

*i*nteraction

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- Employment and People with Intellectual Disability
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- Articles on the "Right to Live"
-
- Disability, interdependence and Community

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Contributions (email attachment if possible to aiid@ncid.org.au) and correspondence to:

Australian Institute on Intellectual Disability
PO Box 771 Mawson ACT 2607
Ph (02) 6296 4400, Fax (02) 6296 4488

Internet Email: aiid@ncid.org.au **Home Page:** <http://www.ncid.org.au/aiid.htm>

Editorial Committee: Norma Rigby, Dulcie Stone, Monica Gourley and Mark Pattison

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i Editorial

“Inclusion International asserted that the lives of all future PWD (people with disability), especially those with intellectual disabilities, are at risk because of developments in bioethics and prenatal testing for disability. For most persons with an intellectual disability, the disability is present before birth. Underlying these developments is an intolerance towards diversity which constitutes a denial of the right to be different. Society might soon be making a distinction between lives worth living and those not worth living. This is not an argument about a women’s right to choice, it is about “our right” to be born and to be different. The presence of a disability should not be allowed to become a justification for the termination of life, nor must a disability justify changing the genetic make-up of a person. A strong statement advocating the right to life for PWD should recognize the richness and diversity that PWD bring to the lives of their family and community.”

Daily Summary related to Draft Article 8, RIGHT TO LIFE

Prepared by Landmine Survivors Network

Volume 3, #7, January 13, 2004, Afternoon Session

This is a strong positive statement from Inclusion International on a subject that many would like to be kept silent.¹ It raises fundamental questions about the community’s attitude to people with intellectual disability - whether people with intellectual disability have the status of human beings - and challenges current ideology – a woman’s ‘right to choose’. Because the issues are difficult, does this mean that the community should remain silent? Do those of us who proclaim the humanity of all people become complicit in the community’s denigration of people with intellectual disability if we do not speak out?

At the end of the day, the community will make a judgment about whether people with intellectual disability share the status of ‘human being’. But, if one assumes that the ‘right to life’ is the fundamental right upon which all others are built, then the ‘right to life’ of people with intellectual disability before and after birth must be passionately argued by those who, with Hannah Arendt, see humanity in all people. Arendt when discussing genocide and crimes against humanity, saw these as a denial by the perpetrators that the ‘victims’ were human, ie, have the essence of what it is to be human:

“... crimes against humanity are an attack upon human diversity as such, that is, upon a characteristic of the ‘human status’ without which the very words ‘mankind’ and ‘humanity’ would be devoid of meaning.”

Eichmann in Jerusalem, p. 268 – 269, 1964.

The United Nations is currently drafting and debating a Convention on the Rights of Persons with Disability. Article 8 of the Draft Convention is concerned with the Right to Life. In discussions on Article 8, countries have been asked to include a ban on abortions/terminations of foetuses with disability.

¹ The Inclusion International statement echoes the DPI Europe Declaration on bioethics and human rights (2000) which was published in *Interaction*, Vol. 13#3, with an accompanying article by Dr Christopher Newell. These have been reproduced in this issue as they expand on the points made by Inclusion International.

It is recognised that a ban on abortions where the foetus has an impairment is a very contentious issue. In many countries, termination of pregnancy is legal and there is a strong claim to the right of a woman to decide what happens to her body. Without challenging this right, the question is: is it necessarily the case that there is a conflict between a 'woman's right to choose' and a ban on the abortion of foetuses which may have an intellectual disability?

A woman's right to terminate her pregnancy is based on the premise that she does not want to be pregnant – she does not want to carry a foetus. The reasons why she does not want to be pregnant are irrelevant for our purposes – if the community grants her the right to make the choice to be pregnant or not, then the reasons do not matter.

But, a woman who makes the choice that she does not want to be pregnant does not seek to have medical screening tests to determine whether the foetus has an impairment/defect² or not. She has already made the choice that she does not want to be pregnant and will act according to her choice.

It is only a woman/couple who has decided that she wants to be pregnant who seeks to have medical screening tests to determine whether the foetus that she is carrying has an impairment³ or not. Therefore, if she aborts the foetus because it has an impairment, then it can be rightly said that she is not terminating her pregnancy but aborting the foetus. She wants to carry a foetus to full term, she wants to be pregnant; she just does not want to be pregnant with a foetus that has an impairment.

Abortion is the action of a woman/couple who decides she wants a baby, just not this one. Thus, banning abortion is not a matter of denying a woman choice about her pregnancy, as she has already made this choice. Once she has made the decision that she wants to be pregnant, the only issue that is relevant is the right to life of the foetus.

As Inclusion International states, "this is not an argument about a woman's right to choice, it is about "our right" to be born and to be different".

For people with a prenatal detectable impairment that is associated with intellectual disability, what does this mean?

For the year 2001 – 2002, there were 355 conceptions with Down Syndrome (Trisomy 21) in Victoria. Of these, only 114 (32%) were born, 214 (60%) were aborted. (*Birth Defects in Victoria 2001 – 2002*, p.86, Victorian Perinatal Data Collection Unit, 2004)⁴

The most important point to note about this statistic is that, if 60% of any racial or cultural group was killed, there would be outrage and the charge of genocide would be justly made. The

² A word on language: The words 'defect', 'impairment' and 'abnormality' are used as they are the language of the community. If they jar with you, this is an indication that you are out of step with the community, a community that does not share your values; or, more correctly, a community that does not share their values with certain groups within the community – and thus seeing them as lesser affords them lesser rights and, in some instances, no rights at all.

³ There is a distinct difference between an impairment, "an abnormality in body structure, function or chemistry", and a disability. For example, knowing that someone has an additional 21st chromosome does not tell you about what they will learn, not to mention their personality, contribution to society, family etc.

⁴ For the period 2001 – 2002, 80% of these abortions were for either 'a chromosomal anomaly or central nervous defects (mainly anencephaly or spina bifida)'. (p.21)

issue here is not the termination of pregnancy (or the killing of the foetus) but the 'choice of victims', ie, foetuses with an impairment.

What do these statistics tell us? Or, as Hannah Arendt put it, why does the community not want to 'share the earth' with people with intellectual disability?

The statistics very clearly tell us that the Australian community does not value people with intellectual disability as human beings; ie, the Australian community does not extend to people with intellectual disability the most basic of rights – the right to life. Thus, seeing them as lessor, they may be charitable out of pity for the individuals and their parents, but they will not extend to them the same values and conditions of life that the general community sees as its right.

We as a society are saying that it is permissible to discriminate on the basis of an impairment – and to discriminate at the most fundamental level. The discrimination is not about education, a job or a house; the discrimination is whether the foetus shares the same intrinsic elements of humanity as the majority of the community. The genocidal rate of abortions clearly shows that the community does not hold this view and, by direct extension, the community does not acknowledge that babies with intellectual disability and all people with intellectual disability have a right to life, and are thus disposable.

A woman/couple who has had prenatal screening of the foetus does not abort a foetus that does not have an impairment and where the mother's health is not endangered.

A consequence of the community seeing people with intellectual disability as 'less than human' is that politicians and bureaucrats are able to deny people with intellectual disability and their families the funding support that would enable people with intellectual disability to have the same conditions of life as the general community and to reach their full potential. Acting out of pity, minimal funding is only provided when individuals and families are exhausted after years of neglect.

Is it any wonder that, when the majority of individual women are faced with a prenatal diagnosis of Down Syndrome, they do not see the humanity of their child and only see the financial, emotional and psychological cost? The community clearly does not value their humanity! What is wrong with them? What is best for my family?

Consider how a major newspaper described the situation of a pregnant woman who has a serious mental illness and is carrying a foetus with a physical disability; "a history of psychiatric illness made more profound by *the torment and wretchedness of carrying a disabled child*".

As has been stated, this is a controversial issue and it is an issue that many would prefer was kept silent. It is not acceptable that the community and its representatives do not openly discuss and debate the fundamental issues that are involved. By remaining silent, they acquiesce to genocide, and to the denial that a group within our community has the same status as human beings as the majority.

For all his notoriety, Peter Singer alone has the 'courage' to question whether the foetus (and infants) are human beings (ie, "rational, autonomous and self conscious beings". *Justifying Infanticide* from *Writings on an Ethical Life*, p.186). At the very least, his argument does not discriminate against people with intellectual disability ("This conclusion is not limited to infants who, because of irreversible intellectual disabilities, will never be rational, self-conscious beings." p. 186) and his greatest virtue is that he is prepared to engage in a public debate.

What is not acceptable is for the Australian parties involved in the drafting of the Convention on the Rights of Persons with Disability to remain silent in the hope that the issue and people with intellectual disability will just 'go away'.

The questions are:

1. Do you support a ban on abortion as proposed for Article 8 of the Convention on the Rights of Persons with Disability?
2. Will you actively support this ban at every opportunity?
3. Will you not support the Convention if it does not contain a ban?
4. If not, why do you not want people with intellectual disability to 'share the earth' with you?

People with intellectual disability deserve an open and honest debate that is backed by action.

The Australian parties to the drafting of the UN Convention on the Rights of Persons with Disability must state their position on these most fundamental of issues. These participants are:

Government

- The Hon Philip Ruddock, Attorney General, Australian Government
- The Hon John von Doussa, President, Human Rights and Equal Opportunity Commission

Non-government

- Maurice Corcoran, President, Australian Disability Federation
- Phillip French, Executive Director, People with Disability Australia
- Frank Hall-Bentick, President, Disability Australia

Mark Pattison
Executive Officer, NCID

NB: One of the reviewers of this editorial pointed out that a good analogy for the abortion of children with impairments is the abortion of female fetuses in China as a reaction to the one child policy. Abortion on the basis of gender has been universally condemned, as should abortion on the basis of impairment.

The Knowledge Of Assisting People With Intellectual Disability To Participate In Employment

Paul Cain

cain.paul@bigpond.com

This paper takes a look at the major research and practices that underpin current best practice in helping people with intellectual disability to participate in employment?⁽¹⁾

Capacity to Learn Productive Work Skills

Research from the 1970s demonstrated that people with significant intellectual disability have the capacity to learn skills to work productively. Gold⁽²⁾ published reports that demonstrated that people with severe and profound intellectual disability could complete complex work tasks. Bellamy⁽³⁾ provided a review of the literature demonstrating the productive abilities of people with severe intellectual disability. In 1977 and 1979, Bellamy⁽⁴⁾ published a research-based technology for the instruction, supervision and behavioural support of people with severe and profound mental retardation in vocational habilitation.

Our knowledge about the capacity of all children and adults to learn is such that the issue is now a question of the ability of teachers and human service workers to successfully teach children and adults with intellectual disability. In 1985, McLeod noticing the shift in knowledge, said: "... instead of saying, 'These people ... cannot learn and cannot be trained,' we are now saying, 'We have not been competent enough to teach.' The failing is not with the severely handicapped but with us."⁽⁵⁾

There is now more than thirty years of knowledge and experience in teaching people with intellectual disability productive work skills. This knowledge is essential for employment service personnel to be competent in "how to" teach work skills to support people with intellectual disability in jobs.⁽⁶⁾

Capability of Working Alongside Co-Workers Without Disability

By the 1970s, research and practice began to emerge that people with moderate or severe intellectual disability could achieve employment in integrated employment, i.e., working in a typical business alongside co-workers without disability.

The Employment Training Program (ETP) at the University of Washington was the first formal program in the United States designed to place and train adults with intellectual disability in integrated employment. The ETP made its first successful placement in 1976 and still operates today.⁽⁷⁾ Moss reviewed the program and developed a training manual to teach jobseekers with disability in integrated employment.⁽⁸⁾

In 1978, the Rehabilitation Research and Training Centre (RRTC) at the Virginia Commonwealth University began a program offering training and support for people with

disability to work in integrated work settings, and this program also still operates today.⁽⁹⁾

The ETP and RRTC programs focused on people with significant intellectual impairment. The programs used the 'intelligence quotient' (I.Q.) to determine the degree of intellectual impairment. Jobseekers had I.Q.'s in the range of 30-65 in the ETP with a mean of 56 and 48 in the respective programs. Job retention rates for both programs were around the 50% mark.

Not long after these early trailblazers, other published reports and programs demonstrated that people with significant intellectual disability could work with relative independence in jobs in the community if trained and supported based on the model of *job coaching*.⁽¹⁰⁾ This model included job placement, job site training and advocacy, and ongoing monitoring, follow up and retention.

In Wisconsin, USA, L. & R. Brown published reports about strategies for creating integration and employment opportunities for people with the most severe disabilities in school and employment settings.⁽¹¹⁾

Twenty-one years ago, Bellamy reported in 1984 that:

Two decades of research and development activities have shown that individuals with severe intellectual disabilities are capable of work, whether one emphasizes its meaningfulness, remuneration, integration or complexity.⁽¹²⁾

In 1985, Mank stated that:

... real employment opportunities must be developed and structured so that program participants experience the full range of work outcomes, including income, integration with people without disabilities, good working conditions, and other work benefits.... employment [service] is successful only to the extent that these normal benefits of working are achieved by persons with severe disabilities.⁽¹³⁾

In 1986, Rusch⁽¹⁴⁾ edited a comprehensive text reviewing integrated employment practices across the United States. And in 1987, Nisbet and Callahan⁽¹⁵⁾ published a comprehensive paper on the critical elements of assisting people with severe disability to achieve success in integrated workplaces.

In 1997, David Mank reported that for over a decade it has been:

*.. successfully demonstrated that individuals with severe disabilities are capable of securing typical jobs and working productively within their communities. The term **supported employment** has become synonymous with integrated jobs in the community where persons with disabilities have the opportunity to work alongside people without disability and are provided with individualised supports to facilitate long term success.*⁽¹⁶⁾

We now have almost thirty years of examples of employment assistance practice to support people with intellectual disability to work in typical workplaces alongside co-workers without disability.

New Models of Employment Service

The realisation that people with significant intellectual impairment could learn, develop productive work skills, and successfully work alongside co-workers without disability in typical work settings, led to the design and development of *competitive and supported employment*.⁽¹⁷⁾

The creators of *supported employment* placed an emphasis on *persons with more severe disabilities*, including those with *behavioural challenges*, working in *integrated employment settings*.⁽¹⁸⁾

Competitive and supported employment models provided new practices based on research knowledge to assist people with significant intellectual disability to work in the regular workforce alongside co-workers without disability for real wages. These new models of employment assistance were listed in the Australian Disability Services Act in 1986.

It is important to note that in the United States the terms *competitive employment* and *supported employment* continue to refer to employment service models that assist people with disability in integrated jobs alongside workers without disability. In Australia, the term *supported employment* has been perverted and misinterpreted and become synonymous with *sheltered workshops* – i.e. segregated employment. Warth wrote about this perversion in 1988, noting:

THE MYTH OF RELABELLING – *Change the name and you're done ... sheltered workshops are not the same as supported employment; yet, a number of sheltered workshops are already calling themselves supported employment.*⁽¹⁹⁾ To avoid confusion with the old sheltered/segregated employment, the term *open employment* has become synonymous with integrated/inclusive employment practices in Australia.

New Knowledge in Australia

In Australia, it was, and continues to be, demonstrated that people with significant intellectual impairments can develop skills to work productively, and be successfully employed alongside co-workers without disability in integrated employment settings.

Project Employment in Perth, Western Australia (now known as *Edge*) started in 1984 to *secure award wage jobs in open employment for disabled job seekers*. A 1987 paper⁽²⁰⁾ by Project Employment states that all people with disability are capable of working in open industry, that training technologies can be used on site at an integrated employment setting, and that it tailors jobs to suit workers.

Between 1984 and 1987, Project Employment placed 180 people with intellectual disability in award wage jobs in open employment with a retention rate of 60%–29% had a moderate to severe intellectual impairment. *All workers regardless of I.Q. were performing on average at acceptable levels of safety, attendance and productivity.*⁽²¹⁾

The *Project Employment* report challenged the notion of *job readiness*, finding that access to employment and effective training is far more useful than a 'readiness' test that only prevents people with disability gaining access to real jobs. Thus, access to the program at *Project Employment* requires a desire to work and the support of the person's family.⁽²²⁾

A further report by *Project Employment* in 1988⁽²³⁾ indicated that it had secured 200 jobs for people with intellectual disability, with approximately one-third in the moderate to severe range of I.Q. The paper acknowledges that the model of job support used by *Project Employment* is largely based on the research of Gold and Bellamy. This is a model of *place and train*, where a job is first secured and then training is provided on the job.

Jobsupport (Sydney, NSW), from 1981 developed as a vocational program to assist high school students in special education programs. *Jobsupport* assisted its first jobseeker with

intellectual disability into a job in 1981. Between 1983 and 1985 the program placed a number of people with intellectual disability from high school into jobs in the community.⁽²⁴⁾

In 1986, *Jobsupport* received funding from the Commonwealth under the new Disability Services Act 1986 in order to demonstrate the new models of employment service for people with intellectual disability. This recognised the importance of resources for the ongoing training and support required to ensure employment success for people with significant intellectual disability.

The model of employment support practiced by *Jobsupport* is a replication of the employment programs developed by the University of Washington and the Virginia Commonwealth University discussed above, and is an Australian example of this approach of *supported and competitive employment*.

Jobsupport published a report in 1987⁽²⁵⁾, which indicated that it had assisted 44 people with intellectual disability into integrated jobs. These people had an average I.Q. of 54, were working an average of 28 hours per week, received an average weekly wage of \$172, and had been welcomed and accepted by employers and their co-workers without disability.

The report by *Jobsupport* also provided an indication of the development of guidelines in the U.S.A. and Australia on how to establish effective transition programs from schools to the new work options of *supported* and *competitive* employment programs.⁽²⁶⁾

The implications of the success of the *Jobsupport* program cannot be understated. In the years 1980, 1981 and 1982, only 6 of 177 moderately intellectually disadvantaged school leavers from Sydney's special schools achieved a real job, and even these were at token wages.⁽²⁷⁾

A published report in 1999 showed that *Jobsupport* had assisted 300 people with intellectual disability in integrated jobs. These people had an average I.Q. of 51, an average weekly wage of \$243 (\$47 - \$620) and worked an average of 24 hours per week.⁽²⁸⁾ *Jobsupport* recently celebrated the achievement of helping 400 people with intellectual disability into paid integrated work in 2003.⁽²⁹⁾

In a further study of *Jobsupport* in 1992, it was found that: *supporting people with significant intellectual disability in .. employment can be compared favourably with other models of support and with payments of pension only, in both cost and outcomes*. The report found that *Jobsupport* clients were not dissimilar to clients of *sheltered workshops* and, if anything, *may have higher support needs*.⁽³⁰⁾

An analysis of the costs and outcomes of the *Jobsupport* program also revealed that this model of assistance produced better employment outcomes, together with long-term financial benefits for people with intellectual disability and the Government, as compared to existing *sheltered workshop* and *post school options* in New South Wales. *Jobsupport's* average weekly wage of \$243 in integrated employment settings compares well with the average weekly wage of *sheltered workshops* of \$53.⁽³¹⁾ Other reports have found similar comparative benefits in terms of cost and outcomes.⁽³²⁾

There were other new Australian employment programs and demonstrations which assisted people with intellectual disability to work in integrated employment settings for real wages in the mid 1980s, and of course others since.⁽³³⁾

Implications Of This New Knowledge

Competitive and *supported employment* programs evolved from research based on the premise that people with intellectual disability had the potential to work productively in integrated community jobs.⁽³⁴⁾ This is the great contribution of the employment researchers and practitioners of the 70s and 80s.⁽³⁵⁾

This research needs to be understood in terms of the history of the treatment of people with intellectual disability. The *state of art* services for people with intellectual disability up until the 70s was segregated and congregated models of service – i.e. sheltered workshops and activity therapy centres.

The assumptions of these models of service were that people with intellectual disability need to be *with their own kind*, are unable to work productively, learning is best done in a congregation of people with disability, and that support can only be provided in a segregated setting.

The successful employment of people with intellectual disability in regular jobs, in settings alongside workers without disability, illustrated that segregation (*distancing people with disability from people without disability*), and congregation (*grouping people with disability together*) **is not a need**, but a human service practice that is comparatively poor in achieving positive or typical employment outcomes. Grouping people on the basis of a disability category produced comparatively poor outcomes.

The research found that integrated employment models are significantly better than segregated models of employment service in the attainment of (real) jobs, income generation and interaction with people without disability.⁽³⁶⁾

The research discovered that adults with significant intellectual impairment can work alongside co-workers without disability, can work productively in a valued economic capacity, can learn work skills on-site, and can receive personal and employment support on-site.

The demonstration of the successful employment of people with intellectual disability over a period of almost thirty years provides a rich knowledge of both technical practices and outcomes for the inclusion of people with intellectual disability in the regular workforce.

More Effective To Teach People With Intellectual Disability In Inclusive Settings

Skills are best learnt in the setting where they are to be used.⁽³⁷⁾ The core of this technical issue is universal to all human beings. For people with cognitive impairment, this is even more critical, as this group finds it the most difficult to transfer skills to different settings.

This *pedagogy*⁽³⁸⁾ and/or *androgogy*⁽³⁹⁾ has been known for a long time. What the employment research did, however, was to confirm the practical application of the known research about teaching work skills.

Over thirty years ago, Wolfensberger⁽⁴⁰⁾ wrote that:

If we are serious about working for the goal of preparing a person toward independence and normative functioning, then we must prepare him to function in the context of the ordinary societal contacts which he is expected to have and to handle adaptively in the future.

A fundamental reason why *supported and competitive employment* successfully demonstrated that people with intellectual disability could work productively in integrated settings was that

the *program* was focussed on gaining skills on the job at the integrated worksite.

This also provides an explanation as to why sheltered workshops and other segregated day models have been largely unsuccessful at preparing people to get a job in the regular workforce or learn adaptive community skills. Programmatically, segregation is particularly self-defeating in any context that is claimed to be habilitational.⁽⁴¹⁾

In a review of successful employment practices, Nisbet and Callahan⁽⁴²⁾ found that social and communication skills must be considered equally as important as job skills. Such skills are dependent on the context of the setting; the teaching of these skills in sheltered environments with the expectation that these skills will transfer to an integrated setting is *not a professionally sound practice*.

The concept of *flow through* or *getting ready* in a segregated setting has repeatedly been demonstrated to be ineffective in supporting people with disability into real work. Yet such ideas still command the attention of our sector and politicians.⁽⁴³⁾

The research has found that segregated workshops are characteristically unsuccessful in preparing people with disability for real work. Movement to non-sheltered environments is extremely rare; the chances of making progress are at best minimal; and regression is the rule.⁽⁴⁴⁾

The Level Of Intellectual Disability

The research base of integrated employment was founded upon people with significant intellectual impairment. *Indeed the creators of supported employment were concerned with people usually found in activity centers and habilitation programs rather than people with less severe mental retardation found in sheltered workshop settings.*⁽⁴⁵⁾

Common to the research is that those with the most severe disabilities, including those with behavioural challenges, had the capacity and right to work in integrated employment settings.

It is a common mistake to believe that the more *impaired* one is, the more a person needs to be segregated or congregated in order to learn, work and receive personal support. The education and employment research provides substantial evidence that such an assumption is not valid. The ability to learn, develop work skills, be productive, have a real job and work alongside co-workers with disability can be achieved by people with a range of impairment from mild to severe.

Such a finding challenges the long-held belief that there is a need for a continuum of service models from the segregated to the inclusive to cater for a range of *need* or *disability*.⁽⁴⁶⁾ Segregation or congregation is NOT a human NEED for people with intellectual disability. Nor do segregated models produce better employment or education results for people with significant impairment. This is but an historical habit.

The research informs us that people with significant intellectual disability can work in integrated work settings with people without disability – even receive support and training in inclusive environments.

It is, however, that the more severe your impairment, the more you are at risk of being segregated, congregated and provided models of service that are incoherent with research⁽⁴⁷⁾ – and so, at risk of not developing to one's full potential and interacting with one's peers and

community.

What Do We Know

In summary, we know that people with intellectual disability can:

- learn work skills;
- work productively;
- work successfully alongside workers without disability in typical work settings; and
- do so despite the degree of impairment.

The limitations are:

- the commitment of the community to provide the funding for assistance;
- the competence of the service to support people with intellectual disability to participate in the workforce and so transact inclusive employment; and
- the general economic capacity of a town, city, region or State.

The conclusion of the research is that:

- Work-related behaviours and logistics required in integrated work settings need not function as barriers to people with severe disability;
- Co-worker relationships, transportation logistics, communication problems and physical difficulties are not viable reasons to exclude persons from employment programs;
- People with severe disability demonstrate that they can perform complex work; and
- Employment problems are not due to lack of individual potential or readiness, but rather to the lack of appropriate employment services and opportunities.

New vocational models for persons with severe disabilities that emphasize community integration have been developed, demonstrated and shared with the international community.⁽⁴⁸⁾ These models have built upon the research and demonstration that people with intellectual disability can successively and productively work in integrated work settings.

New research and new practices were the basis for a *new direction* – as the *old direction of segregation* was based on an ideology incoherent with developmental science or modern societal values of an inclusive society.

OUTCOMES OF THE NEW SERVICES

The following is a brief overview of the information that is available on the performance of the new employment services funded through the DSA since 1986. This includes information from the Morgan Research (1991 - 92), the National Information Management System (1995 – 99), and the Commonwealth Disability Services Census (2000 / 01).

Morgan Research 1991-1992⁽⁴⁹⁾

In 1991, the Roy Morgan Research Centre conducted an evaluation of the new competitive and supported employment services established under the DSA.⁽⁵⁰⁾ Results indicated that the competitive employment model was much more common than the four supported employment models (i.e. individual supported jobs [ISJ], enclaves, work crews and small businesses).

According to the Morgan research, competitive employment services were employing

approximately two-thirds (1,121) of the estimated 1,748 clients in work. The supported employment sector consisted predominantly of small businesses, which employed over half of the 627 clients in the supported employment sector (340 or 54%). Work crews employed 149 people or 24%, ISJs employed 121 or 19%, and enclave models employed 17 or 3% of the supported employment sector.

This Morgan research evaluation assessed employment services against ten key indicators of program performance which were designed to reflect the aims of the Disability Services Act 1986:

.. to place clients in socially valued jobs (indicator 1) which they would have the ability and support to retain (job retention: indicator 2) .. at award or near-award rates (indicator 3) and work on full award conditions (indicator 4) .. earning an adequate income would promote independence, including financial independence and self-sufficiency (indicators 5 and 6) .. working in conventional employment would provide opportunities for social integration and contact with non-disabled workers (indicator 7) .. promoting fair treatment (indicator 8), job satisfaction (indicator 9) and enhanced life satisfaction (indicator 10).

Competitive employment services had favourable results on nine of the ten indicators. The exception was indicator 4, where the percentages of workers receiving full award conditions were lower than those for the general working population. Only 71% of working clients received paid sick leave, 66% paid recreation leave and 57% superannuation.

The supported employment sector rated favourably on six of the ten indicators: job retention, independent income management, full award conditions, fair treatment at work, job satisfaction and life satisfaction. Those in supported employment, however, were less likely to have received award wages, used independent modes of travel to work, less likely to have done the same tasks as workers without disability or have mixed socially with their work mates.

Most clients in competitive employment had a low level of disability and hence low support needs. In contrast, approximately half of the supported employment clients had a low level of disability and the other half a moderate or high level of disability.

National Information Management System 1995-1999

From January 1995, the National Information Management System (NIMS) for employment services was introduced. Employment agencies entered data into a specially designed data capture application and, at the end of each quarter sent data to the Australian Institute of Health and Welfare (AIHW), where it was collated into a national data set. NIMS was in operation until July 1999 when it was shut down by the Australian government.

AIHW issued annual summary reports of the data between 1995 and 1999.⁽⁵¹⁾ These reports provided a unique national understanding of the performance of Australian employment programs focused on the integration of people with disability into the workforce.

Between 1995 and June 30 1999, the number of employment services focused on assisting jobseekers with disability working in integrated jobs increased from 260 to 345. The number of people receiving assistance grew from 18, 527 in 1995 to 34, 347 in 1999. People with intellectual disability made up 55% of the total client population but had decreased to 41% by 1999.

The number of people with disability who actually found work was consistently around the 50% mark from 1995 to 1999—that is, for every two persons who sought assistance, approximately

one got a job. The job retention rate from 1995 to 1999 was approximately 75%. The most common type of work was as a labourer or related work (60%) with a range of job types across all industry types.

Between 1995 and 1999, the average worker was employed between 31 - 33 weeks, worked 24 - 26 hours per week, and earned between \$229 - \$236 per week. For people with intellectual disability in 1998/99, the average worker was employed for 24 hours per week and earned \$8.83 per hour or \$209 per week.

In terms of the degree of disability, the NIMS data utilised a statistical concept known as *the frequency of assistance required by a client for activities of daily living (ADL)* and differentiated by categories of 'none', 'occasional', 'frequent' or 'continual'. This refers to the frequency of assistance required in the areas of self-care, mobility and/or verbal communication. In 1998-99 data, 33% of clients required frequent or continual assistance, whereas 65% of clients required either none or occasional assistance.

Commonwealth Disability Services Census

The data system currently in use in Australia is the Commonwealth Disability Services Census which presents national data on services for people with a disability funded under the Disability Services Act. The data presented below is for the period 2000-2001.⁽⁵²⁾

The Census data tells us that in 2000/01 there were:

- 360 employment services assisting job seekers to be employed in integrated workplaces in Australia.
- 37,559 people received employment assistance, of which 11,620 (30.9%) were people with intellectual disability.
- 16,078 people were employed in integrated workplaces, which is an employment placement rate of 42.8%.
- 6,073 (37%) people with intellectual disability were employed in integrated jobs in the community, which is an employment placement rate of 52.3%.
- 37.5% of workers with disability in integrated workplaces earned more than \$300 per week, 59.9% earned more than \$200 per week and 83.3% earned more than \$100.

The Census data, while not as comprehensive as the NIMS data system, does however corroborate the trends identified in terms of access rates, employment rates, and employment outcomes of remuneration and hours of work.

A few thoughts on the data presented

The data provides a picture of an emerging employment services sector focused on assisting jobseekers with disability into integrated employment. The data indicates that one out of every two people seeking assistance actually gets a job. The average hours per week are approximately 24 hours per week with an average wage of around \$230 per week.

It is not the intention of this paper to provide an in-depth analysis of such data. It is illustrative of a service sector that has been operating for almost two decades. There is, however, a need to look back at the origin of the industry, and the research, and begin to examine the current *state of art* in terms of assisting people with intellectual disability to participate in the labour force.

Are there any practices or strategies that are more successful than others? What are the current 'cutting edge' service practices that are producing good outcomes for jobseekers? What are the unique and successful practices by *Edge* and *Jobsupport* which demonstrate successful employment outcomes for people with significant intellectual disability? How can such knowledge be transferred to existing services or new services?

Some Ideas To Grow The Employment Sector

It is clear that people with significant intellectual disability can work productively in integrated work places. Yet the history and ideology of segregation weighs heavy on our ability to offer every person with intellectual disability a quality employment service focused on the new direction of integration. Like an addiction, segregation appears to be the strategy we return to again and again despite the vast knowledge we have acquired. There is an urgent need to re-focus and re-build our efforts to learn and understand the practice of inclusion in employment. The demonstrated success over a quarter of a century of the inclusion of people with intellectual disability in the workforce requires:

- The commitment of Australian governments to ensure that ALL people with intellectual disability leaving school have access to services that know how to transact the latest practices of inclusive employment; and
- The employment service sector to commit to acquiring the competencies to transact inclusion and assist jobseekers with intellectual disability to participate in the workforce.

The need for an employment research model

We need to build a research culture in Australia that examines the interrelationship between employment assistance practices (e.g. job search, on the job training, marketing, maintenance support, etc.), employment outcomes (e.g. remuneration, hours of work, skill and career development, integration, durability and retention) and cost efficiency (e.g. resource inputs and offsets).

From this, the specialist employment sector could build a notion of professional practice that continues to innovate and design as we learn how to support the inclusion of people with disability in employment – bearing in mind that such practice is relatively infant compared to centuries of perfecting the art of segregation.

For example, the early demonstration services in the 1980s published short papers, which would articulate what model of service was used, what outcomes they achieved in terms of jobs, wages and hours, and what it cost in terms of training and support.

These reports were drawn upon to explain the outcomes achieved in the US and Australian demonstrations of supported and competitive employment. However, such demonstration and sharing of knowledge appears to have slowed to a trickle in Australia.

Reinvigorating a dialogue about integration in employment, its practice and outcomes appears to be an urgent priority.

The need to replicate models of employment service for people with significant intellectual impairment

Despite the effective demonstration of employment services and outcomes for people with significant intellectual impairment there are few employment services which specialise for this

group, and thus few gaining employment. Services such as *Edge* and *Jobsupport* are unique rather than common.

For many people with intellectual disability and their families, segregated employment or segregated day programs become the default option through lack of choice – rather than a carefully made informed decision.

In order to achieve the vision of *integration*, it is necessary for a greater number of specialist employment services skilled in assisting people with significant intellectual disability to be simply available.

In the US in 1995, employment services assisted more than 140,000 people, yet a relatively small percentage were people with severe or profound intellectual disability.

.. in 1995, more than 140,000 people (Wehman et al. 1996). Analysis of characteristics of these individuals shows that fewer than 7% of those in ...employment have severe or profound mental retardation. Persons with mild, moderate, or borderline mental retardation [and other disabilities] ... constitute 93%.⁽⁵³⁾

In Australia, we have not collected data on the degree of intellectual impairment. However, NIMS data, estimated by open employment outlets for all clients between 1995 –1999, refers to the frequency of assistance required in the areas of self-care, mobility and/or verbal communication. NIMS in 1998-99 found that approximately 11% of workers with disability had a continual frequency of assistance for activities of daily living.

The Australian data is not useful for determining the employment outcomes of people with differing degrees of intellectual impairment. However, the data, together with anecdotal evidence and the size of the population of people with intellectual disability currently in day programs, highlights an urgent need to develop a responsive and quality employment service system for people with significant intellectual disability.

Moving the focus to generating knowledge

Whereas much is now known about the capacity of people with intellectual disability to productively work in integrated work places, there is in Australia a general lack of innovation and dialogue about practices and knowledge. What has been forgotten is that there is a need to invest in the development of *the practice* of assisting people with disability to participate in the regular workforce. People can't improve if they don't know how to.

We need to monitor and discuss practices and positive outcomes, both domestically and internationally, and consider the relationship between employment service practice and employment outcomes.

What is surprising is that *integration* is a key object of all Australian disability service legislation, yet it is a conversation and area of study that is rarely considered or studied. One would think that, due to its importance and standing, there may be a dedicated professional journal, or perhaps a research centre attached to an Australian university, or a focus of discussion amongst professionals considering the nuances of the principle of integration in employment.

The need for powerful models of employment assistance

People with significant intellectual disability need relevant and powerful models of employment assistance in order to prevent long-term unemployment or long-time loitering in

adult day programs.

The Senate *Inquiry into Poverty and Financial Hardship* found that generic employment assistance programs for the unemployed had marginal impact and that people with disability were likely to be part of the population of long-term unemployed.⁽⁵⁴⁾ *People with disabilities and their carers are vulnerable to poverty and disadvantage and it has been observed that poverty is 'disability's close companion'.*

This bleak assessment underscores the importance of investing resources in models of employment assistance that demonstrate relevance and power in achieving positive employment outcomes.

Service models that are achieving outcomes in terms of integration, wages, reduction in dependency on welfare, and job retention should be the focus of Government, community and service sector examination. The architects of the Disability Services Act foresaw this simple yet profound strategy in writing one of the objects;

.. to ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account in the granting of financial assistance for the provision of such services; ..

To achieve this object, we need to re-focus on building an employment service sector that is vigorous in building its capacity to support the inclusion of people with significant intellectual disability in integrated jobs.

Endnotes

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The above is an abbreviated version of the full report by Paul Cain "**People with Intellectual Disability and Employment: History, Knowledge, Outcomes and Policy – An Australian Perspective**". Copies of the full report are available from NCID. For details, please contact:

Guna Adens
 Tel: 02 6296 4400 / Fax: 02 6296 4488
 Email: ncid@dice.org.au

Harvie Krumpet: Narrating the ethics of disability and death

Dr Gerard Goggin &
Associate Professor Christopher Newell, AM

*Some are Born Great, Some Achieve Greatness, Some Have
Greatness Thrust Upon Them ... and then there are others.*

It is in this way that a most remarkable modern day parable commences. *Harvie Krumpet*, an award winning short film about Harvie, a person with disability, as *other*, provides us with a superb opportunity for the exploration of the ethics of disability and death. It has been acclaimed at international level and has charmed the world. Yet disturbingly absent from the commentary on this Australian film is the recognition that it teaches us much about disability, freedom and death.

The Story

Here is how the back cover of the DVD itself narrates the story:

Harvie Krumpet is the biography of an ordinary man seemingly cursed with perpetual bad luck. From being born with Tourette's syndrome to getting struck by lightning, from having his testicle removed to developing Alzheimer's disease – Harvie's troubles seem unending! Yet, Harvie learns many lessons in life and enjoys his many fruits. He finds love, freedom, nudity and ultimately the true meaning of what it is to be human.

It is of course in the narration of Harvie that we discover why it is that this film has become something which has charmed rather than shocked, something that has delighted rather than devastated. Why it is that it has not demanded the attention of editorial leaders everywhere. It is precisely because *Harvie Krumpet* is told as the story of a person with disability, who acquires further disabilities along the route of life, and as a migrant who is consigned to a variety of menial tasks associated with being both a person with disability and an immigrant. These roles are so dominant that almost any of the outrageous things that are thrown at Harvie, and done to him, are accepted. Conforming to dominant non-disabled accounts of personhood, with disability as *other*, we have no expectations of anything but a tragic existence in the classical Greek sense. Accordingly, as the film unfolds, we root for the underdog, in that great Australian way, as a charming socially disconnected individual, rather than exploring the structural reasons associated with why Harvie is the underdog in the first place. Compounded with this, we see the important role of the medical profession in defining freedom and the good in life, a prime example being the historical role of the profession in defining cigarettes as therapeutic. Harvie smokes cigarettes, encouraged by his doctor: “.. soothing for the lungs ...” says his doctor.

This medicalisation of disability and death is present as sub-text in the film, but goes largely unremarked. For example, it seems very unlikely that with Harvie's diagnosis of disability he would have been allowed to emigrate to Australia. Certainly there are significant case histories regarding immigration policy, whereby Harvie most certainly would not be allowed into Australia today based upon his medical diagnosis and suggestion of cost to Australian society.

A recent horrendous case – one truly of human rights going up in flames – is found when on Monday, 2 April 2001, Shahrzad Kiane set himself alight in front of Parliament House in Canberra, Australia. Over two months later, on 26 May 2001, Kiane died in Concord Hospital, Sydney, of massive infection and an acute abdominal problem due to extensive burns to most of his body. Kiane set himself alight because of his utter frustration at a fruitless five-year struggle to bring his wife and three daughters to Australia. The prime reason why the Australian government would not grant his application was because one of the daughters, Anum, had a disability. Like Anum, Harvie would not have been welcomed – yesterday or today.

Likewise, Harvie's body is further subject to taken-for-granted medical dominance¹ in his admission to Pleasant Paddocks, a nursing home, indicative of how relieved we are when the deviant body and unhinged mind are consigned to an institution. Harvie is made safe, although, as ever, the unasked question is who is being protected from whose sense of reality and presence?

We are here reminded of the 2002 embryonic stem cell debate and the central role of disability, as people were confronted by limited stereotypes of physical disability, especially Christopher Reeve, as catastrophe, and then comforted that disability had been dealt with via policy and the promise of the technological miracle. The Council of Australian Governments' (COAG) 'stem cell accord' and 'united nation' is one of the latest and most highly publicised moments in which biotechnology has been central to Australian politics and identity. The debate over stem cells in the first half of 2002 provides a fascinating case study of how disability is represented. It is yet another example of how disability is central to our cultural, social, political and economic life as a nation. Yet, when such legislation was delivered, the popular image was that disability was taken care of, despite the fact that the pressing everyday issues of so many *Harvies* – people with disability – remain unnoticed, unremarked, out-of-sight.

Politics, Culture and Disability

As we have elsewhere explained, we understand disability in cultural and political terms.² Stories of disability such as Harvie Krumpet structure our culture – something evident in media as well as other cultural, literary and artistic forms. Disability also is often central to how we understand ourselves as Australians, something made clear by the continued references to biotechnology delivering people with disability from their mundane tragic existence. Christopher Reeve as a cultural icon is so enduring that these days we even have stories framed around his approval for particular biotech solutions. Deeply held attitudes and ideas about disability are very much shaped by and circulated through media cultures. Indeed, media is one of the most important contemporary institutions that 'teaches' us about disability and death. Media plays a

¹ For an exploration of this concept, see for example: Willis, E. *Medical Dominance*. Sydney: George Allen and Unwin; 1983.

² See especially: Goggin, G. & Newell, C. *Disability in Australia: exposing a social apartheid*, UNSW Press, Sydney, 2005.

crucial role in reproducing power relationships of disability and death in contemporary Australia; it articulates discourses in which disability is pivotal to governing and the exercise of power.³

In examining Harvie Krumpet, we are reminded that there is a fundamental and difficult aspect to a cultural understanding of disability. This is the sense in which disability is both everywhere yet nowhere. Disability is actually present, not absent, in many cultural texts. In this way, representation of disability differs from that of other marginalised social groups and identities.

Disability as the Antithesis of Freedom

There is a sense in which *Harvie Krumpet* conforms to the dominant account of disability as being the antithesis of freedom. Yet, on a closer reading, we can also discover an understanding of disability and death which challenges these cultural stereotypes. In challenging these, we also start to encounter that these dominant accounts of disability as the antithesis of freedom are to be found within the bioethical literature. For example, in answer to Kuhse and Singer's famous study *Should the Baby Live? The Problem of Handicapped Infants* (OUP, 1985), Allison Davis in a singular yet forgotten review aptly entitled "Yes the Baby Should Live" argues:

I was born with severe spina bifida, and am confined to a wheelchair as a result. Despite my disability and the gloomy predictions made by doctors at my birth, I am now leading a very full, happy and satisfying life by any standards. I am most definitely glad to be alive.

Likewise, in Julian Savulescu's more recent work with regard to disability and his suggestions with regard to children with Down Syndrome and their access to cardiac resources, he asks: "Do we really want 'equality of access'?" Answering 'no', Savulescu properly notes that "It is probably unlawful" to place lower priority on children with Down Syndrome and other disabilities who need heart transplants. Yet he asks: "But is it unethical?"⁴

Otherness and Transforming Relationships

In our recent study *Disability in Australia: exposing a social apartheid*, we explore the routine ways in which disability is constituted in taken-for-granted ways as *other*, and the implications for public policy including bioethics.⁵ *There is a sense in which such dominant accounts of disability as other* are found in the narration of Harvie's life and in the newspaper headline to do with yet another reflection: "Retarded migrant survives lightning strike" and in his being not just a person with disability, but someone who needed to have his testicle removed, let alone a nudist and animal liberationist. Can there be any more signs of *otherness*! Then of course his status as *other* is confirmed as he slowly loses his mind – through the narration that: "It wasn't long before they took him away when a neighbour found him trying to withdraw money from a microwave."

³ An early and still important discussion of discourse and disability is given by Gillian Fulcher in *Disabling policies?: a comparative approach to education, policy, and disability*, Falmer Press, London and New York, 1989.

⁴ Julian Savulescu, "Resources, Down's syndrome, and cardiac surgery", *British Medical Journal*, 14 April, 2001;322, pp 875-876.

⁵ Goggin, G. & Newell, C. *Disability in Australia: exposing a social apartheid*, UNSW Press, Sydney, 2005

Yet the paradox and significant commentary is found in the way in which Harvie is narrated not just as *other* but as a living, breathing person with whom we can identify. Despite the dominant social narratives of disability as *other*, we encounter Harvie as one of us – as someone for whom we root, with whom we identify, whether it is as someone who bucks the system, engages in the freedom of the nudism that we have all wanted to do, or just in keeping on going despite the fact that he really shouldn't survive all the devastating things that happen to him.

Then there is his admission to the “Pleasant Paddocks” nursing home where “everyone sat around and waited to die” which the messages would suggest that it is really relationships which are actually crucial in terms of quality of life. As the film narrates, he was put on a new drug to tackle his depression “but the only thing that would really tackle his depression was letters from Ruby” (his daughter with disability – as if Harvie doesn't have enough problems!)

Here we encounter an important lesson. Relationships can either confirm the tragedy of disability as we learn to be *other* and are constituted as the antithesis of freedom – or everyday settings and relationships can become transforming. Bioethics literature largely makes pronouncements based on disease labels, as highlighted above, but those disease labels are a very small part of the picture – and context – in terms of quality of life. An account of bioethics which focused on life-sustaining relationships would have very different literature emerging to do with disability and death, and yet in so doing would also be critiquing the dominant accounts of disability and people encountering death as *other* – something significant in a world where non-disabled bioethicists have become the new high priests.

Given Harvie's situation, surely we would all understand when he chooses to die? Yet in a special moment, as he talks through the night with a woman who is waiting for death, eventually he decides he has more living to do, and she actually decides to take the overdose. The dominant account of disability would mean that it would be understandable, sanitary, inevitable, desirable for him to take his life. Yet, instead, Harvie goes back to a life whereby he enjoys sitting nude, waiting at the bus stop.

When we listen to the stories of many people who desire euthanasia – or medically assisted suicide – we often find perceptions of estrangement, difference and fear of being *other*. In terms of dominant culture, disability and its loss of bodily (physical and mental) control is a form of living death.

Harvie as Counter-Cultural

Yet in this counter-cultural story, Harvie is given a new lease on life by a conversation in the middle of the night with a woman with obvious disability, as he contemplates a desirable end—the drug overdose he holds in his hand. As we examine this moment, all of a sudden our narrow rationalistic Western conceptions of freedom and choice are challenged. The desirable, understandable thing for a person with multiple disabilities is found in the technical fix found in the tablets Harvie holds in his hand – not only would Harvie be freed from his mundane, tragic existence, but so would we. Yet in relationship with a despised, objectionable, ugly, disconcerting *other*, Harvie finds goodness to his life and exercises his freedom in a shocking way. He decides to live and finds strength from that despised *other* to whom society would largely not give any time of day.

After all, as Harvie has learnt in amassing his ‘fakts’: “Fakt 1034: Life is like a cigarette. Smoke it to the butt.”

It is largely this message which has been told in different ways by the international disability rights movement as it has sought to engage with the dominant accounts of disability as *other* and an account of freedom which finds disability to be its antithesis, even the enemy of freedom. Harvie Krumpet may be found to be a profound ethical text. In narrating the story of Harvie as *other*, it actually calls us into relationship with him and does something that most of the bioethical literature fails to do. It establishes disability as not just the epitome of *otherness*, not as an unrequited tragedy, it calls us into relationship with the *other*, names the *other* and, in identifying with the *other*, we claim him as part of us.

Despite being a person with disability, Harvie enters into a valued relationship as he does something that people with disability should not do – he marries. He is subjected to a variety of prejudices and yet, as he ages, he does not know that he really would be better off dead – even if we as an audience are always expecting something similar to happen. Likewise, the moment when it looks as if Harvie will finally, understandably, clinically and yet with great compassion, have the moment for death in difficult circumstances. Yet again, that meta-narrative is disrupted as the euthanasia we all expect is transcended. “Thank you” says Harvie to the body of the woman who has just died. Via relationship with an appalling looking woman, as he has talked about life and death, he’s found that he still has some living to do as he continues on with something that normally we would never entertain in our dominant culture – a life with significant disability, intellectual impairment, whereby he is happy to sit in the nude at the bus station.

Harvie Krumpet provides us with a subtle yet effective challenge to the meta-narratives of disability and death. Yet, it is only when we examine and make clear the sub-text associated with Harvie Krumpet that it becomes something more than charming – it becomes an ethical text of counter-cultural proportions. Harvie Krumpet provides us with an alternative glimpse, a different narration, an opportunity to reflect on the ethics of freedom, death and disability in very different ways. The political question is whether Australian society will be prepared to do so – and entertain the profound implications for social policy?

About the authors:

Dr Gerard Goggin is an ARC Australian Research Fellow in the Centre for Critical and Cultural Studies, University of Queensland (g.goggin@uq.edu.au).

Associate Professor Christopher Newell, AM is Associate Professor of Medical Ethics in the School of Medicine, University of Tasmania (Christopher.newell@utas.edu.au). He is a person with disability.

Disability, Interdependence and Community

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(Keynote address: Physical Disability Council of Australia Annual Forum, Fremantle, November 19-20, 2004)

The disability movement has put much effort into having people with disability accepted as citizens with rights equal to those of others: including rights to access to premises, to education, and to be a valued individual. But where are we after almost 25 years of IYDP? Have we “empowered ourselves and others”? And should we push for equity in a society whose values of individualistic competition and consumerism are root causes for much of our disadvantage and exclusion? It is perhaps time to look back and acknowledge the past, but also have a keen eye for the present and renew our vision for a better future. Are goals of individual independence and autonomy, enshrined in rules and standards, part of a sustainable vision for the disability movement? I will explore such questions and suggest a vision and strategies that may allow us to go forward from here. I want to emphasise interdependence over independence, people over consumers, and connectedness over separateness. Such a different vision may reinvigorate the disability movement as a contributor to and advocate for genuine community where diversity is the breath of a good life for all citizens.

I want to start with a short story told to me by a fellow who had quadriplegia, similar in type to mine. I think of his story as not just his but as our story—the story of people who have disabilities. He was pushing his wheelchair along a busy Perth city footpath. And as those who push their wheelchairs know, the camber on most footpaths can be a real killer. You’re always fighting being pulled off the path, into the gutter. Well, the camber of this path was such indeed that he lost control, veered to the kerb, stopped just in time and just balanced there precariously with one wheel overhanging the gutter. For him it was the equivalent to one of those cliff-hanger scenes in the movies—you know, where a car is dangerously perched over an abyss and the people inside don’t dare to breathe in case the car overbalances. Well, that’s what it was like for him. A fall out onto the road could have caused serious injury to him. Movie watchers would be on the edge of their seats, almost physically reaching out to stop the car going over the edge. But in his case the shoppers kept shopping and the businessmen kept going on about their business, leaving him hanging there. Until, after some time, an elderly lady stepped off the path, walked around in front of him and said politely, ignoring the obvious awkwardness of his situation: “Excuse me Sir, but are you alright?” “No”, he croaked breathlessly, “help—pull me back”. She did and so, thankfully, he could continue on his journey.

I am telling you this story as I want to put out some challenges to our ways of thinking—ways of thinking about disability, about the place of people with disability in the world and what the disability movement can do about that.

The lady may as well have asked the question that the passers-by may have taken for granted: “Are you OK there while you are exercising your right to self determination and choice whether to fall off the kerb or not—and we exercise our choice about whether to assist you?” Or, perhaps they did not stop to wonder about his situation at all.

As the story indicates, people have become disconnected and as a result feel less responsibility towards each other. Our society values people most in their roles of consumers and producers of goods and services. The values that those roles are based on emphasise individual self-interest. They involve a belief in competition as the route towards material gain, where material gain is held to be the source of our wellbeing. Our society celebrates those attributes that are thought to enhance such competitiveness: such as health, wealth, physical beauty and intelligence. If any person does not possess many or any of such attributes, and consequently looks and behaves very differently to such ideals, they embody everything that is thought of as bad about life. People with disability thus can arouse fears in others about the possibility that life is not perfect after all, that they too are fragile and mortal. They may then be ignored or become the subjects of efforts of segregation, of cure or of elimination. We see some of those fears played out in debates about euthanasia, stem cell research, genetic modification and abortion. Too often people with disability are still merely physically a part of this world and the world often thinks it can, or even should, do without them.

The position of people with disability is at best as shaky as ever. While tremendous effort has gone into accessible travel, buildings, education and participation in the workforce, services of many kinds, including legislation to achieve these, all this is at risk. It’s at risk because these achievements exist by the grace of those who are in power and who subscribe to the individualistic social values of self-interest that exclude us. And I don’t have to tell you that, besides keeping what we have gained, much more remains to be done.

The achievements in access, education and employment are largely buttressed by law and by money—and through a *tolerance* of us as the Other. It remains to be seen how strong our community’s *commitment* is towards people with disability in a political climate where escalating public policies of individual wealth maximisation and safety from undesirable ‘others’, are directly at odds with the support of dependent and vulnerable people. We must acknowledge historically unprecedented levels of public money applied to disability. But what do we think will happen in a near future when the dollars now earmarked to the so-called ‘burden of disease’—associated with a disproportionately growing aged and disabled population—will be eyed by a younger generation? Power is only ever borrowed, so that younger generation will inevitably obtain its own political and economic power. If we do not have *their* genuine commitment to *our* welfare, I think our future is predictable.

After all, what has that generation learned from us? More than ever, our society is about being “relaxed and comfortable” while politicians have us wage a permanent war on terror and on illegal immigrants. It’s a society where public trust and commitment to others—essential to our wellbeing—have been rolled and fear is a prime motivator in deciding how to live. Closely allied to these insecurities and fears is fear of imperfection, discomfort, dependence and vulnerability as this is embodied by people with disability. This situation spells grave risk to us.

So it does not make sense to put faith in those same values that cause our exclusion. Yet that is what much of the disability agenda still seems to be about. In part, this is understandable as pursuits of rights to participation, to autonomy, empowerment and choice have historically been

the bread and butter of our movement and we very much needed to raise them. But have we gone too far and are we still effectively using this framework? We have even called ourselves consumers in order to achieve equal status, except that in many respects of course we are denied the wherewithal and real choices to fit that role.

As a minor example of such emasculated consumerism, I contacted the hospital—a place where patients are now customers—for my usual stock-up order of medical supplies. I asked for a change of product because it had spectacularly failed me lately. “But you have never complained about them before. I have already ordered your brand in” she replied—“for the next six months to fit in with the hospital’s new budget cycle”. I could see it now, my house filled with boxes: “You want a seat? Just pull up a box of medical supplies. I have no room for chairs”. I was told that I must first make an appointment to discuss a change, involving a 70km roundtrip—but then what else would I be doing with my time as a disabled person anyway? When I incredulously said that I had now told her what the problem was over the phone, this woman who had known me since 1978 rebutted: “but I cannot just change orders because any Tom, Dick or Harry requests it” I was flabbergasted. Disconnection, distance, bureaucracy...

So who wants to be a consumer anyway? Consumers are diminished human beings, stripped of the dignity that comes from being valued for one’s individual potential to develop. But in our lobbying, funding submissions and on advisory councils, we are often seduced into using the language of the dominant culture of choice and self interest. That culture has strait-jacketed the needs of people with disability within purchaser-provider-business models, and moulded them to the perimeters of corporate plans. Cost-cutting, bean counting and even profit-making have increasingly become part of human service. We are not sufficiently challenging this culture as directly counter to our interests. Merely calling for more rights and more money from that culture’s elected leadership is not going to do it. And we are not really challenging the big bioethical issues, some linked to powerful corporate interests, that threaten a new eugenics. Weakening us further, much of our organisational funding comes from those same governments that operate on the values that exclude us. (The most recent example of this vulnerability is the de-funding of a Perth Citizen Advocacy group, apparently for doing their job.) We must also acknowledge that our dominant discourse of autonomy and rights excludes those people with the most significant cognitive disabilities and for whom empowerment is meaningless. A strong disability movement needs solidarity across such divisions.

This society is about winners and losers. If the winners are per definition always the powerful, the fast, the beautiful and the rich, then most people with disability will always remain behind the eight-ball. Obviously, no amount of legislation, empowerment or rights of choice could save the man in our story. The assistance he needed cannot be compelled. Such assistance depends on a genuine feeling of connection between people, and rights legislation by itself cannot bring this about.

As appears to be the case with the world we live in, the place of people with disability in society is at a crossroads, as is the disability movement. I suggest that we honour the disability movement’s many achievements, take stock of their effectiveness in a rapidly changing world and build on them. I propose a renewal of the disability movement. But, unlike the Federal Opposition’s response to their recent election loss, I do not suggest that we fall in line with the apparent winners. But what values then *do* we use—values that can apply to the full spectrum of people with disability? Well, simply enough, I’d suggest we use our own disability experience—and push that agenda.

There is a strong body of research that shows that most people who have significant impairments report a wellbeing or life satisfaction that is equal to, or even better than that of the general population. This goes against public expectations of life with disability as miserable—to be cured if possible or reason enough for abortion or euthanasia. Why is this so? — it is relationships and the disability experience of interdependence.

The primary source of our wellbeing is the quality of our relationships. This is true for people with disability as it is for anyone. I call it the disability experience of interdependence. It is simple – briefly, we are all particularly vulnerable and dependent at various times in our lives. Just think of newborn babies, toddlers, or when we are ill or in frail old age. We would not survive and develop without unconditional love and assistance from others at those times. But many people with disability are often greatly dependent on others for fundamental and intimate needs, including dressing, showering and toileting—all of the time. But by consciously developing mutual, committed relationships, these people transcend negative experience of dependence and could find life satisfaction. In my own research among 20 people with quadriplegia in the Netherlands and in Australia, my participants described the following process: at some point they accepted their impairment as a fact, as a conscious choice. Next they actively reached out to their carers to improve their circumstances. In the process, they gained interpersonal qualities and changed themselves into more sociable human beings than they felt they were pre-injury. Their transformation, or growth, within their now deeper relationships became their source of wellbeing under challenging circumstances. Their impairment had not gone but their experience of disability had changed. Dependence on those with whom you have a trusted relationship is no longer a problem—even if they assist with the most intimate of tasks. Their vulnerability to ill-effects of disability had been reduced. As one participant said:

It is possible that people will discover that particularly people with a disability have gained a certain wisdom that society needs: that people have to learn to live with the unknown; with the fact that any moment of the day anything can happen, whereby life is changed completely. (Leipoldt, 2003, p.224).

In overcoming situations most people fear and, in achieving a rewarding sense of life satisfaction, all they had done was to acknowledge life as it is: imperfect, unpredictable and dependent on others. It was just that their extreme experience of dependence and vulnerability had pushed them with their noses on that which makes life worth living—committed relationships. This is so for anyone. What helps us lead lives, well worth living, is the expression of those social values in people that make them supportive—the other side of the coin to individual self-interest. This committed interaction is the meaning of interdependence. It calls forth the best in us.

I stress that I am not suggesting that people with disability are saints, heroes or stoic victims or that disability is merely something that ought to be transcended by the individual as their private tragedy. To the contrary, I am saying “anything about us is about *all of us*”. Anyone of us is subject to disability—it forms part of a whole life. Improving the experience of disability depends on a social model that recognises that first and foremost our wellbeing lies in good social relations. Presently, people with disability who are not productive in the economy receive the trickle-down crumbs from the full table of our wealthy nation, as their safety net. A society based on the values of committed relationship would support each person’s human needs and interests out of a sense of inherent equal worth based on each person’s capacity for development.

Using our own experience of interdependence in our activism embeds our needs within

universal human needs and interests. No more separatism, apartheid or special needs. Community is enriched by the diversity of the full presence of all kinds of people, people with disability among them. A genuine community—a civil society—a sustainable world—is not possible without them.

Unrealistic? Utopian thinking you say? This is what author and Federal Parliamentarian Lindsay Tanner has to say about relationship as a basis for broad social and economic policy:

The depth and quality of our human relationships determines the strength of our society and the quality of our lives. It's time to put relationships at the centre of the political debate. We can reignite the hope that is so vital to social and economic progress, and heal the divisions crippling our efforts to build a more cohesive and inclusive society. Building stronger relationships is the key to creating a better society. (Tanner,L., 2003. Crowded lives. Australia: Pluto Press, p.111)

Of course the world in the interdependent view is not Paradise on earth. Disability, hardship and difficulty will not be absent. We will just be better at surfing the wave rather than be wiped out by it. And Tanner is not alone in his sentiments. For instance, important streams within feminist thought emphasise social policy around human dependence and environmentalists value social and biodiversity. And emerging think tanks such as the Australia Institute, The Australian Collaboration and WA Collaboration base their work on interconnectedness. We could add value to our message and gain strength in co-operation with such groups and *they* would benefit from our focus on what life is about at its deepest levels.

Undoubtedly this is a difficult task. Take for a start the difficulties in talking about dependence and vulnerability as something to be acknowledged as part of a whole and flourishing life. *Of course* this is rejected knowledge in a world that fears these states. For good reasons, the disability movement has itself been silent on such topics. You'd be a wimp to even mention them. But I believe that the *practical* agenda of our experience is one that may lead to a sustainable society where respect for diversity means something: that is, full engagement with all aspects that make up life and with all those who are in it.

What does this mean in practice? Briefly, I see four broad categories that would identify a disability movement that was based on interdependence. Firstly, it would use the common human denominator of relationships in framing its vision of people with disability as integral to a civil society. Secondly, it would strengthen alliances among the like-minded, both internal and external to the disability movement. This would mean alliances across disability labels and with other social groups that put relationship central. It would also mean supporting and strengthening those parts of the disability movement and services that already genuinely focus on relationship. Thirdly, it would emphasise relationship and connection in its own language and in its organisational structure. The latter would feature diverse funding sources and networks leaning away from one-dimensional funding sources and hierarchical models. Fourthly, it could put greater effort into engaging with the difficult bioethical issues that go to the heart of our existence. That's because these are precisely the issues where dependency and vulnerability loom large.

In conclusion, the times seem ripe for us to reorient ourselves to rapidly changing circumstances. More than ever, the world is in need of the kind of resilience that comes from acknowledgment of the human condition as involving dependence and vulnerability.

The knowledge of interdependence involves that of knowing how to live well with limits, in relationship to others and our environment. The disability experience is rich in such knowledge. Accepting people with disability as integral to a sustainable community would be the most important safeguard that we could achieve in our turbulent world. The disability movement possesses some hard-won foundations upon which it can build and renew itself, along the lines of the disability experience of interdependence. It could realign the disability agenda with that which makes us **all** potentially more fully human. We have to be the change we'd like to see. In a word, that means drawing on our experience of relationship. Our man in the cliff hanger story at least would agree that there is much power in that.

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CONFERENCES

6-9 October, 2005

2005 National Advocacy Conference for People with a Disability

Ability Incorporated

Valla Beach Resort

Nambucca Heads, NSW

Contact:

Tel: 02 6628 8188 or 1800 657 961

Email: aiadvoc@bigpond.net.au

www.nor.com.au/community/aiadvoc

Overseas Conferences (*details will be provided when available*):

21-24 September, 2005

"Many Voices, One Vision"

AAMR Summit

Washington DC, USA

September/October, 2005

ASSID Conference

New Zealand

The right to live and be different:

An exploration of the significance of the DPI Europe Declaration on bioethics and human rights

Dr Christopher Newell, PhD
(Reproduced from Interaction 13#3)

In February of this year I had the opportunity to participate in a unique two day conference organised by Disabled Peoples' International (DPI) Europe. A hundred and thirty people with disabilities, their parents and delegates from twenty-seven countries in Europe, Africa, Australia and North America, met in Solihull in the UK to discuss bioethics and human rights. It was the first time that such an international conference for and of people with disability had been held to explore and define bioethical issues from a disability perspective.

At the conclusion of the conference a declaration was made, facilitated in large part by the work of Rachel Hurst, OBE. That declaration was informed by the workshops, papers and discussions of the two days. Given the diversity of opinions with regard to a variety of bioethical issues, the fact that any such declaration was possible is remarkable and reflects the commitment of delegates to working together to find common ground. It is especially a recognition of the shared experience of oppression. People from intellectual, psychiatric, learning, physical and sensory disabilities as well as Deaf people were present and the declaration (*which is reproduced in full as an appendix to this article*) was arrived at, with each clause being debated at the end of the conference.

There are many implications for the engagement of Australians with disabilities with a bioethics and social policy in general. In the first place, there is the trenchant demand in the statement “nothing about us without us” pointing to the exclusion from debates about bioethical issues. This rings true with the experience of people with disability and their carers in Australia. Whilst our national engagement with regard to bioethics goes back to 1990 (Disabled Peoples' International, Australia, 1990), we have yet to achieve a national conference for and of people with all types of disabilities, defining and responding to bioethical issues from a disability perspective. So often documents in Australian bioethics and social policy with regard to emerging biotechnology have excluded the voices and considerations of people with disability.

Yet, we need to recognise that there have been significant wins in Australia. For example, it became clear at this international conference that the successful political lobbying which led to the incorporation of a disability perspective on the Australian Health Ethics Committee, as mandated in the *National Health and Medical Research Council Act 1992*, and the requirement for several stages of public consultation, was actually the first of its kind in the world.

The next key statement of “richness in diversity” has enormous implications for Australian social policy. The claim “...that a society without disabled people would be a lesser society” has enormous implications for Australian society, especially lawyers, law makers and those involved in bioethical decision-making to grasp. Here is the international claim by those of

us with disability that we are far more than deviants or second class deficits, or indeed merely the constructions of dominant discourses, especially medical and charitable discourse (Fulcher, 1989). Disability is an inevitable part of society and there is a rejection of the norms and standards used by non-disabled people in deciding who should be born and who should live. The Australian disability community can also learn from the recognition of the importance of forming alliances with scientists, the medical profession and all other professions which have an impact upon social policy decisions. Quite simply, we need to be a lot smarter in creating alliances across the professional and political divide. (See for example the work of Newell & Meumann, 1997)

The third key mission message is that “all human beings are born free and equal in dignity and rights”. Clearly, we have an Australian society where, in the terms of *Animal Farm*, all are equal — its just that some are more equal than others. The implications of this claim, upheld by human rights instruments, are fundamentally important, applying not just to abortion and other bioethical issues, but to the provision of goods and services beyond even that envisaged by the *Disability Discrimination Act 1992*.

After all, that legislation may in places be seen to deny full human rights, and allows discrimination in such areas as social security, law and immigration, as well as allowing those of us deemed as insurance risks to be denied insurance. As Australian consultant ethicist, Nicholas Tonti-Filippini, observes with regard to the pressing issue of genetic discrimination not adequately tackled by our Australian Parliament:

I have a serious disease of unknown origin and which might have a genetic basis. Not only have I been refused insurance and superannuation pension entitlements, but my children are not insurable. In regard to financial institutions, even though I work full-time and had more than sufficient income to cover a mortgage, I could only take out a mortgage with a guarantor because I am dependent on life support. I have even had to fight to retain a driver's licence even though my physician certifies that my condition is stable and as a driver my health does not pose a risk. The Road Traffic Authority was not concerned about my health now but what it might become and the same logic might be applied once there is more genetic information available. (Tonti-Filippini, 1998)

The DPI Europe declaration “The right to live and to be different” stands as a landmark claim to equality and the dignity of those of us who live with disability. In Australian society, we need to draw this declaration to the attention of policy makers and those involved in the bioethical arena. After all, how else can we move from having abstract human rights to these being enacted in our everyday lives, and social and bioethical policy?

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APPENDIX

“The Right to Live and be Different” ***DISABLED PEOPLES’ INTERNATIONAL EUROPE***

On 12/13 February 2000, 130 disabled people and parents, delegates from DPI organisations in twenty-seven countries in Europe, African, Australia and North America, met in Solihull, UK to discuss bioethics and human rights. This was the first occasion of its kind and it is with pride that we make the following declaration.

First and foremost we demand:

- **Nothing about us without us**

Up until now most of us have been excluded from debates on bioethical issues. These debates have had prejudiced and negative views of our quality of life. They have denied our right to equality and have therefore denied our human rights.

We demand that we are included in all debates and policy-making regarding bioethical issues.

We must be the people who decide on our quality of life, based on our experiences.

We also call on our organisations to give support, encouragement and reassurance to those of us who are representing our views on bioethical regulatory bodies.

Particular support must be given to empower the voice of mental health survivors, people with learning difficulties, people who cannot advocate for themselves and disabled children, in the debate.

- **Richness in Diversity**

We are full human beings. We believe that a society without disabled people would be a lesser society. Our unique individual and collective experiences are an important contribution to a rich, human society.

We demand an end to the bio-medical elimination of diversity, to gene selection based on market forces and to the setting of norms and standards by non-disabled people.

Biotechnological change must not be an excuse for control or manipulation of the human condition or bio-diversity.

We recognise that the only way to ensure universal support for and positive recognition of our particular qualities is through stating our right to diversity clearly, with good arguments, in open

and democratic discussion. We must form alliances with scientists, the medical professions, ethicists, policy-makers, human rights advocates, the media and the general public.

- **All Human Beings are born free and equal in Dignity and Rights**

Human rights are the responsibility of the state as well as the individual. Disabled people, our organisations, families and allies must work to ensure that international, regional and national legal instruments include the implementation of rights throughout all scientific advances and medical practices concerning the human genome, reproduction, assessments of quality of life, therapeutic measures and alleviation of 'pain and suffering'.

Biotechnology presents particular risks for disabled people. The fundamental rights of disabled people, particularly the right to life, must be protected.

In particular we demand:

- An absolute prohibition on compulsory genetic testing and the pressurising of women to eliminate - at any stage in the reproductive process - unborn children who, it is considered, may become disabled.
- The provision of full and accessible (ie. jargon-free, easy to read and in alternate media) information from which people can make informed decisions.
- That European governments do not ratify the Convention on Human Rights and Biomedicine as some sections are in contravention of the two documents adopted at the 1999 UNESCO Conference on Sciences.
- That disabled people have assistance to live - not assistance to die.
- That having a disabled child is not a special legal consideration for abortion.
- That no demarcation lines are drawn regarding severity or types of impairment. This creates hierarchies and leads to increased discrimination of disabled people generally.

Disabled people must join together in solidarity to ensure our voices are heard in these life-threatening issues.

STRENGTH IN UNITY!

Contact Details:

DPI Europe: 11 Belgrave Rd, London SW1V 1RB, UK

Tel: +44 207 834 0477 Fax: +44 207 821 9539 E-Mail: dpieurope@compuserve.com

Dr Christopher Newell, Senior Lecturer, School of Medicine, University of Tasmania, GPO Box 252-33, Hobart, Tasmania, 7001. Mobile Phone: 0418545611; Phone: 03 62248584; Fax: 0362236174; Email: Christopher.Newell@utas.edu.au

Book Review

Understanding Autism

by Susan Dodd

Elsevier. Sydney. 2004. 283pp + appendices. ISBN 1-875897-80-1 \$39.95

Understanding Autism by Susan Dodd is an excellent reference for people interested in the world of autism. Dodd comprehensively addresses this complex area as she covers the nature of autism, possible causes, trends and treatments, current controversies, diagnostic and assessment procedures as well as the practical day to day issues of sensory impairments, communication, behaviour management, play etc. The chapters on the thinking and learning styles and the emotional understanding of people who have this disorder leave the reader with a better understanding of the impact of autism.

Throughout, the book is highly practical. Dodd uses scenarios about individuals to illustrate points being made as well as providing the reader with numerous strategies to assist with topics as diverse as toilet training, bullying and play. In addition, the book is liberally illustrated with schedules, visual sequences and social stories so that the novice in this field can clearly see how to present information to a person who has an autism spectrum disorder.

Suitable for both parents and professionals, this book is easy to read while at the same time being packed full of information. *Understanding Autism* would also be a suitable book for students, though academics using this book for university courses might welcome more direct references to the research. The bibliography, glossary, index and appendices all play an important part in helping the reader access information. The local contacts in the appendices will be particularly welcomed by Australian families.

One of the hazards when writing about a subject that includes as much controversial research as the autism field does, is the risk that before publication something significant will occur that makes information in the book out of date. In Dodd's case this has been the retraction by Dr Wakefield about the link between MMR and autism.

In the section on current trends, Dodd mentions ABA, TEACCH, PECS, vitamin and dietary intervention among others. However, a noticeable omission is the lack of information about Relationship Development Intervention (RDI)—a new approach which is currently gaining ground in Australia.

The last fifteen years has seen an explosion in the number of books published on all aspects of autism spectrum disorder. This book by Australian author, Susan Dodd, stands out as it couples theory with an easy-to-read style and a comprehensive, highly practical focus.

Parents and professionals alike will find that this valuable book will rarely be on the bookshelf!

Gay von Ess

Autism Consultant and Special Educator, Canberra.



Australian Institute on Intellectual Disability

PO Box 771

Mawson ACT 2607

Ph: (02) 6296 4400

Fax: (02) 6296 4488

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