Sex Disabil (2011) 29:275–289
DOI 10.1007/s11195-011-9203-y

ORIGINAL PAPER

Conditionally Sexual: Men and Teenage Boys with Moderate to Profound Intellectual Disability

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Published online: 13 March 2011
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Abstract This article presents qualitative research data about the sexuality of men and teenage boys with moderate to profound intellectual disability. Research findings pointed to a conditional construct of sexuality based within a biopsychosocial framework. The notion *Conditionally Sexual* represents the perceived limitations, within a rights-based discourse, of these men and teenage boys' sexuality. The limitations to person-centred service delivery from a policy vacuum in the area of sexuality and intellectual disability represents a major challenge for paid staff. We suggest that a move toward better understanding how to support such a conditional sexual construct will assist the development of a healthy masculine sexuality for men and boys with intellectual disability.

Keywords Intellectual disability · Sexuality · Men · Boys · Research · Masculinity · Australia

Background

People with intellectual disability were historically character as being denied sexual rights, treatment as "eternal children", perceived as being either asexual or deviant, viewed as morally corrupt, and were thought to engage in profligate breeding of more people with intellectual disabilities [1–3]. In the 1960s a philosophical shift occurred in how people with intellectual disability were viewed and treated; the "rights" of people with disabilities

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becoming formally enshrined by the United Nations (UN) in the 1970s [4]. The 1975 UN *Declaration on the Rights of Disabled Persons* conferred the right to individual autonomy and personhood irrespective of one's disability. Reflecting this paradigm shift, three significant gatherings were convened in the early 1970s where the sexuality of people with intellectual disability was formally debated as a concept beyond segregation, sterilisation, and/or eugenics. The first conference, held in Hot Springs, Arkansas in 1971, was titled *Human Sexuality and the Mentally Retarded* [5]. A second gathering held in 1974 in Washington D.C. was called *Symposiums on Reproductive Rights of the Mentally Retarded* [6]. The third conference took place in West Germany in 1975 and was entitled *Mental Handicap, Human Relationships, Sexuality* [7], its aim was to further stimulate the rights-based dialogue.

McCarthy [8] provided a comprehensive summary of the development of the current sexuality discourse in western countries as it progressed through the 1970s, 1980s and 1990s. McCarthy reaffirms that the 1970s were a decade focussed mainly on the "right" to, and need for, sex education, together with a focus on the "right" to date and marry. The 1980s represented a continuance and enhancement of sex education programs with a growing recognition of reproductive "rights". As the area of sexual supports for people with intellectual disability became more prominent, disability services started to reflect this via the adoption of formal policies and procedures. The 1990s, argued McCarthy, saw a major paradigm shift as the uncomfortable truth of people with intellectual disability as both victims and perpetrators of sexual abuse was confronted. McCarthy also suggested that the 1990s moved toward a positive focus on same-sex relationships, gendered power relations, ethnic and cultural awareness, and HIV prevention work. Into the 21st century, Cambridge [9] cited the development of special issues of research journals related to sexual matters and intellectual disability as part of a continuing discourse. Cambridge asserted that this discourse is shaped by the ongoing awareness of sexual abuse, the articulation of "rights", and emerging themes such as HIV, consent, and the sexuality of men and women with intellectual disability [10]. Another feature of this developing discourse was a central focus on social constructionist perspectives, or sexual sociology, an approach that places socio-cultural factors, such as social scripts (e.g., [8]), at the centre of the expression of sexuality.

The most recently published empirical studies relating to sexuality and intellectual disability continue to refer their sexual rights, however, boundaries, or the limitation of rights and hence individual autonomy, continue to be placed on the sexual expression of people with intellectual disability. Hamilton's [11] research found that while support staff held generally positive views toward the sexual rights of people with intellectual disability, this was mostly curtailed by an inadequate framework to provide proactive support for sexual expression. Likewise, Hollomotz and The Speakup Committee [12] identified that access to sexual privacy within community-based group homes was often curtailed by staff who have a limited policy framework to guide their practice. In another study Yacoub and Hall [13] found that male research participants felt services were positive about their relationships and sexual lives. However, these data still highlighted a range of limitations on how the men's relationships were enacted and their sexual desires fulfilled. Furthermore, Healy et al. [14] found that both cultural and social barriers inhibiting sexual autonomy still existed.

Despite the promise of those gatherings in the 1970s and with several decades for a rights-based discourse to develop, the right to full sexual personhood remains an unfilled reality for some people with intellectual disability. The reasons for this are quite complex and for people reliant upon paid caregivers this complexity is compounded by the dilemma

for staff of both promoting rights, but also assuring safety within a risk hierarchy. As Hamilton [11] identified, inadequate policy and procedure frameworks appear at the centre of this dilemma. Moreover, navigating capacity of people with intellectual disability to consent to sexual contact with another person continues to be fraught with difficulty with inadequate frameworks to assist staff [15, 16]. Concerning research to practice, a recent review of research that explored sexual matters for people with intellectual disability stated that there is "…a dearth of empirical evidence for the ideas and practice in this field. Second, when research has been conducted, it often lacked the scientific rigour (pp. 328–329)" [17]. Likewise, Grieve et al. [18] in their review of sex education resources highlighted not only methodological concerns but also a bias toward resources more suitable for people with borderline to mild intellectual disability. While the current discourse suggests sexual autonomy should be possible, a fulfilling sexual life remains an unresolved dilemma for people with intellectual disability and the staff who support them.

Men and Boys with Intellectual Disability

Men and boys with intellectual disability represent 60% of all people with intellectual disability [19]. In a review of the research literature we found that sexual matters for men and boys with intellectual disability were often framed by a focus on socio-sexual pathologies such as criminal/anti-social behaviour and problematic sexual behaviour [20]. We have termed this a "problematised" male discourse that is underpinned by factors such as a reported disproportionate rate of sexually inappropriate behaviour [21, 22], inappropriate masturbation [10, 23], use of anti-libidinal medication [24, 25], and inappropriate touch of female care staff [26]. Absent within this discourse are studies that focus on the right to sexual expression for enjoyment and strategies to facilitate the development of a healthy masculine sexuality.

Reporting on the sexual health needs of men and boys with intellectual disability in the research literature is similarly limited in its scope, although some gender-specific issues are clear. For example, we know that increased rates of hypogonadism affect men and boys with intellectual disability [27, 28]. Furthermore, despite the increased incidence of testicular cancer [29] and undescended testes [30], we know little about testicular screening in this population. Likewise, studies into prostate screening for older men with intellectual disability do not appear in the research literature. Although van Schrojenstein Lantman-de Valk et al. [30, 31] identified rates of STDs in males with intellectual disability eight times greater than in their non-disabled peers, this matter also receives limited, if any, research.

The present study sought to begin to construct an understanding of a *healthy masculine sexuality* for these men and teenage boys [32]. We concur with Health Canada's [33] definition of sexual health and define a healthy masculine sexuality as a framework that promotes sexually healthy outcomes (e.g. self-esteem, respect, non-exploitation, sexual satisfaction, rewarding human relationships, the joy of desired parenthood) and specifies ways to avoid negative outcomes (e.g. unintended pregnancy, STD/HIV, sexual coercion). The aim was to frame the basis for a positive and contemporary framework that would shed some light on how to support the right to a healthy masculine sexuality. Central to this study was an appreciation of not only healthy male sexuality, but also the theoretical notion of masculinity and how constructs of masculinity acted to shape the sexuality of these men and teenage boys. The study was deliberately aimed at uncovering these issues for those men and teenage boys with more marked degrees of intellectual disability (moderate to profound). A person with moderate intellectual disability typically has limited language

skills and needs some assistance with self-care; a person with profound intellectual disability cannot understand verbal requests, has very limited communication, no self-care skills and is usually incontinent [34].

As an ethnographic study, data were collected from a combination of in-depth interviews with paid disability support workers and observation of interactions in community-based group homes. The men and teenage boys were not interviewed themselves due to communication limitations. Analyses of the environmental and the context of service delivery offered a deeper insight into factors affecting the men and teenage boys' sexuality. The notion of *Conditionally Sexual* represents the core concept that emerged from the study. Other findings from this study that represent less central concepts have been published elsewhere and relate more specifically to the intersection of masculinity and intellectual disability, and to gendered caring roles in disability-specific group homes [35, 36].

Method

Ethical approval was granted by the University of Sydney Human Research Ethics Committee. The present study was focussed on five individual men and teenage boys with moderate to profound intellectual disability living in three separate community-based intellectual disability-specific group homes in Australia. The disability-specific group homes were run by small to moderate sized non-Government organisations based in the one geographical region of the state of New South Wales. One group home housed one man and four women with intellectual disability; the staff team were all female apart from one full time male. A second group home housed two teenage boys, one teenage girl and two young women with intellectual disability; the staff team were all female except for two younger males. The third group home housed one teenage boy, one younger man and one young woman with intellectual disability; the staff team were all female.

Data were collected from several sources: (1) interviews with paid disability support workers (15 female, 3 male) employed in the three group homes, (2) participant observation in the group homes, and (3) collection of relevant artefacts (e.g., policy and procedures, training calendar, environmental, geographical and architectural setting). Interviews were conducted in the group home at a time convenient to the rhythms and patterns of each home, each interview lasted, on average, 1 h. Semi-structured interview questions focussed on four topics: (1) sexual health, (2) masculinity, (3) gender, (4) gendered caring roles. Participant observation data were recorded as field notes. Data were analysed using the constant comparative method of grounded theory [37]. Data were initially analysed by the first author however, themes developed collaboratively with input from all authors. Data that are presented in *"italics"* represent direct quotes; phrases and/or words in [parenthesis] are added by the researchers to enhance the clarity of direct quotes.

Findings

Conditionally Sexual

The Overarching Concept that Emerged from the Present Study—Conditionally Sexual—can be summarised by disability support worker interview responses such as "[sex] *education…depending upon cognitive function"; "masturbation…but only if that's possible"; "understand* [sexual/relational] *feelings…if they are able"*. Underpinning these responses

was the notion that the developmental capacity of the individual was central to the construction of one's sexuality, together with the perspective and influence of paid disability support workers. That is, variations, and staff perceptions of these variations, in cognitive, emotional, physical, anatomical, hormonal, functional and social development were central to how one's masculine sexuality was constructed and to the gate-keeping role of staff in overseeing sexual behaviour. Furthermore, it was constructed against normative societal expectations of self-exploration, sexual experimentation, relationship formation, marriage and childbirth. The themes of Conditionally Sexual are: self-discovery, hormones, pleasure, insight, staff belief-systems, duty of care, and staff as interactional gate-keeper; each theme will be discussed in detail.

Self-Discovery

> *…it's not a dirty thing…more exploratory.*

A limited range of sexual behaviours included masturbation, anal stimulation and masturbating in *"…not the usual way"* such as rubbing one's penis through trousers or up against pieces of furniture. Less usual methods to masturbate are reportedly common where hand action is limited and a strong drive exists to find an effective method to self-stimulate [38]. Where physical disability does limit movement, set times can become opportune in the desire for self-discovery:

> *because he is not able to touch himself, because of the clothes that he has on and the limited dexterity he has, leaving him in the bath…and supervising from a distance…he does respond to that time…it's a needed and healthy time…like [*the other male client*] it's hard to say if it's a sexual or an arousal thing.*

One of the teenage boys displayed a range of what staff described as non-sexual self-pleasuring such as gentle rubbing of the skin and hair across his body and choosing not to wear many clothes: *"He does a lot of things that are purely sensory focussed: scratching his arms, grabbing your hands to squeeze his head, that kind of thing, so he does other things that he finds enjoyable"*. Disability support staff felt that these kind of self-pleasuring behaviours were not sexually motivated as there was never any obvious and consistent sexual trigger; if this teenage boy wanted to masturbate he would just go ahead and do it. The matter of non-sexual stimulation during the delivery of intimate personal care, such as penile hygiene, was also raised and we have discussed this issue at length in a companion paper [39]. Here, disability support staff framed the usually-sexual response (an erection), as non-sexual stimulation as this afforded them a degree of security that they were staying within professional boundaries.

The construct of self-discovery also involved non-sexual physical contact with female staff:

> *…he…knows that females have got breasts and he'd like to cuddle, and put his head into your breasts…in his own little way he maybe knows that females are a little bit different to males…I don't think it's sexual…I just think it's like a cuddle, getting some motherly comfort…that doesn't bother me, as long as he doesn't hurt me that's fine.*

Another female staff member mentioned one man who attempts frottage (rubbing against another person while clothed for sexual pleasure) on some of the female staff from behind:

> *…lately he has had, I would say sexual behaviour…we have a female client here, he'll grab her on the boob, or grab her on the butt…occasionally we've have had*

> [female] *staff bending over and he'll walk up behind them and* [staff member motions frottage action]*…but not in a dirty* [sexual] *way…it's more in an exploratory way…I don't think he has the capacity to understand 'dirty' in the way that normal social circles govern that…it's self-discovery and probably trying to discover what's going on, you know, with the opposite sex.*

Interestingly, this behaviour was not framed through any normative socio-sexual scripts that the man may have learnt, for example, from media images. Likewise, other forms of self-discovery were also described that were not framed through socio-sexual scripts, but more from an intrinsic sexual instinct:

> *…occasionally we've had a few people say he'll get down on his hands and knees actually up against this* [staff member motions to chair/her leg]*…and rub his groin…kind of doggy-style, and I think that's purely instinct because he is severely intellectually disabled.*

The extent that these behaviours are viewed as exploratory, as opposed to inappropriate, largely rested on the degree of intellectual impairment:

> *…inappropriate touching maybe from their behalf,* [inappropriate] *because they don't understand.*
> *Interviewer: inappropriate touch as in sexually inappropriate?*
> *That all depends on the views that they would have I would assume…what they feel or think that is happening in their mind…I don't see it as that* [sexual intent].

These responses were marked by the absence of socio-cultural descriptions that would usually underpin exploratory sexual behaviours.

Hormonal Influence

> *It's more an arousal thing.*

Hormonal influence was framed within the recognition of a biological sex-drive, natural variations in hormone levels, and hormonal changes across the lifespan. Hormones were referred to, to illustrate both excessive and limited sex drives; hormones were framed "causatively" as they gave staff a degree of explanatory power for client sexual behaviours and staff's response to them. For example: *"…they have the same* [hormonal] *feelings but…do they understand what these feelings are about?…you know, they obviously feel the same requirements that we would but they can't tell us, they don't know what it is".* One younger female staff member linked this lack of insight as feelings that can be displayed physically when a male client may try to inappropriately touch female staff: *"…they do, they want to touch, they want to do this* [touch me]*, but I brush it off…and leave well enough alone".* Hormonal urge was also used as an explanation to trivialise young males sustaining frequent erections: *"…he's got an erection 98.9% of the time so it's not such a big thing for us".* While this teenage boy was given the scope to respond to his sexual hormonal urges, other males with similar urges might not be afforded such understanding: *"…different sexual needs as well come into it …someone might be overly sexually active…he's discouraged more because they're* [staff/the sector] *a little bit afraid of what he might … he might cross boundaries".* These findings appear to reflect Wheeler and Jenkins [22] statement that a strong sex-drive, or sexual desire, can be behind some sexual behaviour being constructed by staff as "challenging".

Hormonal change was also described as being intrinsic to one's individual sexual development. Changes in the frequency and potency of erections across the 24-hours, including morning erections stimulated by male hormones and nerve reflex, are one sign of hormonal changes during puberty [40]. One disability support worker suggested that "*…first thing in the morning seems to be a key time for these guys* [getting an erection and masturbating]*…it's normal, my brothers did that…out of respect I just close the* [bedroom] *door*". For another teenage boy, support workers felt that night time was important:

> *He has to have his quiet time…quite often you're on night duty you can hear him, awake in his bed* [masturbating]*, I just let him go…let's face it, it's a normal thing, a comfort thing…he's a male and he's…*[doing what] *boys do.*

Support workers felt that for older men, the influence of hormones was less visible:

> *…he's an older man now…so they have less sexual* [needs]*…for a younger person, I think, it's much more of an issue;*
> *…I don't think he has a wide scope of sexual needs, his* [older] *age and his disability, probably, preclude him from conceiving any kind of sexual relations, or desires, or whatever.*

There was also concern raised by support workers about future growth when younger adolescent boys become bigger and stronger men:

> *…I think we should be addressing all those* [sexual] *issues…we should be looking at the fact they will have sexual needs* [as they grow] *and how are we going to address that…would it be safe to promote that or should we sort of hide it behind the cushion?*

Pleasure

> *If something makes you feel good, it feels good.*

Pleasure was partly described by support workers within a bio-psycho narrative; where a physiological and/or emotional dividend from sexual actions provided a reinforcer. Disability support workers also described a range of interpersonal social interactions, such as hugs, that, for some males, was reciprocated and subsequently reinforced by staff as a non-sexual and social interchange of mutual regard. Interestingly, this level of interaction was not described through any learnt social scripts, but more about the pleasurable/emotional dividend from hugging someone. On a physiological level, pleasure referred to the perception of derived comfort, release, intimacy, sensory stimulation, touch, and pleasure: "*…if it feels good, let him do it*". The opportunity to *"feel good"* as a result of masturbation also had wider benefits:

> *If you let him have his free time* [to masturbate] *his behaviours are better, the behaviour of putting his hands down his nappy and up his bum…he has had the opportunity to work out his frustrations* [by masturbating].
> *For someone that is…low functioning…doing something like that* [masturbating] *will make them feel good and will get rid of anger…the way you're feeling, the bad feelings.*

These statements suggest there is some kind of a physical/behavioural release to be gained from successfully masturbating which extends beyond the cycle of sexual arousal, plateau, orgasm, and resolution described by Cerver [41]. The suggestion by staff here is that successful masturbation to orgasm can lead to calmer day with fewer challenging

behaviours: *"A lot of behavioural issues may stem from a number of factors,* [unmet] *sexual health* [needs] *could be one of those factors"*.*"Cuddles"* and *"hugs"* were generally described as a positive and essential form of interaction and staff conveyed that there was a desire from most of the men and teenage boys in the present study to seek physical contact: "[He] *loves physical affection";* "[he] *loves cuddles and I don't have a problem whatsoever with giving him a cuddle"*. While there was a belief that mutually responding to hugs was a basic human need, there was also concern by staff about a working culture that questions the value of such contact, for example:

> *…the slightest show of affection for instance, normal things, you might come up to a guy and* [motions physical contact/arm around shoulder] *'how was your weekend'…I've been in situations where contact was absolutely forbidden even if you just did that* [arm around shoulder]*…that* [limiting contact] *is very negative…*[it's] *detrimental to proper expression of a relationship…they* [people with intellectual disability] *recognize us as a significant other, they look up to us.*

A younger female staff member described the difficulty in being affectionate when a Government official who visits the house clearly stated that it was wrong:

> *…lately,* [he has been] *trying to get hugs from staff, he's always coming up and wrapping his arms around you…it's important for him, I suppose, to have some sort of…human contact…but um, the Community Visitor* [Government official] *has come here and said 'no', we've got to, sort of, push him away…*[then] *with an email from his mother she said give him a hug for me.*

One older female staff member expanded on the need for human contact quite eloquently:

> *They* [clients] *need it* [cuddles/comfort]*…they haven't got the parental contact, so they get it from the staff…and I think it's lovely, I don't mind it at all…it's also rewarding for the staff…that tactile comfort…not physical love, but like parental contact.*

The physical affection described by staff was generally initiated by the men and teenage boys in this study; staff were responding to that need and reinforcing it as a socially appropriate human interchange.

Insight

> *I suppose they do* [have sexual needs]*…I've often wondered…but, I find that hard to comprehend in someone that's as intellectually disabled as* [him].

Insight in the men and teenage boys referred to both understanding and recognising the emotive self plus feelings of inadequacy and frustration. The capacity for insight appeared as the fulcrum for an important stage of sexual development; the point between cognitive incapacity and capacity. A lack of insight was suggested as a reason why *"…someone that is low-functioning…unfortunately might find out the wrong way about sex…maybe when they're in institutions, or other group homes, because of the more higher functioning men* [clients]*"*. That is, a lack of insight infers vulnerability and, in turn, the need for protection as a vulnerable person. There was also a concessionary perspective toward some of the men and teenage boys' sexual behaviours due to a perceived lack of insight:

> *…if he was…considered normal, I don't think he would behave in such a way* [grabbing females on breast, buttock]*…I say that because his parents are*

> *church-goers and he would show much more restraint because he is autistic…because they* [people with autism] *don't understand…other people.*

Therefore, it appears that a person with intellectual disability's lack of insight into socio-cultural norms can place them at risk, just as it can get them out of trouble. For example, one teenage boy who has started to grab female staff on the breast was excused due to the level of his insight and perceived lack of insight into social rules: *"He does just grab you on the breast … but I think he doesn't know any better"*.Sex education was mentioned as a conditional, construct: *"…he has a lot of sexual need, he masturbates … but don't educate him to a level where he really wouldn't understand"*. Along this theme, it was felt any client would need to provide the first step or sign that they were ready to experience the next developmental level, or degree, of sexual expression:

> *…if they can recognizes it for what it is, sexual feelings are something you can't correct…if it's not coming from the person themselves, there is no use imposing it on them …you wait for their question…everything in life comes when we are ready for it…usually you see some kind of display of readiness, or eagerness in the form of a question, or some sort of action…*[if there's] *no indication, leave it alone.*

Therefore, without cognitive insight, which staff perceived enables understanding, there was a fatalistic assumption that sex education was perhaps not required. Furthermore, where a person's disability also extended beyond cognitive impairment and included limited communication and function, their capacity to express such a need also lessens:

> *…depending on their level of disability…may determine their level of functional ability…and their sexual health situation…the more functional you are* [it is] *highly likely that your sexual health needs will be met…*[those who are lower functioning, their disability is] *a barrier to being sexually active.*

Staff Belief-System

> *There is still a lot of restraint…people* [the staff] *are still afraid of the subject* [of sexual matters].

Disability support workers offered an insight into something deeply personal about themselves; they involve some of their feelings, morals, fears, views, and perspectives on male sexuality. This theme suggested that the views and opinions of staff can impose another barrier. In addition, a picture relating to staff gender started to emerge when staff focussed on their own beliefs; that a feminine perspective might be different from a masculine perspective; these findings have been described in detail elsewhere (see 36). One younger male disability support worker suggested that *"…they* [female staff] *feel potentially intimidated by it* [one male client's sexual expression], *and that combined with his continuing strength, he's continually getting stronger, so it kind of verges on, what will he become with all these issues amplified?"* While no female disability support workers used the word *"intimidated"*, there was a definite anxiety about male sexual expression when combined with physical strength:

> *When the boys get older what will we do then? They're getting older…they're different to the females and they have different needs, like the independent time* [to masturbate] *that the girls don't necessarily need…these young men are…getting to an age when it does need to be addressed.*

The potential use of pornographic material provided another diverse range of responses reflecting divergent staff belief-systems. One younger female disability support worker felt that using pornography was part and parcel of *"…being a guy"*. An older female disability support worker felt that *"R-rated videos, maybe porn to a certain extent"* might be a useful aide for some men with intellectual disability. By contrast, one younger male disability support worker felt that that *"providing illicit* [pornographic] *material…I think I would not want to go down that kind of path…it's a whole new kettle of worms…it could have positives associated with it, but I can see a lot of negatives associated with it"*.

Duty of Care

Disability support workers believed that they have duty of care to assume an educational role, to plan for the future, to adhere to occupational health and safety policies, and to complete relevant documentation. Only one of the three disability service organisations had a wider policy relating to sexuality that clearly conveyed to support staff what *not* to do, but extremely limited in telling them what they can do. Such a lack of policy guidance creates a socio-structural feature unique to disability-specific community group homes. The growing emphasis on risk assessment, under the umbrella of occupational health and safety law, now involves most areas of practice and hence affects the cultural context of the group home. When pressured with the demands of the job and set timeframes, doing the basics well while being cautious of risk may become more important to staff and may present an obstacle to offering meaning:

> *…is this job about extra* [working] *hours…or is it more about what can I achieve with the guys today, what can I facilitate, what can I try that's new?…at what point do you draw the line between OH&S* [occupational health and safety] *issues and providing activities that are actually helpful to the guys?.*

That is, by fulfilling duty of care through avoiding risk the staff have achieved a professional requirement, but this can be at the expense of an individualised focus on the little things that enhance life satisfaction. For example, despite that staff knew one teenage boy only had time to masturbate during bath time, the opportunity is not offered due to "*… time restraints, convenience … you can't leave him unsupervised* [due to risk] *so they* [male clients] *don't have personal time to do it* [masturbate]". Meaningful service delivery is almost paralysed by the emphasis on risk minimisation. Becoming more focussed on time and convenience is partly because:

> *…the job is intense…having stopped doing* [the job] *full time…I was able to reflect on how draining it can be on your mind…it's very easy to just become 'okay, I've got 7 h I've got to do these things'…it's more intense in these situations, it's very physically demanding, it's very hard when you are dealing with people* [clients] *who…take an hour to feed…it all becomes in the 'too hard' basket, it kind of becomes about efficiency.*

Staff as Interactional Gatekeeper

> *…the different backgrounds and ages of people* [staff] *definitely reflect what informal policies are put in place.*

Staff described a part of their role as monitoring; monitoring affection between clients, between clients and staff, and monitoring self-exploratory behaviour between the public/private domains of the community group home. Staff largely relied upon their own values framework to perform this role in the policy vacuum that existed; yet another layer that creates a unique cultural environment. The monitoring role was framed by a differentiation between what individual staff framed as "appropriate" and "inappropriate" interaction. For example, *"…he will play with himself, as I'm cooking in the kitchen he is sitting on the chair …not masturbating in the real sense* [rubbing penis through trousers] *…it wouldn't be offensive so I don't make a big deal about it"*. Another of the disability support workers felt that this approach from staff was *"…because* [he] *is very placid…no one is bothered by it …if he was more aggressive it could present* [staff with] *more problems"*.

An account from the study related to what was described as one teenage boy's *accessible penis*; here disability support workers had complete control over his access to his penis. This teenage boy wore incontinence pads 24 h a day and would always try to touch himself/masturbate during pad changes. As a strategy to stimulate himself while lying on the floor fully clothed (he was otherwise in a wheelchair), he would kick himself in the groin using his heel. Despite disability support staff recognizing that he was masturbating, albeit in an atypical manner, access to his penis outside of pad changes was rarely offered. Importantly, disability support workers neither sought nor desired this control; the control was not constructed through their position of power, but through the powerlessness arising from the teenage boy's intellectual and associated physical disability. Disability support workers were forced to either deny, limit or give access to the opportunity for self-discovery based on their own personal and professional perspectives. Institutional pressures, such as time, constituted pervasive socio-structural factors that influence staff responses, as did the needs of other clients. It was an unenviable situation, but one which confronts those in a care-cared for relationship such as this.

Discussion

The findings from this research highlight that implicit within one's sexual development is the importance of cognitive and physical capacity; with the degree of sexual "rights" being linked to degree of intellectual disability. Conditionally Sexual recognizes that the men and teenage boys in this study have sexual rights…but that these rights are realised only up to a point. This point appears constructed by the combination of individual sexual development and the influence of support staff. These men and teenage boys have a right to self-discovery, a right founded upon hormones, pleasure, insight, and self-care, but rights are experienced within the context of gendered service delivery dynamics governed by limited or non-existent policy and procedural guidance. This limitation forces staff to assume the role of interactional gatekeeper, while bearing in mind their duty of care, leaving staff with little to guide them but their own belief system.

Conditionally Sexual, while clearly a biopsychosocial construct, can be interpreted less by social scripts and more so by a combination of bio-psychological factors (such as hormonal drive and emotional dividends), cognitive and physical development, emotional maturity, and staff influence. In addition, the policy vacuum and the rhythms and patterns of a working group home create non-normative socio-structural features that become additionally limiting aspects of masculine sexuality. The lack of social scripts to describe masculine sexuality is notable, in that a number of authors have written about sexuality and intellectual disability where the role of social scripts has been at the forefront of their

dialogue and research observations (e.g. [8, 42–44]). Our study explored masculine sexuality for men and teenage boys with a moderate to profound intellectual disability, so our finding that social scripts were absent suggest that intellectual capacity may be an important prerequisite in order to take on board the social scripts central to notions of socially constructed sexuality. Our findings reflect a limited repertoire of sexual behaviours that are restricted to different masturbatory techniques and "contact" with support staff. Beyond this there were few, if any, socio-sexual behaviours, such as dating rituals and petting, that one could attribute to normative social scripts.

Research concerning sexuality and intellectual disability (e.g. 17) also tends to conclude that staff attitude has a significant impact, which it clearly does, but perhaps fails to appreciate the wider picture that staff often have little other guidance. That is, the socio-structural limitations created by the sexuality policy vacuum are perhaps the more important issue. By ignoring these socio-structural barriers and instead focussing on staff attitude, staff become yet another "symbol" of oppression to the lives of people with intellectual disability. Yet our findings highlight that staff are performing admirably, often with ethically and morally challenging issues, within an inadequate policy structure. The ethical dilemmas that staff encounter are illuminated very clearly for example, by the findings on access, touch, hugs, and masturbation. This is perhaps best illustrated by the example of how staff have no policy guidance on how to react to a male clients' erection during the delivery of intimate personal care [39].

The issue of using pornography to support a healthy masculine sexuality remains another contentious matter. Yacoub and Hall [13] reported that several male participants with mild intellectual disability in their study viewed pornography regularly, although this practice was curtailed for one participant as it was apparently offensive to a female (it is not clear in the article if this female was another client, a visitor, or a staff member). Pornography has been caught up in changing social attitudes towards the exploitation of women [45], however it is used by a number of men and boys as part of normative sexual development. Therefore, does pornography offer a potential assistive tool for men and teenage boys with intellectual disability as one staff member suggested *"…if you* [the male client] *were not able to engage in a sexual activity"*? Although there are no studies describing the use of pornography for this population, Cambridge and Mellan [45] have suggested that the use of pornography should be incorporated into a reconstruction of sexuality for men and boys with intellectual disability. Whether ethical and moral issues would enable this to be explored, as one part of a healthy masculine sexuality, for men and teenage boys with moderate to profound intellectual disability remains open to conjecture.

The sexuality of these men and teenage boys is limited to masturbation and some forms of physical contact with staff. There is no indication that their sexuality encompasses the additional features inherent to our stated definition of a healthy masculine sexuality. That is, that a healthy masculine sexuality also extends to fostering meaningful human relationships, opportunities to develop one's masculinity, a focus on self-esteem, and sexual satisfaction. Instead, Conditionally Sexual is a life that is reduced to a penis/body-centric experience. Furthermore, the focus on these men and teenage boys' masculine sexuality is not geared toward what is developmentally normative, what feels nice and what is fun. Instead, their sexuality is problem-led within a service-centric risk-hierarchy that renders to a secondary consideration the "right" to develop a healthy masculine sexuality. Their lives, and their masculine sexualities, are circumscribed by an environment whose prime purpose is led by their day-to-day high "physical" support needs at the expense of supporting an individual within a broader socio-cultural "sexually healthy" framework. Their "personhood", as espoused by documents such as the UN Declaration [4], is denied because of cognitive limitations and policy shortcomings.

Conclusion

This article has described findings from a study that explored how sexuality for men and teenage boys with moderate to profound intellectual disability can be constructed. The notion Conditionally Sexual was introduced and represents the delicate balance underpinning these men and teenage boys' right to a sexual life, but a right that is often limited due to the challenges arising with more severe cognitive impairment and the socio-structural constraints of formal care settings. There are some limitations to this study, the most significant being the focus on men and teenage boys who live in disability-specific group homes. A large number of men and boys with intellectual disability live with family or independently, so these findings cannot be generalised to these groups. We acknowledge that living in a disability-specific group home is a less than normative "home" setting, and it is expected that different environments will influence behaviour differently. However, whether the limited forms of sexual expression, such as different masturbatory techniques and "contact" with caregivers (in this case paid staff), would differ in the home context currently is unclear. Furthermore, these findings relate to men and teenage boys with the more severe intellectual disability; so these findings cannot be generalised to individuals with borderline to mild intellectual disability. In addition, these data were collected and findings contextualised within a Westernised and Judeo-Christian context; in differing cultural contexts it is possible that these findings may also be limited.

The present study suggests that when these men and teenage boys do express themselves sexually, their desire to do so is underpinned by a normative biological urge. This normative urge sometimes develops into sexual practices that are affected by a range of individual and environmental factors that often ends up as sexual expression in less-usual ways. This poses the question: are normative constructs of sexuality less relevant for this population and do we need to move beyond this to accept a more individualized and less-normative framework to support a healthy masculine sexuality for men and boys with intellectual disability? Or, does the issue go much deeper than this such as the denial of personhood due to cognitive limitation that Parmenter [46] has previously identified? Future studies that seek to be person-centred might embrace the notion of a healthy masculine sexuality; that is uncovering the layers that underpin one's sexual expression such as self-esteem, respect, sexual satisfaction, developmental aspects, and factors which support rewarding human relationships. Developing the policy frameworks to support such a healthy masculine sexuality within contemporary consent frameworks represents our most significant suggestion for future research and practice.

Acknowledgments This article is based upon the Doctoral studies of the first author which were supported by a University Postgraduate Award (UPA) through the Faculty of Medicine at The University of Sydney, plus a small grant from the Blue Mountains Health Trust. No restriction has been placed on free access to or publication of the research data.

Conflict of Interest No conflicts of interest are declared.

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