

**THE GENESIS AND PROGRESSION OF THE HIV/AIDS
PROGRAMME IN KWAZULU-NATAL: IMPLICATIONS FOR
LEARNING AND INTENSIFIED ACTION**

**SUBMITTED IN FULFILMENT OF THE REQUIREMENT
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY
(NURSING)**

BY

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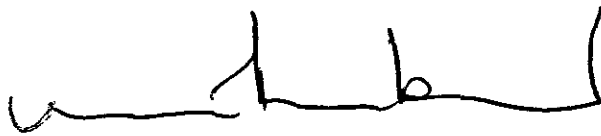
TO

**The Department of Nursing Science: University of
Zululand (Durban-Umlazi Campus).**

**SUPERVISOR: PROF D NZIMAKWE
JANUARY 2005**

DECLARATION

I hereby declare that the study of the “Genesis and Progression of the HIV/AIDS Programme in KwaZulu-Natal: Implications for learning and intensified action” is my own work and that all the sources of information have been indicated and acknowledged.



07/04/2005

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W.M.N. MTHEMBU

DURBAN

JANUARY 2005

DEDICATION

This work is dedicated to my late mother, Inah, my late father, Albert and my late uncle, Reuben, who all attached importance to education and instilled this in me; my sister-in-law Rose Mngadi who unexpectedly died at the time of finalizing this document; my sister Nomusa and family; my brother Dumisani and family, my dear husband Mvi; my children Ntokozo, Mpume, Nkule and Nazo (wife to Ntokozo); my special daughters Khethiwe and Dudu; one of my sons S'fiso, who unexpectedly died at the finishing touches of this report; my dear granddaughters Ntetho; Sane; Ziyanda and little Sisanda.

I further dedicate this work to all those who are infected and affected by HIV/AIDS; those presently experiencing the bitter pangs of pain because of HIV/AIDS as well as those who are no more in this world because of AIDS.

Lastly, this work is dedicated to all the warriors against HIV and AIDS in KwaZulu-Natal and beyond.

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ABSTRACT

This study explored the origin and progression of the HIV/AIDS programme in KwaZulu-Natal from inception to December 2003. Its objectives were to trace the origin of the HIV/AIDS programme in KwaZulu-Natal, identify the HIV/AIDS activities and the organizations that implemented them, identify the support system for the programme, highlight the challenges that have been faced and the lessons learnt during the implementation of the programme and lastly, determine the extent to which the participation of NGO/CBOs in the HIV/AIDS programme grew over the years.

A qualitative research design with a focus on the historical method was used. The identified sources of data were primarily the written records (archival and current) and to a narrow extent, human subjects from a population of HIV/AIDS managers. Purposive sampling strategy was applied in the selection of key informants and the services that would be visited for data collection. A questionnaire and a checklist were used as instruments for data collection.

The study revealed that the HIV/AIDS programme in KwaZulu-Natal originated in 1985 when the then Natal Blood Transfusion Service started testing the donated blood

for HIV; HIV/AIDS activities fell under the broad categories of “Prevention” and “Care”; the support system for the HIV/AIDS programme comprised human resource, human resource development, research, policies, plan, committees/ forums/ groups/ councils, political backing and/or support by high profile individuals as well as partnerships; the challenges of the pre-1994 General Democratic Elections (GDE) period were centred around the legal and ethical aspects of HIV/AIDS, followed by political violence, while those of the post-1994 GDE period were predominantly logistical followed by an increase in the number of people who need care; the lessons learnt by the service providers were more on the legal and ethical aspects of HIV/AIDS and the participation of NGO/CBOs in the HIV/AIDS programme grew over the years with 2000 - 2002 as the peak period. In addition, data on HIV/AIDS programme activities obtained from the records indicated that two HIV/AIDS epidemic campaigns have been held in KwaZulu-Natal (Pre-1994 and Post-1994), each with its own combatants and most combatants of the first campaign having disappeared.

The following recommendations were made based on the findings of the study and literature review:

- That the Provincial AIDS Action Unit identifies and invites the combatants of the pre-1994 HIV/AIDS campaign who are not currently in the HIV/AIDS programme to come on board and share ideas with those who are still battling to attain victory over HIV/AIDS;
- That the Provincial AIDS Action Unit facilitates the provision of more trained Care Givers to address an increase in the number of people who need care and concomitant shortage of staff;

- That the Provincial AIDS Action Unit (PAAU) fully adopts and intensifies an HIV/AIDS control strategy whereby males as dominant partners in sexual relationships are encouraged to take a lead in the fight against HIV/AIDS;
- That the Provincial AIDS Action Unit and the Department of Health steps up the funding of the NGO/CBO/FBOs committed to implementing HIV/AIDS activities, provide training in basic project management, consistently mentor the funded organizations and ensure that all the funded projects are appropriately monitored and evaluated;
- That the PAAU liaises with the Environmental Health Service to ensure that the project of “high transmission areas” include safety practices at barber shops, ear-piercing as well as tattooing shops;
- That the HIV/AIDS trainers stress the need for family members to be around their loved one when he/she faces death so as to facilitate a “good death”; if this is impossible, Health Workers (HWs) endeavour to intensify the filling of this gap;
- That the Department of Health (DOH) and PAAU consider the payment of stipends to all unemployed volunteers in the HIV/AIDS programme, ensuring equity in the amounts of stipends received.
- That the PAAU ensures regular communication with blood transfusion services with a view to getting an update on the statistics and blood safety practices.
- That all Health Workers administering injections, intravenous therapy etc. assure patients of safety from contracting HIV in the process by showing the sealed sterile materials to a relevant patient/client or relative prior to using them.

- That the PAAU identifies and invites the Pre-1994 HIV/AIDS warriors to come on board and share ideas with those who are still battling to attain victory over HIV/AIDS.

- That the government, committed organizations and individuals intensify socio-economic development initiatives with a view to addressing poverty as one of the challenges identified by the HIV/AIDS role players.

- That the PAAU facilitates the undertaking of research on the HIV/AIDS discriminatory practices in the public, private and business sector.

OPSOMMING

Hierdie studie het ondersoek ingestel na die oorsprong en progressie van die MIV/VIGS program in KwaZulu-Natal vanaf die instellingsdatum tot Desember 2003. Die doelwit was om die oorsprong van die MIV/VIGS program in KwaZulu-Natal na te speur, die MIV/VIGS aktiwiteite en die organisasies wat die geïmplementeer het, te identifiseer, die ondersteuningstelsel vir die program te bespreek, die uitdagings wat gestel is en die ervaring wat opgedoen is tydens die implemetering van die program, toe te lig en laastens om vas te stel in watter mate deelname deur nie-regeringsorganisasies (NRO) en gemeenskapsbaseerde organisasies (GBO) oor die jare toegeneem het.

'n Kwalitatiewe ondersoek met die fokus op die historiese metode is onderneem. Die geïdentifiseerde databronne was hoofsaaklik geskrewe rekords (argiewe en kontemporêr) en tot 'n kleiner mate, respondente uit 'n groep MIV/VIGS bestuurders. Doelgerigte toetsstrategie is toegepas by die seleksie van sleutelinformate en die dienste wat besoek sou word vir data-insameling. 'n Vraelys en kontrolelys is gebruik as instrumente vir data-insameling.

Die studie het aan die lig beging dat die MIV/VIGS program in KwaZulu-Natal in 1985 'n aanvang geneem het toe die destydse Natalse Bloedoortrappingsdienste begin het met die toetsing van geskenkte bloed vir MIV; MIV/VIGS aktiwiteite het onder

die breë kategorie van “Voorkoming” en “Sorg” geressorteer; die ondersteuningstelsel vir die MIV/VIGS programme het bestaan uit menslike hulpbronne, ontwikkeling van menslike hulpbronne, navorsing, beleid, beplanning, komitees/forums/groepe/rade, politieke steun en/of ondersteuning deur hoë profile individue asook vennootskappe; uitdagings van die tydperk voor die 1994 Algemene Demokratiese Verkiesing (ADV) het rondom die wetlike en etiese aspekte van MIV/VIGS gesentreer, gevolg deur politieke onrus, terwyl dit na die 1994 Algemene Demokratiese Verkiesing hoofsaaklik logisties van aard was gevolg deur ‘n toename in die aantal mense wat sorg nodig gehad het; die lesse wat deur die diensvoorsieners geleer is was meer gerig op die wetlike en etiese aspekte van MIV/VIGS en die NRO/GBOs se deelname aan die MIV/VIGS programme het toegeneem tydens die spits tydperk 2000 – 2002.

Data oor die MIV/VIGS program wat van die records verkry is, dui daarop dat die veldtog teen die MIV/VIGS epidemie in KwaZulu-Natal (voor-1994 en na-1994) op twee fronte gevoer is, elk met sy eie deelnemers, en dat die meeste deelnemers aan die eerste veldtog nie langer op die toneel is nie.

Gebaseer op die bevindinge van die ondersoek en die literatuurstudie is die volgende aanbevelings gemaak:

- Dat die deelnemers aan die voor-1994 HIV/VIGS veldtog geïdentifiseer word en aangemoedig word om aan die huidige veldtog deel te neem en idees uit te ruil met diegene wat steeds ‘n stryd voer teen MIV/VIGS.
- Dat die Provinsiale VIGS Aksie eenheid en die Departement van Gesondheid fasiliteer die voorsiening van meer opgeleide versorgers

om die stygende aantal mense wat sorg nodig het en die tekort aan opgeleide versorgers te bedien.

- Dat die Provinsiale VIGS Aksie-eenheid (PVAE) 'n MIV/VIGS beheerstrategie aanvaar en intensifiseer deel, middel waarvan mans as dominante metgeselle in seksuele verhoudings aangemoedig word om die leiding te neem in stryd teen VIGS.
- Dat die Provinsiale Vigs Aksie-eenheid en die Departement van Gesondheid die bevonding van alle NRO/GBO's wat betrek is by die implimenting van MIV/VIGS aktiwiteite, versnel, opleiding in basiese projekte bestuur voorsien, opgereelde basis optree as mentor vir die bevondse organisasies en verseker dat al die bevondse projekte toepaslik gemonitor en geëvalueer word
- Dat die Provinsiale VIGS Aksie-eenheid (PVAE) 'n MIV/VIGS beheerstrategie aanvaar en intensifiseer deur middel waarvan mans as dominante metgeselle in seksuele verhoudings aangemoedig word om die leiding te neem in die stryd teen VIGS;
- Dat die PVAE op gereelde basis met die Omgewingsgesondheidsdienste skakel om te verseker dat die projek vir "hoë transmissie-areas" behoorlike veiligheidspraktyke instel vir haarkappers en salonne wat spesialiseer in die maak van gaatjies in ore en die aanbring van tatoeërmerke;
- Dat die MIV/VIGS opleiers die noodsaaklikheid beklemtoon vir familieledes om by hulle geliefdes te wees wanneer hy/sy dood in die gesig staar sodat die persoon "n goeie dood" kan sterf; indien dit nie

moontlik is nie, dat die Gesondheidswerkers poog om hierdie gaping te vul.

- Dat die Department van Gesondheid en die PVAE oorweging verleen aan die betaling van 'n toelaag aan alle werklose vrywilligers aan die MIV/VIGS programme, en dat betaling van die toelaes op regverdige wyse geskied.
- Dat alle PVAE toesien dat daar gereelde skakeling is met die bloedoortappingsdienste ten einde op hoogte te bly met statistieke en bloedbeveiligingspraktyke.
- Dat alle Gesondheidswerkers wat inspuitings of binne-aarse terapie toedien, toesien dat pasiënte beveilig is teen blootstelling aan MIV/VIGS tydens die proses deur die verseelde steriele material aan die pasiënt/kliënt te wys voordat dit gebruik word.
- Dat die regering, organisasies en individuele sosio-ekonomiese ontwikkeling initiatiewe versterk in die lig daarvan om armoede as een van die uitdagings te identifiseer by MIV/VIGS rolspelers.
- Dat die PVAE navorsing oor diskriminasie ten opsigte van MIV/VIGS in die openbare, private en besigheidsektore fasiliteer.

UMBIKO OFINGQIWE

Lolucwaningo lubheka ukuphenjwa nokuqhubeka kohlelo lokulwa neSandulelangulazi/neNgculazi esifundazweni saKwaZulu-Natal kusukela luqalwa kuze kube nguZibandlela ka-2003. Inhloso kwakuwukufuna ukuthi lwaphenjwa nini lolu hlelo KwaZulu-Natal, yini eyenziwayo kulolu hlelo, futhi yenziwa ngobani, yiziphi izinto ezisekela ukuqhutshwa kohlelo, yiziphi izinselelo abaqhubi balolu hlelo ababhekana nazo futhi yikuphi abakufundayo ngesikhathi beqhuba lolu hlelo; ekugcineni, kwakuwukubheka izinga lokuthuthuleka kwezinhlangano kulolu hlelo unyaka nonyaka.

Kwasekusetshenziswa uhlobo lokucwaninga lomlandu, olugxila kakhulu kulokho okuqoshiwe. Imininingwane yacashunwa kakhulu kulokho okubhalwe phansi; mincane kakhulu eyaqoqwa ngqo kubaphathi bohlelo lokulwa neSandulelangulazi/neNgculazi. Ekukhetheni ukuthi ngubani ozovakashelwa kucelwe imininingwane, nokuthi yiziphi izukhungo ezizovakashelwa, kwasetshenziswa indlela evele iqonde ngqo lapho kwethenjwa ukuthi lungatholakala khona ulwazi olufunekayo. Mabili amathuluzi asetshenziselwa ukuqoqa imininingwane, ngelokubuza kanye nelokuhlola.

Ucwaningo luveze ngokuthe bha ukuthi uhlelo lokulwa neSandulelangulazi/neNgculazi KwaZulu-Natal lwaphembeka ngo-1985, lapho inhlangano yokuthekalisa ngegazi yaseNatal yaqala ukuhlola ukuthi likhona yini igciwane lengculazi egazini lalabo ababenikela ngegazi. Kwavela ukuthi uhlelo lokulwa nengculazi lwalunemi-

sebenzi engaphansi kwemikhakha emibili, owokuvikela nalowo wokunakekela; izinto ezisekela ukuqhutshwa kohlelo lokulwa nengculazi: yizisebenzi, ukuqeqeshwa kwezisebenzi, wocwaningo, yinqubomgomo, wukuba nohlelo lokuqhuba umsebenzi, yizinhlaka ezithile njengamakomidi amabhodi nokunye, wuxhaso lwabaholi bezombusazwe nolwabantu abahloniphekile emphakathini, kanye nokusebenza ngobambiswano; izinselelo ezazikhona ngaphambi kokhetho luka 1994 zazizinze kakhulu kulokho okuphathelene namalungelo azungeze ingculazi, kulandelwe wudlame lwezombusazwe, kanti ezazikhona emva kokhetho luka 1994 zazizinze ekwesweleni izinsizakusebenza (imali, izisebenzi nokunye), kulandele ukukhula kwesibalo sabantu abadinga ukunakekelwa. Okwafundwa yizisebenzi ngesikhathi ziqhuba lo msebenzi kwakugxile kulokho okuphathelene namalungelo azungeze ingculazi kanti ukubamba iqhaza kwezinhlangano ezizimele nezomphakathi kwakhula unyaka nonyaka, kwafika eqophelweni eliphezulu kusukela ku 2000 kuya ku 2002.

Ukwengeza kulokhu, imininingwane ngemisebenzi eyenziwayo ohlelweni lokulwa nengculazi yaveza isithombe semikhankaso emibili yokulwa nengculazi KwaZulu-Natal, lowo ongaphambi kokhetho luka 1994 nalowo ongemuva kokhetho luka 1994, lowo nalowo mkhankaso unezisebenzi zawo, iningi lezisebenzi zomkhankaso wokuqala sezasithela emkhankasweni wokulwa nengculazi.

Izincomo ezingezansi zenziwa zisuselwa elwazini olwatholakala kulolucwaningo kanye nasemibhalweni ngezinhlelo zengculazi emhlabeni jikelele:

- Ukuthi uphiko lokulwa nengculazi KwaZulu-Natal malufune ngandlela thile bese lumema labo ababesemkhankasweni wokulwa nengculazi ngaphambi

kuka 1994 ukuba beze ngaphambili babhunge nalabo abasalwa nanamhlanje bephokophele ukunqoba ingculazi, kumbe kungaqhamuka amasu angeziwe okulwa nalolubhubhane;

- Ukuthi uphiko lokulwa nengculazi kanye nomnyango wezempilo KwaZulu-Natal wenze ngcono isimo sokwabela imali izinhlango ezizinikele ekulweni nengculazi, uziqeqeshe ekuphatheni lo msebenzi qede ubelokhu uziqaphe ngeso lokusiza nokwesekela ngolwazi; ekugcineni uhlole ukuthi umsebenzi uhambe kanjani;
- Ukuthi uphiko lokulwa nengculazi KwaZulu-Natal malwamukele ngokugcwele futhi luqinise isu lokulwa nengculazi eliqindiswe ngqo kubantu besilisa, bagqugquzelwe ukuthi njengoba behola emakhaya kanye nakwezocansi, mabahole ngobuqotho emkhankasweni wokulwa nengculazi;
- Ukuthi uphiko lokulwa nengculazi maluxhumane nabahloli bezempilo ukuqiniseka ukuthi izindawo zokugunda, ukuchambusa nokuqopha izithombe nemibhalo emizimbeni zisebenzisa izindlela ezibaphephisyayo abantu ekutholeni igciwane lengculazi;
- Ukuthi abaqeqeshi emkhakheni wokulwa nengculazi mabagcizelele isidingo sokuthi amalungu emindeneni mawabe nalowo othandiweyo wawo ngesikhathi ebhekene nokufa, ukuze ashone enokuthula emphefumulweni; uma engekho, izisebenzi zezempilo mazizame ukusigcwalisa lesi sikhala;
- Ukuthi umnyango wezempilo nophiko lokulwa nengculazi KwaZulu-Natal usibhekisise isidingo sokukhokhela amavolontiya engculazi asuke engaqashiwe ndawo futhi ubhekisise nokuthi isitayiphende siyalingana naleso esikhishwa ezinye izinhlango endaweni;

- Ukuthi uphiko olulwa nengculazi KwaZulu-Natal malwenze isiqiniseko sokuthi kukhona ukuxhumana okuhlelekile phakathi kwalo nenhlangano ethekalisa ngegazi ukuze kwabelwane ngezibalo nezindlela zokuqinisa ukuphepha kwegazi;
- Ukuthi zonke izisebenzi zezempilo ezinikeza imijovo nokunye okungena emzimbeni ngale ndlela, mazinike isiguli isiqiniseko sokuthi siphephile ngokuthi zikhombise isiguli ubumsulwa balokho okusetshenziswayo ngaphambi kokuthi kusetshenziswe kuso;
- Ukuthi uHulumeni, izinhlangano kanye nabantu abazinikele baqinise amasu okuthuthukisa umphakathi ukuze kubhekanwe nenselelo yokwanda kobuphofu okubikwa yizinhlangano ezilwa nengculazi.
- Nokuthi uphiko lokulwa nengculazi KwaZulu-Natal lubhekele ukwenziwa kocwaningo ngokucwasa okuhlobene nengculazi emikhakheni ehlukeneyemisebenzi KwaZulu-Natal.

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CHAPTER 1

1.1 INTRODUCTION

This introductory chapter on the study of “the genesis and progression of the HIV/AIDS programme in KwaZulu–Natal: Implications for learning and intensified action” will cover the aspects background, the study problem, the purpose of the study, motivation of the researcher, objectives of the study, significance of the study, delimitation of the field of study, research design, definition of concepts and conclusion. It is aimed at introducing and orientating the reader to the entire study.

1.2 BACKGROUND

The KwaZulu–Natal (KZN) Province of South Africa has been very hard hit by the HIV/AIDS pandemic. The HIV prevalence amongst pregnant mothers attending ante-natal clinics at the Government’s health facilities in 2003 was 36.5% (Department of Health, 2004). It is estimated that by 2010 life expectancy at birth will be 35 years (Desmond, 2001: 13). In an interview with the Durban Burial Services Official by Ukhozi FM on 14 August 2001, the interviewee said that the cemeteries were full in the Black townships of Umlazi and KwaMashu and highlighted that the public needed to consider other burial methods (14/08/01 at 08h00 a.m.). It is further estimated that while non-AIDS deaths will be 80000 in 2010, AIDS deaths will be 180000 (Desmond, 2001:11); to repeat the words of Barnett and Whiteside (2002: 7): “Abantu Abaafa!-People are dying. Children are being orphaned. The elderly are left uncared for. Already disgraceful poverty is made worse”. Be it as it may, KZN people did not

fold arms at the face of this gigantic malady, many and varied programmes were developed and implemented.

Before discussing the study, it is appropriate to first give a profile of the study area.

1.3 THE STUDY AREA

The study area is the whole of the KwaZulu-Natal province.

1.3.1 DESCRIPTION OF THE STUDY AREA

1.3.2 THE GEOGRAPHICAL DESCRIPTION

KwaZulu-Natal is aptly called South Africa's garden province. It forms the east coast of South Africa, stretching from Port Edward in the South to the Mozambique border in the North. The Drakensburg Mountains forms its boundary in the west. The size of the area is 92 000 square kilometres and forms 7.6% of the area of South Africa (South Africa Year Book, 2001; South Africa Year Book, 2003/04:14-15).

1.3.3 THE CITIES

Durban constitutes one of the fastest growing urban areas in the world. It's port is the busiest in South Africa and also one of the 10 largest in the world (South African Year Book, 2000/2001). This factor has been advanced as one of those that fan the spread of HIV infection. Pietermaritzburg and Ulundi were joint capitals of the province during the period of the study due to the coalition government in the

provincial legislature (South African Year Book, 2000/2001: 11; South Africa Year Book, 2003/04: 14), however at the time of the compilation of this report, the capital of KZN has become Pietermaritzburg.

1.3.4 THE TOWNS AND PRODUCTION

Richards Bay is an important coal export harbour. In the interior Newcastle is known for steel production and coal mining; Estcourt for meat processing; Ladysmith and Richmond for mixed agriculture (South African Year Book, 2000/2001; South Africa Year Book, 2003/04: 15). These manufacturing industries and mines serve as fertile ground for migrant labour, truck driving and commercial sex workers, which play a major role in the spread of HIV.

1.3.5 INDUSTRIES

There has been rapid industrialisation in recent years due to abundant water. The industrial towns are Newcastle, Ladysmith, Dundee, Richards Bay, Durban, Hammersdale, Richmond, Pietermaritzburg and Mandeni (South African year Book, 2000/2001). This has also had an influence on increased urbanisation amongst the Blacks and a concomitant increase in low socio-economic conditions, exposing the communities to HIV infection.

1.3.6 AGRICULTURE

Sugar cane constitutes the mainstay of the economy along the Indian Ocean and it is the core of agriculture in the province. Farmers in the hinterland focus on vegetables, dairy and stock farming. Vryheid, Eshowe, Richmond, Harding and Ngome focus on forestry. The western areas are drier with very cold winters and snow (South African Year Book, 2000/2001:15).

1.3.7 OTHER HIGHLIGHTS

KZN is the only province with a monarch specifically provided for in the constitution (South African Year Book, 2000/2001: 11; South African Year Book, 2003/04: 14). Dukuduku and Kosi Bay constitute some of the South Africa's best protected indigenous coastal forests found along the coastal area of KZN (South African Year Book, 2003/04: 15).

1.3.8 SOME STATISTICS

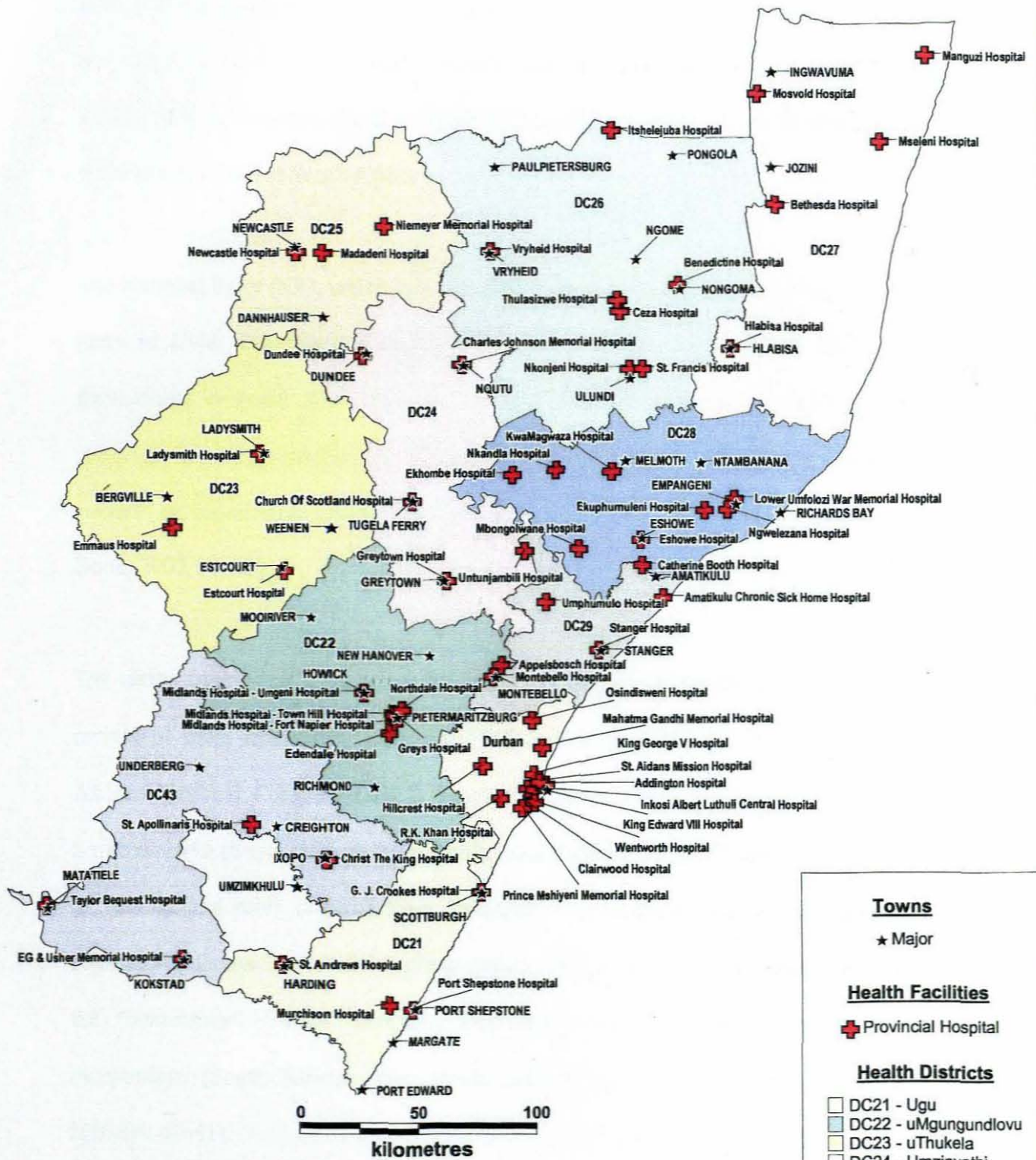
- Language: IsiZulu = 80.9%, English = 13.6%, Afrikaans = 1.5%
- Population: 9.4 million people (South African Year Book: 2003/04: 15)
- Fertility Rate: 3.3 %
- Life expectancy at birth: Lower than 50 years (now)
- Infant Mortality Rate: 51/1000 (Department. of Health 1997: 1)
- Human Development Index: .602
- Gini Coefficient: .54

- Safe Water: 32.8%
- Flush Toilet: 34.7%
- Telephone Facility: 27%
- Pit Latrine: 47.9% (statistics South Africa, 1999: 72-79)
- Electricity: 48.8% (Statistics South Africa, 1999: 72 – 79)
- Unemployment: 37.5% (Desmond, 2001:3)

1.3.9 BASIC HEALTH STRUCTURES

There are 11 Health Districts, 63 Hospitals, 367 Residential Clinics and 156 Mobile Clinics (Department of Health, 2004). Refer to Figure 1 (Map) regarding the position of the first two structures. These structures serve as points of care for the HIV/AIDS patient/clients. Refer to Figure 1.

Figure 1: KZN map showing Health Districts and Hospitals



Towns
★ Major

Health Facilities
✚ Provincial Hospital

Health Districts

- DC21 - Ugu
- DC22 - uMgungundlovu
- DC23 - uThukela
- DC24 - Umzinyathi
- DC25 - Amajuba
- DC26 - Zululand
- DC27 - Umkhanyakude
- DC28 - Uthungulu
- DC29 - iLembe
- DC43 - Sisonke
- Durban - eThekweni
- all others

Complied and Produced by
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1.4 THE POLITICAL CONTEXT

In view of the historical nature of the study, it is necessary to discuss its contemporary historical context as background with special reference to the two opposing political eras that affected it, viz. apartheid and democracy. It should be noted that the political system used in KwaZulu-Natal was part of the political system of South Africa since KZN is a province of South Africa.

The National Party (NP), which introduced the ideology of apartheid, became a ruling party in 1948. The tenet of apartheid lay in its determination to maintain white domination, to uplift poor Afrikaners, to challenge the pre-eminence of English speaking Whites in public life, the professions and business and to eliminate the remains of imperialism (South African Year Book, 2000/2001; South African Year Book, 2003/04: 41).

The taking over of political reigns by the NP occurred against the background of a revival of mass militancy during the 1940s which included the formation of the African National Congress (ANC) Youth League in 1943 and the Mine Workers Strike in 1946 (South African Year Book, 2000/2001: 3). The NP instituted a policy of "divide and rule" referred to as "separate development" and this divided the African population into artificial ethnic nations each with its own homeland. Four of the "homelands", Venda, Transkei, Bophuthatswana and Ciskei were declared independent (South African Year Book, 2000/2001; South African Year Book, 2003/04: 40-41).

There were forced removals of Blacks from the so-called “White areas”. Vast rural shack areas were created in the homelands, which were used as “dumping grounds for people”. The pass laws and influx control were extended and harshly imposed as means to “keep Blacks out of Whites areas” (South African Year Book, 2001/2001).

1.4.1 PRE-1994 POLITICAL CONTEXT AND ADVENT OF HIV/AIDS

A lot of development and important events occurred within the ruling party in South Africa and the Black Liberation Movement since the enforcement of apartheid laws to the discovery of the first AIDS case in the world in 1981 (Clive, Patel, Ansory and Hira, 1993: 1) and in South Africa during 1982 (NDHPD: 1989). At the arrival of AIDS, South Africa, including KwaZulu-Natal, was still under the apartheid system of government.

At this stage of the early eighties the Government embarked on a series of reforms, e.g. the recognition of Black trade unions to stabilise labour, the reformation of the constitution to allow Coloureds and Indians limited participation in “separate and subordinate houses of parliament” (House of Representatives and House of Delegates respectively), the institution of executive presidency and doing away with the title of Prime Minister by P.W. Botha (South African Year Book, 2000/2001: 32; South African Year Book, 2003/04: 43). The pass laws were scrapped in 1986. It is at this stage that the first AIDS case was diagnosed in KwaZulu-Natal. A range of economic sanctions and boycotts were instituted by the international community in support for the anti-apartheid action (unilaterally and through the United Nations). There was also a lot of violence particularly in KZN and this had some influence on the course of

HIV/AIDS programme and its implementation. The health service like all other services was fragmented with each "Homeland", the Coloureds, the Indians and the Whites having their own health services.

F.W. De Klerk, who had replaced P.W. Botha as State President in 1989, took the Parliament and the country by surprise when he unbanned the liberation movements and released the political prisoners, the prominent release of which was that of Dr Nelson Mandela in February 1990 (South African Year Book, 2000/2001, South African Year Book, 2003/04: 43-44). The enabling factors for this decision were many and varied and the unbanning of the liberation movements led to the commencement of a negotiation process on a democratic South Africa.

1.4.2 POLITICAL CONTEXT FROM APRIL 1994

Subsequent to a long negotiation process which was laden with ups and downs like opportunistic violence from the "right wing and its surrogates" and in some instances sanctioned by the elements of the state (including KZN), South Africa successfully held its first democratic elections in April 1994 under an interim constitution (South African Year Book, 2000/2001: 33; South African Year Book, 2003/2004: 45). The ANC won with a 62% majority and thus became the ruling party led by President Nelson Mandela with Dr Thabo Mbeki as Deputy President. The Inkatha Freedom Party (IFP) became the ruling party in KZN and Dr Ben Ngubane became Premier of the Province.

The NP participated in the Government of National Unity but withdrew in 1996 (South African Year Book, 2000/2001). The ANC led Government introduced the Reconstruction and Development Programme (RDP) which entailed pursuit of democratisation and socio-economic change; this intention of improving the socio-economic circumstances of people was of importance in the enhancement of the HIV/AIDS Programme, given the bearing poverty has on HIV/AIDS. HIV/AIDS became one of the programmes that had special RDP fund allocation. Openness and a culture of human rights were adopted and this had an influence on the HIV/AIDS policy and that of the entire health care system.

From the very outset there was emphasis on meeting the basic needs like housing, piped water, electricity, rural health care, etc. (South African Year Book, 2000/2001: 34). Priority was also placed on safety and security. All this has had a positive bearing on the implementation of the HIV/AIDS programme in KwaZulu-Natal.

The second democratic elections were held on June 1, 1999 and Dr Thabo Mbeki took over presidency. A sharp decline in NP support (which had ruled from 1948 to 1994) was noted and was eventually replaced by the Democratic Party (DP) as the official opposition party of the South African Parliament. The two parties (NP and DP) later merged to form an alliance which dissolved in 2003.

President Thabo Mbeki "promised tough hands on management style geared to efficiency and delivery" (South African Year Book, 2000/2001: 35; South African Year Book, 2003/04: 46). He was also committed to the African Renaissance concept based on democracy, development and a co-operative approach to addressing the

political challenges across Africa. This has had an influence in shaping the HIV/AIDS programme in the country, because the people of KwaZulu-Natal can copy and share HIV/AIDS lessons directly with African countries (especially Uganda) and thus intensify its fight against HIV/AIDS.

The next South African democratic elections would be held in April 2004.

1.4.3 EFFECTS OF THE PRE-1994 AND POST-1994 POLITICAL ENVIRONMENTS ON THE HIV/AIDS PROGRAMME

Like all other services the HIV/AIDS programme was grossly fragmented in South Africa (including KwaZulu-Natal), during the period of apartheid ideology. Different health authorities had their own HIV/AIDS programmes in South Africa and in KZN. In KZN these were the KwaZulu Homeland, the Natal Provincial Administration, City Health Departments, House of Representatives, House of Delegates, the private sector, the NGO/CBOs and FBOs. Similar structures existed in the rest of South Africa. After the 1994 general democratic elections, however, all the bits and pieces of HIV/AIDS activities by different races were moulded into one, a common strategic plan structured and followed by all, platforms created for partnerships amongst sectors and an effort made to ensure that all HIV/AIDS initiatives are co-ordinated into a coherent whole and all operate under the national HIV/AIDS policy framework.

Having provided the background, it is appropriate now to focus on the study itself.

1.5 STATEMENT OF THE STUDY PROBLEM

There is no coherent document on the history of HIV/AIDS programme implementation in KZN although many interventions have been made to combat the disease.

1.6 PURPOSE OF THE STUDY

“The genesis and progression of HIV/AIDS programme in KwaZulu-Natal: Implications for learning and intensified action” was aimed at documenting the history on how KZN responded to the HIV/AIDS pandemic and the circumstances under which the response took place.

1.7 THE SCOPE OF THE STUDY

From the inception of the HIV/AIDS programme implementation in KZN to December 2003, i.e. pre-1994 general democratic elections (GDE) and post-1994 GDE periods.

1.8 MOTIVATION OF THE RESEARCHER

The researcher has worked for the KZN Provincial Department of Health as an HIV/AIDS Programme Manager and observed that while KwaZulu-Natal has engaged in a lot of activities to combat HIV/AIDS, e.g. the initiation of the Cabinet’s AIDS campaign in 1997; the contribution of the NGO/CBOs, business sector, etc., not

all of these activities have been documented. Where these activities happen to be recorded, the context in which they took place is seldom analysed. Furthermore there is a lack of coherent historical information on the HIV/AIDS programme implementation in the province.

Apart from HIV/AIDS as one of the diseases being studied by students following health related courses, universities such as MEDUNSA and Stellenbosch now offer a graduate course specifically focusing on HIV/AIDS, which, in MEDUNSA, was officially launched by the Deputy President of South Africa, Dr Jacob Zuma early in 2001. In most KZN educational institutions, HIV/AIDS is now incorporated into the curriculum, e.g. at the University of Zululand all lecturers have been asked to spend 2-3 minutes each day talking to students about HIV/AIDS (University of Zululand, May 2004).

The researcher aspires that the findings of this study should serve as a referral document in respect of both the learner and the educator.

The researcher has been the HIV/AIDS Programme Manager in KwaZulu-Natal under the Department of Health from 1996 to 2001, during which she developed a passion for the programme as well as empathy towards the infected and the affected. During her term of office she witnessed the agonising loss of many young people, some of whom were close relatives.

The researcher regards it as essential that the history of the HIV/AIDS epidemic especially with regard to KZN, be documented for future study purposes.

Furthermore, the researcher intends extending her contributions towards the HIV/AIDS programme in the country through studying and documenting HIV/AIDS interventions in KZN, including the context in which implementation has taken place, and make certain recommendations based on the findings of the study.

1.9 RESEARCH OBJECTIVES

a. **To trace the origin of the HIV/AIDS programme in KwaZulu – Natal.**

- Here the researcher intended to find out when the interventions against HIV/AIDS began in KZN.

This information would be obtained from the 1980 - 1990 records.

b) **To identify the HIV/AIDS activities and the organisations that implemented them.**

- Here the researcher wanted to identify HIV/AIDS activities and the organisations that implemented them.

This information would be obtained from the KZN's Provincial AIDS Action Unit, NGO/CBO records, a visit to 15 service providers and 5 key informants as well as from interviewing NGO/CBOs at their meetings with the Department of Health.

c) To identify what has been the support system for the HIV/AIDS Programme.

- Here the researcher wanted to highlight the support of the HIV/AIDS programme by human resources, human resource development, research, funds, planning, policies, committees/forums/groups, councils, political backing or support by high profile individuals.

This information would be obtained from the records of service providers and key informants.

d. To highlight the challenges faced and the lessons learnt during the implementation of the HIV/AIDS programme.

- Here the researcher wanted to highlight the problems or concerns of the service providers as well as what they had learnt in the course of programme implementation.

The bulk of this data would be obtained from the records.

e. To determine the extent to which participation of the NGO/CBOs in the HIV/AIDS programme grew over the years.

- Here the researcher wanted to gauge the number of organisations who became involved in the programme each year up to 2003.

This data would be obtained through administration of a questionnaire at the NGO/CBO meetings with the Department of Health.

1.10 SIGNIFICANCE OF THE STUDY

The significance of the study is as follows:

It will add a historical dimension to the theory and practice of HIV/AIDS prevention and care, not only in KZN but in the whole of South Africa;

It will motivate potential role players to also join the struggle against HIV/AIDS; and encourage those who are already in the battle against HIV/AIDS in KZN to intensify their actions;

It may lead to the challenges of role players being addressed as a result of recommendations that will be made;

It will provide evidence that KZN responded proactively to the HIV/AIDS epidemic within the constraints of its resources, knowledge and skills;

It may lead to clarification of confusing issues around HIV/AIDS and eliminate ignorance that often breeds unnecessary controversy in the programme;

It will form the basis on which researchers and authors aspiring to work on HIV/AIDS can build;

Lastly, the study will help all people concerned, including future generations, to take stock and determine new directions in the implementation of the HIV/AIDS

programme; this in turn will lead to new decision-making, formulation of new policies and the structuring of new plans.

1.11 DELIMITATION OF THE FIELD OF STUDY

- The study is confined to KwaZulu-Natal; places outside the province like the rest of South Africa and other countries will feature where relevant, for instance in the introduction, literature review, etc.
- Only the organisations found in the records and attending the meetings with KZN's Provincial AIDS Action Unit will feature in the report.
- This study does not evaluate the HIV/AIDS programme but discusses the HIV/AIDS programme and its context, the service providers, the support system, challenges and the lessons learnt.
- The study does not include the activities that occurred after December 2003 and includes those that occurred from the first HIV screening of donated blood in 1985 and the encounter with the first AIDS patient (Mercury, 9 January, 1986).
- The study does not look into the HIV/AIDS activities of each district but highlights what is happening in the province; some areas in certain districts feature here and there to represent what is happening in the province around HIV/AIDS.
- The study cannot and shall not cover all the HIV/AIDS activities; neither shall it mention all the people or organisations that have participated in the KZN's HIV/AIDS programme.

1.12 THE RESEARCH DESIGN

This study will use a qualitative research design with a focus on the historical method. Data shall therefore be primarily obtained from the records.

1.13 THE THEORETICAL FRAMEWORK

Betty Neuman's Health Care Systems Model for Nursing will be used in this study. Its strength lies in its comprehensiveness, being holistic, and putting emphasis on prevention whereby the client is assisted to deal with stressors. Furthermore, emphasis is put on health education, wellness, management of ill health, collaboration and coordination; these aspects play an important role in the fight against HIV/AIDS. In the case of this study HIV/AIDS presents a typical example of a stressor to which Neuman refers.

1.14 DEFINITION OF CONCEPTS

GENESIS: Origin or beginning (Kirkpatrick *et al.*, 1994:562).

Operationally this refers to the beginning/ commencement of an event or process.

PROGRESSION: Movement in successive stages (Kirkpatrick *et al.*, 1994: 1059).

By "progression" the researcher refers to the gradual growth or progress of an event or process.

SUPPORT SYSTEM:

Support: “Give strength to”, “enable to last or continue”, “keep from falling or sinking” (Pollard & Liebeck, 2000: 806).

System: “A set of connected things or parts that form a whole or work together” (Pollard & Liebeck, 2000: 814).

By “support system” in this study the researcher refers to all that sustain the HIV/AIDS programme, e.g. human resources, human resource development or training, research, funds, plans, policies, committees/ forums/ groups/ teams, councils and political backing or support by an elite person.

HIV (Human Immuno – Deficiency Virus): The virus or micro – organism/germ that causes AIDS (Van Dyk, 1993).

AIDS (Acquired Immune Deficiency Syndrome): A name given to a group of serious illnesses caused by the inability of the body to fight infection (Van Dyk, 1993). It is referred to as acquired because it is not inherited.

Immunity refers to the ability of the body to defend itself against infection.

Deficiency refers to the fact that the body’s immune system has been weakened and thus can no longer defend itself against infections.

A **syndrome** is a medical term referring to a collection of specific signs and symptoms that occur together and that are characteristic of a particular pathological condition (Van Dyk, 2001: 4)

PROGRAMME: “A plan or outline of proceedings or actions to be carried out” (Kirkpatrick, 1994: 1059) or “a plan of action or events or a list of series of planned events” (Pollard & Liebeck, 2000: 267).

By “programme” the researcher refers to a group of interventions or strategies directed at the problem in order to prevent it or make it less serious. Sometimes by a “programme” she refers to a single intervention or strategy, e.g. a Sexually Transmitted Infections programme, as will be seen in chapter 5 under the discussion of HIV/AIDS programmes.

EPIDEMIC: A sudden unusual increase of a disease, exceeding the number that is expected on the basis of experience (The World Bank, 1997: XXIV).

PANDEMIC: “An epidemic occurring over a very wide area and usually affecting a large proportion of the population” (Last, 1988: 94). The concepts epidemic and pandemic will refer to HIV/AIDS in this study.

PREVALENCE of HIV: Number of people with HIV at a point in time often expressed as a percentage of a total population (The World Bank, 1997: XXV).

CHALLENGES: A difficult task that stretches one’s physical and mental ability (Kirkpatrick, 1994: 215).

By “challenges” in this study, the researcher refers to genuine challenges as defined above, as well as problems or concerns.

1.15 ACRONYMS COMMONLY USED IN THE STUDY

1. CBO: Community Based Organization
2. DOE: Department of Education

3. DOH: Department of Health
4. FBO: Faith Based Organization
5. GDE: General Democratic Elections
6. HBC: Home Based Care
7. HWs: Health Workers
8. IEC: Information, Education and Communication
9. KZL: KwaZulu
10. KZN: KwaZulu-Natal
11. LSE: Lifeskills Education
12. NACOSA: National AIDS Convention of South Africa
13. NAPWA: National Association of People Living with AIDS
14. NDOH: National Department of Health
15. NDOPD: National Department of Health and Population Development
15. PAAU: Provincial AIDS Action Unit
16. PLWHA: People Living with HIV/AIDS
17. WAD: World AIDS Day

1.16 CONCLUSION

This chapter was aimed at introducing and orientating the reader to the study. It dealt with the background, description of the study area, motivation of the researcher, the purpose of the study, the objectives, the significance of the study, delimitation of the field of study and the definition of relevant concepts. The rest of chapters comprise information on the following:

Chapter 2: Literature review

Chapter 3: Methodology

Chapter 4: Theoretical framework

Chapter 5: Data Analysis

Chapter 6: Findings, limitations of the study, conclusion and recommendations.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This literature review, which is based on the research topic “The genesis and progression of the HIV/AIDS programme in KwaZulu-Natal: Implications for learning and intensified action”, will look into the concept programme, broadly discuss HIV/AIDS as a target to which the programmes have been directed, the origin of the HIV/AIDS programme world-wide, the service providers and the growth in their participation, the programmes implemented globally to combat HIV/AIDS, the support system for the implementation of the programme, the challenges and the lessons learnt.

2.2 THE CONCEPT PROGRAMME

In the title of this study, by “programme” the researcher refers to a group of interventions or strategies directed at the problem in order to prevent it or make it less serious. In the discussion of HIV/AIDS interventions by “programme” the researcher refers to a single intervention, e.g. life-skills education programme, home based care programme, etc.

Kirkpatrick (1994: 1059) defines a programme as “a plan or outline of the proceedings or actions to be carried out” while Pollard and Liebeck (2000: 267) define it as “a plan of action or events” or “a list of series of planned events”. The

concepts “programme” and “projects” are sometimes confused or taken as synonymous. The two are only related. Rory (1992: 19) defines a project as “a group of activities that have to be performed in a logical sequence to meet the present objectives set by the client”. Project management is “a way of making this happen” (Rory, 1992:19). “The project has a distinct life cycle comprising a start-up phase, a building phase, a maturing phase and a termination phase.” (Meredith & Mantel Jr., 2000: 22).

Based on the above definitions it seems clear that although there are common features between a project and a programme, the project is short-term and may be a component of a programme while a programme is long-term, it has sub-programmes sometimes referred to as strategies and it does not always have a fixed time for termination if the problem still exists, but can be reviewed and modified, e.g. a TB programme, nutrition programme, HIV/AIDS programme etc.

In the forthcoming discussion of programmes, projects shall therefore be cited as components of specific programmes under the HIV/AIDS programme umbrella. HIV/AIDS programme therefore refers to all interventions or strategies aimed at combating HIV and AIDS.

Prior to the discussion of programmes, who implement them, the support systems for their implementation, the challenges and the lessons learnt, it is appropriate to first discuss HIV/AIDS as a problem to which the programmes are directed, its epidemiology and its impact, so as to sharpen the reader’s insight into the rationale behind the implementation of the programmes that will be cited; furthermore the

progression of the programme has been propelled by the progression of the HIV/AIDS epidemic.

2.3 HIV/AIDS: THE DISEASE

People who had mentally reached adulthood by the early seventies, especially the health-literate, will recall that the most feared disease of the time was cancer of any form. The fear, “which imprisons us and which is also our worst enemy” (Lanctot, 1995:138), appeared to be centered around the fatality nature of the condition, associated with the absence of a cure.

In the eighties, when humans started becoming aware of the disease HIV/AIDS, the cancer phobia seemed to shift its position and ultimately became overtaken by HIV/AIDS with its concomitant elements of severe stigma and prejudice.

HIV/AIDS today is present in every continent and in almost every country (Snidle & Yeoman, 1977).

2.3.1 WHAT HIV/AIDS IS

HIV (Human Immuno-deficiency Virus) is the name of the micro-organism that causes AIDS. It is the beginning stage of AIDS (Acquired Immune-Deficiency Syndrome) while AIDS is the end stage of HIV positivity (World Bank, 1997; Van Dyk, 1993; Snidle & Yeoman, 1977). Fitzsimons, Hardy and Tolley (1995:13) stress

that “let there be no misunderstanding, AIDS is caused by HIV, the Human Immuno-Deficiency Virus”.

On the other hand Illingworth (1990) states that HIV is the name of the virus “thought” to be responsible for AIDS and AIDS is the end stage of the disease. “It has yet to be shown conclusively that everyone who is HIV infected will have AIDS” (Illingworth, 1990:3). According to this author it is thought that 50% of the HIV positive people will develop full-blown AIDS. He further warns against referring to HIV as the AIDS virus and argues that it is not known that everyone who is HIV positive will eventually get AIDS, and to him this is misleading.

Van Dyk (1993) emphasises that AIDS is not a “specific illness” but rather a collection of more than 70 conditions that occur as a result of the destruction of the immune system; however, it is often referred to as a disease.

2.3.2 TYPES OF HIV

Two types of HIV have been identified.

HIV 1: This is the most common type of HIV found world-wide including South Africa. There are at least 9 slightly different sub-types within HIV 1 (World Bank, 1997).

HIV 2: This type is mostly found in West Africa (WHO/UNAIDS/UNISA/DENOSA: 2001).

2.3.3 WHAT HIV DOES IN THE HUMAN BODY

HIV affects the immune system, weakens it and eventually destroys the cells that fight against infection, known as lymphocytes/monocytes and CD4 cells (Snidle & Yeoman, 1997; WHO/UNAIDS/DENOSA/UNISA: 2001; Fitzsimons *et al.*, 1995; Illingworth, 1990).

2.3.4 HISTORY OF HIV/AIDS

Cases of AIDS were first observed in USA during the summer of 1981 when a very rare type of pneumonia caused by pneumocystis carinii and kaposi sarcoma (a rare kind of skin cancer) were suddenly diagnosed in young homosexual men with a lowered immune system. This was initially called "Gay related Immune Deficiency Syndrome", but when non-homosexuals also contracted the disease, the name changed to "AIDS" (Van Dyk, 1993; Illingworth, 1990; Snidle & Yeoman, 1997; Perrow & Guillen, 1990).

In 1982, the Center for Disease Control in Atlanta (Georgia, USA) formally named the condition "AIDS" and began to undertake a formal surveillance of the disease (Snidle & Yeoman, 1997). France isolated a retrovirus and the disease was called "Lymphadenopathy Associated Virus" (LAV). This virus was found in the USA during 1984 and was called "Human T. Lymphotropic Virus Type III". It is today known that this was the same virus as LAV (Snidle & Yeoman, 1997).

In 1985, Elizer, a blood test to detect antibodies against HIV, was developed. The International Committee on Taxonomy of Viruses renamed the virus HIV or Human Immuno-deficiency Virus (Snidle & Yeoman, 1997). In 1987, HIV-2 identification was done in West Africa.

It is believed that HIV 2 can cause AIDS, however, the time from initial infection to clinical infection is much longer compared to HIV 1. The methods of transmission are the same though (Snidle & Yeoman, 1997).

2.3.5 MODE OF HIV INFECTION

HIV is transmitted mainly through sexual intercourse, contact with infected blood and / or blood product transfusion or by injecting materials for piercing, tattooing, etc. as well as mother to child transmission (WHO/UNAIDS /UNISA/DENOSA, 2001).

It should be kept in mind that HIV cannot be transmitted through swimming, handshakes, work or school contact, using toilets, using telephones, sharing cups/glasses, coughing, sneezing, insect bites, hugging, touching, etc. (WHO/UNAIDS/UNISA/DENOSA, 2001). This is of importance to note so as to prevent unnecessary discrimination, isolation and prejudice (WHO/UNAIDS/UNISA/DENOSA, 2001).

2.3.6 STAGES OF HIV/AIDS

The battle between HIV and the white blood cells is fought in different stages.

2.3.6.1 Primary /acute stage

This stage commences from the infection time to the time when the initial immune response of the body picks up some degree of control over the replication of the virus, usually lasting for a few weeks. The CD4 cell count drops sharply. About 30-70% of people experience symptoms similar to those of flu, which in 3 weeks time (when the CD4 and T cell count recovers), usually disappear (World Bank, 1997; Snidle & Yeoman, 1997; WHO/UNAIDS/UNISA/DENOSA, 2001).

2.3.6.2 Asymptomatic stage

This stage takes 80% of the time from infection to death. The antibodies to HIV can only be detected in the blood stream at this stage. Prior to this stage it is not possible to determine whether a person is infected with HIV or not (World Bank, 1997; Snidle & Yeoman; WHO/UNAIDS/UNISA/DENOSA, 2001). Most people remain healthy clinically. In the meantime the immune system fights a covert battle against the virus. HIV destroys a large number of CD4 and T cells. The bone marrow counterbalances this by expediting the production of new cells; the replacement rate cannot, however, keep up with the rate at which cells are lost (World Bank, 1997).

The CD4 cell count, which normally ranges between 800 and 1000 per cubic Ml of blood in a non-infected person, decreases gradually by 50-70 cells per year (World Bank, 1997).

2.3.6.3 Symptomatic stage

When the CD4 cell count is reduced to 200 per cubic Ml of blood, there is an escalation in the reduction of CD4 and T cell count and the person becomes susceptible to opportunistic illnesses (communicable or non-communicable). This begins the final stage of HIV infection (World Bank, 1997).

2.3.6.4 Clinical AIDS or full blown AIDS

This stage is characterised by illnesses such as TB, Pneumonia, other STDs, fungal infections, meningitis, skin diseases, chronic diarrhoea, cancers, e.g. Kaposi's Sarcoma (WHO/UNAIDS/UNISA/DENOSA, 2001).

2.3.7 SURVIVAL AFTER HIV INFECTION

The World Bank (1997) asserts that it has not yet been proven whether HIV infection is always fatal; a view that is also held by Illingworth (1990). The World Bank states that the survival rate after infection with HIV appears to follow a normal distribution curve whereby a few number of people at one side of the curve rapidly progress to full blown AIDS and thus quickly die while on the other side of the curve lie a small number of people that have been infected with HIV for more than 12 years but remain healthy (World Bank, 1997).

2.3.8 EPIDEMIOLOGY OF HIV/AIDS

This refers to the distribution and determinants of HIV/AIDS amongst humans.

2.3.8.1 The global picture

In December 1999, UNAIDS (The Joint United Nations Programme on HIV/AIDS) estimated that 33.6 million people world-wide were living with AIDS (Tembo, 2001). 69% of these cases (23.3 million) were in Africa. It was estimated that from the start of the epidemic to the end of 1999, 16.3 million people globally had died. Of these deaths, 13.7 million (84%) were in Africa (Tembo, 2001: 7). Approximately 50% of all people who acquire HIV become infected before they turn 25 (UNAIDS, 2000).

2.3.8.2 The African picture

According to Tembo (2001) most African countries reported their first cases of AIDS in the early 1980s. At present the highest HIV prevalence rates are found in Sub-Saharan Africa. The majority of HIV/AIDS cases are concentrated within the 15-49 years age group, which is highly productive. The male - female ratio is 1:1 (Tembo, 2001:7).

In younger age groups, females outnumber the males significantly in areas where the spread is rapid. There is a rise in HIV infection amongst females within the age group of 15-19 years (Tembo, 2001: 7). According to Tembo (2001) the slow pace in admitting the existence of AIDS in Sub-Saharan countries accounts for high HIV

infection rates. It however gives a glimmer of hope that Uganda, which was once an epicentre of the disease in Africa, has had the HIV prevalence rate reduced from 14% in the early 90s to 8% by the close of the 20th century (Tembo, 2001).

2.3.8.3 The picture in the developed countries

In the industrialised countries HIV/AIDS cases are found in specific high-risk group populations, especially men who have sex with other men (MSM) and injecting drug users (or IDUs) (Monitoring the AIDS Pandemic (MAP) Network, 2000).

The antiretroviral drugs referred to as highly active antiretroviral therapy (HAART) which has been available in these countries since 1995/1996, have prevented or delayed the progression to AIDS and death amongst those treated. Survival of AIDS cases improved, and the annual AIDS incidence and mortality decreased since 1995 (MAP Network, 2000). Regrettably, however, from 1998, there has been no reduction in AIDS cases and deaths in many of these countries probably due to treatment intolerance, drug resistance, late diagnosis of HIV/AIDS, refusal of HAART and termination of HAART. England and Wales have also had a 13% increase in HIV infection per annum (1996). Canada cases increased from 4000 to 49 000 by 1999 (MAP Network, 2000). England and Wales had 30% increase in Intravenous Drug Abusers (IDUs) reporting sharing needles and syringes. In Canada the latter remained at 40%, i.e. no decrease/ increase (MAP Network, 2000).

In these countries, Sexually Transmitted Diseases (STDs), a major condition that fans HIV transmission, show an increase as well. Between 1995 and 1998 Britain reported

a 25% increase in gonorrhoea. In San Francisco there has been an increase in MSM populations, related to sex without a condom. There has been a syphilis outbreak among MSMs in Seattle (USA), Vancouver, Canada and some urban areas of England (MAP Network, 2000). It is thought that this may all be due to a false sense of security following the perception that HIV is a normal treatable health problem (MAP Network, 2000).

The ethnic minorities in these industrialised countries are hit harder by HIV/AIDS. For an example in England and Wales, the Africans who form 0.5 of the population have increased HIV prevalence rates. In the USA, HIV prevalence is higher among the Blacks than Whites (MAP Network 2000).

2.3.8.4 The South African picture

In South Africa the HIV prevalence amongst women attending ante-natal clinics in government health facilities show that it has steadily increased since 1990 and reached 23% in 1998. Between 1998 and 1999 it showed no significant change (MAP Network, 2000); teenage HIV prevalence declined from 21 to 18% but remained unchanged amongst women in their 20s (27%). Mortality rates in the 25-29 age group was 3.5 times higher than in 1985 and 2 times higher in the 30-39 age group (MAP Network, 2000).

It is estimated that life expectancy at birth can drop from 54 years (2001) to 41 in 2010. The yearly total deaths can increase from about 587,000 to 1.2 million in 2010

and the proportion of deaths that are related to AIDS would be 23% in 2001 and will soar to 66% in 2010 (DENOSA, 2001).

The HIV prevalence study by the Human Science Research Council commissioned by the Nelson Mandela Children's Fund found high HIV prevalence rates amongst the 2-14 year age group (6 out of every 100 infected children). Another significant deviation in this study was that KwaZulu-Natal was not the most highly infected province in South Africa, but ranked number 4 (Sowetan, December 6: 2002; HSRC, 2002: 7).

In South Africa 39% of deaths in 2000 were attributed to AIDS according to the Medical Research Council (MRC) (Sowetan, May 15, 2003:1)

2.3.8.5 The KwaZulu-Natal picture

According to the 2000 HIV prevalence study amongst pregnant mothers attending ante-natal clinics at government health institutions, the HIV prevalence was 36.2% in KwaZulu-Natal while that of South Africa was 22.4% (Department of Health, 2001). In a similar study during 2003 this prevalence was 36.5% (Department of Health, 2004). This upward trend has persisted since the early annual HIV surveys (1990) whereby the first prevalence rate was 1.6% in KZN and .76% nationally (Desmond, 2001). In 1999, there was an HIV prevalence range of 26-35% amongst the KZN Health Districts (referred to as "Regions" during this period).

The possible reasons advanced for the high HIV prevalence rate in KZN are amongst others urbanisation; social mixing due to good transportation (KZN has the 2 largest ports in Africa); poverty (with the gini coefficient of 0.54, human development index of .5, unemployment rate of 59% amongst the age group 16-25 years); male absenteeism in rural families; risky sexual practices (a 1998 study found that only 22.2% women aged 15- 49 years in KZN reported having used a condom); political violence, which probably gave rise to a silent spread of HIV whereby people were displaced and families disrupted with subsequent effects; extensive truck routes, the drivers of which tend to enter into sexual relationships with the commercial sex workers (Desmond, 2001).

2.3.9 IMPACT OF HIV/AIDS

“Impact of HIV/AIDS” refers to the negative effects or consequences of HIV/AIDS.

2.3.9.1 Demography

HIV/AIDS influences the demography of an area due to its fatality rate as well as its potential for reducing fertility.

2.3.9.2 Life expectancy (LE)

According to Loewenson and Whiteside (2001) AIDS related mortality is heading for a decrease in the Life Expectancy (LE) at birth to less than the 1950s levels in the worst hit countries, and an increase in infant and child mortality rates. Sub-Saharan

Africa will have 71 million fewer people by 2010 (Loewenson & Whiteside, 2001). The populations may start being reduced by 2003 in Botswana, South Africa and Zimbabwe. An increase in widows, widowers and orphans will increase dependency (Loewenson & Whiteside, 2001). In South Africa this dependency will add to the one created by a high rate of unemployment. In some Sub-Saharan African countries, life expectancy at birth is predicted to drop to below 40 years as a consequence of AIDS deaths (Hunter & Williams, 1998; Lyons & Werner-Weiss, 1999). Life Expectancy (LE) in Zimbabwe has been reduced by 22 years and in South Africa by 7 years, according to US Census Statistics for 1996-1997 (World Bank, 1998). Malawi had a life expectancy of 37 in 1993 while Uganda (with a population of 22 million) had a LE of just over 42 years according to USA CIA (1998), in Loewenson & Whiteside (2001).

LE at birth in Botswana is now estimated to be 39 years instead of 71 without AIDS; in Zimbabwe 38 instead of 70; in the Bahamas 71 instead of 80; in Haiti 49 instead of 57. Asia, Cambodia, Thailand and Myanma have lost 3 years of LE at birth (MAP Network, 2000:11).

According to the Natal Mercury of 19/04/01, it is estimated that AIDS will push down the life expectancy of South African Women sharply over the next few years as follows: 1999 = 54 years, 2005 = 43 years and 2010 = 37 years while, men will survive till 38 years of age.

2.3.9.3 Population growth and mortality

At the beginning of the 21st century the population growth in Zimbabwe had been reduced to nearly zero due to AIDS mortality based on a new population projection done by the US Census Bureau (MAP Network, 2000: 310). The other countries with drastically reduced population growth rates include Botswana, Malawi, Namibia, South Africa, Swaziland and Zambia (MAP Network, 2000: 10). In the Asiatic countries slightly reduced population growth rates are observed in Myanma, Cambodia and Thailand (MAP Network, 2000).

By 2003 Botswana, South Africa and Zimbabwe will be experiencing a negative population growth down to 0.1 - 0.3%, from the growth of 1.1 - 2.3% it would have been without AIDS (MAP Network, 2000:10).

The estimated crude death rates including AIDS mortality are up by 50 to 500% in Eastern and Southern Africa than they would have been in the absence of AIDS (MAP Network, 2000). In South Africa, with an estimated 20% adult HIV prevalence, crude death rates are twice as high (14.7 per 1000 as they would have been without AIDS (14.4 per 1000 population).

2.3.9.4 Population structure

AIDS mortality will produce new population structures particularly in the hardest hit countries. For example, it is predicted that South Africa and Zimbabwe's population

pyramids will change to a “population chimney” due to the magnitude of HIV/AIDS (MAP Network, 2000:11).

2.3.10 IMPACT ON FAMILIES AND COMMUNITIES

Families and communities constitute the most important social structure severely hit by HIV/AIDS, since the impact exerted on other structures have a point of departure in families and communities.

The scarcity of health care in the health institutions imposes a significant burden on families and communities, which must now render care to the sick. Quite often the sick and dying person is a breadwinner at home; those that must render care to him/her are unable to do so when they are hungry; they are also unable to provide meals to the sick, as a result the sick dies prematurely.

The caregivers (family members) suffer from stress due to illness and impending death in the family as well as the fear of they themselves getting infected in the process of caring (own observation). This kind of care by the family members may be unsupported and poorly managed because care workers at the health institutions are also too overburdened to give support and mentoring; this may lead to the Care Givers becoming HIV infected (Loewenson & Whiteside, 2001).

HIV/AIDS makes poverty worse in the family. Domestic labour becomes diverted to care rather than to production of food and other assets (Loewenson & Whiteside, 2001). In Ethiopia loss of labour in the family reduced time spent on agriculture from

33.6 hours per week for non-AIDS affected households to between 11.6 – 16.4 hours for those affected by HIV/AIDS. In Zimbabwe adult deaths from all causes led to small farm maize outputs to fall by 45%, but when AIDS was the cause of death, this increased by 61% (Loewenson & Whiteside, 2001: 10). This is cause for concern since maize constitutes the most important staple food for the families in these countries. On the death of a breadwinner other members of the household can lose housing and land tenure (Loewenson & Whiteside, 2001).

In Rakai (Uganda) it is reported that 4% of households with an adult death have had to dispose of the bicycle and the radio that the family had owned, due to growing poverty. In Kagera (Uganda), households without adult deaths accumulated assets while those with deaths did not (World Bank, 1997; Marangadura 2000 cited in Loewenson & Whiteside, 2001). In Chiang Mai (Thailand), 41% (nearly half) disposed of land after a death of an adult, while in Zimbabwe households disposed of cattle, goats, furniture, poultry, clothes, television and wardrobes. The depletion of assets during illness as well as for funerals affects the family's struggle for continued survival (World Bank, 1997; Mangadura, 2000 cited in Loewenson & Whiteside, 2001).

2.3.10.1 HIV/AIDS and orphans

The immediate human product of an adult AIDS death is often an orphan or orphans. The feelings of being loved and secured suddenly become a severe loss to the child on the death of parents, or a parent, especially the mother.

According to the US Census Bureau of Statistics, 6.2 million children were orphaned by AIDS globally in 1998 (Lyons & Lerner-Weiss, 1999). The clearly visible toll of the epidemic is centred around Sub-Saharan Africa where the magnitude of HIV/AIDS is higher than in any continent in the world (Lyons & Lerner – Weiss, 1999). In rural areas of East Africa, 40% of all orphans have lost a parent from HIV/AIDS (UNAIDS, 1998; WHO, 1998).

If therapeutic care and treatment remains unavailable to women in the developing countries, the number of orphans will continue rising (Lyons & Lerner-Weiss, 1999). In a study in Kagera (Tanzania) amongst the orphaned and the non-orphaned children, half of the children who had lost one or both parents showed stunted growth (WHO, 1998). Children endure emotional and psychological suffering while isolated in fear, and expected to be secretive about the history of HIV/AIDS in the family because they may be discriminated against or rejected. This can impair physical and intellectual growth (Audiman, Geballe & Gruendel, (1995) cited in The World Bank, 1997). Another painful experience is for a child that has lost one parent to expect to lose the other one (World Bank, 1997).

Children orphaned by AIDS are left with stigma compared to those whose parents died of other conditions. This presents difficulty in taking a child to stay with another family (UNAIDS, 1999). Over and above stigma and discrimination, these children also become subjected to abuse and exploitation because they have no adult people caring for them (UNAIDS, 1999). These children are taken by adults who lack a caring spirit and those who live on their own, work as servants or serve as “sexual objects” (UNAIDS, 1999). Millions of children are subjected to sexual abuse within

their own homes or families (UNAIDS, 1999). The International Labour Organisation (ILO) estimates that the number of children who are fully at work world-wide are 120 million. Millions of children, the majority of which are girls, work as domestic servants, often in concealed settings where they can be easily subjected to abuse and violence (ILO, 1996 cited in UNAIDS, 1999).

In South Africa, as the epidemic consistently takes its toll, it is predicted that the population of orphans will increase and unless appropriate interventions are put in place, these orphans will be recruited into crime due to poor upbringing, i.e. the absence of parents, relatives or welfare organisations or when the fabric of society has disintegrated. Lack of guidance, care and support for HIV positive people (including children) will worsen the situation.

Orphaned children will have no role models for the future and will thus resort to crime in order to survive (MacKay, 1999 cited in Loewenson & Whiteside, 2001: 12). In a series of interviews undertaken with young South African men serving a jail sentence or involved in crime, it was found that most felt unloved because they had been abandoned, expelled from home or rejected by those they lived with (Sergal *et al.*, 1999 cited in Loewenson & Whiteside, 2001:12).

2.3.11 **IMPACT ON THE WORKER**

In Western economies 90% of the HIV positive may be in employment (Goss & Adam-Smith, 1995). Even though HIV/AIDS and the consequent loss of human resources in the Western world (industrialised countries) has not been as big as

anticipated early in the epidemic, HIV/AIDS has left its mark on many aspects of organisational practice, including discrimination and prejudice against those thought to be HIV infected (Goss & Adam-Smith, 1995). Discrimination and prejudice have very damaging effects especially on the employee concerned. The organisation can also become deprived of the quality product the worker would have yielded in the absence of prejudice and discrimination.

In some work settings HIV positive employees are manipulated into resigning as a concealed form of discrimination (Fitzsimons, Hardy & Tolly, 1999).

According to Watchirs (1999), employment laws should ensure that all forms of discrimination at workplaces are prevented. This includes prohibiting HIV screening prior to employment; protection from discrimination whereby the HIV status of a worker is known or questioned by the co-workers, clients, union or the employer; maintenance of confidentiality regarding medical information including HIV/AIDS, as well as protection from occupational HIV transmission. A number of attempts have been made to improve workplace practices (Goss & Adam-Smith, 1995: 151). These attempts are indeed in line with Fitzsimons *et al.*'s warning that a worker has to be seen as an equal colleague and not as a vector of infection.

2.3.12 IMPACT ON THE ECONOMY

The impact of HIV/AIDS on the worker further imposes an impact on the economy of the family, the country and the world. The quality and supply of labour falls because of increased absenteeism and death; the loss of skills and experience incurred leads to

a shift towards employing the less experienced workers. This subsequently results in loss of production. This is felt both at the work place and in household settings. According to Loewenson and Whiteside (2001: 96), HIV/AIDS is “already putting a break on economic growth in the worst hit areas.” It is estimated that in 1990 AIDS will have reduced per capita annual growth by 0.8%. The cost per worker per year of HIV/AIDS has been estimated at between US \$20 and US \$200. This is due to the lost work time as well as benefits. In a recent South African study, it was found that the cost of AIDS for 1 company would be 7.2% of total salary (Loewenson & Whiteside, 2001: 9). The potential impact of AIDS on customer buying power in Southern Africa has caused one firm to relocate and open up business in Poland and the Czech Republic (Loewenson & Whiteside, 2000: 9).

2.3.13 IMPACT ON WOMEN

Women are generally hit harder by HIV/AIDS, particularly in Africa. In two African cities (Harare and Francetown) 40% of the ante-natal clinic attendants are HIV positive (Tembo, 2001). HIV/AIDS impacts harder on women psychologically, physically, socially and economically particularly in the developing countries. In India and other third world countries, cultural pressures force women to conceive a child in order to be accepted by her in-laws regardless of her HIV status; if pregnancy fails, the man will marry any other woman claiming that the first wife is “barren” (Lyons & Werner-Weiss, 1999:27). There are a lot of social norms making it inappropriate for women to be knowledgeable about sexuality or suggest condom use. These gender stereotypes make women unable to engage in a dialogue about sex, and as a result they can easily get HIV infected (Tembo, 2001).

The impact of AIDS on food makes women and children in particular vulnerable to contracting HIV, yet the contribution made by women on food production exceeds 50% in Sub-Saharan Africa and Asia (Muchopa and Murangadura, 1998 cited in Loewenson & Whiteside, 2001: 11). Women constitute a vital link between food production and its security; they also become stressed in the process of struggling to sustain food. As a result they respond to stresses by selling land in order to meet medical costs, taking girl children out of school and sending them into the labour market (Loewenson & Whiteside, 2001).

Women are generally low-income earners; this makes them vulnerable to coerced sex which is unprotected; it also makes some resort to sex work (Tembo, 2001). This makes them more vulnerable to contracting HIV. Biologically the large surface area of the woman's genitalia increases the risk of HIV infection as well as contracting other sexually transmitted infections or STIs (Tembo, 2001). It is well known that other sexually transmitted infections provide a fertile ground for HIV.

The social dynamics of male promiscuity in some cultures perpetuate women's vulnerability to HIV infection (Tembo, 2001). These gender stereotypes lead to men having many girlfriends for sexual partners. Low educational status also adds to women's vulnerability.

The psychosocial impact of HIV/AIDS on women takes many forms. These include isolation due to discrimination and "media hype" (Bury *et al.*, 1992). Women may not like to mix socially due to physical appearance since they are more affected by any cosmetic asymmetry than men and of social "proscriptions" or stereotypes and

myths about women's appearance (Bury *et al.*, 1992). Poor self-image leads to anxiety and depression. Fear related to dying a slow and painful death, isolated from the people they know and care about nag their conscience (Bury *et al.*, 1992). Women also suffer profound grief due to loss of health and body image, sexuality and reproductive potential.

It is common that HIV positive women experience an overwhelming desire to leave behind some creation in the form of a child (Bury *et al.*, 1992:25), yet HIV/AIDS can negatively affect their fertility.

2.4 HIV/AIDS PROGRAMMES OR INTERVENTIONS: A GLOBAL PICTURE

Many and varied HIV/AIDS programmes have been developed world-wide; however, before citing these, it seems appropriate to briefly discuss the origin of the HIV/AIDS programmes, the features of a good HIV/AIDS programme and the principles observed in the implementation of such programmes.

2.4.1 THE ORIGIN OF HIV/AIDS PROGRAMMES

The HIV/AIDS programme world-wide commenced with assessment, an attempt to diagnose and provision of care, based on the signs and symptoms of illness presented. This was followed by diagnosis and ongoing surveillance. The commencement of the programme was influenced by the following historical events:

- Observance of clusters of extremely rare diseases by USA doctors in 1979 and 1980. This phenomenon was first reported in the Morbidity and Mortality Weekly report of the 5th June 1981 (Barnett & Whiteside, 2002:28).
- The observance of the first cases of AIDS in San Francisco (USA) during the summer of 1981 when a very rare type of pneumonia caused by pneumocystis carinii and kaposi sarcoma (a rare kind of cancer) was diagnosed in young homosexual men with lowered immune system. This was initially called the “Gay Related Immune Deficiency Syndrome” (Van Dyk, 1993; Illingworth, 1990; Snidle & Yeoman, 1997; Perrow & Guillen, 1990; Barnett & Whiteside, 2002).
- The naming of the disease as “AIDS” and commencement of surveillance by the Centres for Disease Control (CDC) in Atlanta-Georgia (Snidle & Yeoman, 1997).
- The isolation of a retrovirus and the disease called Lymphadenopathy Associated Virus (LAV) in France. This virus was found in the USA in 1984 and called Human T Lymphotropic Virus Type 3. It is today known that this was the same virus as LAV (Snidle & Yeoman, 1997).
- The development of the Elizer blood test to detect antibodies against HIV in 1985. The International Committee on Taxonomy of Viruses renamed the virus HIV or Human Immuno-Deficiency Virus (Snidle & Yeoman, 1997).
- The identification of HIV-2 in West Africa. According to Snidle & Yeoman (1997) it is believed that HIV-2 can cause AIDS; however, the

time from initial infection is much lower compared to HIV-1. The methods of transmission are the same though.

- The diagnosis of the first case in South Africa in 1982, approximately 16 months following the identification of the first case in the world. The discovery of this first case in 1992 and the screening of the donated blood for HIV in 1985 in South Africa marked the beginning of the HIV/AIDS programme (Department of National Health and Population Development, 1989).

2.4.2 SOME FEATURES OF A GOOD HIV/AIDS PROGRAMME

Before exploring the developed programmes it is essential to highlight some feature of a good HIV/AIDS programme citing an example of a country. Having been very successful in its fight against HIV/AIDS, Uganda reflects some of the characteristics of a good HIV/AIDS programme, which are strong political commitment; existence of support structures like AIDS commissions and councils, e.g. the Ugandan HIV/AIDS Commission; existence of strategic and operational plans; good co-ordination of services; existence of AIDS information centres; openness about HIV/AIDS, e.g. the Ugandan President was the first head of state to declare war against HIV/AIDS (DENOSA, 2001); existence of such programmes as voluntary counselling and testing, community mobilisation, mass media communication, a school AIDS education programme; a child and orphan welfare programme with political backing, free primary school education for all; a strong TB and STD programme; encouragement of cultural values that help support orphans within their families and communities as opposed to orphanages; training of families and communities in

home/community care, writing of wills, etc.; lastly encouragement of PLWHAs and orphans to live positively (DENOSA, 2001).

2.4.3 PRINCIPLES FOLLOWED IN THE IMPLEMENTATION OF HIV/AIDS PROGRAMME

These include involvement of PLWHAs, peer support and education, collaboration, an integrated approach, forging of partnerships, cultural sensitivity, community participation and empowerment, combating stigma, marginalization and isolation, ensuring exercise of universal precautions, building on success and respect for human rights (WHO/UNAIDS/UNISA/DENOSA, 2001).

2.4.4 TYPES OF HIV/AIDS PROGRAMMES

Some of the programmes that have been developed world-wide shall be discussed under the categories "Prevention" and "Care", citing examples.

2.4.4.1 Prevention

Prevention constitutes the best and most cost-effective way of managing HIV/AIDS.

The following are some of the measures taken world-wide to prevent HIV/AIDS.

2.4.4.2 Prevention of mother-to-child-transmission (PMTCT)

Looked at more widely, the efforts made to reduce MTCT constitute a way not only of reducing MTCT but also of reducing HIV transmission generally as well as its impact. Indeed a point of departure in the prevention of MTCT is the protection of women and men of becoming HIV infected (PAAU in Ilanga: 11/03/2002; UNAIDS, 1999: 6). It does not only entail the use of anti-retroviral drugs. It should be noted that regardless of interventions, two out of three babies of HIV positive mothers are born uninfected. In the developing countries the risk of infection is 30-35% where the HIV positive women breast-feed and 15-25% in the developed countries like the USA and Western Europe, where mothers do not breastfeed (Tapper, 2000). Examples of the methods used are cited below.

Cleansing of the birth canal during labour and delivery constitutes one of the methods of preventing MTCT. Vaginal lavage using an antiseptic, e.g. chlorhexidine, is done. The rationale behind this is that the antiseptic reduces the HIV load in servico-vaginal secretions, thus giving some protection to the baby as it passes through the birth canal (Tapper, 2000).

Scandinavian countries found that cleansing of the birth canal reduces vertical transmission (MTCT). In two clinical trials in Malawi and Kenya, it was found that the antiseptic did have a positive impact in a group of women who had early rupture of membranes as HIV transmission was low (Tapper, 2000: 46).

Vitamin A and multivitamin preparations are also used as a measure to prevent MTCT. Dr Fawzi in Tanzania found that vitamins increased maternal antibodies against HIV (Tapper, 2000). A Malawi study yielded similar results and this included general protection against the diseases of infants, especially those of the developing countries (Tapper, 2000).

Caesarean Section (C/S) is also a method of preventing MTCT that is used mostly in industrialised countries. It entails treatment of the mother with anti-AIDS drugs, delivery by C/S and supported by formula feeding. In these countries it has brought down the HIV infection risk to less than 5% (Tapper, 2000). In 1998, while under 1000 infants were infected in Western Europe, more than half a million children were infected in Africa (Tapper, 2000).

The use of Nevirapine constitutes one of the modern methods of preventing MTCT. Nevirapine is one of the drugs used in combination cocktail since 1996. In June 1999 it was found that a single dose of Nevirapine given to a woman during delivery and to the baby in the form of syrup during the first three days of life reduced the risk of HIV infection. Nevirapine is regarded as the most affordable and practical antiretroviral drug (\$4 per case). It is 200 times cheaper than the long AZT course and 70 times cheaper than the Thai short course of AZT. It also needs no refrigeration (Tapper, 2000) and stops the virus from replicating (belongs to the reverse transcriptase inhibitors drugs). In the mothers who do not breast-feed, most babies who get HIV infected, acquire the infection during the last trimester and two thirds of the babies acquire it during labour and delivery (Tapper, 2000:43). According to research findings, trials in Cote d' Voire and Burkina Faso suggest that the effects of

prophylaxis are maintained during the first 6 months of life (breast-feeding or not). However, the micro-biologist Phillippe van de Perre signaled a warning as follows: “although shorter regimens seem to be effective, in Africa the transmission rates are still higher than those of Europe and USA, therefore suggests avoidance of breast-feeding” (Tapper, 2000: 48). Prof Catherine Peckham added that “antiretroviral therapy of mothers who breastfeed is not immediately negated by increased post natal transmission, but if breastfeeding is continued for long, the beneficial effects of drug treatment is likely to decrease” (Tapper, 2000: 48).

Provision of family planning services and termination of pregnancy (TOP) where this is legal (e.g. South Africa) constitutes one of the ways to prevent MTCT (UNAIDS, 1999: 6). This enables women to prevent unwanted pregnancies and thus increase the number of babies with AIDS.

2.4.4.3 Commercial sex workers' programme

World-wide there have been HIV/AIDS programmes that target Commercial Sex Workers (CSWs) and their clients. An example is the High Transmission Areas (HTA) project of South Africa whereby trained people have been employed and placed at the identified areas of high HIV transmission like truck stopping stations, brothels, street dwelling areas, taverns, etc. to initiate the project. Such projects entail HIV/AIDS education, condom distribution, counselling, peer education, STD referral, income generation through undertaking specific projects (KwaZulu-Natal Department of Health, 1999).

The rationale behind this approach is based on the views of legal and ethical experts and UNAIDS' guidelines, which maintain that laws prohibiting sexual activity between consenting adults in privacy like adultery, sodomy, etc. can impede the provision of AIDS programmes. Examples of reforms in this area are that in Russia, a law criminalising homosexuality enacted over 70 years was repealed in 1992 (Watchirs in UNAIDS, 1999). In South Africa the rights of sexual minorities have been enshrined in the 1996 constitution and have recently been upheld in a challenge before the courts (Watchirs in UNAIDS, 1999: 55).

Other principles addressed are that the draconian (severe or inflexible) measures of law enforcement around the area of AIDS should be avoided and that there should be no victimisation of CSWs. However, victimisation like the use of children as sex workers and adults who are trafficking into the industry should continue being subjected to criminal penalties. If the fear of prosecution and harassment by police is removed, CSWs will be more likely to attend health services on a regular basis for advice, counselling, testing, treatment, etc. In the commercial sex industry the appropriate features of the law should therefore include elimination of mandatory HIV testing, and an appropriate code of conduct introduced, e.g. provision of condoms by the management, managers and clients prohibited from requiring unsafe sex and also the classification of Commercial Sex Workers as employees with industrial benefits who contribute towards income tax (Watchirs in UNAIDS, 1999: 57). For example, the Forum of CSWs in Calcutta i.e. India, which has lobbied parliamentarians on the issues of HIV/AIDS and legal recognition of CSWs' rights and the National Conference of CSWs (held in November 1997), were both attended by the Union Home Minister (India).

2.4.4.4 Blood transfusion and HIV

The risk of contracting HIV from transfusion of contaminated blood is 90%. Various countries have taken drastic steps to ensure the safety of blood used for transfusion. South Africa, for instance, started screening donated blood for HIV in 1985. In 1993 the Ugandan Blood Transfusion Service study showed that it was cost-effective for the Government to subsidise proper HIV screening by preventing a total of 2278 infections (Watchirs in UNAIDS, 1999). The India Supreme Court ordered the creation of a National Council for Blood Transfusion, the licensing of Blood Banks and following an NGO petition, ended the professional sale of blood (Watchirs in UNAIDS, 1999).

When dealing with blood transfusion, authorised persons need to ensure that there is an informed consent by the recipient of the donated blood; that there is a national non-profit blood transfusion service accountable to the Government, as is the case in Namibia, South Africa, Zambia, Zimbabwe etc.; that blood donation is voluntary rather than using hired donors; lastly, that blood is screened for HIV, Hepatitis B and C as well as syphilis (Watchirs in UNAIDS, 1999).

2.4.4.5 Voluntary counselling and testing

Voluntary Counselling and Testing (VCT) constitutes one of the most important programmes implemented by countries. In South Africa this programme initially used the Elizer Test to screen blood for HIV. The programme was based on ATICs (AIDS Training, Information and Counselling Centres) and funded by the Department of

Health; it has since been intensified through increasing the number of sites and using the Rapid Test kits (DOH, 2000: 16). One of the important legal/ethical aspects of VCT is informed consent; this protects health workers against legal proceedings. In the Netherlands, for example, a person has a legal right not to be informed of test results (Watchirs in UNAIDS, 1999). Quality control should be exercised with the use of home test kits and should be legislated if government opts for using the method. In South Africa, for example, home testing is not supported because of the loss of counselling opportunity, the potential for misinterpretation of results as well as inappropriate and secret use by employers, insurers, etc. Legislators need to provide mechanisms for individuals to obtain redress by making use of a medical ombudsperson; this is more accessible, quick and cheaper than the courts (Watchirs in UNAIDS, 1999).

Obligatory testing targeted at some groups in some countries, e.g. pregnant women, the military, couples seeking to marry, migrant workers, refugees, travellers, etc. is the violation of non-discriminatory principles (Watchirs in UNAIDS, 1999).

The European Court of Justice has maintained that subjecting candidate employees to disguised HIV testing without informed consent is illegal. In countries like Uganda, South Africa and others, HIV prevalence is monitored using sentinel surveillance (use of blood drawn and collected for another purpose). In Netherlands, a person may legally object to sentinel testing if he/she wishes; this is supported by the law (Watchirs in UNAIDS, 1999).

2.4.4.6 Sexually transmitted infections (STIs) and barrier methods programme

a) STIs

This refers to the intervention focusing on diseases that are transmitted through sexual intercourse other than HIV, e.g. syphilis. Nowadays the approach adopted is referred to as the Syndromic Approach. The approach was recommended by WHO (World Health Organisation) to all countries. The adoption of this approach is based on the facts that contracting HIV infection during a single episode of hetero-sexual intercourse is less than 1% if no other STI is present (Department of Health or DOH, 1998); the risk of HIV infection increases 4-5 times in the presence of a discharge; while the risk increases 8-10 times if there is a genital sore/ulcer. In a Tanzania (Muanza) study, it was found that improved STI management using the syndromic approach reduced HIV infection rates by 42% (DOH, 1998). Drug protocols have been drawn up to treat the most common causes of each syndrome, e.g. drugs are prescribed to treat a discharge in gonorrhoea and chlamydia rather than wait for the diagnosis.

The rationale behind the adoption of the syndromic approach is that many STIs do not cause typical symptoms; mixed infections are common; laboratory tests are expensive and difficult; treatment is given at first point of contact, and there is more time for providing IEC (Information, Education and Counselling). It is therefore cost-effective (DOH: 1998).

The above approach to STI management maintains that completion of treatment (Rx), Counselling, Condom Promotion and Contact Management (4 "C"s) are the important

strategies in STI management (DOH: 1998). Internationally, the focus in the management of the STI programme is mainly on capacity building (training) on the line of human resources in the public and the private sector. It is interesting that research findings have attributed the lack of reduction in the STI infection rate in South Africa to (amongst other things) the judgmental attitudes of health workers (DOH, 1998). A non-judgemental attitude is therefore regarded as important in the control of STIs.

b) Barrier Methods

Condom use has been encouraged not only for preventing STIs and HIV/AIDS but unwanted pregnancies as well. So far the male condom is predominantly used worldwide. A female condom has been developed and in South Africa (including KZN) it is still undergoing trial. Quality condoms, which meet the South African Bureau of Standards, are provided free of charge to the public (DOH, 1996). The criteria for quality condoms include the following: being made of latex rubber, having an expiry date, having a heatproof cover, having water base versus oil base lubricant and having no holes. Chemists and the private sector also provide condoms in South Africa; the former provide them at a cost though.

A KAP (Knowledge, Attitude and Practice) study that was undertaken in Region H of the Uthungulu South District of KZN in 1998, found that 50% of sexually active people were using condoms (KwaZulu-Natal Department of Health, 1998).

2.4.4.7 Information, education and communication (IEC) programme

World-wide this programme has included public education through mass media, training of HIV/AIDS Educators, and life-skills education for youth in and out of schools.

a) Life-skills Education

The Wedge Programme of San Francisco serves as an example of a good, well sustained life-skills education programme which operates in and out of schools helping young people acquire skills such as decision making, assertiveness, self-confidence, ability to overcome peer pressure, HIV/AIDS and STI prevention, etc. (The Wedge Programme, 1995). In South Africa life-skills education (LSE) for youth in schools has been incorporated into the school curricula (DOH, 2001), while NGOs manage LSE for youth out of schools.

b) IEC

IEC initiatives have always been at the forefront of other HIV/AIDS interventions world-wide. One example is that of South Africa whereby, since the launch of “partnership against AIDS” initiative in 1998, the South African Government exploits every public holiday to educate the public on HIV/AIDS and the related problems, e.g. Valentine’s day, Human Rights day, Workers’ Day, World TB Day, Youth Day,

Women's Day, etc. (Government's AIDS Action Plan or GAAP), 1998). On these public holidays, HIV/AIDS messages are moulded into the type of a public holiday.

2.4.4.8 Other preventive interventions/ programmes

2.4.4.8.1 Closure of transmission sites

The "bath-houses" in the USA, especially in New York and San Francisco, were closed in order to prevent HIV spread (Perrow & Guillen, 1990: 30).

2.4.4.8.2 Exchange System of Needles

In Amsterdam in the Netherlands, a needle exchange and syringe programme was developed by an NGO called Return Foundation in St Pietersburg, through an outreach programme. This entailed an exchange system for needles, distribution of condoms to prostitutes who are drug users, distribution of leaflets on Intravenous Drug Use (IDU); drugs and AIDS education programmes started at homes and schools, and providing guidelines to parents and teachers. The use of bleach was encouraged for needle and syringe sterilisation (Macklin, 1989: 60). In Nepal this programme has contained HIV prevalence under 2% while it has increased among IDUs in the neighbouring countries (Macklin, 1989:60).

2.4.4.8.3 Harm reduction approach

This has proven effective in reducing HIV transmission amongst Intravenous Drug Users (IDUs). The approach accepts that illicit drug use is entrenched in many countries. It includes education (especially peer education); promotion of the use of

sterile injecting equipment, removing obstacles that prevent access to sterile materials, e.g. policing and legal barriers; increasing availability and accessibility of drug treatment; increasing access to primary health care especially through services designed to be friendly to IDUs, and research and education undertaken in collaboration with the community (WHO, UNAIDS, UNISA and DENOSA, 2001:12). This approach has been introduced in Nepal, Australia, New Zealand and parts of Western Europe, e.g. the Netherlands and Switzerland (Macklin, 1989; Watchirs in UNAIDS, 1999).

2.4.4.8.4 Decriminalisation of drug use

This has had trials for lawful heroin use in Switzerland, while the Netherlands provides it to users who did not succeed in previous treatment. Evaluation of both the needle exchange and decriminalisation of drug use programme have shown that these programmes have not encouraged greater use of drugs but increased the demand for drug treatment, decreased the number of unsafely disposed equipment and helped to contain AIDS. These studies have been done in North America, Europe, Asia and South Pacific (Watchirs in UNAIDS, 1999: 53).

2.4.4.8.5 Universal precautions

Health workers can protect themselves and their client/patients against HIV infection by applying universal precautions, whereby all people and materials handled be regarded as potentially HIV infected (Van Dyk, 1993; Bury et al., 1992). All infection control measures should be observed and invasive procedures avoided

wherever possible, and medical waste safely and properly managed, as it also ensures appropriate supply management (John Snow Inc., 2003).

2.4.4.8.6 Work-place programmes

To be successful, the work-place programmes should involve participation, continuity, appropriate messages, condom availability, control of Sexually Transmitted Infections, health care and support, supportive policies and peer education (Fitzsimons, Hardy & Tolley, 1995).

In Zimbabwe David Whitehead Textiles commenced an HIV/AIDS Programme in 1989 (Fitzsimons & Tolley, 1995). This work-place programme included training, Education, provision of condoms and funding of a theatre group. As a result of these interventions there was a fall in Sexually Transmitted Infections (STIs) at the Chequtu Factory by 53% between 1989, and in 1992 by 75% (Goss & Adam-Smith, 1995).

At Rio Tinto in Zimbabwe, training of volunteers was undertaken in 1990, AIDS Support Groups formed, and condoms provided in the change rooms, beer halls and social clubs within the premises of the company (Fitzsimons et al., 1995). This proved very effective (Fitzsimons et al., 1995).

The Eastern Highlands Tea Estates in Zimbabwe started peer education programmes in 1991 and campfire counselling meetings where workers talked openly about sex and STIs. On evaluation, the programmes showed effectiveness.

The Zimbabwe Congress of Trade Unions has also focused on awareness and Information, Education and Communication (IEC) as well as human rights issues (Fitzsimons et al., 1995: 350).

The Body Shop International PLC Company has established work-place programmes in the USA, India, Nepal and England (Head Office). This company uses World AIDS Day as part of Body Shop's campaigns, whereby their offices are covered by big red ribbons (Fitzsimons et al., 1995). The Chad Cameroon Oil Pipeline, supported by the World Bank, has incorporated HIV/AIDS prevention interventions (Watchirs in UNAIDS, 1999).

Goldfields in South Africa have embarked on a rigorous prevention programme facilitated by trained peer educators (DENOSA, 2001:24).

2.4.4.8.7 Involvement of people living with HIV/AIDS (PLWHA)

Programmes involving PLWHA have been developed around the globe. Examples are the Wedge programme of San Fransisco whereby PLWHAs who go public with their HIV status are deployed to various areas, especially schools to address audiences and educate people to protect themselves against HIV, and thus putting a face to AIDS. A central authority regulates their operation including their training. To prevent stigma, PLWHAs involved are commonly referred to as "speakers". On evaluation this programme was found very effective among school children regarding attitudinal changes towards PLWHAs and the delay of sexual activity as long as possible (The WEDGE Programme, 1995 and the researcher's personal participation and observation).

The FACEs Project in South Africa commenced in 1996 as a government initiative. It involved employment of PLWHAs who were public with their HIV status. These were trained and gradually placed in each district. Their responsibilities included HIV/AIDS education, counselling (including peer counselling), establishment of support groups who engage (amongst other activities) in income generating projects and advocacy on relevant human rights issues (KZN DOH: 1996).

GIPA (Greater Involvement of People with AIDS) is a UNAIDS project which came about as an outcome of the Paris Summit of Leaders of States in 1994. It was aimed at strengthening the involvement of PLWHAs in the National HIV/AIDS programmes. It was initially piloted in Malawi and Zambia (1997), using National United Nations volunteers and GIPA field workers placed in various sectors; in 1998 it was started in South Africa. It involved capacity building and provision of micro grants for support groups (UNAIDS, 2000:24).

2.4.4.8.8 Initiatives involving ethical and legal aspects (addressing discrimination)

In view of discrimination (coupled with stigmatisation) constituting a stumbling block in the efforts that are made to combat HIV/AIDS, there is a need to design Information/Education and Communication programmes that rigorously address discrimination, thus creating a conducive environment for those infected and affected by HIV/AIDS. Behaviour towards PLWHAs should demonstrate a non-discriminatory attitude. Examples of prominent interventions against discrimination

are amongst others the MTV video programme referred to as "Staying Alive" that was broadcast on World AIDS Day in 1998, targeting the youth and addressing discrimination and other behaviours globally (Watchirs in UNAIDS: 1999); the late Princess Diana of Wales publicly made physical contact with PLWHAs by shaking hands, hugging or kissing them (Watchirs, in UNAIDS: 1999); workshops for parliamentarians were held in Honduras, Mozambique, Panama, etc. to raise awareness and sensitise politicians on human rights, which has proved successful in *creating a non-discriminatory climate in parliaments; and the going public of the then Honourable President Kaunda of Zambia acknowledging that his son had died of AIDS* also had a positive impact on addressing discrimination (Watchirs, in UNAIDS: 1999).

According to Watchirs in UNAIDS (1999), to address discrimination, a Member of Parliament in Britain spoke of his brother's death from AIDS. In January 1999, a two-day workshop was held on HIV/AIDS, Law and Ethics; which targeted the judiciary in some countries, e.g. one held in Mumbai (India) whereby a keynote address was given by Judge Edwin Cameron of South Africa and Justice Michael Kurby of Australia. On 20 April 1999, Justice Cameron publicly disclosed before the South African Judicial Commission that he was a PLWHA (Watchirs in UNAIDS: 1999). Many campaigns have been run on discrimination, e.g. Australia and Spain. In 1992, for instance, Australia launched a campaign that supported Disability Discrimination Act of 1992 (Watchirs in UNAIDS: 1999). Lastly, in Australia there is a project which targets health care workers (HCWs) by reviewing institutional and professional matters linked to discrimination (Watchirs in UNAIDS, 1999).

2.4.4.8.9 Vaccine development

The world is currently in a struggle to develop an effective and accessible HIV vaccine to strengthen the currently available preventive measures, because the presently used methods have only slowed down the spread of HIV infection rather than stopping it. The current treatment has done something similar in the countries where they are used; it has neither cured nor stopped HIV/AIDS and is teeming with a lot of challenges (ICASO, 2000). The process of developing a safe and effective vaccine will take many years, considering the 3 long phases involved (ICASO, 2000). In the 15 years since HIV was identified, over 30 candidate vaccines have been tested in Phase one (ICASO, 2000). Only one vaccine concept has progressed to Phase III efficacy trials and only two have progressed to Phase II. Two Phase III trials are under way in Canada, the Netherlands, Puerto Rico and the USA, primarily in men who have sex with men (MSM), based on HIV sub-type B (ICASO, 2000: 5).

The other trial is being undertaken among Intravenous drug users (IDUs) in Bangkok, based on sub-type B and C. The results from this trial would be available in 2002 or early in 2003. In South Africa the Medical Research Council is in the preliminary stages of developing Clade C. HIV Vaccine, which will be suitable for Africa (ICASO, 2000 and Watchirs in UNAIDS, 1999). Vaccine trials are also taking place in other developing countries, e.g. Phase I in Brazil, China, Cuba and Thailand x3; Phase II in Thailand x3 and Uganda, plus Phase III in Thailand (Watchirs in

UNAIDS, 1999; ICASO, 2000). It would appear that there is still a long way to go before an HIV vaccine becomes available.

2.4.5 CARE AND SUPPORT

While "Care" also has a preventive element, it constitutes a special essential strategy against HIV/AIDS, especially at the current phase of the pandemic with increased numbers of people who have HIV/AIDS. Counselling and support forms an integral part of care. Regarding counselling, Kelly and St Lawrence (1988) as well as Van Dyk (1993) assert that human resource training is of utmost importance if a programme is to be successful.

Cameron (1993) emphasises the need to also care for "the dying" person. He maintains that while much is done to be with the bereaved, not much is done to be with "the dying" person. In view of this omission, it is of importance that the care of "the dying" be part of human resource development on care, counselling and support. According to Cameron (1993: 80), the dying person needs to be surrounded by his/her loved ones; this helps the person die peacefully. To Cameron (1993: 80) health workers in particular need to be trained to "facilitate a good death". The author maintains that a good death has characteristics such as acceptance of death; view of death as part of life; personal control; dignity, not suffering; peace with people; peace with higher power or God; belief in a pleasant after-life, and loved ones by one's side (Cameron, 1993). Research suggests a need to educate society, health care personnel, dying individuals and loved ones on how to die well (Cameron, 1993). This view of a "good death" is shared by Snidle & Yeoman (1997) who, on a religious perspective,

maintains that patients should be helped to “die into life” whereby a dying person travels mentally to the cradle and not to the grave.

2.4.5.1 Antiretroviral therapy

This entails the administration of drugs which suppress the growth and multiplication of HIV. These drugs have prevented or delayed the progression to AIDS and death amongst the HIV positive people treated (UNAIDS MAP Network, 2000).

The Highly Active Antiretroviral Therapies (HAART) have been available since 1995/96 in the industrialised countries. These have improved survival, decreased annual AIDS incidence and decreased AIDS mortality. However, since 1998, there has been no reduction in AIDS cases and deaths in many of these countries. For instance the UK (England and Wales) had a 13% increase in the number of cases. In Canada, cases increased from 40,000 to 49,000 in 1999. This is thought to be due to intolerance, drug resistance, late diagnosis of HIV, refusal of treatment by a number of people and exhaustion from taking large amounts of drugs daily (UNAIDS MAP NETWORK: 2000).

Based on this finding it is of utmost importance that a balance be struck between care and preventive initiatives. Watchirs in UNAIDS (1999: 80) asserts that “Consumer Protection Products Liability or Therapeutic Goods Legislation need to ensure that fraudulent claims regarding the quality, safety and efficacy of HIV related drugs, vaccines and medical devices are prohibited and effectively enforced.”

The availability of antiretroviral drugs (ARVs) in the developing countries is hampered by the fact that there are still a number of new HIV infections diagnosed each year. According to Watchirs in UNAIDS (1999: 81), the issue of price is particularly problematic in developing countries; as “cost of safe and effective treatment drugs, particularly ARV triple therapy is a significant barrier to accessibility”. In Costa Rica the government is obliged, through the ruling of the Supreme Court, to provide free HIV treatment under its National Health System (Watchirs in UNAIDS, 1999). Albania and Brazil have had similar court rulings. An NGO called FASE in Spain has been working for 5 years to have AIDS (now HIV infection) to be considered a chronic disease under the court of law. As a result since December 1995, ARV drugs are given free of charge and non-retroviral drugs obtained at 10% discount (Watchirs in UNAIDS, 1999).

In Argentina too, 8 NGOs presented a petition for state protection against the Ministry of Health in 1996. The courts have consistently found that the Ministry is obliged to provide full treatment free of charge to PLWHAs who cannot pay for them and are not covered by social security (Watchirs in UNAIDS, 1999).

2.4.5.2 Home-based care (HBC)

Health Institutions have become so overburdened with HIV/AIDS patients that Home Based Care has become a necessity. Home Based Care refers to the care that is rendered at home in order to promote, restore and maintain an individual's maximum level of comfort, function and health (Doctors For Life, 1998; Nzimakwe, 1999; National Department of Health, 2000).

The models of Home Based Care world-wide are many and varied. Besides Zambia (Chikankata) and Uganda having one of the best and older models, South Africa has also developed a comprehensive HBC programme (with an exclusive budget) and human resources (KZN DOH, 1999). Three models have emerged in this programme viz. the Hospice based, the NGO based and the Health Sector based HBC. Furthermore an integrated approach involving the Department of Health, NGO/CBOs, the Department of Social Development and the Department of Education has been adopted in HBC. As part of this approach, HBC is rendered to all those who need it (regardless of their HIV status); and TB prevention and nutrition activities are incorporated into HBC (KZN DOH, 1999).

2.4.5.3 Orphans support programmes

HIV/AIDS has been responsible for the death of women and men, leaving orphans behind who need care and support. Various countries have developed orphans support programmes, a few of which will be cited like the Buddy programme in India whereby a child is adopted by a buddy (pal) in a developed country who sends medicines for opportunistic infections or antiretroviral drugs (if needed). In return, a child/parent/guardian sends pictures and letters (Lyons & Lerner-Weiss, 1999). Homes for orphans have been established, e.g. India NGOs and CBOs have found a few homes for children orphaned because of AIDS although according to experts orphanages should be the last resort (Lyons & Lerner-Weiss, 1999). There are about 12-15 orphanages and also over 50 informal Child Care institutions (McDermott et al., in Tapper, 2000).

Save Children) in 1986. It promotes community based fostering, operates relief and welfare programmes and advocates for children's rights (Hunter, in Lyons & Lerner-Weiss, 1999). Zambia on the other hand has the largest Orphans Support Project called the Chikankata Orphans Support Project funded by UNICEF. It is community based and benefits 1,500 children and their families; it is structured into small care and prevention teams (CPTs) that co-ordinate health and development activities. Within each CPT, Children in Need Committees were established at village levels to help identify and list orphans and to report to and work with CPTs. They are involved in ensuring that children go to school and receive adequate care, sensitising and mobilising people to provide resources for burdened families and putting up communal structures that orphans and other children can access, e.g. communities secure free tuition by contributing labour to the construction of school structure and thus get a tuition waiver in exchange for their labour (Tapper, 2000). Older orphans get skills training to enable them to fend for themselves. Children identify their needs themselves.

Income/ wealth generating ventures for families have been developed so that they are able to look after orphans and prevent a negative attitude whereby families see orphans as a burden. Zambia had 800,000 orphans and 75% of all households took care of at least one orphan. By the year 2000, however, the country had 90,000 street children who had run away from ill treatment; in 1997 this Figure was 36,000 (McDermott et al., in Tapper, 2000). According to McDermott et al in Tapper (2000: 154), most of these children "go onto the streets because their parents have died of AIDS".

Religious Institutions in both Uganda and Zambia provide strong support for orphans and advocate for their rights. As a national response to the AIDS crisis, Zambia is presently having an array of church organisations (NGOs and CBOs) working with children affected by AIDS; the coverage by these organisations though is only 10% (Hunter in Lyons & Lerner-Weiss, 1999).

Child Participation in Orphans Care in Malawi serves as a good example of “Child participation in Orphans Care.” The family or community mechanism of bringing up orphans involves children. Most of the time, it is other children who identify children that the Village Orphans Committee (VOC) has not thought of including. The VOC operates relief and welfare programmes as well as promotes respect for children (Hunter in Lyons & Lerner-Weiss, 1999).

In Zambia the “Children in Need Network” links the organisations working with children and supported by UNICEF with \$42,000 annually. Among other activities, community leaders are trained in simple management in order to run community based care of orphans. UNICEF is assisting the government to set up a body to develop standards/guidelines to be observed by all sectors (Hunter cited in Lyons & Lerner-Weiss, 1999).

AIDS orphans are on the increase in South Africa including KwaZulu-Natal Province, as a result Thandanani Association in Pietermaritzburg (KZN) undertook an orphans community outreach project comprising the establishment of community “children in Distress” funds as well as capacity building in respect of Child Care Committee

members (Halkett, 1999: 52). Pietermaritzburg Child and Family Welfare has also developed a cluster concept of orphans care called CINDI (Halkett, 1999: 52).

2.4.5.4 Support groups for PLWHAs

In Uganda the Integrated Mobile Home Care Service caters for the needs of PLWHAs, their families and Orphans while AWOFS (AIDS Widows, Orphans Family Support) supports families of PLWHAs and orphans with grants and loans for Income Generating Projects. This includes vocational training, post-vocational support, counselling and care for child headed families (Hunter et al., in Lyons & Lerner-Weiss, 1999). NACWOLA (National Community of Women Living with AIDS) on the other hand empowers women in ways to reduce their vulnerability and dependency, provides legal advice for property ownership and runs a Memory Project to help parents talk about their children before dying so as to help them cope (Hunter cited in Lyons & Lerner-Weiss, 1999). Lastly, the GIPA, Faces and the Wedge projects cited under prevention above, form part of PLWHA support initiatives in this context since over and above having prevention and care interventions, they involve facilitation of the establishment of PLWHA support groups and provision of micro grants for running and sustaining the projects that are undertaken.

2.4.5.5 The service providers

World-wide, the service providers in HIV/AIDS are the public and the private sector. The public sector includes the Department of Health or DOH (which is often an

HIV/AIDS lead role player in most countries) and other government departments which have increasingly been getting involved in the HIV/AIDS programme, and establishing their own workplace programmes.

According to the African National Congress (1994: 71), “the Private Sector is a large industry consisting of a number of different institutions, organisations and personnel”. These include amongst other structures like the pharmaceutical industry, medical technology industry, private hospitals and facilities, medical aid schemes and a range of private practitioners including traditional healers (African National Congress, 1994: 71). Indeed these structures have participated in their own way not only in health care generally, but in the HIV/AIDS battle too.

In South Africa, other government departments have initiated their own workplace HIV/AIDS programmes through the support of the DOH initially but are now increasingly gaining independence but working collaboratively with the Department of Health. In many countries around the globe, like Uganda, all government departments have their own HIV/AIDS programmes (personal experience). In South Africa the Health Economics Research Department of the University of Natal (HEARD) has developed tool kits for these structures to develop their workplace HIV/AIDS programmes (personal experience in KwaZulu-Natal).

Non-Governmental Organisations (NGOs), Community Based Organisations (CBOs) and Faith Based Organisations (FBOs) have played a significant role in the HIV/AIDS programme. In many instances NGOs have paved the way for sustainable health care services at the community level and have the capacity to initiate

innovative services that are more sophisticated than the conventional health service provision (African National Congress, 1994: 71).

The difference between NGOs and CBOs is that NGOs are registered as non-profit organisations and may operate both internally and externally. Sometimes CBOs are registered and tend to only operate locally.

The NGOs and CBOs play a significant role in the HIV/AIDS programme; they complement the work of the Department of Health. Examples of such NGOs in South Africa are the Health Systems Trust, which runs a variety of projects including the Male Sexual and Reproductive Health Programme, the National Progressive Primary Health Care which has been primarily involved in Human Resource Development; the Treatment Action Campaign which has been lobbying for the provision of antiretroviral drugs by the government to the HIV infected; National Association of People Living with HIV and AIDS (NAPWA) which advocates for the rights of people living with HIV/AIDS (PLWHA); to name but a few (personal observations). Liu and Fangs (2000: 521) cite an example of the Beijing Association of STD/AIDS prevention and control as an NGO, which has played a significant role in AIDS prevention. Salds (2000: 262) asserts that the NGOs involved in the HIV/AIDS programme have contributed significantly to policy development in the Philippines.

The KwaZulu-Natal CBO Network has engaged in an integrated approach to the fight against AIDS in the sense that it has included Nutrition and TB in the HIV/AIDS Programme. This innovative approach which is gaining popularity at the time of this review was strongly supported by the former national Minister of Health, the

Honourable Dr Nkosazana Dlamini-Zuma and the MEC for Health in KwaZulu-Natal, the Honourable Dr Zweli Mkhize. The focus of the CBO Network in Northern KwaZulu-Natal (Senzokuhle) has been orphans care, nutrition, Home Based Care, TB, etc. (KwaZulu-Natal CBO network, 1996 and personal experience).

The examples of FBOs involved in the fight against AIDS are amongst others Sinethemba of McCord Hospital which has been involved in care, counselling and support of the infected and affected as well as income generation projects. Diakonia Council of Churches has been involved in AIDS awareness, human resource development, lobbying for support of the infected and the affected and organising special AIDS events like the marches against HIV/AIDS and poverty on Good Fridays (personal experience).

The business sector like Cadburys – KZN supported the AIDS campaign by the Department of Education and the Department of Health through material contribution to pupils and adults; the South African Beer Company (SAB) in 1996 funded the AIDS Foundation of South Africa to train traditional healers; while Unilever supported orphans in KZN by supplying toiletries through the Department of Health; to cite but a few examples (personal experience 1996, 1997 and 2003 respectively). These have also initiated their own workplace HIV/AIDS programmes, e.g. Toyota, Woolworth's, Ithala Corporate services etc. The workplace programme development have been supported amongst other organisations by the Department of Health, and tool kits that were developed by the Health and Economic AIDS Research Department (HEARD) of the University of KwaZulu-Natal, as well as a toolbox developed by Felicity Young, etc.

Tertiary institutions have also increasingly become involved in the HIV/AIDS programme of KZN as well as other Provinces; some of the examples are the University of KZN (formerly University of Natal) and the University of Zululand (Department of Speech and Drama). The former constitutes one of the oldest universities participating in the HIV/AIDS programme in KZN; it has initially focused on life skills education through drama working with KZL Departments of Health and Education (Dramaide report: 1993).

The international organisations have been involved in the HIV/AIDS Programmes in terms of financial donations for the implementation of programmes, provision of technical assistance, appropriate technology as well as “sharing of knowledge and experience” about successful programmes in other countries (African National Congress, 1994: 73). Examples of donors are the CDC (Centre for Disease Control in Atlanta), the European Union, etc. On the other hand examples of international NGOs implementing the HIV/AIDS projects are the USAID (United States Agency for International Development), John Snow Inc. (JSI of USA), etc. Both of the latter organisations are involved amongst other activities in Injection Safety projects funded with the USA President’s Emergency Plan For AIDS Relief (PEPFAR); this project has sites in South Africa, Botswana, Malawi, Tanzania, Haiti and Kenya (JSI, 2003; personal experience, 2004).

The United Nations Development Programme has undertaken a project focusing on poverty alleviation and HIV/AIDS with sites in KwaZulu-Natal, Eastern Cape and Limpopo (personal experience and UNDP, 2004). Hope World-wide, founded in

1991, based in the USA, mobilise communities to help fight HIV/AIDS, train care givers to offer care and support, and training and child care to people living with HIV and AIDS. They also track orphans and vulnerable children or OVC (NDOH, 2003).

It is noted that as the magnitude of HIV/AIDS grows, so does the participation and partnerships against HIV/AIDS; however, no study has been done to determine this growth.

2.5 THE SUPPORT SYSTEM

By a support system, the researcher refers to all that is required in order that a programme can be effectively implemented and sustained. It includes human resources, human resource development (including learning aids such as books, videos, etc.), research, funds, plans, policies, committees/forums/groups, councils, partnerships and political backing or support by high profile individuals. These will be briefly discussed.

2.5.1 HUMAN RESOURCES

Human resources simply refer to staff or people carrying out the work. According to Booyens (2000: 24) human resource is a factor that influence the “success and functioning” of the health system. Human resource is the most expensive item in a budget (Booyens, 2000: 24); it is estimated that 2/3 of the budget goes to salaries (Booyens, 2000: 189). Health Systems Trust (2002:11) maintains that “human resources are the bedrock of a well-functioning health system” and staffing needs to

be adequate in both quality and quantity". Adequate staffing can therefore not be overemphasised in combating the pan epidemic.

Initially HIV/AIDS programmes were managed and implemented by persons who were responsible for other communicable diseases, but later on as the epidemic grew, the programme became vertical at national and provincial levels in South Africa and thus acquired its own human resource (personal observation).

Schneider (1994: 10) asserts that "AIDS Action Teams cannot function adequately without personnel to implement the decisions".

2.5.2 HUMAN RESOURCE DEVELOPMENT

Human resource development refers to the education and training of personnel. According to Booyens (2000: 24), education and training is of utmost importance in providing a comprehensive health service to meet the health care needs of the population. Different organisations have had different categories and quality of staff for the HIV/AIDS programme. Even if staff can be adequately provided, the organisational goals cannot be met if they are not trained. Indeed staff training has received priority in the HIV and AIDS Programme world-wide. In South Africa AIDS Training, Information and Counselling Centres were the first structures established to provide staff training in AIDS Education and later Counselling (Department of Health, KwaZulu: 1989). The international organisations have also been heavily involved in human resource development, e.g. UNAIDS Kenya Workshop on Strategic Planning in 1990, John Snow Inc. Workshop on Injection Safety in Uganda

– 2004; to name but a few. Training is enhanced by learning aids such as books, videos, etc. many of which have been written and developed not only overseas but also in South Africa.

2.5.3 RESEARCH

Burns and Grove (1993: 16) in Brink (2000: 3) define research as “diligent systematic inquiry to validate and refine old knowledge and generate new knowledge”. In this context research has supported the HIV/AIDS Programme world-wide by providing the knowledge that has guided the implementation of the programme. Countless research projects on HIV/AIDS have been undertaken and the results used as a guide. An important research project that is being undertaken in South Africa is that of AIDS Vaccine Development. Research results have given the HIV and AIDS programme a direction, e.g. research on Prevention of Mother to Child Transmission and research on antiretroviral drugs gave a green light on whether these programmes could be implemented in the country.

2.5.4 FUNDS

Money constitutes the backbone of any service and has been the most important resource in the implementation of HIV/AIDS Services. Support systems such as human resource, human resource development and research mentioned above would not be possible without funds. According to Booyens (2000: 188), budget constitutes the basic financial document in most health organisations. The HIV/AIDS funds have been provided by the government (Taxpayers), international donors and countries like

the USA's PEPFAR (President's Emergency Funds for AIDS Relief), the business sector, and special funds, e.g. in South Africa some of the HIV/AIDS activities have been funded by the Reconstruction and Development Programme funds from 1994 (African National Congress, 1994: 142–146). Allocated budgets have increased with an increase in inflation and in the HIV/AIDS epidemic not only in South Africa but around the globe.

2.5.5 PLAN

According to Cuthbert, Duffield and Hope (1992: 15) and Ehrat (1994:37) in Booyens (2000:82) "planning is the cornerstone of good management and is grounded in the vision, mission, philosophy, goals and objectives of the organisation". Without planning it becomes difficult to give guidance to staff and the organisation becomes a "haphazard type of organisation". It gives direction and prevents wastage of resources in terms of time and personnel (Nel, 1986: 33 in Booyens, 2000: 82).

South Africa, for instance, developed a comprehensive strategic and operational plan referred to as a NACOSA Plan in 1994 and this was used as a guide throughout the country from 1994 (NACOSA, 1994). Other national strategic plans have been developed, the current of which is the 2000–2005 National HIV/AIDS Strategic Plan in South Africa (Department of Health: 2000). The previous governments did develop strategic plans, albeit very late (Department of National Health and Population Development's AIDS plan of 1990 and that of KwaZulu Department of Health, 1992). HIV/AIDS as a major health threat therefore needs a clear and sound plan in order that the already stressed personnel can be directed in their activities.

2.5.6 POLICIES

Like planning, policy formulation is of paramount importance in the implementation of HIV/AIDS programmes especially because it is a new disease and may be having a lot that is still unknown, besides, it is laden with controversies particularly the ethical aspects. According to Booyens (2000: 48) policies “ensure standardisation”, guidance and a “uniform response” from all involved.

In view of HIV/AIDS having been first identified in the western world, the first responses to it also commenced there. According to Goss & Adam Smith (1995:6-7) interventions have followed three stages in the western world, viz. the initial stage, which was characterised by policy development and limited government action, but with considerable efforts made by the groups. There was little scientific agreement about the virus, and growing media attention and concern from the public, with a lot of anxiety, which led to stigmatisation and identification of risk groups (Goss & Adam-Smith, 1995). The normalisation of AIDS (second stage) started in 1988. It was facilitated by the apparent slowing of the spread of HIV, decline in the fear and loss of public and media interest (Goss & Adam-Smith, 1995). Attempts to combat the pandemic were reactive and uncoordinated. Some employers began screening workers for HIV. Most governments were persuaded by the argument that universal compulsory HIV testing was impractical and unethical.

Introduction of an HIV/AIDS policy was emphasised as an alternative way by which employers could address the fears of HIV/AIDS (Goss & Adam-Smith, 1995). In the United Kingdom this period saw the publication of government guidelines relating to

employment practice. Adoption of a policy was limited to large companies and public sector employers (Goss & Adam-Smith, 1995). The USA started incorporating people living with AIDS (PLWHAs) into the “Americans with Disability Act”. It was the first policy of this kind in the European countries and occurred in 1988.

The United Kingdom developed a “declaration of the rights of (PLWHAs)” which had provisions for no HIV screening, a good working environment, and rights to privacy and protection against discrimination. Complaints related to AIDS were channelled through trade unions as reflected on the policy of the union (Goss & Adam-Smith, 1995). The policy covered protection from discrimination, provision of HIV/AIDS information to members, and measures to minimise the possibility of workers getting HIV infected at work settings (Goss & Adam-Smith, 1995).

In South Africa policies have been formulated on aspects like managing HIV in children, testing for HIV, management of occupational exposure to HIV, rapid HIV testing, feeding of infants of HIV positive mothers, ethical considerations for HIV/AIDS clinical and epidemiological research, prevention of Mother-to-Child HIV transmission and management of HIV positive pregnant women (Department of Health, 2000). KwaZulu-Natal developed policy guidelines in 1996 but focused on management of HIV positive adults and children as well as ethical considerations (KwaZulu-Natal Department of Health, 1996).

2.5.7 COMMITTEES/ FORUMS/ GROUPS

Structures/ Forums/ Groups constitute a pillar against which programmes like that of HIV/AIDS can lean and they have served as a think-tank for the entire programme. Examples of such structures are the AIDS Action Teams that were established in the majority of health wards in KwaZulu-Natal as well as the AIDS Task Group (KwaZulu Department of Health, 1993). Other structures that were developed before 1994 were those which brought together various health departments like KwaZulu, Department of National Health and Population Development, Natal Provincial Administration, House of Representatives, House of Delegates, University of Natal, Medical Research Council, AIDS Training and Information Centres, etc. They were called the Regional AIDS Group (a sub structure of the National AIDS group of that period), the NACOSA (National AIDS Convention of South Africa) 1994, the Provincial AIDS & STD Forum (PASFO) 1996, AIDS Media Committee 1996, etc.

2.5.8 COUNCILS

According to Pollard and Liebeck (2000: 181) a council is “an assembly of people to advise on, discuss or organise something”. In South Africa, the AIDS Council called the South African AIDS Council (SANAC), was established in 1999 while in KwaZulu-Natal an AIDS Council was established in 2000. AIDS councils in South Africa are composed of a wide range of sectors like NGO/CBOs, organised labour, academic institutions, the Traditional Healers Association, Faith Based Organisations, National Association of People living with HIV/AIDS, etc. They have terms of reference describing their structure, responsibilities and powers. SANAC is chaired by

the Deputy President and administered by the Government's AIDS Action Plan (GAAP) directorate while the KZN AIDS Council is chaired by the Premier and administered by the Provincial AIDS Action Unit (KwaZulu-Natal Department of Health, 2000).

2.5.9 POLITICAL BACKING/ SUPPORT BY HIGH PROFILE INDIVIDUALS

Nabarro David, a medical doctor who was a senior lecturer in the Liverpool University's School of Tropical Medicine (Department of International Community Health) often emphasised the need for all health programmes to have a political backing or support by high profile individuals in a country (personal participation in Health Interventions Class, 1988). In South Africa this has only been visible during the post 1994 general democratic elections period whereby the KwaZulu-Natal Cabinet launched a campaign against AIDS under the leadership of the then Premier of the Province, the Honourable Dr Ben Ngubane and the MEC for Health, the Honourable Dr Zweli Mkhize (Department of Health, 1997), following the results of the national HIV/AIDS review. Another significant example is that of the national launch of "partnership against AIDS" campaign by the then Deputy President of South Africa, the Honourable Dr Thabo Mbeki on October 9, 1998 (National Department of Health, 1998).

The above campaigns seem to have born sustainable fruit in the sense that as all sectors were called upon to participate in the struggle against AIDS, a significant increase in multi-sectoral responses have been observed.

2.6 CHALLENGES AND LESSONS LEARNT

By “challenges” the researcher refers to problems, or concerns people experienced during the implementation of the HIV/AIDS programme, and by “lessons learnt” the researcher refers to what people learnt in the course of HIV/AIDS programme implementation.

2.6.1 CHALLENGES

The early challenges of the programme were centred around blame, moral judgements, prejudice, denial, stigmatisation, discrimination, misconceptions and ignorance (Sabatier, 1988); the leaking of HIV positive results despite attempts to keep them confidential (KwaZulu DOH, 1992); claims by traditional healers that they could cure AIDS, to name but a few. The latest challenge is that the antiretroviral drugs have to be taken for the rest of one’s life; possible drug resistance, etc. (Sunday Times, 24/09/2003).

2.6.2 LESSONS LEARNT

In the course of HIV/AIDS programme implementation, a number of lessons have been learnt although documentation of these lessons has not received the necessary attention. Some of the lessons observed are that a disease must not be stigmatised from its budding stage because it will be hard to control and eliminate; the sufferers of a disease must never be discriminated against because this may fan the spread of the

diseases such as HIV/AIDS due to isolation and concomitant anger; human beings must be taught human sexuality as part of their upbringing so that communication becomes easy when sexually transmitted diseases strike.

2.7 CONCLUSION

This literature review provides base line information on what the researcher could possibly find under similar circumstances in the study of the genesis and the progression of the HIV/AIDS programme in KwaZulu-Natal.

Despite challenges faced in the implementation of HIV/AIDS programmes, many lessons have been learnt and role players have developed many and varied programmes as weapons to fight against HIV/AIDS, which, coupled with other factors like poverty, gender inequality, etc. constitute a major health and social problem in the world, particularly in Sub-Saharan Africa. Without the support system of human resources, human resource development, funds, plans, structures like committees and councils, policies, research, partnerships and political backing, it would be impossible to effectively implement HIV/AIDS programmes globally.

CHAPTER 3

THEORETICAL FRAMEWORK

3.1 INTRODUCTION

All the existing theories on nursing fit in varying degrees into the study of the genesis and the progression of the HIV/AIDS programme in KwaZulu-Natal, but the researcher has found Betty Neuman's Health Care Systems Model for Nursing as the most suitable for the provision of a theoretical framework for the study. The strength of the model is centred around its emphasis on prevention, health education, wellness, management of ill health and an inter-disciplinary approach; the aspects which play a prominent role in the fight against HIV/AIDS. However, prior to the discussion of the above model, it is of importance that a conceptual model be defined and explained in relation to a theory. This chapter will therefore deal with the discussion of a conceptual model and a theory, a full discussion of Betty Neuman's Health Care Systems Model for Nursing, justification for use of the model and the relevance of the model to identified aspects of the study.

3.2 DESCRIPTION OF A CONCEPTUAL MODEL AND A THEORY

3.2.1 CONCEPTUAL MODEL

Lipitt (1973); Nye and Berardo (1981) in Fawcett (1986: 1) define a conceptual model as "a set of concepts and the propositions that integrate them into a meaningful

configuration". The concepts of a conceptual model are highly abstract and general. These are not observed directly in the real world and they are also not limited to a specific person, group, situation or event (Fawcett, 1989:1). Furthermore, the propositions of a conceptual model are very abstract and cannot be observed directly or tested. Some propositions of a conceptual model provide a seedbed for further development (Fawcett, 1989: 1). According to Kirkpatrick (1994:1064) a *proposition* is a statement "for which something is affirmed or denied".

A conceptual model gives a conspicuous frame of reference for those who adhere to it, giving them a direction on what they ought to look at and ponder about. Of importance is that a conceptual model provides a guide on a worldview as well as the aspect of the world that an individual needs to take into consideration (Redman, 1974, Rogers, 1973, in Fawcett, 1989: 3). Conceptual models provide organisation for thinking, observation and making sense of what is seen; the models also provide an organised or systematic structure and justification of activities (Fawcett, 1989:3); give a guide in the search for questions around the problem; lead to pragmatic solution of problems and also provide general criteria for making a judgement whether a problem is solved or not (Fawcett, 1989: 3).

A conceptual model is applied if the purpose is to communicate a distinctive knowledge about a particular phenomena; it is also applied if the work is abstract, general and comprehensive, e.g. if the work identifies the physiological needs as an assessment parameter but does not explain the differences between normal and abnormal functions of the body systems (Fawcett, 1989: 27).

In a conceptual model three steps are required for its testing, i.e. formulation of a conceptual model, derivation of a theory from the conceptual model and assigning of operational definitions to the theory concepts, and lastly, a hypothesis is formulated (Fawcett, 1989: 27).

To Fawcett (1989: 28), “a model is a heuristic device that facilitates the understanding of a theory”.

3.2.2 THEORY

A theory constitutes “a statement that purports to account for or characterise some phenomena”. (Stevens, 1984 in Fawcett, 1989: 20). Like conceptual models theories are made up of concepts or propositions (Fawcett, 1989: 20); they may be descriptive, explanatory and predictive (Fawcett, 1989: 21).

Theories address phenomena with much greater specificity compared to conceptual models (Reese & Overton, 1970; Reily, 1975 in Fawcett, 1989: 20); this is a requirement in a theory. Theories are also attached more closely to particular people, groups, situations or happenings, e.g. blood pressure, social support, pulse, temperature, etc. Propositions of a theory are more specific; all theory concepts require definitions and these spell out how the concept has to be measured. Of importance is that all theories are developed from theoretical models (Fawcett, 1989: 24). If the work includes an intensive description of behaviour or how specific factors influence specific behaviours, the work is more likely a theory (Fawcett, 1989: 27).

It is therefore clear that a theory without a conceptual model would be incomplete

and a model with no link to a theory would not be eligible for use (Fawcett, 1989:28).

3.2.3 COMMENT ON THE USE OF CONCEPTUAL MODEL VERSUS A THEORY

According to Fawcett (1989: 28) “a conceptual model cannot be used directly but linked with one or more theories to form the conceptual-theoretical system of knowledge needed for action”.

Betty Neuman’s conceptual model is well linked to theories since it is believed to have derived within the systems category of theories (Steven, 1984 in Fawcett 1989: 186). Neuman has drawn on several theories, e.g. systems theory, stress adaptation, and Gestalt and Field theories. There are also elements of a developmental theory in her model (Pearson & Vaughan, 1986: 105-106). All the above theories stress how humans live in a “carefully balanced equilibrium” (Pearson & Vaughan, 1986: 106). If a problem arises tension ensues and disturbs the equilibrium. This disruption or disturbance constitutes the driving force that propels a person to interaction with the environment and thus adapt or change (Pearson & Vaughan, 1986:106).

Neuman states that she and her colleague Audrey Koertvelyessy “jointly identified the major theory for the model as the theory of *Optimal Client System Stability*” (Fawcett, 1989: 187). Neuman also states that several other theories are inherent within the model, which could be “clarified with the goal of optimising health for the client” (Fawcett, 1989: 187). According to Fawcett (1989: 187), although Neuman did not identify her model as a theory, her proposition of “prevention” could be considered the beginning of a theory (Fawcett, 1989: 187). Pearson and Vaughan (1986: 106)

state that although Neuman's model was initially used for the development of the curriculum, it has been tried and tested in clinical settings and as a framework for management. Other than minor difficulties, it seems to have been found useful in both areas.

Fitzpatrick and Whall (1983:215) assert that the model can be used for "conceptualisation of research problems and issues"; it can also be used to further the body of knowledge for nursing through researching the model itself.

For the above reasons and those that will be stated after a full discussion of the conceptual model, the researcher believes that Neuman's Health Care Systems Model for Nursing is credible and suitable for use in this study.

3.3 ASSUMPTIONS OF NEUMAN'S CONCEPTUAL MODEL

- Each individual or group as a client system is unique and a mixture of common factors.
- Many universal stressors exist (known and unknown) and each has a different potential for disturbing a client's ability to cope with a stressor.
- The client has variables, which are interrelated; these are physiological, psychological, socio-cultural, developmental and spiritual. These variables can affect the extent to which the client reacts to a stressor or stressors.

- Over time each client system has acquired a normal range of responses to the environment.
- When the line of defence is no longer able to protect the client system against a stressor, the stressor gets into the line of defence.
- When a client is in good health or illness, he/she is a “dynamic mixture of the interrelationship” of the physiological, psychological, socio-cultural, developmental and spiritual.
- Inside each client system there is a set of internal resistance factors referred to as lines of resistance which help the client obtain homeostasis (Fawcett, 1989: 171).
- Primary prevention refers to general knowledge applied in client assessment, identification and reduction of risk factors related to the stressors from the environment (Fitzpatrick & Whall, 1983:204).
- Secondary prevention refers to the symptoms following a reaction to stressors, prioritisation of actions and treatment in order to reduce symptoms including early detection and treatment (Fitzpatrick & Whall, 1983: 204).
- Tertiary prevention refers to the adaptation processes which take place at the beginning of reconstitution and the maintenance factors taking the client back

towards primary prevention (Fawcett, 1989: 171; Fitzpatrick & Whall, 1983:204).

3.4 CONTENT OF THE MODEL OR CONCEPTS OF THE MODEL

(a) Person

- This is a client system consisting of the physiological, psychological, socio-cultural, developmental and spiritual variables. The word client is used because it honours respect for the “client caregiver collaborative relationships” and wellness perspectives of the model (Neuman in press: in Fawcett, 1989: 172).
- Client is seen as an open system interacting with the environment.
- Physiological variables refer to the structure of the body and function, psychological variables to cognitive processes and relationships, socio-cultural variables to social and cultural functions, developmental variables to developmental processes of life and spiritual variables to the spiritual aspect. Spiritual variables are seen as a continuum from complete unawareness or denial to a consciously developed high level of spiritual understanding. The five variables are interrelated in each client system (Fawcett, 1989:172; Fitzpatrick & Whall, 1983: 207-208).
- Neuman has developed a graphic presentation of the client system with a central core surrounded by rings as seen in Figure 2. The core central rings represent three mechanisms that protect the basic structure. The outer ring is the flexible line of defence, which serves as a buffer for the client’s normal state. Its ideal function is to protect the client system from invasion by stressors (Fawcett, 1989: 173).
- The flexible line of defence is thought of as a “dynamic, accordion-like mechanism”, rapidly expanding away from or drawing closer to the normal line of defence. When the flexible line has expanded away from the normal line of defence, greater protection against stressor invasion is provided, when it draws closer to the normal line, less protection is provided (Neuman in press, 1985 in Fawcett, 1989: 174).

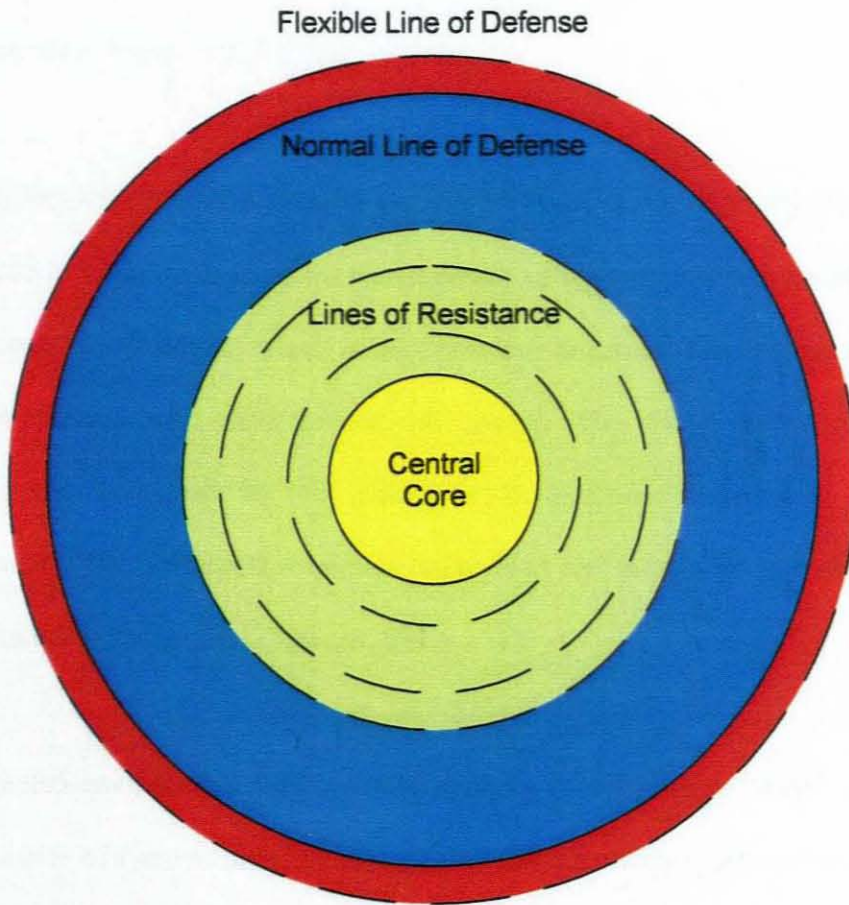
The normal line of defence is situated between the flexible line of defence and the lines of resistance. This second protective mechanism is the client normal state. Expansion of the normal line of defence reflects an enhanced wellness state, while contraction reflects a reduced state of wellness.

The innermost cocentric rings are the lines of resistance. This third protective mechanism is involuntarily activated when a stressor invades the normal line

of defence. The lines of resistance attempt to stabilise the client system and foster a return to the normal line of defence such as mobilisation of white blood cells. If the lines of resistance are effective, the system can reconstitute. If they are ineffective, death may ensue (Neuman in press, 1985: in Fawcett, 1989: 174).

- The flexible line of defence protects the normal line of defence and the line of resistance protects the basic structure.
- The flexible line of defence is immediately called into action when the client system encounters a stressor and attempts to maintain stability (Fawcett, 1989: 174). Refer to Figure 2.

Figure 2: Neuman's Health Care Systems Model for Nursing



Graphic representation of the client system (Adapted from Neuman, B & Young, R J (1972) in Fawcett, 1989: 173)

(b) Environment

According to Neuman, “environment is that viable arena which has relevance to the life space of the system” (Neuman in press, 1985: in Fawcett, 1989: 175). It is all internal and external factors or influences surrounding the identified client system (Fitzpatrick & Whall, 1983: 210).

The relationship between the client and the environment is reciprocal. The client may influence or be influenced by the environment. Neuman identifies the environments, viz. internal environment, which is intra-personal in nature. The external environment is interpersonal and extra-personal in nature. The third environment is sub-consciously developed by the client as “a symbolic expression of system’s wholeness”. The created-environment supersedes and encompasses both the internal and external environments (Fawcett, 1989: 175).

The created-environment acts as an immediate or long range “safe” reservoir for maintenance of systems integrity expressed either consciously, unconsciously or both (simultaneously). The created-environment is dynamic and represents the clients’ subconscious mobilisation of all the variables of the system including the basic structure energy factors, forward system integration, stability and integrity. Its function is to offer a protective shield or safe arena for a system’s function. It is based on the unseen unconscious knowledge, self-esteem and belief influences, energy exchanges, and system variables (Fawcett, 1989: 175).

Neuman classifies stressors as intrapersonal, interpersonal and extra-personal. Intrapersonal stressors are within the internal environment of the client/client system and include such forces as auto-immune responses. The interpersonal stressors occur at the boundary between the client and the proximal external environment and include forces such as role expectations and communication patterns. Extra-personal stressors are also in the external environment. They occur at the boundary of the client system and the distal-external environment and include forces such as financial concerns or social policies (Fawcett, 1989: 176).

(c) Health

Like Fawcett (1989: 176), Neuman sees health as synonymous with wellness. It is defined as “the condition of optimal stability of the client system”. To Neuman, when the needs of the client system are met, a state of optimal wellness exists and when the needs of the client are unmet, a state of wellness is reduced (Neuman, 1989: 176).

Reconstitution takes place after the person’s reaction to stressors (Fitzpatrick & Whall, 1983:209). It involves the return and maintenance of the system’s stability subsequent to treatment of stressor reaction. If reconstitution does not take place, death follows.

(d) Nursing

According to Neuman, nursing has to do with all the variables affecting a person’s response to stressors (Fawcett, 1989: 177). Nursing’s major concern is keeping the

client system stable through accuracy in accessing the effects of environmental stressors and assisting the client's adjustments required for an optimal wellness level. The goal of nursing action is to help the client in creating and shaping reality in a desired direction related to retention, attainment and /or maintenance of optimal system wellness through purposeful interventions, which are directed at reducing stress factors and unfavourable conditions which affect or can affect the functioning of the client.

Neuman presents a nursing process format comprising nursing diagnosis, nursing goals and nursing outcomes. Nursing diagnosis includes obtaining the appropriate data that identifies, assesses, classifies and evaluates the dynamic interactions among the physiological, psychological, socio-cultural, developmental and spiritual variables consisting of a client system. The first step of the nursing process is concluded when a nursing diagnostic statement is made (Fawcett, 1989: 178; Fitzpatrick, 1983:268).

The second step of the nursing process entails the formulation of nursing goals, and this is done in negotiation with the client for the attainment of desired changes. The third nursing process step is nursing outcomes intervention strategies, using one or more aspects of prevention as intervention modalities are implemented. Primary prevention is described as the action required to retain client system stability, the secondary prevention is the action needed to obtain systems stability and the tertiary prevention is the action to maintain system stability (Fawcett, 1989: 178; Fitzpatrick & Whall, 183:207).

According to Neuman in Fawcett (1989: 178), intervention involving primary prevention is selected when the risk of or hazard from a stressor is known but a reaction has not yet occurred. According to Neuman, health promotion is a component of primary prevention with the main purpose of preventing illness and increasing wellness (Neuman in press: in Fawcett, 1989: 178).

Intervention related to secondary prevention is selected when a reaction to a stressor has already occurred. Intervention pertaining to tertiary prevention is selected when some degree of client system stability and reconstruction has occurred subsequent to secondary prevention interventions.

According to Pearson and Vaughan (1986: 108), goals of nursing can be placed in the prevention phases in order to prevent maladaptation, restore adaptation and maintain adaptation. The final step in the nursing process when outcome goals are evaluated is to confirm their attainment or to guide reformation of nursing goals (Fawcett, 1989: 179).

(e) Nursing Process

According to Fawcett (1989: 189) nursing diagnosis is determined by data base which includes the consideration of the dynamic interaction of the physiological, socio-cultural, developmental and spiritual variables, e.g. identification of potential and the actual stressors, assessment of the condition or strength of basic structure, determining the variance from wellness, e.g. determining the client's level of wellness, systems stability needs, resource identification to accomplish goals, etc. (Fawcett, 1989: 189).

The nursing goals are determined by negotiating with the client for the desired prescriptive change to correct variances from wellness based on the needs that have been classified and resources that have been identified. Appropriate interventions which are aimed at retaining, attaining and maintaining the client system's stability as desired by outcome goals (Fawcett, 1989: 180).

The nursing outcomes are determined by nursing interventions achieved through use of one or more of the prevention modes, viz. primary, secondary and tertiary prevention: primary prevention, e.g. provision of information to strengthen the client system's strength, educate, etc., secondary prevention, e.g. facilitation of treatment, and tertiary prevention, e.g. education and re-education (Fawcett, 1989: 181).

3.5 DISCUSSION OF THE SELECTED CONCEPTS FROM BETTY NEUMANS MODEL IN RELATION TO SOME HIV/AIDS ASPECTS

3.5.1 COMPREHENSIVENESS AND THE HOLISTIC NATURE OF THE MODEL

- The model can be used by all role players in the HIV/AIDS programme since it is not only nurses and doctors who fight against HIV/AIDS, but all people regardless of the sector they come from, their social status, educational status, cultural background, age, political affiliation, etc. Even Neuman regards her model as appropriate for providers of health care other than nurses (Fawcett, 1989: 171).
- People with HIV/AIDS need to be cared for holistically since their condition like other health conditions affects not only themselves but their families (children, spouses, their communities, etc.); it is clearly a social disease which also needs a comprehensive/wide social response other than the individual response. These groups often comprise people from different backgrounds and serve to meet the psycho-social needs of the patient/client.

3.5.2 DISRUPTION AND RESTORATION OF EQUILIBRIUM

Like other systems theories, Neuman's model deals with how humans normally live in a well balanced equilibrium. If a problem arises, tension ensues and disrupts such equilibrium (Pearson & Vaughan, 1986: 107).

When a person learns of his body having been afflicted by HIV, he experiences more tension than that which he/she would experience when he hears that his body has been afflicted by other health conditions. Thus HIV/AIDS tension is experienced beyond the individual level, i.e. the family, the friends, the relatives, the community and the society at large. Such tension disrupts the individual and social equilibrium; for example, orphans crop up, street children are generated, crime escalates e.g. rape, theft, murder; poverty comes in; at workplaces HIV/AIDS has a potential for loss of production, loss of economy etc. All these conditions are conducive to increased tension if something is not done to restore equilibrium. If opportunistic infections are not treated, counselling is not done, immune boosters are not given, etc. the immune system gets defeated and death ensues. The development and implementation of the HIV/AIDS programme constitutes an effort to prevent such tension, and to restore the equilibrium physically, mentally and socially.

This is relevant to the study objective of "identification of HIV/AIDS activities and the organizations that implement them". The implementation of activities, forms part of restoration of client's or group's equilibrium that has been disrupted by the stressor HIV/AIDS and this is implemented by individuals and organizations. Restoration would therefore be undertaken at secondary and tertiary prevention levels. The study

looks into how the HIV/AIDS role players have responded to a stressor HIV/AIDS from inception (genesis) to 2003 and the context in which activities have been carried out i.e. the support system (including the participants and how the participation of NGO/CBO grew over the years), the challenges and the lessons learnt in the execution of such activities.

3.5.3 PEOPLE AS OPEN SYSTEMS

By being an open system, humans are both at an advantage as well as at a disadvantage. It becomes easy for an open system to get external and internal knowledge about HIV/AIDS and how others fight against it; it also becomes possible to assimilate knowledge that is imparted. On the other hand it becomes easier for the people to infect one another from either inside or outside a specific environment if they are open systems as individuals, families, communities or countries.

3.5.4 THE BASIC CORE STRUCTURE IN EACH INDIVIDUAL

People with HIV/AIDS all experience pain, stress, tension, etc. but the magnitude or degree to which this is experienced differs from person to person; even their tension threshold and coping mechanisms differ. This difference in coping mechanisms and tension thresholds results in some PLWHAs dying prematurely and others living for a longer time.

3.5.5 LINES OF RESISTANCE

HIV attacks the very lines of physical resistance, i.e. the immune system (cited by Pearson & Vaughan 1986: 106 as an example). Under normal circumstances the immune system maintains harmony between the internal and external factors by attacking all microorganisms invading the body. In HIV/AIDS, the line of resistance often fails and death ensues.

3.5.6 TYPES OF STRESSORS

- (a) : Intra-personal: AIDS as a disease is an intrapersonal stressor and results from HIV infection. Exposure to life events such as grief is common in HIV/AIDS nowadays, due to frequent deaths from AIDS related conditions. The developmental changes such as those of puberty with increased desire for sexual intercourse predispose young people to HIV infection. It is the overcoming of this intra-personal stressor (developmental change) that is encouraged among young people so as to prevent HIV infection.

- (b) Interpersonal Stressor: HIV/AIDS is an interpersonal stressor. The mere infection with HIV takes place between a person who has HIV and the one who does not have HIV. The awareness that a family member or a spouse is HIV infected can result in severe conflict within the family; lead to a divorce between the married people, breakage of relationships between lovers; discrimination of and by family members/ workers/ students/ church members etc.

The response to HIV/AIDS as a stressor is interpersonal too. It is a human being that gives care to another human being; it is human beings that educate or counsel other human being.

All HIV/AIDS interventions are about people interacting with other people. Some negative deviations which stress the recipient of care, counselling, education/ training, etc. can occur in the course of the above interventions and these will be interpersonal. Role changes and dependency cited by Pearson and Vaughan (1986) apply in HIV/AIDS when the death of parents leads to some children heading families, older people burying younger people, or grandparents looking after grandchildren. On the other hand an AIDS patient may lose a job and thus becomes dependent on others for the bare necessities of life.

(c) Extra-personal stressors, e.g. poverty, deprivation, cultural, educational systems: Poverty constitutes one of the major extra-personal stressors in HIV/AIDS. Some people contract HIV as a result of poverty, e.g. prostitutes, a dependent wife, street children, etc. Amongst those that are already HIV infected, some die prematurely because of poverty, i.e. they cannot afford a nutritious diet, immune boosters, antiretroviral drugs, money for transportation to a health care facility, etc. Some may have antiretroviral drugs from the government but these may be ingested on an empty stomach. It is for these reasons that a contemporary HIV/AIDS programme in South Africa and KZN emphasises poverty alleviation.

Lack of education leads to inability for one to comprehend what is being taught, as a result a person may be unable to protect himself against HIV infection. Furthermore, it is easier for an illiterate person to mystify HIV/ AIDS than a literate one; such a person will not easily change attitude or inappropriate practices around HIV/AIDS. Cultural practices may contribute to the spread of HIV, e.g. traditional circumcision, incisions by traditional healers, ear piercing, tattooing. Furthermore, culture can perpetuate the spread of HIV/AIDS e.g. gender stereotypes which accord a very low social status to women in society.

3.5.7 THE VARIABLES: PHYSICAL, PSYCHOLOGICAL, SOCIO CULTURAL, DEVELOPMENTAL AND SPIRITUAL

HIV/AIDS affects the person physically, psychologically, socio-culturally and developmentally, i.e. the physical body is sick, the illness affects the person mentally because he/ she is worried about having a disease that is regarded as fatal and which is stigmatised; a disease that often leads to cosmetic asymmetry to most people, dependency and disfigurement. In turn the significant others become physically, mentally and socially affected because the sick person may be a breadwinner. The sick may lose friends, may be discriminated against and isolated or even ostracised.

The socio-cultural factors may force a woman who is HIV positive to have children so as to be accepted by the family even if she is aware of the risks attached; an HIV positive widow may be inherited within the family as a wife of her brother-in law (following the death of her husband) and all these practices may fan the spread of HIV.

The developmental factors, e.g. puberty occurring to young people without prior preparation or life skills education, may lead to behaviour that is conducive to HIV infection. On the other hand, it is necessary that the interventions against HIV/AIDS include human sexuality as an aspect of life skills education so as to help young people practice the primary prevention that is advocated by Neuman.

The spiritual variable constitutes an important asset to a person with HIV/AIDS because it becomes a pillar of hope and strength, a firm support system. People with HIV/AIDS and their significant others are often faced with death and its consequences; the spiritual aspect of life plays an important role in the healing of those that remain behind and facilitating a "good death" to the dying person. That is why some of the HIV/AIDS interventions include spiritual counselling.

3.5.8 PREVENTION

Neuman regards all health care as preventive and highlights three aspects of prevention, viz. primary prevention, secondary prevention and tertiary prevention.

These prevention phases apply as follows in HIV/AIDS:

3.5.8.1 Primary prevention: In an effort to combat HIV/AIDS, prevention in terms of public information, education and communication (IEC) has been regarded as a cornerstone because once HIV has entered the body, it cannot be reversed. One of the primary responsibilities of a nurse or any HIV/AIDS role player is therefore to give health education to the patient/client. In HIV/AIDS control, all people are called upon to participate in all aspects, including primary prevention. Primary prevention is critical in the fight against HIV/AIDS since the first world countries have recently seen a rise in the number of new infections following the use of anti-retroviral drugs; this could be caused by complacency feelings, or there could also be failure in striking a balance between the administration of antiretroviral drugs and prevention of HIV infection.

3.5.8.2 Secondary prevention: This prevention in an HIV/AIDS programme manifests itself in the treatment of opportunistic infections (OIs), treatment with antiretroviral drugs, monitoring of such treatment, care, counselling and support. Treatment of OIs prevents possible death from an OI while treatment with antiretroviral drugs prevents rapid progression to full-blown AIDS and premature death. During this phase of prevention the patient is taught how to protect others from getting HIV infected as well as how to avoid re-infection. It is at this stage that possible death and disability is prevented, even in the case of other diseases.

3.5.8.3 Tertiary prevention: In dealing with an HIV/AIDS programme, this prevention should ideally involve skills training (as it happens in the first world) or rehabilitation so as to prepare the patient/client for resuming his normal occupation. Sometimes at this stage PLWHAs are referred to a relevant support group involved in income-generating projects. It would appear though that the HIV infected individual does not from this phase absolutely move in a circular manner to primary prevention as Neuman's theory asserts, but rather behaviourally helps other individuals not to get infected, i.e. help keep them at primary prevention level. The PLWHA at this level of prevention also needs to continuously protect himself from OIs and from re-infections with other strains of the virus.

3.6 FEATURES THAT MAKE NEUMAN'S HEALTH CARE SYSTEMS CONCEPTUAL MODEL FOR NURSING A CONCEPTUAL MODEL OF CHOICE IN THIS STUDY

- Relevant not only to the objectives of the study but also to the title of the study. Refer to discussion on relevance in 3.7 below.
- Emphasis is given to prevention, health education and wellness as well as the management of ill health. These aspects constitute critical areas in HIV/AIDS interventions. This will be expanded upon when discussing the relationship between the study and concepts/propositions for the model.
- The comprehensive nature of the model: Neuman herself suggests that this model is not restricted to nursing, but can be shared by any person operating in the health care arena (Pearson & Vaughan, 1986:105). The model therefore fits in well with a study dealing with HIV/AIDS interventions because a very wide range of stakeholders participate in the programme.
- The conceptual model encourages an inter-disciplinary approach to health care instead of a fragmented health service and draws the goals of many disciplines concerned with health care together (Pearson & Vaughan, 1986:105). The

importance of this feature cannot be overemphasised in the handling of an HIV/AIDS programme; without a concerted effort in combating HIV/AIDS, the set goals cannot be achieved.

- Neumans health care systems model also looks into the problem that is being addressed by implementing HIV/AIDS activities i.e. HIV/AIDS.
- The model sees the role of a nurse as a caring, collaborating and co-ordinating health care worker. This precisely describes the role a nurse practitioner commonly plays in the HIV/AIDS programme and stresses the need for a well co-ordinated HIV/AIDS programme in order to achieve the set goals and objectives.
- The two globally recognised broad categories of a viable HIV/AIDS programme, i.e. prevention and care, are well accommodated in Neuman's conceptual model.
- The theory looks beyond the client i.e. it also looks at the Care Givers' circumstances.

3.7 RELEVANCE OF BETTY NEUMAN'S HEALTH CARE SYSTEMS MODEL FOR NURSING TO THE STUDY

3.7.1 EXPLANATION OF A FEW SELECTED CONCEPTS OF BETTY NEUMAN'S MODEL AS UNDERSTOOD BY THE RESEARCHER IN THE CONTEXT OF THIS STUDY

To facilitate reader's understanding of the model's relevance to the study, it is important that a few concepts be explained.

3.7.1.1 **Client:** This can be a patient, client, care-giver, HIV/AIDS role player, PLWHA, group, community of society and it will be used interchangeably as such in the discussion.

3.7.1.2 **Client System:** Refers to all the circumstances of an individual, patient, group, variables like the psychological, economic, social, physiological etc and will be interchangeably used as such in the discussion.

3.7.1.3 **Developmental:** This can refer to development, progressing or growing; it can also mean starting or building something; for instance the building of a programme is often referred to as programme development.

3.7.1.4 Created environment: Over and above the meaning given by Betty Neuman, this can mean that which the individual or a group has conceptualized and acted upon independently, based on what he/ she has internalized. It can also mean all the circumstances of the individual or group, which resulted from his/ her interaction with the environment. Furthermore it can mean a belief or an attitude adopted by an individual or a group towards certain aspects of life.

3.7.2 THE RELATIONSHIP BETWEEN BETTY NEUMAN'S HEALTH CARE SYSTEMS MODEL FOR NURSING AND THE STUDY OBJECTIVES

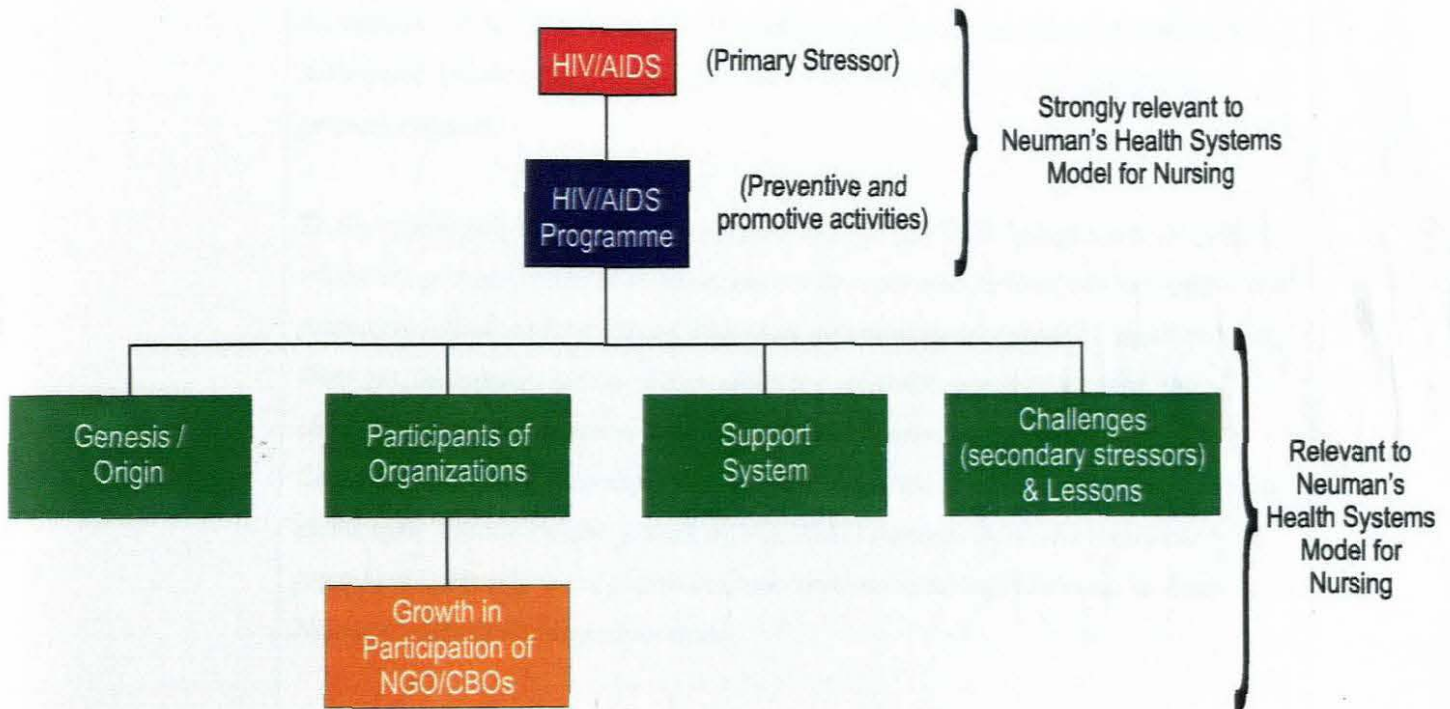
3.7.2.1 Study Objective no. 1: To trace the origin of the HIV/AIDS programme in KwaZulu-Natal.

Although it is observed that the preventive and promotive concepts of Betty Neuman's Model, which are catered for in objective 2 of the study (relating to HIV/AIDS activities), are the most conspicuous in Betty Neuman's Model, the above objective has some relevance to the model as can be seen in the explanation below.

Betty Neuman maintains that a client has variables, one of which is the developmental variable. The origin of the HIV/AIDS programme is seen by the researcher as programme development or programme building or programme commencement. Seen in the past perspective, origin of phenomena presupposes having grown, developed and progressed.

Furthermore, the close relationship between the prominent concepts of the model (preventive and promotive activities) and the origin of these activities adds to the relevance of Betty Neuman's model to this objective. Refer to Figure 3 regarding this relationship.

Figure 3: Breakdown structure showing the relationship amongst the key concepts of the study objectives seen in relation to Betty Neuman's Health Care Systems Model.



Explanation of Figure 3

HIV/AIDS is a stressor to which individuals and organizations have responded to by implementing preventive (primary, secondary and tertiary) and promotive activities. The implementation of preventive and promotive activities has had a beginning (genesis) and has taken place in a specific context. Challenges represent a negative consequence and therefore regarded by the researcher as secondary stressors. To distinguish between the two stressors, the researcher refers to HIV/AIDS as a primary stressor.

To the researcher, HIV/AIDS as a stressor and the HIV/AIDS programme activities, which are preventive and promotive, cannot be separated, neither can preventive and promotive initiatives be divorced from their commencement (genesis), those carrying them out, the support system within which the activities are executed, the challenges, the lessons learnt in the course of implementing such activities. Compared to other key concepts of the study objectives (support system, participants, challenges, lessons and the growth in NGO/CBO participation), the researcher regards the preventive and promotive interventions as strongly relevant to Betty Neuman's Health Care systems model.

Based on the model, the preventive and promotive activities are carried out to and by individuals with physiological, psychological, socio-cultural, developmental and spiritual variables. These variables influence the way in which a client responds to interventions as well as how the service provider delivers services.

The implementation of preventive and promotive activities, whereby the nursing process (comprising nursing diagnosis, nursing goals and nursing outcomes) is followed, constitutes the gist of the relevance of Betty Neuman's Health Care Systems Model to this study.

3.7.2.2 Study objective no. 2: To identify the HIV/AIDS activities and the organizations that implemented them.

This objective bears the gist of the relevance of Betty Neuman's Health Care Systems model to this study. The objective is accommodated under the nursing process aspect of the model whereby prevention (primary, secondary and tertiary) and promotion is referred to. Refer to 3.5.8 regarding how prevention applies in the implementation of HIV/AIDS programme. The implementation of preventive and promotive activities has a bearing on all the objectives of this study as can be seen in Figure 3 above.

An example of health promotion in HIV/AIDS activities can be lifeskills education for youth; primary prevention examples can be all "Information, Education and Communication" (IEC) activities on HIV/AIDS as well as prevention of Mother to Child Transmission of HIV; Secondary prevention examples are treatment of opportunistic infections, ART, HIV/AIDS counseling, institutional and Home Based Care etc. Tertiary prevention examples are formation of support groups for PLWHAs, care of orphans re-education and skilling of PLWHAs.

The above activities involve all the variables of the client Betty Neuman refers to i.e. the "physiological", in "secondary prevention" when the care to the already infected or ill is rendered; the "psychological" in AIDS Counselling and the formation and use of support groups; the "socio-cultural" in information, education and communication (IEC); the "developmental" in the IEC, income generating projects of the support groups etc. and the "spiritual" in counselling, particularly spiritual counselling.

Based on Neuman's model, the "promotion" activities are aimed at increasing wellness and prevention activities at preventing illness. The primary prevention activities are aimed at strengthening the "flexible

line of defense” (a “buffer” to the client) so that HIV does not enter the “normal line of defense”. Furthermore, the prevention and promotion in the form of AIDS education is aimed at preventing maladaptation, care at restoring maladaptation and rehabilitative activities at maintaining the client system or client’s stability.

Furthermore, the AIDS activities are rendered to and by the individuals and groups that have internal, external and created environments. The created environment for instance determines the type of a response a client gives to AIDS interventions, be they at primary, secondary or tertiary prevention levels.

3.7.2.3 Objective no. 3: To identify what has been the support system for the HIV/AIDS programme.

The support system as defined in chapter 1, page 19, provides a conducive environment or seedbed for the implementation of preventive and promotive HIV/AIDS activities. It is clear therefore that the support system constitutes enabling factors for HIV/AIDS programme implementation, without which the HIV/AIDS programme would be non-existent. There is a close relationship between the implementation of HIV/AIDS activities (preventive and promotive) and the support system for the HIV/AIDS programme.

Refer to Figure 3 above.

Betty Neuman sees the role of the Care Giver as collaborating. This indicates the working together of two or more people to achieve an objective or goal. The mere working together has a supportive element to the people or organizations involved; that is why committees/ councils/ forums and partnerships are identified as some of the components of a support system. Neuman also refers to client/care giver collaborative relationship, which indicates collaboration between those involved in the process of prevention and promotion activities.

Furthermore, Neuman refers to the external environment of the client and the components of the support system such as funds, human resource, human resource development, policies, plans, councils, committees, political backing etc. form part of this external environment for the individual or group. Neuman also refers to the client being an open system and human resource development, which is one of the components of the support system, cannot take place if the system is closed. Neuman also refers to evaluation of outcomes as an aspect of the nursing process; research, which is one of the components of the support system, can be evaluative in nature. Some of the research that was undertaken can be likened to the nursing diagnosis referred to by Neuman in the discussion of the nursing process.

3.7.2.4

Objective no. 4: To highlight the challenges faced and the lessons learnt during the implementation of the HIV/AIDS programme. The challenges faced and the lessons learnt during the implementation of HIV/AIDS activities are seen as consequences of programme implementation i.e. they arose out of the implementation of preventive and promotive activities. Refer to Figure 3.

While the lessons learnt are seen as positive, and thus boosters of the lines of defense and resistance in respect of the client and the care giver, the challenges are seen as negative and unpleasant and when looked at in relation to HIV/AIDS, the researcher refers to them as secondary stressors, which then means HIV/AIDS becomes a primary stressor.

Neuman maintains that the stressors can be intrapersonal e.g. the experience of pain by a person with AIDS, worrying about having HIV/AIDS etc, interpersonal e.g. the social problems experienced by a person with HIV/AIDS e.g. conflict between a wife and husband or a parent and a young person or, a person with HIV/AIDS and the community, resulting in the former being ostracized and extrapersonal

e.g. lack of money, lack of shelter etc. The cited stressors shift from intrapersonal to extrapersonal.

The findings of the study will highlight the secondary stressors (challenges) of the HIV/AIDS role players in KwaZulu-Natal.

The question of lessons learnt is accommodated in Neuman's theory since a reference is being made to a client being an open system, which means an individual or group can learn. Furthermore learning is linked to the developmental variable referred to by Neuman; when one learns, one develops or grows.

The socio-cultural variable of a client system is relevant to the learning since learning involves human interaction and imparting of knowledge or cognitive culture. Furthermore, in the process of an individual's interaction with the external environment, learning takes place; with HIV/AIDS this interaction can be local, national and international.

3.7.2.5 Objective no. 5: To determine the extent to which participation of NGO/CBOs in the HIV/AIDS programme grew over the years.

This objective probes further into those implementing the preventive and promotive HIV/AIDS activities and looks into the size of NGO/CBO participation in terms of new participants per year. Here, the size of NGO/CBO participation is dependant on the existence of participants (NGO/CBOs); the existence of participants in turn is dependent on the existence of the preventive and promotive HIV/AIDS activities, which constitutes the core of the relevance of Betty Neuman's Health Care Systems Model for nursing to this study. Refer to Figure 3 above.

The driving force that propelled NGO/CBOs into action against HIV/AIDS is the stressor HIV/AIDS, which has incessantly grown over the years in KwaZulu-Natal.

When Betty Neuman's graphic presentation is seen as a community structure, NGO/CBOs can be likened to the flexible line of defense and an individual served, to the normal line of defense (bearing the lines of resistance). Based on this view, if growth in participation is observed, it can be taken as an expansion away from the normal line of defense and thus protective to the individuals and groups in the community but if the flexible line of defense shrinks to the normal line, the individuals and groups will not be protected.

Neuman maintains that the client system has a developmental variable; if there is growth in participation, this will be compatible with the view of Neuman as well as with "progression" in the title of the study.

Furthermore, the mere establishment of a community structure to meet the needs of the community and growth in the establishment of such structures and their functions is developmental and progressive.

3.7.3 RELEVANCE OF BETTY NEUMAN'S MODEL TO THE TITLE OF THE STUDY

Title: "The genesis and progression of the HIV/AIDS programme in KwaZulu-Natal: Implications for Learning and intensified action".

The theory of Betty Neuman is not only relevant to the objectives of the study but it is also relevant to the concepts of the study title as explained below.

- 3.7.3.1 **Genesis:** Betty Neuman refers to the developmental variables of the client system. The HIV/AIDS programme was started or developed i.e. it has an origin. We do often refer to building a programme as "programme development".
- 3.7.3.2 **Progression:** This can be seen as developmental because the HIV/AIDS programme progressed from its origin to what it is to-day and this occurred in stages.
- 3.7.3.3 **HIV/AIDS:** This is regarded as an intra-personal, interpersonal and extra-personal stressor if based on Betty Neuman's theory.
- 3.7.3.4 **Learning:** This is compatible with Neuman's developmental variables of the client; it is also linked to her assertion that a client is an open system since learning can take place where the system is open. The inter-personal environment of Neuman also makes it possible for learning to take place.
- 3.7.3.5 **Intensified Action:** This has a developmental element or meaning and indicates progression in action. Neuman refers to a developmental variable of a client and thus makes "intensified action" compatible with her Health Care Systems Model for nursing.

3.8 CONCLUSION

The Neuman's Health Care Systems Conceptual Model for Nursing, which is based on the Systems, Gestalt, Stress Adaptation, Field and Developmental theories, has been found the most suitable in this study. It is not only relevant to the study objectives but to the title of the study as well. Although prevention of ill-health and promotion of wellness seem to be the dominating concepts in the model, the concepts nursing process and its steps, the variables of the client system, the various environments and the parts of the graphic presentation of the client system are not only user-friendly in this study but are also as mutually inclusive as those of the study objectives.

The above discussion sets a tone for the anticipated relevance of the model to the findings of the study of the genesis and progression of the HIV/AIDS programme in KwaZulu-Natal and the implications thereof.

CHAPTER 4

RESEARCH METHODOLOGY

4.1 INTRODUCTION

According to Leedy (1985:91) “methodology is merely an operational framework within which the facts are placed so that their meaning may be seen more clearly”. It is the type of data intended to be collected that dictates the research methodology. This discussion of the methodology used in “The study of the genesis and progression of the HIV/AIDS programme in KwaZulu–Natal: implications for learning and intensified action” will cover the purpose and objectives of the study as background, and the research design with the focus on the historical method; and ethical considerations.

4.2 PURPOSE OF THE STUDY

To obtain historical information on how KwaZulu–Natal responded to the HIV/AIDS epidemic and the circumstances under which interventions took place, with a view to highlighting areas of improvement.

4.3 RESEARCH OBJECTIVES

4.3.1 To trace the origin of the HIV/AIDS programme in KwaZulu – Natal.

- 4.3.2 To identify the HIV/AIDS activities and the organisations that implemented them.
- 4.3.3 To identify the support system used for the HIV/AIDS programme.
- 4.3.4 To highlight the challenges faced and the lessons learnt in the implementation of the HIV/AIDS programme.
- 4.3.5 To determine the extent to which the participation of NGO/CBOs in the HIV/AIDS programme grew over the years.

4.4 RESEARCH DESIGN

The research design has a focus on research data and is therefore of the utmost importance, since data bear the truth about the problem being studied and can give a direction towards the solution.

Leedy (1985: 96) maintains that a research design is the visualisation of the body of the data and the problem associated with the employment of those data in the entire research project. To him it is “the common sense and the clear thinking that is necessary for the entire research, the complete attack upon the central research problem.”

The researcher needs to bring research planning and design into clear focus by providing answers to the questions on the type of data needed, where data are located, how data will be secured and how it will be interpreted (Leedy: 1985: 79 – 98).

On the other hand Brink (2000: 214) refers to the research design as “the overall plan for gathering data in a research study”.

In view of the study looking into the history of the HIV/AIDS programme implementation in KwaZulu–Natal, the researcher selected a historical as well as a phenomenological method of data collection, which falls under the broad umbrella of a qualitative research design. This makes the study a descriptive or narrative type.

4.4.1 QUALITATIVE RESEARCH DESIGN

This design is used by researchers “who wish to explore the meaning or describe and promote understanding of human experiences such as pain, grief, hope, caring, mutilating surgery, etc.” (Brink, 2000:119). There are a number of varied designs falling under qualitative research, e.g. phenomenological, historical, ethnographic etc. These methods may differ in focus and goal but the fact that all of them focus on qualitative aspects, i.e. meaning, experience and understanding binds these methods together (Brink 2000: 119). The historical methodology was selected for this study, the reasons being as follows:

- The study on the genesis and progression of the HIV/AIDS programme in KwaZulu constitutes a study of the history of HIV/AIDS programme implementation, the historical methodology was therefore the appropriate to use.
- Researching is essentially a truth finding exercise about a specific phenomenon, it would be impossible to find all the truth in a study of this

nature without the use of historical methodology since human beings forget but written records can be kept for a long time.

- Historical methodology prevents bias since the written records remain primary and authentic (if humans have not tampered with them) but if historical information is collected directly from relevant people, it gets influenced by the subject's attitude, culture and other communication barriers including mental capacity and thus rendered unreliable.

- This study is aimed at developing a KZN HIV/AIDS implementation data bank which cannot only be used by health or HIV/AIDS role players and researchers but also by the authors of general history; it was therefore of utmost importance that the researcher uses a methodology that would yield credible results.

- If a post facto study (which uses a retrospective research design) was employed, it would be impossible to get all the people who could provide the required data and would also be difficult to access a few that are still alive.

- The use of historical methodology in this study would make it easier for the researcher to evaluate data by internal and external criticism since the data was abundant.

- History is the heritage of the nation; the use of the historical method the nation get a clearer understanding of the past and the present so that it can develop wiser plans for the future; without the use of an appropriate method in this

study, the plans for the future could be distorted if solely based on the findings of this study.

- The historical methodology is not often used in the study of health related phenomena; the researcher herself had never used it, one of the reasons for its use was therefore to explore its use with a view to acquiring knowledge and skills as well as find out if any HIV/AIDS problems could be resolved by its application.

- Lastly, besides relevance, the researcher used the historical methodology because of abundant availability of records on HIV/AIDS programme implementation; authors and researchers have produced a lot of good work on the subject.

4.4.2 HISTORICAL METHOD

Since this constitutes the core method of data collection and analysis used in this study, it will be fully explained.

i) **What the historical research method is**

Historical research studies past events. This method must be distinguished from the ex-post-facto research whereby a retrospective design is used. It entails a detailed study and analysis of events, individuals, institutions or specific periods of time (Brink, 2000: 116). According to Brink (2000:116), the purpose of historical research is to gain a clearer picture of how the past impacts on the present and the future.

Jankowicz, (1995: 176) maintains that a historical method may be used in order to “illuminate the present”. Jankowicz (1995: 176) further states that, “the importance of an issue is due as much to its provenance as to its content; it can also be a useful source of hunches or more informal hypotheses”.

ii) **Data collection in the historical method**

Brink (2000:119) states that the historical method involves the “review of written materials but may include oral documentation as well”. She cites examples of written materials used as books, maps, letters, diaries, etc. Other documents that may be used in this method are memoranda, policy documents, minutes of meetings, newspapers, etc. De Vos (1998: 80) supports the fact that documents should be used in the historical method.

It is important that documents be original or primary sources, as the researcher needs to rely only on primary data, if at all possible (Leedy, 1985:119; Brink, 2000:119). Jankowicz (1995:172) maintains that with the historical method, one directs one’s question at people and at written sources concerning issues and events in the past and present and predictions of the future.

iii) **Evaluation of data in the historical method**

According to Brink (2000:117) and Leedy (1985:120), historical data should be subjected to external and internal criticism (sometimes referred to as external and internal evidence). External criticism looks into the genuineness or authenticity of the

data while internal criticism concerns itself with the accuracy of the data (Brink, 2000: 117). In other words, external criticism establishes the validity of data while internal criticism establishes the reliability of data (Brink, 2000: 117). However, to ensure that the interpretations are correct the researcher should substantiate the document in question by another collaborating source to safeguard the correctness of interpretations (Brink, 2000: 117).

Leedy (1985: 120) makes a distinction between “evidence” and “criticism” by stating that the former looks at the problem from the viewpoint of the data while the latter looks at the same problem from the attitude of the researcher. To Leedy, external evidence asks the question, “Is it genuine?” while internal evidence asks the question, “What does it mean?” (Leedy, 1985: 120).

iv) **Data analysis in the historical method**

According to De Vos (1998:16), “data are presented in the form of words, quotes, documents and transcripts”. He further states that “data are analysed by extracting themes, motifs and categories”.

v) **Chronology in historical method**

Leedy (1985: 121), states that events need to be presented in the order of the happening. He however warns that these must not just be a mere listing of dates and events but what the events mean and the relationship of events to each other and to the

problem under study, must be explained. Historical time and space must be clearly indicated.

vi) **Concluding remarks on the historical method**

The study of the genesis and the progression of the HIV/AIDS programme in KwaZulu-Natal is essentially a study of the history of the HIV/AIDS programme which is implemented by human beings who have “experienced”, “perceived” and developed “meanings” that can be expressed verbally, in writing or through use of other symbols e.g. artefacts. The use of historical method which is described above is therefore justified in this study.

4.4.3 DESCRIPTIVE STUDY

This refers to a “research study in which phenomena are described or the relationship between variables is examined; no attempt is made to determine the cause and effect relationship”. The study is descriptive in the sense that it describes how KZN people responded to the HIV/AIDS epidemic as well as the circumstances under which this happened; the documents obtained and information from service providers will be descriptive.

4.4.4 THE STUDY POPULATION

A study population is a complete set of persons or objects that possess some characteristics that is of interest to the researcher (Brink, 2000: 213). According to

Leedy (1985: 144) population parameters and sampling procedures are of utmost importance if a study is to be successful.

The “element or unit of analysis most typical in nursing research is individuals but other entities can form the basis of sample or population such as document, blood, or groups of people, etc.” (Burns & Grove, 1993: Bloss & Higginson-Smith, 1995 in Brink, 2000: 133).

Although the study is historical, and data were chiefly collected from records, it was necessary to obtain information from the service managers of both the governmental and the non-governmental sector.

4.4.5 THE SAMPLE

This refers to a subset of a population selected to represent the population (Brink, 2000: 214). TerreBlanche and Durrheim (1999: 45) state that what will be sampled is determined by the unit of analysis. In this study the HIV/AIDS programme is the unit of analysis and this lies in the hands of a manager.

4.4.6 SAMPLE SIZE

TerreBlanche and Durrheim (1999: 45) maintain that types of research that are less concerned with the statistical accuracy than with detail, do not draw large or random samples; various types of purposeful sampling may be used. In this study 20 contemporary and past managers of the HIV/AIDS programme were sampled for data

collection. These included the heads of the government's AIDS programme and the heads of the relevant NGO/CBOs. Five of the 20 managers were identified as key informants and 4 of these key informants had been the managers of the HIV/AIDS programme before the 1994 general democratic elections (GDE).

“Sampling to redundancy” as referred to by TerreBlanche and Durrheim (1999: 45), whereby the researcher does not define the sample in advance but looks for information until the “same issues and themes come over and over again”, applies here because information was looked for beyond the sample so as to strengthen external and internal evidence. The only difference is that the sample was defined from the outset in this study. In view of the historical nature of the information needed this searching for relevant information beyond the confines of the sample (e.g. newspapers and government archives) was appropriate.

4.4.7 SAMPLING STRATEGY

Purposeful sampling strategy was used. The former (purposeful sampling) involves obtaining information from specific types of people who can provide it; they may be the only ones who have it (Sekeran, 2000: 278). This sampling strategy was chosen because no person knows better about a programme than its manager. Besides knowledge, he has authority to provide relevant documents, e.g. the AIDS Directory for KwaZulu-Natal, the list of NGO/CBOs that the Department of Health works in partnership with, etc.

Five (5) key informants were also selected by purposeful sampling.

In view of the need to cross-check the data that had been collected at the HIV/AIDS meetings between NGO/CBOs and the Provincial AIDS Action Unit, as well as to undertake the internal and external validity/criticism, it was necessary that some services be visited. Brink (2000: 143) states that qualitative studies are undertaken with fewer subjects. Fifteen (15) organisations (governmental and non-governmental) were selected by purposive sampling from the list of NGO/CBOs compiled at the two (2) NGO/CBO meetings which the researcher had attended. This selection was based on researcher's convenience in terms of time and cost; it covered 75% of the Health Districts.

Refer to Annexure 5, regarding the list of NGO/CBOs that the researcher visited.

4.5 DATA COLLECTION

This refers to the gathering of “pieces of information or facts during a research study” (Brink, 2000: 207). Subsequent to the selection of respondents, data was collected for a period of 8 weeks.

4.5.1 DATA COLLECTION INSTRUMENTS

Two instruments were used for data collection, viz. a questionnaire and a checklist. A questionnaire was designed to collect information that would serve two purposes i.e. building of NGO/CBO data base and gathering information that would be used for determining the extent to which NGO/CBOs participation in the HIV/AIDS programme grew over the years. The critical question for the latter was “the year

during which AIDS activities” commenced; the other questions provided data on the profile of an NGO/CBO and challenges faced.

Refer to Annexure 3.

A checklist was used for observation and data collection carried out at service sites and designed in the light of the set study objectives comprising two (2) sections, viz. a First Section and a Second Section. Both sections were used for collecting information at service points and key informants, but the second section alone was referred to when requesting written HIV/AIDS information from the institutions and individuals who were not part of the study.

Documents needed in the Second Section were those whose content was believed would provide answers to the set objectives/ questions, viz.:

- I Documents/items with HIV/AIDS Programmes, e.g. VCT, Life-skills, PMTCT, IEC, etc. as well as special projects.
- II Document/items on support systems for the HIV/AIDS Programme, e.g. funding, staff, committees, forums, councils, training, research (published or unpublished), plans (strategic and operational), policies, transport, etc.
- III Documents/items reflecting the commencement of the programme in KZN.
- IV Documents/items with NGO/CBOs involved in the HIV/AIDS Programme and the activities in which they were engaged.

4.5.2 CONTENT OF FIRST SECTION

The first section of Annexure 3 was designed to obtain the following:

Background information about the institution/individual.

HIV/AIDS interventions the individual or institution had engaged in.

The support system for the programme.

Challenges that had been faced.

Lessons that had been learnt.

Refer to Annexure 3, First Section.

4.5.3 CONTENT OF SECOND SECTION

The Second Section was designed to guide the researcher in the collection of the appropriate documents and serve as a control tool for the benefit of both the information provider and the researcher. It comprised the following:

A list of documents/items needed for the study (themes).

Names of data sources.

An indication of whether the provider wants the items to be returned or not.

Refer to Annexure 3, Second Section.

4.5.4 PRE-TESTING OF THE INSTRUMENTS

The pre-testing of the questionnaire was done to four (4) NGO/CBOs that attended a seminar on Voluntary Counselling and Testing and thereafter refined accordingly.

Pre-testing of the checklist was done by visiting and administering the checklist at five (5) convenient HIV/AIDS service points that were not part of the sample. This was done to ensure that it was reliable and valid. The instrument was thereafter modified accordingly.

4.6 DATA COLLECTION

4.6.1 SOURCES OF DATA

Data were primarily obtained from the following records: government memoranda, reports, minutes of meetings, letters/minutes, policy documents, policy speeches, circulars, operational and strategic plans, posters, pamphlets, AIDS billboards, AIDS directories, books, journals, diaries, magazines, newspapers, websites, templates, video, television, photos, artefacts, radio tapes, etc. The areas visited for data collection were the Department of Health, Provincial AIDS Action Unit (PAAU), parastatals like the ATICCs, NGO/CBO and FBOs, newspapers, the SABC, tertiary institutions, hospitals, communicable diseases control clinics and relevant independent individuals (key informants).

4.6.2 HOW DATA COLLECTION WAS UNDERTAKEN

Subsequent to sampling, the letters requesting information and securing an appointment were written and processed to the Secretary for Health, the PAAU, Ukhozi FM (SABC), newspapers, the Directors of Health Districts, the Director General of KZN Government, Virology Department, etc., informing them about the study, requesting information and securing appointments. Twenty selected managers

of HIV/AIDS service points (present and past), 5 of which had been identified as key informants, were specifically requested to provide information and visits to their workplaces sought. Over and above liaison with the above offices the researcher requested slots at the forthcoming HIV/AIDS role players' meeting in order to introduce and give an orientation on the study. Slots were successfully given at two meetings (May and June, 2003) for this purpose. Role players showed interest in the study and expressed eagerness to see the results.

Data collection leaned heavily on the collection of records rather than on verbal information. The combination of the two methods of data collection was aimed at getting not only what people claim they do, but also what they are recorded as doing (TerreBlanche and Durrheim, 1999). Data were collected according to the dictates of the questionnaire and the checklist.

Data were collected in two phases. Phase one (1) comprised visiting the service points and the key informants and collecting information from the managers; it also involved visiting the libraries, media offices and archives (government and newspapers). Phase two (2) of data collection, which was an extremely time consuming one, commenced immediately after the visit to the above data collection areas; it involved reading, identifying and extracting data that provided answers to the research questions/objectives.

The "personal learning logs" whereby, according to Wisker (2001:142), the researcher uses his own experiences as research data, applied in this study because from 1996 to 2001 the researcher was a manager of the HIV/AIDS Programme in KwaZulu-Natal.

The use of such experience also partly assisted during the external and internal criticism exercise, the discussion of which follows below.

4.6.3 HOW THE DATA WERE EVALUATED

The collection of the data was fully explained under the discussion of the historical method. Refer to 4.4.2 (ii) and 4.5.1 above. The collected data was subjected to external and internal criticism purposefully and sometimes automatically when the researcher, for instance, came across information in a quarterly report, seeing the same information in the policy speech, memoranda, diary, video cassette, etc.

External criticism or evidence was undertaken by (among other methods) cross-checking the document at hand with that coming from other sources, checking whether the document was final or a draft, making a telephonic follow-up with the people who had provided the information if, for instance, the document had not been signed, not dated, or if the authenticity was doubted.

Internal criticism was undertaken by checking if the document content was being interpreted correctly by the researcher; at times this automatically occurred when the researcher came across similar information in a number of documents. Whenever necessary the researcher made impromptu telephone calls to the human sources of information to check if the interpretation of a specific document was correct.

The 1990 – 2001 documents did not present a lot of problems with this exercise because the researcher was familiar with some of the content and issues; however, the

researcher ensured that she did not become the only source of determining the genuineness and accuracy of specific data.

4.7 ETHICAL CONSIDERATIONS

In view of this study having to do with a highly sensitive subject, HIV/AIDS, rigorous compliance with research ethics was applied by the researcher.

Brink (2000: 39 – 40) identifies and explains three basic ethical principles that guide researchers, all of which were seen applicable to this study; these are the principles of respect for persons, beneficence and justice.

Authority to visit the HIV/AIDS service points was successfully sought from the Head of the KwaZulu–Natal Department of Health. Refer to Annexure 2.

The Heads of the selected NGO/CBOs and the individuals who had been identified as key informants were telephoned to secure appointments. All were assured that the research would not be a faultfinding mission but a search for new knowledge which will benefit all concerned.

To ensure that the prospective respondents participate willingly, informed consent was successfully obtained. The exercise involved giving a full explanation of the research project covering the aspects purpose, benefits, possible risks and the voluntary nature of participation. Participants were assured of privacy, confidentiality and anonymity particularly regarding the concerns/challenges. Furthermore in view of the historical nature of the study, the respondents were informed that their names as

well as those of their organisations would appear wherever relevant in the study and consent sought to this effect.

The HIV/AIDS service managers were also informed that their names as well as those of their organisations would appear whenever relevant in the study and their verbal consent successfully sought.

The providers of information, who wanted the submitted documents returned, were promised that the documents would be returned as soon as possible and this promise was honoured. Furthermore these information providers were consistently kept assured of the security of their documents during the course of data searching and extraction.

In addition to the above, the researcher observed the scientific honesty as reflected in the declaration appearing the beginning of this report.

4.8 CONCLUSION

The study of the genesis and progression of the HIV/AIDS Programme in KwaZulu-Natal, which is descriptive, was carried out following a historical method which falls under the broad umbrella of a qualitative design. The data was primarily obtained from the records and ethical principles of respect for persons, beneficence and justice were observed.

CHAPTER 5

DATA ANALYSIS AND INTERPRETATION

5.1 INTRODUCTION

While the previous chapter dealt with how the researcher collected data for the study of “the genesis and the progression of the HIV/AIDS programme in KwaZulu-Natal: Implication for learning and intensified action”, in this chapter the researcher will discuss and demonstrate what she did with the collected data, i.e. the data analysis. It will comprise a definition of data analysis, how the data was organised, analysed and interpreted based on the five objectives of the study.

Kerlinger (1986: 125-126) in De Vos (1998:16) states that analysis of data means the categorising, ordering, manipulating and summarising of data to obtain answers to research questions. The rationale behind data manipulation is to reduce it to a form that can be easily comprehended so that the “relations of research problems can be studied, tested and conclusions drawn” (Kerlinger, 1986: 125-126 in De Vos 1998: 203). According to De Vos, data in qualitative research can be analysed by extracting themes. Brink (2000:178) maintains that data analysis entails “categorising, ordering, manipulating and summarising the data and describing them in meaningful terms”.

Furthermore, according to De Vos (1998:16), in the historical method “data are presented in the form of words, quotes, documents or transcripts”. He further states that “data are analysed by extracting themes, motifs and categories”.

Although the researcher had used the qualitative method only in the collection of data, to better provide answers to objectives four (4) and five (5), i.e. the challenges and lessons learnt by the respondents as well as the extent to which participation by organisations in the HIV/AIDS programme had grown over the years, a quantitative method of data analysis was applied. This was done through the use of percentages and graphics to link the respondents to responses.

According to Brink (2000: 183) “a percentage is the number of parts per 100 that a certain proportion of the whole represents” and it falls under simple descriptive statistics. Brink (2000: 191) further maintains that the “use of graphics is recommended for all types of data”. To Brink graphs “have a visual appeal that may cause the reader to analyse the data more closely than would be the case if a written description data were presented”. Examples of graphs are bar charts, pie charts, etc. (Brink 2000: 192).

5.2 DESCRIPTION OF HOW DATA WAS ORGANIZED

Based on the review of data analysis in qualitative research by Brink, 2000 and De Vos, 1998 and the fact that a historical method of data collection was used in this study, the researcher manually categorised the collected qualitative data into themes. Each theme was based on the study objectives. These themes were the Genesis, Programmes, Support System, Challenges, Lessons and Organisations. These were further broken down into sub-themes, e.g. the support system theme had the following sub-themes:

Human Resource, Human Resource Development, Plan, Policies, AIDS Structures, e.g. Committees, councils, etc. and partnership.

Data was also categorised according to historical periods viz. Pre-1994 General Democratic Elections (GDE) and Post-1994 GDE. Index Cards bearing the above themes were developed. Data, which had been mainly collected from the records, were entered into the cards under relevant themes.

The principle of chronology and that of space were observed by recording the data in the order in which they occurred and where indicated, the geographical area where they occurred was mentioned. The researcher was, however, more interested in understanding the meaning of the events and their relationship to each other than the mere chronology and space. According to Leedy (1985: 121), chronology is the “grist of the research mill. It provides the first step in the process of data interpretation, and interpretation is as previously stated - the indispensable element of all research”.

Data was presented in a narrative form and by using graphs, as will be seen under data analysis and interpretation. It was necessary, however, to do simple statistical analysis to obtain information that would meet the requirements of objectives 4 and 5, i.e. determining the extent to which NGO/CBOs participated in the HIV/AIDS programme as well as identifying challenges and lessons learnt.

5.3 THE STUDY OBJECTIVES

The data that were analysed had to meet the following objectives:-

- 5.3.1 Trace the origin of the HIV/AIDS programme in KwaZulu-Natal.
- 5.3.2 Identify HIV/AIDS activities and the organisations that implemented them.
- 5.3.3 Identify what has been the support system for the HIV/AIDS programme.
- 5.3.4 Highlight challenges faced and the lessons learnt in the implementation of the HIV/AIDS programme.
- 5.3.5 Determine the extent to which participation of the NGO/CBO in the HIV/AIDS programme grew over the years.

5.4 ANALYSIS AND INTERPRETATION

5.4.1 OBJECTIVE NO 1: THE ORIGIN OF THE HIV/AIDS PROGRAMME IN KWAZULU-NATAL

5.4.1.1 Events

The following are available data which marked the genesis of the HIV/AIDS programme in KwaZulu-Natal. They were obtained from archival records from newspapers and key informants. Some data were further personally cross-checked with key informants:

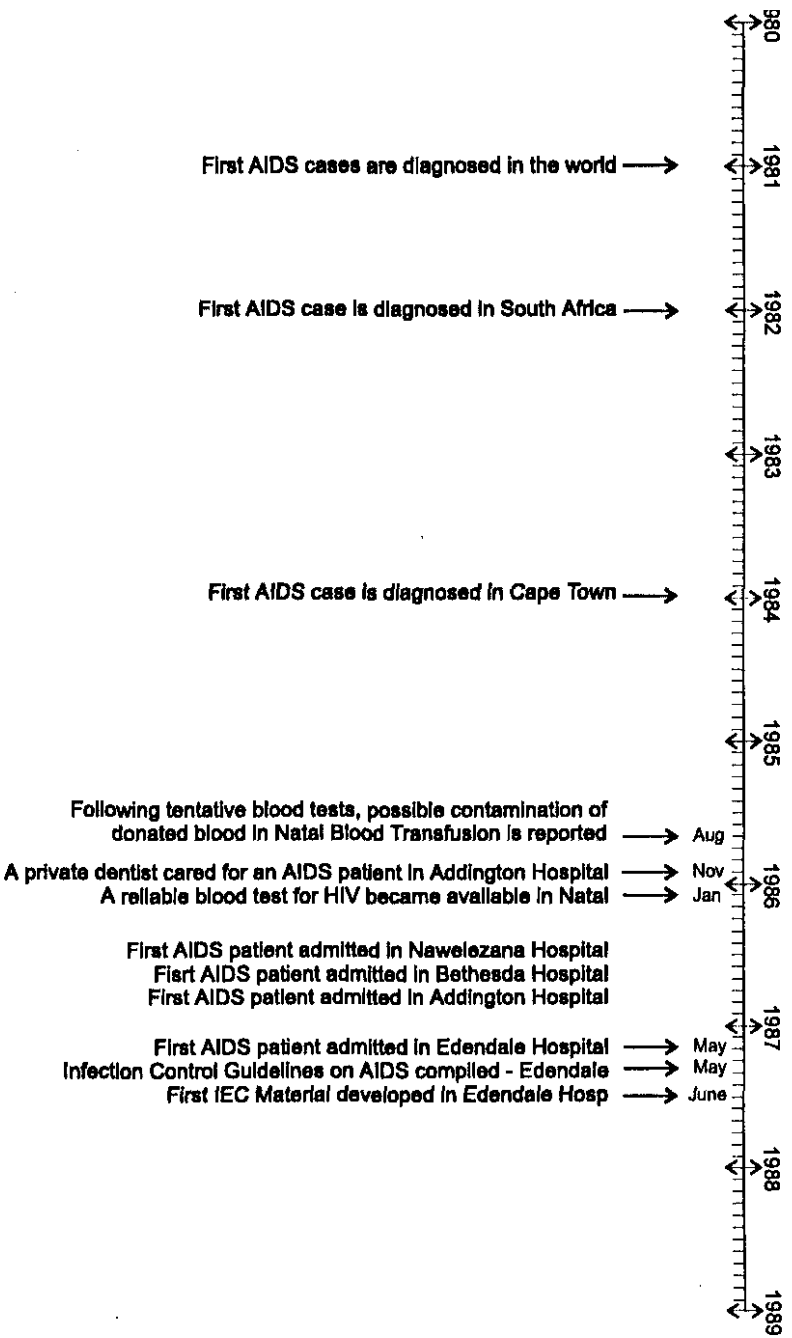
- A report that the blood which had been donated to Natal Blood Transfusion Services (NBTS) was possibly "contaminated" with AIDS following tentative blood tests (Daily News, 21/08/85).
- Two Durban clinics were reported to have denied a private dentist to treat AIDS patient in their facilities (Daily News, 3/12/85; Mercury, 3/12/85).

- A private dentist cared for an AIDS patient (Mercury, 3/12/85).
- Addington Hospital Management accepted the AIDS patient referred by a private dentist (Daily News, 3/12/85).
- A reliable AIDS test became available (Mercury, 15/1/86).
- The first AIDS patient in Natal was admitted in Addington hospital (Mercury, 3/11/86).
- A person who had previously been admitted to Addington hospital and suspected to have had AIDS committed suicide in October 1986 (Daily News, 3/12/86).
- The first patient with AIDS died naturally in Addington hospital (Daily News, 3/12/86).
- The first AIDS patient was admitted to Ngwelezana hospital in 1986 (Personal communication with Mrs N. Haselau, 2003)
- The first AIDS patient was admitted to Bethesda hospital in 1986 (communication with Dr A. Jaffe, 2004)
- The first AIDS patient was admitted to Edendale hospital with Kaposi Sarcoma in May 1987 (Dr J.M. Muller, in Memo to Dr Evans 18/5/87; personal communication with Dr J.M. Muller: 2003)
- The first Information Education and Communication Material on HIV/AIDS was developed by Dr M. Mhlongo, in Edendale hospital: June 1987. Refer to Figure 4.

According to Leedy (1985: 120) chronology is of importance in historical research; however, he warns that “we must seek not to identify the chain of events of substantive history but also to understand the meaning of these events, both as to their

relationship to each other and to the problem under study". Leedy (1985:121) suggests the use of linear chronography whereby a series of events are placed along a time continuum at the exact points becomes easier for the researcher to understand the meaning of events and their relationship to each other if plotted as seen in Figure 4.

Figure 4: Linear Chronology of Events marking the Origin of the HIV/AIDS Programme in KZN



Key: | | | | | = months

Pattern of Linear Chronology from Leedy (1985: 122)

5.4.1.2 Clarifications on the above events

- Early in the HIV/AIDS era a person referred to as an AIDS patient could have been a person who had or had not reached full-blown AIDS; at this stage there was no emphasis on the distinction between the two, e.g. the “possible AIDS contamination of blood” referred to above means that the blood was suspected to be infected with HIV.
- The person who was reported having committed suicide following admission to Addington hospital was not formerly regarded as the first AIDS patient dying in Natal because he did not directly die of AIDS but killed himself.
- The persons that had signs of AIDS in 1985 could not be confirmed as AIDS cases since KwaZulu-Natal started using reliable AIDS test kits only in early 1986 (Mercury, 9/1/86).
- The patient that was accepted by Addington hospital after a referral by a private dentist appears to be the same patient as the one that had been refused by the two clinics in Durban.

5.4.1.3 Interpretation

From the highlighted events, it would appear that the HIV/AIDS programme in KwaZulu-Natal commenced in 1985, i.e. before a reliable blood test became available. The mere reporting by the media raised awareness about the disease, while the tentative tests done on donated blood marked the beginning of surveillance and prevention of HIV spread to the recipients of donated blood; care, counselling and support started from the first health worker’s encounter with the patient. The

exercise of universal precautions done at this stage adds an impetus into the suitability of Betty Neuman's Health Care Systems conceptual model for nursing. Besides, being told that one has AIDS was probably even more stressful early in the epidemic than at present.

It has also come out clearly that the programme started at the peripheral rather than Head Office levels of that period and was not vertical as at present, but rather incorporated into the existing Communicable Diseases Control Programme due to the low magnitude of the disease at that stage. Indeed staff had limited knowledge about HIV/AIDS at this early stage but according to UNAIDS (2003: 29) "nurses know what to do to care for the patient, even if they don't have special knowledge about HIV/AIDS".

The HIV/AIDS challenges of discrimination and suicide did manifest themselves at the very first invasion of KwaZulu-Natal by HIV/AIDS.

5.4.1.4 Comment on the origin of HIV/AIDS programme with reference to Betty Neuman's theory/model.

Betty Neuman in her theory of Health Care Systems, refers to the developmental variables of a client system. HIV/AIDS programme therefore was developed by the NBTS in 1985, progressed and grew to what it is to-day. This is seen as developmental and therefore relevant to the theory of choice for this study.

Furthermore, the testing of blood for HIV by the NBTS is compatible with the nursing diagnosis Betty Neuman refers to when discussing the steps of the nursing process.

Refer to chapter 3: 3.4

5.5 OBJECTIVE NO. 2: IDENTIFICATION OF THE HIV/AIDS PROGRAMME ACTIVITIES AND THE ORGANIZATIONS THAT IMPLEMENTED THEM

Data for providing answers to this study objective was obtained in three ways viz. perusal of the available archival records, administration of a questionnaire to NGO/CBOs that attended the two (2) meetings of the Department of Health (193 NGO/CBOs), and thirdly by the visits subsequently paid to 15 of the 193 organizations with a view to confirming the existence of activities and filling of the gaps in the information that had been collected.

The data obtained from the records were categorised into pre and post-1994 General Democratic Elections periods; this presupposes a prior arrangement of data in a chronological order. The data on the activities of service providers (NGO/CBOs), obtained through the use of a questionnaire and a checklist from 193 NGO/CBOs were streamlined into themes viz. Information, Education and Communication, Adult Care and Support, Child Care and Support, Human Resource Development and Research. The number of organizations currently involved in each of the above activities were counted and assigned the number of NGO/CBO engaged in them as shall be seen in the relevant section.

A ANALYSIS ACCORDING TO WRITTEN DATA

SECTION I: PREVENTION: Prevention remains the “cornerstone of HIV/AIDS management” (Health Systems Trust, 2003). The main aspects of prevention explored were VCT, PMTCT, and management of STIs and Barrier Methods.

5.5.1 HIV TESTING

HIV testing is a blood test which determines whether a person is HIV infected or not. According to Van Dyk (2001: 55) the two of the best known HIV antibody tests are the Eliza and the Western Blot tests. These tests cannot trace the virus itself in the blood, but react to the HIV antibodies formed by the immune system in an unsuccessful effort to protect the body against HIV. These antibodies are usually detected from the blood within 4-6 weeks following an infection but an infected person can become HIV positive approximately 6 weeks after infection, and sometimes from between 3 and 12 months.

There are other HIV tests that have since been developed, the most common of which is the Rapid Test, which yields results in 10 to 30 minutes.

5.5.1.1 Pre-1994 General Democratic Election’s period

HIV testing marked the first HIV/AIDS intervention as seen in the following

events:

- The screening of blood donated to Natal Blood Transfusion Services (NBTS) commenced but there were no confirmatory test kits at the time.
- A report that blood which had been donated to Natal Blood Transfusion Services showed signs of HIV “contamination” as detected through a tentative blood test (Daily News, 21/8/85). At this stage there was no reliable HIV Test; it was expected that in November 1985 the confirmatory test kits would be available in South Africa (Daily News, 21/8/85).
- Early in 1986 it was reported that a reliable blood test kit was still not available in KZN (Mercury, 9/1/86).
- Shortly afterwards a reliable blood test kit for HIV became available in South Africa (Witness, 10/1/86).
- Although there were no confirmatory HIV blood tests when the NBTS started screening the donated blood for HIV, and thus those that tested HIV positive on the first test not told about the results, the at risk blood was not used for blood transfusion as articulated by the then Director of the NBTS, Dr Peter Brian in the following words: “although tests for AIDS being carried out at present were not always accurate, the precaution had to be taken” (Daily News, 2/8/85).
- Dr J.M. Muller of Edendale Hospital suggested that the NBTS refer HIV positive people to their nearest health facilities for counselling (minute to NBTS from Dr J.M. Muller, 4/6/87).
- Dr Murray Short of the KwaZulu-DOH informed Edendale Hospital of the availability of funds for HIV testing (2000 tests only) and suggested that these be done at STD clinics (KZLDOH: August 1988).

The following table gives a clearer display of the above events

**Table 1: Events that marked the first HIV/AIDS Intervention i.e. HIV Testing:
KZN: Pre-1994**

Event	Year	Month
1. Testing of blood for HIV commenced	1985	August
2. Donated blood reported "contaminated" with HIV	1985	August
3. A confirmatory HIV test kit became available	1986	January
4. Confirmation that precautionary measures had been taken to prevent cross infection even before a reliable blood test kit became available.	1987	August
5. Suggestion that the NBTS refers HIV positive people to their nearest health facility.	1987	June
6. Edendale Hospital informed of availability of funds for HIV testing from the KZL-DOH	1988	August

5.5.1.1.1 Interpretation

The above procedures for HIV testing means that the screening of blood donated to NBTS was an AIDS activity or intervention. It marked the beginning of those HIV/AIDS activities falling under the broad umbrella of "Prevention" since it prevented the spread of HIV through the donated blood. Furthermore it contributed towards public AIDS awareness and education because the media reported on the

events and the NBTS educated their clients to protect others. The arrival of the reliable test kits led to appropriate diagnosis, treatment and care of AIDS patients.

Following the initial availability of reliable test kits, various institutions (including the private sector) collected blood for HIV testing and these were confirmed by the Virology Department of the then University of Natal's Medical School.

5.5.1.2 Post-1994 general democratic elections

The following events occurred around HIV testing during this period:

- HIV testing by use of the Eliza and Western Blot test kits continued.
- Voluntary Counselling and Testing (VCT) commenced at this stage still using the Eliza test; it was funded by the National Department of Health (NDOH) and undertaken at the three ATICs (AIDS Training, Information and Counselling Centres) in Pietermaritzburg, Durban and Empangeni. The ATICs subcontracted private laboratories to do the tests (but would do pre-test counselling, taking of blood, post-test counselling and the issuing of results themselves). Confirmatory tests were done by the Virology Department of the then University of Natal in Congella (KZN-DOH, 1996).
- From April 1998, the NDOH could no longer provide funds for HIV testing and KZN DOH had to foot the bill (personal experience). To defray costs, the services of private laboratories were stopped and all the testing done by the Virology Department of the University of Natal (KZN DOH memo 261/98).
- In 2000, testing was expanded and made even more humane.

- The year 2000 involved a lot of ground work preparing for this breakthrough initiative, one of which was staff training (KZN-DOH memo, 19/1/01).
- The initial sites for VCT were as follows:
 - a) Ilembe district: Prince Mshiyeni Memorial Hospital,
KwaMashu Polyclinic and Enduduzweni Community Centre
 - b) Zululand district: Benedictine Hospital
 - c) Uthungulu district: Empangeni AIDS Centre, Enseleni Clinic and Esikhawini Clinic.
 - d) Indlovu district: Edendale, Greys and Northdale Hospitals, Imbalenhle Clinic.
 - e) Mzinyathi district: Church of Scotland

The NDOH provided funds for VCT.

What the VCT initiative entailed

It entailed:

1. Provision of information to the individuals which would enable them to decide whether to undergo testing with a view to knowing their HIV status and managing their condition.
2. Marketing of VCT through media and open AIDS events.
3. Training of trainers as well as people who would serve at the sites.
4. Identification of VCT sites based on specific criteria.
5. Collection of data and statistics on the results of VCT.
6. Provision of resources, e.g. counsellors, test kits etc. (PAAU, 2002:2).

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6. Provision of resources, e.g. counsellors, test kits etc. (PAAU, 2002:2).

Expected results of VCT

The Government hoped that:

1. By the year 2005, 25% of people between the ages of 15 - 39 would know their HIV status.
2. More people would go for VCT voluntarily and would accept their status.
3. Having accepted their HIV status, they would readily disclose their status.
4. AIDS would be destigmatised.
5. The HIV positive would be helped to live longer (KZN-DOH, 2001).

In 2001, 21 VCT sites were established, 6 of which were non-medical (PAAU, 2002: 2):

- By the end of March 2003, 118 VCT sites had been established at clinics and hospitals, 28 of which were non-medical sites.
- 389 Lay Counsellors had been employed by the end of March 2003, which yielded a total of 715 AIDS counsellors in the field.
- A counsellor mentor co-ordinator and a trainer were employed in each district in 2003.
- By the end of March 2003, of the 56 839 people that had been counselled, 55 400 consented to be tested and of those that were tested, 26 219 were found to be HIV positive, i.e. 42.2%.

Table 2(a): Events Around HIV Testing: Post 1994 GDE

Events	Year
1. HIV Testing using Eliza test	1995
2. Confirmatory tests done by Virology Department-University of KZN.	1995
3. Testing of blood by private Laboratories stopped	1998
4. Voluntary Counselling and Testing commenced	2000
5. VCT sites identified	2001

Table 2(b): VCT Statistics: KZN, by March 2003.

Event/Activity	Number
6. HIV Testing using Eliza test	118
7. Confirmatory tests done by Virology Department-University of KZN.	715
8. Testing of blood by private Laboratories stopped	56839
9. Voluntary Counselling and Testing commenced	55400
10. VCT sites identified	26219

Source: PAAU, 2002:2.

5.5.1.3 Interpretation

From the above events it can be said that HIV testing was first done by the Natal Blood Transfusion Services in 1985, albeit through a lack of confirmatory test kits and counselling. This was followed by reliable tests in 1986, which helped

institutions diagnose some infected patients. Later on Voluntary Counselling and Testing (VCT), which used the Eliza Test that still needed to wait for confirmatory tests (early post- 1994 GDE period) followed. Eventually a faster and more humane VCT was established in 2000 using Rapid Test Kits. These tests played a big role in the control of HIV infection, given the fact that they were coupled with counselling, which included education plus that the person did the test voluntarily. VCT started yielding concrete and useful results by 2003 as can be seen in Table 2 above.

5.5.2 BLOOD TRANSFUSION: PREVENTIVE MEASURES

Only the pre-1994 GDE period data was available to address this question. Preventive measures around blood transfusion in KZN can be seen in the following events:

- KwaZulu-Natal took early precautionary measures to ensure that the blood donated to the Natal Blood Transfusion Service (NBTS) was safe to the public, i.e. the testing of blood for HIV started in 1985, albeit not reliable till early in 1986 (Daily News, 21/8/85).
- Only the South African Blood Transfusion Service (i.e. one agency) dealt with blood donation in South Africa with a branch in Pinetown, KZN.
- Donors of blood were not paid in KwaZulu-Natal, and in South Africa, as has happened in some countries (Mercury, 13/8/85); this prevented possible trading blood.
- High risk donors, homosexual and bisexual males were warned by the NBTS that “under no circumstances should they donate blood” (Daily News, 21/8/85).

- People who suspected that they might have HIV and/ or PLWHAs were advised and warned not to donate blood (Mercury, 13/8/85; Daily News, 21/8/85).
- The NBTS employed a Belgian protein chemist, Dr Jean-Marie Mathijs, to study AIDS Testing in Paris to be part of his duties on his return to South Africa (Daily News, 21/8/85).
- The NBTS initiated a procedure to routinely review its records to identify past donations by a donor who then tested positive for antibodies to HIV. The past donations would be traced to the recipients of blood products (Minute from NBTS, 10/8/87). This "look back" programme had been started nationally (Press release, 20/8/87).
- Homosexual men who had engaged in sex for the last 7 years were not allowed to donate blood (Regional AIDS Advisory Group, KZN 19/2/90).
- The NBTS announced that people could donate blood for their own future use, i.e. autologous blood transfusion (Daily News, 30/11/90).

Table 3: Events that show the taking of precautionary measures around blood transfusion: KZN: Pre-1994

Event	Year	Month
1. Donated blood tested for HIV	1985	August
2. High-risk blood donors warned by the NBTS not to donate blood.	1985	August
3. Those suspecting that they might have HIV advised and warned not to donate blood.	1985	August
4. A Belgian protein chemist sent to Paris by the NBTS for AIDS Testing Course.	1985	August
5. Routine review of records to identify past donations by a donor who then tested HIVpositive undertaken.	1987	August
6. Homosexual men who had engaged in sex for the last 7 years not allowed to donate blood.	1990	February
7. Autologous blood transfusion encouraged by NBTS	1990	November

5.5.2.1 Interpretation

KwaZulu-Natal started protecting its people against HIV infection through blood transfusion in 1985, i.e. in the 4th year following the diagnosis of the first AIDS patients in San Francisco (USA), by screening all donated blood for HIV. The NBTS also initiated a procedure to routinely review its records to identify past donations by a donor who then tested HIV positive and traced these to those who had received the blood donated by the then HIV infected person. The introduction of autologous blood

transfusion, networking with the relevant institutions and education of the HIV infected was deemed a step in the right direction.

5.5.3 INFORMATION, EDUCATION AND COMMUNICATION (IEC)

This programme refers to the education of the public on HIV/AIDS, which constitutes the most important AIDS strategy.

5.5.3.1 Information, Education and Communication (IEC) during Pre-1994 GDE period

5.5.3.1.1 IEC in 1985-1989

The following events marked the implementation of HIV/AIDS Information, Education and Communication in KZN:

- The reporting of the results of the tentative blood tests for HIV by the NBTS in 1985 (Daily news, 21/8/85).
- The education of health staff on AIDS following the diagnosis of the first AIDS cases in Ngwelezana, Addington, Bethesda, etc. (Personal communication with Mrs N. Haselau, Mrs N.M. Shangase, Dr A. Jaffe 2003).
- Education of HIV positive blood donors by NBTS (Daily News, 21/8/85).
- The development of IEC materials and negotiation with the media to get slots for AIDS education done by Dr Mandla Mhlongo in 1987 (KZL DOH, May 1987).
- Address of the top hierarchy for the Lutheran church on AIDS by the late

Dr M.V. Gumede in March 1988 (minute from Dr M.V. Gumede to Dr J.M. Muller, 28/3/88).

- Communication in writing by the late Dr M.V. Gumede and the President of the then Inyanga's Association, Mr J Mlotshwa of Durban with a view to soliciting co-operation in the fight against HIV/AIDS and requesting of slots for AIDS education at their meetings (Letter from Dr M.V. Gumede to Dr J.M. Muller, 17/5/88).
- Organizing and facilitation of AIDS workshops by Mrs Mary Mngadi of the KZL-DOH and Dr Sonto Nkosi of Edendale Hospital - these were run for health staff from July to September 1988 throughout KwaZulu (KZL DOH, Ref 12/12/P, 1988).
- A trauma video was shown to the press; this had been produced by a Durban Company called Impact Video Production in partnership with the SA Institute of Medical Research, the Inyanga Society and the Natal Medical School (Mercury, 8/8/88).
- The commencement of a school AIDS Campaign in KwaZulu in September 1988 through School AIDS Teams (KwaZulu -NHDOH, 1988).
- Honouring of World AIDS Day - The Department of National Health and Population Department did AIDS education at Richards Bay and Durban ports in 1988 (Regional AIDS Advisory Group - KZN, 17/10/88).
- Honouring of World AIDS Day (WAD) whereby a Durban company called AMD Hygiene Services designed Anti-AIDS Packages for employees; it included a video with sound tracks in English, Xhosa, Zulu and Sotho; trainers were employed and provided with training guides (Mercury, 13/12/88).

Table 4 below categorises and quantifies the above IEC events:

Table 4: IEC Events: 1985 – 1989: KZN

IEC Activity	Frequency
1. AIDS Awareness through media	3
2. Education of HIV positive blood donors	1
3. Education of Health Personnel	2
4. Development and use of IEC materials	3
5. AIDS Awareness at churches	1
6. AIDS Awareness to Traditional Healers' Association	1
7. Honouring of World AIDS Day (WAD)	5
8. Work place AIDS awareness initiative	1

5.5.3.1.1.1 Interpretation

The above table shows that World AIDS Day events followed by AIDS awareness through media as well as the development and use of IEC materials were becoming prominent IEC activities during this period.

The above data it would appear that the focus was on awareness and networking as shown by a convention on AIDS in respect of HWs (Health Workers) and consultation of Traditional Healers, lobbying for their support for the prevention of AIDS. Sensitization and education on AIDS through mass media and the honouring of WAD marked the beginning of social mobilization on HIV/AIDS.

Workplace AIDS awareness programmes were also introduced.

The above table shows that World AIDS Day events followed by AIDS awareness through media as well as the development and use of IEC materials were becoming prominent IEC activities during this period.

5.5.3.1.2 Information, Education and Communication: 1990 - 1993

The following events show the highlights of Information, Education and Communication during this period:

- The address of the KwaZulu Legislature on AIDS by Dr F.T. Mdlalose, the KwaZulu Department of Health Minister, 1990 (KwaZulu Department of Health memo, 4/7/90).
- The presentation on AIDS by Dr A. Jaffe at the Rural Health Conference, 3-5/8/90 at Kwanzimela and a puppet show (Minute from Dr A. Jaffe to Dr J.M. Muller, 1990).
- PAAG's president, Rose Smart developed an AIDS training package for the Pietermaritzburg Chamber of Commerce; peer educators were trained and staff assisted with the formulation of Tatham Gallery AIDS Program tours, workshops, lectures and films in Pietermaritzburg (PMB) which extended to Ashdown, a Black community (Witness, 30/11/90).
- An AIDS Education programme started at Umgeni Waters Occupational Health Centre under Lindi Mathobela (Witness, 30/11/90).
- A special AIDS presentation of Drama and Video; at the Natal Society Library from the University of Natal, PMB; (Witness, 30/11/90).
- The Sobantu Family Planning Clinic held an AIDS Awareness event in 1990 (Witness, 29/11/90).

- A Mobile Edu Unit on AIDS was put up in Pinetown (Minutes of Regional AIDS Group 26/9/90:3). In 1990, an AIDS Booklet "Linda and Zakes" took the form of cartoon characters. It was produced by PAAG and distributed through payslips (Witness, 30/11/90).
- In 1991, WAD musical dramas "fate of Africa" and "Masheshisa" were performed in Pietermaritzburg (Witness, 30/11/91).
- Dr Zweli Mkhize of the Progressive Primary Health Care Network (PPHC) addressed people at the launch of PPHC and said, "AIDS knows no political party, no race or ideology, no power-base or constituency - it kills" (Mercury, 30/11/91).
- A person living with AIDS (PLWHA) travelled around PMB using himself/herself as a face of AIDS (Witness, March 1990).
- Red Cross Society-Durban provided a First Aid kit designed to protect first aiders from contracting AIDS; it included a mouthpiece with a one-way valve for protected mouth-to-mouth resuscitation with first aiders orientated on HIV/AIDS and use of kits (Daily News, 2/4/90).
- ATIC Durban held a poster competition and a street AIDS campaign on WAD in 1990 (Mercury, 1/12/90).
- An interview with a PLWHA who had gone public with his / her HIV status was done and an article published in the Echo Newspaper. The Edendale Hospital HIV/AIDS Co-ordinator, Mrs Nelisiwe M Shangase went around with the PLWHA, giving him/ her slots to educate people (Regional AIDS Group, KZN 22/5/91: 1)
- AIDS puppet shows were held around KwaZulu from 1-27/6/92 (KZL-DOH 7/5/92).

- Mr Myeni of Ubombo visited 15 000 Hlabisa school children in August and September 1992 giving AIDS education (KZL-DOH, 1992:2).
- ATICs, DONH and PD, Amatikulu and PPHC were sources of AIDS education materials for WAD (KZL-DOH, 1992:3).
- The University of Zululand's Music and Drama Department undertook a pilot project on AIDS education by use of Drama (KZL-DOH, 1992).
- In 1992, the University of Zululand's Department of Music and Drama, in contract with the KwaZulu Department of Health, undertook a visible AIDS and Lifeskills education programme in KwaZulu schools as a pilot project called the Dramaide. It ran in 3 phases viz. (1) a short play to raise awareness (2) participatory teaching about AIDS (3) an open day where the learners present their own responses to AIDS in the form of songs, plays, dance, poetry and posters. Evaluation of this project yielded positive results (KZL-DOH, 1993: 2).
- Dr Humphreys from Eshowe started an AIDS education programme on the North Coast, talking to schools, universities, business, farm workers, churches and hospital personnel. He had approached the late Dr Murray Short (former Director of Communicable Diseases Control - KZL) to ask for authority for undertaking this project (Regional AIDS Group: KZL 26/6/93).

Table 5(a) below categorises and quantifies the above events.

Table 5(a): IEC Events: 1990-1993

Events	Frequency
1. AIDS Address by high profile people	2
2. AIDS puppet show	2
3. Development and use of AIDS materials	5
4. Establishment of workplace AIDS programme	3
5. AIDS awareness events	3
6. AIDS education by PLWHA	11
7. School AIDS Education Programme	1
8. AIDS Programme by Tertiary Institutions	3
9. AIDS Education to farm workers	2
10. AIDS Education to church members	1

5.5.3.1.2.1 Interpretation

The above table shows that the development and use of AIDS education materials followed by Tertiary institutions-driven and workplace AIDS programmes were leading, followed by AIDS address by high profile people.

The above table shows that the development and use of AIDS education materials followed by tertiary institutions-driven and workplace AIDS programmes were leading, followed by AIDS address by high profile people.

Many and varied IEC initiatives mushroomed during 1990 to 1993 when the AIDS epidemic was becoming more visible. PLWHAS started going public with their HIV status, IEC material supplies improved and there was an increase in the use of media. Dr ZL Mkhize, the Honourable MEC for Health at the time of this study, featured in the fight against AIDS not only after the 1994 GDE as seen under "support system"

(5.3) but even before. An innovative project on AIDS in KZL schools (Dramaide) began; collaboration amongst sectors is also reflected during this period.

5.5.3.1.3 Post-1994 Information Education and Communication (IEC)

The implementation of IEC during this period can be seen in the following activities:

- The Department of Education (DOE) contracted MacMillan Boleswa in 1995/96 to train two teachers on lifeskills education (LSE) - per school. When the programme was evaluated, weaknesses were identified (National DOH , 1997: 46)
- Public education done through radio, TV, newspapers (adverts and articles); Ukhozi FM provided ongoing slots on alternative Tuesdays (KZN-DOH, 1997).
- Impromptu AIDS education campaigns launched at funerals of PLWHAs who had gone public with their HIV status and in consultation with their relatives (KZN-DOH, 1997).
- AIDS messages put on payslips, billboards, train coaches and long distance taxis in 1998 and continued in 1999 (KZN-DOH, 1998).
- A High Transmission Areas project whereby four people were trained on HIV/AIDS and STIs and employed to educate people at the sites of high HIV transmission viz: hostels, street dwelling places, truck stopping stations, brothels, etc. was undertaken (KZN-DOH, 1998). One of the four people had been a commercial sex worker herself.
- The Director of Programmes in the KwaZulu-Natal Department of Health offered some funds which were under Primary Health Care for undertaking a

specific project. The Provincial HIV/AIDS office in collaboration with the District AIDS coordinators undertook a HIV/AIDS Communicators' (HACS) project whereby AIDS educators were trained and placed in all areas where there were no Community Health Workers (CHWs) or oNompilo. These educators operated as volunteers who received a stipend. It was planned that the HACs would in future become CHWs. The content of training included subjects on how to carry out a situational analysis, education on TB, Diarrhoea, community entry etc. (KZN-DOH, 1998).

- In 1998 the Department of Education (Arts and Culture) in partnership with the Department of Health engaged in a HIV/AIDS campaign whereby learners incorporated HIV/AIDS into their arts and cultural activities, e.g. drama, music and dance (KZN-DOH, 1998).
- "Phusha siyay'dudul'ingculazi", an AIDS awareness project involving unemployed youth was undertaken in Ilembe District as a collaborative effort between the AIDS Foundation of South Africa (AFSA), the South African Breweries, the Provincial DOH and the KZN Youth Council. The focus of the campaign was on life skills (Makhanya, 1999).
- Oupa Jackson invented an AIDS game that could educate a person on AIDS while enjoying the game (KZN-DOH 1998). This game was subsequently used in the province after 2000.

5.5.3.1.4 IEC: Social Mobilization

The events below are those that have not been mentioned in the previous sections of IEC.

- 1988 - A gala function was held at the Alhambra Theatre in Durban in aid of the immunology and research fund of the Natal University in December. Tickets were sold at R250 per couple (Daily News, 1/12/88). The function was concerned mainly with AIDS education and awareness.
- 1990 - An AIDS Analysis Africa newsletter was launched; produced by the AIDS Policy Research Group under the directorship of Dr Jack van Niftrik, Andries Spier, Director of Sincom and Prof Allan Whiteside of the then University of Natal Economic Research Unit (Minute from AIDS Policy Research Group, Rivonia, Congella and McGregor to Dr J. Muller, 1990).
- 1997- The First PLWHA to go public with his HIV status after the 1994 GDE, Alfred Tito Ntimba, died and an AIDS awareness campaign was held at his memorial service and funeral at the approval of relatives - 18/1/97. He had been educating the public on HIV/AIDS; he had also featured in the media.
- 1998- ML Sultan Campus of the Durban Institute of Technology held a week's AIDS campaign from May 4 - 8th (KZN- DOH, 1998).
- 1998- The targeted AIDS Interventions NGO led by Getwana Makhaye launched a Shosholoza AIDS project on 24/10/98 targeting KZN soccer players. Events held in Pietermaritzburg, Newcastle, etc. (Researcher's Diary 1998; KZN-DOH, 1998).
- 1998- An AIDS Campaign was held at the funeral of Hlalaphi Hlabisa on 5/9/98. Hlalaphi, a PLWHA who had gone public with her HIV status, had educated the public on AIDS beyond KZN since she and her Hlabisa AIDS Support Group members featured in the video "Umuntu ngumuntu ngabantu" (KZN DOH, 1998; Researcher's diary, 1998). The Sermon of her funeral was conducted by Rev L. Mthombeni.

- 1998- A Nomkhubulwane Traditional Ceremony under the leadership of Nomagugu Ngobese was held at Bulwer; KZN DOH supported the event, provided the necessary materials and addressed the audience on HIV/AIDS - 28 - 30/8/98 (KZN-DOH, 1998).
- 1998- An Umhlanga Ceremony held on 12/9/98: The DOH supported the event by display of posters and distribution of HIV/AIDS and STI pamphlets (KZN DOH, 1998; Researchers' diary 1998).
- 1998- Women with a Purpose CBO of Umlazi ran a series of street campaigns on HIV/AIDS talking to people and distributing condoms and pamphlets (KZN-DOH, 1998).
- 1998- Diakonia Council of Churches held an AIDS and poverty awareness Good Friday Sermon and a march carrying a cross to the Durban City Hall building where proceedings of the event were continued (DCC, 1998).
- 1998- An April Road Show was held from PMB to Durban with a station along the way and AIDS materials including playcards distributed to people along the way (KZN-DOH, 1998).
- 2000- In July 2000, a big steel AIDS ribbon was erected at Central Park in Durban in the honour of Gugu Dlamini who had been murdered in 1998 after disclosing her HIV positive status. The official opening was done by the Deputy President, the Honourable Dr Jacob Zuma (KZN-DOH, 2000; personal observation; Researcher's Diary). A Drop-In-Centre was later on established in the park.
- 2000- An International AIDS Conference was held in the Durban International Convention Centre (ICC), from 9 - 14 July 2000 (Personal experience; Daily News, 10/7/00).

- 2000- The Sweetwaters Drop-In-Centre was officially opened on 6/12/00. The centre had been donated by Mr R Thusi and the Glaxo Wellcome Company funded the renovation of the building. An NGO, SAHECO led by Mqansa Makhathini, administered the centre (KZN-DOH, 2000).
- 2001- An abstinence walk from Durban City Hall to Empangeni was held on 8/6/2003, organised by the Hope Foundation founded in 2001 as an outreach programme of the Durban Christian Centre. The 250 km walk formed part of youth celebration aimed at educating people about abstinence and being faithful (NAPWA-Informer, 2003: 2) and was supported by True Love Waits. The walk was sponsored by ABSA, Coca Cola, Spoornet, MTN, Inkosi Albert Luthuli Hospital, Ethekewini Municipality, Ilembe Municipality and Virgin Active A (NAPWA, 2003: 2).
- 2003- Manning Rangers visited Westville Prison to give support to inmates infected and affected by AIDS, encouraging them to live a full and happy life. They were escorted by Mrs Z Dlamini, AIDS Co-ordinator: Correctional Services (NAPWA, 2003).
- 2003- A South African AIDS Conference was held in the Durban ICC, chaired by Professor Jerry Coovadia. The conference combined scientists, the neighbouring community and an African perspective (NAPWA, 2003).
- 2003- Prayer day for Health Care workers as well as the 5th Anniversary of Partnership Against AIDS was held at Kings Park Stadium. Attended by churches of various denominations (Personal experience; Researcher's diary, 2003).

Tables 5(b) and (c) below condenses post-1994 IEC activities including social mobilization.

Table 5(b): Categorized and quantified events showing general IEC Activities:

KZN: Post-1994.

Activity	Frequency
1. Sub-contracting of other organizations to do IEC work	1
2. IEC through Mass Media	2
3. AIDS Education by PLWHA	1
4. Special Projects on AIDS Education	2
5. Mass Dissemination of AIDS Messages	1
6. Incorporation of AIDS Education into existing programmes	1
7. Collaboration in AIDS IEC	3
8. Innovation in IEC	1

Table 5(c): IEC Activities showing social mobilisation: Pre and Post 1994

Activity	Frequency
1. Gala function on AIDS	1
2. Official launch of AIDS work	3
3. AIDS Campaign Around PLWHA's funeral	2
4. AIDS Campaign by Tertiary Institution	1
5. Incorporation of AIDS education into traditional ceremonies	2
6. Women driven AIDS Education Campaign	1
7. Road show on AIDS	3
8. AIDS conferences	2
9. Visit of prisoners by a national soccer club	1
10. Prayer Day for HWs	1
11. Anniversary: Partnership Against AIDS	1

NB: The above activities represent the examples of AIDS activities in KZN; the Figures do not give the total quantity of work performed during the period under review.

5.5.3.1.4.1 **Interpretation**

KZN started talking about AIDS at funerals of those who had gone public with their HIV status provided relatives consented. The use of mass media communication in disseminating AIDS messages could then be done by one entity representing the whole province. Many and varied projects were undertaken, but it is not clear whether baseline studies were done prior to the commencement of each project; neither is it clear whether monitoring and evaluation was appropriately done. People started showing creativity in AIDS education methods and there was a backing of IEC by major AIDS events in the form of social mobilization. The holding of the international and national conferences in KZN constitutes one of the salient features of HIV/AIDS activities in the province.

5.5.3.1.5 **HIV/AIDS Projects**

These were transient HIV/AIDS initiatives which were undertaken as an aspect of the entire HIV/AIDS programme. They leaned more towards “prevention” than “care”.

5.5.3.1.5.1 **Faces Project**

This is a project of AIDS awareness whereby a PLWHA sensitise and educates people on HIV/AIDS using himself / herself as an example i.e. putting a “face” on AIDS.

- Started in 1996. One Person Living with HIV/AIDS (PLWHA) was trained employed and based at the Provincial AIDS office. It was initiated and funded by the National Department of Health. Duties of PLWHAs was to educate/

sensitise people on HIV/AIDS, disclosing their positive HIV status to them; educate them on the rights of people living with HIV/AIDS (PLWHAs), peer counselling and establishment of support groups (KZN-DOH, 1996). By 1998, all Districts had employed PLWHAs at R2 500-00 per month (at the beginning). The PLWHAs held membership with NAPWA (National Association of People Living with AIDS). The main purpose of the project was to put a face to AIDS as part of enhancing AIDS education, thus addressing stigma, discrimination, myths, ignorance etc. (1996/97 and 1997/ 98, KZN DOHs Operational plan: Diary of Researcher, 1997: NDOH HIV/AIDS Directorate Minute, February 1996).

5.5.3.1.5.2 Disclosure and Acceptance Campaign

- Undertaken by KZN NAPWA in November 1997. This meant disclosing one's HIV status and acceptance of this person by others and was aimed at encouraging disclosure by PLWHAs and promotion of acceptance of this person by families and community at large. This acceptance also referred to the acceptance of those affected by AIDS (NAPWA, 1997).

The reasons for disclosing were (amongst others) making a hidden and invisible disease a visible reality, provide positive role models demonstrating that one can live with HIV, show that HIV diagnosis was not a death sentence, challenge the notion that AIDS did not exist: Others wanted to challenge that AIDS was African (NAPWA, 2000; personal communication with Lucky Barnabas, 2003). The other reasons advanced were to substantiate the

statistics and put a human face to it and lastly it was to challenge stigma and prejudice (NAPWA, 2000).

NAPWA undertook this campaign by preparing and supporting the PLWHA, family and friends, helping PLWHA to disclose and helping family and friends to express their feelings about the disclosure and how they had coped and supported their loved ones. Both the PLWHA and the significant others would talk from the same platform.

The key message to PLWHA was: It is important to live positively with HIV and to be a role model to others. The key message to family, friends and the community was: It is important to accept, love and support a PLWHA (NAPWA, 2000).

5.5.3.1.5.3 Young Living Ambassadors' Project

This project on AIDS was initiated by the National Youth Commission in 1998 whereby young people who were public with their HIV status were recruited to sensitise people about HIV/AIDS prevention, care and support; sensitise people about the human rights aspects, assist PLWHAs to form Support Groups and do Peer Counselling (Researchers Diary, 1998).

5.5.3.1.5.4 Commercial Sex Workers' Project

The Provincial AIDS Action Unit (PAAU) in partnership with the Department of Health and the Department of Transport established and launched a Truck Stop Clinic

in Ladysmith. The other 3 truck stop clinics were planned for Mooi River, Pongola, Mkhuze and South Coast. A full time Professional Nurse and a Counsellor have been employed by PAAU at the clinic (Informer, 2003: 1). The project provided condoms, treatment for STIs, counselling, education as well as referral.

5.5.3.1.5.5 Projects Targeting Men

- In 2001 Health Systems Trust (HST) initiated a project on Male Sexuality and Reproductive Health whereby males were encouraged to participate more meaningfully in the fight against HIV/AIDS (HST: 2002). The sites were Mondlo, Ulundi in 2001; Hlabisa and Ubombo in 2002; Mhlabuyalingana in 2003.
- PAAU established Hostel dwellers' HIV/AIDS Project in partnership with KZN PPHC. PAAU funded the latter NGO to manage the project at 11 Durban hostels in North and South Council (PAAU, 2002).
- Transport Industry Targeted campaign was initiated by the Department of Transport and funded by the DOH and PAAU. Eighteen (18) taxi ranks were reached in 2001, and the popular "Emzini wezinsizwa" cast featured. The taxi drivers and taxi owners were subsequently trained as Peer Educators (PAAU, 2001:5).
- A total of 155 Amagosa and Izinduna zezinsizwa (leaders of regiments) were trained in partnership with "Emzini wezinsizwa" cast. S.J. Smith Hostel, KwaMashu Hostel, Mandeni, Nhlazuka, Hluhluwe and Dalton Hostels were successfully targeted (PAAU, 2001; KZN DOH, 2002: 29).

5.5.3.1.6 Interpretation

The HIV/AIDS programme in KZN developed special projects targeting people who were infected by HIV, those engaged in risky sexual behaviour as well as males. The main aim of the projects targeting PLWHAs (and their significant others in the case of disclosure and acceptance) was that of assisting people put a face on AIDS and thus get rid of ignorance, myths and misconceptions about the disease; this would then help them adopt behaviour that would protect them against HIV infection. The PLWHAs project would also help in the elimination of stigma and discriminatory attitudes people often adopt towards people with AIDS. The interventions of PLWHAs would boost their self esteem and help them deal effectively with the stress of being infected by HIV, i.e. strengthen their lines of defence and resistance. Teaching others about appropriate behaviours would help them get prepared to set good examples.

The commercial sex workers project reflects good partnership between Govt Departments, i.e. (Health and Transport) and shows being proactive since the Truck Stop Clinic was not established to stop commercial sex work but to ensure that in the course of their business, people protect themselves from HIV and sexually transmitted infections and thus protect the nation. Men were targeted as leaders in the communities and at homes and so as to influence communities and family members adopt behaviour that is conducive to protection against HIV infection.

Other than the Male Sexuality and Reproductive Health project it is however not clear whether the commencement of the above projects was preceded by a baseline study,

the results of which would serve as a yardstick for the measuring of their effectiveness.

5.5.4 LIFE SKILLS EDUCATION FOR YOUTH IN AND OUT OF SCHOOLS: PRE AND POST-1994 GDE

Lifeskills refers to “personal skills needed by each individual to act in a responsible and creative manner in each of the following: learning, work and play, personal and social development and interpersonal relationships” (Tromp, 1996). The following are the events in the progression of lifeskills education:

- The Dramaide under the leadership of Prof L Darynmpile incorporated lifeskills education in its pilot project on AIDS in 1992 (KZL-DOH, 1992).
- In 1996, Debbie Tromp of the Pietermaritzburg AIDS Action Group co-ordinated Lifeskills Education (LSE) in KwaZulu-Natal for the Department of Health (KZN-DOH, 1997). Late in 1997, Ntombifuthi Mtshali co-ordinated LSE programme.
- LSE was done in partnership between the Department of Health, Pietermaritzburg AIDS Action Group and the Department of Education (PAAG, DOH and DOE).
- In 1998 selected Teachers in Post-Primary schools were trained in LSE (KZN DOH, 1999).
- In 1999 Teachers in Primary schools started being trained on LSE (KZN-DOH, 1999).
- LSE Incorporated into the curriculum and programme transferred to the DOE in 2000 (KZN-DOH, 2000).

- LSE for youth out of schools undertaken by some NGOs e.g. PPASA (Planned Parenthood Association of South Africa).
- LSE focusing on Traditional values was undertaken by Izimbali Zesizwe project, under the leadership of the late Princess Nonhlanhla Mahlangu, His Majesty the King's sister. This project strived to restore the traditional value of abstinence from sexual intercourse till marriage. The target was the youth in and out of schools (initially females and later on, males too). The project was sensitive to human rights issues in the sense that the young people who did not wish to participate were not forced (Personal Communication with the late Princess Nonhlanhla Mahlangu, 1997). The project focused on the youth of the deep rural areas (Personal observation 1996-2000).
- Durban Christian Centre established an LSE programme focusing on abstinence (NAPWA, 2003:2).

Table 6 below gives the streamlined version of lifeskills education activities cited above.

Table 6: Lifeskills Education Activities: KZN: Pre and Post 1994

Activities	Year
1. Undertaking of the Lifeskills education (LSE) Project	1992
2. Identification of the first LSE Co-ordinator	1996
3. LSE project focusing on Traditional values undertaken	1996
4. Training of selected teachers on LSE in Post-Primary schools	1998
5. Training of selected Primary School teachers in LSE	1999
6. LSE incorporated into the school curriculum	2000
7. LSE programme transferred from the DOH to DOE	2000
8. LSE project focusing on abstinence established by a church-based organization	2001

5.5.4.1 Interpretation

LSE started before 1994 GDE period. The Department of Health ensured that the capacity of the DOE was fully built before handing the LSE programme over. The DOE accepted the responsibility for LSE once it got capacitated. The subjects and activities of LSE were relative to place and values e.g. saying no to sex was a skill which could be valued more in deep rural areas whereas appropriate use of a condom could be valued more in an urban setting. Church-Based organizations introduced LSE with emphasis on abstinence.

5.5.5 MANAGEMENT OF SEXUALLY TRANSMITTED INFECTIONS (STIS) AND BARRIER METHODS

Sexually Transmitted infections are all those diseases that are transmitted through sexual intercourse. Barrier methods refer to the devices or materials used to prevent microorganisms from invading the body e.g. a condom, cream or microbicide etc. can be used to prevent HIV from entering the human body (own explanation).

5.5.5.1 STIs (Sexually Transmitted Infections): Pre and Post 1994 GDE

- The Syndromic Approach in STD (STI) management was introduced in 1991 (Dlodlo and Jinabhai, 1996: 2).
- There was recognition that the prevention and appropriate treatment of STIs had to be the cornerstone of AIDS prevention (KZL DOH: 1992)

- Treatment protocols for clinics were revised and distributed (KZL-DOH, 1992).
- STIs Trainer workshops were planned and run in 1993 (KZL-DOH, 1992 Annualreport; KZL-DOH, 1993).
- In 1996 STD management involved the training of staff in the syndromic approach. This meant treating an STD (now STI) by signs and symptoms versus dependency on laboratory findings e.g. a penal discharge would be treated instead of gonorrhoea, a genital sore instead of syphilis etc. This approach had been encouraged by a Muanza (Tanzania) study which found a 42% reduction in HIV infection amongst those who had been subjected to the syndromic approach (KZN-DOH, 1996).
- Treatment protocols were modified and distributed to hospitals and clinics in 1996 (KZN-DOH, 1997).
- The private sector e.g. General Practitioners (GPs) were orientated on the treatment protocols (1997/ 98 AIDS Operational Plan, KZN-DOH).
- Traditional healers given elementary knowledge on STIs (KZN-DOH: 1997).
- A supervisory tool for STIs developed and administered, management of congenital syphilis, 24hrs STD service in clinics, STD management in Family Planning (FP) clinics and partner notification (MRC, 1997: 52).
- The training of staff in STI management, supply of clinics and hospitals with syndromic STI management charts, booklets and contact notification cards.
- An STI event drawing the private sector in was held in Durban, organized by the DOH (DOH, 1999).

- A truck stop STI clinic was established at Tugela Plaza through a partnership between PAAU, Department of Transport, Road Freight Association and Learning Clinics (PAAU, 2003).

5.5.5.2 Barrier methods: Pre and Post 1994 GDE

- Male condoms were made available by the Government in KZN free of charge during pre-1994 GDE period (KZL-DOH AIDS Task Group or ATG, 1990).
- Condom distribution started to double in 1992 (KZL-DOH, 1992).
- After 1994 GDE the male condom remained the main barrier method used and condom use was regarded as a key strategy for combating AIDS (KZN-DOH, 1994).
- The female condom or femidom was initially put on trial at a Durban clinic in 1997 and gradually extended to other clinics; by 1999, 59 sites were identified for further trial (KZN-DOH, 1999).
- A trial of nonoxynol 9 microbicide was reported having failed (national HIV/AIDS Directorate, 1999) and therefore stopped. The use of condoms with nonoxynol 9 was banned with immediate effect (Personal experience; National DOH, 1999).
- The acquisition of condom dispensers as well as provision of written instructions for condom use was done from 1997 (KZN-DOH, 1998).
- The KZN- DOH undertook a project whereby condoms were distributed at KZN Tarvens (KZN-DOH, 2002: 28).
- In 2003 free female condoms were made available at G J Crookes Hospital, Pietermaritzburg Life Line, Olivershoek Clinic, Mason Street Clinic, Vryheid,

Mtubatuba PHC Service, Nkandla Hospital, Lovu Clinic, Matatiele PHC Services, Cator Manor Clinic and Valley Trust (NAPWA, 2003: 2).

- By March 2003, 201 469 female condoms had been distributed, the male condoms that had been distributed were 19 413 208 (PAAU, 2003).
- The Government of KZN and SAB (South African Breweries) established a partnership whereby SAB supplied condoms to all the outlets it serviced and also funded the initiative (PAAU, 2003).

Table 7(a) below gives the streamlined version of the activities listed under 5.5.5.1 above.

Table 7(a) STIs (Sexually Transmitted Infections) activities: KZN: Pre and Post 1994 GDE

Activity	Year
1. Introduction of the Syndromic Approach in STI Management	1991
9. Treatment protocols for clinics revised	1992
10. STIs Trainer's workshops run	1993
11. Staff trained in STIs Management	1996
12. STIs Treatment protocols modified and distributed to hospitals and clinics	1996
13. Private Sector e.g. GPs orientated on STI treatment protocols	1997
14. Traditional healers orientated on STIs	1997
15. A Supervisory tool on STI Management designed	1997
16. STI event bringing in private sector held	1999
17. A Truck Stop STI clinic established at Tugela Plaza	2003

Table 7(b) below gives the streamlined version of the activities listed under 5.5.5.2 above.

Table 7(b) Barrier Methods activities: KZN: Pre and Post 1994 GDE

Event/Activity	Year
1. Male condoms provide by the Government free of charge	Pre 1994
2. Doubling of condom distribution	1992
3. Femidon (female condom) put on trial	1997
4. Condom dispensers acquired and used	1997
5. Trial of nonoxynol 9 microbicide reported having failed	1999
6. Use of condoms with nonoxynol 9 banned	1999
7. A project whereby condoms were made available at taverns was undertaken	2001
8. Free female condoms made available at a large number of health facilities	2002
9. Marked increase in condom distribution	2003
10. Supply of condoms by SAB to its branches	2003

5.5.5.2.1 Interpretation

STI management using the syndromic approach appears to have been well entrenched in KZN. The interventions in this AIDS strategy have focused on capacity building in respect of both the staff of the Government Sector and the non-governmental sector on the syndromic approach in STIs management including the traditional healers. The female condom use was on trial from 1996 and could be obtained at the selected areas at the time of writing this report. Male condoms remained the most commonly used barrier method in KZN. Partnership with the business sector was secured.

5.5.6 Prevention of Mother-To-Child Transmission (PMTCT)

PMTCT is a new programme whereby women who are HIV infected are given amongst other things nevirapine, an antiretroviral drug that will reduce the risk of HIV transmission to the baby. Voluntary Counselling and Testing (VCT) is done to

assist such women make informed decisions on whether they wish to continue with pregnancy or not.

- In 2000 PMTCT was put on trial at King Edward Hospital (KEH), Prince Mshiyeni Memorial Hospital, KwaMashu Poly Clinic, Umlazi D, Umlazi K Clinic, Greys Hospital, Church of Scotland Hospital (COSH), Edendale Hospital, Imbalenhle, Sobantu and Tailors Halt clinics; Northdale Hospital (NAPWA, 2002).
- In 2002, it was distributed to 49 hospitals, 228 clinics and 10 Community Health Centres (NAPWA, 2002).
- Nevirapine is a tablet given to a woman in order to take at the onset of labour or at least 2 hours before delivery; with a view to reducing the risk of infection during labour. The baby also gets nevirapine after birth.
- Women were educated that there was no cure for AIDS yet, nevirapine only reduces the chances of the baby getting infected and does not prevent infection during pregnancy or after delivery, it also does not cure the mother from her HIV infection (Mercury, 7/3/2002: 3).
- Mixed feeding is regarded as unsafe in this programme. The 2 main ways of feeding are (1) exclusive formula feeding (2) exclusive breast-feeding x 6. Mixed feeding not recommended because it has the highest risk of HIV infection.
- Other ways of preventing MTCT were:
 - prevention of HIV infection (it is better than the use of nevirapine)
 - prevention and treatment of STIs

- Dealing with economic factors that make women and young girls vulnerable (PAAU, 2002: 1).

5.5.6.1 Interpretation

PMTCT by use of nevirapine did not exist in KZN before 1994 GDE neither did it exist before the year 2000. Administration of nevirapine is aimed at helping the baby not to become HIV infected if the mother is HIV positive. PMTCT cannot take place without VCT. The restrictions put on the feeding of the baby are challenging; particularly in view of the mother's milk being regarded as the best milk for the baby. The best PMTCT appears to be the prevention of HIV infection by all people and the boosting of socio-economic development.

5.5.7 PREVENTION OF HIV INFECTION FOLLOWING A NEEDLE-STICK INJURY

AZT full doses for 6 weeks was used after needle-stick injury at a clinical setting based on the policy (KZL-DOH, 1989) to prevent sero-conversion. At present a combination antiretroviral treatment is still given following a needle-stick injury for prophylactic purposes based on the policy.

SECTION II: CARE AND SUPPORT

This refers to the care of people infected and affected by HIV/AIDS. It includes general care, counselling, treatment and support or dealing with the impact.

5.5.8 DISCUSSION OF CARE AND SUPPORT

This is divided to the periods pre-1994 GDE, 1994-1999 and 2000 onwards.

5.5.8.1 CARE AND SUPPORT DURING PRE-1994 GDE PERIOD

As the demand for care and support grew with the HIV/AIDS epidemic, care of HIV/AIDS patients was initially confined to the health institutions from 1986 to-date. KZN only started to have HIV prevalence statistics in 1990, through annual National HIV survey done on pregnant mothers. Between 1990 and 1994 the KZN HIV prevalence range was 1.6% - 14.3%. This does reflect that care and support started in the early 90s. The following events show what is reported to have been done under care and support:

- 1986: The dentist who treated an AIDS patient and the hospitals that diagnosed their first cases of AIDS are the first people who provided care for the HIV/AIDS patient. Refer to 5.4.1: the origin of HIV/AIDS Programme.
- An AIDS Support Group was formed in 1986 in Durban and was formally launched. The purpose was to assist people with AIDS to continue with their day-to-day lives. It would help them pay the rent, get essential groceries, look after their homes and talk to their loved ones (Mercury, 23/11/86).
- Life Line started training health staff in elementary counselling in 1988 (KZL-DOH circular 12/12/5, 1988; Personal communication with Peggy Zuma the then Nursing Manager, Head Office, Jan. 1989).
- Liz Towel from Durban ATIC started running counselling courses for staff in 1989 (KZL-DOH, 1990).

- Addington Hospital established a new non-racial clinic (Daily News 19/12/89; Mercury, 20/12/89). The clinic catered for AIDS patients as well.
- Edendale Hospital established an HIV follow-up clinic on 15/12/89 at the initiative of Dr Jimmy Muller in 1989 and run by Sr Shangase and Mr Mantshongo (KZL-DOH, 1991).
- Ngwelezana Hospital set up an HIV follow-up clinic at the initiative of Dr Peter Haselau and managed by a Matron (KZL-DOH, 6/2/91).
- A pilot project on Home Based Care (HBC) was undertaken in KwaZulu-Natal in 1992 at Ceza, Nkonjeni, Ngwelezana, Hlabisa and Edendale Hospitals. This was based on the Chikankata Hospital Model in Zambia. According to this model, HBC was offered to HIV positive people during post-test counselling. If the patient/ client accepted the offer, he/ she was visited by a mobile team which usually comprised a (P/N) Professional Nurse, an (S/N) Staff Nurse and (ENA) Enrolled Nursing Assistant or Health Assistant (Lucas, Mfeka, Dlamini, Harber, Philpott and Ross, 1996). The project commenced in July 1992 to July 1993. On evaluation, vehicles and salaries were found the most costly, (Lucas et al, 1996). It was also found that 73% of the PLWHAs accepted the HBC. In 1994, a follow-up situational analysis was done on HBC in the above hospitals and the results were that the model was inappropriate for KZN because the health services could not afford to sustain it (Stuart James, 1994 in Lucas *et al*, 1996).

5.5.8.2 Care and support during post 1994 GDE period (1994 - 1999) - General

Home Based Care needs to be seen as a continuation of care and support provided at home and community; it could be also seen as all kinds of care accessed by patients nearer to their homes. The activities that could be followed to enhance Home/community based care are: (1) Identification of Home Care Givers (2) Training on basic home care of PLWHAs (3) Training of Health Workers (HWs) to meet medical needs of PLWHAs (4) Provision of counselling services to PLWHAs (5) Establishment of support groups. (6) Conducting of regular home visits (7) Holding regular consultative meetings with care givers (8) Mobilisation of resources for the destitute orphans (NDOH, 1998: 7).

- The models of HBC in KwaZulu-Natal have been the hospital outreach HBC, the integrated community HBC, the NGO/CBO HBC model and the Hospice outreach HBC model. The example of the latter is South Coast Hospice since 1992 to the time of writing this report.
- KZNs approach to HBC has been that of caring for all people in need of home or community care regardless of their HIV status, AIDS patients, the HIV positive and care for the TB patients with a view to providing Directly Observed Therapy, short course (DOTS).
- The training on Home Based Care has been provided by HBC Trainers, ATICs, Regional AIDS Training Teams, some NGOs like Doctors for Life Lethimpilo Youth Organisation in Mondlo and some Tertiary Institutions like the University of Zululand's Nursing Science Department at the initiative of Professor Doris Nzimakwe (Personal communication with Mrs S Mbatha of Lethimpilo: 2003 and Professor D Nzimakwe of Unizul, 2001).

- The main problems of HBC is lack of transport in respect of volunteers (these volunteers are often jobless and thus do not have money for transport), starvation of PLWHAs and concomitant premature death; lack of standardization in the content of HBC training module constitutes one of the problems (KZN-DOH, 1999; personal communication with the Care Givers, 1998).
- A 6 months pilot project was undertaken on the use of the developed care kits in Ngwelezana and Church of Scotland Hospital in 1998 (KZN-DOHs minutes of the AIDS Clinical Advisory Committee 16/9/98). The results of the pilot was that the health institutions accessible to the Care Givers needed to top up the care materials if the DOH was to economise.
- Drop-in-Centres whereby people drop in for AIDS information, care and counselling, were initially established in Durban, Empangeni and Pietermaritzburg and by 1999 there were 15 Drop-In-Centres which were mostly resourced by the AIDS counsellors and multi-skilled AIDS workers (KZN DOH, 1999; Personal observation).
- Support Groups for PLWHAs were formed by NAPWA, the Faces Project Officers, ATICs, NACOSA and other NGOs, the HIV/AIDS counsellors (Personal observation: 1996 - 2000).
- The AIDS Legal Network in Pietermaritzburg supported PLWHAs by monitoring the incidences of PLWHAs discrimination which was funded by the Department of Health (KZN-DOH, 1998).
- The NGOs e.g. AFSA, NACOSA, Senzokuhle CBO Network, etc; the parastatals e.g. ATICCs as well as the Department of Health supported PWLHAs by giving them employment (Personal observation and involvement, 1996 to 2000).

5.5.8.3 Care and support from 2000: General

- The programmes PMTCT and VCT discussed previously as exclusive programmes, came into being during this period (KZNDOH: 2000: 29) and involved care and support even though they fall under prevention in view of their definitions being based on the purpose.
- By March 2003, 12 745 Care Givers (CGs) had been trained and supplied with the care kits. While some CGs work purely on volunteer basis, others e.g. TEBA, Welfare Department, Red Cross, Lethimpilo and Cindi receive a stipend, the amount of which differed from organization to organization.
- In 2000/ 2003, a total of 63 428 households had been visited by the CGs (PAAU, 2003).
- By the beginning of 2003, there were 49 functional Drop-In-Centres and 14 of these were jointly managed by the Department of Welfare, Education and the Provincial AIDS Action Unit (PAAU, 2003).

5.5.8.4 Care and support of Orphans

- In view of the low level of the AIDS epidemic before 1994 GDE, there are no records of orphans care programmes in the AIDS programme, the Pietermaritzburg Family and Child Welfare however, raised concerns about the anticipated rise in the number of orphans as the epidemic grew (Minutes of Regional AIDS Group, 1992).
- The most commonly used model of orphans care in KwaZulu-Natal amongst the Blacks was that of an extended family whereby the relatives especially the

- grandmother in the case of AIDS, automatically take care of the children.
- Fostering and adoption constitutes another method of caring for and supporting the orphans. For instance in 1996, Pietermaritzburg Child and Family Welfare Society's statistics showed that in the previous year the number of applications for foster care grants from relatives had increased from 20% of the society total intake to 80%. Most of these applicants were either a grandmother or a sister of a daughter that had died or a sister (Lucas *et al*, 1996: 24).
 - Thandanani Association of Pietermaritzburg (PMB) undertook a community outreach project for the care of orphans. The project comprised the establishment of a community children in distress fund as well as capacity building in fundraising and organizational/administrative capacity in respect of child committee care members (Halkett, 1999, SANC for Child and Family Welfare (CFW): 52).
 - A cluster concept of orphans care is also used in KZN: PMB child and welfare is a key role player in an association of collective NGOs i.e. Children in Distress or CINDI. CINDI gets supported by the Local Municipality and employs a full-time co-ordinator. Funding is obtained from amongst other funders, Mandela Childrens Fund. Each of the clusters has specific responsibilities e.g. Khayaletu provides street level facility and reception centre, employs street workers; PMB CFW provides training in HBC, care and support for children and bereavement (Halkett, 1999: 52), also runs a small place of safety; Project Gateway also provides training particularly in income generation, temporarily care for children etc; Thandanani Association cited above forms part of this cluster (Halkett, 1999, 52).
 - Residential Care for Orphans. The homes have not been commonly used for keeping orphans by the Blacks in KwaZulu-Natal during the past. At present it would appear that these are on the increase although there is no statistic to

substantiate this. Some residences for orphans which have recently mushroomed are

Lethimpilo in Mondlo, the Lily of the Valley, the AGAPE of Valley Trust, Othandweni in Groutville, Senzokuhle in Eshowe, etc. but the majority of orphans are nurtured within the extended family.

- Orphans AIDS Trust was established in February 2002 during which the eminent business person Vivian Reddy donated R250 000 towards the Trust. The former President of South Africa, Honourable Nelson Mandela was the guest speaker at the function and the Honourable, MEC for Health, Dr Z.L. Mkhize, Mr V. Reddy, Mr G. King, Prof J. Coovadia and Mr P. Biprvig were nominated as trustees (PAAU: 2002: 4; KZN-DOH 2002: 29).
- His Majesty, King Goodwill Zwelithini kaBhekuzulu and Queen Mantfombi have nurtured orphaned children by providing them with a shelter and the other bare necessities of life at kwaKhangela Palace. When asked about this gesture, the King is reported having said "It is my duty as a King to set an example for my people that orphans also need love and care just like other children" (Sunday Times, 14/12/2003:12).

5.5.8.5 ANTIRETROVIRAL THERAPY/TREATMENT (ART)

- In November 2003 the South African Government and the National DOH announced a roll-out plan to provide antiretroviral treatment (ART) in the public sector (NDOH, 2003).
- Patients would only be given ART when their CD4 cell count is below 200 i.e. late in the disease. However, an HIV positive person who does not qualify for ART

will be given nutritious food and immune boosters if he/ she cannot afford.

- Training and employment of more staff needed.

Challenges will be (1) the side effects (2) the fact that ART is not a cure (3) drug resistance.

- ART projects had already been undertaken in 2002 at Cator Manor Health Centre in Durban, St Mary's Hospital in Marianhill, Ithembalabantu (Peoples Hope Clinic) at Umlazi. In the latter centre, 72 HIV positive people were already receiving ART and it was the people without medical aid that were catered for. It is funded to treat 100 people (NDOH, 2003).

5.5.8.5.1 How ART would work

Patients would be identified by VCT; people qualifying for ART would be counselled appropriately; patients on ART would be monitored closely; special service points would be identified for ART and within a year there will be one service point in every Local municipality (NDOH, 2003).

5.5.8.5.2 Reasons for availability of ART

The price of ART has decreased: would cost R980 per year (This Day, 17/2/2004); there is more international and local experience in using ART safely and effectively; there are more people now seeing the importance of nutrition to health and in making ART work better; Infrastructure for providing ART is available; the Government now has funds for ART (NDOH, 2003).

Table 8 below gives a shortened version of the care and support events/activities during pre-1994 GDE Period.

Table 8: Care and Support events/activities during pre-1994 GDE period

Events/Activities	Year
1. A dentist treated an AIDS patient	1986
2. AIDS support group formed in Durban	1986
3. Life Line started training health staff in counselling	1988
4. ATIC Durban started training staff in counselling	1989
5. Addington Hospital established a non-racial AIDS Clinic	1989
6. Ngwelezana Hospital set up an HIV follow-up clinic	1990
7. Training in HBC provided by Chikankata Zambia Hospital	1992
8. A pilot project on Home Based Care was undertaken in KZN at 5 hospitals	1992

Table 9 below gives a streamlined version of some of the Care & Support events/activities during 1994-1999.

Table 9: Some of the Care & Support Events/Activities: 1994-1999: KZN

Event/Activity	Period
1. Training on Home Based Care	1994 onwards
2. Rendering of Home Based Care	1994 onwards
3. Establishment of orphan centres	1995 onwards
4. Employment of PLWHAs by NGO/CBOs & Govt	1996
5. Formation of Support Groups for PLWHAs	1996 onwards
6. Monitoring the incidences of discrimination of PLWHAs	1998

Table 10 below gives some statistics on care and support outputs.

Table 10: Some Care & Support outputs: 2002/2003 period: KZN

Activity	Number
1. Care Givers (CGs) trained	12 745
2. Care Kits provided to CGs	12 745
3. Households visited by CGs	16 428
4. Drop-In-Centres (functional)	49

Source: PAAU, 2003.

Table 11 below shows some of the activities/events addressing the problem of orphans

Table 11: Some activities/events directed at preparing for/addressing the problem of orphans: KZN: Pre and Post-1994 GDE Period.

Activity	Year
1. PMB Child and Family Welfare started raising concerns on possible increase of orphans	1992
2. Thandanani Association of PMB undertook a Community Outreach project on orphans	1996
3. A cluster care of orphans commenced by CINDI (Children In Distress, PMB)	1998
4. Residential care of orphans established by some organizations	1998 onwards
5. Orphans Trust established in KZN	2002
6. His Majesty the King was reported keeping orphans in one of his palaces.	2003

5.5.8.5.3 Interpretation: Care & Support

Care and support did not receive much attention during pre-1994 GDE period due to the fact that HIV prevalence was still low, however, it has transpired that as early as

1986, an AIDS support group was formed. AIDS counselling was carried out and Home Based Care was piloted before 1994 GDE. After 1994 GDE, Drop-in-Centres were established. More support groups were formed, Home Based Care service was strengthened, training on care and support was intensified, PLWHAs got employed, mushrooming orphans received attention even from the high profile individuals and eligible PLWHAs would get antiretroviral treatment from the government health facilities in 2004. In view of the challenges accompanying ART, it would appear that prevention of HIV infection could remain the best option in the fight against AIDS.

B. THE ACTIVITIES OF AIDS ORGANIZATIONS BASED ON THE DATA THAT WAS OBTAINED THROUGH THE ADMINISTRATION OF A QUESTIONNAIRE TO NGO/CBOs

The following is the analysis of the NGO/CBO activities: The questionnaire was administered to 193 NGO/CBOs that attended the AIDS meetings which had been organized by the Department of Health in 2003. This Figure includes the 15 NGOs that were visited to determine the internal and external evidence as well as to fill the gaps in the information that had already been provided.

5.5.9 ACTIVITIES OF NGO/CBOs

Table 12 below shows the activities of NGO/CBOs that provided data through a questionnaire.

Table 12: Activities of NGO/CBOs and the number of NGO/CBOs involved in each HIV/AIDS activity: 2003.

Programme	Number	Percentage
Information, Education & Communication (IEC)	71	37%
Human Resource Department HRD	33	17%
Care and Support	110	57%
Research	1	1%

It is worth noting that some organizations were engaged in more than one AIDS activity, hence the imbalance related to 193 NGO/CBOs that provided the data.

From the above table, most organizations were engaged in Care & Support (57%). Care & support included the care and support of orphans and the PLWHAs. The care and support activities entailed counselling, support, HBC, income generation and relevant training. The care of orphans included provision of clothing and other materials, ensuring children's engagement in formal education, child grants, food, shelter etc.

37% of NGO/CBOs were engaged in IEC. IEC included education on AIDS, and STIs, lifeskills education, education on care and support including ethical and legal aspects. 17% of NGO/CBOs were engaged in training. This included training in AIDS education, counselling, HBC, lifeskills, special skilling for income generation etc 1% (1) was engaged in AIDS research.

The above data reflect that most NGO/CBOs have flown to Care & Support, probably due to the demand made by the magnitude of HIV/AIDS pandemic. It is commended that NGO/CBOs have not abandoned AIDS education following an announcement that the anti-retroviral drugs would be offered to eligible PLWHAs as this would yield catastrophic results as presently experienced by the first world countries i.e. drug resistance and a rise in new HIV infections. Refer to 2.5.1 of Chapter 2. Only one NGO was engaged in research and this was no cause for alarm since most research in KZN was undertaken by the academic institutions who were not part of the meetings. The limitation in the above data is that not all NGO/CBOs attended the DOH's meetings referred to above.

Refer to Annexure 5 regarding the names of some organizations engaged in HIV / AIDS activities in KwaZulu-Natal.

5.5.9.1 Remarks on the organizations that implemented the HIV/AIDS programme

Other than NGO/CBOs, HIV/AIDS activities as seen in the historical data presented under 5.5, were carried out by staff of hospitals, clinics, private sector (including the surgeries, private laboratories, blood transfusion services etc.) the business sector, labour sector, political and professional organizations, sports associations, traditional healers, religious sector, Government Departments, the traditional healers, political organizations, welfare institutions, educational institutions (including tertiary institutions) and community structures.

5.5.9.2 General comments on HIV/AIDS Activities and those who implemented them

The analysed data on the HIV/AIDS programmes and those who implemented them show that the HIV/AIDS role players carried out various activities under the broad umbrellas of “Prevention” and Care & Support” i.e. counselling and testing, Blood Safety, Information/Education of communication, special HIV/AIDS projects, STI management and barrier methods, prevention of mother-to-child transmission, care of orphans, Home Based Care and antiretroviral treatment. Furthermore the data on the activities and when they were carried out, which have been obtained from the records, reflect two HIV/AIDS epidemic campaigns that have been undertaken in KZN, each with its own combatants and the combatants of the former HIV/AIDS war appearing to have disappeared with their weapons, leaving behind questions on their whereabouts and whether they had attained victory or not. If they had attained victory, the how of this could make a meaningful contribution towards sharpening the skills of those AIDS combatants presently remaining in the battle and fighting fiercely to defeat HIV/AIDS. The highlighted finding, however, could be attributed to the paucity of information the researcher could access.

5.5.9.3 Comment on HIV/AIDS activities and those who implemented them with reference to Betty Neuman’s model

The prominent concepts of Betty Neuman's theory are prevention and promotion and all the activities that were carried out were covered under these concepts e.g. health promotion was covered by such activities as AIDS education campaigns, lifeskills education for youth etc., primary prevention covered by AIDS education, prevention of Mother-to-Child transmission programme etc., secondary prevention by nursing care, treatment of opportunistic infections, home based care, ART etc. and tertiary prevention by support groups of those infected and affected by HIV like PLWAs, Care of orphans, skilling of PLWHAs and engagement in income generating projects.

The variables of a client referred to were catered for in the implementation of the activities e.g. counselling catered for the psychological, socio-cultural and spiritual, education and engagement in income generating projects catered for the developmental. ART, treatment of opportunistic infections and general care catered for the physical variable.

The above activities occurred in an inter-personal, extra-personal and created environment of the client.

The organizations that implemented the programme represented the "client" or the "care giver" referred to by Betty Neuman. Refer to chapter 3.3.4.

5.6 OBJECTIVE NO. 3: THE SUPPORT SYSTEM FOR THE HIV/AIDS PROGRAMME

The answers to this study objective were obtained from the records (archival and current) as well as through the use of the checklist on visits to 15 service sites and 5 key informants. This section will however deal with the data obtained from the records. The components of a support system for the HIV/AIDS programme in KwaZulu-Natal were the human resource, human resource development, research, funds, plans, policies, committees/ forums/ groups/ councils, political backing or support by high profile individuals and partnerships.

5.6.1 SUPPORT SYSTEM DURING PRE AND POST 1994 GDE PERIODS

5.6.1.1 Human Resource

Schneider (1994: 10) asserts that "AIDS Action Teams cannot function adequately without the personnel to implement the decisions made".

5.6.1.1.1 Pre-1994 GDE Period

From 1986 to 1991, there were no posts specifically created for HIV/AIDS work in KZN due to the level of HIV/AIDS epidemic, however, HIV/AIDS related duties were carried out by either those responsible for communicable diseases control or infection control. The following events mark the dynamics in staffing:

- KZN (KwaZulu) DOH asked all Health Wards (mother hospitals) to identify one suitable person to be an AIDS Information Officer. The criteria for selection were (1) Interest in AIDS (2) Understanding the disease (3) A good communicator (KZL Circular 12/12/5 AIDS: 07/12/89).
- KZL DOH appointed a Director for AIDS, Dr James Stewart in 1991 (KZL DOH,

1991).

- Motivation for counsellors and counsellor trainers posts (KZL-DOH, 1991: minute from Dr A. Jaffe to Matron Monaheng of Edendale Hospital).
- Staff Nurses' posts released for AIDS Education - October 1991 (KZL-DOH, 1991: Minute from Dr A. Jaffe, 23/10/91).
- KZL-DOH Nursing Division agreed to motivate for a Professional Nurses (PN) to be released in every Health Ward/ Hospital to provide AIDS information (KZL-DOH, 9/7/92).
- Nursing posts dedicated to all Health Wards/ Hospitals Professional Nurses (P/Ns, Staff Nurses (SNs) and Enrolled Nursing Assistants or ENAs were created (KZL-DOH, 2/9/92).
- AIDS counsellors placed into all wards in Edendale Hospital (personal communication with Matron Monaheng in 1993).

5.6.1.1.1.1 Interpretation

From the available data the provision of staff specifically for HIV/AIDS work prior to 1994 GDE commenced in 1992 in KwaZulu Department of Health. This appears to have been influenced by the growth in the HIV prevalence amongst pregnant mothers in KZN from 1.6% in 1990 to 4.7% in 1992, the appointment of a Director for HIV/AIDS and the intervention of the University of Zululand's Music and Drama Department through the provision of AIDS education using drama.

The limitation here is the fact that data have not been obtained on the status of human resource in other erstwhile Departments of Health of this period.

5.6.1.1.1.2 Post-1994 GDE period

a) Management

The background and dynamics in the management of the HIV/AIDS programme in KZN during this period are as follows:

- The formation of NACOSA (National AIDS Convention of South Africa), KZN planning structure in 1993.
 - Integration of all HIV/AIDS programmes in KZN i.e. NDOH & PD (National Department of Health and Population Development - KZN office, KwaZulu Department of Health (KZL-DOH), House of Representatives and House of Delegates: From April 1994.
 - The Management of the HIV/AIDS programme by Ms Vimla Moodley of the former NDOH & PD from April 1994 to April 1996 at a Chief Community Liaison Officer's (CCLO) level, operating from the head office of KZN-DOH.
 - The management of the HIV/AIDS programme by Wanda Mthembu from March 1996 to February 2001 at a Deputy Director's level, operating from the head office of KwaZulu-Natal Department of Health.
- NACOSA had recommended a Director's rank for this responsibility (NACOSA, 1994).
- The management of the HIV/AIDS programme by Dr Sandile S.S. Buthelezi from March 2000 to-date, at a Directors level. This came with the birth of a

Provincial AIDS Action Unit (PAAU), which belonged to all the Govt Departments, although housed in the KZN DOH at the mandate of the Premier.

5.6.1.1.2.1 Interpretation: Management

The management of the HIV/AIDS programme in KZN changed with the changes in structures and processes including those that were political. There has been a significant growth in the rank occupied by the manager i.e. from CCLO's level to Director's level. However, although there has been this growth in rank, a disparity is observed between the first rank of the HIV/AIDS Director in KZL-DOH (Pre-1994 GDE) and that of the first two ranks of the post-1994 GDE especially given the fact that the scope of the manager's responsibilities had been extended after the 1994 GDE period due to amalgamation of all the Departments of health that had been based on race.

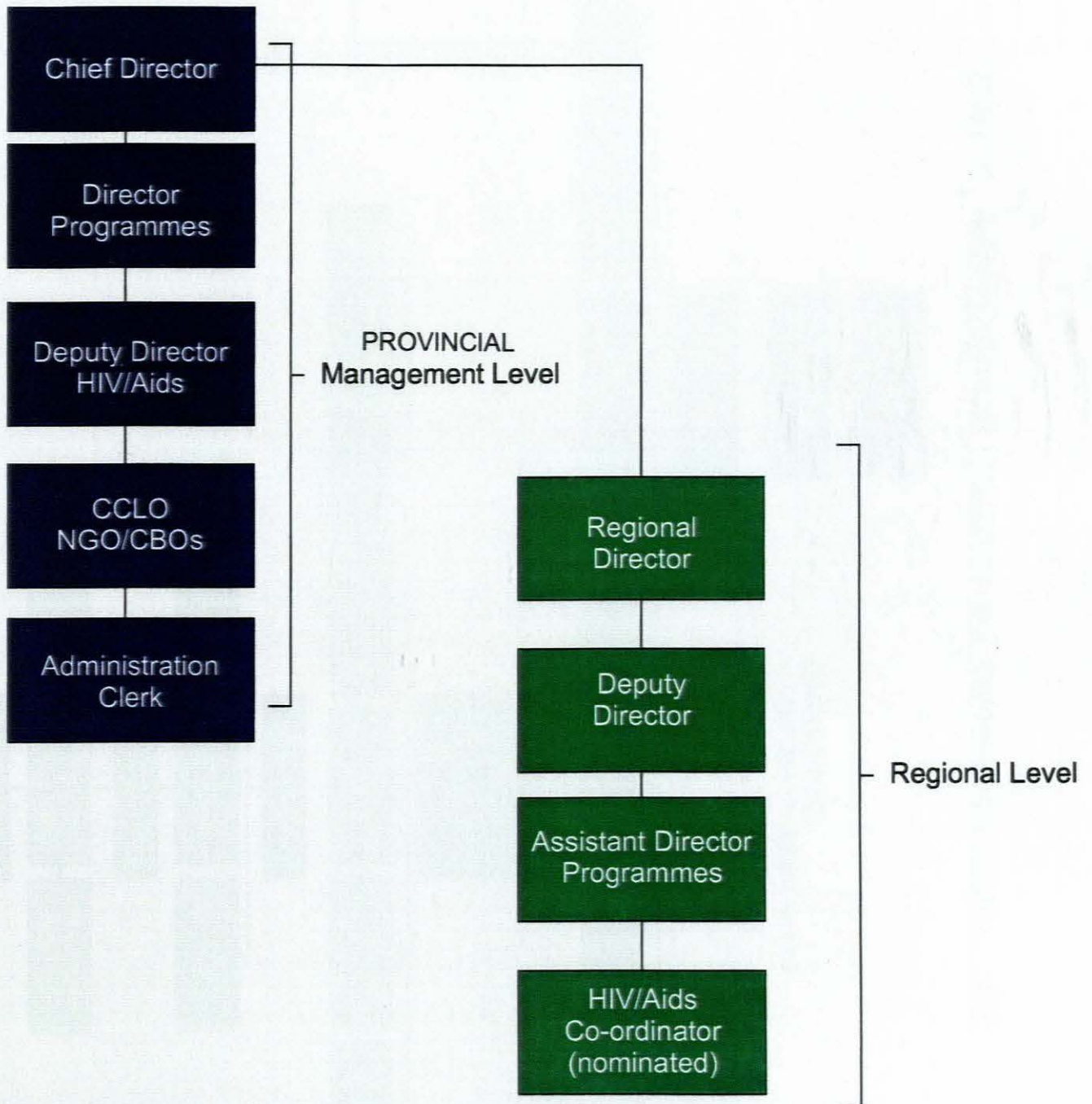
b) Other Human Resources

- The first two managers worked with one clerk (Medical Research Council or MRC, 1997: 50). Refer to Figure 5.
- Regional (now District) HIV/AIDS co-ordinators were nominated in 1996 from the Nursing ranks and their ranks ranged between Senior Professional Nurse and Chief Professional Nurse. These initial co-ordinators were Mandisa Dlamini from Ilembe, Mabuyi Mnguni from Ugu, Gay Koti from Zululand, Lindiwe Nkosi from Umzinyathi, Nelisiwe M. Shangase from Indlovu, Gill Felce from Uthukela, Thoko Luthuli from Uthungulu and Sipho Vumase from UMkhanyakude District (MRC,

1997: 50). Janet Dalton was also nominated as a co-ordinator of Sexually Transmitted Infections at an Assistant Director's post (MRC, 1997: 50).

- Khumbu Mtinjana was employed as a Chief Community Liaison Officer (CCLO) for NGO Support in 1997.
- Ntombifuthi Mtshali was nominated as a Lifeskills programme co-ordinator at a Chief Professional Nurses (CPN) post; Gay Koti was nominated and recruited to co-ordinate care and support in 1998 at CPN's post (KZN-DOH, 1998).
- The NDOH provided 2 Assistant Directors' posts to KZN (the Internal and External Liaison officers); these posts resulted from "Partnership Against AIDS" initiative that had been launched in 1998 by the then Deputy President Thabo Mbeki and would ensure social mobilization within and outside the Government (KZN-DOH, 1999:1). Refer to Figure 6.
- On the birth of the Provincial AIDS Action Unit (PAAU) in 2000, a new staff structure was established. Refer to Figure 7.
- In 2003 posts for the District AIDS co-ordinators were created and filled (PAAU: 2003).

Figure 5: 1996 - 1998 HIV/AIDS Programme Structure: KZN



Source: Diary 1997: January 13
KZN - DOH, 1996

Figure 6: KZN HIV/AIDS Programme Provincial Structure: 1999

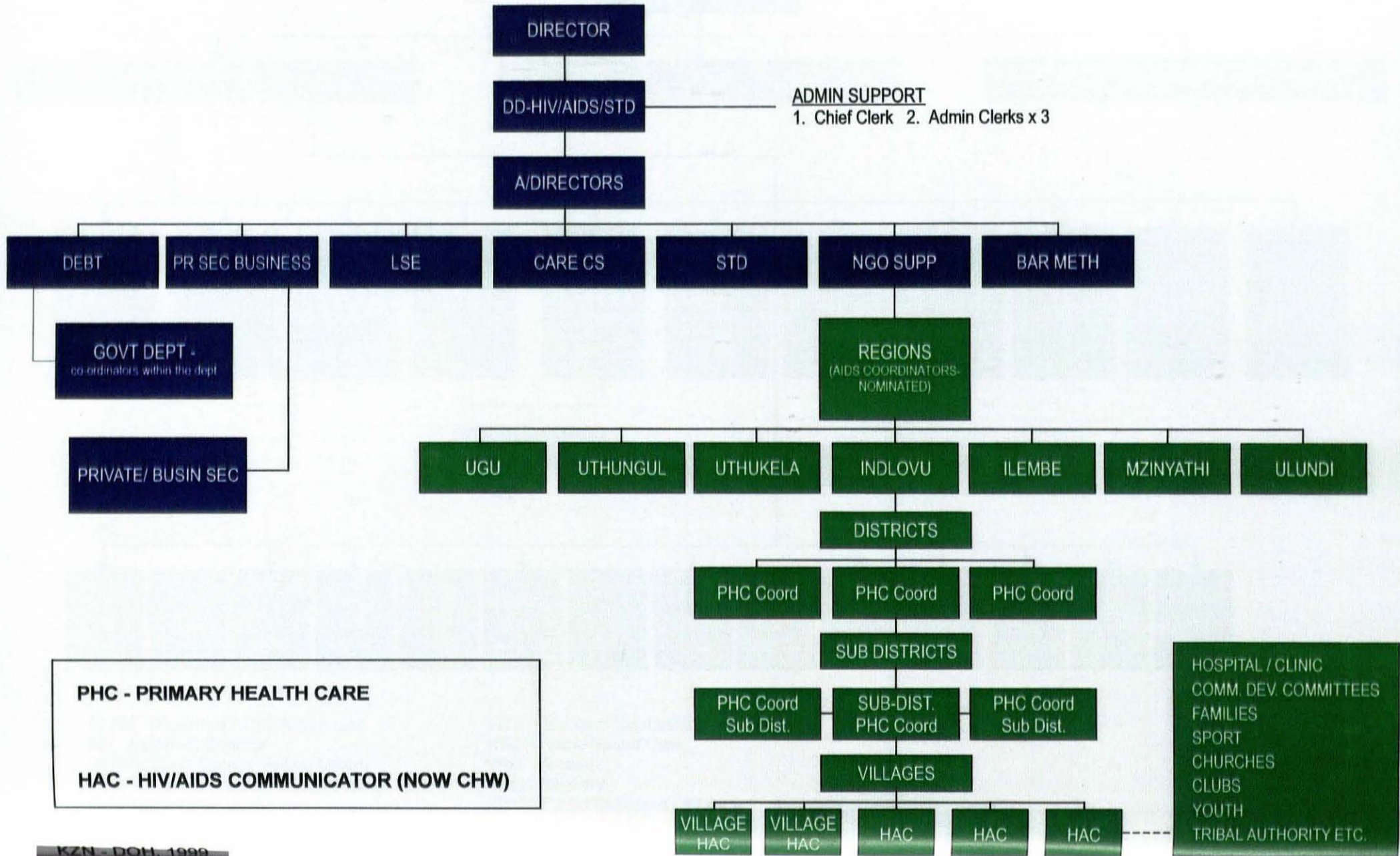
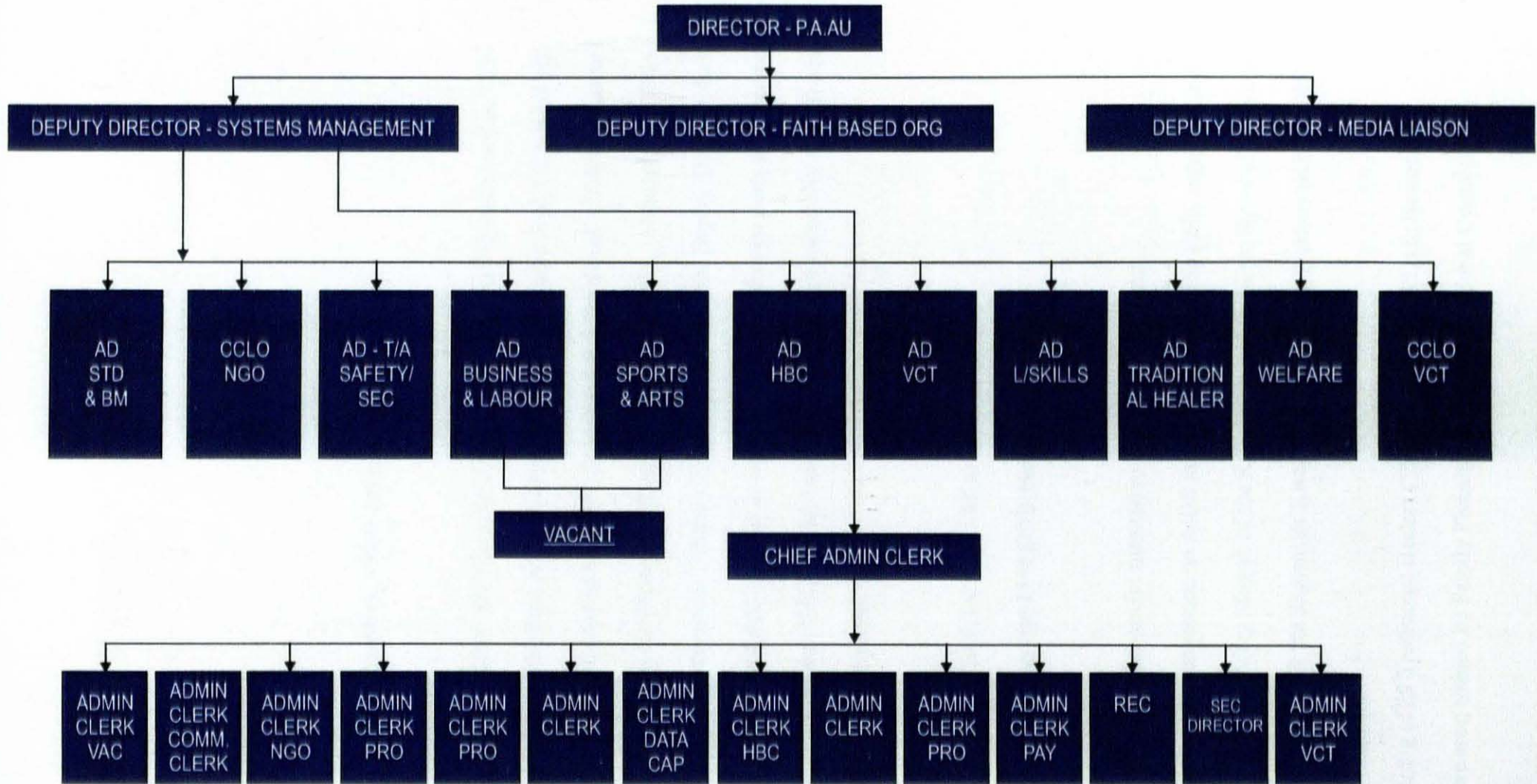


Figure 7: Provincial AIDS Action Unit Organogram: 2000 -2003



PAAU: Provincial AIDS Action Unit
 AD: Assistant Director
 CCLO: Chief Comm Liaison Officer
 STD: Sexually Transmitted Diseases
 BM: Barrier Methods

VCT: Volunteer Counselling and Testing
 HBC: Home Based Care
 VAC: Vacant
 REG: Registry
 PRO: Public Relations Officer

5.6.1.1.2.2 Interpretation: Other Human Resources

There has been a gradual growth in the staffing of the HIV/AIDS programme in KZN albeit some delay. The birth of the PAAU occurred 5 years after NACOSA KZN put it down as the first activity area of the AIDS plan that a Provincial AIDS Programme be established within the Premier's office (NACOSA, 1994: 7). Although NACOSA (1994: 7) had recommended 2 Deputy Directors, at least one Deputy Director then existed at the birth of PAAU. Again it was a breakthrough that the posts of Regional AIDS co-ordinators that NACOSA advocated for in 1994 were eventually created and filled in 2003 (after 9 years).

5.6.2 HUMAN RESOURCE DEVELOPMENT (HRD)

5.6.2.1 HRD during Pre-1994 GDE Period

HRD during this period can be mirrored in the following events:

- The holding of a convention on AIDS from July to September 1988, organized and facilitated by Mrs Mary Mngadi of the KZL-DOH and Dr Sonto Nkosi of Edendale Hospital. Run in all the Regions of KwaZulu for the Health Workers (KZL-DOH - 12/12 P, 1988).
- The training of 29 Traditional Healers (THs) on AIDS and STIs in Newcastle, Philisiwe area; trained by Family Planning Association Regional Organization -

Paula Kosik (Sunday Tribune, 28/8/88).

- Training of KZL staff (including Managers) on elementary counselling by Life Line on 22 - 23/11/88 (KZL-DOH, Circular 12/125/1988).
- NDOH & PD ran a counselling course at Prince Mshiyeni Memorial Hospital in 1989 (Memo from Matron Dambuza to Dr J Muller, 15/3/90).
- Liz Towel of Durban ATIC ran a series of AIDS Education and Counselling courses for staff (KZL-DOH, 1990). The AIDS Training Information and Counselling Centres in Durban (ATIC), Pietermaritzburg and Empangeni were the pioneers of formal training in HIV/AIDS in KZN from 1989 when the 1st ATIC in Durban was established (Personal Observation; KZL-DOH, 1990).
- The Natal Sugar Association in Richardsbay appointed their own AIDS Trainer in 1990 (Natal Regional AIDS Group, 1990).
- Home Based Care Seminar run for staff at Sun Berry Quest farm in July 1991 (KZL-DOH, 1991).
- Chikankatha Trainers of Zambia ran a course on Home Based Care (HBC) on 19 - 23/08/91 at Kwanzimela (KZL-DOH, 12/12/5: 1991).
The course was aimed at preparing for a crisis that would occur when hospitals would be unable to accommodate patients. 50 Care Givers were trained here (KZL-DOH, 12/12/5, 1991).
- In 1991, the University of Natal trained peer counsellors and "House with vacancy" play on AIDS was performed in the campus (Witness, 28/5/91).
- Lennon Company organized and financed AIDS workshop for staff; held at Mkhuze (Minute from Dr A Jaffe to Dr J Muller, 23/7/92).
- Train the Trainer AIDS Counselling course was facilitated by Vicky Tallis and Mr M Heyns on 10 - 14/8/92; 12 PNs were trained (KZL-DOH, 1992).

- 13 Counsellor Trainers trained by Durban ATIC in 1992 (KZL-DOH, 1992).
- KwaZulu Department of Education (KZL-DOE) psychology inspectors were trained by trainers from the NDOH & PD on Lifeskills. These inspectors started training teachers (on lifeskills and sexuality) as well as 28 P/Ns, SNs and Enrolled Nursing Assistants who had been employed for AIDS Activities (KZL-DOH, 1992).
- In 1992 Prof Allan Whiteside of the University of KZN, HEARD, developed a 2 weeks course on planning for HIV/AIDS in the developing countries.
- A workshop on surveillance was run for AIDS staff from all hospitals with Ngwelezana Hospital as a venue on 3/3/93 (KZL-DOH, 1993).
- In March 1993, Nongoma, Bethesda and Madadeni started the training of Councillors (KZL-DOH, 1993). At this stage the counsellor training at Edendale, Ngwelezana and Prince Mshiyeni Memorial Hospital was well established.
- A book on "Facing up to AIDS: The Socio-Economic Impact in Southern Africa, 1993, by Whiteside, A of the University of KZN, HEARD (Personal Communication with Prof Allan Whiteside, 2003).

Table 13 below chronologically displays some of the information about HRD activities which occurred before 1994 GDE period

Table 13: Human Resource Development on HIV/AIDS: KZN: Pre-1994 GDE**Period**

Course/Workshop	Provider	Target	Place	Year
1. Orientation on HIV/AIDS	KZL-DOH	Health Staff	Each Health Region	1988
2. AIDS Counselling (Elementary)	Life Line	Health Managers	Durban	1988
3. AIDS Counselling	NDOH&PD	Health Staff	PMM Hospital	1989
4. AIDS Counselling	ATIC Durban	Health Staff	City Health Dept, DBN	1990
5. Home Based Care	Chikankata Hospital-Zambia	Health Staff	Sun Berry Quest Farm Stanger	1991
6. Home Based Care	Chikankata Hospital-Zambia	Health Staff	KwaNzimela (Melmoth)	1991
7. AIDS Counselling	University of Natal	Students	Durban	1991
8. AIDS Training	ATIC Durban	13 Prospective Trainers	Durban	1991
9. Planning for AIDS in the Developing countries	University of Natal	HIV/AIDS Managers	Durban	1992
10. HIV/AIDS	Lennon Company	Ingwavuma & Ubombo Health Staff	Mkhuze	1992
11. Lifeskills	NDOH&PD	Psychology Inspectors	Pretoria	1992
12. Lifeskills	KZL-DOE	Health Staff	KZN	1992
13. AIDS Surveillance	KZL-DOH	Health Staff	Ngwelezana Hospital	1993
14. AIDS Counselling	Edendale, Ngwelezana & PMM Hospitals	Health Staff	Edendale, Ngwelezana & PMM Hospitals	1993

5.6.2.1.1 Interpretation

Human resource development was seen as the first step in the fight against AIDS. The content of training was focused on the needs of the period viz. AIDS/ STI education, counselling, surveillance, lifeskills and care. Due to the level of the epidemic at this stage, training focused more on education and counselling than on care. ATICs were the leading training organizations and the ripple effect kind of training was adopted, whereby prospective trainers were trained to train others at their work settings; this was cost-effective. A two weeks HIV/AIDS Planning course for the managers was developed during this period. The authorities that provided training included the Government, the private and the business sectors: the parastatals, the NGOs and the tertiary institutions. International collaboration in HRD was observed even before 1994 GDE period. Learning aids in the form of AIDS books started being produced in KZN.

5.6.2.2 Human Resource Development (HRD) during post-1994 GDE period

In view of the paucity of data, a few HRD events will be cited below:-

- Professor Allan Whiteside of the University of KZN continued running courses on planning for HIV/AIDS in the developing countries which were attended by Southern African AIDS role players in Management positions (Personal experience in 1999; HEARD, 2003).
- Subsequent to the formulation of AIDS clinical guidelines, a series of workshops were held at all Health Districts, orientating staff on the guidelines. The AIDS Clinical Advisory committee (chaired by Prof Pudifin and later by Prof Gathiram from the then University of Natal-Medical School) took the

responsibility to present the guidelines and address queries. The presenters were Dr J. Muller, Ms van Rooyen, Dr Jeena and Dr P. Haselau and workshops were run from September to October 1996 (Personal experience; KZN-DOH, 1997).

- A counselling comic booklet was developed by ATIC and PAAG and distributed to Doctors with a view to giving them a basic idea on counselling (KZN DOH, 1996).
- A two-day workshop organized by ACAC members through the University of Natal was run in 1998 at Elangeni Hotel (now Holiday Inn Crown Plaza), targeting nursing and doctors. It was aimed at updating the knowledge of nurses /health care personnel on AIDS (KZN DOH, 1998).
- The University of Natal in partnership with the DOH ran an update symposium on HIV/AIDS for 3 days in Holiday Inn Crown Plaza in 1999 (KZN DOH, 1999).
- Doctor's for Life organization trained staff on care and support (KZN-DOH, 1999).
- Mrs Buyie Ngesi from Ugu District was sent to USA - New York to pursue a sexual and Reproductive Health course in May 1997 (KZN-DOH, 1997).
- All the HIV/AIDS coordinators from various Health Districts participated in the undertaking of the national HIV/AIDS Review in 1997 (KZN-DOH,1997).
- Ntombifuthi Mtshali and Mandisa Dlamini went to Uganda to observe HIV/AIDS programmes as organised by the AIDS Foundation of South Africa in 1998 (KZN-DOH, 1998).
- Toolkits and Briefs on HIV/AIDS produced by Whiteside A. The former publication has assisted various sectors including the Government

Departments start workplace programmes and the latter has assisted sectors plan for HIV/AIDS, especially the Govt of KwaZulu-Natal (KZN-DOH, 1999).

- Staff trained on VCT and PMTCT programme: 2001, 2002 and 2003 respectively. To cite but a few examples of HRD at this period.
 - Human Resource Development in the HIV/AIDS programme was supported by literature and other teaching / learning aids produced in KwaZulu-Natal such as:
 - A book written by Whiteside, A on "AIDS challenge for South Africa". Whiteside was assisted by Sunter C, a businessman. The book was aimed at alerting South Africans to the threat carried by AIDS (Personal communication with Prof Allan Whiteside, 2003).
 - Guidelines for the preparation and execution of studies of the social and economic impact of HIV/AIDS developed in 1999 by Prof A. Whiteside and Dr Tony Barnett (Personal Communication with Prof Allan Whiteside 2003).
- Not all the produced teaching-learning AIDS could be listed due to limitations.

Table 14(a) and (b) below categorise and give a breakdown of HRD activities which occurred after the 1994 GDE period

Table 14 (a): Breakdown of HRD activities: Post 1994

Workshop/ Course	Provider	Target	Place	Year
1. Planning for AIDS in the developing countries	UKZN	HIV/AIDS Managers	Durban	1994 - onwards
2. AIDS Clinical Guidelines	AIDS Clinical Advisory Committee	Health Staff	Each Health Region	1996
3. HIV/AIDS Update	UKZN	Doctors and Nurses	Elangeni Hotel, DBN	1998
4. HIV/AIDS Update	UKZN & KZN-DOH	Doctors and Nurses	Holiday Inn Crown Plaza (Elangeni)	1999
5. Home Based Care	Doctors of Life	HIV/AIDS Co-ordinator	DOH-Ethekwini	1999
6. VCT	DOH	Health and HIV/AIDS Staff	Durban	2000
7. VCT	DOH	Health Staff	Durban	2001
8. PMTCT	DOH & UKZN	Health and HIV/AIDS Staff	Durban	2002
9. ART	DOH & UKZN	Health and HIV/AIDS Staff	Durban	2003

Table 14 (b): Other Human Resource Development Activities: KZN: Post-1994**GDE**

Activity	Provider	Year	Comment
1. Course in Sexuality and Reproductive Health-USA	USAID	1997	1 HW attended from KZN
2. Education tour of Uganda	AIDS Foundation	1998	2 HWs participated
3. Development of Toolkits on workplace AIDS Programme	UKZN-HEARD (Prof A. Whiteside)	1999	Tools used by various sections
4. Guidelines for undertaking studies on socio-economic impact of AIDS	UKZN-HEARD (Prof A. Whiteside)	1999	Used inside & outside KZN

5.6.2.2.1 Interpretation

Human Resource Development (HRD) commenced with orientation of Health workers on HIV/AIDS followed by orientation on counselling and AIDS counselling. After orientation, courses were run on AIDS education and counselling and Home Based Care. The latter was done in preparation for a pilot project on HBC. Training of trainers on counselling was done to bring about a ripple-effect kind of teaching which subsequently followed.

In view of a need for HWs to make an informed contribution towards AIDS surveillance, a workshop was run for them and regular updates on HIV/AIDS were made in respect of HWs. Subsequent to the compilation of AIDS clinical guidelines, workshops were run at various Health Districts explaining the contents. When new

programmes like VCT, PMTCT and ART were introduced, workshops on these programmes dominated HRD on HIV/AIDS. The courses on AIDS counselling and Education have been run from the late eighties (80s) to-date by the HIV/AIDS Training Centres. HRD targeted both an individual and groups and exchange of knowledge on HIV/AIDS was at provincial, national and international levels.

5.6.3 RESEARCH

Research is of importance if a programme is to be effectively implemented. It determines the what, who, where, when and why of the service i.e. it directs the planning and programming. In view of HIV/AIDS being a new and ever challenging health condition, there is a lot of research that has been undertaken in KwaZulu-Natal particularly by the Nelson Mandela Medical School of the University of KZN, Health Economics AIDS Research Department of the University of KZN, MRC etc. a few research projects, (not necessarily undertaken by the above institutions) including papers are cited below).

- An HIV prevalence survey of 800 consecutive admissions in Edendale Hospital Result: 1.3% HIV prevalence (Regional AIDS Group, 26/9/90).
- A survey conducted by the STD Clinic in Pinetown looking at HIV prevalence, Results: 3.1% (Regional AIDS Group 26/9/90).
- A survey on Medical waste management in Pietermaritzburg (Regional AIDS Group (RAG), 26/9/90).
- A Malaria-linked HIV prevalence study by MRC in 1990. Result 1.2%. Repeated in 1991 - Results 2.3% (KZL-DOH, 1992).

- A Pilot study on HBC in KwaZulu (Edendale, Mosvold, Ceza, Nkonjeni, Ngwelezana Hospitals) by the University of Natal (KZL-DOH, 1992)
- A study of sexual practices amongst 12 commercial sex workers operating from a truckstop in Ladysmith (PAAG, 1992: 7)
- The annual HIV prevalence study amongst pregnant women in South Africa was undertaken from 1990, led by Prof Allan Smith of the Virology Department (University of KZN) during post-1994 GDE period (KZN-DOH, 1996).
- Research on a needlestick injury by Dr Barker (Minutes of RAG, 1992).
- The study of the Quality of STD Management (Community Health, University of Natal, Department of Community Health: 1996).
- Economic impact of HIV/AIDS epidemic in a District Health system and Identification of strategies to respond to the impact by Wilkinson, D. (Directory: Health Systems Research: page 140).
- Social and Economic issues of HIV/AIDS in Southern Africa: A review of current research, 1997 by Loewenson R and Whiteside A. (Barnett and Whiteside, 2002).
- Management of STDs in migrant labourers by Lurie, M (Directory, Health Systems Research: Page 136).
- The SAAVI HIV Vaccine Research Unit is undertaking research on the AIDS vaccine (clinical trials); led by MRC and Working in partnership with Chris Hani Baragwanath Hospital (NAPWA , 2002: 11).
- Treatment of opportunistic infections by a herbal approach was carried out in Philani Clinic (under Ngwelezana Hospital) as an initiative by Dr Peter Haselau. Mrs Anne Hutchings, a researcher in traditional medicine from the

University of Zululand's Botany Department undertook the project assisted by Dr Lisa Joy Mthlane (University of Zululand, 2002: 39).

Research Papers

- AIDS in Southern Africa: A position paper - 1990 by Whiteside A, HEARD, University of KZN - 1990 (HEARD, 2003).
- A Drama Approach to AIDS Education- by Darlymple, L. 1992. Published in AIDS Bulletin (Dramaide, 1993).
- A Drama Approach to AIDS Education in KwaNgwanase, 1993: by Darlymple, LI and Mlungwana J. (Dramaide, 1993).
- The impact of HIV/AIDS on Planning issues in KZN 1995 by Whiteside A, HEARD, University of KZN (HEARD, 2003).
- Home Based Care in Ngwelezana Hospital by Haselau Nomathemba, 1996 (KZN-DOH, 1996; personal observation).
- Enhancing Care Initiatives, by Havard University in USA, commenced in 1999, aimed at contributing to the building of appropriate response to care challenge, had as its purpose reviewing of the quality of care in specific home, community, workplace and hospital settings in KZN. The study was both qualitative and quantitative and its results subsequently informed care interventions in KZN (KZN-DOH, 1999).

Table 15 (a) below highlights areas of some HIV/AIDS research undertaken in KZN.

Table 15(a): Areas of Research work: KZN: Pre and Post 1994 GDE

Areas of Research	Number
1. HIV prevalence	4
2. STIs and HIV/AIDS	2
3. Care and support	2
4. IEC	1
5. STIs Management	1
6. Universal Precautions	2
7. Impact of HIV/AIDS	2
8. Sexual Practices and HIV/AIDS	1
9. Anti-retroviral treatment	1
10. Vaccine Development	1

Table 15(b) below gives the areas of some of the research papers that were given by KZN individuals.

Table 15(b): Areas of Research Papers: KZN: Pre and Post 1994 GDE

Areas of Research Papers	Number
1. Epidemiology of HIV/AIDS	1
2. Information Education and Communication	1
3. Impact of HIV/AIDS	1
4. Care and Support	2

The above tables show that research has mostly been undertaken on HIV prevalence followed by STIs, care and support, impact of HIV/AIDS and Universal precautions.

5.6.3.1 Interpretation

It would appear that research on HIV/AIDS commenced during pre-1994 GDE period but was dictated by the circumstances of the period. For instance the scientists were first curious to know whether there were any HIV infected persons; if so, what was the HIV prevalence? This was followed by a need to determine the link between STIs and HIV/AIDS. As the epidemic grew, a need to determine whether the communities would be overloaded by patients; with the care of AIDS patients at the time when the hospitals would not be coping; do health workers protect themselves against HIV infection at the workplace? i.e. do they observe universal precautions as spelt out in the policy? Then the researchers went on to study how HIV/AIDS affects the health system; as well as impact of HIV/AIDS on other sectors. The drugs for STIs (Sexually Transmitted Infections), opportunistic infections as well as the anti-retrovirals have only been used following thorough research in KZN. It is also noted from the above data that research on HIV vaccine constitutes one of the challenging research work of our time.

5.6.4 FUNDS

Funds constitute the backbone of any service. A limitation to this component of a support system is the lack of data regarding the funds that were allocated to AIDS work during the pre-1994 GDE period. The available data even in the case of KZL-DOH is that of 1992/ 93 to 1993/ 94, which was R4 558 240 (KZL-DOH, 1992). Of

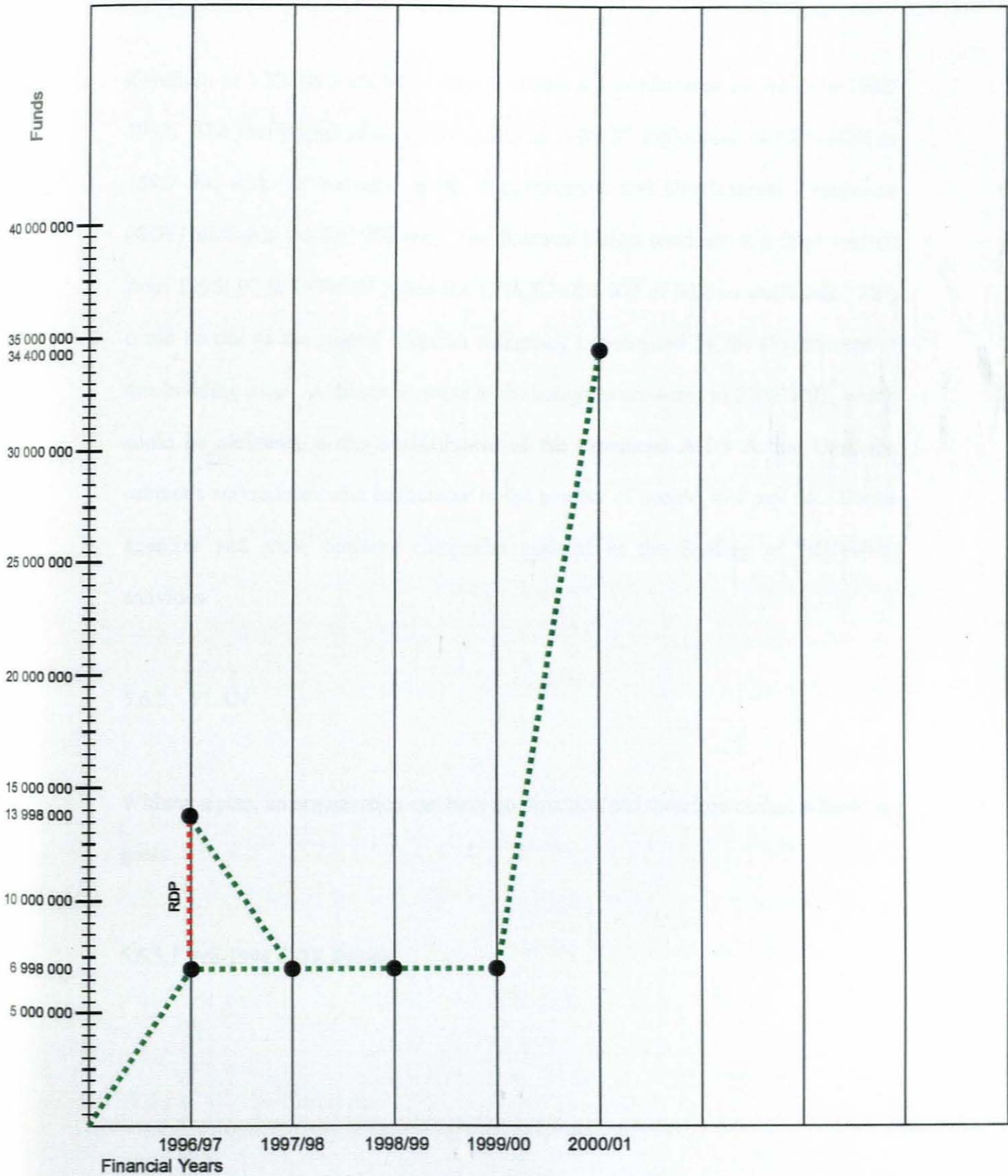
this money, R3 500 000 was committed in 1992/ 93. It was the first AIDS budget. R3 500 was given to each Health Ward or Hospital / Health centre to spend on materials not available through the usual channels, and towards World AIDS Day (KZL-DOH, 1992). During the Post-1994 period the budget was as follows:

Year	Allocated budget
1996/ 97	R6 998 000 (KZN-DOH, 1996)
	R7 000 000 (RDP)
	Total= R13 998,000
1997/ 98	R6 998 000 (KZN-DOH, 1997)
1998/ 99	R6 998 000 (KZN-DOH, 1998)
1999/ 00	R6 998 000 (KZN-DOH, 1999)
2000/ 01	R34 400 000 (KZN-DOH, 2000)

Some funding had been received from international donor agencies and the business sector, e.g. the European Union and SAB respectively (KZN-DOH, 1998). The AIDS Foundation of South Africa locally has funded some AIDS organizations in KZN since its inception (AFSA, 2003). Some NGO/CBOs have been directly funded by the National DOH's HIV/AIDS Programme.

From 1996, the British Consulate gave financial support to a number of KZN organizations including the Health Department through provision of specific materials, e.g. containers for education and counselling, wheelchairs, beds, etc. (KwaZulu-Natal Department of Health, 1997;KZN-DOH, 2000). Also refer to Figure 8 below regarding budget provided by the DOH and RDP.

Figure 8: AIDS Budget Allocation: 1996/97 to 2000/2001 KZN



Source of figures: Dept. of Health, 1997; Dept. of Health, 1998; Dept. of Health, 1999; Dept. of Health, 2000; PAAU, 2001

5.6.4.1 Interpretation

KwaZulu or KZL only started to have a budget solely allocated for AIDS in 1992/1993. The first budget allocated for AIDS in 1996/97 tripled that of KZL-DOH in 1992/93, with the inclusion of the Reconstruction and Development Programme (RDP) allocation i.e. R13 998 000. The allocated budget remained at a fixed amount from 1996/97 to 1999/00 (when the 1996 R7 000 000 of RDP is excluded). This could be due to the general financial stringency experienced by the Government at this budding stage. A drastic increase in the budget is projected in 2000/2001, which could be attributed to the establishment of the Provincial AIDS Action Unit, the cabinet's commitment and an increase in the number of people who pay tax. Donor agencies and some business companies assisted in the funding of HIV/AIDS activities.

5.6.5 PLAN

Without a plan, an organization can have no direction and therefore cannot achieve its goals.

5.6.5.1 Pre-1994 GDE Period

The KZN office of NDOH and PD had its first strategic plan on AIDS in 1990 (Natal AIDS Advisory Group, 1990) while KwaZulu DOH had its first strategic plan as well as operational plan in 1991 which was approved in 1992 (KZL-DOH, 1992).

5.6.5.2 Post-1994 GDE Period

The National AIDS Convention of South Africa (NACOSA) was formed in 1992 with a branch in KwaZulu-Natal. NACOSA KwaZulu-Natal, a multisectoral structure started planning for a post-apartheid AIDS era during the apartheid period. From April 1994 the NACOSA plan started being used (NACOSA, 1994: ix).

The NACOSA plan was so comprehensive and user-friendly that even the current plans bear the elements of this document. This plan was officially launched on 11/10/94 at the Royal Hotel in Durban; the then Minister of Health, the Hon. Dr Nkosazana Dlamini-Zuma attended the launch which had been organized by Vimla Moodley subsequent to the completion of the AIDS strategic plan (KZN-DOH, 1994; KZN-DOH, 1996).

From 2000 when the National HIV/AIDS Directorate produced a 5 year strategic plan, the provincial plans have been based on its content but modified to suit the needs of the province. All the NGO/CBOs which were visited had their own plans which were based on the National 5 year AIDS strategic plan.

5.6.5.2.1 Interpretation

There is paucity of information regarding the AIDS plans of some of the Health Departments of the past. Albeit late, the NDOH and PD and KZLDOH did develop strategic and operational plans. The NACOSA plan has been the most comprehensive plan whose content still permeate through the current strategic plan. All the visited NGO/CBOs had plans which were based on the National AIDS Strategy.

5.6.6 POLICIES

Policies are useful tools in the implementation of any service. The researcher intended to determine whether there were policies available for the direction of staff in their AIDS activities. The following policies on AIDS were formulated.

5.6.6.1 Pre-1994 GDE Period

- 1988: Guidelines for Nursing Personnel and other Health Care workers on the management and investigation of a patient with Acquired Immune Deficiency Syndrome (AIDS): In circular 54 of 1988 Ref 12/ 12/ P (KZL-DOH, June 1988).
- KwaZulu clinics STD Policy - September 1989 (KZL-DOH, 1989).
- Policy on employment and utilization of HIV positive staff: Circular 1230 of 1989 dated 23/10/89 Ref 12/ 12/ 5 AIDS (KZLDOH, 1989).
- AIDS and Workman's Compensation 12/ 12/ 5P AIDS 30/5/90 - Dr Murray Short (KZL-DOH, 1990).
- Needle-stick injury policy issued by the Natal Provincial Administration Circular Minute WS/ 90, Ref S21/1 (KZL-DOH, 1990).
- Prophylactic use of AZT: Possible HIV infection: Ref 12/ 12/ 5 of 07/3/91(KZLDOH, 1991).

- Policy on Injury on duty: Possible HIV Infection, Seconded Staff: Circular 11 of 1991 - Ref 12/12/5: AIDS of 27/5/91 (KZL-DOH, 1991).
- New treatment protocol for STDs Circular 93 of 1992 (KZL-DOH, 1993).

5.6.6.2 Post 1994 GDE Period

- 1996 - AIDS Clinical Guidelines for the care of adults and children with AIDS; psychosocial, legal/ ethical and primary care (KZN DOH, 1996).
- 1996 - Department of Correctional Services formulated and adopted an AIDS policy whereby both prisoners and staff would get AIDS education (PAAG, 1996).
- 1996 - The Premier's office issued an HIV/AIDS policy for KZN Provincial Administration in Personnel Circular 28 of 1996: dated 18/3/96 (personal observation, 1996).
- 2000 - May: The NDOH's HIV/AIDS Directorate formulated the following policies for use by the provinces including KZN:
 1. Prevention of Mother-to-Child-Transmission and Management of HIV positive pregnant women.
 2. Ethical considerations for HIV/AIDS clinical and epidemiological research.
 3. Feeding infants of HIV positive mothers.
 4. Children in Distress (CINDI).
 5. Rapid HIV testing.
 6. Management of occupational exposure to HIV.
 7. Testing for HIV.

8. Managing HIV in children.

Table 16(a) and 16(b) below display some of the Pre and Post 1994 GDE Periods Policies on AIDS

Table 16(a): Pre 1994 GDE AIDS Policies: KZN.

Policy	Identity	Month	Authority
1. Management and Investigation of a patient with Acquired Immune Deficiency Syndrome.	Circular 54 of 1988	June	KZL-DOH
2. Employment and utilization of HIV positive staff	Circular 1230 of 1989	October	KZL-DOH
3. AIDS and workmens Compensation	12/12/5 AIDS	May	KZL-DOH
4. Needle-stick injury	Circular WS 90	-	NPA
5. Prophylactic AZT	Ref 12/12/5	March	KZL-DOH
6. Injury on duty: Possible HIV infetion	Circular 11 of 1991	May	KZL-DOH
7. STD Management	Circular 93 of 1992	-	KZL-DOH

NPA = Natal Provincial Administration

- = **Information not available**

Table 16(b): Post 1994 GDE AIDS Policies: KZN

Policy	Authority	Year
1. AIDS Clinical Guidelines for the care of adults and children with AIDS	KZN-DOH	1996
2. HIV/AIDS Policy for the employees	Correctional Services	1996
3. HIV/AIDS Policy for KZN Provincial Administration	KZN Dept of Premier	1996
4. PMTCT and Management of HIV positive pregnant mother	NDOH	2000
5. Ethical consideration for HIV/AIDS clinical and epidemiological research	NDOH	2000
6. Feeding infants of HIV positive mothers	NDOH	2000
7. Rapid Testing	NDOH	2000
8. Management of occupational exposure to HIV	NDOH	2000
9. Testing for HIV	NDOH	2000
10. Management of HIV in children	NDOH	2000

5.6.6.3 Interpretation

Two years after the first cases of AIDS had been identified in 1986, the KwaZulu Government DOH formulated a policy to guide the health workers on the management of HIV/AIDS. The sensitive aspects of AIDS like those pertaining to labour relations, the legal and the ethical aspects were addressed by policy formulation. Early in the nineties attention was paid very early to the appropriate management of STIs due to their relationship to AIDS, by ensuring that staff was

guided through policy and training. Both the national and provincial Health Departments worked together in the formulation of the policies. Late in the post-apartheid era policies on the new programmes were formulated.

5.6.7 COMMITTEES/ FORUMS / GROUPS/ COUNCILS

5.6.7.1 Pre-1994 GDE Period

- The Natal Regional AIDS Advisory Group (NRAAG) was formed in 1987 to deliberate on AIDS; it was a branch of the National AIDS Advisory Group and included all Health Departments in the province, the University of Natal and MRC (Minute from the chairperson of NRAAG, (Prof Pudifin) to Dr J. Muller, November 1987).
- KZL formed an AIDS Task Group in 1990, the composition of which gradually improved to include representatives of all Health Regions, the SABC, social workers, health inspectors, educators, ministers of religion, the Natal Provincial Administration (NPA), DNH and PD, NPPHC (KZL-DOH, March 1993).
- Edendale Health Region formed a Regional AIDS Committee led by Dr J Muller in 1992 (Minutes of Regional AIDS Committee, 1992).
- The Regional AIDS Planning Sub-Group (RAPS) was formed in 1992 and was multi-sectoral in nature (RAPS, 13/04/92). This was a sub-structure of NACOSA.
- AIDS Action Teams established in each Health Ward in 1992 (KZL-DOH, 1991; Schneider, 1994:5).
- KZN National AIDS Convention of South Africa NACOSA, a sub-structure of National NACOSA was formed (under the leadership of Dr Nkosazana

Dlamini-Zuma) and played an instrumental role in the drawing up of the HIV/AIDS plan for all people in South Africa (NACOSA, 1994).

- The AIDS Clinical Advisory Committee (which was a component of RAPS) was formed in 1992, chaired by Prof Pudifin (KZL-DOH, 1992).

5.6.7.2 Post-1994 GDE Period

- The AIDS Clinical Advisory Committee was carried forward to the post-1994 GDE (KZNDOH, 1996).
- The KwaZulu-Natal Inter-Departmental AIDS Committee (KIDACO), chaired by Wanda Mthembu was established in 1996 and officially opened in 1997 (KZN DOH, 1997). It was aimed at ensuring that the workplace AIDS programmes were established and well co-ordinated in various KZN Government Departments.
- A Provincial AIDS and STI Forum PASFO was established in 1996 by Wanda Mthembu with membership from all sectors. It served as a think-tank for the HIV/AIDS programme (KZN-DOH, 1996: MRC, 1997: 47).
- The Provincial Media Forum was formed in 1996 as a substructure of PASFO (KZN DOH, 1997).
- The STD Co-ordinating Committee was established in 1996 chaired by Dr Steve Knight assisted by Ms Janet Dalton (KZN-DOH, 1996).
- The Civil Military Alliance started in 1998 as introduced by the National AIDS Directorate; however, it was only officially launched in 2000. It was a structure which put the SADF in partnership with the civil society in combating AIDS.
- The Provincial AIDS Council was established in 2000 with membership from all sectors, e.g. business, labour, tertiary institutions, media, traditional

leaders etc. It was chaired by the Premier and co-ordinated by PAAU (PAAU, 2000).

- The Ethekwini AIDS Council was launched on November 8, 2002 with the National Minister of Health Dr Manto Shabalala-Msimang as a guest speaker (NAPWA, 2003: 2).

Table 17 below displays a streamlined version of support structures that were established in KZN

Table 17: Some of the support structures for HIV/AIDS programme: KZN: Pre and Post 1994 GDE period

Support Structure (Committees, Groups, etc.)	Year formed
1. Natal Regional AIDS Advisory Group	1987
2. AIDS Task Group	1990
3. Edendale Regional AIDS Committee	1992
4. Regional AIDS Planning Sub-group	1992
5. AIDS Action Teams (in each Health Ward)	1992
6. KZN branch of National Convention of South Africa	1992
7. AIDS Clinical Advisory Committee	1992
8. KZN Inter-Departmental AIDS Committee (KIDACO)	1996
9. Provincial AIDS and STI Forum (PASFO)	1996
10. STD Co-ordinating Committee	1996
11. Provincial Media Forum	1997
12. KZN Civil Military Alliance	1998
13. Provincial AIDS Council	2000
14. Ethekwini AIDS Council	2002

5.6.7.3 Interpretation

Based on the available data, the formation of KZN AIDS structures appears to have started on time, i.e. the first AIDS cases were diagnosed in 1986 and the first structure (KZN branch of National AIDS Advisory Group) formed in 1987; this was when Edendale Hospital had just diagnosed its first case in May. The data also show that as democracy drew closer, the AIDS structures that had been formed were modified to be more representative of relevant sectors. After the 1994 GDE, the newly formed structures were made widely representative of all sectors from the very outset, e.g. the KZN AIDS Council.

5.6.8 BACKING/SUPPORT OF HIV/AIDS PROGRAMME BY HIGH PROFILE PEOPLE

5.6.8.1 Pre-1994 GDE

- His Majesty, King Goodwill Zwelithini kaBhekuzulu has incorporated AIDS and Sexually Transmitted Infections (STIs) in his speeches since the early eighties after hearing about the existence of AIDS. The platforms he has used for this purpose are those of Umkhosi Womblanga, Umkhosi Wokweshwama, Umkhosi Welembe etc. His messages on HIV/AIDS and STIs at these ceremonies have always included poverty alleviation, especially food security. In Umkhosi Welembe he is quoted as saying, "This plague, which knows no limits, its like an attacking army, destroying the nation, that is why I am saying: My people, arm yourselves and face this deadly disease" (Mason and

KZN-DOH, Sex News Special Edition 1998: 3). At the Umkhosi Womhlanga His Majesty is quoted as saying, “As the foundation of our nation and the custodian of our culture and treasures, I believe that we should return to our traditional values which could be a remedy for this epidemic and help us raise our youth in the traditional way so that our young women will always be the flowers of the nation. This can save us from HIV/AIDS”. (Mason and KZN-DOH, Sex News Special Edition, 1998:3).

- In 1989, the then Hon. Minister of Health in KwaZulu, Dr FT Mdlalose talked broadly about HIV/AIDS in his policy speech. Addressing the legislature and the public he said, “I appeal to all of you (here) to assist me and my Department, to bring us your suggestions and proposals for stemming the advance of this fearsome disease” (KZLDOH, 7/12/89).
- In 1990 the Daily News reported that in his policy speech Dr Mdlalose warned that unless attitudes towards sex were changed, the nation would be destroyed. The same paper reports that Dr Mdlalose referred to the words of His Majesty the King saying, “unless there was a return to the old tradition in which sex between a man and a woman was confined to marriage”, AIDS will destroy the nation (Daily News, 1/6/90).

5.6.8.2 Post-1994 GDE

- From 1994 onwards, the MEC for Health, in KZN, the Hon. Dr Zweli Mkhize has always emphasised the need to fight fiercely and collaboratively against HIV/AIDS and monitored the HIV/AIDS programme very closely.

- The then Premier of the Province, the Hon. Dr Ben Ngubane and the Hon. MEC for Health, Dr Zweli Mkhize launched and led the KZN cabinet's AIDS Campaign in November 1997 (KZN-DOH, 1997). The slogan for the campaign was. "Together we can win"
- The above initiative followed the results of the HIV/AIDS Review that had been undertaken from April to July 1997, which found (amongst other things), that there was lack of political commitment (MRC, 1997).
- The following are some of the messages by the members of the cabinet:

"sooner or later AIDS will affect your life as well as mine. For this reason my cabinet and I are launching an AIDS awareness initiative in which we will invite all to take part in building the foundation we need to fight AIDS. Please make a commitment to support us in this" (Dr B.S. Ngubane quoted in Sex News no 4: Special Edition, 1 December 1997:3 by Mason and KZN DOH).

"If AIDS occurred like deaths from gunshots, people would take immediate action. But AIDS deaths are the opposite. They are extremely quiet" (Dr Z.L. Mkhize quoted in Sex News, Special Edition, 1998: 5 by Mason and KZN DOH).

"It's like using a seat-belt - it only works if you make it your business to use it. Lets make the fight against AIDS our business" (The then Hon. Minister of Transport, Dr Sbusiso Ndebele, quoted in Sex News, Special Edition, 1998:4 by Mason and KZN DOH).

All the members of the cabinet had their special messages in the campaign.
- The campaign was not a once-off initiative but was continuously kept alive by the holding of AIDS events at each public holiday, e.g. on Workers' Day a focus was on encouraging workplace AIDS programmes (KZN-DOH, 1998).

- When the then Hon. Deputy President Thabo Mbeki and the National Cabinet launched the “Partnership Against AIDS Initiative on October 9, 1998, KZN participated in this national initiative (KZN-DOH, 1998). This initiative called upon people to join hands in the fight against AIDS. KZN got 2 Assistant Directors posts from the funds allocated to this campaign.
- In December 1998 Hlabisa Community was addressed by the former President of South Africa, the Hon. Dr Nelson Mandela on World AIDS Day, calling upon people to destigmatise AIDS, not to discriminate against those infected and affected by AIDS, to care and support the PLWHAs and orphans and to protect themselves against getting HIV infected (Personal experience, first December 1998; KZN-DOH, 1999).
- In support of the Cabinet’s AIDS Initiatives, the then Hon. Minister of Home Affairs Dr M.G. Buthelezi is reported by Sex News: Special Edition, (December 1998:1 by Mason and KZN-DOH) as having said, “An HIV positive person is as reliable a father, mother, worker or friend as anyone”. He addressed some AIDS events in KwaZulu-Natal, e.g. in Vryheid, 1999 (personal experience) where he talked to traditional leaders on AIDS, in their language of sex.
- On the 29th of October 1999, a launch of yet another Cabinet AIDS initiative took place referred to as “AIDS challenge 2000” which introduced the Provincial AIDS Action Unit (PAAU). The cabinet of KwaZulu-Natal, under the leadership of the then Premier Dr L.P.H. Mtshali who worked in close liaison with the Hon. MEC for Health, Dr Zweli Mkhize, committed R20 000 000 towards the establishment of the PAAU. The PAAU would belong to the Department of the Premier but housed in the Department of Health. At the launch of

the initiative Dr L.P.H. Mtshali called upon individuals to act saying “If it were to be reliably predicted that within 10 years a comet would hit South Africa and that six million people will die, can you imagine what the reaction would be?”(Premier L.P.H. Mtshali’s speech, delivered: 29/10/99, Durban).

5.6.8.2.1 **Interpretation**

High profile persons in KZN have played a significant role in the support of the HIV/AIDS programme. His Majesty the King appears to have been the first high profile person to warn KZN people about HIV/AIDS. The King used a very cost-effective vehicle for driving these messages home, i.e. by simply incorporating the messages into the content of speeches that were prepared for the existing ceremonies.

Although democracy had not yet been attained in the country, concern on the AIDS epidemic was mirrored in the content of the 1991 policy speech by the Hon. Dr Mdlalose, former Minister of Health in KwaZulu. The KwaZulu-Natal cabinet was very prompt in positively responding to the results of the HIV/AIDS review of 1997. The campaigns were not just once-off events, but were maintained by relevant use of public holidays.

The KZN HIV/AIDS programme did not only get the backing from high profile people living in KZN but also from outside the province, e.g. the Hon. Dr Nelson Mandela, the former President of South Africa and the then Deputy President of South Africa (President of South Africa at the time of this study, the Hon. Dr Thabo Mbeki.

The growth in the quality of the campaigns from that of 1997 to the AIDS challenge 2000 is noted, i.e. the latter campaigns had more funding attached to them. This is also compatible with the trend seen in the annual budget for HIV/AIDS under 5.6.4 above.

5.6.9 PARTNERSHIPS

The partnership of the Department of Health, with other Government Departments and other sectors is mirrored in the following events:-

5.6.9.1 Pre-1994 GDE Period

The erstwhile National DOH and Population Development entered into partnership with local authorities to establish and run AIDS Training and Information Centres (ATICs) in Durban (1989), Empangeni (1993) and Pietermaritzburg (1992) (Minutes of Natal of AIDS Advisory Group, 1993).

Through partnership with the University of Zululand's Speech and Drama Department, the KwaZulu Department of Health and the Department of Education were able to implement a project which used drama to disseminate AIDS messages to the learners of KwaZulu schools from 1992 (KZL-DOH, 1992: 2).

5.6.9.2 Post-1994 GDE Period

- In October 1996 South African Breweries provided funds for the training of traditional healers and these were administered by the AIDS Foundation of South Africa in liaison with the Department of Health's HIV/AIDS unit (KZN-DOH, 1997).
- Department of Education and Pietermaritzburg AIDS Action Group worked with the Department of Health in Lifeskills Education: 1997.
- Partnerships have been seen in HIV Testing as well where the health institutions, private laboratories, ATICs and the Virology Department worked together with the latter handling confirmatory tests (KZN-DOH, 1997; Personal experience).
- Department of Education incorporated AIDS education into cultural activities in 1997 (Personal experience).
- Cadburys, Coca Cola, Clover etc. have worked together with the Department of Health to provide specific materials at HIV/AIDS events with Ukhozi FM giving media coverage since 1997 (KZN-DOH, 1998; Sex News Special Edition, 1998).
- Glaxo – Wellcome provided funds for the building of a Drop-In-Centre in Sweetwaters: 1998.
- The University of Zululand has worked with the Chicago State University to build capacity amongst staff and partners of the University; workshops dealing with the incorporation of HIV/AIDS into the University curricula have been successfully held (University of Zululand, 2002: 37).
- The Department of Housing (DOHO), Department of Education (DOE) and Department of Welfare (DOW) worked together on the programmes targeting children and the youth infected and affected by HIV/AIDS. The Departments

of Agriculture (DOA) and that of housing (DOHO) were brought on board; DOA was brought in to provide food and DOHO to provide housing (PAAU, 2002).

- In 2001 the DOE trained 62 teachers as master trainers in Lifeskills Education (LSE), 3121 Primary School Educators in Lifeskills and 623 Secondary School Lifeskills Educators; furthermore 1820 Peer Educators amongst pupils were trained in LS Education and 15 officials were also trained in counselling. The Early Childhood Development Unit held a puppet show at Mpopomeni, Howick (PAAU, 2002: 6).
- The Department of Welfare was able to draw up an AIDS strategic plan and identify sites for the integrated programme for youth infected and affected by HIV/AIDS. The Department of Welfare also ran an AIDS awareness Campaign in Ulundi addressed by Prince G.L. Zulu, the then Hon. MEC for Welfare (PAAU, 2002: KZN-DOH, 2002:29).
- The DOHO adjusted the Institutional Housing Policy as a mechanism to cater for the housing needs of children infected and affected by HIV/AIDS; established 2 cluster homes for children in distress, e.g. Lilly of the Valley and the Gods Golden Acre projects (PAAU, 2002).

The Department of Housing allocated special funds for the following projects:

- Home of Comfort: Inland Region at the value of R543 375-00 (45 beds).
- Agape - Hillcrest, at the value of R258 030-00 (224 beds).
- Shepherd's Keep - Coastal Region, at the value of R672 000-00 (60 beds).
- Ekusizaneni - Coastal Region, at the value of R672 000-00.
- Rehoboth - Coastal Region, at the value of R1 120 000-00 (100 beds).

- The DOA started workplace AIDS programme that would be soon brought into the housing programme (PAAU, 2002).
- Ongoing funding of NGO/CBO for AIDS related activities by PAAU (PAAU, 2002). In 2001/ 2002, 49 NGOs were funded for HIV/AIDS education, training of community leaders, lifeskills, condom distribution, etc. (PAAU, 2002).
- Consistent interaction with all stakeholders regardless of who funded them (PAAU, 2002).
- PAAU provided R11, 5 million to The Valley Trust NGO as well as KZN PPHC for the Administration of Community Health Workers Service in 2002 (PAAU, 2003).
- Glaxo-Smith Kline Pharmaceutical Company built a cluster home for the orphans of Nongoma (Sinkonkonko) with 17 orphans in 6 rondavels. A nutrition project was also undertaken in this orphanage. This home was officially opened by the Hon. MEC for Health, Dr Zweli Mkhize in 2002 (PAAU, 2003: 3).

Table 18 below streamlines the information on some of the organizations that joined hands with the DOH in the fight against HIV/AIDS (cited above)

**Table 18: Some of the organizations that worked in partnership with the DOH:
KZN: Pre and Post 1994 GDE**

Organization	Contribution	Year Started
1. Local Authority, Durban	AIDS Training and Counselling	1989
2. Local Authority, Pietermaritzburg	AIDS Training and Counselling	1992
3. Local Authority, Empangeni	AIDS Training and Counselling	1993
4. University of Zululand (Dept of Speech & Drama)	AIDS Education	1992
5. SAB	Funds for the Training of Traditional Healers	1996
6. Cadburys	Refreshments at AIDS events	1997
7. Department of Education (Arts & Culture)	In corporated AIDS into cultural activities	1997
8. Department of Education	Lifeskills education	1997
9. Pietermaritzburg AIDS Action Group	Lifeskills education	1996
10. Coca Cola	Refreshments at AIDS events	1998
11. Glaxo-wellcome	Building of Drop-In-Centre: Sweetwaters	1998
12. DOE, DOW, DO Housing and (PAAU)	Worked together in the Intergrated programme of children Infected and affected by HIV/AIDS	2000

PAAU = Provincial AIDS Action Unit

DOW = Department of Welfare

5.6.9.3 Interpretation

Partnership between the Department of Health and other sectors in the fight against HIV/AIDS have been formed and predominantly involve other Government Departments, the business sector, local authorities and educational institutions. It is also reflected that partnerships have gradually grown over the years reflecting a positive response to the call by the then Honourable Deputy President Thabo Mbeki on "Partnership against AIDS" in October 1998.

5.6.9.4 Comments on the support system with reference to Betty Neuman's Health Care Systems model

Human Resource that was provided are likened to the "care giver" that Neuman refers to while Human Resource Development is compatible with the developmental variable of a client system. Human resource development took place because the client was an "open system".

The establishment of committees, councils, forums etc represent collaboration and interdisciplinary approach that Neuman refers to. Partnerships form part of collaboration.

The development of plans is accommodated under the second step of the nursing process Betty Neuman refers to re formulation of nursing goals. The evaluation of outcomes, which is the third step of the nursing process was accommodated both at

clinical settings and by research since some research that was carried out as a component of the support system was evaluated.

5.7 OBJECT NO. 4: CHALLENGES AND THE LESSONS LEARNT IN THE IMPLEMENTATION OF THE HIV/AIDS PROGRAMME

5.7.1 INTRODUCTION

By this objective the researcher intended to highlight the problems or concerns, challenges in the literal sense as well as the lessons learnt in the course of programme implementation.

5.7.2 BACKGROUND TO DATA ANALYSIS

Data that would provide answers to this objective were obtained from the records (archival and current), the completed questionnaire administered to 193 NGO/CBOs as well as the records of the checklist used at the service sites of 15 organizations that were subsequently visited. The ages of people who represented the organizations ranged between 25 and 65 years. It should be noted that the latter organizations were visited only after the completion of the questionnaire mentioned above. The random selection of the 15 organizations that would be visited was done by use of NGO/CBO names in the completed questionnaire, i.e. they were drawn from the 193 NGO/CBOs. The organization that had provided sufficient information in the questionnaire was not asked to provide that data again during service site visits.

The challenges were categorised into those that occurred prior to the 1994 GDE and those that occurred after the 1994 GDE. Those challenges which occurred prior to 1994 were all obtained from the old records of the Department of Health (DOH) and the newspapers (archival), while those that occurred after the 1994 GDE period included responses to the questionnaire by the NGO/CBOs and observations recorded on the checklist used during the visits to the service sites. It was further necessary to develop themes on the challenges in order to streamline them.

The lessons learnt were straight forward and few, as a result they were presented as stated, with very slight modifications. These were obtained from the verbal responses made by 20 people (15 HIV/AIDS managers at the visited sites and the 5 key informants).

5.7.3 PRE-1994 GDE OR EARLY CHALLENGES

In view of these challenges having all been extracted from the various records on the HIV/AIDS programme, they will be presented raw but assigned specific categories. They are divided in to pyscho-social, service related and ethical/ legal. All data were obtained from the records (archival).

A. Psycho-social

- Misconceptions, e.g. that a traditional healer can cure AIDS (Mercury, 10/09/88), AIDS is contagious, HIV is mostly contracted from the clinical settings etc.

- Difficulty in using mass media, subject too sensitive (Dr Jaffe, A. December 1989; Mrs Haselau N, 2003: personal communication).
- Who will care for orphans resulting from AIDS?
- Blame, stigmatization, denial, moral judgements and prejudice (Sabatier, 1988).
- Jumping of some businesses on the "AIDS bandwagon" (Mercury, 9/1/86).
This meant that some businesses were starting to exploit the situation of the AIDS pandemic for their own economic gain.
- The values of the religious sector clashed with the use or education on condoms (Mercury, 30/11/89); e.g. the myth that sexual intercourse with a virgin will remove HIV from the infected.
- Violence or political unrest (Witness 13/8/91; Department of Health KwaZulu, 1989; Regional AIDS Group 11/3/89).
- Negotiation on the use of condoms by a female.

B. Service Related

- Delayed action.
- Lack of resources for care, e.g. Home-Based Care (HBC) that needed staff, vehicles, materials, etc.
- Lack of AIDS policies.
- Fear of contracting HIV by the Health Workers (HWS).
- Whether contracting HIV at work was compensable.
- The capacity of hospitals to admit all AIDS patients.

C. Ethical/Legal

- A wish by some employers that pre-employment HIV screening should be done.
- Discriminatory practices at workplaces.
- Motivating HIV positive patients to bring their contacts for HIV testing or to inform them of their HIV positive status.
- Leaking of HIV results despite an attempt to keep them confidential (KwaZulu Department of Health, Regional AIDS Task Group Minutes 29/04/92).
- How to handle an HIV positive staff member admitted to Hospital (KwaZulu Department of Health, 1992).
- People having a tendency to hide their HIV positive status from sexual contacts (Mercury, 15/1/86).

In the above data it is shown that the pioneers of the HIV/AIDS programme implementation were faced with psycho-social, health, service-related and legal/ethical challenges, the most sensitive of which was the latter, followed by the social aspect. These challenges served as additional “stressors” or secondary stressors as most staff members were not yet capacitated to deal with them.

5.7.4 POST-1994 GDE PERIOD CHALLENGES

The challenges that were faced by the HIV/AIDS role players after the 1994 GDE to 2003 are presented below with data obtained from the completed questionnaire and the checklist from 193 subjects. They were grouped according to the categories psychological, social and economical, legal/ ethical and service-related.

A. THE PHYSICAL, SOCIAL AND ECONOMICAL CHALLENGES OF THE POST-1994 GDE PERIOD IN KZN.

The physical, social and economical challenges of the Post-1994 GDE period are shown in Table 19 below.

Table 19: The challenges faced in the implementation of the HIV/AIDS Programme in KZN and the number of respondents: Post-1994 GDE Period

CHALLENGE	NUMBER	%
1 Denial	1	.5%
2 Lack of change in behaviour	2	1%
3 Opposition	1	.5%
4 Too many people in need of care	14	7.3%
5 Stigma	2	1%
6 Ignorance	1	.5%
7 A need to take ART for life	1	.5%
8 Delayed welfare grants	2	1%
9 Crime	2	1%
10 Failure to balance rights with responsibilities	1	.5%
11 Laziness to fight AIDS	1	.5%
12 Increased commercial sex work	1	.5%
13 Poverty	10	5.2%

ART: Anti-retroviral treatment

B. THE LEGAL/ ETHICAL CHALLENGES: POST-1994 GDE PERIOD

The legal/ ethical challenge during the post-1994 GDE period was that of **discrimination** only (1.6%).

C. SERVICE-RELATED CHALLENGES DURING THE POST-1994 GDE PERIOD.

The service-related challenges during the post-1994 GDE are shown in Table 20 below.

Table 20: The service-related challenges faced during the Post-GDE 1994 Period and the number of respondents: KZN.

CHALLENGE	NUMBER	%
1 Lack of funds	134	69.0%
2 Human Resources shortage	21	10.9%
3 Material Resources shortage	21	10.9%
4 Lack of transport	16	8.3%
5 Lack of accommodation	8	4.0%
6 Lack of infrastructure	4	2.0%
7 Poor co-ordination of services	2	1.0%
8 Failure to compensate volunteers	3	1.6%
9 Lack of treatment	2	1.0%
10 Lack of compliance with treatment	1	.5%
11 Lack of interest in learning	1	.5%
12 The fact that nevirapine does not help the mother to improve her health	1	.5%
13 Defaulting of patients	1	.5%
14 Inability to reach the targeted rural areas	1	.5%
15 New Programmes viz. VCT, PMTCT and ART impose extra workload	1	.5%
16 Transformation	1	.5%
17 Slow procurement process	1	.5%
18 The need to present coursework	1	.5%
19 Ill-treatment of HIV positive patients by HWs	1	.5%
20 Politicization of HIV/AIDS	1	.5%

PMTCT: Prevention of mother to child transmission
VCT: Voluntary Counselling and Testing
HWs: Health Workers

5.7.5 COMMENT ON THE POST-1994 GDE CHALLENGES

The challenges during this period were centred around resources problem (i.e. logistics) especially funds (69%), followed by human resources, material resources, transport, poverty and the increase in the number of people who need care. The shortage of human resources is incompatible with the increase in the number of those who need care respectively. The most leading challenges seem to have something to do with services. There is a significant reduction in the challenges that are related to the legal and ethical aspects as can be seen when comparing the challenges of the two periods (Refer to table 18 and 19 above as well as Figure 12 in chapter 6).

The assertion that transformation was one of the challenges is of interest given the fact that the majority of people in KZN wanted the change. One other challenge, which did not appear under the pre-1994 GDE challenges, is that of poverty: 5.2% respondents mentioned this.

The challenges around funding also included selective funding, lack of uniformity in the funding mechanisms (amongst the government departments) and delayed funding or a slow funding process. Human resources problems included inadequate assignment of ranks to responsibilities and lack of certain essential skills amongst HIV/AIDS role players.

On the whole there is a general reflection of having moved from ignorance, which constitutes one of the major challenges that were faced in the budding stages of the HIV/AIDS programme.

5.7.6 THE CONTROVERSIAL CHALLENGES

During the analysis of challenges, those that tended to trigger controversy were identified and separated into the two periods i.e. the pre and post-1994 GDE. These are listed below:

5.7.7 PRE-1994 GDE CONTROVERSIAL CHALLENGES

- An HIV positive woman should rather not have a baby than to run the risk of infecting her baby with HIV.
- Does the Health Worker (HW) have the right to refuse treating an HIV positive patient purely on the ground that such treatment poses a risk to the HW?
- Is it legitimate to alter the kind of treatment provided to an HIV positive patient purely because the standard treatment, e.g. operation is perceived to be risky to the HW?
- Does the HW have a **need** to know the HIV status of any patient whom he/ she treats (with a view to protecting herself/ himself)?
- Does the HW have a **right** to know the HIV status of any patient whom he / she treats (in order to protect herself/ himself)?
- Are there limits of confidentiality owed by the HW to his/her HIV positive patient?

5.7.8 POST-1994 GDE CONTROVERSIAL CHALLENGES

- Whether AIDS should be a notifiable medical condition.
- Whether nevirapine should be given to HIV positive mothers and generate more orphans (if the baby survives).
- Exclusive bottle-feeding is regarded as the most protective feeding of a baby whose mother is HIV positive yet, breast milk is regarded as the best milk for the infant.
- HIV positive women should rather not fall pregnant than to risk infecting their babies with HIV.
- Are there limits to the “duty to confidentiality owed by the Health Worker” to his/ her HIV positive patient? (Barker, 1995:6 in AIDS Bulletin Vol.14. No. 2, December 1995).

Based on the above challenges, which have bearing on both the AIDS legal and ethical implications, AIDS being “a legal octopus with many sinister tentacles” as articulated by Mr Sorgarager of Technikon RSA in the Mercury, 26/11/88, cannot be better confirmed.

The challenges of HIV/AIDS service providers therefore were mainly psycho-social, service-related, ethical, legal and economical. Significant progress in the effective handling of legal/ ethical challenges during the post-1994 GDE is clearly reflected.

5.7.9 LESSONS LEARNT

This section of responses to objective 4 of the study had scanty data. Of the 20 people targeted to provide answers to the question appearing in the first section of the checklist, 6 stated what they had learnt; this yields a 30% response rate. What the respondents learnt can be seen in table 21(a) and 21(b) below.

Table 21(a): The Lessons Learnt by the HIV/AIDS Service Providers in KZN: pre and post-1994 GDE

INTERPRETATION OR THEME	STATEMENT
Early planning and policy formulation is important.	Have plans and policies in place from the very outset so that staff stays directed and guided.
Life is a valuable asset.	Learn to appreciate life as a gift from the creator; "many a human life has been lost through AIDS but mine has been spared".
Stigmatisation worsens the Disease.	Never to stigmatise a disease; it becomes difficult to control.
Early provision of necessary resources can save lives.	Mobilize and provide the resources for curbing the spread of a disease from the very outset so as to prevent or minimise loss of lives; the big damage may only be visible when it is too late.
Think and arm for all possibilities around a new health problem.	Think beyond a problem at hand and develop a foresight into its possible destination or progression then act proactively.
Sexual intercourse is an optional activity in love.	I have learnt that a person can be healthy and happy without sexual intercourse.
Life abstinence and absolute indulgence in sex (by all) can both lead to human extinction.	Both lifelong abstinence from sex by all people and life indulgence in sex by all people at present have a possibility of human extinction.
Discrimination worsens the Disease.	Never to discriminate against the sufferers of a disease because this may fan its spread and make the condition worse.
Early positive response to a warning on a life threat is safer.	The importance of listening and positively responding when warned about a health threat, believing what is said or not; the old expression of "better be safe than to be sorry", should be observed.
Self-management and appropriate management of relationships can prevent AIDS.	Self management and management of one's relationships is important, lest others do this with undesirable effect.
To be non-judgemental and Non-discriminatory.	Learn to adopt a non-judgemental and non-discriminatory attitude towards an HIV positive person.
To be assertive in life relationships.	The practice of assertiveness protects young people from contracting HIV infection.
Knowledge about human sexuality enhances insight into sexually transmitted diseases.	People must be taught human sexuality at an early stage so that it becomes easy for them to talk about sex when a disease like AIDS strikes.
Importance of socio-economic development in the fight Against AIDS.	The improvement of socio-economic conditions of all people is the cornerstone of preventing and combating HIV/AIDS.

Having streamlined the wording of the lessons learnt it is appropriate to determine the number and proportion of those who provided the responses below, so as to get a clearer picture.

Table 21(b): Streamlined lessons learnt by HIV/AIDS service providers in KZN, pre- and post-1994GDE periods and the number of respondents

THEME	NO	%
1. Early planning and policy formulation important	2	33.3%
2. Life is a valuable asset	1	16.6%
3. Stigmatization worsens the disease	3	50%
4. Early provision of necessary resources	3	50%
5. Think and arm for all possibilities	1	16.6%
6. Sexual intercourse is an optional activity in love	1	16.6%
7. Life abstinence from and absolute indulgence	1	16.6%
8. Discrimination worsens the disease	3	50%
9. Early positive response to a warning on a life threat is safer	1	16.6%
10. Self-management and appropriate management of Relationships can prevent HIV/AIDS	1	16.6%
11. To be non-judgemental and non-discriminatory	3	50%
12. To be assertive in life relationships	1	16.6%
13. Knowledge about human sexuality enhance insight into Sexually transmitted health conditions	1	16.6%
14. Importance of socio-economic development in the fight against AIDS	2	33.3%

Total Number of respondents: 6 (out of 20)

The commonly learnt lessons were around elimination of stigma and discrimination; early provision of resources followed by the need for socio-economic development, planning and policy formulation (refer to Table 21). This merges with the challenges

commonly found among the service providers as can be seen under 5.7.9 above.

5.7.10 COMMENT ON THE CHALLENGES AND LESSONS LEARNT WITH REFERENCE TO BETTY NEUMAN'S MODEL

While HIV/AIDS is a stressor, the challenges faced by the HIV/AIDS role players added to the stress.

The challenges that were faced were intra-personal e.g. feelings of guilt or feelings of rejection and denial, interpersonal e.g. discrimination or rejection and extra-personal e.g. political violence, increase in the number of people who need care, poverty, etc. This is compatible with the types of stressors Betty Neuman identified. Refer chapter 3:3.4 (b). Betty Neuman maintains that when the needs of the clients are unmet, wellness is reduced and when they are met, wellness is attained; the lack of funds reported by NGO/CBOs therefore gives an indication of unmet needs and constitutes an extra-personal stressors especially when the definition of health is considered i.e. the state of complete physical, social and mental wellbeing, not merely the absence of disease or infirmity (WHO: 1975).

The significant shift of legal/ethical problems of pre 1994 from being the leading challenges indicates a developmental occurrence because apart for this having been due to an increase in the knowledge about HIV/AIDS and its legal/ethical concomitants, the mere downward trend is a sign of improvement or development. An increase in the number of people who need care is also developmental, albeit negative development.

Lessons learnt are well linked to Betty Neuman's theory by her assertion that the client has (amongst other variables) developmental variables because learning is an indication of development. Learning took place between two or more people or between a person and his/her environment. In pre 1994 GDE period, the AIDS role players learnt about how to deal with both the primary stressor (HIV/AIDS) and the secondary stressor (challenges). The created environment referred to by Betty Neuman determined the extent to which the learners assimilated and practised what they had learnt, at the same time gave them ammunition for dealing with similar stressors if they occur in future.

5.8 OBJECTIVE NO. 5: THE EXTENT TO WHICH NGO/CBOs PARTICIPATED IN THE HIV/AIDS PROGRAMME

The 5th objective of the study is to determine the extent to which NGO/CBOs participated in the HIV/AIDS programme. To meet this objective the researcher made use of the data which had been collected through the administration of a questionnaire (Annexure 3.1) from 193 NGO/CBOs who attended the Department of Health's meeting in May and June 2003 respectively. A questionnaire had been administered to all the participants at the meeting. Fifteen of these NGO/CBOs had also been visited at their workplaces to cross-check the information that had been given with what was observable and verbally reported. Only one single answer was needed to meet the study objective, i.e. the year of the establishment of the organization. Only the period of entrance into the HIV/AIDS programme was of interest to the researcher if the organization had initially been established for other services, e.g. welfare.

Manual analysis of data using a tally technique was done. Years from 1986 (the period when the first AIDS case was diagnosed in KwaZulu-Natal) to 2003 (when the data for the study was collected) were listed. Each NGO/CBO profile was studied and a tally for each organization entered under the appropriate year as can be seen in Table 22 below. (The number of new NGO/CBOs participating).

Although the study is predominantly qualitative, it was necessary to show the growth in participation by use of a simple table and a barchart as can be seen in Table 22 and Figure 9 below.

Figure 9: Bar Chart showing the number of New NGO/CBOs / FBOs participating in the HIV/AIDS Programme from 1986 to 2003: KwaZulu-Natal

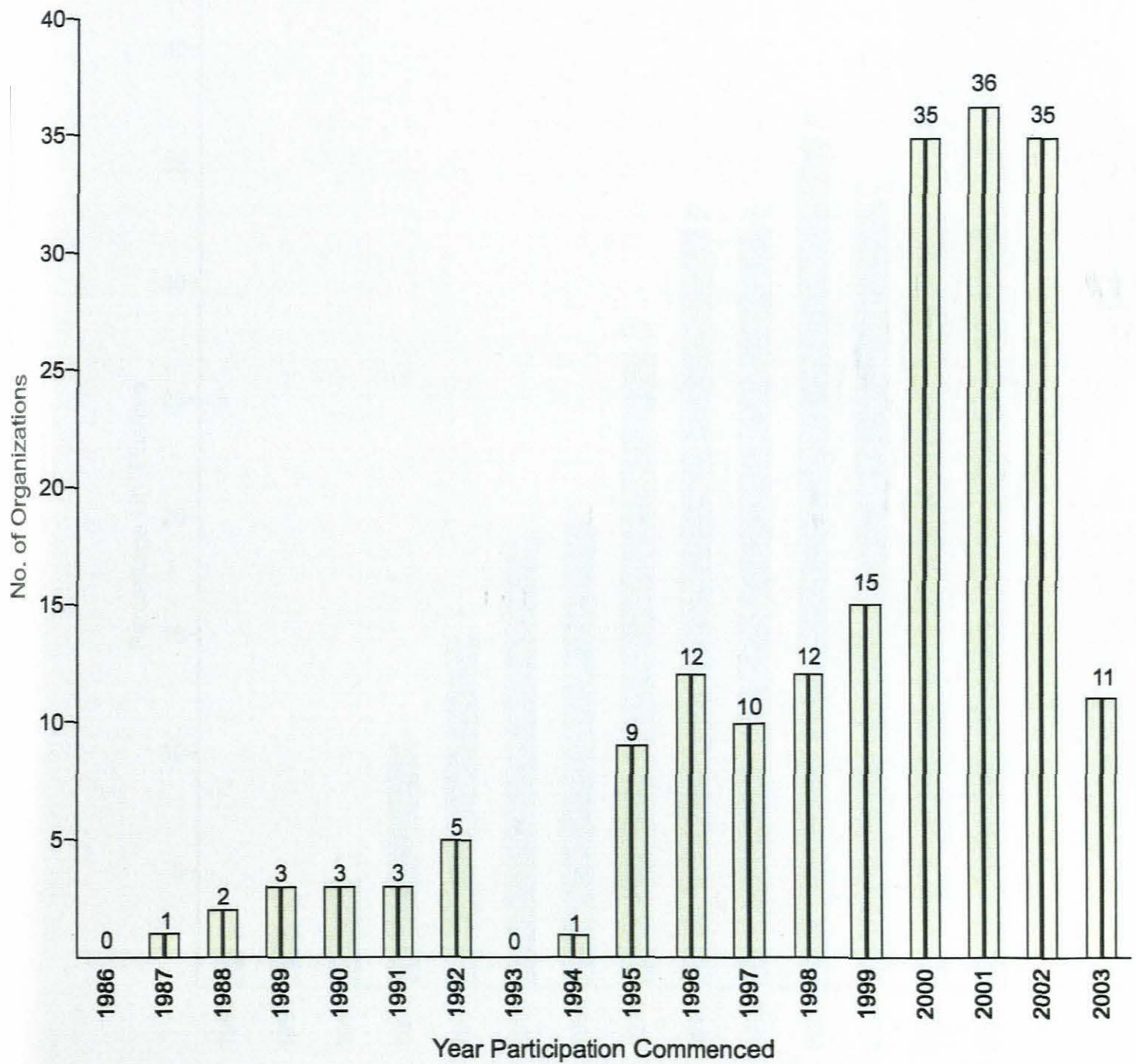
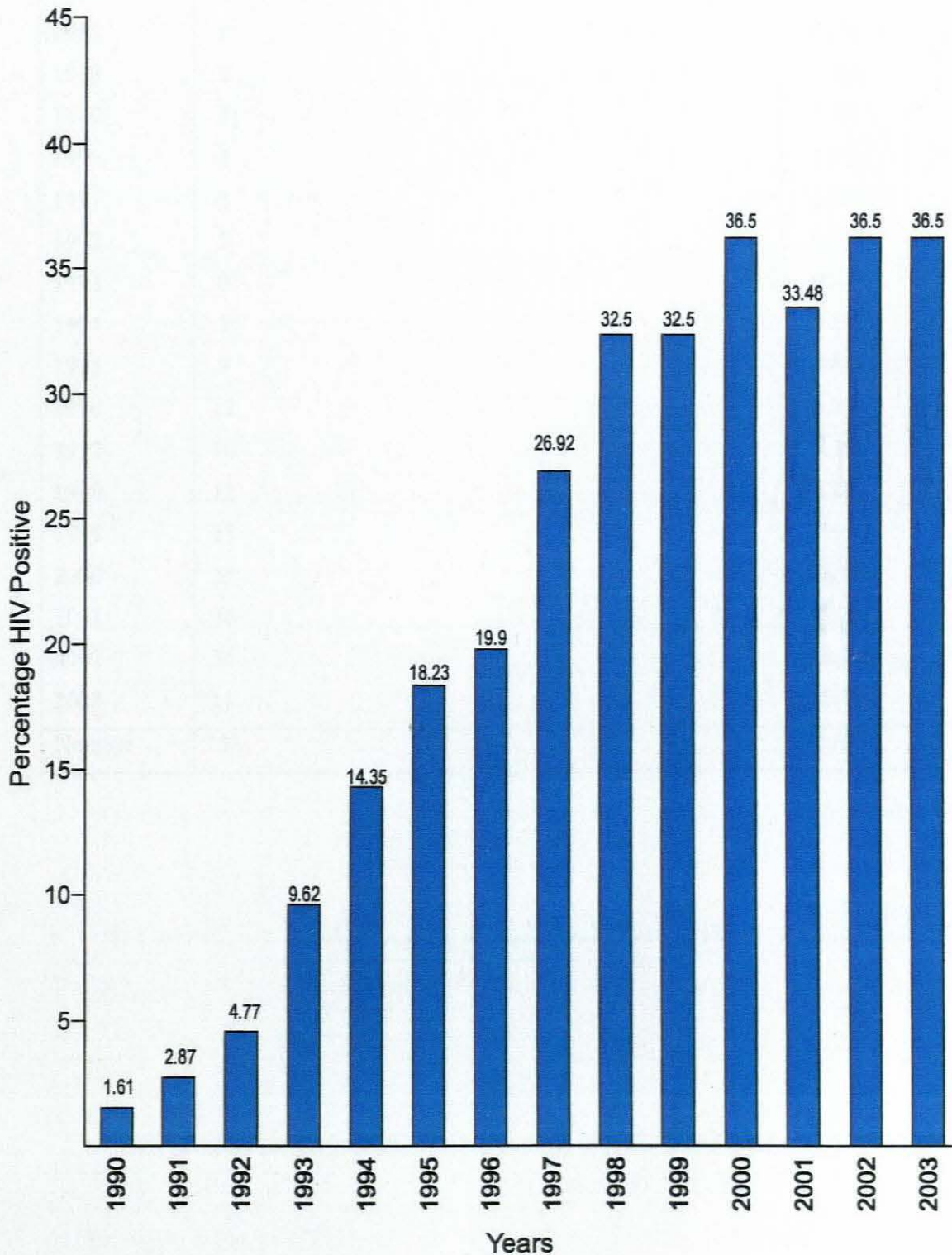


Figure 10: Bar Chart showing HIV Prevalence amongst Ante Natal Mothers from 1990 to 2003: KwaZulu Natal



Source of Data: Prof. Allan Smith, Virology Department,
University of KwaZulu Natal, Durban: 2004

Table 22: Number of new NGO/CBO Participating in the HIV/AIDS Programme in KwaZulu-Natal: 1986 to 2003

Year	Number of New NGO/CBOs participating	%
1986	0	0%
1987	1	0.5%
1988	2	1.0%
1989	3	1.5%
1990	3	1.5%
1991	3	1.5%
1992	5	2.5%
1993	0	0%
1994	1	0.5%
1995	9	4.8%
1996	12	6.2%
1997	10	5.2%
1998	12	6.2%
1999	15	7.9%
2000	35	18.1%
2001	36	18.7%
2002	35	18.1%
2003	11	5.8%
Number	193	100%

5.8.1 INTERPRETATION

- The peak participation period of new NGO/CBOs falls within the 2000 - 2002 period.
- Not all the HIV/AIDS Organizations attended the 2 meetings at which data were collected, however, Table 21 and Figure 9 do serve to depict the growth in their participation.
- The number of new organizations shown under 2003, i.e. 11 (eleven) is not significant since it was still early in the year when the data on NGO/CBOs were collected.
- The "0" (zero) and "1" (one) new organizations under 1993 and 1994 respectively could be attributed to the fact that this was a period of extreme violence in the province of KZN and it was also a period of transformation.
- The lack of new organizations in 1986 and very few of these in 1987 to 1992 could be due to:
 - the fact that it was still early in the AIDS pandemic and people also directed more attention to the political process and concomitant violence (which displaced a lot of families).
 - The growth in the HIV/AIDS and its magnitude from the late nineties to date could account for the growth in NGO/CBOs participation. Refer to Figure 10: Bar chart, showing HIV Prevalence amongst Ante-natal Mothers from 1990 to 2003: KwaZulu-Natal.
 - The availability of funds, e.g. the global fund and PEPFAR (President Bush's Emergency Plan for AIDS Relief) could also account for the growth in NGO/CBO participation.

- President Thabo Mbeki's call for "partnerships against AIDS could also serve as a factor that influenced the growth in the participation.
- Communities could be more knowledgeable than before on how to form an organization and manage a project.

The participation of new NGO/CBOs has been determined. It is however not known how sustainable this participation has been over years since this study objective focused on the new NGO/CBOs in each year.

The participation of the NGO/CBO serves as an indication of communities reacting to a stressor, in this case HIV/AIDS. Based on Newman's Health Care Systems Model for Nursing, these organizations are making use of their "lines of defence" and "lines of resistance" in order to stabilize their communities which have been severely invaded by a giant "stressor," HIV/AIDS.

5.8.2 COMMENT ON THE EXTENT OF NGO/CBO PARTICIPATION WITH REFERENCE TO BETTY NEUMAN'S MODEL

NGO/CBOs responded to the stressor HIV/AIDS by implementing preventive and promotive HIV/AIDS activities. If the NGO/CBO – client is looked at as a coherent structure, the NGO/CBOs can be regarded as flexible lines of defence for the client and therefore were protective to the individuals and community groups. The findings that participation grew, constitutes development as well as progression; this is in line with Betty Neuman's view of a developmental variable possessed by the client. The

mere fact that communities established organizations in order to address their needs reflects a developmental gesture.

5.9 CONCLUSION

Data analysis was carried out using the qualitative method and to a limited extent, a quantitative method was used based on the study objectives.

The analysis showed that the HIV/AIDS programme originated in 1985 when the Natal Blood Transfusion Services started screening the donated blood for HIV, despite a lack of a confirmatory test at that stage; the HIV/AIDS activities carried out by the role players were enshrined in "Prevention" and "Care & Support categories"; the components of the support system for the HIV/AIDS programme were human resources, human resource development, research, funds, committees / forums/ groups, the planning, policies, the backing by high profile individuals and partnerships. The major challenges faced by the service providers centred around logistics and the HIV/AIDS pandemic itself while the lessons learnt had to do with the magnitude of HIV/AIDS and the attitudes adopted. The peak participation of NGO/CBOs in the programme fell within the period 2000 - 2002.

Seen in relation to Betty Neuman's Health Care System's Model, people of KZN were invaded by the stressor HIV/AIDS. Some individuals and organizations, whose participation in the HIV/AIDS programme grew over the years, responded to the stressor by implementing preventive and promotive HIV/AIDS activities in the context of a sound support system. In the process, secondary stressors in the form of

challenges emerged and the lessons learnt helped strengthen the lines of defence and resistance; this in turn assisted the role players in a struggle to attain homeostasis.

The analysed and interpreted data, which are based on the five (5) study objectives, do mirror an environment of HIV/AIDS battle that has been created by the people of KwaZulu-Natal.

The next chapter (chapter 6) discusses the analysed data, highlights the findings, identifies limitations and makes recommendations based on the findings.

CHAPTER 6

SUMMARY, CONCLUSION AND RECOMMENDATIONS

6.1 INTRODUCTION

While the previous chapter dealt with data analysis and interpretation, this chapter will highlight the findings of the study, state its limitations and make recommendations. Prior to highlighting the findings, background is given on the sources of data.

6.2 LIMITATIONS

- In view of the use of historical methodology, the study primarily focused on written data, therefore the work of those who cannot record by writing could have been left out.
- Time and financial constraints made it impossible for the researcher to visit all HIV/AIDS service points and thus the use of purposive sampling it also led to most NGO/CBO data collected at convenient meetings.
- The main method of data collection was time consuming in that the researcher had to read through considerable amounts of documentation in order to extract the information that would meet the study objectives.
- The study placed importance on chronology; however, the human subjects could not always remember all the periods specific events occurred. To

address this shortcoming, the researcher had to rely more heavily on written information.

- The fragmentation of the services of the past made it difficult to find all relevant HIV/AIDS records.
- The Government archives (Durban and Pietermaritzburg) had not yet archived the AIDS files, so the researcher relied more on those archival records that had been kept by specific key informants, the libraries, the Department of Health and newspaper companies.
- Although the data obtained was abundant, the time constraint made it impossible for the researcher to use all of it.
- Not all the individuals who contributed towards the HIV/AIDS programme implementation could be mentioned in this study due to time and financial constraints.
- Not all support system components could be analysed, e.g. transport.
- Not all the HIV/AIDS NGO/CBOs attended the two meetings where data was collected, so some information could have been missed.
- The linear chronography could not be constructed in the analysis of all historical data due to data abundance and time constraint.

6.3 THE SOURCE OF DATA

Data on which the findings of the study were based, had been predominantly obtained from the written records; other data were obtained through the administration of a questionnaire and a checklist, and personal interviews used to a limited extent based on the selected contents of the instruments.

6.3.1 WRITTEN RECORDS

These were obtained from the Department of Health, the Provincial AIDS Action Unit, key informants, newspaper archives, Governmental records, libraries, visited organisations, websites, television and radio.

6.3.2 (a) Questionnaire

193 NGO/CBOs completed the questionnaire. Refer to Annexure 3.1 and chapter 4, 4.4.1

6.3.2 (b) Checklist

This was used on visits to 15 NGO/CBO managers and 5 key informants. Refer to Annexure 3.2 and chapter 4, 4.4.1

6.3.3 PERSONAL INTERVIEWS

15 NGO/CBO managers and 5 key informants were interviewed. Refer to Annexure 5 and 6.

The key informants were:-

- Mrs Nomathemba Haselau of Empangeni
- Dr S.S.S. Buthelezi of Provincial AIDS Action Unit, Pietermaritzburg
- Dr Allan Jaffe of Eshowe
- Dr Jimmy Muller of Pietermaritzburg

- Professor Allan Whiteside of the University of KwaZulu-Natal, Health Economics and AIDS Research Department.

6.4 DATA OBTAINED

The questionnaire and the checklist elicited information on the origin of the HIV/AIDS programme in KwaZulu-Natal, the HIV/AIDS interventions/ programmes and the organizations that implemented them, the support system for the programme, the challenges and the lessons learnt as well as the growth in NGO/CBO participation. This data was based on the objectives of the study.

6.5 THE FINDINGS

These were based on the study problem and the objectives of the study.

6.5.1 THE PROBLEM

The study problem was "there is no coherent document on the history of HIV/AIDS programme implementation in KwaZulu-Natal although many interventions have been made to combat the disease". This problem has been addressed by this study because its findings are historical and thus can be used by historians to compile the history of HIV/AIDS programme implementation in KwaZulu-Natal. The information is comprehensive, covering the programme dynamics from 1985 to 2003 viz. the origin of the HIV/AIDS programme, the interventions of the programme and the organizations that implemented them, the support system for the programme, the

challenges, the lessons learnt and the extent to which the participation of NGO/CBOs grew over the years.

6.5.2 THE OBJECTIVES OF THE STUDY

These were:

- To trace the origin of the HIV/AIDS programme in KwaZulu-Natal.
- To identify the HIV/AIDS activities and the organizations that implemented them.
- To identify what has been the support system for the HIV/AIDS programme.
- To highlight the challenges faced and the lessons learnt in the implementation of the HIV/AIDS programme.
- To determine the extent to which the participation of NGO/CBOs in the HIV/AIDS programme grew over years.

6.5.3 OBJECTIVE 1: THE ORIGIN OF THE HIV/AIDS PROGRAMME IN KWAZULU-NATAL

This objective has been met in the study through the finding that the programme commenced when the then Natal Blood Transfusion Service (NBTS) first screened the donated blood for HIV in 1985 and discovered that some blood samples contained the HIV. Despite the lack of confirmatory HIV blood test kits during that time, those who tested HIV positive on the initial test were given HIV/AIDS education by the NBTS staff; furthermore, the mere reporting of these early HIV infections by the media made the KZN public aware of HIV/AIDS, its dangers and how it could be

prevented; this marked the commencement of AIDS “prevention”. The discovery of AIDS cases in 1986 by the private and the public health institutions, which occurred soon after the confirmatory HIV blood test kits became available, introduced “care and support” aspects of the HIV/AIDS programme in the sense that the admitted cases were treated for opportunistic infections and received nursing care. Furthermore, the first AIDS Support Group was formed in 1986. This “care and support” ran parallel to “prevention” in the form of AIDS education.

The stressor HIV/AIDS triggered the first screening of blood for HIV by NBTS in 1985 and the subsequent commencement of preventive and promotive HIV/AIDS activities. The activity of the first screening of blood for HIV can be likened to the nursing diagnosis of the nursing process referred to by Betty Neuman.

Furthermore the first screening of blood for HIV by the Natal Blood Transfusion Service can be equated to the development of the HIV/AIDS programme (programme development), which progressed through the years. This finding cements the relevance of Betty Neuman’s theory to this study objective since she refers to the developmental variables of the client system.

6.5.4 OBJECTIVE 2: THE HIV/AIDS ACTIVITIES AND THE ORGANIZATIONS THAT IMPLEMENTED THEM

This objective has been met in the study. On review of written records, various interventions falling under the broad umbrellas of “Prevention” and “Care and

Support” were identified. Under “prevention” the identified activities were as follows:-

- HIV testing: found by this study as being the first AIDS intervention, gradually grew to be more humane, culminating in being referred to as Voluntary Counselling and Testing (VCT).
- Blood Safety: Control measures were instituted, e.g. screening of donated blood for HIV; having one authority responsible for blood transfusion services, education of blood donors and prospective blood donors on eligibility to donate, use of voluntary blood donors rather than hired donors etc.
- Prevention of Mother-to-Child Transmission (PMTCT): moved from conventional method to a new programme in 2001 which used an anti retroviral drug nevirapine.
- Management of Sexually Transmitted Infections (STIs) and use of Barrier Methods: STI Management which focused on the syndromic approach and realised mainly through staff training on how the approach could be applied. In 1995 a Tanzanian (Muanza) study found a 42% reduction in HIV prevalence using the syndromic approach.
- The dominant barrier method used was that of a male condom and the trial of a female condom or femidom was gradually extended to a large number of sites.

MRC (1997:26) in the National HIV/AIDS Review found that the syndromic approach was used in STD Management in KZN. Furthermore MRC (1997: 14) in the National HIV/AIDS Review found one institution keeping condoms

in the Matron's office and that commercial sex workers expressed a need for a female condom.

- Information, Education and Communication (IEC) included AIDS education, social mobilization through AIDS Campaigns, mass media communication and special projects which focused on IEC such as the "High Transmission Areas" project, the "faces" project, male targeted AIDS projects, the HIV/AIDS communicators' project, etc.

Under "Care and Support" the following interventions/ programmes were identified: Institutional Care, Home-Based Care with different models viz. the hospital-based, the NGO-based with use of volunteers (paid and unpaid), the hospice-based which is an outreach programme, e.g. that of the South Coast Hospice, and lastly the integrated Home-based care programme whereby the NGO/CBOs, the Department of Health (with CHWs or Onompilo), the Department of Welfare and the Department of Education work collaboratively under the programme referred to as the "Integrated Programme for Children Infected and Affected by HIV/AIDS" (KZN-DOH, 1999). The DOH tended to incorporate TB and Nutrition into HBC (KZN-DOH, 1999). Lucas *et al*, (1996) in their analysis of the HIV/AIDS Programmes in KwaZulu-Natal found only the hospital-based model of Home-Based Care, since it was still early in the epidemic. The other highlights of the findings in this aspect were as follows:

- Care of Orphans using the Extended Family model, fostering and adoption, an integrated approach to community care of children (involving welfare, police, hospitals, clinics and community). This finding was similar to that of Halkett(1999).

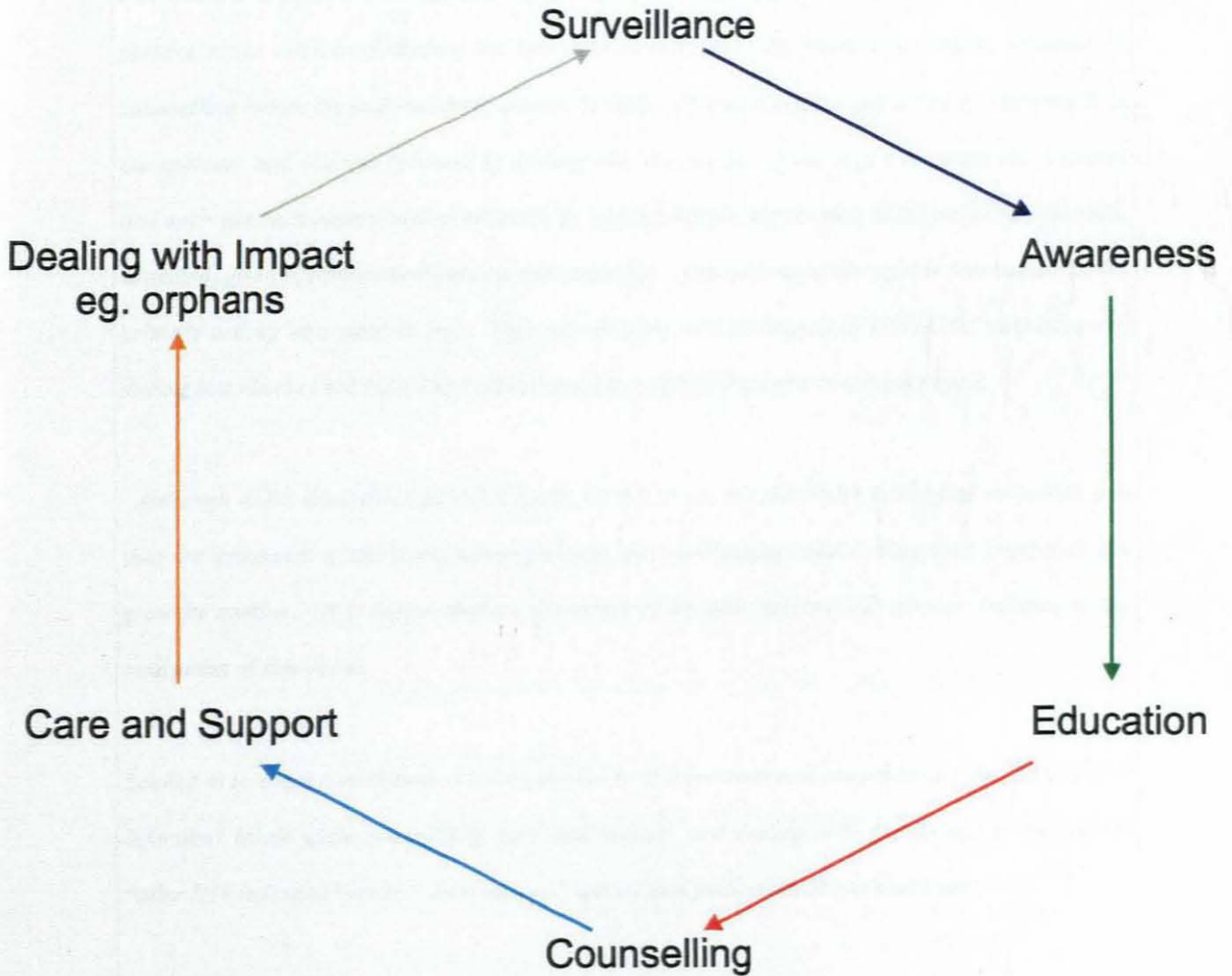
- The running of Drop-In-Centres whereby people dropped in for care counselling, support and/ or advice. These centres had increased over the years.
- The provision of anti-retroviral treatment (ART) for PLWHAs whose CD4 cell count is below 200 was announced in November 2003; it would commence in 2004 and would be administered according to the government's roll-out plan.
- Some Businesses like Anglo American, BMW, Daimler-Chrysler etc. had started providing ART to their employees.

MRC (1997: 14) in the National HIV/AIDS Review found that the management of people who were HIV positive and well, was generally not available at hospitals and clinics.

- There were special projects on care such as the Enhancing Care Initiative and an Integrated Programme of Children Infected and Affected by HIV/AIDS.
- According to the analysed data from the records "Prevention" (with all its aspects) appears to have been the first HIV/AIDS activity which dominated the pre-1994 GDE period while "Care and Support" activities have gradually grown during the post-1994 GDE period; these had overtaken "prevention" by 2003.

Refer to Figure 11 below.

Figure 11: Cycle of HIV/AIDS activities in KZN from 1985 based on the findings of the study



EXPLANATION OF THE CYCLE AND COMMENTS SUGGESTING A DESIRED DIRECTION OF MOVEMENT WITHIN THE CYCLE.

Based on the analysis of the AIDS activities of the past, the first activity was to check if there was HIV in the donated blood (HIV testing, represented by surveillance in the cycle). When there were reports that some blood specimens had HIV, the public became aware through the media and those that had tested positive were educated about AIDS although they were not informed of their HIV positive status until confirmatory test kits were introduced. AIDS education began, followed by counselling (when the staff had been trained in this). Care and support got driven by the growth in the epidemic and this was followed by dealing with the impact. These stages are mutually inclusive and each has been represented at all levels, in varying degrees e.g the first AIDS patient was nursed, educated, given symptomatic treatment and supported. The naming of the level is determined by the primary activity at a point in time. However, dealing with the impact of HIV/AIDS only occurred during late nineties but once it arrived and settled, it formed part of a continuous cycle.

Although AIDS education has cut through all the levels, it needs to be intensified in such a way that the occupants of the levels of counselling, care and support and dealing with impact do not grow in number. It is hoped that the discovery of an HIV vaccine will give an impetus to the realization of this vision.

Looked at through non-historical lenses, the levels of awareness and education are the "before HIV infection" levels while counselling, care and support and dealing with the impact levels are the "after HIV infection" levels. "Surveillance" started and permeated through all levels.

The immune boosters, antiretroviral treatment and good nutrition should be so effective that people at levels of "counselling", "care and support" and "dealing with impact", remain there as long as they could have done without HIV/AIDS. Surveillance should help monitor the process.

Should a cure be found, those at the levels of "counselling", "care and support" and "dealing with impact" should again go to the "before HIV infection levels," i.e. awareness and education, and never return.

- The analysis of the data collected from NGO/CBOs using a questionnaire indicates that the majority of NGO/CBOs were engaged in "Care and Support" followed by prevention, human resource development and research respectively. An effort of the KZN NGO/CBOs to strike a balance between Care and Prevention seems to be a step towards the right direction and could help KZN prevent the challenges of antiretroviral drugs faced by the first world countries to-day i.e. lack of reduction in AIDS deaths since 1998 due to treatment intolerance, drug resistance etc. (MAP Network, 2000). One possible reason for the above problem could be complacency brought about by the availability of antiretroviral treatment.

Drug resistance was reported being already a problem in the first world countries; researchers at the 2002 international AIDS Conference reported that 10% of 1,600 European patients newly diagnosed with HIV and who had never taken the antiretroviral drugs had strains of blood resistant HIV. This was seen as suggesting that some people had not complied well with their treatment (Sunday Times, 28/9/03).

- There is an indication of a slight impasse in the implementation of community based HIV/AIDS activities during 1994 and this could be attributed to political violence, the challenges of the transformation process which strived to mould the HIV/AIDS programme into one in KZN. The focus could have been solely on planning during this period as shown by the production of a NACOSA Strategic Plan document in 1994; furthermore, the records showing some of the work that had been done, could have been there but not accessed by the researcher.

- Furthermore, the data on the AIDS activities that were obtained from the records seem to reflect two AIDS epidemic campaigns that have been fought in KZN; each with its own combatants; the most combatants of the first war having disappeared with their weapons, leaving behind questions about their whereabouts and the reasons for their disappearance since no victory over HIV/AIDS had been announced. If these combatants did attain victory, their sharing of how they achieved this could help people on the ground and those who are still battling fiercely against HIV/AIDS to re-sharpen their AIDS weapons.
- The HIV/AIDS programme in KwaZulu-Natal was initially implemented by the health institutions in the public and private sector followed by NGO/CBOs and FBOs; at present the programme is implemented by almost all organizations and committed individuals regardless of social standing.
- The findings regarding the HIV/AIDS interventions (obtained through the written records and the administration of a questionnaire) were therefore compatible.

The activities carried out are relevant to Betty Neuman's Health Care Systems Model for nursing since they are accommodated under the most prominent concepts of the model viz. Prevention and promotion modes. Lifeskills education represents health promotion, IEC activities represented primary prevention, care e.g. treatment of opportunistic infections, ART etc. represented secondary prevention and support of PLWHAs, care of orphans, skilling or engaging in income generating projects etc.

The psychological, socio-cultural and the spiritual aspects referred to by Betty Neuman were catered for through counselling and support while the physical through the treatment of opportunistic infections and ART. It was expected that as an outcome of these interventions, individuals exposed would develop created environment that would be conducive to wellness. The interpersonal environment that Neuman refers to was created through AIDS education, support groups, counselling, etc. In turn this created an environment of a battle against AIDS. The organizations that implemented the programme represented the "Care Giver" or "client" referred to by Neuman and the AIDS interventions were the demonstration of their use of the flexible line of defence. These organizations also provided the socio-cultural, the spiritual, developmental and the physical needs and they represented the interpersonal and extra-personal environment referred to by Betty Neuman.

6.5.5 OBJECTIVE 3: THE SUPPORT SYSTEM FOR THE HIV/AIDS PROGRAMME

This objective has been met in the study and the finding was that human resources, human resources development, research, funds, plans, policies, committees / forums/ groups, councils, backing by high profile individuals and partnerships comprised the support system for the HIV/AIDS programme.

MRC (1997: 49) found that political commitment was weak; however, there was verbal commitment from one politician. MRC (1997: 36) in the National HIV/AIDS review further found that "there was an attempt to facilitate collaboration through the

formation of a Provincial AIDS Forum” and the Department of Health had established a post of Chief Liaison Officer to coordinate NGO/CBO activities.

The components of the HIV/AIDS support system showed growth in quantity and quality, e.g. funds, human resources, intersectoral structures like AIDS councils etc.

Schneider (1994: 5) found the KwaZulu Department of Health having “AIDS Action Teams” in all wards which returned the questionnaire; these were a component of the support system during this period.

Collaboration referred to by Betty Neuman was demonstrated in the establishment of inter-sectoral structures like AIDS councils, forums, etc, partnerships as well as client-care giver collaborative relationship Neuman refers to. The support system components formed part of the external environment Betty Neuman refers to.

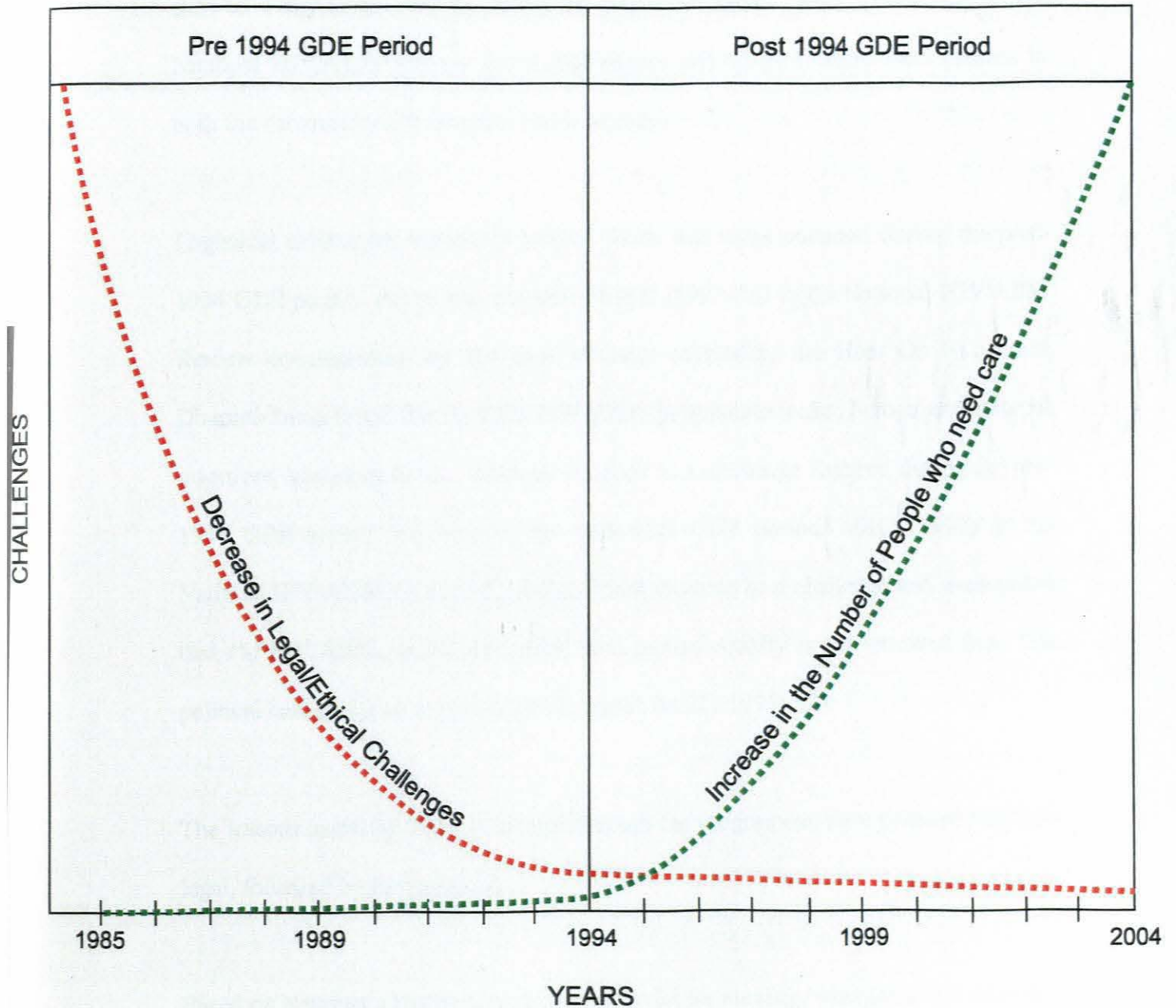
Human resource development which is a component of the support system is compatible with the developmental variable of the client and learning took place because people were open systems; KZN as a Province also demonstrated being an open system by accepting and exchanging knowledge with foreigners.

Research was been identified as part of the support system; evaluation of outcomes, which is part of the nursing process, was realized through research.

6.5.6 OBJECTIVE 4: THE CHALLENGES FACED AND THE LESSONS LEARNT IN THE IMPLEMENTATION OF THE HIV/AIDS PROGRAMME

This objective was met by the finding that there was a slight difference between the pre-1994 GDE and the post-GDE challenges. The challenges on the ethical and legal aspects of HIV/AIDS dominated the pre-1994 GDE period while logistics and increase in the number of people who need care dominated the post-1994 GDE period. Figure 12 below gives a clearer picture of the gradual decrease in the legal and ethical challenges and a gradual increase in the number of people who need care.

Figure 12: Diagram showing the trend of legal/ethical challenges of HIV/AIDS and that of the number of people who need care: KZN: Pre and Post 1994 GDE periods.



Pattern of diagram adapted from Burke, 2003:34
(Comparing Level of Influence vs Cost of Changes in Project Management).

In the study of the AIDS Education in KwaZulu, discrimination, misconceptions and myths were identified as the main problems encountered by the AIDS Educators (Mthembu, 1989). The ethical and legal challenges, e.g. stigma, discrimination, etc. showed a significant decline during the post-1994 GDE. MRC (1997: 21) in the National HIV/AIDS Review found that stigma and discrimination were present in both the community and amongst health workers.

Logistical challenges, especially lack of funds was more common during the post-1994 GDE period, and so was poverty. MRC (1997: 50) in the National HIV/AIDS Review commissioned by the then Minister of Health, the Hon. Dr Nkosazana Dlamini-Zuma found that the KZN HIV/AIDS programme lacked human and material resources, including funds. Political violence as a challenge featured during the pre-1994 GDE period and early in the post-1994 GDE period. MRC (1997) in the National HIV/AIDS Review did find political violence as a challenge and even stated that, "if HIV/AIDS, which will affect both groups equally is not removed from this political battlefield, no progress can be made" (MRC, 1997: 52).

The lessons learnt by those who implemented the programme were primarily ethical/legal, followed by the logistical.

Based on Neuman's Health Care Systems Model for nursing, what came out from this objective was that while HIV/AIDS was a "stressor" itself, additional stressors were experienced by the service providers in the form of the highlighted challenges. The lessons learnt are likened to Neuman's lines of "defence" and "resistance", which

subsequently capacitated the service providers to deal effectively with HIV/AIDS and concomitant challenges.

The shift from legal/ethical challenges of the pre-1994 GDE period to logistical challenges, increase in the number of people who need care followed by poverty (of post 1994) was developmental in nature and therefore compatible with Betty Neuman's developmental variables of the client system. The identified challenges were intra-personal e.g. feelings of rejection, feelings of guilt etc. and extra-personal e.g. an increase in the number of people who need care, political violence, poverty, etc. This is in line with the types of stressors Betty Neuman identified.

The lack of funds reported by NGO/CBOs imposes an extra-personal stressor and indicates that the need of a client were not met in this regard; Neuman maintains that when the needs of a client are unmet, wellness is reduced and when they are met, wellness is attained.

Learning is well linked to the developmental variables of the client system; learning is an indication of development. Learning takes place between two or more people, involves the imparting of cognitive culture and a clients interaction with the external environment; the socio-cultural variable of the client referred to by Neuman is well catered for in the finding that the the AIDS role players learnt about HIV/AIDS, particularly its legal/ethical aspects. From what the client had learnt, a created environment was acquired and this would help the client arm for future challenges.

6.5.7 OBJECTIVE 5: THE EXTENT TO WHICH PARTICIPATION OF THE NGO/CBOs IN THE HIV/AIDS PROGRAMME GREW OVER THE YEARS

This objective was met in the study. The peak period of the NGO/CBO participation in the HIV/AIDS programme was 2000 - 2002. This could be attributed to the magnitude of HIV/AIDS and the availability of project funds, e.g. global funding, PEPFAR funds, etc. Although not all NGO/CBOs in KZN completed the questionnaire, this finding is significant given the magnitude of the pandemic and the availability of funds.

If the graphic presentation of the client system by Betty Neuman were seen as a community structure, the flow of the NGO/CBOs into the HIV/AIDS programme and interventions thereof could be seen as the strengthening of the flexible lines of defence so that the individuals and groups could be protected.

The growth in NGO/CBO participation in the implementation of preventive and promotive HIV/AIDS programme is seen as a normal trend and compatible with Betty Neuman's view of a client having a developmental variable (amongst other variables). Furthermore, the mere forming of a community structure to meet the contemporary needs of the community and the preparedness to run HIV/AIDS projects reflects development and progression. The developmental element involved in the growth of NGO/CBO participation is therefore compatible with the view of Betty Neuman in her Health Care Systems model for nursing.

6.5.8 CREDIBILITY OF RESULTS

In view of having predominantly used primary historical data and evaluated such data through internal and external criticism, the findings of the study of “the genesis and progression of the HIV/AIDS programme in KwaZulu-Natal: implications for learning and intensified action” are valid despite the highlighted limitations.

6.6 RECOMMENDATIONS

The following recommendations are advanced based on the findings of the study, literature review and the magnitude of HIV/AIDS in KwaZulu-Natal at the time of this report.

It is recommended that:

- The HIV/AIDS trainers stress the need for family members to be around their loved one when he/she faces death so as to facilitate a “good death”; if this is impossible, Health Workers (HWs) fill this gap.
- The Provincial AIDS Action Unit (PAAU), NGO/CBOs and parastatals e.g. ATICCs, develop training packages that result in multi-skilling so that an individual can deal with HIV/AIDS from education up to care and support.
- The PAAU adopts an HIV/AIDS control approach whereby males are encouraged to take a lead in the fight against HIV/AIDS since it would appear that they remain dominant partners in sexual relationships.
- The Department of Health, PAAU and NGO/CBOs ensure that “prevention” remains a priority in the fight against HIV/AIDS and it is made a thread that permeates through all interventions.

- The PAAU liaises with all organizations that fund HIV/AIDS activities in KZN (e.g. AFSA) so as to avoid duplication and facilitate transparency in funding.
- The PAAU, NGO/CBOs and KZN Government adopt an integrated approach to HIV/AIDS implementation, which will encompass poverty reduction, food security and TB especially amongst the poor.
- The PAAU, NGOs and other role players incorporate human sexuality and gender into HIV/AIDS education and develop simplified ways of presenting such information to the illiterate.
- The PAAU identifies those who are still alive amongst the HIV/AIDS soldiers of the pre-1994 period with a view to creating a platform for them to share their experiences and lessons with the current role players.
- The PAAU facilitates the provision of more trained Care Givers to address an increase in the number of people who need care and concomitant staff shortage.
- The PAAU facilitates the identification and honouring of all those people who died after having gone public with their HIV positive status and had made a contribution towards HIV/AIDS advocacy and education in KwaZulu-Natal.
- The Department of Health considers the payment of stipends to all unemployed volunteers in HIV/AIDS programmes to enable them to pay for transport, soap, etc. and thus keep them motivated.
- The PAAU, NGO/CBOs and KZN AIDS Council facilitate a negotiation process that can bring about parity in the income of volunteers who are presently receiving stipends.

- The PAAU ensures regular communication with blood transfusion services with a view to getting an update on their statistics and practices pertaining to blood safety.
- The PAAU liaises with the Environmental Health office to ensure that the programme of "high transmission areas" includes barbers, ear-piercing and tattooing shops.
- All professional Health Workers (HWs) administering injections, intravenous therapy etc assure patients of safety from contracting HIV by showing each patient the sealed, sterile materials prior to using them on the patient.
- All HWs, the public, managers and workers of all sectors, families and individuals adopt a non-judgemental, non-discriminatory and more humane attitude towards a PLWHA or a person with an STI so as to help eliminate the HIV/AIDS stigma.
- In crisis situations or periods of change, the Government together with committed people plan in such a way that services pertaining to a life threatening health conditions like HIV/AIDS receive priority and smooth continuity effected.
- HIV/AIDS records be kept safely so as to help future generations to learn from the past.
- Each and every KZN citizen or group mobilize their residual energy and fight more fiercely against HIV/AIDS.
- The Government, committed organizations and individuals intensify socio-economic development initiatives with a view to addressing poverty as one of the challenges faced by the communities that are served by the HIV/AIDS role players.

Further Research

The content of this report has elicited a number of researchable questions. It is therefore recommended that research be undertaken on the following topics:

- The HIV prevention practices in relevant small businesses, e.g. barber, ear piercing, tattooing shops, etc.
- The potential and challenges of an HIV/AIDS volunteer and his/her motivation thereof.
- The potential of male HIV/AIDS educators in the community.
- The profile and potential of the pre-1994 GDE HIV/AIDS workers.
- The history of HIV/AIDS programmes in each KZN Health District.
- The study of discrimination practices in the public and private sector.
- The challenges faced by the health institutions regarding care of patients with HIV/AIDS.
- The analysis of HIV/AIDS activities in 1994.

6.7 CONCLUSION

The content of this study reflects the history of HIV/AIDS programme in KwaZulu-Natal and it is compatible with Betty Neuman's Health Care Systems model for nursing.

The HIV/AIDS programme in KwaZulu-Natal has its roots in 1985 when the then Natal Blood Transfusion Services started testing the donated blood for HIV. Many and varied programmes were subsequently developed under the broad categories of "prevention" and "care" and a multi-sectoral approach to their implementation adopted. As HIV prevalence grew over the years, so did the quality of the programme and its support system. Despite the programme having been sensitive and challenging, some lessons can be learnt from the practices of the past and the struggle against HIV/AIDS can be intensified in order to achieve a better health status for the nation.

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ANNEXURE 1

THE STUDY PROPOSAL

**THE GENESIS AND PROGRESSION OF THE
HIV/AIDS PROGRAMME IN KWAZULU-NATAL:
IMPLICATIONS FOR LEARNING AND INTENSIFIED ACTION**

A RESEARCH PROPOSAL FOR A DOCTORAL DEGREE (NURSING)

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2:LOGISTICS

3:DEFINITION OF TERMS

4. ABBREVIATIONS AND ACRONYMS

REFERENCES

1. INTRODUCTION

Two decades have gone by since the 1981 global discovery of HIV/AIDS epidemic (Clive, E; Patel, L; Ansory, M A; Hira, S K (1993:1). Ever since this discovery, HIV/AIDS has increasingly become a major health threat especially in Sub-Saharan Africa. At the end of 2000, there were 36.1 million people living with HIV/AIDS globally, 5.3 million new infections and 3 million deaths (Whiteside, A, 2001: 1).

Since the epidemic began, 21.8 million people have died of AIDS. Of conspicuous significance, Sub-Saharan-Africa continues to be at the forefront of the pandemic with 70% of total infections and 72% of new cases in 2000. Women are hit harder by the malady in these countries; for an example in 1999, 55% of the cases were adult females (Whiteside, A, 2001: 1).

In South Africa the results of the HIV prevalence amongst pregnant mothers attending Ante Natal Clinic in Government health care facilities was 24% in 2000; KwaZulu-Natal (KZN), which has consistently dominated the epidemic had a prevalence of 36.5% amongst pregnant mothers during this period. In 1998 it was estimated that in KZN alone, more than 50 people of prime age were buried per week; it would appear that this figure has more than doubled at present. It is reported that cemeteries in the Townships around Durban are at present full and that the public will be asked to consider other burial methods e.g. cremation, reuse of old graves etc. (Ukhozi FM, interview of Durban Metro Burial Authority representative: 14th August, 2001).

The impact of HIV/AIDS on families, communities and workplaces is no longer seen at a long distance as has been the case before but closely seen in a concrete form. It is estimated that 420000 children have lost their mothers or both parents due to AIDS in South Africa since the start of the epidemic (Whiteside, A, 2001: 1) and KZN alone is thought to be having more than 250000 of these orphans. Citing a very close example, an 83 years old mother of the researcher is staying with 2 children who were orphaned by the death of the researcher's nephew. Worse still, next door to the researcher's mother, three children are orphaned and

it would appear that the cause of the parent's death was AIDS. This process of death and emergence of orphans seems incessant at the present moment, making people live in fear of death and stigma attached to AIDS.

Programmes directly addressing the epidemic have been developed and implemented in differing gravity since the global identification of the virus in 1982. Although there is no cure for AIDS yet, the first world countries have achieved increased survival rates amongst HIV/AIDS patients through the use of antiretroviral drugs (Nokes, K M: 2001; personal observation: Whitman-Walker Clinic, Washington DC-USA: 1999).

In South Africa, including KZN Province, committed organizations have developed prevention and care programmes, with the latter entailing Home Based Care, Counselling and treatment of opportunistic infections.

One of the biggest problems however is that the severity of HIV/AIDS epidemic and the concomitant pressure exerted on the service providers gives little or no time to document all the interventions (including the analysis of the context in which these activities take place), so as to institute improvements.

In view of the availability of some information related to KZN HIV/AIDS programme in various articles written by different Authors, there is a need for compiling one coherent document that will reflect the history of the programme. It is therefore intended that the proposed research project, the details of which will follow, meet this need.

2. MOTIVATION

The researcher has observed that while KwaZulu-Natal has engaged in a lot of activities to combat HIV/AIDS, not all of these activities have been documented. Where these activities happen to be recorded, the context in which they take place

is seldom analysed. Furthermore there is lack of coherent historical information on the programme in the province.

Apart from HIV/AIDS being studied as one of the diseases by the students following health related courses, universities such as MEDUNSA and Stellenbosch now offers a course specifically focusing on HIV/AIDS, which (in MEDUNSA) was officially launched by the Deputy President of South Africa, Dr. Jacob Zuma early this academic year (2001). The findings of this research will therefore play a major role in enriching the historical aspects of HIV/AIDS theory and directing the future course of action.

The researcher has been the HIV/AIDS Programme Manager in KwaZulu-Natal under the Department of Health from 1996 to 2001 during which she developed additional passion for the programme as well as the empathy towards the infected and the affected, let alone the fact that during her term of office, she endlessly witnessed the severe loss of many young people, one of whom was her niece, through AIDS related conditions.

The researcher now aspires to extend her contributions towards the HIV/AIDS programme in South Africa through the analysis of HIV/AIDS interventions in KwaZulu-Natal, including the context in which the implementation has taken place and make relevant recommendations.

3. STATEMENT OF THE PROBLEM

There is no coherent document on the history of HIV/AIDS programme implementation in KwaZulu-Natal although many interventions have been made in an effort to combat the disease.

4. PURPOSE OF THE STUDY

To obtain historical information on how KZN responded to the HIV/AIDS epidemic and the circumstances under which implementation took place, with a view to highlighting successes as well as areas that require improvement.

5. RESEARCH OBJECTIVES

1. To trace the origin of the HIV/AIDS programme in KwaZulu-Natal.
2. To identify the HIV/AIDS activities and organizations that implemented them.
3. To identify what has been the support system for the HIV/AIDS programme.
4. To highlight the challenges faced and the lessons learnt in the implementation of the HIV/AIDS programme.
5. To determine the extent to which participation of NGO/CBOs grew over the years.

6. SIGNIFICANCE OF THE STUDY

- ❖ The study will add a historical dimension to the theory and practice of HIV/AIDS prevention and care, not only in KZN, but in the whole of South Africa.
- ❖ The exposure of the achievements and interventions of participants will motivate the potential role players to also join the struggle against HIV/AIDS and those already participating to intensify the struggle.
- ❖ It will lead to the identified challenges being addressed.
- ❖ It will give evidence that KZN did not fold arms at the face of the epidemic but responded proactively within the constraints of resources.
- ❖ It will clarify confusing issues around HIV/AIDS and eliminate ignorance that often breeds unnecessary controversy in the programme.
- ❖ It will form the basis on which future researchers and authors will build their HIV/AIDS work.

- ❖ The study will help all people concerned, including future generations to take stock and determine new directions in the implementation of the HIV/AIDS programme; this in turn will lead to the taking of new decisions, formulation of new policies and the making of new plans.

7. DELIMITATION OF THE FIELD OF STUDY

- This study will be confined to KZN; places outside the province like South Africa and other countries will only feature where relevant, like in the introduction, literature review etc.
- Only the organizations found on the records and at the NGO/CBO meetings will be mentioned.
- The study will not evaluate the HIV/AIDS programme but will discuss HIV/AIDS programme and its context, the service providers, the support system, challenges faced and lessons learnt.
- The study will not look into HIV/AIDS activities by each district but will highlight the activities that were occurring provincially.
- The study will not cover all the HIV/AIDS activities that were carried out in KZN and will not report on all the organizations that implemented the programme.
- The study will not include events/activities occurring after December, 2003 and will include those which occurred prior to 1994 General Democratic Elections (GDE)..

8. RESEARCH DESIGN

A qualitative research design with a focus on the historical method will be used in the study.

9. THE STUDY POPULATION

In view of the research project being historical, descriptive and focussed on the HIV/AIDS programme history and its context, all KZN HIV/AIDS programme managers in the public and private sector will constitute the study population; this will include the present and past managers.

10. SAMPLING METHOD

A purposive sampling method shall be used to select the subjects to which a questionnaire will be administered, the total size of which will be 200 subjects. Of the 200 subjects, 5 will be key informants. The services that will be visited for observation of activities and validation of the already collected data will also be selected through purposive sampling, making sure that at least 75% of the health districts are covered and the size will be 15.

11. INSTRUMENTS/TOOLS FOR DATA COLLECTION

- Questionnaire: This will be designed to obtain data on HIV/AIDS programme and its context from the study subjects (sample), including key informants i.e. people who will be well versed in HIV/AIDS matters.

- Checklist: This will be designed to obtain information at the 15 HIV/AIDS service sites that will be visited.

12. DATA COLLECTION

Data collection shall take the following form:

12.1 Passive data collection: Published and unpublished materials e g reports, policy speeches, newspapers (old and current), internet information, relevant SABC videos etc shall be consulted in search for the suitable data. It is anticipated that the bulk of the historical information shall be obtained through this exercise. This data shall be compared and merged with the one obtained through interviews and observation made at the visited sites. This aspect of data collection will include prospective monitoring of new events up to December 2003.

12.2 HIV/AIDS service visits using a checklist.

12.3 Interviewing of all subjects from the sample through administration of a questionnaire.

12.4 Interviewing of key informants using the questionnaire.

13. VALIDITY AND RELIABILITY

13.1. VALIDITY OF DATA

In view of the study using a historical method, data obtained will be checked for the internal and external evidence or criticism.

13.2. VALIDITY AND RELIABILITY OF INSTRUMENTS

Pre-testing of the instruments shall be administered to 5 individuals that will not be forming part of the sample, and where necessary, modified accordingly prior to their use in the main study.

14. DATA ANALYSIS AND INTERPRETATION

Based on the study questions, data will be chronologically arranged and categorised into pre-1994 general democratic elections (GDE) and post 1994 GDE periods.

Microsoft Word and Power Point programmes shall be used in the organization of qualitative data into tables, charts and graphs where necessary.

15. ETHICAL CONSIDERATIONS

In view of the study having to do with a highly sensitive subject (HIV/AIDS), compliance with research ethics cannot be overemphasized. Fundamental ethical principles underlying the security of humans in research shall be observed.

(Brink, 2000: 39 – 40) identifies three (3) ethical principles in research viz. the principle of respect for persons, the principle of beneficence and the principle of justice. To observe these principles, authority to collect HIV/AIDS service data from the service sites shall be sought from the Head of the KwaZulu-Natal Department of Health, the heads of NGO/CBO/FBO services as well as those of the Govt offices concerned. These authorities shall be assured that the research is not a fault-finding mission but a search for new knowledge which will benefit all concerned.

The willingness of prospective respondents to participate shall be ensured through obtaining informed consent while making them aware that the respondents will be free to cease participating at any level of the study. Participants shall be assured of privacy, anonymity and confidentiality. Highly sensitive issues shall be recorded in consultation with the individuals or groups concerned. Study subjects and authorities concerned shall be given a feedback on the results of the study and allowed access to research information at any time during and after the study.

16. LITERATE REVIEW

Published and unpublished local and foreign materials on HIV/AIDS and its management/programmes shall be consulted, documented and used as framework for this study. Immediately after the approval of this proposal, a special attention shall be paid on literature review and will be submitted as chapter 2 of the research project.

17. ORIENTATION AND UPDATE

Provincial HIV/AIDS/STD office shall be approached to provide slots in the scheduled meetings for orientation, updating and presentation of preliminary and final results. This will provide an opportunity to fully brief the prospective respondents on the content of the instruments, enlist their cooperation, make a follow-up on data provision and ensure that all the data needed are made available.

ANNEXURE 1

WORK PLAN

Task	Period
1. Literature Review	September 2001
2. Development of instruments	September 2002
3. Pre-testing and refining of instruments	November 2002
4. Selection of the sample	February 2003
5. Meeting with HIV/AIDS coordinator	March 2003
6. Data collection	April 2003
7. Analysis of data	June 2003
8. Interpretation of data and the writing of preliminary report.	July 2003
9. Presentation of the preliminary report.	September 2003
10. Report writing and submission	December 2003

ANNEXURE 2

LOGISTICS

Personnel:

Other than the researcher, there will be no staff specifically employed to collect data. The assistance of the HIV/AIDS coordinators in fast-tracking data provision shall be solicited.

The coordinators are responsible for facilitating the implementation of the HIV/AIDS programme and thus knowledgeable about the information required. The researcher has knowledge and skills for research and holds a Masters degree in Community Health.

Facilities:

Library facilities will be available in the University of Zululand, University of Kwazulu Natal and in the community. The computer will be available for recording and analysis of data.

Budget:

Stationary	= R 1000.00
Telephone	= R 1000.00
Fax	= R 600.00
Travelling and accommodation expenses (Orientation, updating and presentation of results)	= R 4 000.00
Typing, printing and binding of report	= R 2 000.00

Grand Total = R 8 600

ANNEXURE 3

DEFINITION OF TERMS (OPERATIONAL)

Genesis: Origin or beginning (Kirkpatric, 1994: 562)

Progression: Movement in successive stages (Kirkpatric, 1994: 1059)

HIV (Human Immuno-Deficiency Virus: The virus (germ) that causes AIDS.

AIDS (Acquired Immune Deficiency Syndrome): A name given to a group of serious illnesses that are caused by the body being unable to fight infection (Van Dyk, 1993: 5)

Epidemic: A sudden unusual increase in the cases of a disease, exceeding the number that is expected on the bases of experience (The World Bank, 1997: xxiii)

Pandemic: Simultaneous occurrence of the disease in many or all the countries (The World Bank, 1997: xxiv)

Prevalence of HIV: Number of people with HIV at a point in time often expressed as a percentage of a total population (The World Bank, 1997: xxv)

Challenges: A difficult task that stretches one's physical and mental ability (Kirkpatric, 1994: 215).

Concerns: The things that make a person uneasy or disturbed (Kirkpatric, 1994:269).

ANNEXURE 4

ACRONYMS

NGO: Non-Governmental Organisation

CBO: Community Based organisation

FBO: Faith Based Organization

GDE: General Democratic Elections

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ANNEXURE 2

2.1 LETTERS REQUESTING AUTHORITY TO
UNDERTAKE THE STUDY

2.2 LETTER OF RESPONSE FROM THE HEAD OF THE
DEPARTMENT OF HEALTH

76 Clarence Road
13 Crassula Court
Morningside
Durban
4001
15th January 2002.

The Secretary
Department of Health
Private Bag X9051
Pietermaritzburg
3200.

Attention: Mr. G J Tromp

Request for authority to undertake HIV/AIDS research in KZN

I am a registered PHD (Nursing) student at the University of Zululand, Durban-Umlazi Campus.

As fulfillment of my wish to continue making a contribution towards the fight against HIV/AIDS, I have planned to undertake research on an HIV/AIDS related topic.

The Ethics Committee of the above university has approved my research proposal, the topic of which is "The genesis and progression of the HIV/AIDS programme in Kwazulu Natal: Implications for learning and intensified action". Attached please find the copy of the proposal and a letter confirming registration with the university.

The study is aimed at developing a coherent and comprehensive HIV/AIDS programme history in the province. This will clearly mirror the contributions of the Governmental and Non-Governmental structures in this great battle, enabling the role players to summon renewed courage for appropriately dealing with the inherent challenges.


Based on the above background, authority is hereby sought to:

- Interview selected HIV/AIDS role players at provincial and district levels.
- Pay visits to sampled HIV/AIDS service points to observe activities and collect information.
- Gain access to relevant records/documents e.g. reports, policy speeches etc.
- Be given communication slots at the identified HIV/AIDS gatherings with a view to giving a brief on the study as well as feedback when due.

There are no financial implications on the part of the Department and data will be treated with ethical sensitivity.

Your authorization and support of this venture will be appreciated.

Yours sincerely,

 16/01/2002

Wanda M N Mthembu (Mrs)

76 Clarence Road
13 Crassula Court
Morningside
Durban
4001
1st February 2003.

The Director
Provincial AIDS Action Unit
Private Bag 9051
Pietermaritzburg
3200

Attention: Dr. S S S Buthelezi

Request for data collection: HIV/AIDS Programme

Dear Sir,

I am pursuing my PHD (Nursing) through the University of Zululand, Durban-Umlazi Campus. To fulfill a requirement for this degree, I have to undertake research. The topic I have chosen for my research work is titled "The genesis and progression of the HIV/AIDS programme in Kwazulu Natal: Implication for learning and intensified action".

The study is aimed at developing a coherent and comprehensive history of the HIV/AIDS programme in Kwazulu Natal, based on the set objectives.

Permission is hereby sought to collect data on HIV/AIDS programme from HIV/AIDS role players at a provincial and district levels from April to June 2003. Attached please find the copy of a letter from the Superintendent General authorizing the undertaking.

The exercise will entail the collection of HIV/AIDS data from the sampled past and present HIV/AIDS managers (including those of NGO/CBOs) and key informants, collection of relevant records and making observation at service sites. Individual appointments shall be made with the selected subjects.

It will be appreciated if you could also provide a 15 minutes' communication slot in your scheduled Coordinators' meetings between March and April 2003 so that I can explain the project and specify data needed.

Data shall be handled with appropriate ethical sensitivity.

Your support and direction in this regard will be deeply appreciated.

Yours sincerely,


Wanda M N Mthembu (Mrs.)

Telephone: 031-3031765 Cellular telephone: 0721930709

03/02/2003

PROVINCE OF
KWAZULU-NATAL
HEALTH SERVICES

ISIFUNDAZWE
SEKWAZULU-NATALI
EZEMPILO

PROVINSIE
KWAZULU-NATAL
DEPARTEMENT VAN GESONDHEID

NATALIA
330 LONGMARKET STREET
PIETERMARITZBURG

TEL. 033-3952111
FAX 033-3426744

Private Bag :X9051
Esikhwama Seposi : Pietermaritzburg
Privaatsak : 3200

Enquiries: Mr G.J. Tromp
Extension: 2761
Reference: 9/2/3/R Vol.6

22 MAY 2002

Mrs W.M.N. Mthembu
13 Crassula Court
76 Clarence Road
Morningside
DURBAN
4001

Dear Mrs Mthembu

REQUEST FOR AUTHORITY TO UNDERTAKE HIV/AIDS RESEARCH IN KZN

Your letters dated 16 January 2002 and 11 February 2002 refer.

Please be advised that authority has been granted for you to undertake HIV/AIDS research in KwaZulu-Natal provided that:-

- (a) Prior approval is obtained from the Heads of the relevant Institutions;
- (b) Confidentiality is maintained;
- (c) The Department is acknowledged; and
- (d) The Department receives a copy of the report on completion.


SECRETARY: DEPARTMENT OF HEALTH
KWAZULU-NATAL

AJK/mthembu

ANNEXURE 3: Instruments

3.1 QUESTIONNAIRE

3.2 CHECKLIST

THE GENESIS AND THE PROGRESSION OF THE HIV/AIDS PROGRAMME IN KZN: IMPLICATIONS FOR LEARNING AND INTENSIFIED ACTION

ANNEXURE 3.1: QUESTIONNAIRE TO OBTAIN INFORMATION ON THE ORGANIZATIONS PARTICIPATING IN THE HIV/AIDS PROGRAMME

NB: Confidentiality shall be observed, however, the name of the organization and its activities may appear in the report: Consent requested

1. Position of the informant in the organization.....

2. Name of the organization.....

3. Type of organization (NGO, CBO or FBO).....

4. Year HIV/AIDS activities were commenced.....

5. Name/s of the area/s of operation.....

.....

6. List of HIV/AIDS activities carried out by the organization.....

.....

7. Challenges that have been faced by the organization.....

.....

Thank you for providing the information about your organization.

The “Genesis and progression of the HIV/AIDS programme in Kwazulu–Natal: Implications for Learning and Intensified Action”

ANNEXURE 3.2: A checklist to obtain information on the history of the HIV/AIDS programme from a service point.

NB: The provided information shall be handled with confidentiality.

1st Section

A. Background information

- 1. Date of visit: _____
- 2. (a) year of involvement in HIV/AIDS Programme: _____
 (b) Position held by the respondent: _____
- 3. Contact number: _____
- 4. Name of institution/organization: _____
- 5. Type of organization e.g. NGO, Govt. etc: _____
- 6. Year established (if NGO/CBO/Govt AIDS Unit): _____
- 7. Catchment area: _____

B. Activities/ Interventions

	<u>Yes</u>	<u>No</u>	<u>Comments</u>
1. AIDS Education (IEC)			
2. Life-skills Education			
3. Counselling			
4. Voluntary Counselling and Testing (VCT)			
5. Institutional Care			
6. Home Based Care			
7. Support and Care of Orphans			
8. Prevention of MTCT			
9. Antiretroviral Treatment			
10. Training (HRD)			
11. Other (specify)			
C. Support System			
1. Plan			
2. Policy			
3. Committees/Councils/Forums			
4. Political backing			
5. Funding			
6. Staffing			
7. Research Projects			
8. Transport			
9. Books			
10. Other (specify)			

SECTION 2

G. Names of Data Sources Provided

Item	Theme	Qty	Pre '94	Post '94
1. AIDS Directories				
2. Official Documents with NGO/CBO List and activities they are engaged in				
3. Reports on HIV/AIDS Programme				
4. Policy and other HIV/AIDS speeches				
5. HIV/AIDS plan				
6. HIV/AIDS policy documents				
7. HIV/AIDS circulars				
8. Memoranda on HIV/AIDS				
9. Minutes of Meeting on HIV/AIDS				
10. Journals with HIV/AIDS Articles				
11. Magazines with HIV/AIDS Articles				
12. Newspaper Articles on HIV/AIDS				
13. HIV/AIDS video cassette				
14. HIV/AIDS cassette for radio/recorder				
15. HIV/AIDS CDs				
16. Artefact e.g. Relevant photo				
17. Books and Booklets				
18. Research papers				
19. Pamphlets				
20. Posters				
	Total			

Grand Total items:-

NB: Indicate if item must be returned: Yes or No

Collected by: _____

ANNEXURE 4

LIST OF VISITED ORGANIZATIONS

ANNEXURE 4

THE LIST OF ORGANIZATIONS THAT WERE VISITED:

1. National Association of People Living with HIV/AIDS (NAPWA), Durban.
2. University of KwaZulu-Natal, Durban.
3. AIDS Training, Information and Counselling Centre (ATICC), Pietermaritzburg.
4. AIDS Training, Information and Counselling Centre (ATICC), Durban.
5. Empangeni AIDS Centre, Empangeni.
6. Diakonia Council of Churches (DCC), Durban.
7. AIDS Foundation of South Africa (AFSA), Durban.
8. Educate and Develop, Umhlabuyalingana.
9. Nobuhle Project, Pietermaritzburg.
10. Lethimpilo Youth Organization, Mondlo.
11. CDC Clinic, Edendale Hospital, Pietermaritzburg.
12. Isiphephelo, Ubombo.
13. Dramaide, University of Zululand, Empangeni.
14. Siyaphila, Pietermaritzburg.
15. Unyezi, Hlabisa.

ANNEXURE 5

LIST OF ORGANIZATIONS THAT COMPLETED THE QUESTIONNAIRE

ANNEXURE 5

a) SOME ORGANIZATIONS ENGAGED IN IEC

Maphumulo Youth in Action, Ibutho Projects, Sinothosonke CBO, Chatsworth Child and Welfare, Bumbanani DC 28 Network, Khanyalaph'ukhona, Zuzimpilo, Ntabamhlophe, Lethimpilo Youth Organization (LYO), Umndeni AIDS Centre, Ziphakamise, Mabaphile, Qhubeka, Amakhuze Community Initiative, Lower Umfolozi Development Organization, Mandeni D.I.C, Nkandla AIDS Network, Masikhulisane, Emangweni Youth Initiative, Masingobe Youth Development, Zamimpilo-Loskop, Sizanani, Hillcrest AIDS Centre, Senzokuhle CBO Network, NPPHC, Diakonia Council of Churches, Regional AIDS Programme, Nkonjeni Trust, KZN Youth Council, NAPWA, Vusimpilo, Unyezi, Isiphephelo, Dramaide, Izimbali zeSizwe, Ntilingwe Community Development, Gods Golden Acre, Masixoxeni Health Project, Sizanani-Nkandla, Siyanqoba, Sakhisizwe, Zenzeleni Peace Message, Human People to People, Todoxin, Sekwenele Bakwethu, Indonsa CDO, KwaMashu OUCO., Sekusile-KwaMashu, Singenzenjani TB/AIDS, Themba lethu, Zethembe, Multi RFRD, Ikusasa Lesizwe Com. Org., Shape, Siyakha, CHOES Life Org, Sekwenele Y.O., Ekuphumuleni Centre, WAIRC, Tip-Top Training and Development, SAHECO, Sibambene, Umbumbulu RUD, Igugu, SACTWU, MPDC, Madadeni Trad. H. Assoc., Rotary AIDS Committee, SAYC, Phumalanga, Siyathuthuka-Ekombe, Amaoti SHG, KwaDukuza Municipality, Sinani PSV, Qhubeka, TCE, Impumelelo, CHAMP.

b) **SOME ORGANIZATIONS ENGAGED IN CARE AND SUPPORT**

Maphumulo Youth Organization, Lethuk'khanya, AGAPE, Nobuhle Project, Impendle Drop-In Centre, St Clerments HBC, Ibutho Projects, Thandanani HB Carers, Chatsworth Child and Family Welfare, Sinozwelo Drop-In Centre, Khanyalaph'ukhona, Hlanganani, Celimpilo Club, Masisizane, Zuzimpilo, Masiqhubeke MaKristu, Masenzenjani, Siyathuthuka, Ntabamhlophe HBC, Lethimpilo, Umndeni AIDS Centre, Ziphakamise, Khanyiselani Development Trust, Bhambayi Settlement Project, Sundumbili Support Group, Mandeni Drop-In Centre, Nkandla AIDS Network, Sekusile Youth Org., Masikhulisane, Masingqobe Youth Development, Sizanani, Thandukuphila, Hillcrest AIDS Centre, Senzokuhle CBO, Light, Diakonia Council of Churches, NAPWA, AFSA, Sinikithemba, Catholic Dioc. of Durban, Vulamehlo, Makaphuthu, Transwerk, Hlanganani-Emangweni, Todoxin, Sekwenele Bakwethu, Advocate and Associate, Themba, Bambayi Orphans, Uthingo Lwenkosazana, Ukuvikela Izingane, Amajuba Care Project, KwaMashu Operation U.C., Sekusile-KwaMashu, Sekusile-Madadeni, Sweet Waters D.I.C., Life Line- Durban, Loskop TB/AIDS Supporters, NAWA (National Association of Women Empowerment), Themba lethu, Zethembe, South African Red Cross, Ikhaya Lobomi, Zane-Themba HBC, Masiphile, SHAPE, Siyasizana, Friends for Life, St Johns-Siyakhula, Albert Luthuli FM, S'nothando, CHOES Life Org., Cathulani Y.O., Masiphile, Zamuk'phila D & T, Green Network, Ekuphumuleni Centre, WAIRC, SAHECO, Izandla Zothando TAC, Zweliphilile, Sibambene, Umbumbulu RUD, Igugu, SACTWU, Ziphatheleni HBC, MPDC, CINDI, Rotary AIDS Comm., Lamontville AIDS Centre, Siyathuthuka-Ekombe, Amaoti SHG, Woza Moya, Lethiwe-

Nomcebo, Sakhisizwe, TCE, Impumelelo, Sobantu DIC, Siyaphila, Sizanani HBC, Muthande, Sesiyenza, Mothers of Compassion, Lindelani HBC, Isibanisezwe, Impendulo Yesizwe, Ubusha Buyigugu Mazenod DP, Amadlelo.

c) **SOME ORGANIZATIONS ENGAGED IN HUMAN RESOURCE DEVELOPMENT**

Pietermaritzburg ATIC, Empangeni AIDS Centre (previously Empangeni ATIC), Durban ATIC, ECAP, Eagle Training and Development, Ibutho Projects, Sinothosonke CBO, Chatsworth Child and Family Welfare, Bumbanani DC 28 Network, Masiziloleni, Philisani, Lethimpilo, Umndeni AIDS Centre, Ziphakamise, Lower Umfolozi Development Organization, Hillcrest AIDS Centre, Senzokuhle CBO Network, IMA Hour of Light, NPPHC, Diakonia Council of Churches, AFSA, Msunduzi Hospice, NAWA (National Association for Women Empowerment), Treatment Action Campaign, Tugela AIDS Programme, Masiphile, SHAPE, Tip-Top Training and Development, CEED, SAHECO, Qhubeka, Yazini, Sobantu DIC.