

# Psychological and psychosocial treatment interventions for people with intellectual disabilities who have been exposed to sexual violence

## A Systematic Review including Ethical Aspects

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### Conclusions

There are too few well-conducted studies to be able to draw any conclusions about the effects and experiences of psychological and psychosocial treatments interventions for people with intellectual disabilities who have been exposed to sexual violence.

People with intellectual disabilities are often dependent on others and may find it difficult to report abuse due to fear of the reactions of those around them as well as lack of knowledge about their rights, or where to find support and help. Being subjected to sexual violence means violations of the person's integrity, self-determination, and dignity. It can have a significant negative impact on future quality of life, mental and physical ill-health and damage the person's opportunities to live a secure, rich, and independent life. This means that ethical values such as health and well-being, autonomy, and integrity, but also professional and research ethical aspects are important to consider.

### Background

Research shows that compared to the general population, people with disabilities are more exposed to violence, and more specifically, people with intellectual disabilities (IF), are even more exposed to sexual violence, even in societal interventions such as daily activities or special housing. People with intellectual disabilities who have been sexually abused are more often women than men, although there may be unreported figures related to gender. In addition, studies show that younger children with intellectual disabilities are more vulnerable than children outside the group. Research also shows that people with intellectual disabilities who have been exposed to sexual violence are at higher risk of developing reactions and symptoms that include emotional, physiological, and behavioural changes compared to people without disabilities.

Health care, including habilitation and student health care within adapted schooling, has an important role for this group. In addition, to offer good care and treatment, based on the person's individual needs, there are additional roles and responsibilities for care, including being a link in the legal process. There is literature and educational material on how sexual violence can be identified and dealt with after the abuse. However, there is a lack of national

guidelines, and guidance regarding treatment and communication with people with intellectual disabilities.

## **Aim**

To evaluate the body of evidence for psychological or psychosocial treatment interventions given in health care for people of all ages who have an intellectual disability and who have been exposed to sexual violence.

## **Method**

This systematic review has been conducted in accordance with the PRISMA statement. The protocol is registered in Prospero ID 519021.

For a study to be included in this systematic review, the following inclusion criteria needs to be fulfilled.

### **Inclusion criteria:**

*PICOs for studies with quantitative design*

#### *Population*

All ages of people with intellectual disability (IF) who have been exposed to sexual violence.

- Studies that do not separately report the results for people with intellectual disabilities, such as studies of a population where the people have several diagnoses, for example autism, are excluded. If there are studies that include people with an additional diagnosis than an intellectual disability, intellectual disability is weighted more heavily, and the study is included.
- Studies that examine trauma or violence in general are only included if the majority, i.e. at least 50 percent of the participants, have experienced sexual violence.

#### *Intervention*

Psychological and psychosocial interventions that can be given within the framework of health care in Sweden. The interventions may include the person who has been subjected to sexual violence, as well as people close to them (i.e., family, care activities, etc.).

#### *Control or comparison*

A different intervention than that given to the intervention group. The treatment must be relevant to a Swedish context and can be treatment as usual, medication, waiting list or active control, i.e., some other type of ongoing treatment given to the comparison group.

#### *Outcome*

The outcomes must be linked to the person with an intellectual disability.

- Mental illness: in the form of symptom reduction, diagnosis ((e.g., anxiety, depression, Post traumatic stress syndrome (PTSD), suicide attempts, self-harm behaviour, isolation, fear of dental care)) and co-morbidity (eating disorders, addiction problems).
- Function (social)
- Quality of life
- Cessation of violence
- Relationship/connection to non-offending caregiver.

#### *Study design*

Prospective studies with a comparison group, and systematic reviews based on such studies.

*SPICE for studies with qualitative design*

**Setting (S)**

Studies conducted in settings similar to health care in Sweden.

**Population (P)**

Persons, regardless of age, with an intellectual disability who have been subjected to sexual violence. The perspective can be the vulnerable, their families, care activities or other people in their immediate environment.

**Intervention (I)**

Psychological and psychosocial interventions that can be given within the framework of health care in Sweden.

**Control/comparison (C)**

A different intervention than that given to the intervention group. The treatment must be relevant to a Swedish context and can be treatment as usual, medication, waiting list or active control. It is not necessary that the study included a control treatment.

**Experience (E)**

The evaluation must refer to the experiences of the victim, its family or the carer that have taken part in the interventions.

**Other inclusion or exclusion criteria**

All types of primary studies with qualitative methodology regardless of data collection or analysis method. Mixed-methods studies are also included.

**Language:** English, Swedish, Danish, and Norwegian.

**Search date:** The final literature search was conducted in *June 2023*.

**Databases searched:**

- CINAHL (EBSCO)
- Cochrane Library (Wiley)
- Criminal Justice Abstracts (EBSCO)
- EMBASE (Embase.com)
- Ovid MEDLINE(R) ALL
- APA Psycinfo (EBSCO)
- PTSDpubs (ProQuest)
- Scopus (Elsevier)
- Social Services Abstracts (ProQuest)
- Sociological Abstracts (ProQuest)
- SocINDEX (EBSCO)

Supplementary searches for ongoing and published systematic reviews and HTA reports were conducted in the following databases:

- The Campbell Collaboration
- Epistemonikos
- International HTA Database

**Client/patient involvement:** No

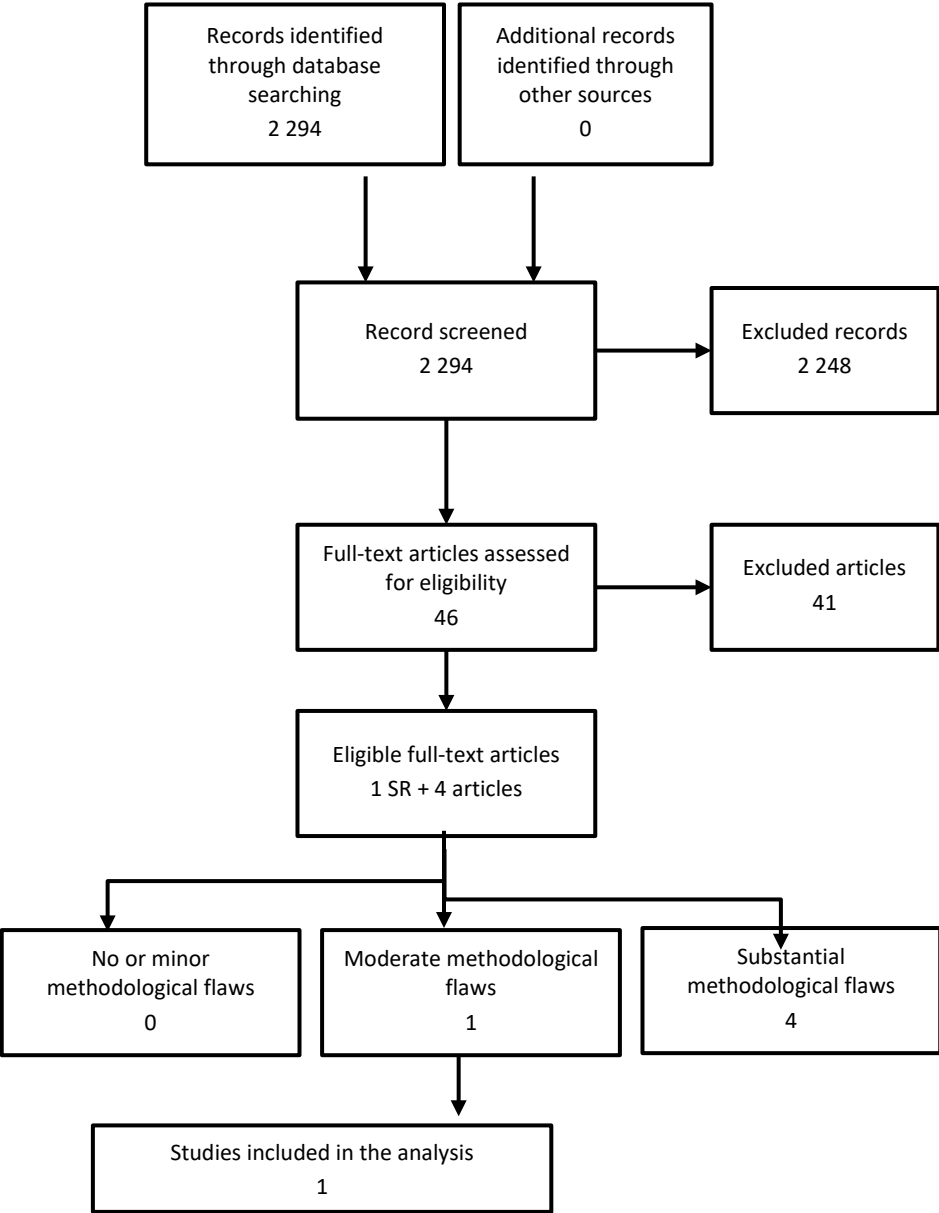
## Results

There is a lack of quantitative scientific studies on the effect of psychological or psychosocial treatment interventions given in health care to people with intellectual disabilities who have been exposed to sexual violence.

One qualitative study with moderate methodological flaws was included. It is a British study with seven women aged 26-47 years with intellectual disability who have been exposed to sexual abuse and participated in group discussions. The calls were conducted once a week on 20 occasions. Initially, the group discussions focused on getting the participants to feel safe in the group, which was significant because some participants expressed that it was very difficult to talk about the abuse. To then feel supported in not being alone in having been exposed to sexual abuse became an important part of the treatment process. It is reported that the group talks helped the women gain more knowledge about sexuality and contributed to them feeling less fearful and depressed, compared to when they started the group discussions. However, it took several months before there was an improvement in the participants' well-being. The study also shows that the participants' caregivers gained a greater understanding for and knowledge of the women's well-being after the completion of the intervention.

As the scientific basis only consists of one study, no synthesis or certainty of evidence was performed.

**Flow Chart**



## **Ethics**

Being exposed to sexual violence means negative consequences for the person, which means that detection, care, and support are important for health and quality of life. Although this report shows that there is a lack of scientific basis for interventions, there are great risks in failing to provide care and adequate interventions.

People with intellectual disabilities have both an ethical and a legal right to be heard and listened to, and to receive individually adapted information. These people are often in strong dependent relationships, which limits their freedom. They may also have difficulty identifying and reporting abuse due to fear of the reactions of those around them, or lack of knowledge. Despite the difficulties that people with intellectual disabilities may have in consenting to care and research, there are several initiatives to develop consent processes.

It may be more important for a person's health and future quality of life to talk about abuse, even if this involves a certain violation of privacy, a person's integrity. Adequate treatment that is adapted to the individual's level of functioning and ability is essential to minimize the risks of privacy violations that may be caused by an investigation.

A general and difficult professional ethical dilemma is between, on the one hand, providing interventions that lack or have weak scientific support to those in need of care or support, or, on the other hand, not doing so. Interventions with poor quality or non-investigated methods can be harmful and should often be avoided, but at the same time the need for care can be both urgent and significant. Decisions must be made on a case-by-case basis and rest on the best possible medical, nursing, ethical and legal grounds, whether to provide an intervention or not.

There are privacy considerations that must be weighed against potential benefit. Researchers must ask themselves if, for example, the research involves treatment in a group, raises privacy problems, and if there are ways to minimize risks of damage to privacy.

There are strong ethical and scientific reasons for making it easier for people with intellectual disabilities to participate in research studies as active research subjects. They have the right to be heard and to have an influence on things that concern them, and their experiences are an important source of knowledge.

## **Discussion**

No previous systematic review of psychosocial and psychological interventions in the event of sexual violence for the group has been identified. This makes it difficult to obtain guidance in the development of supportive and preventive interventions aimed at the group. One study with qualitative methodology was included. In contrast to quantitative studies, there were more qualitative studies that were relevant, although not sufficiently well done due to shortcomings in, for example, the description of the analysis.

One interpretation of the results is that there is a need for a greater range of interventions for treatment that are adapted to the target group, and that the effect of the interventions should be examined scientifically by using both qualitative and quantitative research.

## Conflicts of Interest

In accordance with SBU's requirements, the experts and scientific reviewers participating in this project have submitted statements about conflicts of interest. These documents are available at SBU's secretariat. SBU has determined that the conditions described in the submissions are compatible with SBU's requirements for objectivity and impartiality.

### Project group

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## Appendices

[Reference list of included studies](#) (Link)

[Characteristics of included studies and studies with high risk of bias](#) (PDF)

[Search strategies](#) (PDF)

[Excluded articles](#) (PDF)