



GETTY IMAGES

**THIS GIRL HAS
SPECIAL NEEDS,
AND ONE DAY
DREAMS OF
BEING A MUM.
DOES ANYONE
HAVE THE RIGHT
TO STOP HER
HAVING A BABY?**

Disabled Australian girls as young as 10 are being forcibly sterilised to prevent them from menstruating or getting pregnant – but there's suffering on both sides of this moral and ethical dilemma. Stephanie Osfield investigates

It was a Friday morning in September, 1990, when 12-year-old Bella's* parents announced suddenly, "You're having your appendix out today!" Though horrified at the thought of being operated on, "I was as quiet as a mouse about it because my mum and dad said I could have a special doll if I was a very good girl," recalls Bella, now 34. "So I was as good as I could be." The day after her operation, Bella was promptly given a blonde-haired, blue-eyed doll she christened "Polly". She hugged it tight, wrapped it in a little blanket and pretended to feed it. For years she played with that doll, imagining she'd one day cradle a real baby of her own.

Nine years later, Bella had all but forgotten about the operation when, during a routine pelvic exam and pap smear, she was told it was her uterus, not her appendix, that had been removed. "I was so shocked I felt all chokey here," says Bella, lifting a hand to her throat as she stirs a cup of tea in the kitchen of her Sydney unit. "My parents lied to me," adds Bella, with a quavering voice, "but when I yelled at them that night my mum cried a lot, too, so I never talked about it again. She said I wasn't clever enough and might have dropped my baby or forgotten to feed it. That really hurt."

Bella, who works as a kitchen hand, suffers from a mild intellectual disability, caused by repeated epileptic seizures she suffered as a baby. Without her knowledge or consent, she became the victim of forced sterilisation – surgery on girls with intellectual or physical disabilities to prevent them from menstruating or becoming pregnant. The procedure may involve a tubal ligation (tying of the fallopian tubes) or a partial or full hysterectomy – where the uterus is removed, sometimes along with the ovaries. According to the Australian Human Rights Commission, girls as young as 10 have been subject to sterilisation applications.

Thirteen years on from her heart-breaking discovery, Bella's grief and anger are still raw. "I can't look at you while I talk about this because it makes me sad, sad, sad and mad," she says. The trust she had in her parents and hospital



Australian Medical Association federal president Dr Steve Hambleton says doctors who perform an illegal sterilisation can be charged with medical assault. Top right: Senator Sue Boyce argues more respite is needed for parents of children with disabilities. Right: Anita Smith of Tasmania's Guardianship and Administration Board says there's recently been an increase in doctors enquiring about sterilisation.

staff, she explains, was violated. "They all smiled and smiled at me while they were stealing something from my body. If they'd told the truth and asked me, I would have shouted 'No!'"

Forced sterilisation is justified by some parents, carers and doctors as a kind option for women with a disability to prevent them from being upset by menstruation or at risk of unwanted pregnancy. Although it occurs worldwide, there are no clear figures on its

no protection against that. "In fact, it may increase the risk because there is less evidence of abuse if the abuser knows there is no chance of pregnancy."

Bella was so ashamed of her sterilisation that she only told her boyfriend, Joe* (who has Down syndrome), when they moved in together after a year of dating. He hugged her and cried for a long time. They've now been together for five years, but never spoke of it again. "My sterilisation makes me feel I'm less

"THEY WERE STEALING SOMETHING FROM MY BODY. IF THEY'D TOLD THE TRUTH AND ASKED ME, I WOULD HAVE SHOUTED 'NO!'" BELLA, NOW 34

prevalence. Proponents say sterilisation is in the best interests of the women in question, and their parents who could find themselves responsible for a baby when they may not have the means.

"Though we need to be sympathetic to the needs and pressures on the parents, there are far less invasive methods, such as hormonal implants, that can last two to five years, or the pill, to prevent conception and avoid periods," argues Professor Gwynnyth Llewellyn, of the Faculty of Health Sciences at the University of Sydney, and director of the Australian Family and Disability Studies Research Collaboration.

While women with a disability suffer higher incidence of sexual assault, Professor Llewellyn says sterilisation is

of a woman when I have sex because I'm not normal down there," says Bella. "When I see other mums holding their babies, I look away and cry because I won't ever know that happiness."

Did Bella's parents act in her best interests or violate her rights? It's a polarising question. "Though sterilisation gets sidelined as a medical issue, it is actually about protecting fundamental human rights," says Carolyn Frohmader, executive director of Women With Disabilities Australia. "No-one makes applications to sterilise boys, so I think, in part, this is about society's discomfort with these women having sexual desires and sexual enjoyment."

Under several conventions, the United Nations recognises forced ▶



“Though I don’t plan to have children, I at least have had the right to choose,” says Stella Young, who is “eternally grateful” that her parents refused a doctor’s suggestion that she undergo a hysterectomy as an infant.

sterilisation as both a form of torture and act of violence against a child. While the federal government’s National Human Rights Action Plan Exposure Draft contains a number of new actions, including working with the states on the issue, others are calling for radical reform.

“We need to create Australian law around sterilisation under the crimes act, just as we did in 1995 to prohibit female genital mutilation,” says Frohmader. “We have legislation to prevent children from using solariums, or having cosmetic surgery to get breast implants, because they are too young to decide. Yet a recent draft bill of the Mental Health Act in Western Australia** included a clause to allow the sterilisation of minors as long as the child has given their consent! That’s ludicrous given that a child has no idea of the consequences, and if they have disability they may be experiencing coercion by their carers or have difficulty understanding what a sterilisation will mean.”

There’s a wider controversy, too: is society trying to cleanse the gene pool of “defective DNA”? “There is no doubt that there is a eugenic undercurrent to the practice,” says Graeme Innes, Australia’s Disability Discrimination Commissioner, who is trying to compile figures on the rate of sterilisations because the federal government has none. “There is a rarely spoken concern that people with disability will produce children with ‘genetic defects’, though in

most cases, statistically, their child is no more likely to experience disability. If these women did not have an intellectual disability, there would be public outcry about them being sterilised, often without even being told the truth about what is being done to their bodies. As a society, we clearly have the view that someone with disability is a lesser person and does not deserve the same access to choices.”

What about quality of life for the carer? “It’s so very easy for people who don’t have a child with disability to have strong opinions on this issue,” says Melbourne woman Claire

Grant*, 53, whose daughter Ellie*, 26, developed severe intellectual disability after a bout of meningitis at the age of two. Ellie can’t use a hormonal implant because it causes recurrent infection and the contraceptive pill makes her nauseous and gain weight. When she gets her period she often screams, thinks she

There is no way Ellie could be a parent either – she can’t dress herself, she doesn’t wipe her bottom properly and she will often throw food at the wall if given a meal she doesn’t like.” Claire says she lays awake at night terrified Ellie will become pregnant again. “This is why I wish I could have her sterilised.”

Though sympathetic to Claire’s plight, many parents of children with disability don’t agree with sterilisation. “I think the issue arises because parents are exhausted and given too little support and respite, and there are not enough education services to help people with disability,” says Queensland senator Sue Boyce, whose 28-year-old daughter, Joanna, has Down syndrome and still lives at home with the family.

“Joanna used to freak out at the sight of blood, but I never thought sterilising her was the answer. It took a great deal of education to teach her how to manage her menstruation in places like school, so that she knew how to be discreet and get rid of a pad properly and change it regularly so she didn’t ‘flood’. But she did learn and we have got by.”

“I AM NOT THE ENEMY – I WANT THE BEST FOR MY DAUGHTER, BUT I ALSO NEED TO LIVE. I AM EXHAUSTED AFTER YEARS OF CARING” ONE MOTHER

is dying and scratches her arms in distress. “She has never understood that pulling up your dress and touching yourself in front of other people is not appropriate in public,” says Claire. “She has lived in a care facility for the past five years and in the past 10 years she has been pregnant twice.”

Claire has no idea of the circumstances, or if the sex was consensual. On the first occasion, Ellie miscarried, much to her family’s relief. “The second time we took her for a termination, which was so upsetting because she didn’t really understand what was happening to her,” says Claire. “[But] I am not the enemy – I want the best for my daughter, but I also need to live. I am exhausted and emotionally fragile after years of caring for and worrying about Ellie. Taking on the care of a child if she had one would burn me out completely.

Twenty years ago, parents or carers of girls with a disability needed only to find a sympathetic doctor to perform a surgical sterilisation. Or, they might be offered sterilisation on the spot by a doctor, as happened to the parents of Stella Young, the editor of ABC’s Ramp Up website. Stella, 30, has osteogenesis imperfecta, which means her bones are extremely fragile and may break when she sneezes or knocks a limb. She was born with fractures all over her body and has had hundreds since. The condition has affected her height (she is 88cm) and means that she has to use a wheelchair. Stella recalls: “I was in Adelaide at the age of four and my leg broke and when my parents took me to the hospital the specialist suggested that I might as well have a hysterectomy while I was there to save me from the inconvenience of menstruation later ▶



Amanda, 29, who has a mild intellectual disability, relishes her role as mother to thriving twin girls, Elizabeth (left) and Lily.

on. I am still shocked by this idea and so eternally grateful that Mum and Dad were absolutely horrified and said 'no'. Though I don't plan to have children, I at least have had the right to choose."

In 1992, a landmark High Court decision, known as Marion's case, aimed to outlaw the practice. The court found sterilisation was illegal unless permission was granted by the Family Court or Guardianship Board in the relevant state, but only after proof of a medical emergency or the life of the woman with

tions are slipping under the radar, with some parents sidestepping the need for permission by waiting until their daughters are 18, then encouraging or coercing them into being sterilised. "There are also unsubstantiated stories of doctors using different Medicare numbers – such as for a dilation and curettage – to perform sterilisations, thinking they are helping families, but without going through the proper channels," says Graeme Innes. "Clearly, far more investigation of this area is urgently needed."

"IF WOMEN WITH INTELLECTUAL DISABILITY DO BECOME PREGNANT, RARELY DOES ANYONE SAY, 'CONGRATULATIONS!'" DR MARGARET SPENCER

the disability was under threat. Over the ensuing decade, family courts and guardianship boards reported a dwindling of the practice. A Human Rights and Equal Opportunities report showed there were 1045 sterilisations officially recorded between 1992 and 1997.* Nowadays most states receive about one application a year. Yet recently, according to Anita Smith, president of the Guardianship and Administration Board in Tasmania, there has been an increase in calls from doctors enquiring about sterilisation.

Some say this might signal the tip of an iceberg. People working in disability are concerned that unlawful sterilisa-

Under current legislation, doctors can be charged with medical assault if they conduct an illegal sterilisation. "They would be struck off permanently by the Medical Board and face medical and criminal penalties which could see them end up in prison," says Australian Medical Association federal president Dr Steve Hambleton. To date, no Australian doctor has even been prosecuted. Anti-sterilisation advocates say the state-by-state handling of the issue is unsatisfactory and are pushing for national legislation. "This should ban all sterilisations of girls under the age of 18 years and the prohibition of sterilisation of adults in the absence of

informed consent, except in circumstances where there is a serious threat to health or life," says Frohmader.

While society accepts that people with disability have the right to work and live independently, the right to parenthood is not a given. "It's mistakenly presumed that someone with intellectual disability is a perpetual child so couldn't possibly raise a child safely and successfully," says Dr Margaret Spencer, a coordinator at the Intellectual Disability Rights Service in Sydney. "Sadly, if women with intellectual disability do become pregnant, people often respond as if it's a disaster. They're asked, 'How on earth did this happen?' and feel they have been naughty. Rarely does anyone say, 'Congratulations!'"

Margaret's 29-year-old stepdaughter, Amanda, has a mild intellectual disability, but with family support she is successfully raising twin girls, Lily and Elizabeth, who are eight. "When she told me she was pregnant with twins my biggest concern was that she wasn't in a healthy relationship, and as it turns out her partner, who did not have a disability, left within weeks of the news," says Spencer.

When her girls are home from school in the afternoon, Amanda's small home is just like any other with tweens – the girls chatter and giggle while doing craft and listening to their favourite band, One Direction. In the kitchen, Amanda is making pasta with roast capsicum and goat cheese for dinner to serve alongside roast pork and snow peas. She admits her disability can create limits – she doesn't know how to drive a car and can't advise her girls on their maths homework – but their Saturday tutor helps out there if needed. Clearly, she's doing a fantastic job raising her girls.

"I am fine with fixing their food and all the other things like remembering their notes and going to the doctor if they are sick and cleaning the house," says Amanda. "My girls know that when I say, 'No', I mean it. The main thing I sometimes need help with is just having my stepmother take them if I need a break. It is beautiful being their mum and seeing them reach their milestones and grow and play together. I wouldn't have missed this for the world." ■