



City Research Online

City, University of London Institutional Repository

Citation: McCann, E., Marsh, L. & Brown, M. (2019). People with intellectual disabilities, relationship and sex education programmes: A systematic review. *Health Education Journal*, 78(8), pp. 885-900. doi: 10.1177/0017896919856047

This is the accepted version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/27895/>

Link to published version: <https://doi.org/10.1177/0017896919856047>

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

**People with intellectual disabilities, relationship and sex education programmes:
a systematic review**

Edward McCann^a; Lynne Marsh^b; Michael Brown^b

- a. School of Nursing and Midwifery, Trinity College Dublin, Republic of Ireland
- b. School of Nursing and Midwifery, Queen's University, Belfast, Northern Ireland

Corresponding author:

Dr Edward McCann
Trinity College Dublin
School of Nursing and Midwifery
Dublin D2
Ireland

Email: mccanned@tcd.ie

ORCHID: 0000-0003-3548-4204

Twitter: [@EddieMcCann](https://twitter.com/EddieMcCann)

People with intellectual disabilities, relationship and sex education programmes: a systematic review

ABSTRACT

Objective: The aim of this systematic review was to examine the research evidence concerning the views and experiences of people with ID regarding their participation in and the effectiveness of RSE programmes.

Methods: A systematic search of relevant electronic databases was conducted using defined inclusion criteria. All papers reviewed were from October 1998 to October 2018. The PRISMA guidelines were followed in the design and reporting of the systematic review.

Results: A total of eight studies published in English were included in the review. Data were analysed and the key themes identified were (i) designing and developing RSE programmes (ii) participating in RSE programmes (iii) perceived benefits of RSE programme participation.

Conclusion: This review has identified that people with ID are accessing RSE programmes and appear to find them helpful. Further research is required to investigate the extent to which programmes impact on long-term behaviour change that enables the development of sustainable relationships and reduces the unintended consequences of sexual activities. Implications for policy, practice and future research developments are discussed.

Keywords: Relationships, sexuality, intellectual disabilities, education, programmes

Introduction

Sexuality is a fundamental part of being human and takes multiple and diverse forms. The World Health Organization has conceptualized sexuality as:

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

Arising from this position, there is a global interest in ensuring equality of access to appropriate healthcare and health education for all (Australian Human Rights Commission, 2014; Department of Health, 2013; Ontario Human Rights Commission, 2014), and for specific groups with distinct needs such as young people, people with mental health issues and people with intellectual disabilities (Sun et al., 2018; Whittle & Butler, 2018; McCann et al., 2019). In terms of evidence-based research, there is a growing body of literature regarding the general youth population investigating sexual health improvement and prevention concerns such as HIV, STIs, pregnancy and early childbearing (Henderson et al., 2007; Oringanje et al., 2009; Bailey et al., 2010; Shepherd et al., 2010). Influenced by the wider research evidence and social concerns, there is an increased attention and recognition of the need for structured evidence-based relationship and sexuality education (RSE) programmes. It is routine practice for RSE programmes to be delivered directly to youth within school settings as an integral part of the mainstream education curriculum (Lohan et al., 2018). In this regard, the factors that make RSE programmes effective, acceptable, sustainable and implementable have been explored (Pound et al., 2017). A key aim of RSE programmes is:

To embrace the challenges of creating a happy and successful adult life, pupils need knowledge that will enable them to make informed decisions about their wellbeing, health and relationships and to build their self-efficacy. Pupils can also put this knowledge into practice as they develop capacity to make sound decisions when facing risks, challenges and complex contexts. Everyone faces difficult situations in their lives. These subjects can support young people to develop resilience, to know how and when to ask for help, and to know where to access support. (Department of Education, 2018 p6).

In some countries, governments have established policies to support the relationship and sexuality education needs of young people with a clear focus on the implementation of RSE programmes within mainstream schools (Department of Education, 2018). More recently, Scotland has gone further to become the first country in the world to embed the teaching of lesbian, gay, bisexual, transgender and intersex (LGBTI) rights in the school curriculum (Scottish Government, 2018). Similarly, there have been significant developments and improvements in the lives of people with ID in recent decades. These changes have seen a move away from

institutional models of education and care to more inclusive supports within the community. Part of these intentions have been to enable people with ID to have more autonomy and control over their lives and the decisions that they make (Department of Health, 2009; Scottish Government, 2013). These decisions must also include those related to the expression of their sexuality and all that this entails.

Existing literature recognises the rights of people with intellectual disabilities (ID) to have fulfilling lives and make independent life choices (Family Planning Association, 2006; Curryer et al., 2015). People with ID want friendships, meaningful relationships and some may want intimacy (Brown and McCann, 2018). However, the expression of sexuality is an area where potential freedoms are often limited, compared to the non-ID population (Jahoda and Pownall, 2014). Additionally, people with ID are often misperceived as being either asexual, hypersexual or sexually immature (Conder et al., 2015). Studies have highlighted the potential conflicts that exist between autonomy versus vulnerability, exploitation and risk of harm, acknowledging that supportive interventions can help to address some of the concerns (Fisher et al., 2016). Parents and families of people with ID and education, health and social care practitioners recognise that many people with ID are interested in and engage in sex. However, people with ID often possess less knowledge about sexuality, display more inappropriate sexual behaviours and may not understand the consequences of engaging in unprotected sex (Ballan, 2012).

Young people with ID are more likely to practice unsafe sex and are at an increased risk of sexual abuse and exploitation (McDaniel and Fleming, 2016). They are less likely to use contraception, have an increased risk of unintended pregnancy, and a greater exposure to HIV and STIs, compared to the non-ID population (Jahoda and Pownall, 2014). They may also have difficulties in forming and maintaining healthy relationships due to limited communication skills, loneliness, social isolation and low self-esteem (Baines et al., 2018). There is well established evidence that indicates that people with ID are further at risk of developing mental health conditions such as anxiety, depression and PTSD (Public Health England, 2016). While some RSE programmes have been developed for people with ID to address these concerns, they appear to focus on knowledge acquisition regarding the biology of sex, risky sexual behaviours and capacity and consent, lacking a wider focus on relationships, intimacy, informed choice and decision making (Baines et al., 2018). Further, it is well recognised that people with ID experience barriers to accessing health care,

health prevention programmes and health education that it relevant and appropriate to their particular needs (Truesdale and Brown, 2017). While there is evidence of RSE programme delivery specific to the needs of people with ID and their families and carers, it remains to be established if the programmes are accessible, acceptable and outcome-focused. Therefore, the purpose of this review was to identify the views and experiences of people with ID regarding their participation in RSE programmes and how they perceive their effectiveness. It will also highlight issues that address future policy, practice and research and provide recommendations for future RSE programme developments.

Methods

Review questions:

1. What are the views and experiences of people with ID regarding their participation in RSE programmes?
2. What is the perceived benefits of RSE programmes from the perspective of people with ID?

Search strategy

A subject Librarian assisted with the literature searching. The databases searched were PsycINFO, CINAHL, MEDLINE, and Sociological Abstracts. An example of the search strategy used in one electronic database is shown in Table 1.

Insert Table 1 here

The data were published from October 1998 to October 2018 and was limited to academic peer reviewed research papers written in English. This review considered studies that utilised qualitative, quantitative and mixed methods approaches. The PRISMA guidelines were followed in the design and reporting of the systematic review and a flow chart is provided (Figure 1) that contains the results of the searches (Moher et al. 2015).

Insert Figure 1 here

Inclusion criteria

Included studies had to explicitly address the views and experiences of people with ID and their participation in RSE programmes. The settings included schools and health and social care services. Studies that did not focus specifically on the views and experiences of people with ID were excluded.

Study selection and data extraction

Following the removal of duplicate papers, two reviewers (EM and LM) screened the titles and abstracts based on the inclusion criteria. Full text papers were retrieved and screened independently by the same reviewers. Any disagreements were resolved by critical discussion.

Quality assessment

Two reviewers (EM and LM) appraised the included papers for methodological quality. An internationally recognized and widely used critical appraisal tool was selected from a range of possible options to assess the quality of the selected papers (Critical Appraisal Skills Programme, 2018). A total of ten questions were applied to the data (Table 2). Each item was rated as ‘yes,’ ‘no,’ and ‘can’t tell.’ A ‘yes’ response indicated that a clear statement appeared in the paper that directly answered the question. ‘No’, indicated that the question was answered negatively in the paper, and ‘Can’t tell’, indicated that there was no clear statement relating to the question. There was a high amount of ‘yes’ responses across most of the papers for a significant number of questions indicating good quality overall. Question number 6 had particularly low ratings involving the consideration of research relationships. Any disagreements were discussed with a third reviewer (MB) and consensus reached. All of the studies addressed the objectives of the review and were therefore deemed suitable for inclusion.

***Insert Table 2 here ***

Characteristics of the studies

The data were extracted by two of the reviewers (EM and MB) and verified by a third reviewer (LM). The eight papers that addressed the systematic review aims are presented in Table 3. Most studies (n=3) were conducted in Australia. The remainder were carried out in Ireland (n=2), Sweden (n=1), United Kingdom (UK) (n=1) and the United States (US) (n=1). Sample sizes ranged from 4 to 5,070 study participants involving young people and adults with ID. A selection of data collection methods was used in the studies including survey, questionnaires and interviews. A total of three studies were quantitative, adopting a range of measures and survey approaches, four studies used qualitative approaches including interviews or focus groups, and one paper utilized a mixed method design.

***Insert Table 3 here ***

Data synthesis and analysis

In conducting the systematic review, suitable methods for synthesising mixed literature sources were applied (Mays et al., 2005). A detailed and comprehensive thematic analysis of the data was undertaken. All of the emergent themes were systematically identified across the studies and coded by EM and MB, with further verification provided by LM. The themes were grouped into concepts to allow for contrasts and comparisons to be made between themes and studies. The research team (EM, LM, MB) discussed, verified and agreed the final themes (Caldwell et al., 2011).

Results

Following the systematic analysis of the studies, three key themes were identified: (i) designing and developing RSE programmes (ii) participating in RSE programmes (iii) perceived benefits of RSE programme participation.

Designing and developing RSE programmes

Any planned RSE programme developments need to ensure that young people and adults with ID are fully involved in programme content to reflect their particular learning requirements (Dukes and McGuire, 2009). The concept of co-production should be at the core of all RSE programme design and developments to ensure the needs and concerns of people with ID are integrated and accurately reflected (Frawley

and Bigby, 2014). This is viewed as important as concerns have been expressed that people with ID have not been fully involved in the development of the existing RSE programmes. This was regarded as a limitation, given the emphasis on the assurance that RSE programmes are ‘fully responsive to their needs and concerns’ (Gardiner and Braddon, 2009; Frawley and Wilson, 2016). Furthermore, peer educators, where people with ID educate and support other people with ID, was suggested as a possible useful educational approach. The findings from one study suggested that peer educators may be beneficial in facilitating the acquisition of new knowledge about forming and maintaining relationships, developing relationship skills and facilitating access to networks and community resources. It was also suggested that the role of peer educator benefited the individual by developing their own knowledge and increasing their confidence and self-esteem (Fawley and Bigby, 2014). For the effective development of RSE programme content, it was highlighted that a collaboration involving young people with ID, health professionals and special education teachers was seen as necessary (Barnard-Brak et al., 2014). Therefore, RSE programme content development needs to be based on the identification and inclusion of shared learning needs, including lesbian, gay, bisexual and transgender (LGBT) issues and concerns (Dukes and McGuire 2009; Löfgren-Mårtenson, 2012). There is also a need to ensure that RSE programmes enable participants to recognize and critically question the prevailing sexuality and gender norms and assumptions that exist. Furthermore, there is a tendency for current RSE programme content to focus on concerns regarding ‘risky sexual behaviours’ to the exclusion of other aspects such as pleasure, desire and intimacy (Löfgren-Mårtenson, 2012).

Participating in RSE programmes

Several of the study findings suggest that RSE programmes were valuable to the participating young people and adults with ID (Dukes and McGuire, 2009; Frawley and Wilson, 2016; Finlay et al., 2015; Gardiner and Braddon, 2009; Garwood and McCabe, 2000; Löfgren-Mårtenson, 2012). One study indicated that the increasing severity of ID may influence whether individuals were included or participated in RSE programmes (Barnard-Brak et al., 2014). However, concerns regarding implementation and delivery of RSE programmes were related to a lack of prior knowledge and understanding of relationship and sex issues as well as limitations related to effective communication (Gardiner and Braddon, 2009; Löfgren-

Mårtenson, 2012; Finlay et al., 2015; Frawley and Wilson, 2016). For some participants, undertaking RSE programmes was made more challenging by the use of long sentences and abstract concepts which resulted in some participants remaining unclear, thereby reducing benefits. The apparent confusion detracted from the individuals understanding of already complex and sensitive topics (Finlay et al., 2015). It is evident that expressing sexuality and talking about it was considerably difficult for some study participants and this situation further compounded their limited understanding of relationship and sexual knowledge (Garwood and McCabe 2000; Finlay et al., 2015; Frawley and Wilson 2016). As a consequence of participants limited knowledge and access to information regarding relationships and sex, there was a natural curiosity to know more about the issues (Frawley and Wilson 2016). Another concern identified as impacting on RSE programme delivery was the lack of a clear theoretical framework with an absence of measurable outcomes and improvement in knowledge and application (Garwood and McCabe 2000). It was noted in one study that there was a particular focus on 'risky sexual behaviours' rather than the potential for positive and meaningful relationships (Löfgren-Mårtenson, 2012).

Perceived benefits of RSE programme participation

A recurring theme for young people and adults with ID, following the evaluation, related to the positive benefits and willingness to take part in the RSE programmes (Garwood and McCabe, 2000; Dukes and McGuire, 2009; Gardiner and Braddon, 2009). People with ID enjoyed the opportunity to meet with others to share and learn from each other. Wider benefits to participation from the perspective of people with ID, were improvements in self-esteem, positive feelings about sexual experiences and improved knowledge of sexuality issues (Garwood and McCabe 2000; Gardiner and Braddon, 2009). Additional benefits were also identified with further positive outcomes identified for some by way of improved decision-making capacity. The improvements in decision-making related to consent to sexual relations and the right to decline. Participants also reported improvements in sexual knowledge and the importance of personal safety practices (Dukes and McGuire, 2009).

Discussion

The aim of this systematic review was to ascertain the views and experiences and perceived benefits of participating in RSE programmes. The findings highlight wider areas requiring attention and development to more fully meet the relationship and sexuality need of people with ID. Implications for policy, practice, and future research developments are discussed. From the systematic review and critical appraisal of the literature, it is apparent that there are difficult and complex issues that need to be addressed, with many people with ID continuing to lack essential knowledge and understanding to make informed decisions regarding meeting their relationship and sexuality needs (Gardiner and Braddon, 2009; Frawley and Wilson, 2016). It is important to recognize that a diverse range of attitudes and values already exist regarding relationships and the expression of sexuality by people with ID, their families and practitioners and within wider society (Hall, 2010; Brown and McCann, 2019). These may include paternalistic behaviours, heteronormativity, prejudice and discrimination. Compounding this position is the prevailing views that people with ID are either asexual or hypersexual (Yau et al., 2009). Therefore, RSE programmes need to focus on challenging established gender, relationship and sexuality norms and assumptions (Löfgren-Mårtenson, 2012). The reality, from the perspective of people with ID, is that most simply seek or desire friendships, relationships and intimacy, with some being or wishing to be sexually active (Brown and McCann, 2018; Whittle and Butler, 2018).

From a policy perspective, it is necessary to ensure that all children and adults with ID are able to access education regarding relationships and sexuality. In some areas, RSE programmes have been developed that are specific to the needs of people with ID. However, the issues of sexuality and its expression and the supports required must be more comprehensively and systematically reflected and integrated as a core element of education and health and social care policy (Baines et al., 2018; Barnard-Brak et al., 2014). Therefore, structured evidence-based RSE programmes need to be a visible component of all education, health and social care policy initiatives, then embedded within the education curriculum in schools as a key starting point (Pound et al., 2017). Relevant policies also need to ensure that to maximise ongoing impact and effectiveness, RSE programme delivery is extended into adulthood as part of comprehensive service provision (Frawley and Wilson, 2016). This is necessary, given the clear evidence that people with ID are often socially isolated, lacking

friendships and social networks and vulnerable to potential exploitation and harm (Gilmore and Cuskelly, 2014). Policy implementation therefore has the potential to influence the opportunities for people with ID to form meaningful friendships and relationships. Without such opportunities, many will continue to remain unfulfilled in terms of their future relationship hopes and aspirations (Schaafsma et al., 2013).

There is a need to develop RSE programmes that integrates both the relationship and sexuality aspirations of the individual with ID by providing knowledge, information and creating networks of support (Dukes and McGuire, 2009; Barnard-Brak et al., 2014; Frawley and Bigby, 2014). People with ID usually live in the family home or in supported living settings, often requiring services and supports from education, health and social care services. However, evidence demonstrates that care and support can often be restrictive rather than facilitative (Gardiner and Braddon, 2009). There is a need therefore for practitioners within services and agencies to be self-aware and prepared to challenge prevailing attitudes, assumptions and stereotypes. This is necessary to support them to fully meet the relationship and sexuality needs of people with ID while also addressing the concerns of parents and families (Brown and McCann 2019). Therefore, their practice needs to be informed by anti-discriminatory, inclusive, person-centred approaches (Department of Health, 2009; Scottish Government, 2013). Families are often concerned about the risk of personal safety, abuse, exploitation and harm of their family member with ID, further supporting, not diminishing, the need for education and support. The concerns, however, can lead to over-protection and sometimes excessive control that may inadvertently further limit life opportunities for the person with ID. An essential element of professional practice therefore needs to address concerns regarding protection, safeguarding and capacity to consent to sexual relationships and the positive benefits of participating in RSE programmes (Goli et al., 2018). This is necessary as practitioners delivering RSE programmes need to respond to the potentially conflicting tension between the need to protect versus freedom of choice and the right to self-determination (Fisher et al., 2016).

From a practice perspective, practitioners across services and agencies need to be aware that some people with ID will require additional time, resources and support to enable their individual relationship and sexuality needs to be comprehensively and accurately addressed (Finlay et al., 2015). By responding to these issues, RSE programme content and delivery should be co-produced and person-centred, thereby

aiming to situate people with ID at the centre of the process (Frawley and Bigby, 2014). Additionally, practitioners within their day-to-day roles, need to recognise the relationship and sexuality aspirations of people with ID and respond effectively to their education and information needs (Frawley and Wilson 2016). For this to become a reality, it may be necessary for collaborative working between agencies and organisations such as schools, care organisations, day care providers, sexual health services and specialist intellectual disability health services (Dukes and McGuire 2009; Barnard-Brak 2014; Baines et al., 2018). Therefore, as part of the service models within schools and day service provision, RSE programmes need to be provided for children, young people and adults with ID by practitioners with the knowledge, skills and confidence to facilitate effective delivery (Garwood and McCabe 2000; Hanass-Hancock et al., 2018). To address these issues there are opportunities for professional education and continuing professional development (CPD) programmes to integrate relationship and sexuality issues as a core element of the curriculum and staff development and the role of RSE programmes (McCann and Brown, 2018).

It is clear that some people with ID are sexually active and some wish to be. People with ID want access to more information that will enable them to make decisions regarding forming and maintaining relationships and sexual intimacy. Participation in RSE programmes can have positive benefits for people with ID including improved decision making, sexual knowledge and safety, self-esteem and rights and responsibilities (Dukes and McGuire, 2009; Gardiner and Braddon, 2009; Garwood and McCabe 2000). This is important, as evidence already exists demonstrating the barriers to accessing appropriate information and healthcare (Whittle and Butler, 2018). Given that concerns regarding HIV, STIs, unintended pregnancies and family planning, these are critical areas that need to be responded to if this population is not to be further disadvantaged. Therefore, there is an opportunity for RSE programmes that fully address sexual health concerns, in a way that is accessible and sensitive to the distinct needs of people with ID. RSE programmes therefore need to promote autonomy and informed decision making and also effectively challenge paternalism, stigma and discrimination, if supporting fulfilling relationships and promoting fully the expression of sexuality to be realized (McCann et al., 2016).

Future research directions

This systematic review presents an analysis and synthesis of the existing research evidence presenting the subjective views and experiences of people with ID regarding their participation in RSE programmes. The studies included in this review were undertaken using different research methods including qualitative designs, utilising focus groups and individual interviews. The other studies used quantitative designs, utilising questionnaire and survey methods. One study used a mixed method design. There were no controlled trials or intervention outcome studies. There was no multi-centre, international or longitudinal studies examining the impact and outcome of participating in an RSE programmes. Therefore, it is not possible to determine the extent to which knowledge acquisition has influenced long-term behaviour change, for example, by the establishment of relationships and a reduction in HIV, STIs and unintended pregnancies. Consequently, future research priorities in this area should focus on systematically identifying and evaluating existing RSE programmes to determine a range of key factors including the underpinning theoretical models, programme structure, content and qualitative and quantitative outcome measures (Pound et al., 2017). This is necessary to be able to clearly establish what constitutes the ‘gold standard’ and the long-term effectiveness of RSE programmes for people with ID. There is also scope to undertake research studies that are multi-centred to enable larger samples with a national, international and transcultural focus. By addressing these issues, it will be possible to confirm the effectiveness of a theoretically driven, structured RSE programme that is specific to the distinct needs of people with ID and their families and carers.

Strengths and limitations of the review

This review has identified that people with ID are accessing RSE programmes and appear to find them helpful, however, further research is required to investigate the extent to which they impact long-term behaviour change that enables the development of sustainable relationships and reduces the unintended consequences of being sexually active. Further limitations exist due to the quality of some of the study designs and small sample sizes thereby impacting on the ability to apply the findings more widely.

Conclusion

There is well established evidence that some people with ID have limited knowledge and skills regarding relationships and sexuality issues. This impacts upon an individual's ability to establish or maintain relationships and to access the necessary social networks and supports, potentially leading to social isolation and loneliness. People with ID can experience health concerns such as sexually transmitted infections and other unintended consequences in keeping with the non-ID population. From the available evidence, RSE programmes appear to be useful and acceptable to people with ID. Furthermore, parents and families play an important part in the lives of their family member with ID, and they too have education and support needs that may enhance their understanding and response to their family members expression of sexuality. If the expression of a person's sexuality is a basic human right for all, any RSE programme needs to be consistently and comprehensively designed, developed and delivered in partnership with people with ID and their parents and families. Further research is required to determine content, accessibility and acceptability and the benefits and long-term outcomes of RSE programmes on the lives of people with ID.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

References

- Australian Human Rights Commission (2014) *Face the Facts: Lesbian, gay, bisexual, transgender and intersex people*. Sydney: Australian Human Rights Commission.
- Bailey JV, Murray E, Rait G, et al. (2010) Interactive computer-based interventions for sexual health promotion. *Cochrane Database of Systematic Reviews* 8;(9):CD006483. doi: 10.1002/14651858.CD006483.pub2.
- Baines S, Emerson E, Robertson J, et al. (2018) Sexual activity and sexual health among adults with and without mild/moderate intellectual disability. *BMC Public Health*, 18:667
- Ballan M (2012) Parental Perspectives of Communication about Sexuality in Families of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 42, 676–684.

Barnard-Brak L, Schmidt M, Chesnut, S, et al. (2014) Predictors of access to sex education for children with intellectual disabilities in public schools. *Mental Retardation* 52(2), 85-97.

Brown M and 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.

Brown M and McCann E (2019). 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. *Research in Developmental Disabilities* 90, 80-91.

Caldwell K, Henshaw I and Taylor G (2011) Developing a framework for critiquing health research: An early evaluation. *Nurse Education Today* 31(8), 1-7.

Conder JA, Mirfin Veitch BF and Gates S (2015) Risk and Resilience Factors in the Mental Health and Well-Being of Women with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities* 28(6), 572-583.

Critical Appraisal Skills Programme (2018) CASP Qualitative Checklist. Available at: <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf> Accessed: 15 March 2019

Department of Education (2018) *Relationships Education, Relationships and Sex Education (RSE) and Health Education: Guidance for governing bodies, proprietors, head teachers, principals, senior leadership teams, teachers*. London: HMSO.

Department of Health (2009) *Valuing People Now: The Delivery Plan: Making it happen for everyone*. London: HMSO.

Department of Health (2013) *Healthy Ireland: A framework for improved health and well-being 2013-2025*. Dublin: Department of Health.

Dukes E and McGuire B E (2009) Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research*, 53(8), 727-734.

Family Planning Association (2006) *Out of the shadows: A report of the sexual health and well-being of people with learning disabilities in Northern Ireland*. London: Family Planning Association.

Finlay W M L, Rohleder P, Taylor N, et al. (2015) 'Understanding' as a practical issue in sexual health education for people with intellectual disabilities: A study using two qualitative methods. *Health Psychology*, 34(4), 328.

Fisher MH, Baird JV, Currey AD, et al. (2016) Victimisation and Social Vulnerability of Adults with Intellectual Disability: A Review of Research Extending beyond Wilson and Brewer. *Australian Psychologist*, 51(2), 114-127.

Frawley P and Bigby C (2014) “I’m in their shoes”: Experiences of peer educators in sexuality and relationship education. *Journal of Intellectual and Developmental Disability*, 39(2), 167-176.

Frawley P and Wilson NJ (2016) Young people with intellectual disability talking about sexuality education and information. *Sexuality and Disability*, 34(4), 469-484.

Gardiner T and 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(4), 327-329.

Garwood M and McCabe MP (2000) Impact of sex education programs on sexual knowledge and feelings of men with a mild intellectual disability. *Education and Training in Mental Retardation and Developmental Disabilities*, 269-283.

Gilmore L & Cuskelly M (2014) Vulnerability to loneliness in people with intellectual disability: an explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192-199.

Goli S, Noroozi M and Salehi M (2018) A comprehensive sexual health care program for educable intellectually disabled adolescent girls: protocol for a mixed methods study. *Reproductive Health*, 15(1), 141.

Hall E (2010) Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research* 54 (Suppl. 1), 48-57.

Hanass-Hancock J, Nene S, Johns R, et al. (2018) The Impact of Contextual Factors on Comprehensive Sexuality Education for Learners with Intellectual Disabilities in South Africa. *Sexuality and Disability*, 36(2), 123-140.

Henderson M, Wight D, Raab G, et al. (2007) Impact of a theoretically based sex education programme (SHARE) delivered by teachers on NHS registered conceptions and terminations: final results of cluster randomised trial. *BMJ*;334(7585):133.

Jahoda A and Pownall J (2014) Sexual understanding, sources of information and social networks; the reports of young people with intellectual disabilities and their non-disabled peers. *Journal of Intellectual Disability Research* 58(5):430-441.

Löfgren-Mårtenson L (2012) “I want to do it right!” A pilot study of Swedish sex education and young people with intellectual disabilities. *Sexuality and Disability*, 30(2), 209-225.

Lohan M, Aventin Á, Clarke M, et al. (2018) JACK trial protocol: a phase III multicentre cluster randomised controlled trial of a school-based relationship and sexuality education intervention focusing on young male perspectives. *BMJ Open* 8(7): e022128.

- Mays N, Pope C and 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 and 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.
- McCann E and Brown M (2018) The inclusion of LGBT+ health issues within undergraduate healthcare education and professional training programmes: A systematic review. *Nurse Education Today* 24:204-214.
- McCann E, Donohue G, De Jager J, et al. (2019) Sexuality and intimacy issues among people with serious mental illness: a systematic review of qualitative research. *JBIM Database of Systematic Reviews and Implementation Reports* 17(1), 74-125.
- Mc Daniels B and Fleming A (2016) Sexuality Education and Intellectual Disability: Time to Address the Challenge. *Sexuality and Disability* 34:215–225.
- Moher D, Shamseer L, Clarke M, et al. (2015) Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* 4(1), 1-9.
- Ontario Human Rights Commission (2014) *Policy on Preventing Discrimination Because of Gender Identity or Gender Expression*. Ontario Human Rights Commission, Ontario.
- Oringanje C, Meremikwu MM, Eko H, et al. (2009) Interventions for preventing unintended pregnancies among adolescents. *Cochrane Database of Systematic Reviews* 4:D005215.
- Pound P, Denford S, Shucksmith J, et al. (2017) What is best practice in sex and relationship education? A synthesis of evidence, including stakeholders' views. *BMJ open*, 7(5), p.e014791.
- Public Health England (2016) People with learning disabilities in England: Main report 2015 [Retrieved from http://www.improvinghealthandlives.org.uk/securefiles/170407_1640/PWLDIE%202015%20final.pdf].
- Schaafsma D, Stoffelen JM, Kok G, et al. (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(2), 157-166.
- Scottish Government (2013) *Keys to life: Improving quality of life for people with learning disabilities*. Edinburgh: The Stationery Office.
- Scottish Government (2018) *LGBTI Inclusive Education Working Group: Report to the Scottish Ministers*. Edinburgh: The Stationery Office.

Shepherd J, Kavanagh J, Picot J, et al. (2010) The effectiveness and cost-effectiveness of behavioural interventions for the prevention of sexually transmitted infections in young people aged 13-19: a systematic review and economic evaluation. *Health Technology Assessment* 14(7):1-230.

Sun WH, Miu HYH, Wong CKH, et al. (2018) Assessing participation and effectiveness of the peer-led approach in youth sexual health education: systematic review and meta-analysis in more developed countries. *The Journal of Sex Research*, 55(1), 31-44.

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

Whittle C and 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.

World Health Organization (2013) *Addressing the Causes of Disparities in Health Service Access and Utilization for Lesbian, Gay, Bisexual and Transgender (LGBTQ) Persons*. Geneva: World Health Organisation.

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

Yau MKS, Ng GSM, Lau DYK, et al. (2009) Exploring sexuality and sexual concerns of adult persons with intellectual disability in a cultural context. *The British Journal of Development Disabilities*, 55(109), 97-108.

Figure 1: PRISMA Flow Diagram with search results

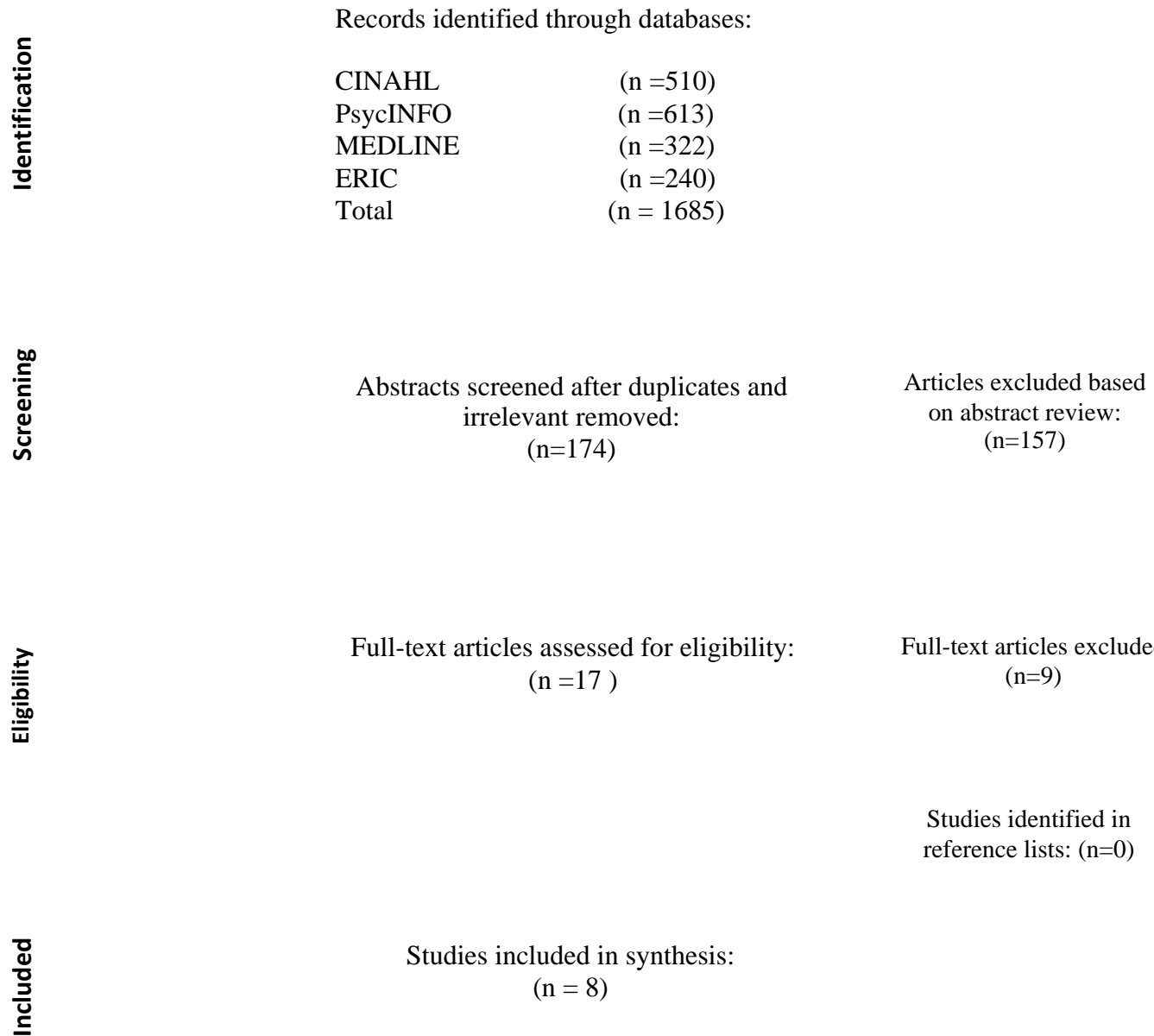


Table 2: CINAHL search strategy and results

Search code	Query	Results
S1	intellectual disab*	20,552
S2	mental retard*	2,877
S3	mental handicap	468
S4	developmental disab*	9,798
S5	learning disab*	7,691
S6	intervention	331,863
S7	education	556,834
S8	training	164,554
S9	program*	403,294
S10	sexual behaviour	10,089
S11	sexual*	85,009
S12	intimacy	2,942
S13	relationship* or love	278,135
S14	friendship*	5,825
S15	S1 OR S2 OR S3 OR S4 OR S5	34,182
S16	S6 OR S7 OR S8 OR S9	1,138,085
S17	S10 OR S11 OR S12 OR S13 OR S14	355,044
S18	S15 AND S16 AND S17	1,205
S19	Limiters: Years 1998-2018; academic journals; English language	510

Table 3: Papers included in the review (n=8)**Table 2: CASP quality scores**

CASP criteria	Barnard-Brak et al. (2014)	Dukes & McGuire (2009)	Finlay et al. (2015)	Frawley & Bigby (2014)	Frawley and Wilson (2016)	Gardiner & Braddon (2009)	Garwood & McCabe (2000)	Löfgren-Mårtenson (2012)
1. Clear statement of aims	Y	Y	Y	Y	Y	CT	Y	Y
2. Appropriate methodology	Y	Y	Y	Y	Y	Y	Y	Y
3. Appropriate research design	Y	Y	Y	Y	Y	N	Y	Y
4. Appropriate recruitment strategy	Y	CT	Y	N	Y	Y	Y	Y
5. Appropriate data collection methods	Y	Y	Y	Y	Y	CT	Y	Y
6. Research relationships considered	N	N	CT	CT	N	N	N	CT
7. Consider ethical issues	N	Y	Y	Y	Y	N	Y	Y
8. Rigorous analysis	Y	Y	Y	Y	Y	CT	CT	Y
9. Clear findings	Y	Y	Y	Y	Y	CT	CT	Y
10. Value of the research	Y	Y	Y	Y	Y	Y	CT	Y

Y: Yes; N: No; CT: Can't tell

Study Citation, country & setting	Aims	Sample	Study setting	Data collection method	Key Findings	Recommendations
Barnard-Brak et al. (2014) USA	Identify factors influencing the delivery of sex education to students with ID	5,070 students with an ID Aged 14-18 years Teachers	Schools	National longitudinal survey	Findings suggest that many students do not receive sex education and some teachers believe that RSE would benefit these students. The more severe the ID the less likely students are to receive sex education when compared to non-ID students. The more developed the level of expressive communication skills influences participation in RSE programmes.	There should be equal access to RSE programmes for all people with ID. RSE programme development and delivery should include collaboration between people with ID, health educators, special education teachers.
Dukes and McGuire (2009) Ireland	Evaluate a sex education intervention to improve knowledge and capacity in people with a moderate ID	People with ID Male (n=2) Female (n=2) Aged 22-23 years	Social care	Questionnaires	All study participants improved their decision-making, capacity to consent on all measures: consent, sexual knowledge and safety practices.	Larger efficacy study using mixed methods and RSE programmes delivered to groups based on shared learning needs required. Development of a sex education website and evaluate its effectiveness. Include LGBT issues in future RSE programme content.
Finlay et al. (2015) UK	Examine 'understanding' and identify barriers in delivering a sex education programme for people with ID	Young people with ID Aged 16-19 years Teachers (n=16)	Schools	Interviews and video content analysis	Effective communication important as long sentences and abstract concepts can impact on understanding. Analysis of the videos identified contextual issues that can impact upon understanding.	Further research needed to examine further how RSE programmes are delivered more effectively and potential solutions identified.
Frawley and Bigby	Explore the	Peer educators with	Social care	Interviews	Peer educators with ID felt	Further research is required

(2014) Australia	experiences of a co-facilitated relationships and sex education programme involving people with ID	ID (n=16) Ages 20-40 years			empowered as credible trainers with skills to support others with ID.	to identify the impact of people with ID as peer educators in RSE programme delivery.
Frawley and Wilson (2016) Australia	Explore the views and experiences of participating in a sexuality education programme	Young men (n=14) Young women (n=11) Aged 17-20 years	Schools and social care	Focus group interviews	Participants had some knowledge about relationships and sex issues but had limited access to information. Wanted the opportunity to explore sexual interests, desires and experience sexual relationships to develop their knowledge.	Sexuality and relationship education and information needs to be accessible for young people with intellectual disability, with peer support. Want to be fully involved in the design and delivery of RSE programmes.
Gardiner and Braddon (2009) Ireland	Evaluate a sex and relationship education programme for people with ID	People with ID (n=60). Ages undefined	Social care	Interviews	Participants reported improvements in self-esteem and knowledge of sexuality issues and knew more about rights and responsibilities.	More RSE programmes required to raise awareness of issues and advocate for and support people with LD in the full expression of their sexuality.
Garwood and McCabe (2000) Australia	Evaluate the knowledge and experiences of men with ID participating in two RSE programmes.	Men with ID (n=6) Aged 12-25 years	Social care	Questionnaires	Identified improvements in knowledge. All participants had difficulty taking about their sexuality. Following participation, positive feelings identified about previous sexual experiences.	Knowledge and feelings should be assessed in all RSE programmes and fully evaluated. Utilise recognized theoretical models in RSE programmes. Further research required using larger samples.
Löfgren-Mårtenson (2012) Sweden	Explore RSE for young people with ID	Young people with ID Females (n=9) Males (n=7)	Schools	Interviews	RSE programme content focused on risky sexual behaviours over pleasure, desire and intimacy.	RSE programmes need to include content focusing on pleasure, desire and intimacy. A critical education approach within RSE programmes is

		Ages 16-21 years				needed to challenge gender and sexuality norms and assumptions. Future studies should include youth with ID as both participants and collaborators in research.
--	--	------------------	--	--	--	---