

***A STUDY OF COMMUNITY GENETICS AT  
UMLAZI TOWNSHIP OF KWAZULU-NATAL***

***BY***

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**A STUDY OF COMMUNITY GENETICS AT  
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**NTOKOZO VERA MCANYANA**

## **DEDICATION**

This work is dedicated to all community health nurses in KwaZulu-Natal, who make the struggle worth it and to my sons, Lungelo, Sdingo, the late Wandile and daughter Amahle.

(ii)

## DECLARATION

I, NTOKOZO VERA MCANYANA hereby declare that this dissertation on **“The Study of Genetic at Umlazi Township of Region “F” in KwaZulu-Natal”** is my own work in conception and operation.

All the sources that have been used or quoted have been acknowledged by means of complete references.

NTOKOZO VERA MCANYANA

**NTOKOZO VERA MCANYANA**

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- Aunt Beauty Cele for love, and support in many ways.
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## **ABSTRACT**

The main aim of the study was to investigate the incidence of genetic disorder at Umlazi Township, and the ability of the present structure of health care services to provide necessary genetic service to this community.

The study revealed that the health care practitioners who come in contact with clients or patients with genetic disorders encounter problems in rendering care to them. This, they attributed to the fact that they themselves are not trained in genetics, have no facility or means of communicating genetic information to the community.

The majority recommended that special training in genetics be provided for all health care personnel, essential genetic services be incorporated in the practice into the present comprehensive health care service and that genetics be focused on primary prevention of genetic disorders.

## OPSOMMING

Die hoofdoel van die studie was om die voorkoms van genetiese afwykings in die Umlazi woongebied te ondersoek, as ook die vermoë van die huidige gesondheidsorgdienste om die nodige genetiese ondersteuningsdiens aan die gemeenskap te lewer.

Die studie het aan die lig gebring dat gesondheidsorgpraktisyns waaat in aanraking kom met kliënte of pasiënte met genetiese afwykings probleme ondervind om die nodige ondersteuning aan hulle te verleen. Hulle het dit toegeskryf aan die feit dat hulle nie self die genetika opgelei is nie, en dat hulle nie die fasiliteite of vermoë het om genetiese informasie aan die gemeenskap oor te dra nie.

Die meeste van hulle het aanbeveel dat genetiese opleiding aan alle gesondheidsorgpersoneel verskaf word, dat noodsaaklike genetiese diense as deel van omvattende gesondheidsorg aangebied word en dat die genetika primêr konsentreer op die voorkoming van genetiese wanordes.

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# CHAPTER 1

## ORIENTATION TO THE STUDY

Chapter one discusses the orientation to the research study, important concepts used in the study and the outline of the final report.

### 1. INTRODUCTION

Genetic disorders have serious physical, psychological and economic implications for the affected, the family, the community and the state. Except for the price of care which is estimated to be approximately R2000 000 000 per person per annum", Searle (1993:389), genetic disorders are usually of serious nature and cannot be treated.

Many world wide surveys results do illustrate the extent of such disorders. Firstly, the report of the "Year of Disabled Persons of South Africa" as quoted by Searle (1993:388) reflects that, of the total 12,7% of disabled persons in South Africa, 40% have a genetic disability.

The second report is that of Scriber (1991) cited in Nzimande, (1996:218), which states that of the total population, 5% will have a genetic disorder by the age of twenty five years. It further points out that 90% will have the age of onset by puberty, the life expectancy of such will be reduced by 60% and 70% will have their reproduction functioning greatly reduced.

The above reports together with the increase in the recognition of diseases entirely caused by defective genes, " . . . . . from four hundred and twelve disorders in 1958 to . . . three thousands, eight hundred and seventy six in 1986", (Kibel 1996:43), led to a world wide recognition of genetic services as a powerful new discipline necessary to effectively combat ill health and human suffering, as discussed by

Nzimande (1996:218).

This study on community genetics at Umlazi Township will explore the following:

- the incidence of genetic disorders at Umlazi Township,
- the level of knowledge about genetics of parents whose offspring have such disorders (as perceived by the health personnel),
- the availability of resources at a community level aimed at combatic genetic disorders on a primary prevention stage.
- the problems that the health personnel encounter in rendering such and
- lastly the recommendations on how to provide an effective genetic service.

## **2. BACKGROUND OF THE STUDY**

In 1975, in South Africa a genetic services component was established within the Department of National Health, and Population Development, (Nzimande 1996:218). This was in 1975. The main objective of these services is the prevention and treatment of inherited disorders.

The department have since gone through a number of changes, and so have the services. The current focus of health care dispensation is an Progressive Primary Health Care with emphasis on health promotion and primary prevention of diseases. This calls for an establishment of a genetic service at a community level, addressing genetic disorders at a primary preventive level. Basically because in genetics, like in any other field, prevention is better than cure.

The ability of the existing genetic services have to address the problem of genetic disorders of primary prevention level is doubtful, hence the need for the investigation.

### 3. MOTIVATION FOR THE STUDY

The researcher was motivated for the present study by a number of factors, which will be discussed below.

During recent clinical practice the recurring births of children with genetic disorders to parents with gene aberrations, that should have been prevented, are repeated.

Women with family history of genetic disorder, or present with such history themselves, repeatedly fall pregnant and show no sign of understanding the genetic nature of the disease that affect her offspring.

Lastly, the screening serum alpha feto protein (AFP) which is routinely done in antenatal clinics in other countries, for diagnosis of genetic disorders is not routinely in antenatal clinics in the areas where the researcher have practised.

The above factors pointed at the need of questioning whether the present genetic service is able to effectively address the genetic disorders at a primary prevention level.

Diagnosis during pregnancy is not at an ideal time. Also addressing people who do not appreciate the potential problem is unrewarding, as pointed out by Harper (1988:127). The above observation suggest the ideal point of intervention to be before the onset of the problem, that is at a primary prevention level.

As means of addressing the above the following questions should be asked:

- is genetic counselling done?
- importantly still, are the nurses at community primary level equipped to provide genetic counselling effectively?
- what problems face the health care personnel in provision of the services? and
- lastly are there any improvements that can be implemented to accommodate the genetic service into the present comprehensive health care structure.

Seemingly an extensive change is necessary. As Harper (1988:128) observes the time is long overdue to move genetic counselling away from people who are trained in medical genetic only and who are medically trained, but should be disseminated to communities in need, health workers and all concerned.

Presently, in South Africa, a comprehensive genetic services is offered by the Department of National Health and incorporates the education and training services, diagnostic services and genetic nursing services, Nzimande, (1996:229)

Unfortunately for the communities in need, and for the health personnel at primary level, "these services are situated at academic departments of medical schools and teaching hospitals", ( Kibel 1996:54).

There is a need for genetic services at the community level, and for increasing community awareness about the realities of genetic risks.

The researcher being practically involved in maternal and child health care services have observed a number of cases with genetic aberrations. Therefore, there has been an indication to establish the reasons for the problems observed.



#### **4. STATEMENT OF THE PROBLEM**

There is a need to determine the strengths and weaknesses of genetic service at a primary prevention level. This is emphasized more by the following factors:

- repeated births by women at risk
- tendency of looking at genetic disorders as the symptoms with which they present, thus failing to note the genetic nature of such
- lastly, the even more questionable ability of the health care personnel to handle such amount and type of work.

This study is concerned with investigating the Umlazi community regarding the extent of genetic disorders, the availability of services to combat these disorders, the ability of health personnel to handle such and handle such and lastly looking at possible means for improvement of such services. The available statistical reports reveal that more than 40% of birth defects are genetically determined.

Presently the genetic services are situated at regional levels of the Department of Health and Population Development, and this may be associated with the possible lack of such services at community level.

Another factor is that some genetic disorders have not even been diagnosed as such, therefore do not fall within the presented statistics.

#### **5. AIMS OF THE STUDY**

The study aims at examining the extent of genetic problems at Umlazi Township, the ability of the present services to address the problem and the feasible means of commissioning appropriate community genetic services.

## **6. OBJECTIVES OF THE STUDY**

The objectives of the study are:

- to determine the extent of genetic disorders at Umlazi Township.
- determine the ability of the present community service and health personnel to handle such problems.
- to identify feasible means of mobilising communities to take active action in community genetics.

## **7. RESEARCH QUESTIONS**

The present study will attempt to answer the following questions:

- what is the present statistics of the genetic disorders at Umlazi Township?
- are there resources available for people with these disorders at community level?
- what can be done to improve such services?

## **8. DELIMITATION OF THE STUDY**

The study will be conducted at Umlazi Township. This falls in Region "F" of the Department of Health in KwaZulu-Natal. It will involve all twenty one sections including informal settlements within the boundaries.

## **9. DEFINITION OF CONCEPTS**

### **9.1 Genes**

Genes, are defined by McCance (1990:16), as the basic units of inheritance. They are divided into two types, namely the structural and regulatory genes.

The former dictates the make up of proteins whereas the latter initiate and terminate the physiology of man.

## **9.2 Gene mutation**

This is an inherited alteration of genetic material.

## **9.3 Gene Locus**

The site or position of a particular gene on a chromosome, Hartl (1988:450).

## **9.4 Genotype**

This is the composition of genes as a given locus.

## **9.5 Incidence**

“Incidence” is defined by McMahon (1970:60) as a number of cases which come into being during a specified period of time.

## **9.6 Phenotype**

This is the outwards appearance at an individual. It is determined to a certain extent by the genotype and to some by the environment, (McCance 1990:18).

## **9.7 Primary Health Care**

This is essential health care made accessible at a cost the country and community can afford, with methods that are practical, scientifically sound and socially acceptable. Every one in the community should have access to it, and everyone should be involved in it (Vlok, 1996:29).

### **9.8 Health for all by the year 2000**

This is the global strategy used for monitoring progress towards health for all by a definite date, and applies especially to the third world countries. It was defined in 1978, at the Alma Ata Conference by the World Health Organisation, (WHO) (Vlok, 1996:26).

### **9.9 Community genetics**

A field of genetics focusing and having its emphasis on primary prevention of genetic disorders through family studies, case findings, health education, counselling and community involvement.

## **10. LITERATURE REVIEW**

The review of literature will be done and aimed at identifying the extent of genetic disorders at Umlazi Township, and the extent of availability of community based programmes for primary prevention of genetic disorders.

Focus will be on health care constraints, reviewing of health, educational, and other support service availability, resource distribution and other relevant areas in health case dispensation at community level at Umlazi Township.

The researcher will consult books, periodicals, journals and conduct necessary interviews with community members regarding the subject of genetics and, or community genetics.

## **11. THEORETICAL FRAMEWORK**

The LAPPNECT Model of Health Education of Nzimande, forms the basis for this research study.

## **12. RESEARCH METHODOLOGY**

### **12.1 Research design**

A descriptive survey will be used, by administering structured questionnaires to the respondents, seeking information regarding prevalence, distribution and knowledge about community genetics and resources available.

### **12.2 Sampling techniques**

In his discussion of research designs, Seaman (1983:214), points out that one of the critical factors that should be observed when using a survey is that of random selection. This technique will be used in this study, to select a representative sample of the target population and to allow a considerable degree of representativeness.

### **12.3 Research tool**

The researcher will use structured questionnaires. This is because of a wide geographical area to be covered a large number of respondents to be incorporated and the importance of maintaining anonymity. One set of questionnaire will be used on all respondents.

### **12.4 Pilot study**

Seaman, (1983:215-6) observes that "the accuracy of the survey is a result of a careful pretesting the tool a pilot study will be conducted, where questionnaires will be administered to one fifth of the total population. Then the tool will be reviewed as per indications.

The subjects participating in the pilot study will not form part of the main study subjects.

### **13 ETHICAL IMPLICATIONS**

Written application letters will be written to nurse administrators of the participating hospitals and clinics. Informed consent will be obtained from all respondents in which the following will be highlighted:

- confidentiality and anonymity of all the participants;
- freedom of choice as far as participation is concerned; and
- that there will be no compensation, material or otherwise, that will be gained from participating in the study.

Finally, the basic aims of the study will be made known to all participants.

### **14. DATA REPRESENTATION AND DATA ANALYSES**

After the analysis of the research answers, data will be presented in tables and graphs.

### **15. SUMMARY AND CONCLUSION**

The main findings of the study will be on the following:

- incidence of genetic disorders in the given area
- availability of services for primary prevention of the disorders
- knowledge that the health personnel have about genetics and conclusion will be drawn to answer research questions as previously presented.
- recommendations on feasible means that can be employed to improve such services.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **1. INTRODUCTION**

This chapter consists of review of literature gathered from relevant national and international books, journals and publications.

Literature reviewed on genetics, community genetics specifically reveal that there have always been a call especially from the World Health Organisation for incorporation of genetic services to present structures of comprehensive health care services in all countries.

The researcher consulted available documented information on community genetics especially from the publications of the World Health Organisation and those of the Department of National Health. This chapter is organised under subtopics.

Firstly, the researcher reviewed historical developments of community genetics, then looked at the effects of genetic disorders on health and health services. Further on, the indications for incorporating community genetics into comprehensive health care system were looked into together with the problems in establishment of community genetics services. Lastly genetics within the African cultural context was discussed.

#### **2. HISTORICAL DEVELOPMENT OF COMMUNITY GENETICS**

With the continuing problem of malnutrition and communicable diseases, genetic services have not yet received attention in the developing world, as Kibel (1996:54), observes that "genetic services are fairly recent arrivals in the medical scene". Though it has been observed that many patients with genetic disorders have been

cared for as nearly as the beginning of the Nineteenth century, Kibel (1996:54), further observes that "it was not till 1941 that the first genetic clinic was founded in the he university of Michigan in USA . . . and in 1946 a genetic service was opened at the hospital for the sick, Great Ormond Street, London". For South Africa, it was "only in 1975 that the first genetic service was established", Searle (1996:349).

The developments in South Africa were "initially guided by the developments in Europe and United States, scientific and laboratory technology and individual/academic research interests, Hitzeroth, (1995:2). Nzimande (1996:218) also observes that "the realization of the overall nature and extent of genetic diseases guided the development of genetics in South Africa". The drastic increase in the knowledge about genetic disorder may also have aided in the developments.

Kibel (1996:43), observes that "in 1958 there were only four hundred and twelve disorders that were recognised as being entirely caused by defective genes. In 1971 the number increased to one thousand, eight hundred and seventy six and by 1986, it had increased to three thousand, nine hundred and seven".

Though South Africa has a comprehensive, active national genetic service employing primary, secondary and tertiary preventive measures," Vlok (1996:107) state that it has been observed that these services could "handle, at the most about 1% of those requiring a genetic service",

Searle (1996:348). Also these services, as, Kibel (1996:54) further observes" are situated at academic departments of medical schools, teaching hospitals, and department of health genetics service. Access to these is through referral by obstetricians and other specialists".



Research by the World Health Organization (WHO) has led to "birth of the concept of community genetics which is relevant to many aspects at Primary Health Care", (Hitzeroth 1995:15). This concept puts emphasis on application of genetic knowledge at the community level and on initiation of programmes that are suitable for incorporation into existing community health services, aimed at primary prevention of genetic disorders, Hitzeroth (1995:16).

An ideal community genetic service should "be relevant to primary health care and public service, be incorporated to primary health care, family planning and other relevant services, and should form an integral part of primary health care system", (Hitzeroth, 1995:16).

### **3. EFFECTS OF GENETIC DISORDER ON HEALTH AND HEALTH SERVICE**

In his opening address, Kibel (1996:1) points out that "with the decrease in infectious diseases and nutritional disorders, genetic disorders are assuming increased importance and now make a major contribution to the total bureau of community diseases."

This is further supported by Vlok (1998:107) where she says that "genetic disorders not only place a heavy economic burden on the health resources of the nation, but also exact a heavy toll in terms of the quality of life of some 3 - 5% of the population".

The local and overseas literature reviewed discussed the effects of genetic disorders on individual's health, on family functioning an on state's economy.

### **3.1 Effects on individuals health**

"In South Africa form seven hundred thousand to one million people suffer from a handicap due to a genetic disorder and though not common as individual disorders as a group they comprise over 5% of paediatric hospital admissions", Vlok (1996:107). The subtopic looks at these effects under physical psychological aspects and socio-economic aspects.

It has been observed that genetic disorder have life long effects, are often incurable and are mostly incapacitating. Common disabilities like blindness, mental retardation , and depression are 50% genetic predisposed. Genetic factors" play a significant role in development of cardiovascular diseases, hypertension an cerebrovascular diseases in males, Clark (1996:772).

"It is a well established factor that there is a genetic predisposition for the development of allergic disorders,, Lewis (1987:173) and Clark (1996:464) also highlights that "conditions like asthma, hay fever allergies involve genetic predisposition."

The results of a study, published by Lewis (1997:184) points out at the genetic influence on the following conditions:

- premenopausal breast cancer was three times higher and premenopausal breast cancer five times higher in females with family history of the condition.
- lung cancer was increased with the smoker with the history of lung cancer in the family than a smoker who did not.
- leukemia was increased I identical twins.
- neuroblastoma was increased among siblings.

Also "cancer of breast and uterus are repeatedly identified using a genogram", Clark (1996). Lewis (1996:1254), further highlights that "genetic inheritance is known to play part in development of Type I diabetes".

"Family studies have clearly shown that genetic predisposition is the most important single factor in the development of alcoholism, . . . it has been identified in 35 - 45% cases Lewis (1987:1774). Clark (1996:114-115), further explains that "genetically determined pathways for alcohol metabolism leading to rapid rise and delayed clearance of blood acetaldehyde levels explain the differences in physiological response to alcohol."

"Genetic factors also determine mood swings, tendencies towards violence and suicide, other forms of substance abuse and other psychiatric disorders, e.g. schizophrenia", Clark (1996:785).

All the above conditions are incapacitating, life threatening, chronic and greatly affect the physical well being of individuals.

The psychosocial effects include isolation, peer rejection, feelings of guilt withdrawal and mental retardation.

Socio-economic effects include, poverty, unemployment, social outcast and lack of resources

### **3.2 Effects on the family**

This can be better seen in the report of Human Sciences Research Council, illustrated by Searle (1996:352). It points out that " $\pm$  30% of parents with a child with a genetic disorder either changed their work or became domicile".

Feelings of guilt, blame, and family disorganization as a result of lack of knowledge about the genetic nature of the child's disorders, often results in financial burden as

family seek medical services to aid the child, special school services to meet the child learning needs and other numerous special needs of a child with a genetic disorder.

### **3.3 Effects on the state**

"The estimated costs of care of a genetically disabled person, including education and training amounts to  $\pm$  R2000 000 000 per annum", Searle (1993:389).

The World Health Organization have made it possible to understand the cost burden of the state. This, WHO achieved by analysis of what is called "hidden" costs of caring for a person with a genetic disorder, and these include, for example:

- **DOWNS SYNDROME:**  
Costs for paediatric heart surgery, treatment infections, institutional care and special education and training facilities.
- **CYSTIC FIBROSIS:**  
Costs for paediatric infections and physiotherapy.
- **DUCHENNES MUSCULAR DYSTROPHY**  
Costs for neurology and orthopaedics and for support services.
- **THALASSEMIA:**  
Costs for paediatric services and haematology.
- **NEURAL TUBE DEFECTS:**  
Costs for paediatrics and orthopaedics surgery and support services.
- **HUNTINGTON'S DISEASE**  
Costs for psychiatric services and institutional care (Hitzeroth, 1995:45).

As it can be seen, "community genetic services are relatively inexpensive and highly cost effective, in view of the great social and financial burden of chronic disease avoided", Hitzeroth (1995:33).

Hitzeroth, 1995 further observes that the tendency of classifying diseases in terms of their curative requirements pose a great constraints in determining clearly how much the state really spends on management of genetic disorders.

#### **4. INDICATIONS FOR THE INCORPORATION OF COMMUNITY GENETICS IN A COMPREHENSIVE HEALTH CARE SYSTEM**

The extent and the effect of genetic disorders on human health is best illustrated by Scriber's report of 1991, as cited by Nzimande (1996:218), that 5% of population will have a genetic disease by twenty five years of age, 90% will have age of onset by puberty, about 60%, in about 70% of cases reproductive function will be significantly reduced, all patients and affected families will experience social problems and 30% of cases will have central nervous system involvement to an extent that full social adaptation will be impossible.

Vlok (1996:107), further points out that although genetic disorders "do not often exist as individual disorders, as a group they comprise over 5% of paediatric hospital admissions, they are for life, and affect not only the individual, but also his family, the local community and the wider national community.

Another factor that gives an indication for inclusion of community genetics in primary health care is pointed out by Kibel (1996:43) where he observes that "scientists suggest that nearly every person carries about three to four mutant genes which when present in double dose will cause a defect in the offspring.

The ever increasing identification of the diseases entirely caused by defective genes, "from four hundred and seventy in 1986" Kibel (1996:43) also indicates that steps should be taken to combat the problem at primary level.

"The usually prolonged period of child bearing up to relatively advanced maternal age means that higher proportion of babies are born to older aged women increasing the risk of having babies with genetic disorders "Nzimande (1996:219). Larger families increase the risk of recurrence where a "100% risk of recurrence is implicated; Searle (1996:352). Lack of knowledge and resources increase the risk of recurrence. Consanguineous marriages also increase the risk of all children with genetic disorders" Nzimande (1996:219).

Searle (1996:351) observes that in the developed countries nearly 20% of beds in paediatric wards are taken by children with a genetic disorder", and in South Africa about forty thousand babies with genetic disorders are born every year".

The success, other countries enjoy of the results of a primary prevention campaign of neural tube defects make it obvious that the idea works. The study summary was published by the Nursing Times (1997:16-25).

The study revealed that between 1993 and 1996 the total percentage of women who took folic acid supplements increased from 1.8% to 30.6%. Two thirds revealed that they got the advice from their family doctor and out of six hundred and seventy nine that were pregnant for the first time, none got delivered a child with neural tube defect.

Another area at success may be seen in the report by Hitzeroth (1995:41), where the incidence of neural tube defects in Scotland fell by almost 60% after introduction of AFP screening and another almost 30% due to a change in dietary habits.

As previously observed "community genetic services are relatively inexpensive and cost effective I view of the great social and financial burden of chronic diseases avoided" Hitzeroth, (1995:33).

## **5. PRESENT PROBLEMS IN ESTABLISHING COMMUNITY GENETIC SERVICES**

There are a number of problems that were identified.

Firstly is the use of Tandem approach in provision of health care facilities. In this approach" various health services are fragmented and prioritised. Hitzeroth (1995:18). This unfortunately puts genetic services at the end of the line.

The other problem is that genetic services are still somehow viewed as a luxury service for countries who still have problems with communicable diseases and malnutrition disorders. Kibel (1996:14) observes that "in developing countries where infant mortality rate still exceeds a one hundred in a one thousand live births, available scarce resources still need to be channelled to sustaining of immunization programmes, community maternity services, prevention of birth asphyxia and improving nutritional state and combating iodine deficiency".

This can be observed in South Africa where "a genetic service was established in 1975", Searle (1995:349), but in 1996 the Department of Health was still "running a surveillance programme on primary prevention through health education", (Kibel, 1996:56).

## **6. GENETIC IN THE AFRICAN CULTURAL CONTEXT**

Literature addressing the African cultural context of genetics could not be identified, both locally and overseas. Other resources were then used i.e. an interview with Mrs

Lebentlele an ex-lady teacher at Maseru High School Mrs Takane a Chief Professional Nurse at Prince Mshiyeni Memorial Hospital and Miss Ntshona an ex-teacher at Lovedale College. The Zulu culture forbid boys from sharing same sleeping squatters with girls and their huts were situated at different ends of the kraal. When they grew, it was culturally not accepted for people of the same family or clan to marry or to produce children, for fear of producing an "abnormal" offspring. This was further evidence in the old Zulu saying "induku enhle igawulwa ezizweni", which meant an ideal marriage partner is the one from afar. People used not to travel very far those days, therefore one's close relations were those from his or her area of birth.

If by mistake close relations happened to be involved to bear children a calabash with milk was destroyed, and a goat slaughtered to ask for forgiveness from the ancestors. This shows that they had an idea of genetic disorders, but not of how to effectively combat them.

The Xhosa culture uses the same procedure except that when relations become involve they will slaughter a white goat to "cleanse-off the relationship".

The Sotho culture allows marriage to cousins and observes no fear of abnormalities from the offspring.

## **7. CONCLUSION**

Looking at the cost-benefit analysis as discussed previously it is obvious that the "restraint of reproduction by the at risk couples and selective abortion of affected fetuses, saves money even in the short term", Hitzeroth (1995:42).

Though presently the costs may seen fairly high, "but the cost of saving both in currency and human suffering is almost immeasurable", Hitzeroth (1995:47).



Therefore the present responsibility is to intend to the developing communises genetic services and integrating them into the present health system, educating the relevant health workers, ensuring quality control and monitoring the services to promote high quality and continuig progress”, Hitzeroth, (1995:33)

The above presentation provides *crucial points* to be observed during the research investigation. It *forms basis* for the study conducted.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **1. INTRODUCTION**

Research methodology is defined by Polit (1991:648-649) as “the steps and the strategies for gathering and analysing data in a research investigation”.

In this chapter the researcher describes how data was collected to meet the objectives set out in chapter one.

#### **2. RESEARCH METHOD**

A quantitative research method was used to determine how the present structure of community health care service afforded the Umlazi community a sound genetic service.

This methods was chosen because the researcher wanted to use “quantitative statistical techniques to summarise and interpret data “Seaman (1991:174) and this method allows such.

#### **3. RESEARCH DESIGN**

A survey was used in the study. This was because, as Polit (1991:155) puts it, “a survey is designed to obtain information from population regarding prevalence, distribution and interrelations of variables within the population”.

Another reason for choosing a survey as a design for this study were the advantages of using a survey, which are better illustrated by Seaman (1987:215)) that “ . . .data

is collected at a more natural setting, . . . large amounts of data can be gathered at a fairly reach many people and ensure respondents anonymity”.

A questionnaire was chosen as a research technique, for its advantages as described previously in this chapter. This technique will be described further later in the same chapter.

#### **4. SCOPE AND DELIMITATION OF THE STUDY**

Delimitation of research study are defined by Treece and Treece (1986:362) as used in Nzimakwe (1996:53) as “those restrictions that the researcher puts on the study prior to gathering data”, and “establish parameters” Seaman (1987:134). The study was conducted in Umlazi Township. This lies in Region “F” of the eight regions of the Department of Health of KwaZulu-Natal.

The study covered all twenty one sections including the informal settlements within the boundaries.

The research was limited to health personnel.

#### **5. TARGET POPULATION**

The target population consisted of the following people:

**Table 1**

	<b>CLINICS</b>	<b>PERINATAL</b>	<b>OTHER SERVICES</b>
Doctors	-	2	-
Nurses	15	5	-
Social workers	-	-	3

Table 1 shows the Target population for research.

## **6. SAMPLE AND SAMPLING**

Seaman, (1987:233) defines sampling as a process by which the study subjects or objects are chosen from a larger population . . . which will later determine whether the findings from a sample can be generalized to the population”.

Systematic sampling method was used. The subject names were obtained from allocation lists where they practised. These were arranged in the alphabetical order according to their area of specialization.

Then every fifth name from the sampling frame was selected for the study. The total number of twenty five subjects were chosen to participate in the study.

This number formed about 20% of the total population. The researcher felt that this allows a fair representation of the total population, as Polit (1991:265), observes that “thought there are no simple formulas that indicate how large a sample is needed in the given study . . . the larger the sample, the more representative of the population it is likely to be”.

## **7. ETHICAL CONSIDERATION**

The following ethical aspects were considered during the study:

### **7.1 Permission to conduct the study**

The permission to conduct the research study was obtained from the Deputy Director of Nursing Services at Prince Mshiyeni Memorial Hospital, under which the satellite clinics fall.

## **7.2 Informed consent**

Informed consent implies, as Seaman, (1987:23) states, "that promises will be kept, the self respect for the subjects will be protected, and ethical guidelines will be carefully followed".

The covering page of the questionnaire addressed the respondents on all of the above.

## **7.3 Anonymity and confidentiality**

The covering address of the questionnaires stressed to the respondents not to include their names, addresses, signature or any form of identification that may breach their anonymity.

# **8. RESEARCH INSTRUMENT**

A questionnaire was used to collect data. This is defined by Seaman (1987:435) as a technique of collecting data by means of written questions that subjects answer in writing, with little if any help from the researcher".

# **9. DESIGNING THE QUESTIONNAIRE**

## **9.1 The covering letter**

The covering letter addressed the respondents on the title of the study, the uses of the study and the role of the respondents in it, ending with the reassurance that confidentiality will be highly maintained.

The full names of the researchers are given in the covering letter.

## **9.2 Instructions to the respondents**

The instructions were clear and straight to the point. The respondents were further instructed not to furnish their names or addresses. As Seaman (1987:276-7) emphasises, instructions were given throughout the questionnaire.

## **9.3 The questions**

Though the fixed alternative, close ended questions are accurate and easy to analyse, they have their disadvantages, observes Seaman (1987:277). Therefore the researcher have used these type of questions in 3/4 of the questionnaire "section C" was provided for those answers that did not fall within the "yes" or "no" categories.

A checklist adapted from Seaman (1987:279) was used to check for the following characteristics (clarity, simplicity, applicability).

## **TYPES OF QUESTIONS**

### **SECTION A**

#### **Item 1**

This identifies the area of employment of the respondent. This was aimed at identifying the respondents from primary health care sectors from those in secondary health care areas.

#### **Item 2**

This item looked at the nature of employment. This is because of the ability of different categories of the health care personnel to assess the health care sector or provision according to their categories, differently.

**Item 3**

This item looked at the number of years the respondent has spent in the same category as on the day of the study. This aimed at identifying the response and views of the respondents who have been in the field longer and have been in the service for more time and at those with lesser time especially those who have less than five years period of practice.

**SECTION B****Item 4**

Aimed at identifying if the respondents were ever involved in the care of clients with genetic disorders.

**Item 5**

Aimed at identifying if the respondents had any problems in their rendering of care to the above clients.

**Item 6**

This item looked at the possible cause of the problem stated in item 5.

**Item 7**

This item looked at the respondents rating of the level of knowledge the parents of children with genetic disorders displayed about the genetic nature of their children disorders.

**Item 8**

This item looked at the usual time the respondents first encountered the clients for genetic counselling.

**Item 9**

This item looked at the screening tests that were employed at the areas where the respondents are employed and practising.

**Item 10**

Investigated the indication for the above stated screening tests if they were done.

**Item 11**

This enquired if the respondents were trained in genetics or had any colleague (in the same institution) who has training in genetics.

**Item 12**

Investigated if, there were any teaching aids or any equipment the respondents could use to communicate genetic information to the communities, (where the respondents practised).

**Item 13**

Investigated if the respondent saw any need for incorporation of a genetic service where they practised.

**Item 14**

Looked at how urgent the respondents viewed the matter.

**SECTION C****Item 15**

Allowed the respondents to state how they felt they could provide an effective genetic service for the community.



## 10. TESTING TOOL FOR VALIDITY

Polit and Hungler (1991:374) describes tool validity as “the degree to which an instrument measures what is supposed to be measuring”. This is further confirmed by Seaman (1987:318) that validity is judgement of the extent to which a component of research reflects theory and concept . . . and a valid instrument measures what it suppose to measure.

In view of the above the researcher tested the tool for validity in the following two methods:

Firstly, the tool was submitted to research and professional experts for criticism, recommendations, and improvements.

Secondly, a mini study whose sample had the same quality as that of the major study was conducted where the questionnaire (that had been improved after the research experts had seen it) was administered. This was done to improve the research process.

## 11. RETURN RATE OF THE QUESTIONNAIRE

Out of twenty five questionnaires that were sent out nineteen were returned which gave the researcher 76% of a return rate percentage.

	SENT OUT		RETURNED		%
	COMMUNITY SERVICES	HOSPITAL	COMMUNITY SERVICES	HOSPITAL	
DOCTORS	2	3	1	1	
NURSES	10	6	9	5	
SOCIAL WORKER	3	1	2	1	
TOTAL	15	10	12	7	76

## **12 CONCLUSION**

The account in chapter three describes in detail how the researcher has adhered to scientific procedures during data collection. Data analysis will be done in chapter four of this study.

## CHAPTER FOUR

### PRESENTATION, ANALYSIS AND INTERPRETATION OF DATA

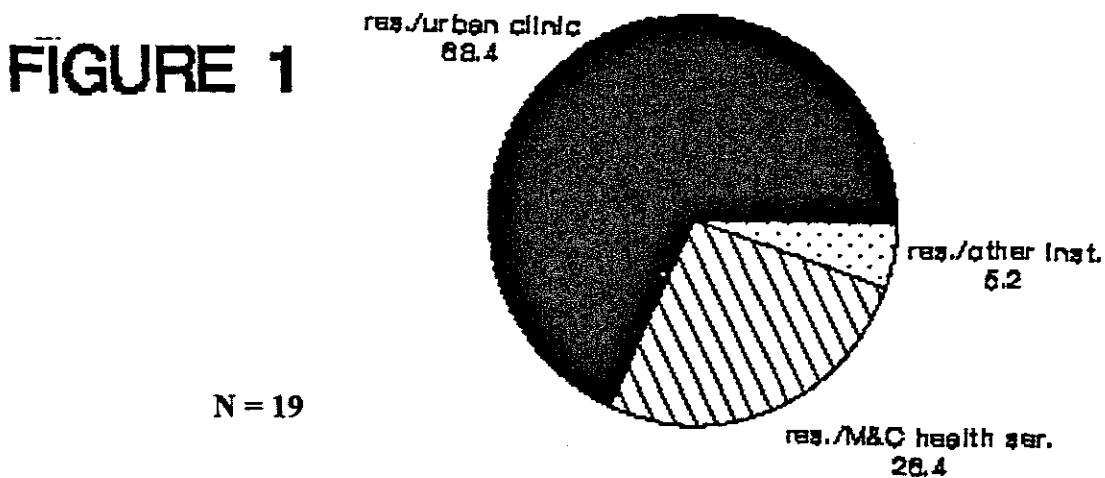
#### 1. INTRODUCTION

This chapter contains presentation, analysis and interpretation of data collected from respondents working in community health services and mother and child health services at Umlazi Township.

Since the researcher had used quantitative research methodology, during data collection, a quantitative descriptive statistical analysis was used to analyse data. Research questions asked in chapter one are answered in this chapter.

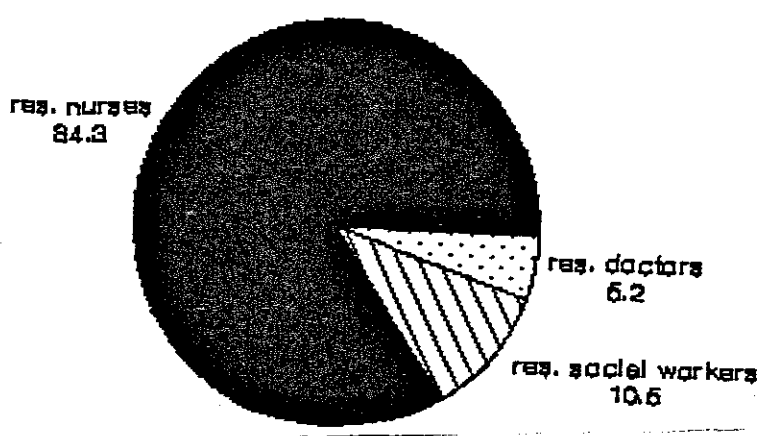
#### 2. ANALYSIS OF DATA

Because the services where the study was undertaken are administered by one department, the research respondents were treated as one body.



The item investigating the respondents areas of practice showed 68,4% (13) respondents working in urban clinic, 26,4%(5) working in mother and child health services and a 5,2%(1) working in other health care institution.

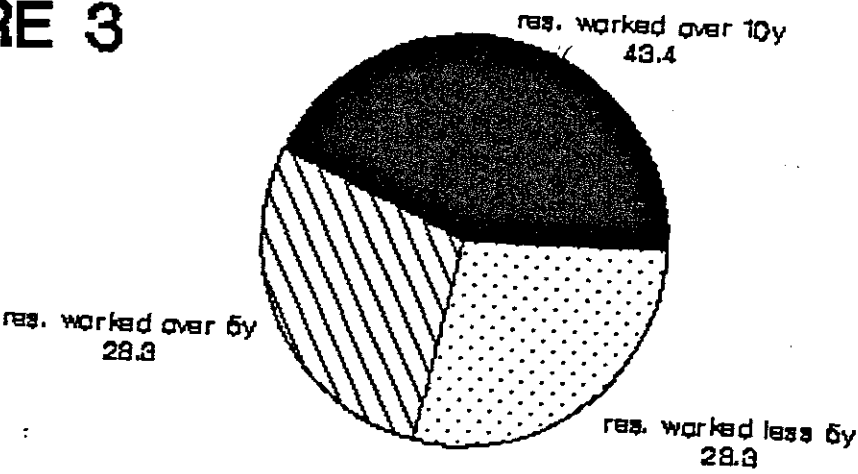
FIGURE 2



N = 19

The item investigating nature of employment or respondents, which aimed at identifying the category of health care team which was directly involved in the clients with genetic disorder revealed that 84,3%(16) were nurses, 10,5%(2) were social workers, and 5,2%(1) were doctors.

FIGURE 3



N = 19

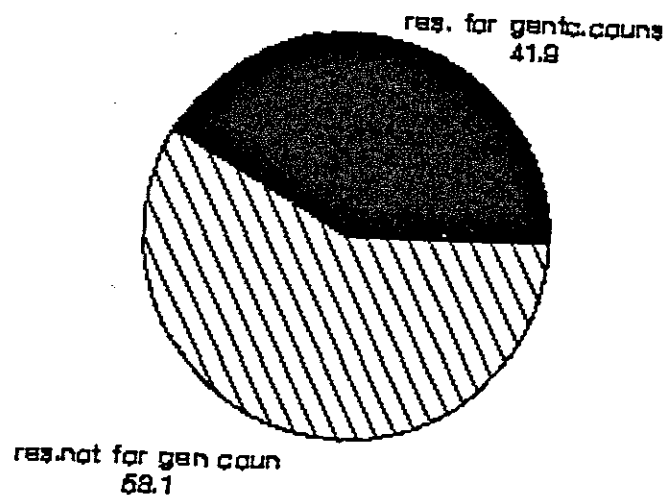
The number investigating the number of years the respondents had spent practising in that similar area of situation, aimed at identifying the experience level of the respondents, revealed that 43,4%(8) have worked in that similar setting for a period that is over ten years, a 28,3%(5) have worked for a period of between five and ten

years and a further 28,3%(5) have worked for a period of between one and five years.

This item aimed at identifying problems that were long standing in rendering genetic services.

**SECTION B**

**FIGURE 4**



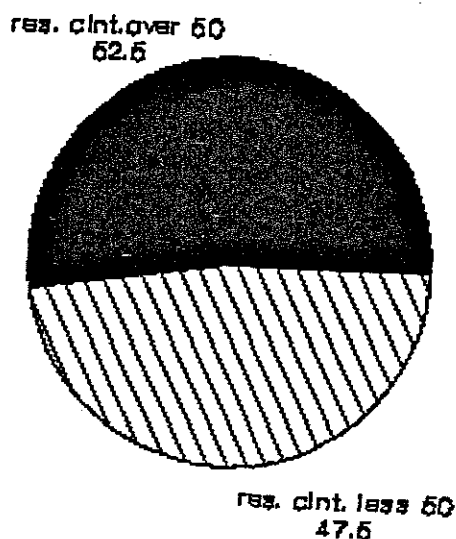
N = 19

This item investigated the number of respondents who were directly involved in caring for clients with genetic disorder at any level of intervention.

This aimed at identifying if any of the respondents had a contact and/or saw any need for genetic counselling at a primary prevention level.

This revealed that 41,9%(8) said they were involved, an 58,1%(11) said they were not.

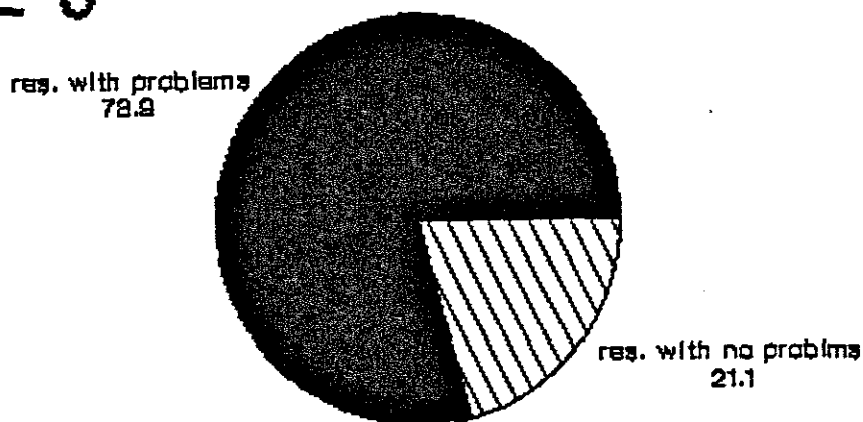
## FIGURE 5



N = 19

This item investigated the approximate number of clients with genetic disorders that the respondents encountered over a period of one month revealed that 52,5%(10) said they saw more than fifty clients in a month and a 47,5%(9) respondents said they saw more than ten but less than fifty clients in a months time.

## FIGURE 6

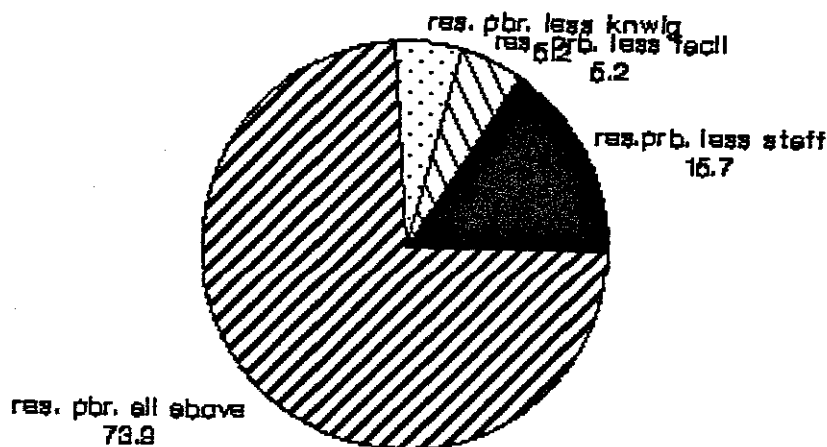


N = 19

Item investigated if the respondents have experienced any problems in rendering care to the clients discussed previously. The results were as follows:

A 78,9%(15) respondents said they had problems and a 21,1%(4) said they did not have any problems.

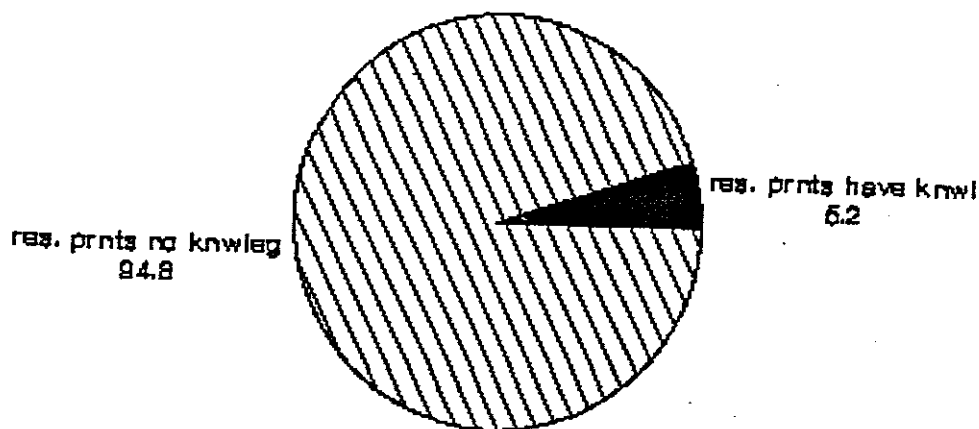
# FIGURE 7



N = 19

Item investigated the cause of problems as seen by the respondents. A 73,9%(14) revealed that lack of facilities, personal restraints and lack of knowledge were the cause of problems. A 15,7%(3) pointed out at personal constraints as a major cause of problems. A 5,2%(1) each saw lack of facilities and lack of knowledge as a major cause of their problem in rendering care to clients with genetic disorders.

# FIGURE 8



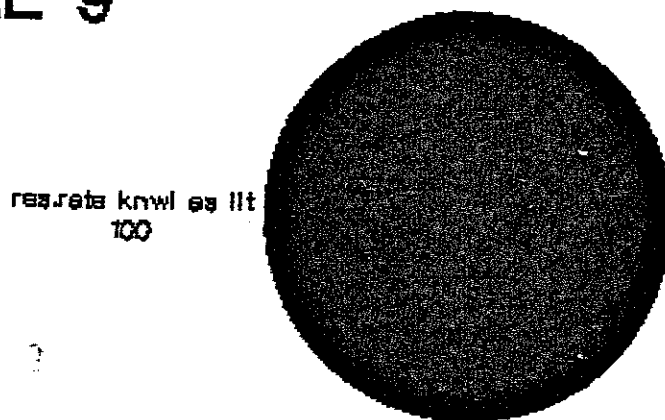
N = 19

The item investigated, if according to the respondents assessment, parents of children

with genetic disorders show any knowledge of the genetic nature of their children's condition.

A 94,8%(18) revealed that these parents showed no sign of knowledge of genetics and a 5,2%(1) said there was little level of knowledge displayed.

**FIGURE 9**

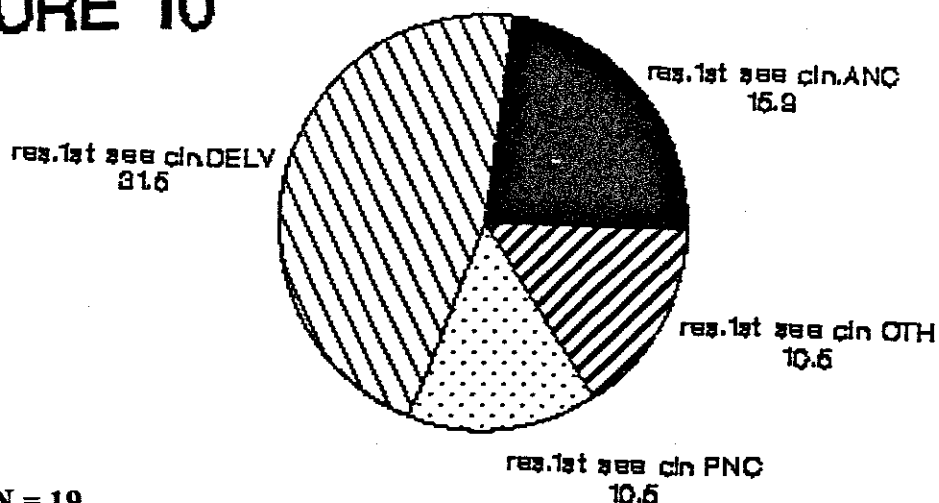


N = 19

Item investigated how the respondents rated the level of knowledge that parents displayed on genetic nature of their children's condition.

A 100%(19) the level of knowledge by respective parents was very little.

**FIGURE 10**

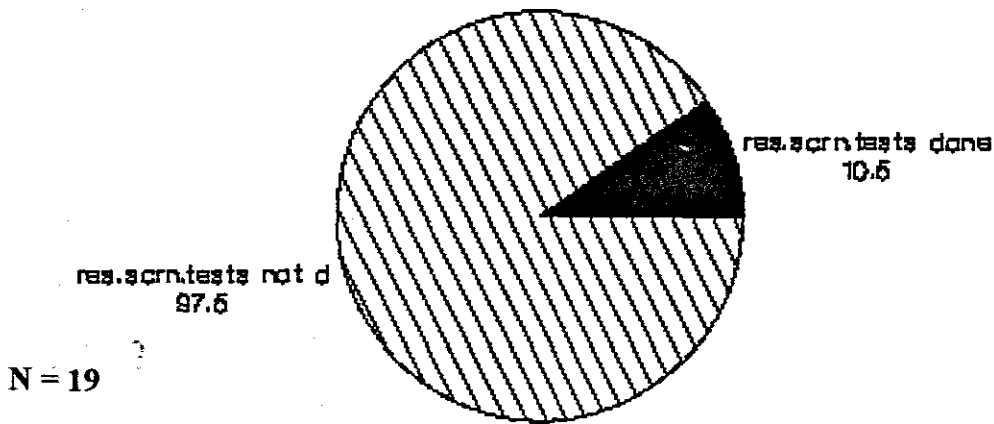


N = 19



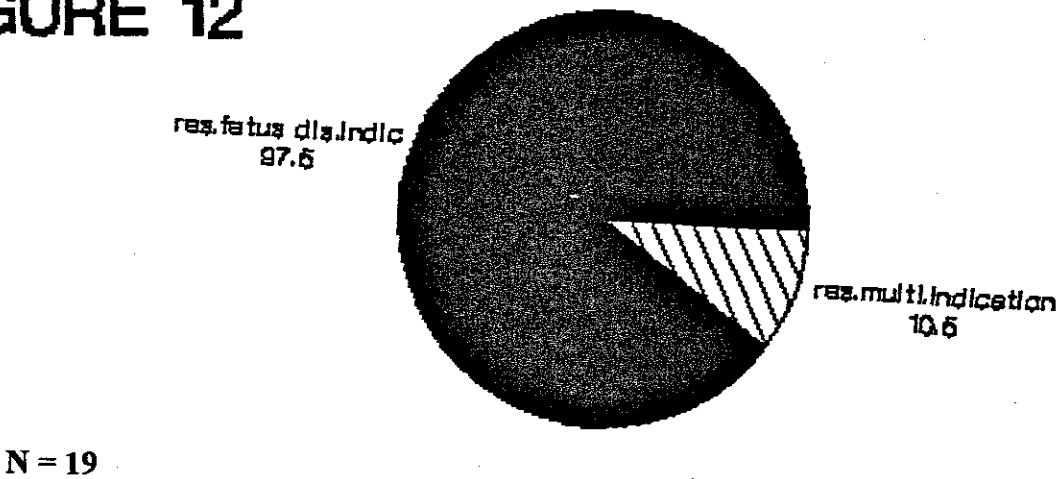
This item investigated the usual time of initial encounter of the respondents with their prospective clients. The results showed a 15,9%(3) as seeing these clients at ANC (antenatal clinic), of 31,5%(6) saw them at delivery, a 10,5%(2) saw them post natively and lastly a (10,5%(2) saw them at other times. These may be social workers, when parents have encountered social problems and needed assistance.

FIGURE 11



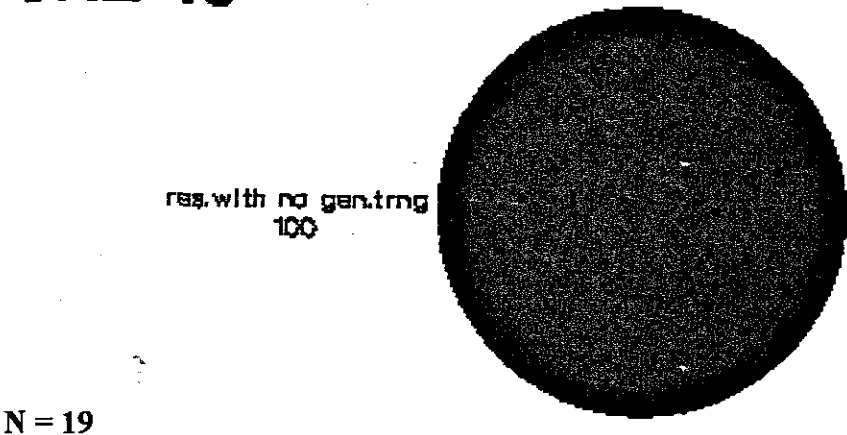
This item investigated if according to the respondents knowledge there were any screening tests that are routinely done to exclude genetic disorders. The results showed that a 97,5%(17) respondents revealed that such tests were not done, and a 10,5%(2) respondents said such screening tests were routinely done.

FIGURE 12



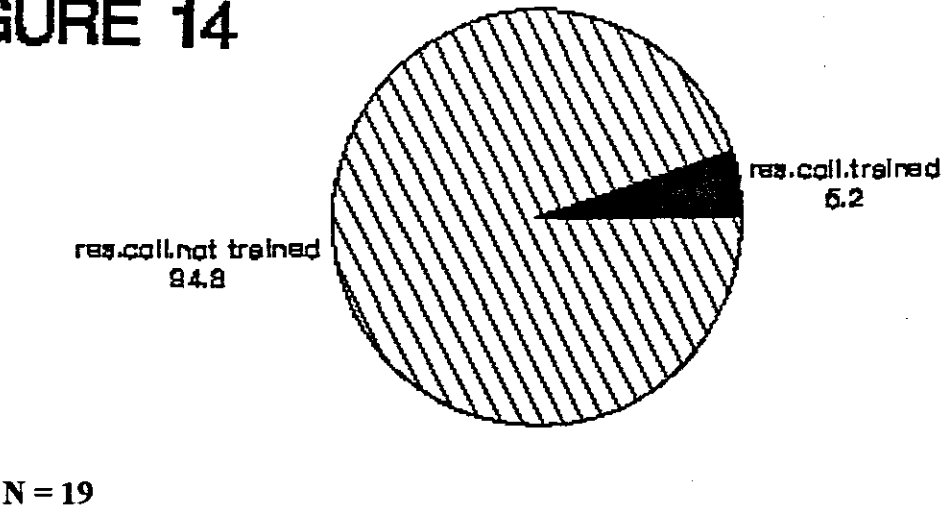
This item investigated the indication for the screening tests according to the respondents knowledge. A 97,5%(17) revealed that the indication have been the suspected genetic disorder of the present foetus, and the 10,5% said they were a multitude of indications.

FIGURE 13



This item investigated if any of the respondents had any training in genetics. A 100%(19) showed that none had been trained in genetics though previous responses have shown that a number of respondents were involved in caring for clients with genetic disorders over a lengthy period of time.

FIGURE 14

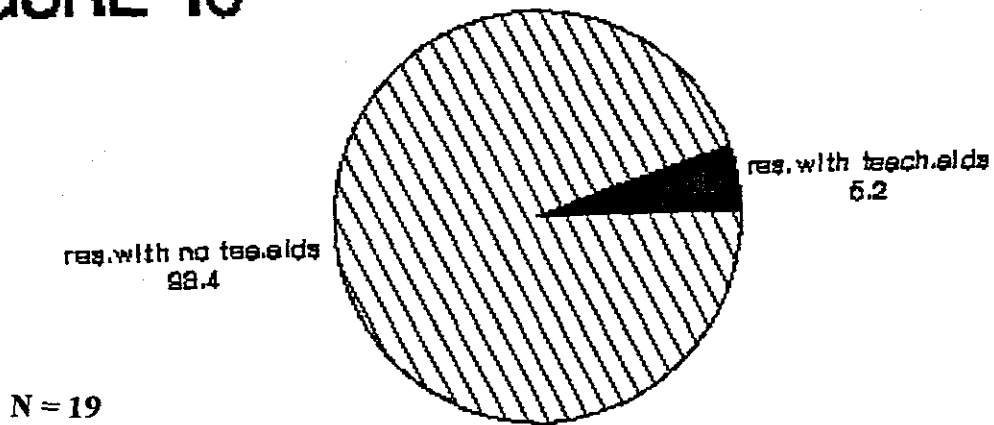


Investigated if according to the respondents knowledge, was there any colleague of theirs at their institution who has had training in genetics.

The results were as follows:-

A 94,8% said they did not have such, where as 5,2%(1) said there was a colleague who is trained in genetics.

**FIGURE 15**



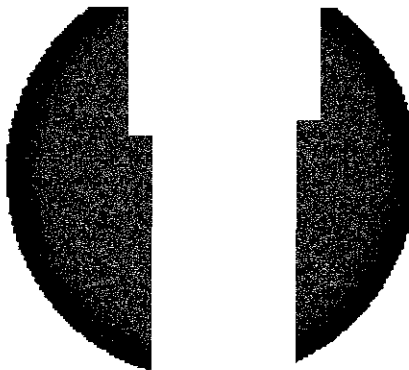
This item meant to elicit if in this institution the respondents worked, existed any teaching aids or any equipment necessary to effectively communicate genetic knowledge to clients.

A 94,8%(18) showed that they did not possess such equipment where as a 5,2%(1) said they did.

**FIGURE 16**

N = 19

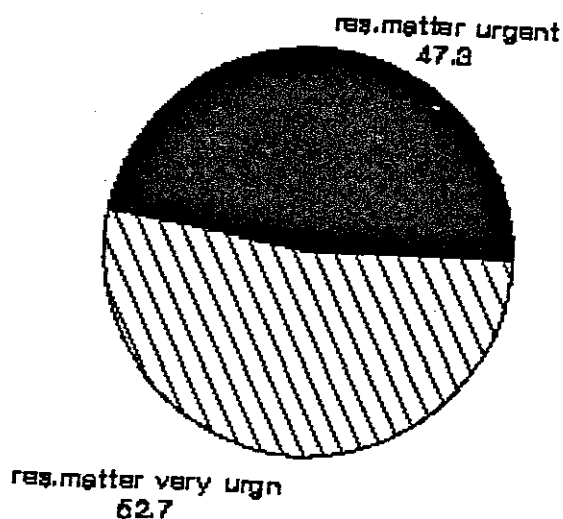
res.want gen.service  
100



This item investigated if the respondents wanted to have a genetic service incorporated into their present structure of health care service. A 100%(19) response was an affirmative response.

**FIGURE 17**

N = 19

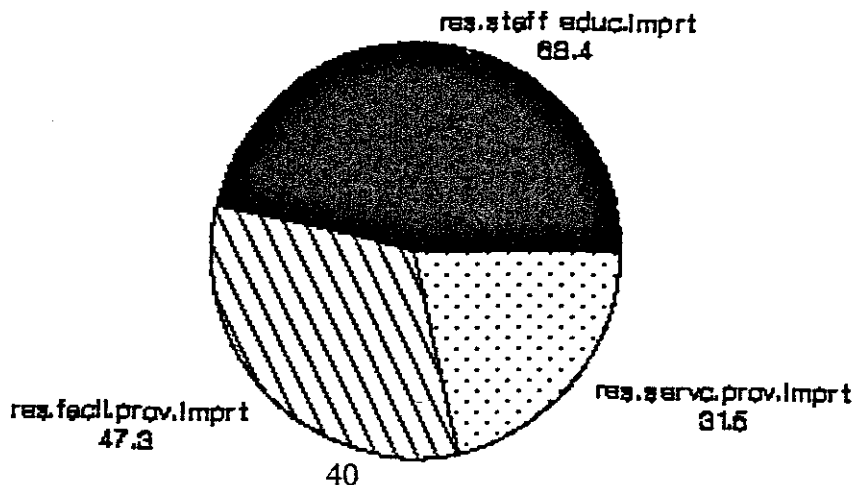


This item investigated the urgency of the matter according to the respondents view.

A 52,7%(10) rated the matte as very urgent and the (47,3%) rated as urgent. No responded rated the matter as “not urgent at all”.

**FIGURE 18**

N = 19



This item was open ended and investigated the respondents suggestions on the possible requirements necessary to improve this genetic service in the communities.

The suggestions are listed according to the ratings.

- |    |                                    |   |                   |
|----|------------------------------------|---|-------------------|
| 1. | Importance of staff education      | - | cited x 68,4%(13) |
| 2. | Importance of providing facilities | - | cited x 47,3%(9)  |
| 3. | Importance of improving services   | - | cited 31,5%(6)    |

### **3. CONCLUSION**

The researcher concludes that the incidence of genetic disorders at Umlazi Township, the present state of resources servicing clients with genetic disorders, and the implications for such conditions have been identified.

The summary and conclusions for these findings will be done in the next chapter.

## **CHAPTER FIVE**

### **SUMMARY, CONCLUSION AND RECOMMENDATION**

#### **1. INTRODUCTION**

In this chapter the researcher discusses the summary, conclusion, and limitation of the study. Recommendations will also be discussed.

#### **2. SUMMARY OF THE STUDY**

The study investigated the incidence of genetic diseases at Umlazi Township, the availability of community resources to serve these people. It also investigated the problems encountered by the health care personnel in rendering genetic services and lastly it investigated the feasible means necessary to make community genetic services a reality for the community.

A quantitative research method was used to determine how the respondents viewed the present state of genetic services in their community, how successful they felt these services were addressing the genetic needs of their community and lastly how the respondent felt about the need of addressing the present genetic services.

A sample of twenty respondents was selected to complete the questionnaire. This number of respondents formed a 50% of the total sample from different institutions that were investigated.

The researcher's questions were:-

- what is the present statistics of the genetically transmitted disorders at Umlazi Township?
- What are the problems that are encountered by the health care team when providing genetic services?

- How do they feel the present state of community genetic services could be improved?

The answers to the above questions will be discussed under conclusion in this chapter.

### **3. CONCLUSION**

Findings of this study have highlighted significant concerns of the respondents about community genetic services at Umlazi Township. These concerns will be discussed under:

#### **3.1 VIEW ON THE ABILITY OF THE HEALTH CARE TEAM TO OFFER AN EFFECTIVE GENETIC SERVICE**

About 78,9% of the respondents pointed out that they experienced problems in rendering the genetic service to clients in need. Only, 21,1% responded as having no problems in rendering the same service.

#### **3.2 VIEWS ON DETERMINING THE CAUSE OF THE PROBLEM AS SEEN BY RESPONDENTS**

About 73,9% viewed the cause of the problem as lack of facilities, personnel constraint as the cause of their problems. A 5,2% pointed out at lack of staff education on genetics and lack of facilities each.

### **3.3 VIEW OF RESPONDENTS ASSESSMENT OF PARENTS LEVEL OF KNOWLEDGE ABOUT THE GENETIC NATURE OF THEIR CHILDREN'S CONDITION**

A significant 94,8% rated the parents knowledge as very little, as a negligible 5,2% viewed it as adequate.

A significant 75,6% pointed out delivery time for initial encounter with clients for genetic counselling. A minimal 15,7% had antenatal care as their period of initial encounter for genetic counselling and a 10,5% first encountered their clients for initial genetic counselling post-natally.

### **3.4 VIEWS ON WHETHER THE ROUTINE TESTS THAT AIMED AT SCREENING GENETIC DISORDERS FOR PREGNANT WOMEN ARE EMPLOYED WHERE RESPONDENTS ARE PRACTISING**

A significant 98,5% pointed out that such tests are not regularly or routinely employed. A negligible 11,5% confirmed that such tests were done.

### **3.5 VIEW ON THE INDICATIONS FOR THE SCREENING TESTS IF EVER THEY ARE DONE**

A significant 84,9% pointed out at "patient's presentation with the history or signs of a genetic disorder as an indication for a screening test.

A 2,1% said the screening tests are only employed to confirm a potential diagnosis of a genetic disorder.



### **3.6 DETERMINATION IF ANY OF THE RESPONDENTS HAD ANY TRAINING IN GENETICS**

A significant 100% had no training in genetics.

### **3.7 VIEWS ON WHETHER ANY COLLEAGUE OF THE RESPONDENTS AND TRAINING IN GENETICS**

A 94,7% had no colleague who is trained in genetics at the institution where they practised. A negligible 5,3% had a colleague who is trained in genetics.

### **3.8 VIEW ON THE AVAILABILITY OF TEACHING AIDS OR EQUIPMENT TO EFFECTIVELY COMMUNICATE GENETIC KNOWLEDGE TO COMMUNITY IN THE INSTITUTIONS WHERE THE RESPONDENTS PRACTICE**

A significant 94,7% had no such equipment, and only a 5,2% had some.

### **3.9 VIEW ON WHETHER THE RESPONDENTS WANTED TO HAVE COMMUNITY SERVICES INCORPORATED INTO THE PRESENT STRUCTURE OF HEALTH CARE SERVICE**

A 100% of respondents wanted to.

### **3.10 VIEW DETERMINING HOW URGENT RESPONDENTS VIEWED THE MATTER**

A 52,6% viewed the matter as very urgent, and 47,3% viewed the matter as not urgent. No respondent viewed the matter as not urgent at all.

### **3.11 RESPONDENTS SUGGESTIONS ON HOW TO IMPROVE THE PRESENT HEALTH SERVICE TO BE ABLE TO RENDER AN EFFECTIVE GENETIC SERVICE**

A 47,3% emphasized the need to provide a full time genetic facility with specialists, at a community level. A 68,4% emphasized the need for staff education on genetics as a specialization. A 31,5% stressed the point of provision of genetic services within the existing community health service.

## **4. LIMITATIONS OF THE STUDY**

Time and financial constraints both led to the researcher delimiting the study to one area, that is Umlazi Township. It would have helped if a more urban area and a more rural area were included, to draw the similarities or differences in the genetic service rendered.

The available statistical reports of clinics (community health service) randomly reflects genetic disorders as such, but rather as a complication that the disorder presents with. This has greatly distorted the actual figures of the clients seen at such institutions.

The study focused on the health care personnel only. It would have been useful to investigate the views of parents of children with genetic disorders as well. The findings on the views of the health care provide and health care recipients about the service, would have been useful.

## **5. RECOMMENDATIONS**

The researcher recommends the following:-

Nurses and other health care practitioners should have the specialized genetics training enabling them to communicate genetic information to communities they encounter on day to day practice. The available training should be made accessible for all nurses it's time to move genetics away from people who are only medically trained, Harper (1988:128).

All community health institutions should provide the necessary facilities aimed at addressing the genetic problems at primary prevention level. Teaching aids should be provided to effectively communicate genetic information to grass root communities, because as, Harper (1988:127) puts it diagnosis during pregnancy is not at an ideal time. Routine screening tests should be made available for all members of the communities, to promote diagnosis in utero and offer an alternative termination of fetus to save the mother from suffering and costs.

To allow and enable every citizen access to genetic information. This can be done by including "genetics" to daily vocabulary of the health care practitioners. Like Aids and HIV, malnutrition, rehydration and family planning, genetics should be made a daily topic for both health care practitioner and recipient. This may help the concerned to appreciate the realities of genetic problems. Addressing people who do not appreciate the potential problem is unrewarding, Harper (1988:137).

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**ANNEXURE ONE**

2255 KwaMakhutha Township  
P.O. AMANZIMTOTI  
4126

**THE SENIOR NURSING SERVICES MANAGER**

Dear Sir / Madam

**AN APPLICATION TO CONDUCT A RESEARCH STUDY**

I hereby apply for a permission to undertake a research study in your Hospital and Clinics.

The focus is on community genetics, determining the Prevalence of the disorders and the extent of resource availability in the community.

The study is for the study purposes towards a Senior Degree, and for improvement of Health Care Services in the community.

Thank you

Yours faithfully

---

**MISS NTOKOZO MCANYANA**

Miss Ntshwano Mchanyane

27/1/99

**ANNEXURE TWO**

**REPLY FROM DEPUTY DIRECTOR TO CONDUCT THE STUDY**

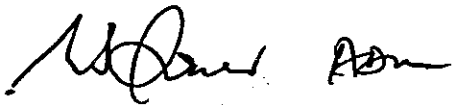
Dear Madam,

Permission is hereby granted for you undertake research proposed in the clinics under Prince Mshiyeni Memorial Hospital.

You are reminded to conduct yourself with respect and adhere to principles of confidentiality. You are also need to get the permissin of the patient where indicated.

Good Luck with you studies !!!

Thank you



for/ACTING CHIEF MEDICAL SUPERINTENDENT

### ANNEXURE THREE

**TABLE:** Number and types of formal training courses held and number of attendees, for the period 1988-93

	TYPES OF TRAINING COURSES					
	1 - DAY		3 - DAYS		1 - WEEK	
	Number	Attendees	Number	Attendees	Number	Attendees
1988 (mean)	8	631 (79)			1	14
1989 (mean)	5	204 (41)	4	54 (14)		
1990 (mean)	9	557 (62)	2	49 (24)	2	33 (17)
1991 (mean)	10	518 (52)	4	69 (17)	1	22
1992 (mean)	8	418 (52)	5	76 (15)	1	10
1993 (mean)	20	710 (36)	4	78 (20)	2	38 (19)

**1. The 1-Day courses were held at the following localities:**

1988: Pietersburg, Nelspruit, Newcastle, Empangeni, East London, Queenstown, Kroonstad, Bloemfontein  
 1989: Durban, Pretoria (2x), Venda, Johannesburg  
 1990: Vanderbijlpark, Germiston, Johannesburg (2x), Pretoria, Klerksdorp, Kimberley, Upington, Pietersburg  
 1991: Atteridgeville, Ermelo, Secunda, Roodepoort, Queenstown, Kwazulu (2x), Kroonstad, Pietersburg, Venda  
 1992: Giyani, Lebowa, Johannesburg, Atteridgeville, Welkom, Schweizer-Reneke, Potchefstroom, KaNgwane  
 1993: Springs, Kempton Park, Groothoek, Boksburg, Lenasia, Johannesburg, Kimberley, Upington, Vanderbijlpark, Mankweng, Pietersburg, Port Elizabeth (4x), Humansdorp, Port Alfred, Stormberg, East London, Fort Beaufort

**2. The 3-Day courses were held at the following localities:**

1989: Port Elizabeth, Durban, Mafikeng, Pretoria  
 1990: Pretoria, Bellville  
 1991: Pretoria, East London, Durban, Bloemfontein  
 1992: Venda, Howick, Pretoria, Giyani, Bloemfontein  
 1993: Durban, Mmabatho, Potchefstroom, Pretoria

**3. All 1-Week courses were held in Pretoria:**



## **ANNEXURE FOUR**

### **A STUDY OF COMMUNITY GENETICS AT UMLAZI TOWNSHIP IN KWAZULU-NATAL**

#### **QUESTIONNAIRE FOR HEALTH PERSONNEL**

Dear Respondent

The study of community genetics at Umlazi Township is aimed at examining the extent of genetic disorders in the area and identify community based programmes that aim at primary prevention of the disorders, and to identify recommended, feasible means of pioneering community genetics in this area.

The information gathered in this study will be disseminated to health institutions participating.

Your participation in this study by completing the questionnaire will contribute to developments of comprehensive strategies to combat the problem at primary prevention level.

Confidentiality will be highly maintained.

Thank you for your co-operation.

**RESEARCHER**

---

**NTOKOZO MCANYANA**

## **INSTRUCTIONS**

1. ANSWER ALL QUESTIONS
2. MAKE A TICK (✓) IN THE SPACE PROVIDED TO INDICATE YOUR RESPONSE.
3. IF YOU WOULD LIKE TO EXPAND ON YOUR ANSWERS, PLEASE USE SPACE PROVIDED IN SECTION C.
4. DO NOT WRITE YOUR NAME OR ADDRESS.

**SECTION A. : EMPLOYMENT HISTORY**

**For office use:**

**1. TYPE OF INSTITUTION**

Hospital	
Rural clinic	
Urban clinic	

Other \_\_\_\_\_

**2. NATURE OF EMPLOYMENT**

Doctor	
Nurse	
Social Worker	
Health care worker	

Other \_\_\_\_\_

**3. NUMBER OF YEARS FOR WHICH YOU HAVE WORKED  
IN THIS SETTING**

Less than 1	
1-5	
5-10	
10 and above	

SECTION B: HEALTH CARE ACTIVITIES

For office use:

4. ARE YOU INVOLVED IN CARING FOR CLIENTS WITH GENETIC DISORDERS?

Yes	
No	

If "NO" proceed to 5

If "YES"

4.1 APPROXIMATELY HOW MANY DO YOU SEE IN ONE MONTH?

Less than 10	
Less than 50	
50 and above	

Other \_\_\_\_\_  
\_\_\_\_\_

4.2 DO YOU HAVE ANY PROBLEMS RENDERING CARE TO THESE CLIENTS

Yes	
No	

4.3 IS YOUR PROBLEM DUE TO

For office use:

Lack of facilities	
Personell constraints	
Lack of knowledge	
All of the above	
None of the above	

Other: (specify) \_\_\_\_\_  
 \_\_\_\_\_

5. DO PARENTS OF THESE CHILDREN DISPLAY ANY KNOWLDEGE ABOUT THE GENETIC NATURE OF THEIR CHILDREN'S CONDITION?

Yes	
No	

If "NO" proceed to 6.

If "YES"

5.1 THEIR LEVEL OF KNOWLEDGE CAN BE RATED AS

Little	
Adequate	
Enough	

6. WHEN IS YOUR USUAL TIME OF ENCOUNTER WITH THE CLIENTS WHOSE CHILDREN HAVE A GENETIC DISORDER OR WHO HAVE A HISTORY OF GENETIC DISORDER IN THE FAMILY ?

Specify: \_\_\_\_\_

7. WHAT TYPE OF SCREENING TESTS DOES YOUR ANTENATAL CLINIC ROUTINELY EMPLOY?

For office use:

Rh and WR only	
Rh, Wr, and AFP	
AFP (amneocentesis)	
All of the above	
None of the above	
Other: (specify)	

8. IN ALL YOUR YEARS OF PRACTICE HAVE YOU ENCOUNTERED ANY CLIENT WHO WAS DON AMNEOCENTESIS FOR THE PURPOSE OF GENETIC DEFECT SCREENING?

If "NO" proceed to 9

If "YES"

The indication for screening was:

History of a genetic disorder in the family	
Clients request	
Other: (specify)	

9.1 ARE YOU TRAINED IN GENETICS?

Yes

No	

9.2 DO YOU HAVE A COLLEAGUE WHO IS TRAINED IN GENETICS IN YOUR INSTITUTIONS ?

Yes	
No	

If "NO" proceed to 10

If "YES"

For office use:

9.3 WHAT TYPE OF THE COURSE DID SHE/HE ATTEND?

1 - days course	
3 - days course	
1 - week course	

Other (specify) \_\_\_\_\_

10. DO YOU HAVE TEACHING AIDS OR NECESSARY TECHNOLOGICAL EQUIPMENT TO HELP YOU IN COMMUNICATING GENETIC KNOWLEDGE TO YOUR CLIENTS?

Yes	
No	

If "NO" proceed to 11

If "YES"

**PLEASE USE THE SPACE PROVIDED TO EXPAND ON YOUR ANSWERS, FOR GENERAL COMMENTS AND TO RESPOND TO QUESTION 13**

**For office use:**

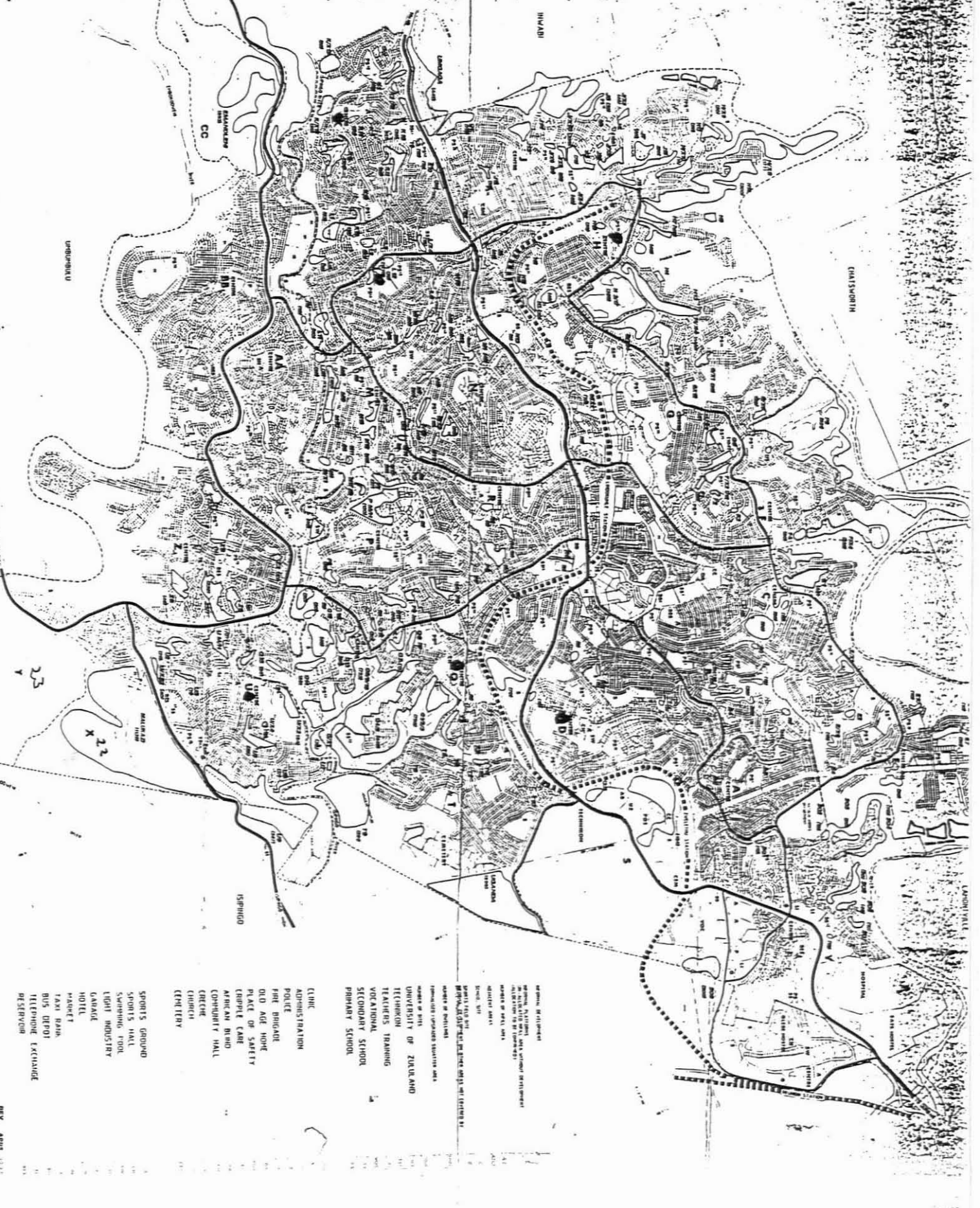
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# ANNEXUR FIVE

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UMLAZ

NEW APRIL 1972