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Submission on the National Health Bill

August 2003

University of Cape Town

For attention:
Portfolio Committee on Health
National Assembly
Parliament

Submission on the National Health Bill

By the
Children's Institute,
University of Cape Town

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1. Introduction

The Children's Institute welcomes the National Health Bill and the potential that it has to bring clarity and structure to the health system. We thank you for the opportunity to make a submission.

As a children's rights organisation that has a long history of involvement in children's health policy development, health care service provision, research, and training, we would like make recommendations on how the bill can be improved to ensure that children's health and well-being is prioritised within the health system.

We strongly recommend that children's health issues must enjoy specific mention and attention in the bill given that there is no other piece of national legislation that addresses child health services issues.

The Constitution [section 28 (1)(c)] and the UN Convention on the Rights of the Child (CRC) oblige us as a country to give special consideration to children in all matters that affect the interests of children. Besides the legal obligations to prioritise children's needs, that fact that children make up just under half of the entire South African population, out of necessity requires us to ensure that the system that we design is child appropriate. The governance, structure and delivery systems created in the Bill therefore must take into consideration children's needs.

We therefore urge Parliament to consider seriously whether the Bill takes us forward in our mission to promote, protect and fulfil children's rights.

We ask of you to please give careful consideration to our arguments in favour of the bill providing special protection for children. The arguments are based on the Health Department's explicit prioritisation and attention given to children in health policy documents since 1994, international and constitutional law obligations, international precedents, domestic precedents in other departments, the constitutional obligations imposed on the state by the Constitution, and the health status of the nation's children.

2. Precedents for taking a child focus in the National Health Bill

The lack of a child focus in the draft bill is not in keeping with international or domestic precedent. The international trend and the trend in new South African legislation and practice demonstrates a recognition of the value of providing dedicated services for children.

South African examples include the draft Child Justice Bill, the draft Children's Bill, the creation of the Office on the Rights of the Child within the President's Office, the establishment of the parliamentary Joint Monitoring Committee on Children, Youth and Persons with Disability, the establishment of the Youth Commission, the continued existence of the Child Protection Units within the South African Police Service, and the National Programme of Action situated in the Office of the President.

History has taught us, both on an international level and in South Africa, that children's needs are best met through creating dedicated structures, ring fencing dedicated resources and appointing and training staff in specialised child services. When children's needs have to compete with other priorities for attention and resources, the result more often than not, is that children find themselves at the bottom of the list of priorities. This is because children are not represented in government, are often not able to speak up for themselves, do not vote, and due to their youth are vulnerable to being neglected and abused. They invariably find themselves in a position of powerlessness in the hierarchy of society.

In the health care setting, in order to ensure that children's needs are provided for and prioritised, dedicated child health services structures, resourcing and staffing is needed.

3. Children's constitutional right to health care

The Constitution refers to health rights in three sections of the Bill of Rights:

Section 27

Section 27 (1) provides that everyone has the right to have access to health care services, including reproductive health care.
Section 27(2) obliges the State to take reasonable legislative and other measures, which its available resources, to achieve the progressive realisation of the right to have access to health care services.
Section 27(3) provides that no one may be refused emergency medical treatment

Section 28

Section 28(1) (c) provides that every child has the right to basic health care services.

Section 35

Section 35 (2) (e) provides that detained persons have the right to conditions of detention that are consistent with human dignity, including the provision, at state expense of adequate medical treatment.

The inclusion of children's rights to basic health care services [section 28(1) (c)] in the Constitution has been interpreted to mean that children's basic health care needs should enjoy priority when the state drafts legislation, allocates budgets or makes executive policy decisions.

This precedent set by the Constitution should be followed in all national legislation including the National Health Bill. The National Health Bill should therefore provide for the national, provincial and local government health systems to incorporate specific structures, mechanisms and considerations in order to adequately provide for children's health needs.

Further argument in favour of a child-focussed approach is the legal difference between the wording used in section 27 and section 28 of the Constitution. While the health rights of everyone (section 27) are “rights of access to”, the health rights of children (section 28) are “rights to”.

The "access rights" have been interpreted to place an obligation on the State to create an enabling environment for people to be able to gain access to the right. On the other hand, a “right to” requires the state to deliver the right directly to the person. Furthermore, children’s right to health care is not expressly limited by “resource availability” and “progressive realisation” as is the general right to health care in section 27(1). While the children’s right to health care does not exist in a vacuum separate from the general right to health care and the limits placed on that right by section 27(3), a Court will still require a higher standard of justification from a state body that has failed to deliver health rights to children versus failure to deliver health rights to everyone.

4. The state of the nation’s children

The state of child health in South Africa also presents a good argument for the National Health Bill to take a special focus on children.

High mortality (death) rates in Children

Our Infant Mortality Rate (IMR) is 45 per 1000 live births. This means that out of 1000 births, 45 babies will not live to see their first birthday. In some rural areas in the Eastern Cape, the IMR is as high as 100 per 1000 live births. Our average IMR is higher than Cuba, Vietnam and Botswana, countries with comparably weaker economies to South Africa. The main causes of infant deaths are preventable conditions such as gastro, respiratory infections and malnutrition. HIV and trauma injuries also claim a significant number of infants’ lives.

Our under-5 mortality rate is 60 per 1000 live births. Thus 60 children per 1000 do not live to their 5th birthday. The main causes of death in this age group are trauma, gastro infections, respiratory infections, malnutrition and HIV.

The mortality profile of children aged 5 to 14 shows that the major cause of death is trauma (violent intentional trauma and accidental trauma).

Mortality figures, especially the IMR, are key indicators used by international community and bodies such as the UN Committee on Children’s Rights as a measure of the extent to which a society protects the health and well-being of children. The current IMR reflects a situation worthy of serious concern for South Africa.

Morbidity (illness) in Children

Infants and children under 5 continue to suffer from preventable and easily treated conditions such as gastro, malnutrition and respiratory infections. Furthermore, many

children are being disabled unnecessarily due to acute and chronic conditions not being diagnosed and treated properly, especially at the primary level of care.

Challenges for child health services

This section provides a thumbnail sketch of the current main challenges for child health services:

- To effect good co-ordination between programmes that are responsible for child health
- To improve the overall management including the financial management of child health programmes and services
- For policy makers and those in control of national and provincial budgets to understand their obligation towards children as stipulated in the Convention on the Rights of the Child.
- To improve the quality of child health services.
- To improve equity between provinces and between richer and poorer areas within provinces (*Reality check, Kaiser Political Survey, December 1998*)
- To define a complete basic minimum package for child health. A draft document produced on behalf of the Department of Health contains a proposed minimum package of services at a primary level for all components of health care including for children, as well as norms and standards for community-based facilities. This document does not spell out the minimum package for other levels of care (*The primary health care service package. Department of Health. Pretoria. February 2000*).
- To prioritise the conditions that currently threaten the health and well-being of children such as malnutrition, respiratory infections, gastro infections, HIV/AIDS and trauma and violence (*South African Health and Demographic Survey. Preliminary report. December 1999*) by urgently compiling and implementing national plans to tackle each problem.

The health of the nation's children needs to be taken into account by Parliament when deciding whether and how to tailor the bill to prioritise children's health services. It is our submission that the health indicators above point to a dire need to entrench the gains we have made over the past 6 years, through legislating for the continued existence of key child health structures and programmes, and to dedicate more resources, time and energy to improving the health of all the children in South Africa.

5. Comment on the lack of child focus in the Bill

The draft bill does not recognize that children are a vulnerable category requiring special focus and attention; that children have specific health requirements that are different from those of adults; and the bill in some instances actually takes retrogressive steps away from a child friendly approach:

- The bill does not create or entrench existing structures tasked with ensuring that children's health needs are given special attention (a previous draft of the bill included a section obliging each district and province to ensure that Maternal Child and Women's Health services were provided)

- The list of users rights does not contain a user's right to be treated with dignity and respect and the right not to be discriminated against
- The list of user's rights in chapter 2 does not include children's rights to consent, participation and confidentiality.
- The legislative provision entrenching free medical care for pregnant women and children under 6 and free primary health care for everyone has been removed from the bill (it appeared in an earlier draft) and replaced by a clause giving the Minister a discretion to decide whether to grant or take away free health care to any particular category of persons.
- Previous drafts of the bill included schedules that clearly listed the functions of each level of government. These schedules were modelled on the lists in the White Paper and started to provide greater clarity. However, the tabled bill departs from this progress towards clarity especially with regards to the list of functions of district health authorities. This has implications for the delivery of child health services.

6. Summary of main recommendations

We recommend the following in order to strengthen the bill:

- Legislating for free primary level health care services for all people; free health care services for pregnant women and children under 6 years; and free health care services for people with disabilities. This should pertain to persons without medical aid cover user public sector facilities.
- Entrenchment of the MCWH (Maternal Child and Women's Health) Directorate as a structure that must be established, adequately staffed and resourced at all levels of government (National, Provincial and District)
- A provision providing clarity that the MCWH Directorate is responsible for co-ordinating all health services for children in consultation with other relevant Directorates (eg. HIV Directorate with respect to services for children with HIV, Chronic Diseases Directorate with respect to services for children with chronic illnesses)
- The ring fencing of the budgets for priority child health programmes and related support systems to ensure that such programmes are not undermined if budget shortages occur at a national, provincial or district level (the Primary School Nutrition Programme is currently ring-fenced while other priority child health programmes are not. For example the budget for printing and distributing road to health cards, MCWH staffing and resources, Protein Energy Malnutrition Scheme, School Health Services).
- Obligations to draft detailed plans to address urgent child health priorities with stipulated timeframes for implementation (eg. PMTCT, malnutrition, trauma injuries)
- MCWH representation on the National, Provincial and District Health Councils and Advisory Committees.
    - The National Health Council should include the MCWH Chief Director and the Director of Child Health
    - Provincial Health Councils should include the provincial MCWH Manager and the deputy director in charge of child health

    - District Health Councils should include the district MCWH programme manager
- Chapter 2 of the bill must include a user's right to be treated with dignity and respect and the right not to be discriminated against
- Chapter 2 should incorporate children's health rights to consent, participation in decisions and confidentiality. These can be taken from the draft Children's Bill.
- A provision must be included stipulating that minimum norms and standards on child health services must be set by the National Department and that such minimum norms and standards are mandatory for provinces and districts
- An obligation on the National Department to adequately support provinces in the implementation of the minimum norms and standards
- An obligation on the National Department to determine and issue norms and standards on emergency services and ambulances to ensure the equitable provision and accessibility of such services

7. Detailed comment on the provisions of the draft bill and recommendations to improve

PREAMBLE

Comment 1

We support the inclusion of children's rights to basic health care services in the preamble. This was not specified in the 2002 Department Draft and we are pleased to note that it has now been included.

However, mere inclusion of the right in the preamble and two more mentions in the Definitions and Objects sections, with no subsequent clauses aimed at putting the promise outlined in the preamble and objects clause into action, does not do justice to children's health rights.

Recommendation

The bill needs to follow through on the vision and spirit of the Preamble through the inclusion of specific clauses aimed at giving effect to that vision and spirit. Essential will be clauses obliging each level of government to provide MCWH services in accordance with national policy on MCWH services, and ensuring that MCWH managers are represented on the national, provincial and district health councils and advisory committees.

Comment 2

The Preamble does not refer to children's rights to basic nutrition [s.28(1) (c) of the Constitution). However, the Definitions ["health services"] and Objects sections [2(1)(c) (iii)] include the right to basic nutrition. The Department of Health is currently considered the Department responsible for promoting and protecting children's rights

to basic nutrition and has produced and implemented a number of policies and programmes aimed at improving child nutrition. These include the Integrated Nutrition Programme, the Primary School Nutrition Programme, and the Protein Energy Malnutrition Scheme.

Recommendation

It would therefore be in keeping with the precedent for the preamble to include children's right to basic nutrition and for this right to be echoed in the definitions and objects sections.

Comment 3

The Preamble mentions that the NHB is being enacted "in order to provide for co-operative governance and management of health services, within national guidelines, norms and standards in which each province, municipality and health district must address questions of health policy and delivery of health care services."

We would like to raise a question as to the legal status of national policy decisions and documents that set national norms and standards. The National Department has produced policy documents in the past that have not been regarded by all the provinces as compulsory standards to follow.

Clarity on what issues the National Department may set national policy and national norms and standards needs to be provided in the bill as well as clarity on the legal status of national norms and standards and the consequences of not adhering to the norms and standards.

For example, the National Department has just finalised a policy document on School Health Services. School Health Services has been accepted at a national level as an important part of the primary health care package[1]. However, not all the provinces currently provide a school health service.

The question that this example raises is; does the School Health Services national policy document contain minimum standards that the provincial and district level managers will be **obliged to adhere to** within their own operational plans? Or will the minimum standards be regarded as providing guidance only, to the extent that a province can decide not to provide a school health service at all? Some provinces for instance may decide that they do not have the resources to provide health care services at schools and make a policy decision to rather encourage parents to bring their children to the clinics. Is such a decision as to **whether or not to provide a particular service** a decision to be made at a national, provincial or district level?

Recommendation

The bill is not clear on what issues the relevant spheres of government may make policy decisions.

[1] Primary Health Care Package. February 2000. National Department of Health.

We recommend that the provisions throughout the bill that refer to the various functions and areas of jurisdiction of the three levels of government, be re-written to provide clear and unambiguous direction.

DEFINITIONS

Section 1 – Definitions

Insert definition of "Basic health care services"

Comment

Section 2 (a) (iii) of the bill provides that the Act is aimed at, among other things; "respecting, promoting and fulfilling the rights of children to basic nutrition and basic health care services contemplated in section 28 (1) (c) of the Constitution". However, no-where in the bill is "basic health care services" for children defined.

Children's right to basic health care services has not yet been defined in national legislation or by a court of law.

The lack of a definition makes it difficult for health care providers to know what they must do to ensure that children's constitutional health rights are being upheld.

For example: One health care provider may consider medication for asthma (a very common chronic illness) as falling within the definition of "basic health care services", whilst another health care provider in a province with less resources may consider the long term chronic medication required to treat the asthma, as treatment that falls outside of the concept of basic health care services.

Without a national standard on what constitutes "basic health care services" for children, inequity across the provinces and districts will continue and children's basic health care needs will not be consistently prioritised.

However, it is important to allow for the definition to be developed over time so as not to force the state to define the concept too narrowly.

Recommendation

The "basic health care services" package for children should be determined by the Minister after consultation with the National Health Council and published as a compulsory National Policy. [See s.3(1) (d) with regards to "essential health services" and a procedure for prescribing what constitutes "essential health services".]

The package can be amended every five years as the health profile and priorities of the country change.

It is important that the determination of “basic health services” and the five yearly amendment be a participatory process involving child health care providers and civil society. The National Health Council should therefore be obliged to consult with the public, especially the children’s sector, before making a recommendation to the Minister.

Suggested draft

“basic health care services” means the package of promotive, preventive, curative, rehabilitative and palliative health care services for children determined by the Minister in consultation with the National Health Council.

“norm”

Comment

The bill requires the National Department of Health to “*issue and promote adherence to”* norms and standards on various matters, including the provision of health services and nutritional interventions [see section 20 (2) (b)]

Section 1 defines a “norm” to mean “a statistical normative rate of provision or measurable target outcome over a specified period of time.”

The legal status of the norms and standards determined and issued by the National Department needs to be clarified. The definition of a "norm" does not provide any further clarity. Besides the list provided in section 20 (2) (b), which is very limited, it is not clear to what extent and on what health functions the National Department can determine and impose a national norm upon a provincial or district level of government. It is also not clear how the adherence to the norms and standards will be enforced by the National Department.

Given the current inequality that exists across the provinces for children, we believe that its is essential that the National Department be empowered to set basic norms and standards that must be adhered to by the provinces and districts.

Example: Ambulance services are a provincial function. The National Department is currently drafting norms and standards on emergency services in order to address the problems that relate mainly to issues of equity. Will these norms and standards set minimum standards of service that the provinces and districts must adhere to when designing and delivering their emergency and ambulance services? If yes, how will these minimum standards be enforced? For example: the minimum standards document may provide that there must be an emergency service point within 100km of centres with a population density over 500 000 people. If a district with a large population does not provide emergency services within a 100km distance, what recourse will that community have to ensure that the national policy is enforced?

Recommendation

Clarify the legal status of national norms and standards to ensure they are considered as compulsory national policy that is binding for all levels of government.

CHAPTER 1

OBJECTS OF ACT, RESPONSIBILITY FOR HEALTH AND ELIGIBILITY FOR FREE HEALTH SERVICES

Section 2 – Objects of Act

Comment - whole section 2

The bill provides that the "objects of this Act are to regulate national health and to provide uniformity in respect of health services across the nation by –

(a) establishing a national health system which –
    (i) encompasses public and private providers of health services; and
    (ii) provides the population of the Republic with the best possible health services that available resources can afford;
(b) Setting out the rights and duties of health care providers, health workers, health establishments and users; and
(c) Respecting, promoting and fulfilling the rights of -
    (i) the people of South Africa to the progressive realisation of the constitutional rights of access to health care services, including reproductive health care, within available resources
    (ii) the people of South Africa to an environment that is not harmful to their well-being; and
    (iii) children to basic nutrition and basic health care services contemplated in section 28(1) (c) of the Constitution."

In our opinion, the phraseology appears back to front. A state does not **regulate by respecting and promoting rights**. Instead one rather **promotes and respects rights by regulating.**

Recommended draft

"The objects of this Act are to respect, promote, protect and fulfil the rights of everyone to basic health care services by –

(a) establishing and regulating a national health system that encompasses public and private providers of health services;
(b) providing uniformity in respect of health services across the nation
(c) providing the population of the Republic with the best possible health services
(d) setting out the rights and duties of health care users and providers
(e) prioritising the provision of health services to vulnerable groups and people living in rural areas

Comment - Section 2 (b)

The bill states that the objects of the Act include "setting out the rights and duties of health care providers, health workers, health establishments and users".

We welcome the inclusion of a chapter on rights and duties for providers and users, however, we are concerned by the lack of recognition of children as a category requiring special rights and by the non-inclusion of certain key users rights, such as the right to be treated with dignity and respect and not to be discriminated against.

Recommendation

If a stated object of the bill is to set out rights and duties of users and health care providers, it should be as inclusive as possible and include at least all the relevant rights, especially a users' right to be treated with dignity. Please see our comments and recommendations under Chapter 2.

Section 3- Responsibility for Health

Comment - Section 3 (1)

In our opinion, it is not necessary for the Bill to include the words "within the limits of available resources". This limitation is provided in the Constitution and it is not necessary to repeat it in legislation. The continuous repetition of the phrase creates a negative impression that shifts the focus from the state's good intent to provide health care services within a framework of progressive realisation.

Recommendation

We recommend the deletion of the words "within the limits of available resources".

Comment – Section 3(1) (a)

Sub-section (a) provides that the "Minister must, within available resources – **endeavour** to protect, promote, improve and maintain the health of the population"

The use of the word "endeavour" implies that the Minister must try his or her best. This is not a phrase that is usually used in legislation. Legislation establishes clear duties, it does not guide or implore or urge someone to do something.

Recommendation

We recommend that the word endeavour be removed and a clear duty imposed on the Minister.

Suggested draft

(a) ~~endeavour to~~ protect, promote improve and maintain the health of the population;

Comments – Section 3(1) (b)

Sub-section (b) provides that the "Minister must, within available resources – **promote** the inclusion of health services in the socio-economic development plan of the Republic"

The use of the word ""promote" does not impose a clear duty on the Minister.

Recommendation

We recommend rather the use of the word "ensure".

We would also like to query the term "the socio-economic development plan" of the Republic. Is this a Policy or a National Plan that currently exists or is it a new concept? Is it a reference to the RDP and GEAR? The bill should clarify what it is referring to otherwise it is not possible to measure whether the Minister has complied with the duty.

Suggested draft

(b) ~~promote~~ **ensure** the inclusion of health services in the (socio-economic development plan) of the Republic

Comments - Section 3(1)(d) and (e)

Section (d) provides that the "Minister must **within the limits of available resources** - ensure the provision of such **essential health services** to the population of the Republic as may be prescribed after consultation with the National Health Council".

Section (e) provides that the "Minister must, **within the limits of available resources** – **prioritise** the health services that the State can provide taking into consideration health needs and **available resources**."

The Constitution provides that everyone has a right to have access to **health care services**, including reproductive health care and that the State must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of this right. The Constitution does not say that everyone has a right of access to **essential** health care services.

The use of the word "essential" in the bill, qualified further by the use of the words "within the limits of available resources" place a lesser obligation on the state than was envisaged by the drafter's of the Constitution. If the obligation to provide essential health services remains in the bill, it should not be qualified by the phrase "within the limits of available resources", as this amount to a double qualification that is not what was intended by the drafters of the Constitution.

The use of the words “available resources” twice in sub-section (e) also needs to be corrected.

Sub-sections (d) and (e) appear to mean the same thing.

Recommendation

We recommend that the Bill must clearly oblige the Minister to provide everyone with health care services as provided in the Constitution. Any reference to essential health care services should be made rather in the section that deals with prioritising health care services within the framework of progressive realisation. The section referring to prioritising health care services should refer to the Constitutional imperative to prioritise the delivery of basic health care services to children [s.28(1) (c) of the Constitution] and should echo the White Paper’s emphasis “ give priority to maternal, child and women’s health (MCWH)”[2]

Suggested draft

3. (1) The Minister must, ~~within available resources –~~
   (d)ensure the provision of ~~such essential~~ health services to the population of the Republic as ~~may be~~ prescribed after consultation with the National Health Council;
   (f) **in keeping with the principle of progressive realisation**, prioritise the health services that the state can provide **at a given time**, taking into consideration health needs **of the nation as a whole, and the constitutional imperative to prioritise the delivery of basic health care services to children, and primary health care services for everyone.**

Section 4 - Persons eligible for free health services in public health establishments

Comment

The bill provides that the Minister may determine that certain persons are eligible for free health services at public health establishments.

The bill does not list the categories of people eligible for health services.

A previous draft of the bill (May 1998) provided in section 3:

[2] Page 15 of the White Paper for the Transformation of the Health System in South Africa provides in section 1.1.1 that the restructuring of the health sector has the following aims:
“ (a) To unify the fragmented health services at all levels into a comprehensive and integrated NHS
(b) to reduce disparities and inequalities in health service delivery and increase access to improved and integrated services, based on primary health care principles,
(c) to give priority to maternal, child and women’s health (MCWH); and
(d) to mobilise all partners, including the private sector, NGOs and communities in support of an integrated NHS.”

(1) Subject to any limitations which the *Minister* may *prescribe*, state and state-funded clinics and community health centres shall provide -

(a) **pregnant and lactating women and children below the age of six**, who are not medical aid schemes members or beneficiaries, with **free medical services;**

(b) **all persons**, except members of medical aid schemes and their dependents and persons receiving compensation for compensable occupational diseases, **with free primary health care;**

(c) women, subject to the provisions of the Choice on Termination of Pregnancy Act (1996), free termination of pregnancy services; and

(d) services free at the point of delivery to any other group.

The May 1998 draft incorporated into law, the free health care notices published in 1994 and 1996 respectively.

The change in the bill from the May 1998 draft, means that the provision (and removal) of free health care services will be a decision vested solely with the Minister of Health. The shift from an intention to entrench free primary health care in the bill to an intention to give the Minister the power to make and repeal these notices without consultation and thereby removing people's rights to free primary health care is concerning.

The decision on the category of persons eligible for free health care services, should be a decision taken in consultation with the elected representatives of government, namely Parliament. Leaving this decision to the Minister's sole discretion is not in the spirit of a participatory democracy.

Furthermore, it is not clear as to whether the new Act will repeal the two free health care notices issued in 1994 and 1996 respectively and the announcement of "free health care services for people with disabilities". Legally, the two notices remain in force unless repealed by the Minister. The bill does not explain the department's intention in this regard.

Recommendation

Free primary health care for all and free medical care for pregnant women and children under 6 is a cornerstone of our new health system which should not be removed but which should be protected through incorporation into the National Health Bill.

The government is constitutionally obliged to provide health services to vulnerable groups within society (Grootboom CC), including children living in poverty, children infected or affected by HIV, children who have been

orphaned, children with chronic illnesses or disabilities, street children, and abandoned children.

Removing the right to free primary health care for everyone, will be considered a retrogressive step towards the progressive realisation of the right to health care services. In the context of children, such a retrogressive step would be domestically and internationally condemned by the Constitutional Court and UN Committee on the Rights of the Child.

Suggested draft

Delete section 4 and replace with May 1998 draft plus new underlined words:

5. Persons eligible for free health services in public health establishments

(1) Subject to any limitations which the Minister may prescribe **in terms of sub-section 3**, state and state-funded clinics and community health centres shall provide -

(a) pregnant and lactating women and children below the age of six, who are not medical aid schemes members or beneficiaries, with free medical services **at the appropriate level of service;**

(b) all persons, except members of medical aid schemes and their dependents and persons receiving compensation for compensable occupational diseases, with free primary health care **at the appropriate level of service;**

(c) women, subject to the provisions of the Choice on Termination of Pregnancy Act (1996), free termination of pregnancy services; and

(d) services free at the point of delivery to any other group which the Minister, in consultation with the NHA and Parliament declares by notice in the government gazette to be a group entitled to free health services.

(3) (a) The Minister may prescribe conditions for eligibility for the above mentioned groups provided such conditions do not reduce access for the users concerned.

CHAPTER 2

RIGHTS AND DUTIES OF USERS AND HEALTH CARE PROVIDERS

Comment - the right to dignity and respect

We welcome the inclusion of a chapter on rights and duties of health care users and providers. We are concerned however, by the non-inclusion of the right to be treated with dignity and respect and the right not to be discriminated against.

Recommendation

The right to be treated with dignity and respect and not to be discriminated against should be included in the bill.

Suggested Draft

"Dignity and Respect[3]

Health care providers shall respect health care users rights to, human dignity, and privacy, and shall not unfairly discriminate on one or more grounds including race, gender, ethnic or social origin, colour, sex, sexual orientation, age, educational level, level of income and ability to pay for health services, disability, health status (including HIV status), pregnancy, marital status, religion, conscience, belief, culture, language, or nationality."

Comment - children's health rights

We are also concerned by the lack of recognition of children's special needs through the non-inclusion of a section on children's rights. Children are particularly vulnerable within the health system due to competing priorities and their inability to speak for themselves. In a busy hospital with many priorities and patients competing for the attention of the health care providers, children often find themselves at the bottom of the list. Health care providers should therefore be made acutely aware of the need to take extra care when dealing with children within the system. A list of child health rights incorporated in the bill and an obligation to display the list prominently on the walls of the health facility will go a long way in ensuring children are given the care that they are entitled to.

In further support of this point, the South African Law Commission has recommended in its Discussion Paper on the Review of the Child Care Act, that the National Health Bill should include a list of children's health rights[4].

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[3] This provision appeared in the May 1998 draft of the bill

[4] The Commission recommends on page 36 of the Executive summary of the Dicsussion Paper that the following health care rights of children should be included in the National Health Bill:

- the right not to be unfairly discriminated against on the basis of HIV/AIDS status;
- equal access to health care services;
- right to mental and psychological health care;
- the provision of HIV/AIDS prevention information or health promotion information;
- confidential access to contraceptives regardless of age;
- informed consent as a requirement for HIV testing, and testing only when it is in the child's best interests;
- a child's right to confidentiality regarding his/her health status;
- the right to be treated with dignity regardless of health status;
- treatment of an acceptable standard;
- protection against female genital mutilation and other harmful cultural practices;

Recommendation

A special list of children's health rights should also be included in the bill. Key rights to include:

- the right to participate in decisions about their health and treatment and about health research, in a language that is developmentally appropriate for the child
- the right to confidential access to non-oral contraceptives regardless of age and oral contraceptives for children 12 years and older
- the right to confidentiality of health status and health records

The Head of each Health Establishment should be obliged to display the list of rights prominently on the walls of the facility.

Suggested draft

Part 3: Protective measures relating to health of children

Consent to medical treatment and surgical operations

142. (1) Subject to section 5(2) of the Choice on Termination of Pregnancy Act (Act 92 of 1996), a child may be subjected to medical treatment or a surgical operation only if consent for
such treatment or operation has been given in terms of either subsection (2), (3), (4) or (5).

(2) (a) A child may consent, subject to paragraph (b), to medical treatment or a surgical operation, provided the child –

(i) is at least 12 years of age; and

(ii) is of sufficient maturity and has the mental capacity to understand the benefits, risks, social and other implications of the treatment or operation.

(b) A child may not consent to a surgical operation in terms of paragraph (a) without the assistance of –

(i) the parent of the child; or

(ii) the primary care-giver of the child.

(3) The parent or primary care-giver of a child may, subject to section **41,** consent to the medical treatment of or a surgical operation on the child if the child is

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- right of boys not to be subjected to unhygienic circumcision and other harmful cultural practices;
- an accessible complaints procedure;
- the right to use alternative health care systems if so desired.

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(a) under the age of 12 years; or

(b) over that age but is of insufficient maturity or does not have the mental capacity to understand the benefits, risks and social implications of the treatment or operation.

(4) The superintendent of a hospital or the person in charge of the hospital in the absence of the superintendent may consent to the medical treatment of or a surgical operation on a child if –

(a) the treatment or operation is necessary to preserve the life of the child or to save the child from serious or lasting physical injury or disability; and

(b) the need for the treatment or operation is so urgent that it cannot be deferred for the purpose of obtaining consent that would otherwise have been required.

(5) A children's court may consent to the medical treatment of or a surgical operation on a child if –

(a) the child has been abandoned; or

(b) the parent or primary care-giver of the child –

(i) unreasonably refuses to give consent or to assist the child in giving consent;

(ii) is physically or mentally incapable of giving consent or assisting the child in giving consent;

(iii) is deceased; or

(iv) cannot readily be traced.

(6) No parent or primary care-giver of a child may refuse to assist a child in terms of subsection (2) (b) or withhold consent in terms of subsection (3) by reason only of religious or other beliefs, unless that parent or primary care-giver can show that there is a medically accepted alternative choice to the medical treatment or surgical operation concerned.

HIV-testing

143. (1) No child may be tested for HIV except when –

(a) this is in the best interest of the child and consent has been given in terms of subsection (2); or

(b) the test is necessary in order to establish whether –

(i) a health worker may have contracted HIV due to contact in the course of a medical procedure involving contact with any substance from the child's body that may transmit HIV; or

(ii) any other person may have contracted HIV due to contact with any substance from the child's body that may transmit HIV, provided the test has been authorised by a court.

(2) Consent for a HIV-test on a child may be given by –

(a) the child, if the child is –

(i) 12 years of age or older; or

(ii) under the age of 12 years and is of sufficient maturity to understand the benefits, risks and social implications of such a test;

(b) the parent or care-giver, if the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a test;

(c) a designated child protection organisation arranging the placement of the child, if the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a test;
(d) the superintendent or person in charge of a hospital, if –
    (i) the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a test; and
    (ii) the child has no parent or care-giver and there is no designated child protection organisation arranging the placement of the child; or
(e) a children's court, if –
    (i) consent in terms of paragraph (a), (b), (c) or (d) is unreasonably withheld; or
    (ii) the child or the parent or care-giver of the child is incapable of giving consent.

HIV-testing for foster care or adoption purposes

144. If HIV-testing of a child is done for foster care or adoption purposes, the state must pay the cost of such tests.

Counselling before and after HIV-testing

145. (1) A child may be tested for HIV only after proper counselling, by an appropriately trained person, of –
(a) the child, if the child is of sufficient maturity to understand the benefits, risks and social implications of such a test; and
(b) the child's parent or care-giver, if the parent or care-giver has knowledge of the test.

(2) Post-test counselling must be provided by an appropriately trained person to –
(a) the child, if the child is of sufficient maturity to understand the implications of the result; and
(b) the child's parent or care-giver, if the parent or care-giver has knowledge of the test.

Confidentiality of information on HIV/AIDS status of children

146. (1) No person may disclose the fact that a child is HIV-positive without consent given in terms of subsection (2), except –
(a) within the scope of that person's powers and duties in terms of this Act or any other legislation;
(b) when necessary for the purpose of carrying out the provisions of this Act;
(c) for the purpose of legal proceedings; or
(d) in terms of an order of a court.

(2) Consent to disclose the fact that a child is HIV-positive may be given by –
(a) the child, if the child is –
    (i) 12 years of age or older; or
    (ii) under the age of 12 years and of is sufficient maturity to understand the benefits, risks and social implications of such a disclosure;

(b) the parent or care-giver, if the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a disclosure;
(c) a designated child protection organisation arranging the placement of the child, if the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a disclosure;
(d) the superintendent or person in charge of a hospital, if –
    (i) the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a disclosure; and
    (ii) the child has no parent or care-giver and there is no designated child protection organisation arranging the placement of the child; or
(e) a children's court, if –
    (i) consent in terms of paragraph (a), (b), (c) or (d) is unreasonably withheld and disclosure is in the best interest of the child; or
    (ii) the child or the parent or care-giver of the child is incapable of giving consent.

Access to contraceptives

147. (1) No person may refuse –
(a) to sell condoms to a child; or
(b) to provide a child with condoms where such condoms are provided or distributed free of charge.

(2) Contraceptives other than condoms may be provided to a child on request by the child and without the consent of the parent or care-giver of the child provided –
(a) the child is at least twelve years of age;
(b) proper medical advice is given to the child; and
(c) a medical examination is carried out on the child to determine whether there are any medical reasons why a specific contraceptive should not be provided to the child.

(3) A child who obtains contraceptives or contraceptive advice in terms of this Act is entitled to confidentiality in this respect, subject to section **168**.

In addition, we would like the Minister to :

(a) Broaden the confidentiality clauses to include other health status conditions and not just HIV. We recognise, however, that children with HIV need extra protection.

(b) The bill needs to be more specific as to how unaccompanied minors will be helped to consent, especially those under 12. An accessible procedure needs to be designed

Section 10 - Discharge reports

Comment

The bill provides that "a health care provider must provide a user with a discharge report at the time of the discharge of the user as an inpatient from a health establishment containing such information as prescribed"

Primary health care facilities are required to do follow up treatments for children with chronic illnesses who have been treated at secondary or tertiary levels of care. If the child is not accompanied by a document explaining the follow up treatment required, the child may not receive the appropriate treatment from the primary level of care, resulting in the child relapsing and having to be re-admitted to the secondary or tertiary level. A discharge report with the detailed treatment regime would assist the primary health care provider to administer the correct treatment to the child and prevent the child having to be referred up to a higher level of care. The lack of doctors and nurses skilled in paediatric care at a primary level facility can be supplemented through the information supplied in the discharge report received from paediatric specialists at a secondary and tertiary level. It would also help to train nurses in paediatric expertise.

Children in residential institutions such as places of safety and children's homes are frequently looked after by numerous care workers doing shift work. If a child with a chronic illness is discharged from a hospital without a discharge report and the child requires a detailed treatment regime, the child's health may suffer as the care workers involved are not informed on how to treat the child. It is our experience that many children infected with HIV/AIDS are dying unnecessarily from secondary infections in residential institutions due to the care workers being uninformed on how to administer the treatment or medication required.

Children who have been orphaned and who are living in child headed households who attend health care facilities without adult supervision and who are supported by various NGO home based care workers or neighbours also need written discharge reports. A report would enable the adults caring for the child and the local health care facility to administer the correct treatment.

We therefore support the inclusion of this right to a discharge report.

Section 18 - Laying of complaints

The sections should prescribe that the complaints procedure must be open, fair and accessible and child friendly, and that users must receive a response within a stipulated timeframe. The section should also prescribe that the procedure for laying complaints must be displayed prominently on the walls of the health establishment and communicated orally to users, especially children.

CHAPTER 3

NATIONAL HEALTH

Legislating for the statutory establishment of the Maternal, Child and Women's Health Chief Directorate

Since the election of the first democratic government in 1994, several important changes have taken place within the health system of South Africa. A number of these changes had been debated for several years prior to 1994, and with the onset of the new political order and resultant political will, many of these changes were introduced *(A National Health Plan for South Africa, African National Congress, 1994*).

For children, a major change has been the government's explicit commitment to making children a priority and thus heeding to the "First Call" for children. Until 1994, child health services have been organised and structured as part of the overall health system. No specific emphasis was placed on children and there were very few policies and programmes that specifically targeted children. Post-1994, a number of new policies and programmes within health services that specifically targeted children were formulated.

History has taught us, both on an international level and in South Africa, that children's needs are best met through creating dedicated structures, setting aside ring fenced resources and appointing and training staff in specialised child services. When children's needs have to compete with other priorities for attention and resources, the result more often than not, is that children find themselves at the bottom of the list of priorities. It is for this reason that dedicated child health services structures, resourcing and staffing is needed.

The most important change towards this approach in South Africa has been the creation of specific programmes at national and provincial level: the Maternal, Child Health and Women's Programme, (MCWH). The MCWH programmes are being managed through the Chief Directorate for MCWH at a national level and through Deputy Directorates for MCWH at provincial level. The MCWH programmes are required to oversee all MCWH activities in the country (*White paper for the transformation of the Health System in South Africa; Department of Health, Notice 667 of 1997; Maternal Child and Women's health. Department of Health; 1 February 1995*). The need for the MCWH programme was spelt out in the White Paper on the Transformation of the Health System and the programme was subsequently set up.

Those of us working in the child health sector had expected that the National Health Bill would entrench and protect the gains made in child health services over the past 6 years by legislating for the permanent existence, structure, prioritisation and resourcing of the MCWH Chief Directorate.

While a previous draft of the bill (May 1998) contained a section (s.93) requiring the provision of MCWH services, the November 2001 draft does not contain such a provision and does not entrench the establishment of the MCWH programme.

The new National Health Bill will be the most important piece of health legislation in the country. It is therefore paramount to ensure that this legislation adequately spells out the vision for child health services that is encapsulated in the White Paper.

Recommendation

To entrench the gains in child health services made over the past 6 years, the MCWH programme should be established as a permanent health programme with a defined structure and ring-fenced budget within the National Department of Health. Each province should be required to establish and resource a provincial MCWH structure with adequate staffing and resources to ensure the delivery of quality child health services. Each district authority should also be required to establish a MCWH structure to ensure the co-ordination and management of child health services in the district.

This is how the MCWH programme is currently functioning in South Africa, with the exception of a number of districts that have not yet appointed MCWH managers.

Establishing the structure in national legislation will bind all levels of government to ensure that health services for children are accorded the priority that children are constitutionally entitled to, and will help to ensure co-ordinated and equal services across the provinces and districts.

Legislating the functions of the national MCWH structure

Within government, child health services are managed at three different levels: National, Provincial and District level**.**

The national level is responsible for the formulation of policies, laws and programmes that govern child health. This is executed through the Chief Directorate for MCWH. Within the MCWH chief directorate are three directorates. One is responsible for maternal health, one for women's health and one for child, youth and adolescent health (*MCWH draft policy, National Department of Health, 1 February 1995*). All national policies, laws and programmes on child health are formulated and co-ordinated through this directorate.

The directorate for child, youth and adolescent health services is directly responsible for curative child health services, preventative child health services, school health and youth and adolescent health. In addition they are responsible for perinatal services, i.e. services for pregnant mothers, obstetric services for the delivery of babies and postnatal services that care for the newborn and the mother.

In addition to the child health directorate, a number of other programmes at a national level are also engaged directly in activities that impact on child health (*Provincial maternal, child and women's health profile update. Child Health Policy Institute 1999*). These include:

- The Directorate for chronic diseases, disabilities and geriatrics, that oversee programmes targeted at children with chronic diseases disabilities and mental health problems. (This Directorate is currently drafting a policy on the management of chronic illnesses in children).
- The HIV/AIDS directorate that oversees matters relating to HIV/AIDS. (It is this Directorate which is currently delegated to formulate policy on HIV/AIDS and its impact on children)
- The Directorate for health promotion that oversees and develops health promotion programmes. (a current activity is the development of the Health Promoting Schools initiative).

- The Directorate for Nutrition. This directorate is directly accountable to the Chief Director for MCWH.(the Nutrition directorate is responsible for the PSNP and PEM scheme)
- The Chief Directorate for district development that oversees all matters pertaining to district development of which child health services, their organisation and management would form a part.
- The Chief Directorate for health information, that would be the clearinghouse for all national databases that contain child health information.

A recent change to the structure at a national level has been the formation of clusters, where the cluster for MCWH would be responsible for co-ordinating all activities pertaining to MCWH, even those that fall outside their chief directorate. This is aimed at getting good co-ordination between the different areas and to avoid duplication, fragmentation and lack of co-ordination at a national level.

The national MCWH Chief Directorate thus currently oversees all health activities pertaining to children from health promotion, through to rehabilitation[5].

The national MCWH programme is also responsible for supporting the nine provincial MCWH programmes.

Recommendation

The functions of the MCWH Chief Directorate should be legislated for in the National Health Bill. These functions should include:

- co-ordinating and formulating national policy on all matters that affect children's right to health care services in consultation with other relevant directorates
- co-ordinating child health services across the country by regularly meeting with and supporting the nine provincial MCWH Managers
- responding to child health priorities with co-ordinated programmes with detailed operational plans

Section 20 – General functions of national department

Comment – motivation to include emergency services on the list of norms and standards

Section 20 (2) provides that the Director General must, in accordance with national health policy issue and promote adherence to, norms and standards on health matters. An open list of matters which require norms and standards is then provided.

The problem of the inequitable distribution and availability of emergency services and ambulances still exists, preventing many people from reaching the clinic or hospital in time for their life to be saved. The inequality results in the majority of poor

[5] For curative care the chief directorate responsible for academic hospitals is directly responsible for overseeing and funding highly specialised curative services that are rendered only at selected hospitals such as Red Cross Children's hospital. An example of such a service would be the separation of Siamese twins and complex transplant operations.

people living in informal settlements and rural areas not being able to timeously access ambulance services and or emergency centres.

Context and importance of emergency services in South Africa

The context and importance of this right is relevant when deciding how much national regulation, resources and prioritisation should be afforded to emergency services in South Africa.

The Infant Mortality Rate in South Africa is 49 per 1000 live births. In under-resourced areas like rural areas in the Eastern Cape, the IMR is as high as 100 per 1000 live births. Factors contributing to this high IMR are malnutrition, diarrhoeal disease, respiratory infections, HIV, prematurity, perinatal asphyxia, and trauma injuries.

The under-5 mortality rate in South Africa is 60 per 1000 live births. A major cause of death is trauma.

Trauma due to various causes is the **leading cause of death** in the 5 to 14 years age group. This includes road accidents, burns, assaults, sharp injuries, firearm injuries, and drowning.

South Africa's child mortality rate is considerably higher than countries with comparable socio-economic indicators. Many of these children's deaths could be prevented if emergency services were accessible, resourced and timeously provided.

With injuries accounting for a significant number of adult deaths in South Africa, many children are being orphaned. Again - accessible and adequate emergency health care services could prevent many of their parent's deaths.

Furthermore, many children with acute and chronic illnesses (such as asthma) are dying unnecessarily due to not being able to access emergency services in time.

Recommendation

The Minister should be obliged to prescribe in regulations, a core minimum of ambulance and emergency services. Besides availability, emergency centres should also have to comply with minimum standards with regards to available equipment and staffing in order to ensure that it can respond effectively to the most common emergencies in that area.

Section 21 - Establishment and composition of National Health Council

The National Health Council does not provide for child health manager representation. As the body primarily responsible for advising the Minister and determining national health policy, it is essential that children's health concerns are represented on this structure.

The composition of the National Health Council should include the Chief Director and the Child Health Director of the MCWH Chief Directorate.

Section 23 - Establishment and composition of the National Health Advisory Committee

As for the Council, the Advisory Committee should also include child health representatives.

Section 25 – Preparation of national health plans
In order to entrench the prioritisation of children in all health policies, programmes and activities, the Minister must stipulate that ***ALL*** national plans and programmes ust have a specific section in which the health needs of children are considered. The passing of such national health plans must be subject to children having received due consideration in the development of the plan and the related implementation guidelines.

Section 26 – National Consultative Health Forum

It is essential that the National Health Consultative Forum must have representatives from the children's sector, to ensure that health matters pertaining to children are duly represented.

CHAPTER 4

PROVINCIAL HEALTH

Section 27 - Provincial health services, and general functions of provincial departments

This section must specify that provinces must provide, as well as adequately support districts in the provision of :

- maternal, women and child health services
- nutritional services to children

Section 28 –Establishment and composition of Provincial Health Council

Provincial Health Council's should include child health representation. We recommend that the provincial MCWH manager should be a member of the Council.

Section 29 – Functions of Provincial Health Council

We suggest the addition of:
targets, priorities, norms and standards within the province relating to the provision and financing of child health care services.

CHAPTER 5

DISTRICT HEALTH SYSTEM FOR REPUBLIC

NB: All Districts should be obliged to appoint a dedicated MCWH Manager.

Section 36 – Establishment of District Health Councils

District Health Councils should be obliged to include child health representation. We recommend that the district MCWH manager should be a member of the District Health Council.

Section 37-Health services to be provided by municipalities

The specific services to be delivered by municipalities must be stipulated. Given that the bulk of child health services are delivered at this level of care, we recommend that this section specifically stipulates that:

- Municipalities have the responsibility to provide the following health services to children:
- Preventive and promotive health services
- Emergency services
- Acute curative services with appropriate referral and follow-up
- Chronic health care services that are responsive to the needs of children with long-term health conditions
- Rehabilitative services
- Convalescent and palliative health care
- Home based care

All such services must be delivered in an integrated and co-ordinated fashion and must be appropriately resourced.

Section 39- Transitional arrangements concerning municipal health services

A clear time frame for the completion of this service level agreement must be provided.

CHAPTER 11

REGULATIONS

We suggest that the Minister must make regulations setting out norms and standards for :

- child health services
- child nutrition services
- emergency services and treatment

- school health services

8. Conclusion

Thank you for the opportunity to comment on the bill. If you require further information, please contact us.

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