Constructing sexual identities: people with intellectual disability talking about sexuality.

Azzopardi-Lane, C. and Callus, A.M.

Accessible summary

- People with intellectual disability need to be able to talk about the things that are important to them in their lives.
- This includes talking about their sexuality and the type of relationships they would like to have.
- A self-advocacy group did research about this subject with our support.
- Together we found that sexuality is an important topic for many people with
- intellectual disability.
- There are those who would like to have more opportunities to have sexual relationships.

Abstract

This paper presented research undertaken in collaboration with a self-advocacy group using inclusive research methods and puts forward the views of people with intellectual disability on the topics of sexuality and relationships. The paper presents the perceptions of sexuality of the people with intellectual disability and how these are influenced by social and cultural norms. Using Judith Butler's concept of performativity, the analysis of the findings shows how some people with intellectual disability accept the sexual norms that are ascribed to them, while others resist them. The paper also shows how the inclusive research process itself enabled the people with intellectual disability who took part to articulate their acceptance or resistance of these norms.

Keywords Empowerment issues, intellectual disability, sexuality

Introduction

Talking about and exploring one's sexuality are deeply personal ways of expressing oneself. However, not every- one can enjoy this way of self-expression. People with intellectual disability are a particularly disadvantaged group as they are very often excluded from opportunities even to talk about their sexuality, let alone actively explore and develop it. Nor do they have many opportunities to make their voices heard in many areas of their lives. Opportunities to voice their opinion may only be afforded to them in self-advocacy groups. These provide settings that are expressly structured to support and enable people with intellectual disability to speak for themselves. Unfortunately, everyday settings such as at home, at work and in service provision do not usually promote opportunities for self-advocacy.

If self-advocacy is about talking and voicing one's opinion about all aspects of life, then talking about one's sexuality can be a particularly effective way of advocating for oneself, as it is such a personal subject. The research presented in this article is about just that – people with intellectual disability talking about sexuality and relationships. The research was undertaken by the authors in conjunction with a self-advocacy group, with the topic being of the group's own choosing. As explained below, the research process itself was inclusive. Self-advocacy was therefore being practised both in the research process and in terms of providing an environment in which people with intellectual disability could express themselves and talk with non- disabled people about what they thought about their chosen topic.

The article first presents the main issues related to sexuality and self-advocacy for people with intellectual disability. This is followed by a description of the inclusive research process employed. The article then presents the main findings identified by the people with intellectual disability involved in the research. Finally, the social construction of people with intellectual disability as

asexual or sexually vulnerable people and their resistance to this construction are considered.

Main themes

The right for people with intellectual disability to develop a sexual identity has been denied partly due to the lack of knowledge around issues related to sexuality and disability (Fitzgerald & Withers 2013). Negative social attitudes and restrictive social perspectives, emerging out of ignorance and fear, have influenced the development of sexual identities in people with intellectual disability adversely (Whitney 2006). The denial of their sexual maturity is one of the social barriers encountered by people with intellectual disability. It is a barrier that stems out of the imagery that depicts people with intellectual disability as living in suspended adolescence and creates societal attitudes that perceive adults with intellectual disability as perpetual children (Bane et al. 2012; Fitzgerald & Withers 2013). Such stereotypes are difficult to challenge as they are not perceived by the general population as harmful, but rather as benign. As a consequence, the internalisation of stereotypical attitudes towards people with intellectual disability may result in barriers to self-expression (May & Stone 2010; McCarthy 1999).

People with intellectual disability are also often restricted in their sexual options by the prejudices and anxieties of carers, staff or the general public. When this is the case, parents' and service providers' perceptions towards the

sexuality of people with intellectual disability tend to be negative, prohibiting and regulating (Bernert & Ogletree 2013; Evans et al. 2009; Garbutt 2008). These perceptions at times stem from the belief that people with intellectual disability are either asexual or hypersexual, as well as from the responsibilities services and families are afraid to have to assume (Bernert 2011; Noonan & Gomez 2011). As a consequence, sheltering attitudes towards people with intellectual disability

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are often adopted by family members and service providers. Empowering people with intellectual disability requires moving away from the idea of overpro- tection, de-sexualisation and sexual suppression.

Many people with intellectual disability have asserted their right to make choices related to their sexuality and to form relationships (Kelly et al. 2009; National Institute for Intellectual Disability 2009), as they seek ways in which to gain more control over their lives. One of the most effective ways of doing this is by engaging in self-advocacy, on an individual or a collective level. The term self-advocacy has been ascribed different, but related, meanings by different self-advocates and non-disabled persons. Brechin and Walmsley (1989) see self-advocacy as a process of self-actualisation through which people with intellectual dis- ability can become aware of their feelings and wishes, as well as of their circumstances, and the positive and negative aspects of their lives. This can lead to the type of action which People First (London and Thames) have defined as constituting self-advocacy:

• Speaking up for yourself;

• Standing up for your rights;

• Making choices;

• Being independent;

• Taking responsibility for yourself.

(Cited in Walmsely & Downer 1997).

Self-advocacy, then, can be an effective means through which people with intellectual disability can express them- selves with regard to sexuality and relationships. This article in fact is based on research that was co-produced in Malta by a self-advocacy group and two non-disabled researchers

(the authors of this article). The following section sets out the methodology used.

Methodology

The self-advocacy group involved in carrying out this research is the Consultative Committee of Persons with Intellectual Disability (KCC) (KNPD 2012). It is made up of forty people with intellectual disability who hold regular meetings with assistance from two support members, one of whom is Anne-Marie. The ages of the KCC members vary from the early 20s to the late 50s. Many of them attend day centres, with a few being in full-time employment and a few others pursuing vocational education. Membership is evenly balanced between males and females. The meetings are planned and led by the Core Group, a group of seven persons with intellectual disability (four females and three males) who are elected by the KCC members themselves. The two support members also assist the Core Group members is planning the KCC meetings, taking minutes and organising the logistics of the meetings (Cone 2000).

The work of the KCC is described extensively by Callus (2013) and Deguara et al. (2012). In 2011, the Core Group opted to explore the subject of sexuality and relationships and Anne-Marie suggested bringing in Claire to support the research because of her expertise on the subject Azzopardi-Lane (2011). The research plan was developed and implemented on the principles of inclusive research, which presupposes that people with intellectual disability can engage meaningfully as researchers in their own right, although it is very often carried out in collaboration with non-disabled people. Some people with intellectual disability do work unsupported (Walmsley & Johnson 2003). However, the majority require support, as these authors report.

As Rodgers (1999) states, no research process can ever claim to be fully inclusive. We were therefore mindful of the principles of inclusive research as well as the potential pitfalls. The

research team drew up a list of questions that they would ask the other KCC members about the topic. Not all aspects of sexuality and relationships were explored. For example, in the course of planning the research and the focus groups meetings, none of the people with intellectual disability involved mentioned homosexuality as a topic for discussion. The only exception was a couple of remarks by two KCC members during one of the group meetings about how some people fall in love with members of their own sex. The apparent lack of interest in other types of relationships is of course significant in itself. Noonan and Gomez (2011) highlight the need of discussing different kinds of sexuality with people with intellectual disability.

After the first two group meetings, the Core Group decided to hold another meeting for males and one for females only. This was because they had noticed that in the previous meetings, some female members were uncomfortable raising certain issues in front of the males, and vice versa. We suggested that in these meetings, Claire would use some material, such as pictures, story books and video clips to stimulate discussion on the subject of sexuality and relationships.

The meetings were recorded, with the consent of the participating KCC members. Through listening to the recordings, the main issues raised were identified and discussed with the Core Group. To support the participants in the process of data analysis, they were asked questions that encouraged them to reflect on the points made by the KCC members and what these showed about what people with intellectual disability think about sexuality and rela- tionships. A thematic analysis approach was used at this stage.

The Core Group members wanted to end the research process by organising a seminar in which they would present the research findings primarily to their parents, but also to other family members and service providers. They were supported to make a PowerPoint presentation in easy-

to-read format and presented this in a seminar for which they invited the other KCC members, family members and service providers (KNPD 2013). On our part, and with the consent of the Core Group, the two of us then carried out our own data analysis, which is presented in this article. In this way, we addressed an issue that is often debated in inclusive research. This concerns whether inclusive research should simply be the account of individuals with intellectual disability or whether the non-disabled researchers involved can also present their own analysis of these accounts (Walmsley & Johnson 2003).

Any research in the social sciences is bound to raise ethical issues, which need to be addressed. In the case of this research, these issues were mostly related to the involvement of persons with intellectual disability and to the discussion of sexuality, a sensitive and deeply personal subject. Involving persons with intellectual disability in research raises issues regarding obtaining informed consent (Drummond 2006). An easy-to-read invitation was sent to each Full Committee member, together with a letter to the parents informing them about the seminar. Although we did not explicitly request their consent for their sons and daughters to participate, they could effectively act as filters in deciding whether these should participate, especially in the case of KCC members who cannot read and relied on others (notably parents) to have the letter read to them. In this way, consent can be said to have been obtained through other adults who acted as gatekeepers (Dye et al. 2003). Not all those who were invited participated in the group meetings. We can only speculate as to the reasons. It may be that they were not interested or could not make it on the days when the meetings were held. But it is also possible that there was someone acting as gatekeeper who prevented them from attending. What is certain is that the nineteen people who participated did so because they wanted to and were not prevented from doing so. These KCC members gave their consent to participate in the research after it was explained to them that what they said would

remain confidential and anonymous. They were also actively involved in the presentation of the research findings in the seminar organised for parents and service providers. These findings are summarised in the next section. All the names used are pseudonyms.

Sexuality – the perceptions of people with intellectual disability

The findings generated from this research illustrate how people with intellectual disability are not only aware of their sexuality but also of how it is perceived by others. It clearly shows that they are sexual beings and that sexuality is a topic that is of direct interest to them. It is also a topic in which they engaged at length and in depth during the discussions that resulted from the various meetings that were held. As Joseph asserted:

It doesn't mean that because you have a disability you cannot have a relationship.

Yet while everyone's sexuality is controlled by social mores and laws, the sexuality of people with intellectual disability is controlled by further factors. People with intellectual dis- ability participating in this study reported feeling con- strained because of lack of privacy, limited finances, as well as reliance on others for support, including transport. They claimed that parents and carers limit their sexual expression and exert control over whether they can have a relationship. Sara, whilst referring to her parents, claimed:

They would scold me if they found out I was dating a young man.

This is the case for the majority of people with intellectual disability living in Maltese society, who spend most of their lives living with their immediate family, where they run the risk of being overprotected and unexposed to sexual experi- ences and sex education (Azzopardi-Lane 2011). Within this context, it is not usual to talk openly about sex and sexuality. Furthermore, Maltese

culture is still heavily influenced by Catholic religious mores. This was evidenced through the language used by participants to describe situations or events as well as through their reactions to sexually related material used during the meetings. Participants for instance used the term 'making babies' instead 'intercourse' or simply 'sex', indicating how they have been directly or indirectly taught to equate the sexual act with the act of procreation. It should also be pointed out that there were research participants who evinced a degree of embarrassment about the subject of sexuality. One said she looks away when there are love scenes on television. Non-age appropriate behaviour towards sex- ually related material used during the focus groups mani- fested itself in both the groups of male and female participants. Some male participants giggled when presented with a picture of a heterosexual couple hugging (taken from McCarthy & Thompson 1993), while some female partici- pants giggled as a reaction to sexually suggestive material, such as a picture of a man consentingly touching a woman's breast (taken from McCarthy & Thompson 1993).

Significantly, it was Joseph who said:

There's no need to laugh. Isn't this a normal subject?

The fact that he had to make this statement indicates that for some, and perhaps many, people with intellectual disability it is not a normal subject but one which they do not often find scope for discussing. In both situations, the reactions can be interpreted as an indication of the lack of exposure to such sexually related conversation and images. Sexuality is frequently not believed to be an integral part of the lives, and experiences of people with intellectual disability and other non-disabled people may not be necessarily convinced that they can assert their sexual status (De Palma & Atkinson 2007). Some participants in this research reported having experienced dismayed reactions when publicly expressing their sexuality although in socially appropriate ways:

Once I did that [kiss in public] and people started staring. I don't do that in front of people anymore.

For some participants, the discussion that was provoked by pictures of couples kissing, shown during the focus group meetings, did not centre on whether couples should kiss but in which contexts this is appropriate. Among the issues discussed was whether one should kiss one's boyfriend or girlfriend at school during the break:

School isn't a place for kissing. But the break is all ours. We could almost do what we like.

Many of the participants in the research thus put forward ideas that are very much in line with what people of their age would talk about – going out with a boyfriend and girlfriend, how far they go or would go with them, getting married, having children or what the ideal man or woman is like for them. Peter claimed:

I like a girl to be good looking, dressed nicely and well educated.

For Joseph, who does not live with his parents, his problem was the lack of consent from his girlfriend's parents. For him, this was an important matter and felt that his relationship could not go on unless her parents' did consent. (He eventually reported terminating the relation- ship because of this issue).

It is important that the families know each other. If there is not consent from the families, there is no relationship.

The KCC members highlighted a number of issues during the seminar. They made particular reference to society's perception of people with disability and their sexual expres- sion, in particular to them having relationships, arguing that society had to be educated about the rights of

people with intellectual disability to have relationships. Another issue that was brought up during the seminar was the wish of these people with intellectual disability to have more opportunities to socialise with people their age, rather than to spend their free time with their family members. While acknowledging their limitations and their need for support from family members, they underlined the tendency towards overprotection that is often experienced by people with intellectual disability in relation to sexuality. The KCC members noted that it was still not possible for people with intellectual disability in Malta to be given state support to live together with a partner and recognised that this was financially impossible for them to do on their own. In conclusion, this group of people with intellectual disability summed up their aspirations towards living a more independent and autonomous life, where they are accepted as sexual beings, and where they are supported in their quest to be more educated on sexuality issues, establish and maintain relationships and express their sexual needs.

This section analysed the concerns of the people with intellectual disability as they were presented and discussed during the research meetings and the seminar. The themes are those that were picked up on by the KCC researchers themselves, that is the ones that were important to them and their fellow committee members. It is interesting to see how these research participants constructed themselves in this research by what they said and the points they raised.

Constructing sexual selves

Social constructionism considers identity to be a socially produced phenomenon that arises out of our interactions with others (Burr 2003). Identities therefore are ever-changing and multifaceted. Furthermore, they are constructed by our own perceptions, other people's perceptions of us, and our perceptions of others' perceptions (Mead 1934). As Burr (2003) argues, these perceptions are

built on the discourses that are made available to us, which we either accept or resist in the ongoing process of constructing ourselves.

In considering how the people with intellectual disability involved in this research constructed their sexual identities, it is important to note that it not possible to generalise from the opinions of nineteen people with intellectual disability, even in a country with a population as tiny as Malta's. However, it should also be pointed out that the people with intellectual disability who participated in the research are very articulate and actively involved in self-advocacy.

With this in mind, it is opportune to reflect on the themes presented in this article and the insights that can be gleaned about how people with intellectual disability construct their sexuality identity. Potter and Wetherell (1987) argue that the context in which any discourse is produced is an integral part of the meaning of that discourse. In this research, the Core Group can be said to have created a context in which they could construct themselves as sexual beings and show awareness of their own sexuality, first among themselves in the research meetings and then in front of the people closely involved in their lives in the seminar. In this way, they also created a context in which they could resist the stereotypical picture of people with intellectual disability as being asexual and replace it with a picture of themselves as sexual beings.

Judith Butler's concept of performativity is very relevant here (Butler 1999). Butler's performativity refers to the socially constructed nature of one's identity and how the construction of that is constituted at once by socially inscribed norms and personal acceptance of or resistance to those norms. The research process, and especially the seminar, was a way for the Core Committee to resist the sexual norms ascribed to them as people with intellectual disability.

This is not to say that all the research participants resisted these norms. There were research

participants who evinced a degree of embarrassment about the subject. Mikela said she looks away when there are love scenes on television, while Abigail, when sexual intimacy was being discussed stated '...we follow God not the devil'. Equating the sexual act with making babies, as seen earlier, is another way in which sexual norms were seen to be absorbed by some research participants, who also omit any talk of sex as an act of pleasure for both parties (Bernert & Ogletree 2013). This contrasts sharply with Tina's assertion (below) about having a right to sex outside marriage and Mark's statement in one the research meetings that:

Physical intimacy is important, otherwise what do you stay doing, watching TV?

Thus, it can be seen that through this research, a context was created in which research data could be generated, analysed and presented in a way that put forward the sexual aspect of the identity of people with intellectual disability and resist stereotypes, such as that of people with intellectual disability as being sexually vulnerable (Hollomotz 2011). Parents are seen as specific targets of this resistance. Sara, for instance, states:

Parents need to trust us, we are old enough to be in a relationship.

Sara's performativity as an adult with sexual desires to fulfil therefore takes on and resists different norms that are foisted upon her and other adults with intellectual disability, and especially women. This is because vulnerability is an issue to a greater extent for females with intellectual disability than it is for males. This concern was expressed by one mother during the seminar when she stated:

...a girl is worse than a boy...when you've got a daughter, it's easy that she brings home a baby.

During one of the research meetings, Tina uses the language of rights when discussing one of the stories about a couple with intellectual disability:

they have every right to have sex.

Within the context of the discussion during which these words were said, it is clear that Tina meant having a right to have sex outside marriage. But it is important to note this discussion also took place within the bigger cultural context of Malta, a context which was heavily influenced by Catholicism. This statement goes beyond simply asserting one's right.

It also enables Tina at once to show that she is aware of and also resist the cultural norms that govern sexual behaviour.

These statements reflect the research participants' oppos- ing threads of thought, indicating a possible internal battle between what people with intellectual disability have been brought up to believe and what their parents insist on in contrast to the feelings and wishes they have themselves.

Concluding remarks

In this article, it has been seen how an inclusive research project enabled a self-advocacy group to explore and discuss the subject of sexuality and relationships. It was also seen how, in the process, some of the self-advocates involved resisted the stereotypes and misconceptions that are all too often associated with the sexuality of people with intellectual disability. These self-advocates sought to use this research to bring about concrete change in their lives – by inviting their parents to a seminar in which the research was discussed and during which they talked about themselves as sexual beings. Whether or not it did bring about concrete change in their lives is not easy to establish. As observed earlier, people with intellectual disability do not have much scope for self-advocacy in their lives. As Riddell et al. (2001) say, they tend to lead 'lives of extraordinary regulation'.

But it can be said that the research project, and the processes involved, made a contribution to changing socially accepted ideas regarding the misperceived asexuality of people with intellectual disability, especially through their active participation in all stages of the research process.

References

Azzopardi-Lane C. (2011) *Sexuality and People with Learning Disability in Malta: Realities and Potential*. Unpublished Ph.D. thesis, University of Kent.

Bane G., Dooher M., Flaherty J., Mahon A., Donagh P. et al. (2012) Relationships of people with learning disabilities in Ireland. *Br J Learn Disabil*, 40: 109–22.

Bernert J. (2011) Sexuality and disability in the lives of women with intellectual disabilities. *Sex Disabil*, 29: 129–41.

Bernert J. & Ogletree R. (2013) Women with intellectual disabilities talk about their perceptions of sex. *J Intellect Disabil*, 57: 240–9.

Brechin A. & Walmsley J., editors. (1989) *Making connections: reflecting on the lives and experiences of people with learning difficulties*. Sevenoaks, Hodder and Stoughton.

Burr V. (2003) *Social constructionism*, 2nd edn. London, Routledge.

Butler J. (1999) *Gender trouble: feminism and the subversion of identity*. London, Routledge.

Callus A.M. (2013) *Becoming self-advocates: people with intellectual disability seeking a voice*. Oxford, Peter Lang.

Cone A. (2000) Self-advocacy group advisor activities and their impact/relation to self-advocacy group development. *Int J Disabil Dev Educ*, 47: 137–54.

De Palma R. & Atkinson E. (2007) Strategic embodiment in virtual spaces: exploring an on-lone discussion about sexualities equality in schools. *Discourse Stud Cultur Polit Educ*, 28: 449–514.

Deguara M., Jelassi O., Micallef B. & Callus A.M. (2012) How we like to live when we have the chance. *Br J Learn Disabil*, 40: 123–7.

Drummond E. (2006) Attitudes towards; a pilot study in Ireland. *Learn Disabil Pract*, 9: 28–34.

Dye L., Hare D.J. & Hendy S. (2003) Factors impacting on the capacity to consent in people with learning disabilities. *Tizard Learn Disabil Rev*, 8: 11–20.

Evans D., McGuire B., Healy E. & Carley S. (2009) Sexuality and personal relationships for people with intellectual disability. Part II. Staff and family carer perspectives. *J Intellect Disabil Res*, 53: 913–21.

Fitzgerald C. & Withers P. (2013) 'I don't know what a proper woman means': what women with intellectual disabilities think about sex, sexuality and themselves. *Br J Learn Disabil*, 41: 5–12.

Garbutt R. (2008) Sex and relationships for people with learning disabilities: a challenge for parents and professionals. *Ment Health Learn Disabil Res Pract*, 5: 266–77.

Hollomotz A. (2011) *Learning difficulties and sexual vulnerability: a social approach*. London, Jessica Kingsley.

Kelly G., Crowley H. & Hamilton C. (2009) Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted'. *Br J Learn Disabil*, 37: 308–15.

KNPD (2012) *Indaqs* January 2012. St Venera, Malta, Kummissjoni Nazzjonali Persuni B'Dizabilit a. Available at: http://www.knpd. org (last accessed on 2 June 2012).

KNPD (2013) *Rapport ta' Hidma 2012*. St Venera, Malta, Kummissjoni Nazzjonali Persuni B'Dizabilit a. Available at: http://www.knpd.org (last accessed on 2 June 2013).

May A. & Stone A. (2010) Stereotypes of individuals with learning disabilities: views of college students with and without learning disabilities. *J Learn Disabil*, 43: 483–99.

McCarthy M. (1999) *Sexuality and women with learning disabilities*. London, Jessica Kingsley Publishers.

McCarthy M. & Thompson D. (1993) *Sex and the 3Rs: rights, responsibilities and risks*. Pavillion, Brighton.

Mead G.H. (1934) *Mind, self, and society*. Chicago, IL, University of Chicago Press.

National Institute for Intellectual Disability (2009) All we want to say: Life in Ireland for people with learning disabilities. Available at: http://www.tvd.ie/niid/reserach/projects/Allwewanttosay.php (last accessed on 2 June 2012).

Noonan A. & Gomez M.T. (2011) Who's missing? Awareness of lesbian, gay, bisexual and transgender people with intellectual disability. *Sex Disabil*, 29: 175–80.

Potter J. & Wetherell M. (1987) *Discourse and social psychology: beyond attitudes and behaviour*. London, Sage.

Riddell S., Baron S. & Wilson A. (2001) *The learning society and people with learning difficulties*. Bristol, Policy Press.

Rodgers J. (1999) Trying to get it right: undertaking research involving people with learning difficulties. *Disabil Soc*, 14: 421–33.

Walmsely J. & Downer J. (1997) Shouting the loudest: self-advocacy, power and diversity. In: Ramcharan P., Roberts G., Grant G., Borland J., editors. *Empowerment in everyday life: learning disability*. London, Jessica Kingsley: 35–47.

Walmsley D. & Johnson K. (2003) *Inclusive research with people with learning disabilities: past, present and future*. London, Jessica Kingsley.

Whitney C. (2006) Intersections in identity – identity development among queer women with disabilities. *Sex Disabil*, 24: 39–52.