

# Research studies – what can they tell us?

## Is research any better than ‘common sense’?

I have been involved in designing and carrying out research studies into the development of children with Down syndrome since 1980. Research is the core activity of The Down Syndrome Educational Trust and it underpins everything else that we do, but why do we consider research to be so important? I will try to answer that by considering the information in the first three articles in this issue. These three articles focus on three questions that parents often ask:-

- What can we expect our baby with Down syndrome to be able to do when she is a teenager?
- Our baby has Mosaic Down syndrome. Will his development be the same as children with standard Down syndrome?
- Our family is bilingual, I am English and my husband is Spanish. Should we speak two languages to our baby with Down syndrome?

In addressing these questions, we have looked for research evidence to help us to answer them. Some readers may say why look for research findings – what can research tell us that our everyday experience cannot? What are the advantages of research findings and what are some of the limitations? We can explore some of the answers to these questions by considering the content of the three articles.

On the first question, we do have some information on the development of teenagers with Down syndrome based on surveys of representative groups of young people and in the first article, we provide quite a detailed overview of the range of achievements of teenagers in Hampshire, UK. We have surveyed the progress of teenagers twice, first in 1987 and again in 1999. Each time we traced all the teenagers in a geographical area in order to have

a sample of teenagers that would include teenagers from a wide variety of family situations and a sample that would include teenagers of all abilities and needs. The first study included 90 young people and the second study reported here involved 46 young people.

### Representative samples

These numbers indicate that the first benefit of conducting a research study is that we can collect information from large numbers of people. The authors working on this study have many years of experience in this field and we know many teenagers with Down syndrome but if we relied on our experience only to describe the progress of teenagers, we would not have had the detailed knowledge of as many teenagers. The second benefit is that we used the same standard measures with all the teenagers, so that we have the same information for each person. If we had relied on our knowledge of individuals, we would not have had the same information for each person, measured in the same way.

### Factors influencing progress

If we collect enough measures, we can investigate individual differences such as the effects of school placement on progress as reported in the last issue, or the effects of health or behaviour difficulties on progress.

### Research often contradicts common sense

The research findings on the progress of bilingual children illustrate this point. Most teachers and therapists have advised parents to use only one language assuming two will be more difficult and may delay progress in a first language.

The evidence is that this is not the case – learning two languages seems to have no negative effects. It is not wise to rely on ‘common sense’ as evidence on which to base advice.

### Research is not always helpful to individuals

The article on Mosaic Down syndrome illustrates this point. Research suggests that, as a group, these children may be less delayed than children with standard Down syndrome but this does not allow the parents of a baby to predict future development as the progress of the two groups actually overlaps considerably. Some children with Mosaic Down syndrome will be less able than some with standard Down syndrome, even though the group as a whole are less affected. This means that we need to look more closely at early developmental progress to see if we can predict later progress more accurately.

### Research provides objective evidence

Research is about testing our assumptions and common sense beliefs by collecting unbiased evidence to answer specific questions. Our inclusion research illustrates the importance of this. We hoped to find that inclusion would benefit all aspects of development but our findings show no differences in social and practical skills, much larger benefits for speech, language and literacy than we had predicted and some friendship issues to be addressed. Only by being open to collecting evidence – often over many years, can we find out how best to help the development of our children and how best to design educational provision for them.

*Editor*