



CHILDREN'S CONSENT FRAMEWORK

Policy and Practice for Maturity-Aligned Engagement of Children in
Decisions about HIV-Related Medical and Social Services and Management
of Confidential Information



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This publication was prepared by Kipling Beardsley (Palladium) of the Health Policy Plus project.

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Purpose

The **purpose** of this framework is to provide clear and consistent policy and practice to support the engagement of children and their proxies in making informed decisions about HIV-related prevention, testing, care, social support, and treatment, as well as management of confidential HIV data. Clinical and social service providers recognize that, in many settings, children—especially those who are vulnerable and marginalized—are at high risk for HIV and poor treatment outcomes. However, as explained in World Health Organization guidance (WHO, 2013b), the design and implementation of many policies and guidelines for HIV prevention, testing, treatment, and care, as well as management of confidential HIV data, do not adequately address the unique needs of children for a number of reasons, such as:

- Lack of training, tools, and staffing
- Medical, cultural, social, and moral complexities related to children
- Compounded needs of HIV during childhood and adolescence
- Stigma and bias related to the role of children and the behaviors that put them at risk for HIV
- Lack of clarity and conflicting laws regarding consent
- Inconsistent guidelines and practices related to:
 - ◆ Assessing child and/or caregiver capacity to give or withhold consent
 - ◆ Documenting the need for supportive proxies to help children navigate consent decisions

This framework focuses on settings and issues specific to HIV-related prevention,

testing, care, social support, and treatment for children, as well as management of confidential HIV data for children. While concepts regarding informed consent and confidentiality have broad application and should be harmonized across medical and social services for children, HIV presents critical issues involving stigma and discrimination, the potential for ongoing risk of transmission and need for identification of partners, and living with a chronic disease throughout the developmental stages of childhood and adolescence. Additionally, concepts of decisional capacity have broad application to both children and adults.

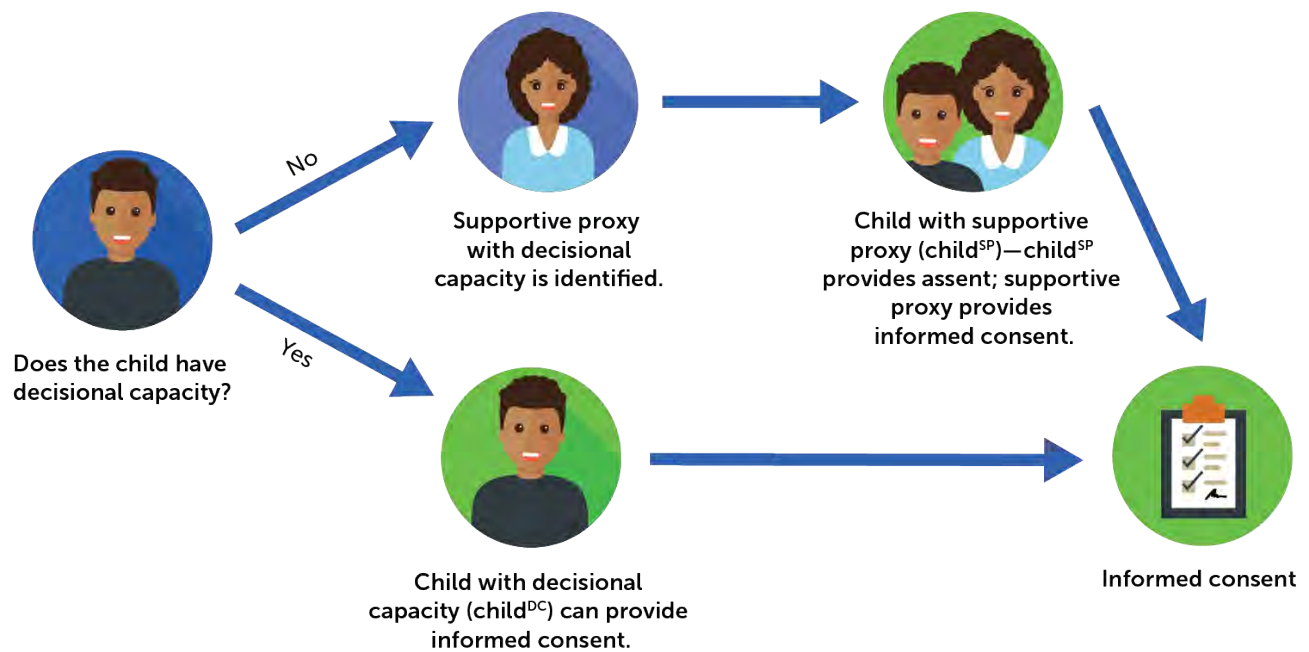
The **audience** for this framework includes individuals involved in program design, implementation, and oversight. In addition, provider and community advocates will find this framework useful to identify and improve policies and protocols at clinical and national levels. It is not the intent of the framework to be definitive or prescriptive, but rather to provide a conceptual structure to help address these complex issues and tools that support and acknowledge the authority, expertise, judgment, and bias that health and social providers bring to the provider/child relationship. For providers, the intent is to lower professional and legal risks, and for children, the intent is to reduce barriers to access and to improve consent and confidentiality practices, as well as health outcomes (Appelbaum, 2007; WHO, 2013b).

The framework is built on the **fundamental concept** that cognitive and emotional capacity determines who gives consent for children. Within this framework is information on how to assess decisional capacity of children to provide consent for themselves, as well as tools to guide an assessment. In the absence of a supportive parent/guardian, the concept of a supportive proxy is discussed. This concept expands beyond the

biological and/or legal relationship to identify and assess sources of support in instances where a parent/guardian are not present or able to provide beneficial support. Tools to identify and assess a supportive proxy are also provided later in the framework. As illustrated in Figure 1, once the mechanism is identified by which consent will be provided or withheld—either through the child or a supportive proxy—providers access existing

operational protocols to seek and document informed consent. Likewise, once informed consent is obtained, existing clinical, social work, or confidential HIV data management protocols should be implemented. Assessing decisional capacity supports providers to access mature minor clauses and/or seek supportive proxies depending on the capacity of the child and local law.¹

Figure 1. Capacity-Aligned Informed Consent



¹ Mature minor is meant to be synonymous with *emancipated minor* and will be used to refer to both concepts throughout the document.

Definitions

Definitions used in the context of this document include:

- **Child/children** aligns with the international standard of someone below the age of 18. In the case of this framework, it is most likely to be applicable to children above the age of 10 who are defined by bodies such as the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and WHO as adolescents.
- **Child/children^{DC}** is a child who has been assessed to have decisional capacity to consent.
- **Child/children^{SP}** is a child who has been assessed to not have decisional capacity and requires a supportive proxy for providing or withholding informed consent.
- **Minor** identifies an individual who is under the legal age of consent in the country.
- **Decisional capacity** is the emotional, cognitive, social, and physical capacity to provide or withhold consent.
- **Supportive proxy** identifies an individual who (1) has decisional capacity, and (2) is supportive of the child. This individual may be a parent, guardian, child^{DC}, healthcare/social service provider, informal caregiver, or other supportive adult.
- **Confidentiality** is the ethical requirement that information on the health status of an individual not be directly or indirectly shared.
- **Informed consent** is the ethical requirement to assure understanding of the right to participate or decline interventions and the consequences of that decision.

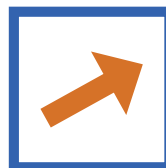
Scope

This framework encompasses HIV consent and confidentiality processes and practices for children that apply across health, social work, and education settings and addresses medical and social interventions and management of confidential HIV data.

While the following are critical and important to address, it is important to note that this framework **does not** address consent and disclosure issues for:

1. Suspected or documented emotional, physical, or sexual abuse
2. Underage sexual activity
3. Unconsented or coerced use of HIV self-testing technologies
4. Child abuse and neglect due to withholding of medical or social services
5. Required reporting of infectious diseases
6. Research
7. Exposure risk and treatment for providers in occupational settings
8. Emergency diagnosis, medical care, or social support

Also, it is important to note that assessment of decisional capacity in the context of medical or social services or decisions regarding sharing of confidential HIV data **does not** imply physical, cognitive, or emotional capacity on issues such as marriage, sexual behavior, or criminal/legal liability.



RESOURCE:

[WHO Adolescent HIV Testing, Counselling and Care Website](#)

Fundamental Framework Concepts

As stated previously, the **purpose** of this framework is to provide clear and consistent policy and practice to support the engagement of children and their proxies in making informed decisions about HIV-related prevention, testing, care, social support, and treatment, and management of confidential HIV data.

Childhood and adolescence is a period of rapid social, cognitive, and physical development and engagement of this population must align with the individual's capacity to make decisions. During this period of physical and psychological development, children are generally extraordinarily self-conscious and many of their health-related problems are associated with behaviors that they find secretive, shameful, and embarrassing—all of which can be exasperated and made even more intense for children at risk for or living with HIV.

Laws on the age of consent for sex, marriage, and access to health services are important structures to protect children and young people from abuse. However, these laws can also limit access to services, which requires adopting an approach to consent that balances protection and autonomy (UNESCO, 2013). Age of consent laws provide a formulaic answer to the question of authority to provide or withhold consent; they do not answer the more relevant question of determining the ever evolving capacity to provide/withhold consent. And while there is no formula for when a child needs to engage a supportive proxy or when a child is capable to take full responsibility for decisions on HIV-related care and social support services and management of confidential HIV data, this framework proposes some standardized policies and practices to help medical and

Key Human Rights Standards

The best interest of the child is the primary consideration

International human rights frameworks direct that actions of public or private institutions, including parental and guardian entities and family and alternative care arrangements, have the best interest of the child as the primary consideration (UN, 1990a, 1979, and 2010). This standard includes direction to meet children's needs and protect their humanity and dignity in detention settings (UN, 1990a). The standard of the best interest of the child is further defined as a guiding principle in the context of HIV testing, care, and treatment (WHO and UNICEF, 2010; WHO, 2013b).

Children have the right to the highest attainable standard of health

Closely aligned with the principle of the best interest of the child is the right to the highest attainable standard of health (UN, 1990a). This right is of special importance for children without parental care and compels governments to assure accessible HIV testing and counseling services for children (UN, 2010; WHO and UNICEF, 2010).

social services providers navigate these child- and situation-specific decisions.

This framework does not supplant existing law. The framework identifies policies and practices representing global standards in consent and confidentiality. It draws from and aligns standards from health, social work, and education settings. While these standards can be used to assess and advocate for changes in country policy, providers must base their practice decisions on the established law in

the country of practice, while acting in the best interest of the child (WHO, 2013b).

The framework builds on international human rights principles. The framework seeks to support the engagement of children and supportive proxies in making informed decisions about healthcare, social support, and confidential HIV data in a way that prioritizes the best interest of the child and promotes the highest attainable standard of health for the child.

The framework must address the needs of the most vulnerable. The most vulnerable and marginalized children are at the highest risk for HIV infection and poor treatment outcomes. Children are excluded from services because of age, lack of information, discriminatory attitudes of service providers (including those based on gender), and societal norms (UNICEF, 2015). Vulnerability stems from little or no access to basic needs and rights. These rights include a “right to a safe home and community environment; education; love, family care and support; sufficient food and nutrition; protection from maltreatment and neglect; protection from abuse and violence; adequate clothing; and the right to make lifestyle choices” (WHO, 2011, p. 26).

Children have a right to be engaged in decisions regarding their healthcare and confidential HIV data. Policy and practice must support dynamic engagement based on the maturity of the child, ranging incrementally from age-appropriate information, to assent/dissent, to full capacity to provide or withhold informed consent (UN, 1990a).

The informed decision to provide/withhold consent is required in all circumstances.

Ongoing informed consent is required (and may be withdrawn at any time) for:

- Behavioral interventions (CHALN, 2007)
- Biomedical prevention (UNICEF, 2015; PEPFAR, 2017)
- HIV testing, including provider-initiated HIV testing and counseling (WHO and UNICEF, 2010; WHO, 2013b and 2016a)
- Partner notification (WHO, 2016b)
- Medical treatment and antiretroviral therapy (OHCHR, 2003; WHO, 2013a)
- Care and social support (IFSW, 2018)
- Sharing of confidential HIV data (WHO and UNICEF, 2010; WHO 2013b)

In addition, such consent applies to all settings:

- Hospital and clinical (WHO and UNICEF, 2010)
- Social work (IFSW, 2018)
- School health (WHO, 2014)
- Juvenile detention (UN, 1990b)

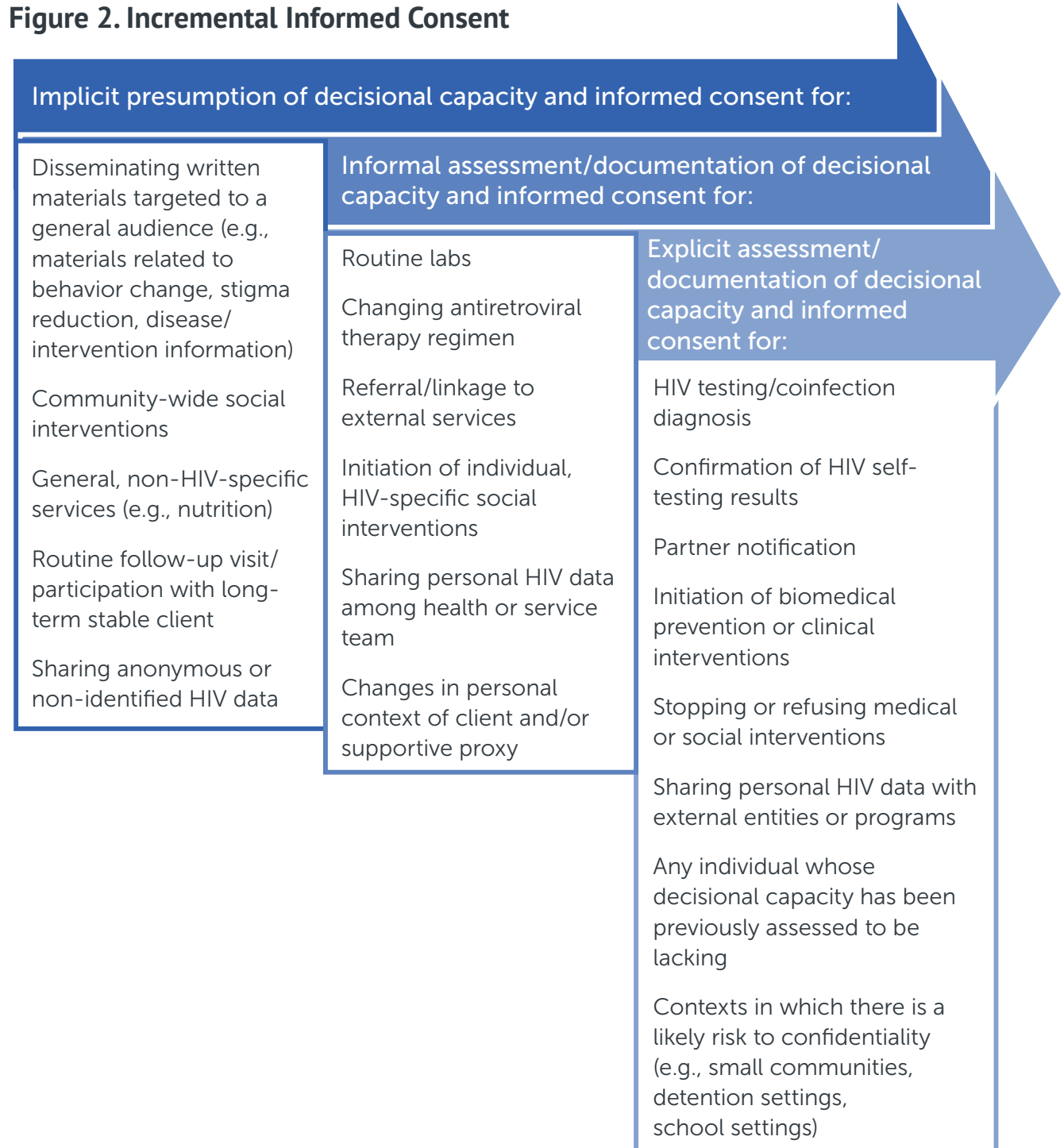
Alignment across services. This framework presents structures and practices that align across HIV-related healthcare (prevention, testing, and treatment), HIV-related social services (care and support), and management of confidential HIV data, and can be used in the health, education, and social work sectors. This alignment supports regulatory and practice harmonization to facilitate access to and linkage across a holistic spectrum of HIV prevention, treatment, and care (WHO, 2013b).

Incremental implementation. While core values of providing/withholding informed consent and data confidentiality are non-negotiable, the decisions about the formality to which this framework is implemented should be scaled to the risk posed to the provider and child by the medical or social intervention or data sharing request. As

illustrated in Figure 2, as risk grows, the implementation of the framework moves from implicit to explicit and documentation may move from assumed to verbal to written.

To reduce implementation inconsistencies, program managers should map the intervention on a risk spectrum and align framework application accordingly.

Figure 2. Incremental Informed Consent



Core Framework Philosophies

Decisional Capacity to Provide/Withhold Consent

Providing or withholding informed consent requires decisional capacity. At the very core of seeking informed consent is the assumption that the individual making decisions about the engagement or non-engagement in medical or social services or the sharing of confidential HIV data has the emotional, cognitive, social, and physical capacity to consent. This implicit, intrinsic, and requisite assessment should be present in every provider-child interaction, regardless of age of consent laws (Appelbaum, 2007; Chenneville et al., 2010; Ho et al., 2005; WHO, 2016a).

Assessing decisional capacity of a child or supportive proxy is comprised of four components to identify if individuals understand information that is being presented to them:

- **Understanding.** Does the child or supportive proxy grasp the fundamental meaning of the information that is being provided by the clinical- or social-service provider?
- **Appreciation.** Does the child acknowledge their medical condition (or the supportive proxy acknowledge the condition of the child) and the impact it may have on their life? Do they fully understand the various impacts and consequences of decisions to engage or not engage in medical treatment, social interventions, or sharing of confidential HIV data? Appreciation goes beyond *understanding* to a child or supportive proxy *applying* this information to their own situation.

- **Ability to express a choice.** Can the child or supportive proxy express a preferred option to engage or not engage in medical treatment, social interventions, or sharing of confidential HIV data?
- **Reasoning.** Is the child or supportive proxy able to process and/or manipulate information? Do they use logical thought processes in making decisions?

In either the explicit or implicit assessment of these components, it is important to remember that the purpose is to assess understanding based on information that has been discussed with the child or supportive proxy, not an assessment of background knowledge (Chenneville et al., 2010). It is also likely that the intensity of the assessment will vary directly with the seriousness of the likely consequences of the decision at hand (Appelbaum, 2007).

Regardless of the country's age of consent laws, a child assessed to have decisional capacity (child^{DC}) must ethically consent to or refuse the medical or social service or data sharing under question. If, on the other hand, a child is assessed to be without decisional capacity (child^{SP}), then a supportive proxy is needed, and they too must possess decisional capacity to consent (Appelbaum, 2007). See the "Practice Support Tools" at the end of this framework for sample tools to assess decisional capacity of children, identify a supportive proxy, and assess decisional capacity of a supportive proxy.

Decisional capacity is task-specific, situational, and variable. The existence or absence of decisional capacity at one point in time for one domain of HIV prevention, testing, care, and treatment, and management of confidential HIV data, does not assume capacity for the future or in all domains. For example, a child^{DC} or supportive proxy may have the capacity

to make decisions about HIV testing and treatment, but may not have the appreciation or reasoning capacities to make decisions about sharing confidential HIV data. (In the taxonomy of this framework, the child would be considered a child^{DC} for HIV testing and treatment, and a child^{SP} for decisions regarding sharing of confidential HIV data.)

Also, because decisional capacity is variable and will change over time, assessment must be ongoing and an intrinsic and requisite component of any medical or social service provider interaction (Chenneville et al., 2010).

Mature Minor Doctrine

Mature minor clauses provide a mechanism to allow minors to provide/withhold consent.

Often the definition of a mature minor includes specific authorizing circumstances such as being married, pregnant, sexually active, or otherwise believed to be at risk for HIV infection, or being an emancipated minor (WHO, n.d.; UNDP, 2011). While this language can be useful to indicate a need for access to services, it does not provide acknowledgment of decisional capacity to provide/withhold consent for services or the sharing of confidential HIV data. The following language from the South Africa Children's Act (GOSA, 2005, Section 130) provides support for assessing the maturity of the child.

Consent for an HIV-test on a child may be given by –(a) the child, if the child is – (i) 12 year[s] of age or older; or (ii) under the age of 12 and is of sufficient maturity to understand the benefits, risks and social implications of such a test...

While this language identifies options to use either biological (age) or cognitive (maturity) criteria, it fails to identify the requirement that all children have sufficient maturity. An example of maturity-aligned policy language

Framework Implementation

For jurisdictions that have and support use of mature minor language—inclusive of cognitive capacity—for the service being provided, classifying a child^{DC} as a mature minor is an option to obtain informed consent.

If however, the jurisdiction does not have or support using mature minor language, providers may consider the following:

1. If the individual is a child^{DC}, the child^{DC} must provide or withhold consent.
2. Once the child^{DC} has provided or withheld consent, discuss with the child^{DC} the need for additional supportive proxy engagement.
3. Work with the child^{DC} to identify a supportive proxy.
4. Engage the supportive proxy in the provision or withholding of consent.

While this is not an ideal option, it is best positioned to support providers in honoring ethical requirements that the child^{DC} provide or withhold consent and at the same time operate within the local legal structure.

that incorporates the concepts of this framework would be:

Consent for HIV-related services may be given by an individual of sufficient maturity to understand the benefits, risks, and social implications of such services.

Mature minor language may have inconsistent policy application. For example there may be a mature minor exemption for HIV testing, but not HIV treatment (GOSA 2005, Sect 129),

Framework Implementation

Children^{SP} provide assent/dissent, which must be combined with a supportive proxy providing or withholding informed consent. Obtaining assent/dissent is more likely to be informal.

establishing a potential policy and practice conflict between HIV testing and treatment. A "Policy Assessment Tool" is available at the end of this framework to help identify policies that are absent, contradictory, restrictive, or supportive of maturity-aligned consent.

Assent/Dissent for Children^{SP}

Children must provide their views and have their view given due weight (OHCHR, 2003). Children^{SP}, while not able to provide/withhold informed consent, have the right to a maturity-aligned role in the decisions that affect them. In all cases, it is important to involve the child^{SP} in their health and confidential HIV data decisions, commensurate to their developmental age and level of maturity (WHO and UNICEF, 2010). In the field of social work, this incremental engagement can be aligned to the concept of respecting the right to self-determination (IFSW, 2018).

The major difference between exercising decisional capacity and assent/dissent is that assent/dissent does not require the capacities of reasoning and ability to express a choice. Assent/dissent includes the following elements:

1. **Understanding.** Helping the child^{SP} achieve a developmentally appropriate awareness of the information being provided by the clinical or social service provider.
2. **Appreciation.** Helping the child^{SP} achieve a developmentally appropriate awareness of the nature of their condition. Telling the child^{SP} what they can expect (good and bad) with proposed HIV-related tests, treatment(s), and interventions, or shared confidential HIV data. Evaluating the child's^{SP} understanding of the situation and the factors influencing how they are responding (including whether there is inappropriate pressure to accept testing or therapy).
3. **Accept or reject provider/proxy reasoning and choice.** Soliciting an expression of the child's^{SP} willingness to accept or reject the proposed HIV-related test, therapy, or intervention, or sharing of confidential HIV data. The intention should be to solicit the child's^{SP} views and take them seriously. If the situation dictates that the child's^{SP} perspective will not influence the final decision of the provider and supportive proxy, that fact should be disclosed to the child^{SP}.

A child's^{SP} dissent should be taken seriously, especially when the HIV-related test, treatment, or intervention, or sharing of confidential HIV data, is not immediately essential and/or can be delayed without substantial risk. Taking time to come to terms with fears or other concerns of the child^{SP} will be of long-term benefit (Bartholome, 1995).

Identification of a Supportive Proxy

Engagement of a parent is not always possible or in the best interest of the child. Parents may be absent (e.g., migrant workers), incapacitated for other reasons (e.g., ill health), or judgmental and unsupportive of the services required for children from key, marginalized, and

vulnerable populations (WHO, 2013b; UNICEF, 2015). For cases in which children seek HIV prevention, testing, care, or treatment without parental consent, it stands that they may do so because of lack of parental involvement or fear of revealing stigmatized behaviors (Chenneville et al., 2010).

Proxies (whether a biological parent or other individual) who support children^{SP} in assenting or dissenting and make decisions to provide/withhold consent to medical or social interventions or sharing of confidential HIV data have a responsibility to act in the best interest of the child^{SP}. When observing the interactions of a proxy and child^{SP}, the following characteristics should be present:

- The proxy identifies and protects the child^{SP} from emotional, physical, sexual, or religious abuse.
- The proxy engages in respectful, two-way communication with the child^{SP}.
- The proxy fosters self-resiliency in the child^{SP}.
- The proxy is non-judgmental of the child's^{SP} HIV status and risk behaviors.

Providers can also engage children^{SP} in helping to identify a supportive proxy.² Some questions that providers might ask would be:

- Who do you want to be with you when you are scared?
- Who listens to what you have to say?
- Who do you trust?
- Who takes care of you?
- Who makes you happy?

² Medical and social service providers may find themselves in a situation in which they are supporting a biological parent or relative in planning for succession guardianship of a child. In this case, providers have an opportunity to use some of these same elements of support to assist the parent or relative in assessing and identifying a supportive proxy.

Framework Implementation

Once decisional capacity has been documented for a child^{DC} or a supportive proxy, providers should follow program or country policies for informed consent.

If a supportive proxy is not available, the health or social service provider can provide/withhold informed consent for the child^{SP}, provided they are acting in the child's^{SP} best interest (WHO and UNICEF, 2010).

Informed Consent

Informed consent, in varying degrees of formality, is required and may be withdrawn at any time. Consent requirements are standard for medical interventions and sharing of confidential HIV data. In addition, lessons learned from behavioral and social interventions with marginalized populations have highlighted the need for engaging participants in decisions as to whether or not they want to participate in social interventions (CHALN, 2007).

While details of the requirements for informed consent may vary, they should at least assure that the child^{DC} or supportive proxy understand:

1. The social or health condition
2. The nature and purpose as well as the risks and benefits of the proposed and alternative medical or social intervention or sharing of confidential HIV data
3. Risks and benefits related to the legal and social environment
4. That consent is voluntary and may be withdrawn at any time (Ho et al., 2005)

For children^{SP}, informed consent should be provided by a supportive proxy. In circumstances where a supportive proxy is unavailable or refuses to provide consent for a child^{SP} and life-saving treatment is available, a health or social service provider can provide consent and initiate testing, interventions, or sharing of confidential HIV data if it is in the best interest of the child^{SP} (WHO and UNICEF, 2010).

Confidentiality

The requirement to obtain informed consent for the release or sharing of confidential HIV data is a critical component of the right to confidentiality. Children^{DC} and children^{SP} and their supportive proxies must be informed of their right to confidentiality and engaged in planning how, when, and to whom confidential HIV data should be disclosed (WHO, 2015). Protection of confidentiality has a direct relationship to increasing access to services and improving health outcomes as a risk of sharing of confidential HIV data without consent drives key, marginalized, and vulnerable populations, including adolescents, away from services and discourages retention in care, including in detention settings (WHO, 2013b; NCCHC, 2015).

Sharing of confidential HIV data must be addressed in the following contexts:

- **Among the healthcare provider team.** Shared confidentiality within a healthcare setting and among healthcare providers facilitates provision of quality care. However, confidentiality prohibits sharing of information outside of this team without the consent of the child^{DC} or the supportive proxy of a child^{SP} (WHO and UNICEF, 2010).

In keeping with the overarching framework purpose of engaging

individuals in decisions regarding sharing of their confidential HIV data, the purpose and scope of “shared confidentiality” in a healthcare setting should be discussed with the child^{DC} or child^{SP} and their supportive proxy to obtain agreement as to (1) the benefits of a healthcare team knowing this information, (2) the confidentiality protections and procedures that prohibit sharing beyond this team, and (3) any strategies to address any risks that might be present (e.g., friends/family working in the clinic) (WHO, 2015).

- **Among community networks and services.** It is clear that holistic clinic- and community-based services and support are required for positive health outcomes. However, the role of providers is to identify and refer to resources. Only with specific permission of the child^{DC} or supportive proxy of a child^{SP} can providers directly engage or share information with external individuals or services (WHO, 2015 and 2014). Providers in community, education, and detention settings fall under the same requirements as in healthcare settings to respect the rights to privacy and confidentiality of the child. These rights limit sharing of confidential HIV data outside of the direct “care” team (RELAF and UNICEF, 2011; UN, 1985; WHO, 2003 and 2013b; IFSW, 2012).
- **With parents.** Consent to share confidential HIV data with parents must be obtained from the child^{DC} or supportive proxy of a child^{SP} (Ho et al., 2005).

Grievance Processes

The United Nations Convention on the Rights of the Child identifies the need for

complaint and redress systems, with special attention to the right to privacy (OHCHR, 2003). Jurisdictions should have policies and practices that support transparent complaint and redress systems for the improper collection, use, and sharing of confidential HIV data (UNAIDS, 2014).

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CHILDREN'S CONSENT PRACTICE SUPPORT TOOLS

Assessing Capacity of Adolescents to Consent for HIV-Related Services: Interview Guide for Use by Health and Social Service Providers

Purpose: This interview guide includes a series of questions to help the provider determine the capacity of a child or their caregiver to give/withhold consent for an intervention. It does not replace the need for holistic treatment literacy and understanding of medical procedures. It has been adapted from several sources.³

In these tools [intervention] includes any health or social service (e.g., diagnostic test, medication, support group, or counseling), or sharing of confidential health information.

Instructions: Always begin every interaction by greeting the child and making sure they are comfortable. Discuss the circumstances, need for the intervention, and proposed health or social service or sharing of the child's confidential HIV data.

1. Ask the questions in the "**Assessment of Child Capacity**" interview guide.

If you CAN answer yes to all of the items in the "Assessment of Child Capacity" interview guide then the child has capacity to consent. Follow organizational practices for the child to provide/withhold consent.

If the child is younger than the legal age of consent and there is not policy language allowing mature minors to consent, continue onto 2.

If you CANNOT answer yes to all of the items in the "Assessment of Child Capacity" interview guide then the child does not have capacity to consent. Continue onto 2.

2. Continue with "Identification of Caregiver" interview guide to identify who can provide/withhold informed consent for the child. Then continue onto 3.
3. Continue with "Assessment of Caregiver Capacity" interview guide. Repeat 2 and 3 until a caregiver is identified. Then continue onto 4.
4. Follow organizational procedures for seeking assent/dissent from the child and procedures for the caregiver to provide/withhold consent for the child.

If at any point, you suspect substance use or mental health issues, follow your organizational protocols for assessing and addressing these issues.

³ These tools have been adapted from the following:

Fraser Guidelines/Gillick Competency Checklist. 2010. Available at: [http://schoolnurse.org.nz/Attachments/pdf_files/bestpractice/Best_Practice_Fraser_Competency_Checklist_\(5\)37-91600.pdf](http://schoolnurse.org.nz/Attachments/pdf_files/bestpractice/Best_Practice_Fraser_Competency_Checklist_(5)37-91600.pdf).

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Assessment of Child Capacity to Provide/Withhold Informed Consent

Child Name: _____ Intervention: _____

As much as possible, include the following questions in a dialogue format rather than a question and answer format.

1. Assess understanding: child grasps the fundamental information provided

Conversation topic

- 1.1 Tell me in your own words why you are here today.
- 1.2 What do you remember about the [intervention] that I discussed with you?
(probe for benefits and risks)
- 1.3 What would be the benefits and risks to not doing the [intervention]?

Guidance: Simple paraphrasing of information provided is all that is expected—no analysis or critical thinking is required.

Notes:

Can the child repeat back the advice/information they have been given? Yes No

2. Assess appreciation: capacity to acknowledge impact of intervention options

Conversation topic

- 2.1 Tell me how the [intervention] is going to help you.
- 2.2 What do you think would happen if you decide not to do the [intervention]?

Guidance: Watch for delusions or high levels of distortion or denial.

Notes:

Can the child realistically comprehend and repeat information on the consequences of having or not having the [intervention]? Yes No

3. Assess ability to express a choice: capacity to clearly indicate a preferred option

Conversation topic

- 3.1 Have you decided to accept or reject the recommendation for the [intervention] that I've made?
- 3.2 Can you tell me what your decision is?
- 3.3 [If no decision] What is making it hard for you to decide?

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Guidance: Look for a stable, consistent decision—frequent reversals of choice may indicate lack of capacity.

Notes:

Can the child communicate their decision consistently? Yes No

4. Assess reasoning: capacity to assess decision

Conversation topic

4.1 What makes your choice better than any of the alternatives?

Guidance: Look for reasoning skills. Don't evaluate choice. Just because someone makes a choice you don't agree with doesn't mean they don't have decisional capacity. For decisions that are life threatening, refer to a counselor to explore further rationale for decision.

Notes:

Can the child communicate their reasons for their decision? Yes No

5. Provider questions: to be answered by provider

5.1 Is the level of child capacity identified aligned with the seriousness of the intervention under discussion? Yes No

5.2 Are you confident that you are acting in the best interest of the child? Yes No

5.3 Are you confident that your personal religious or cultural values, or your professional/organizational goals, are NOT influencing your engagement with this child? Yes No

If all answers are "Yes," the child has been assessed to have capacity to provide/withhold informed consent, following organizational practices for the child to provide/withhold consent.

Date: _____ Provider Name/Signature: _____

Facility Name: _____

Provider Title: _____

If the child is younger than the legal age of consent and there is not policy language allowing mature minors to consent, or if there are "No" answers, continue onto "Identification of Caregiver" interview guide (next page).

Identification of Caregiver to Provide/Withhold Informed Consent

Child Name: _____ Intervention: _____

Date: _____

As much as possible, include the following questions in a dialogue format rather than a question and answer format.

1. Gain agreement to engage another individual

Conversation topic

1.1 I'd like to bring someone else in to talk about the [intervention] and help us think about our options.

Guidance: If the child assessment has indicated that the child does not have the capacity to provide/withhold informed consent, get agreement from the child to engage someone else in this discussion.

Notes:

Child agrees to engage another individual to provide/withhold informed consent?

Yes No

2. Child identifies someone to support them in making decisions

Conversation topic

2.1 Did you come with someone else? If so:

- Do you trust this person?
- Do they listen to you?
- Do they support the decisions you make?

2.2 If any part of 2.1 is NO, is there someone else that you would feel comfortable asking to be here with us? Someone:

- Who you trust?
- Who takes care of you?
- Who listens to you?
- Who makes you happy?
- Who supports decisions you make?

Guidance: Have the child assist in identifying an individual to engage in discussions about the intervention. If the law requires a legal or biological family member to provide consent, work with the child to identify the person who best meets physical and emotional safety needs and legal requirements.

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Notes:

Have you done everything possible to persuade the young person to involve their caregiver(s)? Yes No

Did the child identify a caregiver to involve? Yes No

3. Provider provides/withholds informed consent

Conversation topic

3.1 If any part of 2 above is NO, then I would be happy to help you think about your options and make some decisions about what will be best for you.

Guidance: Only engage as a "caregiver" if the law allows providers to provide informed consent.

Notes:

Have you documented clearly why the young person does not want you to inform their caregiver(s)? Yes No

4. Provider questions: to be answered by provider

4.1 Are you confident that you are acting in the best interest of the child? Yes No

4.2 Are you confident that your personal religious or cultural values, or your professional/organizational goals, are NOT influencing your engagement with this child? Yes No

The individual identified to support the child in making decisions about the [intervention] is:

Name of Caregiver: _____

Date: _____

Provider Name/Signature: _____

Provider Title: _____

Facility Name: _____

Continue with "Assessment of Caregiver Capacity" interview guide (next page).

Assessment of Caregiver Capacity to Provide/Withhold Informed Consent for a Child

Child Name: _____ Intervention: _____

Date: _____ Caregiver Name: _____

As much as possible, include the following questions in a dialogue format rather than a question and answer format.

1. Assess understanding: caregiver grasps the fundamental information provided about the [intervention]

Conversation topic

- 1.1 Tell me in your own words why the child is here today.
- 1.2 What do you remember about the [intervention] for the child that I discussed with you? (probe for benefits and risks)
- 1.3 What would be the benefits and risks for the child to not do the [intervention]?

Guidance: Simple paraphrasing of information provided is all that is expected; no analysis or critical thinking is required.

Notes:

Can the caregiver repeat back the advice/information they have been given?

Yes No

2. Assess appreciation: capacity to acknowledge impact of intervention options

Conversation topic

- 2.1 Tell me how the [intervention] is going to help the child.
- 2.2 What do you think would happen to the child if you decide not to do the [intervention]?

Guidance: Watch for delusions or high levels of distortion or denial.

Notes:

Can the caregiver realistically comprehend and repeat information on the consequences for the child of having or not having the [intervention]?

Yes No

3. Assess ability to express a choice: capacity to clearly indicate a preferred option

Conversation topic

- 3.1 Have you decided to accept or reject the recommendation for the child for the [intervention] that I've made?
- 3.2 Can you tell me what your decision is?

CHILDREN'S CONSENT PRACTICE SUPPORT TOOLS

3.3 [If no decision] What is making it hard for you to decide?

Guidance: Look for a stable, consistent decision—frequent reversals of choice may indicate lack of capacity.

Notes:

Can the caregiver communicate their decision consistently? Yes No

4. Assess reasoning: capacity to assess decision

Conversation topic

4.1 What makes your choice better than any of the alternatives?

Guidance: Look for reasoning skills. Don't evaluate choice. Just because someone makes a choice you don't agree with doesn't mean they don't have decisional capacity. For decisions that are life threatening, refer to a counselor to explore further rationale for decision.

Notes:

Can the caregiver communicate their reasons for their decision? Yes No

5. Provider questions: to be answered by provider

5.1 Is the level of caregiver capacity identified aligned with the seriousness of the intervention under discussion? Yes No

5.2 Are you confident that you are acting in the best interest of the child? Yes No

5.3 Are you confident that your personal religious or cultural values, or your professional/organizational goals, are NOT influencing your engagement with this child and their caregiver? Yes No

If all answers are "Yes," the caregiver has been assessed to have capacity to provide/withhold informed consent. If there are "No" answers, another caregiver should be identified to provide/withhold informed consent.

Once a caregiver with capacity has been identified, proceed with organizational procedures for seeking assent/dissent from the child and procedures for the caregiver to provide/withhold consent for the child.

Provider Name/Signature: _____

Date: _____

Provider Title: _____

Facility Name: _____

POLICY ASSESSMENT TOOL

Policies, guidelines, and protocols form the foundation for effective engagement of children in decisions regarding their health and data. When conducting a policy assessment, the following considerations may be helpful to identify policies that are absent, contradictory, restrictive, or supportive of maturity-aligned consent. During the assessment, consider data privacy acts; policies from health, social welfare, and education sectors; service-specific policies; and youth policies.

1. Policy language clearly identifies who has authority to provide or withhold consent for a child, and to what extent.
2. Policy language gives informal caretakers ability to consent or refuse services or the release of confidential HIV data on behalf of a child.
3. Policy language gives healthcare providers ability to consent or refuse services or the release of personal HIV data on behalf of a child.
4. Policy language only requires provision or withholding of consent on behalf of a child from one parent or guardian.
5. Policy language allows for provision or withholding of consent on behalf of a child from either maternal or paternal parent.
6. Policy language identifies grievance, complaint, and redress systems for breaches of consent.
7. Policy language identifies grievance, complaint, and redress systems for breaches of confidentiality.
8. Policy language identifies any data on diagnosis and participation in HIV-related medical and social services as protected personal HIV data.
9. Policy language identifies circumstances (such as pregnancy, marriage, and presence of sexually transmitted infections) that authorize minors to provide or withhold consent to HIV prevention, testing, care, and treatment.
10. Policy language includes recognition of cognitive maturity of minors to consent to HIV prevention, testing, care, and treatment. If mature minor language exists, assess use and support (through review of legal cases and in-country interviews).
11. Consent requirements are applicable to HIV prevention, testing, care, and treatment and sharing of personal HIV data.
12. Policy requires seeking maturity-appropriate assent from children for medical and social services and release of personal HIV data.
13. Document punitive laws that will inform decisions on seeking HIV-related prevention, testing, treatment, and care services and sharing of personal HIV data, such as:
 - a. Criminalization of transmission
 - b. Criminalized behaviors, including same-sex relations, injecting drug use, and involvement in commercial sex work
 - c. Discriminatory statutes
 - d. Restricted services
 - e. Mandatory disclosure to law enforcement or parents
14. Document supportive laws that will inform decisions on seeking HIV-related prevention, testing, treatment, and care services and sharing of personal HIV data, such as:
 - a. Non-discrimination laws
 - b. Human rights protections (including protections from harmful cultural practices)
 - c. Complaint and redress laws (such as those to address discrimination, release of confidential HIV data, etc.)
 - d. Service eligibility

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