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Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature

ABSTRACT

Background

There is a growing and evolving research evidence base regarding sexuality issues and adults with intellectual disabilities. Individuals can face challenges, including the right to express their sexuality and to access necessary education and supports.

Aims

This systematic review explores sexuality experiences, the views and opinions of adults with intellectual disabilities and highlights areas for future practice developments.

Methods and procedures

A comprehensive search of relevant databases from January 2006 to December 2016 was carried out. Included studies had to address specific criteria including: peer reviewed papers, the use of appropriate research methods, and focused exclusively on the individual views and opinions of people with an intellectual disability. The search of relevant databases yielded 230 hits. Following the application of explicit inclusion and exclusion criteria, 23 papers were deemed suitable for the review.

Outcomes and results

The data were analysed and key themes were identified that included: autonomy v's risk of harm, knowledge and sexuality, relationships and intimacy, self-determination and taking control, and encouragement and supports.

Conclusions and implications

Adults with intellectual disabilities need education and support to express their sexuality and to meet individual needs.

Keywords:

Intellectual disabilities, sexuality, intimacy, relationships, social inclusion, LGBT

What this paper adds?

Studies on the topic tend to present the views and opinions of families, carers and professionals. This review highlights issues from the available research that address the unique experiences of adults who have an intellectual disability. The discussion presents areas relevant to policy, practice education and future research priorities.

1. Introduction

The expression of sexuality, including how individuals form and maintain intimate relationships, is a fundamental part of being human (Matich-Maroney et al., 2005; Krebs, 2007; World Health Organization, 2013). In health and social care settings, practitioners are paying more attention to issues related to sexuality in terms of the provision of the necessary psychosocial supports and education (Greenhill & Whitehead, 2010; McCann, 2010; Gasgoyne et al., 2016; Palumbo, 2016). Another important consideration is the emancipatory or human rights position whereby people have opportunities to explore and make decision around how they live their sexual lives (Officer & Shakespeare, 2013). For some, the only boundaries around sexual expression are that they do not include coercive sexual acts and that the right to express ourselves sexually is measured against an individual's rights to privacy and autonomy (Gomes, 2012). The World Health Organization expands their conceptualisation and understanding of sexual health concerns thus:

> *....the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. Indeed, it has become clear that human sexuality includes many different forms of behaviour and expression, and that the recognition of the diversity of sexual behaviour and expression contributes to people's overall sense of well-being and health* (World Health Organization 2015, p4.)

Furthermore, enlightened ways of supporting people in their expression of sexuality is evidenced in the move from a purely biomedical position to a more person-centred and inclusive approach that places rights, choices and voices at the hub of all health and social care developments (Thomas et al., 2017). The changing landscape should

encapsulate fundamental human rights and social inclusion directives that encourages and supports the expression of sexuality (McCarthy, 2014; Winges-Yanez, 2014). Concerns about the expression of sexuality in people with intellectual disabilities is not new and one that has attracted significant attention in the past and remains a contentious issue (Kempton & Kahn, 1999; Aunos & Feldman, 2002; Löfgren-Mårtenson, 2004; Winges-Yanez, 2014). Despite major policy shifts over the past 30 years regarding the care and support of people with intellectual disabilities, notably the closure of long-stay institutions, and the promise of more socially inclusive models of care and support, challenges still exist. The social model of disability emphasizes the human rights dimension of people with disabilities. However, account needs to be taken of the medical, psychological, social and political factors that impact upon individual's lives. Failure to effectively acknowledge and address health needs adequately is another example of discrimination and the further marginalization of people with intellectual disabilities (Shakespeare, 2012). With deinstitutionalization and a focus on the social model of disability it remains questionable the extent to which adults with intellectual disability have control over their lives and the opportunity to realise their potential, including the expression of their sexuality and all that this encompasses (Shakespeare, 2013).

2. Method

2.1 Research questions

The aim of this review is to synthesize current evidence regarding the experiences and perceptions of adults with intellectual disability regarding the expression of their sexuality and their support needs. Therefore, the questions of this review are:

1. What are the experiences and perceptions of adults with intellectual disabilities regarding their expression of their sexuality?

2. What are the sexuality experiences and needs of adults with intellectual disabilities in relation to education, supports and service utilization?

2.2 Search and selection strategy

A subject Librarian was enlisted to assist with the literature search strategy. The databases used in the search were CINHAL, MEDLINE, PsychINFO and Sociological Abstracts. The search terms used were: intellectual disab* OR mental retard* OR learning disab* OR mental handicap OR developmental disab* AND sexuality. The data were accessed from January 2006 to December 2016. An example of the search strategy used in one electronic database is shown in Table 1.

***Table 1 here ***

The searches resulted in 230 hits across all the databases. A hand search of reference list identified a further 2 papers. Duplicates and irrelevant articles were removed leaving a total of 141 papers to be considered. The 141 papers were screened by title and abstract against the inclusion criteria and a further 83 papers were excluded leaving 58 papers for full review. Following full review of the 58 papers, a further 35 were excluded on one or more of the following grounds: the study population did not exclusively look at sexuality issues and adults with intellectual disabilities; other reasons were that the sample included children and young people with intellectual disabilities, families, professionals and support workers. This resulted in a total of 23 papers for full review and analysis.

Studies were identified that used quantitative or qualitative approaches. The inclusion criteria were adults with intellectual disabilities over 18 years of age and focusing specifically on sexuality experiences. Studies not meeting the inclusion criteria were rejected. The inclusion criteria were limited to academic journals, peer reviewed

empirical studies, and written in English. The PRISMA method for reporting the results of the searches was used as detailed in Figure 1 (Moher et al., 2015).

Figure 1 here

2.3 Quality assessment

A recognised quality assessment tool, the *Critical Appraisal Skills Programme* (CASP) was used as an evidence-based framework to review the papers. (Critical Appraisal Skills Programme, 2013). Specific questions were consistently applied to the 23 selected studies (Table 2). Each question was scored zero, one or two out of a possible score of 20 points. A score of zero was assigned if the paper contained no information, one if there was a moderate amount, and a score of two indicated that the question was fully addressed (Rushbrooke, Murray & Townsend, 2014). A score of 17 and above, demonstrating the overall quality of the study, was achieved by 7 of the studies (Dukes & McGuire, 2009; Yau et al., 2009; Bedard et al., 2010; Eastgate et al., 2011; Stoffelen et al., 2013; Sullivan et al., 2013; Rushbrooke et al., 2014). A total of 14 studies scored between 14 and 16, indicating shortcomings in relation to clarity of aims, data collection methods, research relationships considered, and ethics considerations (Siebelink et al., 2006; Leutar & Mihoković, 2007; O'Callaghan & Murphy, 2007; Wheeler, 2007; Yacoub & Hall, 2008; Arias et al., 2009; Bernert, 2011; Fitzgerald & Withers, 2013; Bane et al., 2013; Bernert & Ogletree, 2013; Kijak, 2013; Box & Shaw, 2014 Friedman et al., 2014; Turner & Crane, 2016). The remaining 2 studies received scores of below 14, due to limited information that impacted on the quality and were related to the aims, ethics, and clarity and detail of findings (Klepping, 2008; Azzopardi-Lane & Callus, 2015). All the studies were deemed suitable for the review as they fulfilled the study inclusion criteria. The issues raised in the appraisal will help

guide future research studies which should enhance the overall quality of the available research evidence.

***Insert Table 2 here ***

2.4 Characteristics of the selected studies

The 23 studies included in the review that explicitly addressed the study objectives are contained in Table 3. Most of the studies were conducted in the United Kingdom (n=8). Next was the United States (US) (n=4), then the Republic of Ireland (n=2), and Netherlands (n=2). Each of the following countries had one study respectively: Australia, Canada, China, Croatia, Malta, Poland, and Spain. The studies had sample sizes ranging from single case studies to 376 participants with mild to moderate intellectual disabilities. Most of the studies used qualitative methods (n=18) including individual interviews, focus groups and case studies. A total of five studies used quantitative methods.

Table 3 here

2.5 Data extraction and analysis

A systematic approach, utilizing established methods, was used in the analysis and synthesis of the qualitative and quantitative studies (Mays et al., 2005). The analysis was conducted in the following ways. The emergent themes, related to the research questions, were identified and coded from the papers, individually and then agreed collectively by the researchers. The identified themes were organized into concepts that allowed for similarities and differences within and between the studies. The themes were then examined by the research team for verification and agreement.

3. Findings

Following the systematic analysis of the studies, five themes were identified: (i) autonomy v's risk of harm, (ii) knowledge and sexuality (iii) self-determination and taking control (iv) relationships and intimacy, and (v) encouragement and supports.

3.1 Autonomy v's risk of harm

A range of concerns were identified that related to the balance and tensions between protection from harm within a relationship, autonomy, and the right to make independent decisions regarding relationships. For some, this may involve being sexually active and may include taking risks. The risk elements appeared to relate to taking emotional risks and vulnerability factors, which, you may argue, are components of any relationship, and contains risks related to the decision to enter into an intimate sexual relationship (Yacoub & Hall, 2008). A recurring theme across studies included in this review related to the tensions between self-determination and protection from potential abuse and exploitation (O'Callaghan & Murphy, 2006; Yau et al., 2009; Friedman et al., 2014). Some people were able to describe positive activities associated with dating while other adults with intellectual disabilities spoke about feeling 'confused' regarding acceptable behaviours, such as intimate touching and what would be considered 'acceptable' (Yau et al., 2009; Eastgate et al., 2011; Bernert & Ogletree, 2013). For others, an expressed concern was about how to set boundaries within a relationship that they felt comfortable with (Sullivan et al., 2013). For some, sexual health concerns related to issues about having both an intellectual and physical disability and how these attributes impact on relationships and the expression of their sexuality, including being intimate and sexually active (Bane et al., 2012). Some individuals spoke of their concerns related to limitations arising from the recognition that their cognitive impairment and the ability to make informed decisions may be

impaired to some extent. This may result in placing themselves at risk of exploitation and harm. This realisation, therefore, had significant implications and impacted on decisions related to the person's sexual health and whether or not to seek an intimate sexual relationship (Klepping, 2008).

3.2 Knowledge and sexuality

A recurring theme for people with intellectual disabilities related to the need for education regarding sexuality and relationships. People with intellectual disabilities spoke about their desire to have an intimate relationship and spoke about the need for support in sustaining it, and assistance in addressing and overcoming difficulties that may be encountered (Leutar & Mihokovic, 2007). Linked to this was the identification of education as a means of supporting the development of negotiation skills, necessary within any successful relationship. However, for some their sex education was viewed as incomplete, focusing on protective measures rather than enhancing their sexual knowledge and relationships (Yau et al., 2009). Additionally, having access to opportunities to talk about their sexuality and sexual relationships was desired by people with intellectual disabilities, but in a way that was safe and personal (Kijak, 2013). For some adults with intellectual disabilities, their sexual knowledge was lacking with some holding stereotypical views towards sex and marriage (Yau et al., 2009). Knowledge regarding developing and sustaining relationships was desired by people with intellectual disabilities, underpinned by the development of their knowledge and skills in enhanced decision making to enable choices regarding their sexuality and the relationships they enter into (Siebelink et al. 2006; Dukes & McGuire, 2009).

3.3 Relationships and intimacy

People with intellectual disabilities referred to their wish and desire for relationships and for some, this may be sexual; for others, there was a desire for intimacy and friendship (Siebelink et al., 2006). It became apparent, that a presumption exists that people with intellectual disabilities are somehow ‘asexual,’ not sexually active, and in need of 'protection' (Arias et al., 2009). Conflicting views were apparent between the desire for self-determination, including having choices and making decisions regarding the expression of sexuality and establish relationships, and the concerns of families and carers related to fears of exploitation and sexual abuse and their need to exercise more control (Eastgate et al., 2011). For people with intellectual disabilities currently in a relationship, issues emerged that related to knowledge regarding the age of consent, marriage and the protection afforded through laws (O’Callaghan & Murphy, 2006). People with intellectual disabilities highlighted a lack of privacy as a contributory factor to inhibiting their opportunities to establish relationships and express their sexuality (Bernert, 2011). From the perspective of care providers, organisational policies and protocols were seen by people with intellectual disabilities as a contributory factor restricting their right to express their sexuality and establish relationships that for some may be of a sexual nature (Bane et al., 2012). People with intellectual disabilities highlighted that their views, opinions, needs and the right to self-determination were, in some cases, not recognised and even ignored (Wheeler, 2007; Bernert, 2011).

3.4 Self-determination and taking control

People with intellectual disabilities want to have, and be able to talk about, loving relationships; they seek passion, romance and intimacy (Wheeler, 2007). For some, this may involve being sexually active. People want influence over forming and maintaining intimate personal relationships. They want to be more in charge of this part

of their lives, rather than being controlled by others (Arias et al., 2009). The evidence supported the recognition of the need for support to enabled informed choices and for individual decisions to be made (Bedard et al., 2010). The role of education programmes and independent advocacy was seen as important to facilitate decision making and self-determination, thereby reducing paternalistic protectionism and the possible disenfranchising dependency on families and care workers (Bane et al., 2012). Addressing these needs would enable people with intellectual disabilities to build and grow their personal strengths and attributes, develop emotional well-being and support the full expression of the person's sexuality (Arias et al., 2009).

For some people with intellectual disabilities, relationships extended beyond the biomedical interpretation. Establishing and developing loving and intimate relationships was seen as part of the development of individual sexual identity and the expression of sexuality (Bernet, 2011; Turner & Crane, 2016). People with intellectual disabilities identified psychosocial considerations and potential barriers to the expression of their sexuality. These included practical obstacles such as access to transport and the ability to self-travel. For others, the barriers were attitudinal and related to low personal self-worth and value, and the right to be 'sexual' and experience intimate relationships (Bane et al., 2012). For some, being sexually active was viewed as 'dirty' and something to be avoided (Fitzgerald & Withers, 2013). People with intellectual disabilities highlighted the issue of differences in gender identity and the need for the recognition and acknowledgement of diversity within the intellectual disability communities (Bedard et al., 2010; Stoffelen et al., 2012).

3.5 Encouragement and supports

Central to the expression of their sexuality, people with intellectual disabilities want to know that they are being listened to and their wishes and needs are regarded and

respected (Wheeler, 2007; Fitzgerald & Withers, 2013; Bane et al., 2012). For some, they can feel embarrassed about discussing issues related to their sexuality; a situation that can be compounded by a lack of recognition by families and support staff that people with intellectual disabilities are sexual beings; some are and wish to be sexually active (Yau et al., 2009; Bernet & Ogletree, 2013). The situation is further exacerbated by a lack of attention on the behalf of support staff about the relationships that people with intellectual disabilities have or may desire to have. Opportunities to discuss their sexuality and intimate relationships is not usually on the agenda and is one that appears to be largely ignored (Yau et al., 2009; Box & Shaw, 2014; Friedman et al., 2014; Rushbrooke et al., 2014).

Furthermore, people with intellectual disabilities have highlighted the often-limited sexual experiences, and for those who had, they held negative perceptions about sex. They did not perceive it as an option that they could pursue. The most commonly cited activity was autoerotic sexual behaviour, by way of masturbation, watching adult and prostitution, rather than partner intimacy (Siebelink et al., 2006; Kijak, 2013). For some, the situation was compounded by a lack of self-confidence in their physical appearance and the ability to express their sexuality and to seek and maintain an intimate relationship (Fitzgerald & Withers, 2013). An important issue that was identified as impacting on sexual development related to the level of intellectual impairment; the more severe the level of disability the less developed was the ability to express one's sexuality (Bane et al., 2012). From the perspective of people with intellectual disabilities who identify lesbian, gay, bisexual or transgender (LGBT), opportunities to express their sexuality was sporadic and the necessary available supports were limited. There remains a presumption that people with intellectual

disabilities are heterosexual, with limited recognition of the possibility that some may be non-heterosexual and have experiences and support needs (Stoffelen et al., 2012). From the perspective of people with intellectual disabilities, there is a desire for the development of a person-centred approach from their families, professionals and support workers that enables individuals to explore and express their sexuality (Bane et al., 2012). To enable this, people with intellectual disabilities highlighted the need to have more social experiences that would provide opportunities to meet new people, with the potential to establish friendships or intimate relationships. As part of the experience of expressing their sexuality and seeking, establishing and maintaining an intimate relationship, people with intellectual disabilities expressed the need for access to support services such as advocacy, counselling and talking therapies. (Azzopardi-Lane & Callus, 2015; Friedman et al., 2014).

4. Discussion

This review has identified a range of key issues that exist in relation to the experiences and needs of adults with intellectual disabilities regarding their sexuality. The findings from this review indicate areas requiring attention in terms of policy, education, individual supports and future research developments. A useful way of conceptualizing the issues is through *Bronfenbrenner's Ecological Model* as a framework to present the discussion of areas requiring development *(*Bronfenbrenner, 1979). The model offers a structure to support a strengths-based approach to understanding the needs of people with intellectual disabilities and the expression of their sexuality, and how they may be effectively addressed. The Ecological Model is multi-systemic and contains elements that can help practitioners better understand the experiences and health needs of specific populations (Institute of Medicine, 2011). The model sets out different levels that interface with each other and interact to shape the environment including macro, meso

and micro systems. Each of the systems relates to the environments and interactions throughout the lifespan of the individual that may influence human behaviour (Bronfenbrenner, 1979). Arising from this, is the need for improvements in health and social care services necessary to address social, cultural and political determinants that impact upon and contribute to social exclusion and health inequalities.

4.1 Macro system

The macro system is the overarching template that sets out the societal norms and cultural attitudes that impact on and influence the life of the individual. This review has highlighted issues in relation to the important and necessary developments that have occurred for adults with intellectual disabilities from institution-based models to social inclusion and community orientated approaches to care and service provision (Scottish Government, 2000; Department of Health, 2001). While these developments are necessary and welcome, many people with intellectual disabilities continue to experience prejudice, discrimination, victimisation and a lack of control and decision making within their daily lives (Prime Minister's Strategy Unit, 2005; Overmars-Marx et al., 2014; Simplican et al., 2015; Fisher et al., 2016). This is particularly the case in relation to the expression of their sexuality, which, for the majority in the non-disabled population, is viewed as a fundamental human right and one that it taken for granted (Hall et al., 2010; McCann et al., 2016). There are therefore a range of actions that are necessary from policy makers, implementers and service providers across education, health, social care and non-governmental organisations. Providers of services need to be aware of, and actively address, issues and concerns in collaboration with adults with intellectual disabilities (Kline & Preston-Shoot, 2012).

From a legislation and policy perspective, two themes from the findings, *autonomy vs risk of harm* and *self-determination and taking control*, are particularly relevant with

action required on several fronts. Some relevant legislation has been implemented that provides protection from discrimination and harm and affords access to assessment, treatment, care and support. However, there is still a need to ensure that legislation is evenly applied in a way that is enabling of adults with intellectual disabilities to express their sexuality and not to place needless and unnecessary limits that prevents such expression. This is important as some adults with intellectual disabilities may have limited knowledge and understanding of how legislation can afford them protection and of their own responsibilities (O'Callaghan & Murphy, 2007). From the results of the review, theme two - knowledge and sexuality, highlights that adults with intellectual disabilities want access to education regarding the expression of their sexuality, as well as advocacy and supports about their rights and responsibilities, that also includes protection from exploitation and abuse (Dukes & McGuire, 2009; Schaafsma et al., 2015). However, there are possible tensions and challenges for all concerned in providing support that is least restrictive and more enabling, while responding to and preventing abuse, exploitation and harm (Murphy & O'Callaghan, 2004; Healy et al., 2009; Bryne, 2017). Also, there remains possible conflicts between the rights, autonomy and aspirations of adults with intellectual disabilities regarding control over their sexual expression. However, concerns still exist regarding vulnerability, exploitation and abuse from the perspective of families and carers (Rushbrook et al., 2014).

From this systematic review and the results from theme (iii), *self-determination and taking control*, it is evident that adults with intellectual disabilities have and want intimate relationships and for some, this involves being sexually active. Existing policies, specifically developed to improve the lives of people with intellectual disabilities, need to ensure they adopt a rights-based approach to the expression of

sexuality. Furthermore, the rights of the population to independence and to make decisions that enables to them to take control of their lives, needs to be realised (Department of Health, 2001; Scottish Government, 2013). Therefore, all services and care providers need to ensure that their policies take account of and reflect the rights and aspirations of adults with intellectual disabilities regarding control over decisions regarding their lives, including the expression of their sexuality (Overmars-Marx et al., 2014). More specifically, sexual health policies need to take account of the distinct and unique needs of adults with intellectual disabilities and tailor services accordingly. Necessary adjustments need to be made to services to enable equality of access and additional support to ensure that the needs of the individual are effectively assessed and met (Turner & Robinson, 2011; Heslop et al., 2014). To promote human rights and quality of life, community-based residential and day care service providers need to ensure that their local policies are set within this context and take account of, and clearly reflect, the aspirations and needs of adults with intellectual disabilities, including the expression of all aspects of their sexuality (Verdugo et al., 2012; McCann et al., 2016). From the perspective of adults with intellectual disabilities, the results from theme one – autonomy and risk of harm and theme three – self-determination and taking control, highlights that care organisations may have unnecessary restrictions in place that inhibit rather that facilitate the expression of their sexuality and intimate relationships, suggesting that this continues to be a 'grey area' of continuing ambiguity (Rushbrook et al., 2014). In some areas, specialist intellectual disability services have been developed that include a range of professionals such as clinical psychologists, social workers, nurses and psychiatrists, to work directly with adults with intellectual disabilities and care providers. They may provide access to capacity assessments, therapy, advice and support regarding sexuality and relationship issues for those with more complex

support needs (Slevin et al., 2008). Models of co-production and supported decision making offer a solution that can be used to fully involve adults with intellectual disabilities to inform and shape local policy that reflects their rights and aspirations and organizational responsibilities to protect and safeguard those most at risk of harm (Voorberg et al., 2015; Palumbo, 2016).

4.2 Micro system

The micro system sets out the direct contacts and personal relationships of adults with intellectual disabilities and includes their friends, family, peers, romantic relationships and support workers. Support networks are central to the well-being, ongoing development and social inclusion of all adults with intellectual disabilities who may require access to additional guidance and supports.

From the analysis of the studies forming this review, theme (iv), *relationships and intimacy*, indicates that adults with intellectual disabilities desire and may already experience intimate relationships; some may be sexual. For many, there is a need for additional support, time and resources to assist with understanding and exploring their sexuality (Box and Shaw, 2014). Findings set out in theme (v), *encouragement and supports* highlights the limited opportunities to meet people, with whom they might wish to consider establishing an intimate relationship, due to a range of factors. These may include self-confidence issues, concerns regarding appearance, and awareness of their cognitive limitations (Arias et al., 2009; Turner and Crane, 2016). Women with intellectual disabilities may need access to help and support to enable them to recognise and appreciate their sexuality. For others, there is a need to address issues from their past, including negative self-perceptions and experiences, feelings related to 'missed' opportunities and for some, access to therapy to address experiences of sexual abuse (McCarthy, 2014; Winges-Yanez, 2014; Hellenbach et al.,

2015). For men with intellectual disabilities, they too seek intimate relationships, and yet many experiences obstacles, with a desire to develop what they consider to be a 'normal' sexual identity (Wilkinson et al., 2015). The representation of men with intellectual disabilities within the established body of literature often focuses on them as victims of sexual abuse, vulnerable and open to exploitation (Cambridge et al., 2011). Another perspective emerging from the body of evidence, presents offending behaviours, some of which are sexual in nature and the available treatment options and interventions (Cohen & Harvey, 2016; Fisher et al., 2016). For some men, there are missed opportunities to fully explore and realise their sexuality and sexual potential and to experience intimate relationships (Wilkinson et al., 2015; Wilson & Plumber, 2014). There is a growing and evolving evidence base regarding people with intellectual disabilities who identify as LGBT and the challenges that many experience in expression their sexuality (McCann et al., 2016). Three themes capture the complexity of individual circumstances: (i), *autonomy vs risk of harm* (ii), *knowledge and sexuality* and (iii), *self-determination and taking control*, evidencing the concerns regarding vulnerability and exploitation, limited sexual health knowledge, and same sex relationship opportunities. These issues may be further compounded by limited recognition of a possible LGBT identity by other people with intellectual disabilities, their families and carers. Prejudice and assumptions regarding heteronormativity prevail (Abbott & Burns, 2007; Löfgren-Mårtenson, 2009; Löfgren-Mårtenson, 2012; Elderton et al., 2014). Access to education, LGBT networks of social support and opportunities to meet other LGBT people, are recurring issues that need to be addressed. This is necessary to minimise the potential for social isolation, mental ill-health and to develop resilience and build on positive strengths and capabilities

(McClelland et al., 2012; Stoffelen et al., 2013; Elderton et al., 2014; Conder et al., 2015; Wigham & Emerson, 2015).

Irrespective of sexuality, adults with intellectual disabilities want friendships, social support and social networks as a mean to form new relationships, with the potential, if desired, for intimacy (Yacoub & Hall, 2008; Fitzgerald & Withers, 2013; Box & Shaw, 2014). Theme (v) of this review, *encouragement and supports*, indicates that there are a range of factors that need to be addressed to support adults with intellectual disabilities to develop friendships and build and maintain social networks. These include: access to reliable transport, the proximity to friends and family, the availability and facilitation to access social networks, leadership from professionals, integrative activities, and dealing with potential dilemmas (van Asselt-Goverts, 2013; Craig & Bigby, 2015). Failure to address these issues with adults with intellectual disabilities, further restricts options to participate fully in their community, expand social networks and events, and meet up with friends. This contributes to ongoing wider social exclusion and isolation (Weisel & Bigby, 2014).

4.3 Meso system

The meso system focuses on the relationships and interactions between the adult with intellectual disabilities and the micro system. An example of this is the relationships between the adult with intellectual disabilities, their support worker and *vice versa*.

Recurring themes arising from this review: (ii), *knowledge and sexuality* and (iv) *relationships and intimacy* demonstrates the need for access to education about relationships and a desire to increase knowledge regarding the expression of their sexuality and extends to establishing and maintaining intimate relationships (Leutar & Mihoković, 2007; Dukes & McGuire, 2009; Arias et al., 2009; Eastgate et al., 2011; Box & Shaw, 2014; Freidman et al., 2014). Networks of social support and access to

social activities are important for positive health and well-being, in the creation of opportunities to develop new friendships and possible relationships (Simplican et al., 2015). They are an important issue for adults with intellectual disabilities and one that requires development, as many feel lonely and socially isolated (Gilmore & Cuskelly, 2014). Navigating relationships and resolving conflicts and dilemmas within friendships and relationships are areas where adults with intellectual disabilities want help and support (Box & Shaw, 2014). There is an important opportunity for professionals and support workers to be sensitive to, and create opportunities for the adults they work with, to discuss issues and concerns regarding their friendships and relationships, thereby helping to develop and sustain them.

Two themes from the findings, (i) *autonomy vs risk of harm* and (ii), *knowledge and sexuality* details the occurrence of significant life events such as bullying, exploitation, rape and sexual abuse for some adults with intellectual disabilities. Yet, despite this, access to evidence-based psychological therapies and support is limited (Eastgate, 2011; Stoffellen et al., 2013; Hulbert-Williams et al., 2014; Osugo & Cooper, 2016). Developing positive health and improving health-seeking behaviours is important for many adults with intellectual disabilities, given the evidence of their poor health and barriers to accessing healthcare (Ali et al., 2013; Krahn & Fox, 2014; Cooper et al., 2016). Mental ill-health is common in people with intellectual disabilities by way of depression, anxiety disorder, phobias and psychotic illness. This may be due to biological and genetic factors and life events, being female, the type of support provided, and being of a lower level of ability (Cooper et al., 2007). Therefore, improving access to counselling and talking therapies is necessary to ensure that adults with intellectual disabilities have access to the services they require to promote autonomy, decision making and self-determination (Bane et al., 2012).

4.4 Future research directions

This review highlights the ongoing need for a specific-research focus on sexuality and adults with intellectual disabilities to understand their needs, mechanisms of support that work, interventions and service responses. It is encouraging that some studies that comprised this review had adults with intellectual disabilities as researchers and collaborators and there is scope to develop this further. There is an absence of policy evaluation, education evaluation, sexuality and quality of life studies, epidemiology and intervention studies; these are areas requiring further research. There was a limited focus on the sexuality of adults with intellectual disabilities who identify as LGBT, and an even more limited focus on lesbians and transgender people with intellectual disabilities. There were no multi-centre national or international studies and there is scope for larger projects across different geographical areas and countries. For adults with intellectual disabilities, education and training and access to additional support to explore and discuss their sexuality concerns were important recurring themes; there is a need to research their effectiveness and outcomes. Given the evidence of health inequalities and high health needs of people with intellectual disabilities and concerns related to abuse and mental illness, there is an opportunity to research the effectiveness of treatments and psychological interventions.

4.5 Strengths and limitations of the review

There is an increasing and growing body of research evidence of the experiences and needs of adults with intellectual disabilities regarding their sexuality. This review has uncovered and identified important concerns that can guide and inform policy, education, practice and the support needs of adults with intellectual disabilities. This is necessary if the drive towards social inclusion and responsive, individualized care and support, is to be a reality. In terms of the available evidence, limitations exist due to

the robustness of the study designs; an issue that is a potential challenge when undertaking research with this population. The authors have sought to be rigorous in the review process and acknowledge the potential for subjectivity. To address this, a recognized framework was used and applied consistently throughout.

5. Conclusion

Enjoyment and celebration of sexuality is recognized as a core component of human experience (World Health Organization, 2015). This systematic review exclusively highlights the voices of adults with intellectual disabilities in relation to the expression of their sexuality and identifies key priorities for their future support needs. It has become clear from this review that adults with intellectual disabilities want friendships, meaningful relationships and, for some, intimacy. It is irrefutable that some adults with intellectual disabilities are vulnerable and open to abuse and exploitation. Therefore, it is essential that there are appropriate policies and frameworks in place that afford adults with intellectual disabilities protection from unnecessary risk and harm. For this to become a reality, individuals seek access to education that enables the development of their knowledge and decision making capacity regarding sexuality opportunities. Failure to address these complex and often interrelated issues may result in adults with intellectual disabilities continuing to be viewed paternalistically. Families, professionals and support workers involved in providing care and support have important roles to play in working collaboratively to establish individual hopes and aspirations to help people reach their fulfilment as sexual beings and express their sexuality in whatever form that may take.

Conflict of interest

The authors declared no conflict of interest

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