

Disability, vulnerability and HIV/AIDS risk: Implications for clinical practice.

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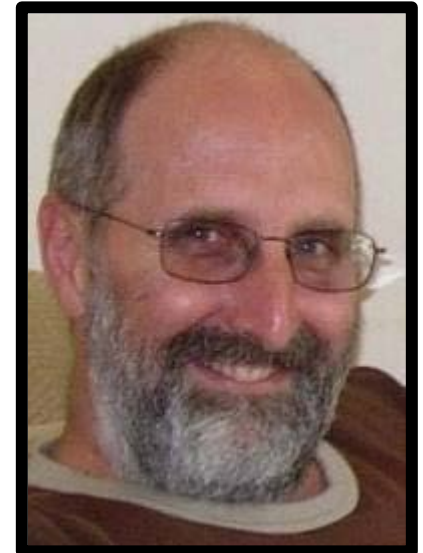
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Disability/HIV working group



Structure of talk

- To describe the relationship between HIV/AIDS and disability through historical and epidemiological data.
- To discuss risk factors for HIV infection for disabled people.
- To discuss ethical issues relating to disability and sexuality including dilemmas for clinicians.
- To present data from my recent PhD thesis on HIV prevention issues for deaf and hard of hearing adolescents illustrating some of these issues.
- To describe achievements in the field to date and challenges ahead.

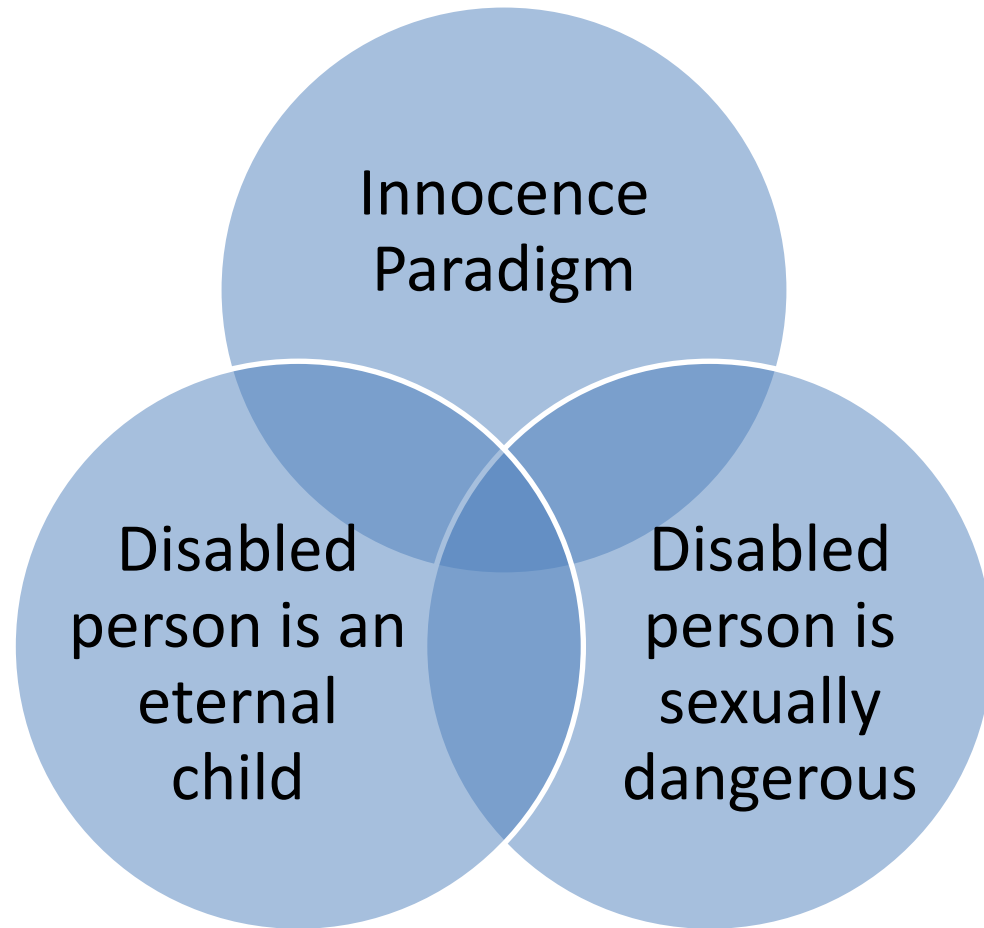
Relationship between disability and HIV/AIDS.

- HIV and disability have a bidirectional relationship.
- HI virus is a risk factor for disability including neurocognitive impairment, hearing loss and physical disability.
- BUT people with sensory, hearing, physical, or intellectual disability are also at risk of HIV/AIDS and this is not always well acknowledged.

Relationship between disability and HIV/AIDS

- Ferguson & Jelsma (2009) found that prevalence of motor delay in HIV positive children (age 1 – 33 months) was 66.7%.
- Smith et al (2006) found poor cognitive development in children perinatally infected with HIV.

Innocence paradigm



Anne Finger:

‘Sexuality is often the source of our deepest oppression; it is often the source of our deepest pain. It’s easier for us to talk about-and formulate strategies for changing-discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction. (as cited in Shakespeare, 1996, p. 5)’

Relationship between disability and HIV/AIDS

- Why is the sexuality of disabled people not acknowledged?
- History of eugenics movement and role in denying disabled people their sexuality.
- Eugenics is 'the doctrine that claims it is possible and desirable through selective breeding and the elimination of undesirable individuals to alter the hereditary qualities of a race or population. Eugenics is based on the struggle for resources between fit and unfit.'
- In 1933 in Germany - reduced standard of care for 'handicapped' patients.
- Most common manifestations are through sterilisations without consent.



Sterilisation of disabled people today

- Ashley ‘the pillow angel’
- Diagnosed with static encephalopathy, a disability that causes severe cognitive impairment.
- Infantile or childlike for her entire lifespan, requiring assistance with basic functions such as eating or going to the bathroom.
- Hysterectomy
- Removal of breast buds.

Sterilisation of disabled people today

- 21 year old intellectually disabled woman (UK)
- Already had 1 pregnancy
- Her mother is in court asking to have her sterilised as child rearing will fall to her.
- Court asks if she lacks the capacity to consent to sterilisation?
- India law passed where a health care provider can be fined if sterilising a disabled woman without consent.

Nora Groce (2003)

THE LANCET

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The Lancet, [Volume 361, Issue 9367](#), Pages 1401 - 1402, 26 April 2003
doi:10.1016/S0140-6736(03)13146-7 [Cite or Link Using DOI](#)

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HIV/AIDS and people with disability

[Nora Ellen Groce](#) 

Although AIDS researchers have studied the disabling effects of HIV/AIDS on previously healthy people, little attention has been given to the risk of HIV/AIDS for individuals who have a physical, sensory, intellectual, or mental health disability before becoming infected. It is commonly assumed that disabled individuals are not at risk. They are incoorectly thought to be sexually inactive, unlikely to use drugs, and at less risk for violence or rape than their non-disabled peers. Yet a growing body of research indicates that they are actually at increased risk for every known risk factor for HIV/AIDS. For example, in a recent article, [S Blumberg and W Dickey](#)¹ analyse findings from the 1999 US National Health Interview Survey and show that adults with mental health disorders are more likely to report a medium or high chance of becoming infected with HIV, are more likely to be tested for HIV infection, and are more likely to expect to be tested within the next 12 months than are members of the general population.

Such findings should not be unexpected for individuals with disability. There are significant risk factors for disabled populations around the globe. For example, despite the assumption that disabled people are sexually inactive, those with disability—and disabled women in particular—are likely to have more sexual partners than their non-disabled peers. Extreme poverty and social sanctions against marrying a disabled person mean that they are likely to become involved in a series of unstable relationships.² Disabled individuals (both male and female) around the world are more likely to be victims of sexual abuse and rape than their non-disabled peers. Factors such as increased physical vulnerability, the need for attendant care, life in institutions, and the almost universal belief that disabled people cannot be a reliable witness on their own behalf make them targets for predators.^{3, 4} In cultures in which it is believed that HIV-positive individuals can rid themselves of the virus by having sex with virgins, there has been a significant rise in rape of disabled children and adults. Assumed to be virgins, they are specifically targeted.⁵ In some countries, parents of intellectually disabled children now report rape as their leading concern for their children's current and future well-being. Bisexuality and homosexuality have been reported among deaf and intellectually disabled adults, while awareness of HIV/AIDS and knowledge of HIV prevention is low in both these groups.⁶ Individuals with disability are at increased risk of substance abuse and less likely to have access to interventions. It is estimated that 30% of all street children have some type of disability and these young people are rarely reached by safe-sex campaigns.⁷

Gregory Fritz (2003)

 The Brown University Child and Adolescent Behavior Letter **Sexuality education** 

for the developmentally disabled. (Commentary).
The Brown University Child and Adolescent Behavior Letter | July 01, 2003 | Fritz, Gregory K. | Copyright

The AIDS epidemic and high adolescent pregnancy rates have spurred a revolution in sex education over the past 16 years. Topics that were once taboo are now discussed openly as part of middle school health classes, and the Internet provides access to all manner of sex education materials for parents and (helpfully or otherwise) children themselves. Over the same period of time, however, much less attention has been focused on how to educate children and adolescents with developmental disabilities about human sexuality.

One possible factor behind adults overlooking sexuality education for those with developmental disabilities is the world's pervasive tendency to view them as asexual. In the past, issues of modesty and privacy for developmentally disabled adolescents were often ignored even in hospitals where they received medical treatment. Adolescent boys and girls were placed in adjoining beds, as though the raging hormones, sexual preoccupations and self-consciousness common to all teenagers somehow became irrelevant because they were mentally retarded. To the degree that parents and professionals focus on the disability rather than the child, it is possible to deny the child's emerging sexuality. Parents' acute awareness of the vulnerability of their developmentally disabled child makes them dread potential exploitation, and some fear that talking about sex will encourage sexual activity. Even for the most sophisticated parent or professional, discussing sexuality with a developmentally delayed child is challenging. Educational materials designed for those without disabilities aren't useful, and it's hard to know what to include and how to say it.

Sexual feelings, interest in their own and others' bodies, concerns about pubertal changes, and sexual curiosity are as important to children and adolescents with mental retardation or specific developmental disabilities as they are to other children. Physical maturation and development of normal secondary sex characteristics occurs in the vast majority of adolescents with developmental disabilities. As changing policies lead to their greater integration into the community, sexual behavior of the developmentally disabled comes under closer scrutiny and real risks of possible sexual exploitation are encountered. While not without controversy, sexuality education is clearly essential.

The American Academy of Pediatrics cogently summarized the goals of sexuality education for children and adolescents with developmental disabilities in a 1996 policy statement. The purpose is broad: to help such individuals attain a life with as much personal fulfillment as possible and to protect them from exploitation, unplanned pregnancy and sexually transmitted diseases. Appropriate education recognizes that sexuality is a source of pleasure and an important component of human relationships. In the broadest sense, sexuality education gives children a sense of being attractive members of their genders with the desire for satisfying

Jones et al (2012)

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This article can be found in the following collections: [Paediatrics \(Child psychiatry, Paediatrics-other\)](#); [Psychiatry \(Child psychiatry\)](#)
Published Online: 12 July 2012

Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies

[Lisa Jones](#) BSo [✉](#), Prof [Mark A Bellis](#) DSo [✉](#), [Sara Wood](#) MSo [✉](#), [Karen Hughes](#) PhD [✉](#), [Ellie McCoy](#) MSo [✉](#), [Lindsay Eokley](#) PhD [✉](#), [Geoff Bates](#) MSo [✉](#), [Christopher Mikton](#) PhD [✉](#), [Tom Shakespeare](#) PhD [✉](#), [Alana Officer](#) MPH [✉](#)

Summary

Background

Globally, at least 93 million children have moderate or severe disability. Children with disabilities are thought to have a substantially greater risk of being victims of violence than are their non-disabled peers. Establishment of reliable estimates of the scale of the problem is an essential first step in the development of effective prevention programmes. We therefore undertook a systematic review and meta-analysis to synthesise evidence for the prevalence and risk of violence against children with disabilities.

Methods

For this systematic review and meta-analysis, we searched 12 electronic databases to identify cross-sectional, case-control, or cohort studies reported between Jan 1, 1990, and Aug 17, 2010, with estimates of prevalence of violence against children (aged ≤ 18 years) with disabilities or their risk of being victims of violence compared with children without disabilities.

Risk factor of sexual abuse

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Special Features

Suspects beaten after disabled girl raped

May 21 2013 at 07:48am

By Tshogo Lepule

[Comment on this story](#)

Cape Town - Two men were beaten to a pulp by angry Khayelitsha residents after they were accused of raping a mentally disabled epileptic girl.

The 15-year-old girl was playing outside her home last Thursday when the two men allegedly lured her to a shack, promising to give her money.

After about two hours of torture and abuse, the girl managed to escape and sound the alarm.

Within 24 hours, the community had tracked down the suspects, beaten them senseless with sticks, sjamboks and fists, and handed them over to police.

On Monday, Msimelelo Tshaka, 27, and Mntuwekhaya Solwandle, 29, appeared briefly at the Khayelitsha Magistrates' Court where they were charged with the teen's rape.



INDEPENDENT NEWSPAPERS

HIV Risk for disabled people including sexual abuse

- Alriksson-Schmidt et al (2010) found that female high school students in the USA who reported physical disabilities were more likely to have been coerced into sexual intercourse (19.6% vs 9.4%; $\chi^2 = 14.51, p = 0.03$)
- Kvam & Braathen (2008) qualitative study of disabled women in Malawi.
- Maart & Jelsma (2010) cross-sectional study of physically disabled adolescents.
- Mall & Swartz (2012) qualitative research in deaf schools.

Kvam & Braathen (2008)

- ‘I thought maybe this was my chance...’
- Qualitative research conducted in Malawi with disabled women.
- Participants had different disabilities.
- Explored abuse.
- Women spoke of experiences of sexual, emotional and physical abuse.

'...because he did not respect me and treat me well...He said 'I made a mistake to marry a person with a disability. He said that I should be thankful that he married me. I was more like a slave in the house, and when he came home to find that I was not there, he could accuse of me being unfaithful, and he would often beat me...'

(Disabled woman Malawi)

Groce, Rohleder, Eide, McClachlan, Mall & Swartz (2012)

- Review article
- Searching for statistics, sex education, general papers addressing HIV and AIDS disability issues.
- 124 papers retrieved:
 - HIV knowledge and risk factors
 - testing and health care access
 - poor data on prevalence

Other HIV/AIDS risk factors for disabled people

- Desire for a sexual relationship.
- Unprotected sexual activity
- Poor knowledge of barrier methods.
- Substance abuse
- Self-esteem issues in relationships (e.g. Cambridge, 1997)
- Disabled mothers/desire to have children

Example from the media...

theguardian

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Comment is free

Disabled people do have sex lives. Get over it

We don't need to exploit prostitutes to have sex – but we do need equality in society for the myths to be debunked



Naomi Jacobs

guardian.co.uk, Monday 23 August 2010 15:00 BST

[Jump to comments \(162\)](#)

The Telegraph picked a particularly shrewd moment to pry into disabled people's care plans, seeing as we are currently are the disproportionate target of a cost-cutting campaign that has started with the poorest and most disadvantaged people in society. The article, reproduced later in the Mail and Express, claims to have found evidence of "taxpayers' money" spent on sex services for disabled people.

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Article history

Society

Disability · Prostitution

Life and style

Sex

Education

Sex education



deaf, gay and
HIV positive.



- *Tonight sees the launch of Channel 4's new documentary series [The Undateables](#). It follows a group of people with different disabilities as they use dating agencies to try to find love. The original blurb said that the show would follow "a range of people whose ability to form relationships is affected by an impairment or challenging condition – such as being deaf, or having Tourette's". I'm not deaf nor do I have Tourette syndrome, but I wouldn't have thought either of those conditions has an impact on a person's "ability to form a relationship". As far as I'm aware, commitment and falling in love doesn't have much to do with whether you can hear clearly or not.*

Sharon Brennan



TREYS
TOYS

*For those that stare at us along the way, they
will no longer see just a Disabled. Dwarf. Midget.
But also a Confident. Fiercely determined.
Mother.*

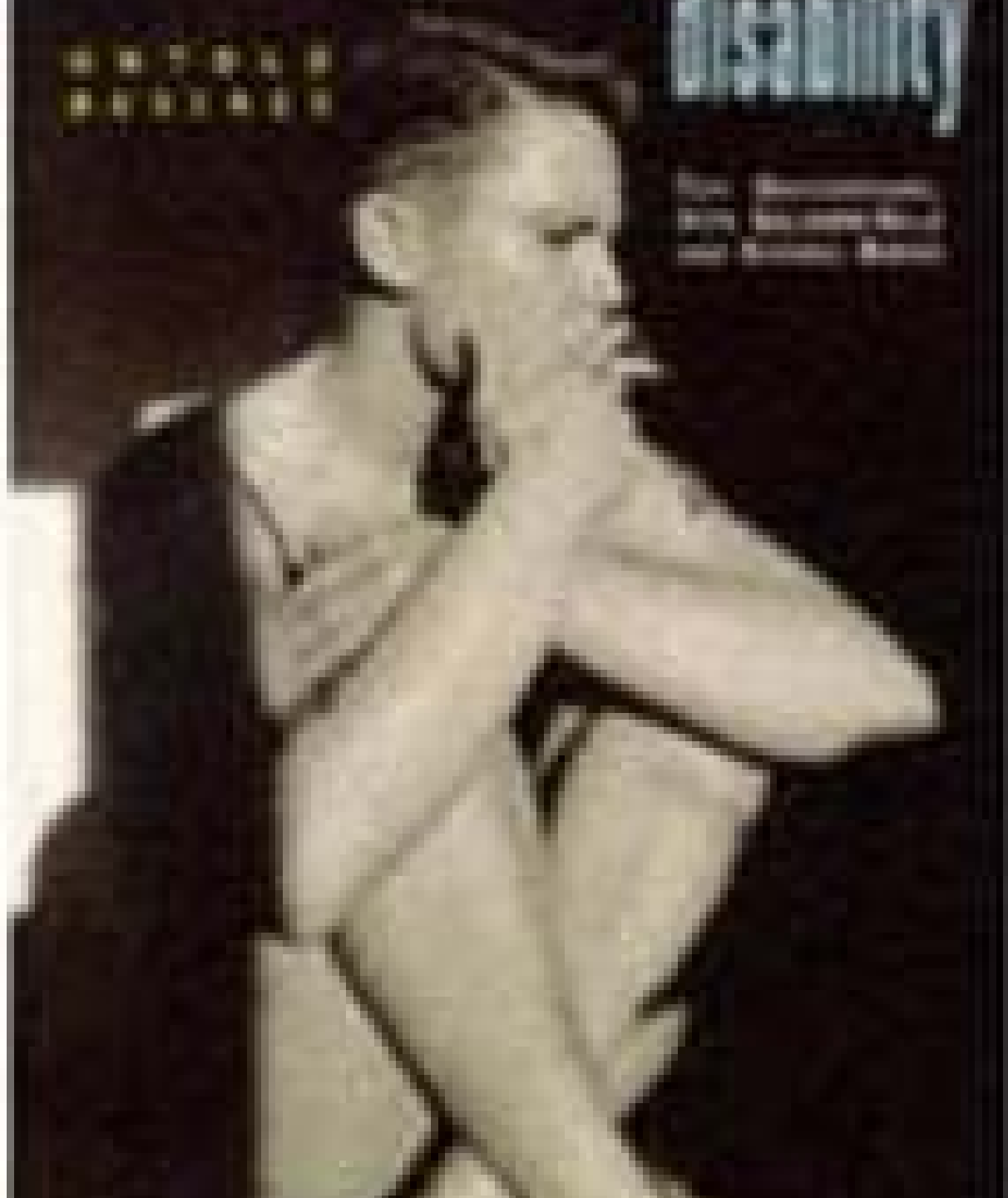
Michelle Harris

Ethical issues relating to disability and sexuality / dilemmas for clinicians

- Clinician discomfort
- Fear of encouraging sexual activity or risk of sexual abuse.

Tom Shakespeare





Emergence of a new paradigm

Mall & Swartz (2012)

EDITORIAL

Sexuality, disability and human rights: Strengthening healthcare for disabled people

The *World Report on Disability*¹ by the World Health Organization and the World Bank marks a watershed in the history of how disability should be understood by healthcare practitioners. Along with a special issue of the *Lancet*,² this report marks recognition by organised healthcare that healthcare practitioners acted paternalistically towards disabled people, often deciding on their behalf what is in their best interests.³ South Africa favours a human rights approach to disability, where the Constitution mentions non-discrimination on the grounds of disability, and globally through the promulgation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).⁴ Historically, health practitioners

Clinician discomfort. Many people, including clinicians, feel uncomfortable discussing sexual matters, discomfort which may increase in the context of disability.³ Mgwili and Watermeyer³ reported that physically disabled women accessing family planning were treated as if they were asexual by clinicians, who berated them for being sexually active. Disabled people are well aware of this discomfort. Wallis¹⁴ expressed his experiences as a person with muscular dystrophy: 'The issue of sexuality and disability is in the main brushed under the carpet. Some of my carers have been visibly embarrassed when sex has been mentioned or shown on a TV programme we have watched together. The general public do not



Emergence of a new paradigm

Appel (2010)

Sex Rights of the disabled

‘Sexual rights are a fundamental element of human rights. They encompass the right to experience pleasurable sexuality, which is essential in and of itself and, at the same time, is a fundamental vehicle of communication and love between people. Sexual rights include the liberty and autonomy in the responsible exercise of sexuality.’

Nick Wallis



'The issue of sexuality and disability is in the main brushed under the carpet. Some of my carers have been visibly embarrassed when sex has been mentioned or shown on a TV programme we have watched together. The general public do not view disabled people as sexual beings and many professionals and family members who are too uncomfortable to address this issue openly share this attitude. Strangely, talking to people - especially parents and carers - about death and dying may be easier than talking to them about sex...' Nick Wallis



PhD study on HIV/AIDS issues for deaf and hard of hearing adolescents

- Adolescence is a critical time of psychological, sexual and psychosocial development.
- Little is known of the experiences of disabled adolescents of sexuality.
- Deaf adolescents face communication barriers, an additional disability.
- It is inappropriate for clinicians to write notes for deaf people.

Methods

- Qualitative research methods employed due to novel, exploratory nature of the project.
- Individual in depth interviews and focus group discussions with teachers, parents, deaf adolescents and members of deaf organizations.
- Adolescence is a critical time of sexual and psychosocial development.
- Research settings were deaf organizations and schools in Gauteng and Western Cape.
- Assistance of a SASL interpreter.

PhD study on HIV/AIDS issues for deaf and hard of hearing adolescents

- 43 schools for Deaf and hard of hearing across South Africa
- Most have historically religious roots.
- Combination of language policies across the schools (e.g. Oralism or SASL or both)
- Complexity of total communication.

Schools' HIV prevention policies

School	Region	HIV/AIDS prevention activities including condom policy
1	Gauteng	Condom education including demonstrations
2	Gauteng	Condom education including demonstrations. Distribution of GALA comic book unsuccessful
3	Western Cape	Condom education minimal. Condom demonstrations discouraged on school premises.
4	Western Cape	Condom education minimal. Condom demonstrations discouraged on school premises.
5	Western Cape	Condom education including demonstrations
6	Western Cape	Condom education including demonstrations

Main findings:

General awareness that deaf adolescents are at risk of HIV/AIDS:

it's that kind of misconception that people have and I think in most of our poorer areas, they are really more at risk and I mean that is a huge problem, because they're not articulate enough to be able to say what they have experienced or what is happening to them and that is where they are being taken advantage of all the time...(high school teacher)

Main Findings:

'what saddens me is that they don't understand what friendship is really all about and I think because they're lonely, they, they are, I think, can be easy victims in that if any boy, I'm talking now I suppose from a girl point of view, but if any, if any male shows any interest what so ever, they immediately think, you know the person loves me, without giving it time and, and because they're so desperate for that affirmation, for that love, for that care...' (high school teacher)

Communication barriers:

The counsellor explained) we gained so much more in this hour with him than we had gained in the whole 6 weeks.” She said she realizes now how much this poor kid had missed out on, they thought that they were doing okay, they kept saying no, coz we kept offering our services, we kept saying we can send a teacher you know, for sessions and they kept saying “no, we’re coping fine, he’s writing, we’re writing to him, he’s interacting, he’s doing fine,” but she said to me after last week’s session, she said she realizes now how important it is for these deaf children to actually have an interpreter, that’s, that they can communicate openly with and so much came out and – it was a positive...

Religious ethos in schools:

*it's (condom usage) not encouraged and I respect, I am not a Catholic but I am the principal of this school and ...I have decided to come and work in this school and that has been the stance of the Catholics ever since I have come into this school and therefore I feel it's right that I uphold their ethos. If I feel, if I can't do that then my services should, I should terminate my service because I have applied to be in this school
(school principal)*

The owners of the school are Catholic sisters ...I don't think it, we're going to get away with that (condom demonstrations) I would say so in the past (condoms were discouraged) because of the Catholic issue, but now I've put a poster up there with A, B, C (Abstain, be faithful, condomise) ... and nobody has taken down you know, taken them downthe only thing they would not allow is the condom dispensers.

(High school teacher)

We don't have any nuns here now, when I was young, they gave us sex education, but it did not start from the nuns, they took somebody from outside to present sexuality to us, 22 years ago, they gave us sex education and showed us on a banana how to use a condom.

(High school teacher)

General discomfort:

So I almost want to say, the thing that's bad, the motivation from the adults (to) use a condom... actually encourages, to say...it's all right,the message that actually comes through is, you can have go ahead and have sex....it's actually a bad message...that is given out to the community...

(High school teacher).

Adolescent Data

There isn't much information so we just gets bits and pieces from, mostly the guys that are hearing ...some of the friends that we have, we just get the info from them...

(Deaf male participant, age 16)

*Mom signs a bit but my Dad doesn't sign at all
I'm a bit shy and they might get angry quickly.
my father died of AIDS and I might get the same.*

(Deaf, male learner, age 17)

I think maybe it's because in their homes they are lonely and they go maybe and look for something that they don't have and then they get raped ... my aunt, let's say she doesn't want me to go anywhere or yet to go out, she just wants me to stay at home not even to socialise with my friends. Sometimes they are raped, so at night it's, it's hard for them to, to hear what's happening behind them or what's happening around them so they get raped ...

(Deaf female learner, age 17)

I know if, if, if I think about having sex, the first thing, the two of us must go to the clinic and get tested for HIV. I want to know and then we'll wait before we get the results from the clinic before because I don't want AIDS. But first we need to get married. If (my prospective marriage partner is HIV positive) I will leave it, I, I won't get married. To another one, yes, but not to the one who's got AIDS...

(Deaf male learner, age 17)

Discussion of PhD findings

- Deaf adolescents at risk of HIV/AIDS.
- Similar risk factors to hearing adolescents.
- Communication barriers and risk of sexual abuse.
- Religious ethos in schools potentially obstructive to appropriate HIV education.
- Parents of disabled children have little choice about where to send their children.

Achievements in disability and HIV field to date:

- Numerous materials for deaf and hard of hearing people.
- Deaf VCT counsellors and GALA comic book
- Rebecca Johns and Ray Lazarus
- Nancy Murphy and the American Academy of Paediatrics
- Gillian Eastgate- New South Wales, Australia.

Testing guidelines

TAKING THE TEST

HIV counselling and testing for
people with intellectual disability



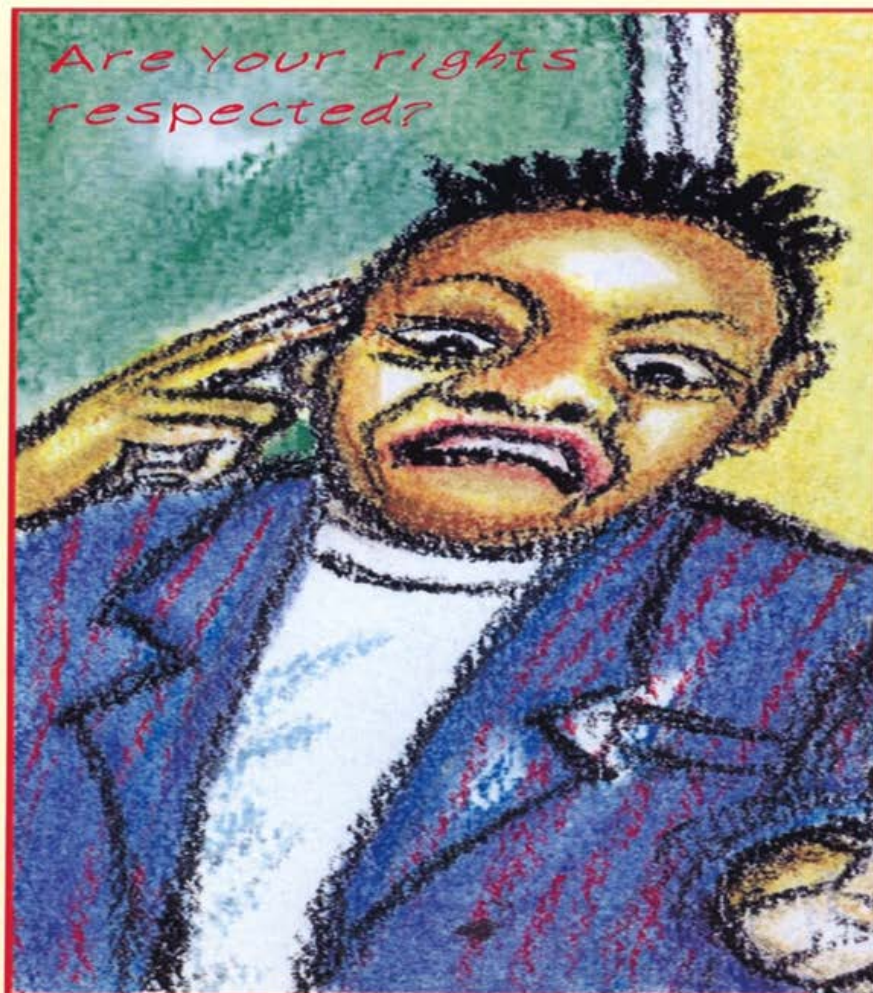
Practical and ethical guidelines for
healthcare and support workers

Rebecca Johns and Ray Lazarus



Western Cape Forum for Intellectual Disability

Gay and Lesbian Archives



AIDS

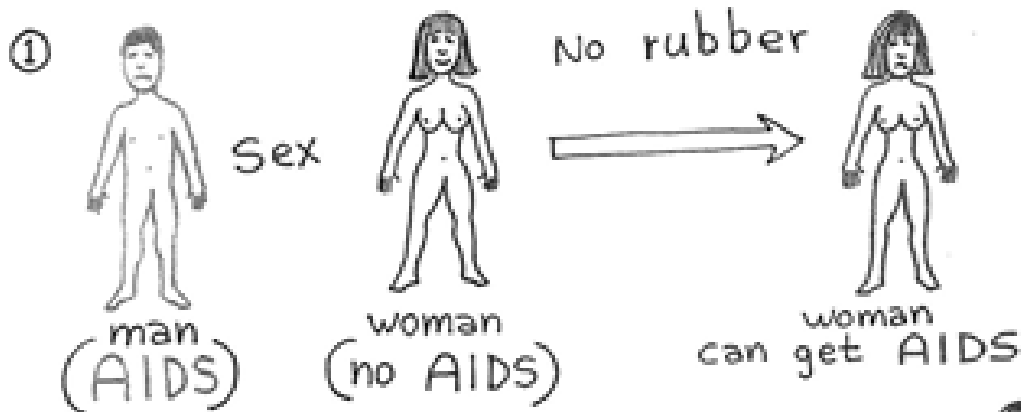


LEARN ABOUT AIDS
BE RESPONSIBLE. BE SAFE.

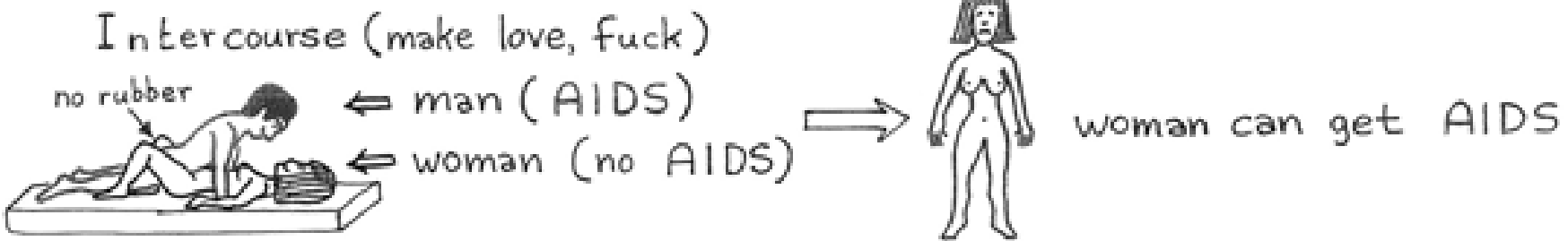
PROTECT YOURSELF FROM AIDS.

(WARNING! SEXUAL GRAPHIC MATERIAL)

HOW CAN GET AIDS:



SEX + RUBBER ⇒ SAFE,
NO AIDS
SEX + NO RUBBER ⇒ AIDS





Gillian Eastgate

Sex and intellectual disability

Dealing with sexual health issues

PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Sexuality of Children and Adolescents With Developmental Disabilities

Nancy A. Murphy and Ellen Roy Elias

Pediatrics 2006;118:398

DOI: 10.1542/peds.2006-1115

National Contraceptive Policy

Health care providers need to take into account the following factors when considering the contraceptive options for the physically disabled:

- immobility and possible increased risk of blood clotting, degree of lack of physical sensation and limitation of manual dexterity;
- whether the condition is stable, and any possible drug interactions with current medication;
- the mental health of the person (such as signs of depression);
- problems the client has handling menstruation and menstrual hygiene;
- for the intellectually disabled, factors such as psychiatric condition and ability to use a method correctly is important;
- vulnerability to sexual abuse or exploitation.

Further challenges ahead...

- Education system- parents have little choice about which schools to send their disabled children.
- Clinicians and carers may experience clash of values.
- Public health system is fraught with resource constraints and challenges.
- Sexual abuse a reality even in residential settings.
- HIV/AIDS epidemic and burden of sexually transmitted infections are a reality.
- Lack of reliable statistics on HIV prevalence in disabled populations.

"Remember to look up at the stars and not down at your feet.
Try to make sense of what you see and wonder about what
makes the universe exist. Be curious. And however difficult life
may seem, there is always something you can do and succeed at.
It matters that you don't just give up."

- Prof Stephen Hawking

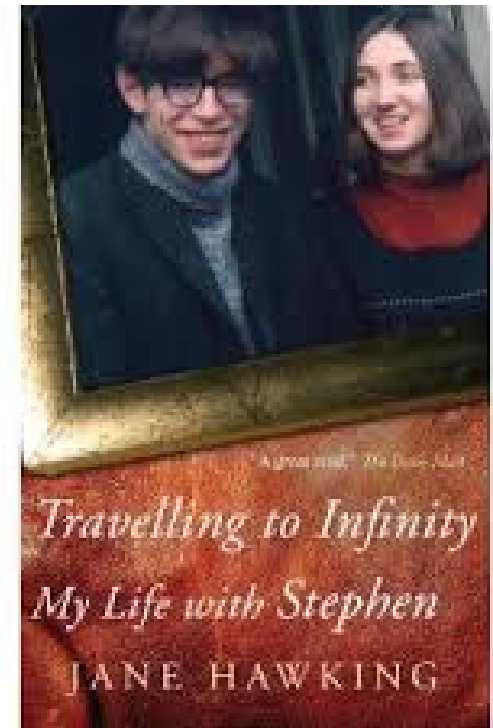
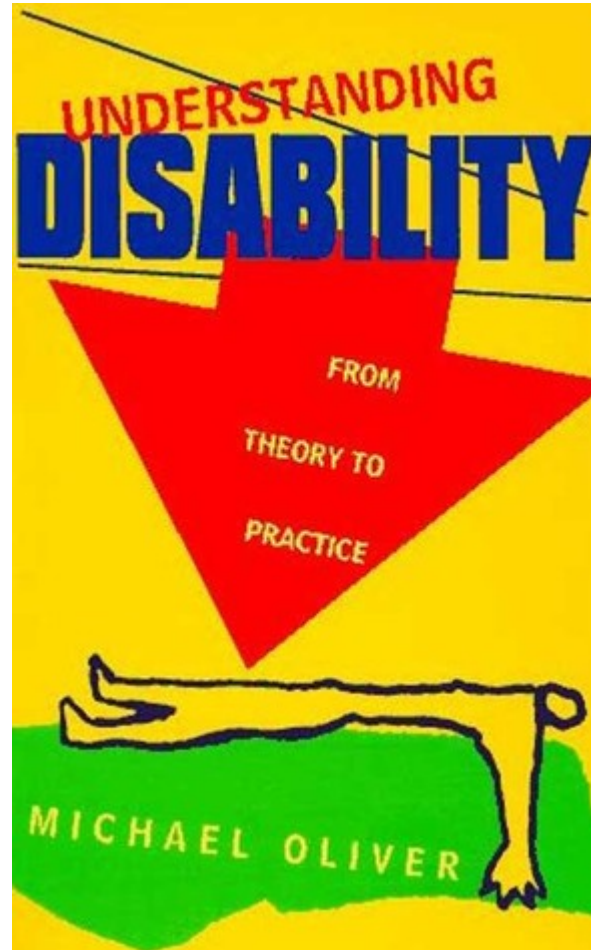


World Disability Report

“I welcome this first World report on disability. This report makes a major contribution to our understanding of disability and its impact on individuals and society. It highlights the different barriers that people with disabilities face – attitudinal, physical, and financial. Addressing these barriers is within our reach...”

(Stephen Hawking, World Report on Disability, 2012)

Conclusion



The Hawking of Stephen Hawking: Celebrity, Cosmology, Disability

'Hawking's relationship to the current disability movement is ambiguous. He has been outspoken, especially against the town and the University in Cambridge, about the need to accommodate those with disabilities, condemning the isolation of the disabled and resisting any effort to identify himself in those terms. At the same time, Hawking is reluctant to think or talk about his condition and consistently stresses how "normal" his life is, that his wheelchair and voice synthesizer are merely "aids" that help him in "overcoming physical deficiencies." Such attitudes nonetheless identify him with the message that disabled people and their advocates have increasingly denounced as part of the charity industry's paternalistic focus on disability as impairment, an affliction that must be overcome if the disabled person is to approach full humanity.'

(Jonathan Smith)

“I intend to propose a few simple, cost effective measures, such as regular visits by a health worker to families where there is disability to check up on their overall welfare as well as on the health of the disabled member. Such measures could ease the sense of isolation and uncertainty which those families suffer...” (Dr Jane Hawking, 1999).

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Thank you!!!!