

Disclosure in young people living with HIV



Dr Nicola van Dongen

Empilweni Services and Research Unit
Rahima Moosa Mother and Child
Hospital

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Intentions

- Importance of disclosure
- Definitions and considerations
- Core principles
- Considerations for the young person
- Challenges
- Supporting the young person



Link:

<https://knowledgehub.health.gov.za/webinar/orientation-children-and-adolescents-disclosure-counselling-flipchartdisclosure-tool-hiv>

Why?



People are surviving with HIV¹

Disclosure → relevant and appropriate

Awareness of chronic illness and consequences

Central to well-being



Improved long term benefits^{1,2}

Physical, emotional, cognitive and social well-being.

Close gaps in prevention

Enhance treatment outcomes



Empowerment¹

Critical health literacy step
Appropriate information for developmental age.

Establish health seeking behaviours

Despite anxiety...



Disclosure

- ↓ Mortality and morbidity¹
- ↑ Psychosocial functioning^{1,2}
- ↑ Empowerment with knowledge¹
- ↓ Stigma^{1,2}
- ↑ Adherence and retention in care¹
- ↑ Agency and health seeking behaviour^{1,2}
- ↓ Transmission¹



Non-disclosure

- Autonomy threatened¹
- Denied their own health information¹
- Psychosocial fallout¹
- Poorer retention¹
- Poorer prognosis¹
- Non adherence¹
- Transmission risk¹

The **process** by which
children, adolescents, or patients
are made **aware** of their own HIV status,
enabling them
to **share it safely** and
engage in health **decision-making**.

(World Health Organization²)

Core principles^{1,2}

Developmentally appropriate
communication

Caregiver
led, HCW/
supported

Gradual structured, repeated conversations

Non-
stigmatising,
non blaming

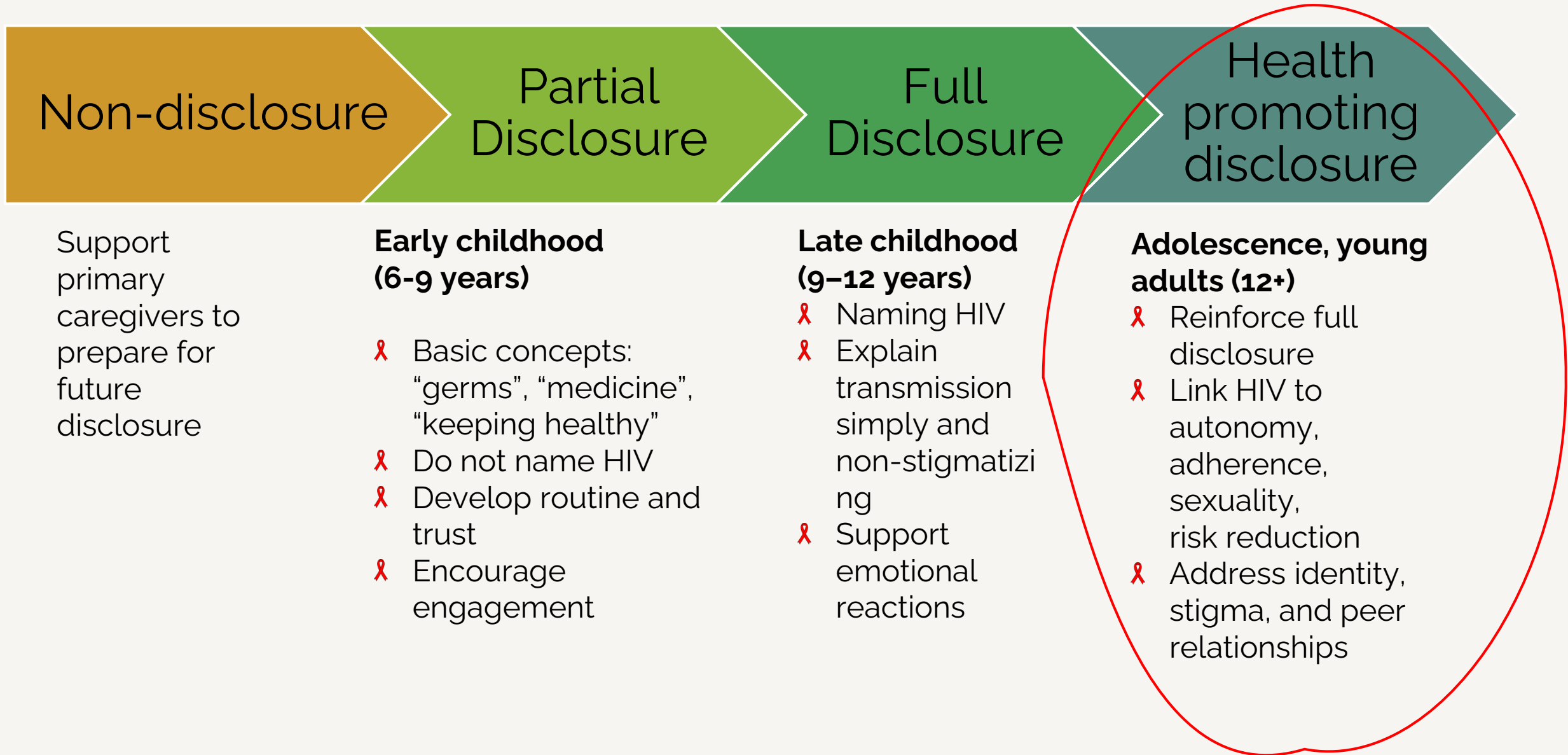
Children have
a right to know

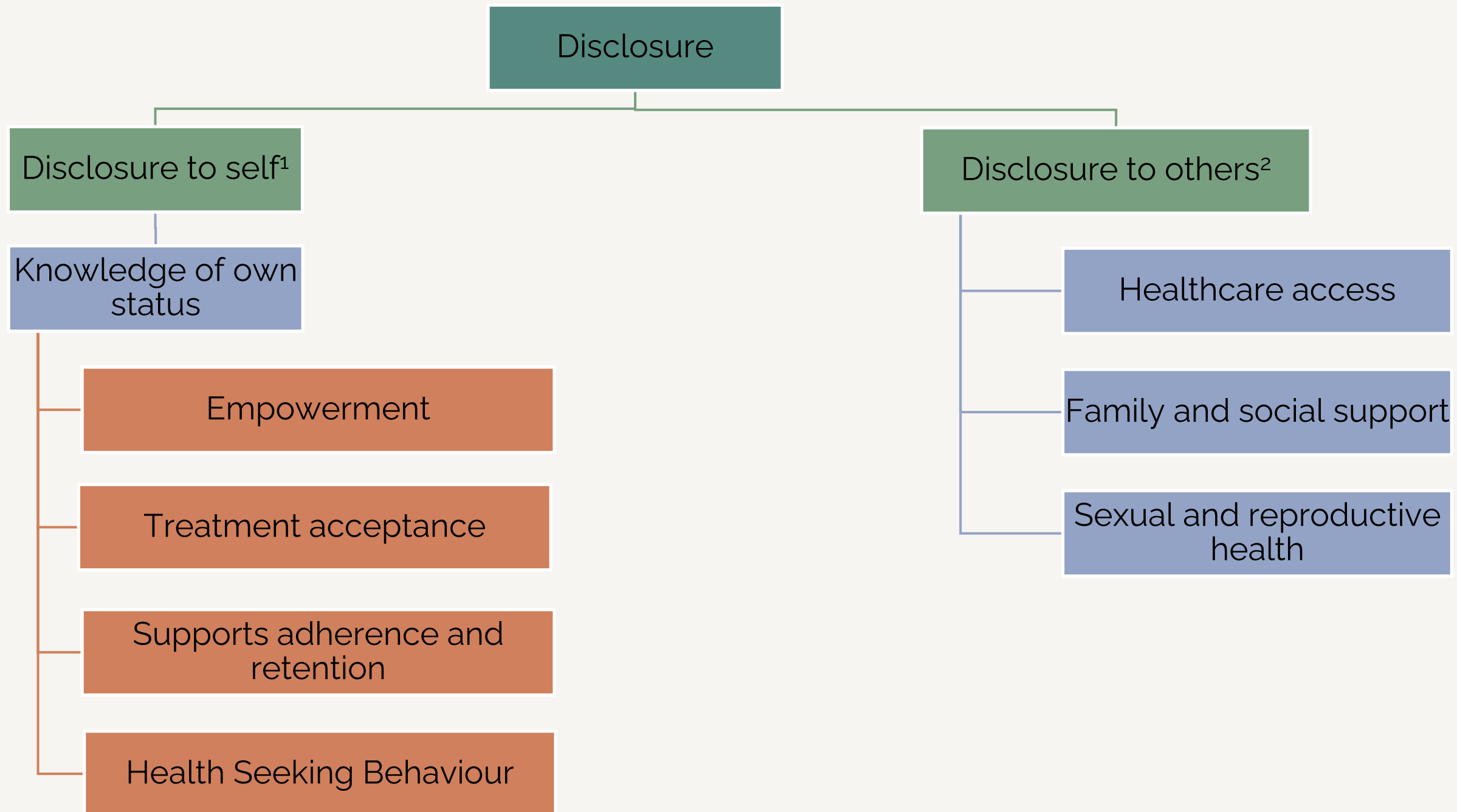
Best interests:
Risk vs benefit

Confidentiality
and privacy

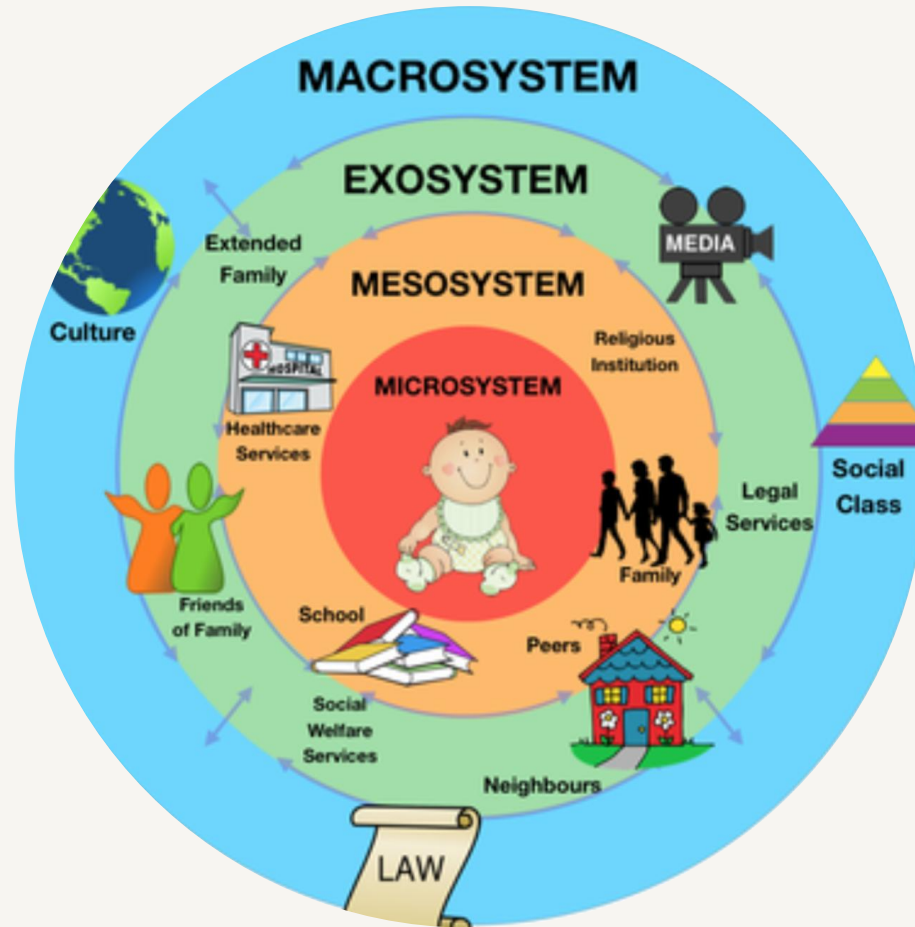
Ongoing
support and
mental health

Disclosure is a process, not an isolated event





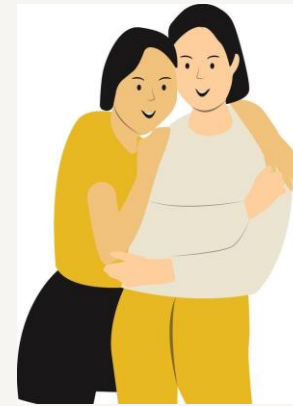
The young person's context¹



Uncomplicated vs Complicated
disclosure determine by¹:

- 🚫 Transmission route
 - 🚫 Trauma
 - 🚫 Violence
 - 🚫 Support
 - 🚫 Disability

New
diagnosis



HIV
positive
youth

Perinatal
infection
with
disclosure

Perinatal
infection
with no
disclosure



Challenges to disclosure¹

Primary Care Giver

- Fear
- Guilt/ Shame
- Involuntary disclosure
- Not prepared
- Acceptance
- Financial implications

Health care professional

- Lack skills/ tools
- Confidence
- Miss opportunities to educate
- Negative attitudes
- Unfriendly staff

Health System

- Identify and intervene
- Child, adolescent and youth friendly spaces



DISCLOSE TOO LATE

Challenges for the young person

Stigma

Internalized, anticipated, and enacted²

Communication

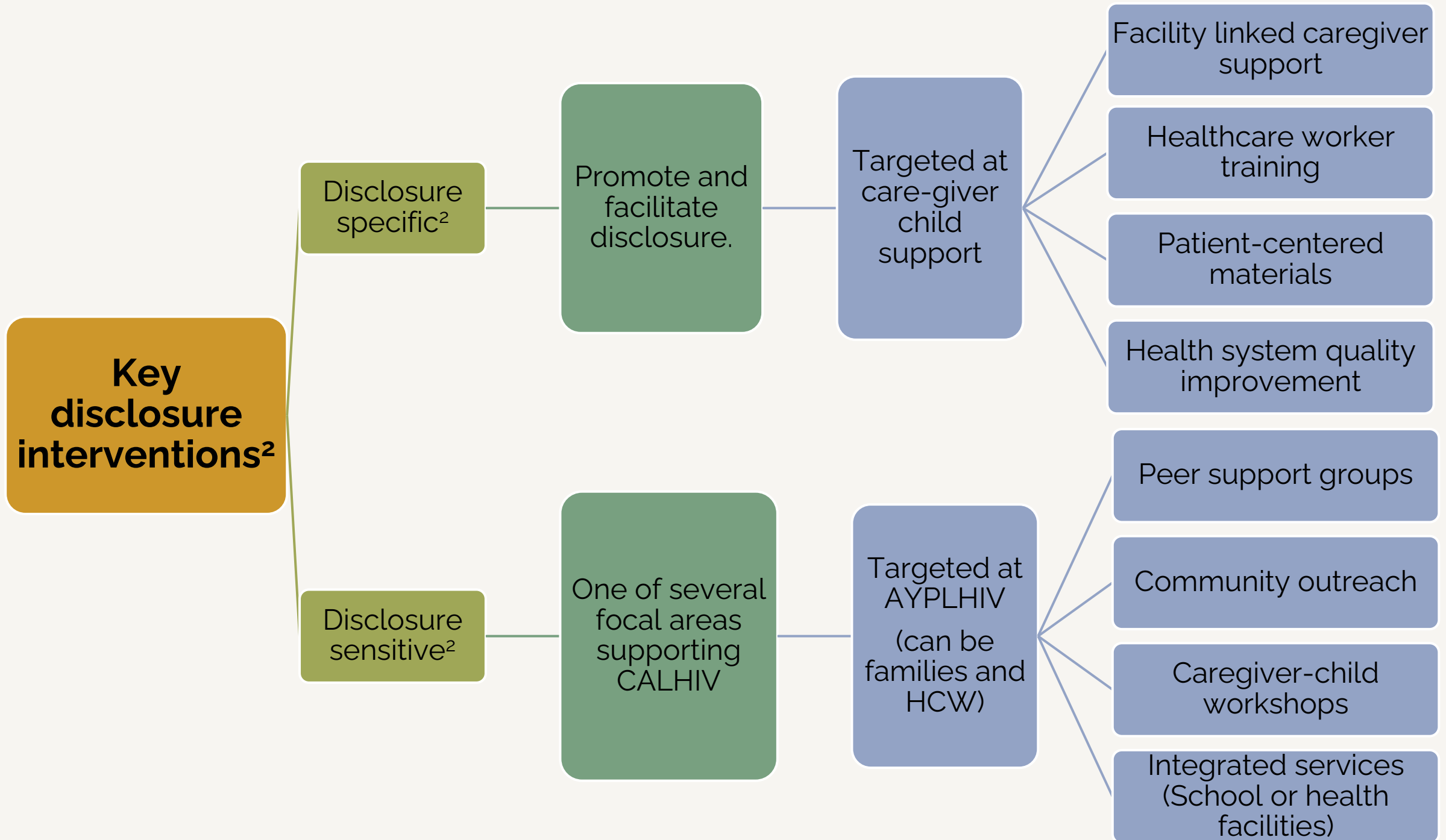
Effective communication of a sensitive topic²

Role of friends and peers

Consequences of onwards disclosure.²

Personal safety

Influence on relationships- family, friends and sexual partners²



Supporting young people after disclosure^{1,2}

Emotional reactions:
fear, anger, sadness,
relief

Building resilience and
self-esteem

Psychosocial support:

- Support groups
- Peer navigators
- YFS

Monitoring mental
health:
screening for
depression/anxiety

Ongoing conversations
about:

- Sexual health
- Relationships
- Substance use

Future planning

- Who: risks v benefits
- Safety planning for consequences
- Ethical disclosure

Successful disclosure¹

- 🚫 Intentional
- 🚫 Start as soon as possible
- 🚫 All stakeholders: prepared to tell the truth
- 🚫 Family-centred: significant role-players in the young person's life
- 🚫 Prepared
 - 🚫 Caregiver, HCW, adequate health services
- 🚫 Health promoting
- 🚫 Adequate support available.
 - 🚫 Family and young person
 - 🚫 Support for complex disclosure
 - 🚫 Ongoing psychosocial support

Take away

- Disclosure improves treatment adherence, mental health, and long-term health outcomes
- “Disclosure is not a single conversation—it’s a lifelong dialogue.”
- It must be **planned, staged and supported**
- Health workers play a central role in empowering caregivers and young people to take knowing your status to empowering healthy decision making behaviours

References

1. South African National Department of Health. *Disclosure Guidelines for Children and Adolescents in the context of HIV, TB and non-communicable diseases*. 2016 Jul [Accessed 29th July 2026]. https://sahivsoc.org/Files/NDoH_hiv-disclosure-guideline.pdf [Accessed 29th July 2026].
2. World Health Organization. *Supporting disclosure among children and adolescents living with HIV: interventions, emerging considerations, key gaps and key actions*. 2025 [Accessed 29th July 2026]. <https://iris.who.int/server/api/core/bitstreams/e59aff84-ba2f-4691-83c8-3af0651d9a14/content> [Accessed 29th July 2026].

