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"Because we look different, we act different, they think our sexual relationships might be different."

— *Robert and Julie Strike*

LOVE RIGHTS

People with intellectual disabilities have sex, marry and raise families, despite an overwhelming tide of social disapproval. MONICA DAVIDSON debunks some of the myths.

There is a young couple living in Western Sydney who have been friends since 1985. They married three years ago and have two bright, happy children. They run their own business and lead full, loving lives, but have spent their entire marriage proving to everyone around them that they can be and do whatever they want. They both have an intellectual disability.

Robert and Julie Strike have built a life surrounded by the myths and prejudices associated with intellectual disability. As a result, they have established a group called Self Advocacy to promote and provide information and support for other people in similar circumstances.

"I think it's important for people to realise that we're just the same blood as everyone else," says Robert. "We might be slow at talking, we might be slow at working...maybe slow at picking things up; but by golly, we can do the same things as anyone else. And we've got the same humanity towards anybody else, like you have."

Intellectual disability refers to a general slowness to learn and function within society, and can be classified into categories ranging from mild to severe. About three per cent of the population has some form of intellectual disability, with roughly three-quarters of those classified as mildly disabled. In Australia, that converts to over 500,000 people.

The issue of sexuality and the intellectually disabled is

extremely uncomfortable for most people to contemplate. If any thought is paid to the notion at all, it usually elicits embarrassment, anxiety, resistance and disapproval. There seems to be one outstanding reason for this. Lynette Byrnes, a lawyer working with the Intellectual Disability Rights Service (associated with Redfern Legal Centre in Sydney) states, "I think that part of the problem is that people don't recognise their own sexuality." Put simply, sex and relationships are very important to people with an intellectual disability, as they are to the rest of the population.

"I think that people in the community should realise that people should be equal. We might have a disability, but think what you can do — think how you fell in love, how you do things for yourself. We're no different," Robert asserts.

Many untruths exist concerning the sexual feelings and behaviour of people with an intellectual disability. "You've got the myths — that they don't have sex, that they're lucky to get what they can, who'd have them anyway, that they're sexually promiscuous and they have no morals, and that they don't have feelings," says Susan Kendall, co-ordinator of the Sexual Assault Service at Royal North Shore Hospital, Sydney.

Perhaps the most damaging myth is that people with an intellectual disability are perverse for having sex. Stories about people masturbating constantly, sleeping with anyone, or indulging in depraved practices. What is more probable is that the sexual lives of people with an intellectual disability are

considered inappropriate because they are highly visible; many are surrounded by carers, support people and medical workers. Privacy, especially in an institution, is impossible. As a result, the idea of perverse sex is more to do with visibility.

Jule Strike argues against the myth of asexuality. "A lot of people that I've known in the sheltered workshops, special schools and the adult training centres that I've been involved with, definitely have sexual feelings and want relationships."

Robert is also angered by the idea that people with an intellectual disability are promiscuous. "I think some people might be promiscuous, some people who are 'normal' might be the same way as well. My feeling is that they forget about the normal people and pick up on the people with an intellectual disability. I think that's wrong."

Another myth is that people with an intellectual disability cannot marry or succeed in marriage because they don't understand the complexities of love. The Strikes find this idea difficult to believe, since they know many other couples like themselves who are married and raising families.

"Some so-called 'normal' people think people with disabilities are stupid. But they're not stupid because they use their common knowledge in the way of finding out about that person — finding out who they love and who they want to have sex with," says Robert.

Perhaps the biggest difference between people with an intellectual disability and the rest of the community is the rate of sexual assault. It is estimated — but difficult to prove — that 70 to 80 per cent of people with intellectual disabilities have been sexually abused. Studies also indicate that 99 per cent of offenders were known to their victims.

Sue Kendall is very aware of these statistics. "We get one referral every fortnight, on average, for a person with an intellectual disability who has been recently raped. Of these, not one has proceeded past the police and into the courts."

The reasons behind this are painfully clear. Deanne MacNeil, also of the Sexual Assault Service, states, "They are not credible witnesses." As the perpetrator is usually known to the victim and may be a relative or carer, many cases do not even make it as far as the police. "People do not go to the police because they want to protect, especially if the perpetrator is a family member," MacNeil says.

Kendall assumes that this is the reasoning behind about half the unreported cases. "The next highest per cent is when the police are unable to act on it because of their witness status."

Involuntary sterilisation of intellectually disabled women is another topic that tends to attract public attention. Thousands

of adolescents and adults worldwide have been sterilised to avoid the consequences of their sexuality, if not the issue itself.

However, under NSW law, and similarly in other States, it is illegal for a doctor to perform a procedure intended or reasonably likely to result in a person's infertility unless he or she has valid consent. If the person lacks the capacity, and is 16 years or older, only the Guardianship Board can consent. For young people under 16, the consent of the Supreme Court is required. Parents are not permitted to make the decision to sterilise their children, whether they're under-age or not.

The Guardianship Board is a legal tribunal with the power to appoint guardians and financial planners to people 16 years and older who may be unable to make decisions for themselves due to a disability. In the case of a sterilisation application, a tribunal of three people — usually a doctor, a lawyer and an experienced community member — decide whether or not the woman in question should be sterilised, or if she is able to make the decision herself.

A spokesperson from the Guardianship Board of NSW relates the figures. "Until February this year, in roughly four-and-a-half years of the Board's operation, we'd had 53 cases. In that time there have only been 15 cases in which we've said yes, and 15 cases in which we've said no, then about 15 where we said the person could make their own decision. The rest were withdrawn."

But these figures may not represent the actual number of people with an intellectual disability who are being sterilised in NSW. Anonymous figures from a Sydney hospital for the period 1978-79 showed that, in fact, 521 women who had an intellectual disability were sterilised. Many were sterilised simply because they had difficulty managing their menstrual cycle.

Lynette Byrnes of the Intellectual Disability Rights Service believes

that the reality of these figures could be higher still. "Whatever there is will be an underestimation, because there are doctors who will perform sterilisations without any authorisation. They're not allowed to but they will, because some of it will be ignorance and some of it will be, 'Well, nobody is going to find out anyway'."

In response to the idea that sterilisation is of benefit to all people with an intellectual disability, the Guardianship Board of NSW spokesperson says, "Well, there are some people who understand very well that people with an intellectual disability want to get on and live their own lives and make their own decisions. Against that there are the people who share Herr Hitler's view that eugenics is a good thing."



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On a positive note, there are still many people with an intellectual disability choosing to marry and have children. Their decision to do so, however, is not always greeted in a positive manner.

Jule Strike relates the trauma herself and Robert endured after deciding to marry: "We got disapproval from our advisers. They both disagreed with us getting married."

Many of the people around the couple, including friends, thought their marriage would fail. "[Another friend] didn't think our marriage would work either. She had doubts, and she only realised at our anniversary last year that we've shown her how it can work, and how well we've been doing," Jule continues.

A study into 45 marriages between people with an intellectual disability found that only 6.6 per cent had been broken by divorce or separation. Forty per cent of the marriages had proved to be mutually supportive; a further 31 per cent were basically caring and not regretted by the partners, but were showing some stress symptoms. The divorce rate shown is significantly lower than that of the "normal" community.

The Strikes encountered similar disapproval when they discovered they were expecting their first child. A friend had taken them for a pregnancy test. Jule relates: "The first thing — when we came out after finding out I was pregnant, and we told him — he said, 'We're terminating the baby, aren't we?' And I said, 'We haven't discussed that yet, I only just found out I was pregnant!'"

Other prejudices had to be faced, too. "I heard a comment that Jule was a child having a child, and I told that person that's wrong — you never ever think of a person that's an adult as a child," says Robert.

Ignorance extends even into the medical profession. When the Strike's first child was born, a doctor at the hospital told the couple that the baby had an intellectual disability. "We thought, 'Oh-oh, here we go — how does Amanda-Lee have an intellectual disability? What have you done to prove this?'," says Jule. "And he said, 'We don't know yet, we're doing tests.' This was a doctor who thought that if we have an intellectual disability then our child must have one too."

Before the pregnancy, Robert had genetic counselling and found out he had a 10 per cent chance of fathering a child with an intellectual disability — only slightly greater than the rest of the community. Time has proven that Amanda-Lee and the Strike's second baby, Bradley, are both intellectually normal.

Most people with an intellectual disability know very well why their sexual lives are the subject of so much public scrutiny and myth-making. "It's the unknown. Because we look different, we act different, we walk different...they think our sexual relationships might be different. We're no different to any other normal human being in the world" says Robert.

Intellectual disability is only a small part of most people's lives. Carol Pein, a woman with an intellectual disability who works at the Intellectual Disability Rights Service agrees: "We might have an intellectual disability, but it's only a little part of us."

The assumption within the "normal" community is that living with an intellectual disability would be a horror story. Beneath that, however, and underneath the sexual assault statistics and the fear of sterilisation, there are thousands of people in Australia with an intellectual disability living as we all do — falling in love, having sex, marrying and raising families. ■

Special thanks to Robert and Jule Strike, and all involved with this article. Thanks also to Michael Lynch.

CONTACTS

SELF ADVOCACY: There are a selection of offices in each State. Call to find out if there is a Self Advocacy organisation in your city.
Independent Advocacy in the Tropics ph: (077) 252 506
Independent Advocacy, SA ph: (08) 232 6200
People First, ACT ph: (06) 251 2929
Reinforce Ross House ph: (03) 650 7855
Self Advocacy, Sydney ph: (02) 687 2130
Speak Out Association of Tas ph: (004) 312 344
WA Association for Self Advocacy ph: (08) 481 6233

GUARDIANSHIP BOARD: For information and advice on financial and medical matters for people with an intellectual disability.

Guardianship Board, NSW ph: (02) 566 6600
Guardianship Board, SA ph: (08) 269 7615, toll free in SA (008) 800 501
Guardianship Board, Tas ph: (002) 202 070
Guardianship and Administration Board ph: (03) 600 1525; toll free in Vic (008) 136 829
Guardianship and Administration Board, WA ph: (08) 261 7888; toll free in WA (008) 191 009
Guardianship and Management of Property Tribunal, ACT ph: (06) 267 2713
Intellectually Disabled Citizens Council Of Qld ph: (07) 234 0666; toll free in Qld (008) 177 581
Office of Adult Guardianship, NT Dept. of Health and Community Services ph: (089) 852 896

SEXUAL ASSAULT: For advice or counselling for sexual assault and intellectual disability. Contact your local sexual assault service (in phone book) or one of the following organisations:

FAMILY PLANNING: NSW: (02) 716 6099 ACT: (06) 247 3077
NT: (089) 480 144 Qld: (07) 252 5151 SA: (08) 315 177 Tas: (002) 347 200 Vic: (03) 429 3500 WA: (08) 227 6177
Intellectual Disability Rights Service ph: (02) 686 7277
Lifeline in your city.
Rape Crisis Centre (NSW only) ph: (02) 616 6666, toll free in NSW (008) 424 017

DEPARTMENT OF COMMUNITY SERVICES and related services in each State:

NSW Dept. Of Community Services ph: (02) 716 2222
Qld Dept. of Community Services and Aboriginal and Torres Strait Islander Affairs ph: (07) 224 2111
ACT Dept. of Human Services and Health ph: (06) 269 1556
Vic Dept. for Health and Community Services ph: (03) 412 7777
WA Dept. for Community Development ph: (08) 222 2555
NT Dept. of Health and Community Services ph: (089) 89 2911
SA Dept. of Family and Community Services ph: (08) 226 7000
Tas Dept. of Community Services and Health ph: (002) 333 443

INFORMATION: The NSW Council for Intellectual Disability offers information on a range of disability services in NSW. Call toll free (1-800) 424 666; Sydney (02) 211 1611. Information can also be obtained from the National Council on Intellectual Disability, ACT ph: (06) 282 3624. Telephone numbers for representatives in other States can be obtained from the National Council.