Supporting siblings of children with a special educational need or disability: An evaluation of Sibs Talk, a one-to-one intervention delivered by staff in mainstream schools

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A group often overlooked for specific supports in schools are siblings of children with a disability, special educational needs or a serious long-term condition (SEND). In this article we review the current sibling research and identify a lack of literature on interventions, particularly within a school context. We then present a description of Sibs Talk, an example of a new school-based intervention to support siblings. Sibs Talk is a ten-session, one-to-one intervention approach for schools to complete with Key Stage 2 children who have a brother or sister with SEND. Finally, we present an initial evaluation of the effectiveness of Sibs Talk, using a pre and post evaluation format with a sample of 55 children from 11 schools. The data presented in this evaluation indicate that Sibs Talk may have contributed to positive outcomes for participating children.

Key words: **Siblings, families, intervention, evaluation, disability.**

Introduction

Schools have a responsibility to safeguard, ensure the well-being and enhance the education of the children in their care. A group often overlooked by UK schools are siblings of children with a disability, special educational needs or a serious long-term condition (hereinafter referred to as SEND). It has been estimated that approximately 7-17 per cent of children are siblings of children with a chronic condition/disability (McKenzie Smith *et al*., 2018). Therefore, there are an estimated two to five siblings of children with SEND in the average UK classroom. The research evidence for sibling outcomes is rather mixed, with some studies indicating quite large negative differences in psychological well-being for siblings of children with SEND (Goudie *et al*., 2013), whilst other research indicates these well-being differences may be small and more likely due to indirect effects related to factors such as family socio-economic disadvantage (Neely-Barnes and Graff, 2011; Emerson and Giallo, 2014; Hayden *et al*., 2019). Other research also indicates benefits and positive experiences of siblings of children with SEND (Mulroy *et al*., 2008).

More research needs to be done to understand sibling educational outcomes and experiences in school (Hastings, 2014; Kovshoff *et al*., 2017). There are some data to suggest siblings may be negatively affected educationally, with poorer functioning at school (Goudie *et al*., 2013). Whereas Chien *et al*. (2017) found that although siblings of children with autism had more behavioural problems and poorer attitude to school work, they had comparable academic achievements to children with a brother or sister without autism.

Generally, UK schools do little to support siblings of children with SEND as a specific target group. Some siblings will get support with well-being issues provided through general safeguarding and pupil support policies. However these are not targeted specifically for siblings of children with SEND. Furthermore this support may only materialise once concerns regarding siblings have already arisen – and there is a case for perhaps anticipating the needs of siblings – identifying and supporting this group before some siblings may encounter problems. A group that have recently gained more recognition from health and educational providers in the UK are young carers. The introduction of the Children and Families Act 2014 and the Care Act 2014 recognised and afforded new rights to young carers in England. According to census data from 2001, there are at least 175,000 young carers under the age of 18 in the UK (Becker and Becker, 2008) with some reports indicating the figure could be nearer 700,000 (BBC, 2010). Although data

suggest that most young carers are providing care for a parent, a large proportion are caring for their sibling – data varies, but would suggest between a quarter (Cheesbrough *et al*., 2017) and up to half of young carers are caring for a sibling (The Children's Society, 2013). It remains unclear however, to what extent these young carers have a brother or sister with SEND, or whether they are helping with their younger 'typically' developing siblings. Therefore, schools should be considering sibling experiences when supporting young carers as well.

We have identified three systematic literature reviews that explored interventions for siblings of children with SEND (Hartling, *et al*., 2014; Tudor and Lerner, 2015; McKenzie Smith *et al*., 2018). These systematic reviews highlight two factors making the present intervention unique. Firstly, the vast majority of interventions are delivered in hospital or other medical settings, community contexts, summer camps or in family contexts: it was not explicit that any interventions reviewed were based within the participating siblings' school contexts. The second factor of note from these reviews is that, with very little exception, these interventions were peer group based rather than being multiple, one-to-one interventions between an individual sibling and an adult. Therefore, a one-to-one intervention delivered in siblings' own schools may have unique potential benefits that are worthy of exploration.

Intervention information and basis

Sibs Talk is a one-to-one, manualised support intervention developed by the UK charity Sibs for pupils in Key Stage 2 who have a brother or sister with SEND. Sibs Talk consists of ten sessions spread over a school term aiming to improve siblings' well-being and their engagement with learning (Sibs, 2018). The Sibs Talk intervention was informed by almost twenty years of the charity Sibs' work. Knowledge developed through practice, working both directly and indirectly with siblings, indicated that many siblings were not identified in their school settings. Siblings' needs can be overlooked, leading to problems with well-being and progress at school. These children face various barriers to learning, including disrupted sleep, anxiety about their brother or sister's health, and less parental support with homework due to the demands of care. Sibs has worked with organisations across the UK to help them develop and run sibling support groups. These involve both recreational and discussion activities, providing siblings with a space outside the family home to meet other siblings, to share experiences and feelings, and to learn coping strategies. Over the past five years, fewer organisations have had the necessary funds or staffing levels to continue to run these

groups in their local authorities. With this change in the funding climate, Sibs developed Sibs Talk, a one-to-one intervention for schools that would deliver some of the outcomes that were achieved through the support groups while responding to requests from school staff for a tool to support siblings. As most of these requests had been provided by primary schools, the Sibs Talk pilot was designed for Key Stage 2 pupils.

The content and format for Sibs Talk was based on the approach that Sibs teach professionals to use in sibling groups, with a key focus on acknowledging siblings' feelings and experiences, and facilitating discussion around coping strategies. A ready-to-use manualised tool was developed to minimise the time it would take for schools to run a one-to-one intervention, with the hope that this would increase Sibs Talk participation. Design decisions were made through discussions with siblings, parents and school staff. These discussions led to decisions on the main topics covered in Sibs Talk, the number and length of the intervention sessions, which staff members would deliver the intervention, as well as the training needs of these staff. Once the Sibs Talk pupil activity booklet was written, it was sent to a reader panel for feedback before the final version was produced. The reader panel consisted of a primary school head teacher, a SENCO, a school counsellor, a sibling support worker and an adult sibling. Each Sibs Talk pack consisted of a pupil activity booklet, a leaflet for parents about Sibs Talk, stickers, a certificate upon completion of the intervention, ethical documentation and the evaluation forms for staff and pupils to fill in.

There are ten sessions in the intervention to be carried out during one school term. Each session lasts about 25 to 35 minutes. Most schools decided to complete sessions with siblings during scheduled lessons rather than at lunch time or after school. The staff member guides the sibling through an activity page in the booklet, using the instructions in the Sibs Talk staff instruction manual. The first session starts with sharing basic information about each sibling's family and circumstances to help the sibling develop trust and rapport with the staff member leading the intervention. As the booklet progresses the sessions focus in more depth on their brother or sister's disability or condition, the sibling's feelings and experiences, and the issues that are challenging for them at home and school (see Figures 1 and 2). The sessions also look at the skills, knowledge and attributes that siblings have acquired and how their school can support them.

Prior to leading the intervention, staff attended a two-hour training session at their own school or at a host school nearby. The training focused on the micro skills
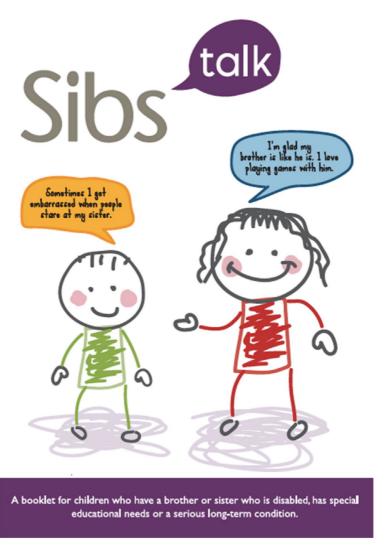
Figure 1. Front cover of the Sibs Talk intervention manual [Colour figure can be viewed at wileyonlinelibrary.com]

required for listening to and acknowledging siblings' feelings. This involved a role play to practice how to respond to siblings' emotive questions and statements such as 'Will my brother die?' or 'I hate my sister'. Many school staff told us that

9. How school can help me

Siblings tell us that school can be difficult for lots of different reasons.

Colour in the circles if any of these things are difficult for you at school.

- Struggling to get homework done
- Feeling tired
- Having to sort things for my brother or sister in school
- Not being able to join in with things after school
- Being bullied
- Feeling worried or sad
- Not having the right stuff with me for school
- Being late or missing lessons

I feel tired at school.

I would like these things to happen

- Give me extra time to complete homework when I need it
- Help me to meet other siblings like me
- Let me check in at home when I am worried
- Keep an extra PE kit at school for me to use
- Don't tell me off if I am sometimes late

School ideas

This week I can...

tick · Write down one thing which would really help me at school and give it to my teacher and my parent

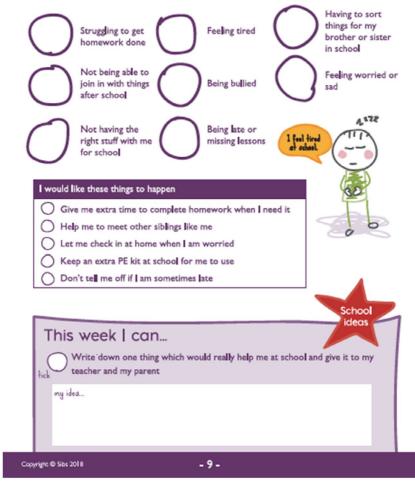my idea...

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Figure 2. Session nine activity in the Sibs Talk intervention manual [Colour figure can be viewed at wileyonlinelibrary.com]

their instinctive responses would be to explain things to the pupil or to help find a solution to the problem, so the training enabled staff to acknowledge siblings'

feelings before taking any other action. Once the intervention was underway staff could contact Sibs staff for further advice if required. There were very few of these queries and most were to discuss support for specific siblings rather than for clarifications on delivering the Sibs Talk intervention.

Schools were recruited by approaching academy chains, individual schools and school staff in local authorities who had already shown an interest in sibling support or had a previous link with the charity. The Sibs Talk pilot information was also sent out through local Educational Psychology networks to recruit new schools. Sibs then identified and made connections with key people in local authorities who had access to local inter-school communication networks. Recruitment of schools was eased by linking Sibs Talk to the schools' existing policies and programmes on well-being and resilience, young carers, difference and diversity, anti-bullying, safeguarding and SEND support. Once schools agreed to take part in the pilot project and staff had participated in training, regular contact was maintained with the school for support, guidance and feedback.

Evaluation of Sibs Talk

The participants and their schools

The Sibs Talk Pilot was evaluated to help inform Sibs' future work with young siblings. In total, 55 evaluation questionnaires from 11 schools were returned and completed sufficiently to include in the evaluation. For eight of these schools, all children who completed the intervention also had the questionnaires completed and returned. The remaining three schools in the sample each returned four out of five of the possible completed questionnaires. Siblings were in Key Stage 2 and aged between seven and 11 years old (mean age = 9.18 years). There were slightly more female than male siblings in the sample (54.5% were female). In terms of ethnicity, 43.6 per cent of the siblings were white-British and the three next largest ethnicity groups for siblings were Pakistani (23.6%), Black Caribbean (9.1%) and Black African (7.3%). Almost half of the siblings had a brother or sister with autism (49.1%), the rest of the siblings had a range of other disabilities including Down syndrome, hearing impairments or chronic medical conditions. In the sample, 36.4 per cent of the children attracted Pupil Premium funding, and 36.4 per cent of siblings spoke English as an additional language. Both of these factors occurred at a higher

percentage than the UK school population average (GOV.UK, 2018). Although Sibs is a UK-wide charity and we have drawn on UK-wide data to understand siblings generally and understand the sample further, the sample of schools for this study were based in England only. There were 11 primary schools in total that returned evaluations for participating siblings. These schools included a faith school and an academy as well as schools from both rural and urban areas from across England, although with a particularly high uptake from schools in the South East of England.

Full institutional ethical approval was gained before 270 intervention packs were sent to 35 schools between March 2017 and February 2018. Schools voluntarily agreed to take part in Sibs Talk after receiving information from Sibs, UK. The Sibs Talk recruitment information was distributed by sharing information through local education networks, which vary greatly from place-to-place. Sibs expanded their existing school contacts to promote Sibs Talk by approaching Academy chains, individual schools, local Educational Psychology networks and school staff in Local Authorities that had shown an interest in siblings through previous contact with Sibs.

Schools were recruited and trained by Sibs staff before the intervention took place and the intervention was led by a school staff member, most commonly a learning mentor, teaching assistant, or SENCO. The intervention packs included the evaluation questionnaires as well as the relevant information sheets, consent forms and the ethical procedures form. The school provided parents and carers with information sheets about the study. Parents and carers were given the opportunity to withdraw their consent to their child taking part in the intervention and the evaluation. The participating children were given age-appropriate information on the study evaluation and provided assent to their answers being shared with Sibs and the researchers. Class teachers were asked to complete a measure on participating siblings. They were provided with a full information sheet and would only complete the measure if they consented to take part in the study. Sibs' main contact at the schools – a member of each school's senior leadership team – also signed a document confirming that their schools had followed the ethical procedures for the evaluation data collection. Full information and training was provided to relevant school staff members to assist them in following the ethical procedures. All pupils' names were removed from any evaluation documentation before being sent to Sibs. This ensured that the children's identities were kept anonymous from both Sibs and the researchers.

Measures and methods

There were two questionnaires used, which were both completed before the intervention and after the intervention. Firstly, the class teacher completed the Strengths and Difficulties Questionnaire with Impact Supplement (SDQ; Goodman, 1997; Goodman, 1999). This measures the behavioural and emotional well-being of the siblings. The items provide seven distinct scales: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviour, total difficulties and an impact score.

Secondly, the participating children completed the 'How I Feel About My School' Questionnaire (HIFAMS) (Ford, 2013; Allen *et al*., 2018). The HIFAMS was completed by the children during the first, and again, during the last intervention session. This questionnaire includes seven statements about school. For example, siblings are asked to respond to: 'When I am in the playground, I feel…'. Children then select an emoticon graphic to complete the statement to indicate feeling 'Happy', 'OK' or 'Sad'. These seven responses are then combined to create an overall score ranging from 0-14 with higher scores indicating the child is happier in school.

Basic socio-demographic information was provided by a member of the senior leadership team. Participating children also provided short, written comments to four prompts. As this activity was part of the child's personal work over ten activities, additional permission to share this information was sought from the sibling before they completed the activity – resulting in 31 siblings sharing these written responses for the evaluation.

Both the SDQ and HIFAMS questionnaires were analysed using paired-sample t-tests. This test provides the difference in the children's mean scores for the range of measures described above between two points: at the beginning of the Sibs Talk intervention and at the end of the Sibs Talk intervention. Content analysis was employed to examine the written responses from the siblings. Content analysis benefits from being a flexible, (Hsieh and Shannon, 2005) clear and systematic way of analysing written data (Seale and Tonkiss, 2012).

Findings from HIFAMS and SDQ questionnaires

The main results are presented in Figure 3. This shows the mean scores on each scale in the questionnaires, before and after Sibs Talk, for the whole sample of
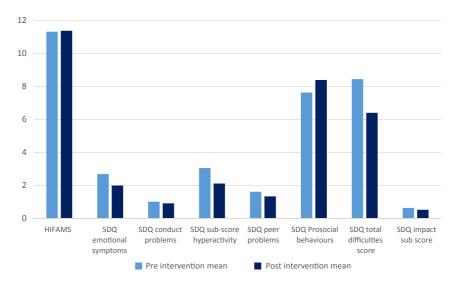
Figure 3. Pre and post intervention means [Colour figure can be viewed at wileyonlinelibrary.com]

children involved in this evaluation. Across all measures, children had more positive scores at the end of the intervention period than at the beginning. The mean scores pre and post intervention and also the effect sizes associated with the change in scores are summarised in Table 1. To test whether these changes were statistically meaningful, we compared the pre and post-intervention scores using paired samples t tests. The results of these tests revealed that the improvement in SDQ hyperactivity scores ($p < .001$) prosocial behaviours ($p = .002$); total SDQ difficulties ($p = .009$); and emotional problems ($p = .016$) were all statistically significant. The changes in the HIFAMS score and SDQ conduct problems, peer problems and overall SDQ Impact scores were not statistically significant.

Findings from the siblings' written responses

Siblings also wrote short responses to four written prompts. One statement prompted 'These people can help me with sibling stuff at school…'. Siblings then listed people they felt could help them. All 31 of the siblings referred to their teachers in this response.

There were a further three writing prompts which were analysed collectively, being coded and categorised. These prompts were: 'I've learnt that… The

Table 1. Summary of paired sample T tests for HIFAMS and SDQ pre and post intervention measures

	Pre Mean (SD)	*Post Mean (SD)*	*Cohen's **d** (effect size)*
HIFAMS	11.31 (1.975)	11.37 (1.980)	.03 (small)
SDQ emotional symptoms	2.69 (2.922)	2.00 (2.145)	.38 (small)
SDQ conduct problems	1.02 (1.703)	.92 (1.683)	.07 (small)
SDQ sub-score hyperactivity	3.06 (2.789)	2.12 (2.487)	.55 (medium)
SDQ peer problems	1.62 (1.652)	1.34 (1.757)	.20 (small)
SDQ prosocial behaviours	7.63 (2.383)	8.39 (1.845)	.47 (medium)
SDQ total difficulties score	8.44 (5.922)	6.40 (5.711)	.38 (small)
SDQ impact sub score	.64 (.908)	.53 (1.392)	.09 (small)

For the HIFAMS and prosocial behaviours sub-score, higher scores indicate a more positive response for/about the sibling. For all other SDQ sub-scores and total difficulties score, lower scores indicate a more positive response.

activities have helped me because [and]… Something I want to tell people about being a sibling like me…'. There were 15 initial codes identified. These were then reduced, combined and clustered together to communicate four overarching categories: Learning and Understanding; Communication and Relationships; Coping Strategies; and Challenges and Responsibilities.

Learning and Understanding was identified as a category for 24 of the siblings. This included the siblings indicating that they had learnt new things about disability more generally. The siblings also highlighted learning about their brother or sister's SEND specifically as well as learning 'to be more open-minded':

> 'I know a lot about my sister. I learnt that people do listen to what I have to say. I learnt to be more open-minded'.

> 'To learn about my feelings when I'm angry, sad, jealous, lonely, guilty, worried, embarrassed'.

> 'I had learnt that other people had different conditions and how people can help you with it'.

Communication and Relationships were mentioned by 21 siblings. Furthermore, all 31 siblings could name individuals they could talk to about sibling issues in response to that specific prompt, with all siblings naming a teacher they could talk to about their sibling experiences. Some siblings wrote positive things about their brother or sister such as:

'Me and my brother have a special bonding'.

'I have a sister that's autistic and that makes me proud'.

The sibling comments were generally written positively with regards to their sibling relationships, the selected quotes highlight the way in which these siblings felt their relationships were unique and something to feel proud of. Some siblings wrote about their relationships with teachers, parents and organisations that could help. Siblings wrote about feeling more able to talk about their feelings and experiences, highlighting that they felt listened to:

'I don't have to keep things to myself. That it is not my brother's fault he is how he is. I have learnt that I can share things with you'.

'It's okay to talk about my brother. I know a lot more about my brother's disability. People want to listen to me and talk to me... It's helped me talk to my family and think about my family. It's been some special time for me… I need somebody to talk to. People need to explain things to me and talk to me. I need to think about my little brother'.

The sibling that wrote the above comment was able to articulate their needs and expectations of support from adults and themselves with regards to their sibling experiences. A combination of learning about SEND and feeling listened to may contribute to helping siblings feel less alone in their experiences, for example, one sibling wrote: 'There are millions of children who have disabled siblings like me'.

Coping Strategies were mentioned by 12 siblings in their written responses. This included learning how to manage, talk, or reflect on feelings and emotions as well as more practical tools when encountering challenging situations:

'I take a deep breath and count to ten and walk away'.

'I have a feelings box and when I don't want to say my feelings out loud I write in my feelings box'.

Challenges and Responsibilities were a category in 16 of the siblings' responses. This category involved a range of factors, such as physical and verbal aggression from their brother or sister, or difficulty communicating their feelings as siblings of a child with SEND.

'My brother's behaviour is very violent because he wants his own way all the time and gets really angry'.

[I have learnt] *'how to deal with tough stuff such as keeping an eye on him all the time'*.

Those few siblings who wrote more negatively about their sibling relationships identified experiences of heightened physical aggression from their brother or sister with SEND. This category also encompasses some of the additional caring or supporting roles and responsibilities some siblings had at home. For their role in supporting their families, siblings seemed both positive and proud of these roles:

'I support him and help him learn'.

'There is not a medicine for autism. I'm proud of the things I do for my sister'.

These challenges or responsibilities were often phrased with a sense of acceptance of their brother or sister with SEND. For instance one sibling wrote: 'It's hard but I still love him'.

Conclusions

Although the evaluation results indicate some small, positive improvements for the participating siblings from the start of the intervention until the end of the intervention, a number of cautions when interpreting these data should be highlighted. Firstly, it must be remembered that this evaluation is not a randomised control trial, which has the benefit of reducing the effects of biases. There are numerous other factors which may have contributed to the resulting change in children's questionnaire scores from the first point the measures were administered before the intervention, and the second time point, at the end of the intervention. In addition, the teacher and child knew that they were going to or had been involved in Sibs Talk and so their responses may be biased.

In addition, the sample size is small, especially given the larger number of intervention packs distributed. The schools that were able to allocate staff time to complete both the intervention and evaluation with pupils may not be representative of schools more generally. There is also probably a great deal of variation between the school staff members who led the intervention in terms of knowledge and

experience of disability. The measures used in this study are also limited in scope. For example, the short written answers from the siblings in response to prompts indicate that some of the siblings had learned things about their brother or sister's SEND, special educational needs or medical condition, and this development was not captured in the questionnaires. In addition, the second evaluation questionnaires were completed shortly after or during the final intervention. Therefore, whether improvements in scores would be maintained over time is indeterminable. Furthermore, the sibling comments were in response to very specific writing prompts, and were completed with the school staff member who led the intervention. This may have influenced the siblings' written responses.

Considerations for further study

Although these results indicate small improvements for the siblings taking part, a more robust evaluation would be necessary to decipher a more complete and confident picture of the impact and value of the Sibs Talk intervention. Ideally, this would take the form of a randomised control trial to reduce the risk of research bias in the evaluation. Any further evaluation would also benefit from a more representative sample, both in terms of socio-demographic factors, and also in terms of the range of conditions the siblings' brothers and sisters have. This would allow us to ask questions about how different sub-groups of siblings respond to the intervention. There may be some value in including other outcome measures, such as a parent report, whether siblings ask staff for help at school after completing the intervention, or a measure of the siblings' knowledge of disability, given some of the more qualitative comments written by siblings. The HIFAMS measure had a lot of missing data due to children selecting multiple responses to indicate variability in their feelings. This may indicate that the guidance we provided staff members in assisting the siblings to complete the questionnaire needs to be improved, or perhaps indicates another measure easier for a non-researcher to administer would be more suitable.

Broader considerations and implications

School spending per pupil has recently fallen in real terms in England by about 8% (*Institute for Fiscal Studies*, Sibieta, 2018). Therefore the Sibs Talk pilot was developed and Sibs began recruiting schools to take part at a time when school funding was higher. Although Sibs noted that school ethos appeared to influence school participation in Sibs Talk, the main barrier for schools in deciding to take part or completing

the intervention through to the end was staff time pressure due to financial cuts. This made it difficult to allocate staff time to facilitate the Sibs Talk intervention.

The school recruitment and data collection process of this evaluation was time intensive, particularly for a small charity such as Sibs. Recruiting schools, training school staff, the administration processes and maintaining school involvement over many months involved significant staff time. Retention of schools proved challenging, as 270 intervention packs were sent to 35 schools, yet for this evaluation only 11 schools returned evaluations for 55 siblings in the timescale for these data to be analysed.

Sibs has explored the possibility of staff delivering Sibs Talk to pupils in small groups as a way of reducing the staff time involved, though this would significantly alter the intervention with the loss of the confidential one-to-one aspect of the work. It would also involve additional planning time to match pupils together so that they could progress through the intervention at the same pace. Other options for delivering Sibs Talk such as through staff in special schools or community organisations would remove the relationship between school staff and pupils being formed during the intervention which is one of the main elements of Sibs Talk.

Sibs originally hoped that following a successful pilot that Sibs Talk could be rolled out to many more primary schools across the UK, and then to secondary schools with a modified version of Sibs Talk for pupils in Key Stage 3. With the current funding situation for non-teaching staff in schools in the UK the charity acknowledges the significant challenges in getting more schools on board to deliver Sibs Talk.

In summary, the indicative evaluation of Sibs Talk suggests there may be small to moderate benefits for siblings who take part, and it is available as a tool for supporting siblings in schools that have the staff capacity to deliver it. A robust research evaluation needs to be conducted to understand the effects of Sibs Talk further. This would take the form of a randomized control trial, with a larger more representative sample of siblings, which would follow up with siblings both immediately after the intervention, and a year after the intervention concludes to test ongoing effects.

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