

Services and self-help groups – how do we ensure that everyone gets the help that they need?

Do we set up our own services or try to work in partnership with local providers?

The next two articles describe groups set up by parents to help their children's development. At the Trust we are receiving more and more requests to help groups to improve local services and this is the reason for beginning to develop Branches and Affiliated groups (see page 107). In the first article, from Ann Haig in Ireland, she describes the way in which she has set up a group with other parents. The group provides support and it aims to specifically promote the children's development through structured activities. The second article is from the founders of the Bristol Branch of The Down Syndrome Educational Trust – our first fully fledged Branch. Here parents have worked with the statutory services to provide speech and language therapy groups and they also offer a chance for parents to meet and talk over coffee. The speech and language therapist works for the local National Health Service Trust but the Bristol Branch pay for her time for one day per week.

If we were designing services to support children with Down syndrome and their families in the early years from birth to school age, how would we do it? What do families and children need? In my experience, we could describe their needs under three headings, information, support and practical help to promote their child's development.

Information

When we meet parents in the first days and weeks after their child's birth, they are usually looking for as much information as possible on the needs of their baby and their

family. They have not had much contact if any with children with Down syndrome and are keen to learn all that they can about the new situation facing them.

Support

Most families find that meeting other families is helpful for the shared understanding of how they feel and for practical tips and information on how to cope and where to get services.

Practical help

Most parents are keen to do the very best for their child and want advice on how to help their children to progress as fast as possible. They require practical tips and activities which can become part of their daily routines. This practical help may be needed for health issues such as feeding, for motor skill development, for speech, language or cognitive development or social development and behaviour.

Parents and professionals

If we are going to meet these needs, we are going to require parent and professional partnerships if we are to be as effective as possible. Information to new families can be provided by parent organisations or by professionals. Opportunities to meet with other parents can also be provided by services or parents setting up groups. When we come to expert advice on how to help children progress then we will do best if we can work with experienced professionals. Not all professionals are experts in Down syndrome and

often parents have more knowledge because they have read up on the issues or been on training courses. However, professionals will have skills that parents do not necessarily have and a partnership is likely to be the best way forward. For this reason we encourage parent groups who want better services in their area to try and work with local service providers to get these services going.

Training

Both parents and professionals may benefit from training. Parents running support groups will find themselves dealing with a whole range of personal and family concerns, as well as being asked about children's specific needs. They will need more knowledge and skills than they needed just to help their own child. Professionals also need training as we learn more about the most effective ways to help children with Down syndrome all the time. As we ask services to be inclusive, many staff in nurseries, schools and services have had no special training in the needs of children with developmental disabilities. Local parent groups can be effective in identifying the local training needs and bringing training to their area. This might be a workshop for health services, for speech and language therapists or for educators. The Trust is beginning to work with regional groups to plan and provide the training that they need in their area. We are expanding our expert team over the next six months in order to be able to provide this service.

Editor