



COMMONWEALTH OF AUSTRALIA

PARLIAMENTARY DEBATES



**THE SENATE**

**PROOF**

**ADJOURNMENT**

**World Down Syndrome Day**

**SPEECH**

**Tuesday, 16 March 2010**

BY AUTHORITY OF THE SENATE

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## SPEECH

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**Questioner**  
**Speaker** Boyce, Sen Sue

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**Question No.**

**Senator BOYCE** (Queensland) (8.31 pm)—I am delighted to rise tonight to advise the Senate that the fourth World Down Syndrome Day will be held this Sunday, 21 March. World Down Syndrome Day has very deliberately been held on the 21st day of the third month of the year, because Down syndrome is caused by a triplication of chromosome 21. It is otherwise, in its most common form, known as trisomy 21. It was in 1866 that Dr Langdon Down first identified the list of characteristics, of which most people with Down syndrome have some, but it was only 50 years ago last year that the cause of Down syndrome was discovered—that is was caused by a triplication of chromosome 21. Before this, people had thought that it was caused by a lack of a chromosome.

I would like very briefly to outline for the Senate the attributes of people with Down syndrome, that is caused by this triplication of chromosome 21. Having Down syndrome does not define who people are. It is still possible, sometimes, to hear people refer to ‘downsies’. People with Down syndrome are people first. Down syndrome is not a deficit; it is an attribute. People with Down syndrome have unique personalities, abilities, skills and interests. They are not all happy all the time. Every child with Down syndrome I have ever met loves music, but then again every child I have ever met loves music. Although Down syndrome is associated with developmental delays and learning difficulties, how disabling these are depends as much on community attitudes and support as on an individual’s level of ability.

One other myth about Down syndrome that I would like to talk about now, because it is becoming more and more important for the parents and carers of people with disability, is that people with Down syndrome no longer die young. It was common, 50 years ago, before antibiotics and before the ability to undergo heart surgery, for the vast majority of people with Down syndrome to die before they got to 30, but this is no longer the case. And it is no longer the case that people with Down syndrome primarily live in institutions. I was delighted to have, as a family guest to our house recently, a woman with Down syndrome who is 64. She lives in supported accommodation. She continues to work part time, three days a week, and she has a busy social life. It certainly does not look, in any way, as if she is going to stop doing any of that at any time soon.

I would like to tell the Senate tonight that I consider—and so do many people in the disability community—that there are still threats to people with Down syndrome. One of the greatest threats at the present time is evidenced by a case that was recently heard in the Brisbane Family Court by Justice Cronin. Justice Cronin agreed to a request by the parents of an 11-year-old girl for her to have a hysterectomy. The primary reason given for this hysterectomy was that this young woman was more susceptible to epileptic episodes when she was menstruating. This young woman has a profound disability. She has Rett syndrome and evidence was given that despite the fact that she is 11 her abilities in many areas might be those of a six-month-old.

I would like to contrast that situation with the agreement that Australia signed up to. It was signed by the Howard government and ratified by the Rudd government under the Convention on the Rights of Persons with Disabilities. I particularly want to draw the Senate’s attention to section 23(c), which states:

States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that ... persons with disabilities, including children, retain their fertility on an equal basis with others.

I would ask the Senate to consider what our view would be if parents of an 11-year-old girl without a disability were given the right to have a hysterectomy performed on her because of menstrual issues. We would all be appalled, as would every Australian.

To treat an 11-year-old girl with a disability differently, in my view, is to discriminate against her on the basis of that disability. I find it particularly ironic that whilst we are allowing this sort of discrimination to occur against people—young women in particular—with disabilities, we are encouraging the abortion and termination of pregnancies of many people who are carrying a foetus with Down syndrome. Some years ago, I was involved in the development of a position statement on this topic. Our view was that Down syndrome in itself is not a reason to terminate a pregnancy. How ironic then that we consider it okay to sterilise women with disabilities yet at the same time we are preventing the existence of many of these women.

It is not all doom and gloom though, and on Saturday I hope there will be celebrations—real celebrations of the many advances—on World Down Syndrome Day. There are two events which I think will assist. One is the Productivity Commission's inquiry, to be launched in April, into long-term planning and the development of a system which would allow for long-term essential care and support of people with severe or profound disabilities, no matter how they are acquired. The inquiry will examine a range of options for long-term care and support, including the consideration of a no-fault social insurance approach to disability and whether that would be appropriate for Australia. We would need to look not just at its feasibility but also at its cost. The Productivity Commission will do this at the beginning in April and will report in June 2011. Given that the inquiry was announced in November last year, one might have hoped for a slightly quicker development of this. Nevertheless, the result will be useful for people with disabilities and for their families for generations to come.

The other event is the Community Affairs References Committee inquiry, one with which I am personally involved and am a member of. We will be looking into the access of planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and to their carers.

This links directly to my earlier point that people with Down syndrome and those with other disabilities are now living longer—and are often outliving their parents. It would be wonderful to have a scheme which provides good, paid services and accommodation for these people but, unless we have people who care around people with disabilities, they still remain vulnerable. They can live in the biggest and best house in the street, with all the best services, but still be open to exploitation and abuse if there are not people who care around them. This is the point of the community affairs inquiry, which is open to receiving submissions until 28 May and will report back to the Senate by 2 September. I would encourage all of you to get involved in activities this Saturday for World Down Syndrome. (*Time expired*)