

SYSTEMATIC REVIEW

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Young people with disabilities and their sexual health: a descriptive review of needs, recommendations and interventions

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Abstract

Background Worldwide, almost 180 million young people aged between 10 and 24 live with disability. They are often perceived as asexual, lacking in sexual desires, or as sexually inadequate. The sexual health of young people with disabilities thus remains a blind spot in health promotion. The aim of this descriptive review was to describe and analyze articles exploring needs, recommendations and interventions for promoting the sexual health (SH) of young people with disabilities.

Methods We searched the PubMed and PsycINFO databases for international scientific articles on SH needs, recommendations or health promotion interventions for young people with disabilities (aged 10–24), published after 2013. Data were extracted using a standardized grid and analyzed quantitatively and qualitatively.

Results Twenty-one articles were included, encompassing 13 SH interventions, 6 SH need studies, and 2 recommendations studies. Most studies were carried out in the United States (12/21), focusing on intellectual disability (6/21), with 7/21 studies involving parents. Among the needs studies, 2/6 explored the specific needs of young people, while the remaining 4 asked about their difficulties. None of the interventions were designed, co-constructed, or facilitated by young people with disabilities.

Conclusion Very few studies have been done to understand the needs and to develop relevant interventions for promoting the sexual health of young people with disabilities. Research with rigorous methodologies is still required to better understand needs and to intervene as relevantly as possible. To this end, participatory research would be a valuable methodology, as it involves target audiences in the various stages of research.

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Keywords Adolescent health, Young adults, Adolescent sexual health, Disabled persons, Health promotion

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Introduction

Around the world, nearly 180 million young people aged 10 to 24 live with a significant physical, sensory, intellectual or mental disability that impacts their daily lives [1]. Over the last 20 years, increasing attention has been paid to their rights to access education, employment and housing [2]. However, young people with disabilities are still under the “stigma of disability” [3, 4]. Because of this stigma, people with disabilities are perceived “as asexual, lacking sexual feelings and desires, or as sexually inadequate” [5]. Such a perception probably explains why most of these young people still do not receive comprehensive sexual education [6, 7]. Very few programs and resources aim to teach and assist young people with disabilities to develop healthy relationships and to keep themselves safe [8].

However, an increasing body of scientific literature has shown that young people with disabilities have needs related to their sexual and reproductive health. A study in the United States published in 2020 concluded that adolescents and young adults with mild to moderate intellectual and/or developmental disabilities were just as likely to be sexually active as their peers without disabilities [6]. Individuals with disabilities experienced higher rates of sexual abuse [9]. A Canadian study published in 2019 found that individuals with disability had a 4–10 times greater risk for sexual abuse than the general public [8]. This high rate of sexual abuse is also supported by a study carried out in the United States which estimated that the lifetime risk of sexual abuse could be around 25% for women with intellectual disability [6]. These findings have increased awareness of the need to develop interventions for sexual and reproductive health and to affirm the rights of young people with disabilities [10].

Sexual and reproductive health education is considered as a top priority intervention for the general population [11] and is now viewed as important for young people with disabilities [9, 10]. It requires new approaches since as yet they receive little or no formal sexual health education [12]. School personnel lack training and there is a dearth of materials appropriate to the special needs of these students [12]. To develop such a new approach, the first step would be to carry out a descriptive overview of the sexual health needs of young people with disabilities and of the current recommendations and health promotion interventions that have already been developed. Through a descriptive review of published scientific studies, we aimed to identify the sexual health needs of young people with disabilities and to describe the existing recommendations and interventions for sexual health promotion.

Methods

This descriptive review was structured in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Supplementary Material 1) [13]. The study protocol has previously been published in the PROSPERO International Prospective Register of Systematic Reviews (PROSPERO 2023 CRD42023421365) (Supplementary Material 2).

Inclusion and exclusion criteria

Studies were included according to the following criteria: (1) study of young people aged 10–24 years according to the WHO definition (average age or age range 10–24 years) [14]; (2) study of a population with disabilities (disability according to the WHO international classifications and/or resulting from chronic diseases [15], which include a wide range of disabilities from autism to cancer); (3) study targeting at least one of the following aims for health promotion: (i) assessing the need to develop health promotion, (ii) establishing recommendations, good practices or guidelines to develop health promotion, (iii) presenting an intervention for health promotion; 4) study on sexual and reproductive health, 5) study published after 2013 in English, French or Spanish.

Studies were excluded according to the following criteria: (1) the full text could not be accessed despite requests to the corresponding author, (2) the Methods section failed to provide most basic information (in particular, intervention studies that failed to include a basic description of the intervention).

Search strategy

To determine the perimeter of the search (peer-reviewed publications only or inclusion of gray literature also), attempts were undertaken to prospect the gray literature. These exploratory tests showed that the great majority of the gray literature would be excluded because their Methods sections failed to provide the most basic information. We therefore restricted our search to peer-reviewed publications.

The international peer-reviewed literature was searched through PubMed and PsycINFO, which are the two reference databases for systematic reviews in public health.

The search was organized using four groups of keywords and terms of reference: 1) population (youth and adolescence); 2) disabilities; 3) sexual health promotion needs, recommendations, or interventions; and 4) sexual and reproductive health. Two search strategies were tested: truncation versus use of synonyms and lexical fields. The second option was selected as the more effective. The electronic search strategy is described in Supplementary Material 3.

Study selection

References collected through the search strategy were assessed by the first author (N.V.) and verified by a second reader (E-B.G.) in a three-step process. First, they independently screened the titles and abstracts to identify eligible studies. When the abstract was not sufficiently clear to determine eligibility, the full text was read. Disagreements between the two readers who reviewed the titles and abstracts were resolved by discussion and with the third author (P.M.), who also read the title and abstract of the reference. Secondly, the full text of studies selected during the first step was retrieved. When the full text could not be retrieved, the corresponding author was contacted by email. Lastly, two readers (N.V. and E-B.G.) read all the full texts retrieved and independently evaluated their eligibility for inclusion. Studies that did not sufficiently describe their needs, recommendations or intervention methods were excluded. As previously, disagreements were resolved by discussion and by another of the authors (E.L.R.), who also read the full text. Articles published up to October 16, 2023 were evaluated.

Data collection

A standardized data collection form was developed and approved by the three authors. This extraction grid was developed following the PICOTS framework (Populations, Interventions, Comparators, Outcomes, Timing, and Setting) to collect information. The studies were classified according to three different types: needs, recommendations and interventions. The extraction grid collected data on study characteristics, target population, specific sexual health theme, descriptive data on needs, recommendations or interventions, and the limitations and biases stated by the authors. Two authors (N.V. and P.M.) reviewed the references and independently extracted data from the studies.

Analysis

A descriptive analysis was carried out on the type of study collected, the content of the references (study population, sexual health needs, recommendations, and interventions) and the methodologies employed. The quality of the studies included was assessed according to the percentage of completion of the extraction grid. Evaluation results were not analyzed due to the major differences in objectives, methods and results of the studies.

Results

The electronic search strategies identified a total of 2820 references after removing duplicates (Fig. 1). Based on title and abstract screening, 112 full texts were evaluated, and 21 studies were included in this review. Inter-reader agreement for the 21 studies finally selected was 81.25%.

These studies included are cited in Supplementary Material 4.

Description of the studies and populations

Twelve of the 21 studies were published between 2013 and 2018 (Table 1) [16–27]. Most were intervention studies (13/21), while 6 studies investigated the sexual needs of young people. Studies were mostly based on collaboration between professionals in the field and researchers (9/21), or on researchers only (8/21). No study was conducted with the participation of young people with disability. These studies are detailed in Supplementary Material 5 (including the disciplines, subjects and study populations, etc).

The study populations were mainly from the United States (12/21 studies) [16, 18, 19, 23, 25, 28–34] and from Europe (6 studies) [21, 22, 24, 26, 35, 36] (Table 2). Only three studies were from other geographical zones (2 studies from Turkey and one from Cuba) [17, 20, 27]. Fourteen of the 21 studies exclusively included young people, whereas 6 of 21 included their parents [18, 23, 27, 29, 32, 33] (5 studies included parents only). Regarding age group, 6 of the 21 studies covered teenagers [10–17 years] [17, 18, 20, 26, 29, 32], 4 included young adults [18–24 years] [19, 21, 28, 36] and 6 included both [10–24 years] [16, 22–24, 31, 35]. Five of the 21 studies provided no details on population age, stating only that they were young people [25, 27, 30, 33, 34]. Six of the 21 studies dealt exclusively with intellectual disabilities [17, 27, 29, 33, 35, 36], 5 exclusively with autism spectrum disorder [18, 21, 23, 26, 32] and 4 with spina bifida [16, 30, 31, 34]. Concerning living arrangements, in 10 studies the young people lived with their parents (4/10 young people with autism, 4/10 young people with intellectual disabilities, 1/10 with Down syndrome and 1/10 with neurological diseases), while 11 studies provided no information on this point [16, 17, 19–21, 24, 25, 30, 31, 34, 36].

Sexual health needs studies

Six of the 21 studies aimed to explore the sexual health needs of young people with disabilities [16, 21, 23–25, 36]. Of these 6 needs studies, 2/6 dealt with autism [21, 23], 1/6 with intellectual disabilities [36], 1/6 with spina bifida [16], 1/6 with cancer [24] and 1/6 with mobility impairment [25]. Two of these 6 studies specifically inquired about young people's needs, while the other 4 inquired about their difficulties. Four of the 6 studies asked the young people themselves about their needs [16, 21, 24, 36], while 2 asked parents or health professionals [23, 25] (one of these two studies dealt with autism spectrum disorder and the other with young people with mobility impairment). The sexual needs identified were usually formulated in a very broad and non-specific way in terms of “intervention needs” rather than “sexual

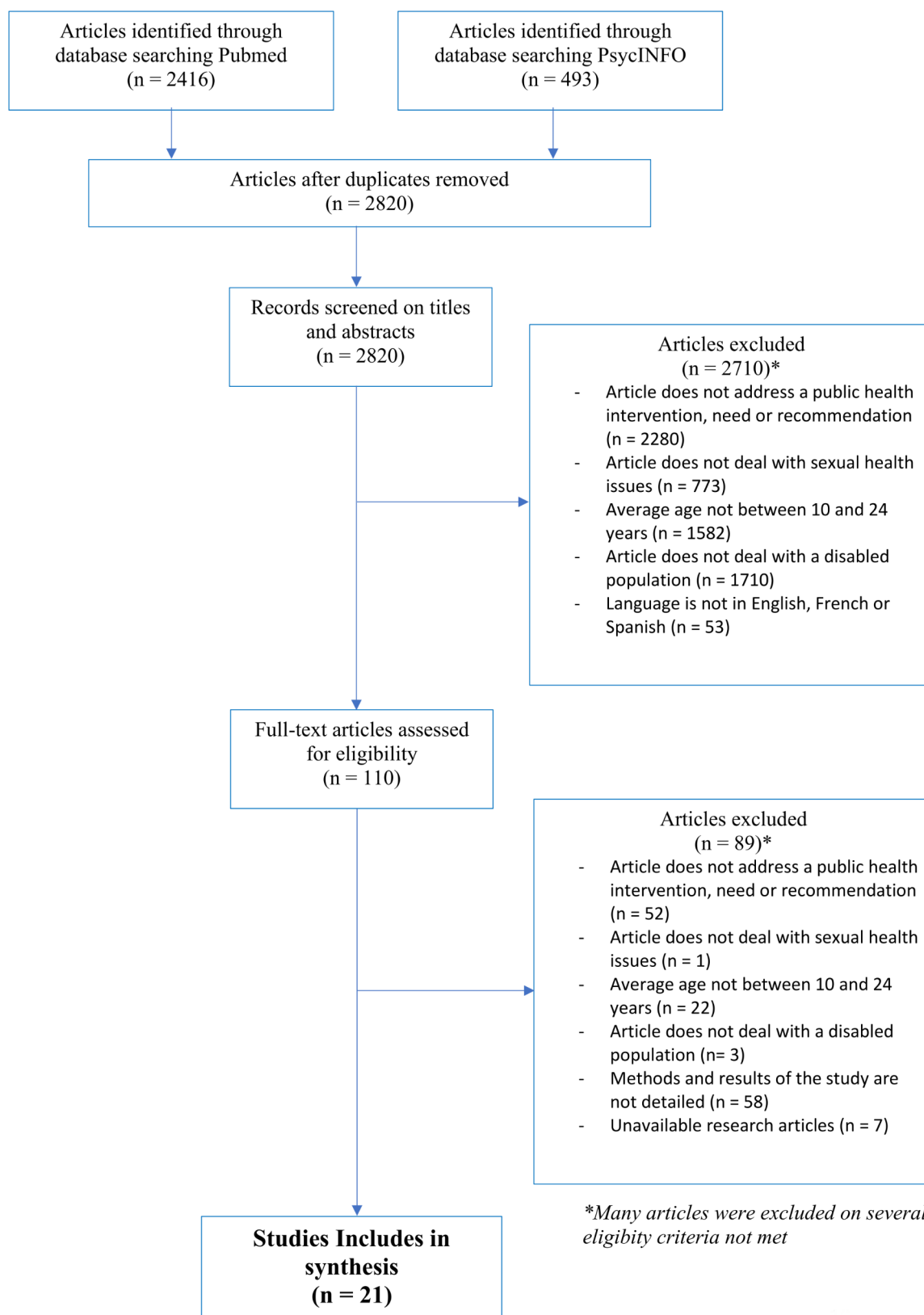
**Fig. 1** Flow chart of the literature reviewing process

Table 1 Characteristics of the 21 articles reviewed

	<i>n</i>	%*
Year of publication**		
2013–2018	12	57
2019–2023	9	43
Purpose of the study		
Intervention	13	62
Needs	6	29
Identified as a need and as a difficulty	5	24
Identified as a difficulty only	1	5
Recommendations	2	10
Study objective		
Determine sexual and reproductive health (SRH) knowledge and needs	6	29
Evaluation of an SRH intervention only	6	29
Implementation and evaluation of SRH interventions	3	14
Implementation of SRH training/intervention/education only	2	10
Develop and diffuse a guide or recommendations to promote SRH	2	10
Description of an SRH educational intervention	1	5
Description of the challenges for SRH education	1	5
Type of study		
Intervention studies		
Pre-post study	8	38
Randomized controlled trial	2	10
Quasi-experimental	1	5
Prospective pilot study of implementation and pre-post study	1	5
Intervention description	1	5
Needs studies		
Cross-sectional	4	19
Longitudinal prospective	1	5
Cohort	1	5
Recommendations studies		
Literature synthesis	1	5
Working group	1	5
Method		
Mixed method	8	38
Quantitative	6	29
Qualitative	4	19
No information***	3	14
Investigators conducting the study		
Professionals in the field and researchers	9	43
Researchers and research students only	8	38
Professionals in the field only (healthcare professionals, teachers, social workers...)	4	19
Participatory research	0	0

* The totals do not systematically add up to 100% due to rounding. **Time period limited to 10 years. ***Study of recommendations or description of intervention

health needs” (for example, need for theoretical learning and need for education about sexuality). Three studies cited the need for parental involvement in their children’s sexual education (for young people with autism, mobility impairment and spina bifida) [16, 23, 25], but in 2 of these, this need was expressed by parents or health professionals [23, 25]. A table in the Appendix cross-references the different needs by type of disability (Supplementary Material 6).

Recommendations studies

In the two studies on recommendations [30, 34], some recommendations met the needs identified in the 6 studies on sexual health needs. Some recommendations such as “make the parents educational partners”, “provide age- and stage-appropriate education” or “discuss healthy relationships and safe-sex practices” were in line with perceived needs.

Table 2 Study populations of the 21 articles

	<i>n</i>	%*
Country of the study		
United States of America	12	57
United Kingdom	2	10
Turkey	2	10
The Netherlands	2	10
Poland	1	5
Cuba	1	5
Sweden	1	5
Population		
Young people	14	67
Parents	5	24
Young people and parents	1	5
Healthcare professionals	1	5
Age		
Teenagers (10–17 years)	6	29
Teenagers and young adults (10–24 years)	6	29
No details but focus on young people	5	24
Young adults (18–24 years)	4	19
Gender		
Both	16	76
Female	4	19
No information	1	5
Living arrangements		
Young people living with their parents	10	48
No information	11	52
Disability		
Intellectual and developmental disabilities	6	29
Autism spectrum disorder exclusively	5	24
Spina bifida	4	19
Neurological diseases**	2	10
Diabetes	1	5
Intellectual and developmental disabilities and autism	1	5
Down syndrome	1	5
Cancer	1	5

* The totals do not systematically add up to 100% due to rounding. ** Spina Bifida, cerebral palsy, neuromuscular diseases, mobility impairments

Intervention studies

The 13 intervention studies are presented in Table 3 [17–20, 22, 26–29, 31–33, 35]. The purpose of the interventions was principally to instruct and provide appropriate sexual education (7 of 13 studies). Ten of the 13 interventions were collective actions (5/10 for young people with intellectual disabilities [17, 19, 27, 29, 33], 2/10 those with autism [18, 32], 1/10 with diabetes [20], 1/10 with spina bifida [31] and 1/10 with neurological diseases [22]). Five of the 13 interventions were addressed in whole or in part to parents [18, 27, 29, 32, 33] and 4 exclusively addressed parents of young people with intellectual disabilities or autism [27, 29, 32, 33]. The interventions were developed by researchers only (5 of 13) [18, 19, 26, 27, 32] or by health professionals only (5 of 13) [17, 20, 22, 29, 31], while 3 interventions were designed by both researchers

Table 3 Interventions carried out (*n* = 13 articles)

	<i>n</i>	%*
Purpose of the interventions		
Instruct/provide appropriate sexuality and sexual education to the young	7	54
Encourage, communicate and provide sexuality training/education to parents	4	31
Provide sexuality education to adolescents and their parents	1	8
Promote sexual health and help to discuss sexuality and relationship issues	1	8
Type of the intervention		
Collective action	10	77
Group educational workshop and training using assortment of activities	5	39
Group education training using role-playing	3	23
Group curriculum/education session	2	15
Individual action	3	23
Individual training program	1	8
Online role-playing intervention	1	8
Online intervention and curriculum	1	8
Intervention designer		
Healthcare professionals only (including sexologist)	5	39
Researchers only (including health agency)	5	39
Researchers and healthcare professionals	3	23
Young people with disabilities	0	0
Intervention leader		
Healthcare professionals	5	39
Researchers (including research students)	3	23
Healthcare professionals and researchers	3	23
Teachers and healthcare professionals	1	8
Teachers, researchers and healthcare professionals	1	8
Disabled peers	0	0
Specific action for disabled young people		
Specific	12	92
No information	1	8

* The totals do not systematically add up to 100% due to rounding. ** Participatory workshops, talk groups, peer counseling, etc., *** Application, website, online games...

and healthcare professionals [28, 33, 35]. None of the interventions were designed, co-constructed, or facilitated by young people with disabilities. A summary table of the interventions presenting the type of information, sexual health topic addressed, objectives, progress and description of the interventions further illustrates the above comments (Supplementary Material 7).

Table 4 describes the evaluation methods used for the 13 interventions. All intervention studies carried out an effectiveness evaluation, with process evaluation (8/13) [18, 19, 22, 26, 27, 31, 32, 35] or without (5/13) [17, 20, 28, 29, 33]. Twelve of these 13 intervention studies were pre-post evaluation studies and one provided no information on this point [29]. Four of the 13 intervention studies did not report their outcomes [17, 22, 29, 31]. The majority (7/13) of the intervention studies evaluated a population

Table 4 Methods used to evaluate the interventions ($n = 13$ articles)

	<i>n</i>	%*
Nature of the evaluation		
Effectiveness and process	8	62
Social validity (process)	3	23
Feasibility only (process)	2	15
Feasibility and satisfaction (process)	1	8
Satisfaction and utility (process)	1	8
Feasibility and acceptability (process)	1	8
Effectiveness only	5	39
Process only	0	0
Study design of the evaluation		
Pre-post study	12	92
No information	1	8
Research outcomes		
No information	4	39
Knowledge and cognitive outcomes regarding sexuality	3	23
Sexual behaviors and knowledge/cognitive outcomes regarding sexuality	3	23
Sexual behaviors	1	8
Appropriate social interactions	1	8
Attitudes/beliefs about sexuality and level of comfort in communication	1	8
Evaluation sample size		
$n < 10$	3	23
$11 < n < 30$	4	31
$31 < n < 50$	2	15
$51 < n < 100$	2	15
$n > 100$	1	8
No information	1	8
Assessment quality		
Precise/complete (85–100% of the extraction grid could be completed)	6	46
Information lacking (50–84% of the extraction grid could be completed)	1	8
Poor and imprecise (5–49% of the extraction grid could be completed)	5	39
No assessment described	1	8

* The totals do not systematically add up to 100% due to rounding

size of less than 30 [18, 20, 22, 28, 31, 33, 35]. Lastly, regarding the quality of assessment, the methods used to evaluate the interventions were not fully described in the majority of intervention studies (7/13), and 85% of the extraction grid could be completed in only 6 studies. To illustrate this point, the evaluations of the interventions have been described in greater detail in the Appendix: type of evaluation, measurement tools, evaluation design, description and evaluation results (Supplementary Material 8).

Discussion

Principal findings

Over the last decade, only 21 studies have explored sexual health needs, recommendations and interventions for

young people with disabilities. In addition, more studies address interventions than sexual health needs, even though such interventions should be needs-based. This descriptive review revealed several limitations of the sparse existing literature and identified two main issues: 1) the need for solid methodology to develop appropriate interventions, 2) the difficulty of asking concrete questions about the sexual health needs of young people with disabilities.

How can robust research methods in sexual health promotion for young people with disabilities be developed?

Concerning the quality of the studies analyzed, this descriptive review revealed major methodological limitations in the articles selected. In the 13 intervention studies the number of participants was very low, with over half including fewer than 30 participants in both the interventions and evaluations. This raises the question of whether these results can truly be generalized to disabled young people, given the small sample sizes [37]. Moreover, a clear description of the research processes of these intervention studies was often lacking. A single study stated that it followed the Medical Research Council (MRC) guidelines for development of complex interventions [38]. Moreover, most articles (7/13) did not accurately describe the methodology used to evaluate the effectiveness of the intervention, and it was not possible to complete the evaluation section of the extraction grid for these studies in our review. For example, it was not always possible to identify the hypotheses evaluated, outcomes targeted, or numbers of subjects. Lastly, it was possible to complete 85% of the evaluation part of the extraction grid for only 6 of 13 studies.

Description of the methodology and rigorous evaluation would have provided essential information on the effectiveness and usefulness of interventions. A 2006 study highlighted the importance for researchers of evaluative research for improving knowledge, decision-making and practical application [39].

Only two recommendation studies were retrieved, showing how little information is available on concrete recommendations for young people with disabilities. Moreover, these two studies did not describe their method for drawing up their recommendations, and spoke only of “professional grouping”. Nor did they use scientific consensus methods for understanding reasons for disagreements in the development and choice of recommendations [40]. Without a consensus method, it is questionable whether these recommendations are really reliable, and whether a larger number of experts in the field would agree with them [40]. According to a literature review published in 2022, consensus development methods facilitate the decision-making process [41]. To

guarantee the reliability of a consensus, common basic principles such as subject definition, expert selection and direct or remote interaction processes are essential. Few validation studies have been carried out. The failure to implement these basic principles and the absence of scientifically validated consensus methods are two frequent reasons for suspicion about the validity of consensus methods [42]. These principles are essential to ensure consensus on common ground [42].

Professional consensus, in the broadest sense of the term, must also be applied to the development of methodologies. On the one hand, intervention methodologies cannot be effective without the involvement of field workers, who are essential to the successful creation and running of interventions. Field workers are indispensable to adapt to the specific needs of the young people, needs that differ greatly depending on their disabilities. For example, young people with an intellectual disability may have specific needs due to slower cognitive processing time, difficulties in generalizing and applying what has been learnt to a new context, difficulties in processing language, and the need to repeat things to acquire new knowledge [43]. On the other hand, research professionals are needed to validate, verify and transpose research methods. Unfortunately, most of the interventions identified in the review were developed either by researchers (5 of 13 studies), or by professionals working in the field (5 of 13 studies). These two milieus rarely collaborate in the development and evaluation of interventions (3 of 13 studies). However, such collaboration seems essential. A 2010 Norwegian study, as well as an integrative literature review, highlighted the importance of research in improving professional practices and knowledge [44, 45]. Conversely, the involvement of field professionals in research can provide practical solutions to a problem and make actions more relevant [46, 47].

How can we study the real sexual health needs of young people with disabilities?

Few studies in this descriptive review explored the sexual health needs of young people with disabilities. These needs were expressed more as general needs for sexual education/intervention than specific sexual health needs. Moreover, needs studies addressed difficulties much more than needs. For example, researchers found that young people spoke of a lack of intimacy in their sexual lives, but the researchers did not explore concrete needs to guarantee greater intimacy (such as spaces dedicated to their sexual lives).

One possible explanation of this orientation toward difficulties instead of needs could be that researchers do not interview the right informants. In our descriptive review, 2 of the 6 needs studies and 5 of the 13 interventions did not interview the young people themselves, but instead

interviewed parents or healthcare professionals on the needs of young people with disabilities. This finding is in line with a 2010 Australian study suggesting that most research on children with disabilities relied on parents or guardians to gain insight into their child's experiences [48]. Communicating with young people with communication or learning disabilities can be particularly difficult [49]. For this reason, professionals often turn to parents to re-establish communication [49]. This approach could have major consequences, as we may posit that when parents and healthcare professionals are questioned, they are not able to discuss needs, but only the difficulties young people with disabilities are facing and how to deal with them. Needs and difficulties can only be expressed by the young people themselves.

This limitation in published studies could explain why very few articles use or mention digital media as a potential medium for promoting the sexual health of young people with disabilities. If young people themselves had been interviewed, these media would probably have emerged, considering the importance of social media in young people's lives. In other contexts, digital sexual health interventions have proved effective in acquiring knowledge and developing healthy sexual behavior, and they could make a useful contribution to sexual health education in schools, clinics and directly online [50].

Interviewing young people with disabilities can be challenging. They often have difficulty expressing and understanding their emotions and needs [51]. A 2009 study carried out in the United States indicated that some young people with certain disabilities (cerebral palsy, intellectual disability, Down syndrome, developmental disorder) may have impairments in language production or comprehension [52]. A United States study published in 2001 found that much of the responsibility for the immediate communication of young people with intellectual disabilities lies with adult communication partners and peers who have typical communication skills [53]. Little research has been undertaken on how children with disabilities are encouraged to express their opinions and difficulties and to participate in decision-making [54]. Researchers and professionals in all fields are often ill at ease with sexual health issues and are not trained to deal with them adequately [55]. A UK study published in 2005 found that most general practitioners were relatively unprepared for contraceptive and sexual health care, and that their training and assessment should be improved [56].

Adolescent voices are still largely excluded from research and decision-making processes affecting their own lives [57]. Young people with disabilities are perceived as eternal children with no gender identity [58]. The difficulties of communicating with disabled young people and the greater perceived accessibility of parents

raise the question of how researchers can be trained to investigate, question and understand the point of view of disabled young people and non-verbal communication. To achieve this aim, appropriate research methodologies need to be developed to explore the real needs of this population.

None of the 21 studies selected in this review cited participatory research or the involvement of young people with disabilities in their studies or methods. Involving the young people concerned in research can open up new perspectives and new possibilities to affirm or challenge existing work [59]. Young people with intellectual disabilities should be actively involved in planning their learning, with in-depth interviews to explore how they would like information about sex education to be delivered and what sexuality topics they would like to discuss and find out more about [60]. Participation of young people in research, not only by questioning them, but also by involving them in research methods and intervention design, is increasingly being encouraged, considering them as the best partners to raise their own issues and judge the adequacy of the actions [61]. To achieve improved research, it seems important to question young people at every stage. For example, if we were to address the communication problem discussed above, involving disabled young people in the design, formulation and completion of questionnaires would enable us to create questionnaires adapted to young people and their real needs. Disabled young people need to be included at all stages of research if resources are to be developed for them. It is essential to take into account their skills and capabilities with regard to disability. In participatory research, vulnerable young people could be involved and considered as powerful agents capable of exerting political influence, so that research methodology and health promotion interventions could be better designed [62].

Furthermore, the role of specialized educators did not emerge in the 21 selected studies, even though they could be key players, essential and complementary to the role of peers and parents. Their knowledge of disability, their proximity to the young people concerned and their specific skills make them essential partners in sex education, and they should be involved at various stages of the intervention [63].

Strengths and limitations

This is the first descriptive review of needs, recommendations and interventions relating to the sexual health of young people with disabilities. It takes into account the broad spectrum of disability, based on scientific articles published in international peer-reviewed journals to provide a solid base for analysis. One of the strengths of this review is that it covers sexual health needs, recommendations and interventions in the same study.

Methodologically, its strength lies in the double reading and double extraction of the articles included, ensuring the validity of its findings.

Regarding limitations, only a small number of studies were retrieved and young people with disabilities are still a blind spot in public health research on sexual education. However, it would be interesting to extend this work beyond PubMed and PsycINFO by including other databases. A prospective exploratory study recommended that to optimize searches in systematic reviews, at least Embase, Medline, Web of Science and Google Scholar should be searched to achieve an adequate and efficient coverage [64]. Extending this literature review to the Google Scholar database would have allowed us to include other relevant articles [8, 43, 60]. Another refinement would be to consider literature beyond public health, particularly by reviewing literature in the educational sciences. Works in this field are sparsely referenced in PubMed and PsycINFO, and to include them it would be interesting to search ProQuest and CINHALL as well.

An important limitation of this work was that the 21 selected papers did not always fully describe their methodology and it was difficult to compare one study with another.

Another limitation was that because of the small number of studies selected, it was not possible to analyze them according to type of disability. Lastly, most studies were carried out in high-income countries and these findings should not be generalized worldwide.

Conclusion

Given the very limited number of articles included in this review, we can conclude that little attention has been paid to the sexual health needs, recommendations and interventions of young people with disabilities. In addition, the few studies addressing this topic often encountered several methodological limitations. This underscores the need to develop rigorous research methods for addressing the sexual health of disabled young people and developing appropriate interventions. In this context, participatory research seems an interesting and useful approach. It would make it possible to create a health democracy in research and health policies that could respond to the sexual health needs of all stakeholders and targeted populations.

Abbreviations

MRC	Medical Research Council
PICOTS	Populations, Interventions, Comparators, Outcomes, Timing, and Setting
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
WHO	World Health Organization

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12889-025-21927-w>.

Supplementary Material 1: PRISMA 2020 Checklist

Supplementary Material 2: PROSPERO protocol

Supplementary Material 3: Search strategies

Supplementary Material 4: Studies included in the descriptive review

Supplementary Material 5: Studies and populations included

Supplementary Material 6: Description of sexual health needs

Supplementary Material 7: Interventions included

Supplementary Material 8: Evaluation of the interventions

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Author contributions

N.V. contributed to every stage of this article: from the conception of this descriptive review, to the design of the method, to the collection and analysis of the data and the writing of the article in its entirety. E.L.R. contributed to the design of the descriptive review and the work on the method. E.L.R. took part in analysing the data from the descriptive review and was involved in writing the scientific article. P.M. contributed to the design of this descriptive review and the work on the method. P.M. participated in the extraction and analysis of data from the descriptive review and was involved in writing the scientific article. All the authors approved the submitted version of the scientific article. E.L.R. contributed to the design of the descriptive review and the work on the method. E.L.R. took part in analyzing the data from the descriptive review and was involved in writing the scientific article. P.M. contributed to the design of this descriptive review and the work on the method. P.M. participated in the extraction and analysis of data from the descriptive review and was involved in writing the scientific article. All the authors approved the submitted version of the scientific article.

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Data availability

The datasets generated and/or analyzed during the current study are available in Supplementary Material 4 and via the PubMed and PsycINFO databases.

Declarations

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