

Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

The views and experiences of families and direct care support workers regarding the expression of sexuality by adults with intellectual disabilities: A narrative review of the international research evidence

Michael Brown^{a,*}, Edward McCann^b^a School of Nursing and Midwifery, Queen's University Belfast, Northern Ireland, United Kingdom^b School of Nursing and Midwifery, Trinity College Dublin, Ireland

ARTICLE INFO

Keywords:

Intellectual disability
Sexuality
Families
Carers
Support workers
Systematic review

ABSTRACT

Background: There is a growing and evolving research evidence base regarding sexuality issues and adults with intellectual disabilities. However, the experiences and views of families and direct care support workers and their support and development needs in the topic area are unclear.

Aims: The aim of this narrative review was to explore the views and experiences of families and direct care support workers in relation to the expression of sexuality by adults with intellectual disabilities and to identify their distinct support and development needs.

Methods and procedures: A comprehensive search of relevant databases from May 1998 to June 2018 was undertaken. Included studies had to address specific criteria: peer reviewed papers, the use of appropriate research methods, and focus exclusively on the individual views and opinions of families and direct care support workers. The search of relevant databases yielded 313 hits. Following the application of explicit inclusion and exclusion criteria, 11 papers were deemed suitable for the review. The PRISMA checklist was utilised in the process. Quality was assessed using a recognized framework.

Outcomes and results: The data were analysed and key findings highlighted issues for families and direct care support workers including: attitudes and beliefs; fear of abuse, exploitation and harm; new technologies; supporting developments in practice; and education and training programmes.

Conclusions and Implications: Families and direct care support workers have specific support and education needs. Future healthcare initiatives need to be developed that are fully responsive to the identified concerns and requirements of families and direct care support workers.

What this paper adds?

Adults with intellectual disabilities (ID) may require care and support from families and carers to enable them to lead independent lives and make choices and decisions. This review highlights issues and concerns from the available research among families and direct care support workers in enabling adults with ID to express their sexuality. The discussion presents areas relevant to policy, education and future research priorities.

* Corresponding author.

E-mail address: m.j.brown@qub.ac.uk (M. Brown).<https://doi.org/10.1016/j.ridd.2019.04.012>

Received 19 August 2018; Received in revised form 29 April 2019; Accepted 30 April 2019

Available online 10 May 2019

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1. Introduction

The aim of this paper is to present the views and experiences of families and direct care workers regarding the expression of sexuality by people with ID. For the purpose of this review, a direct care support worker refers to a paid member of staff who works on a day-to-day basis with the person with ID providing direct care and support.

There has been a drive towards a more socially inclusive healthcare system that is receptive to all aspects of the needs of the individual, achieved through the development and delivery of responsive, person-centred healthcare services (World Health Organisation, 2015). A fundamental component in human development is the expression of sexuality (World Health Organisation, 2013). Whilst there is more recognition and attention being paid to sexuality across healthcare settings, the impact of appropriate supports and interventions remains elusive (World Health Organisation, 2010). People with ID want friendships, relationships and intimacy (Rushbrooke, Murray, & Townsend, 2014; McCann, Lee, & Brown, 2016; Turner & Crane, 2016; Bates, Terry, & Popple, 2017; Brown & McCann, 2018). A recent systematic review that highlighted the views, experiences and aspirations of people with ID regarding their sexuality set their hopes and aspirations and a range of challenges and areas of potential conflict experienced by people involved in their support and care (Brown & McCann, 2018). Despite their desires, it is particularly evident that many face additional barriers and challenges to achieving this and fully expressing their sexuality, with families and carers unsure how best to provide support (McCann et al., 2016; Rushbrooke, Murray, & Townsend, 2014).

This is regardless of the social model of disability that highlights the importance of equality, human rights and the inclusion of people with disabilities as equal citizens (Simplican, Leader, Kosciulek, & Leahy, 2015). This requires that care providers and caregivers adopt more empowering, person-centred and inclusive approaches to the services and supports provided to people with ID (van der Meer, Nieboer, Finkenflügel, & Cramm, 2018). These factors, along with changes in social policy, such as deinstitutionalization strategies, has presented opportunities to address issues such as the expression of sexuality. Increasingly, with the locus of care being situated in the community, families and carers play a central role in providing the on-going care and supports to people with ID (Vanegas & Abdelrahim, 2016). While there have been significant developments in models of care in many countries across the world that have brought about positive benefits to the lives of people with ID, the extent to which they have led to opportunities for self-determination and decision-making remains open to debate (Chou, Wehmeyer, Palmer, & Lee, 2017; Shogren, Wehmeyer, Lassmann, & Forber-Pratt, 2017). However, despite such wide-spread policy initiatives, there has been resistance from some parents and families to deinstitutionalisation who view them as not offering the necessary care, support and protection for their family member (McConkey, Keogh, Bunting, Garcia Iriarte, & Watson, 2016; Inclusion Ireland, 2018).

Therefore, it is apparent that many issues and conflicting views remain regarding the subject area. A useful framework (Bronfenbrenner, 1979) has been used in the conceptualization of specific issues, beyond those experiences by the individual with ID and demonstrates how different systems, processes, attitudes, values and beliefs can interact to influence important aspects of the lives of people with ID (Brown & McCann, 2018).

There is clear international research evidence regarding the scope and extent of the health inequalities and health needs experienced by people with ID, including their sexuality and distinct sexual health needs (Azzopardi-Lane & Callus, 2015; Brown & McCann, 2018; Truesdale & Brown, 2017). There is growing interest in the range of supports available to parents and other caregivers of people with ID regarding sexuality issues (Yıldız & Cavkaytar, 2017). A positive way of addressing some of the issues is through sexuality education programmes aimed specifically at families and carers (Peter, Tasker, & Horn, 2015). Such programmes may take the form of knowledge and skills acquisition that aim to help families and carers explore and more fully understand the various aspects of sexual expression and needs from their own viewpoint, and the perspectives of people with ID (Gardiner & Braddon, 2009; Kok & Akyuz, 2015; Schaafsma, Stoffelen, Kok, & Curfs, 2013; Yıldız & Cavkaytar, 2017). Other areas include sexual health needs (Thompson, Stancliffe, Broom, & Wilson, 2014), the potential for exploitation and harm, including online targeting (Byrne, 2017; Chadwick, Quinn, & Fullwood, 2017), sexuality beliefs and misconceptions (Rushbrooke et al., 2014b) and how families and carers can support the expression of sexuality and the development of intimate relationships in people with ID (Fulford & Cobigo, 2018; Wilkinson, Theodore, & Raczka, 2015). The aim of this review is to explore the views and experiences of families and direct care support workers in relation to the expression of sexuality by adults with ID. Therefore, the questions of the review are:

- 1 What are the views and experiences of families and direct care support workers regarding the expression of the sexuality by adults with ID?
- 2 What are the support and development needs of families and direct care support workers regarding the expression of sexuality and adults with ID?

2. Method

2.1. Search and selection strategy

A subject librarian was enlisted to assist with the literature search strategy. The databases used in the search were CINAHL, MEDLINE, PsycINFO and Sociological Abstracts. The search terms used were: intellectual disab* OR mental retard* OR mental handicap OR developmental disab* OR learning disab* AND sexuality OR famil* OR carer* OR support worker*. The inclusive dates were May 1998 to June 2018. An example of the search strategy used in one electronic database is shown in Table 1.

The inclusion criteria for the searches were limited to academic journals, peer reviewed empirical studies, and written in English. The studies had to focus specifically on the views and experiences of families and direct care support workers regarding the

Table 1
PsycINFO search strategy and results example.

Search code	Query	Results
S1	intellectual disab*	32766
S2	mental retard*	44,656
S3	mental handicap	3,605
S4	developmental disab*	36,993
S5	learning disab*	31,559
S6	S1 OR S2 OR S3 OR S4 OR S5	100,506
S7	sexuality	35,756
S8	famil*	507,904
S9	carer*	9,205
S10	support worker*	2,812
S11	S8 OR S9 OR S10	515,132
S12	S6 OR S7 OR S11	168
S13	Limiters: Years 1998-2018; peer reviewed papers	83

expression of sexuality of adults with ID. Studies that used a qualitative, quantitative or mixed methods approach were considered for inclusion in the review. The searches revealed 313 hits across all the databases. A PRISMA flow diagram (Fig. 1) contains the results of the search and selection process (Moher et al., 2015). A hand search was also conducted of the reference lists of the identified papers leaving a total of 11 papers for the review.

2.2. Characteristics of the studies

The data were extracted collectively by the reviewers. The 11 studies that addressed the study aim and objectives are presented in

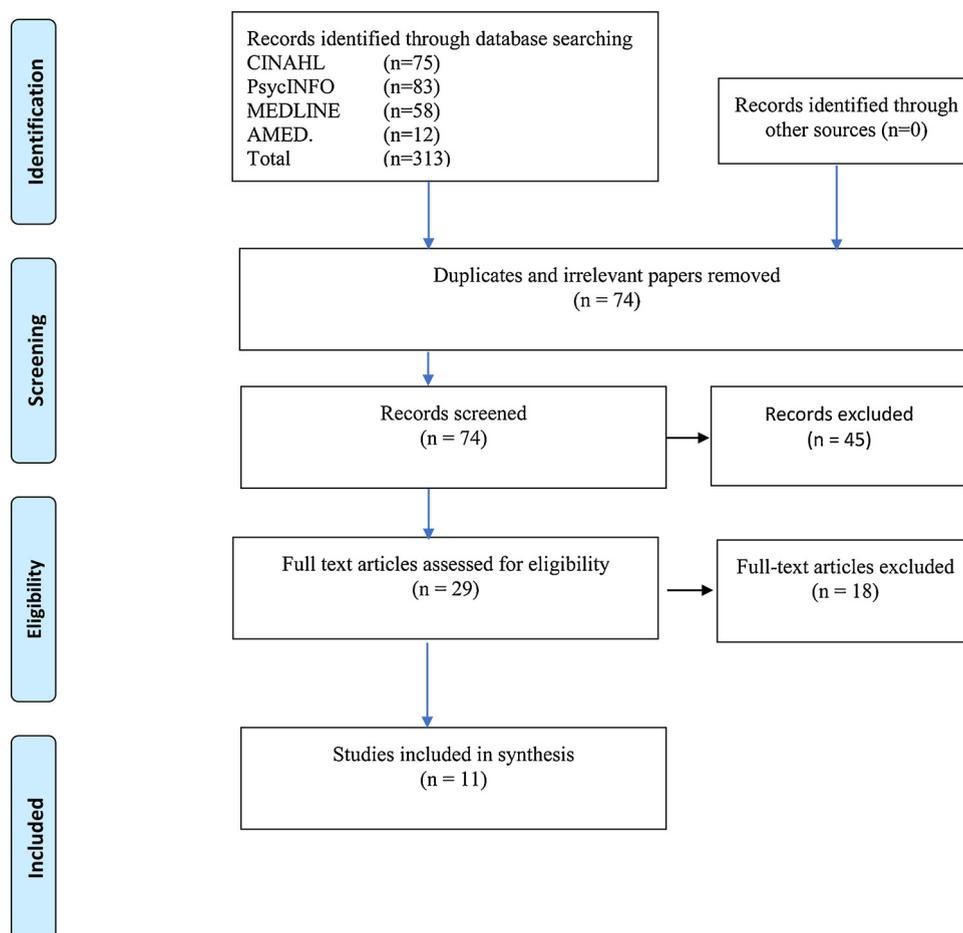


Fig. 1. PRISMA flowchart of systematic review process.

Table 3. The majority of studies ($n = 3$) were conducted in the United States (US). The remainder were carried out in Australia ($n = 2$), Canada ($n = 2$), Ireland ($n = 1$), Mexico ($n = 1$), Turkey ($n = 1$) and United Kingdom (UK) ($n = 1$). Of the 11 studies,

a total of 4 focused on the views and experiences of families (Ballan, 2012; Gürol, Polat, & Oran, 2014; Nichols & Blakeley-Smith, 2009; Pownall, Jahoda, Hastings, & Kerr, 2011), 4 studies on direct care support workers (Gilmore & Chambers, 2010; Pebdani, 2016; Saxe & Flanagan, 2014, 2016), and 3 combined both groups (Eastgate, Scheermeyer, van Driel, & Lennox, 2012; Evans, McGuire, Healy, & Carley, 2009; Morales, Lopez, & Mullet, 2011). Sample sizes ranged from 8 to 308 study participants and included families of people with ID and support workers involved in the day-to-day care of people with ID. All of the studies considered in the review used a selection of data collection methods that included surveys, questionnaires and interviews. A total of four studies were quantitative, adopting a range of measures and survey approaches. No controlled trials or planned intervention studies were identified. Seven studies used qualitative approaches including interviews or focus groups, and no papers utilized a mixed method design.

2.3. Quality assessment

The authors jointly reviewed and appraised the papers for methodological quality. Given the lack of controlled trials and intervention studies and the descriptive nature of data analysis, the same quality assessment tool was used as an evidence-based framework to review all papers (Critical Appraisal Skills Programme, 2013). This approach was adopted to enable the analysis and comparison of both quantitative and qualitative data and the identification of useful findings relevant to policy, practice, education and future research within the framework of a narrative review of the evidence. Specific questions were consistently applied to each of the selected studies (see 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 et al., 2014a). A total of 5 studies achieved a score of 17 or greater, indicating good quality information (Ballan, 2012; Gilmore & Chambers, 2010; Nichols & Blakeley-Smith, 2009; Pebdani, 2016; Pownall et al., 2011). A score of between 14 and 16 was given to 6 studies that showed that there were information gaps related to clarity of the aims, appropriate recruitment strategies, data collection methods, research relationships considered, ethics statements and lack of data analysis (Eastgate et al., 2012; Evans et al., 2009; Gürol et al., 2014; Morales et al., 2011; Saxe & Flanagan, 2014, 2016). All of the studies addressed the objectives of the review and therefore were deemed suitable for inclusion.

2.4. Data synthesis and analysis

The review process was guided by recognized methods involving the synthesis of mixed literature. The reviewers had intended to conduct a meta-analysis, however as a result of the wide range of differing methodological approaches used across the studies, secondary data extraction was not possible. Therefore, a narrative synthesis was selected as the most appropriate approach, relying on key word identification and text to identify the emergent themes (Popay, Roberts, & Sowden, 2006). They were grouped into concepts to allow for contrasts and comparisons to be made between themes and across studies. The themes were identified independently and then discussed, verified and agreed by all the research team, thereby seeking to address potential reviewer bias and achieve consensus (Caldwell, Henshaw, & Taylor, 2011).

2.5. Findings

Following data analysis, five main themes emerged that were: (i) attitudes of families and direct care support workers, (ii) fear of abuse, exploitation and harm, (iii) concerns about new technologies (iv) supporting developments in practice, and (v) education and training programmes.

2.6. Attitudes of families and direct care support workers

Many adults with ID continue to live at home with their families or live in supported living, with involvement from direct care support workers. The attitudes held by family members and direct care support workers has a direct effect on the ability of both adults with ID to express their sexuality and make decisions about how to express it (Gilmore & Chambers, 2010; Pebdani, 2016; Pownall et al., 2011; Saxe & Flanagan, 2016). A recurring theme across some studies was the ability and confidence of family members to discuss sexual matters, with the need for access to education, training and support to develop their skills (Ballan, 2012; Gürol et al., 2014; Nichols & Blakeley-Smith, 2009). Direct care support workers were more likely to actively discuss sexuality and relationship issues, concerns and needs directly with the adults with ID than family members, with differences in attitudes, values and beliefs identified between older and younger support workers (Evans et al., 2009; Gilmore & Chambers, 2010). Across studies involving both families and direct care support workers, diverse views were held regarding the expression of sexuality by adults with ID, including the need to enable and fully support sexual expression and relationship aspirations (Evans et al., 2009; Gilmore & Chambers, 2010; Morales et al., 2011; Pebdani, 2016; Saxe & Flanagan, 2016).

2.7. Fear of abuse, exploitation and harm

Both families and direct care support workers were of the view that adults with ID were potentially at risk of sexual exploitation and sexual abuse (Ballan, 2012; Eastgate et al., 2012; Gürol et al., 2014; Nichols & Blakeley-Smith, 2009; Pownall et al., 2011). Some

Table 2
CASP quality scores.

CASP criteria	Ballan (2012)	Eastgate et al. (2012)	Evans et al. (2009)	Gilmore and Chambers (2010)	Gürol et al. (2014)	Morales et al. (2011)	Nichols and Blakeley-Smith (2009)	Pebdani (2016)	Pownall et al. (2011)	Saxe and Flanagan (2014)	Saxe and Flanagan (2016)
1. Clear statement of aims	2	1	2	2	2	2	2	2	1	1	2
2. Appropriate methodology	2	2	2	2	2	2	2	2	2	2	2
3. Appropriate research design	2	2	2	2	2	2	2	2	2	2	2
4. Appropriate recruitment strategy	2	1	2	2	1	1	2	2	2	2	2
5. Appropriate data collection methods	2	2	2	2	1	2	2	2	2	2	2
6. Research relationships considered	0	0	0	0	0	0	1	0	0	0	0
7. Consider ethical issues	2	2	0	2	2	1	0	2	2	1	0
8. Rigorous analysis	2	2	1	2	1	2	2	2	2	2	2
9. Clear findings	2	2	2	2	2	2	2	2	2	2	2
10. Value of the research	2	2	2	2	2	2	2	2	2	2	2
Total scores out of 20	18	16	15	18	15	16	17	18	17	16	16

Table 3
Papers included in the review.

Study Citation and Country	Aims	Sample	Data collection method	Key Findings	Recommendations	CASP scores out of 20
Ballan, M. (2012) USA	Explore communication about sexuality by children with autism and their parents.	Parents (n = 18)	Semi-structured interviews	Sexual victimization greatest concern. Misconceptions around their child's sexual behavior and intent. Challenges to discussion sexual matters with professionals and the children.	Sexual decision making with children needs further research attention. More applied prevention programmes including family-based interventions to help target 'normative' sexual behaviours.	18
Eastgate et al. (2012) Australia	Identify supports regarding sexuality, relationships and abuse prevention for families and support workers.	<i>Interviews:</i> Family members (n = 7) Support workers (n = 3) <i>Focus groups:</i> Family members (n = 5) Support workers (n = 13)	Individual interviews and focus groups	People with ID are lonely, disempowered and vulnerable to abuse. New risks from the sex industry, internet and mobile phones. Gaps in sexual knowledge and sex education.	Research needed to explore internet and mobile phone risks to inform education and support programmes. Rigorous evaluation of education programmes needed. Legal and ethical issues require clarification.	16
Evans et al. (2009) Ireland	Assess the attitudes of staff and family carers to the sexuality of people with ID	Staff carers (n = 153) Family carers (n = 155)	Postal survey	Staff carers more likely to openly discuss sexuality issues with service users and suggest environmental factors as impediments to sexual expression. Attitudinal differences exist between support workers and family carers and between older and younger carers. Support workers likely to support intimate and non-intimate relationships.	Need to provide opportunities for staff and family carers to discuss sexuality issues and a need for training in the area of sexuality.	15
Gillmore and Chambers (2010) Australia	Examine attitudes of disability support workers and leisure industry staff re the sexuality of people with ID	Support workers (n = 169) Leisure industry workers (n = 50)	Attitudes to sexuality questionnaire	Both had positive attitudes to the sexuality of people with ID. Men had less control than women. Support staff cautious about parenting and people with ID. Women had less sexual freedom than those without IDs	Need guidelines and policy in practice regarding sexuality and ID. More mandatory education and training around sexuality issues for support workers and leisure industry workers.	18
Gürol et al. (2014) Turkey	Evaluate the views of mothers of children with ID regarding their children's sexual education	Mothers (n = 9)	Focus group interviews	Sexual education not given by mothers but recognized it was required and provided by rehabilitation centres. Saw children as asexual and family planning unnecessary. Concerns about sexual abuse and exploitation.	Sexual education should be provided as standard to nurses, rehabilitation centre staff and special school staff to promote sexual development and to protect from abuse.	15
Morales et al. (2011) Mexico	Explore the attitudes of families and support workers towards people with ID	Parents (n = 120) Family carers (n = 75) Support workers (n = 75)	Interviews using case vignettes	Responses to sexual expression in people with ID were: unacceptable (37%), acceptable (36%) or dependent on individual circumstances (27%).	Research into delivery and evaluation human sexual rights training programmes.	16
Nichols and Blakeley-Smith (2009) USA	Examine parental attitudes towards sexual expression in young people with ASD and evaluate the effectiveness of an education programme	Phase 1: Parents (n = 21) Phase 2: 2 Parent education groups (n = 5) in each	Focus groups Interviews and measures	Main concerns were around exploitation, safety and misinterpreted behaviours. Parents willing but felt unprepared – lacked knowledge and resources. Benefits of the education programme were getting support and guidance from other families.	More community education resources required. Education programme needs to be longer. More rigorous evaluation needed – pre, end of course and follow-up.	17

(continued on next page)

Table 3 (continued)

Study Citation and Country	Aims	Sample	Data collection method	Key Findings	Recommendations	CASP scores out of 20
Pebdani (2016) USA	Attitudes of group home workers towards sexual expression in people with ID	Group home workers (n = 71)	Questionnaire and measures	Participating in an in-service training on sexuality and ID has a positive influence on attitudes. Women had a more positive attitude to sexual rights and about an ID person's ability to exercise self-control. No policies on sexuality (50%) response. Mothers experienced challenges towards enabling independence and maintaining control. Lack of opportunity for young people to meet others and form relationships. Sexual matters ignored. Mothers lacked confidence and awareness around sexuality issues and felt risks were apparent but unaware of available supports. Schools should provide sex education.	Access to training for all employees. Need guidance and policies addressing sexual expression. Research focusing on the impact of training needed.	18
Pownall et al. (2011) UK	Explore mothers' experiences of supporting sexuality in young people with ID	Mothers (n = 8)	Interviews	More liberal attitudes shown by support workers where there is no religious affiliation and they are more advanced educationally. Greater acceptance of LGB sexuality but against anal intercourse. Support workers lack experience and confidence around sexuality issues. Sex education course should include prevention and protection, appropriate behaviours and positive relationships. Significant absence of sexuality related policies.	Need a better understanding of sexuality and its social contexts. Autonomy versus control. More education and support to mothers and other family members. Professionals need to be proactive in engaging with families to discuss sexuality issues.	17
Saxe and Flanagan (2014) Canada	Identify support workers attitudes towards the sexual behaviours of adults with ID	Support workers (n = 18) Non-support workers (n = 7)	Questionnaire and measures	More liberal attitudes shown by support workers where there is no religious affiliation and they are more advanced educationally. Greater acceptance of LGB sexuality but against anal intercourse. Support workers lack experience and confidence around sexuality issues. Sex education course should include prevention and protection, appropriate behaviours and positive relationships. Significant absence of sexuality related policies.	Need to address biased attitudes in training programmes. Increased training opportunities for support workers. Need sexuality related policies.	16
Saxe and Flanagan (2016) Canada	Identify support workers confidence towards sexuality issues, education for service users, and sexuality related policies.	Support workers (n = 16)	Survey and open-ended questions	More liberal attitudes shown by support workers where there is no religious affiliation and they are more advanced educationally. Greater acceptance of LGB sexuality but against anal intercourse. Support workers lack experience and confidence around sexuality issues. Sex education course should include prevention and protection, appropriate behaviours and positive relationships. Significant absence of sexuality related policies.	Sex education required for support workers before commencing employment. Sex education workshops for staff. Need to develop clear policies and ensure staff are familiar with them.	16

families and direct care support workers experienced dilemmas in acknowledging the rights and desires of the individual with ID to express their sexuality and form friendships and develop intimate relationships, that for some may be sexual, versus fears related to sexual exploitation and abuse (Ballan, 2012; Eastgate et al., 2012). Family members were concerned that the desire for friendships could be misconstrued and misinterpreted, thereby placing their family member with ID at risk of exploitation and abuse (Ballan, 2012; Nichols & Blakeley-Smith, 2009). Access to education that supports adults with ID to enable self-determination and develop their knowledge of risks and how to protect themselves, was seen by both families and direct care support workers as an area requiring investment and development (Nichols & Blakeley-Smith, 2009; Pebdani, 2016; Pownall et al., 2011; Saxe & Flanagan, 2016). For other family members, there was the view that providing access to education and support was not necessary and would 'encourage' their family member to more freely express their sexuality and seek new friendships and relationships (Ballan, 2012; Gürol et al., 2014). While some families acknowledged the right of their adult child to have self-determination that would enable them to develop independence and new relationships, they were thankful for the lack of skills to self-travel and manage money, which were factors that restricted choice that would perhaps protect from the risk of abuse and exploitation. Maintaining 'control' was viewed as important for some families and support workers as a means of protecting people with ID from harm and possible abuse (Ballan, 2012; Eastgate et al., 2012; Evans et al., 2009; Nichols & Blakeley-Smith, 2009).

2.8. Concerns about new technologies

Some adults with ID are lonely and socially isolated and lack social networks and friendships (Ballan, 2012; Pownall et al., 2011). Families and direct care support workers highlighted that with the advent of access to digital technologies such as the internet, tablets and mobile phones, adults with ID have new opportunities and possibilities to communicate, develop and maintain friendships (Eastgate et al., 2012). Families were of the view that such technologies can help protect adults with ID from potential harm and victimisation (Ballan, 2012). Families and direct care support workers both expressed concerns about the risks of wider access to the internet and mobile phones and the ability of some adults with ID to protect themselves from being targeted by sexual predators (Eastgate et al., 2012; Nichols & Blakeley-Smith, 2009; Saxe & Flanagan, 2016). Due to gaps in sexual knowledge and access to sex education, concerns were identified by some families and direct care support workers that some adults with ID may be placed at risk of exploitation, abuse and prostitution due to their inability to accurately interpret the true intentions of people seeking to 'befriend' them (Eastgate et al., 2012; Nichols & Blakeley-Smith, 2009).

2.9. Supporting developments in practice

Adults with ID desire relationships and intimacy, with a need for support to facilitate decision making regarding the expression of their sexuality and help protect them from potential harm (Ballan, 2012; Gürol et al., 2014; Pebdani, 2016). The scope and extent of practice was an area of concern for some direct care support workers, a situation further exacerbated by a lack of policies and guidelines within care organisations (Saxe & Flanagan, 2014). To ensure that policy frameworks are understood and embedded in routine day-to-day practice, it was highlighted that organisational policies and guidelines need to be included within induction and education programmes for all direct care support workers. Addressing this will help to ensure that the workers are familiar with this area of their practice and have the opportunity to discuss concerns (Saxe & Flanagan, 2014, 2016). Failure to address the policy and guideline vacuum leaves direct care support workers confused and unclear about the scope and extent of this aspect of their role, with the need for further clarity regarding legal and ethical issues and concerns (Gilmore & Chambers, 2010; Eastgate et al., 2012; Saxe & Flanagan, 2014; Pebdani, 2016; Saxe & Flanagan, 2016).

2.10. Education and training programmes

The most commonly recurring theme across the included studies was the need to develop and provide education and training opportunities. Programmes need to provide creative spaces that brings together family members and direct care support workers to discuss and explore their views, experiences and concerns and to identify ways to best help and support the family member with ID (Ballan, 2012; Evans et al., 2009; Pownall et al., 2011). Both families and direct care support workers were of the view that mandatory training regarding sexuality should be included as standard practice across disciplines, such as health, rehabilitation and special school staff and direct care support workers working for care agencies. Both groups suggested that training should enable workers to undertake their role more effectively and efficiently to the needs of adults with ID and their families (Gilmore & Chambers, 2010; Pownall et al., 2011; Ballan, 2012; Saxe & Flanagan, 2014; Gürol et al., 2014; Pebdani, 2016; Saxe & Flanagan, 2016). Both groups recommended that robust evaluation of education programmes is advocated to identify their impact and effectiveness before, during and after delivery (Eastgate et al., 2012; Morales et al., 2011; Nichols & Blakeley-Smith, 2009).

3. Discussion

The aim of this review was to elicit the views and experiences of families and direct care support workers regarding the expression of sexuality by adults with ID and to identify their support needs. A range of issues that exist in relation to the experiences and view of families and direct care support workers have been identified and the review findings highlight areas requiring attention in terms of policy, education, supports, and future research developments. *Bronfenbrenner's Ecological Model* has been used as a framework to structure and present the discussion (Bronfenbrenner, 1979). The model provides a helpful theoretical framework for the discussion

as it focuses on assets and strengths, thereby developing the understanding of the perspectives of families and direct care support workers. It also enables the identification of the aspirations of adults with ID and how they might be addressed. With a multi-systemic focus, the different elements help develop the understanding of the needs and experiences of specific populations (Institute of Medicine, 2011). The model sets out the macro, meso and micro systems that interact with each other from an environmental perspective and the impact of the factors on service systems and human behaviour (Bronfenbrenner, 1979).

3.1. Macro system

The macro system of the model relates to the overarching factors of the cultural and societal norms and their impact on the individual. This review has identified a number of issues that need to be addressed within this system. While the shift from institutional models of care in many countries has been welcome and can have a positive impact on the lives of people with ID, concerns remain of the extent to which self-determination and decision making is a reality, including the expression of their sexuality and the pleasure derived from developing an independent sexual identity and experiencing relationships and intimacy (Brown & McCann, 2018; McCann et al., 2016; Simplican et al., 2015; Sinclair, Unruh, Lindstrom, & Scanlon, 2015; Turner & Crane, 2016; Wilkinson et al., 2015; Winges-Yanez, 2014).

The theme, *attitudes of families and direct care support workers*, highlights the need for clarity and understanding for both groups of the legal and ethical context of fundamental equal human rights of adults with ID, and concerns related to the desire to protect (O'Callaghan & Murphy, 2007; Rushbrooke et al., 2014b; Schaafsma, Kok, Stoffelen, & Curfs, 2015; World Health Organisation, 2015). While it is the case that some adults with ID may at points in their lives require protection from harm, there remains a fundamental right to take risks and experience, for example relationships and intimacy, and all the consequences that may ensue (Healy, McGuire, Evans, & Carley, 2009; Bryne 2017; Whittle & Butler, 2018).

The theme, *supporting developments in practice*, has been identified in this review as a gap that needs attention and development. The absence of clear policies may inadvertently place adults with ID at risk of harm as many are sexually active yet may lack knowledge and skills required to navigate relationships, including reporting sexual abuse and exploitation (Baines, Emerson, Robertson, & Hatton, 2018; Reid, 2018). There is therefore opportunity and need to fully engage adults with ID in the future development of organisational policies and guidelines related to sexuality issues. Areas that should be addressed include autonomy and sexual decision making, sexual health, LGBT + relationships, capacity and consent, sexual abuse, protection and safeguarding, developing relationships and responding to potential risks related to use of the internet and mobile phones (Brown & McCann, 2018; Chadwick et al., 2017; McCann et al., 2016; Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014; Reid, 2018). Adults with ID are sexual beings and many are sexually active, therefore policies and guidelines need to be enabling and facilitative and embedded in organisational culture and practice, while reflecting the need to protect and safeguard where indicated (Baines et al., 2018; Pebdani, 2016; Saxe & Flanagan, 2016; Franklin & Smeaton, 2018).

3.2. Micro system

The micro system element of the model sets out the personal relationships and networks of support. From an ID perspective, this may include, families, friends, peers and support workers and the availability of and the opportunity to access social support and social support networks. Two themes relate to the micro systems of the model; *fear of abuse, exploitation and harm* and *concerns about new technologies*. Families face many dilemmas regarding the right to autonomy and decision making and the risk of potential targeting and exploitation and abuse, leaving them with complex decisions to make that can limit and inhibit the opportunities for their family member with ID to develop friendships and relationships (Ballan, 2012; Amado, Stancliffe, McCarron, & McCallion, 2013; McCann et al., 2016; Brown & McCann, 2018; Whittle & Butler, 2018). However, families and direct care support workers often lack the knowledge and confidence to discuss concerns about exploitation and abuse with adults with ID and would benefit from targeted prevention programmes to help identify the necessary protective interventions that need to be in place (McCarthy et al., 2016). Concerns regarding exploitation and abuse often focus externally on strangers, yet it is necessary to recognise the risks posed by people closely associated with adults with ID, including other people with ID, who may be the perpetrators of such harm. Therefore, access to networks of support and advice are necessary for both adults with ID and their families (Bowen & Swift, 2017; Northway et al., 2013).

An emerging area within the research literature relates to the theme, *concerns about new technologies*, and the positive and negative role that these can play in placing adults with ID at risk of harm (Eastgate et al., 2012; Chadwick et al., 2017). Adults with ID want friendships, relationships, and for some, intimacy, with evidence of increasing use of social media, often with positive benefits and experiences (Sallafranque-St-Louis & Normand, 2017; Brown & McCann, 2018; Chadwick & Fullwood, 2018). A good example is the access to friendships and dating programmes, which have been found to have a positive effect on quality of life and be effective in increasing social networks and decreasing interpersonal violence (Ward, Atkinson, Smith, & Windsor, 2013; Caton & Chapman, 2016). While positive benefits are apparent, concerns exist regarding the targeting of adults with ID through the use of, for example, social media and dating sites, which may be compounded by judgement and awareness of the risk of exploitation (Holmes & O'loughlin, 2014; Buijs, Boot, Shugar, Fung, & Bassett, 2017). Therefore, access to education and support regarding safe internet and social media use is indicated for adults with ID, their families and direct care support workers (Sanz, Gómez-Puerta, & Moltó, 2017).

3.3. Meso system

The meso system element of the model relates to the relationships and interaction between adults with ID, their families and direct care support workers and the wider macro factors. The theme, *education and training programmes*, is a significant area arising from this review. Adults with ID want access to education and support to enable them to develop and sustain relationships, friendships and experience intimacy, thereby reducing the possibility of abuse and exploitation (Murphy & O'Callaghan, 2004; Rushbrooke et al., 2014b; McCann et al., 2016; Turner & Crane, 2016; Brown & McCann, 2018). Likewise, families and direct care support workers face challenges regarding risk and autonomy and require access to education and support programmes to enable them to develop their knowledge and understanding. As part of this process, induction and development programmes for direct care support workers need to incorporate sexuality and sexual health issues, thereby ensuring that they are core to practice and effective in providing the type of support that adults with ID want and need (Rushbrooke et al., 2014b). Families too, want access to education programmes that builds upon their knowledge and confidence to help them to have sensitive conversations with their family member with ID (Kok & Akyuz, 2015; Yıldız & Cavkaytar, 2017). Central to the development, implementation and evaluation of education and development programmes is the inclusion of adults with ID. At present this is lacking, with a need to be explicit regarding how the outcomes achieved impact on their sexual lives (Schaafsma et al., 2015; Schaafsma, Kok, Stoffelen, & Curfs, 2017).

3.4. Future research directions

This review has identified a number of areas that require to be addressed to effectively support the sexuality needs of adults with ID. It is evident that there is an absence of research studies focusing on the development and implementation of policies and guidelines and of the impact, effectiveness and outcomes achieved from the education programmes that do exist. No studies were identified that focused on shared education programmes involving adults with ID, families and direct care support workers; this is an area requiring further research. No studies focused on the views and experiences of families with a family member who identified as LGBT + and their needs in relation to supporting the expression of sexuality and is another area worthy of research attention. All the studies included in this review were single centre; there were no multi-centre national or international studies, revealing the opportunity to undertake larger studies across geographical areas, countries and continents. There is therefore an opportunity and need to more fully research and understand their hopes and aspirations and the contributions and supports provided by families and direct care support workers can make in relation to the full and equal expression of their sexuality.

3.5. Strengths and limitations of the review

There is a growing interest in the sexuality needs of adults with ID and the important role that families and direct care support workers play in enabling and inhibiting this expression. Families and direct care support workers have their own particular support and education needs that require to be met if adults with ID are to have a life that recognises and responds to all their needs, including the full expression of their sexuality in all the forms that may take. There are limitations in the existing research evidence due primarily to the small sample sizes and robustness of the study designs employed and the absence of comprehensive evaluations of education and support programmes. The authors have attempted to be rigorous in the literature identification and review process and acknowledge the potential for subjectivity.

4. Conclusion

It is apparent from this review that families and direct care support workers have specific concerns regarding the expression of sexuality by adults with ID. They also have distinct support and education needs that need to be recognised and met. Organisations involved in the care and support of adults with ID need to ensure that clear policies and guidelines are in place that are reflective of the hopes and aspirations of adults with ID regarding expressing their sexuality. Direct care support workers have an important role to play in the day-to-day lives of the adults with ID, yet there is a need for a clearer and stronger focus on the scope and extent of their role and remit in relation to enabling the exploration and expression of sexuality for the people that they care for and support. Developing evidence-based programmes that enhance the understanding of the relationship needs, hopes and aspirations of adults with ID is an area that requires attention. This can only be achieved if undertaken with people with ID at the centre of such endeavours.

Conflict of interest

The authors declared no conflict of interest

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