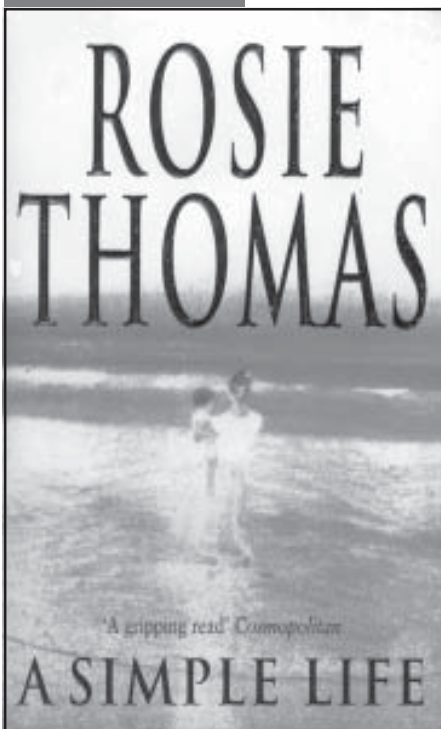
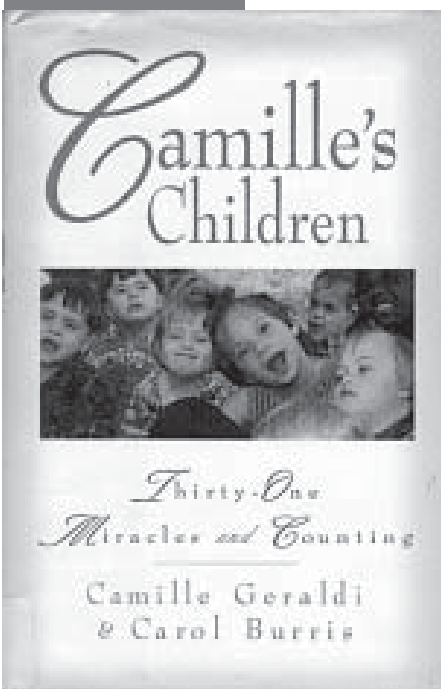


books for CHRISTMAS



published by William
Heinemann/Arrow Books.



A Simple Life is not my usual type of read and I'm not altogether sure I would have persevered with this rather bleak and laboured tale had I not been asked to review it. However, persevere I did through the main character's (Dinah) disorientation, disconnection and final disintegration.

Basically the plot revolves around Dinah and Matt who place their firstborn for adoption as she has Down syndrome - "She was handed into oblivion because she didn't match our notion of perfection". Fourteen years, two sons, a brilliant career and an affair for Matt and a change of country later, the consequences of their decision threaten their marriage, "We have some sickness between us that is never mentioned, even though the pain gnaws" and Dinah returns to England to find Sarah, her daughter.

In a rather contrived sub-plot and to

provide contrast to Dinah's own considerable angst, she befriends Milly, a troubled teenager who was adopted.

The author obviously researched the syndrome and brief mention is made of the chromosome difference ("Each of the 47 chromosome within those cells which make you what you are"), the simian crease and hypotonia. However, the author's negativity surfaces on numerous occasions - "Down's children form a small population of their own. They are different from the general population but they also differ individually"; "Her fin-hands were passively folded in front of her"; "Short clumsy fingers"; "Her cheeks plumped out and her eyelids creasing upwards. Her tongue protruded between small, uneven teeth"

I found this novel contrived with predictable, stereotypic characters who fail to engage the reader. DS

I found it immediately off-putting that the cover blurb said, "Move over Mother Teresa, here comes Camille Geraldi!" It also didn't help that through out the book children were referred to as 'Down's children'.

Although written as though through her eyes; it is written by a reporter rather than Camille herself.

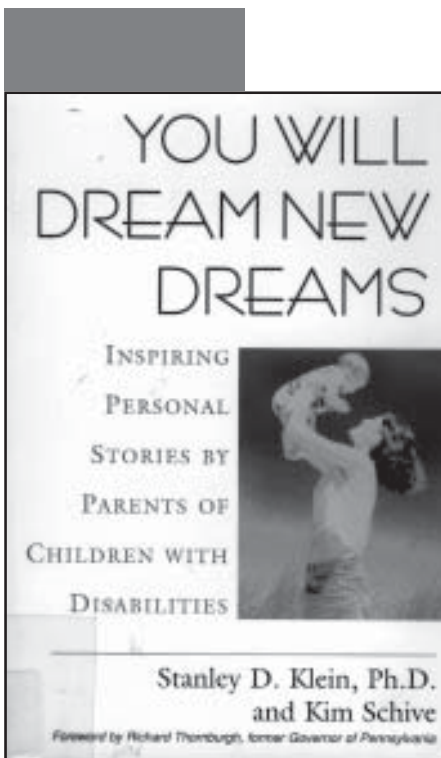
Camille and her paediatrician husband live with 31 adopted children with learning difficulties (many with Down syndrome) and 9 live-in staff. They need three houses to live in, with smacks of an institution rather than family environment to my eyes.

There are glimpses of Camille as a warm-hearted caring person able to counsel parents of newborns with DS as well as adopt their children, but mainly the book dwells on negative attitudes to DS and the

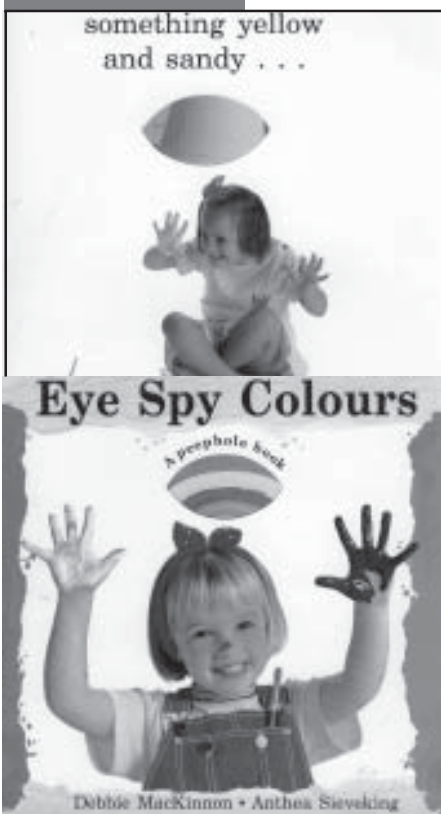
organizational management this unusual family needs.

Still it's a very different kind of book about Down syndrome which may make you see your own circumstances in a different light and help you realize what a great job you're doing by raising your child in your own small family

"I watched the staff get the children ready. The night before we had packed their backpacks. There were 11 children going to school that morning....Champ, Karley and four others were in the first group to leave. This part of the day had to run like clockwork, or we were all in trouble. I brushed Tiffany's hair. I scooped it up in a ponytail on top of her head, tied a ribbon around it and stood back to check how she looked. "You're such a pretty girl, Tiffany Geraldi. Do you know how much mummy loves you?" AH



publisher Kensington books



publisher Frances-Lincoln

This would make an ideal ‘coffee table book’, if only I led the kind of lifestyle where I had an immaculately tidy house so I could leave books on the coffee table and have relaxed time to sit and browse through them. It will work just as well as a ‘toilet book’ in a household like mine and that I guess of many families who have a child with Down syndrome. By this I mean not that it’s a poor book, but rather that it’s the kind of book that can be dipped into and read for just a few minutes at a time, suitable even for those few minutes in bed at night before you drop asleep with exhaustion.

It consists of sixty three essays (chosen from over two hundred contributions) about living with a child with a disability. Around a quarter of the stories feature children with Down syndrome but many of the others cover issues which are also of relevance to our families.

There is very little sentimentality, just painful honesty. The reality leaps off the page, and strangely their blunt truth led

me to reassurance as I found something I identified with in almost every essay.

I love getting real-life stories for the nzdsa newsletter and collected the stories for the nzdsa welcome pack. This book is like an extended, wider reaching version of the “Our Stories” booklet in the welcome pack.

Reading such stories is a humbling experience. Told without embellishment or self-pity, they show how closely joy and pain are linked and how being the parent of a child with a disability exposes people as they really are, fallible and hurting maybe, but strong and determined as they try to do the best for their child.

It is an American book, but the issues covered are trans-cultural and just as applicable in NZ.

I found the book in Auckland central library, so you may be able to borrow it rather than buy.

AH

I had been looking for a book to teach colours to my 4 year old son, Noah.

I picked up this book just because it looked like it had hard to tear pages, good clear photos and peep-through holes.

Each page is about a different colour and features a different child. When we got to the yellow page, Noah pointed to the girl and said “Lily” (his sister who has DS) and when I looked closer I realized the little girl had Down syndrome, although no special mention was made of it and she was just included as one of the children.

I was so pleased I wrote to the publishers Frances-Lincoln asking if we could feature the book in this newsletter and saying,

“We love it when we see children with Down syndrome quietly included in books without a ‘song and dance’ being made about it.

This is true inclusion and is what our parents love to see!

Please pass my thanks onto whoever chose the children for the book

Are there any other books you produce which feature children with Down syndrome?”

These are the lovely replies from the publisher and illustrator.

“I am not aware that we have any other books where Down Syndrome children are depicted, but I will mention this to the editorial and design team so that they can keep it in mind. We are building an area of the list which deals with children with certain special needs (autism, blindness) but I take your point about representing people who belong to minority groups without making a special issue out of them.”

“Glad you appreciated the quiet inclusion of a Downs syndrome child. I feel it is important and I would like to include other children with disabilities. You might note that I also include a wide range of children from a variety of ethnic backgrounds. I try and show children playing naturally in a non sexist way.

Best wishes and thank you very much for the feedback.”

It was with some trepidation that I began reading the true life story of *Choosing Naia* – a bitter sweet tale of hope momentarily lost, but found once again in love, acceptance and ultimate devotion.

Choosing Naia recounts the true story of Greg and Tierney Fairchild – a young, professional and upwardly mobile couple – more commonly known as “yuppies” – who are excitedly looking forward to the birth of their much awaited and longed-for baby. However, a routine ultrasound turns that notion on its head. All is not well with junior’s heart, as the scan frighteningly reveals. The Fairchilds are devastated by this news, only to be disturbed yet again by what the heart defect may possibly point to – a child with a chromosomal abnormality. They are then forced to undergo an agonising wait to determine if the baby they expected, and wanted, is the baby that will arrive.

Reeling from the devastating news their unborn baby girl has Down Syndrome, Greg and Tierney travel down the unenviable road of astonishment, trauma, sadness and fear, to name but a few of the seesawing emotions *Choosing Naia* so poignantly records. It is a well-written and detailed book, and its author, award-winning Journalist Mitchell Zuckoff, has attempted to sensitively recall events as they unfold. It’s almost as if Zuckoff is inside both Greg and Tierney’s minds, as he recounts their thoughts and feelings.

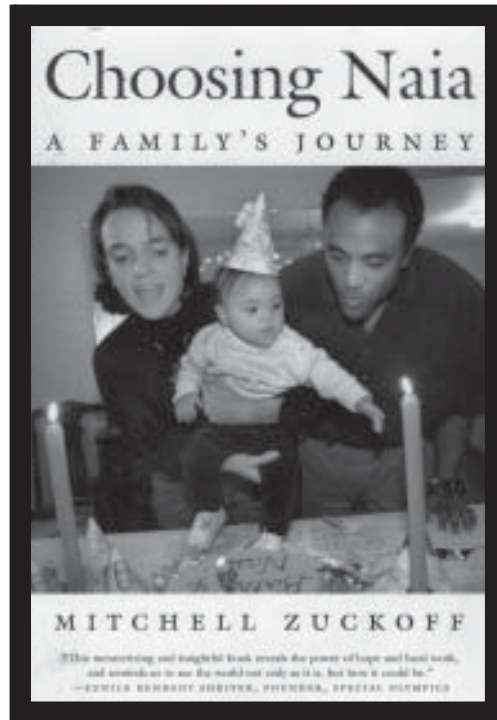
While I was reading *Choosing Naia*, I was struck by a sense of someone shaking a dice, like you’d experience during a game of Black Jack or similar, with myself as a reader waiting to learn how the dice had rolled on to the table for Greg and Tierney.

There was this powerful feeling (*mine*) that their whole lives were to be summed up in a series of odds and percentages, that things were happening purely by chance, or so it seemed. How were the odds going to stack up? What was the statistical likelihood of a 32-year-old woman conceiving a Down Syndrome baby? What were the odds that one (or both) had somehow caused this? Or was it purely a random event, as in 95% of cases?

I found I was taking a walk down Memory Lane, as *Choosing Naia* recounted Greg and Tierney’s emotional roller coaster journey into medical technology, genetic testing, family reactions and a mind racing with too many thoughts, too many future scenarios and what ifs. I found myself painfully identifying with the Fairchilds, as they talked late into the night, frantically trying to make sense of what they had been thrust into. They were forced to ask themselves some soul-searching questions concerning life and death, their ability as parents in the face of tragedy, their beliefs surrounding abortion and their perception of disabilities.

The book was especially gripping and affecting for me, as I too had experienced almost everything that Greg and Tierney were going through as they grappled with the prospect of raising a child with a disability. Even Tierney’s emotional outbursts were similar

to mine: “I’m not going to give up my hope that this isn’t going to happen to us”, she tearfully told her husband as the first lot of test results came in. Tierney struggled to stay positive: “... (she) alternated between numbness and pain. As the results sank in, Tierney knew she needed to stop hoping it wouldn’t be Down Syndrome. It wouldn’t be easy... If anybody could cope with such a challenge, Tierney had told herself, she and Greg could. But that was to keep her spirits up, before she knew for sure. ‘Now, all of a sudden, it *is* going to be us’...”

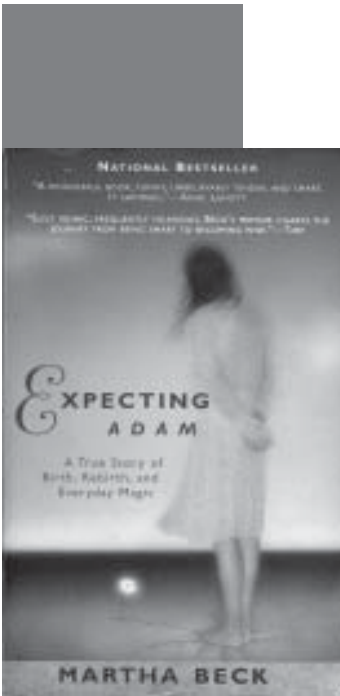


**Choosing Naia,
by Mitchell Zuckoff.
Published by Beacon Press.**

Greg and Tierney took longer to definitely decide against abortion than I had experienced. For myself and my family, the decision to choose Courtney (our DS daughter) was made from the time I was first pregnant. The fact that it was unearthed Courtney was not quite the baby we were expecting *before* she arrived, never once prompted us to believe we would terminate. Greg and Tierney were somewhat different. I am not making a moral judgement – they were just different. Being the intellectual couple they were, they seemed to need to process and digest all the facts in a slow but methodical way. Unfortunately for them, some family members made this process all the more heart wrenching. Tierney’s well meaning, but interfering brother and sister-in-law had their own agenda - ...”George began pressing the case for abortion. He said the doctors with whom he and Allison had spoken warned that the heart defect could mask other deformities and could even be devastating all by itself. It might well be irreparable, dooming the baby to a brief and horrible life. If you add mental retardation to the equation, why should you put yourselves and this child through such

an ordeal”? Reading this made me angry and fired up all over again, as I too recalled the negative comments from so-called well meaning people. Fortunately, my extended family, while understandably upset and disappointed, were supportive from the outset. It was the medical professionals who pressed the case for abortion. It’s always hard when you have a diagnosis *before* you have a baby.

Naia was welcomed into Greg and Tierney’s family, and I think it’s fair to say, she was, and is, a child who is beyond their wildest hopes and dreams. It’s obvious too, her extended family are crazy about her. Funny how things turn around. *Greg* and Tierney were particularly concerned about Naia’s possible level of ‘mental retardation’ before she was born. It was always their earnest desire Naia would be a highly functioning child with Down Syndrome. Reading through *Choosing Naia*, it becomes clear the Fairchilds – in spite of their initial fear and hesitation – have become their little girl’s greatest fan club, who will spur her on to be all she can be – and more. And yes, I believe this little girl will grow and mature into adulthood to be a person with Down Syndrome who will be a little dissimilar from most like herself, if only because her parents believed in her enough to make a *difference*. AD



Publisher Berkely Books



ISBN: 1591298822

This is one of those books that is bound to polarise people. Personally I found some elements of it quite discomfoting notwithstanding the fact I couldn't put it down. It is fluently written, often very funny and clearly sincere but so provocative in its spin on the decision to keep a foetus with Down syndrome that I suspect most people will either hate it or love it.

Overtly, this is the story of a woman's decision not to terminate a pregnancy in which she's found to be carrying a baby with Down syndrome. By so doing she is putting her work, her husband's future and their standing within their working community at risk. We learn her intellectually gifted family will also fail to understand and support her decision. And as if all this isn't difficult enough, the pregnancy itself nearly kills her. But she has the baby and her life is transformed in ways unimagined when she and her husband were still blinkered, goal orientated yuppies.

So far so good. There must surely have been something courageous about challenging the beliefs of this particular community since it is none less than the academic elite of Harvard University where she lectures and her husband is finishing his Ph.D. While there probably are academics as narrow minded and arid as some of these she describes, she draws them with such a broad stroke that the attempt to explore attitudes to disability in society dies in the frighteningly bigoted cloisters of the ivory tower these two-dimensional figures inhabit.

Instead what we're offered is the far from ordinary process by which she comes to defy her peers and face her horror of intellectual handicap. And it is here that I lost interest. It isn't just that I'm tired of the association of people with Down syndrome with angelic forces, nor that I disbelieve in psychic

Author Alan Balter writes this novel about his son Richard a young man with Down Syndrome, his best friend Penny who is Autistic, and a kind generous man Max who gives them both many opportunities. The purpose of the book is to dispose of the myths and misinformation that we as parents are so often subjected to.

Richard lives at home with his parents, but the time has come for him to venture out into the world alone. This story is about his independence, his feelings and his desire to succeed and be accepted for who he is. It explores Richard and Penny's innermost

experiences. What I found difficult was a subtext that read as an apologia for having a deficient child in the first place. It is as though in her own mind the only way to deal with such an aberration is to have a Very Special child, not just your common or garden variety. For this is no ordinary pregnancy and child.

She does a good job of letting us know that she's actually a rationalist who would normally debunk off-beam beliefs and experiences in others but by the end of the book we're in no doubt that Adam is divinely intended. She is introduced to this idea by voices, synchronicities and startling telepathic connections and, when the going gets really tough, she's supported and protected by a seraphic host who appear with irritating predicability and wearing sandals right up to the birth.

While for some this will require a leap of faith (it's much easier to suspend your disbelief with fiction!) others will find it a revelation. What is convincing and valuable, is the genuine new vision Adam's birth brings to his parents and the range of feelings and insights his mother so eloquently describes once he is born. For this the book is worth reading. For the psychobabble of angels it isn't.

P.S. On a personal note, we once met a kind and gentle lady who to pass the time while she waited for an alien abduction, read auras, cast spells and rubbed feet. She volunteered to rub my son's. While so doing he fell asleep and she proceeded to tell us that of course people with Down syndrome were actually aliens of super intelligence who incarnated as humans in order to experience feeling rather than intellect. Fine.

It's probably safest to regard them as people first, though.

JA

thoughts and covers areas of death, sexuality, suicide, euthanasia and depression.

I found this book to be very well written. It certainly held my attention, I found it to be sensitive and humorous, but also at times a little sad, (although other readers might not see it as I did – my child is only 4 and I have a lot to yet experience). It had lots of little one-liners that I'm sure many parents can relate to. How often have we told our child to put his tongue in, and to stand up straight? I really liked that the author had the ability to write it as though his son was standing there having a conversation, it was very easy to visually imagine. A good weekend read.

BR