS organisations agree that funding is never enough as the activities to ensure greater access to healthcare have to be carried out throughout the year. Thus

dependence on donor funding means that activities are closely tied to the amount of funding available. Lack of funding implies that some activities have to be put on hold even though there is need for activism to continue. As one activist noted, people continue to get infected with HIV, rapes continue unabated, yet the silence about these is deafening all due to lack of funding.

Despite seeming like they are well-funded, HIV and AIDS organisations, like NCD organisations struggle with the lack of funding. While the large HIV and AIDS organisations have to cut down their activities, the smaller ones struggle to the extent of not having funds to run their daily operations and to pay staff and volunteers. Small HIV and AIDS organisations have had to shift from doing work in communities to working among corporates and charging them for the training on HIV and AIDS. With the little funding available the activities have also had to be cut down to be able to work within the available budgets.

Although the large HIV and AIDS organisations on principle do not accept funding from the South African government or the American government and its agencies the small organisations are not choosy. Due to lack of funding the small organisations accept the available funding regardless of the source. Small HIV and AIDS organisations apply for funding from the lottery and from the provincial government.

### **3.4.3 Comparison of NCD and HIV and AIDS organisations in accessing funding**

Findings from the financing of activities across organisations dealing with HIV and AIDS and those dealing with NCDs point to some interesting differences. Although both types of organisations tend to rely on donor funding, it appears that organisations involved in activism against NCDs appear to be involved in activities that bring them funds which are able to sustain their basic operations. On the other hand, organisations dealing with HIV and AIDS seem to rely on donor funding for all their activities. In cases where they make attempts to raise their own funds, accruing revenue is too little to even sustain their basic operations. The NCD organisations appear to all be locally funded except for the one that also deals with HIV and AIDS. However the HIV and AIDS organisations receive most of their funds from external donors although there are those that also receive local funding from the lottery and provincial departments.

Both among the NCD and HIV and AIDS organisations, lack of funding is a key theme and this influences the activities that the organisations can implement. For NCD organisations,

the donors often dictate how the funding must be used. However it appears that the HIV and AIDS organisations have the leeway of how to use the funding as long as they can account for the expenditure. Thus a lot of funds among the HIV and AIDS organisations are allocated to prevention, advocacy, and awareness campaigns.

The target of NCD organisations is all groups of people in order to ensure that NCD related illnesses are reduced. The result is that the NCD organisations attract both the rich and poor, those with and without medical aid. Those with medical aid are referred to specialists dealing with their condition. Those without medical aid are referred to public health facilities to access treatment. Where treatment is not available, some NCD organisations intervene to ensure that their members can access gain access to specialist treatment at little or no cost. Thus where lack of funding is an issue, NCD organisations have found innovative ways of addressing the funding challenge through cross subsidization. The lack of funding for NCD and HIV organisations implies that they have to cut down on their activities and sometimes and sometimes the very small organisations, particularly those based in rural areas have to shut down. One of the organization noted that many of their members belonging to small organizations had shut down their organisations due to lack of funding. While NCD organisations might screen individuals and advise them where to get treatment, the HIV and AIDS organisations' activism is directed at ensuring the health system works in order to delivery comprehensive care for people living with HIV and AIDS because that is what their funding is able to do.

Whereas the NCD organisations might refer individuals with a specific condition to the private sector for management of their condition, the HIV and AIDS activism refer members to the public health sector for treatment and care. The focus of the HIV and AIDS organisations has been on ensuring that PLWHA can access treatment in the public health sector as healthcare is a basic human right. Given that HIV and AIDS is a pandemic, the masses that are largely without medical aid cannot rely on the provision of care by the private healthcare system.

Before the government started providing treatment in public health facilities, the HIV and AIDS activists also used funding to access generic drugs produced outside South Africa. The HIV and AIDS organisations' activism is targeted towards prevention as much as it is targeted at ensuring that medicines are available in the public sector.

While both types of organisations attract donor funding, the organisations dealing with HIV and AIDS seem to attract funding from a range of international sources to the extent that they can even choose who funds them. Both organisations dealing with NCDs and HIV and AIDS appear to attract local funding but both types of organisations agree that such funding is highly inadequate for their activities. That is the reason that both types of organisations go out of their way to get involved in fundraising.

In discussing the funding issue a major concern cited across the different organisations is that funding is never sufficient for the activities. Another concern about funding also related to the healthcare system where the funding for healthcare is grossly unequal. A small percentage of the population has access to world-class healthcare whereas the masses have access to poor and inadequately resourced services. A participant noted that the healthcare system is unacceptable and needs restructuring.

The funders also have a huge influence on how funding is spent and some of them specify what it can be spent on and so in accounting for the funds the organisations have to give very accurate reports. However the influence of the funders greatly constraints the other activities of the organisations. If for example a donor puts the conditionality that funds can only be spent on testing kits, then the organisations' activities in preventative work remain poorly resourced. A participant noted,

If you send your proposal, you already have in mind what it is you want to do. So if they say yes, you just take the money and don't ask questions (KII\_3).

A key challenge to accessing funding and which is affecting mainly NCDs relates to Black Economic Empowerment (BEE) legislation. As participants explained, funding of organisations will now be linked to BEE criteria. That means that the funder has to ascertain that the majority of beneficiaries in the organisations funded are black. If not then the BEE rating of the funder is affected. At least three organisations dealing with NCDs were against the use of such criteria as it would greatly affect their funding. The sustainability of funding was also cited as a challenge:

...funding is always an issue. Sustainability is a problem and it is usually linked to a champion...To be able to sustain there are a number of issues... so you got to pay attention to that and be creative about how we can ensure our strategies are transformed into reality. So particularly at the moment... particularly with this economic climate where there are funding constraints all around...it is getting harder- that is the one thing (KII\_7).

The response to the question about funding elicited laughter from one participant who sarcastically and rhetorically asked, “Can I laugh now or later?” (KII\_8). The participant proceeded to explain that, “You, know, we are struggling. Unfortunately our services will be delayed because we need money and I think it is applicable to all NGOs. We have member organisations that are being forced to close down because of funding” (KII\_8).

The issue of inadequate funding was common across the organisations sampled for this study. Another participant reported that,

Well, you can never have adequate funding especially in this economic climate so we are struggling like other organisations. We had to cut our budget this year (2013) from R42 million to R25 million and this has implications on the services we provide and the campaigns we take up. We can’t take up more than what we can do because of capacity (KII\_10).

It is notable that while some organisations were willing to take funds from donors who accepted their proposals, some organisations, particularly the HIV/AIDS organisations were more cautious. A participant noted that,

But what I want to highlight in the issue of funding is that even though we are struggling we still do not take money from the United States of America... that is PEPFAR, USAID- we don’t take money from them as a matter of principle and we also don’t take money from pharmaceutical companies. So even though we are still struggling we still want to retain our independence (KII\_10).

What emerges from the discussion of funding is that both beneficiaries of funding and the funding donors also play their own level of politics. Both organisations dealing with NCDs and HIV and AIDS are willing to make adjustments in order to access funding for their programmes. For organisations dealing with NCDs, they will write a proposal and if the donor gives money for specific programmes they will take the funding. In the case of HIV/AIDs, when donor organisations have funding not directly related to their programmes, they are willing to shift ground in order to access the funding. For example one HIV and AIDS organization confirmed that when funds are available for campaigns against women abuse, the organization applies for it.

It is however notable that HIV and AIDS organisations have in fact set their standards in terms of which agencies can finance them and which ones they would like to keep away. What is not clear is the criteria for determining who to accept or reject as a funder. In the

case of organisations dealing with NCDs, it appears all funding is welcome even when certain conditionalities are attached. The funders for HIV and AIDS organisations are diverse; they are both local (Department of Health, Gauteng Province, Lotto). Other funders are international such as – Global Women’s Fund, African Women’s Development Fund in Ghana, Bill and Melinda Gates Foundation, Atlantic Philanthropy.

Some of the organisations have had to question the funding criteria of some donors. An example is that of an HIV/AIDS organization:

but we stopped asking money from Lotto... because there were lots of problems; that is why even last year we had to march to Lotto offices because they would rather pay that money for that Youth Conference than for good work (KII\_9).

The lack of financing has a direct impact on the activities of organisations dealing with HIV and AIDS and also those dealing with NCDs as reported:

it really cripples the administration; it cripples the work that is supposed to be done like for instance if we were to do door-to-door... we would do it for 16 days ...[but] now we choose 4 days... we are having to cut down the phone, everything... how you do things but you’re not sure if you’re going to sustain yourself in the coming future. You could want to train and charge for training but who is going to afford... (KII\_9).

### **3.5 Summary**

This study set out to compare the strategies used by civil society organisations dealing with NCDs and HIV and AIDS in accessing health care in South Africa. The study has shown that a range of strategies are used by both NCD and HIV and AIDS type of organisations. Similarities abound in terms of the strategies used as well as the extent to which the common strategies are used. Both NCD and HIV and AIDS organisations use the media, public education, advocacy, partnerships as well as policies to ensure access to healthcare for their constituencies. What is however different is how these strategies are used. While NCD organisations might use public education campaigns to create awareness around a particular condition and leave it to the target groups to apply the knowledge, the HIV and AIDS organisations monitor how their members use the information. HIV and AIDS activists follow up to check whether the rights of PWLAs are violated and are also empowered to report violations of their rights. HIV and AIDS organisations appear not only to teach about prevention but also how to manage the HIV and AIDS, treatment and how to engage the healthcare providers to ensure maximum benefit. The strategy of engaging

healthcare providers as a result of community education does not seem to be a strategy applied by the NCD organisations

Whereas the NCD organisations use different strategies independent of one another, the HIV and AIDS organisations use a systematic approach. The HIV activists begin by using passive strategies such as engagement and when all else fails they resort to the more radical activist strategies such as civil disobedience and public demonstrations. Given that HIV and AIDS issues are a matter of life and death, the activists reported the use of concurrent radical strategies. For example a demonstration might be going on while the lawyers are busy with litigation either against government or the pharmaceuticals.

Both NCD and HIV and AIDS organisations reported that funding is a major issue that influences their activist strategies. The NCD organisations largely depend on local funding sources whereas the HIV and AIDS organisations depend on external donor funding. What is common is that the lack of funding seriously impacts on the operations of both types of organisations in terms of their operations and the scope of their activities. It is evident that most NCD organisations seem to be struggling for funding such that they are willing to accept the conditionalities attached to their funding. NCD organisations also accept the funding donated to them as often they operate on shoe-string budgets. However the HIV and AIDS organisations seem to have some level of leeway to determine how funding is used. Although some HIV and AIDS organisations can choose whose funds they are willing to accept, the NCD organisations do not seem to have such luxury. For the NCDs, funding is always short and when it is made available the organisations are willing to comply with the conditionalities. Not all HIV and AIDS organisations have the luxury of being able to choose their funders. Some of the HIV and AIDS organisations, just like the NCD organisations, are willing to accept the available funding and comply with the conditionalities because their very existence depends on the funding.

Both NCD and HIV and AIDS organisations are involved in a range of partnerships. For the NCD organisations the focus is on preventing the increase of NCDs in the general population that does not suffer from the NCDs. The public education programmes focus on prevention messages but a few organisations also disseminate information on what should be done once an individual has an NCD. The NCD activists on assessing individuals can either refer them to the private or public health facilities, depending on whether the individual has medical aid. The focus of HIV and AIDS is on prevention too but also on ensuring that treatment is readily available in the public sector for the general population.



Given the pandemic proportions of HIV prevalence, the HIV and AIDS activists focus on ensuring that the public health sector can provide comprehensive care for PLWAs.

The partnerships that the NCD organisations forge are both in the private and public sectors. Most the partnerships that HIV and AIDS organisations forge are largely in the public sector. Where the HIV and AIDS activists forge partnerships with the private sector, these are short-term and for specific purposes such as the provision of education on HIV and AIDS and the medicines available to treat the various conditions arising from the disease.

Both NCD and HIV and AIDS organisations have had their measure of success in using their various strategies for accessing health care. The measure of success and effectiveness was largely described in terms of the number of people that have benefitted from the programmes of the different type of organisations. For some NCD organisations about 5.9 million people have been reached by the advocacy message; children had been able to speak to power about their needs and rights and messages about cardiovascular diseases had been disseminated through multi-media advertising of specific brands of food in the market. The greatest success of the HIV and AIDS organisations lay in the fact that the government yielded and provided medicines for the PMCT; Litigation had forced pharmaceutical multi-nationals had yielded to the call for the production of generic drugs to save lives in the context of the HIV and AIDS epidemic; and government had succumbed to pressure to provide comprehensive care to people living with HIV and AIDS.

In terms of policy and practice, both NCD organisations had been able to influence national policies on NCDs and HIV and AIDS. This was done through inputs to policies aimed at addressing the growing NCD crisis. HIV and AIDS organisations had also influenced government policy to allow the provision of drugs for PMCT, and the comprehensive care for people living with HIV and AIDS. While it is not clear what influence NCD organisations have had on policy internationally, HIV and AIDS organisations through addressing the daily challenges of their members were able to convince the multi-lateral and bilateral agencies to take a multi-sectoral approach to tackling the HIV and AIDS epidemic. Thus it is not uncommon for HIV and AIDS donors to also provide funding for domestic violence.

This study argues that the difference in the strategies used by NCD and HIV and AIDS organisations and how the strategies are applied, accounts for the differences in outcomes. Thus HIV and AIDS organisations might appear to be more successful yet the strategies to access care are similar to those used by the NCD organisations. The difference lies in how

the strategies are used, the level of funding available and the level of flexibility that organisations are allowed in helping increase access to healthcare for their target groups.

## **CHAPTER 4      COMPARATIVE                      ANALYSIS                      AND RECOMMENDATIONS**

### **4.1      Introduction**

The previous chapter has reported the findings from the study of various CSOs. The findings suggest that civil society organisations use a range of strategies to help members access healthcare. What emerges is that both HIV and AIDS organisations use the same strategies as the CSOs that deal with NCDs. Findings suggest that the funding of HIV and AIDS organisations appears much less than that received by the CSOs that deal with NCDs. What is however clear is that organisations that deal with HIV and AIDS have contributed much to ensuring comprehensive care and treatment for people living with HIV and AIDS. Although organisations that focus on NCDs also have huge budgets and activities, their impact cannot be compared to that of HIV and AIDS organisations. HIV and AIDS organisations succeeded in making the condition a political issue, about equity and about justice. NCD organisations have taken a different approach. Organisations such as CANSA, Heart and Stroke Foundation, SADAG Phango use evidence to deal with NCDs but they have not politicised these as much as HIV and AIDS was politicised through litigation, demonstrations and confrontation with government and multinationals. The National department through the National Strategic framework for NCDs has devised a plan to deal with NCDs, their risk factors, prevention, and control.

### **4.2      Summary of research findings**

#### **Addressing the challenges of using the various strategies**

The challenges that NCD organisations face in using the various strategies suggest that the lack of funding is a key constraint to achieving the objectives of creating awareness, preventing the increase in NCDs and in managing the NCDs. Lack of funding affects all the organisations dealing with NCDs regardless of size. Funding impacts on the range of activities, the extent to which these activities can reach and the size of staff they employ to carry out their activities. The struggle to retain qualified staff to deal with mental issues has meant that organisations have a high turnover of staff. The qualified professions that join some of the NCD organisations simply join to get the experience and then after a short period, they move on to better paying jobs. Some NCD organisations have found innovative ways to deal with the shortage of qualified professionals. One of the organisations drew their staff from university students that needed internships and in that way were able to

provide the much needed services to deal with mental health issues. Another strategy for addressing the challenges was to partner with professional practitioners. The deal struck was for the organization to refer clients with medical aid to the private practitioners and in return these professionals then provided their services pro bono to the organization. Such innovative partnerships were helping to provide highly specialized services to marginal groups at no cost.

Organisations have also had to find innovative ways of raising funds in an economic climate where funding to non-governmental organisations is steadily declining. Mental health organisations have entered partnerships with corporates. In such partnership the NCD organization manages the telephone lines, deals with corporate staff mental health issues in return for a monthly fee. Given that corporates seek the involvement of NCD organisations to address staff wellness issues, the NCD organisations now charge a fee instead of providing their services for free.

Some NCD organisations note that given their detailed input into bills and issues affecting their members sometimes such organisations are not invited to meetings with the relevant departments. Such organisations then have to find out when workshops relevant to their constituencies are happening and contribute their input. The idea of writing letters, petitions and making contributions to bills represents the attempts by NCDs to get their voices heard even when it appears that these voices are not welcome.

### ***Partnerships***

Partnerships are cited as one of the strategies that civil society activists use to ensure access to health care in general. However a range of partnerships had specific objectives:

- Raising funds for the civil society organisation
- Creating awareness about a specific health condition
- Conducting research into a specific condition
- Influencing policy regarding NCDs
- Ensuring compliance with the constitutional provisions for access
- Ensuring access to healthcare services
- Providing education regarding specific health conditions (Pharmaceuticals with HIV and AIDS organisations)
- It is evident that partnerships have been formed between civil society organisations and stakeholders in a range of sectors. These include:

- The law enforcement authorities (SAPS)
- Government departments
- The private sector (corporates)
- Other non-profit organisations
- Communities
- Funders – bilateral and multilateral donors
- Foundations (Bill and Melinda Gates)
- Lottery

While most of the partners might appear to be funders, the partnerships are often more complex. The partnership with communities suggests that the civil society organisations have an avenue for carrying out their work in a receptive environment. The partnership with the government department works both ways. Civil society organisations are able to use government health awareness campaigns to create awareness about a specific health condition such as cancer. This implies that the activist organization benefits financially from the awareness campaigns funded by the government. On the other hand when government, has to formulate policies and pass these, then civil society organisations are available to contribute to the content of the policies as well as form the critical mass that is often required to pass such legislation. Partnerships with the communities work both ways. The activist organisations are able to access communities without any threat of intimidation as they have the support of the communities. On the other hand the communities benefit from the information provided in terms of being able to access specific healthcare services.

### ***Partnerships of NCD organisations***

The partnerships forged between NCD organisations and stakeholders suggest that these partnerships broadly focus on certain elements:

- Provide avenues for creating awareness about NCDs
- Ensure access to healthcare services for individuals with a specific condition
- Ensure awareness is created about a specific NCD
- Provide the avenue for NCD organisations to influence policy to help reduce prevalence of NCDs
- Ensure that marginal groups are reached with information about specific NCDs
- Create a strong lobby in the reduction and prevention of NCDs

### ***Partnerships of HIV and AIDS organisations***

- Provide funding for the organisations
- Ensure that HIV and AIDS organisations can explore a range of strategies before selecting the most effective
- Ensure that the availability of drugs, treatment and access to healthcare is monitored by its partners at the grassroots level
- Ensure that members are aware of the drugs available in the market for HIV and AIDS conditions
- Enable HIV and AIDS organisations access free training about medicines and how to manage the condition
- Provide education to members about health rights and what to do when these are violated
- Ensure that where litigation is required to enforce constitutional rights, the HIV and AIDS organisations are well represented
- Partnerships ensure that the rights of members are protected
- Partnerships with doctors organisations are useful in influencing policy and practice on HIV and AIDS
- Provide social support, networks and hope to PLWA
- Creation of a strong lobby in the prevention and treatment of HIV and AIDS

For both organisations dealing with NCDs and those dealing with HIV and AIDS, it appears that the most effective partnerships are those that result in a sustained flow of income. However the effectiveness of partnerships forged by organisations dealing with HIV and AIDS go beyond access to sustained funding to providing support to people living with and affected by HIV and AIDS. For HIV and AIDS organisations, partnerships at the most basic level has provided PLWA with social networks, support and hope.

## **4.3 Recommendations**

South Africa is faced with a double burden of disease from both communicable and non-communicable diseases. While communicable diseases account for the highest rates of mortality non-communicable diseases have also been on the rise and have gone unchecked for some time and have only recently (2011) attracted the attention of the nation and international community. In comparing civil society activism among HIV and AIDS organisations with activism among NCD civil society organisations, it becomes clear that their strategies are similar. Both HIV and AIDS CSOs and NCD CSOs use the media, public education, lobbying through their strategic partnerships, advocacy and bottom up

strategies. Lobbying is a key strategy of both NCD and HIV and AIDS CSOs and this has resulted in a range of policies addressing both types of illnesses. Lobbying is the furthest that NCD CSOs appear to get to. When lobbying has failed to yield the desired results, HIV and AIDS organisations have gone further to use public demonstrations as a way of getting the general public and the government in particular to pay attention to critical issues of concern such as access to treatment and relevant medicines for the management of HIV and AIDS. In Demonstrations, HIV and AIDS have been cast as human rights issues which government has to address. HIV and AIDS CSOs have also cast their concerns as issues around equity. Given that human rights and equity are the bedrocks of the South African constitution, the demonstrations have often put government and critical stakeholders in a complex position where the only option was to work with the HIV and AIDS CSOs to address the concerns. From the literature and documentation reviewed, NCDs have not been cast as human rights concerns nor issues that relate to equity. Often NCDs are cast as lifestyle related hence apportioning blame on the victims. Human rights and equity concerns remain the missing elements in NCD CSO activism.

For some constituencies such as government and pharmaceuticals, public demonstrations do not always yield the intended result. HIV and AIDS organisations have proceeded to use litigation against government and pharmaceuticals in a bid to access relevant medicines and comprehensive care. The strategies of public demonstration and litigation have yielded more for HIV and AIDS CSOs than other strategies could have. On the other hand, few if any NCD CSOs have resorted to litigation in a bid to draw attention to critical issues. Organisations such as CANSA and DSA seem to rely on research evidence and lobbying to draw attention to concerns around NCDs such as cancer, cardiovascular diabetes and mental illness. Such strategies are useful but have not generated as much public debate and action as HIV and AIDS organisations.

In comparing civil society activism for HIV and AIDS and that of NCD organisations, it is evident that the purpose of both types of organisations is to improve access to healthcare. For HIV and AIDS organizations, the purpose has been to improve access to comprehensive care. Like NCD organizations, the purpose of the HIV and AIDS organisations has also been to ensure support for individuals and families affected by HIV and AIDS organizations. The impact of activism by HIV and AIDS organisations has been greater awareness of HIV/AIDS, public action to control the pandemic and support for the prevention efforts. HIV and AIDS organisations also succeeded in highlighting the plight of the affected and mobilised support for families and AIDS orphans.

Given the amount of funding, available to NCD organizations compared to HIV/AIDs organisation, the research, and partnerships of both types of NGO there is not much difference between the strategies. What is missing in NCD organisations are strategies like civil disobedience, public demonstrations and litigation.

This study suggests that the comparative research methodology (CRM) is a useful approach in understanding the effectiveness of civil society activism in understanding and facilitating greater access healthcare in South Africa. The CRM is also useful approach is helping to distinguish between what strategies work with what effect. What the CRM is however not able to do is to unravel the planning that goes into the strategies employed by the different civil society organisations in seeking greater access to healthcare. What the CRM is also unable to do is to measure current impact of each strategy used by the different civil society organisations. As a result, the impact and effectiveness of civil society activism can then not be attributed to a specific strategy rather to a range of strategies. As shown by the HIV and AIDS organisations the gains from activism were derived from the accumulation of a range of strategies.



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# APPENDIX 1: Key Informant Interview Guide

## Civil Society Activism in Accessing Healthcare in South Africa -- Key Informant Interview Guide

August 2012

Good (morning/afternoon/evening), I'm \_\_\_\_\_ and we are conducting a study for the Human Sciences Research Council (HSRC). The HSRC regularly conducts studies amongst the South African population. Topics include a wide range of social issues. Today we would like to ask you some questions that help us understand civil society activism in accessing healthcare in South Africa.

To obtain reliable, information we request that you answer the questions that follow as **frankly** as possible. Your views are important in this research. There are no right or wrong answers. It is your opinion that counts. You have been selected because of your knowledge in civil society activism for healthcare in South Africa. The information you give to us will be kept confidential. You will not be identified by name or address in any of the reports we plan to write.

### PARTICULARS OF INTERVIEW

	DAY	MONTH	TIME STARTED		TIME COMPLETED		**RESPONSE
			HR	MIN	HR	MIN	
First visit	/ / 2012						

### STRICTLY CONFIDENTIAL

Name of Interviewer .....

Number of interviewer


Checked by

Signature of supervisor \_\_\_\_\_

Date\_\_\_\_\_

## **Civil Society Activism for Healthcare in South Africa**

### **Key informant Interview Guide**

1. Type of organisation
  - a. Date of establishment
  - b. Vision
  - c. Mission
  - d. Objectives
2. Location
  - a. Headquarters
  - b. Branches
  - c. Size of organization in terms of
    - i. Number of staff
    - ii. Size of board
    - iii. Membership
3. Formation of organisation
  - a. How did your organisation come to be?
  - b. What were the concerns when it was first formed
  - c. To what extent do the original intentions of the organisation still inform its current activities
  - d. What about your organisation has changed in terms of its mission and focus areas
  - e. What about your organisation's mandate has remained the same and why?
4. Strategies used in accessing healthcare
  - a. What strategies has the organisation used over the years to draw attention to the specific healthcare issues that the organisation focuses on
  - b. Why did your organisation choose to use the strategies cited?
  - c. What effect have these strategies had in increasing access to improved healthcare of people living with the specific condition?
  - d. Among the strategies your organisation has used which have been the most effective and why?

- e. What have been the challenges faced in using the various strategies in ensuring greater access to healthcare for members?
  - f. How has your organisation dealt with the challenges?
- 5. To what extent has your organisation succeeded making the specific health condition an issue of concern in South Africa
- 6. Partnerships
  - a. What partnerships does your organisation have with grassroots organisations to ensure awareness about this health condition?
  - b. Which of the partnerships cited have been the most effective and why
- 7. What has been the response of the following towards awareness about the health condition that your organisation seeks to address:
  - a. Government
  - b. Private sector
  - c. Communities
  - d. Individuals at risk of getting the condition
  - e. Other
- 8. Given the current discussion on civil society activism for access to healthcare, what do you see as the future role of your organisation in this arena?
  - a. How adequate is the funding of the activities that your organisation is involved in?
  - b. How does your organisation finance its activities?
  - c. In what ways does the financing influence the organisation's activities?
- 9. If there are any other issues relating to civil society activism in accessing healthcare in South Africa, this is the opportunity to do so.