

# EXTRAORDINARY people

Durban photographer Angela Buckland has published a book about special-needs children in collaboration with a social scientist.

**PETER MACHEN**

chats to her about this fascinating product.

**Z**ip *Zip My Brain Harts* is the title of an unusual book about the experience of raising children with special needs.

It is unusual in that it is the joint work of art photographer Angela Buckland, two psychologists, Leslie Swartz and Amelia van der Merwe and an anthropologist, Kathleen McDougall. It is unusual also in that it is essentially (although by no means typically) a medical text that explores its subject using Buckland's images as both a starting point and central reference.

The images in the book are culled mostly from Buckland's exhibition of the same name which was shown at the KZNSA Gallery (then the NSA Gallery) three years ago, on the strength of which she was nominated for the 2003 DaimlerChrysler award for creative photography. Like that exhibi-

tion, the book doesn't focus on specific conditions, but instead tries to get close to the emotional truth and visceral experience of living with children who don't fit to the bell curve of normality.

The book is broken into several sections. There is the "Dysmorphic Series" in which Buckland double-exposes images of her son Nikki (whose set of conditions remains undiagnosed to date) with X-rays of his different abnormal features. In one of these dysmorphic expressions Nikki appears to be sleeping inside his own skull, at once both haunted and peaceful.

In another, he appears to be crawling away from his own physical body.

Then there is the "Stickytape Juice Collection", a set of stylised images of clothes that have been altered by loving

parents or relatives to fit unusual bodies or bodily habits.

Buckland sees the images as "extraordinary" acts of love, and despite the practical nature of their construction, their existence recognises that the experience of disability is not only about the disability itself but about others' perceptions of it.

At the heart of the book is "Where's

Nikki?", which explores the experience of seven South African families who have a disabled or special-needs child (the book mostly used the term "disabled", although not without due consideration and discussion). There is no common illness or syndrome among these children, a fact that is evident from the text, even though its authors intentionally avoid specificity. What is common is the fact that they are different to people who have all their

physical and mental faculties intact; they are different to "normal" people.

One of the book's many currents

explores the concept of normality, expanding, if you like, the horizon of normalcy and suggesting that an entirely inclusive world,



while it might be a superhuman challenge, is not an impossible dream. Although we all like to consider ourselves "normal", the fiction of the perfectly normal family is exactly that — a fiction — and there are areas in all our lives in which we do not fit snugly into that fiction; a fiction that is broadcast with the most enthusiasm not by our friends or neighbours but the world of advertising and media. Buckland is only too aware that her life is nothing like a detergent ad or a Woolworths commercial. But then whose life is? The book's writers ask for recognition of that fact, suggesting that by acknowledging our own hidden idiosyncrasies and differences, we might more easily accept those who are more visibly different to us.

But lying underneath this cautious discussion is something else that is central to the book, even if it is seldom articulated. And that is the immense love of these parents for their children, despite the fact that their situations are desperately trying at times. And this love is perhaps the common thread that any parent of any child will be

able to weave in to their own experience of the book.

For while these specific parents face particularly trying conditions, the love expressed in the pages of *Zip Zip*'s pages is a universal experience. All parents want their child to be "normal", to fit in, to have the requisite number of fingers and toes.

All parents are aware that, in the words of my own mother, "life is hard enough if you're normal". And every parent notes the subtle or not-so-subtle differences between their own child and all the other children in the world.

To use Buckland's disarmingly frank phrase, which appears several times in the book, "every parent's secret dread is having a 'dodgy' child". In our interview she talks about Ireland where, apparently, "you get all these 'dodgy' adults and they have places in society. They're visible — they might pack in the supermarkets or something — but they're visible!"

It is this invisibility that haunts the par-

ents of disabled children, the lack of acknowledgement of the very existence of their progeny.

One parent talks about how

the birth of a disabled child is heralded in a very different way to a child that is born complete with

all its faculties. The gift and congratulations that usually accompany birth are conspicuous by the

absence, a fact that only serves to accentuate the sense of aloneness or abandonment.

ment experienced by such parents.

The title of the book *Zip Zip My Brain Harts* are the words of Luke Osborn, who suffers from cerebral palsy, and while this phrase indicates something of Osborn's condition, it also indicates a child with a love of words. And he does amazing things with these words precisely because his own linguistic parame-

ters are so different.

Osborn's words are a repeated mechanism in both the book and the exhibition and they are remarkable in their ability to draw the reader into the various discussions of disability. And, in their twisted lyricism, resides also the notion of the special or unusual gifts of a disabled child.

This notion of the "special" child as a gift — usually from God — is not necessarily a notion that goes down well with the parents. Some of them recall with silent horror being given a poem entitled *Heaven's Special Child*, having their experience reduced by cliché while dealing with

one of the greatest confrontations of their lives. At the same time, another parent felt that she was "meant" to have the child that she had, that his disabilities are as much a part of her destiny as they are of his own.

About the book's beautifully restrained design, Buckland was adamant that there would be no negotiation. Garth Walker was the only possible option. And Buckland's insistence has paid off. Walker's gently unobtrusive layout resonates perfectly with the text, its occasional typographic idiosyncrasy a gentle nod to its content.

But despite the graphic design skill of Walker, the experience and knowledge of the three writers, and Buckland's remarkable photographic skills, the book was still something of a risk for all parties — an experiment in different modes of working, while at the same time trying to convey the fluid and ambiguously defined experiences of raising disabled children.

Of course, no book can ever have the emotional weight of a child, no book can ever have a pulse (although the best of them seem to do so). And that is *Zip Zip*'s secret dread, that the experiences and discussions it contains will be mis-

taken for experience, for gospel truth, for life itself.

For all the pressure, stress and challenges that the book's creators experienced — particularly its photographer, who although at the centre of the book, was necessarily edged away from the centre during

its production — the book, complete with its text and recontextualised images, has a very similar impact on this me as Buckland's exhibition did three years ago. I am left with a sense of my subconscious filling in the missing pieces, trying to solve the mystery of these lives that are

suggested in the visuals. The similarity of my response indicates to me that the book has treated both its very difficult subject matter and its central artist with respect.

It will be both a pity and a surprise if this *Zip Zip*

*My Brain Harts*, aimed at health professionals, the parents of disabled children and those who buy art books, doesn't transcend those three tiers and attract a wider public. Unique both as an art book and as a medical publica-

tion, the restraint, care and love involved in producing it have paid tremendous dividends. While I imagine that it will be an enormously useful resource for those directly involved in caring for disabled children, it speaks to us all.

Albie Sachs, who spoke at the Johannesburg launch of *Zip Zip My Brain Harts* (he also wrote the book's introduction), and who is himself differently abled — "a member of the democracy of the disabled" as he puts it — recognised the importance of

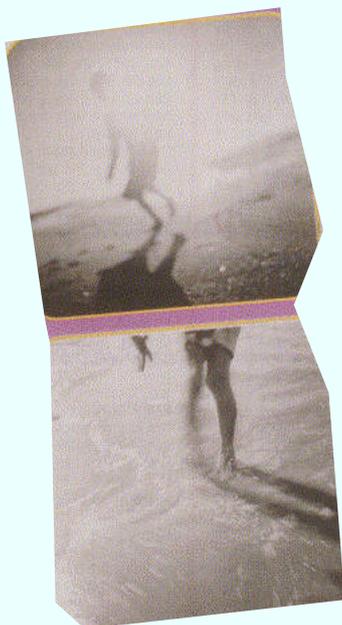
the book when he said that it reflects the South African imagination, the evolution of our culture and our willingness to explore.

The final section of the book, entitled "Shadow Catching", shows Nikki

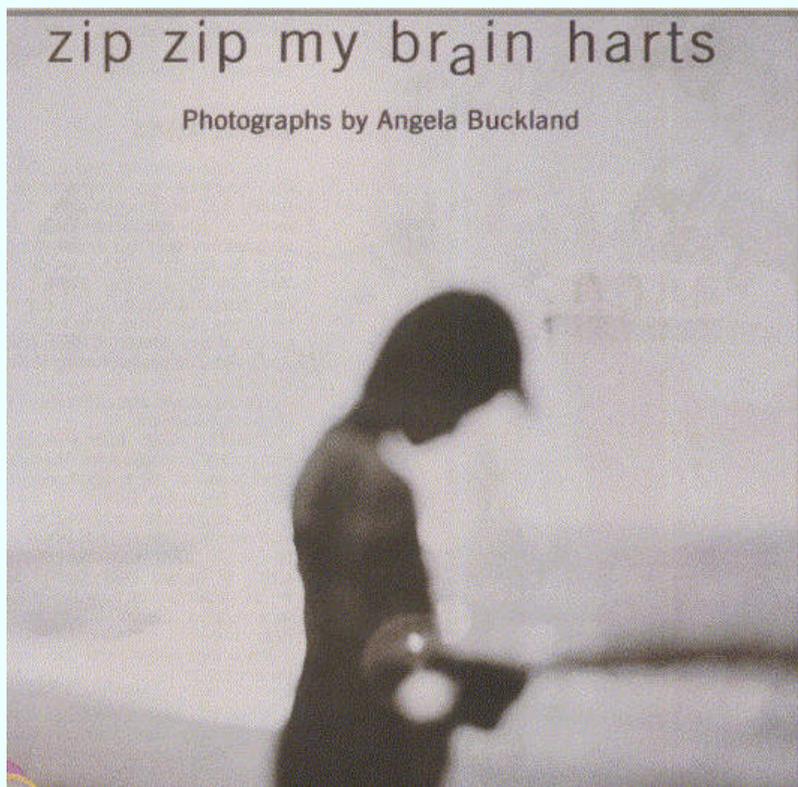
behaving like any ordinary child, playing with his shadow-twin. Except that we know by now that he is extraordinary. And these images, which seem full of pure joy while maintaining a sense of ambiguity, are perfectly resonant final pages for a sub-

ject which is so very far away from anything approaching a conclusion.

• You can find *Zip Zip My Brain Harts* at *Exclusive Books*, *Adams*, *Kalahari.com*, *HSRC Press*. It is also available as a free download.



Two images entitled  
'Shadow Catching'



ABOVE: Images from  
*Zip Zip My Brain Harts*.



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