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Gender, sexuality and relationships for young Australian women with intellectual disability

Amie O'Shea and Patsie Frawley

School of Health & Social Development, Faculty of Health, Deakin University,
Geelong, Australia

ABSTRACT

Gender has often been overlooked in the lives of people with intellectual disability, resulting in a limited understanding and service response. This is in part due to a lack of knowledge about the way people with intellectual disability negotiate and build a gendered identity. In this article we present research undertaken with six young women with an intellectual disability who worked with the first researcher to co-develop some stories from their lives. We show how, facilitated by an innovative method which focused on meaningful engagement, the women told stories of richly gendered lives and subjectivities. Their stories showed how gender can be a desired and productive subjectivity, and how consideration of gender can help to identify resistance and agency in their lives. Their stories illustrate how gender is necessary in forming a comprehensive understanding of the lives of women with intellectual disability.

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Points of interest

- Gender is part of how young women experience and understand their lives.
- The research showed why gender should be increasingly recognised as an important part of the lives of people with intellectual disability, in both feminist and disability research fields.
- Sexuality and relationships are important parts of how young women with intellectual disability experience their lives.
- Research with people with intellectual disability should continue to take new and creative approaches to hear from them.

CONTACT Amie O'Shea  amie.oshea@deakin.edu.au

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Introduction

Women with intellectual disability are insufficiently acknowledged as women living gendered lives. Much like the 'gender blind' approach critiqued by women with disability (Frohman 2014), for women with intellectual disability there may be additional, compounding factors. We argue that this includes, in part, the influence of normalisation on the field of intellectual disability research and practice, and also the defining nature of 'intellectual disability' which limits the space for other possible identities or experiences.

The discourse of normalisation has had a significant influence on disability service provision and intellectual disability research in Australia and many other countries (Cocks and Stehlik 1996; Walmsley and Johnson 2003). Hilary Brown argued that the principle of normalisation was problematic for any group outside the majority and that it caused a de-gendering of people with intellectual disability while also promoting little effect on people's sexual rights (Brown 1994; Brown and Smith 1992). Despite the decades which have passed since, this work continues to resonate within the findings of the present research.

The idea of intellectual disability is itself grounded in an ontological position of negation – it is about incapacity, lack and deficiency measured by disciplines which focus on intellect, activities of daily living and so on. By extension of this view which originates with what the person cannot do, their legal rights and even their moral personhood are called into question (Kittay 2005; Singer 2009). This discourse operates so effectively and completely that lesser known discourses may succumb to the 'tyranny of the globalising discourse' (Foucault 1980, 83). In this article we seek to unearth how one such discourse – that of gender – can be viewed and understood in the lives of women with intellectual disability.

Issues that are reported in the literature as being of particular concern for women with intellectual disabilities include the denial of reproductive rights, including the ongoing practice of non-therapeutic, involuntary sterilisation (Thompson et al. 2012), and lack of access to women's health screening programmes such as Pap tests (Brown et al. 2016) and breast screening (Truesdale-Kennedy, Taggart, and McIlpatrick 2011; Xu et al. 2017). Another key issue is violence and abuse. High levels of violence against Australian women with intellectual disabilities are widely acknowledged (Didi et al. 2016; Frawley et al. 2015; Women with Disabilities Australia 2015). There remains a significant need to find out more about the barriers to accessing services and to influencing policy and practice in this area.

It can be very difficult for women with intellectual disability to have their sexual agency acknowledged (Gill 2015). Normalisation allows a version of approved femininity, where contemporary cultural ideas align to form an 'ordinary' woman. As a result, women with intellectual disabilities may find

only a limited range of gender identities available to them. The parameters of normalisation confine such expressions to a neutral, minimised version of appropriate gender expression, while aspects such as sexual behaviour remain closely monitored. Gender is permitted in some sanctioned roles at certain times, often in widely shared videos in which an appropriately dressed young couple attend a school formal and share a dance. Other possibilities which do not align with ideas of appropriate gender performances (e.g. non-normative sexual or gender expression) may be actively forestalled.

Following Foucault, dominant discourses establish the ways in which women with intellectual disabilities are constructed, defining how they can (and cannot) know themselves and be known by others. Authoritative knowledges about intellectual disabilities take over, appearing to represent their whole truth, while other aspects such as gender are largely silenced. Perhaps the concepts of deficit and incapacity that define intellectual disability are assumed to extend to all aspects of people's lives and experiences. One result may be that women with intellectual disabilities are not seen as capable of 'correctly' or 'appropriately' being women and therefore are subjected to increased monitoring of their sexuality and relationships, restricted from getting married and prevented from being mothers.

There are conceptual similarities between women and people with intellectual disabilities: both have traditionally been seen as products of biology (Williams 1992) and as irrational, volatile and unable to make their own decisions. The ways in which they are understood at times appears to be a battle between the roles of gender and intellectual disability. If gender is present in the literature, women with intellectual disabilities are sometimes described as more likely to hold traditional or stereotypical gender roles (Bjornsdottir and Traustadóttir 2010; Burns and Davies 2011; Parkes and Hall 2006). Simultaneously, they may be positioned as likely hypersexual subjects, liable to uncontrolled expressions of 'inappropriate' sexual behaviour. This is informed by a residue of earlier discourses that produced subject positions including the feeble-minded woman and the moral imbecile (Carlson 2010). Yet gender is part of all aspects of our lives – a sometimes concrete, sometimes flyaway element of the lives and experiences of people. In this article we explore the connections and intersections between gender and intellectual disability by exploring the areas of sexuality and relationships.

This article presents findings from research with six young women with intellectual disability in the state of Victoria, Australia. We explore the stories they told of their lives with a focus on gender, in particular stories of romantic relationships. We take Frederick's (2017) assertion that 'disability is the undesired future, the risk, which mothers are held chiefly responsible for containing' (p. 78), and we explore what happens for the daughters born of

such risk. How do contemporary young women with intellectual disability relate to ideas and experiences of lives lived within discourses of gender and intellectual disability?

Literature review

Too often, the broader literature on people with intellectual disabilities pays attention solely to intellectual disability, to the exclusion of other personal factors such as gender. While still representing a comparative paucity of work, there has been attention given to meaningful inclusion of women with disabilities in the academic literature. Pioneers in this space have engaged with issues of gender and race (Atkinson et al. 2000; Walmsley and Downer 1997) and reflected on challenges in bringing inclusive or participatory work to the academy (Goodley and Moore 2000).

Authors have pointed to the significant potential for such work to inform policy, service and legislative responses to disability. Feminist disability studies has been recognised as an opportunity to generate new insight and renewed reflection while also challenging ideas of disability as deficiency (Garland-Thomson 2005; Hall 2015). Contemporary developments that engage with both philosophical and disability studies have begun interrogating ideas of impairment (Tremain 2002), intelligence and the human (Goodey 2011; Runswick-Cole and Liddiard 2016), and gender (Carlson 2001, 2005; Thomas 2006; Wong 2002).

Commonly defined by deficit-based discourses of intellectual disability, women with intellectual disabilities are known in limited ways. In much academic literature, they appear genderless: not 'real women' or men, simply (defective) 'people' (Clements, Clare, and Ezelle 1995). This is reflected in the literature: a comprehensive review conducted by Michelle McCarthy (2014) into research on what women with intellectual disability say about their sexual lives describes the 'negative perceptions, negative experiences, thwarted ambitions and abuse' that dominate their experiences (p. 126).

Empirical intellectual disability research literature has explored topics such as sexuality and relationships (Burns and Davies 2011; McCarthy 2014; Ramasamy, Rillotta, and Alexander 2017; Stoffelen et al. 2018; Vehmas 2019), deinstitutionalisation (Johnson 1998), physical and mental health (Conder, Mirfin-Veitch, and Gates 2015; Xu et al. 2017) and motherhood (Booth and Booth 2003; Mayes, Llewellyn, and McConnell 2011; McConnell, Feldman, and Aunos 2017; Traustadóttir and Sigurjónsdóttir 2008). Some studies have explored how women with intellectual disabilities manage various other identities or labels, including sexuality or ethnicity (Abbott and Burns 2007; Richardson and Stoneman 2019; Walmsley and Downer 1997). Subsequent to this research, young people with intellectual disability in Australia have

confirmed the importance of relationships in their lives, alongside experiences of exclusion and segregation (Merrells, Buchanan, and Waters 2019).

There are several themes that can be found in the literature on what women with intellectual disability find important in their lives. Love and relationships, families, identities and equality are consistent themes across this body of work (Atkinson et al. 2000; Barron 2004; Conder 2014; Ramasamy, Rillotta, and Alexander 2017; Traustadóttir and Johnson 2000; Welsby and Horsfall 2011). New areas of exploration include experiences of ageing (Strnadová et al. 2015) and – perhaps interestingly considering the high rates of compulsory removal of their children described by women with intellectual disability – childbirth and postpartum health (McGarry, Stenfert Kroese, and Cox 2015; Mitra 2017).

While sexuality and relationships are constants in this literature, the realisation of desired relationships is not always straightforward. In one study, participants with intellectual disabilities described the barriers and challenges they faced, highlighting the attitudes of family, caregivers, services and, particularly, society (Rushbrooke, Murray, and Townsend 2014). Participants indicated being sexual and having relationships as of particular importance to them. Elsewhere, women with intellectual disabilities have described how their expectations of sexual autonomy were limited by service policies or programmes (Bernert 2011). A recent Australian study has confirmed that doctors still hold less than positive attitudes to sexuality in people with intellectual disabilities and, in particular, to sexual freedom and parenting, often holding the view that sterilisation is ‘a desirable practice’ (Gilmore and Malcolm 2014).

Motherhood is one of the strongest gendered roles available to women, defining contemporary ideals of womanhood and femininity. Mothers with intellectual disability are highly marginalised women (Booth and Booth 2005; Frohmader and Meekosha 2012; Mayes, Llewellyn, and McConnell 2011). The research in this area demonstrates the significant role of the state in the policing of marginalised and vulnerable families (McConnell, Feldman, and Aunos 2017). This form of regulation is particular to women with intellectual disabilities and their construction as undesirable mothers having undesirable children.

The field of feminist disability studies has opened up new possibilities for the generation of new insights in this area, and also to make visible the assumptions about disability that inform feminism. From this we can begin to explore the ways in which able-mindedness is also gendered and racialised (Taylor 2015). There is, however, much work still to be done, as feminist and philosophical discursive perspectives on disability still need to build a body of work to inform and support a feminist understanding of intellectual disability (Hall 2015).

In conducting this study we viewed the participants' inclusion and representation in research as inextricable from the research questions themselves. Yet as we continue to build up the field of literature in which people with intellectual disability can directly represent themselves, it is entirely possible that they will see themselves in ways other than what is prescribed by dominant, essentialist intellectual disability discourse which speaks with authority on their lives. By using Foucault's (1998) ideas of discourse, power and subjectivity, in this article we seek out counter discourses and subjugated knowledges which can tell us more about gender and intellectual disability.

Research process

Historically, research has operated from a medicalised view of incapacity and deficit, and people with intellectual disability have been subjected to research, not engaged as part of it (Walmsley and Johnson 2003). Institutionalisation and other responses to intellectual disability that have removed people from society have meant that their experiences and voices have been ignored. Instead, professionals have spoken for them – simultaneously reinforcing their authority and legitimacy to speak for people with intellectual disabilities. An important element of the research reported in this article was the development of a collaborative and inclusive approach to data collection.

The research sought to understand how gender appeared in the lives of young women with intellectual disability and how this could contribute to our understanding of their lives. This was a small qualitative study involving six women aged 18–30 years in Victoria, Australia, approved by the La Trobe University Human Research Ethics Committee. The women had all used a service designated for people with intellectual disability; as per Voronka (2019), we present a brief generalised summary of participant characteristics. This approach acknowledges the challenges of anonymity within a small sample size while giving a sense of the demographics and diversity of the group. Of the participants, two were from culturally diverse backgrounds, two were married, one was engaged and one identified as sexually diverse. They lived in a mix of metropolitan and regional areas in Victoria, Australia – two lived independently and the others lived at home with their families. They were all either involved in part-time paid (supported) work, job-seeking or further studies. Participants gave their own consent to participate in the research, supported by a plain English and accessible process. To address any potential ethical concerns related to ending the three-month participant engagement period, our interactions were framed around the concrete task of telling, producing and refining written stories of their life. This followed a

process which culminated in the participant receiving her stories, forming a natural and pre-empted closure to the research relationship.

To maximise opportunities for the women to tell their stories, the research method captured elements of narrative, ethnographic and PhotoVoice methods. The first author met with each participant seven times to collaboratively produce the stories from their life. The method prioritised time spent together which, over several months in total, produced opportunities for greater depth and accessibility both during and in the space between the research encounters. Participants had digital cameras on which they took photographs to discuss in the interviews. Some of the photographs were then chosen by participants for inclusion in their stories, along with images from the Internet (e.g. a map of one woman's parents birth country, and for another woman a rainbow [LGBTIQ pride] flag). Participants chose their pseudonym, which included a first name and surname – for us, reading a case study about 'Hayley' can evoke a different response to reading about Hayley Bos, in her words.

A total of 28 stories and almost 200 photographs were produced by the six women, and given titles such as 'My wedding', 'The Devil's Story' and 'My Mum'. Along with revising the words, and then working with the researcher on the titles and images, the women made decisions about the layout of the stories including page numbers and headers (O'Shea 2016). This approach was reinforced when one woman, directing the researcher, chose a large bold pink font with a double underline. Text is often underlined to indicate its importance or veracity, such as in a title, headline or key phrase: she directed the researcher to apply this style to her whole story. This was a remarkable reminder that attention to such detail itself produced meaning and opportunities for reflection and increased understanding.

The stories were then coded in open codes followed by a thematic analysis informed by the work of Foucault (1998) on power, discourse and subjectivity. Analysis identified several themes relating to the women's engagement with ideas of intellectual disability and gender in their lives, in particular the appearance and function of gender discourses in informing their lives and experiences as women. Reflecting the literature described earlier, themes included motherhood, violence and abuse, and the disability identity. In this article we present findings from within the broad theme of relationships, which was one of the most significant across the women's stories.

Results and discussion

Our review of the literature highlighted the significance that people with intellectual disabilities accorded to romantic, familial and platonic

relationships, and their importance in achieving a good life. Romantic relationships were highly significant to the women in this research; the only topic about which they all spoke, unprompted and often at length. Specifically, they wrote stories about how gender played out in their relationships, how they negotiated their relationships and what their family's responses were to their relationships.

Within intellectual disability discourse, women may be positioned as unable to understand or contribute to 'real' romantic relationships, and as vulnerable and in need of protection as a result. Strong echoes of the innocent, 'eternal child' discourse remain. In this way, relationships function as a productive site for understanding gender in their lives.

Given the greater surveillance and the influence of conservative attitudes from parents, disability care staff and the broader community, family responses to relationships may well be expected to affect these women more significantly than they do other young people (Ditchman et al. 2017; Pebdani 2016; Wilson and Frawley 2016). For these reasons, romantic relationships may appear to be largely unavailable for young women with intellectual disabilities. Yet the women responded to this environment when they each spoke about love and marriage, according high value to the subject positions of wife (Anne), girlfriend (Neslihan, Hayley and Ginette) and fiancée (Mandy).

Re-telling 'imaginary' relationships

In comparison to her silence on topics such as her Down syndrome, Ginette Green (aged 19 years) spoke about her relationship with Simon in descriptive detail:

I have a boyfriend; his name is Simon and he calls me his girlfriend. I see him sometimes. I don't call him up on the phone because Mum says I'm not allowed to, so I use Facebook. Sometimes he comes on my Facebook, talks to me online. I said, 'How are you?' and he said, 'I'm fine'. He is friendly and good looking and a nice person.

Ginette's description of Simon referred to several desirable traits that are valued in a relationship. It also provides an insight into what being a girlfriend meant for her, in their occasional contact in person and online.

Ginette seemed to face some obstacles in her relationship with Simon and while, as with Mandy, the reasons for this are not given, Ginette acknowledges that her mother does not want them speaking on the telephone. She did not dwell on this aspect of her story, but instead mentioned that they connect using Facebook, presumably circumventing her mother's disavowal of the telephone while still able to maintain the relationship. How her

mother feels about their relationship is not acknowledged; instead, Ginette's story begins by validating her role as Simon's girlfriend in his and her eyes.

Like Ginette, Neslihan Kunduk (aged 18 years) used Facebook to keep in touch with her boyfriend while keeping details of her relationship from her parents:

Author: How do you keep in contact?

Neslihan: Usually on Facebook, we chat. So it's like, we keep up. It's just Facebook, mainly because I already know him; we talk on Facebook and everything; we usually just chat on Facebook that's mainly it. We don't talk on the phone.

Author: What about text message?

Neslihan: He hasn't been sending it to me, so I've been sending it to him lately ... but he hasn't replied yet because he's out and he can't reply ... I saw him last week and he said he was missing me, so it's like ... [laughs]

Author: Oh! Where did you see him?

Neslihan: I saw him at the train station last week; he was there. And then a couple of weeks ago I saw him at the shops; he was there with his mum, so I met his mum for the first time

This is comparable to many young people today and their use of technologies with which their parents may not be familiar. The women came from a generation who grew up with the possibility of such forms of communication, and it is clear that it represents, as it does for their peers without intellectual disability (Lenhart et al. 2010; Löfgren-Mårtenson, Molin, and Sorbring 2018), a fruitful and productive space.

Discourses around romantic relationships are highly gendered. They are also constructed by drawing on various cultural discourses. That they met seemingly by chance in a public place rather than an arranged meeting does not matter to Neslihan's mention of 'meeting his mum for the first time'. Drawing on the cultural significance of meeting his mother may have been another way for Neslihan to signify and enhance her experience as his girlfriend. Whether they were not permitted to have relationships or simply chose for their parents not to know, Ginette and Neslihan resisted the removal of romantic relationships from their lives. Instead, they found ways of maintaining their relationships without their parents' knowledge. In their stories, their resistance was successful. It was also complex as, without directly challenging how they were being described or viewed by others, they demonstrated several creative efforts to produce themselves as girlfriends.

The relationships that Neslihan and Ginette described differed from discursively normative definitions of a romantic relationship, in that they did not talk about spending time together or about regular contact initiated by

either party. Such elements are generally assumed in romantic love discourses of 'healthy' or 'normal' relationships. Where they do not, as may arguably be the case for Neslihan and Ginette, similar relationships have been explained as 'imaginary' (Hollomotz 2011) or 'claimed' (Angrosino and Zagnoli 1992). Drawing on discourses of incapacity and deficit, this might suggest that claims to 'girlfriend' status can be dismissed because relationships are not 'real' (Angrosino and Zagnoli 1992, p. 57. Hollomotz 2011, p. 64). However, they were 'real' to both Ginette and Neslihan, who claimed a – clearly subjugated – knowledge of themselves as girlfriends.

This draws to mind the influence of dominant discourses on intellectual disability, whose truth claims are so strong that they have called similar resistance 'denial' of the inherent truth of intellectual disability. Individuals 'in denial' face a 'catch-22' situation, where any rejection of intellectual disability is seen as a result and further proof of their intellectual disability and inability to see their own truths. Faced with these choices, while silence can be understood as a way of negotiating between different positions, claiming subjugated knowledges can equally be viewed as actively using power to articulate themselves in preferred ways.

Mandy Stewart (aged 19 years) likewise managed her representation of her relationship, ceding to her mother the compromised description of 'slightly engaged' while in all other ways continuing to claim her status as Shayne's fiancée. Their engagement formed a significant part of the way she saw herself, in a literal as well as figurative sense: in our first interview, she proudly showed me her engagement ring. Perhaps in comparison to the medicalised truths of disability produced by others since her birth with cerebral palsy, being engaged presented Mandy with the opportunity to incorporate a more desired way of seeing herself. Drawing on gendered discourses of adulthood and romantic love, being engaged signified that her relationship was mutual, serious and valid.

Later, Mandy described her mother's view of the relationship:

She knows that we're slightly engaged but she doesn't accept it. She just wants to treat it as boyfriend-girlfriend thing. To say that my engagement ring is a friendship ring.

Clearly, Mandy wished to be engaged, while her mother did not want to accept her relationship status. Although not disallowing it entirely, she had made several attempts to negate or downgrade the relationship. Mandy's engagement ring was renamed a 'friendship' ring, and her fiancé was treated as her 'boyfriend'.

Mandy recognised (but did not accept) her mother's efforts to rename the relationship and downgrade her position of 'fiancée'. Her mother's actions may have been a protective response, drawing on ideas of vulnerability and incapacity in intellectual disability discourse, Mandy's age (19 years old) or

other factors not ascertainable. Regardless, her mother's response at first appears to represent a solid, unarguable position – after all, one is either engaged or not engaged: it is not possible to be 'a little bit engaged'. Faced with the difference in how she and her mother viewed her relationship, Mandy created a significant new position for herself, 'slightly engaged'. Mothers are accorded a particular authority in speaking about their children with disability, which meant her mother's views might supersede her own. In response, Mandy found a way to incorporate them into her preferred subjectivity. Her use of agency and her creation of this new subject position meant that she could simultaneously manage how she and her mother constructed her relationship. This was deftly achieved: without directly challenging her mother's view (or any possible reasons on which it was based) and by avoiding the undesirable 'not engaged' status entirely, while also minimising any threat to the mother–daughter relationship through an open challenge to her mother.

Mandy's story was not the only one in which parents featured as mediators of the romantic relationships of their daughters with intellectual disabilities. This is not surprising, given that parents of people with intellectual disabilities can continue to limit their children's movements and unsupervised activities to older ages than those of their non-disabled peers. While parents' actions in this regard may be about safety or skills, they can also be motivated by attempts to control their offspring's sexuality and reproduction (Rogers 2009).

The function of traditional gender roles

Arguably, the principal way that Mandy, Anne, Ginette and Neslihan experienced themselves in gendered ways came in their positioning within romantic love discourses. One side effect of the prevalence of western ideas of romantic love is that the subject positions are clearly known. Romantic relationships presented highly sought-after ways for the women to see themselves and be seen by others. Their roles as, or aspirations towards, 'girlfriend', 'fiancée', 'bride' and 'wife' positioned the women in positive ways as desirable, capable and lovable. Their relationships were sites of various forms of resistance or circumventions of power relations acting to remove, monitor or downgrade their relationship status. Neslihan used text messages and Facebook to navigate her relationship, and when Ginette was not allowed to call Simon on the telephone, she, too, used Facebook. Ginette, Neslihan and Mandy resisted their potential positioning as non-girlfriends or non-fiancées along with any efforts to restrict or minimise their relationships – Mandy's status as 'slightly engaged', and relationships as 'not allowed' or 'imaginary' for Ginette and Neslihan.

Anne McMahon (aged 29 years) told the story of her wedding after being asked about some of the things she had done in her life of which she was proud:

I never thought I'd get married before I was 30 ... I thought I was just not worth marrying.

Her family and many friends attended the wedding, and Anne described their responses:

Me, my grandparents were both in tears. My dad said, 'I don't want to let you go'.
... My mum was in tears as well and my friends were whistling.

Anne's idea of herself as 'not worth marrying' may reference the way that intellectual disability discourses had functioned to position her as unable or unlikely to marry, or someone for whom a wedding is either unnecessary or not 'real'. Unlike intellectual disability, which Anne said she felt she must hide to avoid discussions where family members disagreed about the label, her presentation as a bride was unanimously supported by her family. The actions of her family and friends – crying and whistling – were undisputed evidence of celebration and validation.

Anne's story contrasts with what is considered the normal (single) relationship status for women with intellectual disabilities. It shows her as desirable, beautiful and loved in a committed adult relationship: gender presented Anne with her 'greatest achievement' – getting married before 30 years of age. Her wedding is a success story, perhaps implicitly situated against the power relations of an intellectual disability discourse that sought to silence her sexuality or capacity for a romantic relationship, her ability to join the institution of marriage or to celebrate it legitimately with others through a traditional wedding ceremony.

When Anne first talked about her wedding day, she began by describing her appearance:

Being the bride is a weird feeling – everyone is watching you – all of the attention is on you and no one else. But it's good for a while. My dress was so big and heavy! It came in at the waist, sucked me in and made me thinner so you couldn't see any extra. It was nice. The veil's got diamonds or diamantes or something on it. I don't know how to explain my hair, but it was very full of pins. I couldn't find my way through it! My hair was long and they said 'we've used 150 pins in your hair!' Lucky the men don't have to go through what we do.

Anne drew on cultural ideals of beauty and femininity to describe her wedding day. Anne's markedly feminine bridal presentation had made her feel pleased with her appearance and the experience of being looked at. Anne enjoyed her appearance, which seemed to enhance her femininity through a kind of illusion: a dress that made her thinner and 150 pins that held up her hair. Her joke that men 'don't have to go through what we do'

gave the impression that Anne validated her sense of femininity through her difference from men and felt a similarity with the researcher and other women more broadly.

Women with intellectual disabilities are often similarly designated as physically unappealing or undesirable, regardless of their body shape. On her wedding day, Anne resisted being seen in such negative ways, drawing on the cultural ideal of 'bride' and using the illusion provided by her dress and hairpins.

The use of traditional ideas of femininity that Anne engaged may be understood using Judith Butler's (1990) ideas of 'overplay', or the amplification of key elements of discourse. It is easily situated within the overstated or emphasised ideas of 'feminine beauty' present at many western weddings, for example. Here, gender performance is accentuated in:

The clothes worn during the wedding ritual (e.g. the ornamental and 'purity' declaring white dress or the less visible but serious tuxedo), [which] highlight the constructions of the female's femininity and the male's masculinity in highly symbolic and culturally specific ways. (Jones 2009, 14)

Anne made clear that she did not expect such a performance from men at weddings. Using overplay positions Anne's story as an assertion of her femininity, claiming herself as woman through the traditional and valued feminine roles of bride and daughter. Importantly, overplay thus becomes functional; to go this far produces an 'override' of intellectual disability by positioning oneself right in the centre of the discourse of femininity. It is an act complete with agency, a productive claim upon a desired discourse as Anne aligned herself with the accepted ways in which gender is both experienced by the individual and expressed to others.

It is possible to see Anne's story as an act that minimises intellectual disability discourse. It may be that claiming gender became a way to resist being positioned as 'intellectually disabled'. For Anne, traditional gender roles were productive as they allowed her to position herself positively within her family. She may have been resisting the erasure of gender in intellectual disability discourse, the way in which she may otherwise no longer have been seen as a 'real woman'.

While the de-gendering effects of intellectual disability discourses may have suppressed knowledge of them as women, femininity was visible in their lives and made clear in their stories. Such traditional roles may have provided easier roles to access, representing subject positions that women are culturally encouraged to desire. Although apparently confined to traditional gender expressions, knowing themselves in this way was important to Ginette, Neslihan, Mandy and Anne, and can therefore be understood as both valid and productive. Regardless, and seemingly despite the decade difference in their ages, gender became a source of power for the women, accessed through the traditional cultural gender relationship roles of girlfriend, fiancé, bride.

Sexuality: finding pleasure and enjoyment

Romantic relationships are commonly intertwined with sexual expression. Interestingly, while relationships were a significant part of the gendered experiences brought forward in the women's stories, this did not correspond to a similar importance of sexuality or a frequency of stories in which it featured.

Shaped by intersecting discursive formations of intellectual disability, sexuality and gender, women with intellectual disabilities are largely constructed as asexual beings (Gill 2015). If sexuality is acknowledged in their lives, it is permitted only in discrete, normative and traditional ways, prone to surveillance through various means of assessment and training. This forms a boundary around the acceptable sexual expressions available to women with intellectual disabilities, outside which they become unacceptable: described as 'inappropriate' in disability services or 'invisible' in the research literature (Abbott 2015; Abbott and Burns 2007; Noonan and Taylor Gomez 2010). Recent work has explored this with more nuance, reflecting that it may be that lesbian relationships appear invisible because they do not pose the risk of pregnancy and because intimacy and touch between women is less likely to be seen as sexual (Abbott and Howarth 2005; Chapman et al. 2015). This work articulates the need for more studies which explore how women construct themselves and get support around their sexuality (Chapman et al. 2015).

The primary exception to the overall silence on sexuality in this study came from 20-year-old Hayley Bos, who lived at home with her mother. There was a particularly close relationship that had an influence on how she navigated herself within intellectual disability discourses. Her mother continued to feature in Hayley's stories of her sexuality.

Hayley was happy with her appearance. Her clothes and accessories were one way in which she expressed herself as a woman and displayed her femininity to others. Here, Hayley described the jewellery she wore each day to 'feel right':

If I don't have a watch on my wrist, then I'll feel bare. And same with my wristbands. I like to make sure I got my bracelets on. If I don't have my rings, then I feel not right. So I always make sure that I've got a good set of things on: three rings on one hand and two rings on one hand and then a watch and then another bracelet, so I feel myself.

Her accessories reflected how Hayley could 'feel herself' as a woman and how she wanted to present that to others. When making choices about what she would wear, Hayley drew on discourses of gender, fashion and feminine appearance:

I'm a rare girl, not like a real girl-girl-girl-girly girl. I'm sort of like a tomboy kind of girl. I like to be in jeans and black shirt and skate shoes. I do dress up in skirts and dresses and that, but then other days I'm just not. ... Mum says that I should wear my jeans over my hips. No! I wear my jeans on my hips 'cos that's the fashion now – it's ON the hips!

In Hayley's actions, her body itself became a site of resistance as she reconfigured the gendered discourses that imposed ideas of 'suitable' feminine appearance. Hayley literally 'fashioned' her appearance, positioning herself variously between 'real girly girl' and 'tomboy kind of girl', mostly closer to the latter. She knew how to achieve this balance and resisted her mother's attempts to shape her otherwise.

Hayley also positively experienced herself as a woman in her sexuality, and in this respect she is 'a rare girl' in the literature. Hayley's sense of her sexuality was evolving and she described her sexuality using a range of identity terms including 'gay', 'lesbian', 'confused' or 'gay or straight or bi'. Hayley recalled her first kiss with a girl:

I'd never kissed a girl. Her lips were more softer than the guy's. It gave me goose bumps and butterflies. It was a good feeling, nice in a way and it sort of gave that warm spark, like when you first meet someone you get this warm fuzzy feeling in your stomach. Sort of like that. I've kissed boys, but it's different kissing a girl.

Elsewhere, there is a particular silence on sexual enjoyment or satisfaction in discourses around people with disabilities; what Tepper (2000, 283) called the 'missing discourse of pleasure'. In this excerpt, Hayley presents herself as a sexual woman, describing the pleasure she experienced. Like her appearance, sexuality provided Hayley with pleasure and enjoyment, which can be read as resistance to the pleasure-removing and asexualising influences of intellectual disability discourses. Hayley's claiming and ownership of her sexuality stands in contrast to the limited and heterosexual identities that are still largely sanctioned and available to people with disabilities (Gill 2015).

Conclusion

Women with disability have critiqued the absence of gender in the way that they are seen in policy, practice and research (Frohmader 2014). That this is an omission rather than an actual absence of the importance of gender can be seen in the stories explored here. In contrast to the genderless ways in which women with intellectual disabilities are often known, the women's stories showed how their lives were richly and deeply gendered. Taking our cue from Frederick's (2017) connection between disability and gender roles we have considered what happens for the daughters born of the disability risk held by their mothers. We have explored how the stories told by Hayley, Ginette, Anne, Mandy and Neslihan revealed their gendered lives. This made it possible to uncover how gender became a productive, desirable and malleable discourse, more so when implicitly positioned against ideas of intellectual disability to which they were also subject.

It was not our intent or the design of this study to represent all young women with intellectual disabilities. This research occurred in a place, at a time and under recruitment and other conditions that were particular to the study. That six women participated may appear to limit the breadth of potential research claims; however, it simultaneously made possible the depth of research engagement and insights into their lives that were essential to the development of the research findings.

Contesting the idea that they were 'other' or 'invisible', the women's stories resignified their lives. The gendered themes of relationships discussed here were productive in this resignification, the understanding of which is made possible by prioritising a gendered lens. Understanding their gendered lives was part of understanding the women, their lives and experiences (O'Shea 2016). In doing so, the 'othering' disability/ability distance is reduced, showcasing the similarity of their gendered lives to other women. This becomes evident using a Foucauldian reading of what Ginette and Neslihan had to say about their relationships, as well as Mandy's act of literally re-naming her relationship status, allowed a different way of recognising the manoeuvres they conducted as young women to claim desired subject positions.

Hayley's experiences can be seen as a response to the danger of the single story surrounding sexuality and intellectual disability (Gill 2015). Resisting the limited sexual identities which are more commonly made available to women with intellectual disability, Hayley describes the search for her own, and characterises it with descriptions of pleasure so widely missing in the version of sexuality most commonly allowed for people with intellectual disability. Her story reminds us to make space for all forms of sexuality and gender expression, not as a second tier or 'add on' to sexuality policies and procedures but, as Triska (2018, 85) describes it, woven into the fabric of both research and practice.

Anne's story challenges the perception that only certain (alternative) gendered roles can be the site of such resistance. Her celebration of her wedding and her wedding clothes reminds us that traditionally feminine gender roles can also be valuable and productive for those who choose them. Like Hayley, Anne managed her appearance to reflect – and project – her gendered sense of self. We can see how this produces a positive and valued place within her family and a social identity more valued than her intellectual disability, which may also be part of her celebration.

The women harnessed gender discourses – they were functional and productive. Where discourses of intellectual disability originate from ideas of incapacity and lack, gender presented opportunities for competence and the experience of being loved and valued. This in fact is not that far from the socially valued roles so desired by early work which shaped intellectual disability service provision (Wolfensberger 1972, 1983).

We sought to listen to the voices of women with an intellectual disability using an approach which recognised their agency and promoted meaningful opportunities for inclusion. This moves beyond the case-study or vignette approach, reflecting more accurately the whole and complete lives of people with intellectual disability. Doing so was an integral part of the move away from globalising discourses of intellectual disability and towards a more rich and meaningful understanding of their lives. We suggest that such an approach can increase understanding of both gender and intellectual disability which can then be translated into further research and practice about women's health, violence and abuse, and indeed all areas of people's lives.

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