

FOREWORD

by **Fiona Stanley AC**

One of the first things that struck me when I put down this book was the transformation through its pages of the families whose stories are told. From the first moment of stunned disbelief when they learn their new baby has Down syndrome and fear they are never going to be able to deal with raising their child, we watch parents coping with difficult social choices, and with the medical issues that sometimes accompany Down syndrome – and we see them learning to live with the challenges life has presented them.

Then at some point a corner is turned and parents become increasingly proactive: lobbying, fighting health providers and schools and government departments for the rights of their children, creating support groups, and organising the education and accommodation they want for their children. Having a child with Down syndrome certainly changes your life.

With this book Jan Gothard makes an important contribution to the literature on Down syndrome and on disability in general in the twenty-first century. The personal and autobiographical stories are set against a comprehensive account of the broader social and historical context of Down syndrome and of disability generally.

It is the book I'd want to read if I had had a child with Down syndrome. It's the book I'd recommend to parents who already have a child with Down syndrome, or for whom prenatal testing has indicated Down syndrome, and they are wondering what on earth the future holds. As a scientist working in the area of child health, I would also recommend it to all those people – teachers, health professionals including doctors, and policy makers – who work with people with disabilities or who make the decisions which affect them. Professional attitudes play an

enormous role in shaping the lives of people with disabilities and their families, and this book gives a privileged insight into the impact of such decision-making, for better and worse, at a personal level.

What people need foremost is information. Reliable information. The more we know, the less foreign is the terrain and the better we can deal with the masses of misinformation that still abound. And, just as important, we need to know we are not alone, that others have faced the decisions and dilemmas that we are now facing. That our responses are not abnormal. *Greater Expectations* provides all this and more. It shows children, young people, men and women with Down syndrome, 'busy doing perfectly normal things, getting on with their lives.'

Some chapters will be confronting reading for any new parent, but the overriding feeling is deeply positive. In society at large, enormous progress has been made in the last few decades. The period when parents were encouraged to give their children over to institutions, encouraged to believe that their child was beyond schooling and was unlikely to live into adulthood is over – very largely thanks to the 'courage and stubborn persistence' of an older generation of parents of children with Down syndrome 'driven by love or duty to offer their children a better life.'

That better life – with opportunities in education, sport, play and work that were hardly dreamt of a generation ago – is here now, but there is still quite a way to go. As Jan Gothard reminds us, 'We owe all this to the parents who fought against negative expectations; we owe it to our children to keep our expectations growing.' This book will surely feed those greater expectations.

Professor Fiona Stanley AC, October 2010
Patron, Down Syndrome Association of Western Australia

INTRODUCTION

Born in Western Australia in 1977, Christopher Derkacz had Down syndrome. As sometimes happened to children like him in the 1970s, his family relinquished him, he was made a ward of the state and put into care. In January 1979, when he was just twenty-three months old, his foster mother took him to Perth's Princess Margaret Hospital for Children, suffering from croup. She thought she had left him in the best place and the safest hands, but she was wrong. Christopher had a further attack of croup that night but, instead of reviving him, the nursing staff left him to die, because the notes prepared by his doctor were marked: 'Not for resuscitation — no cardiac massage or intubation.'¹ At the inquest, the nurses who had attended Christopher were advised not to give evidence, on the grounds that it might incriminate them; but, according to both the press report and a subsequent question raised in the Western Australian parliament, the doctor in charge of the case said that children like Christopher should not even be admitted into the hospital's intensive care unit, and that if they lived they too often became a social burden.

Australians are not the only people who have refused appropriate medical treatment to people with disabilities like Down syndrome. There have been celebrated cases in both the United States and the United Kingdom of individuals fighting, usually unsuccessfully, for the right even to go on a transplant waiting list. After a much publicised campaign in the mid 1990s, American woman Sandra Jensen finally received a heart and lung transplant, though she died from complications

sixteen months later. She was almost certainly the first person with Down syndrome, and may well be the only such individual to date, to have received a major organ transplant.² But while progress has not always been straightforward, I believe we have come a long way from that moment in January 1979 when a toddler was refused life-saving treatment for an everyday childhood ailment like croup, because a doctor decided that a life with Down syndrome simply wasn't worth living.

This book is not about Christopher and Sandra, but it is about people like them, and their families. It's also about a community. From the day my daughter Madeleine was born in 1992, I have been part of a community which stretches across state and national boundaries, overriding language, race and ethnicity. I have been approached by a Chinese-American family in the Te Papa museum in Wellington, New Zealand who, after a few penetrating glances, wandered over to ask how my daughter was going. Two of my daughters were with me, but I had no doubt which one they meant. I have exchanged smiles with a Korean couple in Cambodia, members of a tour group, as they and their adolescent son explored the Khmer ruins at Angkor. My partner Charlie and I have been known to stare as we drive past an individual on the street, or when we spot a family on the beach or at a shopping centre — are they too part of our 'community'? I once resisted the temptation to stalk a young woman wearing a staff uniform in a hospital corridor, intensely curious to know exactly how she was employed there and whether they had room for another one. We have been approached more than once in coffee shops and parks by parents and grandparents who have remarked on our 'lovely family'. We were out doing normal things, behaving in entirely usual and not always perfect ways, yet the phrase and compliment are always loaded with meaning. The day before

my daughter was born, these people would have remained largely invisible to me, and my family to them.

‘Community’ can be purchased cheaply these days; for the price of a car sticker, anyone can attest that they are friends of the ABC or that their ‘other family’ is the East Fremantle Yacht Club. Members of what I think of as the Down syndrome community, and the disability community more generally, may share nothing more than a familiarity with disability and no doubt many would rather share less. For writer Kathy Evans, the public recognition of her daughter’s ‘community membership’ was no ‘warm and fuzzy moment’.

It served only as a reminder that my child was not just a member of my family, built from the atoms of generations of Celtic ancestors, but part of a distinctly recognizable breed, like poodles or Siamese cats.³

Questions about what it means to have Down syndrome in the family, how individuals and families experience that situation, and the social implications of living within that ‘community’ are contentious. Brian Stratford, doyen of the Down syndrome world, has written glowingly of the community in terms of parent organisations across the world which contain within them otherwise warring parties, bound together by the common cause of improving the lot of their kids. He writes of a variety of such bodies, including ‘Catholics and protestants in Northern Ireland ... work[ing] together towards the development of their children with Down’s syndrome,’ the Indian Down syndrome association with its multi-religious membership, and the Zimbabwean association comprising ‘both black and white, taking into consideration only the needs of their children and their support for each other,’ and concludes that: ‘John Langdon Down has given his name not only to a single pathological condition causing

mental handicap, but to a worldwide community of people with potential.⁴ I am less sanguine than Stratford about the potential for harmony within the Down syndrome community, but less defensive than Evans. This book explores what I consider to be the transcending experience of living with Down syndrome; but it does so in full recognition that, like most communities, the differences within it may be as great as the factors that create it.

Once, a child with a difference was a child to be hidden or denied, but since perhaps the 1950s, as institutionalisation of children with disabilities began to be questioned by professionals and, increasingly, by parents, so too writing about a child with a physical or intellectual disability has developed into an autobiographical genre. One of the first people to publish a book in English about their experiences was singer/songwriter and actor Dale Evans. In 1950, she and her husband, renowned stage cowboy Roy Rogers, became the parents of Robin Elizabeth, who had Down syndrome and who died just short of her second birthday. *Angel Unaware* is written in the voice of baby Robin, cast as an angel sent to earth to spread joy and awareness. The book, motivated by the couple's Christian beliefs, was published only with difficulty — it was not a popular topic at that time. However, as one of the earliest of such 'true confessional' works, the book gave hope to many who read it and has sold over a million copies. In 2004 a fiftieth anniversary edition was published.

Is it easier or harder for families of note to accept their difference? Anne de Gaulle was the daughter of General Charles de Gaulle and his wife Yvonne. Born in 1928 with Down syndrome, she was never separated from the rest of the family and lived a fully included life, her acceptance and protection part of the family's deeply held values. Her death in 1948 left the general devastated.⁵ On the other hand, playwright

Arthur Miller's son Daniel, born with Down syndrome in 1966, was institutionalised at birth, despite the wishes of the boy's mother, Inge Morath, who continued to visit him throughout his life. Though Miller did not mention this son in his autobiography, he was apparently reconciled with him later in life when Daniel left the institution, and shortly before the playwright's death, Miller bequeathed Daniel, along with his siblings, an equal share of his assets.⁶

It took Pulitzer and Nobel Prize winning author Pearl S. Buck thirty years to publicly promote knowledge of her much-loved daughter. Born in 1920, Carol was 'mentally retarded', institutionalised from adolescence and thereafter kept out of the public gaze. Buck's book about Carol, *The Child Who Never Grew* (1950), was re-published in 1992, and as the foreword notes:

For families whose lives were haunted by the sad mystery of mental retardation, all the scientific explanations in the world would not have as much impact as a famous, respected person disclosing publicly, 'I speak as one who knows.'

Perceptively, referring to the courage it took to self-reveal in the 1950s, the foreword also refers to 'the 1990s' tell-all atmosphere of celebrities baring their most private scars.' Whereas having a child with a disability makes most people feel uncomfortably 'different', it somehow seems to give celebrities a veneer of normality by showing that, just like the rest of us, the beautiful people too can experience life's challenges. For that reason, the birth of a child with a disability is often an occasion for the media to descend. Yet the publicity can also become an important and uplifting focus for more 'regular' families, and there is no doubt that giving disability more currency can serve valuable political ends, with disability societies around the world quick to acknowledge or seize the

patronage of celebrities such as racing car driver Damon Hill or rock star Nik Kershaw, both of whom have a child with Down syndrome.

The birth of Domenica Lawson in 1995 gave the Down syndrome community in Britain a powerful public voice through her father Dominic Lawson, former long-time editor of the London *Sunday Telegraph*, and her mother Rosa Monckton. Godmother Diana, Princess of Wales, added further cachet to Domenica's life, although we have not yet seen Domenica appear on television with kitchen goddess aunt Nigella Lawson. Since Domenica's birth, her parents have become highly articulate and outspoken critics of policies such as the assumption of automatic termination of Down syndrome pregnancies and both have written movingly about their rather different responses to their daughter's birth. Just as the death of the Princess of Wales raised awareness about wearing seatbelts and Kylie Minogue's breast cancer led to a rise in mammograms, the well-publicised birth of a child with Down syndrome in a prominent family sends out a message that this can happen to anyone. While it may also have increased the incidence of prenatal screening, the birth of Domenica Lawson underlined the fact that having a child with Down syndrome is not automatically such a bad thing.

That is, after all, the message which permeates autobiographical accounts of living with a child with Down syndrome. Books and TV series with titles such as *Life Goes On* stress the continuities of existence after the arrival of a child with a difference. Michael Bérubé's wonderful *Life As We Know It* is an example of this genre, with Bérubé's son Jamie at the heart of the family, but alongside and taking up no more and no less space than Jamie's elder brother Nick. Nowadays too, there is a gratifying trend away from the beatification approach exemplified in *Angel Unaware*, which left many

parents of less than saintly children a little uncomfortable; although the autobiographical *Expecting Adam* – with its blunt allusion to the supernatural guiding powers of the child with Down syndrome, even *in utero* – is clearly part of that older tradition. Despite their differences, however, what all these books reveal is that, as individuals, people have felt compelled to talk about the profound impact of the birth of a child with disability. Their powerful need to articulate their shock and reaction speaks volumes of the still-hidden nature of disability in society today.

Until recently, intellectual disability was a relatively unexplored theme in social and historical research in Australia, but over the past decade or so more has been written as disability has become an increasingly acknowledged dimension of social difference. This book represents a convergence of two streams of writing: personal and autobiographical parental accounts, and historical and contemporary analysis of disability. It ranges over themes associated with rites of passage and pivotal social moments and discusses birth experience and the acceptance of disability; family and community support; health issues; education; growing up and finding work, and independent living. All these themes are located within a broader social and historical context. The book also looks at family decision-making: continuing or terminating pregnancies; accepting or relinquishing children at birth, and learning how to let them go. Where possible, these themes are explored from the point of view of individuals with Down syndrome, as well as their families.

This book is based on more than sixty personal interviews recorded across Western Australia but it has broad geographical and social application beyond Australia, and certainly reinforces an understanding of the universalising

aspects of some experiences of disability. Western Australia in fact has much to offer as a place to locate a study such as this because of the richness of the research already undertaken into disability and Down syndrome in this state. The 1996 edited collection *Under Blue Skies: The Social Construction of Intellectual Disability in Western Australia* is a pioneering history of intellectual disability in Western Australia and still remains unmatched by publications in other Australian states. Western Australia is also the home of the acclaimed Telethon Institute for Child Health Research whose director Professor Fiona Stanley is Patron of the Down Syndrome Association of Western Australia. The Telethon Institute has been responsible for producing a huge body of research data on issues such as the health and longevity of people with Down syndrome and the impact of prenatal screening. It also produced the *Down Syndrome Needs Opinions Wishes Study Report* in 2007, which surveyed more than three hundred Western Australian families living with Down syndrome. These and other publications have been used to complement the personal accounts in the pages which follow.

The people I interviewed were culturally and socially diverse and included Aboriginal and migrant families. I started interviewing more than a decade ago, which has given me the unexpected opportunity to revisit some of the earliest informants, in what eventually became an unplanned longitudinal study.⁷ In the course of talking to people, it soon became apparent that the biggest factors determining one's experience of Down syndrome were place of residence – metropolitan or regional – and the era when an individual with Down syndrome was born. Services undreamt of in regional settings were often delivered to the doorstep in metropolitan Perth, while predictably, services waxed and waned and educational opportunities differed as state

government policies shifted over time. More important for me than charting changes in policies and provision of services though, was finding out how people had responded to the opportunities available and how the choices they made affected their lives.

The majority of my interviews have been with parents, primarily mothers, and other carers of people with Down syndrome, but about one-third of the people I interviewed had Down syndrome. When I commenced interviewing, I wanted to focus very much on the question of what it meant to have Down syndrome, and I approached this issue in the broader context of finding out how young adults with Down syndrome lived their lives. What I found was how very like, in many ways, were the lives of the people I spoke to, compared to those of their peers who did not have a disability. Ranging in age from sixteen to their thirties when I interviewed them, the majority of those young adults lived at home with their parents. One young woman had taken out a mortgage and was buying her own home, a unit she shared with a friend who also had Down syndrome. Another man rented a unit in Fremantle where he lived by himself. One couple was married and living independently in a larger south-west town. None was in any form of residential facility, and none had been institutionalised at birth, which would have been more typical of older people with Down syndrome. Social interaction, recreation, education and training, relationships, work and family were the main focus of their lives and, while some clear differences existed – largely associated with independence – my interviews reinforced Jan Walmsley's observation that 'being a person with a learning disability is most akin to being a human being.'⁸

Sometimes documenting the normal can be difficult. The discrepancy between experiencing Down syndrome as

‘normality’, and living alongside it as a disability, is a profound one and, in trying to present different understandings of what it’s like living with Down syndrome, one that I needed to keep very much in mind. My own experience of disability, and the experiences related to me by the carers and parents I interviewed, confirmed for me that disability can profoundly affect one’s life. So while this book is based on optimism about the future and an overwhelming belief that people with disabilities such as Down syndrome can, should, and do lead normal lives, it is underpinned by a historian’s awareness of past struggles to bring about change.

A researcher’s position is never neutral, but I have felt particularly challenged by this work. My interest in disability is precisely as old as my daughter. As she has grown up I have become increasingly aware of how an everyday life lived with disability can be a political and social battleground, one of which my daughter still remains largely unaware but one in which her parents engage on a daily basis. I have experienced disability as both oppressive and ‘disabling’ and, as an interviewer, I always kept that in mind. I have much in common with many of the parents interviewed in terms of experiences associated with the recognition of a child’s disability and working through the consequences, but many parents do not share my view of disability as a condition made worse by, but which could be made better by, social attitudes. This is a difficult line to tread but, as interviewer, I attempted to render my personal views invisible in the interviewing situation. My intention was, after all, to see how a range of people experience living with a disability, not to proselytise or see how many people shared my point of view. Clearly however, interviewing from within a community presents a number of challenges.⁹ The Down syndrome community in Western Australia is a reasonably small one and as an interviewer

I always identified myself as a parent of a child with Down syndrome, believing that the informants' awareness that I too had 'been there', in fact still 'was there', could encourage the sharing of deeply-buried and sometimes painful memories. It was also a good starting point for interviews with people with Down syndrome too, explaining that I wanted to ask about their lives and, incidentally, about having Down syndrome, because of my daughter.

Equally challenging has been the question of how to use my own voice. I am an interviewer and researcher, but I too have a story to tell. The question of selecting interview extracts, locating them within the text, and above all, giving them weight, was a difficult one. The responsibility for interviewing, editing and writing was mine. However, in order to give my voice what I hope is no more than equal weighting with other parent voices, I primed a friend to interview me. Like all the other interviews in this book, that one too is used anonymously, and enables me to have 'my' voice heard directly.¹⁰ I cannot deny though that as editor I have had the opportunity to select material and to stage manage to produce effects which suit my own convictions. As historian Ann Curthoys has noted of a similar challenge – writing a historical account of an episode in which she herself was a participant – 'Even if I satisfy myself that I have avoided these traps, will others believe that I have?'¹¹ I have to hope so. This book is not intended to fit into that autobiographical self-revelatory genre of books about how one family lives with disability; rather, it draws on multiple voices to show the plurality of that experience.

Interviewing people with an intellectual disability undoubtedly raises profound ethical questions for a researcher. As an interviewer and as someone who has been involved with disability for many years, I am well aware of the tendency identified by Karen Hirsch of speaking on behalf of people with

disabilities, especially, as in this case, intellectual disability, and I took on board her caution that ‘it is hard to overstate how resistant and pervasive is the cultural assumption that people with disabilities cannot speak for themselves.’¹² Among people with Down syndrome there are many who are more than capable of doing so, of telling an interviewer about the lives they lead, their experiences, interests and aspirations. More generally, in terms of self-expression, there are books authored by people with Down syndrome, ranging from the classic 1967 publication Nigel Hunt’s *The World of Nigel Hunt* to Kingsley and Levitz’s *Count Us In*, now in its second edition in 2007. Australian actor and advocate Ruth Cromer and young American advocate Karen Gaffney are both renowned speakers at international disability forums; in Western Australia, Justin Marshall is a frequent speaker on the topic of having Down syndrome. Such individuals, though, remain a tiny minority. While people with Down syndrome are not all similarly disabled, nor are they equally ‘able’. Some people with Down syndrome are simply not articulate and to interview only those who could sustain a lucid conversation would be to misrepresent the community. As Brian Stratford observes,

it is distressing for parents of a good number of children with Down’s syndrome to be constantly hearing of near normal development and of high individual achievement when their own child is not making anything like that kind of progress.¹³

On that basis, one of the dilemmas I faced in undertaking this research project was balancing my desire to interview the most articulate people with Down syndrome I could find, with the recognition that other people’s stories, less clearly verbalised and sometimes harder to render meaningful for

an audience, were just as valid and perhaps more ‘typical’. As an interviewer, I had more ‘success’ – in terms of lengthier and more in-depth interviews – with individuals who were more vocal, and whose interviews resulted in material which I was able to incorporate fairly directly into my text. But an interview program which focused only on the most successful or the most articulate individual would neglect many of the realities of living with Down syndrome. Other approaches, based on interviewing models employed by other researchers,¹⁴ encouraged me to recognise that the end result of an interview should be more than just a recorded hour of lucid conversation or a flowing transcript. Instead of taking the informant’s words directly, as one would usually do after an interview, as a researcher I have tried to take the meaning gleaned from each ‘yes,’ ‘no’ or silence, in conjunction with material from other sources such as parent interviews to create an indirect but meaningful narrative about individual lives. Thus, I see the role of the interviewer/editor and historian not as disempowering, because it detracts from the authority of the informant, but as enabling. The alternative, for less articulate people with intellectual disabilities, may well be silence.

In writing this book, I have tried to keep two themes in mind. The first is the role of parents in fighting for the advancement of their children. So many of the opportunities enjoyed by people of my daughter’s generation and younger have come about because of the courage and stubborn persistence of an earlier generation of parents. In some cases, they had extremely limited expectations about their kids’ capacities, having been told often enough by professionals that their kids had none. Nonetheless they persevered, driven by love or duty to offer their children a better life. Today parents are no longer handicapped by the belief that their children are beyond aid and as a result of the efforts of those earlier

parents and far-sighted professionals, and of ideological shifts in understandings about disability, we now understand and act on the belief that people with disabilities have a potential which can be tapped and nurtured.

The second theme is belonging and inclusion. Support is increasingly there to assist people with disabilities to engage more fully in the community but it's still a journey down a one-way street. The state of full inclusion could be reached a lot more quickly, and would appear a lot more attractive to those who are still wary of it, if the rest of the community would meet people with disabilities halfway. Inclusion means more than simply having people with disabilities in mainstream classrooms and workplaces. It's about a state of mind which sees people with disabilities accepted as valued, significant and worthwhile members of society: people who have every right to belong. Though we have travelled light years in the past few decades, the absence of this mindset is unfortunately still evident in Australian society today, in places as far apart as maternity wards and the government's department of immigration.

Above all though I have kept in mind the profound changes that have occurred in the lives of people with Down syndrome, which make the story of Christopher Derkacz so confronting to us today. Consider people like Yolanda, Stefan and Judith, Nick, and countless others. Yolanda Berg is a member of the Western Australian government's Ministerial Advisory Council on Disability, contributing the critically important perspective of people living with intellectual disabilities to that forum. Linda Katuna Rich has worked with Coles Supermarkets since 1997, while Nick Cartmel has been employed at what is now the Western Australian state government's Disability Services Commission since 1992. Judith Mincham and Stefan Zwickl, who both have Down

syndrome, got married in 2009. Samala Ghosh has won a prize for art in an open competition. Tom Softly flies with his father in a small plane and has medals for motorbike trials. Since 2007, Stephen Donovan has broken twelve world Down syndrome swimming records. Patrick Ricciardo has competed in the Rottneest Island swim. Julia Hales performed in her own show, *Soapy Dreaming*, in an acclaimed Solo Spot drama festival in 2008. Whether it's learning to read and write, ride a bike, catch a bus, hold down a job or, like Karen Gaffney, swim the English Channel, people with Down syndrome are doing it. Fifty years ago, they weren't. We owe all this to the parents who fought against negative expectations; we owe it to our children to keep our expectations growing.

Finally, I want to start this book by recalling my partner Charlie's words about our daughter Maddie.

When she turned one, we all got round to celebrate her birthday and thought back to the day she was born, all the tears, all the trauma, and I just couldn't help thinking, what on earth was all the fuss about?



chapter 1

'THE BABY I'D DREAMED OF HAVING'

'I remember one of the nurses coming in and saying, "Well you're lucky she wasn't born thirty years ago, because she would have been put away and what have you. She'll go to school and she'll learn to read." I was lying there thinking, yes, but she was going to be a brain surgeon.'

(Heather Burton)

In 1990, two years before my daughter Madeleine was born, Fay Weldon's book *Darcy's Utopia* was published.

I think about my friend Erin as I often do. She has a Down's syndrome baby. We all knew it would be disastrous; we foretold that her husband would walk out, that her other children would suffer: we saw she was the only one of the family unit who couldn't bear not to see the fruit of her womb, however sour, ripen, drop and live. And that's how

it turned out: the child, now twelve, is badly retarded. Erin is no more than its nurse; she manages without a husband, her other children are spiteful and embarrassed. Erin talks about the joy the mindless child brings her — well, so it may, but her love for it has been most destructive for others. Left to us, friends and family, we would have said no, Erin, sorry, not for you. This baby you insist on having keeps other babies out, ones which won't cause this distress to you and yours. Just not this one; Erin, try again.¹⁵

Images of the person with Down syndrome, mostly unattractive, have always been present in our literature. Benjamin Compson, Faulkner's shuffling idiot narrator in *The Sound and the Fury*, is based on a character with Down syndrome, and it's not hard to find similar examples — the sad-eyed Mongol in *Take Me to Paris Johnny* and the 'retarded Mongol brother' with the mismatched ears in *The Jane Austen Book Club* are just two. As every parent of a child with Down syndrome is told though, 'Of course, things are so much better now!' *The Memory Keeper's Daughter*, an enormously popular recent novel which focuses on a baby with Down syndrome relinquished at birth, is light years away from *Darcy's Utopia*.

Today, for those who look, there are many positive depictions of people with Down syndrome in circulation in Australia: television programs such as the memorable SBS series *House Gang*, for example, which featured a group house occupied by people with intellectual disabilities, and the US TV series *Life Goes On*, starring Chris Burke. Pascal Duquenne was the Cannes award-winning star of the 1996 Belgian movie *The Eighth Day* and in 2009, the Spanish actor with Down syndrome Pablo Pineda was awarded the prize for best actor for his role in the movie *Me Too*. In the United Kingdom the fabulous 'docu-soap' *The Specials*, filmed in a household of

young people with disabilities including Down syndrome, is great viewing.

Like the concurrent process of ‘mainstreaming’ Indigenous and ethnic Australians in the media, people with disabilities such as Down syndrome are starting to become more visible as pleasant, even popular incidental characters in mainstream productions. The former Australian television series *GP* featured the engaging Tracie Sammut as a regular cast member; *EastEnders* now features a baby with Down syndrome, and Australian actor Danny Alsabbagh appeared as Toby in the recent ABC TV series *Summer Heights High*. People with Down syndrome have appeared in Target catalogues and in advertising for ABC TV. In 2009 the short film *Be My Brother*, about a young man with Down syndrome, carried off first prize at Tropfest in Sydney for director Genevieve Clay while the lead actor Gerard O’Dwyer (who has Down syndrome) won the award for best actor.

Clearly, disability is now viewed more positively than was the case just a generation ago. Yet the birth of a child with Down syndrome still causes immense grief and untold anxiety for the family involved. The US term ‘retard’ has replaced the term ‘spaz’ (a favourite when I was a teenager) as a contemporary term of abuse among younger people. In Australia in May 2008, the Seven network’s television series *All Saints* featured a young couple – brother and sister – who were expecting a child, and who were told that because the relationship was incestuous, the baby would have Down syndrome. The continuing currency of these sorts of images and this type of extraordinary misinformation makes a family’s immediate response to the news that their child has Down syndrome and an intellectual disability at best ambivalent.

Tied up with the anticipated arrival of a baby is the expectation that the child will bring joy and happiness to the

parents. Implicitly, a child is often seen as an extension of one's family, a link with both past and future. Most parents, particularly during their first experience of parenthood, marvel at the perfection which is their new child, and there can be few who have not harboured secret dreams and expectations. If we don't necessarily yearn to parent prime ministers and brain surgeons, most of us hope at the very least for the health, happiness and, ultimately, future independence of our offspring. At first glance, the birth of a child with Down syndrome seems to dash each one of these aspirations.

In not so distant days, the diagnosis of Down syndrome was so awful that parents were told to abandon all hope for a normal life with or for that child and to pass their Mongol baby straight into the hands of an institution. The legacy of that process of systematic abandonment is still with us today. If Down syndrome is a condition we can test for and screen against; if carrying a baby with Down syndrome is unquestioned grounds for termination; if bringing up a child with Down syndrome was once considered so dreadful a fate that people 'put their child away' instead, then the message is very clear: such a child is something to guard against, not to welcome. What kind of future are we opting for if we accept this child into our home? It is this question in all its starkness which parents have to confront when they learn the news about their newborn child.

Almost all parents of a child with Down syndrome remember the birth and the subsequent diagnosis in extraordinary detail as one of life's most profound watershed moments. The memories are fixed, a mental video to be painfully replayed over and over again. First-time parent Britt Canning's son Jack was born in 1995 at a hospital in Perth's northern suburbs. Britt described receiving the news as 'a huge shock, probably

the biggest shock I have ever had and maybe ever will have, touch wood.’ She and her husband were left ‘quite shattered, absolutely devastated.’

Looking back now, it was kind of bitter-sweet, it was both the worst and the best day of my life. It was quite a textbook labour, nine hours and no problems; he was born normally, naturally. He was a big baby too, a good size. I just remember once he was born I was in heaven, I was totally ecstatic. He breastfed straight away, he got an eight and then a nine in the APGAR¹⁶ test and he was obviously just thriving.

At about nine o’clock, the paediatrician came in to see me. Jack was lying in a bassinet at the time, I was sitting on the side of the bed feeling great, feeling really good. The paediatrician picked Jack up and put him in my arms and then he said to me, ‘Have you heard of a condition called Down syndrome?’ and my world just fell apart, just like that, those words. We were just absolutely shocked. I was holding Jack but I felt numb, completely numb. Now I wonder if it was such a good idea to give him to me, it is amazing I didn’t actually drop him on the spot.

Luke Middleton recalled similar sensations.

I felt absolutely devastated. I remember going outside and sitting on a park bench at the front of the hospital and everything seemed black and dark. I remember thinking that this was a terrible tragedy, a really terrible tragedy, and that all my wishes had collapsed.

Shock, horror and outrage went hand in hand with feelings of numbness, denial and total disbelief, all underpinned by a

profound sense of sorrow and loss: loss of the perfect child whose arrival had been so eagerly anticipated, and loss of a way of life that had been taken for granted. Talking of this moment, people spoke in terms of their world falling apart, the end of life as they knew it; of devastation, anguish and mourning. For many parents, the death of their newborn child could scarcely have been worse and, initially at least, one of the most common sensations was of bereavement.

Recognition by medical staff that a child has Down syndrome is usually almost immediate. The condition is marked by a cluster of certain features which together constitute the 'syndrome' identified by John Langdon Down in 1866. While most of the public can identify people with Down syndrome from the distinctive appearance of their eyes, not all people with Down syndrome share this feature to the same extent, and this is not the feature medical staff rely on for immediate identification. The classical features (or 'stigmata', the technical term) of Down syndrome are visible in the face, neck, feet and hands. The eyes may appear to tilt upwards and be almond-shaped, a fact which led to earlier naming of the syndrome as 'Mongolism', as this feature was viewed as typically 'Asiatic'. The irises, particularly in fair children, sometimes exhibit rather attractive light flecks called 'Brushfield spots'. In some children, the tongue can protrude a little, and the mouth and its cavity may be smaller than normal. Ears too are sometimes smaller and the tips slightly folded over. A child's face sometimes appears flatter, especially the bridge of the nose, and the head smaller. Some children with Down syndrome have a characteristic transverse palmar or 'simian' crease, a single line crossing the palm of the hand instead of two; others have an inward curved little finger. Sometimes a wide gap exists between the first and the second toe.¹⁷

Low muscle tone (hypotonia), which gives the newborn child with Down syndrome its characteristic floppiness, is generally one of the first signs alerting medical staff to the presence of the condition. Some of the 'stigmata', particularly the smaller facial features, have medical implications, but hypotonia is the most significant as it can impact on the rate of a child's physical development. For that reason, while Down syndrome is typically thought of as an intellectual disability, it is also accompanied by delayed physical development in macro areas such as standing and walking, and in micro skills such as grasping and picking up objects. Low facial and oral muscle tone, often responsible for a protruding tongue, can also compromise or delay the child's ability to take solid food or to speak clearly.

As most recent books on Down syndrome are quick to point out, there is no correlation between the number of characteristic physical features a person with Down syndrome has, and their intellectual capacity. While that may be comforting later on, the knowledge that one has a child who can be identified as 'different' from the moment of birth is not.

Once the visible physical features have been noted, a medical practitioner will usually inform the family that Down syndrome is suspected, and that this can only be confirmed by a blood test. Usually the child and both parents are tested, to confirm the clinical diagnosis and to determine whether, as occurs in a very few cases, either of the parents is a 'carrier'. But generally the blood test will not answer the pressing question – *why us?* Apart from the knowledge that the incidence of Down syndrome does increase with maternal age, there is still no explanation for its occurrence.

A blood test, or cytogenetics report, clarifies the type of Down syndrome which the child has. Ninety-five per cent of cases occur in the form of trisomy 21, in which every 21st chromosome forms in triplicate instead of the usual twin

form. Trisomy 21 has no apparent genetic implications. It is not 'carried' or passed from one generation to the next, and to date there is no explanation for this aberrant chromosomal formation. We do know that it occurs naturally in all cultures, though the rate varies according to the age profile of child-bearing women. In Western Australia, Down syndrome occurs in about one in 445 pregnancies.¹⁸

Down syndrome also occurs in two other forms: mosaic and translocation. Mosaicism occurs when not all of the body's cells are trisomic: some cells are normal and some have a third 21st chromosome, distributed in a random or 'mosaic' fashion. This condition has been described as 'incomplete' or 'partial' Down syndrome, and occurs in about four per cent of the population with Down syndrome. The condition is the subject of some research and debate because the extent and impact of the disability may be less than for other forms of Down syndrome.¹⁹ Swimmers with mosaic Down syndrome, for example, compete for records in a separate category from swimmers with trisomy 21 as their performances are not always comparable. Sometimes too the condition may take longer to be identified, as was the case with Graham King in Geraldton whose mosaic Down syndrome was not diagnosed until he was five years old.²⁰

Translocation Down syndrome, the least common form of all, is a condition where the extra 21st chromosome is not attached to the twin 21st chromosomes, but to another chromosome. This seems to be of no additional significance for the child, whose development and appearance will be 'typical' of children with trisomy 21, but it can sometimes have implication for the parents, as this form of Down syndrome may occur where one of the parents themselves has some translocated genetic material.²¹ This is not always the case however, as Trish Weston was well aware.

Will has translocation Down syndrome, and it caused us massive angst waiting for our chromosome tests, to see which one of us was a carrier (the paediatrician had said one of us 'must be'). Will was the first grandchild on both sides and the implications for our siblings and their future children also seemed to be in the balance. It turned out that neither of us was a carrier.

The few days between initial diagnosis and confirmation by blood test are often days of great anxiety and roller-coaster emotions. These days, doctors tend to communicate their belief that the child has Down syndrome soon after the clinical examination, although this may also vary according to hospital policy or the doctor's inclination. When Catherine Slater's daughter Karen was born in May 1979, the London hospital where she was born had a policy of delaying passing on the news.

If there was anything wrong, they wouldn't tell you for five days, for fear the mother might reject the baby. So everyone knew, but no one was telling me. I had absolutely no idea. I noticed nothing different from my first daughter; all you knew in those days about Down's syndrome was photos of people with pudding-bowl haircuts.

When the news finally did come,

It was terrible. We'd had all the congratulatory cards from our friends and our family and everything. I couldn't ring anyone to tell them. I just couldn't.²²

More recently in Perth, one family was denied knowledge of the clinical diagnosis even though trisomy 21 had been mentioned in the hospital case notes. The family was already very familiar with the condition as it had three adopted members with Down syndrome.

The doctors hadn't told them what their suspicions were. They were simply saying, we need to do some tests and Robert had read the file and because of our family, as soon as he saw trisomy 21 he thought, hang on, I know what that is. It was probably a week before the doctors in the hospital were prepared to even suggest that this child might have Down syndrome. They were just playing the game, 'We have to wait till this blood test comes back.' (Helen Golding)

Certainly, once they have informed the parents, doctors generally play down any possibility that their initial diagnosis might prove incorrect. Our doctor, for example, pointed out that if our daughter didn't have Down syndrome, she clearly had something else 'wrong' with her. Nonetheless, parents invariably hope against hope that there has been a mistake. Yet it is generally the initial news of the possibility of Down syndrome rather than confirmation by blood test which is remembered most clearly and most shockingly as the moment when the world fell apart.

What is the best way to break such news? Most parents felt that they should have been informed as soon as there was any diagnosis made by medical staff. But often it was the way in which the news was conveyed as much as the timing which compounded the distress, as was the case after Karen Langley and Paolo da Silva's daughter was born.

The paediatrician arrived and examined Shannon and then said, 'There is a heart murmur, but I don't know how serious it is at this stage.' And then he said, 'But I have to tell you I have concerns about your baby. I think this may be a Downs baby.' We were on the hospital bed and I think the main midwife from the Birthing Centre was there as well, and probably the others were all hovering in the background. Paolo said something like, 'What are you saying? Does

she, or doesn't she?' Because the way he'd put it suggested that she might have; and then he said something which confirmed it. At that point, Paolo burst into tears.

For Loretta Muller, bad as the news was, she believed it had been well handled.

Initially the nursing staff said that they had some concerns because Cameron was born a little bit blue, and so they were talking about that rather than anything else. They weren't saying anything. Although later the midwife came down and said she knew as soon as he was born. But I didn't notice — I didn't know anything about babies! And then the paediatrician wanted to talk to me and my husband and so they took us aside and explained what they thought. He had several signs that suggested he may have Down syndrome, and as for everything else, he was fine. I thought it was really well done. It was without any prejudice. I never got the 'I'm sorry to tell you' or any of that. It was just, 'Look, we think this child has Down syndrome.' That was fine. 'We'll do some tests and we'll see what happens.' I was very shocked but I just thought, 'Poor little bugger.' Really, I thought, we'll just wait and see what happens.

When William Mann went to the hospital to see his wife Muriel on the afternoon of their son's birth in 1967, he was ushered into a little nurse's pantry off the ward where their doctor and an attendant paediatrician informed him that the child had 'Mongolism' and then left William to explain this condition and its consequences to his wife. He hadn't even seen the baby. Even worse was the experience of Mavis Simpson in 1943, who did not receive the news until well after she had taken her son Trevor home.

When I went back to the doctor — after you come home from hospital, you go back after a short period — then the doctor told me. It was a lady doctor and she was a very nice person. But, of course, it was a shock to us.

The different spheres of responsibility of doctors and nurses also determine when the news is passed on. In quite a number of cases, parents had to wait till the appropriate medical staff were present. When Shannon was born in Canberra, her mother Karen had no idea of her disability until thirty-six hours or so after she was born.

She happened to be born in the early hours of Sunday morning, when there wasn't a paediatrician available, who was the only person authorised to tell us. So the midwives knew and the doctor who delivered her knew, but nobody could actually tell us, which at the time upset me enormously ...

Almost instantaneously, when Shannon was born, the midwife who had been there all through my labour and the birth sort of closed up and she just wasn't the person that she had been before. And she actually came to me a day later and apologised that she hadn't been able to handle it. She saw the baby had Down syndrome. She knew she wasn't allowed to say anything and she just couldn't relate to the whole situation. But it was strange, that I had noticed the difference in her and there was actually good reason for it.

As a former nurse Trish Weston was well aware of the difficulties faced by staff having to withhold information, particularly when it is evident the parents are actively concerned about the child's condition.

The nursing staff were particularly supportive once they knew that I knew. Before that though, they really were tiptoeing around the edges, unable to say anything and feeling very uncomfortable about it. I mean, you can just sense that happening all around you. I think it was actively discussed, I've gathered that everyone kind of knew, but things weren't really allowed to be said.

Everyone knew the news was bad, but what it actually meant beyond that was seldom clear. Most fears about the future were based on understandable ignorance and in retrospect, some parents were even able to scoff at their own and their family's responses. Pamela Franklin recalled with laughter how, immediately after she had received her daughter's diagnosis, her first thought was, 'How am I going to go shopping with this kid?'

I thought people would look at me and look at her and that sort of thing. I don't know why it was shopping, it is not as though I really love going shopping or anything, I don't know why I thought that but I did. And my mother-in-law thought, how was she going to tell the bowling ladies?

After his daughter was born in 1995, Nigel Lawson wrote of his grief 'at the thought that Domenica's life expectancy is not much more than half her elder sister's.'²³ The belief that people with Down syndrome still have a much shorter life expectancy than the rest of the population is incorrect, but these and other sorts of misapprehensions about their child's future all contribute to the despair which usually follows a diagnosis of Down syndrome. Most parents felt they had lost any chance of a normal life for themselves and their families. Later on, the feeling that life *could* remain normal – whatever

'normal' might mean in the context of welcoming any new baby into one's household — became a source of great comfort. Yet it was the apparent certainty that a life shared with a child with a disability would always be different that most disturbed Helen Golding when her first grandson was born. She herself had three adopted children with Down syndrome, but she described her feelings when her eldest son Robert (who did not have Down syndrome) had a child with Down syndrome in 1992, in terms of deep shock.

I was very upset. I was distressed because I knew that it meant that their life was not what they had thought it was going to be. Not because he is disabled, that doesn't matter a damn. But because I knew that from that day onward their life was not going to be the road they had thought it was going to be.

None of these families had had any idea of the news awaiting them. Kathy Evans in *Tuesday's Child* talks of her horror pregnancy with her daughter Caoimhe, and notes, 'Later I discovered that mothers carrying babies with chromosomal abnormalities can be sick the entire length of the pregnancy.' But this doesn't correlate with the experience of any of the women I interviewed, many of whom recalled that the pregnancy with the child with Down syndrome had been 'their best,' a model. At least two, however, did recall a 'fey' moment during the pregnancy, perhaps amounting to little more than what many mothers experience awaiting the birth of a child, especially their first. Britt Canning had recorded the moment in her diary.

Towards the end of my pregnancy with Jack, I wrote in my journal that this has been the perfect pregnancy, no sickness, feeling wonderful, feeling better than ever, I hope

I am not being set up for a fall. I read that a couple of months later and it just gave me goose bumps, and it is almost like I did have a little premonition, and I mentioned it in a couple more entries towards the end, 'I just hope this isn't setting me up.'

Karen Langley recalled a similar experience.

There's two things I remembered about the pregnancy afterwards in relation to the Down syndrome. When we had our scan, I said to the woman who did it, 'Oh, and there's no sign of Down syndrome or something like that?' almost like a joke. And I remember her shaking her head, but in a sort of thoughtful way, and not actually saying no, and it's haunted me ever since that maybe she saw something and didn't feel like saying it or wasn't able to say it or whatever. The other thing is, our family doctor – I must have talked to her about the possibility of various difficulties and I remember her clearly, she said, 'I would put money on the fact that this baby will be normal.' I went back and told her after Shannon was born that she had said that to me, and she sort of looked at the sky and said, 'Oh, did I?'

The birth of a child with a difference can have the effect of making one feel totally isolated, underlining the feeling that one has been specially singled out. This was particularly the case for younger women who had a baby with Down syndrome. The 'why me?' element was foremost in many women's thoughts in the early days after the birth and was often reinforced by comments from friends and family. Britt, in her mid twenties when her first son was born, was struck by people's assumption that she was somehow responsible for her son's condition.

I didn't feel guilty myself – I felt more that other people assumed my guilt. No, I absolved myself pretty early on, but a relative wrote to me actually saying that you must feel terribly guilty about it as well. And I remember thinking, 'Well, I don't actually.' And still to this day when I think about that man, I feel like writing back to him and saying, 'You know, it wasn't necessarily me.'

One of the coping strategies sometimes adopted by parents of children with disabilities such as Down syndrome, and exemplified in Dale Evans' 1953 book *Angel Unaware*, was to label their children as 'gifts from God' given only to special parents 'chosen' for their capacity to cope, but that attitude certainly seems less common these days. None of the parents I interviewed saw themselves or their children in this light.

I was angry and I suppose I was angry in a religious sense. I thought, 'How dare God do this to me, I have tried to do the right thing by Him.' But I got all that over with, out of the way and just got on with it. (Pamela Franklin)

The belief that children with Down syndrome are only born to older mothers remains widespread and indeed, some family and friends seem to think that if a woman had a child with Down syndrome then it was her own fault for not taking proper precautions. When Luke Middleton rang his sister with the news, her first response was, 'Didn't she have the test?' Given the prevalence of the view that maternal age was the cause, younger women felt particularly called upon to account for their child's disability. In the absence of years, they surely must have had some other hidden flaw. At the very least, they usually felt they had been particularly hard done by.

Then there was the older mother bit too – that was also hard for people to understand. They said, ‘Why has this happened to you? It shouldn’t have happened to you!’ and I felt that too! But yes, that was one of my first reactions: why did this happen to *me*? Then I looked at the odds of it happening, and I thought, oh great! (Britt Canning)

Maternal age is certainly a factor, with women over thirty-five more likely than younger women to have a child with Down syndrome. However, most children with Down syndrome are born to younger women simply because so many more women below thirty-five have children and, until very recently, fewer had prenatal screening for conditions such as Down syndrome.

Most people want to know why this has happened to them, and in the absence of any clear-cut answers, many look at their own lifestyles and prenatal experience. Trish Weston had worked many years in a hospital.

Had I been exposed to too many X-rays when I was working in the emergency department and those sorts of things? I worked in theatre for quite a long time, and the gases there are known to cause birth defects. I mean, that had been ten years before anyway, but I guess I was just searching for a reason why this had happened. I felt somewhat resentful of other people I knew whose babies were just fine, despite the fact that they smoked and drank through pregnancy and I’d done all the right things. I guess I felt like there was no justice really!

Scientist William Mann actively sought explanations when his son Geoffrey was born in 1967.

The librarian at the biological sciences library got books for me, everything that she could find on Down syndrome

and at that stage, it was still regarded as being a maternal cause. There was a lot of rubbish written about Down syndrome. The book which reported the French discoveries spoke of things in genetic terms, and I could understand that, so it made sense.²⁴ But the best book that I read at the time was Down's original book.²⁵ It was really very informative.

Whether or not it helps parents to be able to point a finger and say, 'That might have been the trigger,' there remains no explanation for Down syndrome.

Getting a straight diagnosis can be complicated by the child's ethnic origins. In cases where the family had an Asian or non-Anglo Celtic background, aspects to the child's appearance which might otherwise have alerted a doctor to consider the possibility of Down syndrome were sometimes overlooked, as Brenda Harvey discovered when her daughter Grace was born in 1992.

I didn't know Grace had Down syndrome until five days after she was born. Looking at her, you couldn't tell. Because they have an Indian father, my girls have always had that Asian look to them. And then the worst part was the waiting, five days of waiting, and not really knowing what I was waiting for. And I asked our doctor what did he think, and he looked at Grace and said, 'Well, she has some of the features but not all of them, so it's possible that she is Down syndrome but probably not.' Anyway, on the fifth day we had the results and my doctor came and told me that she did have it and so even though it was half expected, it was still a shock.

Claudia Mansour, who was originally from Lebanon, had to wait a great deal longer for the truth when her daughter Theresa was born in 1976.