



## NEW WRITING

### *An Alphabet of Helpful Hints: For new practitioners offering family-centred support to children with disabilities / special needs*

By Peter Limbrick

This is a regular feature in IQJ. The alphabet covers issues which have arisen repeatedly in my consultancy and training work over the last 12 years. The suggestions humbly offered here come from my experience as a sibling of a man with severe cerebral palsy, as a teacher of children with disabilities / special needs, and as a keyworker in the 1990s with families of neurologically impaired babies and young children.

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## **F is for Families – and Fathers**

### **Introduction**

My title suggests that I thought of *Family* first and then tacked *Father* on as an afterthought. When we work with children who have disabilities and special needs, this is often what we do. We focus first on the child, then we extend our thinking to the family, and then, we might or might not give some thought to the father. Sheila West wrote about this problem in 2000 in her book entitled **Just a Shadow: A**

*review of support for the fathers of children with disabilities.*

I am taking a broad and inclusive view of families in this alphabet piece in which fathers get a mention but are not a major focus. I feel this is appropriate as Christine Towers has focused on fathers in her Opinion piece in this issue of IQJ. I will give some websites relevant to fathers at the end of the piece. I shall also briefly mention grandparents who are not such close members of the western nuclear family as are fathers, but who are often neglected in our work with children in need.

There have been repeated calls during this decade to think more about families and to be more 'family-centred'. Together from the Start (DfES and DoH, 2003) gave this movement an excellent and official push forward. I am going to suggest that a family-centred approach in our work with disabled children can be thought of as ripples that spread out from a pebble dropped into a pond. As each ripple expands, so we embrace more aspects of family life and more family members from that central starting point where we might have focused on just the child. Obviously, such professionals as family

therapists would have started from somewhere else, but most families meet child-centred practitioners first. Having described where the ripples could take us, I am going to suggest that each of us must work within agreed limits and that some practitioners and services have more room for manoeuvre than others in becoming family-centred.

Most practitioners are asked to be child-centred and family-centred at the same time – and this is what parents might rightly expect. Most of the time, this is possible. Difficulties can arise in a small number of families when, from a professional viewpoint, the needs or wants of the family do not fit with the needs of the child. This is a subject for skilled negotiation between parents and a practitioner they trust (in which both parent *and* practitioner might reflect on their values), or it can become an issue of child protection. In relation to the vast majority of children and families (using another metaphor) I think of child-centred work as the yolk of a family-centred fried egg.

In my view, there are three major phases, or ripples, in a family-centred approach:

1. Offering interventions to the child that fit well with the family.
2. Helping the family with needs that arise from the child's condition.
3. Helping the family with any other needs they might have.

### **Offering interventions to the child that fit well with the family**

If there are too many clinics, assessments and home-visiting practitioners, the family can be run off its feet, with weeks that are too busy, repeated journeys that waste time, energy and money, and young siblings that need childcare arrangements. There might be too many practitioners offering separate home programmes that do not really fit together and for which the parents do not have the time or the space. Parents might or might not give elements of the work with the child the same high priority as each practitioner does. When a parent does not, it might be because she has bigger issues on her mind – her floundering relationship with her partner, the need for accommodation that fits the child, her rapidly sinking financial situation. Or perhaps her mind

is not in a very good state if she has not yet been able to bond with her baby, if the child's condition has brought her to a state of high anxiety and low depression, if she and the rest of the family have not slept for weeks.

Being family-centred within this ripple means working in close and genuine partnership with the parents, organising a collective effort to co-ordinate and rationalise all interventions, and collaborating in small Teams Around the Child (TAC) on each child's programmes. It means tuning in to the family's situation and the parents' emotional state – and starting from there.

### **Helping the family with needs that arise from the child's condition**

In this second ripple comes an attempt to help the family with some of the new challenges they are facing since their child's needs arose or were recognised – some of which were mentioned above. The list might be very long indeed because the needs of a child with a complex of conditions can impact on every aspect of family life. A *short* list might suggest the family needs support with:

- The parents' emotional state and relationship
- Fathers' need to be considered when appointments, clinics, etc are planned
- Siblings' need to voice their feelings and have some of their needs recognised
- Grandparents' need for emotional support – and perhaps for 'training' as they learn to meet the child's needs
- Sleep
- Money and debt
- Stress
- Accommodation

The elements of this sort of support can be discussed and prioritised in TAC meetings and written into Family Support Plans (FSPs) for pre-school children. As some schools are gradually resourced to become family-centred, so these elements of support can be discussed and planned at school-based meetings.

## Helping the family with any other needs they might have

Needs arise in all families from time to time and the families we are discussing here might have some needs that are not connected to the child's condition – needs which might have already been present or have arisen since. Within this last ripple might be a parent's physical or sensory disability or psychiatric condition. There might be a learning disability or a language need. There might be other needs.

There are two reasons for local services, whether council or trust, to try to help families with these needs; firstly, in the UK there is an expectation that people in need will be supported, and secondly, the child with a disability or special need will probably fare better if the family is offered relevant support.

## The art of the possible

Though each practitioner can and should keep an eye on the family situation when planning her intervention, the wider effort to be family-centred is more appropriately a collective effort – both multi-disciplinary and multi-agency. We should not assume that an individual practitioner or an individual service can meet needs in all three ripples. Practitioners who have traditionally focused on the needs of children are not expected suddenly to start work on parents' relationships! Training, support, competence, time and job description are major factors in this.

Team discussions can look at the family-centred approach in a framework of flexibility. Such a framework would list all those things that are not negotiable – those things that definitely *must* be done or definitely *must not* be done. The zone of flexibility, or the area of negotiation, then lies between the two extremes.

## References:

West, S. (2000) **Just a Shadow**: A review of support for the fathers of children with disabilities. UK: Handsel Trust

DfES and DoH, (2003) *Together from the Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families.*

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4007526](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007526)

## Websites about fathers:

Foundation for People with Learning Disabilities 'Recognising Fathers' project:  
<http://www.learningdisabilities.org.uk/our-work/family-support/fathers/>

Fatherhood Institute:  
[www.fatherhoodinstitute.org/](http://www.fatherhoodinstitute.org/)

Gingerbread's Dad Place:  
<http://www.gingerbread.org.uk/portal/page/portal/Website/For%20one%20parents/Dads%20Place>

Contact a Family's 'Fathers':  
<http://www.cafamily.org.uk/pdfs/fathers.pdf>

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