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

<table>
<thead>
<tr>
<th>Ethical Principles</th>
<th>For disclosure</th>
<th>Against</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Autonomy</strong></td>
<td>The right to know&lt;br&gt;Empowering&lt;br&gt;Offers medical benefits&lt;br&gt;-Adherence&lt;br&gt;Safe sex</td>
<td>Parent deals with consequences; parent generally acts in child’s best interests; parent has right to decide</td>
</tr>
<tr>
<td><strong>Beneficence</strong></td>
<td>Increases use of psychosocial services&lt;br&gt;Reduces burden of secrecy&lt;br&gt;Builds parent child relationships</td>
<td>Protects child from burden of knowing</td>
</tr>
<tr>
<td><strong>Non-Malfeasance</strong></td>
<td>Prevents deception of child</td>
<td>Could increase family stigma; could increase anxiety/depression/give rise to parent guilt</td>
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</tbody>
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*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

<table>
<thead>
<tr>
<th>Specific rights related to disclosure</th>
<th></th>
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<tbody>
<tr>
<td>1. Every child has the right to <strong>survival</strong></td>
<td>6. Every child has the right to <strong>privacy</strong></td>
</tr>
<tr>
<td>2. Every child has the right to <strong>healthcare</strong> including mental health</td>
<td>7. Every child has the right to be <strong>protected from discrimination</strong> and stigma</td>
</tr>
<tr>
<td>3. All children have the right to <strong>prevention of disability</strong> and where this exists to have special provisions for special needs</td>
<td>8. Every child has the right to <strong>respect</strong> and <strong>dignity</strong></td>
</tr>
<tr>
<td>4. Every child has the right to <strong>information</strong></td>
<td></td>
</tr>
<tr>
<td>5. Every child has the right to <strong>participate</strong>, including in their own healthcare and decision-making about themselves</td>
<td></td>
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</table>
# CHILDREN’S RIGHTS

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

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