Sexuality & Relationship support for people with an intellectual disability: Policy to practice

Dr Patsie Frawley, Amie O’Shea – ARCSHS
John Willis – Golden City Support Services

Introduction & Background

• Expression of sexuality and having relationships is an integral part of everyone’s lives
• Research tells us that people with an intellectual disability want to be able to express their sexuality and have relationships – and they experience a range of barriers in doing this
• Disability support services have a responsibility to enable people to have relationships and express their sexuality – they face a number of challenges in meeting this obligation
• Policy informed by the aspirations and rights of people is needed to guide support workers in this area
• This part of your work is ‘not negotiable’ – your services need to consider how they can enable you to offer this support
What we know from the research

What people with intellectual disability have said about relationships and sexuality

- They have sexual lives (though these can be hidden and may therefore be unsafe)
- Experiences of isolation, loneliness, rejection
- Experiences of joy, love and celebration in sexuality and relationships (Johnson, Hillier, Harrison & Frawley, 2001)

How others perceive sexuality and relationships in the lives of people with an intellectual disability

- Often a sense of risk or danger and managing this
- Rarely discussed in a positive sense - happiness, pleasure or enjoyment. (Tepper 2000)

The place of sexuality and relationships in the broader disability field

- The focus has been on rights and access to services – sexuality and relationships left lower on the list (Shakespeare, 2000)
- Families who are integrally involved in planning for and with people with an intellectual disability prioritise accommodation, respite, day programs and therapy – sexuality and relationships not identified. (Burton-Smith et al 2009)
Sexual knowledge

• Some areas where people don’t have good knowledge: sexually transmitted infections, sexual health, safer sex practices, legal issues and contraception. (Galea et al 2004)

Attitudes of others

• Many people are uncomfortable with issues to do with intellectual disability and sexuality. (Szollos & McCabe 1995)
• Parenting is the area where people’s attitudes are often the least positive (Cuskeily & Bryde 2004; White & Spencer, 2009)
• This has an impact on people’s ability to parent

Violence and abuse

• Sexual violence and abuse is experienced at a higher rate by people with intellectual disability than the general population – research suggests anywhere from 3 to 10 times more likely (Sobsey & Doe, 1991; Sobsey, 1994; 2000).
• Incidence and prevalence figures for Australia are lacking – leading to a lack of awareness and action (WWDA 2004)
• Increased vulnerability in two ways: societal attitudes about intellectual disability & life experiences of people with an intellectual disability
Hannah’s story - LSSL

• What would you say to Hannah after hearing her story?
• What does her story tell you about the challenges faced by people with an intellectual disability in trying to determine their sexual lives?
• What does her story tell you about the issues women with an intellectual disability can face in relationships and regarding violence and abuse?
• How has the service system impacted on her life and what have the consequences been for her?
• What would you want to see changed for Hannah? And how could you bring about this change?

How can disability organisations respond?

• The policy development journey of GCSS
• Recognising the needs of people with a disability – and the responsibility of service provision
• Quality of life domains
• Recognition of whole of life (person centred planning)
• Individual circumstances
Responsibility and duty of care to staff

- Uncertainty and lack of clarity for staff
- Complex issues that staff are asked to work through and a lack of guidelines for doing this in the area of sexuality
- Protecting staff from legal and ethical wrongdoing

Challenges

- Pressure of other priorities – how do you keep it on the agenda?
- Introducing a controversial subject – placing it in context
- Sharing information – with people being supported (in a format that can be understood)
- with families - with all staff
What is required?

• Commitment to the length of the process – importance of discussion and talking
• Commitment of whole of agency – management, supervisors and staff
• Commitment to following through to implementation (staff, individuals, families)

What does this mean for DSW’s?

• DDA – make adjustments and accommodations to ensure people with a disability are not disadvantaged or discriminated against because of their disability
• Provide Active Support to ensure a person with a disability has the best opportunities to learn, participate in daily life and be self determining
• Balance rights and risks using a Duty of Care framework
• Assume competence – only provide as much support as is needed to ensure the best chance at informed and independent decision making
• Use policy to guide your work
Supporting relationships and sexuality

- Supporting people in intimate relationships
- Support to make and keep friends
- Supporting people to express their sexuality
- Support in broader social relationships
- Supporting people to express their individuality
- Supporting people to develop their own identity

References


Sobsey, D (2000) Faces of violence against women with developmental disabilities *Impact*


