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# Prevention and Intervention Programs Targeting Sexual Abuse in Individuals with Mild Intellectual Disability: A Systematic Review

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## ABSTRACT

**Introduction:** Compared to their non-disabled peers, individuals with mild intellectual disability (MID) are at higher risk of becoming a victim of sexual abuse and more vulnerable to its disruptive effects. This review provides an overview of content and effectiveness of prevention and intervention programs targeting sexual abuse in individuals with MID.

**Methods:** PRISMA guidelines were followed and quality and effectiveness of the programs were evaluated taking into account the rating of the Quality Assessment Tool for Quantitative Studies (QATQS).

**Results:** Twelve studies were included. In prevention programs role-play prevailed, whereas the content of intervention programs varied. All studies received a “weak” QATQS rating. By consequence, effectiveness of the program was downgraded to “unclear” in ten, and “ineffective” in two studies.

**Conclusion:** Further development of programs and higher quality of research is needed to investigate whether they are effective in preventing sexual abuse or reducing its consequences in individuals with MID.

## KEYWORDS

Sexual abuse; mild intellectual disability; prevention; intervention

## Introduction

Compared to their non-disabled peers, individuals with mild intellectual disability (MID; IQ between 50 and 70 and impairments in adaptive and social skills) are at higher risk of becoming a victim of sexual abuse (Byrne, 2017; Horner-Johnson & Drum, 2006). In addition, individuals with MID are also more likely to experience sexual abuse compared to individuals with a moderate or severe intellectual disability (IQ < 50) (Gil-Llario et al., 2019; Morano, 2001; Smit et al., 2019), because individuals with MID participate more actively in society (Morano, 2001).

In the present review, sexual abuse is defined as unwanted sexual activity of any kind, with perpetrators using force, bribery or coercion, making threats or

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taking advantage of victims who are unable to give consent due to young age, immaturity, or cognitive impairment (Graham, 1996).

Several reviews have been conducted on the prevalence of sexual abuse in individuals with intellectual disability (ID). Lack of social skills, lack of sexual knowledge, but also the inequality in relationships and the fact that in some cases individuals with ID need to depend on others, are suggested as possible causes for high prevalence rates of sexual abuse in individuals with ID (McEachern, 2012; Wissink et al., 2015). Byrne (2017) concluded in his review that prevalence rates of sexual abuse in adult individuals with intellectual disability (ID) vary between 7% and 34%. This variation is due to a wide range in definitions of sexual abuse, methodological shortcomings of studies, and different research designs. Moreover, since studies often do not take the severity of the ID (i.e. profound, severe, moderate, mild) into account, it is hard to establish clear prevalence rates of sexual abuse in individuals with MID. What we do know is that approximately 85% of the intellectually disabled individuals are classified with MID, and there is a common expectation that the prevalence rates of sexual abuse in individuals with MID are higher than in individuals with more severe ID (Byrne, 2017; Gil-Llario et al., 2019; Smit et al., 2019).

Although there are no specific studies on the impact of sexual abuse on individuals with MID specifically, there are a few studies that focus on the impact of negative life events, including sexual abuse, on this group of individuals. It was found that negative life events play an important role in the development of behavior problems, mood problems and depressive symptoms (Esbensen & Benson, 2006; Wigham et al., 2014). Also, individuals with MID were found to stand at greater risk of developing a posttraumatic stress disorder (PTSD) (Mevisen & De Jongh, 2010).

In our review, two types of programs targeted at sexual abuse in individuals with MID were distinguished: prevention programs and intervention programs. The aim of prevention programs is to improve knowledge and skills in individuals with MID in order to reduce risk of potential sexual abuse, whereas the aim of intervention programs is to reduce sequelae of sexual abuse.

Similar reviews were conducted by Lund (2011) and by Mikton et al. (2014), both with a wide scope on violence in general and focus on individuals with all types of disabilities. The specific nature of sexual abuse and its consequences however justify a more narrow scope. Such a clearly defined scope was used by Barger et al. (2009). However, this now ten-year-old review was concentrated solely on prevention and included individuals with a broader range of intellectual disabilities.

In the present study, we wanted to provide an updated review exclusively focused on prevention and intervention programs targeting sexual abuse in individuals with MID.

For our review, we selected programs explicitly developed to prevent sexual abuse or to intervene on the consequences of sexual abuse in individuals with MID. Therefore, we excluded programs targeting sexual education. Recently, several studies have been published reviewing sexual education programs (e.g., McCann et al., 2019; Sala et al., 2019), but the focus of these educational programs and thus their assumed outcomes are much broader than only prevention of sexual abuse (McCann et al., 2019).

With this review, we aim to further increase awareness and to provide an updated overview of prevention and intervention programs targeting sexual abuse for individuals with MID. This information may enhance implementation of programs preventing sexual abuse in individuals with MID and help treatment of those who are suffering from sequelae of sexual abuse.

## Method

To ensure the complete reporting and transparency of the systematic review the PRISMA guidelines were followed (Liberati et al., 2009).

### **Eligibility Criteria and Search Procedure**

Studies were eligible for inclusion if they evaluated quantitative results of prevention or intervention programs targeting sexual abuse, included at least one participant with MID, and were published between 1990 and 2019 in an English language peer-reviewed journal. Both studies with participants with MID and a comparison group of participants without MID as well as studies with only participants with MID were included. Reviews and studies without the focus on sexual abuse were excluded. As discussed in the introduction, sexual education programs were excluded, because the aim of these programs is much broader than prevention of sexual abuse. Qualitative studies only focusing on single client experiences were also excluded.

Information sources used to identify relevant studies were electronic databases (PsychINFO, Medline, CINAHL, and Web of Science). Search terms used in electronic databases related to sexual abuse (*sex\* abuse\* OR sexual maltreatment\* OR sexually maltreated OR sex\* trauma\* OR sex offense\* OR sexual harassment\* OR sexually harassed OR sex\* assault\* OR sexual violence OR sex\* victim\* OR sexual violation\* OR sexually violated OR sexual molestation\* OR sexually molested OR ravishment\* OR rape OR rapes OR raped OR raping*) were paired with terms related to mild intellectual disability (*mild intellectual disabilit\* OR intellectual disabilit\* OR intellectual development disorder\* OR cognitive impairment\* OR developmental disabilit\* OR learning disabilit\* OR borderline intellectual functioning OR BIF OR MID OR mental disabilit\* OR mentally disabled OR mental\* handicap\* OR mental\* retard\**) and terms related to prevention and intervention

programs (*intervention\* OR treatment\* OR therapy OR therapies OR prevention OR program\* OR training\**). Studies in the reference lists of review articles and in the reference lists of included studies were added if not already selected.

### **Study Selection Process**

The process of study selection was carried out by the first and second author. First, after removing duplicates, the results of the search in the electronic databases and reference lists of review articles were imported in Rayyan software (Ouzzani et al., 2016). Second, titles and abstracts of every article were screened independently by the first and second author. The percentage of agreement on whether a study should be included or excluded based on title and abstract was 98%, with a Cohen's Kappa of 0.74. Disagreements were resolved by consensus between the two authors. After agreement was achieved full-text studies were independently read by the first and second author, and selected if they met inclusion criteria. After identifying the included studies, the reference lists of the included studies were scanned to further identify possible eligible studies.

### **Data Collection Process and Data Items**

A standardized format was used to extract data from the included studies. First, the included studies were subdivided into (1) prevention studies or (2) intervention studies. Second, each study was coded for: (a) number and characteristics of the participants (age, gender, level of ID), (b) content of the program, (c) study design, (d) primary and secondary outcome measures (i.e. self-report versus proxy report), (e) results of all outcome measures, (f) quality of the study design, (g) assessment of effectiveness without taking risk of bias into account, and (h) assessment of effectiveness but with risk of bias taking into account.

### **Risk of Bias in Individual Studies**

To assess risk of bias in the individual studies and quality of the study designs, the Quality Assessment Tool for Quantitative Studies (QATQS-EPHPP, 1999) was used. The QATQS is a generic tool used to evaluate a variety of study designs and has been judged suitable for systematic reviews (Armijo-Olivo et al., 2012). With the tool the following domains are evaluated: selection bias, study design, confounders, blinding, data collection method, and withdrawals/dropouts. Based on the QATQS guidelines, each domain was rated independently by the first and the second author. Based on the domain ratings the study received an overall rating of weak (two or more weak domain ratings), moderate (one weak domain rating) or strong (no weak domain ratings). There were no disagreements on overall rating between the two authors.

## **Assessment of Effectiveness**

A two-staged decision more specifically on the effectiveness of each prevention or intervention program was made by the first author. First, programs were rated based on the primary outcomes of the studies without taking risk of bias into account. Following Mikton et al. (2014), the program was rated “effective” if there were significant positive differences on all primary outcome measures; the program was rated “unclear” if not all the primary outcome measures showed significant positive differences or if there was insufficient information to decide on these outcomes; and the program was rated “ineffective” if there were no significant positive differences on the primary outcome measures. Second, effectiveness was further qualified taking into account the QATQS overall rating of the risk of bias. If a program was rated as “weak” according to QATQS, the assessment of effectiveness was downgraded from “effective” to “unclear” or from “unclear” to “ineffective” (Mikton et al., 2014).

## **Results**

### **Study Selection**

After eliminating duplicates, 1166 possible eligible studies across all electronic databases, reference lists of review articles, and reference lists of included articles were identified. After title and abstract screening, 51 studies remained. As a result of full-text screening, 39 studies were excluded. Main reasons for exclusion were that programs discussed were not aimed at sexual abuse solely, the results described were not of a quantitative nature, or no participants with MID were included. Eventually 12 studies were found eligible for inclusion. Of these 12 studies, eight studies focused on prevention programs and four studies on intervention programs. [Figure 1](#) displays the information flow through the different phases of the systematic review.

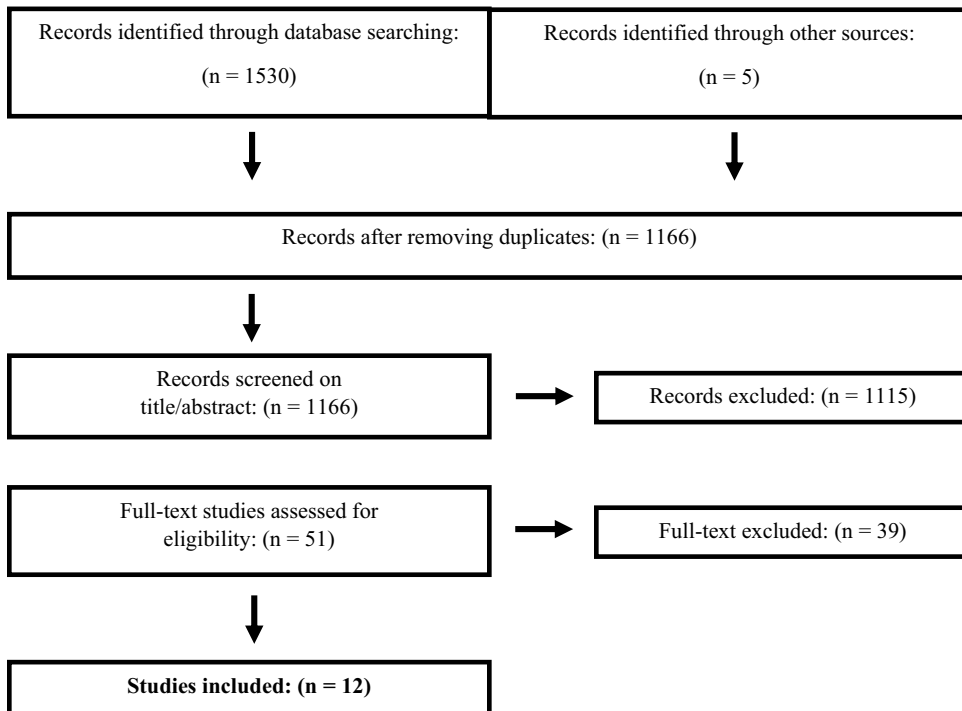
[Table 1](#) provides an overview of the extracted data from the included studies aimed at preventing sexual abuse (Prevention programs) and those aimed at intervening on consequences of sexual abuse (Intervention programs), respectively.

[Table 2](#) provides an overview of the domain ratings and overall rating on QATQS, and on the assessment of effectiveness for the included studies.

### **Prevention Programs**

#### **Participants' Characteristics**

In three of the eight prevention studies only participants with MID (Haseltine & Miltenberger, 1990; Kucuk et al., 2017; Lee & Tang, 1998) were included. Four studies included participants with a moderate or mild ID (Egemo-Helm



**Figure 1.** PRISMA flowchart of study selection.

et al., 2007; Kim, 2016; Lumley et al., 1998; Miltenberger et al., 1999), and one study identified their participants as having a “general” ID (Dryden et al., 2014).

Across these eight prevention studies, the total sample consisted of 126 female participants and 44 male participants, with an age range of 10–57 years. The majority of the participants (67%) were children. In three studies participants were children with an age range of 10–15 years (Kim, 2016; Kucuk et al., 2017; Lee & Tang, 1998), in one study participants were both children and young adults with an age range of 13–21 years (Dryden et al., 2014). In four other studies participants were adults (Egemo-Helm et al., 2007; Haseltine & Miltenberger, 1990; Lumley et al., 1998; Miltenberger et al., 1999).

### **Program Content**

In one study story books were the key element of the program (Kucuk et al., 2017). In seven of the eight studies, the most important tool used in the program was role-play (Dryden et al., 2014; Egemo-Helm et al., 2007; Haseltine & Miltenberger, 1990; Kim, 2016; Lee & Tang, 1998; Lumley et al., 1998; Miltenberger et al., 1999). In five of these studies role-play was

**Table 1.** Characteristics of included studies.

Study	Country	Participants	Content of program	Study design	Outcome measures	Results
1. Barber et al. (2000)	United Kingdom	6 women with either a history of childhood sexual abuse or being subjected to a serious sexual assault. Age range: 20–33 yr. Level of ID: Moderate to mild	Group therapy based on the therapeutic model of Rogers (1977): 10 weekly 2-hours sessions.	Intervention study Pre-post -12 week-follow up	Primary: 1. Culture-Free-Self-Esteem Inventory (Culture-free-SEI) (self-report) 2. Hospital Anxiety and Depression Scale (HADS) (self-report) 3. Assertiveness Questionnaire (third party: psychologist) Secondary: 1. Satisfaction Questionnaire/Therapeutic Impact Content Analysis System (self-report)	5 of 6 participants self-esteem scores improved slightly, at post-measurements, but the improvements were not maintained at follow-up. 4 of 6 participants scores on anxiety increased on the post-intervention assessment. Depression mean scores dropped slightly at post group intervention, but this was not maintained at follow-up. 5 of 6 participants demonstrated an improvement in assertiveness. All participants generally felt very positive about the impact of group sessions.
2. Davison et al. (1994)	United Kingdom	1 man who was sexually abused whilst in prison Age: 19 Level of ID: Mild	Individual therapy, imaginal exposure to the incident, followed by systematic desensitization to the traumatic experience. Total of 17 1.5/2-hour sessions.	Intervention study Case study: Pre-post-follow up	Primary: 1. Beck Depression Inventory (BDI)(self-report) 2. Revised Impact of Events Scale (IES)(self-report)	BDI score increased from 28 at pre-treatment to 36 at last measurement during treatment (more depressed/clinical). Not completed at follow-up. IES score decreased from 54 at pre-treatment to 14 at follow-up (less symptoms of PTSD/not clinical).
3. Dryden et al. (2014)	United States of America	57 special education high-school students (Intervention: N = 21/ Waiting-list: N = 36). 24 women, 33 men. Age range: 13–21 yr. Type of ID: General ID	Group program, IMPACT: Safety and self-advocacy training for people with cognitive and/or physical disabilities (including role-play). 10 1.5-hour sessions.	Prevention study Pre-post test with waiting list control group	Primary: 1. Self-developed pre/post survey (31 questions) on safety and self-advocacy knowledge, confidence in protecting one's self, self-determination behaviors, feelings of safety, and self-efficacy (self-report)	Intervention group significantly improved on safety and self-advocacy knowledge, confidence in ability to defend self in a dangerous situation, and speaking up to stop unwanted attention. No significant group effects were found for the other questions and constructs.



Table 1. (Continued).

Study	Country	Participants	Content of program	Study design	Outcome measures	Results
4. Egemo-Helm et al. (2007)	United States of America	4 women Age range: 34–47 yr. Type of ID: Moderate to mild	Group program. Behavioral skills training (BST) to teach self-protection skills (including role-play) in combination with in situ. 3 1-hour BST sessions, followed by 1 in situ assessment.	Prevention study Single-case: Multiple baseline across subjects	Primary: 1. Self-report (evaluated knowledge by asking how the participant would respond to a scenario described) 2. Role-play assessment (evaluated by a third party: trainer) 3. In situ assessment (evaluated by a third party: trainer) (all outcome measures scored from 0 – 4, with 4 being the maximum score = good response)	On the self report all participants improved. At 1 month follow-up all participants had a maximum score. At 3 month follow-up 2 out of 4 participants had a maximum score. On the role-play assessment all participants improved. At 1 month follow-up all participants had a maximum score. At 3 month follow-up 3 out of 4 participants had a maximum score. On the in situ assessment all participants improved. At 1 month follow-up 3 out of 4 participants still had a maximum score. At 3 month follow-up 2 out of 4 participants still had a maximum score. 5 out of 8 participants achieved a maximum score after the curriculum. A 1 month-follow up 6 out of 8 participants still had a maximum score. At 6 months follow-up 5 out of 6 participants still had a maximum score (2 participants were excluded). No changes in the scores from pre- to posttraining, suggesting that the subjects had no emotional or behavioral side effects due to participation. After training 2 out of 3 participants had a maximum score on all three probes. 1 participant scored a 3 in one probe and had a maximum score in two probes. All 3 participants improved their in situ score from baseline till the end of training.
5. Haseltine and Miltenberger (1990)	United States of America	8 participants, 3 women and 5 men. Age range: 22–45 yr. Level of ID: Mild	Group program. Curriculum for teaching self-protection skills (including role-play). 9 25–30 -minute sessions. Followed by in situ assessments.	Prevention study Single-case: Multiple baseline across subjects	Primary: 1. In situ assessment (scored from 0–3, with 3 being the maximum score = good response) (evaluated by a third party: research assistant and first author) Secondary: 1. Side-effects Questionnaire (self-report and evaluated by a third party: staff member)	
6. Kim (2016)	South Korea	3 girls Age range: 11–13 yr. Level of ID: Moderate to mild	Individual program, 5 training sessions (including role-play). Followed by in situ assessments.	Prevention study Single-case: Concurrent multiple probes across subjects	Primary: 1. In situ assessment (scored from 0–4, with 4 being the maximum score = good response) (evaluated by a third party: 3 professionals in abuse prevention programs) Criterion level = 3 consecutive scores of 4.	

**Table 1.** (Continued).

Study	Country	Participants	Content of program	Study design	Outcome measures	Results
7. Kucuk et al. (2017)	Turkey	15 children, 9 girls and 6 boys Age range: 10–14 yr. Level of ID: Mild	Group program, educational program with story books, based on the Stein and Glen Story Map Method (1979). 4 weekly 20–25-minute lessons.	Prevention study Pre-post test	Primary: 1. Child Interview Forms (23 closed questions and 4 open) on knowledge about special body parts; good-bad touch and saying 'no'; establishing safe boundaries with strangers; and reporting cases of abuse (self-report)	All knowledge's scores of the participants increased following the lessons and the difference between before and after was statistically significant.
8. Lee and Tang (1998)	China	72 girls (Intervention group: 38/Control group 34) Age range: 11–15 yr. Level of ID: Mild	Group program, Treatment group received a Behavioral Skills Training Program (BSTP), which is used to teach self-protection skills from a behavioral perspective (including role-play). Control group received the Attention Control Program, which covered safety skills unrelated to sexual abuse. Both programs were 2 45-minute sessions.	Prevention study Controlled clinical trial	Primary: 1. Inappropriate/appropriate request recognition (self-report) 2. "What If" Situation test (self-report) 3. Personal Safety Questionnaire (self-report) Secondary: 1. Fear assessment thermometer scale (self-report)	The participants significantly increased in their recognition of appropriate touch requests, but this was not maintained at follow-up. The treatment group performed significantly better than the control group on the "What If" situation test and the Personal Safety Questionnaire at post test and follow-up. Used as a side effects measure, significant lower level of fear for both groups at follow-up.
9. Lemmon and Mizes (2002)	United States of America	1 woman who was sexually abused Age: 32 Level of ID: Mild	Individual therapy, Imaginal exposure therapy; 25 sessions, duration of the sessions not described.	Intervention study Case study Pre-post test	Primary: 1. SUDS: Subjective Units of Distress Scale (normally from 0 to 100, but in this case from 0 to 10) (self-report)	At discharge, the participant no longer appeared psychologically distressed or physiologically reactive when exposed to stimuli associated with the traumatic events (SUDS 1 to 2), anger outbursts and hypervigilance had significantly decreased.

Table 1. (Continued).

Study	Country	Participants	Content of program	Study design	Outcome measures	Results
10. Lumley et al. (1998)	United States of America	6 women Age range: 30–42 yr. Level of ID: Moderate to mild	In pairs program, sexual abuse prevention program, followed by role-play and in situ assessments. Training: 5 60–90 minutes-sessions.	Prevention study Single-case: multiple baseline across subjects	Primary: 1. Nine closed end questions to assess knowledge and skills at baseline, and 1 week after training (self-report) 2. Verbal report: Assessment of verbal response of the participant on a described situation at baseline, training, and follow-up (third party: 2 researchers independently) 3. Role-play assessments at baseline, training, and follow-up (scored from 0–4, with 4 being the maximum score = good response). Criterion level = 3 consecutive scores of 4 (third party: 2 researchers independently) 4. In situ assessments at baseline, training, and follow-up (scored from 0–4, with 4 being the maximum score = good response). Criterion level = 3 consecutive scores of 4 (third party: 2 researchers independently)	Average knowledge score improved after receiving training. 5 out of 6 participants improved on the verbal report following the implementation of the training. Only 1 participant demonstrated the criterion response on the verbal report measure at follow-up. On the role-play assessments, 5 out of 6 participants improved to criterion-level following the implementation of the training. Also, 5 of the 6 participants demonstrated the criterion-level at follow-up. Participants failed to achieve criterion performance during the in situ assessments, although 3 participants improved. At follow up, performance on the in situ assessment remained stable. None of the participants achieved criterion level, demonstrating the lack of generalization of the skills learned.
11. Miltenberger et al. (1999)	United States of America	5 women Age range: 33–57 yr. Level of ID: Moderate to mild	In pairs program (1 individual), Behavioral Skills Training (BST), including role-play, followed by in situ training when the skills did not fully generalize. 10 weekly 1-hour sessions.	Prevention study Single case: multiple baseline across subjects	Primary: 1. Verbal report as response on scenarios at baseline and training (third party: 2 researchers independently) 2. Role-play assessments at baseline and training (Criterion level = 3 consecutive scores of 4) (third party: 2 researchers independently) 3. In situ assessments at baseline, training, and follow-up (third party: 2 researchers independently) All outcome measures were scored from 0–4, with 4 being the maximum score = good response	For all 5 participants verbal report scores improved from baseline to training. Criterion performance was achieved with all participants during training. After 4–8 sessions of in situ training, all subjects achieved criterion level. At follow-up the scores of 3 participants were 3, and 1 participant scored the maximum score of 4.

**Table 1.** (Continued).

Study	Country	Participants	Content of program	Study design	Outcome measures	Results
12. Peckham et al. (2007)	United Kingdom	7 women who were sexually abused. Age range: 26–47 yr. Level of ID: Mild	Group therapy, Survivors Group for women, also an Educational Support group for their caregivers: 20 weekly sessions, duration of the sessions not described.	Intervention studyPre-post-follow-up with 5 measurements: - First baseline (T0) - Second baseline (T1) - Mid-treatment (T2) - End of group (T3) - Follow-up (T4)	Primary: 1. 5 Goal Attainment Scales (GAS) questions on knowledge (self-report) 2. Impact of Events Scale (IES) (self-report) 3. Culture-free Self Esteem Inventory (Culture-free-SEI)(self-report) 4. Novaco Anger Scale (NAS)(self-report) 5. Beck Depression Inventory (BDI)(self-report) 6. Challenging Behavior Inventory (CBI)(self-report) Secondary: 1. Engagement Rating Scale (ERS) 2. Qualitative Interviews	Knowledge increased significantly on all 5 GAS questions between T0-T3 For 5 participants the score decreased significantly between T0-T4. Self-esteem did not significantly increase between T0-T4. Anger did not decrease significantly between T0-T4. Symptoms of depression were significant reduced between T0-T4 Significant reduction between T2-T3, and between T2-T4. The ERS results support the quality of the groups and suggest that the survivors group may have helped participants disclose more personal information and develop more concern for others. All seven clients felt that the survivor group helped and most gave positive reactions why.



**Table 2.** QATQS ratings and assessment of effectiveness.

Study	Selection bias	Study Design	Confounders	Blinding	Data collection methods	Withdrawals and drop-outs	Overall rating	Assessment of effectiveness
1. Barber et al. (2000)	Weak	Moderate	N/A	Weak	Weak	Strong	Weak	Without taking risk of bias into account: Unclear With taking risk of bias into account: Ineffective
2. Davison et al. (1994)	Weak	Weak	N/A	Weak	Weak	Strong	Weak	Without taking risk of bias into account: Unclear With taking risk of bias into account: Ineffective
3. Dryden et al. (2014)	Weak	Moderate	Strong	Weak	Weak	Strong	Weak	Without taking risk of bias into account: Effective With taking risk of bias into account: Unclear
4. Egemo-Helm et al. (2007)	Weak	Weak	N/A	Weak	Weak	Weak	Weak	Without taking risk of bias into account: Effective With taking risk of bias into account: Unclear
5. Haseltine and Miltenberger (1990)	Weak	Weak	N/A	Weak	Weak	Moderate	Weak	Without taking risk of bias into account: Effective With taking risk of bias into account: Unclear
6. Kim (2016)	Weak	Weak	N/A	Weak	Weak	Strong	Weak	Without taking risk of bias into account: Effective With taking risk of bias into account: Unclear
7. Kucuk et al. (2017)	Weak	Moderate	N/A	Weak	Weak	Strong	Weak	Without taking risk of bias into account: Effective With taking risk of bias into account: Unclear
8. Lee and Tang (1998)	Moderate	Strong	Strong	Weak	Weak	Strong	Weak	Without taking risk of bias into account: Effective With taking risk of bias into account: Unclear

(Continued)

**Table 2.** (Continued).

Study	Selection bias	Study Design	Confounders	Blinding	Data collection methods	Withdrawals and drop-outs	Overall rating	Assessment of effectiveness
9. Lemmon and Mizes (2002)	Weak	Weak	N/A	Weak	Weak	Strong	Weak	Without taking risk of bias into account: Effective With taking risk of bias into account: Unclear
10. Lumley et al. (1998)	Weak	Weak	N/A	Weak	Weak	Strong	Weak	Without taking risk of bias into account: Effective With taking risk of bias into account: Unclear
11. Miltenberger et al. (1999)	Weak	Weak	N/A	Weak	Weak	Strong	Weak	Without taking risk of bias into account: Effective With taking risk of bias into account: Unclear
12. Peckham et al. (2007)	Weak	Moderate	N/A	Weak	Weak	Strong	Weak	Without taking risk of bias into account: Effective With taking risk of bias into account: Unclear

accompanied by in situ assessment (Egemo-Helm et al., 2007; Haseltine & Miltenberger, 1990; Kim, 2016; Lumley et al., 1998; Miltenberger et al., 1999). In situ assessment evaluates the participants' behavior in a natural setting without them being aware of this assessment. Egemo-Helm et al. (2007) describe how in situ assessment was applied: "a confederate approached the participant in a pre-determined location (e.g., park or front yard) and presented an abduction lure. If the subject failed to demonstrate the appropriate safety response, the trainer then appeared and implemented training" (Egemo-Helm et al., 2007, p. 100).

In five studies the prevention programs were applied in a group (Dryden et al., 2014; Egemo-Helm et al., 2007; Haseltine & Miltenberger, 1990; Kucuk et al., 2017; Lee & Tang, 1998). In two studies participants joined in pairs (Lumley et al., 1998; Miltenberger et al., 1999) whereas in only one study the prevention program was applied individually (Kim, 2016).

### ***Assessment of Risk of Bias within Studies (QATQS)***

In all studies participants were not likely to be representative of the target population (e.g., because they were not randomly selected) or selection processes were not described, which resulted in a domain rating of "weak" on selection bias for all studies included.

One study was designed as a controlled clinical trial (Lee & Tang, 1998), two studies had a pre-post design, one with a control group (Dryden et al., 2014), one without a control group (Kucuk et al., 2017), and in five studies a single-case design was used (Egemo-Helm et al., 2007; Haseltine & Miltenberger, 1990; Kim, 2016; Lumley et al., 1998; Miltenberger et al., 1999). This resulted in a rating of "strong" on the domain of study design for the trial, "moderate" for the two pre-post studies, and "weak" for the five other studies, respectively.

The two studies that used a control group and controlled for confounders at baseline (Dryden et al., 2014; Lee & Tang, 1998) were rated "strong" on the domain of confounders. The other six studies (Egemo-Helm et al., 2007; Haseltine & Miltenberger, 1990; Kim, 2016; Kucuk et al., 2017; Lumley et al., 1998; Miltenberger et al., 1999) did not use control groups and for these studies the domain of confounders was rated as "not applicable".

In all studies outcome assessors were aware of the intervention status of the participants, the participants were aware of the research question, or blinding was not described. This resulted in a rating of "weak" on the domain of blinding for all studies.

Validity of the data collection tools was not described or could not be determined based on the information provided in all studies. In three studies (Dryden et al., 2014; Kucuk et al., 2017; Lee & Tang, 1998) reliability of the data collection tools was also unclear, but the five other studies used reliable data collection tools (Egemo-Helm et al., 2007; Haseltine & Miltenberger, 1990; Kim, 2016; Lumley et al., 1998; Miltenberger et al., 1999). Overall, this

resulted in a rating of “weak” on the domain of data collection tools for all included studies.

In six studies 80–100% of the participants completed the study (Dryden et al., 2014; Kim, 2016; Kucuk et al., 2017; Lee & Tang, 1998; Lumley et al., 1998; Miltenberger et al., 1999); in one study this was 75% (Haseltine & Miltenberger, 1990). Only in one study, there was more than 40% drop out (Egemo-Helm et al., 2007). This resulted in six “strong” ratings, one “moderate” rating, and one “weak” rating on the domain of withdrawals and drop-outs.

Based on the domain ratings, all prevention studies received an overall rating of “weak” on QATQS.

### ***Effectiveness of the Programs***

Based on the outcomes and without taking risk of bias into account all programs were judged as being “effective”. Taking risk of bias into account (according to the overall scores on QATQS) the effectiveness of all studies was downgraded from being “effective” to being “unclear”.

### ***Intervention Programs***

#### ***Participants’ Characteristics***

In the four intervention studies, level of ID varied. In three studies only participants with MID (Davison et al., 1994; Lemmon & Mizes, 2002; Peckham et al., 2007) were included, whereas one study included participants with a moderate or mild ID (Barber et al., 2000).

Summarized over these four studies, the total sample consisted of 14 adult female participants and one adult male participant, with an age range of 19–47 years.

#### ***Program Content***

In the study by Barber, Jenkins, and Jones (2000) the therapeutic model used was derived from Rogers (1977) and applied in a group setting. Two main areas of change were targeted: The first area of change was conceptual and emotional change with regard to self-esteem and anxiety, and the second area was behavioral and habit change with levels of personal assertiveness.

In the study by Davison, Clare, Georgiades, Divall, and Holland (1994) treatment was applied individually. In this study the guidelines of imaginal exposure (IE) therapy were followed, focused on describing and reexperiencing feelings, and on exposure to cues related to the traumatic experiences. Therapy was carried out in two phases. In the first phase the emphasis was on acknowledging and sharing what had happened, describing and reexperiencing feelings, and beginning to modify beliefs about the meaning of the incident. In the second phase, exposure was extended to the reactions of the participant to the traumatic experience. In the study of Lemmon and Mizes



(2002) IE was also applied individually. The participant received 25 individual therapy sessions. The first four sessions were focused on building rapport and trust. Next, IE was applied with the focus on the ability to describe thoughts and feelings linked to the traumatic event. Trauma-related cues were rated using a Subjective Units of Distress scale (SUDS). Relaxation and breathing exercises were taught to relax when feeling distressed.

In the study of Peckham et al. (2007) a survivor group was set up to help support victims with the consequences of sexual abuse. The content of the program followed in the survivors group is not discussed in the study, but the aim of the survivors group was to improve participants' and carers' knowledge about what sexual abuse is, the consequences of abuse, what they and others can do to help, and irrational negative cognitions about self-blame. In addition to increasing knowledge, the intention was improvement of participants' mental health.

### ***Assessment of Risk of Bias within Studies (QATQS)***

All intervention studies received an overall rating of “weak” on QATQS. Participants in all four studies were not likely to be representative of the target population (e.g., because they were not randomly selected) or selection processes were not described, which resulted in a domain rating of “weak” on selection bias for all.

Two studies had a pre-post-follow up design (Barber et al., 2000; Peckham et al., 2007) resulting in a “moderate” rating in the domain of study design. Two studies were case studies (Davison et al., 1994; Lemmon & Mizes, 2002) and were rated as “weak”.

None of the studies used control groups, so for all studies the domain of confounders was rated as “not applicable”.

In all studies outcome assessors were aware of the intervention status of the participants, the participants were aware of the research question, or blinding was not described. This resulted in a rating of “weak” on the domain of blinding for all studies.

In all studies, validity and reliability of the data collection tools were not described or could not be determined. This resulted in a rating of “weak” on the domain of data collection tools for all the included studies.

In all studies, 80–100% of the participants finished the study, which resulted in a “strong” rating on the domain of withdrawals and drop-outs.

### ***Effectiveness of the Programs***

Based on the outcomes and without taking risk of bias into account two programs were judged as being “effective” (Lemmon & Mizes, 2002; Peckham et al., 2007), and two programs were judged as being “unclear” (Barber et al., 2000; Davison et al., 1994). Taking risk of bias into account the effectiveness of two studies was downgraded from “effective” to “unclear” (Lemmon & Mizes, 2002; Peckham et al., 2007), and the effectiveness of the

other two studies was downgraded from “unclear” to “ineffective” (Barber et al., 2000; Davison et al., 1994).

## Discussion

This systematic review on prevention and intervention programs targeting sexual abuse in individuals with MID identified 12 studies eligible for inclusion: eight studies focused on preventing sexual abuse (prevention programs) and four studies focused on treatment of the consequences of sexual abuse (intervention programs). In the prevention studies, 126 female and 44 male participants were included with role-play and in situ assessment as the most used techniques. In three of the eight prevention programs, all participants were children. In the intervention studies, a far smaller total of 15 adults were included and no children. In both types of studies, the majority of participants were female: in the prevention studies the rate was three to one, and in the intervention studies only one male participated. Based on the primary outcome measures most studies reported effectiveness of the program, but all studies were overall rated as “weak” on the QATQS because of the high risk of bias. The latter was mainly due to poor blinding within studies, absence of a control group, and poor validity and reliability of outcome measures used. This led to an overall rating of “unclear” for 10 studies (eight prevention studies and two intervention studies), and “ineffective” for two studies (two intervention studies).

### *Participants, Program Content, and Outcome Measures*

Unsurprisingly, as the majority of individuals with ID reported to be sexually abused are female (Byrne, 2017), most participants in the included intervention studies were female. Nonetheless, when including participants in either prevention or intervention programs, boys and men with MID must not be ignored because, although less prevalent, the risk of sexual abuse for this group is also relatively high with severe consequences in terms of repeated victimization and perpetration (Balogh et al., 2001; Wissink et al., 2015). The prevention programs did include both children and adults, whereas in the intervention studies only adults participated. One could suggest that intervention programs should also become available for children since sexual abuse also occurs among children with MID (Wissink et al., 2015). These intervention programs should be further adapted to be suitable for children with MID. A key element in the adaptation is parental involvement with the rest of the network around the children (e.g., siblings, teachers) included in these programs as well. Moreover, the program should be provided within a supporting, stimulating, and structured context (Wissink et al., 2015).

In all programs interventions are used for which a certain level of cognitive and verbal skills are required. However, individuals with MID are known to have deficits in reasoning and abstract thinking (American Psychiatric Association, 2013), which limits their introspection and verbal skills (The National Academies for Sciences Engineering and Medicine, 2015). It should be noted that information on whether programs were adapted to the needs and learning style of the participants was lacking. Adaptation to the needs and learning style of individuals with MID could be achieved by, for instance, simplifying language, the use of symbolic communication methods (pictures, symbols, signs), and more repetition (Boardman et al., 2014).

With the need for this kind of adaptations in mind, especially intervention programs could benefit from recent developments in trauma-related treatment. There are some trauma focused treatments that have been found helpful for sexual abuse in the general population, and for which there is emerging evidence also were individuals with MID are concerned. Cognitive behavioral therapeutic interventions (CBT) and Eye Movement Desensitization and Reprocessing (EMDR) have shown to be effective in treating trauma (see e.g., Karatzias & Cloitre, 2019). Although research on the effectiveness of these interventions in individuals with MID is found complicated (Mevisen & De Jongh, 2010) recent studies indicate that EMDR can be feasible and effective for PTSD treatment in this group. Mevisen, Didden et al. (2017), using a multiple baseline across subjects design, found positive results of EMDR therapy for two young participants with a clinical relevant decrease of PTSD symptoms that maintained at follow-up. Another study, where the effectiveness of a program (including EMDR therapy) aimed at parents and children with PTSD and MID was assessed, Mevisen, Ooms-Evers et al. (2020) also found positive results. In both children and parents, trauma-related symptoms and daily life impairment significantly decreased and in parents a significant decrease in symptoms of general psychopathology and parental stress was found.

However, neuropsychological research shows that when reminded of sexual abuse during therapy, activity in brain structures involved in the inhibition of emotions and the translation of experience into communicable language decreases. Therefore, a bottom-up approach, starting with the body and physical sensations may be a suitable form of treatment in facilitating the regulation of arousal and effect (Van De Kamp et al., 2019). Movement- and body-oriented interventions (e.g., psychomotor therapy, dance/movement therapy) provide such a bottom-up approach and may serve as a valuable addition to current cognitive-behavioral therapeutic interventions or exposure-based treatments (Van De Kamp et al., 2019). In addition, movement- and body-oriented interventions rely to a much lesser extent on the verbal capacities of the participant and are increasingly used to prevent sexual abuse (e.g., Casey, 2018) and treat the consequences of sexual abuse in individuals without ID (e.g., Ho, 2015; Price, 2005). Whilst there are recent systematic

reviews reporting on the effectiveness of this approach for individuals without ID (e.g., Van De Kamp et al., 2019), no such studies came up in our search targeted at the prevention of sexual abuse or for treating the consequences of sexual abuse in individuals with MID.

With regard to outcomes, it is noteworthy that five of the eight prevention programs applied in situ assessment (Egemo-Helm et al., 2007; Haseltine & Miltenberger, 1990; Kim, 2016; Lumley et al., 1998; Miltenberger et al., 1999) to test the effectiveness of the prevention program. In these five studies, inclusion of in situ assessment was based on the study by Haseltine and Miltenberger (1990). According to today's ethical standards in situ assessment raises concerns, especially in the case of sexual abuse, as this could cause psychological distress or harm participants by exposing them to seemingly real, although simulated, sexually risk full situations (see Giannakakos, Vladescu, Kisamore, Reeve, & Fienup, 2020).

Besides in situ assessment, self-report measures were used that focused on knowledge about topics related to prevention of sexual abuse, such as self-advocacy and safety (Dryden et al., 2014; Egemo-Helm et al., 2007; Kucuk et al., 2017; Lee & Tang, 1998; Lumley et al., 1998). Although the aim of the prevention studies is often described as increasing knowledge on sexual abuse, it is disputable whether focusing on increasing knowledge is suitable in this case because it does not automatically lead to the acquisition of skills or change of behavior (Kelly & Barker, 2016).

Other outcome measures used in prevention and intervention studies frequently lacked information on psychometric quality and were often not adapted to the target group. For the intervention programs, the outcomes were mainly focused on assessing symptoms of posttraumatic stress disorder (PTSD), mood disorder, or anxiety disorder. However, research indicates that symptoms of sexual abuse in individuals with MID are broader than those of the aforementioned disorders. A recent review by Smit et al. (2019) reports that the consequences of sexual abuse in individuals with MID also express themselves in low self-esteem, avoiding sexual activity, atypical sexual interests (Matich-Maroney, 2003), aggressive behavior (Mansell et al., 1998; Sequeira & Hollins, 2003; Soylu et al., 2013), the possible development of a conduct disorder (Soylu et al., 2013), self-harm (Sequeira & Hollins, 2003), inappropriate sexualized talk (Matich-Maroney, 2003), and poor personal safety. None of the intervention studies measured these symptoms. Based on these findings it is suggested that future studies should not only use outcome measures focusing on PTSD, mood disorder or anxiety disorder symptoms but also measure the other aforementioned possible symptoms.

### **Strengths and Limitations**

A strength of the present study is that, to our knowledge, it provides an update of the literature on effectiveness of prevention and intervention programs specifically targeting sexual abuse in individuals with MID, and extends available reviews. Another strength is that a quality assessment tool (i.e., QATQS) was used in assessing the effectiveness of the included programs.

This systematic review also has some limitations. Some of the studies in the review used heterogeneous samples, including participants with moderate ID next to those with MID but, possibly due to the small samples, none presented separate analyses for these two groups. For this reason, we were not able to control for possible difference in effects. As in all reviews, publication bias may have affected our results. Studies with positive results are more often reported in literature than studies with negative results, which consequently misinforms researchers, practitioners and policymakers (Mlinaric et al., 2017).

### **Implications for Further Research**

Relatively few studies have appeared in the past decade on the effectiveness of programs for sexual abuse in individuals with MID. This is surprising given the increased attention for this topic in news media and epidemiological studies. Next to this, from the studies included in this review, we do not know if and if yes, in which way programs and questionnaires were adapted to these individuals. Future research should be targeted at adapting programs for individuals *with* MID that have been shown effective in individuals *without* MID. An example of a framework for adapting and underpinning programs is the Intervention Mapping protocol (see Bartholemew et al., 2016). By following the stepwise process of the Intervention Mapping protocol programs can be developed and/or adapted for use in individuals with MID.

### **Conclusion**

The objective of the present review was to provide an updated overview of programs – their content and effectiveness – targeting sexual abuse in individuals with MID. The current review shows that although sexual abuse is acknowledged as a serious issue in individuals with MID and although literature on prevalence, screening tools and program development is widely available, there is no robust evidence on their effectiveness. Also, there is no indication that new knowledge on prevention and new approaches found to be effective in individuals *without* MID are studied in individuals with MID who are the most affected by sexual abuse. Building on the studies presented, there is a need to further develop programs and use adequate and state of the art designs to see whether these are helpful in preventing sexual abuse and

treating its adverse and severe consequences.

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