

Researching the support needs of families – the SOFTY Survey

Background information – an extract from *Parents' Support Needs* (2000). Published by the Handsel Trust

The One Hundred Hours keyworker model

One Hundred Hours was a registered charity working during the 1990s in West Yorkshire with families who had a baby or young child with multiple disabilities and complex health needs. The initial brief was to provide 'new' families with a keyworker who would help the parents promote their child's development, play and learning. From the first we adopted particular basic principles; the keyworker would work for the family, she would be responsive to the changing needs of child and family, she would acknowledge and respond to the emotional needs of the parents and she would help them join together all the separate strands from the various therapists and teachers working with the child. Her intervention would be needs-led and would be concerned for the 'whole child' within the family setting.

As we worked with families in this way and responded, within our adopted brief, to the needs we met, we gradually changed our focus from the child to the parents and the family. At the beginning, we did have some appreciation that the disclosure of the child's disabilities would have a significant impact on parents and cause pain and distress. In our work in West Yorkshire, we quickly understood that, for the majority of families, the disclosure is traumatic and probably represents the biggest single event in the life of the family.

As the keyworker's role evolved, she became in a real sense an 'assistant parent' and could help the parents in the tasks imposed on them by the child's needs and the disclosure, and help them during those first months, or first year or two, when they were still traumatised and attempting to sort out their emotions and adjust family life to a whole new set of conditions. Her role was to offer emotional support to parents and other key family members, to help them get all available information about their child's needs, to help them find out about, and access, all relevant services and to help them co-ordinate the many people helping the child.

The qualities we looked for in our keyworkers were empathy, sufficient maturity to be a shoulder to cry on, knowledge of child development and disability issues, a good listening ear with counselling skills and knowledge of local services. The keyworker would be able to develop a close relationship with the parents, to work confidentially with them, to be honest while maintaining a positive stance, to acknowledge and work with the strengths within the family, to avoid being yet another 'expert who knows best' and to avoid giving advice.

This became the One Hundred Hours keyworker model, a model which evolved dynamically out of our flexible response to the needs we encountered in families. It evolved without the benefit of another model to learn from and, although it reflects recent research findings, it was not a research-based model.

We were surprised that the trauma of the parents and the ways in which family life might be rapidly thrown into disarray was generally not acknowledged by those people who plan statutory services and work within them such as doctors, nurses, therapists, teachers and social workers. The exceptions were particular workers from any of the professions who recognised the parents' plight and did what they could to help by 'stretching' their job description and adding to their workload. Such people have been lifesavers for many families. But lack of official acknowledgement of the needs of families perpetuated ineffective and unresponsive services for families.

The SOFTY Survey



The SOFTY Survey had a simple aim - to identify the support needs of parents throughout the UK in the first two years after the disclosure of diagnosis of their child's complex needs. We stressed that we wanted to learn about good practice - the support systems that *are* in place - as much as we wanted to learn about parents' poor experiences.

The questionnaire was very open - at no point did we define support. We were very keen that respondents should be able to come to their own conclusions about their needs and what was, or what might be, appropriate support.

Through One Hundred Hours we were able to spend 9 years developing and refining a model of support (two comprehensive evaluations of this model have been published: *When the Bough Breaks* 1994 and *Listening to Parents* 1999) and we were interested to know to what extent this model could be universal. The SOFTY Survey was our mechanism for testing this.

Postscript: The Handsel Trust

Sadly, during the process of conducting the SOFTY Survey, One Hundred Hours had to cease working as the struggle to obtain funding finally defeated us. However, in an effort not to let all the work that One Hundred Hours had done, and all that we had learned over the previous 10 years, the One Hundred Hours workers together set up The Handsel Trust in 1999.

The Handsel Trust now works to promote the support of parents in services – health, education, social services - throughout the UK. Our focus is very much on the issues brought forward in the SOFTY Survey – a dedicated keyworker role working in partnership with parents; and the co-ordination of all services in place for a child with disabilities.