

What do we know about sex education of people with intellectual disabilities? An umbrella review

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Abstract

Background: Special attention is required when considering any educational intervention aimed at its promotion and development. Our objective is to conduct an umbrella review of systematic reviews that gather evidence from relationships and sex education programmes tailored for individuals with intellectual disabilities.

Methods: The protocol was developed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses Protocol. Systematic reviews were identified through a search in Web of Science, SCOPUS and PsychINFO, using the descriptors: 'intellectual disab*' AND 'sex*' AND 'systematic'.

Findings: The results of the nine reviews included in the meta-review yield relevant outcomes related to 50 sex education interventions carried out with people with intellectual disabilities. This provided the opportunity to delve into the characteristics of these interventions to ascertain the accomplishments achieved to date.

Conclusions: The findings serve as foundation to propose and promote new research on this important area of life, addressing the inequalities identified concerning the sexuality and affective-sexual education of people with intellectual disabilities. It offers valuable information for the educational, social and healthcare fields, facilitating the design of more effective and rights-respecting initiatives.

KEYWORDS

education, health, learning (intellectual) disabilities, literature review, sexuality

Accessible summary

- What we wanted to do: We wanted to see what different studies say about teaching people with intellectual disabilities about relationships and sex education and how well these lessons are working.
- What we found: Our discoveries can help us think of new ideas to help people with intellectual disabilities understand love, relationships, hygiene and body changes and get better at making friends. Educative, social and health centres can use this information to find better ways to support sexuality and rights.

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1 | INTRODUCTION

Sexuality, as defined by the U.S. Sexuality Information and Education Council, is a natural and multifaceted aspect of human existence, spanning biological, social, psychological, spiritual, ethical and cultural dimensions (Ecker & Kirby, 2009). It is a fundamental aspect of human life that transcends physical, intellectual, social, gender and religious differences, encompassing elements such as sex, gender identities, sexual orientation, pleasure, intimacy and reproduction. The right to sexual expression, the formation of relationships and access to sexual health education are fundamental human entitlements that necessitate an affirmative and respectful approach to ensure safe and enjoyable experiences, as highlighted by the World Health Organization (WHO, 2006, 2015) and Hole et al. (2021). Achieving sexual health involves fostering self-acceptance, promoting societal acceptance of diversity and developing the necessary skills, knowledge and behaviours (Chou et al., 2019, 2020; Retznik et al., 2021). In essence, sexuality encompasses the fundamental rights to both love and be loved (Leclerc & Morin, 2022).

There has been a gradual acknowledgement of sexual and reproductive rights for all individuals, including those with intellectual disabilities (Hunt et al., 2017). A pivotal moment came with the World Report on Disability (WHO, 1994 cited in Agaronnik et al., 2020), which shed light on the challenges and discrimination faced by individuals with disabilities regarding family and reproductive rights. This report underscored the necessity of ensuring equal support to enable people with disabilities to exercise these rights (Agaronnik et al., 2020). Subsequently, the focus on family and sexual rights for people with disabilities grew, resulting in international agreements explicitly recognising them. A prime illustration of this acknowledgement is evident in Articles 23 (right to family and home) and 25 (right to health, including sexual and reproductive health [SRH]) of the Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006).

Despite advancements and the undeniable acknowledgements of the significance of interpersonal, sexual and intimate relationships for individuals with intellectual disabilities (Brown & McCann, 2018; Charitou et al., 2020; Parchomiuk, 2022), their sexual behaviours and desires have historically been disregarded, suppressed or punished not only in public contexts but also particularly within private or familial settings (Parchomiuk, 2022). Pleasure and love as components of sexuality are seldom acknowledged for them (Sitter et al., 2019). Frequently, they are viewed as lacking the capacity for sexuality, as asexual, sexually inactive or deviant (Hole et al., 2021; Kulick & Rydström, 2015; McCarthy et al., 2020; Shakespeare, 2000). Several studies have highlighted social negative attitudes to the sexual expression of people with intellectual disabilities as they are considered to exhibit inappropriate sexual behaviour (ISB). This concept refers to behaviour that is developmentally and socially inappropriate or potentially harmful or distressing to others (Tarren-Sweeney, 2008), which may include nonconsensual sexual contact, public masturbation, public nudity, sexual behaviour with objects and explicit sexual conversations.

Various studies suggest that the prevalence of ISB is relatively common, reaching percentages between 18% and 28% among individuals with intellectual disabilities (Falligant & Pence, 2020). Malovic et al. (2020) reported that some people with intellectual disabilities may exhibit ISB due to a poor understanding of concepts such as consent and abuse. Other studies, as the one conducted by Svae et al. (2023), have highlighted the existence of barriers in preventing harmful sexual behaviours among individuals with intellectual disabilities. Behind these barriers lies a lack of knowledge about sexual health.

Unease persists around the sexuality of people with intellectual disabilities, often leading to the denial of their sexual rights under the guise of protection (Friedman et al., 2014; Sitter et al., 2019). Discourses on the sexual and reproductive rights of people with intellectual disabilities often focus on protecting them from forced sterilisation and sexual abuse (Medina-Rico et al., 2018; Ruiz, 2017), while overlooking the societal stigma limiting the sexual expression of this collective (Parchomiuk, 2022) and their need for comprehensive affective-sexual education (Abbott, 2013, 2015; Hole et al., 2021; Jahoda & Pownall, 2014; Pérez-Curiel et al., 2023; Wilkinson et al., 2015). This heightens individuals with intellectual disabilities' vulnerability to sexual exploitation, diseases and psychological issues (Irvine, 2005), particularly among women (Wu et al., 2019). Sexual health education is commonly reactive rather than proactive, addressing problems as they arise, rather than preventing them (Borawska-Charko et al., 2016).

Over the past five decades, there has been intense debate surrounding the inclusion of sexual education and sexual health programmes in educational settings. Previous research indicates that introducing this kind of programmes from early educational levels is very positive, as their contents aim to foster the development of knowledge, positive attitudes and values necessary for making healthy decisions about sexuality and relationships (Swango-Wilson, 2010). In this sense, a sexuality education programme can be defined as a structured set of activities and resources designed to provide individuals with knowledge, skills and understanding related to sexuality and human relationships (Bonjour & van der Vlugt, 2018). Its primary objective is to promote SRH, as well as emotional and social well-being, by fostering a comprehensive and equitable understanding of sexuality. Daly and Heah (2023) note that when implementing an intervention proposal, various terminologies emerge. In the Anglo-Saxon context, the majority of authors use terms such as relationships and sex education (RSE), relationships and health education or relationships, sex and health education, with RSE being the preferred and most widely used term. Following this premise and with the aim of facilitating comprehension, this term will also be used throughout this paper.

In conclusion, an RSE programme is a universal human right, applicable to all individuals, including those with intellectual disabilities. The CRPD emphasises the right of all individuals with disabilities to receive quality education with accessible and comprehensible information. However, it is concerning that sexual education often relies on a medical and biological perspective, without

considering aspects such as sexual pleasure or intimacy (Alexander & Taylor Gomez, 2017; Turner & Crane, 2016). Furthermore, curriculum plans for this group often lack information about gender, sexuality and nontraditional relationships (Löfgren-Mårtenson, 2011).

Acknowledging and honouring the sexual and reproductive rights of individuals with intellectual disabilities is crucial for fostering an inclusive and fulfilling life. Despite the necessity for research on the efficacy of RSE programmes for this population, substantial evidence remains scarce. In addition, there is also a lack of a wide-ranging overview consolidating evidence from systematic reviews on sexual education, programme attributes, impact and empirical support people with intellectual disabilities have received. Therefore, given the increasing number of systematic reviews on sexuality, this study presents an umbrella review focused on RSE programmes for individuals with intellectual disabilities.

As defined, umbrella reviews or overviews of reviews, assessed published systematic reviews or meta-analyses, often used for contentious topics or synthesising extensive research (López-López et al., 2022). This comprehensive overview offers a crucial state-of-the-art summary for education, social work and healthcare sectors, guiding the design of more effective and rights-respecting initiatives.

More specifically, we will address the following research questions:

1. What are the characteristics of the systematic reviews included in this umbrella review?
2. What are the characteristics of RSE programmes conducted towards individuals with intellectual disabilities?
3. What is the effectiveness of these RSE programmes?

2 | METHODS

The protocol was developed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses Protocol (PRISMA-P; Aromataris et al., 2015; Page et al., 2021). The process consisted of the following steps: (a) selection of studies that met the inclusion criteria; (b) assessment of the quality of the selected studies and (c) data extraction to address the research questions.

2.1 | Study selection

2.1.1 | Search strategy

A search was conducted in Web of Science, SCOPUS and PsycINFO. The search strategy primarily focused on the following descriptors: 'intellectual disab*' AND 'sex*' AND 'systematic', essentially containing three filters: (1) following a systematic review methodology, (2) focusing on sexuality as the main theme and (3) addressing individuals with intellectual disabilities as the population of interest. The searches were completed in May 2023.

2.1.2 | Inclusion and exclusion criteria

Inclusion and exclusion of reviews were defined in two stages and specific criteria: (1) screening the reviews based on title and abstract and (2) eligibility assessment for full-text publications.

In the first phase of screening titles and abstracts, we applied the following inclusion criteria. The (scoping, systematic, literature or umbrella) reviews or meta-analysis had to (a) mention intellectual or learning disabilities in the title, abstract or keywords; (b) include empirical studies (qualitative, quantitative, mixed methods); (c) encompass RSE programmes (implemented in social, community or healthcare settings) and (d) have been published from January 2015 onwards. No language criteria were considered. Articles whose content or application was strictly medical were excluded.

Next, the eligibility assessment of full-text reviews was conducted, verifying whether they met the following inclusion criteria: (a) addressing specific RSE programmes, (b) focusing on individuals with intellectual disabilities and (c) providing specific outcomes for people with intellectual disabilities. Reviews specifically discussing topics related to sexual abuse or violence, ISBs, experiences or desires of motherhood/fatherhood, LGBT identities, gender-based violence, institutional violence/abuse or any other topics not specific to RSE programmes were excluded. However, they were considered eligible when these topics were part of the contents of more comprehensive programmes.

2.1.3 | Selection process

The search yielded 129 potential references, with an additional one from Google Scholar. After removing duplicates ($n = 34$), 95 papers underwent initial title and abstract screening. Of these, 73 references were excluded for not being systematic reviews or meta-analyses related to the topic. During this phase, a 100% inter-rater agreement was achieved between the first and third authors for 15% of the references.

The remaining 22 reviews underwent full-text evaluation. Out of these, 13 references were excluded: (a) four lacked the inclusion of interventions (31%) and (b) nine contained interventions not closely related to the main topic (69%). In this phase, a new inter-rater agreement was reached between the first and third authors for 30% of the references. They disagreed on the inclusion of a single study, leading to a 90% agreement rate. The disagreement was resolved through consensus after discussion involving the fourth author.

Consequently, nine systematic reviews (with no meta-analysis) were included for analysis. All of the encountered references were written in English. Figure 1 depicts the diagram summarising the entire study selection process.

2.2 | Quality assessment

The methodological quality of each included systematic review was assessed using the Critical Appraisal Skills Programme (CASP, 2018a)

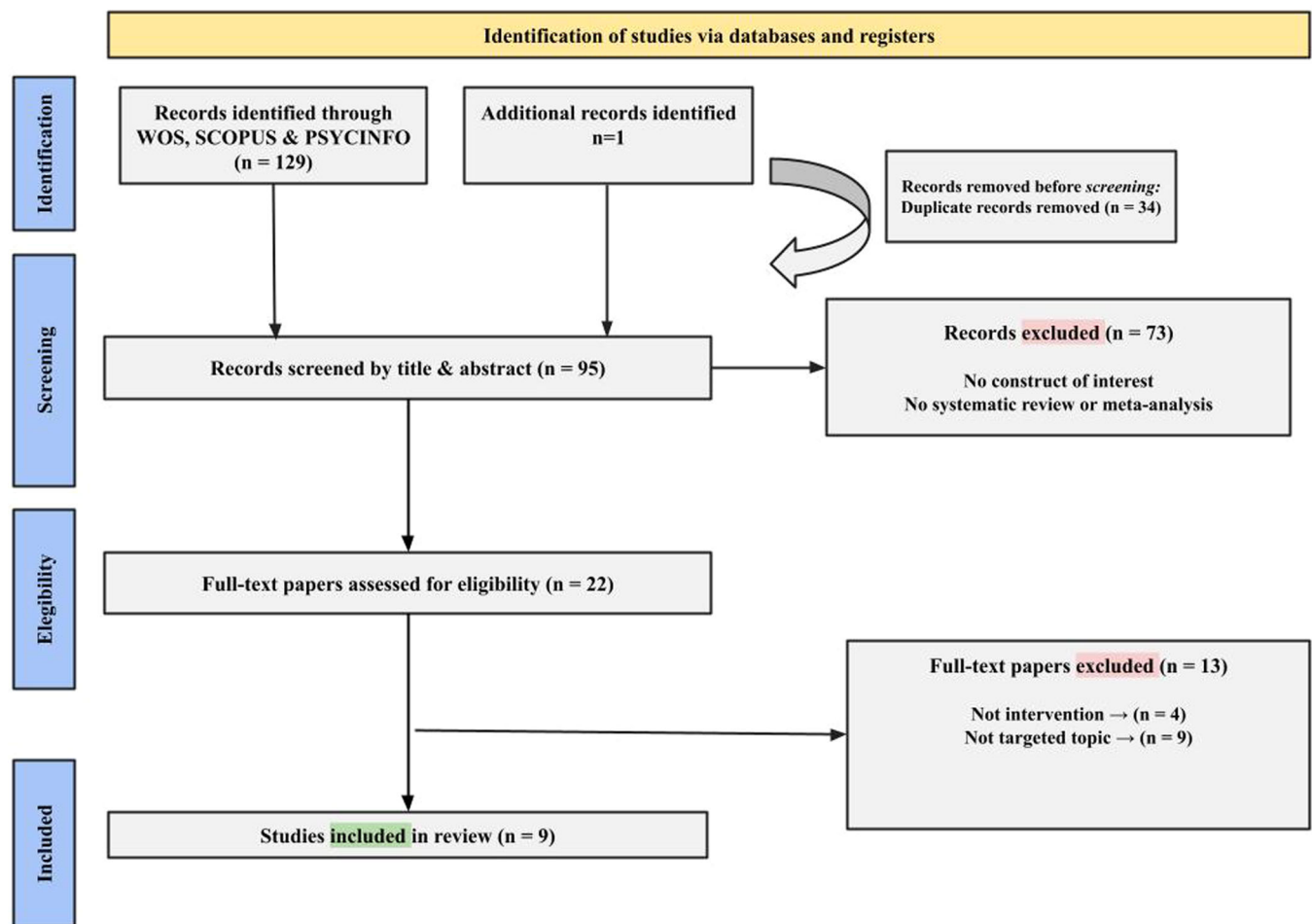


FIGURE 1 Preferred Reporting Items for Systematic Reviews and Meta-analyses flowchart diagram. [Color figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/bd.12577)]

checklist for systematic reviews. Through 10 items (scored as 'yes', 'no' or 'can't tell'), it evaluates three main aspects of a systematic review: Are the results valid? What are the results? Will the results be applicable to the local context?

To gather quality assessment data, the first and second authors independently evaluated each of the included systematic reviews, assigning scores to the 10 checklist items. The initial agreement percentage between the authors was determined by dividing the total agreements for each checklist item by (agreements + disagreements) \times 100, resulting in an initial agreement of 90%. Disagreements were jointly reviewed, suggesting further adjustments until consensus was achieved.

The quality assessment results of the reviews are presented in Table 1. Two systematic reviews (McCann et al., 2019; Schaafsma et al., 2014) scored low (four out of 10 points), while the others achieved scores of 7–9 points ('yes' responses). None of the reviews reached the maximum score (10). Item 7 ('How precise are the results? Hint: Look at the confidence intervals, if given') was the one in which no review received a 'yes' response, as no reviews were meta-analyses and did not analyse result reliability.

2.3 | Data extraction and overlap

Data extraction occurred in two phases. The initial phase aimed to outline the attributes of each selected systematic review (first research question). The second phase aimed to describe the characteristics and efficacy of RSE programmes for people with intellectual disabilities reported in systematic reviews (second and third research questions).

During the initial phase, the following fields were completed for each reference (Table 2): authors, year, affiliation's country, publication type, study type, design(s), purpose, number of primary articles included (years), number of RSE programmes (percent), number of RSE programmes for people with intellectual disabilities, overlap (i.e., percentage of primary studies included in multiple reviews), main findings and quality assessment (number of 'yes' responses in the CASP Systematic Review Checklist). This process enabled evaluating the extent of primary study overlap among systematic reviews through the percentage of primary studies included in multiple reviews for each systematic review and for all reviews collectively and the corrected covered area (CCA).

TABLE 1 Systematic reviews and CASP checklist.

References	1. Did the review address a clearly focused question?	2. Did the authors look for the right type of papers?	3. Do you think all the important, relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. If the results of the review have been combined, was it reasonable to do so?	6. What are the overall results of the review?	7. How precise are the results?	8. Can the results be applied to the local population?	9. Were all important outcomes considered?	10. Are the benefits worth the harms and costs?	Quality assessment (total yes/total)
Paulauskaite et al. (2022)	Y	Y	Y	CNT	Y	Y	N	Y	Y	Y	8/10
Sala et al. (2019)	Y	Y	Y	Y	Y	Y	N	N	Y	Y	8/10
Schaafsma et al. (2014)	N	N	Y	CNT	CNT	Y	N	Y	CNT	Y	4/10
McCann et al. (2019)	Y	N	CNT	Y	CNT	Y	N	N	N	Y	4/10
Exell et al. (2020)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	9/10
Brown et al. (2020)	CNT	Y	Y	Y	Y	Y	N	N	Y	Y	7/10
Pérez-Curiel et al. (2023)	Y	Y	Y	N	Y	Y	N	N	Y	Y	7/10
Horner-Johnson et al. (2019)	Y	N	Y	Y	Y	Y	N	N	Y	Y	7/10
Black and Kammes (2021)	N	Y	Y	Y	N	Y	N	Y	Y	Y	7/10

Abbreviations: CNT, cannot tell; N, no; Y, yes.

TABLE 2 Characteristics of systematic reviews on the sexuality of people with ID and intervention proposals.

References, country	Publication type	Study type	Design(s)	Purpose	N of primary articles included (years)	N of RSE programmes (%)	N of RSE programmes for PwID (%)	Overlap	Main findings	Quality assessment (n yes/total)
Paulauskaite et al. (2022), United Kingdom	PR-A	SR	Qualitative data (n = 27) Quantitative data (n = 6) Mixed-methods (n = 9)	Review existing studies on outcomes of RSE, as the first step in the development of a core outcome set (COS) for students with intellectual disability.	42 (2000–2021)	42 (100%)	19/42 (45.2%)	42.86%	Primary education lacked significant outcomes for RSE (relationship and sexuality education). Topics included the human body, hygiene, relationships, sexuality, consequences of sex, social behaviour, safety, emotions and self-esteem. Focus on knowledge not skills or attitudes. Students with intellectual disabilities, parents and teachers had diverse outcome perceptions. Five tools were utilised, but none validated for this population.	8/10
Sala et al. (2019), Australia	PR-A	SR	Quantitative data including: multiple-baseline pre/postquasi-experimental controlled clinical trial Prospective follow-up randomised control trial (**) With or without control group	Examine (A) current interventions for SRE in these conditions. (B) Inclusive SRE content. (C) Impact on participant understanding and behaviour. (D) Methods of programme delivery. (E) Limitations of existing programmes.	33 (1981–2017)	30 (90%)	26/30 (78.7%)	77.42%	Studies assessed diverse SRE programmes; emphasised biology and safety, neglected personal sexuality and relationships; most programmes boosted outcomes, but study quality was low.	8/10
Schaafsma et al. (2014), the Netherlands	PR-A	SR	Quantitative data including: multiple-baseline pre-post with or without follow-up	Identify methods for sex education programmes aimed at individuals with intellectual disabilities.	20 (1981–2012)	20 (100%)	20/20 (100%)	85%	Studies revealed limited application of skills in real-life scenarios. More attention needed for knowledge and skill retention. Programme	4/10

TABLE 2 (Continued)

References, country	Publication type	Study type	Design(s)	Purpose	N of primary articles included (years)	N of RSE programmes (%)	N of RSE programmes for PwID (%)	Overlap	Main findings	Quality assessment (n yes/total)
			with or without control group						materials, goals and methods lacked specifics. Evidence suggests potential for enhanced sex education knowledge, attitudes and skills among those with intellectual disabilities. Lack of detailed method descriptions hampers understanding of effectiveness.	
McCann et al. (2019), United Kingdom	PR-A	SR	Qualitative data Quantitative data Mixed-methods	Examine the research evidence concerning the views and experiences of people with ID regarding their participation in and the effectiveness of RSE programmes.	8 (2000–2016)	8 (100%)	8/8 (100%)	75%	The review indicates that individuals with intellectual disabilities engage in and benefit from RSE programmes. Additional research is needed to assess the programmes' influence on lasting behaviour changes, fostering enduring relationships and minimising unintended outcomes of sexual activities.	4/10
Exell et al. (2020), United Kingdom	PR-A	SR	Qualitative and quantitative data including: Multiple-baseline A-B single case Case series designs Pre-post with or without control group	Evaluate the current evidence on dating interventions, their theoretical underpinnings and effectiveness for adult neuro-atypical populations.	13 (1987–2019)	13 (100%)	5/13 (38.5%)	38.46%	Despite reporting positive results, drawing definitive conclusions on effectiveness is challenging due to numerous before–after analyses and content/outcome measure variations. Further high-quality studies are necessary to evaluate intervention efficacy. Additionally, consensus is	9/10

(Continues)

TABLE 2 (Continued)

References, country	Publication type	Study type	Design(s)	Purpose	N of primary articles included (years)	N of RSE programmes (%)	N of RSE programmes for PwID (%)	Overlap	Main findings	Quality assessment (n yes/total)
Brown et al. (2020), United Kingdom	PR-A	SR	Qualitative data (n = 9) Quantitative data (n = 3)	Identify the design, content, delivery and evaluation approaches used in RSE programmes for people with intellectual disabilities across the lifespan.	12 (1990–2020)	12 (100%)	5/12 (41.7%)	41.67%	Research indicates unique relationship and sexuality needs for individuals with intellectual disabilities (ID). Evolving research supports tailored RSE programme design. Despite positive progress, limitations in current RSE offerings should be acknowledged. Future programmes must be grounded in evidence-based theoretical models to effectively promote and maintain behaviour change.	7/10
Pérez-Curiel et al. (2023) Spain	PR-A	SR	Quantitative data (47%) including: cross-sectional or predefined cohort design qualitative data (45%), mixed methods (8%)	Synthesise the current qualitative and quantitative evidence related to the content of Articles 23 (home and family) and 25 (health, specifically sexual and reproductive health) of the CRPD, focusing exclusively on people with ID.	151 (1976–2022)	7 (4.7%)	7/7 (100%)	11.92%	Socially viewing individuals with ID as asexual results in their exclusion from sex education. Research reveals their limited sexuality knowledge versus nondisabled individuals. Crucial sex education must be inclusive, personalised and involve parental collaboration, as adults with ID do engage in sexual relationships and activities.	7/10
Horner-Johnson et al. (2019), United States	PR-A	SR	Quantitative data including:	Conduct a literature review on (1) contraceptive	62 (1979–2017)	6 (9.7%)	5/6 (8.1%)	16.13%	Disabled women often opt for fewer contraceptive methods and possess	7/10

TABLE 2 (Continued)

References, country	Publication type	Study type	Design(s)	Purpose	N of primary articles included (years)	N of RSE programmes (%)	N of RSE programmes for PwID (%)	Overlap	Main findings	Quality assessment (n yes/total)
Black and Kammes (2021), United States	PR-A	SR	Observational cohort studies Cross-sectional studies Qualitative data	knowledge among disabled women; (2) attitudes and preferences toward contraception; (3) contraceptive utilisation; (4) obstacles and enablers for informed contraceptive use and (5) efficacy of interventions enhancing informed contraceptive decision-making.	21 (1994–2020)	21 (100%)	21/21 (100%)	72.73%	lesser contraceptive awareness compared to nondisabled counterparts. Knowledge-enhancing interventions hold potential, yet scarcity of data persists on contraceptive preferences within this group.	7/10

Quantitative data including: Pre-post single group repeated measures
Control group used for comparison
Studies with follow-up
Single case design
Multiple-baseline
Multiple probe design across participants and across settings

Identify and summarise studies reporting outcomes of sexuality education programmes for PwID.

Temporal patterns revealed pre-2010 emphasis on abuse prevention studies, shifting to relationship development studies post-2010. Despite distinct curricula and training approaches, content teaching methods remained largely consistent. Diverse impact assessment tools included knowledge measures and behavioural observations. Overall, participants exhibited knowledge and behaviour improvements postintervention across all studies.

Abbreviations: CRPD, Convention on the Rights of Persons with Disabilities; PR-A, peer-reviewed article; PwID, people with intellectual disabilities; RSE, relationships and sex education; SR, systematic review.

The CCA was calculated by dividing the frequency of repeated occurrences of index studies (first occurrence of primary study) in other reviews by the product of the number of index studies and the number of reviews, minus the number of reviews (Pieper et al., 2014). The resulting CCA is expressed as a percentage ranging from 0% to 100%. A CCA of 0%–5% indicates slight overlap, a CCA of 6%–10% indicates moderate overlap, a CCA of 11%–15% indicates high overlap and a CCA > 15 is considered very high overlap.

After identifying references within the reviews that referred to interventions, we selected 62 RSE programmes focused on specifically towards individuals with intellectual disabilities. We excluded (a) eight studies primarily exploring RSE experiences; (b) one unrelated to affectivity sexuality; (c) two aimed at professionals or family members and (d) one because the RSE programme was specifically for people with autistic spectrum disorder.

We ended up with 50 studies containing RSE programmes suitable for a more comprehensive coding. While the vast majority of the references were written in English, two of them were authored in Spanish (Callol et al., 2016; Vizcaino Luque & Aciego De Mendoza Lugo, 2015). For each of them, we coded (Appendix S1A): review that cites it, study information (authors, year, country), aim, population, delivery method, topic tag, content, method or design, data collection, follow-up, measures, main findings, strengths and limitations and considerations for future research and quality assessment. This coding facilitated an exhaustive assessment and presentation of the interventions.

Similar to the approach taken for systematic reviews, a quality assessment was conducted for these studies. Independently, the first and third authors evaluated the quality of 30% of the interventions using the CASP checklist for Qualitative Studies (CASP, 2018b) and for Randomised Controlled Trials (CASP, 2020; item 11 underwent a reformulation, changing from 'would the experimental intervention provide greater value to the people in your care than any of the existing interventions' to 'the intervention is valuable'). For quasi-experimental designs, the criteria outlined in the Joanna Briggs Institute's Critical Appraisal for Quasi-Experimental Studies–Nonrandomised Experimental Studies were adhered to (Tufanaru et al., 2020). The inter-rater agreement reached 87%, with agreement rates of 94% for randomised designs, 87% for qualitative designs and 73% for quasi-experimental designs (Appendix S2B).

3 | RESULTS

3.1 | Characteristics of the systematic reviews

Table 2 presents the attributes of the nine systematic reviews that met the eligibility criteria (Black & Kammes, 2021; Brown et al., 2020; Exell et al., 2020; Horner-Johnson et al., 2019; McCann et al., 2019; Paulauskaite et al., 2022; Pérez-Curiel et al., 2023; Sala et al., 2019; Schaafsma et al., 2014). It also includes the overlap percentage (CCA), a summary of the quality assessment and key characteristics. All these reviews were published in peer-reviewed journals, with 44%

originating from the United Kingdom and 56% being published in 2020 or later. The systematic reviews included in this umbrella review varied in the number of primary articles meeting their independent inclusion criteria, with reviews including as few as eight studies to others that reached 151. These primary studies were published between 1979 and 2022 and exhibited a diverse array of methodologies, including quantitative, qualitative and mixed-methods studies.

Regarding the primary studies included in each of the reviews, an analysis was conducted to determine the number of these references that were RSE programmes and, out of this number, how many addressed individuals with intellectual disabilities or were the primary participants rather than family members or professionals. In this regard, the majority of reviews ($n = 8$) included 100% RSE programmes in their primary studies. However, this percentage significantly decreased when it came to the second step. Only four reviews maintained a 100% inclusion rate of RSE programmes in their references that were specifically aimed at these individuals.

Most (78%) of the analysed reviews had specific objectives focused on RSE programmes. In all of them, at least some of the primary studies analysed were studies on RSE programmes. Two reviews (Horner-Johnson et al., 2019; Pérez-Curiel et al., 2023) included this type of studies as part of their objectives but not as the main focus, representing 10% and 5% of their analysed studies, respectively. It is worth noting that among the RSE programmes identified by five of the reviews (Black & Kammes, 2021; Exell et al., 2020; McCann et al., 2019; Pérez-Curiel et al., 2023; Schaafsma et al., 2014), all were specifically tailored for people with intellectual disabilities, while in the remaining reviews only a percentage of the studies focused on them specifically.

The extent of primary reference overlap ranged from 12% to 85% across the systematic reviews, and only one reference (Schaafsma et al., 2014) included papers that exclusively used qualitative data. Appendix S3C also includes an analysis of CCA, which showed a 2.6% (slight) overlap. In total, we compiled 298 unique primary studies, with 54 references cited in more than one systematic review. This means that only 18% of the systematic reviews share common references as primary articles. Notably, one study (Dukes & McGuire, 2009) was cited in six reviews, while three others (Box & Shawe, 2014; Garwood & McCabe, 2000; Valenti-Hein et al., 1994) were included in four or five reviews.

3.2 | Characteristics of affective or sexual programmes or interventions

3.2.1 | Participants

The majority of RSE programmes (66%) engaged the participation of both men and women with intellectual disabilities; yet, women constituted a larger proportion among the overall participants. Specifically, 14 RSE programmes were exclusively tailored to women (28%), whereas three interventions solely focused on men (6%). A

substantial portion of them encompassed a wide age spectrum, enlisting participants between 20 and 60 years old. However, five RSE programmes were specifically oriented towards teenagers aged 11–19 years, while one of them focused on children aged 6–8 years (Watson et al., 1992). Thirty-one studies (62%) incorporated participants with mild or moderate intellectual disabilities and only six RSE programmes (12%) indicated the involvement of individuals with severe intellectual disabilities, while the remaining studies (26%) did not furnish details regarding the level of intellectual disabilities or support needs.

3.2.2 | Individuals or profiles that implement the RSE programmes

The majority of studies do not explicitly detail the individuals or profiles responsible for delivering the RSE programme. When such information is provided, there is a prevailing tendency for these programmes to be conducted by the researchers themselves or, alternatively, by professionals from the associations that have developed it. Two noteworthy cases involved RSE programmes conducted by individuals with intellectual disabilities. Chou et al. (2020) gives an example of a RSE programme facilitated by two individuals with intellectual disabilities, along with a married couple who also had intellectual disabilities. In the RSE programme developed by Frawley and Bigby (2014), individuals with intellectual disabilities collaborated with other professionals from the disability sector as part of the intervention team.

3.2.3 | Session format

The majority of the RSE programmes (56%) opted for group sessions ($n = 28$), while a smaller proportion utilised individual or one-to-one sessions (14%, $n = 7$). A couple of programmes involved sessions in pairs, and there were no details about this in 13 studies (26%).

While 56% of RSE programmes did not specify the number of sessions, those that did indicated a range from one to 24 sessions, with 10 sessions being the most commonly suggested ($n = 8$). Sessions were typically held on a weekly basis ($n = 9$). However, some RSE programmes offered sessions as needed for participants to achieve desired outcomes (Bollman et al., 2009), and others continued one-to-one sessions until participants met criteria (Kim, 2016).

There was notable variability regarding session duration, ranging from 25-min up to 3 h. The average session duration was approximately 90 min.

The overall duration of the RSE programme ranged from 1.5 h (conducted in one or two sessions) to 36 h (spread over three or 4 months). Among RSE programmes lasting up to 10 h, the most common durations were around 4 or 7 h, but 52% of the interventions opted for durations equal to or exceeding 20 h, with the prevalent range falling between 24 and 30 h ($n = 6$).

3.2.4 | Contents or curriculum

To analyse and categorise the contents covered in the RSE programmes analysed, we considered (1) the proposal of Planned Parenthood (2023), a prominent authority in sex education, outlining the essential topics for a comprehensive sex education programme, and (2) the thematic analysis methodology by Sala et al. (2019).

As a result, we identified four overarching themes, each accompanied by its respective subthemes: (1) biological Information, encompassing (a) basic anatomical and body differences, (b) personal hygiene (PH) and (c) life cycle (LC); (2) personal sexuality, including (d) SRH and (e) menstrual health and management; (3) personal relationships, involving (f) healthy relationships (HRs), (g) family planning (FP) and (h) avoiding pregnancy and STDs; and finally, (4) self-awareness and safety, comprising (i) social boundaries and abuse prevention, (j) Internet/electronic use and (k) social skills (SSs). A visual representation of these themes and subthemes for each of the 50 interventions is provided in Appendix S4D.

A notable focus was evident on abuse prevention within the 'SB-AB' theme, accounting for 54% ($n = 27$) of the RSE programmes analysed, with 12 references exclusively centred on this topic. These programmes aimed to equip individuals with the knowledge to recognise risky behaviours assert their right to refuse and provide tools for handling such situations through strategies fostering empowerment, notably using the 'No! Go! Tell!' approach.

Content related to 'HRs' ($n = 25$) subtheme encompassed diverse aspects such as emotional expression, characteristics of HRs, appropriate behaviours within relationships, marriage, strategies for relationship establishment and maintenance, identification of relationship violence patterns and the significance of consent and affection in relationships.

RSE programmes addressing 'SRH' ($n = 19$) encompassed varied content. This ranged from self-concept's connection to sexuality, decision-making consequences in sexual matters, body image, challenging stereotypes, understanding public and private body parts, sexual behaviours' diversity, protection from sexually transmitted diseases and distinctions between appropriate public and private behaviours.

Content regarding 'basic anatomic and body differences' ($n = 16$) primarily explored bodily changes during puberty, male and female sexual organ anatomy and distinctions between biological sex and gender identity.

'SSs' ($n = 14$) RSE programmes' aimed to enhance self-esteem, assertiveness, emotional control, decision-making, responsible and safe behaviours.

'FP' content ($n = 13$) discussed contraceptive methods, human reproduction, pregnancy, foetal development and childbirth.

'LC' topics ($n = 11$) covered different life stages and their attributes and addressed themes of loss and grieving.

'PH' topics were included in five RSE programmes, four of which also incorporated 'SRH' content, emphasising personal care for oneself and partners.

'MHM' themes appeared in three RSE programmes focused on women, discussing menstrual cycle and menopause.

Remarkably, only one RSE programme (McDermott et al., 1999) adapted its curriculum based on participants' needs and requests. Only one RSE programme addressed internet safety or online relationships, and only three explicitly mentioned the word 'rights', encompassing the right to refuse (Bornman & Rathbone, 2016), 'sexuality rights' (Kim, 2016) and the inclusion of rights and responsibilities in Ss (Sheppard, 2006).

3.3 | Empirical evidence about the effectiveness of RSE programmes

3.3.1 | Empirical design

We found a minority of mixed methods ($n = 4$), followed by qualitative studies ($n = 8$), with quantitative studies ($n = 37$) being the preferred choice (74%). The design of one of the RSE programmes (Batkovic & Teodorovic, 2000) could not be determined due to not being able to access the full text. Within the quantitative designs, the majority ($n = 19$) opted for randomised control trial designs. Seven RSE programmes had a control group, while five were characterised by having a single experimental group, collecting pre-postintervention data and utilising a multiple baseline design.

Regarding the 18 RSE programmes that could not ensure sample randomness, the majority had a control group ($n = 7\%$) and five proposed a single-group design. Four programmes collected pre-postintervention data, but only two of them took multiple measures at both time points (Chou et al., 2020; Graff et al., 2018). Three RSE programmes opted for a multiple baseline design, one used a control clinical trial (Valenti-Hein et al., 1994) and another used a multiple-probe interrupted series design (Watson et al., 1992).

3.3.2 | Measures and outcomes

There was a wide variety in terms of the outcomes assessed to evaluate the effectiveness of the RSE programmes. The majority of them (82%) did not use standardised instruments for data collection. The preferred methods were questionnaires designed ad hoc ($n = 22$), followed by interviews ($n = 13$), role playing ($n = 5$) and focus groups ($n = 3$).

Only nine interventions (18%) used previously validated scales: (a) for evaluating sexual knowledge: the Assessment of Sexual Knowledge (Butler et al., 2004), the Sexual Consent and Education Assessment (Kennedy, 1993) and the Sexuality Knowledge, Experience and Needs Scale for people with intellectual disabilities (McCabe, 1992); (b) for assessing Ss: the KiSS-18 (Kikuchi, 2007); (c) for measuring quality of life: the Personal Outcomes Scale (van Loon et al., 2009); (d) to understand experiences of interpersonal violence: the Interpersonal Violence Interview for Individuals with Intellectual and Developmental Disabilities (IVI; Atkinson &

Ward, 2012) and (e) to gauge levels of empathy: the Victim Empathy Scale (Beckett & Fisher, 1994). Two RSE programmes (Garwood & McCabe, 2000; Plaks et al., 2010) employed the Sex-Ken ID scale, while another two (Ward et al., 2012, 2013) used the IVI.

The RSE programmes approached various aspects (Table 3), such as knowledge, attitudes or prevention strategies. Several programmes highlighted positive outcomes in terms of increased knowledge and understanding of sexuality-related subjects following interventions, particularly in areas such as safety (Dukes & McGuire, 2009; Ward et al., 2013), self-protection (Haseltine & Miltenberger, 1990; Lee & Tang, 1998) and responsible behaviour (Callol et al., 2016; Gutiérrez-Bermejo et al., 2021). Some RSE programmes suggested that certain individuals with lower initial scores experienced improved performance after participation (Box & Shawe, 2014; Chou et al., 2020; Graff et al., 2018; Hayashi et al., 2011).

3.3.3 | Follow-up

Nearly half of the RSE programmes ($n = 23$) lacked information on postimplementation effectiveness assessment, while only six collected data after implementation. Out of the total, 21 provided data on follow-up to assess result maintenance. The majority conducted the follow-up within a few months after the intervention. The most common timeframe was one to 3 months postintervention ($n = 8$), followed by three to 6 months ($n = 4$) and a year ($n = 3$).

Only five RSE programmes suggested multiple follow-ups (Bollman et al., 2009; Egemo-Helm et al., 2007; Haseltine & Miltenberger, 1990; Khemka et al., 2005; Lindsay et al., 1992). Chou et al. (2020) attempted a second assessment after 2 years, but no participants participated.

Miltenberger et al. (1999) was the sole RSE programme suggesting retraining if follow-up results were unsatisfactory, and Khemka et al. (2005) proposed establishing a support group to apply learned content to daily situations after the intervention concluded.

3.3.4 | Intervention quality

Appendix S2B provides the final scores of the RSE programmes as well as the scores obtained in each of the items. Programmes employing mixed methods methodology were evaluated from both qualitative and quantitative perspectives (Box & Shawe, 2014; Chou et al., 2020; Sheppard, 2006).

Among the 16 experimental designs evaluated, 11 achieved scores above 6 (out of 11). Four studies scored 8 and two reached 9, indicating generally high quality (none attained the maximum score). None received 'yes' ratings in items 4a, 4b, 4c and 9, revealing that participants, investigators or outcome analysts were not kept unaware due to single experimental groups or not comparative analysis. Notably, three experimental RSE programmes couldn't be assessed due to inaccessibility.

TABLE 3 Main findings.

Areas	Finding	Studies
Knowledge improvement	After the interventions, participants tended to show significant improvement in their knowledge about sexuality, including better understanding of sexual development, marriage, parental roles, birth control methods and social–sexual relationships.	Box and Shawe (2014); Bratkovic and Teodorovic (2000); Chou et al. (2020); Egemo-Helm et al. (2007); Gardiner and Braddon (2009); Garwood and McCabe (2000); Graff et al. (2018); Lee and Tang (1998); McDermott et al. (1999); Robinson (1984); Rushton (1994)
Skills on abuse prevention and self-protection	Participants demonstrated a high increase in correctly responding during roleplay activities.	Dukes and McGuire (2009); Egemo-Helm et al. (2007); Haseltine and Miltenberger (1990); Lumley et al. (1998); Miltenberger et al. (1999); Valenti-Hein et al. (1994)
Score improvement	Individuals with lower initial scores improved after the intervention in understanding social topics, although they struggled with sexual knowledge.	Box and Shawe (2014); Khemka et al. (2005); Kim (2016); Lee and Tang (1998); Penny and Chataway (1982)
Social skills and empowerment improvement	Interventions were linked to improvements in social skills, empowerment, decision-making and overall understanding of relationships and sexuality.	Finlay et al. (2015); Foxx et al. (1984); Haseltine and Miltenberger (1990); Hayashi et al. (2011); Hickson et al. (2015); Khemka (2000); Vizcaino Luque and Aciego De Mendoza Lugo (2015); Sheppard (2006); Valenti-Hein et al. (1994)
Other areas of improvement	Participants reported improvements in self-esteem, knowledge of sexuality issues, rights and responsibilities.	Chou et al. (2020); Gardiner and Braddon (2009)
Sexual behaviour	No significant increase in appropriate behaviour was observed	Bratkovic and Teodorovic (2000); Chandler et al. (2016)
Sexual behaviour awareness	Majority of participants exhibited high awareness and knowledge about appropriate sexual behaviour related to location, sexual acts and intimate body parts and also effectiveness in improving various components of responsible attitudes towards sexuality.	Bratkovic and Teodorovic (2000); Gutiérrez-Bermejo et al. (2021)
Positive experiences	Most participants reported positive opinions about the intervention, highlighting themes of awareness of sexual rights, empowerment and a change in perspective from focusing on problems to recognising rights. A person-centred approach and acknowledging unique experiences were recommended to help participants.	Box and Shawe (2014); Chou et al. (2020); Gardiner and Braddon (2009); Kim (2016)
Generalisation and maintenance	Although most participants responded positively to training and some maintenance of skills was noted over follow-up periods, there were cases of skills decay.	Miltenberger et al. (1999); Valenti-Hein et al. (1994); Dukes and McGuire (2009); Foxx et al. (1984); Foxx and Faw (1992)

Regarding the 23 quasi-experimental RSE programmes, three were not assessed for quality due to inaccessibility (Bratkovic & Teodorovic, 2000; Mazzucchelli, 2001; Rushton, 1994). Most of the 20 remaining programmes were moderately graded: 10 scored 5–7 points (out of 9), with five points being most common ($n = 6$). Seven points was the highest score reached (it was by three interventions). Fourteen lacked control groups, most of the focusing on a single experimental group ($n = 12$). For programmes with multiple groups, most were homogeneous preintervention ($n = 12$). Items with lower scores were (a) item 3, due to unspecified additional treatments; (b) item 5, with most not conducting multiple measurements and (c) item 6, where follow-up was often lacking or inadequately analysed.

Out of the 12 RSE programmes with a qualitative design, 11 were evaluated (full text of Todd, 2009 not located). Six scored 7–9 points out of 10, indicating generally high quality; yet, none achieved the maximum score. Two programmes (Gardiner & Braddon, 2009; Graff et al., 2018) received very low scores (1 and 2 points, respectively). Nine programmes addressed ethical aspects like participant or guardian consent. Notably, two items had more negative responses: (a) item 6, due to potential bias in question formulation or data collection and (b) item 8, as thematic analysis lacked detail in proposing categories, handling contradictory responses or addressing biases due to absence of triangulation, external evaluation or inter-/intra-rater agreement.

4 | DISCUSSION

The goal of this umbrella review was to present a synthesis of recent systematic reviews related to the RSE programmes conducted for individuals with intellectual disabilities and analyse the key characteristics and efficacy of these programmes, highlighting the available empirical evidence concerning the promotion of sexual rights and providing useful information for designing effective and respectful initiatives.

With nine systematic reviews conducted since 2015 (more than half of them published after 2020) and 50 interventions spanning from 1981 onwards (with around half of them originating from 2005 onwards), it is evident that there is a considerable and growing interest in this subject. Notably, the years following the ratification of the CRPD (United Nations, 2006) saw an increase in studies, with 20 out of 24 publications after that date concentrated between 2006 and 2016. This umbrella review underscores the necessity for ongoing research in this field, utilising the accumulated evidence to guide future research directions and to continue promoting and ensuring the advocacy of the rights of individuals with intellectual disabilities, particularly for women, necessitating an intersectional perspective.

Considering the first research question regarding the *characteristics of the nine systematic reviews* examined in this umbrella review, we found that seven papers had specific objectives focused on RSE programmes, while two had more broader objectives but still encompassed interventions of this nature. A common thread across all reviews was the inclusion of primary studies examining or describing RSE programmes designed specifically for people with intellectual disabilities.

The quality of the systematic reviews, as assessed by CASP, displayed notable variation. Only two reviews (McCann et al., 2019; Schaafsma et al., 2014) garnered low scores of 4 out of 10 points. Encouragingly, the remaining seven reviews missed only two or three quality indicators. Consistent concerns across all reviews encompassed the deficiency in accurately evaluating results and describing participant characteristics. Hence, there is a pressing need to enhance attention to quality indicators within systematic reviews and to consider conducting meta-analyses within this field. Regarding the limited 18% overlap observed among the articles included in the reviews, it is noteworthy that four of the analysed studies (Box & Shawe, 2014; Dukes & McGuire, 2009; Garwood & McCabe, 2000; Valenti-Hein et al., 1994) were featured in multiple reviews. The examination of systematic reviews and the primary studies covered within each of them revealed a wide array of 50 RSE programmes specifically designed for individuals with intellectual disabilities.

Addressing the second research question about the *characteristics of RSE programmes* addressing individuals with intellectual disabilities, the analysis revealed a predominant focus on abuse prevention, HRs, SRH, as well as anatomical and bodily differences. A significant emphasis is placed on biological and anatomical contents, as well as the risks associated with sexuality, sidelining more social or

personal aspects. However, sexuality is a social construct, and as such, any proposal for RSE programmes must stem from the specific social and cultural reality being addressed. In other words, adapting the content and format of RSE programmes to an individual's context is crucial to ensure effectiveness and relevance and making empowerment a reality for this group (Chou et al., 2020). Actually, the nine reviews emphasised the necessity for RSE programmes to (a) be designed within a recognised theoretical framework (Brown et al., 2020) and a person-centred approach (Gil-Llario et al., 2022; McCann et al., 2019); (b) be applied considering individual differences and in cooperation with families (Pérez-Curiel et al., 2023); (c) solely concentrated not only on biology-related and self-awareness/safety aspects (Sala et al., 2019) but also on broader content related to personal sexuality (e.g., sexual orientation, masturbation) and interpersonal relationships (e.g., dating, emotions, parenthood) and (d) facilitate the gradual acquisition of both knowledge and skills over time to ensure generalisability (Schaafsma et al., 2014). Nevertheless, it is noteworthy that group interventions are predominant, typically spanning approximately 10 sessions, each lasting around 90 min (summing up to 24–30 h in total). Considering the importance of tailoring interventions to individual requirements, the flexibility to modify session numbers and durations could enhance outcomes for both individuals and groups: interventions should be fine-tuned to suit unique needs.

In terms of the addressed population, RSE programmes primarily encompass both genders, with a notable focus on women in abuse prevention programmes. Only one intervention focused on children, while a substantial number are aimed at teenagers or adults up to 70 years old, revealing the importance of addressing sexuality across life stages (Dyer & das Nair, 2013). Tailoring RSE programmes to different age groups' specific needs is crucial: for instance, providing FP information for young adults and addressing menopause-related changes for middle-aged women (Moore et al., 2023). Additionally, addressing individuals with intellectual disabilities and high support needs remains a challenge. Few RSE programmes explicitly include participants with severe intellectual disabilities, and none cater to individuals with profound intellectual disabilities (Björnsdóttir & Stefánsdóttir, 2020).

The third research question concerned the *effectiveness of RSE programmes* for individuals with intellectual disabilities. Even though 50 RSE programmes were analysed, none of them were repeated in more than one study or in the same study at different time points. This lack of replication hinders the availability of solid evidence regarding their validity or effectiveness. Regardless, the findings from each programme strongly supported the effectiveness of RSE programmes for people with intellectual disabilities boosting knowledge, changing perceptions, raising awareness and enhancing decision-making abilities. The RSE programmes appear to be useful, particularly in terms of improving participants' knowledge about sexuality (Black & Kammes, 2021; Paulauskaite et al., 2022), but not as much when it comes to the generalisation of skills and behaviours to natural contexts and the sustainability of changes (McCann et al., 2019; Schaafsma et al., 2014).

Although assessed outcomes were broad (mainly sexual knowledge, but also SSs, quality of life, interpersonal violence, empathy), however, most of the RSE programmes use nonvalidated ad hoc scales. While the majority of programmes achieved moderate to good scores, none reached the maximum score. Key limitations of the RSE programmes include the absence of control groups, lack of multiple outcome measures and follow-up, as well as vague or nonrigorous descriptions of the data analysis process. Indeed, the reviews concur in pointing out the limitations and lack of quality in the examined RSE programmes (Brown et al., 2020; Sala et al., 2019), often due to the lack of specificity in their objectives and detailed descriptions of materials and methods, making it challenging to determine the conditions under which they prove effective (Schaafsma et al., 2014). In this context, it becomes evident the necessity for longitudinal and replication studies across diverse contexts and the enhancement of inclusivity in recruitment processes.

This umbrella review encounters several limitations. First, there is a possibility that relevant systematic reviews were missed, as well as RSE programmes for individuals with intellectual disabilities that were not covered in the analysed reviews. Second, the limited participant recruitment in many interventions poses a challenge for generalising the results. The absence of representation from individuals with severe or profound intellectual disabilities highlights the need for caution when considering proposed RSE programmes, emphasising the importance of tailoring approaches to individuals. Another limitation is the broad range of search terms, which, while designed to encompass a wide array of references on the topic, may have unintentionally excluded relevant studies. Additionally, not conducting a meta-analysis of the identified RSE programmes is another limitation. This omission hinders a comprehensive exploration of the results, the synthesis of findings, investigation of effect sizes and analysis of outcome differences. Future research should consider incorporating meta-analysis to enhance precision in effect estimation and increase the power to detect important effects.

Despite these limitations, this umbrella review possesses notable strengths. Adhering to the most recent PRISMA guidelines enhances reproducibility and reliability, reducing variability and uncertainty, thus facilitating robust conclusions on this crucial topic. The high percentage of inter-rater agreements and the evaluation of the quality of included references further contribute to the credibility of this review.

5 | CONCLUSION

There is a compelling need for future research efforts to be rooted in an intersectional framework of human rights, social justice and empowerment when addressing the complexities of sexuality among people with intellectual disabilities. By acknowledging the agency, self-determination and inherent dignity of people with intellectual disabilities, society cannot afford to neglect the need for tailored RSE programmes. They serve as crucial tools to break the cycle of vulnerability and ignorance that hinder people with intellectual

disabilities, the opportunity to make informed decisions regarding their bodies, relationships and personal boundaries. Research points to the necessity for further advancement in this area, including attitudes, RSE programme effectiveness and person-centred approaches that foster empowerment. Recognising the importance of sociocultural nuances within specific contexts is pivotal for ensuring the efficacy and relevance of any RSE programme.

Despite the incremental progress, it is essential to recognise the persistent challenges that impede the full generalisation of acquired skills and behavioural changes. While some research has shed light on these complexities, they invite deeper exploration and refinement of RSE programmes, addressing the existing gaps. In summary, this research is not just a culmination but a compelling call for an inclusive and empowered future for the sexuality of people with intellectual disabilities.

Future research should conduct a comprehensive analysis of how different methodologies influence the outcomes of such interventions, participant engagement and the achievement of objectives. This deeper exploration will provide a more comprehensive understanding of both what has been done and how it has been done, enabling professionals to apply these insights into their specific contexts.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The authors confirm that the data supporting the findings of this study are available within the article and its Supporting Information materials.

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