

POLICY REQUIREMENTS FOR HIV TESTING AND COUNSELLING OF INFANTS AND YOUNG CHILDREN IN HEALTH FACILITIES

WHO Library Cataloguing-in-Publication Data

Policy requirements for HIV testing and counselling of infants and young children in health facilities.

1.HIV infections - diagnosis. 2.HIV infections - prevention and control. 3.Early diagnosis.
4.Counseling. 5.Health policy. 6.Children. 7.Infant. 8.Health facilities. I.World Health Organization.
II.UNICEF.

ISBN 978 92 4 159909 2

(NLM classification: WC 503.1)

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Printed in Switzerland

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This work was undertaken by the Paediatric Care working group of the Expanded Inter-Agency Task Team (IATT) on the Prevention of HIV Infection in Pregnant Women, Mothers and their Children. The following organizations are members of the IATT.



ACKNOWLEDGEMENTS

Overall coordination of this work was led by Siobhan Crowley for WHO and Robert Gass for UNICEF. We gratefully acknowledge the work of Vincent Wong in preparing a first draft of this policy document and Bandana Malhotra for editing of subsequent drafts.

The contributions of the following individuals who assisted in further developing, reviewing and/or editing this document are also gratefully acknowledged: Elaine Abrams, Stephen Arpad, Margaret Brewinski, Nancy Calles, Siobhan Crowley, René Ekpini, Shaffiq Essajee, Robert Ferris, Mary Lyn Field-Nguer, Robert Gass, Sally Girvin, Donna Higgins, Janet Kayita, Jimmy Kolker, Mary Lou Lindegren, Ronnie Lovich, Justin Mandala, Amolo Okero, Christian Pitter, Paul Roux, Gordon Schutze, Diana Silimperi, Michael Tolle, and Helena Walkowiak.

UNICEF and WHO also acknowledge the efforts and dedication of Victoria Anagbo and Sally Girvin for bringing this publication to fruition.

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1. INTRODUCTION

Worldwide, infants and children bear a considerable part of the overall burden of HIV. In 2008, of the estimated 2.7 million new global HIV infections, 430 000 were in children. Of the 2 million HIV/AIDS deaths worldwide, 14% (280 000) occurred in children and 6.2% (2.1 million of 33.4 million) of persons currently living with HIV are children(1).

Identifying and testing the HIV-exposed infant as early as possible is crucial, as timely diagnosis of HIV allows timely access to life-saving care, including antiretroviral therapy for those who are infected. Without antiretroviral therapy, the majority of HIV-infected children will die before reaching their second year of life(2). Guidance from the World Health Organization (WHO) was revised in 2008 as a result of recently published evidence(3) documenting a significant reduction in mortality among infants who were initiated early on treatment. It now recommends that antiretroviral therapy be initiated in infants as soon as the diagnosis is made(4).

Currently, many opportunities to diagnose HIV infection in infants and children are missed within the health system. These opportunities for diagnosis of HIV arise at facilities providing services for antenatal care, prevention of mother-to-child transmission (PMTCT) of HIV, immunization, nutrition, inpatient admissions and within programmes for other vulnerable children. It is estimated that only 8% of HIV-exposed infants received early virological testing in 2008(1). Analysis of international cohort data confirms that very few HIV-infected infants are started on antiretroviral therapy, and those who do receive it, are started when they are already very sick, largely due to a delay in HIV testing(5).

The benefits of expanded access to HIV testing and counselling for infants and children are numerous and include the following:(6,7)

- early identification of HIV-infected infants and children as a first step to treatment and care;
- identification of HIV-exposed but uninfected infants, which facilitates follow-up care and prevention measures that will help to ensure that they remain uninfected and healthy;
- life-planning for parents and/or children who are HIV infected; and
- increased access to care and antiretroviral therapy for parents.

Providing HIV testing for infants and children, however, presents unique challenges for policy-makers, programme managers and health-care providers(8,9). To address these challenges, WHO and the United Nations Children's Fund (UNICEF), in consultation with the Interagency Task Team on Prevention of HIV Infection in Pregnant Women, Mothers and their Childrenⁱ, have prepared this policy brief, which is in line with existing WHO technical recommendations,(10) including guidance on provider-initiated HIV testing and counselling issued by WHO in 2007(6). The brief aims to outline key issues that should be addressed within national policy guidance to support country programming. It is designed to be used by country programmes and technical working groups as they review and develop policy and practice guidelines relevant to HIV testing for children. For the purposes of this brief, infants and children should be considered to include all children who are 14 years of age or younger. Specific attention should be given to those issues related to children below the age of 10 years.

Provider initiated HIV testing also applies to children

ⁱ The Expanded Inter-Agency Task Team (IATT) on Prevention of HIV Infection in Pregnant Women, Mothers and their Children is a collaboration of multiple organizations working to improve paediatric HIV prevention, care and treatment.

2. HIV COUNSELLING AND TESTING IN INFANTS AND CHILDREN: PRINCIPLES AND CONTEXTS

2.1 United Nations Convention on the Rights of the Child

The United Nations (UN) Declaration of Commitment on HIV/AIDS and the Convention on the Rights of the Child both provide an important framework to guide any response to HIV/AIDS prevention, care and support of children; both affirm “the right of the child to the enjoyment of the highest attainable standard of health”(11,12).

The Convention on the Rights of the Child maintains that children have the right to “survival, life and development” (Article 6), and the right to health (Article 24). Consistent with the obligation of duty bearers, as stated under Article 24, governments must ensure that no child is deprived of her or his right of access to necessary health services. State parties should therefore ensure access to HIV testing and counselling for all children, as this is essential to access necessary care and treatment. Health-care providers have a duty to ensure that HIV testing and counselling for infants and children and their caregivers is discussed and recommended where appropriate.

In addition, General Comment No. 3 of the Convention compels governments to give children access to “adequate information related to HIV/AIDS prevention and care”. It states that HIV testing and counselling is “fundamental to the rights and health of children” and should be made accessible along with the protection of their rights(8).

Protection from discrimination of children is also outlined in Article 24 of the Convention. It specifically states that “the best interests of the child shall be a primary consideration” and obliges governments to offer children, in accordance with their maturity, an **increasing** role in decisions that affect them.

2.2 WHO/UNAIDS guidance

The Joint United Nations Programme on HIV/AIDS, UNAIDS/WHO policy statement on HIV testing, defines two main categories of testing:(7)

- client-initiated testing and counselling
- provider-initiated testing and counselling.

Provider-initiated HIV testing and counselling is particularly relevant for infants and young children, who are most often seen in the context of a medical encounter, unless they may receive testing and counselling in door to door or other community events.

WHO recommends that provider-initiated HIV testing and counselling for infants and children be implemented to facilitate diagnosis, and assure linkages and access to HIV-related services(6). Furthermore, a family-centred approach to HIV testing should be emphasized, to maximize all opportunities to identify HIV-exposed and -infected children. WHO recommendations for HIV testing and counselling state that in *all* types of epidemics, health-care providers should recommend HIV testing and counselling as part of the standard of care to all infants, children and adolescents who present to health facilities with signs, symptoms or medical conditions that could indicate HIV infection. HIV testing and counselling should also be recommended by health-care providers for all infants born to HIV-positive women as a routine component of follow-up care for HIV-exposed children, as well as for children from families where another sibling or parent has already been diagnosed with HIV.

Irrespective of HIV epidemic settings, governments are encouraged to designate situations in which health-care providers should recommend and provide HIV testing and counselling for all infants and young children.

Whenever testing of children is performed, the “three Cs” – informed consent, counselling and confidentiality – should be observed. In addition, the assent of the child should be sought in a developmentally appropriate manner. Mandatory testing of children should be avoided in all cases, and State parties should ensure that, where HIV testing is performed, it is conducted in consideration of a child’s “best interests” (see section 4.1 below)(8,13). At the same time, the child also has a right to treatment and care. If a parent or caregiver refuses HIV testing, the health-care provider should offer additional counselling on the rationale for testing and the potential benefits to the child. As a general principle, when life-saving treatment is available, and all efforts to obtain parental consent have failed, the provider has an ethical responsibility to act in the best interests of the child. In this setting the provider should test the child and initiate treatment within the context of national law.

Parents and guardians also have the right to maintenance of confidentiality and privacy within the context of HIV testing(14). Additionally, HIV testing and the status of the person tested must not be used to deny other rights to a child or infant, such as access to housing, education or care.

2.3 When to provide HIV testing

Infants and children should be tested in the following circumstances:(6,13)

- to identify the HIV-exposure status of all infants for the purpose of appropriate follow up, which includes provision of co-trimoxazole prophylaxis, antiretroviral prophylaxis and/or treatment;
- at around 4–6 weeks or as soon thereafter as possible for infants known to be exposed to HIV through mother-to-child transmission to enable early diagnosis of HIV with virological testing;
- to confirm the HIV infection status of children born to HIV-positive mothers six weeks after exposure to HIV has ceased or at eighteen months, whichever is sooner;
- for the purpose of individual diagnosis in a child who is ill (e.g. presenting with an HIV-associated illness, such as tuberculosis or malnutrition, or other recurrent common childhood illnesses such as pneumonia or diarrhea);
- for the purpose of individual diagnosis where another sibling or parent has been diagnosed with HIV or where there is a history that the parents have died as a result of AIDS or other undiagnosed debilitating illness in the family;
- in cases where a child has been exposed or potentially exposed to HIV
 - through sexual abuse or
 - through contaminated needlesticks or receipt of potentially infectious blood or blood products (or through other routes, e.g. wet nursing).

If provision of post-exposure prophylaxis (PEP) is anticipated in response to any of the above situations, HIV testing should be recommended prior to initiation of antiretrovirals. PEP is only relevant to situations of possible exposure.

In settings with low-level and concentrated epidemics, testing of all infants and children is not required, as very few will likely be HIV-exposed or infected. However, efforts should be made to ensure that provider-initiated HIV testing and counselling is recommended for infants and children known to have been exposed perinatally or who present to health facilities with signs and symptoms suggestive of underlying HIV infection, including tuberculosis and malnutrition.

Some high-prevalence countries have debated the utility of determining the HIV infection status of all mothers postpartum and corresponding exposure status of their infant or young child in situations in which the mother did not receive interventions for preventing mother-to-child transmission, including HIV testing, during pregnancy. This approach may be considered in settings with a high burden of HIV or in populations considered to be especially at risk.

3. NATIONAL POLICIES AND GUIDELINES FOR HIV TESTING IN CHILDREN

Within each country, the responsibility for providing diagnostic HIV testing services to infants and young children lies with the government and health sector. As such, ministries of health should develop explicit policy guidance on how HIV testing and counselling services should be provided to infants and children, regardless of their legal status.

Access to HIV testing and counselling by infants and young children is usually regulated by local legislation. Such legislation is often unclear, particularly in the case of those who lack a parent or legal guardian. Updated legal frameworks, national HIV policies and country-level operational guidance need to offer clear guidelines that reflect both the needs and the rights of children. These, in turn, should inform, guide and support health-care providers obligated to provide testing services in their efforts to diagnose, treat and/or care for infants and children.

National policy and programme guidance in high HIV-burden countries (i.e. generalized epidemics) should reflect the need to ensure provider-initiated HIV testing and counselling for infants and children. National policies, however, should not infringe upon children's rights as outlined in international agreements, nor should an absence of such policies impede health-care providers' abilities to provide access for infants and children to urgently needed HIV treatment and care.

National policy guidance needs to specifically address a range of issues and questions, including the following:

- Which infants and children should be tested, when, at what age, under what circumstances; where, how and why?
- Who is able to administer and perform HIV testing in children (including community health workers)?
- What are the various settings in which HIV testing in children may be performed (including as part of child health days and community-based testing campaigns)?
- What are the consent, assent, counselling and confidentiality requirements specific to children according to their developmental and cognitive stages across the life course?
- Who can deliver the test results to minors, and to whom else can the results be provided? To whom is disclosure advised?
- Who pays for all the components of the testing service for children?
- What additional services (health and otherwise) need to accompany HIV testing for children?
- What mechanisms are in place to ensure that infants and young children testing HIV positive access HIV care and treatment promptly? Do mechanisms need to be put in place to ensure that results for infants at higher risk of HIV infection (e.g. those born to mothers with low CD4 counts or started late in pregnancy on ARV prophylaxis) are fast tracked to further expedite treatment initiation for those infected?
- What special provisions may be required for the testing of institutionalized minors to ensure access to health care, education and other essential services?
- What legal, social and educational protections are afforded to HIV-exposed and -infected infants and children?
- What physical and infrastructural requirements need to be in place for services to be provided to children?

- Which authorities should be responsible for ensuring comprehensive services to children who might be exposed to or infected with HIV?
- What training and protocols are required for health-care providers and others performing HIV testing in children?
- What are the special provisions, protections and reporting requirements related to child sexual abuse?

It is essential that policy guidance described above reaches all health centres and community-based providers if this guidance is to be implemented.

4. NATIONAL POLICY GUIDANCE ON HIV TESTING AND COUNSELLING OF CHILDREN: SPECIAL CONSIDERATIONS

Certain elements associated with the testing and counselling of children have been reported to be difficult to address and are therefore expanded upon below.

4.1 Informed consent

In general, while HIV testing should be encouraged, it should be undertaken once the individual to be tested is both informed of the benefits and risks of testing and voluntarily agrees to it⁽⁷⁾. Two significant issues arise, however, with respect to obtaining consent for HIV testing in children, particularly those less than ten years of age⁽¹⁵⁾. These include the following:

- 1. Consent on behalf of a minor:** For children, consent for testing is typically obtained from a parent or legal guardian because of restrictions or concerns related to developmental stage, emotional maturity or legal requirements. However, where there is no parent or legal guardian, obtaining consent for children and infants can be difficult as consent laws are often unclear, do not give consenting rights to informal caretakers or medical staff or are in contradiction to the ages of consent for other procedures. Orphans, child survivors of rape, abandoned infants and street children are specific examples of situations where a parent or guardian may be unavailable to give consent. In such cases the decision to test should be made by the health-care worker, provided it is determined to be in the best interests of the child.
- 2. Involving the minor in the HIV testing process:** The definition of informed consent as it applies to children may be a source of confusion; how should a health-care worker determine whether consent provided by a young child is sufficiently informed, and at what age, stage or level of emotional maturity can the child reasonably provide or be part of the process to provide informed consent for testing? For young children it is not appropriate to seek the consent of the child, however in all cases it is important to involve the child in the process of testing. A child has a right to information about his or her health status, commensurate to their developmental age and level of maturity.

In the case of children less than 10 years of age, parents or legal guardians usually give consent on behalf of their children for medical procedures, including HIV testing. In practice, it is therefore unusual to specifically seek separate informed consent from a child less than 10 years of age. A child above 10 years of age would usually need to be involved in the process of discussing HIV testing and obtaining parental or guardian consent. The child does have the right to “participate in decisions affecting his or her life”⁽¹³⁾ and, according to the Convention on the Rights of the Child, their desires should be “given due weight in accordance with their maturity”⁽¹²⁾. Verbal communication is normally adequate for the purpose of obtaining informed consent from the parent or guardian. Consent from one parent (maternal or paternal) should be seen to be sufficient.

Currently, some health-care providers have reported seeking consent either legally or extra-legally (depending upon a country’s laws) from informal caretakers or representatives of nongovernmental organizations, or simply testing without obtaining consent based on their assessment of the best interests of the child. National consent policies and laws need to strive to offer clear protocols that strike a balance between protecting the child’s rights and ensuring his or her access to medical care.

Health-care workers recommending HIV testing and counselling for an infant or young child should be aware that testing a child most often implicitly tests that child’s mother. Parents may refuse to allow testing of their child based on this or other reasons. Parents may also deny testing for children due to fear of community disclosure of their own status.

Specific consent and reporting requirements are likely to apply to HIV testing in the context of suspected or documented sexual abuse in children, and should be made clear prior to testing.

Specific actions to be taken by national authorities

- National HIV testing policies and country-level guidance must be developed or revised to clearly articulate who may provide consent for a child and at what age children may consent for themselves (or for others, as may be the case with child-headed households).
- Consent laws can be amended to increase access to HIV testing by lowering the age at which a child may consent (e.g. from 18 to 14 or 12 years), making allowances for “mature” or “emancipated” minors, or expanding the role of the informal caretaker or medical supervisor to provide consent for the child if no parent or legal guardian is available(16).
- Jurisdictions that require consent for testing to be given in writing are encouraged to review and revoke this policy.
- Guidance on child-friendly approaches to informed consent need to be elaborated for health-care providers. Child-friendly consent forms and protocols should be used to ensure that age-appropriate information has been given to and is understood by any child to be tested.
- Country-level frameworks or guidelines and training of health-care providers need to be made available to enable them to assess maturity and determine what “informed consent” means with respect to children of different ages.
- In cases of parental refusal to test where such testing is clinically indicated and in a child’s best interest, country-level policies should be in place to enable health-care workers to test for HIV and ensure that the child is not denied access to treatment and care.
- Guidelines and/or training outlining the best interests of children and infants should be provided to help inform health-care providers in their decision-making.
- Health-care workers and counsellors must also be adequately equipped to address specific situations that may arise in relation to consent. This should include protocols for cases where children need testing and are below the age of consent, and/or lack a parent or legal guardian, and cases of sexual abuse.

4.2 Counselling and communication with children, parents and caregivers

Counselling, including post-test counselling, to accompany HIV testing should be made available for both the child and parent(s) or caretaker(s). Appropriate counselling is inseparably linked to HIV testing. Uncertainty on the part of providers regarding how to properly counsel children about HIV is one reason for health-care providers’ reluctance to initiate HIV testing. Counselling children requires skills that differ from adult and adolescent HIV counselling, and providers must have access to adequate training and tools in this area. These skills include assessing maturity, offering age-appropriate communication and informing a child of his or her HIV status.

It is therefore essential that health-care workers be adequately informed and equipped to provide counselling for children. Counselling for children should ideally be provided by health-care workers or care providers trained or experienced in working with children. Informing children (often referred to as disclosure to the child) and disclosing HIV test results to family members and others is a process that usually requires counselling support from trained, trusted health-care workers (*see section 4.3 below*). In cases where there are no specialized counsellors, training in child counselling techniques is needed. Experienced counsellors may also benefit from training in HIV testing.

Specific actions to be taken by national authorities

- Guidance explaining the basic elements of the counselling process with respect to children should be issued. This includes appropriate methods of speaking with children such as using age-appropriate language, pictures, images and symbols, speaking briefly and simply, focusing on feelings and the physical setting, and addressing their fears, assumptions and misconceptions.
- Guidelines, training curricula and tools developed for health-care providers and others working with children or infants which address counselling skillsⁱⁱ should include:
 - Counselling for prevention of mother-to-child transmission
 - Counselling skills for health-care providers working in settings other than HIV and PMTCT programmes (e.g. services for Integrated Management of Childhood Illness, immunization and nutrition clinics, outpatient and inpatient paediatric settings)
 - Parent/caretaker counselling
 - Counselling for sexual abuse
 - Counselling for orphans and other vulnerable children
 - Counselling parents who are reluctant or refuse to have their children tested where it is in the child's best interest to do so
 - Specialist counselling through referral where required.

Additional guidance is provided in the WHO *Guidelines for medico-legal care for victims of sexual violence*(17). WHO is currently developing guidance on disclosing HIV test results to children as well as a manual on HIV testing and counseling for infants, children and adolescents.

4.3 Confidentiality, disclosure and informing the child and/or parent of the HIV status

Every child has a right to have their HIV status kept confidential. The Convention on the Rights of the Child obliges Member States to respect the privacy of the child. Disclosure is defined as “informing any individual or organization...of the serostatus of an infected person...or by the person him or herself... with or without consent”(18). Disclosure as a term is also often used to describe the process of informing a child of their own HIV infection and is best undertaken in a planned and supported way. The benefits of disclosure to the child include improved adherence to treatment and better understanding of HIV infection control, but potential risks may include stigma, discrimination and violence.

Informing the child and/or disclosing a child's HIV status to a parent/caregiver also presents challenges for health-care workers, and guidance on informing the child needs to be elaborated and understood by those performing counselling. Protocols that permit confidentiality (as opposed to anonymity) must be clearly elaborated, while also ensuring the best interests of the child. Providers must be clear as to whom, when and how best they can provide information on or disclose a child's HIV status.

Informing the child of their HIV status may be undertaken by the child's counsellor or health-care worker in collaboration with the caregiver; or by the parent to the child. It is a process that needs to be planned and discussed, based on the age and readiness of the child, and may need to involve other caregivers where there are no parents. This process can occur over time as the child receives care and treatment services.

ii Some specific guidelines have been developed and published for counselling children on HIV/AIDS. These include documents authored by the South African AIDS Training Programme <http://www.satregional.org/content/publications/Skills%20Training%20E/CABA.pdf> and Family Health International.

Disclosure may also occur at a variety of levels: from the counsellor or health-care worker to other stakeholders (including other health-care providers, relatives, school, orphanage), and from the child or child's caregiver to others (including relatives, other children and neighbours). Shared confidentiality within a health-care setting and among health-care providers permits sharing of information needed to provide the best possible care, but prohibits sharing of information without consent outside of this strictly defined group comprising the health-care team.

While models for the disclosure of other chronic or terminal diseases may be of use in establishing guidelines, informing and disclosing the HIV status warrants special consideration, given the possible negative outcomes related to stigma and discrimination for the child and their family. Both advantages and risks exist, and should be communicated and understood by all the parties involved(19,20).

In cases of suspected or documented sexual abuse, national reporting requirements will need to be adhered to, and explained to parents and/or legal guardians.

Specific actions to be taken by national authorities

- Develop standard operating procedures and train staff on maintaining confidentiality and communicating HIV results:
 - to the child
 - to the parents and/or caregivers of the child
 - to other health-care workers
 - on child health cards and patient- and clinic-held records.
- Provide guidance to health-care workers on informing a child of their HIV status including when and how to inform at various levels (e.g. counsellor to child, or parent to child – note that this is frequently called “disclosure” to the child).
- Provide simple guidance for health-care workers or parents disclosing a child's HIV status to other third parties based on a best interest, need-to-know basis.
- Develop standard operating procedures and training for staff on maintaining the security and confidentiality of medical records.
- Provide guidelines and tools that outline the advantages and potential risks associated with informing and disclosure; health-care providers should be aware of both. Reasons for disclosure and non-disclosure in a given country need to be considered for a range of settings (PMTCT programmes, child-care homes, outreach services, etc.) and addressed wherever it is not in a child's best interest (e.g. disclosure to exclude the child from services).

4.4 Addressing stigma and discrimination

Children experience stigma and discrimination due to HIV/AIDS from within the family, the community and its institutions, as well as health-care settings(21). Such discrimination manifests as isolation within families, marginalization among peer groups, discrimination within schools and denial of health-care and social services. Stigma and discrimination against children need to be addressed at each of these levels. Implementers have suggested that stigma results in decreased uptake of testing services by parents. Stigma may also impact issues surrounding disclosure(15). In order to counter stigma effectively, it must be understood, at country or local level, how being HIV-infected affects children within a specific society.

Specific actions to be taken by national governments

- Laws defining the rights of children affected by or infected with HIV need to be enacted and publicized. For example, laws should protect children from discrimination in different settings, as well as from neglect and abuse. They should ensure access to health care and education, protect vulnerable groups such as street children and guarantee inheritance rights.
- Age-appropriate, post-test counselling approaches that assist children and their parents/ caretakers in facing stigma and discrimination should be developed. These approaches should also address stigma by association, where the children of HIV-infected parents are discriminated against.
- Health-care and other facilities working with children living with HIV must work within their systems and communities to reduce stigma and discrimination. This may include actions such as developing institutional policies to protect against discrimination and conducting training to this end.
- Effective initiatives that counter stigma and discrimination against children and infants at both the institutional and broader societal levels should be explored. These may include, for example, the use of child role models, media campaigns to promote acceptance and counter myths, and education programs to sensitize communities.
- Ensure robust community involvement/engagement such as the establishment of community-based child protection committees. These committees should have specific mandates regarding the identification of children at risk for or being stigmatized or discriminated against in the community, with clear guidelines on what action they should take or how existing sociopolitical structures or social groupings such as church groups can be used for protection of such children and mitigation of stigma.

4.5 HIV testing procedures

Age-appropriate testing algorithms are essential for undertaking HIV testing in young children. A missed diagnosis in the first year of life frequently results in death of the HIV-infected infant. In high-prevalence settings, infants or children presenting to child health clinics with malnutrition, tuberculosis or severe sepsis need to undergo HIV testing to avoid missing the diagnosis of HIV which, when undiagnosed, worsens treatment outcomes. Conversely, when infants and children are inaccurately labelled as being HIV infected, it results in missed HIV prevention opportunities, denial of therapeutic interventions, decreased chances of adoption for orphans, and potentially increased levels of stigma, discrimination and psychological distress for the child and parent or caregiver.

Health-care workers and/or anyone initiating diagnostic testing for HIV should be aware of both the recommended testing procedures and the limits of any test used for the diagnosis of HIV in infants and children. For all children, HIV antibody testing is an accurate and reliable way to detect HIV antibody. In the first 18 months of life, interpreting positive HIV antibody tests, however, is complicated by the persistence of maternal HIV antibodies, most notably in the first year of life. Diagnostic (or confirmatory) testing for infants below the age of 18 months should be undertaken with HIV viral tests (such as tests for HIV DNA or RNA). Where viral tests are not available, exposed infants and those who have been diagnosed as HIV positive based on antibody testing alone must have appropriate follow-up services and regular clinical assessments to determine whether a presumptive diagnosis of severe HIV disease can be made(22).

Specific actions to be taken by national governments

- National testing algorithms for infants and children should be aligned with WHO recommendations(23). These should be promoted and training provided to programme managers and health-care providers in the field to ensure that age-appropriate protocols and proper diagnoses are supported.
- HIV testing protocols need to outline diagnostic HIV testing algorithms for sick infants and for systematic follow up of HIV-exposed children.
- HIV viral testing is crucial for the accurate diagnosis of HIV infection in young children below the age of 18 months, and services to provide access to such testing need to be established.
- Dried blood samples from infants can be used to enable testing of specimens from remote locations in centralized laboratories using HIV viral tests.
- The frequency and timing of retesting for infants and children who test negative or in whom the results are discordant should be specified; including in relation to the last exposure, previous negative results, and circumstances in which further testing may be required (e.g. child develops symptoms).
- Documentation of results should be standardized to avoid unnecessary retesting.
- Pre-defined referral pathways to care and treatment for infants and young children testing positive should be described and protocols provided.
- Interventions need to be specified and assured, including co-trimoxazole preventive therapy and vaccinations, while awaiting the viral test results.

4.6 Making HIV testing services family- and child-focused

HIV testing and counselling should be delivered to children through a rights-based approach in a non-judgemental, non-discriminatory, child-friendly and family-friendly manner. While services that offer HIV testing and counselling to adults (such as client-initiated testing and counselling/voluntary counselling and testing, testing at antenatal clinics, community-based testing programmes and facility-based HIV testing within programmes for tuberculosis and sexually transmitted infections) are all potential entry points for the identification of HIV-exposed or -infected children, it is important to enhance the child-focused and family-friendly nature of these services. Four elements need to be considered in order to enhance the ability of programmes to cater to the needs of families and children: physical infrastructure, provider training, systems operation and community involvement.

Physical infrastructure changes may be needed – especially in settings that provide services primarily to adults such as centres for client-initiated testing and counselling. Creating areas that are attractive to children and where child clients can play, read books or view other media while they wait to be tested makes the space feel more welcoming to them. It also serves as a daily physical reminder to providers that they do also see children and encourages adults to bring in children for testing.

Providers will need additional training and skills-building to better understand national policy around paediatric testing, the rights of children to be tested, issues of counselling and consent in children, disclosure to children, how to draw blood in paediatric patients, and what behaviours constitute a child-friendly approach during clinical interactions. In addition to providing didactic training, national programmes may need to create job aids, posters or tools related to testing of children, which can be placed in the testing centre to serve as a ready reference for providers. An example of a job aid that reinforces clinician behaviour to make it more child-friendly is attached in Annex 1.

Changes in the operation of the testing service may be necessary to make them more child-friendly. Successful approaches may include child- or family-focused testing days at voluntary counselling and testing centres, community outreach aimed at identifying HIV-infected or -exposed children, or abolishing user fees for child testing. Standard operating procedures for infant testing in PMTCT and other maternal and child health programmes should be structured to promote a child-friendly approach. Services that offer testing to children should pay special attention to ensure that infected infants and children are referred and tracked to care and treatment services in a reliable and timely manner. There should be adequate and effective linkages and referrals between community outreach services and health facility-level activities that encourage child- and family-friendly HIV-testing services.

Specific actions to be taken by national governments

- Country-level protocols and approaches to the testing of children should be standardized and implemented within private, public and not-for-profit facilities providing services to children and families.
- Policy and clinical care guidelines should clarify the range of settings where provider-initiated HIV testing for children needs to be provided.
- Policy guidance should address reduction or waiving of fees for diagnostic testing of children so that such fees do not act as a deterrent. Policy-makers and programme planners need to consider how to finance the budgetary implications of abolishing fees for diagnostic testing.
- Support should be provided to establish outreach services to minimize the problem of loss to follow up, particularly among children in maternal and child health/PMTCT programmes. Outreach services should also provide age-appropriate HIV testing and counselling for those in difficult-to-reach communities.
- Efforts should be undertaken to minimize and address health-care worker reluctance to provide HIV testing services to children, including training and adaptation of tools to support health-care workers.
- HIV and child health services need to monitor and document successful approaches to reach children in a range of predetermined settings, and ensure that access to testing is increasing for infants and children.

5. CONCLUSION

Children and infants need to have access to HIV testing and counselling services to facilitate early diagnosis of HIV infection and minimize morbidity and mortality. Provider-initiated HIV testing for infants and children exists in many countries, but must be expanded and integrated into national programmes, particularly in regions with a high HIV prevalence. Access to HIV testing impacts treatment, care and prevention, and can result in further desirable effects such as improved health outcomes for children and their families, improved allocation of resources and increased adoption rates. It is the responsibility of governments to provide policies and frameworks that support health-care providers in their efforts to increase and facilitate access to testing for infants and children, as well as promote their best interests. Updated national policies, recommendations, guidelines and tools need to offer clear guidance on the provision of testing services for young children and infants. Specific attention is needed to address the issues of consent, confidentiality, counselling, and ensure their inclusion within national policy guidance. There is a considerable amount of experience and several published guidelines and tools that can assist implementers in developing services for children. WHO has assembled much of this and made it available in the online HIV testing and counselling toolkit⁽²⁴⁾. The incorporation of this experience into country-level guidelines, in combination with training and capacity-building programmes, will both facilitate the scale-up of services for infants and young children in the context of universal access, as well as assist implementers on the ground in providing age-appropriate, quality, non-discriminatory services.

ANNEX 1.SAMPLE JOB AIDE FOR CHILD FRIENDLY CLINICIAN BEHAVIOUR⁽²⁵⁾



THE CHILD FRIENDLY WITH THE CAREGIVER CLINICIAN

- Be relaxed and open
- Think about your body language:
 - Lean towards them
 - Keep your face neutral & friendly
 - Maintain eye contact
 - Sit close by & on the same side of the desk
- Remember that you are trying to develop a long term supportive relationship

WITH THE CHILD

WHAT WORKS?

Get down to the child's eye level: Let the child see your eyes and read your intentions.

Speak softly and directly to the child: Children respond better when you address them and not just the caregiver.

Smile and play: A smiling face makes a huge difference and will help your interaction with the child, and remember that for young children play is very important. If they leave laughing, they will look forward to come back.

Be honest: Hiding the truth from a child leads to loss of trust.

Allow and respect normal emotions: Crying is okay and so is anger – be patient with the child.

Start with the least invasive activity: Keep the child on the caregivers lap as much as possible and don't start with painful or invasive activities such as ear examination or blood drawing.

Give the child choices: Choices provide a sense of control. Let the child choose whether you examine the left or the right ear first, whether to have juice or water with medication.

Engage the child: Talk about things of interest to him or her such as school or friends or hobbies.

Support the parent/child relationship: Parents are the experts on their own children and even teens need their parents.

Maintain your own self-control: If you find yourself "losing it", take a break or get someone else to work with the child.

Operate a "3 needle maximum" policy: If you can't get blood the third time, and its not essential, leave it until the next visit.

WHAT DOESN'T WORK?

Avoid comparing the child to others: Each child is a person with his or her own individuality.

Be careful when you touch children: Physical affection is OK, and you must examine the child for medical reasons, but wait until the child is ready, and don't treat the child like a pet!

Don't forget the child is in the room: If you have to have a private conversation, make a separate appointment with the caregiver. This is especially important when discussing disclosure. Children always understand more than you think.

Don't Pity: Children need love, support and care but not pity.

Don't infantilize the older child: Treat children appropriately for their age.

Try not to say "Be a good boy/girl": Children do the best they can, and making them feel inadequate will not help build a good relationship.

All children are not raised the same: Approaches to child rearing and discipline are never the same in two families. Don't expect your experience to be the same as someone else's.

Stop yourself before you threaten the child: Making the child fear you will not build trust or confidence.

Don't be grumpy: A positive attitude and humor is especially effective with children and adolescents. If you are too serious, children will feel depressed about their illness and their visits to the doctor.



6. RESOURCES

- 1 Office of the United Nations High Commissioner for Human Rights/Joint United Nations Programme on HIV/AIDS (OHCHR/UNAIDS). *HIV/AIDS and human rights: international guidelines*. Geneva, United Nations, 1998. <http://whqlibdoc.who.int/publications/1998/9211541301.pdf> (accessed on 13 October 2009).
- 2 Office of the United Nations High Commissioner for Human Rights/Joint United Nations Programme on HIV/AIDS (OHCHR/UNAIDS). *HIV/AIDS and human rights – revised guideline 6: access to prevention, treatment, care and support*. Geneva, United Nations, 2002. <http://whqlibdoc.who.int/publications/2002/9291730254.pdf> (accessed on 13 October 2009).
- 3 Joint United Nations Programme on HIV/AIDS (UNAIDS). *2004 report on the global AIDS epidemic: 4th global report*. 2004. http://www.unaids.org/bangkok2004/GAR2004_html/GAR2004_00_en.htm (accessed on 13 October 2009).
- 4 Joint United Nations Programme on HIV/AIDS/ World Health Organization (UNAIDS). *Report on the consultative meeting on HIV testing and counselling in the Africa region, 15–17 November, 2004, Johannesburg, South Africa*. Geneva, UNAIDS, 2005. http://data.unaids.org/UNA-docs/ConsultativeMeetingHIVTesting%20CounsellingAfricaReport_1104.pdf (accessed on 13 October 2009).
- 5 Joint United Nations Programme on HIV/AIDS/United Nations Children's Fund/United States Agency for International Development (UNAIDS/UNICEF/USAID). *Children on the brink 2004: a joint report of new orphan estimates and a framework for action*. New York, UNICEF, 2004. http://www.unicef.org/publications/files/cob_layout6-013.pdf (accessed on 13 October 2009).
- 6 Joint United Nations Programme on HIV/AIDS/United Nations Children's Fund (UNAIDS/UNICEF). *Children – the missing face of AIDS: a call to action*. New York, UNICEF, 2005. http://www.unicef.org/publications/files/AIDS_Launch_final_14Oct.pdf (accessed on 13 October 2009).
- 7 World Health Organization. *Recommendations on the diagnosis of HIV infection in infants and children: a public health approach*. Geneva, WHO, 2006.
- 8 World Health Organization. *Scaling up antiretroviral therapy in resource-limited settings: guidelines for a public health approach (2003 revision)*. Geneva, WHO, 2004. http://www.who.int/entity/hiv/pub/prev_care/en/arvrevision2003en.pdf (accessed on 13 October 2009).

7. REFERENCES

- 1 Joint United Nations Programme on HIV/AIDS/World Health Organization. *AIDS epidemic update 2009*. Geneva, UNAIDS, WHO. 2009. http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf
- 2 Newell ML, Coovadia H, Cortina-Borja M, Rollins N, Gaillard P, Dabis F. Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis. *Lancet*, 2004, 364 (9441):1236–1243.
- 3 Violari A et al for the CHER Study Group. Early antiretroviral therapy and mortality among HIV-infected infants. *New England Journal of Medicine*, 2008, 359:2233–2244.
- 4 World Health Organization. *WHO antiretroviral therapy for infants and children 2008*. Geneva, WHO, 2008. http://www.who.int/hiv/pub/paediatric/WHO_Paediatric_ART_guideline_rev_mreport_2008.pdf (accessed on 21 September 2009).
- 5 Sutcliffe CG et al. Effectiveness of antiretroviral therapy among HIV-infected children in sub-Saharan Africa. *Lancet Infectious Diseases*, 2008, 8:477–489.
- 6 World Health Organization/Joint United Nations Programme on HIV/AIDS. *Guidance on provider-initiated HIV testing and counselling in health facilities*. Geneva, WHO, 2007. http://www.who.int/hiv/pub/guidelines/9789241595568_en.pdf (accessed on 21 September 2009).
- 7 Joint United Nations Programme on HIV/AIDS/World Health Organization. *UNAIDS/WHO policy statement on HIV testing*. June 2004. http://www.who.int/rpc/research_ethics/hivtestingpolicy_en.pdf.pdf (accessed on 21 September 2009).
- 8 United Nations. *Convention on the rights of the child: general comment No. 3 – HIV/AIDS and the rights of the child*. 2003. [http://www.unhchr.ch/tbs/doc.nsf/\(symbol\)/CRC.GC.2003.3.En?OpenDocument](http://www.unhchr.ch/tbs/doc.nsf/(symbol)/CRC.GC.2003.3.En?OpenDocument) (accessed on 04 October 2009).
- 9 Joint United Nations Programme on HIV/AIDS/World Health Organization. *Guidance on ethics and equitable access to HIV treatment and care*. Geneva, WHO, 2004. <http://whqlibdoc.who.int/hq/2004/9241592583.pdf> (accessed on 21 September 2009).
- 10 Wong V et al. The lost children of universal access: issues in scaling up HIV testing and counselling. *Vulnerable Children and Youth Studies*, 2006, 1:44–55.
- 11 United Nations General Assembly Special Session (UNGASS). *Declaration of commitment on HIV/AIDS*. 2002 <http://www.un.org/ga/aids/docs/aress262.pdf> (accessed on 21 September 2009).
- 12 United Nations. *Convention on the rights of the child*. 1989. <http://www.un.org/documents/ga/res/44/a44r025.htm> (accessed on 21 September 2009)
- 13 UNAIDS Global Reference Group on HIV/AIDS and Human Rights. *HIV testing of specific populations: children and adolescents. Issue Paper*. Geneva, UNAIDS, 2004. http://data.unaids.org/Topics/Human-Rights/hr_refgroup3_02_en.pdf?preview=true (accessed on 21 September 2009).
- 14 World Health Organization. *Increasing access to HIV testing and counselling: report of a WHO Consultation*. Geneva, WHO, 2002. <http://whqlibdoc.who.int/publications/2003/9241590904.pdf> (accessed on 21 September 2009).
- 15 Family Health International. *Voluntary counseling and testing: a reference guide – responding to the needs of young people, children, pregnant women and their partners*. FHI, 2001.

- 16 World Health Organization. *Increasing access to HIV testing and counselling services for young children: country study: HIV testing and the issue of consent and children in South Africa*. Geneva, WHO, 2007.
- 17 World Health Organization. *Guidelines for medico-legal care for victims of sexual violence*. Geneva, WHO, 2003:75–93.
- 18 Joint United Nations Programme on HIV/AIDS/World Health Organization. *UNAIDS Best Practice Collection. Opening up the HIV/AIDS epidemic: guidance on encouraging beneficial disclosure, ethical partner counselling and appropriate use of HIV case-reporting*. Geneva, UNAIDS, 2000. http://data.unaids.org/Publications/IRC-pub05/JC488-OpenUp_en.pdf (accessed on 21 September 2009).
- 19 Chazal E. *Principles used for recommendations on HIV disclosure in children: results of journal searches, meetings with health professionals working in the domain in France*. MSF, Paris, 2005. http://www.who.int/hiv/topics/vct/toolkit/additional_resources/children/en/index5.html (accessed on 13 October 2009).
- 20 Chazal E. *Therapeutic education: Recommendations regarding disclosure of HIV status to children under ARV in MSF projects*. MSF, Paris, 2005. http://www.who.int/hiv/topics/vct/toolkit/additional_resources/MSF_recommendations_disclosure.pdf (accessed on 13 October 2009).
- 21 Save the Children. *The role of stigma and discrimination in increasing the vulnerability of children and youth infected with and affected by HIV/AIDS*. Arcadia, South Africa, Save the Children, 2001. <http://synkronweb.aidsalliance.org/graphics/OVC/documents/0000059e00.pdf> (accessed on 21 September 2009).
- 22 World Health Organization. Report of the guideline review group meeting on recommendations for the diagnosis of HIV infection in infants and children, WHO Headquarters, Geneva 20–21 November 2008. Geneva, WHO, 2009 (in press).
- 23 World Health Organization. *TC toolkit: an annotated bibliography of peer-reviewed resources and tools*. Geneva, WHO, 2007. <http://who.arvkit.net/tc/en/content.jsp?d=tc.10.23> (accessed on 21 September 2009).
- 24 Paediatric AIDS Treatment for Africa (PATA). The child friendly clinician. <http://www.teampata.org/downloads/Poster-English.jpg>. 2008.

NOTES



For more information, please contact any of the member organizations of the Expanded Inter-Agency Task Team (IATT) on the Prevention of HIV Infection in Pregnant Women, Mothers and their Children which supported the development of this document.

ISBN 978 92 4 159909 2



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