Long term health conditions in children: Towards comprehensive care

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Nearly a quarter of all children have some form of long term health condition (LTHC). Global attention has been focused primarily on such conditions in adulthood. LTHCs among adults, such as diabetes and high blood pressure (also known as non-communicable diseases, or chronic diseases of lifestyle), are placing increasing pressure on health services and national budgets. National governments and health and other services have given much less attention and fewer resources to the needs of the many children with LTHCs. Most of the focus in child health in recent decades has been on the infectious and neonatal conditions responsible for the bulk of mortality and morbidity of children under five years of age. In addition, the range of LTHCs affecting children is much wider than among adults (see Table 1 for a classification of LTHCs among children), and their care is distributed across a wider range of health services with a greater proportion taking place in specialised services. Organising long-term care in health and other services for children with LTHCs is thus more complex than for adults.

This chapter shines a light on the many children in South Africa who have disabling and long-term conditions and whose right to survival, optimal development, basic health and education services and dignity, amongst other rights, are not being met. It argues that condition-specific care, together with routine (or 'non-categorical'[i]) long-term care to help children and families cope with the consequences of the LTHC, constitute "basic health care services" for these children under section 28 (1)(c) of the South African Constitution. It proposes approaches to realising these rights, highlighting children with disabling and life-limiting conditions who, with their families, have the greatest need for a comprehensive response from government and communities.

The chapter seeks to answer the following questions:

- How are the LTHCs affecting children defined?
- What are the LTHCs affecting children?
- What is the health burden due to LTHCs among children in South Africa?
- What are the consequences of having a LTHC for the child and family?
- How can services best work with children with LTHCs and their families?
- What laws and policies are there to guide service providers and society in meeting the needs of children with LTHCs and their families?
- What are the policy and implementation gaps and what are the recommendations?

How are the LTHCs affecting children defined?

Unlike acute conditions that come and go in a short period of time, LTHCs, by virtue of their continuous presence in the life of a child and family over time, are likely to have an impact on the development and life chances of the child unless they are managed well through childhood. As first described by Stein and colleagues,[1] the two essential elements of the definition of LTHCs are the duration of the presence of the condition and the need for health services. Box 8 highlights how duration also brings with it a set of potential consequences for the child and family as does the need for health services over that time. A working definition of a LTHC is outlined in Box 9.

Box 8: Common characteristics and needs of children with LTHCs

- Increased psychological stresses for the child, parents, caregivers and siblings
- Increased financial strain
- Risk of problems with physical growth
- Risk of problems with neuro-development
- Potential barriers to learning
- Increased financial costs
- Challenges in negotiating the transitions of childhood, especially adolescence

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[i] 'Non-categorical' means that children and families living with LTHCs face similar challenges regardless of the category of the long-term condition. This concept is explained further in this essay (see Table 2).

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Box 9: Definition of long term health condition

A long term health condition is one that has a physical, cognitive or mental basis and the following three features:

1. It affects the child for enough time to potentially affect the child's physical or psychological development (more than a year, sometimes for life).
2. The child requires ongoing health and/or other services to function optimally.
3. As a result, the child requires continuous, coordinated and comprehensive health care.

Adapted from: Stein REK, Bauman LJ, Westbrook LE, Coupey SM & Ireys HT (1993) Framework for identifying children who have chronic conditions: The case of a new definition. *Journal of Pediatrics*, 112: 342-347.

What are the long term health conditions affecting children?

Table 11 sets out a classification of the myriad congenital[ii] and acquired[iii] conditions that affect children. Every organ of the body may be affected and many LTHCs affect multiple organs. Long-term mental health and cognitive conditions are included. Some LTHCs, like asthma, are very common; others affect only a few children. A significant number of LTHCs are severe and disabling; others are mild. Some, like certain cancers, are curable; others, like haemophilia or Type 1 diabetes mellitus, are lifelong, or may lead to the child's early demise as many inherited disorders of body chemistry do. Specific conditions may affect children differently. For example, allergic rhinitis (hay fever) can be a mild irritation to one child but can interfere with learning or even lead to life-threatening heart failure in another.

Table 11: A classification of long term health conditions in childhood

Time of onset	Group name	Sub-group by cause	Examples
Before birth	Congenital	Genetic disorders	Down syndrome, haemophilia, muscular dystrophy, metabolic disorders, certain forms of epilepsy
		Congenital infections	Damage from German measles virus
		Foetal damage by external toxins	Foetal alcohol spectrum disorders
		Congenital disorders of unknown cause	Many syndromes; many forms of congenital heart disease
During birth	Perinatal	Consequences of preterm birth	Some forms of cerebral palsy; blindness due to damage to immature eyes
		Consequences of birth injury	Some forms of cerebral palsy; intellectual disability
		Consequences of severe neonatal illness	Some forms of cerebral palsy; deafness
Any time from birth to adolescence	Acquired	Allergic	Asthma, allergic rhinitis
		Post-infectious	Chronic lung diseases, kidney failure
		Infectious	HIV/AIDS, tuberculosis
		Post-traumatic	Traumatic brain injury; limb amputation
		Auto-immune	Diabetes mellitus, juvenile arthritis
		Neuro-behavioural	Autistic spectrum disorders, attention deficit disorders (see Box 10)
		Psychiatric	Depression, obsessive compulsive disorder
		Intellectual disability	Mild, moderate or severe
		Sensory disability	Deafness, blindness
		Nutritional	Obesity
		Tumours and cancers	Acute leukaemia; brain tumours
		Unknown causes	Certain forms of epilepsy

Note: The time at which a long term health condition is first recognised depends on access to screening tests (e.g. ultrasound during pregnancy, examination of newborn babies), parental knowledge (e.g. access to genetic counselling, knowledge of normal child development), access to clinical services (e.g. nurses who can identify children who are at risk), and how long a particular condition takes to show symptoms.

[ii] 'Congenital' means that the cause of the condition occurs during pregnancy before labour commences, e.g. Down syndrome.

[iii] 'Acquired' means that the cause of the condition occurs after the child is born, e.g. cerebral palsy as a consequence of meningitis.

The sheer diversity of childhood LTHCs and their many rhythms and long-term trajectories introduces service delivery challenges that are more complex than with most long term health conditions in adults.

What is the health burden due to LTHCs among children in South Africa?

For many reasons, there are inherent difficulties in establishing how many children have LTHCs given the wide variety of conditions, times of onset, levels of function and mortality rates. No comprehensive attempt has been made to do this within existing surveys or research in South Africa. Inequity of access to accurate diagnosis and specialised care in South Africa means that health service or register data would be an underestimate of numbers and need. Thus, accurate comprehensive data on the number of children who have a LTHC in South Africa are lacking.

Overall, however, based on international figures and what is known in South Africa, it is likely that from infancy to late adolescence about one in every five children in South Africa has a LTHC (i.e. about four million children). A significant but unclear proportion of these children have a severe or complex disorder. Birth incidence of congenital disorders in South Africa was estimated by to be about 83,000 live births in 2012 (6.8% of all live births).[2] With about 30% of these children inevitably dying early due to the severity of their congenital condition, the remaining approximately 60,000 infants per year will require some form of management (often multi-disciplinary including paediatric surgery) and continued long-term care.

In terms of childhood disabilities, combining Statistics South Africa's census-based childhood disabilities estimates[3] that do not include children under five years of age with figures from an international study on developmental disabilities[4] that only counted children under five years of age, a total of 1.15 million children in South Africa are estimated to have sensory, developmental, cognitive and motor disabilities, many of which are congenital.

Overall numbers of children living with a LTHC may not have changed much in recent decades but, for various reasons, the conditions that make up these numbers are likely to have changed. Long-term consequences of vaccine-

Box 10: Attention deficit and hyperactivity and autistic spectrum disorders in childhood

Attention deficit and hyperactivity disorders (ADHD) and autism spectrum disorders (ASD) are the two most common types of neuro-behavioural disorders affecting children in South Africa and constitute a particular challenge in long-term care.

ADHDs are characterised by a mix of poor concentration, impulsivity, fidgetiness and restlessness, learning problems, mild motor difficulties, and poor social skills. Without recognition, careful assessment and management, these lead to poor educational outcomes, difficult family and peer relationships, poor self-esteem and stigma.

ASDs are characterised by sensory sensitivities, difficulties with language, communication and inter-personal relationships, repetitive behaviour and difficulty coping with change. Some children with ASD have major learning problems. This array of difficulties challenges families and education systems and makes many inputs from an array of educational, social and health professionals necessary.

These conditions occur commonly across all class, cultural and language groups in South Africa. Many of these conditions are recognisable well before the child enters the formal education system, the point at which the behaviours and learning traits become more obvious. Early identification and intervention are key, enabling children to access therapeutic and family interventions that can improve their life trajectory and educational attainment. Early childhood development practitioners have a crucial role in identifying children who have difficulties with language, social relationships and abnormal patterns of play (see Case 1).

Optimal management of ADHD and ASDs requires coordinated intervention from health, education and social services – and support for both the child and family. Systems to achieve this are not well established and resourced. Access to assessment and therapy services in the health system is poor especially at the primary care level. Mainstream schools battle to provide educational support and special schools are rare. Social stigma is rife, and these children often experience social isolation, mental health problems, school failure, poor career prospects and difficulty with intimate relationships.

Apart from the generic long-term care approaches espoused in this chapter, specific cross-disciplinary attention needs to be given to ADHD and ASD services across South Africa if the best interests of this large number of children are to be realised.

preventable diseases and common childhood infections have decreased due to immunisation and treatment programmes. Their place has been taken by three groups of children in what is known as an 'epidemiological transition':[5.]

1. Children whom medical science has saved from death but not saved from long-term disability and/or need for services, such as very low birth weight babies ("premature babies") and many children whose congenital defects have been surgically corrected at least partially, congenital heart defects being the commonest in this group.
2. Children with previously life-limiting conditions, such as cancer; HIV/AIDS; cerebral palsy; sickle cell disease; many forms of congenital heart disease; and cystic fibrosis, where medical advances have increased their life span, often into adulthood.
3. The increasing prevalence of children with obesity, chronic constipation, allergic disorders such as asthma, mental health disorders such as depression and anxiety, and neuro-behavioural conditions (see Box 10) such as autistic spectrum disorders (ASD) and attention deficit and hyperactivity disorders (ADHD). These increases are probably related to changes in diet, reductions in infectious diseases, increasing urbanisation, climate change, and/or stressful environments.

There is also a concern regarding over-diagnosis of some LTHCs by practitioners and families, such as food allergies and ADHD.

On the positive front, improvements in access to paediatric care and awareness of conditions such as ASDs mean that fewer children with LTHCs are being missed in South Africa.

In child health in general, prevention of disease, disability and death is a primary concern. To what extent are LTHCs in childhood preventable? Box 11 shows how a wide range of preventive approaches can and should be applied to LTHCs in childhood in South Africa.

What are the consequences of having a LTHC for the child and family?

A number of important consequences for the child and members of the family may occur as a result of the LTHC. An understanding of these consequences and how to deal with them is essential in order to provide optimal care for children

Box 11: To what extent are the prevalent long term health conditions in South Africa preventable?

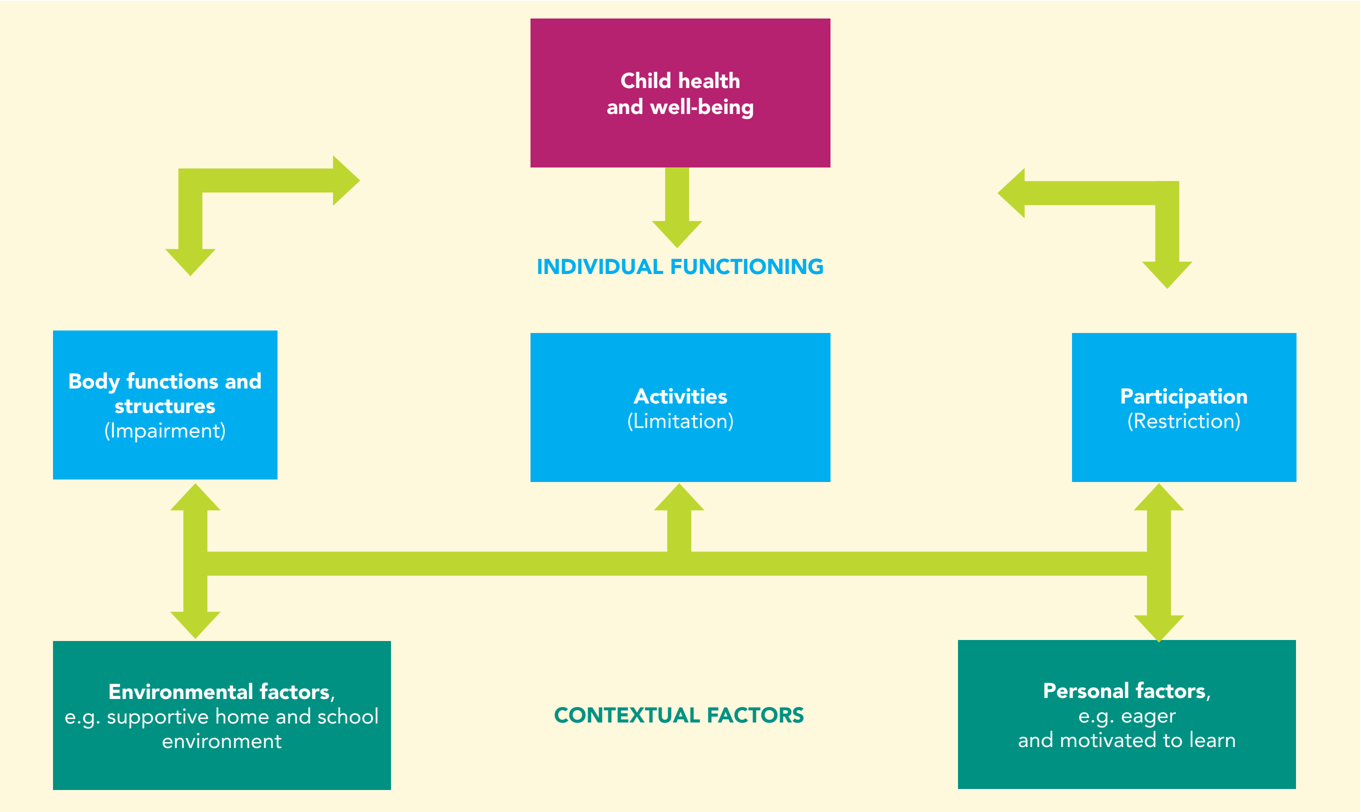
- Primordial prevention aims to reduce factors that increase the overall burden of disease in a population such as pollution, uncontrolled urbanisation, lack of access to healthy foods, climate change and social disruption. The prevalence of some common childhood mental health problems, obesity, allergies and lung diseases would decrease with better urban planning, agricultural and food policies, improvements in air quality, cooler climatic conditions, and safer societies.
- Primary prevention aims to stop the condition from occurring at all. For example, quality perinatal and neonatal care can prevent cerebral palsy (CP) and foetal alcohol syndrome disorders; preventing exposure to tobacco smoke can reduce long term lung diseases such asthma and tuberculosis. Genetic services, including genetic counselling, can play an essential role in primary prevention in childhood. Long term consequences of infections can be prevented in the same ways that the infections themselves are prevented: immunisation, hygiene, prevention of mother-to-child transmission of HIV, etc. Mental health and behavioural problems can be prevented with nurturing care and the recognition and mitigation of risk factors in the classroom. Obesity is preventable through early nutrition education, growth monitoring and exercise programmes.
- Secondary prevention aims to identify risks or conditions and intervene as early as possible. For example, children who are obese are more likely to develop asthma and diabetes. Screening for heart diseases at birth and during childhood can lead to life-saving early interventions. Early childhood intervention (ECI) for developmental difficulties and disabilities is an established and effective form of secondary prevention – see Case 5.
- Tertiary prevention aims to overcome or mitigate the effects of a LTHC, e.g. physiotherapy and orthopaedic surgery in CP; blood products in haemophilia. Tertiary prevention is the focus of much health service effort and is a vital part of reducing the burden of suffering related to all LTHCs in childhood.
- Quaternary prevention refers to preventing suffering as a result of inappropriate health-related fears. For children, concern about food allergies that lead to poor diets and activity limitation is a common example that requires prevention of a "pseudo-LTHC" in many young children.

with LTHCs and their families. While this chapter deals with consequences that may put well-being at risk, many also enhance quality of life for the child and members of the family (for example by promoting greater family cohesion).

Disability or disabilities

Disability is one of the most common consequences of a child having a LTHC, although LTHCs and disabilities in childhood are not the same thing. All children with disabilities have a LTHC because the disabling condition (such as cerebral palsy) is present in the long term. But not all children with LTHCs have a disability. For example, if the condition is mild, well-controlled, or compensated for by an enabling assistive device (e.g. a hearing aid) or an educational or social compensatory intervention (e.g. classroom support), the child who has the LTHC is not necessarily disabled by it. LTHCs can result in **secondary disability**, for example depression in a child who has an incurable condition may reduce their ability to learn and participate at school. For many years, defining **disability** as an individual "problem" (the medical model) was the dominant way of thinking. However, there is growing recognition that the functioning of children with LTHCs is affected by the environments in which they live – their immediate family, physical and social environments. Although diagnoses are important for defining the cause and prognosis, they do not necessarily predict the child's **level of functioning**.[6] It is therefore essential to identify any **limitations of function** that may restrict the child's **ability to participate** in order to develop a care plan for the individual child. A formal medical diagnosis is not necessary for this process to take place. The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)[7] is designed to document both the characteristics of the developing child and the influence of the surrounding environment. The ICF-CY provides a standardised framework for **impairments, activity limitations** and **restrictions to participation**[iv] in everyday life situations and relevant environmental factors (Figure 32). It also presents a common language to enable the documentation and measurement of health and disability in children and youth across different settings. Although largely used in the context of disability, this framework can provide the basis for developing and delivering optimal care plans and systems for all children with LTHCs in addition to

Figure 32: The International Classification of Functioning (ICF) Framework



Adapted from: World Health Organisation (2007) *International classification of functioning, disability and health: Children and youth version.* WHO.

[iv] 'Impairment' refers to a loss or abnormality in body function or structure; 'activity limitation' is a difficulty experienced by an individual in executing a task/action; and a 'participation restriction' is a difficulty experienced by an individual in everyday life situations.

Table 12: Principles for delivering routine long-term care for children

Principles	Definition	Some ways to demonstrate generic care
Comprehensive	Covers all aspects of care needed, from promotive to palliative for all children with LTHCs	• Cover all aspects of care outlined in this table • Ensure all usual child health care (e.g. immunisation) is carried out • Promote optimal development
Coordinated	Planned, seamless and efficient care across sites, sectors, and professionals involved in the child's care	• One member of the health team designated as coordinator of the child's care – could be a specialist nurse or a general practitioner • Ensure parents know who to contact • Multi-disciplinary clinics for complex diseases; teamwork • Book clinics on the same day • Keep all role players informed • Planned patient transport for patients who live far away – a missed appointment could be a disaster • Plan for provision of drugs; servicing of equipment • Individualised care plan carried by parent or caregiver; copy to role players at every level of care; regularly updated by "highest" level of care • Standardised management guidelines • Define the role of each level in a child's care; outreach services from tertiary and secondary levels
Continuity of care	Continuity of people, management and information in the child's care across the life course. Incorporates the C-word "consistency".	• Same faces in the health service as far as possible • Designated "chronic care" nurse(s) in outpatient department • Encourage outpatient nurses to give advice when the child is an in-patient • Notekeeping and care plans track care provided • Integrated data systems across levels and sectors • Anticipatory guidance
Communication	Verbal and written means of transmission of meaning and information for child, family, health care team and other sectors	• Appropriate interpersonal communication and counselling between health team and child and family • Practitioners at all levels to write in the Road to Health Book at every visit • Patient-held record for older children, and children with complex needs • Individualised care plan • Secretarial support • Email/WhatsApp groups/fax/telephones that work • Parents are recognised as an essential part of the team • Integrated data systems across levels and sectors
Community-linked	Services and families are in touch with and using community resources	• Non-governmental organisations, community-based organisations • Community support groups • Support for schools and educators by the health team • Service directories
Capacitated	Capable of performing actions expected of someone or something (child, family members, professionals, systems)	• Basic and post-basic health professional education to include non-categorical or routine long-term care principles and practice • Essential standard patient records, equipment and medication available throughout the system • Outreach systems from specialised levels of care • Patient- and family-centred health education ethos • Recognise that the child needs to understand his or her condition according to the developmental stage – include the child from the start

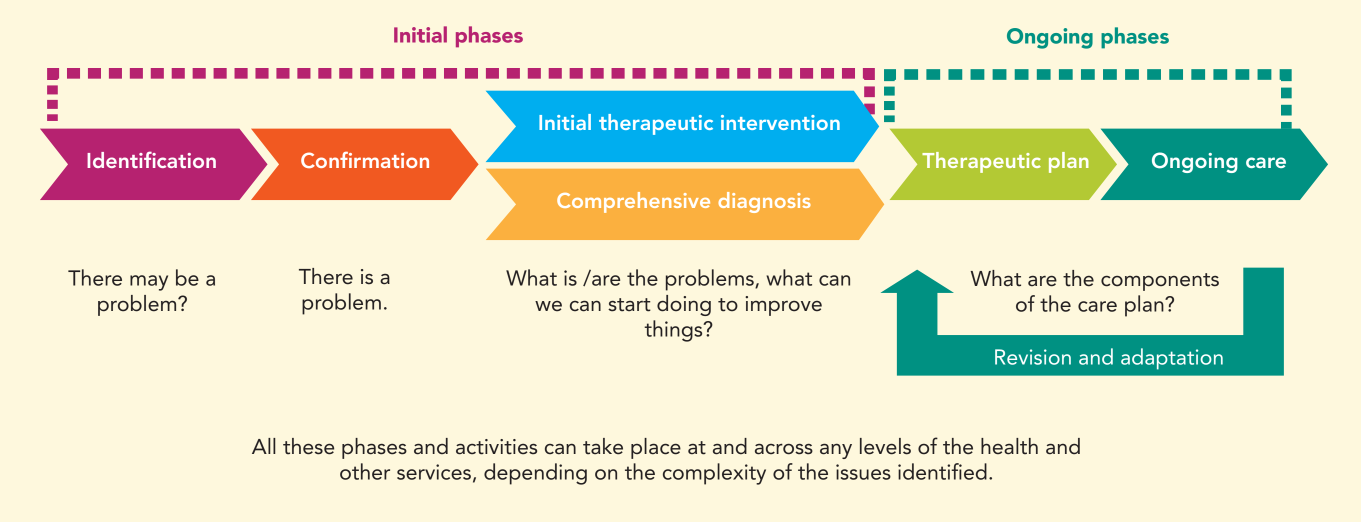
Adapted, with permission, from: Kibel M, Westwood T & Saloojee H (2013) *Child Health for All*. 5th edition. Oxford University Press.

diagnosis-based International Classification of Disease that is usually used in clinical care and health information systems.

A set of predictable and potentially preventable consequences for the child and family

The continuous presence of a LTHC can negatively influence the child's physical growth, psychosocial development, mental health, education and social participation. The LTHC is also likely to have significant effects on family function and dynamics.[8] Understanding the significance of LTHCs on a child

Figure 33: Care pathways for children with long term health conditions



and family is crucial since this dictates our approach to service delivery. These common consequences, to which family, services and society must respond, are set out in Table 12. As this list of consequences is common to all categories of LTHC (Table 11), it is known as the **non-categorical approach**.[9]

The aim of all interventions for LTHCs must therefore be to achieve **maximum function** and **participation** for the child, and to **minimise disability** where possible. In concert, while each LTHC requires condition-specific care, it is as important to routinely take a holistic **non-categorical approach** to minimise the consequences of LTHCs for children and families across all services and society.

How can services best work with children with LTHCs and their families?

The pervasive acute care model of health service delivery with its short-term goals will not be able to respond appropriately to children with LTHCs. Likewise, the conventional primary care approach to child health with its emphasis on programmes for children under five years of age will also not be able to achieve this aim. How then should services be configured to respond effectively?

Figure 33 shows the stages that each child and family need to pass through: from the initial suspicion that a child has a LTHC; through assessment of the child's functioning and responding early to any deficit; confirming the diagnosis (if possible); to establishing how the condition is affecting this individual child and family; and then developing, implementing and reviewing treatment regimens and care plans as the child and family pass through the transitions of life to adulthood or, in some cases, to the death of the child. Thus, the whole system needs to be geared to providing continuity of care for all such children across the life course and across health and other systems, while addressing their condition-specific needs as well as their generic and sometimes complex needs at facility, community and household levels.

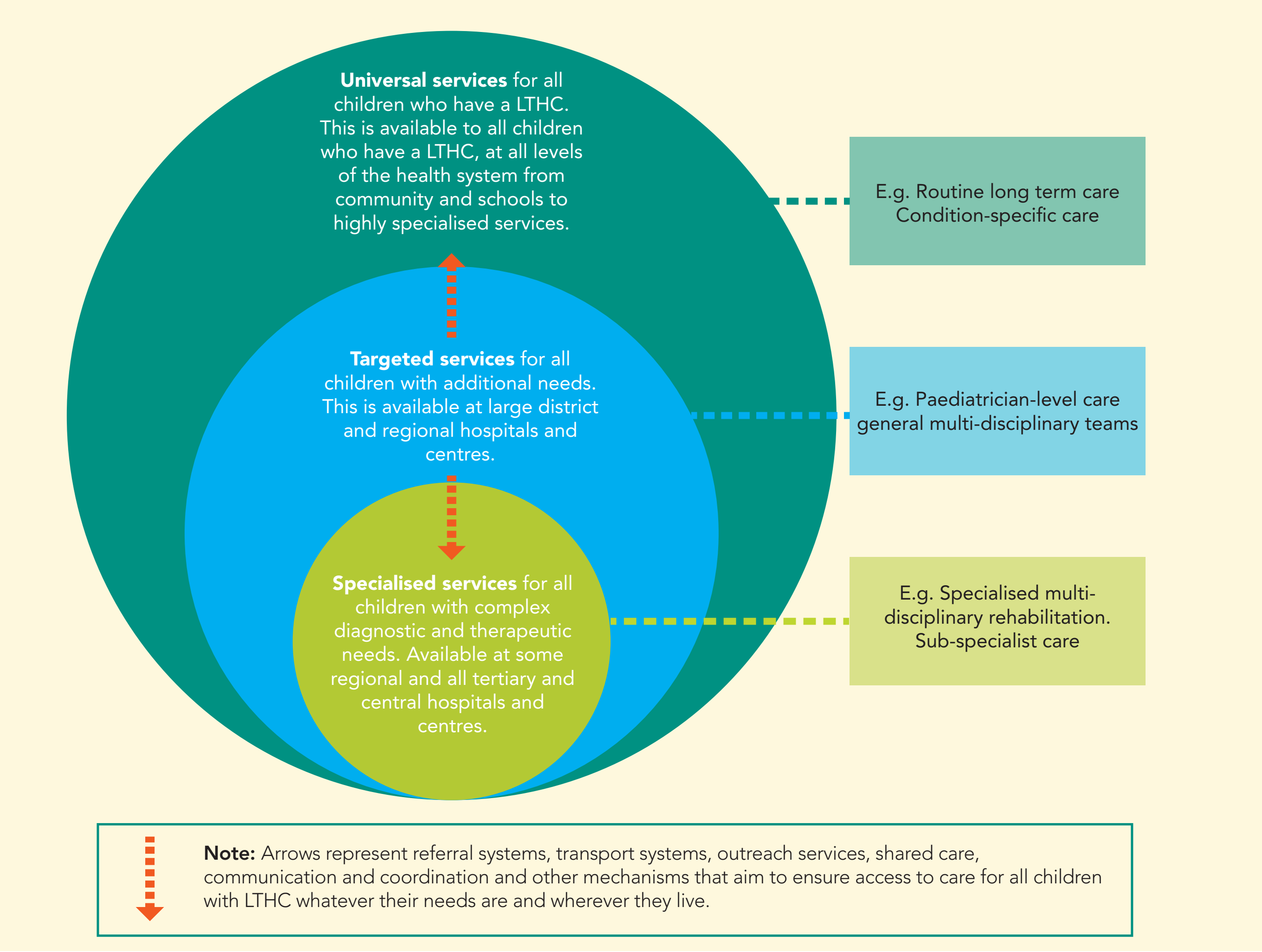
Many parts of the health system, from community level to highly sophisticated services, may be involved in these processes, often repeatedly through childhood. The model of care outlined in Figure 34 shows how non-categorical or routine LTHC care should be available to all children and families at all levels of the health service, while a smaller group of children require special care (e.g. those who need a paediatrician), and an even smaller group who require complex, expensive care involving tertiary services that may include specialised end-of-life care.

These approaches have significant implications for the organisation of services in South Africa's provincially-implemented and inequitably distributed health services at all levels, especially the most sophisticated specialised and highly-specialised services. Interfaces with other services are often necessary, including social and educational services, and non-governmental organisations (such as the Down Syndrome Association), requiring coordinated systems for intersectoral collaboration.

How can care for children with LTHCs be organised to ensure the best outcomes for the child and family? The following attributes characterise such services and systems:

- Services are equitable and accessible to all in need.
- A non-categorical or routine long-term oriented approach is taken at all levels of care.
- Early recognition and intervention occur.
- Multi-disciplinary teams are involved in the care of child and family.

Figure 34. Health services for children with long term health conditions



Note: Arrows represent referral systems, transport systems, outreach services, shared care, communication and coordination and other mechanisms that aim to ensure access to care for all children with LTHC whatever their needs are and wherever they live.

- Leadership and accountability are found, especially for the coordination of a child's care.
- Care is integrated across sectors.
- A family-centred approach is taken, including building partnerships with the child and family so that they can deal with the consequences of the LTHC.
- A palliative care approach is taken (Case 7).

Any health system for children with LTHCs will be most effective if it is characterised by provision of care that is attentive to a number of principles beginning with C, such as Comprehensive, Coordination, Continuity, Communication, etc. Table 12 presents these principles and gives examples of how they can be translated into actions in the health services. Ensuring that all who work with and in services, from policy development and implementation to frontline service delivery and home-based care, translate these principles into policy, protocols and clinical practice provides the key to ensuring that services respond to children with LTHCs and their families. C-words will be bold in the rest of this chapter to demonstrate their conceptual utility in routine long-term care.

Services are equitable and accessible to all

As with all services, those for children with LTHC need to be organised to mitigate inequities such as those between rural and urban, poor and rich, and historically unequal provision of health resources across provinces. Specifically, for LTHC care, referral systems must be set up to allow children to reach the right level for the complexity of their long-term conditions for both the diagnostic and continuing care phases. This can include intra- and inter-provincial referral pathways, tele-medicine systems, shared care[v] and outreach[vi] systems.

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[v] 'Shared care' refers to systems in which health care teams at more than one level of the health system take agreed joint and complementary care of a child and the family, thereby strengthening care that is closer to the child's home.

[vi] 'Outreach' refers to individuals and teams from a more specialised level of the health service bringing insights and skills to a more general level of the health service in an agreed and planned way.

Case 5: The Gauteng Early Child Intervention project[a]

In 2010, the rehabilitation sub-directorate of the Gauteng Department of Health established a multi-disciplinary early childhood intervention (ECI) workgroup in response to concerns over the late identification of children with developmental difficulties and disabilities and the fragmented and variable quality of services in the province. The key objectives of the workgroup are to:

- Raise the profile of ECI in the province.
- Provide provincial guidance and leadership around ECI.
- Improve coordination and standardisation of ECI service delivery at all levels of care.
- Link with partners in the field of early childhood development, education, social development, affiliate health directorates and other relevant partners to address issues with ECI service delivery.

The workgroup prioritised a few key areas to initiate change in the province, i.e. building the capacity of health professionals, providing strategic guidance on ECI, developing resources, engaging with stakeholders, and promoting service-level research and innovative approaches to ECI service delivery.

Since its inception, the workgroup has been hosting at least two workshops a year. The first workshop helps strengthen the ECI knowledge and skills of health professionals (therapists, psychologists, social workers, dietitians, podiatrists, among others) who are new to the province. The second workshop provides a platform for health professionals to share their ECI practices to promote benchmarking, shared learning and innovation. These have included a focus on workshops on child development and ECI for caregivers, educators, early learning practitioners and health care providers; workshops on making toys from waste; transdisciplinary screening and intervention services; and specialised interdisciplinary clinics for children with autistic spectrum disorders.

Regular stakeholder meetings with relevant government departments, non-profit organisations and academic partners have been used to address current gaps and challenges and to improve collaboration and the coordination of services for young children and their families.

Strategic inputs include the development of a provincial ECI policy; guidelines on "How to get started with ECI in your workplace"; integrating key ECI indicators into routine provincial data monitoring systems; and including key tenets of ECI service delivery into the provincial facility audit process.

The workgroup hosts an annual conference which attracts academics and service providers from across the country; publishes a bi-annual newsletter; and produces caregiver education materials on the development of young children for health (and other) professionals.

This investment in strategic guidance, tools and support has led to a growing interest in ECI and ECD within Gauteng and is helping to shift practice from a deficit- to strengths-based approach; place families at the centre at all levels of care; strengthen referral systems and networks; and increase the use of community resources outside the health system.

A non-categorical or routine long-term care approach

Regardless of the LTHC being dealt with, policymakers, service managers (clinical and non-clinical) and frontline professionals should provide care that takes into account the common requirements of child and family – set out in Table 12.

Early identification, diagnosis and intervention

Systems must be geared to the early recognition that a child has a continuing health problem or is at risk from one. At that point (even before a medical diagnosis), systematic early intervention is required. Early Childhood Intervention (ECI) for children with or at risk for developmental delays or difficulties is a well-developed example of this approach.[10] Case 1 presents an example of ECI in Gauteng province. Access to genetic services also improves early identification and diagnosis of congenital and other LTHCs.[11]

The multi-disciplinary team (MDT)

The needs of children with LTHCs and their families are dynamic and often too complex to be met by a single discipline or professional. This requires a transdisciplinary approach to **comprehensive** care, in which professionals work together and share roles across disciplinary boundaries so that **communication**, **cooperation**, shared learning and **coordination** are maximised.[12] Professional roles are not fixed – boundaries are deliberately blurred to allow for

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[a] With contributions from Dr Sadna Balton, Head of Speech Therapy and Audiology Department, Chris Hani Baragwanath Academic Hospital, Soweto and Elma Burger, Deputy Director: Specialised Programmes, Gauteng Department of Health on behalf of the Gauteng ECI Task Team

Case 6: The advanced clinical nurse as a coordinator of complex long term care[b]

In the 1980s all children with tracheostomies were managed as in-patients, often spending many years in hospital. But for the past 30 years, the Breatheasy programme at Red Cross War Memorial Children's Hospital in Cape Town has enabled hundreds of children with tracheostomies to be cared for at home, leading to improved outcomes for the children and saving millions of rands to the health service. Pivotal to this success has been the clinical and service leadership provided by an advanced paediatric clinical nurse (APCN). The role has evolved to include:

- training parents to be independent managers of their children's tracheostomy;
- ensuring full understanding of the home and social circumstances and needs of the family, including through home visits where necessary;
- coordinating the child's and family's care across services and sectors, including the child's school;
- providing psychosocial support to the child and family;
- liaising with community services and organisations, including municipalities (e.g. to arrange electricity supplies to the home) where necessary;
- managing the consumables and equipment needs of the children;
- coordination of the multi-disciplinary team including multiple medical and surgical specialists at the hospital;
- assisting the in-patient nursing team when the children require admission;
- being the go-to person ("medical home") for the families; and
- advocacy and fundraising.

This form of nurse-led clinical leadership has the potential to greatly enhance the efficiency and quality of the care of children with LTHCs, especially in tertiary and school health services.

greater flexibility and responsiveness. A key outcome of transdisciplinary working is the development of "shared meaning" and a joint vision[13] *with the family as an integral part of the team*.

These teams can be constituted at any level of the health service (Figure 34), and often across levels to ensure effective **coordination**. Therapists such as physiotherapists, dieticians, speech and language therapists, and occupational therapists may be part of the initial assessment, and in the follow-up and adjustment of care plans. Para-professionals such as rehabilitation care workers are especially useful in district level services and intermediate care[vii] settings (**community-linked care**). Medical social workers and nurses play crucial roles in supporting the children and their families as they deal with the trauma of learning of the child's condition, the rigours of the medical and therapy regimens over many years, the transitions and ups and downs of life, and in some cases preparing for and following through on the child's death and the family's bereavement.

Leadership and care coordination

This role can be assumed by any member of the MDT, who then becomes the care coordinator or key liaison between the family and the health care team. In countries where this approach has been adopted, e.g. England, this includes care across sectors (health, education and social protection).

Advanced paediatric clinical nurses (APCN) have the potential to strengthen and coordinate care for children with LTHCs in South Africa, but their role is as yet underdeveloped.[14] Case 2 illustrates how the care of children with tracheostomies in Cape Town has been revolutionised (and money saved) through deployment of an APCN to lead the team and coordinate comprehensive care.

Integrated care

As LTHCs affect the child and family in many ways, **comprehensive** support from a variety of services, agencies and organisations is necessary. There may financial support, support in the classroom, or home visits by community workers or faith-based support groups (**community-linked**). This requires care that is integrated and **coordinated** across services (such as health, education and social services) and support systems at district or regional levels. Integrated care is not yet well developed or known in South Africa.

A family-centred approach

Families and caregivers of children with LTHCs assume a central role in optimising the function and participation of these children. Likewise, LTHCs have a profound effect on the child's family including siblings; so a **compassionate** family-centred supportive approach to service delivery is essential.

[vii] 'Intermediate care' is facility-based care that occurs outside of acute hospital care as a bridge to re-integrating children with LTHCs or rehabilitation needs into their home or alternative care.

[b] With contributions from Jane Booth, formerly APCN on the Breathe Easy programme, Red Cross War Memorial Children's Hospital, Cape Town

Case 7: The essentials of palliative care[c]

> *"Palliative care no longer means helping children die well, it means helping children and their families to live well, and then, when the time is certain, to help them die gently."*
>
> *Mattie Stepanik 1990 – 2007.*

Palliative care for a child with a LTHC is the active total care of the child's body, mind and spirit. It also involves giving support to the family. A common misconception is that palliative care is limited to care of the dying child. Palliative care begins when a LTHC is diagnosed whether it is potentially curable, controllable or clearly life-limiting. It should be practised alongside cure-focused interventions. Palliative care takes a holistic view of the needs of the child and family with a LTHC and attempts to meet these needs. The focus is particularly on relieving physical, psychological and spiritual suffering. Where a child does die from a LTHC, palliative care does not end with the death of the child but extends to support for the family during the bereavement stage.

Children have a right to access palliative care. The UNCRC specifically refers to palliative care as a component of children's right to health. This includes the right of access to effective pain relief.

A UNICEF study in partnership with the International Children's Palliative Care Network in 2013 estimated that 801,155 children needed palliative care in South Africa – of these, 304,441 needed more specialised palliative care.[15] The systematic exclusion of certain groups of children means that the numbers of children requiring palliative care are likely to be higher than these estimates.

Given the extent of the need, a key strategy to improve access to palliative care is to integrate such care into the public health system at all levels. This is a key principle in South Africa's National Palliative Care Policy[16] which identifies children as a vulnerable group.

Given the broad range of needs, effective palliative care requires a multi-disciplinary approach that includes the family and makes use of available community resources. It can be successfully implemented even if resources are limited. The Palliative Care Policy recognises that training in palliative care is required across the system; that access to appropriate medication, especially those aimed at pain relief, is mandatory; and expects all provinces to develop implementation plans based on the policy. It also recognises that, beyond the general need for all health professionals to be able to practise palliative care together in a coordinated way, the need for a small number of paediatric palliative care specialists to drive the development of this field and provide specialised support to teams that care of children with LTHCs, especially in the later phases of the care of children with life-limiting conditions.

Priority needs to be given to:

- funding implementation of the national policy;
- improving access to appropriate pain relief (e.g. by including paediatric drugs and formulations in the Standard Treatment Guidelines);
- mainstreaming education in palliative care in all basic health and post-basic professional training; and
- putting practical measures in place to support families after the loss of the child, e.g. by continuing access to the Care Dependency Grant for a period of the death of the child (see Table 13).

Capacitating the child and family

However well organised the long-term care is, it will be most effective if the child and family are active participants and partners in the planning and execution of care. **Building the capacity** of the child and family and allowing their voices to be heard as part of the MDT are crucial elements of care. **Community organisations** can play a vital role in this **capacitation** and partnering with the family.

A palliative care approach

The above principles and practices are all part of palliative care, which aims to reduce pain and suffering and to improve quality of life. This approach requires a view of the purpose of LTHC care that goes beyond medical and rehabilitation care to dealing **comprehensively** with all needs of the child and family. Case 3 expands further on palliative care in South Africa, especially as it applies to children in the later stages of life-limiting LTHCs and children who have intractable symptoms.

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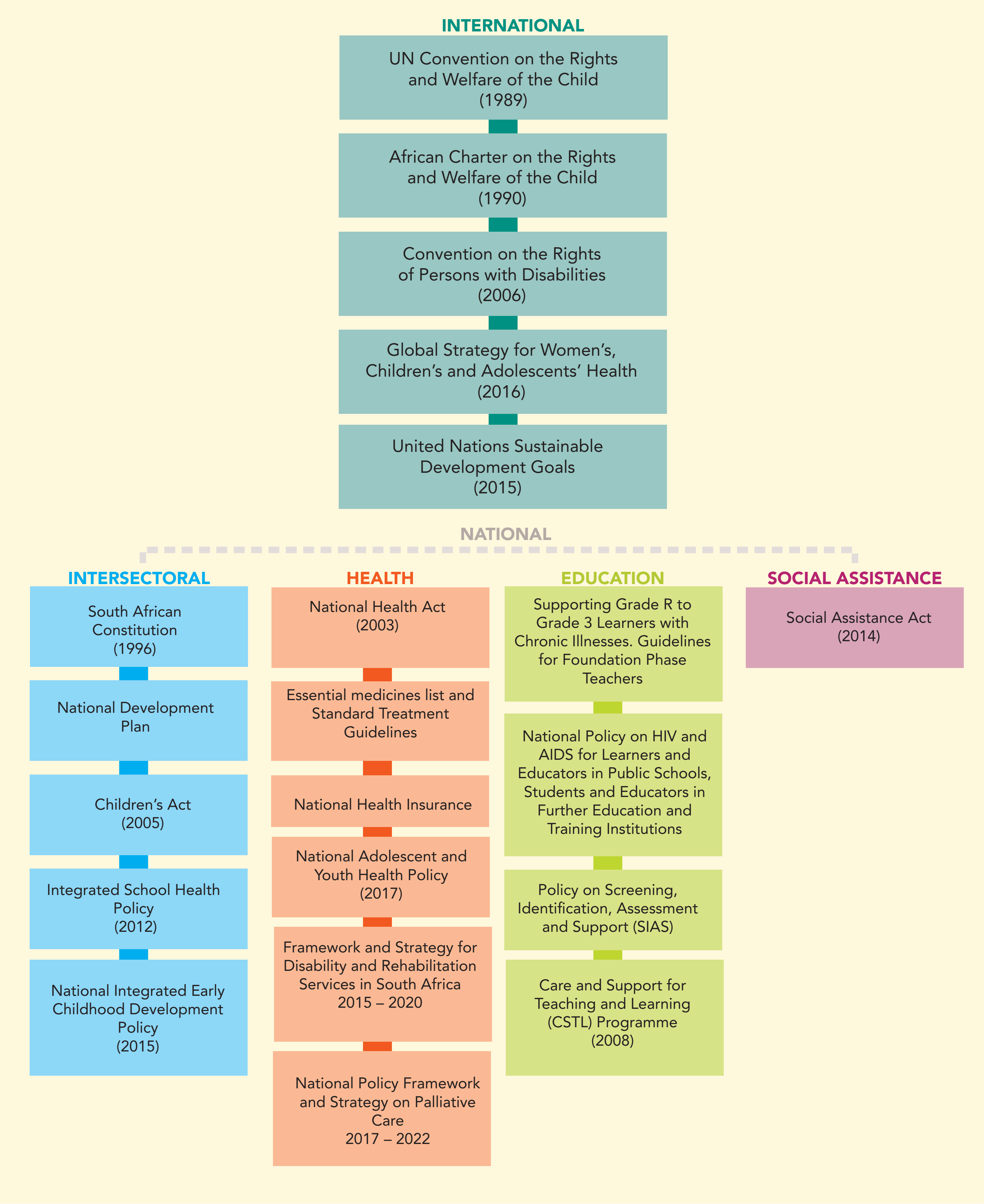
[c] With contributions from Dr Michelle Meiring, CEO PaedsPal and Senior Lecturer, Division of Family Medicine and Department of Paediatrics, University of Cape Town

Figure 35: Summary of the laws and policies that should guide care for children with LTHCs and their families



What laws and policies are there to guide service providers and society in meeting the needs of children with LTHCs and their families?

Figure 35 illustrates the many instruments that South Africa has ratified and developed and which should guide services for children with LTHCs and disabilities.

The international legal and developmental framework

The Government has demonstrated its commitment to realising rights for all children at the highest political level by ratifying and/or endorsing a number of international and regional rights instruments that promote and protect children's rights (including those with disabilities and LTHCs).

Most notably, the ratification of the United Nations Convention on the Rights of the Child (UNCRC) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD) reinforces the importance of protecting and realising fundamental children's rights, including access to education for all children, and emphasises that families of children with disabilities and other LTHCs must be adequately supported to promote their children's participation, inclusion and quality of life.

In 2015, UN member states adopted 17 Sustainable Development Goals (SDGs) to be reached by 2030.[17] Children with LTHCs are not specifically mentioned in SDG 3, the "health goal", although would be included by implication in Goal 3.4: "reduce by one third premature mortality from non-communicable diseases …". Goal 4 for educational development calls on states to "ensure inclusive and quality education for all and promote lifelong learning" … "including persons with disabilities" and stipulates that states shall provide safe, non-violent, inclusive and effective learning environments for all. SDG 10 aims to reduce inequality in part by reducing discrimination against those who have disabilities. The SDGs also call for governments to ensure that "no one [is] to be left behind", which should include the majority of children with LTHCs living in low- and middle-income countries.

National instruments

There is a wide (though not well coordinated) range of laws, policies and guidelines that seek to address the special needs of children with LTHCs and their families from birth through adolescence.

Intersectoral policies and legislation

South Africa is one of a few countries to include disability issues within its Constitution. Consequently, the country has comprehensive legislation and policies protecting and promoting the rights of children with disabilities. The Children's Act[18] provides a comprehensive child protection framework for South Africa. It has a specific section referring to children with disabilities and "chronic illnesses", an outdated term. Section 11 (3) of the Children's Act provides that a child with a disability or "chronic illness" has the right not to be subjected to medical, social, cultural or religious practices that are detrimental to his/her health, well-being or dignity.

The National Integrated Early Childhood Development (ECD) Policy of 2015 in concert with Pillar 4 of the White Paper on the Rights of Persons with Disabilities of 2016 prioritises the prevention of disability, early identification and intervention for children with health, growth or developmental concerns and the inclusion of children with developmental difficulties, disabilities and other conditions that place them at risk.

The 2012 National Integrated School Health Policy (ISHP) includes a focus on (among others) psychosocial and mental health, sexual and reproductive health (particularly among adolescents), and support of children with "chronic illnesses" as an integral component of the school health service. The Integrated Strategy of the Department of Basic Education (DBE) on HIV, sexually transmitted infections and tuberculosis for 2012 – 2016 intersects with the outcomes that relate to learner sexual and reproductive health and LTHCs in the ISHP strategy.

Health

The National Health Act[19] (effective from 2005) provides for free primary level health services for children. However, the provision of free referral services at higher levels of care only applies to children under six years of age as well as children with "moderate to severe disabilities" who are not beneficiaries of a medical aid scheme.

The re-engineering of primary health care (PHC), a core element of the country's National Health Insurance (NHI) plan, aims to improve the quality and reach of essential preventative and curative health interventions, with a focus on maternal and child health. These will mainly be achieved through three complementary delivery strategies: district clinical specialist teams (DCST) providing direction and governance focused on maternal and child health; school health teams; and municipal ward-based outreach teams that deliver health services at household level, largely by community health workers (CHWs). School health is the only delivery strategy that specifically refers to children with LTHCs.

The Framework and Strategy for Disability and Rehabilitation Services in South Africa (2015 – 2020) outlines the suite of comprehensive and integrated disability and rehabilitation services that should be available and accessible at all levels of health care.[20] Although it is largely written with a disability focus, the approaches and services outlined apply to a range of childhood LTHCs.

The continuously updated hospital-level paediatric Essential Medicine List and Standard Treatment Guidelines (STGs) contain an outline of care for many LTHCs. It is strongest on the essential medicines but does not provide enough detail for the comprehensive and stratified management of LTHCs. STGs and essential medicines for children with some LTHCs are found in the Primary Level Essential Medicines List.

The National Adolescent and Youth Health Policy of 2017 seeks to improve the health status of young people through the prevention of ill health, the promotion of healthy lifestyles (prevention of LTHCs) and the improvement of health care delivery systems. From a LTHC perspective, the policy covers HIV and AIDS, tuberculosis, chronic or non-communicable disease, disability, drug and substance abuse, and mental health. The policy also highlights the importance of improving the transition from paediatric to adolescent/adult care and referral processes for adolescents with LTHCs from specialised to primary level services. However, this only currently covers HIV-positive adolescents.

The National Policy Framework and Strategy on Palliative Care for 2017 – 2022, a key development in comprehensive LTHC care, is discussed in Case 7.

In 2018, South Africa launched its new Road to Health Book (RTHB) together with a campaign to link parents and health providers in partnership around the health of young children. For the first time the RTHB contains a specific section on LTHCs that encourages communication and continuity in care. Limpopo and the Western Cape provinces have developed specific LTHC patient-held medical records to encourage communication among service providers.

Education

In 2009, the DBE published Guidelines for Supporting Grade R to Grade 3 learners with "chronic illnesses". They aim to enable educators to attend to the basic needs of learners with LTHCs in their care. They encourage educators to work together with all involved in the child's life to ensure that children feel safe and secure in the classroom, can participate in activities and have a positive school experience. The guidelines align with White Paper 6 on Inclusive Education, the National Policy on HIV and AIDS for Learners and Educators in Public Schools, Students and Educators in Further Education and Training Institutions and the Policy on Screening, Identification, Assessment and Support (SIAS) that includes a toolkit to identify barriers to learning (including health conditions). Case 8 reports on the implementation of SIAS in the Western Cape province.

White Paper 6 on Inclusive Education (2001) promotes an inclusive system for vulnerable learners through the establishment of procedures for early identification and intervention for children who have barriers to learning, including children with disabilities and LTHCs. This intersects well with the aims of the SIAS policy.

Social support and protection

The Social Assistance Act[21] and its regulations make provision for unconditional cash transfer programmes targeting eligible children living in poverty through the Child Support Grant and for those children with disabilities who are requiring permanent care or support services through the Care Dependency Grant (CDG). These grants extend from birth until the child reaches 18 years.

The White Paper on the Rights of Persons with Disabilities in 2016, outlines South Africa's response to the United Nations CRPD, and sets the course for legislation and policy to meet these rights, including those for children. Specific legislative responses have yet to appear.

What are the policy and implementation gaps, and what are the recommendations?

Are these instruments comprehensive and coordinated enough to ensure that children with LTHCs and disabilities and their families enjoy comprehensive, appropriate and accessible support and services? Have they resulted in the delivery of the essentials of long-term care for children and their families from frontline clinical and other services, thereby realising their rights to basic health care and resulting in optimal outcomes for these children and their families?

In short, there are still fundamental deficiencies in access to and the orientation and practice of long-term and disability care for children and their families across most of the service platforms in South Africa. In general, services remain as they historically have been:

- orientated to preventive, promotive and short-term curative care for children under five years,
- providing services for children with HIV infection, and
- more available in urban areas and historically better-resourced provinces.

Much less attention has been given to the equitable organisation and orientation of services for all children with LTHCs and disabilities, despite the policy initiatives described above.

Case 8: SIAS[d]

The Policy on Screening, Identification, Assessment and Support (SIAS) was launched by the Department of Basic Education in Pretoria in 2014. It is aligned to the Education White Paper 6 on Special Needs Education: Building an Inclusive Education and Training System (2001). The purpose of SIAS is to standardise the procedures to identify, assess and provide programs for learners who require additional support to enhance their participation and inclusion in school. It aims to work seamlessly with the Integrated School Health Policy and integrates with learner support structures at classroom, school and district levels.

Additional support may be needed if barriers to learning are identified. The effect that the barrier has on the individual child's learning varies from child to child and may need short- or long-term support. The barriers are not always intrinsic to the child and arise due to the teachers' lack of skills or challenges in the class, school or home or education system.

The Western Cape Education Department (WCED) has developed a comprehensive support pathway for learners who experience barriers to learning, including those with long term health conditions. This involved a geographical mapping of assets and external sources of support, including allied health services, which was then shared with the provincial Department of Health at provincial and district levels.

The support pathway begins with the teacher/parent/guardian/health practitioner identifying a learner who is experiencing a barrier to learning. It is expected that the classroom teacher tries to address the barrier to learning. If the intervention by the teacher is not sufficient, the teacher may request a school-based support team (SBST) meeting to discuss the learner or group of learners. The SBST may advise additional classroom interventions, or refer the child for further support.

If the support available at school level is not sufficient to address the barrier, assistance may be requested from the education department's district-based support team which includes the psychologists, social workers, therapists, learning/remedial support advisors, special school specialists or other intersectoral partners. This could include school health services from the Department of Health, social services from the Department of Social Development and local NGOs. A determination will be made by the circuit/district-based support whether the need for support is low, moderate or high and where the support will be provided.

Over the last three years, training of all those involved in this form of learner support has been rolled out incrementally starting with district-based support teams, full-service/inclusive schools (ordinary schools resourced to provide low-to-moderate levels of support), special schools and school-based support teams at all ordinary schools.

How are these deficiencies to be overcome?

First and foremost, there is a lack of guidance for service and clinical managers at national, provincial and facility levels on how to organise and orientate services to provide long-term care and to do so equitably. None of the instruments described is specific or comprehensive enough to achieve this end. Specifically, policies and strategies on disability and rehabilitation in South Africa do not cover all other children with LTHCs. For the reasons demonstrated in this chapter, this dichotomous approach must cease.

An overarching policy and implementation guidelines for services for children with LTHCs

An initiative to achieve this end, begun in the national Department of Health at the end of the last millennium, was never completed. An overarching policy and implementation guidelines on the care of children with LTHCs (called "non-communicable diseases" at the time) were developed and approved, but not implemented. The re-organisation of services and "baskets of care" envisaged by the NHI initiative, together with the ministerial Committee on Mortality and Morbidity in Children's (CoMMiC)[22] call for an essential package of health care for children, provide an opportunity to revise and update the LTHC policy and guidelines.

These should:

- link and coordinate existing childhood LTHC and disability policies, guidelines and regulations;
- give clear guidance on improving equity of access to all aspects of long-term care;
- provide guidance on how best to deliver comprehensive long-term care;

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[d] With contributions from Berenice Daniels, Director: Inclusive and Specialised Education Support, Western Cape Education Department

- provide a framework for a detailed essential package of long-term and disability care for children, based on the CoMMiC recommendations,[23] NHI deliverables and relevant policies, frameworks and strategies, including those overseen by the Office of Health Standards Compliance, and the Essential Medicines programme;
- give clear guidance on how intersectoral aspects of long-term care will be provided, including integrated care; and
- set out a simple monitoring and evaluation system for facilities and services.

Leadership and governance mechanisms that coordinate the policy, standards, and delivery of services to children with LTHC and disabilities are required, e.g. monitoring from the Office for Disabilities in the Presidency and the South African Human Rights Commission, and with intersectoral coordination led by the Department of Health.

Opportunities to strengthen LTHC care through NHI

The NHI provides further opportunities for improving long-term care for children. The concept of "baskets of care" in NHI is well suited to LTHC care. CoMMiC has long advocated for children with LTHCs in their triennial reports. Their framework for an essential package includes children with LTHCs, and those requiring palliative care. This framework should be brought into the cost-utility work around "baskets of care" under the NHI as soon as possible.

NHI primary health care re-engineering originally included the re-engineering of rehabilitation services at district level. This component should be revived as the current re-engineering programmes have insufficient focus on the large numbers of children with LTHCs and disability. This is especially the case in rural areas.[24] Helping to coordinate long-term and palliative care for children in the district health system and across sectors and to train staff in routine long-term and shared care and outreach should be introduced into the work of the district clinical specialist teams.

Ward-based outreach teams (WBOTS) which, together with the DCSTs, are pillars on PHC re-engineering in NHI, hold potential for increasing access to services for children with LTHCs and disabilities. Roles that community health workers could play to assist children with LTHCs and their families include early identification, family support in long-term care, service linkages, basic palliative care, and delivery of preventive care in the home.[25] WBOTS need to include community rehabilitation workers – these are community health workers with special skills in rehabilitation who are supported by therapists. Section 5.1 of the Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015 – 2020 outlines these roles.[26] Priority should be given to ensuring coverage of these 'reinforced' WBOTS in dispersed and deprived areas in South Africa.[27]

School health service teams are a third pillar of PHC re-engineering. Recommendations for their role in the care of children and adolescents with LTHCs in concert with education services are in Table 13.

NHI, while aiming to cover the maximum proportion of the population with an affordable basket of care, cannot provide for everyone's needs. It needs to have an appeal fund mechanism for the needs of children with rare LTHCs (usually inborn metabolic disorders) that are very expensive to treat.

NHI aims to contract private practitioners as part of its service platform. The private sector is no model of long-term care. Indeed, its current funding methodologies and individualised practices are inimical to the teamwork required for long-term care. Most prescribed minimum benefits are aimed at adult onset disorders, with little provision for some common disabling disorders in children. NHI provides an opportunity to redress some of these deficiencies through funding and accreditation mechanisms that encourage good long-term care as outlined earlier.

Coordination of care and communication across services would be taken forward considerably if the NHI-linked single patient number was introduced as soon as possible.

Other gaps and recommendations

While the overarching LTHC policy and the changes that should come as part of the service re-organisation associated with NHI might be considered medium-term approaches, there are many things that can be done in the short-term to plug gaps in the policy and service delivery environments to better realise the rights of children with LTHCs.

Table 5 indicates the main gaps at policy, service, training and data levels and makes recommendations for each.

In general, there is much to do and much that can be done in the short and medium terms to improve access to quality, comprehensive long-term care for children and adolescents in South Africa.

Table 13: Gaps and recommendations

LEVEL	GAPS	RECOMMENDATIONS
POLICY	*Access* *General services for children* Access to primary care services for children is inadequate in many parts of the country due to distance, topography and other factors. These affect children with LTHCs more than other children as they have greater requirements for health services and often have reduced mobility. *Specialised paediatric services* 1. Access to general paediatricians, skilled paediatric nurses and therapists with paediatric skills is very limited in many parts of the country. 2. There are marked inequities in access to tertiary services for children and adolescents with LTHCs. Some provinces have limited or no tertiary services and there is inadequate access to the services in neighbouring provinces. Many children with LTHCs require tertiary services for the management of common conditions such as congenital heart defects. Paediatric surgical services are commonly required for congenital malformations.	• Prioritise policy and associated funding to improve equity of access to comprehensive primary care services for children and adolescents in under-served areas. The role of NHI in guaranteeing this redress is highlighted. • Strengthen efforts to train, attract and deploy paediatricians, paediatric nurses, and therapists with paediatric skills to under-served – largely rural – areas. Human resources planning related to NHI should rapidly guide the provision of posts for these cadres in under-served areas. • Strengthen outreach services by these cadres and teams within and, where feasible, across provinces. Develop clear mechanisms including service-level agreements between provincial health services that have comprehensive tertiary services and those that do not, especially for paediatric surgical services. This applies particularly to the provinces that surround Gauteng province. • Strengthen the developing paediatric tertiary services in large rural provinces such as the Eastern Cape and Limpopo.
	Financial barriers Many children with LTHCs face the same problems with finance and access as children with moderate-to-severe disability who currently have free health care. Eligibility criteria and implementation of the CDG are inconsistent and don't include some LTHCs. When children with a life-limiting condition die, the sudden withdrawal of the CDG can have severe consequences for a family who have given up earning capacity to support the dying child, and still need time to find employment.	• Ensure that children from rural areas within provinces have equal access to paediatric tertiary services via referral and transport systems. • Provide children who have complex LTHCs with free health care at all levels of the health service and with eligibility criteria similar to those for the CDG but that take account of the child's needs, for example care at multiple services levels, frequent review, multiple admissions to hospital. (See below for further recommendations regarding the CDG.) • Review the eligibility criteria to take into account the burden of care for children with complex LTHCs. • Strengthen consistent implementation of the CDG. • Allow the CDG to continue for three months after a child with a severe LTHC has died.
	Palliative care The 2017 Palliative Care Policy does not have implementation guidelines and a budget at national or provincial levels.	• Provide funding, support and direction for this implementation, with a specific implementation group focused on children (see Case 13).
SERVICES	*Routine or non-categorical long-term care* 1. The most significant gap at service level is the lack of a systematised approach to routine long-term service provision at all levels for children with LTHCs. Such non-categorical care should be seen as "basic health care services" for these children, mandated under section 28 (1)(c) of the Constitution. Coordination of care and communication are generally weak across services and sectors. In all provinces there is sub-optimal use of primary and secondary levels of care to provide care to children and adolescents who have LTHCs.	• Strengthen comprehensive long-term care across the health and associated systems. Clinical managers and frontline teams at and across levels, supported by service managers, can implement many of the attributes of routine LTHC care outlined in this chapter, including practical expressions of the principles outlined in Table 12. • Ensure functional referral pathways and outreach systems. • Develop care plans for all children with LTHCs. (A template was developed in the unimplemented overarching LTHC policy and has been incorporated into the Limpopo and Western Cape provinces' patient-held medical records for children with LTHCs.)

LEVEL	GAPS	RECOMMENDATIONS
SERVICES	*Rehabilitation services* Rehabilitation services for children are inequitable and inadequate.	• Follow through on the provisions of the Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015 – 2020. Specifically, for children, community-based rehabilitation, screening within the Integrated School Health Policy, and developing norms for disability and rehabilitation services need prioritisation. • Develop mechanisms through NHI specifically to improve rural children's access to rehabilitation services.
	School health services The "chronic illnesses" aspects of the Integrated School Health Policy have not been implemented.	• Appoint senior nurses to lead and coordinate the whole system and its links to the health and other systems as part of the NHI PHC re-engineering. • Develop strong links with the health system by the SIAS policy and Care and Support for Teaching and Learning initiatives via mechanisms such as common databases and communication channels. This would significantly improve comprehensive and coordinated care in schools for children and adolescents with LTHCs.
TRAINING	*Education systems for children with special needs* 1. Children with special needs in education, especially those with neuro-behavioural and cognitive disorders, are generally not getting what they require, even from the few full-service schools. The transition of therapeutic care for children from health services to the education sector when they enter formal schooling is fragmented, as there are few professionals such as occupational therapists available to take over their care in the education sector. 2. There has been insufficient progress on inclusive education.	• Improve coordination between health and education sectors (and professionals) to ensure appropriate placement and care of children when they start school. Mechanisms for this coordination and its oversight must be developed. • Put in place strengthened and expanded support systems in the education sector, including the availability of appropriate staff (such as therapists, psychologists etc.) to deliver support as envisioned in the White Paper 6 on Inclusive Education. • Increase dedicated funding to realise the vision of White Paper 6.
	Education and training of health and allied professionals 1. There are major gaps in basic and post-basic training in long-term care for children. 2. Interdisciplinary teamwork is underdeveloped. 3. Certain key multi-disciplinary team health workers are missing in most parts of South Africa: community rehabilitation workers and advanced clinical paediatric nurses. 4. Inadequate care (including transition care) is provided for adolescents with LTHCs and disabilities.	• Introduce standard interdisciplinary modules of training into basic training for all professionals. • Paediatric rotations should include a long-term care case study. • Mainstream interdisciplinary training and training in interdisciplinary care. • Resuscitate programmes that trained rehabilitation workers for incorporation into MDTs and ward-based outreach teams. • Create posts for APCNs. The South African Nursing Council and the Human Resources and Child, Adolescent and School Health directorates in the National Department of Health should take the lead. • Basic training: Ensure a specific focus on adolescent long-term care in basic training, and with an assessment. Specialist training: Strengthen learning opportunities and assessment in adolescent care, including long-term care.
DATA SYSTEMS	Children with LTHCs are largely uncounted.	• Include a new module in the General Household Survey, such as the UNICEF/Washington Group's Extended Set on Child Functioning and Disability[28] to count children with LTHCs and improve understanding of their lives and service experiences. • Add indicators of throughput, quality of care, and outcome for sentinel LTHCs to the District Health Information System. • Ensure that NHI resource allocations are based on service data that adequately reflect ambulatory care, as this is where children with LTHCs receive the bulk of their care and rehabilitation.

Conclusions

This chapter has highlighted the needs of a significant number of South African children who have been left behind in policy and practice in recent decades. It has outlined approaches to improving care provision.

Improving care for children and their families will require re-orientation in training, human resource practices, and organisation of health services. Policies and funding mechanisms that promote these changes are required, with the Department of Health leading, and engaging partner departments such as Basic Education and Social Development and the Office of Health Standards Compliance, as well as higher education institutions and examining bodies, specialist organisations, and non-government and non-profit patient support organisations. At service level, district clinical specialist teams can take a leading role.

NHI provides an opportunity to set the agenda and coordinate these changes so that children with LTHCs and disabilities and their families experience comprehensive, coordinated and continuous quality integrated care from capacitated services, from the time that a problem is suspected, throughout their childhood and adolescence, and into adulthood.

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