

## Who's Missing? Awareness of Lesbian, Gay, Bisexual and Transgender People with Intellectual Disability

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**Abstract** This article arose from an Australian project designed to develop educational and training material in relation to lesbian, gay, bi-sexual and transgender (LGBT) people with disability. The project was supported by the Queensland Association of Healthy Communities (QAHC) and the Queensland Centre for Intellectual and Developmental Disability (QCIDD). A resource was developed and its aim is to create greater awareness and understanding within the community that LGBT people with intellectual disability exist and to provide education and training to disability organizations. We aim to present the complexity of issues which prevent LGBT people with intellectual disability from living full lives and having opportunities for sexual expression.

**Keywords** LGBT · Intellectual disability · Sexuality · Lesbian · Gay · Bisexual · Transgender · Intergender · Queer · Australia

Sexuality is the lens of being a male or female through which a person views and responds to the world. (American Association of Intellectual and Developmental Disability, 2009)

### Introduction

Sexuality is an integral part of a person's adult life and often a part which is inaccessible or denied to adults with intellectual disability. Pervasive attitudes towards sexual expression by people with intellectual disability revolve around two assumptions—that the person is

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asexual or hypersexual OR if the person is sexual, then they are heterosexual, which is reported to be the dominant sexual identity in Australia [1].

The *Australian Study of Health and Relationships* found that 2.5% of men and 2.2% of women (16 years and over) identify as gay, lesbian or bisexual [1], which signifies that there are approximately 510,540 LGB people in Australia. The prevalence of transgender people is more difficult to determine [2]. Using accepted estimates of 2.7% of Australians having intellectual disability [3], there are currently 599,329 Australians with intellectual disability, of whom there may be up to 13,785 LGBT people with intellectual disability; a considerably large population. However, these are estimations because there is currently no national mechanism for measuring the prevalence of people with intellectual disability or indeed exploring their sexual identity [4].

Whilst there are significant shifts in liberalism towards sexual expression in Australia, persistent rejection of lesbian, gay, bisexual and transgender people as members of the community continues to be pervasive [1]. Similarly, people with intellectual disability continue to be viewed negatively by mainstream society regardless of culture [5].

Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. (Brown and Brown, 2009).

## Restrictive Environments

Due to life circumstances, many adults with intellectual disability live in supported accommodation or with their families. Because they may live in shared rooms or houses where staff members are working, there is a lack of privacy. Many people do not choose with whom they live, nor with whom they venture out into the community, nor their daily routine, daily activities or even clothes [6, 7]. People with intellectual disability have limited information about sexual behaviors and role models for sexual expression, and attitudes towards sexual expression by staff and family is usually highly prescriptive [8–11]. Disability services generally have a lack of policy about facilitating sexual experiences for the people who use their services and support workers rarely receive training on sexuality [12]. A person's physical and financial access to where people socialise is restricted and there is a clear omission of relationships and sexuality in life-planning processes [12, 13]. Further, the sexual needs of women and men with high support needs are largely ignored, resulting in a lack of developing friendships, exploring their own sensuality and the need for intimacy being ignored [14].

All these barriers derive from top to down service provision wherein the “decision maker” may determine the service structure and inadvertently or deliberately disallow the person with intellectual disability to experience and to make choices in relation to their own sexuality [6].

## Sexual Expression

Despite the barriers, people with intellectual disability have sex and long-term relationships [15], including relationships other than heterosexual ones [16, 17].

People with intellectual disability generally do not participate in society and community life, or make informed and safe sexual choices, as people without disability do. Thus, they may not have the opportunity to learn from their sexual experiences, or indeed choose their

sexual identity. The lack of relationships affects all aspects of a person's life and people with intellectual disability are no exception [18].

Social sanctioning of what constitutes acceptable behavior for people with intellectual disability can be and historically has been oppressive [19]. Public expressions of intimacy such as handholding and kissing are not considered acceptable for people with intellectual disability [9]. Men who express feelings of closeness to other men, or women to other women are ridiculed, and homosexuality and bisexuality as sexual identities are considered either as anathema or part of someone's development towards heterosexuality [4]. Homosexuality occurs at roughly the same percentage in people with intellectual disability as it does in the rest of the population [20].

Sexually inappropriate behaviors are often seen as problems to be managed rather than genuine expressions of need, need for either information or for a relationship. For example, masturbation may be the only outlet for sexual expression for many people who have limited social opportunities to explore their own sexuality [21]. People with intellectual disability have been seen either as perpetual children who do not need to know about sex or sexually dangerous individuals because they are unable to control their sexual feeling appropriately [7]. Exclusion and powerlessness perpetuate the conditions which make people with intellectual disability vulnerable to sexual abuse and more generally open to exploitation. These obstacles may also exist in transition to adulthood, such as lack of sex education or education for community living. Thus, their sexual rights are relatively neglected wherein priority is given to the individual either as a potential victim of sexual abuse or someone who expresses unacceptable sexual behavior. Either way, they become the focus of protection.

People with intellectual disability have rights to sexual expression and information about bodies and sex. The need to protect people from sexual abuse and exploitation, therefore, has to be balanced with the need to protect people's other sexual rights, such as the right to information. The two aims go hand in hand, as information and language about sex can help empower people to say no or tell someone about abuse. With education, support and wider access to social situations, people with intellectual disability can live sexual lives [22].

## **Sexual Consent**

Sexual consent causes the disability sector great concern and this concern revolves around service provider liability and not about the person's right to sexual expression. Capacity to consent especially by a person who has limited communication and/or cognitive impairment is the key to the concern [23–25]. If capacity is in question, a person with intellectual disability still has the right to access services to support their daily needs including that of sexual expression [8, 16, 19, 26, 27].

## **Positive Environment**

Dependency on a support worker for all aspects of living means that the support worker's attitudes are crucial especially in relation to sexual expression [28]. Support workers need sensitisation to issues of homophobia and hetero-sexism [4] since the dominant social attitude towards sexual expression is biased towards heterosexual-ism [27].

By denying individuals with intellectual disability the opportunity to learn about their sexuality and develop social relationships with others, society has denied them the right to self-fulfilment [27].

A sexually developing individual with intellectual disability needs help to find or create social opportunities through using the telephone, having access to personal mail, and simply going out with peers who do not have a disability in order to learn the social etiquette of friendships. Living circumstances need to include the space to have visitors, to choose their own clothing and body products, and to have private bedrooms. A focus on emotional wellbeing could be encouraged every day. Providing people with more opportunities to explore their sexuality may in fact reduce the enormous cost of responding to “challenging behaviors”.

Talking about sexuality in a group often reduces the tensions and is a less formal way for exploring sexual experiences and needs of people with intellectual disability as well as providing general information on sex. Ideally, sex discussion groups should have separate men’s and women’s workshops and be in a space which feels safe and private to allow participants to talk about their own sexual experiences and preferences, and to introduce good and bad sex, and good and bad relationships. Educational programs for people with intellectual disability should be age appropriate, not centred on their cognitive capacity, and focus on sexual expression as an ordinary part of ordinary life [29]. Talking about sexuality helps people with intellectual disability to recognize if someone is trying to take advantage of them, to avoid social mistakes that might make them look foolish or might be taken for criminal activity, and to be aware of the consequences of sexual activity [30].

## Positive Support

Support workers do not have to agree with or share the same values as the people they support, e.g. heterosexual support workers supporting a lesbian woman with intellectual disability need not impose their own values on her sexual expression [28]. Support workers can respect the values and attitudes of people with disability, and any decisions or actions based on these. This is active support [17, 22]. The only exception is when a person is engaging in illegal or potentially harmful or dangerous behavior, or when a support worker is required to follow particular policy or legal requirements.

Service organizations have a responsibility to ensure that sexuality and sexual health are considered in individual planning for people with intellectual disability [8]. Service providers must include the person, the family, the advocate and support staff in the development of sexuality policy for the organisation. Some Australian states including Victoria, South Australia and Tasmania have successfully developed policies which echo international treaties [31, 32]. This inevitably involves taking risks, providing radical responses and challenging inequalities which lead away from a culture of protection to one of inclusion and empowerment, a better situation for all involved.

The IMPROVE (Investigate, Meet the need, Planned education, Redirection, Optimism, Versatility, Evaluation) and CARE (Consistency, Accuracy, Respect and Empowerment) programs of Family Planning Queensland indicate that approaching masturbation in a no-nonsense way can change how a person sees themselves and subsequently how they respond to others [33]. Masturbation and sexual expression is treated as normal and healthy, and that educating people with intellectual disability to express themselves safely and privately is empowering their lives in general [33].

In the UK and Australia, the *Sexual and Relationship Facilitation Project for People with Disabilities* [12] supports people with disabilities to improve their body feelings and self-esteem. The Sexual and Relationship Facilitators are trained by several people with disabilities and their allies about choice and flexibility and achieving personal goals. Fostering opportunities to explore everyday relationships is a challenge and often pushes people to their limits which is how we all live and is a basic entitlement [21].

## Conclusion

This article recognizes that people with intellectual disability are sexual beings and that they should experience their sexuality according to their international rights as world citizens.

People with intellectual disability experience the same range of sexual needs and desires as other people. ...With appropriate education and good social support, people with intellectual disability are capable of safe, constructive sexual expression and healthy relationships. Providing such support is an essential part of supporting people with an intellectual disability [22].

Over the past decades, the delivery of services to people with a disability has improved, creating greater opportunities to broaden their lifestyles. This has also seen the development by some Australian state governments of policies on sexuality and sexual expression in line with these changes [31, 32]; and yet, for a policy to be effective, it requires action by the organisation and employees.

The current negative approach to sexuality and disability must change. As a country, we have the resources to provide opportunities for sex education and relationships for all. As governments implement international standards, governments and organizations will be at the forefront of this ideal. The community, government and service organizations are in the enviable position of guiding and promoting healthy lifestyles which includes non-discriminatory living environments wherein the individual can choose the sexual path they wish to take, a path that people without disability simply take for granted.

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