

# *i*nteraction

VOLUME 19 ISSUE 2 2005



## *i*NSIDE:

- Service Provision to Parents with Intellectual Disability
- 
- Welfare to Work Policy: A Critique
- 
- Independent Living

## **The Australian Institute on Intellectual Disability**

The Australian Institute on Intellectual Disability (AIID) operates as the information, research and development arm of NCID. The AIID is entering into a new and exciting phase that will see it expand its current role of delivering information to people with intellectual disability, their families, service providers and the broader community.

The AIID aims to support high level, high quality, independent analysis and strategic policy advice in order to improve the effectiveness of disability service systems, and help sharpen the focus of groups advocating for reform and improvement.

The activities of the AIID include:

### ***Publication and Sales***

The AIID publishes and/or distributes a range of books, monographs and reports relevant to the area of intellectual disability

### ***Policy Research Briefs***

The purpose of the AIID's Policy Research Briefs is to establish what is known and not known about an issue utilising and synthesising extant research, then to define the most productive areas of possible research. Two Briefs currently available: *Families with Members with Disabilities: Love, Money and Public Policy* and *Individual Funding: Flavour of the Day or Sea Change?*

### ***Training and Consultancy***

Training and consultancy services are available from the AIID to assist and support people with intellectual disability, their families and support services. Training and consultancy services currently available include:

- Family Skill Development
- Advocacy Skills and Self Advocacy Skills Development
- Inclusive Schooling Strategies

### ***Roundtables***

The AIID aims to provide high-level forums where research is discussed and debated with the aim of proposing policy principles and program directions, furthering the research agenda and fostering new partnerships between participants.

### ***Research & Development***

The AIID aims to commission evidence-based research independent of the political agenda, that will advance the discussions, debate and ultimately the policies affecting Australians with intellectual disability and their families. Key priority areas include unmet needs, accommodation support, employment, inclusive education, family skills development and leadership.

# *i*NSIDE

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**Design & Layout:** Monica Gourley

**Printed By:** Union Offset Printers

Articles in this journal are the responsibility of their author and do not necessarily represent the views of the Australian Institute on Intellectual Disability.

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## **i** Editorial

### **More and Better Social Services and Health – Not Less!**

Would Australians vote for poorer health services, less education and reduced support services for people with disability? People with intellectual disability are generally amongst those living in poverty. Would Australians vote to make their level of poverty worse?

Most, if not all, who are asked this question would say ‘no’ – they want more and better social services and health, not less!

We currently live in a surreal time. On the one hand, we know that our community services could be better and that there are people who are not getting the services they need. The highest profile of these are health services and the waiting lists that seem to only get longer. On the other hand, we have a competition between the Coalition and Labor parties to see who can propose the lowest tax rates. **THERE IS NO WAY THAT THESE OPPOSING ARGUMENTS CAN BE RECONCILED.**

It is now well documented that there is a shortfall in the funding necessary to provide people with intellectual disability and their families with the support that they need to live a good life. The AIHW has provided an estimate of the extent of unmet need and the necessary funding. People with disability and their families are not seen as a priority for what resources are available; and so any discussion of reducing the community’s resource base (ie. taxation) means people losing the support they currently get and those on ever-growing waiting lists getting nothing.

There is very little commentary on the need to fund the health, education and social services that we all use at some time or other. The challenge is how do we get the public discussion that we must have?

**One answer is by the Commonwealth Government taking responsibility for the public discussion and placing all the facts and figures in the context of meeting Australia’s future needs.**

In his ‘Monday Comment’ column on 25 July 2005 in the Sydney Morning Herald, Ross Gittins challenged the assumptions of the Intergenerational Report released by the Treasurer Peter Costello at the time of the 2002–2003 Budget. Ross Gittins points out that three of the report’s principal assumptions are no longer in a negative trend, ie participation in the labour force by older men is increasing, the fertility rate has at least stabilised and immigration is up. This is all good news – it means that the assumed pressure on Australia’s taxes will be less than anticipated as there will be more people paying taxes than estimated.

Why is this important? As Ross Gittins says:

“... these three challenges to the assumptions of the Intergenerational Report are not something Treasuries need be ashamed of. After all, the report was intended to be a self-defeating prophecy – a warning about what would happen unless changes were made.

And it seems to be working. Not so much because of changes in government policy as because of changes in people’s attitudes and behaviour.

The report has prompted a public discussion that's left many people with a clearer idea of what the future holds ...”

This is exactly what we need – a public discussion that will give all Australians a clearer idea of what the future (and present) holds for thousands of people with intellectual disability and their families. What we want is a change in people's attitudes (towards taxation) AND a change in government policy to meet the challenge of providing the resources so that all Australians have equality of life.

The next Intergenerational Report will be released in 2007 (an election year). This 2<sup>nd</sup> report must contain facts and figures on the extent of unmet need and the costs and benefits of meeting the needs through taxation.

As a starting point, Treasurer Costello could do no better than reiterate Senator Rachel Siewert's (WA) very good speech of 14 September, 2005 to the Senate – the final paragraph is reproduced below. Senator Siewert is congratulated on her speech. Her full speech can be viewed on [www.rachelsiewert.org.au](http://www.rachelsiewert.org.au) (Caring for Carers).

“... This is what the carers of Australia want: a policy that respects the human rights of people with disabilities and their families; a policy that ensures the availability of appropriate accommodation support to people with disabilities when they need it; a policy that enables families caring for people with disabilities to have the same opportunities as other families to lead a 'normal' life; a policy that enables young people with disabilities to live independently with dignity, respect and the support they need to contribute to, and participate in, the life of their community; a policy that lets young adults with disabilities leave the family home, as do other young adults; a policy that gets young people out of institutions and nursing homes; and a policy that lets families survive, parents work and old people retire. This is a national problem that requires a national solution.”

Mark Pattison  
Executive Officer



## \* New Look Contents Page \*



### Wondering what the picture of the 'Mouse' means?

From time to time, we receive more articles of a general nature than we can publish in a reasonable timeframe. We are therefore providing readers (and authors) an alternative to publishing a hard copy of some articles.

When a 'mouse' appears beside the title of an article on the Contents page of Interaction, it means that the article is available on our website:

**[www.ncid.org.au/interaction.htm](http://www.ncid.org.au/interaction.htm)**

We hope these additional articles will be appreciated. Your feedback is welcomed.

## Letters to the Editor

Dear Editor:

### Convention on the human rights of persons with disability

I refer to your letter dated 27 April 2005 to our former Executive Director and to your Editorial column in *Interaction* Volume 18#3, 2005. Both concern the drafting of an article on the right to life in the context of the forthcoming United Nations convention on the human rights of persons with disability. They raise in particular the issue of foetal negative selection on the basis of actual or imputed impairment.

Your Editorial column suggests to readers that we have 'kept silent' on this issue<sup>1</sup>; that we have 'not openly discuss[ed] and debate[d] the fundamental issues involved,'<sup>2</sup> 'that we have thereby 'acquiesced to genocide;'<sup>3</sup> and, that we have 'den[ie]d that [persons with intellectual disability] [have] the same status as human beings as the majority.'<sup>4</sup> You then go on to compare us unfavourably to Professor Peter Singer – renowned for his negative views on the human identity of persons with disability - whom you say has the 'courage' to openly question the human status of a foetus.<sup>5</sup> You imply that we hold an equivalent view, but do not have the courage to state it. Finally you accuse us of 'hop[ing] that the issue and people with intellectual disability will just 'go away.'<sup>6</sup>

People with Disability Australia (PWD) has been an active participant in negotiations on the convention within Australia, at the Asia Pacific Regional level and in the Ad Hoc Committee on the convention at United Nations Headquarters in New York since negotiations commenced. We have been at the forefront of efforts by a small group of participating non-government organisations to secure support from States to prohibit or limit pre-birth negative selection based on the actual or imputed impairment of the foetus. We have been pleased to work closely with delegates of *Inclusion International* in this respect. However, you should note that our efforts on this issue predate the intervention you cite by *Inclusion International* in the Ad Hoc Committee Working Group.

The first reading of the Working Group text proposal for Article 8 Right to Life occurred at the Third Session of the Ad Hoc Committee held in New York from 24 May to 4 June 2004. PWD participated in that meeting and, on 25 May 2004, formally intervened in the Committee's debate in conjunction with the Australian Federation of Disability Organisations (AFDO) and the (Australian) National Association of Community Legal Centres (NACLC) with the address set out at Attachment 1 to this letter.

The second reading of draft Article 8 occurred at the Fifth Session of the Ad Hoc Committee held in New York from 24 January to 4 February 2005. PWD also participated in that meeting and, in the lead up to and during the meeting, circulated to delegates and participating non-Government organisations and independent experts a revised text proposal for Article 8 along with associated commentary. This revised text and commentary was based on the outcomes

<sup>1</sup> Mark Pattison, *Interaction* Volume 18#3, 2005 'Editorial' at page 4 paragraph 2, page 6 paragraph 9 and page 7 paragraph 1.

<sup>2</sup> *Ibid* page 6, paragraph 9.

<sup>3</sup> *Ibid* page 6, paragraph 9.

<sup>4</sup> *Ibid* page 6, paragraph 9.

<sup>5</sup> *Ibid* page 6, paragraph 10

<sup>6</sup> *Ibid* page 7, paragraph 1.

of national consultations conducted in Australia (see below) and our own further deliberations. This revised text proposal and commentary is set out at Attachment 2 to this letter.

Apart from these formal interventions, we have been actively engaged in extensive informal lobbying efforts with Ad Hoc Committee delegates over the past three years in relation to this and many other issues.

In July 2004 PWD, in conjunction with the AFDO and the NACLCL, conducted national consultations in relation to the then text proposal for the convention on behalf of the Australian Attorney-General's Department. A variety of consultation strategies were adopted including an E-bulletin (*Countdown to the Convention!*) which sought responses from readers to key issues, public meetings in each State and Territory capital, and focus groups with particular constituencies, including persons with intellectual disability. The E-bulletin and information about the public meetings were circulated to the National Council on Intellectual Disability (NCID).

Issue 9 of *Countdown to the Convention!* focused on the proposed Article 8 Right to Life and sought feedback on a number of matters including in relation to pre-birth selection based on actual or imputed impairment. The same issues were canvassed in each of the public meetings held across Australia and in the focus groups we conducted.

Additionally, a one-day consultation session was held for members of the AFDO, of which NCID is a member, and a NCID delegate participated in the whole of that meeting. A detailed discussion paper was developed and circulated in advance to each participant in the meeting. The discussion paper (and the meeting itself) included a section on draft Article 8 Right to Life that specifically addressed the issue of pre-birth selection based on disability.

A major report on the outcomes of these national consultations was compiled and submitted to the Australian Attorney-General, the Hon Philip Ruddock, MP, and his Department. The report was simultaneously publicly released and widely disseminated, including to NCID. In relation to proposed Article 8 Right to Life, the report recommends that the Australian Government seeks and supports the incorporation of a limitation on pre-birth selection based on actual or imputed impairment. Note that PWD's many other representations to Australian Government Ministers, agencies and officials over the past 4 years in relation to the convention have also called for such a limitation.

All of this material, and much more about the convention besides, is readily available on our website at [www.pwd.org.au](http://www.pwd.org.au)

Therefore, there is absolutely no basis for you to claim or impute that we have been silent on the issue of pre-birth selection based on actual or imputed impairment or that we have not openly discussed and debated the issue. The other claims and imputations you make are offensive and ridiculous. In our view this warrants a formal retraction and apology.

I now turn to the questions you pose for us in your Editorial. Our responses are set out following:

1. *Do you support a ban on abortion as proposed for Article 8 of the Convention on the Rights of Persons with Disability?*

Our policy position is, and has always been, that the convention ought to incorporate a prohibition or limitation on pre-birth selection based on actual or imputed impairment.

2. *Will you actively support this ban at every opportunity?*

We will continue to seek to secure State Party support for a prohibition or limitation on pre-birth selection based on actual or imputed impairment.

3. *Will you not support the Convention if it does not contain such a ban?*

Our support, or otherwise, for the convention will be based upon the totality of its provisions once the text has been settled. At this stage, our focus is on lobbying for the strongest convention it is possible to achieve.

4. *If not, why do you not want people with intellectual disability to 'share the earth' with you?*

In light of the above, it is unnecessary for us to answer this question.

Yours sincerely

**HEIDI FORREST**

President, People with Disability Australia

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**Attachment 1:**

**Address to Ad Hoc Committee 25 May 2004**

**Draft Article 8: Right to Life**

*Delivered on behalf of People with Disability Australia, the Australian Federation of Disability Organisations and the (Australian) National Association of Community Legal Centres*

*Mr Chairman:*

*Thank you for this opportunity to address the Ad Hoc Committee.*

*We strongly support the content of draft Article 8 but seek the inclusion of additional statements elaborating this right as it applies to the specific circumstances of people with disability. We propose that a further sentence is added to the article as follows:*

*“These measures shall include:*

1. *Enacting measures to discourage the elimination of unborn children on the basis of their actual, suspected, imputed, assumed or possible future disability by:*
  - (a) *Providing positive pre-natal information, and post-natal support to parents of children with disability;*
  - (b) *Prohibiting State and non-State actors from limiting or refusing social assistance on equal terms with others on the basis of a parental decision to bear a child with disability;*
  - (c) *The provision of life-sustaining and life-enhancing medical and social interventions that will ensure survival of persons with disability;*
2. *Enacting protections against violence, abuse, and neglect of people with disability;*
3. *Eliminating policies and practices that result in the segregation and isolation of people with disability.”*

*The lives of people with disability are often regarded as inferior to those without disability. Genetic testing is most often used to detect chromosome variations that may result in impairment for the purposes of supporting selective termination on the basis of that impairment. In this*

*respect the Human Genome Project, whatever the benefits it may offer people with disability, also represents a fundamental eugenic threat to the continued existence of many impairment groups.*

*Much of the information that is made available to parents at the time of genetic testing and immediately following the birth of a child with disability is overwhelmingly negative and inaccurate, and induces parents to opt for termination or withdrawal of life sustaining treatments. There is a grave risk that both States and private actors – such as insurers – may deny social assistance to children with disability and parents where parents make a conscious decision to proceed with a pregnancy where disability has been detected prior to birth.*

*Medical and social interventions are often denied people with disability, or given secondary priority. In the absence of these interventions people with disability sometimes cannot survive.*

*People with disability are subject to significantly higher levels of violence, abuse, and neglect than other members of the community. All people with disability are at increased risk, but particular groups, including women and children with disability, indigenous people with disability and people with multiple and severe impairments, are at particular risk.*

*People with disability are also frequently subject to segregation and isolation, which contributes greatly to their vulnerability to violence, abuse and neglect, resulting in an increased fatality rate.*

*For these reasons, it is vital that this convention create an obligation on States to take steps to ensure that people with disability enjoy this fundamental human right.*

*Thank you for the opportunity to make this intervention.”*

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## **Attachment 2:**

***Excerpt from lobbying sheet circulated to State Party delegates, and participating non-government organisations and independent experts in the lead up to the Fifth Session of the Ad Hoc Committee.***

### **Article 8: Right to Life**

*We strongly support the inclusion of the Right to Life in this convention. However, we wish to highlight that the current formulation of the right is essentially the same as that set out in Article 6 of the International Covenant on Civil and Political Rights. It is suggested that the right should be more directly applied to the specific risks to life faced by persons with disability.*

*The lives of people with disability are often regarded as inferior to those without disability. As a result, medical and social interventions are often denied or restricted to people with disability, or given secondary priority. In the absence of these interventions people with disability sometimes cannot survive or develop to their full potential. There is general acceptance of the fact that people with disability are subject to greater levels of violence and abuse leading to higher mortality. In light of this it is suggested that States must accept a special obligation to protect the lives of people with disability.*

*The expression of the Right to Life in the Convention on the Rights of the Child includes a*

*right to survival and development. We strongly suggest that a similar right be incorporated into this convention with respect to people with disability.*

*Pre-natal genetic testing to detect chromosome variations that may result in impairment is most often used for the purposes of supporting selective termination on the basis of that impairment. In this respect, it should be noted that the Human Genome Project, whatever the benefits it may offer people with disability, also represents a fundamental eugenic threat to the continued existence of many impairment groups. For this reason, we believe that this convention should attempt to erect an ethical constraint on the use of genetic information for the purpose of preventing the lives of children with disability.*

*This obviously presents a difficult ethical challenge, not least because of its potential impact on the choice of women in relation to pregnancy. However, it might be possible to address this issue more indirectly. For example, much of the information that is made available to parents at the time of genetic testing and immediately following the birth of a child with disability is overwhelmingly negative and inaccurate, and induces parents to opt for termination of pregnancy or withdrawal of life sustaining treatments. It is possible to impose an obligation on States to ensure that prospective parents of a child with disability receive positive and realistic orientation to their child and its future life. This may reduce the chances that parents will opt for termination of pregnancy.*

*The ability to detect impairment prior to birth brings with it grave risks that both States and private actors – such as insurers – may deny or restrict social assistance to children with disability and parents where parents make a conscious decision to proceed with a pregnancy where disability has been detected prior to birth. This convention must eliminate any risk that social assistance will be denied or limited to parents or children with disability in circumstances where a genetic variation is detected prior to birth.*

*Taking into account these proposals, the article might be redrafted as follows:*

- 1. States Parties reaffirm the inherent right to life of all persons with disability, and shall take all necessary measures to ensure the protection and enjoyment of this right.*
- 2. States Parties to this convention shall ensure to the maximum extent possible the survival and development of the person with disability.*
- 3. States Parties to this convention shall take immediate and effective measures to discourage termination of pregnancy on the basis of actual, suspected, imputed, assumed or possible future disability. This shall include:*
  - (a) Establishing ethical standards and guidelines for genetic information and counselling services;*
  - (b) Ensuring that information and support provided to parents during the pre-natal period provides a positive orientation to the child with disability;*
  - (c) Ensuring the availability of all necessary post natal information and support to parents and the child with disability;*
  - (d) Prohibiting State and non-State actors from limiting or refusing social assistance on equal terms with others on the basis of a parental decision to bear a child with disability.*

# KEY ISSUES IN SERVICE PROVISION TO PARENTS WITH INTELLECTUAL DISABILITY

Cara Newman, Ruth Ziegeler and Sandra Elliott  
Intellectual Disability Services Council (IDSC)

A review of services available for parents with intellectual disability and exploration of best practice in this field were stated goals of this project. This section provides information from the literature, as well as from the services themselves, on the types of parenting services, models and programs that are available. It goes on to explore the factors impacting upon service delivery and the principles underpinning best practice in this field.

The report from the Australian Government's Department of Family and Community Services project entitled 'Parenting Information Project' (FaCS, 2004) provides a background to the information provided in this project. The Parenting Information Project report included a review of the literature and:

“...of best practice parenting programs and information focusing on the messages parents need to know and how these messages are best delivered; and examples of current parenting programs and information in Australia, together with gaps in information provision, were identified and documented” (FaCS, 2004, pg vii).

It also included an exploration of the needs of parents in Australia and provides useful information about parent needs, general parenting services, and models and programs in Australia. The report goes on to focus on South Australia and parents with intellectual disability.

## **Types of Parenting Services, Models and Programs**

There are a myriad of services that provide parenting support and education in each state of Australia. No state has the same structure for services and a variety of approaches and models are used. The myriad of services results in parenting services being provided in an ad hoc or fragmented manner, and can be confusing for both parents and service providers when deciding where to go for information and support. Examples of the breadth of services available can be found on websites such as:

<http://www.kidscount.com.au/links/phone.asp> (accessed February 2005)

<http://www.sa.bubhub.com.au/saessentialparenting.htm> (accessed February 2005)

The result of this fragmented service delivery is that some parents receive the support they require while others do not. This is not helped by a lack of networks and collaboration between agencies. Parents' access to services varies depending upon the circumstances and needs of parents, their knowledge of available services and their ability to advocate for their needs. Access to services is even more confusing for parents with a disability who may also receive supports via a disability agency and who may face difficulties in accessing general parenting

























































