Delivering a support group for siblings of children with learning disabilities

It was identified that the needs of siblings of children with learning disabilities were not being addressed. A group was set up to tailor services to siblings.

ABSTRACT

This article describes the development of a group for siblings of children with learning disabilities. It looks at issues relating to setting up and running the group and gives examples of the problems that may be encountered by the children.

INTRODUCTION
Over the past decade there have been a number of developments designed to raise awareness of the needs of people with learning disabilities and their families. Valuing People was instrumental in setting the scene for a changing service for this group of people (Department of Health, 2001). The document also identified that the emotional needs of siblings of children with disabilities were not being addressed and further improvements were needed to provide support for them. However, Valuing People now did not identify any developments solely for siblings (Department of Health, 2003).

Now established is Sibs, the UK charity for people who grow up with a disabled brother or sister (www.sibs.org.uk). Its vision is for every local authority in the UK to have a dedicated sibling service. However, developing services requires extra resources.

In 2001, the idea of establishing a group for siblings of children with disabilities was first identified as a response to parents’ requests. At that time all that existed for siblings was an ad hoc system where occasionally a day was organised for them to enjoy time together. Parents and healthcare professionals felt that the needs of siblings of children with learning disabilities were not being addressed at a local level. They identified needs including: siblings being able to meet other children who shared similar circumstances; and developing approaches and strategies to address the challenges they were experiencing.

Parents and professionals also recognised that these children were being referred to Child and Adolescent Mental Health Services (CAMHS) with a variety of mental health problems of their own.

Before setting up our group, a brief review of the literature was carried out to identify specific areas to focus on. These are summarised in Box 1.

AIMS OF THE GROUP
The aims of our groups were to:
● Enable young people to meet others with disabled siblings and to encourage them to express their feelings about how it affects them individually;
● Explore strategies to help them deal with the day to day issues they encounter;
● Provide information to improve siblings’ understanding of their brother or sister’s disability.

PLANNING THE GROUP
Initially, the group was run without funding but it is currently supported by local charitable funds. Children are referred from a number of sources, including CAMHS clinicians and education, voluntary and social service providers.

The group is multi-agency, which means members have access to support from professionals with different backgrounds and experiences, such as social workers, community nurses and doctors. Meetings are used to identify the roles individual professionals will have in the planning and delivery of the sessions, and each session is clearly planned out in advance.

A multi-agency groups allows members to have access to support from professionals with different backgrounds and experiences.

The group needs robust planning and organisation.

The group should be organised so those with similar age range can meet as they will have similar developmental needs.

Asking children to write a letter to their parents with ideas on ways to help them cope with their sibling’s disability empowers them to give feedback.

REFERRAL PROCESS
Children are referred to the group by professionals who are working directly with

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BOX 1. MAIN POINTS FOR DEVELOPING THE GROUP

Negative areas identified by sibling of someone with a disability include:
- Limited time and attention from parents;
- Worries about bringing friends home;
- Stressful situations at home;
- Restrictions on activities;
- Guilt and embarrassment;
- Concerns about the future of their sibling (Dodd, 2004).

Groups were most effective if they adopt a problem solving focus (Evans et al, 2001).

Leisure activities are an important way to give children the opportunity to discuss issues while engaged in age appropriate play (Naylor and Prescott, 2004).
the family. The leaders of the group endeavour to advertise it to any agencies providing services to these families. A referral form is provided by CAMHS so that information can be obtained to ensure the group will be appropriate for the child. It is also helpful to ensure that the age range of the group is organised so the children have similar developmental needs.

Group leaders do not meet the children until the first session, so they rely on the referrer being able to give accurate information about the group to the young person and their parents.

ISSUES HIGHLIGHTED DURING SESSIONS
Challenging behaviour
It is not always possible to identify children with challenging behaviour before they attend as the referring professional may not know them well, if at all. Group leaders have adapted strategies to manage this by splitting some of the members into smaller working groups or allocating a leader to be with the child to help them to manage their behaviour. Group leaders can decide to exclude a child from subsequent sessions if they feel their behaviour is detrimental to the group as a whole and the needs of the other children. It is helpful to ensure parents understand and agree with these strategies before their child joins the group.

Absenteeism
Managing frequent absences from the group has been difficult and it is considered unhelpful for a child to attend if they know that can only make a small number of sessions because of other commitments.

Feedback to parents
During the group sessions some children highlight the struggle to get their parent to understand how much their siblings’ disabilities impact on their life. Many of the children who have attended the group explain they do not want to add to their parent’s distress by telling them how unhappy they are at times. This can pose dilemmas for the group leaders, particularly if the family are on the caseload of another professional, which means there is no direct access to the family to discuss this. This situation is compounded by confidentiality agreed within the group, making it impossible to talk directly to parents without the consent of the young person themselves.

To address these difficulties, group leaders work hard in order to empower the young person to discuss their difficulties with their parents. At the end of the sessions the group writes a letter featuring collective ideas for parents on how they could help their children to cope with their sibling’s disability.

EVALUATION OF THE GROUPS
Each group is evaluated. Both children and parents complete a questionnaire before the sessions start and when they end. Individual sessions are also assessed.

Children reported that being collected early from school to attend the sessions was a bonus and made them feel special. Some said that previously their teacher had been unaware they had a sibling with a disability and that they had been more supportive since receiving that information.

Parents reported that their child would have liked to continue attending the sibling group. Existing resources meant this was not possible, so some young people and their parents applied for funding to continue running a monthly drop-in group for teenagers. However, although they were successful in gaining some funding and organised a venue, it was not possible to proceed with the venture because parents were unable to supervise the groups.

Some evaluations of the group have identified that parents thought it would make their son or daughter more caring towards their disabled sibling. If this did not happen they concluded that their child’s participation in the group was not successful. Therefore parents require more information before their children attend the group to help them understand its function.

Evaluations indicated that the children found information about learning disabilities and autism particularly useful. Dodd (2004) found that children needed information about their disabled sibling in order to help them cope.

Further comments directly from the young people included:

“It was the first time I had met anyone who had a brother with a disability.”

“My Mum asked me about the sessions and tried to understand more about what it is like for me.”

“We had great fun together.”

“I learnt what I could say if someone asks me about my sister.”

FURTHER WORK
It is important to recognise that not all families are known to agencies so it can be difficult to identify siblings who would benefit from attending the group. It is hoped that further work advertising the group could be targeted through mainstream schools. This approach would help to ensure families receive information about the group but this requires more time and resources.

Research suggests having a sibling with a disability has negative effects on children’s adjustment (Rossiter and Sharpe, 2001), while some suggest positive effects (Dodd, 2004) and others state there are no differences (Hastings, 2003). Further research is required to help parents meet all of their children’s needs.

Providing sibling groups could help to identify young people who might benefit from additional tailored services (Smith and Perry, 2004). During the sessions, I came across at least one child in each group who would benefit from extraservices and support and this need was identified because they had the opportunity to attend the group.

REFERENCES

NURSING Learning
Nursing Times Learning offers cost effective, high quality online learning. For a unit on equality and diversity, go to www.nursingtimes.net/equality