Supporting disclosure among children and adolescents living with HIV: interventions, emerging considerations, key gaps and key actions

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The document was guided or reviewed by a steering group of WHO staff and consultants: Charles Aristide Billy (WHO Regional Office for Africa), Agnes Chetty (WHO Regional Office for Africa), Lastone Chitembo (WHO Zambia), Magdalena Barr-Dichiara (Global HIV, Hepatitis and Sexually Transmitted Infections Programmes), Frank Lule (WHO Ghana), Ivy Kasirye (Global HIV, Hepatitis and Sexually Transmitted Infections Programmes), Antons Mozalevskis (Global HIV, Hepatitis and Sexually Transmitted Infections Programmes), Busisiwe Msimanga (Global HIV, Hepatitis and Sexually Transmitted Infections Programmes), Clarice Pinto (Global HIV, Hepatitis and Sexually Transmitted Infections Programmes), Ajay Rangaraj (Global HIV, Hepatitis and Sexually Transmitted Infections Programmes), Erica Spielman (Consultant, Global HIV, Hepatitis and Sexually Transmitted Infections Programmes), Nandita Sugandhi (Global HIV, Hepatitis and Sexually Transmitted Infections Programmes), Aliza Monroe-Wise (Consultant, Global HIV, Hepatitis and Sexually Transmitted Infections Programmes).

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Abbreviations

ART	Antiretroviral therapy
CHW	Community health worker
CMO	Context-mechanism-outcome
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
HIV	Human immunodeficiency virus
MDT	Multi-disciplinary teams
PEPFAR	President's Emergency Plan for AIDS Relief
PHRU	Perinatal Health Research Unit (University of Witwatersrand)
RCP	Red Carpet Program
RTC	Right to Care
USAID	United States Agency for International Development
U=U	Undetectable = Untransmittable
VIP	Very important person
WHO	World Health Organization

Glossary of terms

Disclosure: refers to being told one's HIV status or sharing one's status with others. (See Onwards disclosure below).

Disclosure-specific interventions: developed for this brief, this refers to interventions designed specifically to promote and facilitate HIV disclosure to and/or by children and adolescents living with HIV.

Disclosure-inclusive interventions: developed for this brief, this refers to interventions that are broader in nature and include disclosure as one of several focal areas.

Network-based testing: comprise a range of service delivery modalities that broaden the reach of testing services by supporting individuals to disclose to, to refer for, and/or distribute self-tests to partners, families, and other members of their social networks.

Onwards disclosure: refers to disclosure by children and adolescents of their own status to peers, family members, or partners. (See Disclosure above).

Psychosocial interventions: use a psychological, behavioral or social approach, or a combination, to achieve key outcomes.

Children await vaccination during a national polio campaign in Mogadishu, Somalia, 2022 © WHO / Ismail Taxta

Executive summary

Despite progress in achieving key milestones in care and coverage for thousands of children and adolescents living with HIV aged 6–19 years, HIV status disclosure is a continuing challenge for this age group. Being aware of one's own HIV status, as well as being able to share this status with others safely and when ready, is key to closing gaps in prevention and care and enhancing treatment outcomes. Disclosure interventions developed for adults may fail to address some of the developmental and context-specific concerns for children, adolescents, and families. To address these gaps, an up-to-date understanding of the evidence on disclosure interventions for this age group is necessary. This technical brief provides evidence on existing interventions that support children and adolescents living with HIV in the process of disclosure—including interventions that focus on disclosing children's and adolescents' HIV statuses to them, as well as supporting onwards disclosure.

The first part of this document includes findings from a scoping review that identified 25 interventions focused on supporting HIV status disclosure to, and by, children and adolescents living with HIV aged 6-19. Resulting from this were disclosure-specific and disclosure-inclusive interventions. Disclosure-specific interventions were closely analyzed using realist methods to understand key themes highlighting the factors that shape how these work in practice. The common building blocks of these interventions included recognition of autonomy and dignity; strategies and tools to enhance engagement; and components linked to health and broader environments. Overall, these aspects led to improvements in confidence, acceptance, communication, and knowledge, with necessary support to make eventual decisions about disclosure. Disclosure-inclusive interventions were more diverse in nature and were summarized narratively. Commonalities included intergenerational approaches, peer support approaches, and health system strengthening.

From these studies, a set of emerging considerations, key gaps, and key actions were collated, including a focus on adolescent development and the evolving capacity for autonomous decision-making; addressing layered stigma and adopting rights-based approaches; measurement, monitoring, and evaluation; building support systems across families and communities; and the need for innovative approaches in an evolving epidemic. For health workers, policy makers, and other practitioners and researchers working with HIV-affected populations, this technical brief provides an overview of evidence integrated with rights-based approaches that prioritize the role of the child and adolescent wellbeing in the process of disclosure.

Background

As the global fight against HIV/AIDS continues, progress in advancing the 95-95-95 goals has been tremendous. In 2023, of the estimated 39.9 million people living with HIV globally, approximately 30.7 million were receiving antiretroviral therapy, and new infections continue to drop *(1)*. Nonetheless, significant regional and population differences remain. Children and adolescents in particular, experience persistent challenges to HIV testing, linkage to care, and retention *(2)*. One critical gap for children and adolescents aged 6–19 is disclosure of HIV status *(3)*. Disclosure refers to the process of being told one's HIV status (disclosure to children and adolescents previously unaware of their status) as well as the process of disclosing one's own HIV status to others (disclosure by children and adolescents of their own status to peers, family members, or partners; referred to in this brief as onwards disclosure). Being aware of one's own HIV status, as well as being able to share this with others safely and when ready, is key to closing gaps in prevention and care and enhancing treatment outcomes *(4)*. Disclosing HIV status to children and adolescents is the critical first step to building health literacy and empowering them to be engaged in—and increasingly lead—decision-making about their health *(5)*. This capability is essential to lifelong health.

Disclosure to, and by children and adolescents living with HIV, aligns with standards set out by international human rights, extending its significance beyond being a health issue. It is deeply connected to respect for rights like dignity, privacy, autonomy, and access to information. Article 17 of the United Nations Convention of the Rights of the Child (CRC) states that every child should have "access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health" *(6)*. Linked to this principle, Article 5 of the CRC addresses the evolving capacities of children as an enabling principle; it recognizes children's status as rights-holders, and states that when children reach a certain level of maturity and capacity, they should be allowed to exercise their rights independently from their parents. HIV disclosure to children at different ages could gradually influence health decisions taken on their behalf by parents and caregivers, which has a far-reaching and transformative impact on how children are viewed, enabled and empowered within families, schools, communities and society generally. At the same time, children and adolescents living with HIV tend to experience increased disadvantage and intersectional stigma because of their young age and HIV status *(7)*. They may also be compounded by other social stigma, such as being poor, an orphan, a child of someone living with HIV, or perceived as someone who engages in risky behavior; they may also be amplified by self-stigma.

Effective disclosure support needs to be attuned to children's and adolescents' evolving capacity for decision-making about their own health, their individual circumstances, their social support networks, and potential risks that follow disclosure *(8)*. These support mechanisms should be provided universally including and especially at the most basic levels of the health systems – primary care - and adhere to the principles of universal health coverage of accessibility, patient-centeredness, choice and empowerment, quality, collaboration, and sustainability.

This support is key for the individuals responsible for sharing a child's status with them, as well as for the child or adolescent receiving the information. Disclosure needs to be recognized as a fluid, iterative, and ongoing process requiring continual adaptation *(9)* meaning that post-disclosure support can be just as critical as initial support to prepare for disclosure. These complex considerations make it very difficult to approach the topic of HIV status disclosure. They also explain why barriers to HIV status disclosure persist, especially for children and adolescents.

Caregivers of children and adolescents living with HIV may worry about psychosocial consequences, enacted stigma, and self-stigma that comes with disclosing a child's HIV status to them *(4)*. These worries may include their relationship with their child and involuntary disclosure of their own HIV status to others *(10)*. Caregivers often face uncertainty about how to approach difficult topics with their children in age-appropriate ways, especially as they mature through

In the wake of Cyclone Chido, Zinha waits for medical help with her baby in a WHO tent, Mozambique, 2024 © WHO / Tiago Zenero

childhood and adolescence. Healthcare providers may lack the skills and time to address disclosure with the required sensitivity and care. As such, delayed disclosure is an ongoing challenge. Reluctance from caregivers, healthcare providers, or both, prolong the process and further disadvantage children who may be ready to take on more responsibility *(11)*.

Children and adolescents, in disclosing their HIV status to others, frequently experience multiple types of stigma—internalized, anticipated, and enacted—and may lack skills or the confidence to effectively communicate such a sensitive topic *(12)*. These challenges may be made worse by discriminatory attitudes towards youth or other identities. As adolescents become older, friends and peers become increasingly central in their lives and they may be concerned about the consequences of onwards disclosure. They may fear experiencing unintended or unsafe disclosure to others, or disrupting relationships with family and romantic/sexual partners *(13)*. Stigma at school and in other community spaces can be particularly damaging, shaping adolescents' decisions to disclose. Personal physical safety and the threat of intimate partner violence may also be of significant concern, especially for adolescent girls and young women but also for gender and sexual minorities and adolescents who inject or use drugs *(14)*.

Because of the social complexities surrounding HIV, disclosure is often accompanied by others. As a mother discloses her child's HIV status to them, her own status may also be disclosed. An adolescent sharing their status with a partner or caregiver may also lead to disclosure of sexual assault, child sexual abuse, or declaration of gender identity. Importantly, because disclosure is a fluid process occurring differently over time with diverse individuals, prior experiences—positive or negative—shape future willingness and intentions to disclose *(15, 16)*. Disclosure as a process carries immense social significance. Ethical considerations surrounding disclosure of one's own status—deciding who to disclose to, when, in what circumstances—is often complicated further by harmful criminalization laws that make HIV non-disclosure a crime, mandate provider notification, and create barriers to privacy, safety, and care access *(17)*. Coercion linked to disclosure is unacceptable; yet these laws may be a central in the decision to disclose.

These barriers pose significant challenges to effective coverage of HIV testing, care, and treatment, as well as effective prevention efforts for partners and children of adolescents living with HIV. These issues show the extent to which disclosure, and HIV more broadly, continues to be shaped by clinical, psychological, social, ethical, cultural, and legal factors.

Rationale

Despite emerging resources that provide specific guidance on supporting disclosure for children and adolescents *(16)*, there is limited evidence on the effectiveness of approaches to support HIV status disclosure to, and by, children and adolescents. The most recent WHO guidelines for disclosure to children up to age 12 were developed in 2011 *(18)*, reproduced in **Box 1**. While several global toolkits and guidance for adolescents have been produced to support disclosure, the WHO has not formulated any adolescent-specific disclosure guidelines to date. Adolescents are still a priority population in the HIV epidemic, especially adolescent girls and young women and young key populations *(1)*. The same power imbalances, and social and gender inequities, that complicate HIV prevention in these groups also create barriers when it comes to accessing care, initiating ART, and navigating disclosure. The various "directions" of disclosure within programming means that evidence across programs including caregiver-to-child disclosure, child-to-child or adolescent-to-adolescent disclosure, and adolescent-to-caregiver disclosure, also varies. As the HIV epidemic evolves, and new testing, care and treatment options are made available, a synthesis of existing evidence to support future guidelines in this area is much needed.

Box 1: 2011 guidelines on child disclosure (reproduced) *(18)*

1. Children of school age* should be told their HIV positive^ status; younger children should be told their status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure (Strong recommendation, low quality of evidence).
2. Children of school age should be told the HIV status of their parents or caregivers; younger children should be told this incrementally to accommodate their cognitive skills and emotional maturity (Conditional recommendation, low quality of evidence).
3. The decision on who will disclose to the child should be guided by the intent to improve/promote the child's welfare and minimize the risk to his or her wellbeing and to the quality of the relationship between child and parent/caregiver (Conditional recommendation, absent evidence).
4. Initiatives should be put in place to enforce privacy protection and institute policy, laws, and norms that prevent discrimination and promote tolerance and acceptance of people living with HIV. This can help create environments where disclosure of HIV status is easier (Strong recommendation, low quality of evidence).

*School-age children are defined as those with the cognitive skills and emotional maturity of a normally developing child of 6-12 years

^These guidelines are reproduced verbatim from the 2011 guidelines. Current guidance recommends person-centered language, which would include "living with HIV" in place of "HIV positive."

Source: World Health Organization. Guideline on HIV disclosure counselling for children up to 12 years of age: World Health Organization; 2011.

Objectives

This technical brief provides evidence on existing interventions that support children and adolescents living with HIV in the process of disclosure. It is purposefully broad and includes interventions that focus on disclosing children's and adolescents' status, as well as supporting them with onwards disclosure. Specifically, this brief collates existing interventions via a scoping review; assesses key interventions through a realist evaluation lens, identifying what works, for whom, and in what contexts; and highlights emerging considerations, key gaps, and key actions. This brief builds on the 2011 WHO guidelines on child disclosure *(18)*. It also incorporates more recent insights from the WHO's 2021 toolkit, "Assessing and supporting adolescents' capacity for autonomous decision-making in health-care settings," designed to help health workers assess adolescent capacity and support them to make autonomous decisions about their care *(5)*. Because of the diverse ages and stages across which disclosure takes place, as well as the complex family dynamics that can accompany disclosure, a flexible approach to understanding best practices is needed.

Target audience

This document was developed primarily for use by health workers, including lay and peer health workers, program implementers, community-based organizational representatives, researchers, and policymakers working in areas including health, education, financing, and youth and public engagement.

Development of this document

This document was developed in multiple stages, reflected across two core parts described in this section.

- **Part 1:** Includes a **scoping review** to identify interventions focused on supporting HIV status disclosure to, and by, children and adolescents living with HIV. This review gathered and analyzed evidence on existing interventions to understand how these interventions work in practice. This resulted in a series of themes that describe core principles and offer mechanisms for how they work.
- **Part 2:** Includes a set of five **emerging considerations**, drawn from studies in this review and organized by thematic area. Each consideration is accompanied by a brief background, a set of key gaps, and a series of key actions. Where relevant, case examples are used to illustrate.

The scoping review methodology, which provides a detailed overview, can be found in **Annex 1**. A completed PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist is available as an internal supplemental file on request. **Box 2** shares a set of key principles central to this work.

Box 2: Key principles essential for optimal disclosure

- **People-centered care:** This concept focuses on integrated, responsive health services and care that prioritizes the holistic needs of individuals, families, and communities. For decision-making around disclosure to the child specifically, this approach includes a broader focus on family systems.
- **Informed consent:** A core ethical principle in research and health service provision, consent is the ability of a competent person to make an informed decision to participate in a program, interpersonal engagement, procedure, or research study. This also includes permission to gather and store data.
- **Respect for privacy:** This provision governs individuals' ability to control how and when their personal information is shared and protects them from their personal information being shared without consent.
- **Respect for autonomy:** Linked with consent, individuals' ability to make decisions about their own health is a cornerstone of disclosure programming. This includes decisions about timing, audience, and format of disclosure, as well as the decision not to disclose.
- **Doing no harm:** As disclosure is context-specific, resource-dependent, and situated within family environments, it is critical to consider potential risks and unintended consequences that can come from disclosure and ensure approaches do no harm.
- **The child's best interest:** In considering a child's wellbeing as the primary consideration for all actions that affect them, this principle accounts for the child's wishes, their relationships with caregivers and other family, their physical and mental wellbeing, and their protection from harm. It is a cornerstone of disclosure.
- **Mental health and wellbeing:** Across disclosure interventions, emphasizing the mental health and wellbeing of children, adolescents, and families affected by HIV emerges as a foundational requirement.

Part 1

Scoping review highlighting key disclosure interventions

Included interventions

In total, 25 interventions were identified. Eligible interventions were grouped into two categories, based on the types of emerging interventions: 1) ***disclosure-specific*** interventions, and 2) ***disclosure-inclusive*** interventions (see **Figure 1**). These two types of interventions were examined differently, based on their diverse profiles. As ***disclosure-specific*** interventions focused on disclosure as a common outcome or target, a realist analytic lens was applied to analyze these interventions (see Section 1.1).

Realist approaches can help us to better understand what works, for whom, and under which circumstances. Realist evaluation methods are increasingly being used to assess and refine interventions, including those focused on adolescent HIV outcomes *(19)*. Realist methods can help provide a structure that helps to explain and understand interventions as they are delivered in "real-world" settings by looking at the context and the people involved. These approaches also try to draw out mechanisms that explain how different "ingredients" can lead to intended outcomes *(20)*. Rich descriptions were generated for each intervention. In some cases, multiple publications or evidence types were triangulated to build a better picture of how the intervention was ultimately implemented and evaluated. For each of these interventions, using these rich descriptions, a series of context-mechanism-outcome (CMO) statements was generated. These statements pulled from available

Figure 1: Intervention categories for this brief

Disclosure-specific interventions	• Designed specifically for the purpose of promoting and facilitating HIV disclosure to and/or by children and adolescents living with HIV • Often include multiple components, and targeted at caregiver-to-child disclosure support • Examples include facility-linked caregiver support, healthcare worker training, patient centered materials, and health system quality improvement
Disclosure-inclusive interventions	• Broader in nature, and include disclosure as one of several focal areas to support children and adolescents living with HIV and their families • More commonly targeted at adolescents living with HIV but also parents, caregivers, and healthcare workers • Examples include peer support groups, community health worker visiting, caregiver-child workshops, and integrated services for children in school or health facilities

data, author reflections on the intervention findings, and further observations and assumptions gleaned from evaluations. These CMO statements were then combined and thematically grouped to create a series of summary statements to populate a working theory of how disclosure-specific interventions work in practice, covering contextual factors (C) shaping mechanisms (M) theorized to set off specific outcomes (O).

Disclosure-inclusive interventions were examined narratively (see 1.2).

Table 2 provides details of the 25 interventions included in this brief. The sections that follow describe the types of interventions, including the contexts and mechanisms that may play a key role in driving disclosure and related outcomes.

1.1. Disclosure-specific interventions

The review identified and catalogued 11 interventions that specifically focus on promoting HIV disclosure to and/or by children and adolescents (see **Table 2**). Many of these interventions focused on facilitating disclosure of HIV status to a child or adolescent living with HIV. These interventions tended to be staged and developmentally grounded, focused on assessing readiness, preparing for disclosure, initiating the process, completing disclosure, and providing post-disclosure support—accounting for the child and/or adolescent's support system and family environment, and facilitated with the support of health workers. Several interventions included adherence and viral load outcomes in addition to completed disclosure.

Table 2: Overview of included disclosure interventions

Intervention title	Target population; directionality of disclosure	Country of implementation	Overall aim with key information	Type of supporting evidence
Disclosure-specific interventions				
Namibia Ministry of Health and Social Services pediatric HIV disclosure intervention	Health providers, caregivers, children; disclosure to child/ adolescent	Namibia	A multi-component intervention to support disclosure to 7–14-year-olds living with HIV in healthcare facilities, including a 5-chapter child-friendly book with colorful cartoon drawings designed to guide health providers and caregivers in a gradual disclosure process; a tool to assist health providers to assess caregiver and child readiness for full HIV disclosure and systematically work through barriers; a disclosure form to help health providers monitor children's understanding of their disease status over time; and a health provider training curriculum to support use of these tools. The average time to full disclosure was 2.5 years.	Qualitative, quantitative (trial evidence), process data
Adapted Blasini disclosure model	Health providers, caregivers, children/ adolescents; disclosure to child/ adolescent	Haiti; Dominican Republic	A multi-component adapted intervention to support disclosure for pairs of youth living with HIV ages 10–18 and their caregivers, including a multimedia training/support session for healthcare providers participating in disclosure; separate pre-disclosure intervention/ education sessions describing pediatric cancer, diabetes, and HIV (for youth) and building capacity for disclosure (for caregiver); a scheduled supportive disclosure session; and separate one-on-one post-disclosure support sessions with psychologists for caregivers and youth. Adaptation included a video as well as a colorful picture book as a disclosure support tool. No time scale was provided for average completion of disclosure.	Quantitative (quasi-experimental)

Intervention title	Target population; directionality of disclosure	Country of implementation	Overall aim with key information	Type of supporting evidence
HADITHI disclosure intervention	Disclosure counselors, caregivers, children; disclosure to child/ adolescent	Kenya	A culturally adapted, multi-component disclosure intervention for 10–14-year-olds, including patient-centered materials to guide disclosure, disclosure counselors who conduct intensive counselling (both individual and group-based), and post-disclosure child support groups to supplement usual care resources. Limited information on dosage for counselling and group support was available, however, children and caregivers were followed over 2 years as they were exposed to this package.	Quantitative (trial)
Adapted disclosure education intervention	HIV clinic nurses, caregivers, children/ adolescents; disclosure to child/ adolescent	Papua New Guinea, Botswana	An intervention to support disclosure of HIV status to children aged 3–16 years in a developmentally-appropriate, staged process, following early steps, intermediate steps, advanced steps, and continuous reinforcement. Both children and caregivers are engaged in this process through a combination of group and individualized sessions and can be part of the 'partial disclosure' or 'full disclosure' model.	Observational study, intervention description
Sankofa	Adherence and disclosure specialists, caregivers, children/ adolescents; disclosure to child/ adolescent	Ghana	A disclosure-focused intervention delivered by a specialist trained to address information, motivation, and behavioral skills of caregivers of children and adolescents living with HIV ages 7–18, tailored to their circumstances, to facilitate their engagement in the process of disclosure (ie, pre-disclosure, disclosure, and post-disclosure phases) in a manner suitable to the age and needs of the child, delivered over time. Progression through the intervention is guided by stage.	Quantitative (trial)
Family group psychotherapy	Caregivers; disclosure to child/ adolescent	Italy	A family group psychotherapy intervention, facilitated by psychologists, including 8x 2h group sessions once monthly with small groups of caregivers who have a child living with HIV (aged 4–18 years). The aim was to remove barriers that prevent disclosure and work with small groups of caregivers to discuss common problems and feelings to build competence and self-reliance in families and patients, so that parents and their children could effectively manage their own health.	Quantitative (trial)
Kalembelembe disclosure program	Health providers, peer providers, children/ adolescents; disclosure to child/ adolescent	DR Congo	A four-phase hospital-based intervention for adolescents living with HIV ages 10–19 years, facilitated by healthcare workers and peers aged 12–24 years. Phases include preliminary preparation, partial disclosure, full disclosure, post-disclosure support groups.	Observational study

Intervention title	Target population; directionality of disclosure	Country of implementation	Overall aim with key information	Type of supporting evidence
Plan-Do-Study-Act cycles	Health providers; disclosure to child/ adolescent	United States	A quality improvement intervention targeting healthcare workers in an HIV clinic team working with children ages 11 and older to prioritize disclosure and create opportunities for planning and following up on disclosure support. In this iteration, 6 cycles took place and were monitored over 20 months.	Observational study
Quality improvement collaborative	Health providers, caregivers, children/ adolescents; disclosure to child/ adolescent	Zimbabwe	A quality improvement strategy to actively document and follow-up with adolescents living with HIV (aged 10–19 years), including documentation of disclosure status, monthly caregiver support meetings and individual counselling, health worker initiated opt-out disclosure sessions, and peer support counselling pre and post disclosure. These processes were measured after 6 months.	Quantitative (pre-post)
PHRU disclosure intervention	Caregivers, children/ adolescents; disclosure to child/ adolescent	South Africa	A disclosure-focused intervention including two standardized disclosure counselling tools (the Right to Care flipster books and USAID/ PEPFAR disclosure package) and a disclosure counselling form delivered to caregivers and children aged 7–13 years. The intervention took place in 45–60-minute sessions over 78 weeks, alternating 6-weekly between disclosure counselling sessions (Week 72) and psychometric sessions (Week 78).	Qualitative (evaluation)
Story: "Peter's and Julia's Discovery: conversing about health and illness"	Caregiver, children; disclosure to child/ adolescent	Brazil	A storytelling intervention with children across a series of meetings with children living with HIV aged 7–9 years and caregivers, delivered over 7 months.	Qualitative (evaluation)
Disclosure-inclusive interventions				
Sauti ya Vijana	Adolescents; onwards disclosure	Tanzania	An intervention to support the mental health of adolescents and youth living with HIV ages 12–24 through 10 modules delivered in person in groups, by near-peer counsellors in health facilities. SYV is based on principles of cognitive behavioral therapy, interpersonal therapy and motivational interviewing.	Quantitative (trial)
KidzAlive	Health providers; disclosure to child/ adolescent	South Africa	A multi-component, child-centered capacity building package for healthcare workers supporting children and adolescents living with HIV ages 0–12 years. It integrates healthcare worker training, mentorship, a talk tool (storybook) including conversations around HIV and disclosure, and child-friendly spaces to support wellbeing	Qualitative (evaluation)

Intervention title	Target population; directionality of disclosure	Country of implementation	Overall aim with key information	Type of supporting evidence
Red Carpet Program (RCP)	Health providers, school personnel, peer support, caregivers, adolescents; onwards disclosure as well as disclosure to adolescent	Kenya	A package of adolescent-specific services and interventions, beginning at the time of HIV diagnosis through the provision of fast-track, peer-supported VIP (very important person) services for adolescents and young adults ages 15–24 years.	Qualitative (evaluation, process evaluation)
Standardized Patient clinical training intervention	Health providers; disclosure to child/ adolescent	Kenya	A two-day training intervention with didactic and practical components focused on enhancing healthcare workers' skills to provide adolescent-friendly competencies in HIV care. Professional actors were trained to portray 7 cases of adolescents/young adults in a healthcare encounter (15–25 minutes each, with 5 minutes for feedback). Disclosure was one of the health topics covered in these case scripts, and healthcare workers were assessed using video-recorded interactions.	Observational (pre-post)
I ACT	Adolescents; onward disclosure	South Africa	A 6-session intervention driven by healthcare provider to deliver support groups, aimed at reducing loss to follow-up, following diagnosis to commencement of ART (pre-ART group) and improving retention in care (ART support group). Typically delivered by covering one topic per month, including a topic focused on disclosure, for groups of up to 15 adolescents ages 15–19.	Qualitative (evaluation)
ZENITH intervention	Caregivers, children/ adolescents; disclosure to child/ adolescent	Zimbabwe	An intervention to provide community-based support through 12–15 home visits by community health workers (CHWs) to the households of children (6–15 years) newly diagnosed with HIV. CHWs are trained to facilitate structured discussions at critical points in a child's progression through HIV diagnosis, treatment initiation, and long-term maintenance for 72 weeks post HIV diagnosis, with disclosure one of the focal areas.	Quantitative (trial)
Psychosocial support (PSS) program, Right to Care Mini Flipster	Adolescents; disclosure to adolescents and onwards disclosure	South Africa	A facility-embedded, peer support psychosocial support intervention for adolescents and young adults (ages 10–24) living with HIV who are unaware of their status, addressing disclosure, treatment adherence, social support, and HIV treatment literacy. Participants are organized into groups by age (10–13, 14–16, and 17–24 years). The peer supporters use the Flipster facilitation model developed by Right to Care (RTC) to facilitate support group sessions with participants at selected safe spaces.	Qualitative (evaluation)

Intervention title	Target population; directionality of disclosure	Country of implementation	Overall aim with key information	Type of supporting evidence
CHAMP+/VUKA	Caregivers, children/ adolescents; onwards disclosure	Thailand, South Africa	A multi-session intervention (11 in Thailand, 10 in South Africa) designed for caregiver-adolescent pairs (aged 12–16 years) and centered on a cartoon storybook, to support caregiver-child communication, adherence, and youth development.	Qualitative (intervention development); quantitative (trial)
Timiza Ndoto	Treatment supporters (caregivers, siblings, parents, partners), adolescents; onwards disclosure	Tanzania	An add-on to enhanced adherence counselling for adolescents and youth living with HIV (aged 10–19) who are not virally suppressed, including a one-day workshop for adolescents and treatment supporters (caregivers, siblings, parents, partners) engaging them in separate and joint sessions to support better adherence.	Qualitative (process evaluation), quantitative (pre-post)
Yika Mpiko	Caregivers, children/ adolescents; disclosure to child/ adolescent and onwards disclosure	DR Congo	Combines case management and workshops to engage unsuppressed children and adolescents living with HIV and their caregivers to improve viral load suppression. Uses multidisciplinary, facility-based teams (MDT) to address gaps in disclosure, treatment optimization, and viral load suppression in EGPAF-supported healthcare facilities and health zones. Sessions for children and adolescents included both disclosed and undisclosed groups.	Qualitative (evaluation)
Adolescent Transition Package (ATP)	Health providers, adolescents; disclosure to adolescents	Kenya	An intervention combining disclosure and transition tools for healthcare workers to support adolescents living with HIV aged 15–24 in the transition to adult care, enhanced by continuous quality improvement cycles in the first 6 months of implementation.	Protocol; quantitative (trial)
Positive STEPS	Adolescents; onwards disclosure	United States	An adolescent-focused multicomponent intervention to support adolescents living with HIV aged 16–24 with treatment adherence through five in-person sessions with a trained counselor. Adapted from an adult intervention, this incorporated SMS text messages and video vignettes.	Quantitative (pilot trial)
Project ACCEPT	Adolescents; onwards disclosure	United States	A skills-building intervention for newly diagnosed adolescents and youth (aged 16–24), covering two individual sessions, 9 gender-specific weekly group sessions, and one final individual session to promote adjustments and improve engagement in medical care.	Quantitative (pilot trial)
SMART Connections	Adolescents; onwards disclosure	Nigeria	A structured support group intervention delivered on social media, via a secret Facebook group, to adolescents living with HIV ages 15–19 years, to promote adherence and improve retention in HIV care over 5 sessions.	Quantitative (pilot trial)

Understanding disclosure-specific interventions: what works, for whom, in which circumstances?

Across the 11 disclosure-specific interventions, three themes emerged: 1) recognizing autonomy and dignity, 2) strategies and tools to enhance engagement, and 3) components linked to broader structures and the environment. These themes considered how interventions work in practice, and the mechanisms that allow them to reach their intended outcomes (see **Figure 2**). Each theme is supported by several context-mechanism-outcome (CMO) statements and support the overarching theory (Figure 2).

Recognizing autonomy and dignity

The first theme links to contextual components of interventions that enable caregivers and children to learn through intervention interactions and feel valued, leading to improved agency, confidence, and preparation for disclosure.

1. **When caregiver capacity-strengthening is integrated into intervention content and process (Context), caregivers experience opportunities to learn (Mechanism), are better able to exercise agency and make decisions (Mechanism), and feel more confident and knowledgeable (Mechanism), leading to improvements in caregiver-child communication and initiation of disclosure (Outcome).**

For interventions focusing on working with caregivers to disclose to children, enhancing their confidence and knowledge was critical. While caregivers sometimes became anxious about the process of disclosure and anticipated negative reactions and outcomes *(21)*, they later expressed relief and satisfaction with the guided process. Disclosure interventions enabled caregivers to work together with health workers and others to gain key insights on how to communicate and broach difficult conversations *(22)*. These foundational skills supported improved confidence, setting foundations for disclosure to children.

2. **When caregiver and adolescent self-determination are considered important to driving the process of disclosure (C), caregivers and adolescents feel valued and become more involved (M), are supported to exercise agency and make decisions (M), and can manage disclosure on their own terms (O) with better long-term outcomes on adherence and viral load.**

Several focused on providing caregivers and youth with the power and skills to make decisions about the type of support they wanted through a disclosure intervention *(23, 24)*, as well as their preference for being involved in the disclosure process *(25)*. These decisions enabled more trusting relationships to form between health workers and caregivers, fostering knowledge exchange and emotional support, and setting foundations for healthier disclosure to the child or adolescent. Caregivers were supported to consider their own motivations and the effects of disclosure and non-disclosure in their own context *(23, 26)*. Although less common, there were also examples of adolescent autonomy. One intervention allowed participants to bring a trusted friend or family member to a disclosure session as part of a longer-term process *(24)*. This intervention facilitated spaces to enhance mental health and social support immediately following disclosure.

Strategies and tools to enhance engagement

The second theme focuses on intervention components that are structured to support children, adolescents, and caregivers to engage in disclosure interventions.

3. **Interventions that incorporated developmentally appropriate strategies (C) enable caregivers and children to be guided through stages of disclosure readiness and preparation in a way that resonates and feels comfortable (M) and support better knowledge of developmental processes (M), leading to better mental health and improved timing and suitability of disclosure practices (O).**

Intervention fit was important for ensuring that content was matched to children's and adolescents' developmental stages and included considerations around assessing children's developmental readiness to learn about their status *(22, 23, 27)*. Staged approaches to disclosure for caregivers and children included preparation, partial disclosure, full disclosure, and post-disclosure support, and could be used with caregivers and children alike to support gradual disclosure *(22)*. In addition to being responsive to children's age and development when framing status disclosure, some intervention content also aimed to reframe individuals' orientation towards living with HIV—to normalize the experience, identify future goals and aspirations, and instill a sense of hopefulness and positive self-image *(22, 24, 28)*.

4. **Relational strategies that enable peer-peer engagement as well as group-based support (C), lead to a feeling of acceptance and safety (M) as well as increased confidence and knowledge (M), enhancing the mental health of participants, as well as improved acceptance and confidence with disclosure (O).**

Peers can be beneficial for both adults disclosing to children, as well as children and adolescents deciding if and how to initiate onwards disclosure. One hospital-based peer model paired trained youth supporters with health workers *(28)* to support disclosure to children and adolescents in a holistic way; these peers built relationships with adolescent patients, enabling them to feel supported and safe and decrease their sense of isolation. Children and adolescents receiving this peer-based approach reported better mental health and adherence compared to those who were disclosed to by health workers or parents. In another model, adult caregivers who had a child living with HIV were engaged in group psychotherapy where barriers to disclosure were explored and strategies to enhance competence and self-reliance shared *(29)*. Caregivers were able to create connections with other parents and caregivers, explore their inner resources, and practice skills through role-play and discussions—enabling a higher degree of perceived support and increased confidence to initiate disclosure.

5. **Interventions that use tools and materials to support child and caregiver participation (C) can lead to meaningful, guided engagement (M), provide a safe, structured space for enhancing HIV literacy and treatment literacy (M), and enhance child and caregiver acceptance as well as facilitate readiness for disclosure (O).**

Multiple interventions introduced tools and supplemental materials to support child and caregiver interest in participating in the disclosure process. These tools included storybooks designed to prepare children for disclosure through understanding HIV disease and treatment *(22, 30, 31)* as well as other types of visual aids, narrative videos, and animations *(24, 32, 33)*. These tools were used for children and adolescents of diverse ages, as well as their caregivers. One intervention provided tablet-based resources that were functional offline; their portability an asset for expanding self-directed learning for children and adolescents living with HIV, as well as supporting health workers to extend their expertise and skillsets *(33)*. This same intervention identified adolescents' preference for videos and animations that reflected their own lives as a key component in increasing their ultimate self-acceptance following disclosure *(32-34)*. Another utilized visual aids alongside pre-disclosure counselling for caregivers and youth-specific sessions, reinforcing key themes and positive framing through multiple avenues *(24)*.

Components linked to broader structures and the environment

A third theme centered on intervention components that worked across multiple socio-ecological levels, creating enabling environments for disclosure. The evidence supporting these structural aspects was largely confined to adult-to-child disclosure pathways.

6. **Interventions that introduce tools for streamlining and improving health systems around disclosure (C) enhance health workers' ability to manage patient interactions and frame support for caregivers and children (M), leading to better disclosure outcomes (O).**

Several interventions aimed to support health workers with prioritizing disclosure to young patients and to refine existing processes and systems *(25, 35)*. These interventions were largely based on quality improvement (QI) approaches that enabled improvements in documentation and continuity of care, leading to better planning for disclosure. Multiple iterations allowed implementers to monitor and revise strategies to enhance their effectiveness in practice. Importantly, these approaches also reduced duplication of efforts and closed gaps in communication, reducing the possibility of unintended disclosure in health facilities.

7. **Multi-pronged approaches seeking to create a supportive ecosystem both pre- and post-disclosure (C) can increase support for caregivers and children within the health system infrastructure (M), and lead to improved resilience, support-seeking, mental health, and disclosure outcomes (O).**

Several interventions sought to integrate multiple actors and strategies while paying attention to the patient's broader environment. Certain approaches prioritized understanding the personal experiences of, and relationship between, caregivers and children in preparing them for disclosure *(21)*. Health worker support and positive modeling in these cases was critical to facilitating positive disclosure experiences. A number of interventions drew on multi-disciplinary teams and/or streamlining strategies, resulting in more tailored, client-responsive support *(25, 28)* and clearer ideas about how to reduce gaps and better prepare at facility level for patient disclosure *(35)*. Interventions that adopted multiple strategies to tackle disclosure also focused on supporting health worker competencies and knowledge *(22, 27)*, and thereby improving their ability to counsel caregivers and engage with children in a staged disclosure process. Post-disclosure support was also part of several interventions, with additional options for counseling *(25, 28)*, and access to support groups and other social/recreational activities *(24)*.

Figure 2: Overarching emerging theory of how disclosure-specific interventions work in practice

	Contextual components	Leading to caregivers and children:		Resulting in improvements in:	
Recognizing autonomy and dignity	• Caregiver capacity-strengthening skills are part of intervention process • Caregiver and youth self-determination to drive the process of disclosure	• Being valued and involved • Having opportunities to learn • Being engaged and guided through stages of disclosure preparation and initiation • Feeling a sense of acceptance and safety, in a context of health facility support	• Being supported to exercise agency and make decisions • Sensing increased confidence and more accessible knowledge	• Caregiver/child communication and interaction • Acceptance, resilience, and support-seeking • Self-determination to freely decide on disclosure issues	• Disclosure outcomes • Viral suppression and adherence • Mental health and wellbeing across both caregivers and children
Enhancing engagement	• Developmentally appropriate interventions • Relational strategies used, sometimes via peers or group settings • New tools introduced to enhance child and caregiver engagement				
Components linked to environment	• New tools and systems introduced to streamline and improve health systems around disclosure • Multi-level interventions focused on building a supportive ecosystem both pre-and post-disclosure				

Gaps in disclosure-specific interventions:

- Structural factors disrupting strong relationships and service access
- The most vulnerable may not benefit equally without added support
- Intermittent uptake of some interventions may also have to do with caregiver reluctance/ lack of self-acceptance (despite intervention framing and encouragement)
- Few interventions focus on equipping children and adolescents with skills for onwards disclosure
- Healthcare providers may experience an undue burden of tasks

A young couple in Tuvalu reflect on their future as rising seas threaten their shrinking island © WHO / Yoshi Shimizu

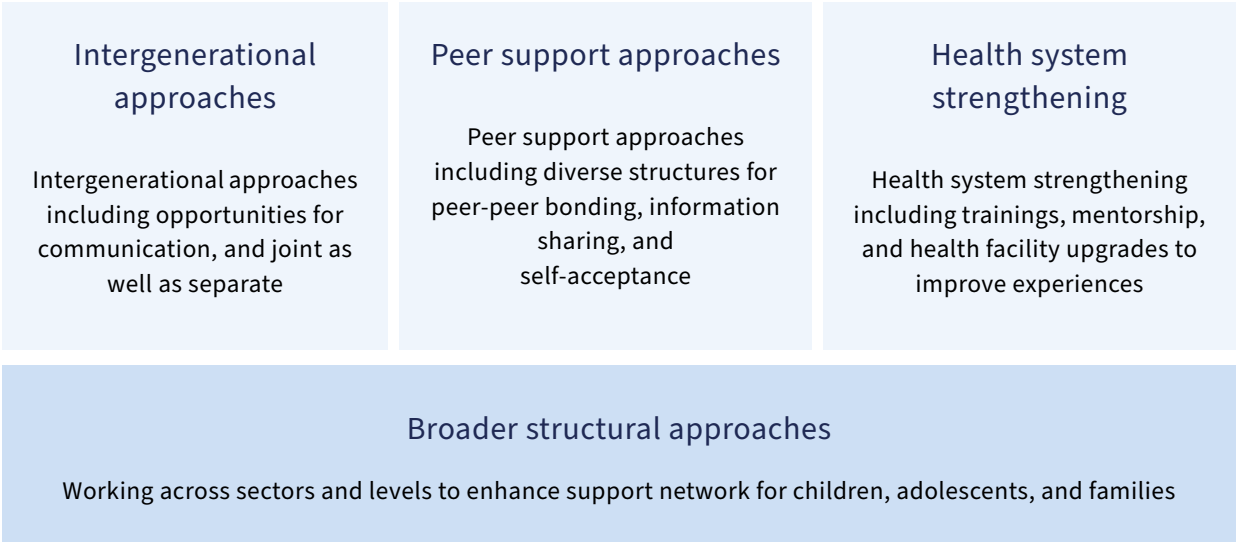
1.2. Disclosure-inclusive interventions

The review identified and catalogued 14 interventions that included content and practices supporting disclosure, yet was not solely focused on disclosure. (see overview in **Figure 3**). In addition to interventions that focused specifically on engaging adolescents and young adults to help them learn how to disclose their own HIV status onwards to others *(36-39)*, there was evidence of caregiver-child programming that supported intergenerational learning and interaction around the topic of HIV after children and adolescents were aware of their status *(40-42)*. Several interventions focused on healthcare systems—aimed at improving healthcare provider skills *(43, 44)*, health system functioning *(45)*, and health-education integration for adolescents *(46, 47)*, to bring about more supported disclosures from caregiver to child. In general, these interventions covered a broader set of skills, with some linked to disclosure as well as a broader set of outcomes that can support disclosure. Importantly, many of these disclosure-inclusive interventions were designed to support longer-term medication adherence by teaching diverse skills and leveraging supportive relationships—much like the disclosure-specific interventions highlighted earlier in this document.

Intergenerational approaches were used in these types of programs. The **CHAMP+** and **VUKA** interventions, both adaptations of the original CHAMP intervention, engaged young adolescents living with HIV and their parents/caregivers across both individual and joint sessions covering diverse psychosocial skills *(40, 41, 48)*. Content included parent-child communication, HIV treatment literacy, stigma and discrimination, social support, and preparation for disclosure of the child's HIV status to others. These sessions revolved around a cartoon story culturally tailored to the intervention context, used to stimulate group discussions. In the Thai adaptation, a vignette from the cartoon introduced the topic of disclosure, enabling caregiver-child discussion while also making the example less personal, as adolescents considered how to prepare for onwards disclosure to peers or partners in the future. **Yika Mpiko** in the DRC and **Timiza Ndoto** in Tanzania, described in more detail below, also engaged children and adolescents facing viral suppression challenges alongside their caregivers *(42, 49)*.

Mechanisms increasing success: The relatability of the VUKA and CHAMP+ cartoon character and their story, followed successively over the intervention's sessions, was described as a key part of the intervention's uptake. A supportive group environment helped decrease stigma for both caregivers and children. A focus on relationships and communication eventually increased the willingness and comfort of participating caregiver-child pairs to discuss difficult topics as a family. For shorter interventions engaging caregivers and children, establishing social support networks and decreasing stigma was another critical success factor.

Figure 3: Overview of key features and mechanisms from disclosure-inclusive interventions



Peer educator Ismo Artur, counsels a young person living with HIV at a clinic at SAAJ da Munhava, Mozambique, 2019 © Frontline AIDS / Peter Caton

Peer support interventions helped build the skills and confidence of children and adolescents to disclose their status onwards to others. Most of these types of interventions could also be seen as a post-disclosure step—providing a supportive space for children and adolescents after they learned about their own status. These included programs that were embedded in governmental health facilities (such as the ***Adolescent Transition Package*** in Kenya) *(50)*; partnerships with local community-based organizations (such as ***Right to Care*** in South Africa) *(38, 51, 52)*; digitally-based interventions for adolescents (***SMART Connections*** in Nigeria) *(53)*; an intervention for newly-diagnosed adolescents and young adults, delivered by a peer supporter and interventionist (***Project ACCEPT*** in the United States) *(54)*; and research-linked interventions aiming to establish evidence of effectiveness (including ***Sauti ya Vijana*** in Tanzania and ***I ACT*** in South Africa) *(36, 37, 55)*. These interventions primarily focused on older adolescents or grouped adolescents by age to ensure age- and developmentally-appropriate content and engagements.

Mechanisms increasing success: Peer support groups were important places for peer-peer bonding and acceptance, destigmatization around HIV, and collective learning and sharing of strategies for adherence, onwards disclosure of one's status to others, and navigating living with HIV. Some interventions more readily integrated reflections on self-acceptance, discussed the importance of communication and choice in disclosure, and promoted tailored solutions and situational assessments to prepare adolescents for disclosure to others. Diverse approaches to peer engagement—for instance, through both general open groups in waiting rooms as well as closed groups for adolescents living with HIV—facilitated adolescent choice and supported engagement while also prioritizing their sense of safety and confidentiality *(37)*.

Health system strengthening was a key component for several programs including disclosure content. The ***KidzAlive program***, implemented by Zoe-life in South Africa, integrated healthcare provider training and mentorship with a storybook-based "talk tool" and resources to create child-friendly spaces in participating health facilities *(45)*. Training, conducted with healthcare providers already delivering HIV-focused services to children and adolescents, covered child developmental stages, child rights, play therapy, communication techniques, support mechanisms for caregivers, and supporting children in distress. These themes were reinforced in clinical practice through mentored supervision. Disclosure specifically was targeted through the culturally-appropriate talk tool storybook, used in individual sessions with children and adolescents to prepare them for disclosure. The **ZENITH trial** in Zimbabwe *(44)* trained and supported community health workers to facilitate

structured discussions during home visits with households of children aged 6-15 years newly diagnosed with HIV. These visits supplemented standard HIV care at health facilities and supported children and caregivers at critical points in the child's progression through diagnosis, treatment initiation, and adherence and maintenance. A. study in Kenya that employed a program the developers called s***tandardized patient actor training*** *(43)* was implemented with a cohort of health workers, who received a 2-day training to support adolescent-friendly health services, motivational interviews, and practice sessions. Workers were evaluated on empathic skills, communication, and technical competence in encounters with young professional actors, trained to portray adolescents and young adults with distinct HIV-related concerns. They also self-rated their own competency, case difficulty, and relevance in these interactions. A related series of programs implemented by the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)—***Yika Mpiko*** in the DRC and ***Timiza Ndoto*** in Tanzania—brought together multi-disciplinary teams at health facility level to engage children and adolescents living with HIV struggling with viral suppression and their caregivers. Through case management approaches and workshops, these programs created opportunities for treatment literacy, peer-peer engagement, and tailored support *(42, 49)*. ***The Adolescent Transition Package*** in Kenya *(50)* used a co-designed toolkit to support health workers in engaging with eligible adolescents and youth living with HIV who were preparing to transition to adult care. Additional tools for youth who did not know their HIV status were integrated to support disclosure.

Mechanisms increasing success of these interventions: Healthcare providers receiving KidzAlive reported improved confidence in clearly communicating about HIV with children at all ages and stages of disclosure. Combining knowledge on child developmental stages and child rights also increased appreciation for how to engage children in their own care, while also adopting a more specific and child-centered vocabulary. Beyond psychosocial and interpersonal skills, the physical transformation of child-friendly spaces in facilities also increased children's comfort and reduced their anxiety, leading to better interactions. Other health system interventions utilized similar multi-pronged approaches, enhancing the applicability of content and support strategies for diverse caregiver-child relationships. Youth peer educators played key roles in shifting the framing for adolescents and youth in the Yika Mpiko and Timiza Ndoto programmes, moving from a focus on medication adherence to future aspirations and ideations.

Broader structural approaches incorporated multiple elements of child and adolescents' environments, reducing gaps in care and enhancing opportunities for disclosure and streamlining access to treatment. **The Red Carpet Program** in Kenya and the **Zvandiri QI initiative** are highlighted in this brief as case examples *(25, 46, 47)*.

Additional tools to support disclosure

A substantial number of toolkits, storybooks, and other materials were shared that are routinely used to support disclosure in a diverse range of settings. As evaluations of these tools were not identified, we did not include details on these interventions, nor use them to build our understanding of how they work.

The Big Catch-up round two targets unvaccinated children, Martino Hospital, Banadir, Somalia, 2024 © WHO / Abdulkadir Zubery

Part 2

Emerging considerations

The disclosure interventions in this brief draw on some crucial considerations for further programming and response for children and adolescents living with HIV. In this section, we present a series of considerations emerging from disclosure interventions, highlighting key gaps and strategic actions for each topic alongside case examples where relevant. The case examples used in this document were found and selected as part of the scoping review, supported by inputs from key expert advisors. Information from identified case examples were collected in a template and relevant focal points of the case examples were contacted provide and validate information.

1. Adolescent development and the evolving capacity for autonomous decision-making

Background

Considering the unique life stage of adolescence is critical for any intervention, especially in navigating the complex process of HIV status disclosure. Disclosure support for adolescents living with HIV is commonly built into programs that focus on a broad set of skills and topics *(36, 38, 46)*. Specific sessions that focus on disclosure can provide safe spaces to discuss necessary support, examine anticipated challenges, and share experiences. They may also offer access to additional services that can help adolescents decide how they would like to disclose. However, safe disclosure may require more targeted, ongoing, long-term relationships with care providers or program facilitators to broach disclosure. In this brief, there was limited evidence for these longer-term approaches.

Readiness may rely on certain developmental factors—which may or may not be related to age *(5)*—and link to recognition of younger adolescents' evolving capacity to make decisions about their own health and care. Considering the time that individuals are engaged in the intervention or health services may also be important for assessing readiness, as some mechanisms may take longer to take effect *(22)*. Children and adolescents may demonstrate readiness but be considered by caregivers or health providers to be too young to handle their own HIV status, leading to potentially harmful delays. In other cases, children talk about having "always known" their status and growing up within a supportive and communicative family unit. The idea of readiness can also extend to adolescents' readiness to share their own status with their parents and caregivers—flipping the script of many of the interventions reviewed in this brief. Conversations about adolescents' readiness can also lead to decisions about waiting until the right time to disclose or not disclosing at all. Expanded options are allowing individuals to promote safety with sexual partners while retaining the agency to determine how, and if, to disclose *(56)*. The WHO's autonomous decision-making tool provides a helpful framework for working alongside adolescents to make these decisions (see **Figure 4**).

Continuing post-disclosure support in various ways can be critical to identifying these new and evolving needs *(24)*. Full disclosure is often used as a marker to begin other discussions—including conversations around transition to adult care. Post-disclosure support can provide children and adolescents with critical preparation skills for difficult conversations in their own relationships. After learning their status, children and adolescents often require further guidance, support and mentorship to determine who to disclose to, and the right way to disclose, as new stages of cognitive and social development bring new understandings about what it means to live with HIV. Considering disclosure along the life course means considering how these needs and priorities evolve over time—and finding ways to link approaches that focus on disclosure to children and adolescents with those that extend to their ability to disclose to individuals in their own familial, social, romantic, and sexual networks.

Key gaps

- Few interventions designed for adolescents living with HIV target onwards disclosure specifically, limiting opportunities to recognize adolescents' growing autonomy and help them reflect on navigating risks and benefits. There was also limited discussion of how to support adolescents with non-disclosure options.

Figure 4: Practical steps for assessing and supporting adolescent capacity for autonomous decision-making (reproduced from WHO guide) *(5)*

The four steps are:

1	**Joint exploration of the situation and options:** Explore with the adolescent the important elements of decision-making and the overalli situation, including the adolescent's psychosocial life, risks and resources. The role of the professional is to provide all the necessary information in appropriate language on the framework of care, the medical condition and the options to help the adolescent in making a choice.
2	**Common synthesis of the situation:** Summarize the issues raised in step 1 and ensure common understanding. The HCP should be particularly attentive to elements that are likely to alter a decision and address them as appropriate to allows deliberation with the adolescent and any relevant partners in order to reach a consensual decision. The involvement of parents or legal guardians and other relevant people should be discussed with the adolescent.
3	**Decision point:** Decide whether the adolescent has the capacity to make an autonomous decision in a given situation at a given time.
4	**Follow-up:** Outline guidelines for follow-up, whether or not consensus is reached on a decision.

- Limited attention to adolescent development and readiness may lead to delayed disclosure for newly diagnosed adolescents and missed opportunities for establishing healthy self-management practices.
- Few models assess adolescent readiness for peer disclosure and sharing outside of structured peer support spaces. Combining group-based support with individualized approaches should be carefully considered.
- Post-disclosure support should also enable adolescents to consider their environments and broader networks that may support their disclosure.
- Expanding access to evidence-informed tools that can help health workers to gauge readiness is needed (see Case example 1 below).

Key actions

- Incorporating skills and strategies that enable adolescents to broach difficult conversations with their caregivers is a key area for action.
- It is important to integrate conversations around the evolving needs of children and adolescents as they transition through HIV care into both foundational training for health workers and in caregiver interactions.
- Such training can also assist health workers and caregivers identify when child and adolescent patients are undergoing key developmental transitions that may bring new autonomy and readiness for decision-making. These can also include a focus on non-maleficence, emphasizing that children and adolescents should be protected from HIV disclosure interventions that could potentially cause harm to them, while ensuring they are not left out of interventions of benefit.
- Key developmental transitions may also provide opportunities for disclosure support. Including when adolescents seek sexual and reproductive health services, and/or when they enter sexual relationships for the first time.
- Protocols for supporting adolescents who are uncomfortable disclosing should be prioritized and shared. This may include providing additional support to ensure partners are protected, such as confidential provider-assisted partner services, couples testing services, secondary distribution of self-testing kits to partners, and other testing services.

Case example 1: EGPAF Disclosure of HIV Status Toolkit for Pediatric and Adolescent Populations

While existing, evidence-based approaches to promoting disclosure have tended towards a more targeted approach, the EGPAF disclosure toolkit provides a set of tools that can be tailored to child and adolescent disclosure at distinct life stages and in line with their needs. These tools are primarily aimed at health workers working with pediatric and adolescent populations living with HIV.

The toolkit covers detailed information about the process of disclosure, including age- and developmentally-specific information, and provide health workers with tools to facilitate diverse types of disclosure. The tools support health workers to undertake partial disclosure and full disclosure, and address both caregiver-to-child disclosure and adolescent-to-adolescent disclosure. These tools include assessment checklists, guided action points, discussion prompts, and sample scripts. The appendices provide further resources for practicing disclosure, such as case studies.

Young peers in a learning session, 2021 © Gibson Kabugi / EGPAF

2. Addressing layered stigma and adopting rights-based approaches

Background

Rights-based approaches should be central to disclosure, to prevent forced disclosure, reduce unintended harms, and support children and adolescents post-disclosure. Programs and practitioners should be equipped to recognize and mitigate potential harms, while providing support towards the goal of disclosure. Caregivers may delay disclosure to their children or adolescents due to confronting barriers in accepting or disclosing their own HIV status; such as critical concerns such as stigma and safety in their homes or communities. Firstly, consent for HIV testing can be a critical challenge, followed by decisions about how to disclose. WHO recommends that adolescents, specifically, "should be counselled about the potential benefits and risks of disclosing their HIV-positive status and empowered and supported to determine whether, when, how, and to whom to disclose" *(8)*. The "why" of disclosure is also important, as the best interests of the child and adolescent are weighed (and as adolescents learn to consider the process of onwards themselves). Article 9 of the CRC emphasizes that the child's best interests include considering the children's right to have their views heard (CRC, Article 9).

Any form of coercion linked to disclosure is unacceptable. In some settings, non-disclosure is criminalized and acts as a coercive mechanism, which can carry significant risks for adolescents and young adults in inequitable partnerships. In other settings, parental/caregiver consent is required to initiate disclosure, which can inhibit disclosure practices in healthcare settings when caregivers are not present or do not consent, and pose additional barriers to accessing other services such as sexual and reproductive health or mental health *(28)*.

As adolescents reach the age where they need to consider onwards disclosure in a more concerted way—as they move to attend boarding school or enter sexual or romantic relationships—specific factors can shape their experiences. Children and adolescents from marginalized groups or identities may face greater risks. For adolescent girls and young women, key legal and policy provisions may shape how easily they can access care, the social environments in which they are living and interacting, and the shifting risks that accompany them into their adult lives *(57, 58)*. Adolescent girls and young women who sell sex, adolescent mothers, and those experiencing early and/or forced marriage may experience even greater levels of risk. For adolescent girls and young women, as well as adolescents who are marginalized or discriminated against in their societies, the possibility of violence within their relationships may be a significant concern *(14)*. Other harms may include stigma and social ostracization, shaming around sexuality, and loss of relationships. Adolescent boys and young men who are marginalized, including young men who have sex with men, and/or those who are gender-diverse, face challenges that range from internalized stigma and anxiety *(59)* to discrimination and criminalization *(60)* that can influence how they engage in treatment and choose to disclose *(61)*. While no studies from this review identified interventions for children whose parents belong to key populations, this group may require additional attention and care to mitigate stigma-by-association.

It is essential for health system interactions to be free from stigma, coercion, and blame; at the same time, these interactions should also be empowering for children, adolescents, and their families as they transition through care and navigate living with HIV. Adolescents who may have multiple disclosures to make—about sexual orientation, gender identity, violence experiences, or other stigmatized experiences—should be able to do so comfortably within healthcare settings. Supportive, non-judgmental care, and counselling focused on empowerment, risk mitigation, and recognition of individuals' circumstances, are critical to healthy disclosure. Youth participation is one way of making disclosure interventions more relevant and acceptable. Adolescents working as peer navigators, as well as adolescents who had both positive and negative experiences learning about their own HIV status at younger ages, have valuable insights that can help shape and refine disclosure interventions.

Key gaps

- Few interventions are guided by rights-based framing, and few include supportive strategies addressing multiple disclosures. Training and intervention content could more explicitly include information on rights and multiple types of stigma, especially linked to intervention setting.
- Disclosure can be a traumatizing experience for children and adolescents. Enhanced counseling and mental health support should be available in line with individuals' needs and preferences.
- There is limited focus within disclosure interventions on how to intervene or provide guidance for children, adolescents, and families who have experienced unintended or forced disclosure.

At a WHO-backed Aleppo school, a mental health worker supports teens during exams, 2023 © WHO / Giles Clarke

- Disclosure support may also expand to provider-assisted partner services and network-based testing, which includes social network testing and family and household testing, as well as secondary distribution of HIV self-testing kits to partners. Such services are evidence-based and cost-effective for improving testing and linkage to care *(62-64)*. However, more evidence on the feasibility and acceptability of these services is needed for adolescents, especially adolescent girls and young women *(65)*.
- While the world of HIV programming has led in prioritizing youth engagement, participation, and activism, more concerted efforts to bring adolescents into conversations around intervention components, mechanisms, and barriers to implementation is a key priority—while recognizing their needs for compensation and skills development *(66, 67)*.
- In many contexts, mandatory provider reporting, mandatory authority notification, mandatory parental notification, and/or criminalization of specific behaviors (i.e., forced disclosure) may jeopardize health providers' willingness to facilitate disclosure. These practices may also limit adolescent willingness to engage.

Key actions

- Recognizing the persistent risks faced by HIV-affected populations, disclosure programming and support should be violence-sensitive, trauma-informed, and stigma-free.
- Health workers, HIV care practitioners, and social support staff (such as counsellors in schools) should be trained to provide supportive, non-judgmental counselling and disclosure support that encompasses respect for autonomy. They should also be aware of legal constraints in their specific contexts.
- Training on core empathic care skills and stigma mitigation should be designed to link with available resources, including other health and social services. Training should also include knowledge of risk assessment procedures, to ensure that health workers are able to respond to at-risk adolescents with sensitivity, compassion, and professionalism.
- Network-based testing services should be offered to adolescents.
- Interventions should include youth as co-developers and evaluators, as this process can support more effective evidence- and context-informed programming. This helps incorporate young peoples' lived experiences and makes interventions more relevant.
- Embedding peer and lay health providers individuals within multi-disciplinary facility-based teams can increase patients' access to quality services while mitigating additional burdens for nurses, social workers, and clinicians. It can also increase alignment and skills transfer, and boost motivation. Adequate initial training, combined with ongoing opportunities for refresher training, mentorship, and supervision, is critical to these approaches.

Case example 2: Integrating peer supporters into facility-based disclosure support

The staff at Kalembelembe Pediatric Hospital in the DR Congo initiated a peer-supported process to facilitate disclosure of HIV status to children living with HIV *(28)*. Peer educators and supporters in this study were aged 12–24, living with HIV and accepted their status, with good adherence to treatment. They were trained to provide mentorship and guidance to child and adolescent patients, under health worker supervision. Workers included nurses, psychological care professionals, general practitioners, pediatricians, and psychiatrists, who worked with parents/caregivers and peers to develop a plan for disclosure to children.

Building on the trust, acceptance, understanding, and empathy that are part of peer supporter-client relationships, the approach engaged peers to take an active role in preparing for disclosure and identifying post-disclosure support mechanisms. Clinic staff found that children and adolescents who were disclosed to by their peers had significantly better viral load suppression and reduced levels of depressive symptoms when compared with children and adolescents who had learned their status from parents or health workers.

Peer supporters, PATA 2024 Summit © PATA

3. Measurement, monitoring, and evaluation

Background

Measuring and monitoring disclosure is critical to understand how well intervention approaches may be working. Importantly, the process of measuring outcomes may include completed disclosures, as well as the building blocks that make disclosure possible. Because of this, disclosure as a program outcome should be carefully considered alongside the factors that make it possible. The many supportive factors and age-appropriate elements that go into the process of disclosure may be more important than the "outcome" of disclosure itself. Child and caregiver HIV literacy, mental health and wellbeing, health worker competency, and caregivers' disclosure status may together assist the process of disclosure and provide the foundations for children and caregivers to be emotionally ready to talk about their status *(23, 27, 29, 32)*. For older children and adolescents who are determining how to disclose, these factors may include self-efficacy to disclose, self-esteem, developmental readiness, and/or the presence of a support network—all of which can be measured to bolster our understanding of disclosure readiness and success.

Alongside more resource-intensive research studies, disclosure interventions and strategies that are integrated into health systems may need to minimize additional monitoring and reporting requirements. However, routine indicators could be framed to capture specific stages of disclosure, which could provide meaningful, usable data for health providers to learn from. Disclosure should not be considered as a once-off event, but an iterative process that evolves as children and adolescents develop and progress through distinct life stages and events. Although this can make it hard to quantify the most robust evidence for disclosure, using standardized approaches and definitions can be helpful in framing disclosure and assist practitioners and researchers identify patterns and best practices based on specific situations.

Key gaps

- Few interventions in this review that were broader in nature (disclosure-inclusive) rarely documented disclosure as an outcome. The interventions in this brief characterized as disclosure-inclusive may in fact target a broader set of skills and mechanisms that can ultimately support disclosure. However, because disclosure is not consistently measured in these interventions and programs, it is difficult to gauge their effect on disclosure.
- Measuring both partial and full disclosure and doing so longer, could help implementers and researchers understand differing timelines that may depend on children's and adolescents' readiness and emotional maturity. This could include considerations that disclosure may be incremental, to allow for a more comprehensive measure, as opposed to viewing it as a simple one-off event *(30)*. Age may be an important consideration, given evidence that later or delayed disclosure can have negative repercussions for adolescent treatment outcomes and wellbeing *(68)*.

Key actions

- More specific, widely used outcome measures for disclosure is needed, including measurement protocols and guidance by context, population, and life stage.
- Standardizing outcomes to track disclosure to, and by, children and adolescents living with HIV can help expand both programmatic and research knowledge on how disclosure takes place. Measures of partial, incremental, and full disclosure, as well as reasons for non-disclosure, should be added to diverse types of psychosocial and educational interventions for this group.
- Measures should link with routine indicators at facility and community levels that are continuously updated at the standard of care. These efforts can include both quantitative, clinical outcome measures as well as qualitative and narrative data—such as measures of improved quality of life—to support more nuanced understanding in each setting.
- Because disclosure is a process, research should track disclosure experiences over time, to help assess longer-term impacts on individual wellbeing. It is also critical to measure related factors such as age at various stages of disclosure to understand how this may align to outcomes. These measures can help us understand how these outcomes affect overall quality of life—as well as how supportive relationships with health workers and others can buffer the negative effects of unintended or mishandled disclosures in the long term.

Case example 3: Quality Improvement (QI) collaborative, Zimbabwe

In response to sub-optimal treatment outcomes and mental health outcomes for adolescents and young people living with HIV, the Zvandiri District Team collaborated with health workers and peer counselors (known as Community Adolescent Treatment Supports, or CATS) in three selected districts (Hurungwe, Nkayi, and Goromonzi) to identify the disclosure status of adolescents and young adults in care and adopt a series of strategies to bolster disclosure. The QI package aimed to work within existing health system structures to 1) document disclosure status in patient files, 2) initiate monthly caregiver support meetings and individual additional counselling, 3) hold health worker-initiated opt-out disclosure sessions, and 4) offer CATS-led pre- and post-disclosure counselling sessions. Health worker initiated opt-out sessions were designed to assist caregivers with disclosure when caregiver counselling was not sufficient.

Ultimately, 360 adolescents and youth and their caregivers received the QI package, and the proportion of those receiving full disclosure increased from 73% (959/1266) to 96% (1266/1319) over a 6-month period. Remaining barriers for the small numbers of adolescents and youth *(53)* who did not receive full disclosure included caregiver unwillingness to disclose and absent caregivers. However, active follow-up and documentation, as well as opt-out disclosure sessions, enhanced opportunities for receiving support throughout this process. This initiative was later shared with Right2Care in South Africa, which is implementing the Zvandiri model across three provinces. From June 2023–October 2024, they managed to assist 301 adolescents receive full disclosure by ensuring adequate documentation of disclosure status, caregiver support, CATS pre- and post-disclosure counselling sessions and assisted disclosure.

Group facilitators from Sauti ya Vijana team, 2024 © Sauti ya Vijana

4. Building support systems across families and communities

Background

Systems of support are a critical part of healthy disclosure. For children and adolescents, their home, school, and community environments have a significant role in shaping their identities and wellbeing. These environments should be structured to provide support prior to, throughout and after the disclosure process.

Caregiver support and engagement in programming around disclosure is a key focus area. Considering individual rights and the best interests of the individual, and ensuring readiness for disclosure, is important for caregivers, just as it is for children and adolescents. One evaluation investigating cases of non-disclosure found that caregivers were less likely to disclose to children who had been on ART for longer periods of time *(34)*. Programming should be responsive to the diverse ways that caregivers' personal history—in some cases, acceptance of their own status, or experience of grief or loss—may add barriers to child and adolescent disclosure. Qualitative data from 519 health workers, engaged in structured conversations around disclosure across 12 high HIV burden countries at the 2023 PATA Summit, revealed persistent concerns observed regarding caregiver readiness, fear, and lack of acceptance *(69)*. Importantly, interventions and programs should also prepare caregivers for how to support their adolescents along the continuum of disclosure. This is especially important given the rapid developmental and emotional changes that characterize the developmental stage of adolescence—and the fluidity of status acceptance and disclosure as a process. At least two evaluations noted that in the immediate aftermath of disclosure, adolescent mental health worsened *(24, 32)*. In the longer term, studies found that mental health had 'bounced back' and adolescents were generally satisfied and secure post-disclosure.

Additionally, programs and policies to support children and adolescents living with HIV are needed in diverse environments, including schools and community spaces. To optimize key HIV outcomes and provide supportive environments for status disclosure, it is important to meet children and adolescents "where they are"—which is often in places other than health facilities. Differentiated service delivery approaches, including those highlighted in the WHO's recent HIV service delivery guidelines, can ensure linkage to care and boost adherence for youth *(8)*. While adolescent-responsive health services have improved in recent years, schools are another key place for health service integration. Sensitively integrating HIV education and care into diverse school settings can provide children and adolescents living with HIV with a sense of comfort and safety. School-based approaches, some of which are highlighted in the case example below, need to balance the need for individual privacy with opportunities for broader de-stigmatization of HIV.

Important to note is that school-based strategies will not be able to reach all children and adolescents and arguably may miss the most vulnerable. However, they should be viewed as one of multiple options that can reduce gaps and enhance the quality of HIV care and support for children and adolescents at a pivotal time. Additional community and public spaces may include religious organizations or groups, as well as sports and recreational spaces where children and adolescents spend their time.

Key gaps

- More rigorous evaluations of cross-sectoral approaches to support disclosure and retention in care for children and adolescents could bolster evidence about what works across distinct high HIV burden settings.
- Few interventions included HIV literacy and knowledge on child and adolescent development for caregivers; a clearer understanding of these areas may be beneficial as their child reaches key developmental milestones and transitions.
- More attention is needed to help health workers navigate instances where caregivers refuse disclosure of HIV status to children and adolescents, as country-specific guidelines on who should be involved may vary.
- Interventions should be cognizant of the structural and environment factors that shape their effectiveness: for instance, structural drivers of poverty, food insecurity, and poor mental health can inhibit engagement *(24)*, and health worker shortages may also disrupt implementation efforts *(28)*.

Key actions

- Engaging and supporting caregivers can ensure that both their child's and their own needs are met throughout the process of disclosure. Group psychotherapy for caregivers (highlighted in this brief *(29)*), as well as other approaches that promote better intrafamily communication and connect families to existing resources *(40)*, may be well-placed to provide ongoing support in pre- and post-disclosure phases.

- Beyond supporting caregivers with skills to initiate conversations around HIV status and adherence, interventions should also focus on equipping them with knowledge about their child's developmental trajectory and stage-specific support.
- For schools that build HIV education into their curricula, it is important to understand the introduction of HIV education, to help caregivers and health workers guide the timing of HIV disclosure to children and adolescents. This alignment can help avoid unintentional disclosure, or children and adolescents figuring out their own HIV status before they have been fully disclosed to.
- Approaches to HIV support that target all students, not just those living with HIV—for instance, normalizing testing and counselling for the full student body—may also reinforce positive messaging.

Case example 4: Red Carpet Program

The Red Carpet Program (RCP), implemented by EGPAF with support from ViiV, is a multi-component package of resources, tools, and guides covering multiple intervention approaches to support effective linkages to care and retention in care for adolescents and youth living with HIV.

In addition to Red Carpet health facilities, which aim to fast-track adolescents through HIV services and ensure additional youth-friendly care, the RCP has been implemented in boarding schools, providing critical services for adolescents requiring additional support *(46)*. Layered interventions include creating enabling environments for learners living with HIV through capacity building for teachers, support staff, and student health champions: integrating communication on HIV within school settings via health clubs and school assemblies; ensuring availability of school-based support for disclosure, adherence, and psychosocial needs, alongside school-wide stigma reduction; and bidirectional linkages between healthcare facilities and schools. Students living with HIV at schools received support for medication storage, attendance to routine clinic appointments, treatment literacy, and disclosure support. Stakeholder engagement is a core piece of the RCP; stakeholders including Ministries of Education, school-based personnel, adolescent and youth champions, and linked RCP health facility staff.

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5. An evolving epidemic requires flexibility and innovation

Background

New advances in HIV testing, care, and treatment for children and adolescents are likely to shift the calculus around disclosure. These advances may benefit individuals living with HIV, as well as complicate well-established modes of disclosure. Expanded multi-month dispensing options for children and adolescents who are virally suppressed *(70, 71)* may change how disclosure can occur. Since some children and families may only be seen 3–4 times per year—which can improve retention, due to reduced burden of frequent health facility visits—there are fewer opportunities for health workers to prepare and discuss disclosure at the facility. This means advanced planning is needed by health workers on when to introduce and follow-up about the disclosure process with caregivers to ensure age-appropriate beginning of the disclosure process. There may also be a need to explore virtual or community support for disclosure in between facility visits, either through facility staff or linkage with community programs, to help address caregiver reluctance or overcome other barriers to disclosure in a timely manner.

Considerations around onwards disclosure for adolescents have evolved alongside innovative testing and treatment options. For instance, HIV self-testing kits offer anonymity, confidentiality, and the ability to first test for HIV in a place that feels comfortable—possibly changing the timing of counselling or guidance around disclosure but also increasing individual autonomy *(72)*. Adolescents receiving new long-acting injectable treatment options *(73, 74)* may feel less urgency or pressure to disclose to romantic/sexual partners when daily pills are not a concern, and when rates of viral suppression are high, or viral load is undetectable. This reduced pressure may be protective for adolescents who are in short-term relationships, or those where there is a risk of violence or social marginalization. These considerations have also shifted with the evidence on viral suppression—that people living with HIV with undetectable viral loads have zero chance of transmitting HIV through sex as long as they take their ART as prescribed, a concept known as Undetectable = Untransmittable, or U=U *(75)*. Adolescents need to be given this information when they are discussing disclosure and choosing the who, what, and how.

Key gaps

- In addition to expanding options for treatment and care, disclosure approaches could and should be expanded beyond face-to-face modalities to accommodate innovative and virtual ways that better support caregivers, children and adolescents in their disclosure journey.
- There is a greater need for harmonization between disclosure and testing, especially as best practices evolve. Network-based testing—which includes partner services, social network testing, and family and household testing—may provide a better way to roll out improved disclosure support.
- Adapted programming and interventions, as well as health worker guidance, could be updated to engage adolescents in conversations around new advances, ethical non-disclosure and how to weigh potential harms as well as assess readiness.

Key actions

- Health workers and implementers should engage directly with adolescents to understand preferences and priorities for new treatment and prevention options, as well as considerations around disclosure.

Conclusion

This technical brief provides an overview of evidence integrated with rights-based approaches that prioritize the role of the child and adolescent wellbeing in the process of disclosure. Disclosure is both a personal decision and a means to safeguard health and HIV outcomes, especially for younger populations. The social, relational, and systemic considerations emerging from the evidence are central to promoting safe disclosure. In highlighting key gaps, this brief also points to broader systems changes that need to be sustained: supportive health systems, professional development and training, harmonization of testing and disclosure, and multi-sector communication and collaboration.

WHO data shows rising childhood obesity in Kazakhstan, leading to a new Ministry of Health factsheet, 2021 © WHO

Annexes

Annex 1: Scoping review methodology

A scoping review of disclosure-focused interventions was conducted to identify interventions, based on the question, "**What is the existing evidence for interventions that support disclosure of HIV status to and by children and adolescents living with HIV?**" Criteria for selection are shown in **Table 1**.

The protocol for this review was reviewed by the technical working group convened for this specific technical brief, which included WHO staff and consultants with extensive expertise across domains relevant to disclosure.

Table A1: Selection criteria for review

Area	Specific criteria
Population	• Children and adolescents 6–19 years of age living with HIV • Caregivers of children and adolescents ages 6–19 living with HIV • Healthcare providers, including lay health workers, who work with children and adolescents ages 6-19 living with HIV • Other adults working with children and adolescents ages 6–19 living with HIV (e.g. teachers in boarding schools, community organization staff) • Any combination of the above groups
Intervention type	• Psychosocial interventions • Educational/literacy interventions • Structural interventions • Structured tools used to guide disclosure
Outcomes of interest	
Primary outcomes	• Disclosure of child/adolescent HIV status by caregiver to child/adolescent • Disclosure of child/adolescent HIV status by health worker to child/adolescent • Disclosure by child/adolescent about own HIV status to others, including sexual partners
Secondary outcomes	• HIV-related outcomes (testing, self-testing, antiretroviral adherence, viral load suppression, retention in care) • Mental health outcomes including positive mental health (quality of life, self-esteem, functioning), depressive symptoms, anxiety symptoms • Sexual and reproductive health outcomes (condom use, contraceptive use, STIs) • Stigma: internalized, anticipated, enacted stigma • Relationship quality, e.g. caregiver-child communication, partner communication • Health service uptake and satisfaction • Self-efficacy to disclose • Caregiver readiness to disclose their own status • Any potential harms/iatrogenic effects (abuse, intimate partner violence, self-harm) • Consent for HIV testing • Others not listed here

Beyond these criteria, we set out additional parameters to identify eligible interventions. Interventions implemented from 2011 – the year the last WHO guidelines on disclosure was published - onwards were included for review, based on the date of the last WHO disclosure guidelines. Target audience: Interventions could include programs designed for diverse target audiences, including children/adolescents individually or in groups, for their caregivers and families, for health workers, other adults in their networks, or some combination thereof. The focus could be on achieving an outcome of disclosure but may also build skills to promote disclosure when individuals are ready (e.g. self-efficacy, recognizing evolving autonomy of adolescents). We included any interventions that targeted children and adolescents ages 6–19 years, however, the study was included if the mean age of participant fell within this range, to accommodate additional evidence from slightly older populations. No restrictions were applied on **language or geographical location**. This review aimed to include diverse ***types of interventions***, including psychosocial interventions (interventions that use a psychological, behavioral or social approach, or a combination of these to achieve key outcomes) *(76)*, educational/literacy interventions, and if applicable, structural interventions. Structural interventions could involve health systems support to limit accidental disclosure or communicate how partial disclosure may have been initiated. Importantly, these interventions could be implemented following testing and diagnosis, as well as at distinct points along the HIV continuum (accounting for delayed disclosure to children). We also paid attention to existing disclosure tools in use with accompanying evaluations. ***Types of evaluations*** included systematic reviews and meta-analyses of relevant interventions; evaluated in randomized trials, cluster randomized trials, crossover trials, factorial trials; interventions evaluated in quasi-experimental studies including pre-post studies; and rigorous qualitative studies and process evaluations of interventions. In addition to peer-reviewed literature, the review also engaged with unpublished reports, pre-prints, conference proceedings, and other relevant project documentation from key implementers.

A series of structured, systematic searches on PsycINFO, PubMed, SCOPUS, and Web of Science databases was conducted in June 2024 (see sample search string below), resulting in over 1 400 final records that were reviewed and evaluated. After reviewing and screening for relevance, most study records were removed for incorrect population, incorrect publication type, or incorrect scope of focus. A draft list of 22 interventions was created and circulated to experts from the Adolescent Service Delivery Working Group and the WHO steering group convened for this document. These experts reviewed the list and shared missing results. Additional documents and evaluations were identified, including peer-reviewed publications and grey literature (not formally published in peer-reviewed journals) including programmatic reports, technical briefs, and conference posters.

Table A2. Sample search string

("Children living with HIV" OR "Youth living with HIV" OR "Adolescents living with HIV" OR "Young people living with HIV" OR "children with HIV" OR "youth with HIV" OR "Adolescents with HIV" OR "HIV-infected child*" OR "HIV-infected youth" OR "HIV-infected adolescent" OR "HIV-infected young people" OR "Mother* living with HIV" OR "mothers with HIV" OR "HIV-infected mother" OR "HIV-infected parent" OR "Healthcare worker" OR "Health care worker" OR "Health worker" OR "Health care provider" OR "Healthcare provider" OR "Community health worker" OR "Lay health worker" OR "Community health volunteer" OR "HIV counsellor" OR "Peer counsellor" OR “young MSM” OR “young men who have sex with men” OR “young gay men”) AND (intervention OR "Psychosocial intervention" OR "Health literacy intervention" OR "Psychological intervention" OR "structural intervention") AND ("Disclosure of HIV status" OR disclosure OR "HIV disclosure" OR "peer disclosure" OR "caregiver disclosure" OR "status notification")

Key information about each intervention evaluation was extracted using a structured template used by the team in previous systematic and scoping reviews of psychosocial interventions. This template included options to extract implementation setting, target age range, target audience, any population-specific considerations, disclosure focus area (specific or inclusive), core components of the intervention, the intervention facilitator/ delivery agent, the delivery platform, intended and actual outcomes, and implementation context.

Applying a “realist” approach to disclosure-specific interventions

Realist evaluation methods are increasingly being used to assess and refine interventions, including adolescent HIV outcomes *(19)*. Realist methods can provide a structure that helps to explain and understand interventions

as they are delivered in "real-world" settings by looking at the context and people involved. These approaches also try to draw out mechanisms that explain how different "ingredients" can lead to intended outcomes *(20)*.

All disclosure-specific interventions were closely reviewed, and rich descriptions were generated for each. In some cases, multiple publications or evidence types were triangulated to build a better picture of how the intervention was ultimately implemented and evaluated. Several interventions had briefer descriptions, limiting the possibility of a deeper analysis of realist evaluation.

For each intervention using rich descriptions, a series of context-mechanism-outcome (CMO) statements was generated. These statements used available data, author reflections on the intervention findings, and further observations and assumptions gleaned from evaluations. These CMO statements were combined and thematically grouped to create a working theory of how disclosure-specific interventions work in practice, covering contextual factors (C) shaping mechanisms (M) theorized to set off specific outcomes (O) (see **Figure 2**). These summary statements were derived from extracted data from 11 disclosure-specific interventions from 13 countries with sufficient richness and which reported on evaluations.

Annex 2. All included interventions, with index publications

Intervention title	Country where implemented	Related published papers
Namibia Ministry of Health and Social Services pediatric HIV disclosure intervention	Namibia	Pediatric HIV Disclosure Intervention Improves Knowledge and Clinical Outcomes in HIV-Infected Children in Namibia (Beima-Sofie 2017); "If I Take My Medicine, I Will Be Strong:" Evaluation of a Pediatric HIV Disclosure Intervention in Namibia (O'Malley 2015); Growing-up just like everyone else: key components of a successful pediatric HIV disclosure intervention in Namibia (Brandt 2015)
Adapted Blasini disclosure model	Haiti; Dominican Republic	Disclosure of HIV status to perinatally infected youth using the adapted Blasini disclosure model in Haiti and the Dominican Republic: preliminary results (Beck-Sague 2015)
HADITHI disclosure intervention	Kenya	Tablet-based disclosure counselling for HIV-infected children, adolescents, and their caregivers: a pilot study (McHenry 2018); Evaluating a patient-centred intervention to increase disclosure and promote resilience for children living with HIV in Kenya (Vreeman 2019); Factors associated with caregiver compliance to an HIV disclosure intervention and its effect on HIV and mental health outcomes among children living with HIV: post-hoc instrumental variable-based analysis of a cluster randomized trial in Eldoret, Kenya (Magill 2023)
Clinic education model for HIV-infected children - Adapted disclosure education intervention	Papua New Guinea	Human immunodeficiency virus status disclosure and education for children and adolescents in Papua New Guinea (Orelly 2018)
Sankofa	Ghana	Clinic-Based Pediatric Disclosure Intervention Trial Improves Pediatric HIV Status Disclosure in Ghana (Paintsil 2020); SANKOFA: a multi-site collaboration on paediatric HIV disclosure in Ghana (Reynolds 2015); Pediatric HIV Disclosure Intervention Improves Immunological Outcome at 48 Weeks: The Sankofa Trial Experience (Shabanova 2023)
Family group psychotherapy	Italy	Family group psychotherapy to support the disclosure of HIV status to children and adolescents (Nicastro 2013)
Kalembelembe disclosure program	DRC	HIV Disclosure to Infected Children Involving Peers: A New Take on HIV Disclosure in the Democratic Republic of Congo (Kitelele 2023)

Plan-Do-Study-Act cycles	US	Optimizing Disclosure of HIV Status to a Diverse Population of HIV-Positive Youth at an Urban Pediatric HIV Clinic (Dantuluri 2021)
Quality improvement collaborative	Zimbabwe	Implementation of a Quality Improvement Collaborative of HIV Status Disclosure of Young People Living with HIV in Zimbabwe (supplied by partner; Sellberg 2023; poster)
PHRU disclosure intervention	South Africa	Guiding caregivers through disclosure: a qualitative investigation into caregivers' responses to a disclosure intervention for HIV-infected children in Soweto, South Africa (handsearched; Joyce 2021; pre-print); Experiences of South African caregivers disclosing to their children living with HIV: Qualitative investigations (handsearched; Joyce 2022)
Story: "Peter's and Julia's Discovery: conversing about health and illness"	Brazil	A story for children to help children with HIV understand the health-disease process (Brondani 2013)
Sauti ya Vijana	Tanzania	Building resilience: a mental health intervention for Tanzanian youth living with HIV (Dow 2019); A group-based mental health intervention for young people living with HIV in Tanzania: results of a pilot individually randomized group treatment trial (handsearched; Dow 2020); Sauti ya Vijana (SYV; The Voice of Youth): Longitudinal Outcomes of an Individually Randomized Group Treatment Pilot Trial for Young People Living with HIV in Tanzania (handsearched; Dow 2022)
KidzAlive	South Africa	Post-training and mentorship experiences of KidzAlive-trained health workers at primary healthcare facilities in KwaZulu-Natal, South Africa (Mutambo 2020)
Red Carpet Program (RCP)	Kenya	Optimizing linkage to care and initiation and retention on treatment of adolescents with newly diagnosed HIV infection (Ruria 2017); Supporting adolescents living with HIV within boarding schools in Kenya (Kose 2021); Experiences of adolescents and youth with HIV testing and linkage to care through the Red Carpet Program (RCP) in Kenya (Kose 2024)
Standardized Patient clinical training intervention	Kenya	Pilot evaluation of a standardized patient actor training intervention to improve HIV care for adolescents and young adults in Kenya (Mugo 2019)
I ACT	South Africa	Integrated access to care and treatment (I ACT) support groups for adolescents living with HIV in public healthcare facilities in South Africa: feasibility and acceptability for scaling up (James 2018)
ZENITH intervention	Zimbabwe	Community health worker support to improve HIV treatment outcomes for older children and adolescents in Zimbabwe: a process evaluation of the ZENITH trial (Dziva Chikwari 2018)
Psychosocial support (PSS) programme, Right to Care Mini Flipster	South Africa	Psychosocial Support Programme Improves Adherence and Health Systems Experiences for Adolescents on Antiretroviral Therapy in Mpumalanga Province, South Africa (Okonji 2022); Implementation of a Psychosocial Support Intervention for Adolescents on Antiretroviral Treatment: Challenges and Experiences from Ehlanzeni District, South Africa (Okonji 2022); Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa (Okonji 2022)

CHAMP+/VUKA	Thailand, South Africa	Cultural Adaptation of an Evidence-Informed Psychosocial Intervention to Address the Needs of PHIV+ Youth in Thailand (Pardo 2017), The VUKA Family Program: Piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa (handsearched; Bhana 2014)
Timiza Ndoto	Tanzania	Timiza Ndoto (Achieving Dreams): Supporting Adolescents and Treatment Supporters in Achieving Viral Suppression (supplied by partner; PEPFAR, USAID, EGPAF, Engender Health; brief)
Yika Mpiko	DRC	Optimizing Viral Load Re-suppression and Disclosure Support for Children and Adolescents Living with HIV in the Democratic Republic of the Congo: The Yika Mpiko Model (supplied by partner; EGPAF, 2023)
Adolescent Transition Package (ATP)	Kenya	Transition to independent care for youth living with HIV: a cluster randomised clinical trial (Njuguna 2022); Adolescent transition to adult care for HIV-infected adolescents in Kenya (ATTACH): Study protocol for a hybrid effectiveness-implementation cluster randomised trial (Njuguna 2020)
Positive STEPS	US	Positive Strategies to Enhance Problem-Solving Skills (STEPS): A Pilot Randomized, Controlled Trial of a Multicomponent, Technology-Enhanced, Customizable Antiretroviral Adherence Intervention for HIV Infected Adolescents and Young Adults (Mimiaga 2019)
Project ACCEPT	US	Stigma Reduction in Adolescents and Young Adults Newly Diagnosed with HIV: Findings from the Project ACCEPT Intervention (Harper 2014)
SMART Connections	Nigeria	An Online Support Group Intervention for Adolescents Living with HIV in Nigeria: A Pre-Post Test Study (Dulli 2018)

Annex 3. Expert inputs

WHO steering group

This document has been guided by a WHO expert steering group (see acknowledgements section) as well as by the WHO adolescent service delivery working group (ASDWG).

WHO ASDWG

The ASDWG is a technical body of adolescent HIV experts that advises on WHO guideline development as it relates to adolescent service delivery as well as its implementation and scale up in countries, as well as other relevant policy issues. The group periodically reviews key documents including policy briefs and articles for publication in peer-reviewed journals and provides feedback and advice to ensure these documents are in line with sound technical and programmatic thinking. For the purposes of this document, the group will provide conceptual, technical, and editorial inputs.

The conceptualization and development of this document was achieved over the course of 2024. All technical collaborations and contributions, including all PEPFAR affiliated collaborations preceded 20 January 2025.

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Department of HIV/AIDS

World Health Organization
20 Avenue Appia
1211 Geneva 27
Switzerland

hiv-aids@who.int
www.who.int/hiv

www.who.int