ANTIRETROVIRAL ROLL-OUT IN SOUTH AFRICA

WHERE DO CHILDREN FEATURE?

A discussion paper by the Children's Institute, University of Cape Town,
commissioned by Save the Children Sweden
August 2004

WHAT ABOUT THE CHILDREN?

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Terms of reference

This paper has been commissioned by Save the Children Sweden. The commission required the production of a 20-page report over a six-week period that explored the question as to whether children are adequately catered for in the current antiretroviral treatment programmes of the South African government. The terms require the paper to cover the following: what the current national plan contains for children, whether this adequately caters for children's needs, what the situation is for children in residential care by looking at one or two children's homes, and to identify the main bodies responsible for ART implementation.

The paper uses children's rights as entrenched in the South African Constitution and the Convention on the Rights of the Child as a reference point.

The paper ultimately aims to contribute to addressing the health needs of children with HIV-infection through a comprehensive policy and programme response, by highlighting the specific needs of children in an ART programme.

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ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti-Retroviral Therapy
ARV	Anti-Retroviral Agents
CI	Children's Institute
CBO	Community-Based Organisation
CRC	Convention on the Rights of the Child
DOH	Department of Health
HIV	Human Immunodeficiency Virus
ICESCR	International Covenant on Economic, Social and Cultural Rights
IMCI	Integrated Management of Childhood Illness
MCH	Maternal and Child Health
NGO	Non-Governmental Organisation
PCP	Pneumocystis Carinii Pneumonia
PHC	Primary Health Care
PMTCT	Prevention of Mother-To-Child Transmission of HIV
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

DEFINITION OF TERMS

Child/children:

All persons from birth to 18 years of age as defined in the Convention on the Rights of the Child (1989).

Child rights:

This refers to the specific positions and protections that children are entitled to in society and which are embodied in legal instruments and treaties such as the Bill of Rights in the South African Constitution and the Convention on the Rights of the Child.

Chronic or long-term health condition:

A chronic condition is any physical condition that has lasted or is virtually certain to last for longer than one year and which requires comprehensive and coordinated long-term health care.

Comprehensive health care:

This refers to health care that covers the full spectrum of health needs including promotion, prevention, cure, rehabilitation and palliation.

EXECUTIVE SUMMARY

The South African government, as represented by the Department of Health, approved the national roll-out plan in November 2003 for the "Comprehensive Care and Treatment for HIV and AIDS" (hereafter referred to as 'the Plan'). Part of this plan makes provision for antiretroviral therapy (ART) within public sector facilities to persons with HIV-infection who meet the qualification criteria. The plan addresses a range of issues for adults and children, from prevention to treatment and rehabilitation, with the focus on systems implementation for the roll-out.

This paper, commissioned by Save the Children Sweden, explores whether children's health needs are adequately addressed in the current national plan for comprehensive care and treatment for HIV and AIDS. Whilst the commission specifically focuses on ART for children, the paper takes a more comprehensive view of the health needs of children with HIV-infection.

Children have a right to basic health care that is guaranteed through the South African Constitution and in keeping with other international treaties such as the CRC that South Africa is a signatory to. Although basic health care services for children have not yet been clearly defined, it can be assumed, given the seriousness, magnitude and urgency of the HIV pandemic, that health services required to maintain and improve the health of children infected with HIV would qualify as basic.

It is imperative, however, that the health needs of children with HIV-infection be looked at comprehensively and that the mere provision of ART not be deemed sufficient. The paper briefly outlines the medical and psychosocial needs of HIV-infected children, recognising their changing needs as they progress from their infant to pre-school to school-going years. Taking this into consideration, the paper proposes a set of services that cut across different levels (primary through to tertiary) and dimensions of care (preventive, curative and rehabilitative), this being contained in Table 1 on page 22. It is crucial to note that prevention of HIV-infection should be the backbone of a comprehensive health service response, and the reduction of HIV-infection in adults, together with the prevention of mother-to-child transmission programme (PMTCT), are the two key intervention strategies requiring maximum attention.

Children's location in the Plan

Firstly it is important to note that most government plans that cater for the general population tend to consider children as a group, rather than a special group with very specific needs. This approach has been borne out in the recently developed National Health Act, where the drafters of the Act made a conscious decision not to address children as a group deserving special attention. As a result the Act contains very little specific legislative intervention for children[1].

The current comprehensive Plan is commendable in that it does highlight children's issues and does give children's needs some attention. This is not, however, done in a comprehensive child-orientated way where children's comprehensive health needs are considered. Given the "best interest principle", the plan does not, in every aspect, consider what the implications are for children. The notion, for example, of family care, or at least comprehensive consideration of the mother-infant pair, is not adequately promoted - considering that healthy mothers and caregivers are crucial to ensuring the well-being of children, especially children who themselves are ill with a long-term condition.

Further limitations include the absence of clear guidelines for care and treatment of children without adult caregivers, and children who are in alternate care such as residential care facilities.

The Plan has a number of additional gaps. Having said this, some of these gaps are addressed in an accompanying set of guidelines developed by a team of professionals under the leadership of Dr Meyers from the Wits Paediatric Aids Unit. However, these guidelines were not yet officially launched at the time of completion of this paper.

The main gaps in the Plan can be summarised as follows:

- The Plan does not give any indication as to how specific counselling needs of children should be addressed. It gives no direction on the age-related considerations for children that are old enough to benefit from counselling, nor does it suggest how health workers should approach counselling of children.
- While outlining when and how to test for HIV in children, the Plan does not outline the complexities with regard to HIV testing in young babies and children. It also does not give any direction on how to address HIV-diagnosis in instances where children have no adult caregivers or are in residential care, especially informal residential care where no legal authorisation to consent on behalf of the child exists. The Meyers guidelines give clear direction on this, but in practice it is still a logistical and legal quagmire.
- While very clearly outlining the different drug regimens available to treat children, the Plan does not recognise the specific difficulties of diagnosing HIV in children, the complexities of diagnosing HIV-associated illnesses like TB in children, and the huge social challenges of ensuring "at least one responsible person capable of administering the child's medication". The section in the Plan dealing with procurement does not mention the special considerations that must be taken into account when procuring preparations for, and providing medication to, children. The need to simplify the dosage to promote adherence, the need to obtain palatable and easy to ingest medication for children, and the need to refrigerate the syrup for children in the

face of massive poverty levels with large sections of the country not being electrified, have for example not been taken into consideration. While alternate regiments are available that do not require refrigeration, ongoing research is required into making drugs for children less complex to take and less reliant on ideal storage conditions.

The Meyers guidelines are a bit more specific as to how children could be supported in the provision of ART, but do not provide viable alternatives for situations where health services, families and children face difficulties in meeting the social criteria, or require support to administer ART on a long-term basis. The guidelines do allude to the need to liaise closely with NGOs and CBOs in this regard.

- There is a similar lack of child-specific considerations in the sections on monitoring, drug availability, staff and human resources, and adherence.

While the roles and responsibilities of different levels of care have been quite clearly defined in the Plan, coordination between ART services for children, and other relevant policies and services such as the current Department of Health policy guidelines on services for children with long-term health conditions, are not considered. This highlights the urgent need for coordination within the Department of Health and between other sectors that impact on the effects of HIV in children. It further highlights the need to contextualise ART provision within a more comprehensive health service framework for children.

The paper takes a brief look at current ART implementation, based on the available roll-out monitor that is being done through the Health Systems Trust Treatment Monitor, and on specific statistics obtained for the Western Cape province, this province being the most advanced in terms of implementation.

Current implementation statistics suggest that, aside from the overall roll-out plan being way behind schedule, the sites currently providing ART for children are in the minority. Where children are catered for, such sites are at present primarily donor-funded. The unavailability of paediatric ART in parts of the country seems to be the major reason for not yet providing the programme to children.

The commission required the paper to specifically look at the situation of children in residential care. A brief analysis, based on two residential care facilities, one formally registered and one informal, suggests that children in residential care facilities who have chronic health conditions such as HIV, are not adequately catered for by the state. In formal residential care, no additional subsidy is provided for children with chronic health conditions, despite the additional medical and transport expenses that the facility would incur in caring for these children. In informal facilities that exist because no other care options are available to children, caregivers struggle to cope with the multiple needs of children and struggle to access treatment such as ART. This is complicated by the fact that they are not legally able to grant testing and other required consent for children and have to traverse complex legal requirements to access testing and treatment.

Due to time constraints, the paper briefly comments on the major role players that are able to render and support ART provision to children. The exact roles and how these are executed are explored.

The main recommendations that emerge from this analysis are outlined below.

The most important priority is to reduce the likelihood of HIV-infection in children through general initiatives to reduce HIV-infection in adults and the PMTCT programme. Where children have been infected, a comprehensive care and support programme is required for the children and their families/caregivers.

Further recommendations include:

At policy level

All policies and plans that hold implications for children must have a specific section catering for children's specific needs, drawn up by child experts.

Different policy and planning initiatives for children must be coordinated between the different programmes in the Department of Health, as well as between other sectors to ensure synergy and sensible planning.

The current Meyers guidelines must be finalised and officially accepted, as these provide crucial detail to the care and management of children currently lacking in the national Plan. In the same vein, the current draft policy framework for children with chronic health conditions must be officially accepted and implemented as a matter of urgency.

Gaps that have been identified in the Plan and the Meyers guidelines must be addressed, with specific reference to child-specific attention in the areas of:

- Monitoring,
- Adherence, and
- Drug provision and procurement.

At service delivery level

Strengthening of the overall health care infrastructure, especially at the primary level of care, is essential, as ART and other HIV-specific programmes such as the PMTCT will be difficult to implement successfully in the absence of a good infrastructure. Specific elements that are much neglected and that need strengthening are chronic care and critical care for children.

Emphasis must be placed on the specific needs of children when up-scaling sites for ART provision, as well as in the training of staff and provision of other resources.

In conjunction with legislative initiatives such as the Children's Bill, clear consensual guidelines on age and development-appropriate practices for counselling, disclosure and confidentiality in children must be developed as a matter of urgency.

Clear guidelines on how to prioritise among eligible children, and how to ensure standardised practices across sites, must be developed.

Pharmaceutical companies that manufacture paediatric medicines must pay specific attention to enhance adherence in children. It is essential to find ways to minimise the number of doses and to ensure palatable preparations.

Children living in especially difficult circumstances who require HIV treatment and support must receive special attention and support through all services, including health, social development, education and NGOs.

Advocacy

Watchdog bodies, such as the National Plan of Action for Children (NPA), and children's rights and advocacy organisations must monitor the care and support of children with HIV, and must advocate for and facilitate possible ways of strengthening social service provision to children to ensure that the best interest of the child is upheld.

This paper concludes that, despite the strong rights-based framework in which South Africa operates, children's health rights and in particular the rights of children with HIV have not yet been met. Neither their basic general health care needs, nor their specific HIV-related needs, have been adequately addressed. While a commendable plan is in place in which children are considered, their special needs and best interests have not been sufficiently recognised.

Given the large numbers of children that already are HIV-infected, the implementation of a comprehensive package of care for children infected with HIV in South Africa is essential and, while daunting, is not impossible. It requires political will from all government departments, careful planning, and a consciousness on the part of policy makers, planners and implementers of the special needs of children.

1. INTRODUCTION

The South African government, as represented by the Department of Health, approved the national roll-out plan for the "Comprehensive Care and Treatment for HIV and AIDS" in November 2003. Part of this Plan makes provision for antiretroviral therapy (ART) within public sector facilities to persons with HIV-infection who meet the qualification criteria. The Plan addresses a range of issues for adults and children, from prevention to treatment and rehabilitation, with the focus on systems implementation for the roll-out.

In previous policy analyses conducted by the Children's Institute, it has become apparent that the specific needs of children are not always adequately addressed in policies, laws and plans that cater for the popuation at large. This is despite the fact that children's health needs differ from those of adults, and differ further depending on the age and stage of development of the child. Any sound policy or plan aimed at the population at large must therefore take into account the specific needs of children. Furthermore, children with HIV-infection have health needs beyond the mere provision of antiretroviral therapy. Any plan that seeks to address the provision of antiretroviral therapy must therefore take cognisance of the comprehensive health needs of children, over and above their needs with regard to the management of their HIV-infection and/or AIDS.

This paper explores whether children's health needs are adequately addressed in the current national Plan for comprehensive care and treatment for HIV and AIDS. While the commission specifically focuses on ART for children, the paper takes a more comprehensive view of the health needs of children with HIV-infection.

Given the brevity of the time and paper length stipulated by the commission, the paper briefly covers the following:

- The extent of the problem of HIV in children
- The rights-based provision for children with HIV-infection
- The requirements of a comprehensive service response
- An analysis of the national comprehensive plan
- Current implementation status of ARV roll-out as it relates to children
- Implementation challenges
- Conclusion and recommendations for improved service delivery

The information on which the paper is based was collected from current national and provincial policy documents and guidelines, relevant reports and discussion papers, and databases such as the Health Systems Trust Treatment Monitor and Western Cape monthly statistics, in order to obtain an idea of current ART implementation. Discussions were also held with individuals engaged in ART for children in three provinces and who operate at NGO, primary and tertiary level facilities.

1.1 The HIV-epidemic among South African children

The estimates of the extent of the problem with regard to children infected and affected by HIV vary, depending on the information source. The quoted figures are the most recent estimates from sources that are deemed fairly reliable. Figures released by the Actuarial Society of South Africa in 2000 estimated that South Africa has at least a quarter of a million children infected with HIV.[2] More recent estimates from a prevalence study conducted by the Human Sciences Research Council suggest a prevalence of 7% in the 2-9-year-old age group and a prevalence of 5% for 10-18-year-olds.[3] Based on the 2001 census figures where children in these two age groups total about 16,5 million, these prevalences suggest that close to a million children in the 2-18-year age group are infected with HIV.

According to the Burden of Disease study released by the Medical Research Council in 2003, HIV/AIDS currently accounts for 40% of all deaths in children younger than five years.[4] The Burden of Disease estimates indicate a trebling of mortality in the 1-5-year age group from 1998 to 2000 due to the HIV-epidemic. The under-5 mortality rate for 1998 showed that deaths in the 1-5-year age group contributed 14 out of the 59 deaths per 1,000 live births. The Burden of Disease estimates of under-5 mortality rates for 2000 show that 36 out of the 95 deaths per 1,000 live births are in the 1-5-year-old age group – reflecting a trebling of deaths in this age group. Furthermore, HIV accounts for 50% or more of all paediatric medical admissions in hospitals around the country – increasing the load on the already overburdened health system and potentially also compromising the ability of health services to care for children without HIV who require admission.[5]

While HIV is a chronic or long-term health condition, most South African children with HIV-infection currently die before reaching their second birthday.[6] However, with the availability of antiretroviral therapy many children could survive into their teens and adulthood. This is currently only true for well-resourced developed countries where the face of the HIV-epidemic has changed completely, although we are seeing the benefits of ARVs in children able to access these at private and selected state facilities that currently provide this care.[7] Current prevalence of chronic conditions indicates that one in every ten children in South Africa has a chronic condition, with this prevalence increasing as a result of the HIV-epidemic.[8]

The major source of HIV-infections in young children is through vertical transmission during pregnancy, delivery and breastfeeding. For newborns and infants, estimates indicate that in the absence of a well-functioning prevention of mother-to-child-transmission programme (PMTCT), approximately 96,000 new infections occur each year.[9] This estimate is based on a 30% transmission rate and does not factor in the reduction in transmission due to the current PMTCT programme. The introduction of the PMTCT programme in a routine service setting has the potential to reduce new infections in newborns significantly as indicated by the experience of the routine service at Coronation Women and Children's Hospital.[10] Transmission rates at six weeks and three months were cited as 8.7% and 8.9% respectively, compared to an assumed baseline transmission rate of 25-30%. Such reductions are possible in well-implemented PMTCT programmes, providing Nevirapine to the mother and the newborn, and selecting formula feeding as the infant feed of choice. Given the positive strides made with the universal implementation of the PMTCT programme, a reduction in new infections in newborns should be reflected in the next antenatal sero-prevalence survey report, provided that the programme is operating effectively. The extent of the reduction on a national scale is not yet known.

HIV-infection in children in South Africa is thus a major public health problem in terms of the numbers of children being infected, the seriousness and complexity of the infection and its related complications, the potential long-term nature of the condition, the compounding effects of poverty, and the inequitable access to good quality health services. There is an urgent need for South African society to adequately address the rights and needs of children infected with HIV.

1.2 The health rights of children with HIV

Children's right to health is a basic human right that is protected through child-specific treaties and instruments, as well as in treaties and instruments that recognise health as a basic human right for all. International treaties to which South Africa is a party, such as the International Covenant on Economic, Social and Cultural Rights (ICESCR)[i], affirms the universal right to health. The ICESCR calls upon state parties to adopt 'special measures of protection and assistance on behalf of all children and young people without any discrimination.'

The Convention on the Rights of the Child ('the CRC')[ii] confers on all children the right to 'the enjoyment of the highest attainable standard of health' and calls upon governments to progressively work towards the full realisation of this right. In line with the CRC, the African Charter on the Rights and Welfare of the Child (the African Children's Charter)[iii] proclaims that 'every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health.'

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[i] International Covenant on Economic, Social and Cultural Rights, art 12, adopted 16 December 1966 (entered into force 3 January 1976) UN Doc.A/6316 (1966).

[ii] Convention on the Rights of the Child, adopted 20 November 1989 (entered into force 2 September 1990). South Africa ratified and signed the Convention in 1995, making this instrument and its principles an obligatory commitment from the South African government and the children of the country. The country needs to give regular reports to the United Nations in terms of its performance on meeting the obligations spelt out in the Convention.

[iii] African Charter on the Rights and Welfare of the Child, adopted 1990 (entered into force 29 November 1999) OAU Doc.CAB/LEG/24.9/49 (1990).

Article 24 of the CRC is the predominant health article in the Convention that provides the foundation for governments as to the specific responsibilities that they have towards meeting children's health rights. It is a composite article that contains a number of specific requirements to ensure that the chief provision of ensuring 'the child's right to the highest level of health possible' is met. The requirements include: (1) the right to access to health services, (2) the duty to diminish infant and child mortality, (3) the duty to provide medical assistance and health care to all children with emphasis on the development of primary health care, (4) the duty to ensure the provision of adequate nutritious foods and clean drinking water and to consider the danger and risks of environmental pollution, (5) the duty to provide pre-and post-natal care for mothers, (6) the duty to ensure that parents and children have information and are supported in the use of basic knowledge relating to child health and nutrition, breastfeeding, hygiene and environmental sanitation and accident prevention, and (7) finally the duty to develop preventive health care guidance for parents and family planning education and services. Article 24 requires signatory countries to pay particular attention to all these provisions.

The realisation of children's health rights also depends on the fulfilment of a number of additional rights that do not fall directly under the jurisdiction of the health sector. Using the comprehensive WHO definition of health, at least ten additional CRC articles embody rights that either directly or indirectly impact on the 'right to highest level of health possible'. These include, among others, the right to care and protection, the right to social security, ensuring that facilities and services are to an agreed standard, the right to education, and the right to play. While specific interventions within the health sector play a major role in the attainment of children's right to health, the non-fulfilment of basic rights and related interventions within other sectors play an equally important part in promoting or hindering the fulfilment of this right. The primary responsibility currently lies with government in ensuring that children's health rights are met, and in this regard the South African government is obliged to report back to the United Nations in terms of progress made towards the fulfilment of the CRC obligations.

South African children have a justiciable 'right to basic health care services' under section 28(1)(c) of the South African Constitution. This provision is in addition to the general provision in section 27(1) of the Constitution that guarantees everyone the right to have access to health care, food, water and social security.

The state is primarily responsible for providing health care and health care services to children and ensuring that the necessary services are in place. While the duty to ensure that children are taken to health care services rests primarily on the parents and caregivers of the child, if the parents or primary caregivers are absent or are unable to ensure such access (e.g. because the parents are poor and cannot afford transport or user fees, or for children in residential care, homeless children or children without any adult caregivers), the obligation falls on the state to ensure that children access the available health care services. This view was affirmed in the *Minister of Health and Others v Treatment Action Campaign*[11] (TAC) where the Constitutional Court again had the opportunity to pronounce on the nature of the state's duty in section 28(1)(c). In this case, the Court stated that the government is obliged to ensure that children are accorded the protection contemplated by section 28, which arises when family or parental care is lacking, and further that it was possible for such care to be lacking even where the child was being cared for by his or her parents.

For children with HIV-infection, the right to basic health care services is no different to that of all other children with acute and/or chronic health conditions. Given that basic health care services have not yet been defined for any specific group requiring health care services, it would be reasonable to assume – given that HIV is one of the major public health priorities in South Africa – that all current available interventions to prevent HIV and alleviate pain, suffering and undue complications as a result of HIV-infection would have to be provided by the state to all children with this condition. In line with the obligations as set out in Article 24 of the CRC, a very comprehensive strategy is required from government to adequately cater for the range of health care and other social needs of children with HIV-infection. Given that many children infected with and affected by HIV live in circumstances where parents and caregivers are unable to adequately care for them due to poverty and/or they being terminally ill themselves, or where parents/-caregivers are absent, the state has a particular responsibility to ensure that such children have the necessary access to and support from health and other social services.

2. THE HEALTH NEEDS OF CHILDREN WITH HIV-INFECTION

Children with HIV-infection have varied and complex health needs. While requiring the same spectrum of health care as children without HIV-infection, the presence of HIV adds many additional dimensions to their health care needs. Aside from medical needs there are numerous psychosocial aspects that children, their siblings and families/caregivers have to deal with. Furthermore, given the eighteen-year span of childhood, the types of health needs of children differ depending on their ages and developmental stages. A Tanzanian study showed the negative impact that adult deaths due to HIV have on children's nutritional status and morbidity patterns, suggesting that children living in HIV-affected households, irrespective of their own HIV status, have additional compromised health prospects over and above the effects of poverty. If children themselves are HIV-positive, their health status is compromised even more.[12]

Despite the differing health needs according to age group, there are needs that apply to all children. The New York State Department of Health clinical guidelines for HIV care and support identify two categories of health care needs of children with HIV,[13] namely medical and psychosocial needs.

Children's medical health needs

Children with HIV require a number of promotive, preventive and clinical interventions to ensure an optimal state of health that will enable their systems to cope with the HIV-infection. A set of comprehensive clinical guidelines for managing HIV in children developed by the New York Health Department identifies nutrition as one of the most crucial health needs that require attention in children with HIV-infection, irrespective of age. Under normal circumstances nutrition is one of the most important factors in ensuring a child's optimal growth and development. Malnutrition in HIV-infected children significantly compounds the impact of the disease. The guidelines emphasise the potential negative impact of a poor nutritional status on the HIV-disease process and in turn recognises the negative impact of the HIV-disease on children's nutritional status. Nutritional status is also one of the important indicators of a child's progression from HIV-infection to AIDS. In the face of large-scale poverty and malnutrition among the general child population in South Africa, with an estimated 74.8% of children in 2000 living below the poverty line of R430/month per capita,[14] one of the most significant challenges in managing HIV-infection is that of ensuring optimal nutrition for children. Appropriate and good infant feeding choices and adequate micronutrient and food intake are essential. While health facilities are instrumental in monitoring nutritional status, treatment of malnutrition and the provision of sound feeding and nutritional advice to caregivers, liaison with social development and education services, home-based services and NGOs and CBOs engaged in food- and nutrition-based programmes is necessary to ensure that this basic health need of children, as well as their families, is adequately taken care of.

The next set of health needs relates to the need for curative care of general illnesses that children acquire, as well as prophylactic and curative care for HIV-related infections that might arise. Basic health care infrastructure at all levels must therefore be in place to deal with the increasing numbers of children that would need acute curative and critical care. In addition, the necessary prophylactic treatment such as the Cotrimoxazole required for pneumocystis pneumonia prophylaxis and TB prophylaxis must be provided.

With the advent of ART, a number of additional health and health service needs arise over and above the ones mentioned above. It requires the screening of children before being placed on ART, the monitoring of treatment, managing any side effects, finding ways to support adherence to treatment, and dealing with issues relating to resistance to treatment when it arises. It thus requires the child's caregiver and, in the case of older children, the child him/herself to fully understand the disease, the medication and the implications that arise as a result of non-adherence.

Palliative care for children that includes pain management and terminal care is a health need that is not always adequately considered, but that goes a long way to support the child, siblings and caregivers in coping with illness.

An additional issue for children in their pre-school years is the need for preventive services that all other children in this age group require, such as developmental screening, nutritional support, dental care and vaccinations. Children in this age group are especially prone to infections such as diarrhoea, pneumonia and other childhood diseases; both those of a general nature and those specifically linked to HIV and which require careful monitoring and support from health services.

Children of school-going age have no specific additional medical needs, although the psychosocial dimensions of HIV become crucial when children enter school. Children have been shown to experience significant stigma from peers and educators and thus require psychological and social support to cope with their health status as well as fulfil their academic requirements.[15]

The majority of adolescents with HIV in South Africa have most likely acquired it through sexual contact or, less likely, intravenous drug use, unlike in Asia and Central Europe. Their disease profile and characteristics are thus similar to those of adults. A small number of adolescents would be long-term survivors of HIV acquired through vertical transmission. It is important in this age group that health needs relating to their own sexual development, sexual health and behaviour are addressed.

With increasing numbers of children being orphaned due to HIV, children living with terminally ill or very elderly relatives, and children living on their own, the difficulties of accessing adequate health care services provide a major challenge to these and other groups of children rendered vulnerable through poor social, economic or health circumstances.

The psychosocial issues

The psychosocial and mental health needs of children are generally not considered by formal health facilities. Given the complexity of the HIV-epidemic, the many psychosocial dimensions that arise are as important for consideration as the medical ones. A lack of interventions and support for children and families that experience significant social problems and psychological fall-out will impact on the ability to adequately address the medical sequelae of HIV. This is a particular challenge in South Africa where poverty is widespread, trauma and violence are escalating with a significant impact on mental health, and child suicides are increasing[16] - the latter being an indication of children's increasing mental health needs.

The most pertinent HIV-specific issues that need consideration are confidentiality and testing for HIV, informing children of their status, disclosure of the child's status, and children's adherence to therapy. It is especially complex for young children, as decisions about these issues are made by parents/caregivers and not by children themselves. It is important that the best interest of the child must be at the heart of these decisions – which might not always be the case when children are in sub-optimal care.

Of special note for children of school-going age is the need to prepare and support children for entering and functioning in their school environment. This is especially important in the case of a chronic health condition such as HIV that might impact on their physical and mental health, where medication might have potential side effects and might require time off from school to visit health services. It is crucial that the school environment is able to support children through possible stigmatisation, possible academic disadvantage as a result of missing lessons, and having to be supervised at school with regard to taking their medication. This is not a need that can be met by health services alone, but needs to be a joint effort between health and education through appropriate and comprehensive school-based programmes and services. Health services have to be sensitive to the fact that children in school are old enough to be included in decisions about their health, being party to information about their illness, as well as being part of decisions as to whether and how their status must be disclosed. Particular additional health needs for children in their adolescent and teenage years relate to their own sexual development and awareness, and their need for support in dealing with their HIV-positive status.

3. A PROPOSED COMPREHENSIVE HEALTH SERVICE RESPONSE

As the use of ART has turned HIV from an inevitable terminal disease to a long-term (chronic) disease, health services for children with HIV-infection must therefore fulfil the same functions as services for children with any other chronic health condition.

The important parameters of health care for children with chronic diseases are effective primary level identification; good and timely referral and communication with secondary and tertiary levels of care for diagnosis; specialised investigations and development of a long-term management plan; continuity of care; availability of medication and support on an ongoing basis at a facility closest to the child; adequate family/caregiver support; a multi-disciplinary and inter-sectoral team approach; and a patient-retained card to reflect ongoing management and assessment that will enable the child to be treated at facilities outside of their residential area if necessary. These elements are clearly outlined in a draft 'policy framework for chronic conditions in children'. This policy has been in the process of development for the past five years and is not yet finalised. If finalised and implemented, it will significantly improve the ability of health services to care for children with chronic conditions.

A comprehensive health service response to children and HIV must therefore consider all dimensions of the disease and cover aspects that include health promotion, primary prevention (general and those specific to HIV), secondary prevention (specifically in relation to complications that may arise as a result of the HIV-infection such as Pneumocystis Carinii Pneumonia, or PCP), curative care (this includes acute, chronic and critical care), rehabilitative care, palliative care and terminal care. These components are in line with those suggested in the South African Department of Health guidelines for managing HIV in children, released in 2000.[17]

Additional service requirements relate to specific support needed for adolescents. The youth and adolescent health policy guidelines[18] have recognised the need to have adolescent-friendly health services, in the form of 'youth-friendly clinic models', such as the service initiated through the National Adolescent Friendly Clinic Initiative (NAFCI). The youth and adolescent health policy guidelines do require provinces to provide centres to enable adolescents to be supported through their transition from childhood into adulthood. The policy framework for chronic conditions in children offers a set of guidelines that can assist health services in their support to adolescents during this transitional period.

The additional complexities that form part of ARV provision to children with HIV-infection require additional measures to be put in place. As part of the '3 by 5' initiative that aims to provide ART to 3 million people by 2005, the WHO has published guidelines and recommendations for an emergency scale-up of ART in resource-limited settings; current South African national and provincial guidelines are based on these.[19] A report of the WHO/UNAIDS consensus meeting on technical and operational recommendations to achieve '3 by 5' describes the essential package of care, prevention and support services that must be in place before ART can be introduced into the health system. It also describes services that can be introduced concurrently with ART and then progressively expanded over time. The report recommends that antiretroviral therapy should be initiated in facilities at all levels of the formal health sector as soon as the following minimum conditions are available:

- HIV testing and counselling
- Personnel trained and certified to prescribe ART and follow up recipients clinically
- An uninterrupted supply of antiretroviral drugs
- A secure and confidential patient record system

In addition, adherence support and community mobilisation and education on antiretroviral therapy must be made available at all levels concurrent with and following the introduction of antiretroviral therapy.

These guidelines are focused on ART in adults and make some, albeit inadequate, distinction between the services and care for children as compared to adults. There are, however, important differences regarding ART in children compared to adults that must be considered in all ART treatment policies, guidelines and protocols.

Some of the important considerations with regard to children are outlined below.

1 Children are growing and developing.
2 Young children are entirely dependent on adult caregivers for everything, including administration of all medicines, consent for testing, disclosure etc.
3 The challenges of making age- and developmental-stage appropriate decisions with regard to consent to testing and treatment, confidentiality and disclosure. This is further compounded by the yet unknown impact in the African context of HIV on neuro-development as children grow older. Age guidelines developed for children without neuro-development problems may have to be adjusted for children that are neuro-developmentally affected as a result of HIV.
4 Paediatric HIV-disease differs considerably to adult HIV with regards to presentation, diagnosis, staging and progression. Unlike adults, most vertically-infected children become symptomatic soon after birth and in the absence of ART rapidly progress to early death.
5 Many of the clinical symptoms and signs of paediatric HIV are not specific to HIV-infection and significantly overlap with health problems seen in children living in poverty, such as malnutrition, tuberculosis and other infectious diseases.
6 Prescribing and dispensing of paediatric antiretrovirals are medicines more complicated than providing ARVs to adults. Dosages must

constantly be adjusted as children grow. Formulations must be child- and parent/caregiver-friendly and available in suspensions for younger children who cannot swallow capsules or pills. Some preparations can only be stored with refrigeration, a luxury not widely available in poor communities, thus requiring the appropriate choice or regimen for children who do not have access to fridges.

7. Care-providers must have general clinical skills and experience in caring for children.
8. Specialist counselling/support skills are required for appropriate voluntary counselling and testing (VCT) and support counselling for children.
9. A criterion for entering the ART programme requires children to have a responsible supportive adult who is able to supervise and take responsibility for life-long treatment – a criterion that many children cannot meet.

A comprehensive health service to children with HIV-infection requires a number of elements that are child-specific and child-orientated in order to ensure that the ‘best interest of the child’ is served and that ‘basic health care services’ to children with HIV-infection are provided.

Table 1 (beginning on the next page) outlines the elements of a comprehensive health service for children with HIV-infection and outlines both general as well as HIV-specific components.

Table 1: A proposed comprehensive service for children with HIV-infection

	General	**Specific to HIV**
Health promotion	This refers to all efforts to promote good health in children and their families, through health facilities, schools, and overall health promotion in society.	This refers to the additional health promotion around HIV, both how to prevent it and how best to live with the infection as individuals and communities. It includes sound nutritional support and advice with regards to infant feeding practices for mothers who are HIV-positive. Voluntary counselling and testing services to counsel and test children and parents/ caregivers. Specific training for counsellors to be able to counsel older children, especially those in their adolescent years, is essential and as crucial as for younger children.
Primary prevention	This refers to all preventive programmes aimed at young children, including the expanded programme on immunisation, developmental screening, growth monitoring and nutritional support such as Vitamin A supplementation. Specific services for adolescents such as adolescent-friendly clinics are essential to ensure that they are able to have their health issues addressed in a caring and sensitive environment.	This refers specifically to interventions such as the prevention of mother-to-child transmission (PMTCT), and ART to children who have been sexually abused and are at risk of acquiring HIV. Specific adolescent-friendly services and school-based programmes must address issues relating to HIV and its prevention with adolescents in a caring and sensitive environment.
Secondary prevention	This refers to measures that prevent an existing condition from worsening or developing complications. For example, physiotherapy to a child with burns to prevent contractures.	This refers specifically to children who have HIV-infection and require interventions to avoid complications from opportunistic infections such as PCP, TB etc. Thus antibiotic prophylaxis, nutritional support and TB prophylaxis should be administered where required.
Curative care	This refers to general acute curative care for conditions unrelated to their HIV-infection as per available guidelines such as the IMCI guidelines. It also refers specifically to critical care services for children that experience life-threatening acute illnesses.	Acute curative care for conditions specifically as a result of HIV, such as PCP pneumonia, thrush and cryptococcal meningitis. Critical care services for children with HIV are imperative as they will experience several episodes of acute illnesses, and due to their immuno-compromised status these children are often

	General	**Specific to HIV**
	Curative care services for adolescents that have to make the transition from childhood into adulthood are vital. It is important for adult services to understand child and adolescent health issues to enable the health services to treat and support adolescents in an appropriate manner when they have to make the transition to adult health services. Chronic care for children is an essential, but neglected component. Two essential components of chronic care services are the need for continuity of care, and good referral networks. Referring children to facilities up or down levels of care requires a solid and well-structured network to be in place. The indications and reasons for referral should be clear, and healthy communication should exist between health care professionals at different facilities and levels of care. This communication can be greatly assisted by patient-held records detailing relevant information and also serves to encourage 'ownership' of illness and ART amongst patients and their caregivers.	severely ill and require immediate life-saving care. Chronic care for children with HIV is a specific aspect that needs attention, as ART to prevent/delay the onset of AIDS is a life-long medication. Principles for chronic care in general must also be upheld for ART. Adolescents who have acquired HIV in their adolescent years will have a disease process that closely mimics that of adults. Adult services must recognise the developmental stage that adolescents are in and must also be able to support their specific emotional and psychological needs Those adolescents infected through vertical transmission or other means in their early childhood and who have survived into adolescence require both child and adult services to understand any particular differences in their disease process. These services should be able to respond to their physical as well as their emotional and psychological needs. Good adherence and effective antiretroviral treatment can be achieved if there is confidence and trust amongst patients in the health care services and providers through continuity of care. Erratic, inconsistent and/or unreliable services will result in poor outcomes and adherence to antiretroviral therapy. Ideally every child on ART and his/her caregiver should develop a healthy relationship with an identified care-providing 'team', led by a medical doctor whose primary role would be to coordinate and monitor the ART and inter-disciplinary services at all the levels of health care. These recommendations are clearly outlined and expanded upon in the current draft chronic disease policy guidelines.

	General	Specific to HIV
Palliative/home-based care and support	This refers to care that makes a child as comfortable as possible when they reach a stage of being terminally ill and/or bedridden.	This refers specifically to children and their families that have become very ill due to AIDS and require ongoing terminal care and support at home
Support to parents/caregivers of children	This refers to the very necessary part of a comprehensive MCH service where health services provide support to parents and caregivers of children through providing information, addressing the health care needs of parents so as to ensure that they are in optimal health to care for their children, and providing home-based care support and other social service support where required.	This aspect is especially important for parents of children with HIV-infection. For mothers, the early support in how to care and feed their HIV infected infants is imperative. Further support on issues relating to confidentiality of children's status, their liaison with the school environment, involving children in the management of their own disease, etc. are vital components of a MCH service. Ensuring access of HIV-infected caregivers/parents to the necessary treatment that they require and thus ensuring optimal health for the adult is probably one of the single most important factors in ensuring the best interest of the child is met.
Support from other sectors	This refers to general support needed from the Departments of Education and Social Development in particular, in order to support children that live in poverty and other difficult circumstances.	Health facilities need to liaise with other sectors, including education, social development, NGOs and CBOs, to ensure that children's health needs are encased in a comprehensive care and support network. Specific support here refers to support for children living with HIV, especially children that are of school-going age and require specific medical, psychological and social support. This can be done through school-based support programmes such as the school health and health-promoting schools programmes, for example. The possibility of providing specific grants to children that have become care-dependent, specifically those who have reached stage 3 or 4 of their disease, is under consideration.

4. THE CHILD-SPECIFIC ELEMENTS IN THE NATIONAL PLAN

The primary focus of this review is to ascertain whether the official national Plan on the comprehensive care and treatment for HIV and AIDS adequately takes into account children's health needs.

The Plan has many general elements that address the needs of both adults and children. The commentary that follows highlights the sections in the Plan that have specific reference to children, and identify the gaps that exist in the Plan. At the time of initiating this discussion paper, a parallel set of 'guidelines for the management of the HIV-infected child', commissioned by the Department of Health, and compiled under the leadership of a paediatrician from the University of the Witwatersrand, was being finalised. These guidelines provide much more specific direction for the comprehensive management of HIV-infected children. The official status of the guidelines is still unclear, as they have not yet been printed and officially released. It is encouraging that the Department of Health has recognised the need for a set of guidelines that address the specific needs of children. The analysis of the national Plan thus also considers the content of the unofficial Meyers guidelines.[iv]

Counselling and testing

The Plan requires the universal availability of prevention counselling, as well as voluntary counselling and testing (VCT). However, the Plan does not give any indication as to how the specific counselling needs of children should be addressed. It gives no direction on the age-related considerations for children that are old enough to benefit from counselling, nor does it suggest how health workers should approach counselling of children. The absence in the Plan of child-specific consideration in this critical aspect of management of HIV is indicative of the general lack of child-specific considerations in interventions and services that impact on the entire population.

Counselling for children must be age-appropriate; counsellors therefore need additional training to know how to counsel children that are old enough to understand issues relating to their HIV-status, as well as being able to judge how much information and participation the child is able to handle. While many facilities currently provide VCT, research

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[iv] The Department of Health guidelines entitled "Guidelines for the care of the HIV-infected child" will be referred to as the "Guidelines" as oppposed to the Plan which refers to the "Comprehensive care and treatment plan for HIV/AIDS", this being the official national Plan that forms the focus of this discussion paper. For ease of reference the guidelines will be referred to in the paper as the Meyers guidelines, Dr. Tammy Meyers being the lead author of the guidelines.

conducted by Giese et al. at the Children's Institute at six sites across five provinces in South Africa found that health workers and counsellors alike were not comfortable in counselling and supporting children. They mostly directed their activities towards the accompanying adult caregiver and admitted that they were not trained or equipped to counsel children, even those that were already entering their teens.[20] This is a crucial component of holistic care of HIV-infected children and requires due consideration by all services that provide VCT. The impending Children's Bill recommends that children aged 12-years and older, being of sufficient maturity, are able to consent to medical treatment and testing. It thus suggests 12 to be the minimum age at which children should be counselled and included in decisions regarding their own health.

The Meyers guidelines provide a comprehensive set of principles for counselling in general, as well as direction on when and how to disclose an HIV-positive result to children. It does not give very clear direction, though, as to when and how children should be counselled, this being a challenging task for counsellors who are primarily equipped to deal with adults.

In addition to the Meyers guidelines, a national consultative workshop held in October 2002 drew up a set of recommendations pertaining to voluntary counselling and testing for children. Approximately 100 representatives from various walks of life, all of whom deal with children, participated in the workshop. Their recommendations are in keeping with the issues raised in the preceding paragraphs.
The workshop recommended that:

- Children's right to participate in decisions concerning themselves is recognised.
- Children's participation needs to be appropriate to their age, maturity and mental capacity.
- Parents/guardians/caretakers take responsibility where children are too young or not of sufficient maturity or mental capacity.
- Facilities must cater for the counselling and testing of children by providing child- and adolescent-friendly and -orientated facilities, with trained counsellors.
- VCT must be part of a comprehensive set of services for children affected by and infected with HIV.

HIV diagnosis

The national Plan and the Meyers guidelines give very specific clinical direction on when to test and which tests to use for children. The national Plan outlines the key directives for HIV testing in children as outlined below.

Serologic (HIV antibody) testing should be done on children over 18 months of age when false positive results are unlikely due to the transfer of maternal antibodies across the placenta. The rapid finger prick testing method is the most appropriate in a primary care level setting as a screening test. A confirmatory antibody test is recommended but not essential.

Infants under 18 months of age need *virological* evidence of HIV-infection by either HIV (DNA) PCR or P24 Antigen testing. Simple methods like capillary sample testing are now available and relatively inexpensive. These services are provided by a reference laboratory, but testing should be done at a primary level so that HIV-infection can be diagnosed early in infants before complications can develop. It is equally important to exclude HIV-infection in infants who are at risk so that services can concentrate on the few who are infected and simultaneously reduce the unnecessary workload on health care services. Where virological diagnostic tests are not available, the WHO recommends repeating the antibody test at 18 months of age. Exceptions can be made in situations where infants present with typical AIDS-defining illnesses, e.g. PCP. Caution should be taken not to assume the presence of HIV-infection based on a positive antibody test, as many clinical conditions associated with poverty can mimic stage 2 and 3 HIV-infection.

The Plan does not, however, outline the complexities with regard to HIV testing in young babies and children. A very comprehensive outline of this is contained in the Meyers guidelines and hopefully these guidelines will be taken into consideration at ART sites.
The Plan also does not give any direction on how to address HIV diagnosis in the instance where children have no adult caregivers or are in residential care, especially informal residential care where no legal authorisation to consent on behalf of the child exists. It is interesting to note that special considerations are outlined in the Plan for the South African Defence Force and Correctional Services, but no mention is made of special considerations for children in settings such as residential care, homeless environments and children without adult caregivers. The Meyers guidelines give clear direction on this, but in practice it is still a logistical and legal quagmire.

A recent Johannesburg High Court ruling in favour of the Wits Paediatric HIV Working Group to obtain consent for testing and treating children without parents or legal guardians has paved the way for a change in definition of who may provide consent for children[21]. This ruling only applies to the children under the care of the Wits group and does not yet solve the difficulties for all other children in the country who do not have parents or legally appointed guardians. Proposed legislation in the Children's Bill suggests lowering age of consent to 12 years. Further provision in the Bill includes the provision of rights and responsibilities to informal caregivers that would include consenting to testing/treatment on behalf of young children. If these clauses in the current Bill become part of the eventual Children's Act, it would certainly assist in removing some of the current difficulties, but until then alternate mechanisms are required to support children and caregivers in the matter of consent for testing.

ART provision

An important component of the ART programme is the criteria that determine when to start a child on ART. Guidelines and indications for commencing ART in children consist of clinical and immunological criteria. The national Plan provides three criteria; namely CD4 count and the presence of symptoms relating to the illness, staging of the illness, and the availability of at least one responsible person capable of administering the child's medication.

The screening investigations required before ART can be considered in any patient are listed below.

CD4 count: Significant immuno-suppression, as measured by the CD4 count, is a defining criterion for starting children on ART. The CD4 count is reported as an absolute count, as well as a percentage of, the total lymphocyte count. The percentage CD4 is more useful in young children as it fluctuates less than the absolute count and is a more reliable measure of immuno-suppression.

Medical criteria for commencement of treatment:

- Recurrent hospitalisations (> 2 admissions per year) for HIV-related disease, or prolonged hospitalisation (> 4 weeks) OR
- Modified WHO stage 2 or 3 disease OR
- CD4 percentage < 20% in a child under 18-months-old, irrespective of disease stage, OR
- CD4 percentage < 15% in a child over 18-months-old, irrespective of disease stage.

This test is usually provided by reference laboratories and is available in most areas of South Africa. New techniques of CD4 measurement that are simple and cheaper are now becoming widely available and should increase the accessibility of this test to most secondary and tertiary centres. Although useful to know, the CD4 count/percentage is not essential if there are clinical criteria indicating the need for antiretroviral therapy. The absolute lymphocyte count is an acceptable alternative as a rough indicator of CD4 count in children with symptomatic disease (WHO stages 2 or 3) when CD4 testing is not available.

Tuberculosis investigations: HIV-infected children are frequently and continuously exposed to tuberculosis (TB) because of its high prevalence among HIV-infected adults. Diagnosing TB in children is notoriously difficult and requires a high index of suspicion. A chest x-ray, tuberculin skin test and (if possible) sputum or gastric lavage should always be done. A chest x-ray may also be needed to diagnose other conditions like Lymphoid Interstitial Pneumonitis (LIP).

Further blood tests that may be required include a full blood count, ALT (A liver enzyme) and fasting glucose and lipid.

The Plan does not recognise the specific difficulties of diagnosing HIV in children, the complexities of diagnosing HIV-associated illnesses like TB in children, and the huge social challenges of ensuring 'at least one responsible person capable of administering the child's medication'. The section in the Plan dealing with procurement does not mention the special considerations that must be taken into account when procuring preparations for children. Therefore special considerations for providing medication to children, such as the need to simplify the dosage to promote adherence, the need to obtain palatable and easy-to-ingest medication for children, and the need to refrigerate the syrup for children in the face of massive poverty levels with large sections of the country not being electrified, have not been taken into consideration. While alternate regiments are available that do not require refrigeration, ongoing research into making drugs for children less complex to take and less reliant on ideal storage conditions is required.

The Meyers guidelines are a bit more specific as to how children could be supported in the provision of ART, but do not provide viable alternatives for instances where health services, families and children face difficulties in meeting the social criteria or require support to administer ART on a long-term basis. The guidelines do allude to the need to liaise closely with NGOs and CBOs in this regard.

Monitoring of children on ART

Children on ART will need regular monitoring of the HIV-disease and drug toxicity, using clinical and laboratory methods. The Plan makes cursory mention of the fact that monitoring requires a combination of clinical and laboratory methods, with no specific reference to the monitoring requirements for children. This is an essential aspect of ART provision as children are likely to be on ART for many years and careful monitoring is required to ensure their optimal growth and development while on treatment. A brief summary of monitoring requirements for children based on the WHO '3 by 5' guidelines and the national Plan is outlined below.

Clinical

Growth is the best indicator of general health, nutritional status and HIV-disease progression. Growth must be closely monitored with weight and height (or length) for age. This requires accurate scales and stadiometers and the skills to correctly use them. Close monitoring of growth is important for calculating drug dosages, as they will need frequent adjusting as children grow.

Developmental assessment and monitoring is crucial as development more frequently affected either directly because of HIV encephalopathy or indirectly due to chronic illness or malnutrition. This requires simple screening of developmental milestones, monitoring head circumference and clinical signs of encephalopathy such as spasticity and hyperreflexia. Currently developmental screening does not take place as part of the routine preventive child health services, with the exception of the Western Cape province where developmental screening occurs to some extent.

Ongoing surveillance of adverse drug events and toxicity should form part of every clinical evaluation and clearly documented when they occur.

Laboratory

Viral Load (VL) and CD4 counts

These are the best and most accurate indicators of HIV-disease and the effectiveness of antiretroviral therapy. They are, however, not essential in the WHO guidelines for scaling up ART in resource-limited settings, but should eventually be widely available when more cost-effective methods are developed. National guidelines include VL and CD4 as part of routine monitoring of children on ART, available in most reference laboratories in South Africa.

ART safety

The following investigations are routinely required to monitor the safety of antiretrovirals: full blood count, ALT, and Ffsting lipids and glucose (Protease Inhibitors). Most primary level facilities have access to laboratories where these tests could be performed.

HIV resistance

The identification of resistant HIV-strains is critical when ART fails and HIV-disease progresses. These complex and expensive investigations are not widely available in South Africa and are not part of routine care, but they will certainly need to be more accessible in the future when more resistant HIV-strains start appearing as more people are on ART for longer times. Resistance patterns in children in developing country contexts are not yet known, as most children have, until now, not lived long enough for such resistance patterns to be adequately researched. Furthermore, for resistance testing to have meaningful application in clinical practice, it should be accompanied by expert interpretation that is not widely available in South Africa.

The Meyers guidelines outline a fairly comprehensive approach to monitoring of general growth and development in children, as well as the monitoring of specific aspects of HIV-infected children who require ART.

Drug availability

It is implicit in the Plan as well as in the Meyers guidelines that first line ARV drugs, as well as drugs to treat general infections, opportunistic infections and HIV-related complications, must be available at designated facilities. All paediatric medications on the Essential Drug List (EDL) should therefore be available and prescribed according to existing guidelines.

The absence in the accreditation criteria outlined in Chapter 4 of the Plan of items such as working fridges to store paediatric syrups, syringes to measure dose volumes, and working scales to ensure correct dosages for children, may just be an oversight.

Staff and human resources

One of the greatest challenges for antiretroviral roll-out in children is the presence of adequate and appropriately trained staff to ensure effective delivery of comprehensive HIV-care to children and their caregivers.

Staffing at a primary care level is essentially nurse-driven and their role in the care of HIV-infected children must be clearly defined with respect to counselling and support, diagnosis, preventive care (e.g. PCP prophylaxis), ART screening, and appropriate referral to the next level. Health care providers must have basic paediatric clinical skills for diagnosing and treating common childhood conditions and minor illnesses, and the ability to recognise and commence emergency treatment for more serious and life-threatening conditions. They should also be familiar with normal childhood nutrition and development and be able to detect problems in either of these. The ability to perform practical tasks like correct height or length measurement, and collecting blood specimens, especially in young children, is essential for routine care.

Further knowledge and experience in paediatric HIV clinical care are essential. Care-providers should be able to correctly stage children, recognise complications and associated conditions of HIV, and diagnose and treat opportunistic infections. They also need to be familiar with the commonly prescribed antiretroviral drugs with respect to indications, contra-indications, doses, side effects and availability of preparations for children.

Staffing at a secondary and tertiary level where ART is prescribed and monitored must ideally be multidisciplinary and should consist of medical doctors trained and experienced in paediatric HIV-care (specialists or medical officers); clinical nurse practitioners and nursing assistants; pharmacists; nutritionists; social workers and/or counsellors; radiographers; and allied medical professionals such as physiotherapists, occupational therapists and speech therapists. The services and expertise of the above disciplines already exist in most tertiary level facilities, but the challenge lies in extending the same level of service to secondary level facilities where the bulk of treatment and monitoring of children on antiretroviral therapy is likely to happen, given that current primary level facilities are struggling to provide even basic support to children infected with HIV.[22]

The Plan does consider the need for health workers to be trained with respect to the management of children, as evidenced by the inclusion of a module on paediatric HIV/AIDS in the proposed training course for health care providers. The Plan, however, focuses quite narrowly on training staff in dealing with the clinical aspects of HIV in children. The Meyers guidelines, if followed closely, require that health workers at all levels be very well versed in the overall requirements for ensuring children's comprehensive health care needs, as well as the specific clinical and social requirements for children with HIV.

Additional human resources that are not adequately considered in either document are required for a multi-sectoral team approach that extends beyond the boundaries of the formal health sector. In resource-limited settings such as South Africa, the role of CBOs and individuals, lay counsellors and NGOs is pivotal in educating and empowering communities with regard to antiretroviral therapy. Promoting and monitoring adherence to ART in children is more complex and difficult compared to adults, and will rely increasingly on the support of such structures. The need for collaboration between health facilities, social development, schools, CBOs and NGOs cannot be overemphasised. It is necessary for areas to have a clear map of who is able to provide what kind of support and to have a facilitator(s) that could coordinate such collaborations. At present ART provision is mostly done through NGOs, all of these having built up some degree of collaborative relationships, and these models should be examined for longer-term sustainability and development of public-private partnerships.

Roles of different levels of care, referral, and continuity of care

The Plan outlines the roles of different levels of care quite clearly.

The Plan suggests that the primary level should be responsible for diagnosing, staging and routine follow-up of HIV-positive patients. It will also be primarily responsible for ensuring ongoing adherence monitoring and support. Where appropriate, ART may be initiated at primary level facilities, depending on capacity. The Plan also emphasises the need for a link between the primary care level and home- and community-based services, in order to ensure good follow-up and continuity of care. Primary level facilities are required to ensure the provision of routine services, as well as Cotrimoxazole prophylaxis to children. The Meyers guidelines outline the elements required for the treatment and support of children at primary level in great detail.

Patients who meet the criteria for ART should then be referred to a district or regional level hospital for a clinician's assessment and confirmation of ART eligibility. This level of care is also responsible for providing the necessary laboratory, pharmaceutical and support services. Good up-and-down referral mechanisms must be in place. In order to address HIV-needs and -care holistically, care must be provided by a multi-disciplinary team.

Tertiary level hospitals are seen as playing an important role in training and providing expert clinical support to lower level facilities.

Neither the Plan nor the Meyers guidelines talk about services for children with HIV in the context of services to children with other chronic conditions. The existence of a draft policy framework for children with chronic conditions[23] that clearly outlines a very detailed plan on how services for children with chronic conditions should be structured and managed is not acknowledged in either document. This is illustrative of the general lack of collaboration between different programmes and initiatives within the Department of Health. The need for an integrated approach is addressed in the draft Continuum of Care Guidelines prepared by the Policy Project, which is to be read with the national roll-out.

Adherence

The Plan addresses adherence largely from the point of view of the patient being able to take responsibility for his or her own adherence, and does not address the needs of children that are reliant for their adherence on adults. The lack of focus on adherence issues in the Plan may lead to the underestimation of the resources needed to support adherence such as pill boxes, reminder tools, pharmacists, education of parents/caregivers, and other support structures that would aid adherence. The issue of adherence is not referred to in the Meyers guidelines.

Adherence in children is of particular importance, as the adherence in the young child is dependent directly on the 'adherence' of their caregiver/parent with the treatment schedule prescribed for the child. Erratic, inconsistent and/or unreliable services will result in poor outcomes and adherence with antiretroviral therapy. Good adherence can be promoted by ensuring consistent support of patients and their caregivers, and ensuring continuity of care as suggested in the current draft policy framework for children with chronic health conditions. Ideally every child on ART and his/her caregiver should develop a healthy relationship with an identified care-providing 'team' led by a health worker whose primary role would be to coordinate and monitor the ART and inter-disciplinary services at all the levels of health care. Children not living with a specific caregiver, children in day care facilities, as well as school-going children require extra support in this regard.

Additional service considerations

A number of additional issues must be considered to ensure smooth and effective service delivery to children with chronic health conditions. In order to refer patients between facilities, reliable and accessible transport needs to be provided for both urgent and non-urgent situations. Frequently families miss their appointments because they cannot afford the cost of transport. This becomes increasingly important and problematic in the rural areas where patients need to travel long distances to access health care. The possibility of subsided transport for children with chronic conditions requiring frequent transport to health services must be considered as part of a comprehensive package of social security. This issue was evidently debated when the national Plan was being formulated; monies were to be put aside for this need but mechanisms for its implementation were not spelt out.[24]

Access to social grants should be made easier, and criteria redefined to include families or caregivers of children on ART who need financial assistance.

In summary, the Plan does give consideration to children. However, this is done in quite a clinical and technical manner and does not adequately consider the comprehensive needs of children. Given the ‘best interest principle’, the Plan does not in every aspect consider what the implications are for children. The need to ensure ART provision to mothers and primary caregivers of children, for example, does not enjoy any special attention, notwithstanding that healthy mothers and caregivers are crucial to ensuring the well-being of children, especially children who themselves are ill with a long-term condition. The notion of family care or at least comprehensive consideration of the mother-infant pair is not adequately promoted.

Further limitations include the absence of clear guidelines for care and treatment of children without adult caregivers and children who are in alternate care such as residential care facilities.

5. CURRENT ART IMPLEMENTATION

Implementation of ARV roll-out is progressing much slower than anticipated by the National Department of Health. Of the 500,000 South Africans who could immediately benefit from ART, only 20-40,000 are currently receiving treatment, the majority of these through the private sector (*South African Health Review 2003/2004*). In the public sector an estimated 4,000 persons are on treatment, against the Department of Health projected figure of 53,000 persons on treatment by the end of March 2004.

Current numbers of children receiving treatment are well below the numbers requiring treatment. The fact that not many more than 2,000 children are currently on treatment, as against the few hundred thousand (newborn babies and children living with HIV) that require treatment, gives an indication of the huge strides that are needed to ensure adequate coverage of the ARV roll-out programme.[25] At the Red Cross Children's Hospital, for example, based on outpatient attendances at HIV-clinics, an estimated 600 children require treatment and only about 200 currently receive treatment. There have been countrywide delays at several steps in the process. Interviewees from the various provinces indicated that some of the constraints in roll-out are due to delays with tendering, procurement of ARV syrup for children, and lack of capacity within facilities to execute an ARV programme. A rapid evaluation as to where facilities are at across the country with regard to provision of ARV to children would help identify the current barriers to implementation in more detail.

As part of their Treatment Monitor Project, the Health Systems Trust (HST) identifies and monitors ARV treatment sites. The main variables available for each site are their province of operation, the number of persons that they treat and the current sources of funding. Information on current implementation status was extracted from the HST treatment monitor site.

At the time of writing of this paper, results from the treatment monitor site in April 2004 showed that there were 43 projects for which detailed information was available. Updated information as at August 2004 was not available from the site. Further detail about the Western Cape sites was obtained from the routine reports that monitor roll-out in this province. Current implementation sites are concentrated in the Western Cape, Gauteng and KwaZulu-Natal (KZN) - the provinces that had in fact started ARV treatment long before the official national Plan was launched. A few additional sites are scattered throughout the other six provinces. The majority of treatment sites in these provinces are currently funded via external sources of funding, but with a working relationship between the NGO provider and the government health facilities. The majority of treatment sites are thus driven through donor-funded projects, as opposed to routine services, some of these projects being operative in more than one geographic area.

In the three provinces with the largest number of treatment sites, the majority of the sites are concentrated in the metropolitan areas. For example, in Gauteng almost all of the sites are concentrated in Soweto, apart from the two that also serve the catchment areas of Johannesburg General Hospital and Coronation Hospital. In the Western Cape and KZN sites are concentrated in the Cape Metropole and the Ethekwini Metropole respectively.

Of the 43 projects (sites), 18 cater for adults only, 13 for adults and children, and 12 cater primarily for children. Of the child-focused projects, six are housed at two sites, thus giving a total of eight child-specific treatment sites. A number of the 43 sites are not yet active. At the sites that do provide treatment, a total number of over 4,000 patients are currently on treatment, of whom 582 (or 26%) are children. A few of the sites that primarily treat children also treat the mothers who are HIV-positive, thus promoting family care.

The numbers of children and the approach to their enrolment onto ART vary between sites. A closer look at the statistics from the Western Cape, which were the only detailed statistics available for the authors to look at, provides an example of provincial-level progress in ART roll-out. This example of the first province to have started ARV treatment, and being the province with the most number of sites, demonstrates a few interesting phenomena. At the end of April 2004, the Western Cape had a total of 19 sites, as indicated by the Western Cape ARV monitoring statistics.[26] Two of the sites, however, had not yet enrolled any patients. Of the 17 sites that had patients on ART, 12 had children enrolled onto the programme. Eleven of the 12 sites are located in the Metropolitan region of the Western Cape. The total number of children treated at each site range from one to 197. These numbers constitute a total percentage of all enrolments at each site of 2% to 95%, the latter being the case at the Red Cross Children's Hospital (the other 5% being mothers put onto treatment). The majority of children on treatment, 556 (76%) out of a total of 717, are receiving their treatment at the three tertiary hospitals, namely Groote Schuur, Tygerberg and the Red Cross Children's Hospital. (The figure of 582 from the treatment monitor site for all children thus suggests that significant strides have been made beyond the period on which the treatment monitor statistics are based).

The remaining 161 children receive treatment at a secondary hospital and three community health centres. Only one of the six sites that are located in the three other more rural Western Cape regions currently treat children on their programme. A total of 110 new children were enrolled onto the programme for the months of March and April 2004.

Of the 717 children on treatment in total, 63% receive treatment via donor funding. At the three tertiary hospitals, 60% of the children are on treatment courtesy of donor funding. At Groote Schuur, where 193 children are on treatment, this is funded 100% via donor funding. The remaining 161 children at the secondary hospital and community health centres all receive treatment through a donor-funded programme. While the majority of children are currently treated at tertiary level facilities in the Western Cape, nearly 90 children receive excellent treatment, care and support through the donor-funded Medicines Sans Frontier (MSF) programme delivered in partnership with local health services in a large peri-urban informal settlement just outside Cape Town. Such experiences demonstrate the feasibility of running an ART programme at the primary level of care. Updated statistics for the Western Cape for August 2004 showed that the number of children on treatment increased to 932, an increase of more than 200 over the four-month period, with 60% of children now being on treatment via provincial funding and 40% still on donor funded treatment - demonstrating the possibility of integrating previously donor-funded treatment into mainstream public sector service provision.

6. SERVICE CHALLENGES FOR IMPLEMENTING ARV ROLL-OUT

Aside from the enormous challenge of rolling out ART to as many additional sites as possible in order to increase the current coverage, a number of challenges from existing treatment sites have been highlighted by service providers who operate at different levels of care. Some of the challenges are discussed in the following section.

General service capacity

The currently ill-equipped primary level facilities are probably the largest challenge faced by the Department of Health in terms of scaling up ART. In a rapid appraisal done by Giese and Hussey in 2001[27] on whether primary level clinics are able to provide basic supportive treatment for children infected with HIV, the survey found that:

- Only a third of facilities were providing Vitamin A supplementation to HIV-positive children.
- Only a fifth of clinics were providing the correct regimen for TB prophylaxis.
- Only a third of clinics had a policy in place with regard to Cotrimoxazole prophylaxis and the majority of clinics were in fact using the incorrect regimen.

Research into the functioning of the current PMTCT provision also highlighted a number of service shortcomings – this being a much simpler programme requiring less complex interventions and resources. This is further confirmed by the primary care facilities survey conducted by the Health Systems Trust, which found primary level services for children to be sub-optimal both in terms of availability and quality of care. The demand to render ART – a complex long-term intervention for very large numbers of children – requires a well-functioning service infrastructure at all levels. There is an urgent need to ensure that prevention programmes such as the PMTCT function optimally. Many HIV-positive pregnant women in South Africa still do not have access to the PMTCT programme. Similarly, lack of access to safe drinking water or free milk formula force women to breastfeed and increase the risk of HIV-transmission to the infant post-delivery.

Improving the public health sector capacity to manage chronic health conditions, including HIV, is imperative, as no functioning chronic care plan currently exists.

Mammoth efforts are therefore needed to correct current service inadequacies at the primary level. While the national Department of Health considers that the huge investment in the ARV roll-out plan will generally improve the quality of care across the board and at all levels of care, especially at the primary level, this will require significant service delivery support, management and investment into the general health care infrastructure.

Interviewees expressed similar concerns about secondary level facilities and have expressed the view that tertiary level facilities are currently the best equipped to manage and support children requiring ART.

The appropriate resourcing of facilities to provide ARV presents a significant implementation challenge. Not enough health care professionals, both medical and nursing, are trained or skilled in paediatric HIV-care and antiretroviral therapy. Most health care facilities at all levels are understaffed and unable to cope with the large number of patients requiring antiretroviral therapy. There is not yet a clear plan on how to integrate the currently donor-funded patients into the routine government health services. The required resources that were to be in place in public sector facilities to facilitate the provision of ART have mostly not been received. Interviews with service providers in four provinces all highlighted similar concerns.

In terms of support services such as laboratories, investigations listed in national guidelines, such as CD4 and VL, are currently only done at reference laboratories in major centres, thus making access to such tests very difficult for people from outlying rural areas.

Coordinating services

Current services for children and adults infected by HIV are not family or child- and caregiver-oriented. Children are often dealt with as separate from their mothers/caregivers, and vice versa. This has also been demonstrated in the work of the Children's Institute where the research found that infected women are not necessarily questioned with regard to their link with children, and thus vulnerable children are often not identified through health services. Furthermore, inadequate planning of health facilities result in very few, if any, public sector facilities having the space to facilitate family-centred care.

Additional coordination between different programmes in the Department of Health, between different disciplines in health facilities, and across sectors, is currently not happening optimally, even though it is vital to the delivery of a comprehensive service to children.

Disclosure, confidentiality and consent

Disclosure of their own HIV-status to children, and at what age it is appropriate to make the disclosure, remains a clinical challenge. Children, as do adults, require significant emotional support in dealing with the potential stigma of having HIV-infection, especially in the case of children that enter school. Such support is often not available. Closely associated with this is the issue of confidentiality and consent for testing and treatment. The impending Children's Bill recommends age 12 as the age at which children could consent to treatment. Current legislation varies on this issue with different ages being recommended for different types of treatment by different laws. Urgent consensus on this is required. Additional factors relating to the HIV-disease process may complicate the issue of the age at which these processes are appropriate. The progression of the disease and the neuro-developmental impact in older children in Africa has not yet been studied. If HIV acquired vertically impairs children's neuro-development, the age of consent and for disclosure of the HIV-status to the child will have to be adjusted, based on the child's level of development. Currently individual health workers and counsellors have to use their own discretion as to children's readiness to participate in health decisions that affect them. Counsellors are often not equipped to deal with counselling of children, as outlined in the research report by Giese et al.[28]

Selecting children to receive treatment

The national Plan does not give any guidelines as to how service providers should prioritise who should be enrolled onto the programme. No clear priority or due consideration is therefore given to children above adults, or women above men. The sites try to enrol as many persons, irrespective of age or gender, onto their programme. Some projects such as ARK specifically prioritise women (and their partners) with children, or the primary caregivers of children, as they feel that keeping the mother/primary caregiver healthy is the best possible way of serving the best interest of children. Each site uses slightly different criteria over and above the minimum requirements for enrolment, which everyone seems to agree with.

In the absence of clear guidelines, prioritisation presents a very difficult clinical and emotional dilemma for clinicians. Once treatment eligibility criteria are met there may be differences of opinion between health care providers related to 'rationing' of services; leading to additional criteria such as whether the most sick children should be prioritised over the less ill, or vice versa. Given the current limitation of resources, it is inevitable that if the roll-out focuses initially on children that are very ill, the children that are less ill will have progressed to being very ill by the time adequate resources become available for roll-out to everyone else.

Adherence difficulties

Aside from the social constraints, such as inadequate treatment monitoring and a lack of support for adherence at household/community level, making adherence difficult, reliable drug procurement and supplies (especially for paediatric formulations) must still be established. There seems to be little interest by pharmaceutical companies in developing child-friendly or combination formulations that would simplify drug administration and improve adherence.

The treatment and care of HIV-infected children in residential care facilities

One of the concerns of Save the Children Sweden is the position of children who are in residential care facilities. One of the briefs of this commission was thus to look at one or two case studies of how children with HIV who are in residential care are looked after. This section depicts two case studies that compare and contrast the position of children in formal and informal residential care. The first case study is Nazareth House in Cape Town, where care and support of children with HIV are very well managed at present. The second case study looks at children in an unregistered non-government-funded facility where care and support for children with HIV represents a huge challenge.

Box 1: The case study of Nazareth House

Nazareth House is a residential care facility in Cape Town that cares primarily for children with HIV-infection. The facility houses 60 children of whom 52 are HIV-positive. Children range from six months to about 12 years, with an even distribution across the different ages. It is believed that all cases except one were infected via vertical transmission, as no other apparent alternate cause for their HIV-positive status has been demonstrated.

Sixty percent of the children are currently on ART. The remaining 40% either do not yet need it or are on TB treatment. All children currently receive their treatment via the Groote Schuur paediatric HIV clinic; all of these children are therefore on donor-funded treatment. A very close relationship with paediatricians at the hospital ensures very good follow-up, and treatment, and general management of all children. However, in the absence of donor funding, children would have to go through the routinely available services as they do for all their other health care requirements and would have to gain access, as do all other indigent children. No special provision is made for children in residential care, except if they have managed to build up a special relationship with service providers who might come out to the home to see the children there.

A further 70 children are in day care in Khayelitsha, a largely informal settlement on the outskirts of Cape Town. Here 25 of the 70 children currently receive ART via the programme delivered by Medicines Sans Frontiers (MSF).

The facility receives a government subsidy that realistically covers about one third of their operational costs.

The remainder is made up from private donations. No additional government subsidy is provided to residential care facilities that house children with long-term health conditions such as HIV, and the subsidy given to otherwise healthy children has to cover recurring medical expenses as well.

Source: Personal communication with social worker in charge of Nazareth house, June 2004

While the case of Nazareth House paints a positive and hopeful picture, many children are in informal residential care where the legal jurisdiction of carers over the children presents a legal quagmire with regard to obtaining consent for HIV-testing, as well as children accessing the required care, support and treatment.

The second case study depicts the situation of an informal children's home in one of the metropolitan areas.

Box 2: The case of an unregistered poorly-resourced children's home

Children's Paradise* is an unregistered children's home in a metropolitan area of the country. It is located five minutes away from a growing informal settlement that is currently unserviced in tems of water and sanitation. The home provides residential care for 14 abused, abandoned and neglected children. The four staff members work as volunteers. Income is approximately R5 000 per motnh and comes via monthly donations from local business concerned, an individual foreign donor, and church collections from a large informal settlement nearby. The Department of Social Developement is aware of its existence, but no formal links exist.

Eight of the nine children had HIV-positive mothers who were too sickly to care for their children. The HIV-status of the children, with the exception of one little girl, is not known. All of the children have one or both parents that are still alive, but are unable to care for them. One of the children was abandoned. Children range from one to ten years. Nine are boys and five are girls. One of the little girls, aged two, is HIV-positive. The home was unable to properly care for her with regard to ensuring her access to ART and other health services that she required. After an intense and unsuccessful search to find a place for her in a formal home that specifically cares for children with HIV, a place was found for her in another unregistered home that had better material resources.

Source: Case study as part of a Masters in Law assignment, courtesy of Paula Proudlock, Children's Institute.

*The name of the children's home has been changed to protect their desire for anonymity.

The first case study demonstrates that formally registered children's homes with good service links are able to care for children with HIV fairly adequately. However, even such homes are not adequately subsidised by the state and the state does not take into consideration the additional costs that are required to care for children with chronic health conditions.

The second case study is a microcosm of what the majority of children requiring residential care probably face. While the preferred scenario is that children should be cared for within the communities where they live, this is not always possible and a certain percentage of children do require placement in residential care. The reality is that residential care facilities are insufficient and are mostly filled to capacity. There are many more unregistered children's homes than registered ones, as compassionate community members respond to the plight of children. Aside from the material challenges that such homes face to care for the children, they also find it much more difficult to negotiate access to formal health and other services, not being the legal guardians of such children. In the case of HIV, testing children for HIV in the absence of legal guardians or carers is a legal quagmire. Ultimately the Minister of Social Development has to give consent for such children to be tested. In the case of TAC versus the DOH, affidavits from several clinicians highlighted the difficulties experienced with getting children without legally appointed caregivers tested for HIV. In some of the provinces alternate arrangements were agreed upon while a formal and legal process for VCT for children is put into place, to try and circumvent the extremely difficult bureaucratic procedures that must be negotiated for consent. The state has the overriding responsibility to ensure that such children are adequately cared for and that they receive any health care that they require. Currently this obligation is not adequately fulfilled for children that are not resident in registered children's homes - these often being filled to capacity.

7. THE KEY ROLE PLAYERS RESPONSIBLE FOR HIV HEALTH CARE TO CHILDREN

The ultimate responsible party for the delivery of health care to South African children is the South African government. The government is obliged, through the Constitution, to ensure children's access to basic health care services.

At government level the national DOH is responsible for formulating child-friendly policies and plans and ensuring that the path for successful implementation of HIV-care and treatment by provinces is made as smooth as possible. The DOH is also responsible for ensuring that adequate provision is made in terms of the required budgetary, human, drug and other resources through mechanisms such as conditional grants, equitable shares, etc. It is necessary that this department recognises children as a special priority group and fast-track crucial interventions for children by reducing barriers to the implementation of priority health programmes for children. Remaining at the national level responsibility, the Department of Finance plays a key role in finding ways of allocating and ring-fencing budgets for children's programmes. Furthermore, the national Departments of Social Development and Education have key roles to play in supporting and collaborating with the DOH and thus ensuring that children's needs are met in a comprehensive fashion.

Watchdog bodies such as the Office on the Rights of the Child, through the National Programme of Action, are responsible for monitoring whether government is indeed fulfilling its obligations to children in this regard. The National Plan of Action for Children, together with the Provincial Plans of Action, are meant to effect intersectoral plans and mechanisms to address children's needs, including their health needs, in a comprehensive and coordinated fashion.

For the implementation of HIV-specific programmes, the provincial health departments, through their HIV and PHC programmes, are responsible for implementing national policy by creating province-specific implementation plans and strategies that take into account provincial realities. As stated in earlier sections of this document, implementation is currently slow and children and their caregivers require greater priority in provincial implementation plans and delivery.

NGOs and CBOs have a critical role to play in working with the DOH, and in some instances playing a watchdog role over children's health rights. In this regard the TAC campaigns have been exemplary in prioritising specific health issues of children with HIV-infection, such as the introduction of the PMTCT, as well as the issue of VCT. Currently the majority of sites that deliver ART are indeed run by NGOs. NGOs therefore play a pivotal role in providing the full spectrum of treatment and support. CBOs are best placed to help identify children in need of care, support and treatment, providing support to families and caregivers that would enable them to fulfil the criteria for ART provision to children, and to work with health facilities in ongoing home-based and palliative care for children.

Children's rights and advocacy organisations have a key role to play in conducting research, monitoring implementation of the ART and other HIV-related programmes for children, as well as playing an advocacy role to ensure that children's specific needs are adequately addressed in national agendas.

8. CONCLUSION

Ten years post-democracy children in South Africa still have a sub-optimal health status in relation to the country's income levels, as evidenced by:

- Rising infant and under-5 mortality rates, largely still from preventable causes.
- The high burden of disease from preventable health conditions.
- Significant numbers of children having long-term health conditions, with a rising HIV-epidemic in children.

The challenge for mustering a comprehensive and effective health service response to improve the status of children's health still remains, and is in fact greater than ever due to epidemics such as HIV. The key emphasis in such a response has to be the prevention of HIV in adults, and then minimising the passing on of the disease from adults to children through an effective PMTCT, as well as strong social programmes to minimise child sexual abuse.

Given the large numbers of children that are already HIV-infected, the implementation of a comprehensive package of care for children infected with HIV in South Africa is essential, and, while daunting, is not impossible. It requires political will from all government departments, careful planning, and a consciousness on the part of policy makers, planners and implementers of the special needs of children.

The national Plan, in combination with the Meyers guidelines, is commendable and provides a good foundation for building a comprehensive service for children. However, the lack of coordination between these two documents and the existing policy framework for children with chronic conditions is concerning, especially as these policy guidelines very clearly and adequately outline the specific implementation requirements for services to children with chronic health conditions.

It is clear, however, that current ART implementation does not always favour the best interest of the child, as services remain largely adult-orientated. Neither do current practices promote equity of service access. A major ethical and moral dilemma exists with providing ART to children who do not have reliable caregivers/parents, through illness, negligence, old age or poor social circumstances. Included in this group are orphans and abandoned children of whom only a few are placed in institutions or adopted, simply because these facilities are scarcely available. Every HIV-infected child has a right to ART and cannot be denied ART simply because there is no reliable person to give to the child. An urgent solution is required to ensure that these children have an equal chance of having their right to health care and their right to life fulfilled.

This paper has to conclude that, despite the strong rights-based framework in which South Africa operates, children's health rights and in particular the rights of children with HIV are not yet met. Their basic, general health care needs are not adequately addressed, nor are their specific HIV-related needs addressed. Children are given thought, but are not necessarily prioritised, in national policies and plans, and children's issues are not necessarily fast-tracked or pushed to the forefront of service delivery priorities.

If we are to stay true to the commitments made to children back in 1994 and 1995 when the Constitution was drawn up and the CRC was ratified and signed, it is necessary to urgently revisit how polices and plans that have a bearing on children are made, how they are implemented, and how they are budgeted for.

9. RECOMMENDATIONS

The most important priority is to reduce the likelihood of HIV-infection in children through general initiatives to reduce HIV-infection in adults, as well as ensuring optimal functioning of the PMTCT programme. Where children have been infected, a comprehensive care and support programme for children and their families/caregivers is required.

Further recommendations

At policy level

All policies and plans that hold implications for children must therefore have a specific section, drawn up by child experts, to cater for children's specific needs.

Different policy and planning initiatives for children must be coordinated between the different programmes in the Department of Health, as well as between other sectors to ensure synergy and sensible planning.

Given the urgency of the HIV-epidemic, the current Meyers guidelines must be finalised and officially accepted, as these provide crucial detail as to the care and management of children currently lacking in the national Plan. In the same vein, the current draft policy framework for children with chronic health conditions must be officially accepted and implemented as a matter of urgency. Gaps that have been identified in the Plan and the Meyers guidelines must be addressed. These include the need to take a child-focused approach, with enabling legislation and policies, clear and standardised service delivery protocols and guidelines in the execution of:

- Counselling and testing (with specific reference to revising the

legislation for testing of children without parents or legal guardians).
- Adherence.
- Drug provision and procurement.

Clear financial and policy directives must create an enabling environment for patients currently being treated at donor-aided sites to be incorporated into routine health care services. As an interim measure, viable public-private partnership models must be established at all sites to ensure a smooth transition.

At service delivery level

Strengthening of the overall health care infrastructure, especially at the primary level of care is essential, as ART and other HIV-specific programmes such as the PMTCT will be difficult to implement successfully in the absence of a good infrastructure. Specific elements that are much neglected and that need strengthening are chronic care and critical care for children - the former being necessary due to the large numbers of additional children that will enter the pool of children with chronic conditions as a result of HIV-infection, and critical care being necessary as children, especially those not on ART, experience several episodes of severe and often life-threatening infections due to their compromised immune system.

Sustainable models of support and care between health services, NGOs that currently provide ART, donor-funded projects, and other HIV-related community-based initiatives must be explored to ensure continuity of care for patients currently on donor-funded ART and for those not yet on ART.

Emphasis must be placed on the specific needs of children when scaling up sites for ART provision, as well as in the training of staff and provision of other resources.

In conjunction with legislative initiatives such as the Children's Bill, clear consensual guidelines on age and development-appropriate practices for counselling, disclosure and confidentiality must be developed as a matter of urgency.

Clear guidelines on how to prioritise among eligible children and to ensure standardised practices across sites must be developed.

Specific attention to enhance adherence in children must be paid by health workers who have to make special efforts to ensure that caregivers of children have adequate understanding of, and are supported in, ensuring adherence. In addition, pharmaceutical companies that manufacture paediatric medicines have to examine ways of promoting adherence by finding ways to minimise the number of doses required per day and ensuring palatable preparations are manufactured.

Children living in especially difficult circumstances that require HIV treatment and support must receive special attention and support through all services, including health, social development, education and NGOs.

Special efforts must be made to support children in schools, and adolescents both in and out of school, through the provision of child-oriented and adolescent-friendly care and support. Optimal use must be made of existing facilities in health, social development and education to identify and support children with HIV and other chronic conditions.

All other sectors that impact on child health, such as departments responsible for food production, water and sanitation provision, transport and housing, have a critical role to play in ensuring that these determinants of health are delivered in areas where children are most at risk of preventable illnesses. The national policy framework suggested in previous drafts of the Children's Bill must be reinstated, as this will play a key role in ensuring a coordinated government response to the needs of children.

Advocacy

Finally, watchdog bodies such as the National Programme of Action, and children's rights and advocacy organisations must play a coordinated role in monitoring the care and support of children with HIV, and must find ways of working with and strengthening social service providers to ensure the best interest of the child is upheld.

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