

## **Early years' experiences of having a child with disabilities**

### **A summary of Dr Anne Emerson's research**

#### **The stories show a common journey and succession of experiences and feelings**

- Having a child with a disability is life changing
- The impact of having a child with a disability, particularly when they have health complications, could be considered as akin to trauma, in that it can trigger feelings of intense fear or helplessness
- The first priority becomes to address the child's health issues, generally picked up at birth
- For those without one, the next priority becomes getting a diagnosis – for a high proportion there is an agonising wait
- Development tends to become the focus only once the above are being addressed
- The succession of appointments is exhausting
- Some felt they had to battle professionals for a diagnosis or support, and worried they would come across as pushy
- Many reported some good help from NHS or other professionals, although from committed individuals rather than 'the system'
- Yet there were many examples of insufficient support and information – even good support was rarely considered frequent enough or for long enough periods
- There was rarely emotional support – all the care is for the child
- And this was in the context of the isolation of forever being in hospitals, eroding the time to spend with siblings and working partners
- And a mixed response from family and social networks
- And for a few attending School for Parents, a sudden change in household finances
- As attention moves to development, there is a realisation it is down to them – the (exhausting) support they give their child between appointments
- Children start comparing themselves to others and realising they are different
- And parents begin to worry about the transition to school
- But... all but one recognised a positive change in themselves, be it confidence, resilience, empathy or an appreciation of the little things in life

#### **Views of SfP were overwhelmingly positive, but with some room for improvement**

- When asked how they benefited, the first response was usually 'meeting other parents'
- The mothers valued the positive, straightforward attitude
- It wasn't about labels, and they didn't need to explain or make excuses for their child
- They were motivated to attend to improve their child's physical and communication skills, and they considered SfP achieved this
- The longer, repetitive and more frequent sessions helped them pick up techniques easier than in physio
- Although some of the most frequently cited benefits for children were confidence, self-esteem and the resilience to learn – these carried through to the home or school
- Some had specific issues in mind, some just wanted anything they could access

- They valued practical information, including on 'the system', and being able to express fears and concerns
- They value the social networks and chance for parents to build their skills together
- But... some wished there was more time to just chat and play, to give parent to parent advice – most were looking for social time, at SfP or elsewhere
- Seeing other people's children progress gave a sense of optimism
- Early sessions could be upsetting, and you want your child to fit in and not be the one to disrupt the others with crying
- Appointments and health issues, and for some travel, are barriers to attending
- Some were frustrated they did not find out sooner
- And the families may be self-selecting, i.e. those determined to overcome the challenges and possibly, those who could afford to change work patterns

## **Recommendations**

### **For SFP**

- A buddying system for new parents run by existing parents including information on how Conductive Education will work
- More time for parents to meet and get to know each other
- Publicity materials that emphasise who can be helped
- A group suitable for more active children enabling them to learn to calm and fit in
- Enlist supportive professionals to work as ambassadors for their colleagues

### **For 'the system'**

- Professionals could acknowledge the trauma and reflect this how they work with families
- Professionals are constrained by time and resources, but more frequent contacts of a longer duration would help
- The experience is better for families when the statutory and charity, health and education sectors work together