



NEW WRITING

An Alphabet of Helpful Hints

For new practitioners offering family-centred support to children with disabilities / special needs

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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.

B is for Balance

Neurologically impaired babies bring with them a need for balanced thinking and actions in their parents, close family members and practitioners. Typically coming with a whole bunch of conditions, disabilities, illnesses, strengths, personality traits and needs, these infants require their parents to become skilled jugglers who can deftly keep a small galaxy of fragile plates spinning in the air at the same time. If a parent fails the balancing act and lets just one plate fall, while giving too much attention to another, consequences can be dire because

these babies (arriving in ever greater numbers) and their families can be very vulnerable indeed.

This sounds like an awesome responsibility, enough to make parents tremble. And they do, at the beginning and then at every step along the way. Those of us who would step in to help, whether we are paediatricians, psychologists, therapists, nurses, teachers, social workers, family support workers or keyworkers should tremble too at the awesomeness of the task and at the honour and privilege afforded us by trusting parents who, in time, might let us relieve them of one or two of the plates – for a time.

What are the various plates that must be kept aloft and spinning? What are all the different ever-moving parts that parents and practitioners have to think about, weigh against each other, harmonise and bring into balance? They are too numerous to list here and anyway the list would differ for each child and family, but we could begin with the following:

- The child's need for loving attention, medical care, nutrition, sleep, fresh air, comfort, feeling safe, respect, confidence and freedom from pain.

- The parent's need for reassurance, praise, celebration, respect, information, sleep, recreation, employment, study, love, someone to trust, someone to listen, someone to cry with and laugh with, and freedom from debt.
- The child's need to stay in one piece as a whole child, to be offered play, therapy and learning opportunities that imperceptibly weld together posture, movement, vision, hearing, understanding, communication, emotions, and so on.
- The family's need to get back to something like normality in which siblings have a valued and rewarding place, in which fathers are acknowledged, valued and involved, in which grandparents are empowered to support the family to the best of their ability, and in which friendships, family relations, short breaks, holidays, treats, hobbies, education and careers are not kept tantalisingly out of reach.

Achieving balance means trying to keep the big picture in mind, learning what all the relevant factors are and weighing them against each other every time a new decision has to be made or a course of action chosen. Balance means never focusing on one of the plates as though it were the only one of any importance because, if you do, the rest will surely come crashing down around you. Balance, for very good reasons, lies behind many of the current buzz words and phrases; 'whole-child', 'family-centred', 'integrated', 'holistic', 'co-ordinated'...

The following are some of the situations I met as a keyworker where I had an opportunity to be alongside a family as they struggled for balance or where I had to work to achieve a balance of my own:

1. Carry or empower?

Parents of neurologically impaired babies, just like everybody else, from time to time will need a prop, a leg-up, a strong back to carry them, and, just like the rest of us, will know when to dispense with the support and continue their journey without it. A trap for practitioners, and a temptation for them to lose balance, is to enjoy being needed and to encourage parents to

become dependent on them. When I say this, please do not imagine nasty practitioners with horns and fangs feeding on susceptible families. This is a trap we can all fall into because of the very motives that brought us into the work – the desire to help. The antidote is to be aware of this possible danger and to reflect on our practice, alone or with others.

2. Safe haven or inclusion in normal life?

I have talked to very many parents, both as a keyworker and as an interviewer in surveys, about what sort of places they wanted to go to in the first couple of years after their baby was born. Families are all unique and parents are all different whether their child has special needs or not, but a pattern emerged in which many mothers (and for the majority of infants I met the mother was the main carer) either had, or longed for, a place to go to for an escape from the four walls or for the child's treatment, therapy and play, where they were known and welcomed, where staff knew their child's name, where the child's behaviour, abilities and care needs would not be remarked upon, and where there would be other parents experiencing much the same anxieties, frustrations and joys. For these reasons, amongst others, many Child Development Centres have been greatly valued. In contrast some mothers told stories of going bravely for the first time to a mother-and-baby/toddler group or a family centre, hoping to meet someone nice only to feel shunned, to find nothing in common with the other mothers and to have no one take any interest in their child. It would be a very brave mother who went back a second time.

Whatever the early needs and experiences, many parents will want to work towards some version of normal family life that includes going to the same sort of places other families go to and this brings repeated challenges to parents, child and brothers and sisters. It seems to me that parents who found a satisfactory and evolving balance between safe haven and the big outside world in the first

couple of years will do better in this adventure than will those who buried themselves in the safe haven too deeply or were forced too quickly in to the outside world.

3. Where is my magic wand?

Caring practitioners from any and all services can sometimes feel impotent in the face of particular child and family needs and can do no more than wish they could wave a magic wand over the family to make everything come right. This is a natural enough feeling but it can be associated with a practitioner feeling despondent, depressed and guilty – guilty for not being Superman or Wonder Woman. Part of the answer for practitioners is to continually reflect on their work to keep a balance between what they are and are not empowered to do, what they do and do not have time and resources for, and what they are and are not competent to tackle.

There also has to be a balanced judgement about how much a practitioner should aspire to do. Families need some space to dig down into their resources to come up with their own solutions. This is how we all grow. The very least, and perhaps the best, any practitioner can do is to be with the family as they struggle, to travel with them through the difficult parts of their journey, to cry with them when they cry and laugh with them when they laugh. When a family accepts you in this way you are deeply honoured.

4. How many practitioners does an infant need?

There is a balance here that, in my experience, is not often considered. For some complicated babies and young children the diagnosis of the condition and the assessment of need evolve as disabilities emerge. The service-providers' response, often in tune with parents' wishes, is to add on yet another practitioner to address each new need. I feel that these infants with multiple and complicated diagnoses deserve a better approach. This new approach would

recognise that babies and some vulnerable young children cannot relate easily to so many people, that offering separate discipline-specific programmes is not in tune with the child's natural need for a whole approach, that families can be overwhelmed and exhausted by so many visitors to the house, so many clinics and centres to travel to each week.

In my vision for a new approach, any thought about adding another service or practitioner will be accompanied by some reflection on:

1. Is the child ready for another person?
2. Is the family ready for another person?
3. Could the proposed new intervention be offered by one of the existing practitioners?
4. If not, can it wait?

Taking this thinking one stage further, a better balance between needs and practitioner-provision can be achieved for some children at some times by agreeing that one practitioner will be the primary interventionist.

5. I cannot get on with my work while the mother is crying

Many practitioners, perhaps particularly those who can work in the child's home, can feel frustrated when the work they would like to do with the child is interrupted by a parent who has persistent questions, needs to talk, or is crying much of the time. A serious imbalance here perhaps between the needs of child, parent and practitioner. Many practitioners resolve the situation by switching attention to the parent and becoming listener and shoulder to cry on. Others try to stick doggedly to their brief of child-centred work. Others try to do both at the same time and probably fail miserably.

There is a balance needed here and some discussion might have to take place between the practitioner and her manager or between practitioner and

team members. A family-centred view could be that the parent's needs must be addressed before she can be properly involved in the practitioner's work with the child. Perhaps a pattern for each session that embraces both parent and child needs can be negotiated with the parent.

I learned a valuable lesson as a keyworker in my first sessions with the mother of a new baby who was recently home from a month or so in hospital after birth. I was visiting, as agreed, twice a week for a couple of hours and for most of each session the mother was distraught, crying and trying to talk through her tears – and continually apologising for it. From memory, I would say this lasted for three to four weeks and during that time I was repeatedly asking myself if this was becoming a job for life. Were we getting anywhere? What was I achieving? What about some focus on the baby?

More experienced practitioners can guess the rest of this story. Little by little the crying abated and conversation became possible – with an increasing focus on the baby's development and learning. Quite soon the mother became less fearful, regained some of her usual self-esteem and regained her poise and some small optimism. Later still, she was a very confident and competent mother who had adjusted to the arrival of this new member of her family. Each of my visits then shared a natural focus between baby and mother as designed into the organisation's keyworker role. I can believe that the long hours spent crying with an empathetic outsider were part of a healing process and that if I had tried to impose my idea of balance on those first visits the mother might well have remained distraught for longer.

I am sure readers will know of many other situations where there are conflicting or competing interests for families and/or for practitioners that need to be reflected on, considered and balanced. One of them might be some disagreement between practitioners and parents about whether or not something is out of balance and needing attention! The answer is rarely to be found inside a single head.

Practitioners need opportunities for reflection with their colleagues and families should have easy access to trusted practitioners when they need someone outside the family to discuss issues with. Everyone needs listening skills, some experience in effective negotiation and an ability to work in partnership. Team Around the Child meetings are a perfect arena for these discussions and much of the work of any child's TAC will be about balance.

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