

ETHICS AND DISCLOSURE TO CHILDREN AND ADOLESCENTS

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ETHICS AND DISCLOSURE

- A mini-workshop
- Experiential and Interactive

Outline

- Disclosure, Ethics and Children's Rights
- Disclosure and Adolescents
- Disclosure and Children

DISCLOSURE

- Disclosure is a challenge:
 - Parents /caregivers disclosing to a child his/her status
 - Parents disclosing their own status to children
 - Adolescents in intimate relationships
 - A challenge for HCP



DISCLOSURE

- Telling children that they have a stigmatised and sexually transmissible disease
- Raises important ethical issues e.g.
 - When HCP recommends disclosure but parent/caregiver refuses
 - Issues of how to disclose



WORKING WITH CHILDREN

Ethical Principles	For disclosure	Against
Autonomy	The right to know Empowering Offers medical benefits -Adherence Safe sex	Parent deals with consequences; parent generally acts in child's best interests; parent has right to decide
Beneficence	Increases use of psychosocial services Reduces burden of secrecy Builds parent child relationships	Protects child from burden of knowing
Non-Maleficance	Prevents deception of child	Could increase family stigma; could increase anxiety/depression/give rise to parent guilt
J. Clin Ethics, 2008, 19(1)		

RIGHTS AND ETHICS

- Human rights and ethics in healthcare are complementary
- Use of both together maximises protection of the child/adolescent





CHILDREN'S RIGHTS

- **South Africa** has adopted a rights-based approach to HIV
- A **fundamental reference point** for disclosure
- Orientation provides a **holistic** and **appropriate** framework for guiding practice
- Important for dealing with the myriad **contextual factors** related to disclosure
- Children's rights approaches and practices often **not widely understood** or supported

CHILDREN'S RIGHTS

Specific rights related to disclosure

1. Every child has the right to **survival**

2. Every child has the right to **healthcare** including mental health

3. All children have the right to **prevention of disability** and where this exists to have special provisions for special needs

4. Every child has the right to **information**

5. Every child has the right to **participate**, including in their own healthcare and decision-making about themselves

6. Every child has the right to **privacy**

7. Every child has the right to be **protected from discrimination** and stigma

8. Every child has the right to **respect** and **dignity**

CHILDREN'S RIGHTS

Are rights being upheld?	Do children?
1. Survival	Understand the importance of treatment adherence
2. Healthcare and mental health promotion	Have access to psychosocial support
3. Prevention of disability/provision for special needs	Enjoy and enabling environment with access to information that addresses their needs
4. Right to information	Obtain developmentally appropriate information; have questions answered; acquire knowledge of HIV

CHILDREN'S RIGHTS

Are these rights being upheld	Do children
5. Participation	Act as active participants in healthcare
6. Privacy and confidentiality	Decide who should know their status
7. Protection from stigma	Have protection from stigma or assistance in dealing with it
8. Respect and dignity	Experience this in families/community



RIGHTS AND THE LAW

- Key legislation pertinent to HIV
 - The Children's Act (No 38 of 2005)
 - Need to reform law regulating provision of medical care for children especially in light of HIV pandemic
 - Sections give effect to children's rights to participate in health treatment decisions
 - Sets out principles concerning the role of children, parents and healthcare professions in making decisions about healthcare services
 - Addresses HIV counselling testing
 - Confidentiality of information

THE LAW AND DISCLOSURE

Key points

- A child's HIV status can be disclosed when:
 - Consent is given for disclosure
 - Disclosure is required by law
- The person who has the right to confidentiality can consent to disclosure to others of the child's status
 - A child of 12 years or older consents to disclosure
 - - The parent or guardian of a younger child consents to disclosure



THE LAW AND DISCLOSURE

- Disclosing a child's HIV status may be required by law
- A HCP can disclose in order to do their job if in child's best interests e.g.
 - Home based care teams
 - Reporting abuse
 - Disclosure may be required for legal proceedings (e.g. Children's Court - fostering, adoption)

POLICIES, FRAMEWORKS & GUIDELINES

Guidelines on HIV Disclosure Counselling for Children up to 12 years of age (World Health Organisation, 2011)

- Lack of disclosure affects well-being
- Cognitively ready for disclosure 8-11 years
- Cognitively and emotionally mature children of school going age should know their status
- Younger children should be told incrementally
- Adopt a process orientated and developmental approach

POLICIES, FRAMEWORKS & GUIDELINES

National Guidelines on HIV Disclosure for Children and Adolescents (in draft)

- Children and adolescents 12-18 years
- National framework offers a model for disclosure
- Facilitates a structured approach
- Emphasises child participation, family, age and stage appropriate interventions, rights of the child (S.A Constitution)
- Reinforces NSP goal of psychosocial support

REFERENCES

- *A guide to the Children's Act for Health Professionals, Children's Institute, June 2010, UCT)*
- *Legal, ethical and counselling issues related to HIV testing of children (2012), HSRC.*
- *Children's Rights Centre Clearing House on HIV and AIDS Disclosure for Children*

www.hivaidsdisclosure.co.za

