

Every parent's dread

There is a large amount of stigma, ignorance and prejudice associated with disability,

writes KERRY CULLINAN

“EVERY parent's secret dread is a ‘dodgy’ child,” says photographer Angie Buckland.

With the birth of her disabled son, Nikki, Buckland has used her professional photographic skills to explore and bring out into the open this “secret dread”.

She describes Nikki as “an undiagnosed child with special needs”. Nikki has been subjected to “endless medical investigation” — Cat scans, MRI scans, X-rays and other tests. Yet no medical professional has been able to identify and name his condition.

Buckland has produced three sets of photographs about Nikki and five other disabled children.

These form the basis of a collaborative book on disability between Buckland and three researchers interested in disability — anthropologist Kathleen McDougall, Stellenbosch Psychology professor Leslie Swartz and psychologist Amelia van der Merwe.

Zip Zip My Brain Harts provides a window into families with disabled children — a largely silent and stigmatised world.

As Judge Albie Sachs writes in the foreword: “Don’t expect a book about disability to be easy. The whole point about disability, whether visible or invisible, physical or mental, is that nothing fits.”

Buckland’s “stickytape juice collection” series involves photographs of disabled children’s clothing that have been altered to try to make them “fit in” better by masking the child’s difference.

Nikki used to dribble a lot, considered inappropriate for his age, so his grandmother sewed him bright T-shirts with disguised bibs sewn into them.

Buttons on other clothes have been replaced by Velcro for a child who can only use one hand. A pair of Woolworths

shoes have been attached to calipers in an attempt to make them more look more ordinary.

“The challenges that face families of people with disability are also often hidden away,” say McDougall, Swartz and Van der Merwe.

FACTS.

“Part of the reason for this secrecy may be that disability is sometimes seen as a shame or a disgrace, something to hide away, a source of stigma.

“These reactions are rooted in the idea that disability is freakish or monstrous, an idea that continues to haunt the ways in which disability is seen, and to affect the experiences of disabled people and their families.”

Buckland speaks about how disability disrupts the notion of “idyllic childhood” promoted by advertisers while the researchers describe the “loss of the ideal family”.

Many of Buckland’s photographs also disrupt the ideal. Some images are blurred, or the disabled children are captured at odd angles or only by body parts.

“In a world in which we expect perfection and in which technologies can change so much, disability can be seen as a kind of moral failure,” note the researchers.

Parenting a disabled child can have a profound impact on family relations, straining marriages and siblings. Parents speak of the exhaustion, stress, confusion and despair. There is also the blame of “it

comes from your side of the family”.

“As a family, parents and as individuals, we were subjected to endless mental, genetic, medical and emotional probings ... silent family histories were exposed, our privacy raided and some difficult exchanges took place,” says Buckland.

The six families adjust to accommodate the disabled child but then “rediscover” their disabilities through the reactions of others.

“This is about more than a lack of wheelchair access. This is about people coming up and telling you that you are a bad parent because your autistic child is running around or is making a loud noise. Parents also rediscover their child is disabled when they cannot find a school for him or her.”

The insensitivity of the medical



profession is a recurrent theme, particularly the way in which parents are told about their child's disability. One psychiatrist simply tells parents that their son is autistic and should be institutionalised, and that they need to move on with their lives and maybe have another baby.

"In this case, the doctor implies that this child is a mistake that should be hidden away. He suggests that the child be replaced with another child. He does not take into account the parents' love for their

child and that this child is not replaceable," note the researchers.

Another equally powerful theme is parents' initial hope that doctors can "fix"

their children's problems.

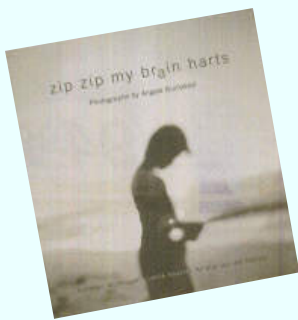
"We have been taught that medicine and science can, or should be able to, fix almost anything," say the researchers.

"At certain times in our lives, we invest a lot of authority in doctors. This belief in doctors' abilities to make it better can verge on the religious," note the researchers.

When this hope is disappointed, parents are often shattered.

But the researchers also pose the question: what do we want to fix? One of the things that needs to be "fixed", they argue, is the stigma, ignorance and prejudice associated with disability.

• *Zip Zip My Brain Harts* is available from leading bookshops and www.hsrapress.ac.za for R160.



LEFT, ABOVE AND ABOVE RIGHT: The cover and selected photographs from the book. "In a world in which we expect perfection and in which technologies can change so much, disability can be seen as a kind of moral failure."