

ABSTRACT

Many South African children suffer from a chronic condition that requires ongoing care. The most prevalent of these conditions are congenital heart disease, neurological problems and HIV. In urban areas asthma affects more than 10% of children. The sequelae of poor perinatal care, poverty and poorly managed infections cause disability and place a high toll on rural families. In addition, a wide range of congenital conditions that affect children globally affect South African children as well. Diseases of lifestyle, previously mainly affecting adults, are now more prevalent as almost 20% of South African urban children are overweight.

SA has the challenge of improving perinatal care, paediatric and child health services, controlling over and under-nutrition and decreasing poverty in order to prevent chronic conditions. The establishment of a family based multidisciplinary service for children with long term illness is a priority. The nature and scope of the service is outlined in the 2002 Policy Framework for Non-Communicable Chronic Conditions in Children.

Excellent specialised services exist in pockets in the country; however, these services are inequitably distributed. For many conditions, children from rural areas are much less likely than their urban counterparts to access specialised care, and thus will inevitably have a poorer outcome and quality of life.

Ensuring equity in provision of service, and establishing good family based care for children throughout South Africa will require innovation and commitment. Centres of excellence that provide care should be maintained and provided with resources to service the region. NGOs, patient-provider organisations and specialist working groups are encouraged to continue and extend the role they play in advocacy and support for service development and best practices.

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INTRODUCTION

HIV-related conditions, perinatal conditions, pneumonia, diarrhoea and malnutrition are the leading causes of death in children under-5 years of age.¹

In addition to this burden of disease, about 20%^a of children in South Africa (SA) have a chronic condition. A chronic condition is a health problem that requires ongoing management over a period of years. These include diseases and impairments.

Many families misunderstand a chronic disease to be a serious illness. This stems from the common usage of the word chronic in this context. In order to avoid this association it has been proposed that the term Long Term Health Condition (LTHC) be used instead. A long term health condition is defined by the Policy on Non-Communicable diseases in Children as:

“...a condition that

- ◆ affects the child for enough time to potentially affect the child’s physical or psychological development (more than a year, sometimes for life);
- ◆ causes the child to require ongoing health and / or other services in order to function optimally; and
- ◆ as a result the child requires coordinated, comprehensive health care.”^a

LTHC can be grouped according to cause as follows:

Sequelae of common childhood diseases and perinatal problems. Examples include cerebral palsy, developmental delay, epilepsy and mental impairment. Rheumatic heart disease, which follows on streptococcal throat infections, affects many older children. HIV infection is now a common chronic condition of childhood. In addition to low birth weight resulting in neurological sequelae, there is evidence that low birth weight is associated with an increased risk of adult onset of chronic disease such as hypertension, glucose intolerance and ischaemic heart disease.²

Congenital disorders and birth defects affect up to 6% of children³ and embrace a wide range of conditions. Some are present at birth and most are evident by 5 years of age. Congenital heart disease is the most prevalent of

these conditions, followed by neural tube defects and hydrocephalus. The incidence of congenital conditions and birth defects is fairly constant throughout the world, but some communities in the developing world have a higher incidence of recessive disorders. This may represent an evolutionary defence against malaria or be as a result of consanguinity.⁴

Acquired chronic conditions of multifactorial aetiology. Examples include asthma, insulin dependent diabetes and renal disease.

The consequences of adopting an unhealthy lifestyle in childhood not only predisposes children to adult chronic disease, but affects older children and adolescents, especially those living in urban areas.

Advances in paediatric and surgical care have resulted in children with chronic diseases from better-resourced areas of the country surviving through childhood and into adolescence and adulthood.

Chronic diseases in children are different to those of adults. Adults suffer from a small range of common diseases (many of them the consequences of adopting an unhealthy lifestyle) such as hypertension, acquired heart disease and arthritis. Primary health care practitioners are usually familiar with the management of these conditions. Children on the other hand, suffer from a wide range of complex conditions that require care from many health professionals, often at different levels of the health care service.⁵

This chapter outlines the burden of LTHC affecting South African children. It uses information from relevant national and international publications, policy documents and guidelines as well as reports available from the internet. In addition it draws on national experts on the subject through interviews and discussions in order to address the gaps. The health sector responses and challenges in addressing LTHC are discussed and recommendations on how to improve service delivery are proposed.

^a Source: Policy framework for non-communicable chronic conditions in children. This is an official document but has not been published and is not on the government web site, however can be obtained from the author on request.



CURRENT SITUATION

BURDEN OF DISEASE

Between 15-30% of children globally have a chronic condition. The prevalence varies between studies partly because different definitions of chronic disease have been used. An estimated 18% of children in the United States have a chronic condition and require health services beyond that required by children generally.⁶

A study conducted in a Cape Town suburb in 1987 showed that 13% of surveyed children had a chronic condition.⁷

Birth prevalence studies provide reliable data about conditions detected at birth. Because some of these disorders affect childhood survival, birth prevalence data cannot be extrapolated into later childhood. There have been relatively few community based studies of chronic disease in SA and the data obtained are prone to some degree of diagnostic uncertainty. Health service data provide disease-specific information on the number of children with chronic conditions.

TABLE 1:
Sentinel Long Term Health Conditions in South Africa

Condition	Prevalence and / or Incidence	Sentinel issues
1. Asthma	Affects up to 14% of school children in urban areas ⁸ and 0.14% of school children in rural areas. ⁹	Common in urban areas. Most cases can be well controlled at primary level if drugs and services are available and accessible. A few children require highly specialised care.
2. HIV	An estimated 5.6% of children under the age of 15 are HIV positive. ¹⁰	PMTCT can prevent over 50% of cases. Half the infected children die by the age of 2 if they do not receive treatment. Comprehensive treatment of HIV requires a well-developed and accessible service.
3. Congenital heart disease	5-7 children per 1 000 are born with a congenital heart disease. ¹¹	Most cases are not preventable. Congenital Malformation most common. All require highly specialised care by a Paediatric Cardiology service. 75% will require cardiac surgery. ¹⁰ Most children live a normal life after surgical correction.
4. Childhood Cancer	70-100 new cases per million children per year. ¹²	Early identification, referral to a Children's Cancer Centre is essential for cure. 60-70% of children can be cured at an accredited Children's Cancer Centre.
5. Epilepsy	7 per 1 000 children suffer from epilepsy. More than half of these have developmental and neurological problems. ^{13,14}	Preventable causes including birth asphyxia and brain injury. Children with developmental problems require rehabilitation and specialist care.
6. Spina bifida	0.5-6 children per 1 000 are born with a neural tube disorder. ^{15,16} Higher birth prevalence are in rural areas.	Folate, food fortification and antenatal screening can prevent spina bifida. Highly specialised care and rehabilitation are required.
7. Haemophilia	1 boy per 10 000 male births. ¹⁷	Rare. Lethal if not identified and treated. Compatible with a normal life if competent well organised care is available.
8. Diabetes mellitus type 1	5/100 000 new cases in WC ^b 2-35/100 000 new cases worldwide. ¹⁸	Not preventable or due to lifestyle. Requires insulin therapy and complex monitoring, nutritional guide and education directed by a Children's Diabetic Centre to secure longevity.
9. Chronic renal failure	12 new cases / million children / year. ¹⁹	Not preventable. All will require dialysis and possible transplantation.
10. Rheumatic heart disease	1-7/1 000 children 5-15 years. ²⁰	Preventable through good primary health care. Requires Penicillin prophylaxis into adulthood. Many require valvular surgery.

^b A conclusion is considered to be sentinel if it is common, preventable or highlights important issues.

However, this information is limited to children who can access the health service. It is likely that the majority of children with chronic diseases in SA do not access appropriate care. A review of health service registers for conditions with a known and consistent global prevalence showed that only 10-20% of rural children access the care they require.^c

There are many LTHC affecting children in SA. Table 1, summarises the prevalence and sentinel^b issues of childhood.

CONGENITAL HEART DISEASE

Congenital heart disease as a group is the most common congenital abnormality. The prevalence of severe congenital heart diseases that require paediatric cardiac care is around 5-7 children per 1 000 live births. Seventy-five per cent of these children require cardiac surgery, and can subsequently live a relatively normal life.¹¹

Based on these figures of the 1 million children born annually in SA, 6 000 will have a congenital heart disease and 4 500 will require surgery.^d

Currently 1 380 paediatric cardiac operations are being performed annually in the public and private sector in SA. This includes operations for rheumatic heart disease.²¹ This suggests that only 30% of children who require surgery, access this care. Fewer children from rural provinces than urban provinces receive surgery. It is estimated that 50% of affected children from urban provinces receive surgery as compared to 10% of children from rural provinces.^e This is due to poor identification of congenital heart disease at primary care level and inadequate specialist centres.

The Modernisation of Tertiary Services (MTS) Paediatric Cardiology Working Group made the following comment:

“We are currently under-servicing our patients because of poor funding, poor equipment and personnel. These services on the whole, provide a huge improvement in quality of life for patients and in many cases a complete cure. The existing facilities are being stretched to the limit and this pressure is affecting quality of care. The current geographical distribution of units is inadequate. There needs to be a national network for referral to the various levels with referral protocols in place.”²¹

NEUROLOGICAL CONDITIONS

The World Health Organization (WHO) figures indicate that up to 10% of children have a neurological disability.²² A community based study in rural SA, identified an epilepsy prevalence of 7 children per 1 000. Of these children, 70% had an associated neurological disability.²³ The same study found the prevalence of cerebral palsy to be 3 per 1 000 children. Mental impairment affects up to 8% of children.²³ The birth prevalence of spina bifida and isolated hydrocephalus are each around 1 per 1 000 live births. Many children have preventable neurological conditions, while a wide range of neurometabolic and neurogenetic conditions affects others.

The management of these children is multidisciplinary and care at different levels of the service is often required for complex cases. The affected children may have a number of impairments and disabilities requiring care, community support, social interventions and special education.

ASTHMA

Asthma is a common chronic condition whose prevalence in the urban areas of Cape Town and Durban is between 10 and 13%.²⁴ Little data are available from rural inland areas. The prevalence in these areas is thought to be lower, but is not known. A study done in 1979 compared the incidence of bronchial hyperactivity in children aged 6-9 years, in Transkei and Gugulethu. The prevalence was 0.14 in rural children and 3.7 in urban children.⁹ Allergy specialists expect the prevalence of asthma in SA to double within the next ten years. Asthma deaths are much higher in SA than in other countries with a similar prevalence.²⁵

c Personal communication, Dr Chris Sutton, Department of Paediatrics and Child Health, University of Limpopo, May 2006.

d Personal communication, Prof. S Delport, Head of Paediatrics Endocrinology and Diabetes Services, Department of Paediatrics, Red Cross Children's Hospital, June 2006

e Personal communication, Dr Chris Sutton, Department of Paediatrics and Child health, University of Limpopo, Polokwane campus, May 2006.



Reasons for high death rates could be lack of access to follow up care.²⁶

Seventy per cent of children with asthma have intermittent or mild persistent asthma. Care for this is available at primary health care level. For persistent asthma, care includes the use of inhaled steroids to prevent acute attacks. Competent care at this level is critical. Specialist supervision of care is required by the 25% of children with moderate persistent asthma. The 5% of children with severe persistent asthma, require subspecialty care.²⁷

CHILDHOOD CANCER

Childhood cancer is relatively uncommon affecting 110-130 per million children annually throughout the world.²⁸ In SA, 70-80 cases per million children are identified per year. The other children who are not identified presumably die before they are correctly diagnosed.

The survival of children with cancer in the last few decades has been remarkable, with 70% of children being potentially curable. This is only possible if the child is treated in a Paediatric Cancer Unit, meeting the International Society of Paediatric Oncology standards (SIOP), and if the child is diagnosed early.²⁹ Cancer care is intensive and extends over 2-3 years.

In SA, there should be 1 400 new cases of paediatric cancer treated each year, but only 600 (less than 50%) children are identified and treated annually. There is a wide variation of cases between provinces as shown in Table 2. Urban provinces detect almost 3 times as many cases.

TABLE 2:
Number of children under-15 years of age with Cancer:
2000-2004

	EC	FS	GP	KZN	LP	MP	NC	NW	WC	SA
Average number of children <15 with cancer per year 2000-2004	61	45	145	129	42	31	19	34	88	596
Cases / million children <15 / year	23	54	70	39	20	28	76	30	71	41

Source: Children's Cancer Register, 2006.^f

“There are several excellent treatment centres in SA which use internationally accepted protocols, and achieve results comparable to hospitals in North America and Europe for similar stages of diagnosis of the illness. However, statistics have indicated that in some communities in SA, over 80% of children are diagnosed with tumours in the late stages, compared with 15% in developed countries. These late-diagnosed children have a much poorer chance of being treated successfully.”²⁹

In an attempt to improve this situation, the South African Children's Cancer Study Group, which includes all of the specialist paediatric oncologists in the country, has prepared a set of 'Warning Signs' (WS), aimed particularly at the primary health care sector.

WS have been adopted by the SIOP for use in all developing countries, and were adopted by WHO in 2002. Another set of WS targeting doctors is available.²⁹

^f Personal communication, Prof. Glyn Wessels, Tygerberg Children's Hospital, July 2006.

Box 1:
Saint Siluan* warning signs for cancer in children

S: Seek:	Medical help early for persistent symptoms
I: Eye:	White spot in the eye, new squint, blindness, bulging eyeball
L: Lump:	Abdomen and pelvis, head and neck, limbs, testes, glands
U: Unexplained:	Fever, loss of weight and appetite, pallor, fatigue, easy bruising or bleeding
A: Aching:	Bones, joints, back and easy fractures
N: Neurological signs:	Change in behaviour, balance, gait and milestones, headache, enlarging head.

HIV

Although other chapters in this Review such as ‘Management of Children Infected with HIV’ discuss HIV in detail, it is important to note that HIV is now a manageable long term health condition. Because it is common, competent family based care at primary health care level is required, with support from specialist services. Integration into other services for children with long term health conditions is required.

DIABETES

Children, unlike adults, are chiefly affected by type 1 or insulin dependent diabetes. Children require insulin injections and monitoring 2-4 times a day. Intensive family and patient education and support are required to establish effective insulin therapy and glycaemic control. Without this, the outcome will be poor.

The international incidence (new cases per year) of Type 1 diabetes in children 0-14 years is 10 per 100 000 children. This varies from 2 per 100 000 in Macedonia to 35 per 100 000 in Finland.¹⁸ The incidence in South Africa is not known. The Red Cross Children’s Hospital Diabetic Clinic that sees most new diabetic children in the Western Cape, has 50-60 new cases of children with diabetes per year and there are currently 600

children registered in this service.^g This could translate to an incidence of 5 per 100 000 cases per year and may be an underestimate of the true incidence. There are far fewer children with diabetes attending clinics at other specialist centres and presumably many children with diabetes never access specialist care.

BIRTH DEFECTS AND CONGENITAL CONDITIONS

“Worldwide, 2-3% of infants are born with a recognisable congenital disorder, and by five years, depending on the country’s health care and socio-economic status, their incidence has cumulated to 5-8% of children having suffered the effects of a serious congenital disorder. In SA with an annual birth rate of just in excess of 1 million infants, this translates into a minimum of 61 000 annual births harbouring a serious congenital disorder. It needs to be emphasised that each of these children is born with a congenital disability. In the best circumstances, in industrialised countries, 30% of children born with a serious congenital disorder will die within a year of life, 30% will live with chronic disability and 40% can be treated or corrected, mainly by paediatric surgery. Data for the developing world are not available, but it is estimated that almost 50% probably die in infancy or shortly thereafter.”³

Children with these problems require multidisciplinary care at all levels, including a full range of surgical services. In addition, these children require rehabilitation services and the management of intercurrent problems. This care needs to be available close to the patient’s home, hence it is easier for children residing in urban areas to access this highly specialised care.

HAEMOPHILIA

The World Haemophilia Foundation (WHF) estimates that worldwide prevalence of haemophilia is 1 case per 10 000 male births.¹⁷ This is most likely to be the case in SA. Information from haemophilia registers demonstrates that many cases remain unrecognised. It is likely that these children die young from untreated bleeds. Many boys suffer disability as the result

^g Personal communication, Professor S. Delpont, Head of Paediatric Endocrinology, Red Cross Children’s Hospital, UCT, August 2006.



of recurrent bleeding into joints and soft tissues. Haemophilia requires frequent expensive treatment with the appropriate replacement factor as well as supportive care and rehabilitation. Dependent on the severity of their disease, factor replacement is required a number of times per week or on demand as prophylaxis when the patient bleeds.

The work of the WHF (SA) through education, to patients, doctors and nurses, support for the development of clinics at all provincial centres, has resulted in a great improvement in the care of children with haemophilia.

CONSEQUENCES OF ADOPTING AN UNHEALTHY LIFESTYLE IN CHILDHOOD

The consequences of an unhealthy lifestyle are the precursor of many chronic diseases in adults. These are increasingly becoming important in childhood, especially in urban based children.

Childhood obesity and being overweight are increasingly evident in SA. The National Household and Food consumption survey reported that 17.1% of SA children between the ages of 1-9 living in urban areas are overweight.³⁰ In contrast, the prevalence of overweight in rural children is still low, for example Monyeki et al. found only 0.25% of girls and 0.43% of boys to be overweight.³¹

Childhood obesity and overweight have negative health implications in children. A study of 5 - 10 year olds found that 60% of overweight children presenting with one cardiovascular risk factor and 25% presenting with two or more risk factors.³² A tenfold increase in type 2 diabetes between 1982 and 1994 has been documented in American children.³³

The Birth to Ten study, demonstrated that 11% of 5 year olds had severe hypertension (>124/84). Blood pressure was also inversely proportional to birth weight, i.e. children who had a low birth weight had the highest blood pressure.³⁴

HEALTH SECTOR RESPONSES

The health sector has responded in a number of ways to the challenge of prevention and care for children with LTHC. There are policies in place as well as prevention strategies. In addition, various services and organisations are applying innovative strategies for care.

POLICY

A Policy Framework for Noncommunicable Chronic Conditions in Children was finalised in December 2002 and approved by the health Minister and Members of Executive Committee (MINMEC). The Policy was drafted under the auspices of the Chronic Diseases Directorate.^a

The implementation of this policy is the responsibility of the National Directorate of Child Health. Currently there is a draft implementation guideline, "Implementation Framework for the Management of Children with Long Term Health Conditions" which outlines a model, framework and standards for the development of services for children with LTHC.^h

Important elements of the policy and its implementation are:

- ◆ The need for a **competent family orientated multidisciplinary service** for children at each level of the service.
- ◆ The key role of the **paediatric nurse (practitioner)** who assists with coordination of the care, therapeutic education, counselling and monitoring. At tertiary level, s / he works in a particular discipline as a liaison person, and provides support to regional and district services.
- ◆ Good Communication through **case management plans** that are developed for each child by the highest level of referral. These will outline the condition, care at each level, including emergency care and contact.
- ◆ **Patient held records** that will aid coordination as patients move between services and disciplines.

h The Draft Document: "Implementation guideline to the policy framework for long term health conditions in children" and Policy Framework for noncommunicable chronic conditions in children was finalised in December 2002 available from Dr A Robertson or Dr T Westwood. arobertson@dhw.norprov.gov.za; Awestwood@pgwc.gov.za

- ◆ **Community and intersectoral linkages.** This ranges from linkages with patient-provider organisations, community organisations, as well as formal and informal social and education bodies.
- ◆ **Monitoring and audit** of the service, will include the development of a number of indicators to monitor equitable care in sentinel conditions

Standards for services at each level are outlined in Appendix 1.

PREVENTION STRATEGIES

Primary prevention of chronic conditions includes good antenatal, perinatal, neonatal and paediatric care, nutrition and food fortification.

FAMILY PLANNING, ANTENATAL, PERINATAL AND NEONATAL CARE

Good care will decrease the incidence of many chronic conditions in childhood and adolescents. All elements of the service contribute to prevention of chronic conditions. They include:

- ◆ Prevention of unwanted pregnancies;
- ◆ Prevention of pregnancy / screening in women of advanced maternal age;
- ◆ Prevention of alcohol ingestion;
- ◆ 5 antenatal visits with routine screening of BP, urine, and foetal growth;
- ◆ Syphilis screening;
- ◆ PMTCT;
- ◆ Health Promotion;
- ◆ Maternal care guidelines and partogram usage;
- ◆ Examination of all newborns; and
- ◆ Newborn care guidelines for sick and low birth weight babies.

Prevention is dependent on the effective implementation of these policies and guidelines.

ADEQUATE CHILD HEALTH CARE

This is provided through involvement of the household, the Integrated Management of Childhood Illness (IMCI) and good hospital care. Nutritional guidelines, and breastfeeding support is provided through IMCI

and integrated nutrition programmes. While malnutrition is a priority, more attention needs to be focused on the prevention of obesity in urban children.

Access to these services is theoretically good, but the coverage and quality of care are problematic. Neonatal and paediatric hospital care is a concern, and is reflected in the Saving Children report.³⁵

FOOD FORTIFICATION

The fortification of staple foods with folate and other micronutrients have been shown elsewhere to decrease the prevalence of neural tube defects at birth. Food fortification commenced in 2003 in SA. The results of surveillance to assess whether there has been a decline in neural tube defects are awaited. Preliminary findings suggest a 30% decline in the prevalence of neural tube defects after the introduction of fortification.^{i,36}

STATUS OF HEALTH CARE SERVICES

The health sector response to children with chronic conditions is varied. Many academic hospitals are responding to the needs of urban children who have access to them. They often work together with patient-provider organisations. Paediatric and neonatal care at these facilities is good. On the other hand, rural residents cannot easily access this care, and services for LTHC in rural areas is very limited.

Additional reasons for the inequitable care are:

- ◆ **Tertiary services are inequitably distributed.**
Most sub-specialist services are currently situated in the 4 major urban centres of Gauteng, Western Cape, Free State and KwaZulu-Natal. They are funded and mandated to provide tertiary services to children from all 9 provinces, but the reality is that children from rural provinces do not access these services as frequently as their urban peers.
- ◆ **Many children are referred too late for effective treatment.**
This may be due either to late recognition of the illness or to bottlenecks in the referral system.
- ◆ **Far fewer children than adults have accessed antiretroviral treatment** to date. Those that do, mostly receive their care at a tertiary level. Few

i Personal communication, Dr David Bourne, Department of Community Health, UCT, June 2006.



level 1 and 2 hospitals have specific organisational arrangements for the care of children with LTHC. As a result there is no foundation on which to build the HIV service. A big challenge is to improve linkages between PMTCT, VCT, IMCI and the CCMT clinics.

◆ **Health care is too centralised at present.**

Tertiary services treat many children who could be treated at level 1 and 2, but they continue to be managed at tertiary level, because of inadequate services, or lack of medication at level 1 and 2. There is also a lack of patient education about the referral system.

◆ **Dysfunctional specialist services.** Secondary (specialist) level services, which are seen as the hub of care for children with long term health conditions are poorly developed. This results in a large communication and service gap between level 1 and 3 services.

◆ **Transport for many patients between hospitals is a problem,** resulting in missed appointments and opportunities for care.

INNOVATIONS

There are a number of services that have introduced innovative ways to provide care.

NATIONAL WORKING GROUPS AND PATIENT-PROVIDER ORGANISATIONS

A number of national organisations and working groups exist for specific conditions, e.g. allergies, children's cancer and cystic fibrosis. In some instances these are supported by patient-provider organisations. They work well together to achieve a number of goals. These include:

- ◆ Advocacy among professionals, community and health services;
- ◆ National treatment guidelines;
- ◆ Increase awareness of illness and early identification of cases; and
- ◆ Training and educating patients and providers.

The Haemophilia Foundation has led with an excellent model. They provide support services for people with haemophilia by developing the services, participating

in care and assisting with practical aspects of care, monitoring and procurement.¹⁷

The Children's Cancer Study Group has ensured that there are guidelines for the early recognition of childhood cancer. In addition, they have a toll free line, for health workers and parents to access telephonic advice. By monitoring the number of cases of children with cancer and promoting an open door policy for new cases in any of the centres, more patients are identified and access care. Much of their work is also supported by a patient-provider organisations.

NURSE PRACTITIONER INVOLVEMENT

A number of services rely on the nurse practitioners. In diabetes care, at Red Cross Children's Hospital (RCCH) they provide an essential role that includes:

- ◆ Education of new patients about their condition, home management and care. This takes many sessions, and early regular follow up is needed.
- ◆ Follow up to ensure care is going well.
- ◆ Monitoring patients.
- ◆ Liaison with other service providers, educators and family.
- ◆ Support groups for parents, patients, adolescents.
- ◆ Camps for patients.
- ◆ Being on call for patient queries.
- ◆ Liaison between the patient and doctors.

The low case fatality rate at the RCCH service is largely a result of this service.

Nurse practitioners play similar roles in care of asthma, epilepsy, HIV and bleeding disorders.

Comprehensive Management of children infected with HIV has highlighted important aspects of a chronic disease service for children. These include:

- ◆ Adequate counselling of the caretaker and child on adherence;
- ◆ Disclosure to the child;
- ◆ Family management;
- ◆ Role of team members such as lay counsellors, pharmacists, social workers, dieticians;
- ◆ Short message services (SMS) and telephonic reminders and support; and

- ◆ Support from groups such as Institute for Health-care Improvement (IHI) has demonstrated that nurses in rural clinics can provide care.

TEAM WORK / MULTIDISCIPLINARY CARE

Many services have a multidisciplinary team of people on the same site at the same time, which facilitates services for patients e.g. Cerebral Palsy and Cystic Fibrosis.

INCREASING SPECIALIST SERVICES

Once a critical mass of specialist services (paediatricians with other team members) is attained at a designated site, more children from the catchment area will be able to access appropriate care.

Children struggle to access specialised surgical care. A number of initiatives providing services for children across provincial boundaries facilitate access e.g. Craniofacial Clinic at Johannesburg hospital.

CONCLUSIONS

- ◆ There are many children with LTHC and impairments in South Africa.
- ◆ Primary prevention such as PMTCT, good perinatal and paediatric care as well as health promotion are a priority.
- ◆ Many children with chronic conditions are undiagnosed, or poorly managed and do not access the care they require. Either the service does not recognise the need, or there are problems with inequitable distribution of health care facilities, the referral system and transport.
- ◆ South Africa does have the expertise within the health sector and the community to develop innovative ways to provide a network of services for children with long term conditions and disability. This expertise is, however, currently housed only in the major urban centres, thus children at academic centres receive good care.

RECOMMENDATIONS

- ◆ Implement the policy on the Management of Children with LTHC.
- ◆ Determine indicators for monitoring, for example:
 - Number of children accessing heart surgery
 - PMTCT targets
 - Paediatricians per population
 - Number of children with sentinel conditions accessing services
 - Treatment targets for children on ARVs.
- ◆ Patient-provider organisations must be encouraged to continue their work, especially within the framework of the policy.
- ◆ Specialist services need to be developed as a matter of urgency. Regional teams must be put in place to care for children with chronic illnesses.
- ◆ There must be recognition of the role of the paediatric nurse in the ambulatory service for children with chronic illnesses. There is also a need to ensure that there are sufficient nurses with adequate skills to provide care for children with chronic illness especially HIV-related diseases. There is also a need to ensure a strong community health worker programme.
- ◆ Services for children with chronic illness should be based in a child and family friendly ambulatory facility that includes a walk in facility for emergency care.
- ◆ Integrate chronic HIV care into services for other children with chronic illness.
- ◆ Designate and accredit centres to take regional responsibility for the care of children with certain conditions. Provincial boundaries must be transcended.
- ◆ Implement the recommendations from the Modernisation of Tertiary Services project.

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APPENDIX 1:

Long term Health Conditions in Children: Minimum Standards for Service Provision

	Clinic / CHC	District Hospital / CHC	Regional Hospital	Tertiary / National Hospital
Definition of level	A clinic is situated close to the community and is staffed mainly by Professional nurses.	A District hospital operates at PHC level with general medical officers.	A regional hospital provides care centred around general specialists i.e. paediatricians.	A tertiary hospital provides sub-specialist paediatric and paediatric surgical care.
Average population served	10 000-15 000	100 000	1 000 000	2.5-5 000 000; 4 million used for data.
Estimated number of children requiring a service	4 000 children under-15; 200 children with a LTHC needing care.	40 000 children under-15; 20% have a LTHC, 2 000 children need LTHC.	400 000 children; 5% need care at this level; 20 000 children need LTHC.	1 600 000 children; 2% will need care at this level. 32 000 children need this service.
Patient profile	Asthma, epilepsy, cerebral palsy and HIV.	Asthma, epilepsy, HIV, cerebral palsy, and co-management of other conditions with regional paediatric service.	Complex asthma, epilepsy, cerebral palsy, HIV, bleeding disorders, congenital and genetic conditions and co-management of children with diabetes, heart disease and other rare conditions.	All children with congenital heart disease, cancer, end stage renal disease, congenital conditions requiring surgery, diabetes and other complex and rare conditions will require care coordinated at this level.
Clinical Service Delivery	Early Identification Referral to doctor or district hospital. Counselling and testing for HIV. Prevention and Care through competent IMCI, PMTCT, Antenatal care, Peripartum care. Management and monitoring of children with LTHC through Case Management Plan. Treatment of intercurrent problems and emergencies. Larger clinics, health centres provide rehabilitation. Initiation of support groups.	Early Identification though appropriate care. Management and monitoring of children with LTHC with support from a regional paediatrician and use of case management plans. Full range of Rehabilitation Social support and Care dependency grants. Follow up of high risk and abnormal babies. Appropriate referral case management plans. Issue and repair of assistive devices.	Paediatric Care of children with LTHC. Development of individual Case Management Plans. Rehabilitation and Social support. Multidisciplinary liaison and care. Assistive devices. Referral to tertiary Support for District hospitals.	Sub-specialised medical, surgical and allied health care. Multidisciplinary care and liaison. Advanced rehabilitation Individual case management plans. Support for regional services. Development of guidelines.
Organisation of the clinical service	As part of integrated PHC services. Additional afternoon clinics and or support groups as indicated Home visits where necessary.	Booked Clinics in a dedicated Paediatric OPD. Multi-disciplinary clinics. Multi-disciplinary meetings. Outreach to PHC clinics. Visits to special schools and centres. Hosting visiting paediatrician once a month.	Daily multidisciplinary specific clinics e.g. HIV, Neurology, Cardiology and Allergy in Paediatric ambulatory unit. Inpatient services. Multidisciplinary meetings. Outreach visits to District hospitals, schools, centres and homes. Hosting visiting sub-specialists.	Full tertiary service that incorporates condition specific multidisciplinary services, in child friendly inpatient and ambulatory environments. Regional support through visits, telephonic and telemedicine links.

	Clinic / CHC	District Hospital / CHC	Regional Hospital	Tertiary / National Hospital
Clinical Staff	Professional nurses trained in IMCI, PHC, PMTCT, and VCT. Larger clinics may have visiting medical officers and therapists.	3 Paediatric medical officers dedicated to service including ambulatory and comprehensive HIV service (Diploma in Child Health is a recommendation). 3 Paediatric nurses in ambulatory service (Training in Paediatrics, IMCI, HIV, VCT, Genetics, Haemophilia, Diabetes). Paediatric ward staff; emergency care staff all allied health workers.	3 Paediatric / Child health nurses in Paediatric ambulatory specialist unit. 3-5 Paediatricians Senior rehabilitation staff, dedicated to the paediatric service. 5 Paediatric Medical Officers for Paediatric service.	Refer to Modernisation of Tertiary (MTS) Services. In most units 2-3 sub-specialists. Multidisciplinary teams in each. Specialist Liaison Nurses for each team e.g. Diabetes, Oncology, Haemophilia.
Facilities	Confidential consultation and counselling rooms. Large room for meetings, support groups and rehabilitation.	Paediatric Ambulatory area with adequate space for consulting, counselling, waiting and playing. Rehabilitation facilities next to OPD. Multidisciplinary work space. Paediatric ward. Mother lodger facility.	Paediatric outpatient area with adequate space for consulting, counselling, therapeutic interventions, waiting and playing. Paediatric rehabilitation facilities. Meeting areas. Paediatric Wards. Mother lodger facility.	Facilities for each discipline according to international standards. Children's wing or separate hospital preferable. Family lodger facility.
Equipment required	No additional	As per District hospital norms.	As per Regional hospital norms. Monitoring equipment for diabetes, asthma, and other conditions.	Refer to MTS Monitoring equipment for home ventilation, oxygen, and dialysis.
Drug management requirements	As found in the Primary care EDL. Chronic care drugs to be obtained on order every 6 months from District Hospital.	As per Primary care EDL and Paediatric hospital level EDL. Additional drugs according to 6 monthly paediatric prescription.	Drugs according to Paediatric EDL and motivation per child.	Specialised drugs, care needs to be taken to ensure that these are available at appropriate level when child is referred back.
Referral and support	To and from district hospital.	To and from a paediatric specialist service, if a level 2 service is not in place then a level 3 service.	Referral to and support and visits from the full range of children's subspecialty services.	National and international organisations. National support for highly specialised services.
Audit and monitoring	Register of children with special needs.	Register of children with LTHCs. Indicators developed with province / regional paediatrician. National HIV data set.	Data-base of conditions. Indicators developed with province / tertiary, sentinel indicators. National HIV data set.	Service data-base and some national registries e.g. children's cancer register. National sentinel indicators.
Community liaison	Implementation of the Integrated Management of Childhood Illness (IMCI) household and community component with use of care groups. List of care centres and CBOs.	List of community organisations, care centres, and schools. Regular liaison with above.	List of community organisations, care centres, and schools. Visits to special schools.	Provincial NGOs. National organisations. Education, Social development.
Responsibility and Coordination of the service	Community Liaison Officer, MCWH coordinator district and MCWH coordinator province.	Paediatric medical officer, Paediatric Nurse, Practitioner District MCWH coordinator.	Regional Paediatrician; provincial led Paediatrician. ⁱ Provincial MCWH coordinator.	Academic institutions. Provincial led Paediatrician.

Source: Draft implementation guidelines on the management of children with long term health conditions, 2006.

ⁱ This is a paediatrician who provides the province with technical support.



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