

## NEW WRITING

# *TAC for the 21st Century: A unifying theory about children who have multifaceted disabilities*

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voluntary services in the UK and Ireland in their attempts to improve support for children with disabilities and their families. This was while he was leading the charity One Hundred Hours which pioneered keyworker-based support for families with neurologically impaired babies. Interconnections provides a consultancy and training service and has developed the Team Around the Child (TAC) system to facilitate integrated, multi-agency support for babies and young children who have ongoing multiple disabilities. Interconnections publishes the free monthly Electronic Bulletin and this Journal.

### **Summary**

We have in the UK an increasing population of children with neurological impairment and consequent multiple disabilities or 'multifaceted disability'. There is a danger of these children and their families being overloaded in the first years by too many practitioners with too many discipline-specific programmes. This comes from

the well-intentioned, traditional practice of providing a new practitioner for each of the disabilities as they emerge. The result can be a fragmented approach to the infant's development and learning with some young children being required to relate to, and accept being handled by, more people than they can cope with. The Team Around the Child (TAC) approach adopts a systems perspective and enables service providers to move from thinking about multiples to thinking about wholes – whole children, whole conditions, whole intervention systems.

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### **Introduction**

This article is about how support is provided in the UK to the increasing population of babies and children who have a 'multifaceted disability'. This phrase, though not in common usage, is, by the logic of this article, more appropriate than such phrases as 'multiple disabilities', 'requiring multiple interventions', 'complex disabilities' and 'complex needs'. The article will suggest that a systems perspective can reduce multiples to manageable wholes and that any problematic complexity is more likely the product of outdated service provision than an inherent feature of any child. (Readers who prefer not to use *disability* could think of children with a 'multifaceted condition').

When Michael J. Guralnick (2005) lists the principles of early intervention relevant to his Developmental Systems Model he gives as the very last one: 'A *systems perspective* is maintained, recognizing interrelationships among all components.' (p 6)

This systems perspective is the subject of this article for it is my belief that systems thinking provides the way out of the cul-de-sac that UK services find themselves in with this growing population of children who are relatively new kids on the block – 'growing' because more and more are surviving birth and the vulnerable first two years and 'new' because in the UK they used to be excluded from education on a spurious IQ assessment and often incarcerated in long-stay 'mental handicap hospitals' from infancy to grave. It is my contention that these new kids need new services and that in stubbornly trying to make the old ways fit we are failing children, families and hardworking practitioners.

### **When new children are failed by old thinking**

While there has been a wealth of creative, scientific thinking and revolutionary advances in molecular biology, genetics, and medical technology since the middle of the last century, there has been no corresponding progress in education, therapy or care for the generality of children who have multifaceted disabilities. It feels as though we are stuck in the age of the steam engine and telegraph as though quantum theory, space travel and the World Wide Web are all still waiting to happen.

So what happens in the UK to an infant who has a multifaceted disability? The traditional and still current approach is to add a new practitioner for each condition, disability or need that we discover. For a child with neurological impairment from birth there could be paediatrician, outreach nurse, health visitor and physiotherapist at the head of the procession, closely followed by speech and language therapist, teacher for visually impaired children, occupational therapist, teacher for hearing impaired children, play therapist, psychologist and so on. The list and the sequence will be different for each child but the dangers are the same. The family can be overloaded by multiple appointments, clinics, assessments and reviews, and by the travel and childcare costs incurred (for any young siblings), and will inevitably encounter duplications, contradictions and gaps

in this dangerous *mêlée* – all adding to their stress, confusion and anxiety. The child can be overwhelmed by the requirement to relate to so many people – far more people than we would impose on a non-disabled child, and might have a daily and weekly routine crammed with discipline-specific programmes. Pre-school practitioners suffer too with increasing demands on their time as they try to meet parents' aspirations for regular sessions of this or that.

We learned in the last century that individual practitioners, whether specialist teachers or therapists, can help children who have an individual disability. We now blindly assume that the answer for children who have multiple diagnoses is simply to multiply the practitioners. This scatter-gun approach has happened by default and, in my view, is not tenable within the resources available in the UK. Nor should we perpetuate it when we give some thought to what is fair to children. Some infants, because of prematurity and/or disability have not yet bonded with their mother. Other infants have communication difficulties. Others are just plain nervous and fearful. For these babies and young children it is illogical to impose ever more practitioners just on the basis that each one has expertise in this or that disability – while we could be asking instead, 'Is the child ready for another practitioner?' or 'Is the family ready for another practitioner?' For some reason children who have a multifaceted disability manage to creep under our 'child-centred' radar and fail to evoke our empathy, sensitivity or professionalism. Could this be because we remain stuck in an overly medical approach and see the disabilities under the microscope but not the child under our nose?

### **A systems perspective**

Ludwig von Bertalanffy (1969) tells us that General Systems Theory is founded on the understanding that there are models, principles and laws shared by different fields of human endeavour, for example, physics, chemistry, biology, economics and sociology. Speaking of the various entities that we encounter in any of these fields (e.g. atoms, molecules, bacteria, humans, factories, supermarkets) he says, '...the entities concerned can be considered in certain respects, as "systems", i.e. complexes of elements standing in interaction.' (p 33) He goes on to say:

The meaning of the somewhat mystical expression, 'the whole is more than the sum of the parts' is simply that constitutive characteristics are not explainable from the characteristics of isolated parts. The characteristics of the complex, therefore, compared to those of the elements, appear as 'new' or 'emergent'.

(p 55)

I take this to mean that if you add four wheels, an internal combustion engine and a steering wheel together you get a means of getting to work. If you add boiler, thermostat and radiators together you get heat all round the house. If you add cerebral palsy, blindness and learning disability together you get a multifaceted condition that is very much more than the sum of its parts. I also take it to mean that we cannot understand cars or central heating unless we learn how the bits fit together, how the bits relate to each other. And that we cannot help a child who has a multifaceted condition by focusing on the separate disabilities as though they were not 'standing in interaction'. Here is a story about how I see the problem:

A group of five pupils in a school in Japan, or China or on another planet, are given the English word 'CHILD' to decipher. The busy teacher designed this as a group activity but instead, each child takes a letter to their desk to work on individually and eventually each comes proudly back to the teacher with their answer. The first reports that the first letter says 'see', the second 'aitch' and so on. The teacher, seeing the misunderstanding and knowing that, as far as words are concerned, the whole is more than the sum of the parts, asks them to work as a group to decipher the whole word – to find out what meaning is created in English when these five letters are strung together in this order.

Are we not in a similar position with children who have multifaceted disabilities? Do we not by tradition, as therapists or specialist pre-school teachers, examine separate bits without

ever getting to the whole 'CHILD'? Do we not report our individual answers back to the parents in pieces for them to fit together themselves?

Presumably our teacher in the above story had already given her pupils instructions in how to join English letters and sounds together to make whole words. If we want practitioners to join all their discipline-specific interventions together then there has to be some sort of science that tells them how to do it – hopefully with effective training, resources and support. In my experience these skills do not come naturally to practitioners who have by training moved their focus from the whole child to this or that specialism. If we do not commit ourselves to a scientific approach with a systems perspective for the education, therapy and care of children who have multifaceted conditions we will remain fumbling in the dark with last century's trial and error strategies.

### **Some implications of a systems perspective**

There is not space here to describe all the implications of a systems perspective on children who have multifaceted disabilities and their families so I will restrict myself to four headings:

1. The Team Around the Child system
2. Collective competence
3. Integration of development and learning programmes
4. Disabilities interacting with each other to create new, emergent disabilities

#### **1. The Team Around the Child (TAC) system**

If the multiple conditions, disabilities and needs interact with each other as a system within the larger system of the whole child (who has *very many* more separate parts than just the disabling conditions), and if the child forms part of the larger system of the family (which exists within the larger systems of extended family, community, society, nation, etc), then it seems to me to be logical to support the child and family with an intervention system in which the separate parts stand in interaction with each other rather than functioning as isolated entities. This is the thinking behind the TAC system (Limbrick, P. 2004) in which a small team of key practitioners around each child

communicate and interact with each other within the larger system of a multi-agency integrated service for these children. (The phrase 'key practitioners' refers to the practitioners who have most regular and practical involvement with the child and family at any given time.)

TAC philosophy dictates that a young child's parent or carer has a full place in their child's TAC and that disabled young people have increasing presence in their TACs as they get older. (See Middleton, N. 2009) The child's TAC can organise initial assessment, planning, intervention and review processes along each child's multi-agency integrated pathway. (Limbrick, P. 2003)

TAC philosophy argues that practitioners cannot be effective for these children if they remain in isolation from each other. The TAC is a forum in which the separate elements of key practitioners, parent/carer and older child can stand in interaction with each other to produce outcomes that are greater than the sum of the parts. In the TAC system the child's wholeness is recognised and honoured with a whole approach.

## **2. Collective competence**

The concept of collective competence acknowledges that competence in providing these children with a whole approach to their development and learning has to be a collective effort. For these children my understanding and skills are relevant but they are not enough on their own. Your understanding and skills are just as relevant but risk being similarly ineffective if they do not stand in interaction with mine. Consider a deaf infant who has cerebral palsy. The mother, the physiotherapist and the teacher for deaf children all risk failing in a whole-child approach if they persist in standing alone rather than standing in interaction.

Competence is only achieved as a collective effort. Everyone's understanding and skills must be offered to the child within a system in which separate competencies are joined into a whole which becomes more than the sum of the parts. The physiotherapist can help the mother and the teacher find positions in which the child can observe signs and copy them. The teacher of the deaf can help the mother and the physiotherapist improve how they

communicate with their child. The mother teaches the other two about effective strategies the family has developed already, about the child's motivations, personality, likes, dislikes, habits, etc. Of course, the child is teaching all three about his or her strategies for learning so we have four people in this competence collective!

## **3. Integration of development and learning programmes**

There are degrees of integration and how far to go will be agreed by each child's TAC in consideration of the child and family's needs and circumstances at that particular time. Integration for the deaf child envisioned above can begin with all three people (mother, teacher for deaf children and physiotherapist) just listening to each other talk about what they are doing and what they are working towards. Even this most basic level of integration would come as a great relief to those parents who fear their practitioners do not know what each other is doing. This process will resolve any mismatch in approaches and goals.

The next stage can be each of the three in the TAC agreeing to take on some of the work of the others. In this way the physiotherapist will use the same signs, the teacher will incorporate the same posture and movement into her sessions and both will adopt successful approaches the mother has developed. Now we have education, therapy, play and the daily activity of family life integrated into a learning system which reflects and supports the child's natural integration of understanding, communication, posture, movement, dexterity, daily activity, play, relationships, memory, motivation and so on.

Two more steps in the integration process might be appropriate:

1. TAC members can each contribute some or all of their approaches and goals to a whole-child programme in which education, therapy and family activity and goals are melted together to become part of the child's meaningful and enjoyable daily experience at home and in the settings he or she goes to. In this way learning can become more relevant, more regular and more consistent. Specialist teachers and therapists would need to make their own professional judgement

about any parts of their intervention that they must keep to themselves for whatever reason. This is not a new requirement; specialist practitioners already have to judge what they can hand over to parents of pre-school children and to school staff for school children. (Limbrick, P. 2007, p 70)

It is worth emphasising, in pursuit of genuine child-centred interventions, that there is no intent here to make vulnerable babies' and children's lives miserable and onerous by loading endless targets into every part of their day. The trap for practitioners to avoid is integrating their interventions and then making the child do more and more work on the 'integrated programme'. TAC philosophy suggests that practitioners might explore how to integrate their programmes into the child's natural activity – for the infant, either rewarding play and socialising or the meaningful daily routines of dressing, mealtimes, bath time, etc. If our interventions are of a high standard then they will enhance the child's experience. This is a key part of the TAC system – to acknowledge each child's right, no matter how many conditions and disabilities are emerging, to be a child, to have as little pain and discomfort as possible and to have the best possible experience of being alive on each day – no matter how many days there might be ahead.

2. The second of these two further integrative steps, is to check whether the number of people directly and regularly involved with the child represents good child-centred practice. This question should arise at the first and all subsequent TAC meetings and one of the first TAC tasks might be to address whether the child has too few or too many hands-on practitioners.

Because TAC is a creative and collective intervention system, each TAC team can find its own creative solution when there are, or soon could be, too many people making too many demands. The options include:

- i. Prioritising interventions so that they do not all have to happen at the same time.

- ii. Using a consultancy model in which a necessary new intervention is offered by one of the current TAC members – for the time being.
- iii. Appointing a primary interventionist for an agreed period who becomes the practitioners doing most of the hands-on work. (Limbrick, P. 2007, p 69)

#### **4. Disabilities interacting with each other to create new, emergent disabilities**

A systems perspective suggests that a child's various conditions and disabilities will stand in interaction with each other and that the resulting, emergent condition or 'multifaceted disability' will be greater than the sum of its parts. The disability resulting from any complex of single disabilities will have new or emergent characteristics that the separate elements do not have. (Please note that *complex* as used here is a noun and not an adjective.)

Let us imagine a child whose diagnosis includes autism and blindness. As a developing infant he has to endure, celebrate, learn and accommodate to, all the things other autistic children are also dealing with. But he has to do it without the advantage of sight. At the same time, he is striving to meet all social, psychological and educational challenges of blindness but with the additional challenges of being autistic. I would suggest the interaction between the two conditions significantly affects the neurological processes and outcomes in his development and learning.

It seems fair to assume that his condition is a lot more complicated than autism plus blindness (A + B) but is in fact an emergent disability which we will have to call autistic blindness (AB) or blind autism (BA). People who have an interest in autism will opt for the latter while people with an interest in blindness will opt for the former. In actual fact they are both the same 'new' disability.

When a child's diagnosis includes autism, blindness and cerebral palsy her developing brain has the task of establishing neural pathways for posture, mobility, co-ordination and dexterity without the advantages of sight and within the constraints of autistic perceptions and social interactions. A, B and

now C merge together into a new complex which is much more than A + B + C. Whether we call the emergent disability ABC or BCA or CAB will depend on our primary interest, but whichever we opt for, we are dealing with a new disability that is greater than the sum of its parts.

The children in the increasing population of neurologically impaired infants invite us to add D for deafness to the complex and then E for epilepsy – and so on. These emergent disabilities of ABCD and ABCDE (and all other possible combinations of disabilities, conditions and needs) at first seem to offer an impossible challenge in which practitioners need access to a bank of computers in order to find a way forward. Not so. The child growing up with ABCDE is still just a child, no more, no less, and the emergent condition is just like any other condition that requires us to carefully observe the child's strengths and needs and then agree a collective intervention plan.

The pitfall for parents and practitioners to avoid is to think A + B + C + D + E and then provide a practitioner and a programme for each element as though the conditions and disabilities were not standing in interaction with each other. The approach for therapists and teachers is again the TAC system in which expert observations are shared and a whole-child programme is agreed. TAC philosophy does not argue for multi-skilled, 'jack-of-all-trades' practitioners because that would inevitably lead to a reduction in standards. On the contrary, TAC is the forum for highly skilled practitioners to find creative solutions for delivering their expertise to the child and family in joined-up, child-centred practice.

**Sharing information about emergent conditions.** But do not these emergent conditions impose a greater responsibility on all of us, whether we are family members, teachers, therapists, medics or academics? Should we not be developing a bank of information about AB, CBD, EBCA, etc. so that we do not have to offer each child a trial and error approach? While I am not advocating putting vulnerable children under a microscope, I am suggesting a careful collection of data from interventionists about what has been effective and what has not. Such an international library would enable all of us to make the best possible start with a new child, bringing effective intervention sooner rather than later or never. It would help over time to

remove the discrepancy between those (single) conditions and disabilities that have established interventions and those emergent conditions that do not – and that are treated as a new mystery each time they appear.

## Conclusion

If our thinking remains clear we can offer effective interventions to these children regardless of the label we attach to them. But we cannot be effective if we remain in last century's discipline-specific ruts. We need radical reforms that echo the change from steam train to air travel, from telegraph to e-mail. Just like the TAC system, this radical change has to be a creative and collective effort – in this case between families, practitioners, senior managers, training bodies, academics, professional associations and government departments. We must move from thinking about multiples to thinking about wholes – whole children, whole conditions, whole intervention systems. Then we will be ready for the 21<sup>st</sup> century.

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