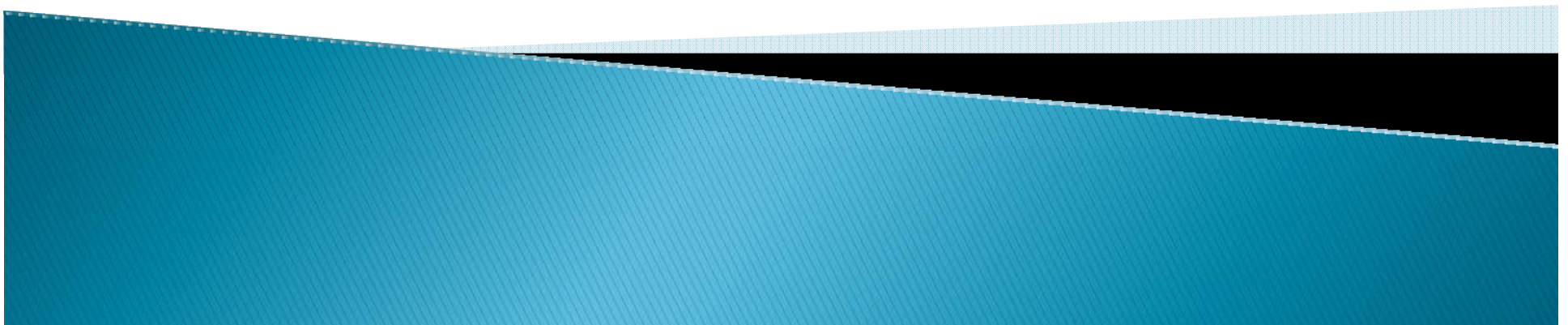


Sexuality of People with Intellectual Disabilities

A Literature Review.

Orla Kelly

National Federation of Voluntary Bodies, 2010



What is Sexuality?

Sexuality

Sexuality is complex, fluid and involves what we do, how we interact with others, what relationships we develop, how we love and how we are loved. It is influenced by the historical, social, cultural and political context that we live. Sexuality includes beliefs, acts, behaviours, desires, relationships and identities.

Bywater and Jones (2007:3)

Myths

Asexual, child-like
Incapable of sexual feeling

(Swango-Wilson, 2008)

In need of protection by society
& physicians
Aggressively sexual with
uncontrollable urges

(Isler et al, 2009)

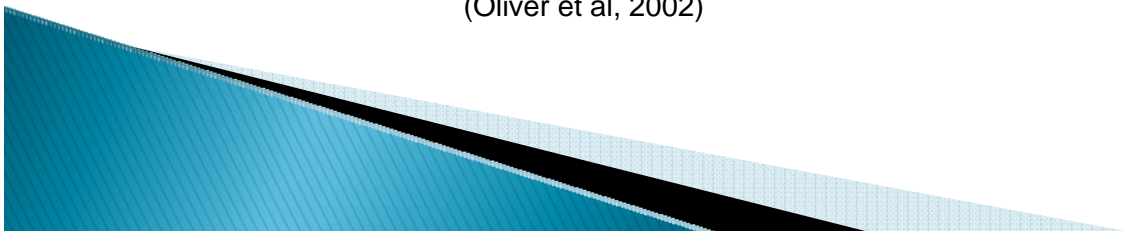
Sexuality

Talking about sex will encourage
sexual experimentation

(Isler et al, 2009)

If they were allowed to have
children they would overburden
society and weaken the gene
pool

(Oliver et al, 2002)



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Sexuality

Facts

People with intellectual
disabilities have varying degrees
of reproductive ability, sexual
interest & sexual response

(Giulio et al, 2003)

Have the same requirements of
love, affection & fulfilling
interpersonal relationships
Tend to be infantilised by society

(Giulio et al, 2003)

Environments restricting sexual
expression often result in
inappropriate sexual behaviour
Community integration needs to
be broadened beyond vocational
and community residential
placement to include the
importance of companionship &
love

(Oliver, 2002)

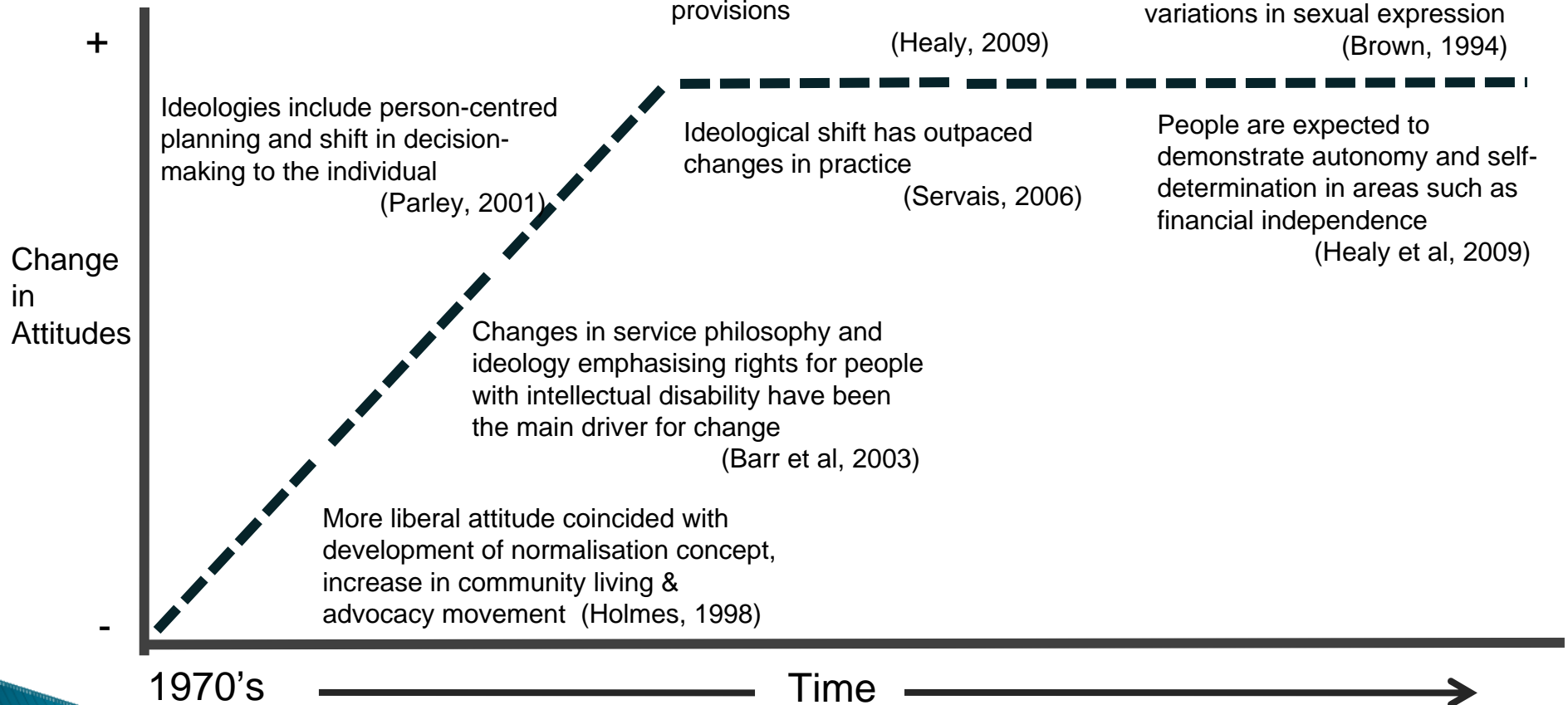
Change in Attitude?

An ideological shift will only hold when it is matched with an equivalent shift in family staff attitudes and in the educational provisions

(Healy, 2009)

Normalization is a restrictive principle as it does not promote variations in sexual expression

(Brown, 1994)



Person with Intellectual Disability

Understanding of companionship, reciprocal nature of relationships, aspire to marriage & children, need for privacy and greater tolerance

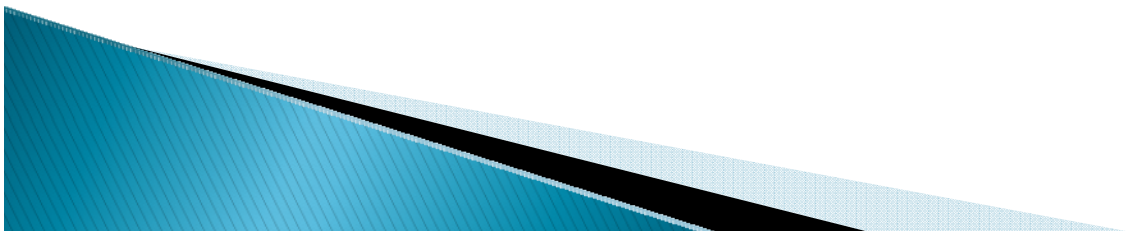
Conservative views about their sexuality
(internalise attitudes of others?)

Need for greater opportunities for intimate relationships
(Healy et al, 2009)

Partial, imprecise, contradictory sexual knowledge
(Szollos & McCabe, 1995)



Attitudes



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Attitudes

Other Stakeholders

Parents more conservative than staff & community groups

Parents & staff less positive about parenthood

Age associated with more conservative views
(Cuskelly et al, 2007)

Higher education associated with more liberal attitudes
(Karellou, 2003)

Women are more conservative than men
(Oliver et al, 2001)

Often view human rights & protection of vulnerable people as mutually exclusive
(Chivers et al, 2000)

Person with Intellectual Disability

51.7% not educated
professionally

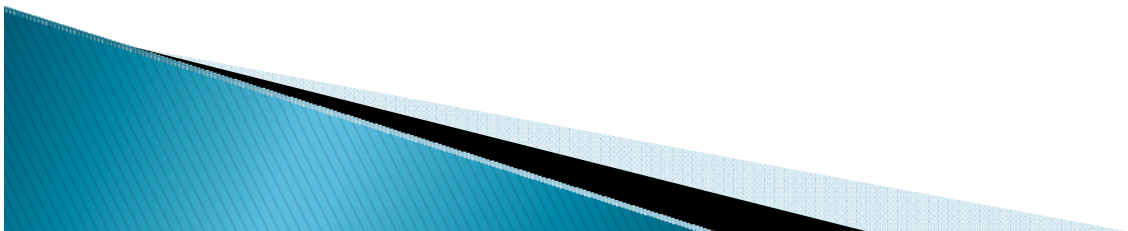
46.7% never talked about sex
with their parents

Knowledge of sex quite low

50% thought sex was kissing and
intimate touching

50% thought only married couples
had sex (Isler et al, 2009)

Knowledge/
Beliefs



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Knowledge/
Beliefs

Other Stakeholders

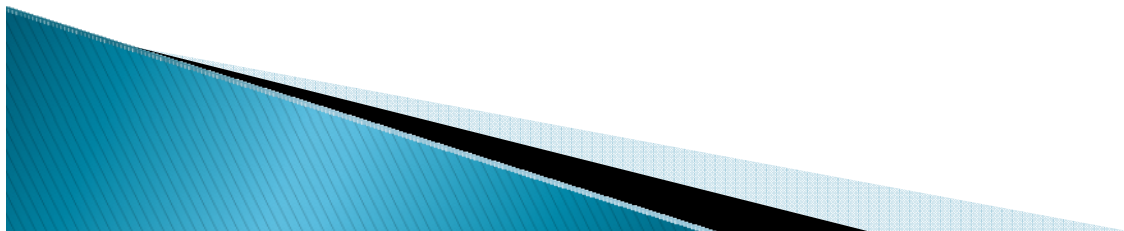
Procreation
– *not acceptable*

Autonomy
– *moderately acceptable*

Partner is of the same age, also has intellectual disability, uses protection

– *more acceptable*

(Ester et al, 2008)



Reluctance to explore sexuality

Evoked sexual impulses

(Konstantareas et al, 1997)

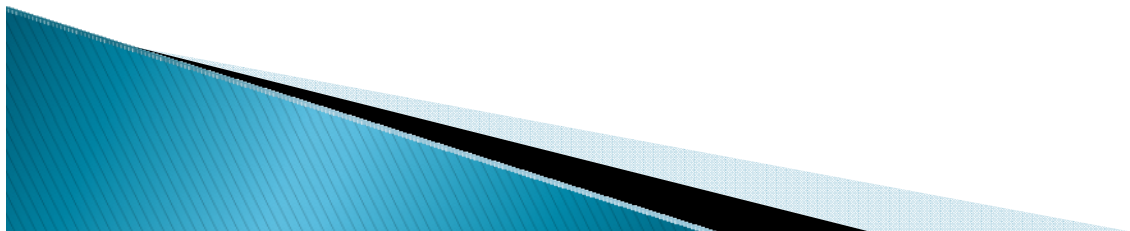
Intrude on person's privacy

(Abbott et al, 2007)

Ethical challenges

Lack of clarity and guidance at a policy & legal level

- ▶ **Section 5 of the Criminal Law (Sexual Offences) Act 1993**
Influential in education and social policy. The criminal law has a limited capacity to achieve the balance between protection and punishment.
- ▶ **Historically, services have been provided by religious organisations**
The Criminal Law (Sexual Offences) Act 1993 firmly aligns itself with the former. (O'Malley, 1996)
- ▶ **Organisation of a Mental Capacity Bill 2008**
Influence of religion on attitudes must be considered. Explicitly excludes the issue of capacity and consent to have sexual relations and to marry (Head 20).
- ▶ **2009 Drummond (2006)**
Only does not modernise the law in relation to capacity and vulnerable adults generally.



Reluctance to explore sexuality

Evoked sexual impulses

(Konstantareas et al, 1997)

Intrude on person's privacy

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Ethical challenges

Lack of clarity and guidance at a policy & legal level

Inadequate knowledge and education

(McCabe, 1999)

Attitudes that mirror the negative attitudes of staff and parents

(Cuskelly & Bryde, 2004)

Vulnerable to sexual abuse

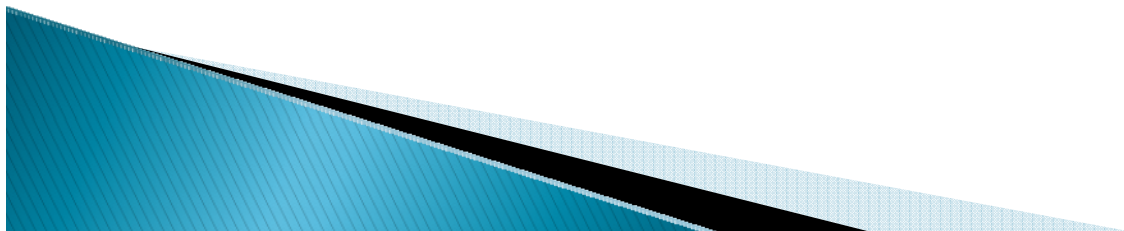
(McCarthy et al, 1997)

May lead to inappropriate sexual behaviour e.g. Sexual assault

(Grieve et al, 2008)



Resulting in..



Contradictions

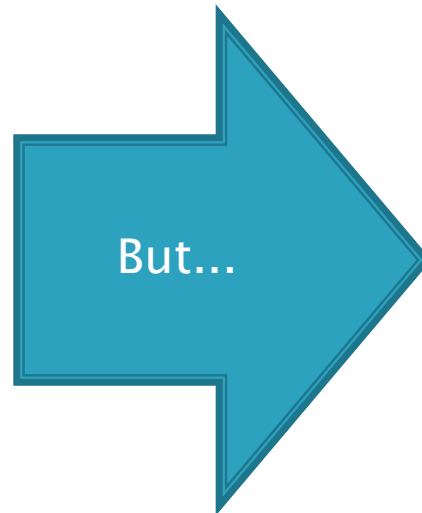
Staff & services are the main educators for social skills through role modelling & social experiences

Staff realise the importance of relationships and sexual roles

In Ireland people with intellectual disabilities have a right to express their sexuality

Support staff hold largely positive attitudes towards sexuality assistance

Agency guidelines acknowledge the right to sexual expression



Do not encourage skill development necessary for individuals to define their sexual roles

(Swango-Wilson, 2008)

Are hesitant to support pursuit of sexual identity

Hold different perceptions of their own and peer sexual identity

The law does not uphold this right, regardless of consent

(Gardiner & Braddon, 2009)

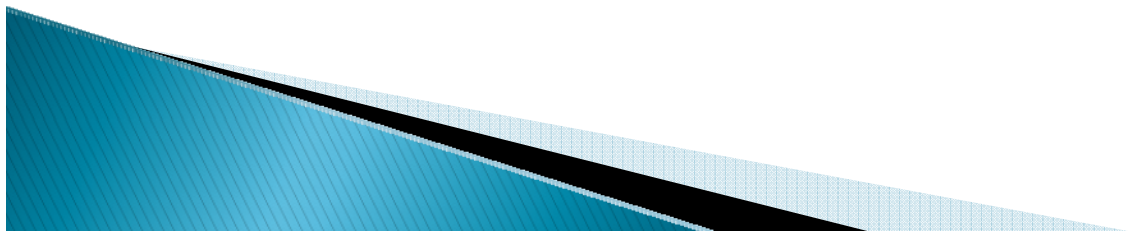
Proactive practice is rarely initiated

(Hamilton, 2009)

Implicitly prohibit instances of sexual activity by not providing privacy

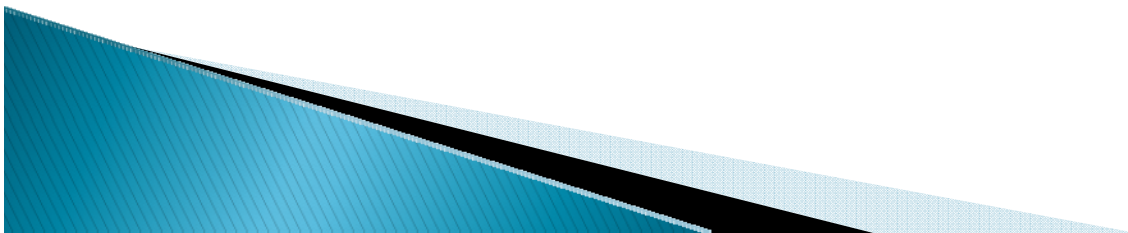
Barriers

- Lack of adequate information
- Lack of understanding or acceptance by services & family members
- Lack of trust
- Lack of confidence
- Need for comprehensive sex educations
- People cannot express their sexuality in an open and supportive way
- Powerless position in society (O Callaghan et al, 2007)
- Staff do not feel competent and often rely on 'experts' to discuss (Chivers et al, 2000)
- Dependence on others, living environments, greater isolation (Bazzo et al, 2007)
- No opportunities (Grieve et al, 2008; Swango-Wilson, 2008)
- Caregivers & Staff feel responsible for the sexual acts & may become authoritarian (Lofgren-Martenson, 2004)
- Internalization of negative attitudes & beliefs (Giulio et al, 2003)
- Often misinformed to discourage interest (Giulio, 2003)
- Values & beliefs of support staff (Christian et al, 2002)



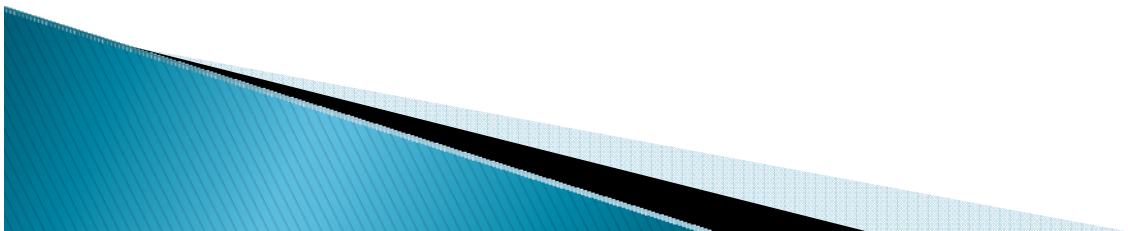
Sexual Programmes

- ▶ Training and education can help to change attitudes and develop awareness (Grieve et al, 2008)
- ▶ Lack of culturally appropriate, ongoing educational support (Drummond, 2006)



Sexual programmes

- Sexuality training is very often missing from staff training curricula – staff need training in this area just as they need training in dispensing medication and implementing individual support plans
(Christian et al, 2002)
- Must address attitudes & perceptions of caregivers
(Swango–Wilson, 2008)
- 5 principles: access; comprehensiveness; effectiveness of approaches & methods; training & administrative support; planning, evaluation, updating and social development
(Giulio et al, 2003)
- Capacity to consent is not static and may increase through facilitation or education on an individualised basis
(Dukes & McGuire, 2009)
- Education is key to empower individuals to identify, report & prevent sexual assault & abuse
(Swango–Wilson, 2009)

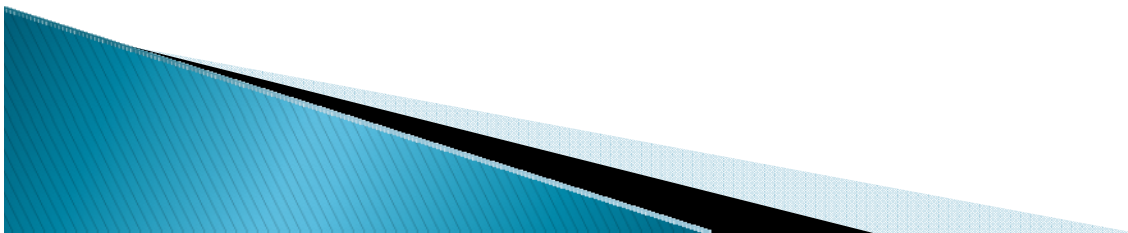


Sexual Programmes

Questions which may aid evaluation:

- Is the intended audience for people with mild, moderate or severe disabilities?
- Is the reading level of the material appropriate?
- Can the materials adequately be adapted?

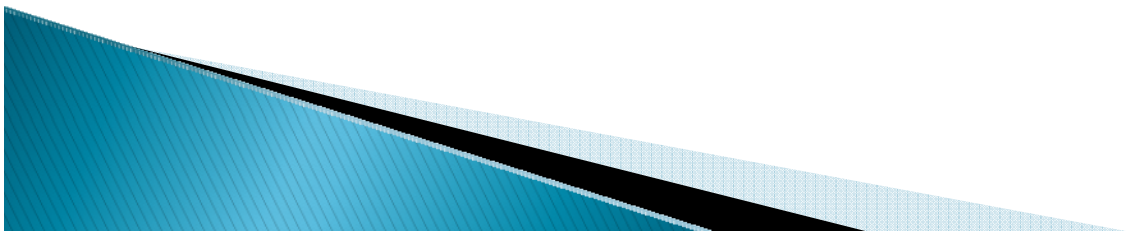
(Wolfe & Blanchett, 2003)



Assessment of Sexual Knowledge

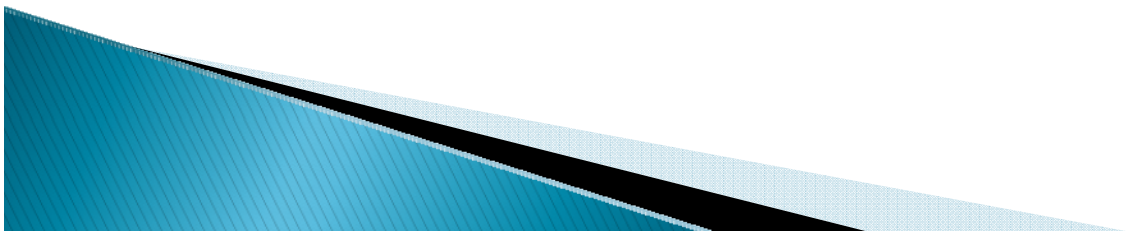
- ▶ An evaluation of sexual knowledge and experiences is the most appropriate way to determine the level of education and support required

(Galea et al, 2004)



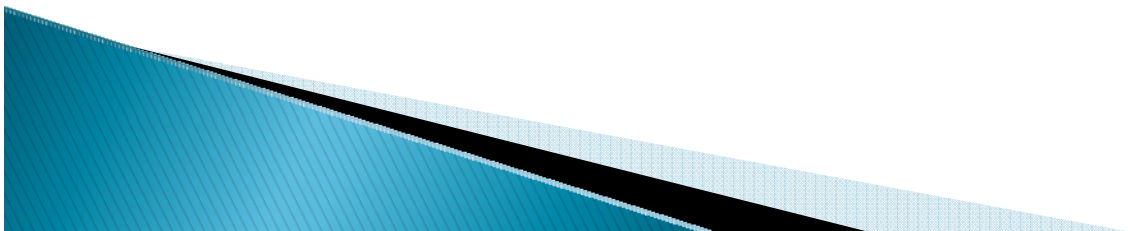
Assessment of Sexual Knowledge

- Assessment of Sexual knowledge (ASK): knowledge section; attitudes section; quick knowledge quiz; problematic socio-sexual behaviours checklist (Galea et al, 2004)
- Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability) (Cuskelly & Gilmore, 2007)
- Socio-Sexual Knowledge and Attitude Test (SKAT) utilised pictures (Wish et al, 1980)
- The Sexual Knowledge, Experience, Feelings & Needs Scale for people with mild intellectual disabilities (SexKen-ID) (McCabe et al, 1999)
- Extending methods of assessment for people with severe learning disabilities – use of talking mats (a visual framework that uses picture symbols to help communication) (Bell & Cameron, 2003)



What is needed?

- All key stakeholders must be equally represented in the development of a best practice approach
(Drummond, 2006)
- Many authors stressed the importance and value of asking people with intellectual disabilities about their views and experiences
(Kelly et al, 2009;Yacoub & Hall, 2008)
- Culturally sensitive sex programmes
- Service providers need to reflect on the barriers in their own agencies
(Christian et al, 2002)
- To translate the right of people with intellectual disabilities to a full sexual life into proactive support
(Kelly et al, 2009)
- Changes to domestic legislation



Key Debate

- ▶ Empower people to make their own sexual choices while also providing safeguards against exploitation and abuse

