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policy brief

H VAN ROOYEN and A STRODE

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Making HIV testing services for children appropriate, accessible and available: Key policy considerations

Background and context

The HIV epidemic in South Africa is substantial, with almost 3.3 million children under the age of 15 living with HIV (UNAIDS 2012). HIV testing rates are low among this group, with only 30% of infected children and adolescents accessing antiretroviral treatment (ART) (UNAIDS 2012; WHO 2013). This policy brief examines the legal framework governing HIV testing services for children. It highlights the challenges and opportunities presented by the legal framework and critically discusses whether it can facilitate national goals aimed at expanding appropriate testing and treatment services to children and their families.

HIV counselling and testing (HCT) and ART coverage has to expand significantly if South Africa is to meet the goals of the National Strategic Plan on HIV, AIDS, STIs and TB, which commits the government to providing treatment access to 80% of all HIV-positive people by 2016 (DoH 2011). At the heart of the low treatment uptake among children are the poor HCT services provided to them. This has led to inadequate identification of HIV-positive children. Reasons for poor identification include poor linkages to infant testing programmes, with the exception of prevention-of-mother-to-child-transmission (PMTCT) services and provider uncertainty on how best to diagnose, treat and counsel infants and their parents or caregivers (Kellerman & Essajee 2010; Rollins et al. 2009). Consequently, many infected children are either never identified or are lost from the system before they can be enrolled in treatment and care (Kellerman & Essajee 2010).

Providing HCT services for children is a crucial part of South Africa's national response to HIV and AIDS. Improving access to HCT could lead to earlier diagnosis, more effective treatment and care, and reduced mortality among children (Kellerman & Essajee 2010; WHO 2013). This requires a two-tiered approach. First-tier scale-up would involve a variation on provider-initiated HCT, in the context of PMTCT services, to include testing newborns when they present for immunisations. Our work shows that testing at immunisation clinics is acceptable and feasible, and increases access to a large number of exposed children (Rollins et al. 2009). Second-tier scale-up would involve using home-based HCT to locate populations who are infrequent clinic attendees or who lack access to care. Using this approach, families affected with HIV could be encouraged to refer members, including children, for testing (Kellerman & Essajee 2010).

The Children's Act defines a child as any person under the age of 18 years. This definition spans newborns and infants; early childhood from about 2 to 6 years; middle childhood; and adolescence from 10 to 18 years.

The legal framework for testing children

Scaling up HIV testing services for children requires an in-depth understanding of the current legal framework regulating HIV testing, as set out in the Children's Act (No. 38 of 2005). Until the introduction of the Children's Act, which deals directly with HIV testing, there were no specific laws setting out when and how a child could be tested for HIV. General norms relating to consent to medical treatment contained in the Child Care Act (No. 74 of 1983) were applied to HIV testing, thus allowing a child to consent independently to an HIV test from the age of 14. However, no express legal protections existed for HIV-positive children. This was a concern, given that HIV testing in the early stages of the epidemic was often not conducted in the best interests of children, who were sometimes tested out of fear, ignorance or prejudice. In addition, the Child Care Act did not protect children against discriminatory testing (such as testing as a precursor to adoption) and also failed to facilitate the obtaining of consent

from orphans and vulnerable children, who did not have parents or guardians to assist them.

In the post-1994 era, following the ratification of the Convention on the Rights of the Child, Parliament passed a number of new laws intended to protect and promote the sexual and reproductive rights of children in order to bring South Africa's legal framework in line with international norms.

The complexities of testing children

HCT of children raises several complex considerations for parents, caregivers and children. HIV testing may have implications for the child's mother and her own HIV status. Parental attitudes towards testing are important to ensure success, but studies show that many parents are often apprehensive about subjecting their children to HIV testing, especially when they are unsure of their own status (Rwemisisi et al. 2008). Parents may also have fears of being stigmatised and discriminated against if their child is HIV-positive.

HIV testing of older children (12–16) raises several concerns because infection has usually been acquired through sex. This has health implications for children, who lack the knowledge and skills to prevent themselves from becoming infected with HIV and have insufficient access to testing and treatment services (UNAIDS 2012). It may also have social implications. Children may deny sexual activity, and may express concerns about testing HIV-positive, afraid of facing family and community disapproval for having engaged in underage sexual activity. In testing older children, issues such as the extent of parental involvement in decisions to test, confidentiality, and coercion to testing merit careful consideration.

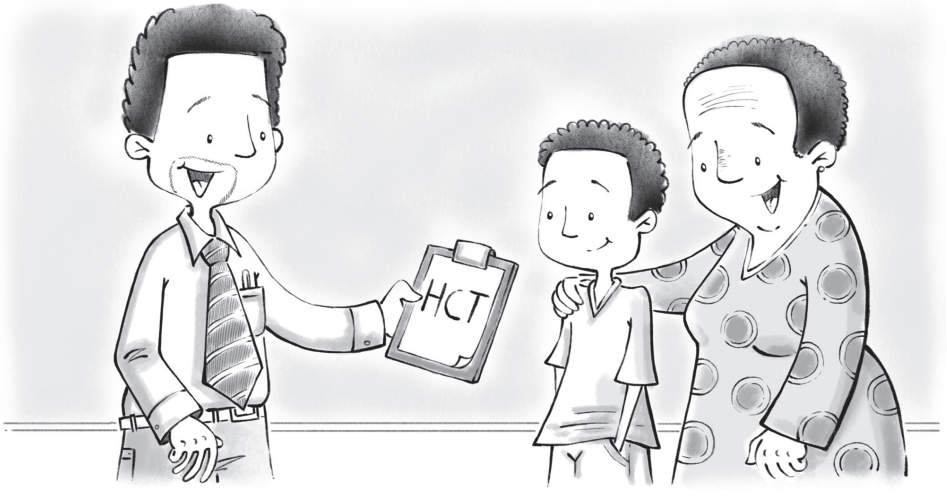
The lack of legal protection for children pre-1994 and documented human rights abuses, including violations of children's rights, led the drafters of the Children's Act to include a number of provisions aimed at protecting children against discriminatory or arbitrary HIV testing.

The Children's Act now stipulates that children may be tested for HIV in only two circumstances:

1. if it is in their best interests and lawful consent has been given for the test; or
2. as a result of occupational exposure, where a healthcare worker, or another person, may have contracted HIV from the child's body fluids.

In the first circumstance, unlike in most other health interventions (where children of a certain age or displaying a level of capacity can act autonomously), HIV testing must be demonstrated to be in the best interests of the child (Strode et al. 2010). The best interests of a child require consideration of whether a decision to test will promote a child's physical, moral, emotional and spiritual welfare.

Most healthcare providers will determine that HIV testing is in the best interests of the child, as it facilitates access to both HIV prevention and treatment. Examples of such circumstances include testing babies born to HIV-positive mothers; testing abandoned babies, where the HIV status and whereabouts of the mother are unknown; and testing child survivors of sexual assault. In all these instances, and many others, children can benefit significantly from HIV testing, especially where it facilitates access to life-saving ART.



The second circumstance under which testing of a child can take place is in the case of possible occupational exposure to HIV, which places a healthcare worker or third party at risk. Of the two circumstances outlined above, this kind of testing normally occurs less frequently. The Children's Act describes when and how such testing may take place.

Independent consent to HIV testing from the age of 12

The Children's Act provides that any child over the age of 12 may consent independently to an HIV test. This means that there is a general legal presumption that all children over the age of 12 have sufficient capacity to consent on their own to HIV testing (DoH 2010).

Those below 12 may consent independently only if they can demonstrate that they have the required capacity – namely, that they have 'sufficient maturity to understand the benefits, risks and social implications of such a test'. However, a welcome inclusion in the Act is an acknowledgement of the right of a child to participate in decision-making related to their own healthcare. This is an important principle guiding interactions between the healthcare provider, child and his or her parent or caregiver. It means that even if children are below the age of consent for HIV testing and need the assistance of a parent or caregiver, they still should be involved in the decision-making process.

Determining the child's level of maturity

It is likely that very few children under the age of 12 years will wish to be tested for HIV without the assistance of a parent or caregiver. Nevertheless, if a child does request such a test, the healthcare provider needs to take into account the age of the child, as well as determine the child's level of maturity to provide informed consent to the HIV test. This may be a little more complex, as the provider needs to be satisfied that the child understands the benefits and risks of an HIV test, as well as the social implications that accompany such a test, in order to consent independently to the test. Furthermore, in determining a child's capacity, the child's circumstances at the time, including age, knowledge, experience, and judgement, should also be taken into account.

Testing children below 12 years of age who *do not* have the capacity to consent independently

If a child does not have the capacity to consent to HIV testing or to disclose their HIV status, a parent or caregiver can consent on the child's behalf. This provision also allows for a caregiver or the provincial head of the Department of Social Development to facilitate HIV testing of orphans and vulnerable children. In their case, care must be taken to ensure that testing does not cause harm because of the greater risk of discrimination and exploitation that these children face (Kellerman & Essajee 2010).

The voluntariness of child HIV testing

Children from the age of 12, or under 12 years and capable of consent, must consent to an HIV test voluntarily and independently. National HCT policy indicates that HIV testing may be initiated by a client or by a service provider (in defined circumstances) (DoH 2010). However, a healthcare provider should ensure that even when an HIV test is initiated by a provider, consent must still be given freely. This is particularly important where a child gives informed consent, since a child can be more easily persuaded or influenced by adults, who are more powerful and often in a position of authority over them.

If a child gives consent to an HIV test in a situation where he or she feels afraid, refuses consent, has been tricked into consenting or has been persuaded to consent for any reason (such as the promise of a benefit), the consent is not informed or free and is therefore invalid.

Children have a right to counselling before and after an HIV test

The Children's Act provides that pre- and post-test counselling by an appropriately trained person must be given to all children being tested for HIV. The Act does not describe the manner in which the counselling should be provided or the information that must be given to children during the counselling processes, but it is assumed that this means that the counselling should conform to national norms and standards. The Act further specifies that if the child's parent or caregiver is aware of the possibility of testing, he or she should also be involved

in counselling. In the case of children who are not sufficiently mature to understand the benefits, risks and social implications of an HIV test (most commonly, children under 12 years), the parent or caregiver may give consent, following counselling.

Children have the right to privacy of their HIV status

The child's right to confidentiality is protected in the Children's Act, which includes strict safeguards on disclosure of a child's HIV-positive status to others. Children from the age of 12, or under 12 years and capable of consent, can decide who should know their HIV status. The national HCT policy recommends that a person who tests HIV-positive should be encouraged to disclose his or her HIV status to at least one other person as a means of obtaining support, including for adherence to treatment (DoH 2010). Although not a requirement to access treatment, healthcare providers should therefore address disclosure (whether with the child or a parent or caregiver) as part of the pre- and post-test counselling process.

Disclosure of a child's HIV-positive status *to the child*

In the case of children, an additional concern is the issue of disclosing a child's status to the child if he or she has not consented independently to the test. Many parents and caregivers find it difficult to do this (Rwemisisi et al. 2008). While healthcare providers should respect their wishes and views, involvement of the child should be encouraged and supported with appropriate disclosure strategies as the child develops. The extent of knowledge and understanding, the emotional responses of the child and his or her stage of development will generally serve as a guideline for the most appropriate means of disclosing a child's status to him or her (Grant et al. 2012; Rochat et al. 2013; Vaz et al. 2010). Information from a parent or caregiver who has been involved in the counselling process can also be of assistance in deciding how to disclose to the child and in how much detail (Vaz et al. 2010).

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The Children's Act provides for a range of mechanisms for the care and protection of children (for example, the Act provides for fostering and adoption of children in need of care). There may be instances where disclosing a child's HIV status is considered necessary in order to properly follow the provisions in the Children's Act and to ensure that the best interests of the child are served. In this situation, a disclosure would be lawful. A child's right to confidentiality may be limited if maintaining confidentiality is not in the best interests of the child. For example, non-disclosure would not be in the best interests of the child if the child is very young and will require active support with maintaining a treatment regime. The enquiry into the best interests of a child requires a balancing of the various factors set out above, where failure to disclose a child's HIV status could harm his or her physical, moral, emotional and spiritual well-being.

Discussion

Scaling up HIV testing is an important step in meeting national and global commitments to expand appropriate testing and treatment services to children and their families. Children and their parents or caregivers interact with healthcare services at many different levels. All these opportunities should be used to facilitate access to HIV testing, prevention and treatment services, as doing so would be in the best interests of children at risk of HIV infection. Widespread implementation rests on increasing the opportunities and mechanisms for children and their families to access HCT and to be linked to treatment and care – for example, through testing at the same time as immunisations are carried out, and family-based approaches to HCT offered in the home. Generally, whether at the clinic or in the home, improved child and youth-friendly services need to be provided.

Successful scale-up of HCT for children also requires careful consideration of the

legal framework governing HIV testing in South Africa. Although the Children's Act aims to protect children from harm and to ensure that HIV testing is used to promote their health and well-being, its provisions should not be seen as a barrier to offering HIV testing to children. However, there are a number of key constraints regarding the way in which the legal framework for HIV testing has been created.

Separating HIV testing from 'medical treatment' has both advantages and disadvantages. On the positive side, it has meant that there are clear norms on when and how HIV testing should be undertaken. These norms do facilitate access to HIV testing by younger children, who are able to consent on their own to HIV testing from the age of 12 and are entitled to confidentiality. However, on the negative side, by requiring HIV testing of children to be in their best interests, this provision treats HIV testing as different from other medical interventions. As a result, some healthcare providers may find it difficult to apply the best-interest principle.

In this regard, the Children's Act is perhaps slightly out of step with current public health approaches to HIV testing, which focus on increasing access to HIV testing as a gateway to realising a child's right to access healthcare services, including ART. The Act's focus on requiring testing to meet the best-interest standard is appropriate in that it requires service providers to act in a way that promotes a child's welfare. However, it may make healthcare workers afraid or uncertain of whether or not they may offer or even promote HIV testing. The inclusion of the best-interest requirement is a reflection of the era in which the Children's Act was initially drafted. At that time, ART was not available and levels of discrimination were high. This prompted Parliament to intervene and set special norms pertaining to HIV testing for children.

The Children's Act has also not taken a nuanced approach to the testing needs of children. It treats all children alike, even though they are not a homogeneous group. Definitions of childhood, children and adolescence are by their very nature arbitrary, although they do make allowances for the various developmental capacities and challenges that children of various ages face. Thus, a distinction could be made in the Children's Act between the legal protections that are provided to younger and older children, for instance.

The approach to counselling and testing children outlined in the Children's Act places an impractical burden on under-resourced, overstretched and often untrained lay workers, who interface with children in health, social and welfare systems. They are required to make assessments of a child's best interests based on very limited information and within a very short space of time. Furthermore, there is a lack of research on whether service providers understand and can apply this standard.

There are also several contradictions within the Children's Act, and between the Act and other pieces of legislation pertaining to children and medical treatment, which make the provision of holistic HIV testing and counselling services difficult. On the one hand, the Children's Act provides that children from the age of 12 years can access a range of sexual and reproductive health services, such as contraceptives, HIV testing and treatment for sexually transmitted infections. On the other hand, the Children's Act also provides in section 54(1) that any person 'who has knowledge that a sexual offence has been committed against a child' must report this 'immediately' to the police. Obligation is placed on all service providers, including doctors, nurses, lay counsellors and health researchers, to report consensual underage sex or sexual activity to the police. Furthermore, until 2013, the Criminal Law (Sexual Offences and Related Matters) Amendment Act (No. 32 of 2007) provided that sex under the age of 16, even if consensual, was a criminal offence.

There have been some developments with regard to the matter of consensual sex between children under the age of 16. The Constitutional Court recently found that the criminalisation of consensual sex between adolescents aged 12–15 years violated the constitutional rights of children to privacy and bodily integrity. The Court referred the Act to Parliament and directed it to amend the Act so that it no longer violates the rights of children (*Teddy Bear Clinic for Abused Children, and Resources Aimed at the Prevention of Child Abuse and Neglect (RAPCAN) v Minister of Justice and Constitutional Development 2013*). Parliament must effect these changes by March 2015. However, although the scope of unlawful teenage sexual activity has been narrowed, the reporting requirements remain in place. This means that if it is discovered, or if teenagers (12–15 years) disclose that they are sexually active and their sexual partners are older than 15 years, their partners are still committing a crime and this must be reported to the police.

Finally, the lack of a common vision of when and how children should be offered HIV testing appears to be hindering implementation of testing services to children. Even though these principles are clearly described in both the Children's Act and in national HCT policy, some confusion has been created in aspects of the recent Integrated School Health Policy (ISHP) (DoH & DBE 2012). The policy provides comprehensive services that address the mental health and sexual and reproductive health needs of school-going children and youth through a range of services — including HCT for sexually active learners — either on site or at the nearest primary healthcare clinic.

However, the policy states that if learners are under the age of 18, they will need the written consent of a parent or caregiver. This is despite the provisions in the Children's Act which provide that children may consent to HIV testing from the age of 12 without the assistance of an adult. The requirement of obtaining written

consent from parents or caregivers in the ISHP may prove to be an obstacle to some children accessing such services. Furthermore, when consenting to individual services, the ISHP states that learners must be at least 14 years old. This approach is out of step with the Children's Act and creates confusion for both service providers and learners.

Recommendations

Despite the challenges, given the vulnerability of children and their need to be protected, it is clear that HIV testing services for children must be expanded as a matter of urgency. Currently, the Children's Act provides a clear, but restrictive, legal and policy framework for HIV testing of children. There is also very poor alignment between the Act and other legal and policy frameworks pertaining to medical treatment and HIV testing of children and adolescents. As a consequence, these frameworks and circumstances limit, rather than facilitate, expanded access to HIV testing for children. In order to address the policy and legal quandaries highlighted above, the following is recommended:

1. Take cognisance of the serious skills challenges of healthcare providers and the limited capacity they have to manage and treat children with HIV and AIDS. Scale-up of HCT for children in accordance with the Children's Act will require investment in key areas, such as training and support of providers, addressing the reluctance of healthcare providers to test children, and training staff to counsel children and their families.
2. Promote and disseminate recent guidelines and tools pertaining to the legal, ethical and psychosocial factors involved in implementing HCT for children. This can be done nationally, through training and information sessions.
3. Provide guidance and tools to assist healthcare providers on how to practically interpret provisions in the Children's Act referring to the best interests of the child. Providers' ability to assess the maturity of children under 12 to consent to a test must be developed and disseminated through training and skills building.
4. Review the Children's Act of 2005 so that it is better aligned both to current public health approaches and to related policy and legal frameworks referring to medical treatment and HIV testing of children and adolescents.
5. Advocate for the narrowing of the mandatory reporting obligations in the Sexual Offences Act so that consensual, underage sex is only reported to the authorities in situations where the child is in need of care and protection.

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POLICY BRIEF AUTHORS

Heidi van Rooyen, PhD; Research Director of the HIV/AIDS, STIs and TB (HAST) Research Programme, Human Sciences Research Council, Pietermaritzburg

Ann Strode, PhD; Senior Lecturer, School of Law, University of KwaZulu-Natal

Enquiries to Dr Heidi van Rooyen: hvanrooyen@hsrc.ac.za