



Confessions of a Clinician . . .

By Stella Acquarone

I never think of myself as a writer, really. Even though there are always books and chapters and articles and case notes flying about. For me, writing is a part of a process. Take this book, for example, "Surviving the Early Years: The Importance of Early Intervention with Babies at Risk". The title was important...a way of referencing the baby, the parents and the professional. At the same time, I wanted to express an important dynamic...the unplanned emotional-level plunge into simple survival that having a special-needs child can bring about OR – from the child's point of view – having parents who aren't coping well. Because I'm really a clinician at heart, I didn't want to write another feel-good/self-help book about early parenthood reverie. The book that needed to be written, I thought, was about the grim reality of genetics, family history, chance and circumstance.

I'll have to admit that getting such a counterintuitive book published was not straightforward. The book emerged as the product of a process...getting the big wheels to turn which turn the smaller wheels. First, I accept invitations to speak at workshops and conferences all over the world so that I can reflect on my own clinical cases and organise a presentation about what works. Next, I organise a conference so I can invite world-class speakers to find out what they do that works in their practice. The speakers refine their presentations by becoming authors of the chapters. Then the process starts to turn these presentations-made-into-chapters into a book. One of the important cogs in the process is finding the right metaphor. In "Surviving the Early Years", I thought of Coleridge's Ancient Mariner who detains a young man going to a wedding and demoralizes him with a dreadful retelling of a ship set out "into a sunny and cheerful sea" which eventually gets hemmed inside a maze of mast-high ice. The metaphor is an apt

frame for the book...surviving the early years can be grim but survivable. What is necessary is hope...ancient mariners, parents and special-needs babies alike search the horizons for hope in any form.

I suppose that any book – not just its title, process and frame – is just a container holding the writer's true questions: What is the inner world of the special needs child like? What is it like to be the parents of the special needs child? Given the constraints and everything we know of genetics, family history, chance and circumstance, what can we do that leads to better outcomes?

It is terribly painful for parents to admit their love when they have produced a deformed child, or a child with severe, possibly life-threatening difficulties. But it is that very possibility for love and good attachment that will make life worthwhile and fuller for the family and the professionals who work with them. The problem for the professional is how to contain the parents

without themselves adopting the same devastating defensive mechanisms they employ, leaving the child with a double deficiency: the syndrome, and an outside world that has difficulty accepting them.

If you were to point out that accumulated trauma is the common factor underneath all of the cases we present, you would be right. Apart from the primary disability of the special-needs child, if the parents don't share and digest their feelings of disappointment and sometimes guilt, then it becomes an unnecessary extra burden that can create a secondary disability.

Certainly, from a clinical point of view, you can see how challenging and interesting the work is!

Now that I've confessed that I'm really a clinician who writes, I should also confess that the urge to get this book written is partly biographical.

I identify with special-needs. Arriving in this country as a young professional, speaking a different language, produced a certain ambivalence in me. Lack of knowledge of the cultural ground rules, looked down on as foreign, not being understood properly, and appearing mentally slow because of difficulties in following conversations produced a feeling of being disabled. On the positive side, the parallel thinking I developed led to a better understanding of autism and special-needs infants. How much more difficult it must be for a fragile or special-care or special-needs child, who has to face the parents' failed expectations and is misunderstood, mistreated, and undervalued. I explored the possibility of becoming a last resource, when all other professionals had given up or could not work with a family, to try to find the unique challenges facing the infant and the family.

Being born premature. So many premature babies are later brought to the clinic with severe mental and emotional disturbances. The disturbances that they presented, such as autism, was a secondary disability born out of the distress of the trauma for survival at 24 weeks.

A personal friend. In the late 1960s a friend of mine had five children and the fifth was Downs syndrome. In spite of the first three years of cardiac difficulties, her Downs -syndrome child was treated no different than the other children. All of the social circles the mother was in were saying, "Poor mother, she was deluded". But at the end of the year, her special-needs child was normal. My friend insisted on treating her child normally...eventually she was driving a car and attending university. At the time that was inconceivable. For me, that was a good lesson.

Spurred on by personal experience, my interest in early interventions has become my specialty. Early interventions are necessary when the destructive emotional factors underlying family dynamics interfere with relationships and development. As clinicians, we all know how destructive emotions can smother constructive development. So, unless we deal with the underlying emotional dynamics, special-needs babies can't reach their cognitive potential...and might even die. One of the strengths of this hypothesis is that it recognises secondary disability, that whatever a child's specific difficulty may be, the parent's sorrow, anger and guilt can be just as damaging to a healthy relationship as the disability itself.

The plasticity of the brain is amazing. And so is the power of the early intervention. Together, they have the power to change outcomes and destinies.

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