

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

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### 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



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## 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 (Cuskelly & 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)

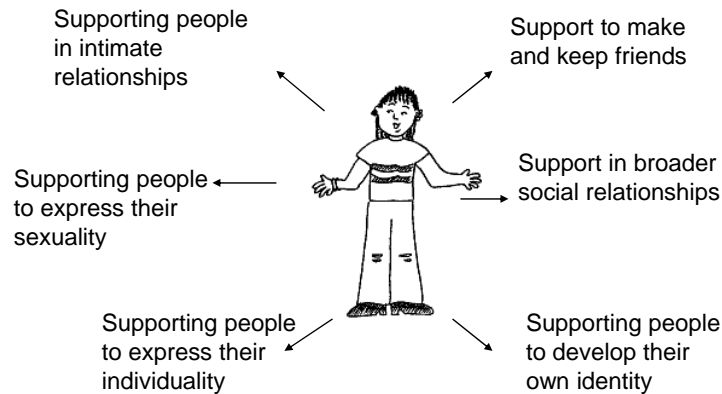


## What does this mean for DSW's

- 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



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