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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

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ABSTRACT

Background

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

Aims

The aim of this 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 including: peer reviewed papers, the use of appropriate research methods, and focused 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.

Outcomes and results

The data were analyzed and key findings highlighted issues for families and direct care support workers including: attitudes and beliefs; fear of abuse, exploitation and harm; new technologies; policies and guidelines; 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.

Keywords:

Intellectual disability, sexuality, families, carers, support workers, systematic review

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.

1. Introduction

A recent systematic review that highlighted the views, experiences and aspirations of people with ID regarding their sexuality set out a range challenges and areas of potential conflict from people involved in their support and care (Brown and McCann 2018). Therefore, this paper focuses on the specific views and experiences of parents, families and support workers involved in the persons' daily lives. 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 (Rushbrook et al., 2014a; McCann et al., 2016; Turner & Crane 2016; Bates et al., 2017; Brown & McCann 2018). Despite such 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 (Rushbrooke et al., 2014b; McCann et al., 2016; Brown & McCann 2018). 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 et al., 2015). This focus requires that care providers and caregivers adopt more empowering, person-centred and inclusive approaches to the services and supports they may provide to people with ID (van der Meer et al., 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 proving the on-going care and supports to people with ID (Vanegas & Abdelrahim, 2016).

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; Truesdale & Brown, 2017; Brown & McCann, 2018). 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 et al., 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 & Brandon, 2009; Kok & Akyuz, 2015; Schaafsma et al., 2013; Yildiz & Cavkaytar, 2017). Other areas include sexual health needs (Thompson et al., 2014), the potential for exploitation and harm, including online targeting (Byrne, 2017; Chadwick et al., 2017), sexuality beliefs and misconceptions (Rushbrook 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 et al., 2015).

2. Method

2.1 Research questions

The aim of this review is to explore the views and experiences of parents, families and support workers in relation to the expression of sexuality by adults with intellectual disabilities. Therefore, the questions of this review are:

1. What are the views and experiences of parents, families and direct care support workers regarding the expression of the sexuality by adults with intellectual disabilities?

2. What are the support and development needs of families and direct care support workers regarding the expression of sexuality and adults with intellectual disabilities?

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 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.

Insert Table 1 here

The searches revealed 313 hits across all the databases. A flow chart (Figure 1) contains the results of the searches (Moher, Liberati, Telzlaff & Altman, 2009). 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 parents, families and direct care support workers views and experiences of sexuality issues in relation to adults with ID. A hand search was also conducted of the reference lists of the identified papers leaving a total of 11 papers for the review. Studies that used a qualitative, quantitative or mixed methods approach were considered for inclusion in the review.

2.3 Quality assessment

A recognized quality assessment tool was used as an evidence-based framework to review the papers (Critical Appraisal Skills Programme, 2013). 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, Murray & Townsend, 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, Jahoda, Hastings & Kerr, 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, Scheermeyer, van Driel & Lennox, N. 2012; Evans, McGuire, Healy & Carley, 2009; Gürol, Polat & Oran, 2014; Morales, Lopez & Mullet, 2011; Saxe & Falanagan, 2014; Saxe & Falanagan, 2016). All of the studies addressed the objectives of the review and therefore were deemed suitable for inclusion.

***Insert Table 2 here ***

2.3 Characteristics of the studies

The 11 studies that addressed the study aim and objectives are presented in 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). Sample sizes ranged from 8 to 308 study participants involving parents and 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, seven papers used qualitative approaches including interviews or focus groups, and no papers utilized a mixed method design.

***Insert Table 3 here ***

2.4 Data extraction and analysis

The review process was guided by recognized methods involving the synthesis of mixed literature (Mays, Pope & Popay, 2005). A thematic analysis of the data was undertaken. All of the emergent themes were systematically identified across all the studies and coded. They were grouped into concepts to allow for contrasts and

comparisons to be made between themes and studies. The emergent themes were identified independently and then discussed, verified and agreed by the reviewers (Caldwell, Henshaw & Taylor, 2011).

3. Findings

3.1 Attitudes of parents, 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 adults with intellectual disabilities to express their sexuality and make decisions about how to express it (Gilmour & Chambers, 2010; Pebdani, 2016; Pownall et al., 2011; Saxe & Flanagan, 2016). A recurring theme across some studies was the ability and confidence of family member 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 intellectual disabilities than family members, with differences in attitudes, values and beliefs identified between older and younger support workers (Evans et al., 2009; Gilmour & Chambers, 2010). Diverse views were held regarding the need for adults with intellectual disabilities to express their sexuality, including the need to enable and fully support sexual expression and relationship aspirations (Evans et al., 2009; Gilmour & Chambers, 2010; Morales et al., 2011; Pebdani, 2016; Saxe & Flanagan, 2016).

3.2 Fear of abuse, exploitation and harm

Adults with intellectual disabilities were viewed as a group who are at risk of sexual exploitation and sexual abuse (Ballan et al., 2012; Eastgate et al., 2012; Gürol

et al., 2014; Nichols & Blakeley-Smith, 2009; Pownall et al., 2011). Dilemmas were experienced by parents of adults with ID where they wanted to acknowledge the rights and desire of their family member 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). Parents were concerned that the desire for friendships could be misconstrued and misinterpreted, thereby placing their family member with intellectual disabilities at risk of exploitation and abuse (Ballan, 2012; Nichols & Blakeley-Smith, 2009). Access to education that supports adults with intellectual disabilities to enable self-determination and develop their knowledge of risks and how to protect themselves, was seen a lacking and an area requiring investment and development (Nichols & Blakeley-Smith, 2009; Pebdani, 2016; Pownall et al., 2011; Saxe & Flanagan, 2016). For other parents, 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; Morales et al., 2011). While some parents recognised the right of their adult child to 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).

3.3 Concerns about new technologies

Some adults with intellectual disabilities are lonely and socially isolated and lack social networks and friendships (Ballan, 2012; Pownall et al., 2011). With the

advent of access to digital technologies such as the internet, tablets and mobile phones, adults with intellectual disabilities have new opportunities and possibilities to communicate, develop and maintain friendships (Eastgate et al., 2012). Such technologies can help protect adults with intellectual disabilities from potential harm and victimisation (Ballan, 2012). Concerns can exist about the risks of wider access to the internet and mobile phones and the ability of some adults with intellectual disabilities 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 have been identified that some adults with intellectual disabilities 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).

3.4 Policies and guidelines to inform 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). However, there remains a lack of policies and guidelines within care organisations and agencies regarding supporting adults with ID to express their sexuality. These need to be embedded within induction and education programmes and direct care support workers are familiar with them and their practice responsibilities (Saxe & Flanagan 2014; Saxe & Flanagan 2016). This 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 (Gilmour & Chambers 2010; Eastgate et al., 2012; Saxe & Flanagan 2014; Pebdani 2016; Saxe & Flanagan 2016).

3.5 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 parents 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 (Evans et al., 2009; Pownall et al, 2011; Ballan 2012). Mandatory training should be viewed as standard practice and perceived as necessary across disciplines, such as health, rehabilitation and special school staff and direct care support workers working for care agencies. Training should enable individuals to undertake their role more effectively and respond more efficiently to the needs of adults with ID and their families (Gilmour & Chambers, 2010; Pownall et al., 2011; Ballan 2012; Saxe & Flanagan 2014; Gürol et al., 2014; Pebdani 2016; Saxe & Flanagan 2016). 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 & Blakely-Smith 2009).

4. Discussion

This review has identified a range of issues that exist in relation to the experiences and view of families and direct care support workers regarding the expression of sexuality by adults with intellectual disabilities. The 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 for the discussion to present areas requiring further attention and development *(*Bronfenbrenner, 1979). The model is helpful as it focuses on assets and strengths and develops the understanding of the needs of families and direct care support workers and the interface with the hopes and aspirations of adults with intellectual disabilities 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). It is useful in the conceptualisation and identification of potential factors and concerns from a political, cultural social and practice perspectives that can impact upon social exclusion and health inequalities.

4.1 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 (Winges-Yanez 2014; Simplican et al., 2015; Sinclair et al., 2015; Wilkinson et al., 2015; McCann et al., 2016; Turner & Crane 2016; Brown & McCann 2018).

The theme, *attitudes of parents, families and direct care support workers,* highlights the need for clarity and understanding 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; Morales et al., 2011; Eastgate et al., 2012; Rushbrook et al., 2014b; Schaafsma et al., 2015; World Health Organisation, 2015). Parents, families and direct care support workers understandably have concerns related

to exploitation, abuse and harm (Evans et al., 2009). 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 et al., 2009; Bryne 2017; Whittle & Butler 2018).

The theme, *policies and guidelines to inform practice,* has been identified in this review as an area requiring attention and development. At present there appears to be an absence of organisational policies and guidelines that set out the role and responsibilities of direct care support workers and the scope of their practice in relation to facilitating and enabling adults with ID to express their sexuality (Gilmour & Chambers 2010; Pendani 2016). Direct care support workers are unclear as to how, if and when they can and should enable the adults they support to express their sexuality (Saxe & Flanagan 2014; Saxe & Flanagan 2016). The absence of such 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 et al., 2018; Reid 2018). Evidently, there is an increased 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, LBGT+ 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 (Evans et al., 2009; Gilmour & Chambers 2010; Pownall et al., 2011; Eastgate et al., 2012; Gürol et al., 2014; Overmars-Marx et al., 2014; Saxe & Flanagan 2014; Chadwick et al., 2017; McCann et al., 2016; Pebdani 2016; Brown & McCann 2018; Reid 2018). Adults with ID are sexual beings and many are sexually

active, policies and guidelines should aim to be enabling and facilitative and be embedded in organisational culture and practice, while reflecting the need to protect and safeguard where indicated (Pebdani 2016; Saxe & Flanagan 2016; Baines et al., 2018; Franklin et al., 2018).

4.2 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.* Parents and families understandably have concerns about the potential for their family member with ID to be the subject of abuse and exploitation, including sexual abuse, with significant consequences for the individual (Gürol et al., 2014; Petska & Wendt 2014; Pownall et al., 2016). Parents and 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; Amando et al., 2013; McCann et al., 2016; Brown & McCann 2018; Whittle & Butler 2018). 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 (Evans et al., 2009; Pownal et al., 2011; Ballan 2012; 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 (Northway et al., 2013; Bowen & Swift 2017).

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., 2016). 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 2017; Brown & McCann 2018; Chadwick and Fullwood 2018). With the advent of the internet, social media and use of mobile phones, there is recognition of the positive and constructive role that they can play in the lives of adults with ID. 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 et al., 2013; Caton & Chapman 2013). 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; Biujs et al., 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 et al., 2017).

4.3 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., 2014a; 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 of the hopes and aspiration of adults with ID regarding the expression of their sexuality and how this can best be facilitated (Evans et al., 2009; Gilmour & Chambers 2010; Nichols & Blakely-Smith 2009; Morales et al., 2011; Pownall et al., 2011; Ballan 2012; Evans et al., 2012; Gürol et al., 2014; Rushbrooke et al., 2014b; Saxe & Flanagan 2014; Pebdani 2016; Saxe & Flanagan 2016). 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 (Evans et al., 2009; Gilmour & Chalmers 2010; Pebdani 2016; Saxe & Flanagan 2014; Saxe & Flanagan 2016). Families too, want access to education programmes that builds upon their knowledge and confidence to help them to hold conversations with their family member with ID, and to enable the discussion of personal and sensitive issues and needs that have been found to be effective (Evans et al., 2009; Pownall et al., 2011; Ballan 2012; Kok & Akyuz 2015; Yıldız & Cavkaytar 2017). Central to the development, implementation and evaluation of education and development programmes needs to be the inclusion of adults with ID, which at present appears to be lacking, with a need to be explicit about how the outcomes achieved through such programmes have impacted on the sexual lives of adults with ID (Schaafsma et al., 2015; Schaafsma et al., 2017). Along with the development and implementation of

education programmes, robust evaluation needs to be built in to identify both their effectiveness and the impact on the lives of adults with ID and the support they provide for families and direct care support workers. Without such evaluations, their true impact will remain unknown (Nichols & Blakeley-Smith 2009; Morales et al., 2011; Eastgate et al., 2012; Schaafsma et al., 2015; Pebdani 2016).

4.5 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. From the findings of this review 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 progreammes that do exist. No studied 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. With the increasing number of young people with ID living into adulthood, some with complex care needs, comes the expectation of a society that is inclusive and responsive to their needs. 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.

4.6 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 plan in enabling and inhibiting this expression. This review has identified important areas that require to be addressed from a policy, education and practice perspectives. 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 recognise the potential for subjectivity. To address potential short-comings, recognised frameworks were used consistently throughout.

5. 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. Family members have concerns about abuse and exploitation of their loved one while recognising their right to be sexual and seek and form relationships. Families face challenges in knowing how best to support their family member with ID on their sexual journey and specific supports need to be developed education programmes are one way of meeting their needs and provide a valuable opportunity to bring together families in similar situations to share their experiences and solutions. Organisations involved in the care and support of adults with ID need to ensure that they have in place policies and guidelines that are reflective of and developed in line with the hopes and aspirations

of adults with ID, thereby enabling the full expression of all facets of 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 develop 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

References

Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013) Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities* 51(5), 360-375.

Azzopardi-Lane, C., & Callus, A. M. (2015) Constructing sexual identities: People with intellectual disability talking about sexuality. *British Journal of Learning Disabilities* 43(1), 32-37.

Baines, S., Emerson, E., Robertson, J., & Hatton, C. (2018) Sexual activity and sexual health among young adults with and without mild/moderate intellectual disability. *BMC Public Health 18*(1), 667.

Ballan, M.S. (2012) Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders* 42(5), 676-684.

Barr, E.M., Moore, M.J., Johnson, T., Forrest, J., Jordan, M. (2013) New evidence: data documenting parental support for earlier sexuality education. *Journal of School Health* 84, 10–17.

Bates, C., Terry, L., & Popple, K. (2017) Partner selection for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 30(4), 602-611.

Brown, M. & McCann, E. (2018) Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities* 74, 124-138.

Bowen, E., & Swift, C. (2017) The prevalence and correlates of partner violence used and experienced by adults with intellectual disabilities: a systematic review and call to action. *Trauma, Violence, & Abuse*, 1524838017728707.

Bronfenbrenner, U. (1979) *The Ecology of Human Development*. Cambridge MA: Harvard University Press.

Buijs, P. C., Boot, E., Shugar, A., Fung, W. L. A., & Bassett, A. S. (2017) Internet safety issues for adolescents and adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 30(2), 416-418.

Byrne, G. (2017) Prevalence and psychological sequelae of sexual abuse among individuals with an intellectual disability: A review of the recent literature. *Journal of Intellectual Disabilities*, 1744629517698844.

Caldwell, K., Henshaw, I. & Taylor, G. (2011) Developing a framework for critiquing health research: An early evaluation. *Nurse Education Today* 31(8), 1-7. doi.org/10.1016/j.nedt.2010.11.025

Caton, S., & Chapman, M. (2016) The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual and Developmental Disability* 41(2), 125-139.

Chadwick, D. D., Quinn, S., & Fullwood, C. (2017) Perceptions of the risks and benefits of Internet access and use by people with intellectual disabilities. *British Journal of Learning Disabilities* 45(1), 21-31.

Chadwick, D. D., & Fullwood, C. (2018) An online life like any other: Identity, self-determination, and social networking among adults with intellectual disabilities. *Cyberpsychology, Behavior, and Social Networking* 21(1), 56-64.

Critical Appraisal Skills Programme (2013) *Ten questions to help you make sense of qualitative research.* Oxford: Critical Appraisal Skills Programme.

Eastgate, G., Scheermeyer, E., van Driel, M.L. & Lennox, N. (2012) Intellectual disability, sexuality and sexual abuse prevention: A study of family members and support workers. *Australian Family Physician* 41(3), 135.

Evans, D.S., McGuire, B.E., Healy, E. & Carley, S.N. (2009) Sexuality and personal relationships for people with an intellectual disability. Part II: staff and family carer perspectives. *Journal of Intellectual Disability Research* 53(11), 913-921.

Fulford, C., & Cobigo, V. (2018). Friendships and intimate relationships among people with intellectual disabilities: A thematic synthesis. *Journal of Applied Research in Intellectual Disabilities* 31(1), e18-e35.

Franklin, A., & Smeaton, E. (2018) Listening to young people with learning disabilities who have experienced, or are at risk of, child sexual exploitation in the UK. *Children & Society*, *32*(2), 98-109.

Gardiner, T., Braddon, E. (2009) 'A Right to Know': facilitating a relationship and sexuality programme for adults with intellectual disabilities in Donegal. *British Journal of Learning Disabilities,* 37, 327–329.

Gilmore, L. & Chambers, B. (2010) Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees. *Journal of Intellectual and Developmental Disability* 35(1), 22-28

Gürol, A., Polat, S. & Oran, T. (2014) Views of mothers having children with intellectual disability regarding sexual education: A qualitative study. *Sexuality and Disability* 32(2), 123-133.

Healy, E., McGuire, B. E., Evans, D. S., & Carley, S. N. (2009) Sexuality and personal relationships for people with an intellectual disability. Part I: Service-user perspectives. *Journal of Intellectual Disability Research* 53(11), 905-912.

Holmes, K. M., & O'loughlin, N. (2014). The experiences of people with learning disabilities on social networking sites. *British Journal of Learning Disabilities* 42(1), 1-5.

Institute of Medicine (2011) *The Health of Lesbian, Gay, Bisexual and Transgender People: Building a Foundation for Better Understanding*. Washington DC: National Academies Press.

Kok, G. & Akyuz, A. (2015) Evaluation of effectiveness of parent health education about the sexual developments of adolescents with intellectual disabilities. Sexuality & Disability 33, 157–174.

Mays, N., Pope, C., & Popay, J. (2005) Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research & Policy* 10 (1suppl), 6-20.

McCann, E., Lee, R., & Brown, M. (2016) The experiences and support needs of people with intellectual disabilities who identify as LGBT: A review of the literature. *Research in Developmental Disabilities 57*, 39-53.

McCarthy, J., Cooray, S., Gangadharan, S. K., Tolentino, E., Torales, J., & Ventriglio, A. (2016). Domestic gender inter-personal violence and people with intellectual disability. *International Journal of Culture and Mental Health*, *9*(4), 434-437.

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M. & PRISMA-P Group (2015) Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* 4(1), 1-9.

Morales, G.E., Lopez, E.O. & Mullet, E. (2011) Acceptability of sexual relationships among people with learning disabilities: family and professional caregivers' views in Mexico. *Sexuality and Disability* 29(2), 165-174.

Murphy, G. H., & O'Callaghan, A. L. I. (2004) Capacity of adults with intellectual disabilities to consent to sexual relationships. *Psychological Medicine* 34(7), 1347-1357.

Nichols, S. & Blakeley-Smith, A. (2009) "I'm not sure we're ready for this…": Working with families toward facilitating healthy sexuality for individuals with autism spectrum disorders. *Social Work in Mental Health* 8(1), 72-91.

Northway, R., Bennett, D., Melsome, M., Flood, S., Howarth, J., & Jones, R. (2013) Keeping safe and providing support: a participatory survey about abuse and people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities 10*(3), 236-244.

O'Callaghan, A. C., & Murphy, G. H. (2007) Sexual relationships in adults with intellectual disabilities: Understanding the law. *Journal of Intellectual Disability Research* 51(3), 197-206.

Overmars-Marx, T., Thomése, F., Verdonschot, M., & Meininger, H. (2014) Advancing social inclusion in the neighbourhood for people with an intellectual disability: An exploration of the literature. *Disability & Society* 29(2), 255-274.

Pebdani, R.N. (2016) Attitudes of group home employees towards the sexuality of individuals with intellectual disabilities. *Sexuality and Disability* 34(3), 329-339.

Pestka, K., & Wendt, S. (2014) Belonging: women living with intellectual disabilities and experiences of domestic violence. *Disability & Society*, *29*(7), 1031-1045.

Peter, C.R., Tasker, T.B., & Horn, S.S. (2015) Parents' attitudes toward comprehensive and inclusive sexuality education: beliefs about sexual health topics and forms of curricula. *Health Education* 115, 71–92.

Pownall, J.D., Jahoda, A., Hastings, R. & Kerr, L. (2011) Sexual understanding and development of young people with intellectual disabilities: Mothers' perspectives of within-family context. *American Journal on Intellectual and Developmental Disabilities* 116(3), 205-219.

Reid, J. A. (2018) Sex trafficking of girls with intellectual disabilities: An exploratory mixed methods study. *Sexual Abuse* 30(2), 107-131.

Rushbrooke, E., Murray, C., & Townsend, S. (2014a) The experiences of intimate relationships by people with intellectual disabilities: A qualitative study. *Journal of Applied Research in Intellectual Disabilities* 27(6), 531-541

Rushbrooke, E., Murray, C. D., & Townsend, S. (2014b). What difficulties are experienced by caregivers in relation to the sexuality of people with intellectual disabilities? A qualitative meta-synthesis. *Research in Developmental Disabilities*, *35*(4), 871-886.

Sallafranque-St-Louis, F., & Normand, C. L. (2017). From solitude to solicitation: How people with intellectual disability or autism spectrum disorder use the internet. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, *11*(1).

Sanz, E. C., Gómez-Puerta, J. M., & Moltó, M. C. C. (2017) Internet and people with intellectual disability: Internet and people with an approach to caregivers' concerns, prevention strategies and training needs. *NAER: Journal of New Approaches in Educational Research* 6(2), 153-158.

Saxe, A. & Flanagan, T. (2014) Factors that impact support workers' perceptions of the sexuality of adults with developmental disabilities: A quantitative analysis. *Sexuality and Disability* 32(1), 45-63.

Saxe, A. & Flanagan, T. (2016) Unprepared: An appeal for sex education training for support workers of adults with developmental disabilities. *Sexuality and Disability* 34(4), 443-454.

Schaafsma, D., Stoffelen, J.M., Kok, G., Curfs, L.M. (2013) Exploring the development of existing sex education programmes for people with intellectual disabilities: An intervention mapping approach. *Journal of Applied Research in Intellectual Disabilities* 26, 157–166.

Schaafsma, D., Kok, G., Stoffelen, J. M., & Curfs, L. M. (2015) Identifying effective methods for teaching sex education to individuals with intellectual disabilities: A systematic review. *Journal of Sex Research* 52(4), 412-432.

Schaafsma, D., Kok, G., Stoffelen, J. M. T., & Curfs, L. M. G. (2017) People with intellectual disabilities talk about sexuality: Implications for the development of sex education. *Sexuality and Disability* 35(1), 21-38.

Simplican, S.C., Leader, G., Kosciulek, J. & Leahy, M. (2015) Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities* 38, 18-29.

Sinclair, J., Unruh, D., Lindstrom, L., & Scanlon, D. (2015) Barriers to sexuality for individuals with intellectual and developmental disabilities: A literature review. *Education and Training in Autism and Developmental Disabilities*, 3-16.

Thompson, V. R., Stancliffe, R. J., Broom, A., & Wilson, N. J. (2014) Barriers to sexual health provision for people with intellectual disability: A disability service provider and clinician perspective. *Journal of Intellectual and Developmental Disability* 39(2), 137-146.

Truesdale M. & Brown M. (2017) *People with Learning Disabilities: 2017 Health Needs Assessment Update Report.* Glasgow: NHS Health Scotland.

Turner, G. W., & Crane, B. (2016) Pleasure is paramount: Adults with intellectual disabilities discuss sensuality and intimacy. *Sexualities* 19(5-6), 677-697.

van der Meer, L., Nieboer, A.P., Finkenflügel, H. and Cramm, J.M. (2018) The importance of person-centred care and co-creation of care for the well-being and job satisfaction of professionals working with people with intellectual disabilities. *Scandinavian Journal of Caring Sciences* 32(1), 76-81.

Vanegas, S. B., & Abdelrahim, R. (2016) Characterizing the systems of support for families of children with disabilities: A review of the literature. *Journal of Family Social Work* 19(4), 286-327.

Ward, K. M., Atkinson, J. P., Smith, C. A., & Windsor, R. (2013) A friendships and dating program for adults with intellectual and developmental disabilities: A formative evaluation. *Intellectual and Developmental Disabilities* 51(1), 22-32.

Whittle, C., & Butler, C. (2018) Sexuality in the lives of people with intellectual disabilities: A meta-ethnographic synthesis of qualitative studies. *Research in Developmental Disabilities* 75, 68-81.

Wilkinson, V. J., Theodore, K., & Raczka, R. (2015) 'As normal as possible': Sexual identity development in people with intellectual disabilities transitioning to adulthood. *Sexuality and Disability* 33(1), 93-105.

Winges-Yanez, N. (2014). Why all the talk about sex? An authoethnography identifying the troubling discourse of sexuality and intellectual disability. *Sexuality and Disability* 32(1), 107-116.

World Health Organisation (2010) *Developing Sexual Health Programmes: A Framework for Action*. Geneva: WHO

World Health Organisation (2013) *Addressing the causes of disparities in health service access and utilization for lesbian, gay, bisexual and trans (LGBT) persons*. Geneva: WHO.

World Health Organisation (2015) *Sexual Health, Human Rights and the Law*. Geneva: WHO.

Yıldız, G., & Cavkaytar, A. (2017) Effectiveness of a sexual education program for mothers of young adults with intellectual disabilities on mothers' attitudes toward sexual education and the perception of social support. *Sexuality and Disability* 35(1), 3-19.

Figure 1: PRISMA flowchart of systematic review process
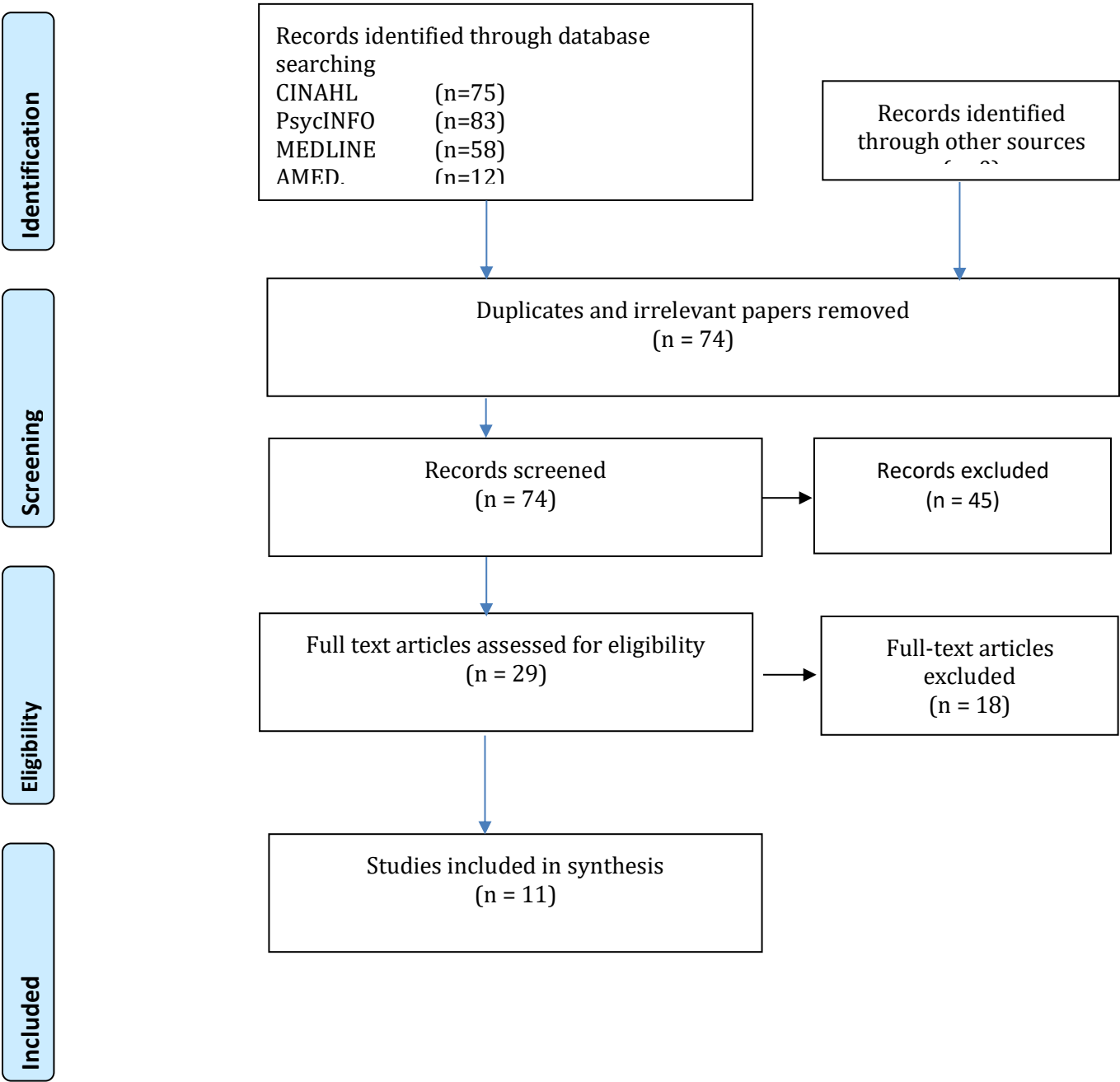
Table 1: PsycINFO search strategy and results example

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

Table 2: CASP quality scores

CASP criteria	Ballan, M. (2012)	Eastgate et al. (2012)	Evans et al. (2009)	Gilmore & Chambers (2010)	Gürol et al. (2014)	Morales et al. (2011)	Nichols & 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.	*Interviews:* Family members (n=7) Support workers (n=3) *Focus groups:* 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	Need to provide opportunities for staff and family carers to discuss sexuality issues and a need for training in the area of sexuality.	15

				workers likely to support intimate and non-intimate relationships.		
Gilmore 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	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	More community education resources required. Education programme needs to be longer. More rigorous evaluation needed – pre, end of course and follow-up.	17

	an education programme			getting support and guidance from other families.		
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.	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	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.	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.	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	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