



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.

E is for Early

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Introduction

In the context of babies and young children who have disabilities or special needs, *early* usually describes some sort of relevant help that comes at or near the time it is first needed. We do not have a single phrase for this. By tradition in the UK we have used the phrase *early intervention* and this corresponds with the International Society on Early Intervention (ISEI: <http://depts.washington.edu/isei/>). There has been a move to distinguish between infants on the one hand and older children, young people and adults on the other by using the phrase *early childhood intervention* for the former and *early intervention* for people in the latter group (who require some sort of prompt action after an accident, illness or onset of some new disabling condition at any age).

In England we now have Early Support (www.earlysupport.org.uk/) under the wing of DCSF (Department for Children, Schools and Families) which came into being after the publication of the groundbreaking *Together from the Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families* in 2003 (http://www.dcsf.gov.uk/consultations/downloadableDocs/177_2.pdf). *Early support* is also used

without the capital letters to equate to *early childhood intervention*. I use all the above phrases from time to time but there would be some advantage in having one agreed phrase that has international understanding. In this article I am going to use just *early intervention*.

As I see it, all the phrases use the word *early* to suggest, rightly in my view, that being early is a good thing in that any support, treatments, interventions or programmes that come late risk losing some or all of their potential value. I do not imagine anyone is going to argue with this concept and that helps explain parents' frustration, disappointment and anger when each required intervention has its waiting list of two weeks, two months, two years or more. They fear that opportunities are being lost forever and that their child's chances of developing and learning are being spoiled. Which parent would not be angry with this?

Can there be too much early intervention?

In my experience there is early intervention which is effective and early intervention which is questionable. Being early is not the only criterion to apply. Sometimes there can be too many interventions and sometimes interventions are offered to the family without good information about their efficacy. The book *Blue Sky July*¹, written by Nia Wyn, describes the experience of Joe and his family after Joe was diagnosed as a baby as blind with severe cerebral palsy. Nia is Joe's mother and she took the route many parents take, to a greater or lesser extent, of seeking very many interventions for her son. The following extracts are from review I wrote of the book soon after it was published:²

Nia Wyn's mission is to battle against impossible odds to heal him. And battle she does. My quick tally of the interventions indicates physiotherapist, speech therapist, medication for epilepsy, 'doctor at the eye clinic', sensory rooms, 'oxygen tanks', patterning, Reiki, cranial osteopath, muscle tapping (all in Joe's first year), and then a private Peto-trained conductor (who helps with the patterning!), music therapy, Steiner nursery, massage, 'rocking' therapy, a 'second skin', botox, and faith

healing. I hear workers in the field, from nursery nurses to neurologists tut-tutting at this 'mum' who is 'in denial' and 'out to get every treatment she can get'. Those who are quick to judge might find themselves doing much the same in a similar situation.

This publication is a stark reminder (and therefore a useful book for professionals to read) that children like Joe are subject to two parallel early intervention approaches; the 'statutory' and the 'others' – in both of which there will be some things of value and some of no value. The trick is to know which is which.... Joe did develop beyond professional expectations. What we do not know is which, if any, of the interventions helped this development and which hindered it.

There is talk of miracles in *Blue Sky July* and the miracle might be that Joe survived the circus, unlike his parents' relationship or his mother's career. These parents found themselves in a common trap and Nia Wyn, speaking of her husband says: 'Alex said he felt damned if we continued Joe's therapies, and damned if we didn't.'

I have not met Joe and even if I had I would not be in a position to say which of his early interventions were of value and which were not. Nor is there any science to tell us how these interventions would impact on each other when offered to a baby simultaneously. In my view there is little or no science about early education and therapy interventions for children with multiple disabilities.

But Joe's story does prompt us to ask questions, even when thinking just about statutory services, about the appropriateness of multiple practitioners offering multiple interventions to babies and pre-school children.

When 'less' can be 'more'

It would not be unusual for a baby with Joe's diagnosis to have hands-on interventions in his

first 18 months from physiotherapist, visual impairment teacher, speech and language therapist, Portage worker, and perhaps occupational therapist, play therapist and psychologist as well. In my view there are some children who, because of very young age, because they have not bonded with their mother, because of the social and emotional implications of their disabilities, because they are generally very anxious about the world and the people in it, are not ready to relate to this many adults or to tolerate being handled by them. Many infants I have met would have benefitted from fewer practitioners and fewer discipline-specific programmes. Some of these would have been better with just one practitioner at first working with child and parent. Even then, the practitioner's best approach for some children might be to work with the child through the parent until such a time as the child becomes ready for more hands-on interventions from that practitioner or additional practitioners.

In the interests of child-centred practice I feel there is collective responsibility on all of us to make sure we are not overloading any baby or young child with too much early intervention. (The same collective responsibility requires us also to consider whether the pre-school child is being offered *too little* help in relation to his or her potential for development and learning.)

These judgements are ideally made by each child's TAC (Team Around the Child)³ and logically take into account the child's capacity at that time to relate to a number of practitioners and to accept being handled by them. Here is set of questions a baby or young child's TAC can address at each meeting:

1. Does the child have too many therapy and education practitioners and programmes at the moment? If 'yes':
2. What is the effect of this overload on the child and on the family?
3. What creative TAC solutions are there to remedy the imbalance for this child at this time?

The intervention overload, or the imbalance between the child's emotional, social and psychological needs and the number of interventions, seems to happen because infants who have neurological impairments have conditions and disabilities that are discovered

over a period of time rather than being evident from the beginning. The traditional response in the UK from services and practitioners that are committed to being as 'early' and as helpful as possible, is to add a new practitioner to the child's list for each newly discovered need. The valid desire to provide timely help seems to take precedence over considering the child's ability to cope with the expanding team. The following questions might provide each TAC with an antidote to the potential overload when an additional intervention is suggested:

1. Is the child ready in every sense for another practitioner?
2. Is the family ready?
3. Will the new intervention fit naturally with the current interventions?
4. Will the new intervention fit into the child and family's timetable and routines?
5. Should the new intervention be postponed for a time?
6. Should an existing TAC member provide some or all of the proposed new intervention for a time? (Perhaps using the consultancy model in which one practitioner hands over some work to another.)
7. Are there other creative TAC solutions to the dilemma?

The outcome of these TAC discussions and negotiations will be reflected in the Family Service Plan and will be revisited at future TAC meetings.

Conclusion

Families are all different and each child with multiple needs is unique. Assumptions and generalisations will get us nowhere. Parents will have views about what is appropriate for their child in early intervention, as will practitioners and their managers. But the infant should have a voice too – what else can 'child centred' mean? Practitioners in the UK aspire to being genuinely child centred and this imposes a clear responsibility on all of us to ensure the child is not being overloaded and that the early interventions, of whatever number and type, are adding to the child's wellbeing and giving him or her the best possible early life experience.

References

1. Wyn, N., *Blue Sky July*. Bridgend, Seren Books, 2007.
2. Limbrick, P., Review of *Blue Sky July*: "...not a book that I would recommend to parents of children with disabilities and special needs" *Interconnections Electronic Bulletin*, October 2007. (The full review can be seen at:
<http://www.icwhatsnew.com/reviews/Blue%20Sky%20July.pdf>)
3. Limbrick, P., *Early Support for Children with Complex Needs: Team Around the Child and the Multi-agency Keyworker*. Worcester, Interconnections, 2004.

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