



Children's Institute

46 Sawkins Road, Rondebosch, Cape Town ,7700
Tel: 021 - 689 5404, Fax: 021 - 689 8330
ci@rmh.uct.ac.za
www.uct.ac.za/depts/ci

Submission on the draft National Health Bill

February 2002



University of Cape Town

For attention: **Director General of Health**
National Department of Health
Fax: 012 - 323 0093
26 pages

Submission on the draft National Health Bill

**By the
Children's Institute,
University of Cape Town**

8 February 2002

Contact persons: Paula Proudlock and Dr Maylene Shung King
Tel: 021 - 685 1583
Fax: 021 - 680 8330

1. Introduction

The Children's Institute welcomes the draft 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 comment on the draft.

As a children's rights organisation that has a long history of involvement in children's health service provision, research, and training, we would like to provide commentary 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 issues. We recognize that the drafters have not singled out any specific vulnerable group in the bill but that we believe that given our obligations in the Constitution and the CRC this consideration should be given to children.

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 precedents, domestic precedents in other departments, the constitutional obligations imposed on the state by the Constitution, the health status of the nation's children, and our expertise as children's health care providers and researchers.

The argument is further based on the recent Discussion Paper on the Review of the Child Care Act published by the South African Law Commission¹ that recommends that the National Health Bill must adequately protect children's health rights and must in the very least include a list of children's health rights. Their recommendation is made in the light of the fact that no other national legislation currently provides for children's health rights and the SALC's intention not to include health rights in the new Child Care Act.²

2. Precedents for taking a child focus in the national health bill

¹ The Discussion Paper, is the culmination of three years of research by a committee of child rights experts

² "As for other areas of the law, the Commission does not recommend, save for cross-referencing to the relevant legislation or where a specific aspect relating to children needs to be addressed, the incorporation in the new children's statute of legislation on children in trouble with the law, sexual offences by and against children, measures aimed at making it easier for children to give evidence in court, education, access to health, and child labour. The effect of this recommendation is that these aspects will remain (or will in future be) in the primary education, health, labour, sexual offences or child justice legislation." Page 3 of the Executive Summary of the Discussion Paper of the SAL on the Review of the Child Care Act.

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 specialised services for children.

South African examples include the draft Child Justice Bill, the draft Child Care Act, 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 invariably find themselves in a position of powerlessness in the hierarchy of society.

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, within 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 special 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 with no cost attached. 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 nations 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 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 considered to be key indicators by the international community and bodies such as the UN Committee on Children's Rights of the importance which a society places on the well-being of its children. South Africa is not doing too well using this indicator.

Morbidity in Children

Infants and children under 5 continue to suffer from preventable and easily treated conditions such as gastro and respiratory infections. Many children are being disabled unnecessarily due to acute and chronic conditions not being diagnosed and treated properly.

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. A recent review by Health Systems Trust showed that the quality of child health services in most provinces is quite poor (*South African Health Review, Health Systems Trust 1998*)
- 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 recent 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 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 and does not take into account children with chronic diseases for example (*The primary health care service package. Department of Health.Pretoria.February 2000*)
- To prioritise the priority conditions that currently threaten children such as malnutrition, 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 the Health Department 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 draft bill

The draft bill does not in any way recognize that children are a vulnerable category requiring special focus and attention and in some instances actually takes retrogressive steps away from a child friendly approach:

- While mentioning the constitutional right of everyone to health care services (section 27 of the Constitution), the preamble neglects to mention children's right to basic health care services (section 28)
- 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 rights in chapter 2 does not take into account children's special rights except in relation to confidentiality and disclosure of health records.
- 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 an unlimited discretion to decide whether to grant or take away free health care to any particular category of persons.

6. Summary of main recommendations

We recommend the following in order to strengthen the bill:

- the inclusion of children's right to basic health care services in the preamble
- legislating for the provision of free primary health care for all pregnant women, and all children under 18.
- the entrenchment of the MCWH 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 to ensure they are not undermined if budget shortages occur at a national, provincial or district level (the PSNP is currently ring-fenced while other priority child health programmes are not eg. 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, child abuse, trauma)
- MCWH representation on the NHA, PHAs and DHAs. The person must be the officer in charge of child health.

- NHA composition should include the MCWH Chief Director and the Director of Child Health
- PHAs should include the provincial MCWH Manager and the deputy director in charge of child health
- DHAs 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 and must take a special focus on children
- A provision that minimum norms and standards on child health services be set by the National Department and that such minimum norms and standards be considered mandatory for provinces and districts
- An obligation on the National Department to support provinces in the implementation of the minimum norms and standards
- an obligation on the National Department in Schedule 1 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

The preamble specifically mentions section 27 of the Constitution - the right of everyone of access to health care services and the right to emergency medical treatment. We welcome the express recognition of everyone's right to health care, however we are concerned by the glaring omission of an express recognition of children's constitutional right to basic health care services (Section 28 of the Constitution). By creating a distinct right to basic health care services for children in the Constitution, the drafters clear intention was to ensure extra protection for children. This intention should be reflected in the national legislation that governs the health system.

Recommendation

Include a reference to section 28(1) (c) in the preamble

Suggested draft

"RECOGNISING THAT -

.....

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

Comment 2

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

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

While this is concerning when the national standard that has been set is a good standard and a province fails to implement the bare minimum, the ability of a province to deviate from the norm may be welcomed if the province is able to provide more than the prescribed minimum.

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 policy documents that set norms and standards and the consequences of not adhering to the norms and standards.

For example, the National Department is about to finalise 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 package³. However, not all the provinces currently provide health care services at schools.

The bill specifies in Schedule 3 that providing services at schools is a District Function. The question that this example raises is; will 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 health care services at schools 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. While the Schedules at the back of the bill and the Schedules in the Constitution provide some guidance to those who understand the health system and who are intimately involved in its implementation, the bill does not provide express clarity.

³ 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.

CHAPTER 1

DEFINITIONS, PURPOSE AND RESPONSIBILITY FOR HEALTH

Section 1 - Definitions

“Basic health service”

Comment

Section 4(1) (d) of the bill provides that the Minister is responsible within the limits of available resources to ensure the rendering of *basic health services* to the population of the Republic.

The bill defines “basic health service” in section 1 as “those services as prescribed by the Minister, after consultation with the National Health Authority.”

Question 1

All health department terminology up to this point in time has referred to "primary health care services". Will the term "basic health services" be defined as "primary health care services" or will it encompass services over and above primary health care?

Question 2

Section 28(1) (c) of the Constitution provides that children have a right to *basic health care services*. 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 childrens’ constitutional health rights are being upheld.

For example: One health care provider may consider medication for asthma as falling within the definition of “basic health care services”, while 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.

When the Minister and the NHA define the concept of "basic health services", will they taken into consideration the need to differentiate between basic health care services for children and basic health care services for all?

Recommendation

The term "basic health service" should be defined by the Minister after consultation with the NHA and published as a compulsory National Policy Statement. The NHA should be obliged to consult with the children's sector before making a recommendation to the Minister. The NHA and Minister should also be obliged to differentiate between basic health services for everyone and basic health services for children in the National Policy Statement due to the special protection afforded to children by section 28(1) (c) in the Constitution. The definition can be amended every four years as the health profile and priorities of the country changes over the years. It is important that the determination of "basic health services" and the four yearly amendment be a participatory process involving child health care providers and civil society.

"norm"

Comment

Schedule 1 requires the National Department of Health to determine and issue norms and standards on various issues, including the provision of health services and nutritional interventions.

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. It is not clear to what extent and on what health functions the National Department can impose a norm upon a provincial or district level 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 district 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.

“user”

Comment and recommendations

The Child Care Act drafting committee of the SALC has made recommendations for new rules regarding children consenting to medical treatment and health services and when parental/care giver authority is required⁴. Their recommendations should be incorporated into the National Health Bill.

Section 2 - Application and interpretation

Comment

The bill mentions that the Health Act applies over any health legislation that conflicts with the provisions in the Act. However, the bill does not list the legislation that will be repealed by the promulgation of the Act. This creates confusion which should be avoided.

For instance, the bill provides in Schedule 1 that a function of the National Department of Health will be “evaluating, regulating and registering drugs and other substances”. This function does not currently appear in the Health Act 63 of 1977. The function of registering medicines is currently a function performed by the

⁴ "The Commission recommends that the age at which children may consent to medical treatment should be lowered to 12, whilst until they are 18 they cannot consent to an operation without the assistance of their parent or guardian. The following should, however, be exceptions to this general rule: (a) a child of any age should be entitled to obtain information on and access to contraceptives; and (b) any child should be able to obtain treatment for sexually transmitted diseases regardless of age. In order to provide for a simpler procedure to obtain consent to medical treatment or an operation, the Commission recommends that a caregiver who is not a parent or guardian of a child may consent to medical treatment for or an operation on that child if that child has been abandoned or his or her parents are deceased. Further, that a parent or guardian of a child may give written consent to a person caring for a child to give consent to medical treatment for or an operation on that child. It is also recommended that the National Health Bill be amended to provide that children from the age of 12 should be consulted in matters relating to their health and children under the age of 12 should be consulted as appropriate to their capacity. The procedure set out in section 39(1) of the Child Care Act which requires a medical practitioner to apply to the Minister for consent (in instances where a parent or guardian refuses consent, or cannot be found, or is deceased, or is by reason of mental illness unable to give consent) is criticised for being impractical in practice. For this reason, the Commission recommends that the children's court, instead of the Minister, be approached to obtain the necessary consent. The Commission further recommends that the new child care legislation should explicitly provide that no child may be submitted to any medical treatment or surgical intervention without informed consent. Informed consent may include consent, on behalf of a child, by the superintendent of a residential care facility or department or organisation arranging placement of the child in terms of the Child Care Act." Page 37 of the Executive Summary of the Discussion Paper on the Review of the Child Care Act.

Medical Control Council in terms of power conferred on the MCC by the Medicines and Related Substances Control Act. How will the provision in schedule 1 affect the new Health Acts relationship with the existing Medicines and Related Substances Control Act? Will the provision in the new Health Bill give the Minister the power to veto the legitimate registration of a drug or to influence the decision as to whether a drug should be registered?

Recommendation

List the Acts and sections that the new Act will repeal. Provide clarity on which body has the authority to register drugs. This should preferably be an independent body with expertise in drugs, such as the Medical Control Council.

Section 3 - Purpose of this Act

Comment

The bill states that the purpose of the Act includes setting out the rights and duties of both health care providers and users. We welcome the inclusion of a chapter on rights and duties, 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 purpose 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 4- Responsibility for Health

Comments

Section 4(1) (c)

We would welcome further clarity on the National Department's responsibility to determine policy and norms and standards on issues that fall within the competency of the provinces and districts.

Section 4(1)(d)

This section provides that the Minister is responsible **within the limits of available resources** to ensure the rendering of **basic health services** to the population of the Republic.

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 *basic* health care services.

The use of the word “basic” 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.

Recommendation

Section 4(1) (d)

The bill should state that the Minister is responsible for ensuring the rendering of health care services not “basic” health care services. Basic health care services is the bare minimum that must be provided.

The qualification in the Constitution of the right to health care services by the phrases "progressive realisation" and “within available resources” has been interpreted by the Constitutional Court (Grootboom) to means that the State is in the very least obliged to provide a basic level of services.

But as the economy improves and the pool of available resources becomes larger, the right to health care services should expand to its full extent, beyond the provision of a core minimum of services. If for example, by 2020 the South African government becomes a wealthy nation and it becomes financially possible for the State to provide the full spectrum of health care services above the basic level, Constitutionally, the state will be obliged to provide such services.

The limiting of this constitutional obligation in the National Health Bill to the provision of **basic** health services only would be subject to a Constitutional challenge if the applicant could prove that the State has resources available to provide above basic health services.

If the obligation to provide basic 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.

Section 5 - 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:

- (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. Legally, the two notices remain in force unless repealed by the Minister. The bill does not explain the departments 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 Bill⁵.

If free primary health care for all is not affordable to the state, then it must in the very least be provided for pregnant women and all children (under 18). The government is constitutionally obliged to provide health services to vulnerable groups within society (Grootboom CC), especially children living in poverty (70% of all children), children

⁵ Half of the SA population lives on less than R144 per month. As growth in the economy is not likely to happen quickly and the trickle down to people even less quickly, the right to free primary health care should therefore be entrenched in national legislation.

infected or affected by HIV, 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.

Children with respiratory infections and diarrhoeal disease often end up being referred to hospitals due to the lack of necessary equipment, expertise or medicine at the clinic or community health centre. Such referrals often end up saving the child's life. If a clinic or community centre is unable to deliver the necessary primary health care services needed by the child and refers the child to a hospital, services at the hospital should be free.

Suggested draft

Delete section 5 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*, 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 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.

(2) Persons in categories (a) and (c) are entitled to free services at hospitals if the hospital provides such services and the person has been referred by a clinic or community health centre due to the clinic or community health centre not having the prescribed primary health care equipment or expertise to treat the condition.

CHAPTER 2

RIGHTS AND DUTIES OF USERS AND HEALTH CARE PROVIDERS

Comment

General

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.

Need for children's health rights to be recognized

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 rights⁶.

Recommendation

General

⁶ The Commission recommends on page 36 of the Executive summary of the Discussion 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;
- 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.

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

The bill should also include a provision obliging the head of each health establishment to display the list of rights prominently on the walls of the health establishment.

Suggested Draft

"Dignity and Respect"⁷

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."

Children's rights

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

- the right to be treated with equality, dignity and respect
- the right not to be discriminated against, especially on the grounds of socio-economic status, health status, HIV status, disability or nationality
- the right to be consulted on decisions about their health in a language understandable to the child
- the right to confidential access to contraceptives regardless of age
- the right to confidentiality

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

Section 7 - Emergency Treatment

Comment

The bill provides that a public health establishment shall not deny a person requiring emergency treatment such treatment if:

- the establishment is open and
- is able to provide the necessary treatment

Interpretation of the constitutional right not to be refused emergency treatment

The history behind the inclusion in the Constitution of the right not to be refused emergency medical treatment lies in many instances during Apartheid when black people were refused admission to ambulances or emergency wards in hospitals due

⁷ This provision appeared in the May 1998 draft of the bill

to their skin colour and suffered harm or died as a result. The law prohibited black people from entering hospitals or ambulances reserved for white people and provided grossly inadequate emergency services for black people.

The intention behind the right not to be refused emergency care is therefore to prevent people being refused entry into an emergency centre or an ambulance on any discriminatory ground such as race, nationality or ability to pay.

Looking at the history behind the right, the right not to be refused emergency treatment in the Constitution can be interpreted to include the right of access to ambulance services.

While in terms of the law, a person may not be refused emergency treatment if they arrive at the doorstep of an emergency centre, the problem of the inequitable distribution and availability of emergency services and ambulances still exists, preventing many people from reaching the doorstep in time for their life to be saved. The inequality results in the majority of poor 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 injuries.

Trauma injuries is the **leading cause of death** in the 5 to 14 years age group. This includes road accidents, burns, assaults, stabbings, shootings and drownings.

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 trauma 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.

The right in the National Health Bill

The way the right to emergency treatment is phrased in the bill makes its interpretation very narrow. It places no obligation on the various levels of government

to ensure the equitable provision of emergency care centres or ambulances. It just requires the state not to refuse treatment at the existing centres if the existing centre is open and is able to provide the necessary treatment.

“if the centre is open”

The qualification of the right by the use of the words “if the existing centre is open” introduces an untenable situation: An emergency centre in a busy rural town could decide to close on week-ends and a person arriving with a trauma injury on Friday night would not be entitled to be treated until Monday morning.

“and is able to provide the necessary treatment”

The qualification of the right by the use of these words is again problematic. A provincial health department may decide that it does not have enough resources to equip its major emergency hospital with an X-Ray machine. The hospital can no longer treat the majority of trauma injuries without an X-Ray machine and people with trauma injuries are turned away at the door and required to travel to another centre.

Recommendation

The wording of the right should be stated as it is stated in the Constitution as "No one may be refused emergency medical treatment" and should not be qualified.

Furthermore 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 9 - Full Knowledge

Comment on 9(1)(b)

The section obliges health care providers to inform a user of the range of diagnostic procedures and treatment options “generally available” to the user. It is not clear whether this requires the health care provider to inform the user of the treatment options available at other public health facilities and private health facilities.

Example

The care givers of a child who has been raped have the right to be informed that prophelactic treatment, in the form of AZT, is available at certain public health facilities or at private facilities. The caregiver and child then can make an informed choice based on their beliefs and resources as to what treatment they would like to have. A health care provider should not decide for a user that they cannot afford the private treatment and therefore refrain from even

mentioning the existence of the treatment to the user. This is a decision that must be made by the user.

Recommendation

The section should clearly read that the user must be informed of all available treatments, in the public and private health system.

Suggested draft

9(1) every health care provider must inform a user in an appropriate manner of -
(b) the **full** range of diagnostic procedures and treatment options ~~generally~~-available to the user **in both the public and private health care system.**

Comment on 9(2)

The bill provides that health care providers must provide a discharge report to any person who has received treatment in that establishment and has requested the discharge report.

While children with a single caregiver may not need discharge reports, children being cared for by multiple care givers should automatically receive discharge reports irrespective of whether or not the child or the care giver accompanying the child requests the report.

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 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.

Recommendation

In order to ensure that children receive quality health care, no child should be discharged without a discharge report.

In the alternative, the following categories of children must automatically receive a discharge report:

- children living in residential care facilities
- children living in child headed households
- children with chronic illnesses including HIV/AIDS
- children that need to be followed up by another level of care

Suggested draft

9(2) Health care providers must provide a discharge report to:

- (a) **any child who has received treatment in that establishment**, and
- (b) any **other** person who has received treatment in that establishment and who has requested the discharge report

or

9(2) Health care providers must provide a discharge report to:

- (a) **any child who has received treatment in that establishment** if the child:
 - (i) is living in a residential care facility,
 - (ii) is living in child headed household,
 - (iii) has a chronic illnesses (including HIV/AIDS), or
 - (iv) requires follow up care or treatment by another level of care
- (b) any **other user** who has received treatment in that establishment and who has requested the discharge report

Section 16 - User's access

No parent should have access to a child's health records with regards to contraceptives, STD tests or treatment and HIV tests or treatment unless the child consents to such access. The section therefore needs to be re-phrased to ensure that a child is always consulted on whether his or her parent can have access to his or her health records on the above listed issues.

Section 20 and 21 - Laying of complaints and complaints procedures

The sections should prescribe that the complaints procedure must be open, fair and accessible 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.

CHAPTER 3

NATIONAL HEALTH - STRUCTURES AND FUNCTIONS

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 incorporated 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 provision 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 not having 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 at 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 rehabilitation⁸.

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 28 - Establishment and Composition of the National Health Authority

⁸ 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.

The NHA 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 NHA should include the Chief Director and the Child Health Director of the MCWH Chief Directorate.

Section 30 - Establishment and Composition of the National Health Management Committee

As for the NHA, the National Health Management Committee must include child health representatives.

CHAPTER 4

PROVINCIAL HEALTH - STRUCTURES AND FUNCTIONS

Section 36 - Composition of Provincial Health Authority

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

CHAPTER 5

THE DISTRICT HEALTH SYSTEM

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

Section 43 - District Health Authority

DHA's should be obliged to include child health representation. We recommend that the district MCWH manager should be a member of the DHA.

8. Conclusion

Thank-you for the opportunity to comment on the bill. If you require further information or assistance from us in ensuring that the bill promotes and protects childrens rights, please contact us.