

# How do we support families effectively in the first year?

## What can parents, associations and practitioners do to get early support right?

### Early feelings

A major theme of this issue is family needs and family support. We have two personal stories from mothers, Sal Hamlyn and Shelley Ducarreaux, who share very honestly their early reactions to the births of their sons with Down syndrome. They do not gloss over the pain and the time it took them to adjust to this news before they could feel real joy and bond with their sons. Reading these stories made me reflect on the tendency that we sometimes have in support organisations to be so positive that maybe we make it difficult for parents to really express their negative and painful feelings in the early months.

### Early support

We also have two articles from parent support organisations in different countries, from Downside Up in Moscow and from the Down Syndrome Support Group in Bradford, UK. In the first article, Pauline Zhiyanova describes the focus on psychological support for families in their Moscow centre, with a clear recognition of the need to think about and support the psychological and emotional needs of parents, particularly mothers. There is also a focus on supporting the bonding and early mother/baby interactions in a skilled and sensitive way.

In the first year of life, support for children and families tends to be patchy in the UK and delivered by a range of professionals and by parent support groups – I suspect this is a similar pattern in many other countries.

### A focus on infant development

There is usually a focus on helping the baby to achieve his or her full potential, rather than an early focus on the needs of parents and the social/emotional and communication development of both mother, father and baby. In the light of the research on attachment and bonding in infancy on later development for all children, these early months matter – and, the sooner we can help parents through some of the early emotional pain, the sooner life returns to normal for them and other children in the family. I am not suggesting that the emotional pain necessarily stops parents loving and enjoying their babies – in my experience, it does not – it is a period of mixed emotions and turmoil as the parent's accounts in this issue describe well.

### UK initiatives in early support

In the UK, there is currently a range of initiatives to improve the services for families with children with disabilities. The principles behind these are summarised in *Together From The Start* – practical guidance for professionals working with disabled children (birth to third birthday) and their families.<sup>1</sup> These are being implemented in a number of ways but the main initiative is the Early Support programme (see [www.earllysupport.org.uk](http://www.earllysupport.org.uk)). Early Support provides a range of materials and guidance – one central tool being the Family Support pack, giving families information and a means of planning what they need from services. Another is a personal key-worker

(advocate) – to enable the family to express their wishes and to receive co-ordinated services. Early Support has developed more detailed guidance for services for deaf children.<sup>1</sup>

The Down Syndrome Educational Trust is working with Early Support to lead the development of similar materials for families with children with Down syndrome and guidance on best practice. Our aims are to provide the information that parents and practitioners need to support them in their task of helping every child achieve their full potential but an equally important focus will be on developing sensitive services from birth though the early months that recognise the need to meet parent's emotional and adjustment needs. This means a focus on training to enable all those in voluntary and statutory services to meet these needs in the first months of life.

The Early Support Down syndrome materials will be available from April 2006 and The Down Syndrome Educational Trust is developing training and video materials to support their effective use, also to be available from April 2006.

*Editor*

<sup>1</sup> See link to these documents on Early Support site [www.earllysupport.org.uk](http://www.earllysupport.org.uk) at /about early support/ government guidance.