

# SIBS: Siblings

SIBS is an initiative for siblings of children and young people with disabilities aged 8-16 years. The purpose of SIBS is to strengthen communication in the family and deal with sibling challenges.

[Camilla Højgaard Nejst](#) | The National Board of Social Services

The sibling intervention SIBS, an abbreviation for Siblings, is a manual-based sibling intervention, which is targeted at siblings of children and young people with disabilities and chronic illness aged 8-16 years and their parents. The intervention focuses on strengthening communication around diagnosis of the child with disabilities as well as the related sibling challenges. The manual has been developed based on literature about siblings of children with disabilities, a descriptive study on support groups for siblings, workshops with practitioners and user organizations, and several pilot trials of the intervention.

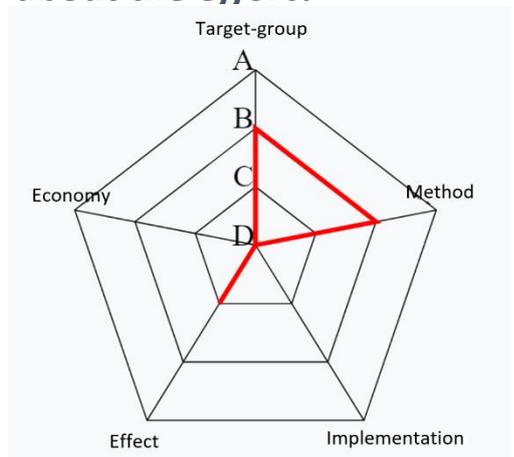
The manual for the intervention was evaluated in a study with 99 families.

Analyses performed in connection with the evaluation of SIBS showed that participation in SIBS leads to better psychological adjustment, increased knowledge about the diagnosis among siblings and strengthened communication in the family.

Pr. June 2020, four municipalities and two hospitals in Norway have implemented sibling groups in SIBS, and per. September 2019, Frambu has completed two courses, which have been held approx. every six months. There are still no Danish municipalities that use SIBS in the work with siblings of children and young people with disabilities (September 2019).

There is currently no knowledge of the financial circumstances of using the sibling intervention SIBS.

## *How much do we know about the effort?*



[Read the whole assessment](#)

This is how we prepared the assessment

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## Target-group

**The target group for SIBS is siblings of children and young people with a wide range of disabilities in age range of 8-16 years old.**

The sibling intervention SIBS, an abbreviation for Siblings, is aimed at siblings of children, aged 8-16 years, with a wide range of chronic diseases/disabilities. The severity of the disability of the brother or sister with disabilities can vary, and SIBS is targeting siblings who are both boys and girls. Of the inclusion criteria described is that the participants must have the status of being siblings and be within the age group of 8-16. Conversely, siblings and parents are not encouraged to participate in the study if they themselves have a chronic disorder (Haukeland et al., 2020).

### Siblings may need extra support

When you are a sibling of a brother or sister with a disability, there may be other roles and a different division of roles in the family (Vermaes et al., 2012).

Several studies have over time shown that siblings of children with disabilities often have more care responsibilities than other children (Cuskelly & Gunn, 2003; Greenberg et al., 1999).

Are the tasks practical, time-limited, with clear expectations, and if you acknowledge the child for the effort, then even siblings can have a positive experience with it (Haugland, 2006).

However, for siblings of children with disabilities, the need to help their brother or sister can fill so much that it has a negative impact on their social life (Vatne, 2014).

Therefore, even though many siblings are doing well, according to Dutch researcher and psychologist Ignace Vermaes, you should think of them as a group of children who may need extra support. According to Vermaes, being a sibling of a child or young person with a disability increases the risk of experiencing mental difficulties in the form of e.g. anxiety and depression as well as behavioural difficulties and social problems (Vermaes et al., 2012).

However, it is important to remember that only some siblings of children with disabilities develop mental health problems and that most have a normal mental well-being. But good mental well-being does not preclude a childhood with many difficult emotions and challenges.

Research suggests that one should think of the target group as a group of children who may need extra support. In other words, the children who are at risk should be identified so that they can be offered the right support (Vatne, 2014).

According to Haukeland et al. (2020) it is necessary to research when sibling interventions are delivered optimally. For example, is it best to give the sibling intervention in a clinical setting to siblings with clinical symptoms of mental difficulties or as universal prevention, i.e. to all siblings. Based on findings of Haukeland et al., it suggests that prevention is the level of intervention that best suits the target group (Haukeland et al., 2020).

## **Need for knowledge and strengthened communication in the family.**

Siblings often have limited and sometimes misleading/ incorrect knowledge about chronic illness/ disability of their brother or sister. Research has shown that less knowledge about the chronic disorder/disability is associated with poorer sibling adjustment, whereas increased knowledge about the disorder/disability has been shown to reduce anxiety and improve the perception of control and adjustment in siblings.

Having children with chronic disorders/ disabilities has been linked to poorer communication in the family (Murphy et al., 2017). In addition, family communication has been documented by several researchers to influence adjustment of children (Barnes & Olson, 1985; Jackson et al., 1998).

Thus, the developers behind SIBS have decided to focus the intervention on strengthening parent-sibling communication and giving parents the opportunity to provide informative and emotional support to siblings (Haukeland et al., 2020).

Read more about the target-group of children with disabilities

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## Method

**The sibling intervention SIBS provides siblings of children and young people with disabilities knowledge about the disability as well as guidance on how parents can listen and communicate with the child about the thoughts and experiences that the child has.**

Norske Frambu is a national competence center for rare diagnoses, which offers information and interventions to families who are affected by rare disorders. In 2011, Frambu identified a need to develop a standardized manual, and together with the Department of Psychology at the University of Oslo, a study called the Sibling Project was launched.

The aim of the project was to develop an experience- and knowledge-based intervention for siblings of children with physical and / or mental disabilities and chronic disorders. An integrated sibling and parent intervention has emerged from this. An intervention that focuses on strengthening communication about the diagnosis and dealing with related sibling challenges. The effort is based on the principles: listen, explore, and confirm (Vatne, 2018).

The intervention is group-based and led by a group leader and organizer, respectively.

The intervention is called SIBS, an abbreviation for Siblings, is manual-based and consists of three thematic conversation modules:

- A module that deals with the children/young people in the group getting to know each other
- A module on diagnosis
- A module on emotions (Vatne et al., 2019).

## Content and structure

The manual for SIBS describes in detail how the intervention is structured, which exercises are to be done when, and what each exercise must contain.

### Frequency and intensity of the five exercises

The SIBS-intervention contains five exercises:

- three separate exercises for children and parents, respectively
- two joint exercises, where parents and child talk in pairs under guidance (Vatne et al., 2019).

The exercises can be carried out during weekend gatherings, during two days of the week or spread over several weeks, as the organizer (municipality, specialized offer, user organization or similar) finds it most appropriate (Vatne, 2018).

### Overview of the five exercises

Table 1: Overview of the five exercises

	Exercise 1 (20 min,)	Exercise 2 (60 min.)	Exercise 3 (20-60 min.)	Exercise 4 (60 min.)	Exercise 5 (20-60 min.)
Children	Get to know each other	The diagnosis	Joint exercise for children and parents on the diagnosis	Feelings	Joint exercise for children and parents on feelings
Parents	Information	The diagnosis	Joint exercise for children and parents on the diagnosis	Feelings	Joint exercise for children and parents on feelings

## Goals for the conversations

The goal for the children groups is:

- that the children talk about their experience with their siblings' diagnosis and formulate a question about the diagnosis to the parents
- that the children talk about their emotional experiences as siblings of a child with a diagnosis that for some is perceived as challenging (Vatne, 2018).

The goal for the parent groups is:

- to give parents knowledge about how to listen (listen), show interest in what the child is saying (explore), and show understanding of how the child thinks (confirms) about diagnosis of siblings
- to give parents increased knowledge about how to listen (listen), show interest in (explore) and show understanding of (confirm) emotional experiences of the child (Vatne, 2018).

The goal of the exercises, in which both children and parents participate (the joint exercises):

- that the children convey their need for information and tell about the challenges they experience by being siblings of a brother or sister with a disability
- that the parents practice different techniques and strengthen their communication skills
- that parents and children get new good conversation experiences under guidance (Vatne, 2018).

## Group composition

The child participates with one of his or her parents, and the same parent participates throughout the intervention. If two siblings from the same family participate in the intervention, both parents can participate. The group with children consists of three to eight children and is led by two adults. There must be one adult for three children. In the parent group, one parent can participate per. children and a maximum of eight in total. There are two leaders of the parent group.

# Equipment and facilities

## The children group

- A screened room with a table where everyone can sit facing each other
- SIBS booklet, which consists of tasks corresponding to the exercises to be done in the children group (printed in the number that is needed)
- Pens/pencils for everyone
- Flipcharts and markers in several colours (Vatne, 2018).

## The parent group

- A screened room where everyone can sit facing each other
- SIBS parent booklet, consisting of information on themes for the parent group (printed in the number needed)
- Pens/pencils for everyone
- Flipcharts and markers in several colours
- Poster or similar, where the message of the session is clearly presented
- PC and projector, possibly. TV for showing films (Vatne, 2018).

## Joint exercises

- A space where parents and children can sit together without being disturbed by the others. Can either be done in a large common room or by using several rooms
- Poster where the goals of the conversation (listen, explore and confirm) are presented clearly (requires more examples if the participants are divided into several rooms) (Vatne, 2018).

The final intervention package consists of:

- a manual
- a leaflet for children
- a leaflet for parents
- four video examples of parents and children talking about disabilities and emotional experiences using the techniques learned in the intervention (Vatne, 2018).

Read more about SIBS on the website of the project

## Roles and qualifications for group leader and organizer

As the communication between siblings and parents has proved to be challenging, the developers (Frambu - National Competence Center for Rare Diagnoses) have incorporated an element of communication training between parents and child in the intervention. However, this expands the role of the group leader to also be supportive and helpful in relation to communication (Vatne et al., 2019; Haukeland et al., 2020).

The descriptive studies that the developers made in connection with the development of the intervention showed great variation in how groups of children communicated and how group leaders moderated the conversations. SIBS therefore requires formalized training of the professionals who are to be group leaders. The manual for SIBS provides specific advice on communication techniques that the group leader can use in children and parent groups, respectively (Vatne et al., 2019; Vatne, 2018).

According to the leader of the sibling project, Torun Vatne, several different professionals can act as group leader for SIBS, e.g.

- pedagogues
- nurses
- psychologists
- social workers (Vatne et al., 2019).

The group leaders can work in many different places (e.g. the health service, the municipality or in a hospital). In Norway, it is the professionals, e.g. health professionals, who are expected to provide preventive measures to children, and who according to Norwegian law are obliged to identify the needs of siblings and refer to places where they can receive support (Vatne et al., 2019).

The group leaders first take an online course. This is followed by a two-day course at Frambu, where the group leaders themselves must hold group exercises, and finally, once they have completed these, they are offered a webinar where SIBS is reviewed again and experiences from the implementation are discussed.

Find the online course on the website of the National Competence Service for Rare Diagnoses.

## **Role distribution**

The role distribution in the groups is:

- The group leader controls the content and direction of the conversation, just as they are responsible for setting boundaries and signalling the need for help from the organizer.
- The organizer acts as a facilitator and contributes to both strength, depth, focus and calmness in the conversation about the theme chosen by the group leader.
- In the joint exercises, both the group leader and the organizer from the child group and the parent group have the role of supervisor for parents and children (Vatne, 2018).

The roles should be clarified and prepared before starting the group (Vatne, 2018).

## **Communication techniques**

The SIBS manual comes with many suggestions and examples of how the group leader and organizer should communicate with children and parents, respectively. In summary it can be said:

- that the group leader and organizer through the group discussions should strive for and follow the mantra of the intervention: listen, explore and confirm
- that the group leader and organizer should avoid the use of professional language in both child and parent groups (e.g. say “be interested in what the child tells” rather than “explore”)
- that in the group discussions it is the goal of group leaders and organizers to create an open dialogue rather than a feeling/ experience of participating in a group interview (Vatne, 2018).

## Background for sibling program SIBS

The thinking behind the Norwegian sibling intervention is based on many years of research in the field. A literature review conducted by the developers behind SIBS in 2012 identified a number of important aspects that have been crucial to the development of SIBS:

Siblings often lack knowledge about the diagnosis (Lobato & Kao, 2002).

Siblings are at risk for psychological difficulties and are less robust compared to their peers (Vermaes et al., 2012).

Communication between siblings and their parents is vulnerable (Mulroy et al., 2008).

Parents attention on how siblings perceive their brother's or sister's chronic disorder is a factor in the resilience of siblings' adaptation (Taylor et al., 2001).

Incorporation of a parent component into the intervention has shown that the intervention can lead to more long-term effects (Mendlowitz et al., 1999; Scholten et al., 2013).

SIBS was first developed in 2013, and the knowledge base in the field has therefore also grown in the time since then. Findings in the period 2013-2017 strengthen the arguments that SIBS is already based on. Namely that:

- siblings of children with chronic disabilities / disorders are at risk of developing psychological difficulties (Tudor & Lerner, 2015)
- illness/ disability in children poses a risk of impaired communication in the family (Murphy et al., 2017)
- the level of emotional communication and support from parents to siblings is important for sibling well-being (Long et al., 2013; Incedon et al., 2015)
- it is crucial to involve parents in interventions aimed at preventing psychological difficulties in children (Scholten et al., 2013).

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## Implementation

**SIBS has been tested and evaluated in a Norwegian context and is described in a manual that guides the group leader in detail and organizes through the five exercises of the intervention.**

The sibling intervention SIBS, an abbreviation for Siblings, has been tested in several Norwegian municipalities and in hospitals. According to the leader of the sibling project, Torun Vatne, SIBS can be led by a number of different professionals, e.g. educators, nurses, psychologists and / or social workers, and they can work in many different places, e.g. the health service or the municipality (Vatne et al., 2019).

However, it requires formalized training of the professionals who must be group leaders, as they, among other things, must be able to support communication between child and parents (Vatne et al., 2019; Haukeland et al., 2020).

From 2014 to 2017, Frambu – National Competence Center for Rare Diagnoses by psychologist Torun Vatne conducted an evaluation study of the sibling intervention SIBS (Haukeland et al., 2020).

Per. August 1<sup>st</sup>, 2020, two municipalities and four hospitals have implemented SIBS groups. A fifth hospital has currently registered participants, and two more municipalities are interested. On August 1<sup>st</sup>, 2020, three courses were completed at Frambu, and a new course is planned for autumn 2020 (Haukeland, 2020).

Overall, SIBS received very positive feedback from both children and adults in their evaluation. However, there is still a need to test the effect of the intervention, which is why the developers behind the SIBS intervention (Frambu) in 2019, an RCT study started with SIBS. The goal is to recruit 288 families (Vatne et al., 2019).

In September 2019, only the institutions and municipalities that participated in the RCT study had been offered the course via Frambu, but those interested can contact Torun Vatne.

Contact Torun Vatna via email

In September 2019, there are still no Danish municipalities that use SIBS in the work with siblings of children and young people with disabilities (September 2019).

## **E-learning course precedes two-day course**

In addition to the e-learning course, Frambu has developed a standardized two-day course. The group leaders first take the e-learning course, after which they attend this two-day course at Frambu. Here, the group leaders themselves conduct a group before they are finally offered a webinar, where SIBS is reviewed again, and experiences from the implementation are discussed. It is free to take the course, but you pay a course fee of 500 Norwegian kroner, which covers lunch, materials, and course certificates.

Read more about the Danish experiences with sibling groups in the article about SibworkS

See also more about sibling groups in the article on the Sibling Program: Giving siblings space

## **SIBS-material**

The testing of SIBS at Frambu has provided good input on how the intervention should be arranged. The Frambu competence center has developed a manual consisting of instructions regarding necessary equipment and tasks to be completed. The manual also contains good advice for group leaders on communication techniques and ways to cope with the difficult situations that may arise during the exercises. (Vatne, 2018).

Likewise, Frambu has developed booklets for both children and parents. The booklet for children consists of tasks that can be completed and shown to the parents, while the booklet for parents consists of written information on the topics for the individual practice sessions. In addition, the booklet of the children contains an agreement to continue talking at home. An agreement signed by both child and parents at the end of exercise five (Vatne et al., 2019).

## **Implementation experiences**

Among the most significant feedback from previous pilot studies was the parents' desire to get more information about the children's group exercises. This was consequently incorporated and is therefore already part of the present manual. This means that the group leader from the children group presents the selected questions from exercise 2 of the children group and the challenge from exercise 4 of the children group to the parent group. This to provide more context and information on how the topic has been discussed by the children (Vatne et al., 2019).

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## Effect

**SIBS has been evaluated in a Norwegian context. According to the results, the participating siblings in SIBS experience significantly fewer psychological challenges, significantly increased knowledge about the diagnosis among siblings as well as significantly strengthened communication in the family.**

## Evaluation study

From 2014 to 2017, Frambu - National Competence Center for Rare Diagnoses by psychologist Torun Vatne conducted an evaluation study of the sibling intervention SIBS (abbreviation for Siblings).

Participants were recruited from six websites providing services to families from all regions of Norway; two national specialists in the field of rare and autism spectrum disorders as well as four national user organizations in the field of autism spectrum disorders, cerebral palsy, congenital heart disease and Down syndrome (Haukeland et al., 2020).

99 siblings aged 8-16 years participated, of which 54.5 percent were girls. They each participated with one parent in the SIBS intervention, but both parents completed the questionnaires. All the participating siblings had a brother or sister with a chronic disorder aged 3-21 (Haukeland et al., 2020).

The participants in the evaluation study were families with children with both rare and more well-known diagnoses, such as Down syndrome, autism, cerebral palsy, and rare genetic conditions, which involve developmental disabilities or physical disabilities. There are thus several different types of disabilities, which have in common that they are chronic conditions.

## Results

The participants in the evaluation, both children and parents, reported a high degree of satisfaction with SIBS. On a scale from 0 to 4, where 4 represent very satisfied, the children had an average score of 3.5 and the parents of 3.4. Both parents and children reported that they especially appreciated the opportunity to talk together about both the diagnosis and the experiences siblings have during SIBS (Haukeland et al., 2020).

Overall, the analysis of the results showed:

- a significant improvement over time in the quality of parent / sibling communication, which was the primary outcome of the intervention.
- an improvement in siblings' reports of emotional and behavioural problems
- an improvement in relation to adaptation to and knowledge about brother or sister's chronic disorder / disability (Haukeland et al., 2020)

These are promising results, although the uncontrolled design does not make it possible to establish that the SIBS intervention alone caused these changes (Haukeland et al., 2020).

## Measurements

The evaluation measured the satisfaction of siblings and parents with the intervention to assess acceptance of the intervention and the feasibility of SIBS by the participants and the group leaders and organizers. The ability of the group leaders to comply with the manual was also measured.

In addition, outcome was measured (outcome/result):

- at start-up (T1)
- three months after participating in SIBS (T2)
- six months after participation in SIBS (T3) (Haukeland et al., 2020).

## Primary and secondary outcome

Parent/sibling communication was the primary outcome. The secondary outcome was:

- emotional and behavioural problems siblings
- adaptation to chronic illness/disability of brother or sister
- knowledge of the disease/disability (Haukeland et al., 2020).

### The primary outcome

A child version of the Parent-Child Communication Scale (PCCS) was used to measure the quality of parent-sibling communication. Siblings rated openness and problems in parent/sibling communication on a five-point scale from 1 (almost never) to 5 (almost always) in relation to the parent who participated in SIBS (Haukeland et al., 2020).

Example: "Is your mother trying to understand what you are thinking?"

### The secondary outcome

Strengths and Difficulties Questionnaire (SDQ) was used to measure emotional and behavioural difficulties of siblings.

To measure sibling adjustment in relation to chronic disorder/ disability of brother and sister, a scale called the Negative Adjustment Scale (NAS) was used. NAS is a customized version of the Sibling Perception Questionnaire.

Sibling Knowledge Interview (SKI) was used to measure siblings' knowledge of their brother's or sister's disorder/disability. Trained interviewers asked siblings to explain chronic illness/disability of their brother or sister in relation to symptoms, cause, and treatment. The interview was conducted either face to face at start-up (T1) or by telephone after three months and six months (T2, T3). All interviews were recorded on tape and their explanations scored from 1 (no understanding) to 5 (exact knowledge) (Haukeland et al., 2020).

## Upcoming RCT study

SIBS has now been evaluated in a Norwegian context and received generally very positive feedback from both children and parents. However, there is still a need to test the effect. Therefore, the developers behind the SIBS intervention started an RCT study with SIBS (Frambu) in 2019.

The RCT study started in September 2019, and the data collection will continue until 2022. In December 2019, three municipalities and three hospitals in Norway will participate in the study, which will recruit siblings for children with neurodevelopmental disorders between the ages of 8 and 16. Focusing on this target group opens up to include siblings of children with every condition that affects the central nervous system (e.g. ADHD, autism, cerebral palsy, epilepsy, Tourette's syndrome).

A requirement for participation is that the child with a diagnosis receives health services in the municipality or the "specialist health service". The goal is to recruit 288 families. The RCT study goes by the name Preventing Mental Health Problems in Siblings of Children with Neurodevelopmental Disorders (Vatne, 2019).

Contact project manager Krister Fjermestad via e-mail

## Sources

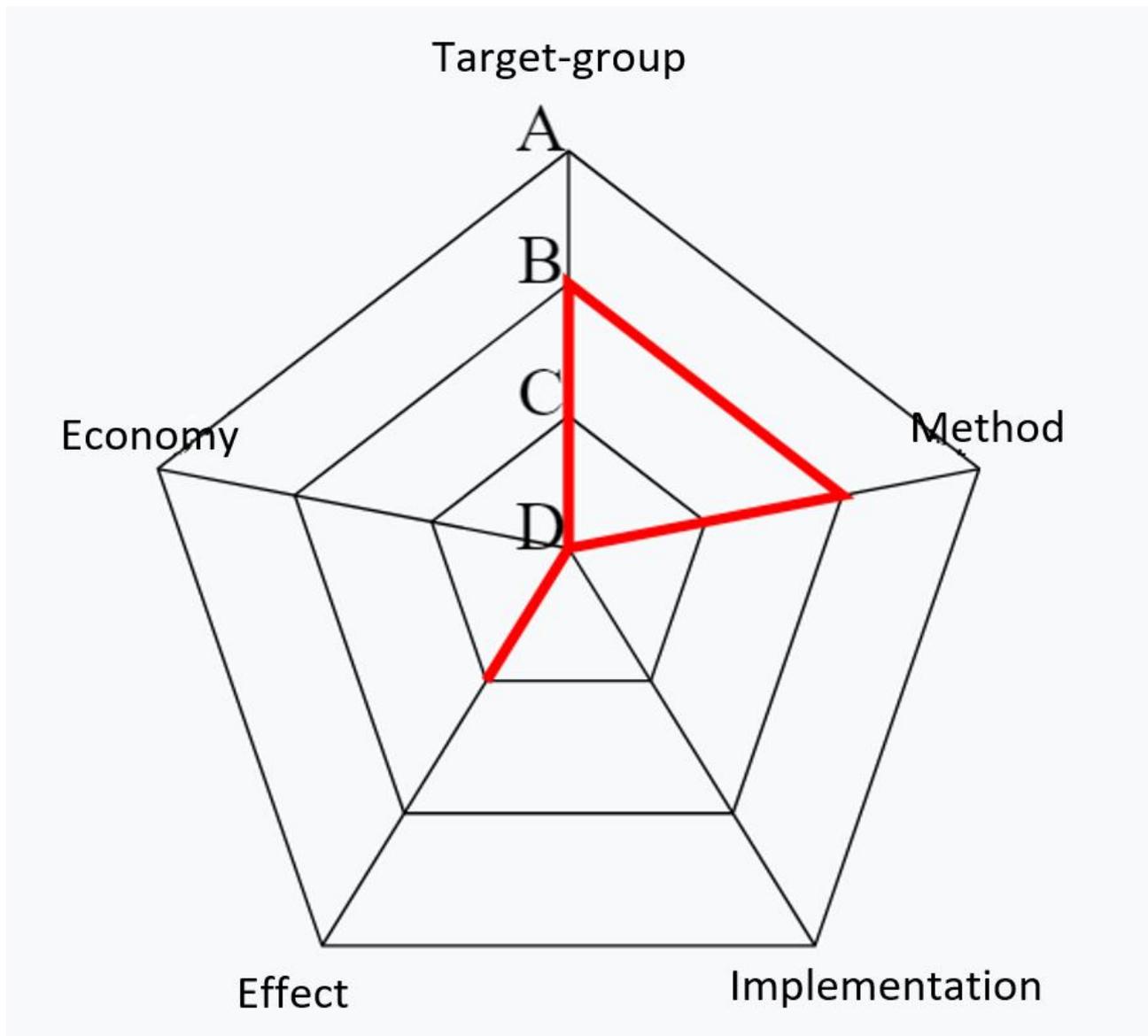
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## Economy

There is no knowledge of the financial circumstances of using the sibling intervention SIBS.

How much do we know about the effort?



#### Target-group

The sibling intervention SIBS is targeted at siblings of children and young people with disabilities and chronic illness aged 8-16 years and their parents. These are siblings of children and young people with a wide range of disabilities.

Research has shown that being siblings to a child with a disability or a chronic illness can pose an increased risk of experiencing mental health issues. There are inclusion criteria for the target group, which is that the participants must have the status of being siblings and be within the age group 8-16 years. Conversely, siblings and parents were not encouraged to participate in the study if they themselves had a chronic illness. It is clearly described what needs the sibling effort SIBS must meet. However, no support tools have been

developed to identify the target group. On that basis, the knowledge base for target group of the effort is awarded the score B.

#### Method

The effort is structured and manual-based, where the course, activities and frequency are described in detail. It is clear what effects or gains the method strives for both the sibling and parent group, just as the method is based on relevant theory and research. In addition, it is thoroughly described which specific tools and physical framework support the effort. Considerations about and recommendations on what qualifications and roles the group leader and organizer should have are also described. There are no descriptions or standards for ongoing and systematic follow-up of the implementation of the effort or achievement of results at citizen level. On that basis, the knowledge base for the intervention method is awarded the score B.

#### Implementation

SIBS has been tested in a Nordic context (Norwegian) and is thus considered relevant in the Danish context. There are Nordic implementation experiences, but they are not yet well described. On that basis, the knowledge base for the implementation of the effort is assigned the score D.

#### Effect

SIBS has been evaluated in a Norwegian context. 99 siblings aged 8-16 participated in the evaluation study. They each participated with one parent in the SIBS intervention, but both parents completed the questionnaires. Both children and parents reported a high degree of satisfaction with SIBS. Both parents and children reported that they especially appreciated the opportunity to talk together about both the diagnosis and the experiences siblings have during SIBS. The analysis showed that there was a significant improvement over time in the quality of parent/sibling communication, in siblings' reports of emotional and behavioural problems and in relation to adaptation to the chronic disorder and knowledge about it. This was a study with a pre- and post-measurement without a control group. On that basis, the score is awarded C.

#### Economy

There is no knowledge of the costs of implementing and operating SIBS. No information on cost-benefit or cost-effectiveness of SIBS has emerged in the systematic literature search. On this background, the knowledge base for economics of the effort is awarded the score D.

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The knowledge in this article is chosen according to criteria of the knowledge portal.