

Actions Speak Louder than Words

Readers will remember all the issues on the UN Convention on the Rights of Persons with Disabilities covered in the editorial in Vol. 18#3 (available from www.ncid.org.au), in particular the Article on the Right to Life. Since then, the Convention has been formally adopted by the UN General Assembly. In the final draft, the Article was reduced to merely say “States affirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others”.

While the Convention was being debated, the American College of Obstetricians and Gynecologists was revising its Practice Guidelines from screening for Down Syndrome in pregnant women over the age of 35 to screening of all women.

The question is, what will have more impact on the community — the Convention or the Practice Guidelines? In 5 or 20 years time, which document will be used on a daily basis to guide decisions? Generally, women/couples only have a prenatal test if they intend to *abort* a ‘disabled’ foetus — if no disability, then no abortion. Therefore, if the ‘equal basis’ test is applied, the abortion of a foetus with disability will be in direct contravention of the Convention.

The Practice Guidelines recognised that ‘counselling has been very effective in the older group, and it is now important to look at younger women, as the risks in older women have been managed so successfully that the largest number of Down Syndrome children are now being born to younger women’. The implication is that testing will lead to fewer children with Down Syndrome being born to ‘younger women’!

The real test is what happens in practice — **actions speak louder than words!** Though it may seem unfair to judge the Convention by one Article, it is fair to say that the most basic right we all have is the right to life (on an equal basis) and that, if this right is not protected/implemented, then what value have the other Articles in the Convention? If the right to life (on an equal basis) can be defined out of all real meaning, so can the other Articles; the whole Convention then becomes meaningless — just ‘nice’ words on many (30!) pieces of paper!

The decision to terminate a pregnancy is (and should remain) a personal one. Though it is acknowledged that such a decision is influenced by many external factors, the main one is the quality of life of the child and the family. If the Australian Government has a commitment to the Convention on the Rights of Persons with Disabilities and, more importantly, a commitment to people with disability and their families, it must act now.

The 4th Commonwealth State/Territory Disability Agreement is currently being negotiated. Why is it that we still have hundreds of families in urgent need of independent living support — a key factor in having any quality of life? Why is it that, after 15 years of three successive Agreements, the Commonwealth/States do not act and meet the needs of so few Australians?

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