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SYSTEMATIC REVIEW

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

Noëline Vivet^{1,2,3*}, Elise de La Rochebrochard^{1,5}  and Philippe Martin^{1,3,4}

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.

PROSPERO registration number PROSPERO 2023 CRD42023421365.

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

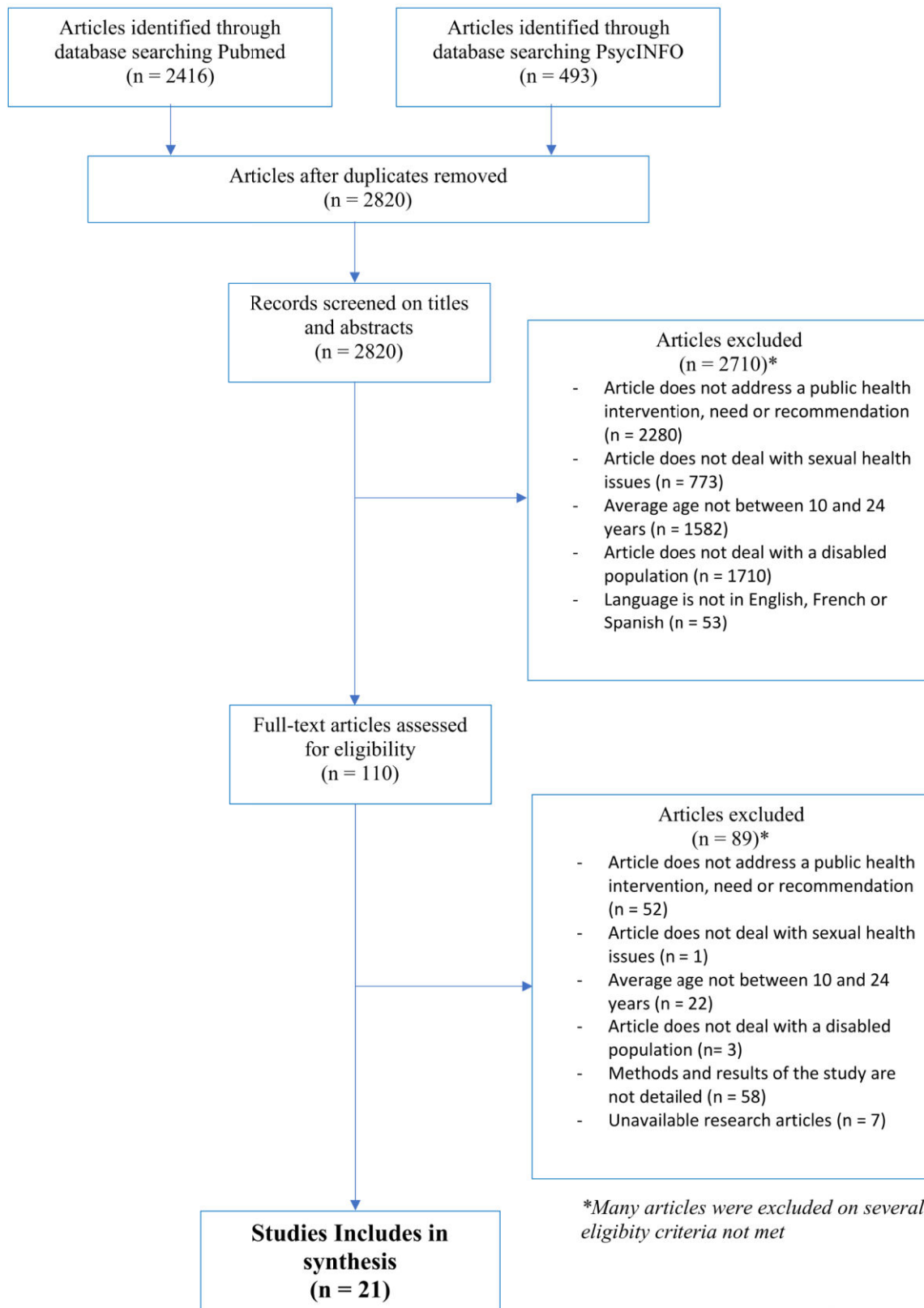


Fig. 1 Flow chart of the literature reviewing process

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

	n	%*
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)

	n	%*
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		
<i>n</i> < 10	3	23
11 < <i>n</i> < 30	4	31
31 < <i>n</i> < 50	2	15
51 < <i>n</i> < 100	2	15
<i>n</i> > 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

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Supplementary Material 1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 Checklist



PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	

Section and Topic	Item #	Checklist item	Location where item is reported
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	
Study characteristics	17	Cite each included study and present its characteristics.	
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	
	23b	Discuss any limitations of the evidence included in the review.	

Section and Topic	Item #	Checklist item	Location where item is reported
	23c	Discuss any limitations of the review processes used.	
	23d	Discuss implications of the results for practice, policy, and future research.	
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	
Competing interests	26	Declare any competing interests of review authors.	
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n7
For more information, visit: <http://www.prisma-statement.org/>

Systematic review

A list of fields that can be edited in an update can be found [here](#)

1. * Review title.

Give the title of the review in English

Sexual and reproductive health promotion intervention needs and recommendations for adolescents and young adults with disabilities : a systematic review

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

Besoins et recommandations d'intervention en matie?re de promotion de la sante? sexuelle et reproductive des adolescents et jeunes adultes en situation de handicap : une revue syste?matique

3. * Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

01/11/2022

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

31/10/2023

5. * Stage of review at time of this submission.

This field uses answers to initial screening questions. It cannot be edited until after registration.

Tick the boxes to show which review tasks have been started and which have been completed.

Update this field each time any amendments are made to a published record.

The review has not yet started: No

Preliminary searches	Yes	No
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here.

6. * Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Noëline VIVET

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Miss VIVET

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noeline.vivet@ined.fr

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10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be

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11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person, unless you are amending a published record.**

Miss Noëline VIVET. Institut National d'Etudes Démographiques
Miss Eva-Boômie Goupande. Institut national des Études Démographiques
Mrs Elise de La Rochebrochard. Institut national des Études Démographiques
Mr Philippe MARTIN. Inserm

12. * Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

Work carried out within the framework of a doctoral thesis financed by the Doctoral School of Public Health through the University of Paris-Saclay

Grant number(s)

State the funder, grant or award number and the date of award

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country must be completed for each person, unless you are amending a published record.**

15. * Review question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

What are the needs, recommendations and interventions existing to promote the sexual and reproductive health of adolescents and young adults with disabilities

16. * Searches.

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

This review will select articles in French, English or Spanish. This review will be based on the international scientific literature through standard search engines: PubMed and PsycINFO. This review will also include a review of the gray literature, in order to have a global state of existing interventions (beyond interventions that have been the subject of scientific research studies).

17. URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search **results**.

https://www.crd.york.ac.uk/PROSPEROFILES/421365_STRATEGY_20230425.pdf

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

Basic health reproduction Health and Rights

Health promotion interventions

Science of education

Epidemiology

Social and human sciences

19. * Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

Adolescents and young adults (10-24 years of age) with one or more disabilities

20. * Intervention(s), exposure(s).

PROSPERO

International prospective register of systematic reviews

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

The interventions selected by the systematic review should be sexual health promotion interventions aimed totally or partially to young people with one or more disabilities.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

The interventions, needs and recommendations will be compared with each other and with data from the scientific and grey literature.

22. * Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

We will include all studies that describe interventions, needs or recommendations used to promote the sexual health of young people with disabilities.

Inclusion criteria:

- (1) Study of a health promotion intervention, need or recommendation
- (2) Study on one or more sexual and reproductive health topics
- (3) Population aged 10-24 years (average age or age range of at least 10-24 years) [WHO defines youth as the period between 10 and 24 years]
- (4) Population with one or more described disability situation (caused by a disability from international classifications and/or resulting from chronic diseases)
- (5) The article describes an impact of the disability on the subject's emotional, sexual, relational or reproductive life
- (6) Study in French, English or Spanish

23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

Disability affects one in six people in the European Union (EU), with a higher proportion of women than men.

More than 80 million citizens are limited in their full and effective participation in society because of environmental and attitudinal barriers. These barriers include the full and effective participation of people with

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disabilities in a safe and caring affective, sexual and reproductive life. People with disabilities have the same emotional, sexual and reproductive needs as people without disabilities. These needs are more present when we talk about young people with disabilities who are entering sexual and emotional life at the time of adolescence. The needs of these young people must be adapted to their disabilities and their specificities, to promote their well-being and autonomy. The sexual health of young people with disabilities is still a blind spot in health promotion, even though for many years research has shown the value of acting on this issue for the well-being and health of these young people. Indeed, many young people, and in particular people with disabilities, receive little or no formal education on sexual health. The few interventions aimed at promoting the sexual health of young people with disabilities focus on specific types of disability such as autism. The sexual and reproductive health of young people with disabilities is therefore still a taboo subject, little discussed in the literature or even by the various health actors. To date, no systematic review has examined existing health promotion interventions for young people for all disabilities.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

Methods and results of existing interventions, needs and recommendations aimed to promote sexual and reproductive health of young people with disabilities.

Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

- Description of disabilities requiring specific sexual health promotion for people with disabilities
- Sexual health promotion interventions, needs and recommendations in the general population that can be adapted for people with disabilities
- The intervention methods used to promote sexual health among young people with disabilities
- Description of the means of implementation and the attractiveness, acceptability and feasibility of these interventions, needs and recommendations.
- Description of the evaluation results (outcomes) of sexual health promotion interventions for young people

with disabilities

Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

The titles and abstracts of the studies will be selected through the search strategy developed will be analyzed by three different authors of the journal in order to validate or not the inclusion of an article according to the inclusion criteria established above. After selection of the articles on title and abstract (TIAB), a full reading of these articles will be carried out by these same authors to check and revise again if the articles meet the inclusion criteria in every respect. A data extraction grid will be used to collect all the data of interest in this literature review.

27. * Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

Risk of publication bias double blind reading articles by two different people

28. * Strategy for data synthesis.

Describe the methods you plan to use to synthesise data. This **must not be generic text** but should be **specific to your review** and describe how the proposed approach will be applied to your data. If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

We will provide a narrative synthesis of the results of the included studies, structured around the type of studies selected and the data relating to the study, the type of intervention, need and recommendation, characteristics of the target population, type of outcome, and content of the articles. The analysis of our data will allow us to analyze the included studies according to their population, country, study duration, quality of the intervention, specificity of the needs and recommendations. We will analyze the methods used to construct interventions, to write needs and recommendations for sexual and reproductive health promotion for youth with disabilities. Finally, we will analyze the evaluative evidence of the impact on sexual health of the established interventions and recommendations.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

No subgroup studies will be conducted

30. * Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

Cost effectiveness

No

Diagnostic

No

Epidemiologic

No

Individual patient data (IPD) meta-analysis

No

Intervention

No

Living systematic review

No

Meta-analysis

No

Methodology

No

Narrative synthesis

No

Network meta-analysis

No

Pre-clinical

No

Prevention

No

Prognostic

No

Prospective meta-analysis (PMA)

No

Review of reviews

No

Service delivery

No

Synthesis of qualitative studies

No

Systematic review

Yes

Other

No

Health area of the review

Alcohol/substance misuse/abuse

No

Blood and immune system

No

Cancer

No

Cardiovascular

No

Care of the elderly

No

Child health

Yes

Complementary therapies

No

COVID-19

No

Crime and justice

No

Dental

No

Digestive system

No

Ear, nose and throat

No

Education

No

Endocrine and metabolic disorders

No

Eye disorders

No

General interest

No

Genetics

No

Health inequalities/health equity

No

Infections and infestations

No

International development

No

Mental health and behavioural conditions

No

Musculoskeletal

No

Neurological

No

Nursing

No

Obstetrics and gynaecology

Yes

Oral health

No

Palliative care

No

Perioperative care

No

Physiotherapy

No

Pregnancy and childbirth

Yes

Public health (including social determinants of health)

Yes

Rehabilitation

No

Respiratory disorders

No

Service delivery

No

Skin disorders

No

Social care

No

Surgery

No

Tropical Medicine

No

Urological

No

Wounds, injuries and accidents

No

Violence and abuse

Yes

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.

English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

France

33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in

Vancouver format)

Add web link to the published protocol.

Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Do you intend to publish the review on completion?

Yes

Give brief details of plans for communicating review findings.?

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Public Health, Sexual Health, Reproductive Health, Youth, Adolescence, Disability

37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

38. * Current review status.

Update review status when the review is completed and when it is published. New registrations must be ongoing so this field is not editable for initial submission.

Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

Provide any other information relevant to the registration of this review.

40. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission). List authors, title and journal details preferably in Vancouver format.

Give the link to the published review or preprint.

Supplementary Material 3: Search strategies used for PubMed search and PsycINFO complementary search

PubMed search strategy

("adolescent"[MeSH Terms] OR "young adult"[MeSH Terms] OR "young people"[Text Word] OR "youth"[Text Word] OR "young"[Text Word] OR "teen*" [Text Word] OR "AYA"[Text Word]) AND ("reproductive health"[MeSH Terms] OR "sexual behavior"[MeSH Terms] OR "sexual health"[MeSH Terms] OR "sexual development"[MeSH Terms] OR "sexual relation"[Text Word] OR "relationship"[Text Word] OR "puberty"[MeSH Terms] OR "love"[MeSH Terms] OR "sexual life"[Text Word] OR "sexual reproduction"[Text Word] OR "contraception"[MeSH Terms] OR "contraception behavior"[MeSH Terms] OR "sexuality"[MeSH Terms] OR "masturbation"[MeSH Terms] OR "intimate partner violence"[MeSH Terms] OR "sex offenses"[MeSH Terms] OR "sexual harassment"[MeSH Terms] OR "abortion, induced"[MeSH Terms] OR "sexually transmitted diseases"[MeSH Terms] OR "pregnancy"[MeSH Terms] OR "pregnancy, unwanted"[MeSH Terms] OR "sexology"[MeSH Terms] OR "rape"[MeSH Terms] OR "gender identity"[MeSH Terms] OR "sex work"[MeSH Terms] OR "orgasm"[MeSH Terms] OR "erotica"[MeSH Terms] OR "sexual rights"[Text Word]) AND ("disability"[Text Word] OR "disabilities"[Text Word] OR "disabled persons"[MeSH Terms] OR "disability studies"[MeSH Terms] OR "genetic diseases"[Text Word] OR "Down syndrome"[MeSH Terms] OR "fragile X syndrome"[MeSH Terms] OR "Prader-Willi syndrome"[MeSH Terms] OR "autistic disorder"[MeSH Terms] OR "autism spectrum disorder"[MeSH Terms] OR "Asperger syndrome"[MeSH Terms] OR "craniocerebral trauma"[MeSH Terms] OR "stroke"[MeSH Terms] OR "meningitis"[MeSH Terms] OR "blindness"[MeSH Terms] OR "amblyopia"[MeSH Terms] OR "amputation"[Text Word] OR "muscular diseases"[MeSH Terms] OR "distal myopathies"[MeSH Terms] OR "quadriplegia"[MeSH Terms] OR "paraplegia"[MeSH Terms] OR "cerebral palsy"[MeSH Terms] OR "spinal dysraphism"[MeSH Terms] OR "osteogenesis imperfecta"[MeSH Terms] OR "psychotic disorders"[MeSH Terms] OR "bipolar disorder"[MeSH Terms] OR "schizophrenia"[MeSH Terms] OR "paranoid disorders"[MeSH Terms] OR "personality disorders"[MeSH Terms] OR "intellectual disability"[MeSH Terms] OR "attention deficit disorder with hyperactivity"[MeSH Terms] OR "epilepsy"[MeSH Terms] OR "diabetes mellitus"[MeSH Terms] OR "multiple sclerosis"[MeSH Terms] OR "amyotrophic lateral sclerosis"[MeSH Terms] OR "neoplasms"[MeSH Terms] OR "cerebral palsy"[MeSH Terms] OR "deafness"[MeSH Terms] OR "hearing loss"[MeSH Terms] OR "motor disabilities"[Text Word] OR "sensory disabilities"[Text Word] OR "learning disabilities"[MeSH Terms] OR "vision disorders"[MeSH Terms]) AND ("needs assessment"[MeSH Terms] OR "sex education"[MeSH Terms] OR "health promotion"[MeSH Terms] OR "health intervention"[Text Word] OR "preventive health services"[MeSH Terms] OR "education of intellectually disabled"[MeSH Terms] OR "health services for persons with disabilities"[MeSH Terms] OR "communication aids for disabled"[MeSH Terms] OR "health planning guidelines"[MeSH Terms] OR "guideline"[MeSH Terms] OR "practice guideline"[MeSH Terms])

PsycINFO search strategy

("adolescent" OR "young adult" OR "young people" OR "youth" OR "young" OR "teen*" OR "AYA") AND ("reproductive health" OR "sexual behavior" OR "sexual health" OR "sexual development" OR "sexual relation" OR "relationship" OR "puberty" OR "love" OR "sexual life" OR "sexual reproduction" OR "contraception" OR "contraception behavior" OR "sexuality" OR "masturbation" OR "intimate partner violence" OR

"sex offenses" OR "sexual harassment" OR "abortion, induced" OR "sexually transmitted diseases" OR "pregnancy" OR "pregnancy, unwanted" OR "sexology" OR "rape" OR "gender identity" OR "sex work" OR "orgasm" OR "erotica" OR "sexual rights") AND ("disability" OR "disabilities" OR "disabled persons" OR "disability studies" OR "genetic diseases" OR "Down syndrome" OR "fragile X syndrome" OR "Prader-Willi syndrome" OR "autistic disorder" OR "autism spectrum disorder" OR "Asperger syndrome" OR "craniocerebral trauma" OR "stroke" OR "meningitis" OR "blindness" OR "amblyopia" OR "amputation" OR "muscular diseases" OR "distal myopathies" OR "quadriplegia" OR "paraplegia" OR "cerebral palsy" OR "spinal dysraphism" OR "osteogenesis Imperfecta" OR "psychotic disorders" OR "bipolar disorder" OR "schizophrenia" OR "paranoid disorders" OR "personality disorders" OR "intellectual disability" OR "attention deficit disorder with hyperactivity" OR "epilepsy" OR "diabetes mellitus" OR "multiple sclerosis" OR "amyotrophic lateral sclerosis" OR "neoplasms" OR "cerebral palsy" OR "deafness" OR "hearing loss" OR "motor disabilities" OR "sensory disabilities" OR "learning disabilities" OR "vision disorders") AND ("needs assessment" OR "sex education" OR "health promotion" OR "health intervention" OR "preventive health services" OR "education of intellectually disabled" OR "health services for persons with disabilities" OR "communication aids for disabled" OR "health planning guidelines" OR "guideline" OR "practice guideline")

Supplementary Material 4: Studies included in the descriptive review

- Akre C, Light A, Sherman L, Polvinen J, Rich M. What young people with spina bifida want to know about sex and are not being told. *Child Care Health Dev* 2015;41:963–9. DOI:10.1111/cch.12282
- Altundağ S, Çalbayram NÇ. Teaching menstrual care skills to intellectually disabled female students. *J Clin Nurs* 2016;25:1962–8. DOI: 10.1111/jocn.13215
- Corona LL, Fox SA, Christodulu KV, Worlock JA. providing education on sexuality and relationships to adolescents with autism spectrum disorder and their parents. *Sex Disabil* 2016;34:199–214. DOI: 10.1007/s11195-015-9424-6
- Faught BM, Moore G, Hande KA, Walker-Hirsch L. Social boundaries in young adult females with Down syndrome as a foundation for sexuality education. *Am J Sex Educ* 2020;15:426–43. DOI: 10.1080/15546128.2020.1831677
- Frank K, Sandman L. Supporting parents as sexuality educators for individuals with intellectual disability: The development of the Home B.A.S.E. Curriculum. *Sex Disabil* 2019;37:329–37. DOI: 10.1007/s11195-019-09582-7
- Graff H, Moyher R, Bair J, Foster C, Gorden M, Clem J. Relationships and sexuality: How is a young adult with an intellectual disability supposed to navigate? *Sex Disabil* 2018;36. DOI: 10.1007/s11195-017-9499-3
- Granela K, Cardoso Y, Gutiérrez A, Carvajal M. Sex education for children and adolescents with type 1 diabetes in Camagüey province, Cuba. *MEDICC Rev* 2013;15:34–7. DOI: 10.1089/jayao.2018.0025
- Hannah LA, Stagg SD. Experiences of sex education and sexual awareness in young adults with autism spectrum disorder. *J Autism Dev Disord* 2016;46:3678–87. DOI 10.1007/s10803-016-2906-2
- Hilberink SR, Kruijver E, Wiegerink DJHG, Vliet Vlieland TPM. A pilot implementation of an intervention to promote sexual health in adolescents and young adults in rehabilitation. *Sex Disabil* 2013;31:373–92. DOI 10.1007/s11195-013-9288-6
- Houtrow A, Roland M. Sexual health and education guidelines for the care of people with spina bifida. *J Pediatr Rehabil Med* 2020;13:611–9. DOI 10.3233/PRM-200743

- Janeslätt G, Larsson M, Wickström M, Springer L, Höglund B. An intervention using the Parenting Toolkit “Children-What does it involve?” and the Real-Care-Baby simulator among students with intellectual disability-A feasibility study. *J Appl Res Intellect Disabil* JARID 2019;32:380–9. DOI: 10.1111/jar.12535
- Lehan Mackin M, Loew N, Gonzalez A, Tykol H, Christensen T. Parent perceptions of sexual education needs for their children with autism. *J Pediatr Nurs* 2016;31:608–18. DOI: 10.1016/j.pedn.2016.07.003
- Levin-Decanini T, Miller E, Houtrow A, Kreashko L, Cassidy B. Implementation of intimate partner violence education for adolescents with spina bifida. *J Pediatr Rehabil Med* 2019;12:339–43. DOI: 10.3233/PRM-180547
- Martins A, Taylor RM, Lobel B, McCann B, Soanes L, Whelan JS, et al. Sex, body image, and relationships: A BRIGHTLIGHT workshop on information and support needs of adolescents and young adults. *J Adolesc Young Adult Oncol* 2018;7:572–8. DOI: 10.1089/jayao.2018.0025
- Pugliese CE, Ratto AB, Granader Y, Dudley KM, Bowen A, Baker C, et al. Feasibility and preliminary efficacy of a parent-mediated sexual education curriculum for youth with autism spectrum disorders. *Autism Int J Res Pract* 2020;24:64–79. DOI:10.1177/1362361319842978
- Rooks-Ellis DL, Jones B, Sulinski E, Howorth S, Achey N. The effectiveness of a brief sexuality education intervention for parents of children with intellectual and developmental disabilities. *Am J Sex Educ* 2020;15:444–64. DOI: 10.1080/15546128.2020.1800542
- Secor-Turner M, McMorris BJ, Scal P. Improving the sexual health of young people with mobility impairments: challenges and recommendations. *J Pediatr Health Care* 2017;31:578–87. DOI: 10.1016/j.pedhc.2017.03.002
- Streur CS, Sandberg DE, Kalpakjian CZ, Wittmann DA, Quint EH. How to discuss sexual health with girls and young women with spina bifida: A practical guide for the urologist. *Urology* 2021;151:72–8. DOI:10.1016/j.urology.2020.06.068
- Visser K, Greaves-Lord K, Tick NT, Verhulst FC, Maras A, van der Vegt EJM. Study protocol: a randomized controlled trial investigating the effects of a psychosexual training program for adolescents with autism spectrum disorder. *BMC Psychiatry* 2015; 15;207. DOI 10.1186/s12888-015-0586-7
- Wos K, Kamecka-Antczak C, Szafranski M. In search of solutions regarding the sex education of people with intellectual disabilities in Poland - participatory action research. *Eur J Spec Needs Educ* 2020;36. DOI: 10.1080/08856257.2020.1769981

- Yıldız G, Cavkaytar A. Effectiveness of a sexual education program for mothers of young adults with intellectual disabilities on mothers' attitudes toward sexual education and the perception of social support. *Sex Disabil* 2017;35:3–19. DOI: 10.1007/s11195-016-9465-5

Supplementary Material 5: Studies and populations included

DOI, authors, title	Year of publication	Country of the study	Discipline	Purpose of the study	n	Type of population	Population characteristics	Age (years)	Disabilities	Gender	Type of the study	Methods	Objectives of the study
DOI:10.1111/cch.12282. Akre et al. What Young People with Spina Bifida Want to Know about Sex, and Aren't Being Told	2015	USA	Public health Medical sciences	Needs study	14	Adolescents and young adults	NI*	13-28 (median 17)	Spina bifida	Both genders	Cohort study	Qualitative	To examine the sexual knowledge, concerns, and needs of adolescents and young adults with spina bifida through their own voices in order to inform the medical community on ways to better support their sexual health.
DOI: 10.1111/joen.13215 Altundağ, Çalbayram Teaching Menstrual Care Skills to Intellectually Disabled Female Students	2015	Turkey	Nursing sciences	Intervention study	54	Adolescents	Young people in specialized schools	13-17 (average 15.14)	Intellectually disabled adolescents	Female	Quasi-experimental study	Quantitative	To teach pad replacement skill among other menstrual care skills with the help of a dummy to intellectually disabled adolescent female students who reached their age of menstruation.
DOI: 10.1007/s11195-015-9424-6 Corona et al. Providing Education on Sexuality and Relationships to Adolescents with Autism Spectrum Disorder and Their Parents	2015	USA	Human and social sciences Psychology	Intervention study	8	Adolescents and parents of adolescents	Young people living with their parents	12-16 (average 13.4)	Autism spectrum disorder including PDD-NOS and Asperger's syndrome	Both genders	Pre-post study	Quantitative	(1) To investigate the feasibility of providing a short-term, group-based sexuality education program to a small group of adolescents with ASD and their parents, and (2) To explore the impact of such an intervention on a variety of parent and adolescent outcomes
DOI: 10.1080/15546128.2020.1831677 Faught et al.	2020	USA	Public health Nursing sciences	Intervention study	6	Young adults	Young people living with their parents Young people after high school	18-23 (average 20.3)	Down syndrome, including trisomy, mosaicism and translocation	Female	Pilot study Pre-post study	Quantitative	To test the usefulness of the Circles app in teaching appropriate social boundaries to 6 young adult females with Down syndrome

Social Boundaries in Young Adult Females with Down Syndrome as a Foundation for Sexuality Education							Young people in employment						
DOI: 10.1007/s11195-019-09582-7 Frank, Sandman Supporting Parents As Sexuality Educators For Individuals With Intellectual Disability: The Development of the Home B.A.S.E. Curriculum	2019	USA	Human and social sciences Public health	Intervention study	NI*	Parents of adolescents	Young people living with their parents	12-19	Intellectual and developmental disabilities	Both genders	Conceptual study describing a health promotion intervention	NA**	To describe the creation of the Home Based Adolescent Sexuality Education for Intellectual Disabilities (Home B.A.S.E.) curriculum to educate parents on their role as the primary sexuality educators for their adolescents with intellectual disabilities
DOI: 10.1007/s11195-017-9499-3 Graff et al. Relationships and Sexuality: How is a Young Adult with an Intellectual Disability Supposed to Navigate?	2018	USA	Human and social sciences Public health	Intervention study	53	Young adults	Young people in schooling	18-27 (average 20.68)	Intellectual and developmental disabilities + Autism spectrum disorder	Both genders	Randomized control trial + pre-post study	Mixed methods	To evaluate the effectiveness of positive choices intervention To evaluate a curriculum
DOI: 10.1089/jayao.2018.0025 Granela et al. Sex Education for Children and Adolescents with Type 1 Diabetes in Camaguey Province, Cuba	2013	Cuba	Medical sciences	Intervention study	20	Adolescents	Young people in schooling	12-19	Type 1 diabetes	Both genders	Pre-post study	Quantitative	To carry out an educational intervention to increase type 1 diabetic adolescents' knowledge of sexuality and sexually transmitted infections
DOI 10.1007/s10803-016-2906-2 Hannah, Stagg Experiences of Sex Education and Sexual	2016	United Kingdom	Human and social sciences Public health	Needs study	40	Young adults	Young people in schooling	18-25	Autism spectrum disorder	Both genders	Cross-sectional study with no follow-up control group	Mixed methods	To identify the feelings and needs that young people with autism spectrum disorder (ASD) have reflecting their experiences of sex education and to examine the sexual awareness levels of young people with ASD

Awareness in Young Adults with Autism Spectrum Disorder													
DOI 10.1007/s11195-013-9288-6 Hilberink et al. A Pilot Implementation of an Intervention to Promote Sexual Health in Adolescents and Young Adults in Rehabilitation	2013	Netherlands	Public health Medical sciences	Intervention study	14	Adolescents and young adults	Young people living with their parents Young people living alone Young people in schooling (some in specialized schools) Young people in rehabilitation center	14-29 (average 19.9)	Neurological diseases: spina bifida, cerebral palsy, neuromuscular diseases (physical disabilities)	Both genders	Prospective pilot implementation study and pre-post study	Mixed methods	To evaluate the feasibility and preliminary effectiveness of a group program to promote sexual health in a small convenience sample of youngsters attending a rehabilitation center or special school
DOI 10.3233/PRM-200743 Houtrow, Rowland Sexual Health and Education Guidelines for the Care of People with Spina Bifida	2020	USA	Public health Medical sciences	Recommendations study	NI*	Unspecified but focus on adolescents in the broad sense	NI*	NI*	Spina bifida	Both genders	Working groups with no clear methodology	NI*	To discuss the Spina Bifida Sexual Health and Education Healthcare Guidelines
DOI: 10.1111/jar.12535 Janeslät et al. An Intervention Using the Parenting Toolkit “Children—What Does It Involve?” and the Real-Care-Baby Simulator among Students with Intellectual Disability—A Feasibility Study	2019	Sweden	Human and social sciences Public health	Intervention study	6	Adolescents and young adults	Young people living with their parents Young people in schooling (some in specialized schools)	17-20	Intellectual disabilities	Both genders	Pre-post study (quasi-experimental)	Mixed methods	To evaluate the feasibility of an upcoming trial to evaluate an intervention using the Toolkit “Children—what does it involve?” and the “Real-Care-Baby” (RCB) simulator among students with intellectual disability
DOI: 10.1016/j.pedn.2016.07.003	2016	USA	Public health	Needs study	15	Parents of adolescents /young adults	Young people living with their parents	14-20 (average 16.40)	Autism spectrum disorder	Both genders	Cross-sectional study	Qualitative	1) To describe parent perceptions of sexual education needs of their children aged

Lehan Mackin et al. Parent Perceptions of Sexual Education Needs for Their Children With Autism			Medical sciences				Young people in schooling						14–20 with an autism spectrum disorder diagnosis, and 2) to determine parent-preferred mechanisms of delivery for tailored educational intervention strategies
DOI: 10.3233/PRM-180547 Levin-Decanini et al. Implementation of Intimate Partner Violence Education for Adolescents with Spina Bifida	2019	USA	Public health Medical sciences Nursing sciences	Intervention study	13	Adolescents and young adults	Young people living in specialized clinics	12-21	Spina bifida	NI*	Pre-post study	Quantitative	To evaluate the feasibility of implementing brief educational training based on an evidence-based intimate partner violence (IPV) intervention in a pediatric spina bifida clinic
DOI: 10.1089/jayao.2018.0025 Martins et al. Sex, Body Image and Relationships: a BRIGHTLIGHT Investigation of Information and Support Needs of Adolescents and Young Adults	2018	United Kingdom	Human and social sciences Public health	Needs study	5	Adolescents and young adults	NI*	16-24	Cancer: hematological cancer and solid tumors	Both genders	Cross-sectional study	Qualitative	To explore the sexual health information/support needs of adolescents and young adults during and after cancer diagnosis as an initial process of patient-led research
DOI:10.1177/1362361319842978. Pugliese et al. Feasibility and Preliminary Efficacy of a Parent-Mediated Sexual Education Curriculum for Youth with Autism Spectrum Disorders	2020	USA	Psychology Public health	Intervention study	84	Parents of adolescents	Young people living with their parents	9-18 (average 13.1)	Autism spectrum disorder	Both genders	Pre-post controlled design	Mixed methods	To evaluate the Supporting Teens with Autism on Relationships (STAR) program to assess the initial feasibility and acceptability of the STAR program, and to examine preliminary efficacy when compared with an attentional control drug and alcohol education program
DOI: 10.1080/15546128.2020.1800542	2020	USA	Human and social sciences	Intervention study	26	Parents of adolescents	Young people living with their parents	NI*	Intellectual and developmental disabilities	Both genders	Pre-post study	Quantitative	To implement brief sexuality education training for parents and caregivers who have children diagnosed with

Rooks-Ellis et al. The Effectiveness of a Brief Sexuality Education Intervention for Parents of Children with Intellectual and Developmental Disabilities			Education sciences										intellectual and developmental disabilities, including autism
DOI: 10.1016/j.pedhc.2017.03.002 Secor-Turner et al. Improving the Sexual Health of Young People with Mobility Impairments: Challenges and Recommendations	2017	USA	Public health Medical sciences	Needs study	10	Health professionals working with adolescents	NI*	NI*	Mobility impairment: spina bifida, cerebral palsy, muscular dystrophy	Both genders	Prospective longitudinal study	Mixed methods	To describe challenges to providing sexual and reproductive health services to youth with physical disabilities from the perspective of health care providers and experts, and to describe health services challenges and sexual health-related experiences of adolescents with mobility impairment
DOI:10.1016/j.urology.2020.06.068. Streuer et al. How to Discuss Sexual Health with Girls and Young Women with Spina Bifida: A Practical Guide for the Urologist	2021	USA	Medical sciences	Recommendation study	NI*	Unspecified but focus on adolescents in the broad sense	NI*	NI*	Spina bifida	Female	Synthesis of literature and experience for recommendations	NI*	A practical guide for urologists providing sexual health education for adolescent girls with spina bifida
DOI 10.1186/s12888-015-0586-7 Visser et al. Study Protocol: A Randomized Controlled Trial Investigating the Effects of a Psychosexual Training Program for Adolescents with Autism Spectrum Disorder	2015	Netherlands	Human and social sciences (Human geography)	Intervention study	189	Adolescents	Young people living with their parents Young people in schooling (some in specialized schools)	12-18	Autism spectrum disorder	Both genders	Randomized controlled trial	Mixed methods	To evaluate the effects of the Tackling Teenage Training (TTT) program for adolescents with ASD on cognitive outcomes, and to investigate the effect of the TTT program on behavioral outcomes

DOI: 10.1080/08856257.2020.1769981 Wos et al. In Search of Solutions regarding the Sex Education of People with Intellectual Disabilities in Poland - Participatory Action Research	2020	Poland	Human and social sciences Public health	Needs study	24	Young adults	Young people in specialized schools	18-24	Intellectual disabilities	Both genders	Cross-sectional study	Qualitative	To learn the state of knowledge about human sexuality, and to analyze the needs, barriers, and expectations of adult students with ID as regards their sex education
DOI: 10.1007/s11195-016-9465-5 Yıldız, Cavkaytar Effectiveness of a Sexual Education Program for Mothers of Young Adults with Intellectual Disabilities on Mothers' Attitudes Toward Sexual Education and the Perception of Social Support	2016	Turkey	Education sciences	Intervention study	44	Parents of adolescents	Young people living with their parents Young people in institutions Young people in employment	NI*	Intellectual disabilities	Female	Pre-post study with control group	Mixed methods	To investigate the effect of the Sexuality Education Program for Mothers of Young Adults with Intellectual Disabilities (SEPID) on attitudes of social support

* NI = no information; ** NA = not applicable; PDD-NOS = pervasive developmental disorder not otherwise specified

Supplementary Material 6: Description of sexual health needs in needs assessments

		Need for theoretical training	Need for sex education, prevention and awareness-raising	Need for assistance and social support (social approach)	Need for sexual supportive care and sexual medical management	Need for professional involvement	Need for involvement of parents in sex education	Need for sexual autonomy	Need for safety	Need for Intimacy	Need for support, formation and training for parents	Need for sexual and reproductive health referrals and practice guidelines
Akre et al. 2015	Spina bifida	X	X		X	X	X	X	X		X	
Hannah, Stagg 2016	Autism spectrum disorder	X	X			X						
Lehan Mackin et al. 2016	Autism Spectrum disorder	X	X	X	X		X			X		
Martins et al. 2017	Cancer	X	X	X		X		X		X		
Secor-Turner et al. 2017	Mobility Impairment	X	X	X	X		X		X			X
Wos et al. 2020	Intellectual disabilities	X	X	X				X	X			
	Total (n)	6	6	4	3	3	3	3	3	2	1	1
	Total (%)	100	100	67	50	50	50	50	50	33	17	17

Supplementary Material 7: Interventions included and their participatory components

DOI, authors, title	Name	Type	Sexual topic	Expected effect of the intervention	Intervention designer	Duration/time	Location	Objective/Purpose	Intervention facilitator	Specific intervention for disabled	Young people's interaction/participation	Intervention description
DOI: 10.1111/jocn.13215 Altundağ , Çalbayram Teaching Menstrual Care Skills to Intellectually Disabled Female Students	No name	Group education training Demonstration of behaviors with the help of a dummy and other materials	- Puberty - Body image - Sexual physiology - Menstruation	Develop biological and functional knowledge, knowledge of oneself and one's body, develop autonomy, hygiene and the technical use of equipment	School nurses	NI*	Specialized school	Teach pad replacement skill and other menstrual care skills with the help of a dummy to intellectually disabled adolescent female students who reached the age of menstruation	Healthcare professionals: school nurses	Yes	Oral exchanges in groups of 5 during learning workshops	Training and skill developing stage 1) Brief information on the age of the onset of puberty and associated physical changes 2) Information on the onset of menstruation (periods, material used, time of menstruations) 3) How to use pads (pad placement and replacement training) 4) Specific cleaning habits (shower, hygiene, cleaning, toilet) Training menstruations with a doll and other materials specific to menstruation (pad, toilet paper, hand towel, wastebasket) Steps shown on the doll, experimented one by one on the doll to observe the skill steps accomplished
DOI: 10.1007/s11195-015-9424-6 Corona et al. Providing Education on Sexuality and Relationships to Adolescents with Autism Spectrum Disorder and Their Parents	No name	Group education training using verbal conversation, prompts and visual representations	- Love and emotional life - Sexual relationships -Sexual well-being - Sexual activity - Sexual violence - Harassment and rape - Sexual consent - Access to sexual and reproductive services - Sex education - Sexual rights - Puberty - Body image - Sexual physiology - Maturation - Masturbation	Develop biological and functional knowledge, knowledge of self and body, develop autonomy and critical thinking skills. Develop social connections communication and emotional skills	Psychology researchers	3 months	University-affiliated autism center	Provide sexuality and relationship education to adolescents with ASD and their parents	Clinical psychology doctoral student and a behavior specialist	Yes	Discussions with each other and with speakers during educational sessions. Opportunity to ask questions and exchange skills throughout the course.	Parent and adolescent sessions took place simultaneously at the same location, but in separate rooms. Education program: six 2-hour sessions over 3 months. Six main topics discussed with the young people and their parents. Verbal conversation and prompts accompanied by visual representations of the subject matter. Each session included a review of the schedule and a list of rules for appropriate conduct. Adolescents received rewards for their willingness to participate and compliance with group rules. The schedule was posted on the wall and referred to throughout the session. The parent sessions covered the same topics. Each subsequent session began with an opportunity for questions about the previous sessions.

			<ul style="list-style-type: none"> - Privacy - Hygiene - Physical contact - Friendship development - Electronic, dating behavior - Personal safety 									
DOI: 10.1080/15546128.2020.1831677	Circles App	Online intervention in the form of role-playing and role-playing situations (videos to be viewed containing information)	<ul style="list-style-type: none"> - Love and emotional life - Social boundaries (including love, sexuality and touching close people) - Sexual consent - Intimacy 	Develop critical thinking, social skills and communication. Develop appropriate social behaviors and intimate social relationships	Researchers and healthcare professionals	NI*	Online	Teach appropriate sexuality and social boundaries thanks to technology	Researchers and healthcare professionals	Yes	NI*	The CirclesVR app utilizes a color-coded, circular rainbow model to teach social distance and demonstrate various levels of intimacy. There are 7 multi-colored, concentric circles within the CircApp, 5 of which offer space for 5 pictures or icons. In the center of the app a purple “private” circle symbolizes the user, who can upload a photograph of themselves or create an avatar. The outer red “stranger” circle does not allow for placement of photos or avatars. The innermost circle that surrounds the purple “private” circle represents intimate relationships, while the most distant circle (red) represents strangers
DOI: 10.1007/s11195-019-09582-7	Home Based Adolescent Sexuality Education for Intellectual Disabilities (Home B.A.S.E.) Curriculum	Educational workshops using an assortment of activities: video viewing with discussion group, small-group discussion where parents meet face-to-face to learn and share experiences, case studies, role-playing, take-home activities and action plan	<ul style="list-style-type: none"> - Love and emotional life - Sexual relationships - Sexual well-being - Sexual activity with partners - Sex education - Sexual and reproductive rights - Sexuality myths - Dating - Sexual communication 	Develop social connections, communication, supportive environments and confidence to communicate about sexuality and healthy relationships	Occupational therapist and clinical social worker	1 month	NI*	Provide sexuality training for parents of adolescents (ages 12–19) with ID Increase parents’ comfort and confidence in discussing sexuality and healthy relationship topics with their adolescents with ID	Clinical social worker + occupational therapist	Yes	NA** Parents can interact with each other in the form of discussion groups and experience-sharing sessions	Three sessions over 1 month. Sessions were held for 2 consecutive weeks, followed by 1 week off before the final session. Each session lasted 3 h. Seven learning objectives on sexuality topics were established. Each session of the workshop addressed many of the seven learning objectives and utilized an assortment of activities, taking into consideration adult, social, and transformational learning theories. Learning activities included watching a video, sharing of experiences, dialogue, small group discussion, case study, role play, take-home activities, action plan, true/false survey Session 1: deconstruction of myths, definition of sexuality, identification of problems, introduction of rights (myths and barriers), group activities and announcement of personal work: making an action plan Sessions 2: resumption of homework, videos on rights, discussion on the benefits of sexuality education, group activities on

												sexuality topics, strategic framework and receipt of resources. Role-playing following the action plan for communication with one's children. Introduction to problem-solving Session 3: Listening to speakers and questions, reactions to the session, completing the action plan, sharing with the group + completing evaluation
DOI: 10.1007/s11195-017-9499-3 Graff et al. Relationships and Sexuality: How is a Young Adult with an Intellectual Disability Supposed to Navigate?	Positive choices (PC)	Group study curriculum for teaching students on sexuality. This curriculum use a teacher's notebook and a student's notebook containing educational material in simplified English with colorful, contemporary images included in the units are a variety of activities including decision making and role playing activities	- Love and emotional life - Sexual relationships - Sexual well-being - Sexual activity - Sexual violence - Sexual consent - Contraception - Reproductive health - Sexual partners - Sex education - Rape and harassment - Self-awareness - Sexual maturation - Sexual life cycle - Sexual safety	Develop biological and functional knowledge, knowledge of oneself and one's body, develop autonomy, critical thinking and decision-making.	Oak Hill Center for Relationship and Sexuality (CRSE)	NI*	At school	Teach students components of healthy relationships, particularly for this age group and population.	Ph.D. student, master's student	NI*	NI*	Curriculum focused on teaching students components of healthy relationships It included a teacher workbook with outlined objectives, goals, lesson plan and activities. The students also had a workbook with educational material, pictures, fill-in-the-blank sections, homework, activity sheets. The curriculum contains five chapters: (1) relationships and self-awareness, (2) maturation, (3) the life cycle, (4) sexual health, and (5) being strong, staying safe. Including decision making and role-playing activities. Chapter assessments were used as pre- and post-tests
DOI: 10.1089/jayao.2018.0025 Granela et al. Sex Education for Children and Adolescents with Type 1 Diabetes in Camagüey Province, Cuba	No name	Courses in a pediatric diabetes clinic that included a workshop using a productive teaching methodology and participatory techniques	- Contraception - Sexual screening - Sexually transmitted infection - Access to sexual and reproductive services	Develop biological and functional knowledge	Healthcare professionals (endocrinology department)	6 weeks	Health structure	Raise awareness about specific aspects of sex education and STIs among type 1 diabetic adolescents treated at the pediatric DM clinic of PEPC's endocrinology service	Healthcare professionals	Yes	Communication at day camp, oral participation in courses, participatory techniques such as	Course in the PEPC pediatric diabetes clinic over a 6-week period. Six weekly one-hour sessions that included a workshop using productive teaching methodology and participatory techniques such as brainstorming. The model also included a DM day camp (a week of day-long educational and recreational activities for young people with diabetes and their parents or guardians) in the Camagüey Diabetic Care Center

		such as brainstorming . The model also included a DM day camp (a week of one-day educational and recreational activities)									brainstorming	
DOI 10.1007/s11195-013-9288-6 Hilberink et al. A Pilot Implementation of an Intervention to Promote Sexual Health in Adolescents and Young Adults in Rehabilitation	No name	Group program in the form of discussion groups, games, crafts activities, role-playing, board games, homework assignment	- Love and emotional life - Sexual relationships - Sexual well-being - Sexual activity - Sexual partners - Sex education - Body image - Guarding borders - Emotions - Making contact	Develop self-awareness, body awareness, autonomy, critical thinking, social bonds, emotional skills, self-esteem and communication	Sexologist	15 months	Specialized school and a health structure	Promote sexual health and help to discuss sexuality and relationship issues with youth with chronic conditions	Pedagogues , psychologists, social workers, sexologist, teacher	Yes	Discussion and exchange of skills during the course	Seven 90-min sessions over 12 weeks. Group program description: 1. Introduction and getting to know each other 2. Attitudes towards romantic relationships and sexuality 3. Who am I and how do I think? Participants play the Emotion game 4. Body esteem. Participants have to color their satisfaction with their body 5. To court and being courted; how to flirt 6. Participants play the board game SeCZ TaLK 7. Items that the group wants to discuss and close of the program Each session ends with a homework assignment focusing on making contact and flirting. Homework assignments challenged the participants to experiment with new types of behavior The trainers of the group program received a train-the-trainer course by the sexologist who developed the group program (EK). The training addressed: (a) the rationale of the program, (b) the various tools, (c) group processes, and (d) implementation in their own setting
DOI: 10.1111/jar.12535 Janeslätt An Intervention Using the Parenting Toolkit “Children—What Does It Involve?”	The Parenting Toolkit and the RealCare Baby® (RCB) simulator	Role-playing using a simulator (RealCare Baby). This simulation was accompanied by knowledge transfer sessions and	- Pregnancy - Reproduction - Fertility - Parenthood	Develop autonomy and parenting skills/knowledge	Researcher and clinician	2 months	At school	Create insights about what it means to have a child so that persons with intellectual disability can make informed decisions about parenthood	Researchers , teachers and healthcare professionals	Yes	Questions and exchanges during the classroom sessions	Toolkit, The Parenting Toolkit, targeting young persons with intellectual disability, developed by researcher and clinician. The toolkit aims to create insights about what it means to have a child, so that persons with intellectual disability can make informed decisions about parenthood. It has been used in clinical practice for many years. In this project, we used two parts of the toolkit. The Parenting Toolkit: One card game, “What I wish”, is an introduction to the

and the Real-Care-Baby Simulator among Students with Intellectual Disability—A Feasibility Study		educational sessions using a toolkit (the Parenting Toolkit "Children—what does it involve?").						The objective of the RealCare Baby® simulator is to convey the needs of a newborn child				topic. It contains questions about wishes for future adult life; if it includes having children. The second part is a guide for conversations "Children—what does it involve?". It contains user material and one manual per topic for the educator. Five topics covered: time, money, relationship, housing, and skills RealCare Baby (RCB) simulator: The baby simulator signals different needs and the carer must interpret and respond to the signals (hunger, rocking, new diaper, etc.). The level of care of the simulator is tracked and recorded
DOI: 10.3233/PRM-180547 Levin-Decanini et al. Implementation of Intimate Partner Violence Education for Adolescents with Spina Bifida	Material adapted from Futures Without Violence	Education session of healthcare professionals using adapted guidelines from the "Futures Without Violence" material	- Sexual violence and assault - Sexual harassment - Rape - Sexual partners - Access to sexual and reproductive services	Developing communication and educational skills	Health clinic	3 months	Health structure	Provide patients with information regarding Intimate partner violence (IPV) prevention	Healthcare professionals	Yes	NA**	Materials and methods adapted from an adolescent IPV educational training program utilizing the Futures Without Violence training materials. For one month prior to an educational training session, baseline data were collected from patients after their clinic visit about whether they discussed IPV during that visit. All interested staff (n = 8) attended an educational training session based on this previously tested, publicly available training The training session reviewed the use of an educational safety card to provide patients with information regarding IPV For two months following the training, adolescent patients were asked to complete a brief survey about their visit
DOI:10.1177/1362361319842978 Pugliese et al. Feasibility and Preliminary Efficacy of a Parent-Mediated Sexual Education Curriculum for Youth with Autism Spectrum Disorders	Supporting Teens with Autism on Relationships (STAR) program	Parent curriculum called Charting the Course: parent's guide with simple visual diagrams, sample conversations and common questions with sample answers Interactive youth	- Love and emotional life - Sexual relationships - Sexual well-being - Sexual activity - Sexual orientation - Gender identity - Sexual violence - Harassment and rape - Sexual consent - Contraception	Develop biological and functional knowledge, knowledge of oneself and one's body, autonomy, critical thinking, group spirit, social bonds, communication and emotions, favorable behaviors for	Research organization and health agency	NI*	Online	Help parents to support and educate their children in learning the skills needed to navigate relationships, sexual health, and sexuality	Researchers and healthcare professionals	Yes	No interaction between young people	The final Charting the Course product is a curriculum designed to help parents of young people with ASD aged 9-18 years to support and educate their children in learning the skills needed to navigate relationships, sexual health, and sex Boardwalk Adventure is an interactive videogame and phone application developed in collaboration with professional designers. Adolescents create an avatar and earn tickets to a concert through beach boardwalk games that reinforce curriculum concepts such as puberty and personal hygiene, friendships and relationships, dating etiquette, and sexuality-related topics in an interactive and fun way

		computer game called Boardwalk Adventure: interactive videogame and phone application	<ul style="list-style-type: none"> - Sexually transmitted infection - Reproductive health - Sexual partners - Sex education - Puberty - Sexual physiology - Hygiene - Sexual communication 	risk prevention								
DOI: 10.1080/1554612.8.2020.1800542 Rooks-Ellis et al. The Effectiveness of a Brief Sexuality Education Intervention for Parents of Children with Intellectual and Developmental Disabilities	No name	Group training for parents and caregivers. Sexuality education groups where parents/caregivers had the opportunity to ask questions (use of role-playing scenarios and social narrative during the training)	<ul style="list-style-type: none"> - Love and emotional life - Sexual relations - Sexual well-being - Sexual activity - Sexual orientation - Gender identity - Sexual violence - Harassment and rape - Sexual consent - Contraception - Pregnancy - Sexual reproduction - Sexually transmitted infection - Sexual screening - Sexual partners - Sex education - Sexual and reproductive rights - Access to SRH services - Puberty - Body image 	Develop communication and the right attitudes and beliefs of parents	Researchers and healthcare professionals	NI*	Rural northeastern state as part of a conference breakout session	Encourage parents and give the keys to communicate about sexuality topics with their children thanks to sexuality education interventions	Researchers	Yes	NA**	<p>Participants completed a brief overview about the study. They were given approximately 10 min to complete the pre-questionnaire.</p> <p>The parent training segment of the breakout session lasted 60 min.</p> <p>The sexuality education parent training included topics that are recommended by national organizations such as the importance of sex education, relationships, sexual behavior</p> <p>Participants were encouraged to deliver direct, structured information about sexuality topics by using the “I do it, we do it, you do it” strategy</p> <p>Parents were encouraged to begin conversations about sexuality with their child. Circles strategy was used to help families categorize their child’s real-life relationship. Another strategy shared was social narratives.</p>

			<ul style="list-style-type: none"> - Sexual physiology - Anatomy - Sexual communication - Masturbation - Abstinence - Sexual fantasy - Sexual values and beliefs 									
<p>DOI: 10.1186/s12888-015-0586-7</p> <p>Visser et al.</p> <p>Study protocol: a randomized controlled trial investigating the effects of a psychosexual training program for adolescents with autism spectrum disorder</p>	Tackling Teenage Training (TTT) program	<p>Training program: individual intervention with discussion session, information transmission, take-home assignment and activities (behavioral rehearsals, knowledge and insight quizzes)</p> <p>Manual for the professional and a workbook for the adolescent</p>	<ul style="list-style-type: none"> - Love and emotional life - Puberty - Physical appearances - First impressions - Physical and emotional developments - Friendships - Falling in love and dating - Sexual relationships - Sexual activity - Sexual partners - Sexual orientation - Masturbation - Sexual relationships - Pregnancy - Social boundaries - Safe internet use 	Develop biological and functional knowledge, knowledge of oneself and one's body, critical thinking, communication and favorable behaviors for risk prevention	Researchers	12 months	NI*	Provide psychosexual guidance and increased knowledge about sexuality	Professionals with a bachelor's or master's degree in psychology or social services, with at least 3 years of working experience with people with ASD	Yes	NI*	The randomized controlled trial (RCT) described in this study protocol aims to investigate the effects of the Tackling Teenage Training (TTT) program on the psychosexual development of adolescents with ASD. This parallel clinical trial, conducted in the South-West of the Netherlands, has a simple equal randomization design with an intervention and a waiting-list control condition. 1849 adolescents and their parents participated in this study. We assess the participants in both conditions using self-report as well as parent-report questionnaires at three time points during one year: at baseline (T1), post-treatment (T2), and for follow-up (T3)
<p>DOI: 10.1007/s11195-016-9465-5</p> <p>Yıldız, Cavkaytar</p> <p>Effectiveness of a Sexual Education Program for Mothers of Young Adults with</p>	Sexuality Education Program for Mothers of Young Adults with Intellectual Disabilities (SEPID)	Family education program applied to an institutional group including mothers (use of visual, audio and printed	<ul style="list-style-type: none"> - Love and emotional life - Sexual relationships - Sexual well-being - Sexual activity - Gender identity - Sexual violence 	Develop communication, attitudes and perceived social support for sexuality education Support development, deal with problems	Experts and researchers	3 days	Seminar hall, Eskisehir Gokkusa gi (Rainbow Café)	Develop the attitudes of mothers toward the sexuality education of their children and their perceptions of social support	Researcher: All stages of the application were conducted by the first author	Yes	NA**	The SEPID is a family education program applied to an institution-centered group including mothers of young adults with ID. Four 1h sessions in a special café with ID people. Around 5 sections such as sexuality, sexual abuse, masturbation, sexual intercourse, sexuality education, relationships Intervention designed by experts to support the development of children in sexual

Intellectual Disabilities on Mothers' Attitudes Toward Sexual Education and the Perception of Social Support		materials, "circle of trust", social story, writing activities, dummy)	<ul style="list-style-type: none"> - Harassment and rape - Sexual consent - Contraception - Sexually transmitted infection - Sexual screening - Reproductive health - Sexual partners - Sex education - Puberty - Body image - Sexual physiology - Privacy - Sexual development - Masturbation - Menstruation - Hygiene 								<p>development areas and to inform about issues and the way to deal with problems</p> <p>This intervention uses visual, audio and printed material like a family guide book, slide, "circle of trust", masturbation training, dummy penis, pictures, social story writing activities</p>
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* NI = no information; ** NA = not applicable; ASD = autism spectrum disorder; DM = diabetes mellitus; ID = intellectual disability; IPV = intimate partner violence; STI = sexually transmitted infection.

Supplementary Material 8: Evaluation of the interventions

DOI, authors, title	Effectiveness	Process	Measurement tools	Design of the evaluation	Description of the evaluation	Assessment results	Population evaluated	Outcomes	Evaluation sample size
DOI: 10.1111/jocn.13215 Altundağ, Çalbayram Teaching Menstrual Care Skills to Intellectually Disabled Female Students	Yes	No	Validated measurement tools: pad replacement skills analysis	Pre-post study by observation	Observational measurement of participants' practice, based on observation of interviewers ticking the tool's items (right/right with help/wrong). Before-and-after study to observe changes in scores. A month after the initial skills and training course, pad replacement skills were assessed after the menstrual cycle of each female student. Observation of each student's pad replacement skills. Skills were marked as "done" (two points), "done with aid" (one point) or "failed" (zero points)	Significant increase in tampon use and menstrual management skills (positive change in test scores)	Young people with disabilities	NI*	54
DOI: 10.1007/s11195-015-9424-6 Corona et al. Providing Education on Sexuality and Relationships to Adolescents with Autism Spectrum Disorder and Their Parents	Yes	Yes satisfaction / utility	Process evaluation: Measuring tools designed for the study: Parent Satisfaction Questionnaire Effectiveness evaluation: Validated measurement tools: Sexual Behavior Scale (SBS) Use of non-validated tools created for the study, such as the Adolescent Knowledge Questionnaire, Parent Questionnaire and the Parent satisfaction questionnaire	Pre-post study	Following the first session, parents completed the Sexual Behavior Scale (SBS), which was developed to measure social and sexual behaviors among adolescents and young adults with ASD. Adolescents completed a ten-question multiple choice questionnaire that contained items about sexuality-related knowledge, as well as knowledge regarding appropriate relationships. A parent questionnaire, developed specifically for the current study, sought to examine which sexuality-related topics parents had previously discussed with their children. Following the final session, parents completed a questionnaire designed to assess parent satisfaction and perceived learning.	Parents reported significantly less total concern following the program Contrary to expectations, no significant difference was found. Parents reported having discussed significantly more topics with their adolescents following the program (m = 14.13, SD = 6.11). The test revealed no significant difference in parent comfort. Parents reported being highly satisfied with the program. All parents strongly agreed that the program was worth their time and effort	Young people with disabilities and parents of young with disabilities	Social and sexual behaviors Knowledge regarding appropriate relationships	8

DOI: 10.1080/15546128.2020.1831677 Faught et al. Social Boundaries in Young Adult Females with Down Syndrome as a Foundation for Sexuality Education	Yes	No	No measuring tools used	Pre-post study	Before-and-after evaluation of the correct positioning of the people identified on the rainbow (before and after viewing a sex education videos).	Cumulative improvement within each circle ranged from 3.4% to 2,700%. The area of greatest improvement was in the dark red "foreign space" circle, the red "foreign" circle and the orange "vague" circle. Notable differences for certain colors corresponding to certain types of relationship. In the case of very close relationships (blue), the score was already good initially so differences were small	Young people with disabilities	Appropriate social interactions	6
DOI: 10.1007/s11195-019-09582-7 Frank, Sandman Supporting Parents as Sexuality Educators for Individuals with Intellectual Disability: The Development of the Home B.A.S.E. Curriculum	Yes	No	NI*	NI*	The authors are currently conducting a pilot study to test the effectiveness of the Home B.A.S.E. curriculum Quantitative and qualitative data will be collected before, throughout, and after the educational workshop	NI*	Parents of disabled young people	NI*	NI
DOI: 10.1007/s11195-017-9499-3 Graff et al. Relationships and Sexuality: How is a Young Adult with an Intellectual Disability Supposed to Navigate?	Yes	Yes socially validity	Measuring tools designed for the study	Pre-post study	Evaluation for all 3 groups with group control for the first group. A paired sample t test was conducted to compare sexual education knowledge. At the end of the course, a questionnaire was given to all participants in the first two intervention groups as a social validity measure. This questionnaire asked participants to rate on a picture Likert scale their thoughts on the topics as not useful, useful, and very useful.	The acquisition of sex education knowledge for units 1 and 2, and moderate for units 4 and 5. Statistically significant gains in the intervention group but not in the control group Chapters containing information on healthy relationships, red flags in relationships and gender-specific health care were perceived as the most useful by participants. Participants said they would like more information on relationships in general, menstruation, types of abuse, health care and caring for a baby	Young people with disabilities	Knowledge acquired from the intervention	41
DOI: 10.1089/jayao.2018.0025 Granela et al. Sex Education for Children and	Yes	No	Measurement tools designed for the study: Diagnosis questionnaire	Pre-post study	Questionnaire administered prior to intervention at the diagnosis step. Three months after the intervention, the same questionnaire was again administered to measure knowledge acquisition	Before the intervention, only 5 adolescents (25%) demonstrated understanding of the concept of STIs (Q4), compared with 16 (80%) afterwards. Increased identification of STIs and knowledge of birth control Overall increase in knowledge	Young people with disabilities	Knowledge acquisition	20

Adolescents with Type 1 Diabetes in Camagüey Province, Cuba									
DOI 10.1007/s11195-013-9288-6 Hilberink et al. A Pilot Implementation of an Intervention to Promote Sexual Health in Adolescents and Young Adults in Rehabilitation	Yes	Yes Feasibility + satisfaction	Process evaluation: Measuring tools designed for the study: Participants' Satisfaction and Experiences with the Group Program Effectiveness evaluation: Validated measurement tools: the RTP, PDSBES, Trainers' Satisfaction with the Group Program + Dutch National Study on Sexuality "Sex under the age of 25'+GSES	Pre-post study	Satisfaction with the Train-the-Trainer Course (self report) Trainers' Satisfaction with the Group Program (self-report) Participants' Satisfaction and Experiences with the Group Program (to assess their satisfaction with the group program and perceived facilitators and barriers) The Rotterdam transition profile (RTP) [19] measured autonomy in participation in 7 life areas The physical disability sexual and body esteem scale (PDSBES) was used	Mean attendance rate was 83 % (range 69–94 %). The 7 group sessions were generally appreciated positively. No association was found with gender, scales, and site. Pairwise comparison of the PDSBES scales showed no change pre-post-intervention. Participants also showed no change in self-efficacy or need for information. No differences regarding experience with courtship and perceived barriers to sex. Post-intervention, participants reported less difficulty in talking about sex with their (eventual) partner.	Young people with disabilities	NI*	14
DOI: 10.1111/jar.12535 Janeslät et al. An Intervention Using The Parenting Toolkit "Children—What Does It Involve?" and the Real-Care-Baby Simulator among Students with Intellectual Disability—A Feasibility Study	Yes	Yes Feasibility (functionality)	Process evaluation: no Effectiveness evaluation: Validated measurement tools: Infant Simulator Attitude Scale and General Efficacy Scale	Pre-post study	Before-and-after feasibility assessment highlighting the feasibility of the intervention through a qualitative study, and the effectiveness of the intervention through a quantitative study The Infant Simulator Attitude Scale measured insights about parenthood The General Self-Efficacy Scale captured the level of self-efficacy Before and after the intervention, the participants responded to a set of questionnaires. To respond to the research questions, data from two questionnaires used in earlier studies, the report from the RCB simulator (overall performance) and the interviews were used. The teacher performed semistructured interviews based on the questionnaires. The research team also	Difficulties in relation to own needs, difficulties in relation to others, benefits of caring for the RCB simulator. Positive experiences of the RCB simulator Pride when taking care of the RCB simulator Reflections about reproductive life Insights about reproduction	Young people with disabilities	Measure insights about parenthood	6

<p>DOI 10.1186/s12888-015-0586-7</p> <p>Visser et al.</p> <p>Study protocol: a randomized controlled trial investigating the effects of a psychosexual training program for adolescents with autism spectrum disorder</p> <p><i>NB : The authors have produced an electronic work compiling all the articles published in international journals on this sexual health intervention. For this table, information published in the book has been used to complete some of the information missing from the scientific article included.</i></p>	<p>Yes</p>	<p>Yes Social validity</p>	<p>Effectiveness evaluation: <u>Measuring tools designed for the study:</u> - psychosexual knowledge test - Self-report scale measuring specific ASD related inappropriate sexual behavior - Parent-reported scale measuring specific ASD related inappropriate sexual behavior <u>Validated measurement tools:</u> - Social Responsiveness Scale (SRS) - The Sex Problems scale of the Child Behavior Checklist</p> <p>Process evaluation: - <i>Satisfaction Questionnaires (SQs)</i> - <i>Adherence measures:</i> 3 measures of protocol adherence were created</p>	<p>Pre-post study controlled</p>	<p>Cognitive outcomes</p> <ul style="list-style-type: none"> - A psychosexual knowledge test for adolescents of 37 questions - Parents were questioned regarding their estimation of the knowledge of their child using a scale with 10 questions regarding psychosexual knowledge - They create a scale that includes both the ability of the adolescent to recognize and indicate their own as well as other people's boundaries with 7 items for parents <p>Behavioral outcomes</p> <ul style="list-style-type: none"> - The Social Responsiveness Scale (SRS) (Constantino & Gruber, 2002) was administered to assess potential changes in the social functioning of the adolescents. 65-item questionnaire - Self-perceived romantic relational skills of the adolescents on a 3-item scale - The Sex Problems scale of the Child Behavior Checklist (CBCL) (Achenbach & Rescorla, 2001; Verhulst & van der Ende, 2013) to determine changes in psychosexual problems. - Self-report scale measuring specific ASD-related inappropriate sexual behavior <p>Parent-reported scale measuring specific ASD-related inappropriate sexual behavior</p> <p>Social validity:</p> <ul style="list-style-type: none"> - <i>Characteristics of the</i> - <i>Satisfaction Questionnaires (SQs)</i> for adolescents and parents. 16 questions on how they appreciated several procedures of the training program. SQs for professionals contained 30 questions in addition to questions regarding their satisfaction with procedures of the TTT program - <i>Adherence measures:</i> 3 measures of protocol adherence. The first 	<p>Cognitive outcomes</p> <ul style="list-style-type: none"> - Adolescents in the intervention condition demonstrated a significantly greater increase in psychosexual knowledge - Parent-reported knowledge of their child increased significantly more in the intervention condition than in the control condition - A significant treatment effect was found on the parent-reported scale measuring adequate boundaries - Following the TTT program resulted in significantly more increase in parent-reported insight in adequate boundaries for adolescents in the intervention condition than adolescents in the control condition <p>Behavioral outcomes</p> <ul style="list-style-type: none"> - Adolescents in both conditions significantly increased their social functioning over time, irrespective of condition - Significant main effects for time were also found on the Sex Problems scale of the CBCL - Decreased problematic sexual behavior in all participating adolescents, irrespective of condition - No significant treatment effects were found on the SRS total score, the self-reported romantic relational skills scale, the Sex Problems scale of the CBCL, nor on the self-reported and parent-reported inappropriate sexual behavior scale <p>Social validity:</p> <ul style="list-style-type: none"> - High overall satisfaction with the TTT program 	<p>Young people with disabilities and parents of young people with disabilities</p>	<p>Cognitive outcomes and behavioral outcomes</p>	<p>189</p>
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					measure was the adjustment of the order of the sessions. The second measure was the number of adjusted exercises, and the third measure was the number of skipped mandatory exercises	<ul style="list-style-type: none"> - Adolescents very satisfied with their contact with the professional and the opportunity to ask questions - Parents also very satisfied with their contact with the professional and the opportunity to ask questions - The protocol adherence forms showed that in 14 of the 83 (16.9%) completed training programs the order of the sessions was adjusted by the professional 			
DOI: 10.1007/s11195-016-9465-5 Yıldız, Cavkaytar Effectiveness of a Sexual Education Program for Mothers of Young Adults with Intellectual Disabilities on Mothers' Attitudes Toward Sexual Education and the Perception of Social Support	Yes	Yes Social validity	Process evaluation: Measuring tools designed for the study Effectiveness evaluation: Validated measurement tools: Family Needs Survey (FNS), adapted + SEIDAS + RPSSS	Pre-post study with control group	The Family Needs Survey (FNS) was used. To assess the effectiveness of the SEPID developed in accordance with the needs analysis, the Sexuality Education of Individuals with Intellectual Disabilities Attitude Scale (SEIDAS) and the Revised Parental Social Support Scale (RPSSS) were utilized. The FNS includes 29 items, the SEIDAS 16 and the RPSSS 31 items The three surveys used a Likert-type scale In addition, a 10-item social validity survey was developed by the first author to obtain participant views on the purpose, content, method and findings of the study (3-point Likert-type scale)	Social validity considered as good: parents satisfied by the intervention Experimental group obtained better results compared with the control group Attitudes of the participants toward sexuality education were related to the group (experimental/control) to which they belonged	Parents of disabled young people	Sexual behavior	44

* NI = no information.