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Natasha Alexander & Miriam Taylor Gomez

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Pleasure, sex, prohibition, intellectual disability, and dangerous ideas

Natasha Alexander ^a, Miriam Taylor Gomez^b

a Clinical Psychologist, Consentability, Brisbane, Australia

b Coordinator, Queensland Centre for Intellectual and Developmental Disability (QCIDD), Mater Research Institute – University of Queensland, South Brisbane, Australia. *Correspondence:* m.taylor3@uq.edu.au

Abstract: *The sexual lives of people with intellectual disability continue to be the subject of prohibition and restriction by disability sectors. Without access to sex education and the concomitant sex literacy, people with intellectual disability are denied the essential conversation about sex, sexual expression, and pleasure. The authors explore the history of sexual repression of people with intellectual disability, and the culture of sexual disempowerment. This propositional paper offers a sense of hope about sex facilitation and sex education for people with intellectual disability which can afford them a full life.* DOI: 10.1080/09688080.2017.1331690

Keywords: sexuality, disability, pleasure, prohibition, rights

Introduction

The authors have a combined experience in the disability sector of more than 50 years, in the UK and in Australia. We are both passionate practitioners who believe in the equal rights of people with intellectual disabilities to make and break relationships, have a sexual life, and a “sexual voice”.¹ There is limited consideration of the importance of pleasure in published discussions of sexuality and intellectual disability. The literature is dominated by conversations about the need for sex education, vulnerability to sexual exploitation, capacity to consent, and protection/safeguarding. Of course, this is essential and necessary, but there is plenty of room for more discourse about pleasure, sensuality, and feeling good. These conversations can be hard for professionals to have within public services. Parents and carers may feel uncomfortable about raising these issues with other people within the support system.² We decided to write this article to share our experience and question the status quo which, at best, ignores sexuality as an integral part of a person’s life and, at worst, prohibits sexual expression for people with intellectual disability.

Pleasure

Pleasure is about sensuality or connection to the many senses – touch, taste, sight, hearing, smell,

and proprioception. Pleasure is connected to the richness of our lives. For example, we experience and celebrate pleasure in eating good food, walking through a park on a sunny, clear day, listening to our favourite music, dressing in our favourite clothes, and taking in the perfume of a beautiful garden. These aspects of our lives are intangible but are essential to us being human. Sexuality and sexual expression are connected to our humanness,³ and integral to the experience of pleasure. The sexual liberalisation in high-income countries in the 1960s led to an appreciation of sexual pleasure beyond love or procreation,⁴ and the dialogue continues. For people with disability, including people with intellectual disability, pleasure may not be seen as important^{5,6} and in their daily lives, there is a distinct lack of discourse about pleasure,^{2,7} leading to an experiential poverty.

One of the authors, Miriam Taylor Gomez, was working with people with intellectual disability who were homeless or living in hostels in Brisbane, Australia when she became curious about the lack of conversation and exploration of pleasure in the lives of people she was working with. In discussions around nutrition, it was obvious that the participants in the group on healthy living had no experience of simply talking about the pleasures of eating and drinking, let alone the vocabulary

that went with it. With the help of a chef, the group's attention turned to simply trying different foods and textures and just talking about the sensations. For many of the group, who were largely middle-aged, this experience of speaking about pleasure in eating and drinking was their first.

Pleasure is not prioritised as it should be in the lives of people with disability. In the world of disability services, interactions must have a practical outcome, for example, showering, eating, and catching the bus. What workers do in a day becomes focused “activities of daily living” and “meaningful occupation”. When money is involved, outcomes need to be clear. Anecdotally, an outcome of “increased pleasure” probably would not be adequate to justify funding. The language used in relation to people with intellectual disability becomes its own self-serving jargon. Everyday activities are described in formal terms. For example, instead of saying “going out”, we refer to people with intellectual disability as having “community access” or “social interaction”. The spirit of “normalisation” has been thwarted by the industrialisation of people with intellectual disability, wherein they become the object of care, and lose their parallel humanity in the process.⁸ Community care services for people with disabilities have been subject to massive structuring and restructuring internationally. The quality of training for staff varies greatly, and carers tend to have poor quality training that does not adequately cover issues of sexuality and relationships.⁹ They are even less likely to receive training about pleasure being an integral part of a good quality of life. Sensory issues are rarely discussed in life planning processes, other than in functional terms. Sensations in the mouth for people whose teeth are in poor shape are issues which are ignored by support organisations and yet these simple sensory issues have such importance for eating, drinking, digestion, and so on. Eating and drinking textures and smells for neurodiverse people (people with autism or sensory challenges) are other issues which are neglected.¹⁰

Speaking about physical sensations may not be actively encouraged and this is nowhere more obvious than in the assumption that people with intellectual disability do not feel pain.¹¹ Pain is not discussed and yet it is one of the main contributors to “challenging behaviours” by people who cannot vocalise what they are feeling.¹² As an industry, the disability industry⁸ is committed to ensuring people are “behaving appropriately”

both in their own homes and in public,¹³ and this amounts to social restraint. Expressions of pleasure by people who are pre- or non-verbal, for example, by making noises, may be discouraged and repressed by others, to ensure that they fit in with social norms. Natural expressions of joy, pleasure, grief, pain, and so on are limited to what is determined as socially appropriate, and thus people with intellectual disability are forced to fit their expressions to what is externally determined.¹³

The other author, Natasha Alexander, was a participant in a general sexuality workshop for women a few years ago. During one exercise, participants had to write down what gets in the way of their pleasure. There were lots of common themes, including guilt, shame, fear, concern that pleasure was trivial, and concerns about being accused of being too self-indulgent. While writing this journal article, Natasha was reminded of this experience. A group of women without disabilities found it difficult to prioritise their own pleasure. Where does this leave people with intellectual disabilities who may be dependent on others to introduce them to pleasure, support them to seek and find what is personally pleasurable, and to support the maintenance of this throughout their lives? Both authors commented on their difficulty in writing about pleasure. Anyone who has met us will know that we are women who are rarely at a loss for words, so we quickly realised that there was something about the subject matter that was getting in the way. What does it say about us that we consistently ask questions about the sexual pleasure of people with intellectual disabilities? Will people question our motives? Will people think we are irresponsible, and misunderstand our intentions?

There is a level of vulnerability involved in putting oneself forward to do this work. The identified issues that got in the way of the (non-disabled) workshop participants' pleasure also get in the way of supporting people with intellectual disabilities in the context of sexuality and pleasure, such as concerns about what people might think. Practitioners who are proactive in this area may be concerned that people may question their preoccupation in pushing for these issues to be addressed. There is the possible criticism that pleasure is not the remit of clinicians or support workers; that pleasure is simply not a priority.

As a clinical psychologist, Natasha is accustomed to receiving referrals around “inappropriate sexual

behaviour”, often with the expectation that the behaviours should be eliminated. Transformation of behaviours is possible though, and we propose that therapeutic and support work with people with intellectual disabilities should involve helping people identify what brings them pleasure. When highlighting the risks of unhealthy relationships, bodily autonomy and self-protection skills, surely we must also talk about healthy relationships and how they can be achieved? This includes relationships with others, as well as the relationship that people have with themselves, with their own bodies.

As Turner states:

“A quality life is one filled with pleasure, not with overprotection. Increasing a person’s sexual self-efficacy gives them access to a larger social community. Additionally, we propose that increasing the sexual literacy of adults with intellectual disability by acknowledging their right to pleasure may be a successful strategy for reducing sexual misuse of this community. Professionals must acknowledge the legitimacy of pleasure for adults with intellectual disability and, most importantly, create the bridges that will provide access to these meaningful experiences. Addressing sexuality only from a pathology or crisis stance would be akin to preparing for the holidays by only talking about all the negatives, e.g. financial hardship, family feuding, and individual stress. What fun would that be? Instead we tend to focus the holidays on all the celebratory positives like hope, community, memories, and happiness. We focus on the pleasure it brings. Should our approach to sexuality and adults with intellectual disability be any different?”²

What people with intellectual disability say

In a series of conversations with people with intellectual disability on 27th and 28th August 2012, one of the authors (MTG) in collaboration with National Disability Services, Queenslanders with Disability Network Inc., Family Planning Queensland, discussed the essentials of positive sexuality and relationships. What was prominent for the people in the group was that they were recognised as people first, in need of relationships and recognising that they need support to develop and maintain relationships including friends and more intimate relationships.

In the research of Fitzgerald and Withers, they discuss sexual expression with women with intellectual disability: “Many women said they were not ‘allowed’ to have sex with their boyfriends and feared the consequences of getting ‘caught’.”¹⁴

Adults with intellectual disability who speak about their sexual experiences are as concerned about love, longevity of relationships, feeling special to someone else, doing the right thing during sex, and so on, as people without intellectual disability.^{1,15,16}

Many advocates for the rights to sexual expression wrote in the 1980s and their work is still relevant.¹⁷ Sadly, these rights appear to be no further advanced, despite the wealth of conventions and declarations enshrining those rights.¹⁸ People with intellectual disability are often reliant on others to advise them about their rights and educate them about what they mean in practice. When staff are reluctant or avoidant, people remain unaware of their rights.

Sex and sexuality appear to be one area where staff may believe their own rights, values, and beliefs are paramount. In her role as a clinical psychologist, in the UK, Natasha was once talking to a female support worker about the possibility that a young woman with intellectual disability was bisexual. The worker shook her head and said, “I don’t like things like that”, and appeared to think that was as far as the conversation should go. The same worker also suggested that the young woman should be sterilised, saying, “She couldn’t look after a baby.”

Gatekeeping

For disability organisations, there are many obstacles to supporting safe sexual expression in their customers with disabilities, such as facing family opposition, or feeling confusion over the legality of their support. For some, their personal prejudices may take precedence over their professional obligations, and, for many, there is simply a lack of organisational consideration for support workers at the frontline of the privacy issues for people for whom they provide care.^{1,19–23}

The disability industry⁸ actively disenfranchises people with disability in many ways, placing the physiological needs of a person (breathing, food, water, shelter, clothing, sleep) ahead of every other aspect of Maslow’s Hierarchy of Needs.²¹ The natural exploration of sexuality and sexual

expression, to which people without disability are accustomed, essentially meets the other needs as described by Maslow in self-actualisation, self-esteem, love and belonging, and safety and security.²⁴ However, this is not the natural assumption for people with disability. People with intellectual disability, in particular, are not often given support to understand their sexual rights,²⁵ nor the opportunity²² or indeed the education, to explore their sexuality and sexual expression.²⁶

There is a culture of disablement^{8,27} wherein access to education about sex and sexuality is limited by policy vacuums and a non-commitment to the genuine well-being of people with intellectual disability.²⁸ But education about sex and sexuality for people with cognitive impairment is possible.²⁹ There is a mistaken belief that staff need to have “special training”,^{30,31} or that education by specialists will be costly. Mixed messages and false information may be given by support staff and parents,¹⁴ in an attempt to prevent people with intellectual disability from having sex, even though support workers have a key role in presenting some very simple and effective information about safe sex.³² There are pockets of staff who try to do this work, but as described they may experience a number of systemic obstacles. Staff may support access to sex workers, but this tends to be “underground” and may not be explicitly mentioned in a life plan.

“Fear seeds”*

There is a societal primal fear that people with disability will reproduce more people with disability and that they will “pollute” the rest of the population, a belief which is similar to racist practices.³³ This belief underpins the concept of eugenics. Eugenics has a long history and thus, our contemporary society can actively yet unknowingly continue to disallow the sexual expression of people with disability.³⁴ There is a conversation around the new eugenics movement to delete disability from our species,³⁵ so the fear of disabled reproducing has not gone away.

People with intellectual disability become victim to a long cultural history of repression of their expression of emotion. Both in Australia and in the UK, the voices of people with disability

who come from culturally diverse backgrounds are doubly marginalised.^{36,37} There is a cultural anxiety about sexuality and people with intellectual disability rising from multiple fears which are based on myths, including that unbridled sexuality will become rampant sex offending, or that people with intellectual disability cannot be good parents.^{31,38–40} There are general misassumptions that people with intellectual disability only want to date other people with disabilities⁴¹ or that those adults with intellectual disability who choose to become sexually active will then be forced to relinquish their bodily integrity.³⁹

There is an ableist fetishism⁴² about disability which mocks the person with disability in sexual relationships⁴³ and makes heroes of the non-disabled partners.²² Within the intellectual disability sector, rape, and sexual assault by co-residents with disability are commonly euphemised to “inappropriate or challenging behaviour or sexualised behaviour”.⁴⁴

The fears which drive attitudes entrench the double standards which direct our service provision. In moving from the UK to Australia, Natasha found a significant difference in attitudes within service provision, and it was difficult for her to understand why Australian colleagues in disability services had such progressive ideas about people with intellectual disabilities and sexualities, whilst the ground level of the disability services appeared to be characterised by caution and fear. Support organisations avoid policy development on sexuality and disability for fear of prosecution through outmoded statutes⁴⁵ and the complexities around capacity to consent.⁴⁶ In a prescriptive culture, a lack of policy means that staff are left believing that they are not able to support a customer’s sexuality, and fearful about the consequences if they do. They may believe that they are “on their own” if they openly support a person’s sexual expression without a policy. It is clear that a context where there is a lack of clarity, policy, or consistency of approach is not conducive to effective proactive and reactive work around sexuality.

In addition, there is a persistent lack of role models and absence of representation in the media of people with intellectual disabilities being sexually desirable, unless it is being portrayed as vulnerability and abuse.⁴⁷ Whilst the authors acknowledge the vulnerability to sexual exploitation,¹⁶ people with intellectual disability are rarely afforded the agency to make their own adult decisions, and we fail to acknowledge that

*From personal communication between S Elliott and N Alexander.

people with disability are already having sex.³⁸ It has been argued that the act of treating adults with intellectual disabilities as vulnerable and in need of protection has the effect of leaving them without the skills required to protect themselves from harm, and strips them of their autonomy. As such, they may in fact end up being more vulnerable to sexual exploitation.⁴⁰

The legal prohibitions

Laws can uphold rights but can also prohibit access to those rights. A section of the Queensland Criminal Code (s216, Act – Criminal Code Act 1899, Qld)⁴⁵ essentially prohibits sexual relationships between people with “impairment of the mind”, a definition which effectively includes people with intellectual disability.

A report from the Queensland Office of the Public Advocate in 2015²³ states that:

“The law in Queensland means that people with a disability or impairment are treated differently from other people. Even though the offence is not often prosecuted, the fact remains that it is there in the law; it effectively makes a large number of sexual relationships illegal until proven otherwise (whilst the inverse is true for people without disability); it has an impact on their lives; and they could be prosecuted. For these reasons, it should be altered (in much the same way as homosexuality and sodomy in general were illegal and, whilst rarely prosecuted, had an impact on people’s lives).”

A persistent lack of policy development by government disability agencies essentially leaves people with disability and their support workers unsupported. For example, in Queensland, a policy on sexual expression has been “in development” for more than 17 years, and therefore, Queensland disability workers and their clients are left confused and unsupported.

Seeds of hope

In contrast to the fear seeds that are frequently scattered around this issue, there are many seeds of hope that have been planted and can take hold. It is not that difficult to support people with intellectual disability to understand their sexual rights and sexual expression. It is being done effectively in other jurisdictions at local or state/provincial levels in countries as diverse as Canada, Sweden, and New Zealand.^{15,26,48,49}

Touching Base trains sex and relationship facilitators around understanding the social context of disability, how impairments affect sexual functioning, social and dating skills, safe handling and lifting techniques, working with survivors of abuse, gender and cultural issues, and ethical considerations.⁵⁰ State-based government agencies have developed and continue to monitor policies on sexuality for the people using their services and their support staff.⁵¹

We teach people many life skills; everything from cleaning their teeth to understanding public and private spaces. Why do we not routinely teach people to have healthy and intimate relationships? Why are the values and beliefs of staff paramount for this particular issue, when we are supposed to be person-centred regarding everything else? These are the questions we raise.

People with disability need to, like all of us, feel sexually free, become educated about sex and their own sexuality, enjoy sexual activities and receive support in a crisis.⁴⁷ Sexuality and sexual expression is a right enshrined in international conventions, and as advocates for change, we must commit to supporting people to lead full lives including sexually free lives.

ORCID

Natasha Alexander  <http://orcid.org/0000-0002-7485-2308>

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Résumé

La vie sexuelle des personnes handicapées intellectuellement continue d'être l'objet de prohibitions et de restrictions de la part des secteurs du handicap. Sans accès à l'éducation sexuelle et aux connaissances de base concomitantes sur le sexe, les personnes handicapées intellectuellement se voient refuser la conversation essentielle sur le sexe, l'expression sexuelle et le plaisir. Les auteurs explorent l'histoire de la répression sexuelle des personnes handicapées intellectuellement et la culture de l'aliénation sexuelle. Cet article fait des propositions et donne un sentiment d'espoir sur la facilitation des relations sexuelles et de l'éducation sexuelle pour les personnes handicapées intellectuellement qui peut leur permettre de vivre pleinement leur vie.

Resumen

La vida sexual de las personas con discapacidad intelectual continúa siendo el tema de prohibición y restricción por los sectores de discapacidad. Sin acceso a la educación sexual y la alfabetización sexual concomitante, las personas con discapacidad intelectual son negadas la conversación esencial sobre relaciones sexuales, expresión sexual y placer. Los autores examinan la historia de represión sexual de las personas con discapacidad intelectual y la cultura de desempoderamiento sexual. Este artículo proposicional ofrece un sentido de esperanza con relación a la facilitación sexual y la educación sexual para personas con discapacidad intelectual, que les puede brindar una vida plena.