

Workshops for young carers looking after their siblings

Carers in Bedfordshire
Sibling Project 4-18



What is the initiative?

Siblings Workshops

Who runs it?

Carers in Bedfordshire

Who does it benefit?

Children and young people aged 4–18 in Bedfordshire who are caring for a sibling or otherwise affected by their brother's or sister's disability, illness or additional needs.

What does it do?

The workshops provide support and information to help sibling young carers understand their brother's or sister's conditions.

When did it start?

2009.

Why was it started?

Following the withdrawal of funding to another charity's sibling young carers project, Carers in Bedfordshire established the Sibling Project to fill the gap in provision to young carers who look after their siblings. Research on children with disabilities in Bedfordshire carried out by Carers in Bedfordshire and Sibs, the charity for brothers and sisters of disabled children and adults, for Central Bedfordshire Council, informed the project. This research showed the types of disabilities affecting children in Bedfordshire and the need for greater support for siblings.

What are the aims and objectives?

Aims:

- To enable sibling young carers to feel less isolated in their caring role.
- To help young carers recognise that many of their peers also have siblings with a disability or health condition.
- To allow young carers to learn about illnesses, disabilities, families and caring in an age-appropriate way.
- To support the wider family of the young carer.

Objectives:

- To provide information to young carers on specific illnesses and disabilities.
- To facilitate discussions about illnesses, disabilities, families and caring.
- To enable young carers to meet peers in similar circumstances.
- To provide additional one-to-one support if needed.
- To support young carers to manage difficult situations and identify their own support networks.
- To provide fun activities for young carers so they can bond with other young carers and enjoy a life outside caring.
- To signpost parents and other family to support where appropriate.

How is it funded?

NHS Bedfordshire, using monies from the Young Carers Breaks fund, covers the majority of the costs of the Siblings Workshops, including the salary of the Project Co-ordinator. Funding from the Aiming High for Disabled Children programme via local government has also been used.

What has it achieved?

“Now I know how to behave around my brother.”

Young carer

“It has made me understand why autistic people act the way they do.”

Young carer

“They now realise they are not alone and lots of children have disabled siblings. You have shown my little boy extra support which has helped him to escape the worry of having a disabled sister. He is now more confident to talk about having a disabled sister.”

Parent

“This service has been one that families have really benefited from, and they feed this back to me regularly at the child in need meetings I hold ... For us as workers, it is great to be able to not only recognise the needs of siblings, but be able to signpost to a service that can meet those needs.”

Family Support Social Worker

The project has received very positive feedback from young carers and their families. Parents often report that the workshops have had a constructive and valuable impact on family life, as they talk more as a family about caring and what it is like to have a sibling who has a disability. Their children have had fewer arguments and have been less stressed. One parent said that his child’s involvement in the workshops had totally changed his own life and enabled him to understand things from his son’s point of view.

Through their family’s involvement with the services for siblings at Carers in Bedfordshire, parents have also been supported to access training for caring for children with disabilities through the NHS and local organisations.

Social workers and other health and social care professionals in Bedfordshire have reported that they have found the workshops and siblings project useful services to refer their clients to. They have also heard enthusiastic endorsement of the workshops from the families they work with.

The success of the project in the two local authorities it works within – Central Bedfordshire and Bedford Borough – has led to it being commissioned by them to run projects for sibling young carers from April 2013. Subject to outcomes of young carers’ improved understanding of their sibling’s needs and improved emotional wellbeing being met, the contract will be renewed annually.

How have carers been involved in planning and delivering this work?

Research undertaken by Carers in Bedfordshire and Sibs, on children with disabilities living in Bedfordshire, involved discussions with sibling young carers and their families. This research helped Carers in Bedfordshire understand what these young carers needed and informed the development of the Sibling Workshops.

An annual feedback questionnaire sent to all Carers in Bedfordshire sibling young carers and their parents is used to monitor the service. Feedback gathered from the young carers participating in the project after each workshop and activity is used to modify future sessions.

How is the initiative run?

There is one full-time Co-ordinator for the Sibling Project and seven volunteers. In March 2013 they were supporting 304 sibling young carers from across the local authorities of Central Bedfordshire and Bedford Borough. Approximately three quarters of these young carers were actively involved in either the Sibling Workshops or other activities provided by the project; the remaining quarter had less intensive support consisting of intermittent phone support. The Sibling Project Co-ordinator has visited and assessed all 304 young carers.

Referrals to the Sibling Project are received either from parents, schools, GPs or social workers using Carers in Bedfordshire's generic registration form or one from a Common Assessment Framework team. Once a referral has been made, the family is contacted and the young carer, their siblings and parents are invited for an assessment either at their home or the Carers in Bedfordshire centre. Sibling young carers are invited to join the Sibling Project, of which the workshops are a core part. One-to-one support from the Sibling Project Co-ordinator is also offered if it is deemed appropriate for the young carer in question.

Workshops are provided for groups of around 8–10 young carers. They can be provided over two full days in the school holidays or after school over a period of six weeks. The format of the workshops follows the Sibs framework, although amendments are made as needed. Workshops can either be generic in content or specialist, depending on the needs of young carers. Specialist workshops aimed at young carers with a sibling on the autistic spectrum are a regular occurrence, for example. If there are several young carers looking after a sibling with a similar condition, then the Project Co-ordinator will try to facilitate a workshop focussed on this issue. If a volunteer has particular knowledge or experience about a certain disability or caring issue, then they would be encouraged to support the delivery of a specialist workshop.

Young carers of different ages can attend the workshops, although where possible they mirror the age range of the clubs of the wider young carers project. For young carers around the age of 4–6, it is usually recommended that they receive one-to-one support from the Project Co-ordinator. By taking place in the young carer's home this can help if they are shy.

The workshops follow a format recommended by Sibs. They comprise of hands-on activities leading into discussions. Activities found to be effective include making stress balls out of rubber balloons filled with rice, and learning about what they have in common with other young carers through a Balloon Feelings activity. Balloons printed with words to describe feelings are thrown into the air. When they are caught, the words are read out and young people share an example of when they have experienced that feeling.

In another activity, by using a large ball of wool, the young carers create a giant spider's web as they sit in a circle. They say something they like and throw the ball of wool to another young carer who also likes that thing, to see how much they have in common with their peers. To collect feedback about the session, the workshop staff encourage each young carer to write a comment on a piece of paper, then screw it up and have a snowball fight, before the workers retrieve them at the end of a workshop.

At the end of a workshop series young carers can remain a member of Carers in Bedfordshire for as long as they wish to. If at any point in the future they would benefit from further workshops, perhaps if their family situation has changed or a specialist workshop is on offer, they are welcome to attend this. In the event of the death of the person the young carer cares for, Carers in Bedfordshire provides continued support with signposting to appropriate bereavement agencies for a period of two years.

Monthly clubs are offered to young carers through Carers in Bedfordshire, providing time away from caring and the opportunity to get to know other sibling young carers. When funding allows, occasional days out and activities are made available to the young carers in the Sibling Project. Carers in Bedfordshire also runs a service

for young carers aged 4–18 looking after an adult and a service called the HUB for young adult carers aged 18–25, which sibling young carers may attend if appropriate.

The Sibling Project is promoted on the Carers in Bedfordshire website, through leaflets and information sheets and through presentations to professionals and parent support groups.

What methods have been particularly effective?

Workshops are an ideal way for young carers to gain information and share their experiences, as the peer support element can be very beneficial. Often children and young people who have a disabled sibling can feel isolated and different from their peers at school. Workshops allow them to see that they are not different from others and enable them to talk about their experiences, anxieties and hopes with other young people who understand their situation.

Volunteers who have personal experience of a sibling with a disability or expertise of a particular condition or disability are a great asset and older young carers who share their experiences in workshops with younger participants act as effective role models. Young carers respond well to first-hand accounts of being a sibling of someone with a disability and caring.

The snowball fight at the end of a session is an effective way to collect honest feedback from the young carers about their feelings and the effectiveness of the workshop.

Have there been any challenges along the way?

Gaining the recognition from professionals and agencies that the siblings of children with disabilities do need to be supported has at times been difficult. Often siblings are overlooked when statutory assessments are made of the needs of the disabled child and family. Now that from April 2013, Carers in Bedfordshire will be commissioned by Bedford Borough Council, Central Bedfordshire Council and NHS Bedfordshire to support sibling young carers, recognition within local authority agencies should improve.

What hints and tips might help me get started?

- Gain recognition from potential partners and funders that sibling young carers need specialist support and seek funding before starting your project.
- Ensure staff and volunteers are passionate about supporting sibling carers and arm themselves with the necessary evidence in order to keep the project running. First-hand knowledge of disabilities and caring can be an advantage.

Are there any useful documents or resources that could assist me?

Read about the **needs** of siblings of children with disabilities and their **common experiences**.

Use the resources on the Sibs website for **activity ideas** for Sibling Workshops and advice for **Sibling Group Leaders**.

Where can I get further information?

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