



Protecting and empowering children : Some complexities:

The legal framework for therapeutic and research interventions
with children

Ann Strode

School of Law & HIV AIDS Vaccines Ethics Group (HAVEG)
UKZN

Children in our legal framework

- Persons under the age of 18 – limited legal capacity
- Major & adult at 18
 - S 17, Children's Act
- Children are not a homogenous group
 - Evolving capacity under 18
 - Infants
 - Middle childhood
 - Adolescents

Children's health is a a key rights issue

- Article 24, Convention on the Rights of the Child
- States should 'recognize the right of the child to the enjoyment of the highest attainable standard of health'
 - (1) ensuring access to health services
 - (2) diminish infant and child mortality
 - (3) provide medical assistance
 - (4) nutritious foods
 - (5) pre-and post-natal care
 - (6) information
 - (7) preventive health care

- S 28 of the Constitution of the Republic of South Africa, 1996 ‘basic health care services’
- S 27 – everyone has the right to ‘access health care services’

Implementing these standards

- Requires norms and standards regarding the **nature of the services** that are going to be provided and norms on **how such services are to be provided so they protect a child's rights**
- Focus on how such services should be provided in both a clinical and research setting
 - Consent
 - Privacy
 - Mandatory reporting

Key health interventions with children

Health intervention	Laws
HIV testing Access to contraceptives & contraceptive advice Medical treatment Male circumcision Operations	Children's Act
TOPs	Choice of Termination of Pregnancy Act
Research	National Health Act

Consent

- **General principle**
- Everyone has the right to bodily integrity
 - S 12 Constitution of the Republic of South Africa, 1996
- Treatment/health services/research may only be provided with consent
 - S 7 of National Health Act - a health service may not be provided to a user without the user's informed consent
 - Exceptions

- S 71 of the National Health Act provides that written consent is required for health research
 - Written consent only not required for record reviews undertaken by health care workers
 - S 16, National Health Act

Consent & children

- Children have evolving capacity within childhood
 - Children may consent independently to various therapeutic interventions
 - Children's Act and Choice of Termination of Pregnancy Act
 - Children always need consent from their parents or guardians for health research
 - Children with 'understanding' will consent alongside the proxy consentor for research
 - S 71 of the National Health Act

Intervention	Age
Medical treatment	12, if the child has 'sufficient maturity' and the mental capacity to make the decision
HIV testing	12
Contraceptives and contraceptive advice	12
Male circumcision	16 + counselling
Operations	12, if the child has 'sufficient maturity' and the mental capacity to make the decision and are 'assisted' by their parents
TOPs	No age specified
Research	18

Complexities

- Complexity with the evolving capacity approach is that parliament has no clear rule or approach
 - 4 different approaches to when a child has the capacity to consent without assistance

No express requirement for capacity to consent	Must be a certain age to have capacity to consent	Must be a certain age and demonstrate capacity	Must be a certain age and meet other requirements to give consent
TOPs	Contraceptives and contraceptive advice Research	HIV testing U 12 Medical treatment	HIV testing over 12 - BI MC – 16 + counselling Operations – 12 + parental assistance

Implications

Therapeutic relationships

Clinicians must be aware of these different requirements

- Presumption at that age they have capacity
- Other requirements are met

Must be able to assess capacity for HIV testing u12 & medical treatment

Research relationships

Parents/guardians will always be involved in the consent process

Privacy

- **General principle**
- Everyone has the right to privacy
 - S 14, Constitution of the Republic of South Africa, 1996
 - S 14, National Health Act - all information concerning a user, including information relating to his or her health status, treatment or stay in a health establishment, is confidential

Privacy and children

- Children's Act
 - Confidentiality on their health status - s 13(1)(d)
 - HIV testing – s 133
 - Condoms, contraceptives and contraceptive advice – s 134
 - Argue privacy regarding interventions to which children can consent independently

- National Health Act
 - No reference to a child's right to privacy
- Choice of Termination of Pregnancy Act
 - Every women has the right to privacy regarding a TOP, s 7(5)

Implications

Therapeutic relationships

Children have a right to privacy regarding

- TOPs (any age)
- Contraceptives, contraceptive advice (over 12)
- HIV testing results (over 12)
- Interventions they have provided independent consent to

Research relationships

Children have no right to privacy regarding research participation as parental/LG consent required

May have the right to privacy regarding certain therapeutic interventions in the study

Mandatory reporting requirements

- **General principle**
- Privacy rights can be limited to protect vulnerable groups

Mandatory reporting and children

- Children's Act
 - Report children who are being abused, neglected or who are in need of care and protection, s 110
 - Mandatory reporting obligations on certain professionals
 - Voluntary reporting on everyone else

- Abuse - ‘any form of harm or ill-treatment deliberately inflicted on a child, and includes— (a) assaulting a child or inflicting any other form of deliberate injury to a child; (b) sexually abusing a child or allowing a child to be sexually abused; (c) bullying by another child; (d) a labour practice that exploits a child; or (e) exposing or subjecting a child to behaviour that may harm the child psychologically or emotionally’
- Neglect is a ‘a failure in the exercise of parental responsibilities to provide for the child’s basic physical, intellectual, emotional or social needs’

- Children in need of care and protection – circumstances
- Eg:
 - Dependant on drugs – no support
 - Child labour

- Sexual Offences Act
 - Report all sexual offences against children
 - Consensual sex between the ages of 12 – 16
 - Sex under the age of 12

Therapeutic relationships

Mandatory obligations on doctors to report, abuse, neglect or children in need of care and protection and under-age sex – these obligations may conflict with other laws eg, obligation to provide contraceptives

Research relationships

Mandatory obligations are only on certain members of the research team

Adolescent research must address reporting consensual sex

Mandatory reporting obligations in ICF

Approach used in the SASHA study

- SASHA study with adolescents developed an ethical-legal memo which was presented to the RECs and used as a guide during the implementation of the study
- Applied these key legal principles to develop 9 norms

Key ethical-legal norms for adolescent prevention trials

- 1) A parent or legal guardian (LG) should provide consent for adolescents to take part in prevention trials
- 2) Adolescents should consent independently for key trial components
- 3) Adolescents should enjoy confidentiality for key trial components
- 4) Adolescents' right to confidentiality can be limited and adolescents asked to disclose to a trusted adult in some instances
- 5) Both parent and adolescent should understand what information will/will not be made available to parents

- 66) If adolescents are being abused, neglected or maltreated, this should be reported to authorities and adolescents should be assisted
- 7) If adolescents are engaged in underage sex that is exploitative and non-consensual, this should be reported to authorities and adolescents should be assisted
- 8) There is no legal obligation to report other offenses but adolescents should be assisted
- 9) Both parent and adolescent should consent to confidentiality limits posed by reporting to authorities.

Conclusions

- There is a complex legal framework governing the provision of therapeutic and research services to children
- Framework is premised on different principles which at times conflict with each other
 - Evolving capacity – child participation/empowerment
 - Child protection

- Careful consideration is required of how to apply these principles in practice