

Blue Sky July

by Nia Wyn

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Author royalties will go to the Joe Alexander Trust

Review of *Blue Sky July*: “...not a book that I would recommend to parents of children with disabilities and special needs”

By Peter Limbrick

The Publishers, Seren, suggest that every parent should read this book. It is not a book that I would recommend to parents of children with disabilities and special needs and I would want to issue a very serious ‘health warning’ for those parents who do get hold of it. Nia Wyn’s story begins when her baby son Joe is diagnosed as blind with severe cerebral palsy and ends when, at seven years, he enters mainstream school as a seeing, walking and talking child. Disability is either ‘an overwhelming tragedy, a life to be lived in suffering and frustration, or – where nothing else can be blamed – it’s sinful’. There is much talk of miracles. 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. It is tempting, using well established metaphors, to suggest that parents quickly get lost in a maze or a jungle, but the prevailing image for me in this book is a circus. A circus with clowns, acrobats, trapeze artists, fortune-tellers, snake oil, whiz-bangs, smoke and funny mirrors – and cash tills. It seems the only treatment/therapy that Joe did not get in his early life was trampolining and face-painting.

Why do we do this to families? Why is society content to welcome disabled babies into the world with this sort of farce? Why do we think this is a good start for a life of extreme challenge and limited opportunity? The story is set in Cardiff but it could have happened in any part of the UK, and still could. There are just as many parents and professionals in Cardiff trying hard to make early intervention more effective as there are in other cities, and battling against the odds just as everyone has to.

We have entered the 21st century without a science of early intervention for children with disabilities and special needs. We have a science for every human endeavour; food production, building, heat and light, space travel and warfare, but we do not have a science to help families like Joe’s. Hence the clowns, the snake oil and the cash tills. 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. We are desperate for a national initiative in this field and the proposed Centre for Early Childhood Intervention would be the perfect place to plant the first seeds of a developing science.

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.’

The book is beautifully written by a skilled writer/journalist and nothing can detract from Joe's mother's love, commitment, enterprise and energy. My heart goes out to the family. Why would I not recommend it to parents of new disabled babies and young children? For two reasons; the book reinforces the message that parents should sacrifice all to offer their infant *every* treatment and therapy available (without guidance about what is worth having and what is not), and it challenges every parent (usually the mother) to strive every minute of the day and every day of the year to produce a cure for the child's disabilities.

Joe's next venture is to swim with dolphins. This will be well-deserved holiday for Joe and his mother but while they are away there will be some mothers of disabled children and teenagers lying awake in the small hours feeling guilty and depressed because they did not work hard enough to help their child develop in the early years.