

The Eye of the Sea: A Response to the Article, TAC for the 21st Century: A Unifying Theory about Children who have Multifaceted Disabilities

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Pamela Bartram was a music therapist before becoming a child and adolescent psychotherapist and adult psychotherapist. She is a clinician and CAMHS manager in a multi-agency service for disabled children and also has a private practice. Working in the psychoanalytic tradition, she has a particular interest in the

non-verbal aspects of human communication, the emotional bonds between parent and child and early infantile experience. Her publications include *Understanding Your Young Child with Special Needs*, published by Jessica Kingsley in 2007.

Summary

This piece is a response to Peter Limbrick's writing about the need for a co-ordinated approach to young disabled children and their families. While agreeing with the need for a TAC (Team Around the Child) approach, it argues that our fragmented activity in relation to families serves a psychic purpose; therefore it cannot simply be given up by an act of will. We may struggle to stay emotionally in touch with children and families who experience and engender in us intense feelings. Inasmuch as we can remain open to these, we will be more effective clinicians. For this, we, like parents and children, need a particular kind of insight and support which the author describes as psychotherapeutic in nature.

We are like boats dashing together; our eyes are darkened, yet we are in clear water.

In the April 2009 issue of this journal and in the ninth of nine essays in his recent publication, *TAC for the 21st Century*, Peter Limbrick argues persuasively for the revision of our approach to children with 'multifaceted disabilities'. He stresses the need for a systemic and holistic approach by the Team Around the Child, a team, he suggests, which should include the mother. This TAC approach should replace a collection of individual professionals who each deal with one aspect of the child's difficulties, a situation likely to give rise to un-integrated care plans and potentially conflicting advice to parents and carers.

Whilst acknowledging the need for professionals to maintain high levels of expertise, as well as citing the danger of training a breed of workers who are jacks of all trades but masters of none, he argues for a sea-change in how we work with these young children and their families. Workers may move in and out of involvement sometimes with a higher, at other times a lower profile in the child's overall treatment plan. Although Peter cites economic considerations which impact on health services as more babies survive prematurity and its vicissitudes, I do not think he is primarily motivated by these but rather by a wish to bring a coherent and integrated experience to children and families. He has a clear picture of what can go wrong. Equally clearly he presents a vision of how things could and should be otherwise.

At Peter's request, and following exchanges during his valuable training sessions for the service I work in, what follows is a response to some of these ideas. This response grows out of my work first as a music therapist and later as a psychoanalytic psychotherapist within a health service for young children many of whom have severe and complex or 'multifaceted' disabilities. My intention is not to critique but to supplement Peter's account of how things are by

drawing on an understanding of the unconscious forces at work when we come into contact with children whose bodies and minds are irreparably damaged by disabling conditions.

As psychoanalytic practice and theory show, when anxiety and psychic pain assail us, we must, for purposes of psychic survival, manage and defend ourselves by whatever manoeuvres we have at our disposal. There are various ways we can do this: a deep depression may serve to numb the threat of acute mental pain; cutting off our knowledge of a situation by denying it may spare us an awareness of something we fear is unbearable; repeated attempts to order the world around us may give us hope that meaning and sense can be found in apparent chaos and irrationality. Such defences, when employed to an optimum degree, are an ordinary part of how we function, as individuals, groups and societies. However, should our defences become too pervasive, too rigid, too powerful, their helpful effect may be mitigated if we become cut off from the taste and touch of experience.

For example, the person for whom order assumes more importance than experience – the books on the shelf must be stored alphabetically but are never opened, read and allowed to impact on him – may preserve a tenuous sense of security, but at a great cost to the experiencing self.

I have observed the way in which new children referred to services often seem to evoke this kind of enthusiasm and an ‘all hands to the pump’ initial response. Yet a few months down the line it turns out that it was impossible to sustain this level of energy, perhaps quite appropriately so.

It is my observation that two main defensive manoeuvres come into play in the context of team work with young children who have complex disabilities. This is a predicament where intense feelings, particularly in the early months and years of the child's life are to the fore both for the family and also for the professionals who allow themselves to be emotionally in touch with them.

The first is the manic defence, which propels us into action proposed to be remedial but which is also aimed at ridding ourselves of the fear that there is little we can do to make a difference; or action proposed to be fact-finding but unconsciously aimed at ridding ourselves of the fear that there is much we do not and cannot know. Peter talks about professionals who launch themselves into therapeutic activity not mindful of the role of those around them or the impact of their demands on the family. I have observed the way in which new children referred to services often seem to evoke this kind of enthusiasm and an ‘all hands to the pump’ initial response. Yet a

few months down the line it turns out that it was impossible to sustain this level of energy, perhaps quite appropriately so. A sort of team depression or dissolution may set in, yet with the next referral of a new child the cycle begins again. In my experience some families actively, though not intentionally, promote and seek a manic response to their young child's difficulties as well as elicit it in the professionals: more is better; every waking hour should have a therapeutic goal. This course of action can be a way of temporarily avoiding deeper feelings of guilt and helplessness.

When Peter writes about therapeutic goals being woven into the daily life of the child rather than imposed as tasks over and on top of daily life, he clearly wishes to spare both child and family the experience of endless therapeutic tasks. However, it may be that a danger of this recommendation is that *everything* becomes a task. Family mealtimes become exercises in posture, feeding and communication rather than a time to relax and commune with one another person to person, not person to disability. When activity is fuelled by the manic defence it is impossible for a playful and creative state of mind to prevail in the parents, the professional or the child.

A second common defensive manoeuvre is that of fragmentation, an effective way of ensuring that we do not have to look at the whole picture, the totality of which may bewilder, frighten or otherwise threaten to overwhelm us. As a child I was told the story of three blind men who were each asked to describe the shape of an elephant. The man who took hold of the ear said it was like a fan. The man who took hold of the trunk said it was like a water spout... And so on. No-one had the whole picture. In his commentary on this story Rumi, the 13th century Persian poet and Sufi teacher says,

‘The eye of the Sea is one thing and the foam another. Day and night foam-flecks are flung from the sea: of amazing! [sic] Let the foam go, and gaze with the eye of the Sea... You behold the foam but not the Sea. We are like boats dashing together; our eyes are darkened, yet we are in clear water.’

(* See reference at the end of the article)

In the case of our work with young disabled children, I believe there is an unconscious resistance to looking at the child as a whole, and so we split him into manageable pieces: fine motor skills; cognitive ability; speech and language. Indeed when we are able to think of the child as a person rather than a collection of areas of strength and difficulty, we are challenged, led from the relative safety of our professional identity into the uncharted waters (uncharted unless by religion and philosophy) of the meaning and value of human life.

My view is that if we work the way we do and organise ourselves the way we do, this is not by chance but because it serves a psychic purpose, whether for the individual, or collectively, for the group. And if we are to give up these ways of working and work differently, as Peter suggests, then we and the families we work with will need more than an injunction to do so. We will need a particular kind of help and support. I suggest that support would be psychotherapeutic in nature, not of course in the narrow sense that everyone involved should 'have psychotherapy' but in the sense that we will need something that strengthens the psyche, the mind or soul so that it can endure how things are, without pessimism or unrealistic aims.

In my experience parents who have been able to find and use emotional support (whether within the couple's relationship, from family, friends or professionals during the traumatic early weeks, months and years of their child's life) do better at maintaining a realistic and yet creative stance towards their child; not towards their child's needs or disability or areas of difficulty, but towards their child as a person. This brings a qualitative shift to family life. Similarly, professionals who do not feel they have to maintain an 'expert', 'have all the answers' stance, may find themselves in a good position to identify with the child's predicament and that of his parents as they care for him. Empathy, the capacity to imagine another person's experience, is essential in all our therapeutic endeavours. For professionals to remain in touch with children and families, they too need support. This includes having the time and space to notice what they are feeling and the opportunity to talk freely about their endeavours, sharing their worries (without feeling judged) as well as their hopes and successes.

Peter talks about parents and children struggling to form a secure attachment while bombarded by many individual therapists each with their own programme. The professional network may mirror the difficulties inherent in a family situation rather than remedy them – as the family situation also may mirror the functioning or dysfunction of the professional network. Peter is right to home in on the idea of attachment as of central importance. In normally developing children the task of the early weeks and months is the formation of a secure and loving personal bond between parent and baby. Where there is a disabled baby, this natural process is more difficult. Yet professionals do not always help parents to see that their relationship with their baby is of central importance; and sadly, parents may, in the face of the many challenges they face, also lose sight of this fact. After all this was not the hoped-for child. This child may be hard to communicate with, difficult to read at times, unresponsive. Could it be the case that lack of secure attachment between parent and child is an anxiety-provoking situation for us as professionals? What do we do in the face of it? Perhaps

faced with these difficult realities professionals focus on programmes, treatment and advice for this skill or that skill, but may not stop to ask, 'What is the most important thing for this parent and this child?' For parents it is often the sense of their child's isolation, the difficulty in reaching them, the worry that they have no secure place in society, which is most distressing.

Child and family are not objects on whom we act, sometimes in a better way, sometimes worse. Parents and children are the people, always hurt, often traumatised, with whom we must form a relationship.

Whatever the lead professional might do practically for a family, a central aspect of her significance for them is as an attachment figure. She is a reliable and available person who does not set out to tell the family what they need but asks them, listens and helps them to speak out. If the family has this sort of support they are more likely to be able to provide it for their own child.

Everyone knows the phrase and its implication, 'Does he take sugar?' It captures the way that the disabled person can become an object for others rather than a subject with whom we share inter-subjectivity. While I agree with Peter that the model of lead professional and TAC potentially offers a better way of delivering services, we must be even more radical. Child and family are not objects on whom we act, sometimes in a better way, sometimes worse. Parents and children are the people, always hurt, often traumatised, with whom we must form a relationship. It is perhaps not fashionable to talk about families' contribution to professionals' lives although I, like my colleague Valerie Sinason**, believe that children and families living with disability and the intense feelings aroused by our contact with them, deepen our understanding of what it is to be human. These feelings are not only the 'negative' ones. Sometimes we stand in awe, watching families love and care for their child, whatever his impairments, whatever their hurt, disappointment and exhaustion.

Inasmuch as we can open ourselves to all this, we will develop therapy programmes which are truly therapeutic.

* Mawlana Jalal ad-Din Muhammed Balkhi (Rumi) *The Elephant in the Dark, from tales from Masnavi*, Wikipedia.

** Sinason, Valerie 1992 *Mental Handicap and the Human Condition*. Free Association Books, London