

# Disabled children and their parents made visible

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ANGELA BUCKLAND speaks with the experience of an insider. As the mother of nine-year-old Nikki, she has been through the heart-wrenching process of discovering that her son is disabled. "Initially, I never realised there was a problem. I thought maybe Nikki was a bit fussy. I remember this terrible silence when I took him to a doctor and she said I should see a specialist immediately – my child was not okay," Angela recounts.

What has further complicated things is that although Nikki has undergone countless evaluations and tests since his birth, he remains undiagnosed. His disability does not have a name. But even if it did, it would not change the way Nikki moves through the world.

What Nikki's impairment has changed, though, is the way Angela moves through the world. He has turned Angela's attention to the way disabled people are understood and represented in society. And he has led her to explore that which, all too often, is hidden away or left unspoken.

As a professional photographer, Angela has been investigating this space from a visual point of view, with reference to her son and to a larger community of disabled children and their families. The result is an acclaimed solo exhibition (which opens in Cape Town on Friday), and the release of a remarkable book, *Zip Zip My Brain Harts* (HSRC Press).

Angela describes the exhibition and the book as "public expressions of the complex and private experience of being the parent of a disabled child in South Africa".

However, *Zip Zip My Brain Harts* (the title is taken from the biographical writings of an 11-year-old cere-

bral palsied child, Luke Osborne) is not just a collection of groundbreaking photographs. It is the result of a collaboration between Angela and three researchers focused on disability issues, who supply dynamic text between the photo essays.

As such, the publication makes a unique contribution to the ongoing dialogue and debate surrounding disability in South Africa.

Contributors Stellenbosch psychology professor Leslie Swartz, research psychologist Amelia van der Merwe and anthropologist Kathleen McDougall say that when they were approached by Angela to work with her, they were "very excited at the opportunity to break free from the usual boundaries of research".

The quality and emotional impact of Buckland's work gave them a chance to try something different and new, they said.

And that's exactly what the book is. While Angela's arresting photographs ambush from a visual perspective, the accompanying text challenges preconceived and discriminatory attitudes found in our society.

Moving from the stereotyped manner in which disabled people have historically been presented – as freaks or medical curiosities – here the viewer feels a part of the image. These are pictures that stress an interconnectedness, away from the "us" and "them" approach of much documentary photography. The text supports this vision.

"Disability is everywhere – every person has some connection to disability. Yet disability is so hidden from society that it sometimes seems it is nowhere. And stereotyped images perpetuate a view that disability is about some people only, not about the able-bodied 'us', but the disabled 'them'," say the authors.

When I meet Leslie Swartz and Angela Buckland to talk about the book, I find that this philosophy – the idea that disability is everybody's issue – is one that is central not only to *Zip Zip My Brain Harts*, but to the disability movement and to disability studies in South Africa. It represents a fundamental shift in the way a society can choose to function.

Leslie explains: "Essentially, people are not disabled. It is the relationship between people and the environment that can create or remove disability." An example would be a situation where somebody in a wheelchair needs to enter a certain building. If that building has wheelchair access, there is no problem. But if it doesn't, then the building has essentially disabled the person in the wheelchair.

Disability, in this sense, can extend to all aspects of the environment – physical space (such as buildings), social space (within one's community, workplace or family), or around aspects of service delivery (the health profession and social services). Poverty, gender and race are also factors.

While South Africa has one of the most progressive constitutions in the world as far as disability rights are concerned, it remains a fact that stigma, alongside physical and practical barriers, still remains. For many, an instinctive reaction when seeing a disabled person is to look away.

"One of the reasons I did these series of photographs is that I found that nobody was talking about what it is like to parent a disabled child," says Angela. She speaks of the "idyllic notions of childhood promised by Pampers nappies and Woolworths advertising which are disrupted by the disclosure of disability".

"There is a certain amount of



stereotyping to produce the 'perfect healthy baby'," says Angela. "When this doesn't happen, it's almost as though people are embarrassed, or think it is somehow your fault. They often treat the child as though he or she were invisible."

One mother, quoted in *Zip Zip*, says "when (my baby) was born and people heard there was something wrong, all the congratulations disappeared. It's like I didn't have a baby."

Disclosure – the discovery that one has a "dodgy child" – can cause a strain on partners' relationships. And, as one parent reports, there is also pressure to "keep a stiff upper lip", as though one is not allowed to show one is depressed, or upset, or just plain worn out from dealing with a special-needs child.

Disclosure is also traumatic from a medical point of view, as it places a particular burden on health professionals.

"It's hard for doctors and specialists," says Leslie. "They're supposed to be the people who fix things. But sometimes they can't. It must be the most difficult thing in the world, to look at a parent and have to say: 'I think there is something wrong with your child.'"

With *Zip Zip* Angela and Leslie

(and the research team) hope to stimulate further debate and discussion around disability issues.

It is part of the drive behind organisations such as Disabled People South Africa (DPSA) that disability be seen as everybody's issue. In this respect, the struggle for the rights of disabled people parallels the anti-apartheid struggle in terms of the common goal of equality.

Unfortunately, discrimination still exists. Angela speaks of a recent occasion when she arranged for Nikki and his sister, Christine, to fly to Mpumalanga.

"I made all the necessary arrangements for two children flying unaccompanied by an adult. And I made it very clear that Nikki was disabled beforehand," she says. "However, when I brought them to the airport, the flight attendant took one look at Nikki and disappeared. Eventually the airport manager told me 'The pilot won't take your autistic child.'"

She gives a small smile. "It is very hard not to get too emotional in a situation like that."

This sort of social oppression is very much a reality in South Africa. However, while *Zip Zip My Brain Harts* does not shy away from the

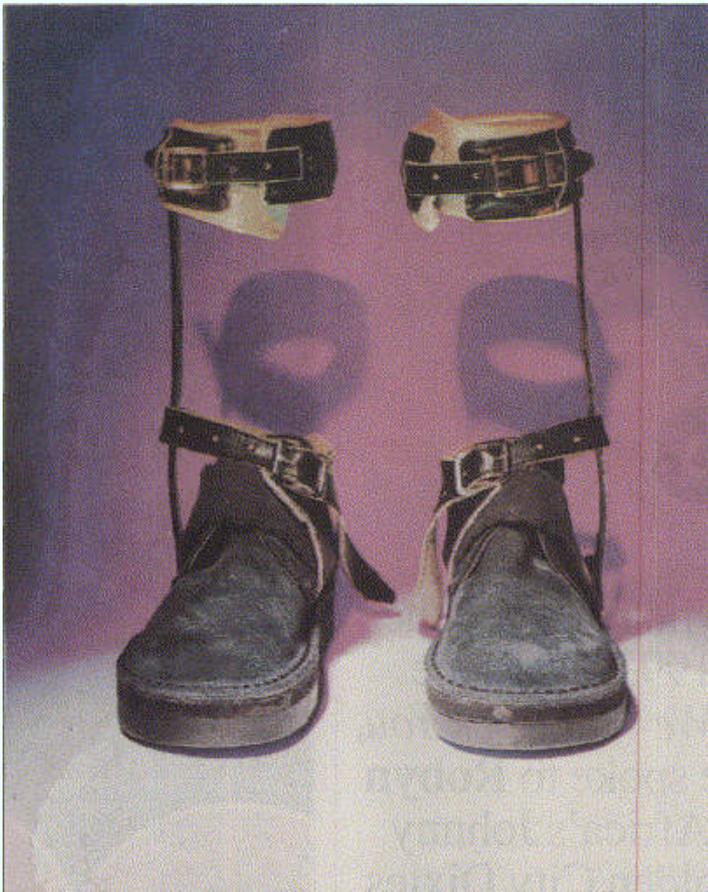
painful aspects associated with disability, it is very much a celebration of life – in all its messy, beautiful, difficult and joyous moments. Ultimately, it is a statement about how similar people are.

While disability and parenting disability need to be recognised and made visible, the book is not talking about an intrinsically different experience of life. As the photographs and text show, we are all, ultimately interconnected. Which makes a commitment to creating an enabled environment everybody's business.

In his introduction to the book, Justice Albie Sachs (himself a disabled person) describes *Zip Zip My Brain Harts* as "a most remarkable piece of visualised literature". He is quite right.

● The exhibition *Zip Zip My Brain Harts* will open at the Michaelis Gallery, UCT Hiddingh Campus, Orange Street, Gardens, on Friday and run until August 9.

● The HSRC will launch *Zip Zip My Brain Harts and Disability and Social Change: A South African Agenda*, edited by Brian Watermeyer, Leslie Swartz, Theresa Lorenzo, Marguerite Schneider and Mark Priestley, on Saturday at the Michaelis School of Fine Art, UCT.



**LOVING SUBTERFUGE:** Callipers are attached to ordinary shoes.



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**TELLING TALES:** Exploring the fragile experience around disability.