



## NEW WRITING

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

By Peter Limbrick

## **A** is for Avoid Assumptions   **A** is for Anticipate   **A** is for Ask

This will be a regular feature in IQJ. The alphabet will cover 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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Each of these 'As' is about learning what a child and family's situation is, what they are feeling, what their strengths are, what they need, etc. So you will not be surprised that the message in the piece is: **asking is always the best policy**. So what is wrong with making assumptions?

Assumptions, when used by practitioners or organisations to plan support for individual families or for the local population of families with particular needs, disempower the child and family and give precedence to the opinions of practitioners. When practitioners and managers

rely on assumptions they are always in danger of deciding the child and family need just what they and their organisation have traditionally offered. Assumptions can allow practitioners and managers to shape provision so that they are meeting their own needs in their work rather than the child and family's. This might sound like a strong accusation but I feel every one of us brings our own needs in to the work and it is better to reflect on this rather than deny that it happens.

The only safe assumption is that assumptions are very likely to be entirely wrong and will lead to real needs being unmet, a child or young person missing a learning opportunity and an increase in child and family frustration, dissatisfaction and stress. As Shirley Young tells us in her essay *When Parents are in Denial* in this issue of IQJ, we cannot even assume that a parent who has struggled to achieve an assessment, a grant or an aid will be pleased when it arrives – because the success in acquiring the item might emphasise the child's disability or bring to an end some hope for a different future. At these times Shirley reminds us that we should ask the parent how they feel

before we celebrate. I remember a young family who were not particularly upset when their baby was found to be blind. Why they were not upset is another story but they certainly proved my assumption wrong!

Having helped 99 families will not tell us what the 100<sup>th</sup> family needs. But, while past work with 99 families does not qualify us to make any assumptions about the next family, what we have learned from the 99 will certainly help us to anticipate what another family's situation might be and this can help us to structure our meetings with them and help us to ask relevant questions. For instance, a practitioner who has worked with many families, who has done a bit of reading and dipped into some current surveys and research, will be aware that:

- many parents experience some negative emotions when the new baby is not the perfect baby they expected
- many babies, children and young people with significant disabilities disrupt the family's sleep routines
- many new families experience a serious downturn in their economic fortunes

Knowing this, equips the wise and sensitive practitioner, when meeting a new family, to explore feelings, sleep and any need for advice about benefits. The child's particular disability and the family's particular situation might lead the practitioner to anticipate other things, e.g. with a very challenging child, that the parent might welcome an occasional short break. While assumptions can lead to unhelpful and even harmful actions and decisions, intelligent anticipation leads to appropriate and sensitive questioning.

### **Are there limits to what a parent can talk about and what a practitioner can ask about?**

What questions a practitioner is prepared to ask a new family, what potential needs she is prepared to explore, and what appeals she is prepared to listen to will depend on how far she sees herself as part of a collective effort. Each practitioner can see herself either as an emissary of a single service or as an intermediary between the new family and the local multi-agency integrated pathway. In practical terms a physiotherapist meeting a new child and family

can keep her concern within the child's posture and motor needs or she can listen as parents speak about other, perhaps more pressing, needs – and then alert other local practitioners and services to these unmet needs. While I would argue that practitioners should feel themselves to be part of a collective effort with a responsibility to listen, think and act with an 'integrated, whole-child and family-centred' hat on, I would argue that practitioners should not operate beyond their limits of competence and should not be asked to become experts in other fields.

New parents have much to learn, much to do and much to worry about. It would be wrong to assume that any new parent we meet has the same focus at that time as we do. Keeping the totality of support in mind, a parent, during all of the early years, might be seeking any combination of the elements of support listed below when she encounters a new practitioner and a new service.

1. To find out what is wrong with the child.
2. To find out why this happened.
3. To find out if there is a cure or a medical treatment.
4. To find out the implications for any siblings.
5. To find out if it is safe to have more children.
6. To find out what this means for the child's health, survival, wellbeing, happiness, education, adult life.
7. To acquire an understanding of the condition.
8. To find out what can be done to help the child.
9. To find out what services and support are available.
10. To acquire necessary skills to help in the child's treatment, care, play, development and learning.
11. To get practical help from practitioners in the child's treatment, care, play, development and learning.
12. To find words to use to explain the condition to strangers, neighbours, friends and relatives.
13. To get support in helping partner, grandparents, siblings and friends understand the condition.

14. To get support in encouraging and facilitating partner, relatives and friends to offer practical help.
15. To get help in balancing the needs of the child with the needs of partner and siblings.
16. To get support in maintaining the relationship with the partner.
17. To get relevant support so that employment can be continued.
18. To get help in remedying an immediate problem or cause of stress such as disturbed nights, the child's feeding, the child's constant crying or other challenging behaviour.
19. To get such support as 'baby-sitting', childcare or short breaks to help in coping with stressful and difficult situations.
20. To have someone to discuss issues with and to help parents come to informed decisions.
21. To have someone to be a listening ear and a shoulder to cry on.
22. To have counselling to help sort out emotions and to develop coping strategies.
23. Help with getting benefits, applying for Family Fund and other grants, securing money for items of equipment, managing the family budget.
24. To get more appropriate housing by moving house, getting adaptations, equipment, etc.
25. To get practical help with household tasks.
26. To get opportunities for family members to spend valuable time apart from each other on rewarding activity – as happens naturally in most families
27. To get help in taking the child to such local facilities as mother-and-toddler groups, playgroups, nurseries, swimming pool, football matches, etc.
28. To get help in keeping family life as normal as possible in relation to outings, socialising, leisure activities, holidays, etc.
29. To be helped to make informed choices about the shape of the whole package of support so that it is a coherent whole which does not make family life impossible and which enhances aspirations of all family members.

30. To have an adviser and advocate to help remove barriers to the parent's aspirations.\*

The list is long and wide-ranging because the adjustments and challenges in caring for a child with significant disability can affect every aspect of family life; finances, housing, leisure, employment, relationships, emotions, beliefs, etc. A parent who has all or many of the needs listed above and who might or might not have articulated them into clear ideas and wishes, can easily become frustrated when services and practitioners are found to have a narrow remit and when no services are found which are designed to meet particular needs.

No single practitioner can answer all of these questions or respond to all of these appeals for support but, in an integrated service, each parent should have the reassurance that she can ask the questions and each practitioner should know she has a responsibility to feed those questions and needs into the local integrated support system.

Assumptions will not help child or family. Questions and sensitive explorations that arise from intelligent anticipation will.

\* The above list of elements of support is taken from Birmingham University's School of Education Distance Learning Module: Early Years Sensory and Multiple Needs: The Child in the Family, Unit 3: Evaluating the Work of Services, written by Peter Limbrick and edited by Linda Watson.

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