

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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Introduction

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- + Health Policy Plus (HP+)
 - Five years (2015-2020)
 - USAID/PEPFAR-funded
- + Framework activity
 - HOP16 funded with support from OVC and HIV

Technical Expert Committee

Amy Bess	Workforce Alliance
Brenda Yamba	USAID
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Denis Tindyebwa	Children Affected by HIV/AIDS
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Sara Bowsky	Health Policy Plus
Seung Lee	Save the Children
Shaffiq Essanjee	UNICEF
Stefan Baral	Johns Hopkins Bloomberg School of Public Health
Tara Reichenbach	USAID

Context



Definitions

- + **Child/children** aligns with the WHO standard of someone below the age of 18. In the case of this framework, most likely children between the ages of 10 and 18.
- + **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 with decisional capacity, health care/social service provider, informal caregiver, or other supportive adult.



Consent and Confidentiality Framework Background

+ Goals for:

- Providers – to increase quality of care and decrease legal risk
- Children – to improve access to and retention in HIV services

+ Implementation of consent

- Lack of training, tools, and staffing
- Cultural, social, and moral complexities related to children
- Compounded needs related to HIV during childhood and adolescence
- Stigma related to children and the behaviors that put them at risk for HIV
- Lack of clarity and conflicting laws
- Inconsistent guidelines and practices

Consent and Confidentiality Framework

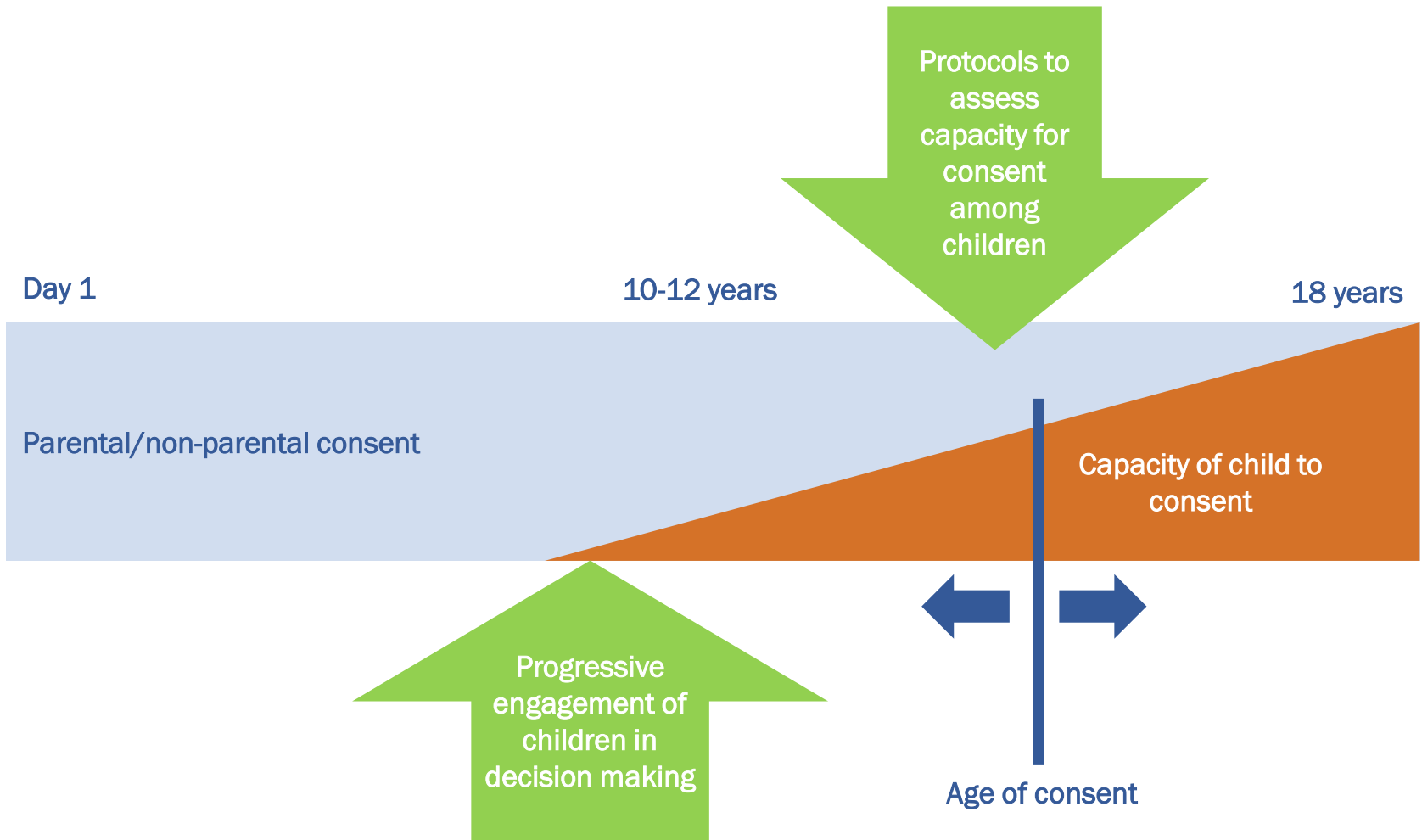
- ✦ Purpose – to provide best practice policy and provider tools
 - Consistent, harmonized, and maturity-aligned engagement of children in making informed decisions
 - Health, social welfare, and education sectors
 - Integration into existing policy frameworks or policy advocacy efforts
- ✦ HIV lens (social and medical services and management of confidential information)
 - Stigma and discrimination
 - Risk of onward transmission
 - Growing up with a chronic disease from childhood and adolescence through adulthood
- ✦ Concepts applicable to broader issues

What the Framework is NOT

- ✦ Framework DOES NOT address consent and disclosure issues for:
 - Suspected or documented emotional, physical, or sexual abuse
 - Underage sexual activity
 - Unconsented or coerced use of HIV self-testing technologies
 - Child abuse and neglect due to withholding of medical or social services
 - Required reporting of infectious diseases
 - Research
 - Exposure risk and treatment for providers in occupational settings
 - Emergency diagnosis and medical care or social support
- ✦ 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.



Fundamental Concepts

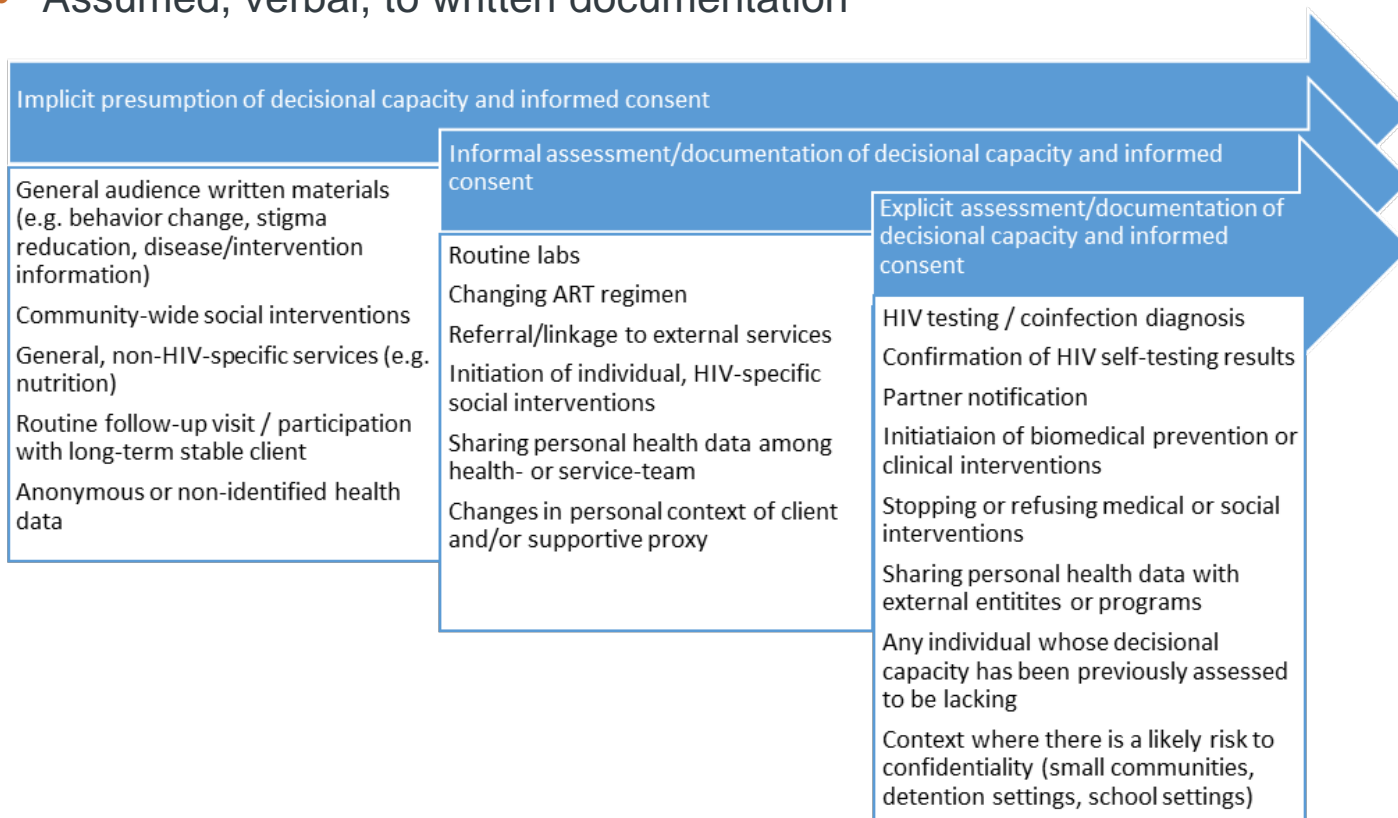


Fundamental Concepts

- ✦ Balance protection and autonomy
- ✦ Based on international human rights of children
 - Best interest of the child is paramount
 - Right to highest attainable standard of health
 - Engagement in decisions
- ✦ Address the needs of the most vulnerable
- ✦ Consent/assent is required in all circumstances
 - Behavioral interventions
 - Biomedical prevention
 - HIV testing, including provider-initiated
 - ART
 - Care and support services
 - Sharing of confidential information, etc.

Incremental Implementation

- ✦ Core values of consent are non-negotiable
- ✦ Formality of implementation is aligned with risk
 - Implicit to explicit
 - Assumed, verbal, to written documentation





Children's Consent

Consent/Assent Required for All Interventions by Either Child or Child+Proxy

Decisional Capacity	Consent	Assent
Understanding of information	X	X
Appreciation of impact	X	X
Ability to express a choice	X	X
Ability to give reasons for a choice	X	

- + Decisional capacity is task specific, situational, and variable
 - Assessment becomes an intrinsic part of every provider-client/patient interaction
- + Supportive proxies identified to support children who do not have decisional capacity
 - Can be parents, caregivers, providers, etc.
 - Supportive proxies must have decisional capacity and must act in the best interest of the child

Age of Consent and Mature Minor Clauses

- ✦ Framework moves beyond age of consent discussion
 - Children who are under the age of consent may have decisional capacity
 - Children who are over the age of consent may not
- ✦ Mature minor clauses are critical for implementation of maturity-aligned engagement of children
 - Must move beyond situational qualifiers as these have no bearing on decisional capacity
 - Marriage
 - Pregnancy
 - Sexually active
 - At-risk
- ✦ For example: Consent for an HIV-test of a child may be given by:
 - (a) The child, if the child is of sufficient maturity to understand the benefits, risks and social implications of such a test

Practice Tools

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

Kenya Policy Assessment

+ Policy assessment in Kenya

- Strong underlying policy framework for rights of children
- Patchwork of inconsistent, conflicting, and often absent policy
- Particular weakness in education sector

HP+

HEALTH POLICY PLUS

Better Policy for Better Health



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