

# *i*nteraction

VOLUME 20 ISSUE 4 2007



## *i*NSIDE:

- From Other to Us
- 
- Social Movements and Social Capital
- 
- Nurturing Community

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

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

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

The activities of the AIID include:

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

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

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

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

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

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

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

### ***Roundtables***

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

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

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

# *i*NSIDE

<b>Editorial</b> .....	<b>4-5</b>
<b>Letter to the Editor</b> .....	<b>6-7</b>
<b>From Other to Us</b> .....	<b>8-1</b>
<i>- by Christopher Newell, AM</i>	
<b>Nurturing Community</b> .....	<b>16-20</b>
<i>- by Christopher Newell, AM</i>	
<b>Intellectual Disability: A social movement in need of revitalisation?</b> .....	<b>21-27</b>
<i>- by Errol Cocks, PD</i>	
<b>Can the concept of social capital contribute to disability policies and practices?</b> .....	<b>8-35</b>
<i>- by Errol Cocks, PD</i>	
<b>Book Review</b> .....	<b>36-37</b>
<b>Conferences</b> .....	<b>38</b>

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

**Australian Institute on Intellectual Disability**

PO Box 771 Mawson ACT 2607

Tel/Fax: (02) 6296 4400

**Internet Email:** [aiid@ncid.org.au](mailto:aiid@ncid.org.au)    **Home Page:** <http://www.ncid.org.au/aiid.htm>

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

**Design & Layout:** Monica Gourley

**Printed By:** Union Offset Printers

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

**Copyright © AIID**

All rights reserved. No part of this work covered by the copyright herein may be reproduced or used in any form or by any means--graphic, electronic or mechanical, including photocopying, recording, taping, or information storage and retrieval systems--without the permission of the publisher.

## A Positive Future for All!

With the renegotiation of the Commonwealth/State and Territory Disability Agreement (CSTDA) and the implementation of the Younger Persons in Nursing Homes project, we are confronted with old arguments about what type of accommodation support should be provided to people with disability.

Of course, the answer has not changed. What type of accommodation support a person chooses is up to them. As with everyone in the community, their choice will be determined by a number of factors including their family. What type of accommodation support that governments should fund is a different question.

As in health and education, there is a community expectation that governments will only fund good quality outcomes which will be judged on research evidence.

A commonsense judgement as to what good outcomes are is to ask ourselves the questions: is this the kind of life that I would like?; and, am I prepared to spend the next 12 months living as this person with a disability? Here the explanation must be why something that is not good enough for me is OK for a person with disability!

Dr Christopher Newell in his article 'From Other to Us' confronts this question. As a 'young' person with disability who was in hospital with a serious illness, Christopher was faced with the real prospect of not being able to go home to his wife and daughter but to a nursing home.

This situation is faced by many families each week as they consider the options (or rather option) for their elderly father or mother. The 'decision' may be made easier with the knowledge that their parent will probably only live for a couple of years and is in need of medical care. But for some families the decision involves their sons/daughters who have many years left of life, and who are only going into a nursing home because there is no funding to support them in a home of their own or adequate funding to support them in the family home.

As younger people move out of nursing homes and disability ministers plan how to meet unmet need for accommodation support, Christopher's articles are a timely reminder that people who require support are real people with families, loves, interests and the will to live lives similar to ours.

This issue of *Interaction* has two articles by Dr Newell. The theme that joins them is community and the place of people with disability in the community. This is a complex issue. Are people with disability seen as members of the community and hence included, or are they seen as different from us and hence separate — the 'other'.

Following these articles, there is a 'response' presenting an alternate view of community and a number of reflections — i.e. two articles by Dr Errol Cocks that take a more theoretical approach to the same question of the inclusion (and the exclusion) of people with intellectual disability from community life.

Both authors challenge us in different ways to view people with intellectual disability as

fellow citizens with equal rights to a quality life as members of the community. They challenge us to resist the 'easy' options of simply housing people and to respond to the *needs* of individuals with intellectual disability as *citizens*, not just as commodities or something that has to be dealt with to muffle the background noise rising from the community for action.

Your comments are invited either by letter or email.

Mark Pattison  
Executive Officer  
NCID

## **Having a Say Conference 2008** *Being the Change*

Wednesday 6th to Friday 8th February 2008

Deakin University  
Waterfront Campus  
Geelong, Australia

**Presentations and Performances by People with Disability  
and Lots More!**

Want to know more?  
Contact VALID  
Email: [office@valid.org.au](mailto:office@valid.org.au)  
Tel: 03 9416 4003  
Website: [www.valid.org.au](http://www.valid.org.au)

## *Letter to the Editor*

Dear Editor,

### **You call *that* a reform? — *This* would be a reform!**

On 1<sup>st</sup> June, Robbi Williams, CEO of the Julia Farr Association, exhorted decision-makers to listen to the voice of those with disability when making decisions about policy and service direction. In making this statement, which many in the community might have thought would happen as a matter of course, he focused on the recent changes that have occurred within Government disability services. As he points out, there have certainly been some changes and he rightly makes the point that the test of these reforms will be better outcomes for people with disability.

However, nothing fundamental has changed other than that the existing system might operate marginally more efficiently. It is useful to look at the money trail that assists people with disability. Under the Commonwealth, States and Territories Disability Agreement, each level of Government takes responsibility for various aspects of the service system. Many families will attest to the nightmare that occurs when your personal circumstances put you in a service “no-man’s land”. Duckshoving and blaming are bread and butter to all Governments and, if you are in this unenviable situation, it can be really tough.

When Governments do decide how much will be provided, say for supporting people in accommodation, their pooled funds are provided to a State Government department, which in turn allocates it to its own service delivery arm or to the plethora of non-government organisations which in turn develop a set of service offerings to people with disability which may, or may not, meet their needs.

Now let me take you back to when your children were born. Do you remember the buzz, the endless questions about whom they look like, the time of their first smile and our growing aspirations for them as they reached milestones, said their first words and developed their skills and personalities? Do you remember fondly the dreams you had for them?

Parents of children with disability share those dreams but it is not long before they get stuck on the “tar baby” which is the current disability system. Slowly their dreams are tarnished by hearing “I’m the doctor and know best”, “We don’t provide that type of service”, “What you want is inconsistent with our policy”, “You think you’ve got problems – look at Mrs. Bloggs down the street”, until they eventually stop dreaming and take what’s offered.

If you are one of those people who keeps your dream aloft, the system is skilled in dealing with you. You will be “unrealistic”, “a problem parent”, perhaps even “a trouble maker”. Eyes will roll at the mention of your name and you will be coerced to stop dreaming and return to the herd. And stop dreaming you inevitably do because they’ve got the money and hence the power! Julie Simpson of Parent-to-Parent, a Queensland organisation committed to assisting parents to regain their dreams, calls this resigned acceptance.

Of course, none of this is done malevolently or indeed even at a conscious level. It’s just the way things have been since charitable organisations first raised money to assist these “unfortunate”

people. It just seemed logical that when Governments started to put money into supporting people with disability, that it should be channeled through those organisations. Interestingly many of the current non-government organisations are one hundred percent funded by Government.

What type of reform would assist people with disability to dream again and take more control of their lives? I would suggest that a radical, two-pronged approach is needed. Firstly, ensure that people with disability and their families and not service systems control the agenda. Secondly, offer the opportunity for the disability funds to be channeled to individuals rather than through organisations. Money is power and a large number of individuals, wielding real money and prepared to use the power it brought, would have a greater effect on service quality and effectiveness than all the top-down accreditation mechanisms that could be invented. Heavens, some people might even choose to buy their services from elsewhere than the “disability industry”.

A pipedream? No it’s already happening. Parent-to-Parent in Queensland has enabled people to determine their own destinies. In the UK, all people with disability are offered the option of funds rather than services and the same is occurring in a number of States in America for a very practical reason – it’s cheaper to administer. The outcomes for people are far better.

In the last few days, the Commonwealth Government announced new disability funding that will go directly to the family. All State and Territory Governments should follow that lead.

Show people with disability the money! Let them relearn how to dream and take control of their lives. Now **THAT** would be a reform!

Richard Bruggemann<sup>1</sup>

---

**Editor's Note:**

<sup>1</sup> Richard Bruggemann was for 22 years the Chief Executive Officer of the Intellectual Disability Services Council and is currently Professorial Fellow in the Department of Disability Studies of Flinders University.

# From Other to Us

Associate Professor Christopher Newell, AM

Edited version of a keynote address presented to  
“Real Homes – From Talk to Action”,  
National Accommodation and Community Services Conference,  
Hotel Sofitel, Melbourne, 11- 12 April, 2006.

The invitation to speak at this Conference occasioned a lot more opportunities for reflection and angst than would normally be the case. Normally for a keynote, I would make a few outrageous statements guaranteed to ensure employment for Melbourne’s MICA ambulances as the incidence of heart attacks increased in the audience, tell a few outrageous pompous stories in order to bond, as well as establish my superiority and, as an ethicist, throw up a few values according to which we can live our lives - provided you buy my latest book... But that formula wouldn’t work for several disturbing reasons.

In the first place, I have had to do some disturbing rethinking about accommodation and community services when I was hospitalised over the 2005 Christmas break for some months – and, as I write this piece many months later, I am still doing the long and painful rehab trail associated with that. It has been a painful time for more than one reason. It’s the fourth time in my life that I have had to do major rehab and it revisited for me many of the deepest-seated fears that I have. Yes, I certainly needed to encounter my own mortality and yet it was something I had to come to terms with when I was very young. The really deep-seated fear I faced is one that, no matter what background, professional interest or other difference unites us as humans in some way, shape or form.

## **Options? The Choice you have when you are not really having a choice**

For all I had gained over the years in terms of job, prestige, even family, I feared I would lose all that and there would be no real options available for me in terms of quality of life and indeed any form of suitable support and accommodation. It took me back to some 20 years ago when I remember talking about quality of life options with the director of nursing of a nursing home at the time. She was tremendously sympathetic, as we thought of a nursing home as an important option for getting me out of hospital. It was a horrendous prospect then — and a horrendous prospect now — a horrible revisiting of the issue of younger people in nursing homes and inappropriate accommodation.

## **Imagining the Important things in life**

Yet as I contemplated the wreck of my life and the deep-seated fear I had of losing my academic position, status and all the things I had worked for, I came to realise what was most important to me and that that had not changed. Indeed, I still had something to sustain me through the dark times. I had managed to achieve something that too few people with disability do achieve- a real home and family.

From my hospital bed, I started to prioritise what was important. First, my wife Jill, who

met me many years ago whilst in hospital as I got ready to die. She was my nurse. With a gross disregard for boundaries, we fell in love. This meant that I went and married my best carer. Secondly, my daughter Christine, who from the earliest age has not focussed on my impairments but, at 11, still sees me as the daddy who can do anything. And thirdly, a house of our own, connected to caring neighbours in our street, where we can sit on the veranda, have a barbeque and ensure that I don't have to talk about quality of life, or indeed any of the medical dramas that sometimes seem to overwhelm my life.

Contemplating all of the wonderful and yet often taken-for-granted things that I had managed to achieve - and to which I was focussed on returning - I realised that once I would never have thought such things realistic for me. Several things became apparent.

### **IYDP and Beyond: The Continuing Story of Disability as Other**

In the first place, when I contrast the situation of so many of us with disability in 2006 with 1981, the International Year of Disabled Persons when we were finally going to break down the barriers, I realised that, for all the optimistic statements to the contrary, Australians with disability continue to have a deep, dark and shameful reality: we are the other — outside of the nice, normal and natural. In a book co-authored with Gerard Goggin *Disability in Australia*<sup>1</sup>, we refer to this situation as a form of social apartheid.

Secondly, for all the codes of practice, legislation, funding programs and value statements that say such pious things, I started to realise why it is that in the area of national accommodation and community support we have managed to arrive at the status quo. Why it is that for all the wonderful principles and values about the programs we offer, the apartheid that knows no name continues. Let me run you past a few excellent statements by John Ralston Saul, who in his book *On Equilibrium* looks at the way in which we need a balance of the essential qualities of humanity in order to achieve equilibrium for the self whilst fostering an ethical society. He notes that our lives are a struggle to achieve a balance of common sense, ethics, imagination, intuition, memory, reason and normal behaviour. Think about it. Each of these resonates by virtue of our experience as human beings.

Yet, when we consider these more deeply, we start to realise how entrenched is the problem we face. For example, in terms of the notion of “commonsense” we start to realise the enduring meta-narrative of disability as despised and despicable *other* means that when we look deep down at our commonsense - our ingrained prejudices - we are still quite happy to have people with disability as second-class citizens. After all, would I really want a person with disability in my household, as my child, dare I suggest as my CEO, politician or prime minister?

Here we start to see the contradiction between pious statements made about people with disability and the routine ways in which we reflect our real social values — the way in which our newspapers narrate the tragedy of disability, and the quest for the medical miracle to cure the deficit body. How profoundly uncomfortable we are with the notion of having intellectual disability, perhaps especially amongst academics such as myself who rely upon their intellect for their sense of status.

Put starkly, the task of creating real homes for people with disability requires us to examine our real lived values as an individual, profession and society. We will need to work not just in

<sup>1</sup>Goggin, G. & Newell, C. (2005). *Disability in Australia: Exposing a social apartheid*. Sydney: UNSW Press.

the disability sector, but with wider society to examine why it is that our accounts of common sense, ethics, imagination, intuition, memory, reason and normal behaviour have a non-disabled face to them.

### **Disability and Human Rights: Inherent Dignity**

Likewise, when we come to reflect upon the notion of human rights, why it is that, in the international human rights arena, disability seems to be that step too far in terms of diversity? We come to reflect on what human dignity or inherent human worth means and we come to realise how in contemporary bioethical debates disability is the inherent *indignity*.<sup>2</sup> In a world where we bow low to choice and autonomy, the antithesis of choice is disability. Here I also want to reject some constructions of conferring respect and dignity upon people with disability suggested by some commentators. By virtue of being a person, people with disability have those attributes - and we cannot take them away. They are inalienable. We can construct people as *other*, outside my moral community, the nice, normal and natural, but we cannot remove people's dignity.<sup>3</sup>

“Ah ha”, I hear you cry, but what of the current euthanasia debate? Here we see a very good example where we construct people as having no dignity. Indeed, have you noticed how usually the grounds we use for saying that euthanasia or abortion or even genetic screening is totally desirable are the conditions that many people with disability have every day? As a society, why are we so comfortable with the contradictions between affirming human rights and yet, over our breakfast cereal every morning, uncritically accepting that so many people with disability are better off dead, or at best second class people? Too often, we watch the infotainment of morning TV or read the paper about the latest development in biomedical science, euthanasia, abortion or even genetic screening without reflecting on the values present in these developments. We construct the homes and accommodation support we have now in accordance with the subterranean values revealed everyday in the narration of the nation, where delivering us from the tragedy of disability is central. How can we have real and wonderful and lovely homes for people when we know those people to be *other*? If in doubt, reflect on our lived values as a society in the treatment of those scary unpeople – detainees – who come in search of homes. So scary and dangerous, they need to be incarcerated in deserts, behind barbed wire, and have special legislation to remove them from the Australian mainland.

### **Autonomy experienced within Relationship**

My next point of critical reflection about what is important in the life of me as a person with disability struggling to envisage getting out of hospital was not that if I were given 20 cc of autonomy then everything would be OK. For I realised that autonomy by itself is cold, cruel and isolating. It is really autonomy achieved and experienced while in mutual relationship with others that is important.

Further, in a world which worships autonomy (“autonomy rules okay”), disability is the ultimate enemy of freedom and choice, rather than just being another dimension of humanity. Our hyped statements to do with people with disability and government programs that take the ‘dis’ out of disability talk in glossy ways – ways that we do not really mean. Everything else about government programs, our daily reality and the media which assails us, reminds us of the

---

<sup>2</sup> For further exploration of this, see: Newell, C. “Reflecting on Human Dignity”, *St. Mark's Review*, No. 173, Autumn, 1998, pp 19-23.

<sup>3</sup> See the Universal Declaration of Human Rights on this point.

tragedy and indignity of disability.

### **Relationships of Integrity**

As I came to reflect on all the enormous benefits that I have acquired in life, I realised that it was through and arising out of relationships of integrity. Someone who failed at school, experienced the joys of a sheltered workshop, went onto an Invalid Pension as it was known in those days, at the age of 18 I knew how little I had to offer the world. It was not government programs that taught me to the contrary.

For example, having been refused rehabilitation because I was regarded as uneducatable, something confirmed by a senior official of the University of Tasmania (where I now teach) who told me I was not capable of doing an undergraduate degree. I still have the letter signed by someone who put BA after his name - which I now understand meant exactly what he really knew!

As I reflected on all the opportunities I have had in life – how I came to have opportunities for life and a home - and indeed how I managed to get out of yet another lovely institutional experience recently, I reflected on the importance of relationships. That is, relationships with people who valued me, and wanted to make and give me opportunities. I still remember knowing how little I had to offer - and how much I was to learn.

Sadly, if there is one thing we can't expect governments or even private enterprises to do it is actually to provide loving, intimate relationships for people with disability as a business. On the other hand, I would suggest that we can do a lot to provide the sorts of everyday support in relationships whereby people with disability come to know what it is to be inherently worthwhile (to have dignity) and via relationships to learn so much.

It has been suggested that one of the problems we face is of not knowing where we are going. Yet, which non-disabled people really know exactly where they are going in terms of family, a career or relationships? The issue is fostering a framework and structure within which we can function and be supported, whilst still being able to aim to be all that we can be.

### **From Talk to Action to Talk to Action...**

It is the primacy of these relationships of integrity that brings me to my next point, that of the importance of moving from talk to action. Yet, we must be careful not to be too hasty, whilst also ensuring that we don't ensure masterful inactivity. The sub-title of our conference on real homes "From Talk to Action" says it well. As I reflect back to IYDP and all of the government programs that have actually occurred since then, I realise that there needs to be a commitment to moving from talk-to-action-to-talk-to-action. Further, too often action has flowed from inadequate relationship or indeed as a knee jerk response to the article about "Pathetic Peg" on the front page about which the minister wants something done. This is something, therefore it must be done...

Many years since 1981 and IYDP, the status quo largely remained the same. If in doubt, try to think about prominent Australians with disability some 25 years after IYDP. Apart from Rhonda Galbally<sup>4</sup> and Graeme Innes<sup>5</sup> we struggle. For all that Graeme's position is Human

---

<sup>4</sup> CEO of "Our Community" in Victoria.

<sup>5</sup> Currently Human Rights Commissioner and Acting Disability Discrimination Commissioner within the Australian Human Rights and Equal Opportunity Commission.

Rights Commissioner, it would appear that the rights of people with disability are so important that we continue to have an Acting Disability Discrimination Commissioner. Real homes, real policy approaches regarding disability demand that, when people with disability say something, people pay heed rather than ignoring it. This has been the case with the Australian government disregarding what the Australian disability community is saying about the importance of filling the vital position of Disability Discrimination Commissioner, preferably with a person with disability.

Even today, we mostly talk in isolation about people with disability, and then bring them in for a choice bit of conversation about their lives, and then return them to their situation. Relationships of integrity, relationships which shape real homes, demand an ongoing dialogue about not just the big-ticket policy but also about where the sofa goes...

As I think upon how government and governance works, I cannot help reflecting on the importance of barbecues and the informal social relationships which are so important in deciding what occurs. Indeed it is such networks which often exclude people with disability. That is why there is just as much to be said for Ministers having a BBQ on a regular basis with friends with disability as there is for more formal meetings. How else can we learn about those we know to be *other*, than by relationships where we give and receive and, in so doing, transform the *other* to *us*, those we enjoy and desire having at our BBQs.

### **The Central and Marginal Role of Disability**

Of course, at times there may be some positives and redeeming moments. For example, those key moments where our society has exclaimed in horror when aspects of the reality of the situation of the hidden apartheid of disability has become apparent.

Yet, for all that, disability is ever present in our media – usually we have seen a little bit of talking by carefully chosen or privileged voices of people with disability, a lot of talk about people with disability and then we as a society have moved rapidly to action to ensure that the situation of ‘Pathetic Peg’ on the front page is attended to. There is a particular formula for how disability is usually narrated and utilised in Australian society. As you will see disability is both central, and yet marginal, in so many respects:

#### **Four easy steps to secure a technology or program:**

1. The tragic life of an individual or several devalued individuals is portrayed in a way designed to elicit maximum affect and pathos;
2. A technology or program is portrayed as delivering a person from disability, provided that society embrace, fund or legitimate such a solution;
3. Securing the technology/program/funding means that disability has then been ‘dealt with’; after deploying such rhetoric, there is to be no more appeal to emotion, and the solution lies in the rational pursuit of the technology identified in step 2 (effectively there is only one, inexorable logical step);
4. Disability as a political issue goes away until next time it is needed in the powerful politics of media representation.<sup>6</sup>

---

<sup>6</sup> After Goggin & Newell, 2005.

We need to move from talking about, to listening to, people with disability and then moving to action and then, as part of a continuous process, moving back to dialogue with people with disability. Yet we also need to see that, in order for us to tackle the hidden and yet disturbingly obvious apartheid that knows no name, the situation of Australians with disability requires more than the perpetuation of the disabled/non-disabled binary.

### **Helping all in Society to nurture US**

The conversations and actions regarding the provision of real accommodation and support options require much more than providing a soapbox for the awkward Christopher Newell. It requires an embrace of the idea of disabled and non-disabled coming together, sharing our common humanity, resourcing and supporting each other. It will also require recognition that real homes require more than just a focus on service provision and attendance to the broader dimensions of how disability is created and replicated in wider society.

For those of you who live without disability and provide important accommodation and community living options, it means providing options for community development and skilling for many of us with disability who have so much untapped potential. It means being understanding of us when we vent our anger and frustration on you. It means providing us with opportunities so that we are not just service recipients but start to imagine a time when we will not just shape and manage particular services but where those services will provide important springboards for us to become all that we can be in ways that we never even imagined were possible.<sup>7</sup> I still remember the ground breaking early work of my friend the late John Newton, OAM, an early Tasmanian manager of a disability service who was also a person with disability.

### **A Quality of Life Matrix as a Means to a Consumer End**

Further, as I contemplated the character forming nature of yet another brush with death and institutionalisation, when I considered the Real Homes Matrix with which we are presented, I did wonder whether or not this was yet another nicely typed idea with some good pious intentions which imposed concepts not entertained in contemplating the lives of non-disabled people. After all, which of us who is non-disabled plans our lives so well and manages things so well we would survive an audit — not just in terms of sexual relationships, contentment with our lot in life, but even in rewarding employment?

If we focus on the real homes matrix as an end in itself, something to be slavishly followed, we risk just perpetuating the status quo. Yet, when we look at the underlying concepts, we can see real merit and that all of them are important in what it is to survive and thrive as a human being. Reflecting upon the relationships and visions that sustained me through my traumas (my relationships with my wife and daughter, and my desire for a barbeque on the deck of my family home without a deep and meaningful conversation about the medical realities of life), I come to see these as encompassing emotional well-being, inter-personal relationships, material well-being and personal development.

In going down this track, however, be warned. One of the biggest challenges we face is that already Quality of Life discussions are becoming Quality OR Life, where people who fail our narrow norms of quality are assessed as worthy of death. We already see that in discussions about the beginning and end of life. If we are not careful, a bureaucratic approach focused on

<sup>7</sup> For an example of such dreaming see: Goggin, G. & Newell, C. "Imagining disability tomorrow", *Journal of Futures Studies*, Vol 10, No 2, November 2005, pp 69-74.

outcomes may not find any benefit in the lives of those who do not measure up.

### **Social Values in Action**

For as we start to tackle these problems, thinking about the values that are enacted in our social institutions which daily perpetuate disability as *other*, we will inevitably bring about social change. The relationships that required us to talk, to listen, to reflect and then to act, and then to continue that cycle in learning from each other, have the potential to bring about a social revolution not just about housing and accommodation support but really about the social apartheid experienced by people with disability. It means that the policy moments that daily assail us all of a sudden become key opportunities for disability reform. The discussions around a fair pay commission and equal opportunity, which largely ignore the subordinate and under-valued role of people with disability in employment, will eventually have a significant disability dimension.

### **The Vital Role of Stories and Narrative Repair**

In all of this, one the key ways proposed of driving better practice is to adopt a Quality Of Life (QOL) matrix or framework, as has been espoused by writers such as Robert Shalock.<sup>8</sup> As we contemplate the important role of quality of life based upon the dignity of the human person, I can't help but reflect on the importance of stories. In order to convey what we mean about so many concepts, we ceaselessly need to tell stories and to convey subtleties that way. Rather than just a checklist, we need to help people to tell stories and identify from them the important aspects of life found in a QOL framework.

Further we will need to attend to the way in which most quality of life problems come from the exclusionary practices of social apartheid. When my whole life and story has been colonised and devastated, told by others for me, I will need to have some purposeful rebuilding not just of my individual story but of the collective story of people with disability. As Hilde Lindemann Nelson argues:

How freely we can exercise our moral agency is contingent on a number of things. Most broadly, it depends on the form of life we inhabit: the niche we occupy in our particular society; the practices and institutions within the society that set the possibilities for the courses of action that are open to us; the material, cultural and imaginative resources at our disposal; the constraints arising from the moral flaws within our roles and relationships; the shared moral understandings that render our actions intelligible to those around us. More specifically, the extent to which our moral agency is free or constrained is determined by our own — and others' — conception of who we are.<sup>9</sup>

### **Concluding: From Other to Us**

Accordingly, in a paper provocatively entitled "From Other to Us", I have sought to introduce reflections on far more than what it is to have real homes. For as we contemplate what is required in providing accommodation and community support, we start to realise that it is far more than having framed value statements gather dust on the walls of the institutions you have when you

---




<sup>8</sup> For the purposes of this paper, I am here particularly referring to the quality of life, work and domains prepared by Shalock as a basis for the Consensus Document prepared by the (international) IASSID Special Interest Research Group On Quality Of Life.

<sup>9</sup> Nelson, Hilde Lindemann. *Damaged Identities, Narrative Repair*. Cornell University Press, Ithaca,

are not having institutions. Real housing, real homes, provide options and relationships through which people can survive and thrive, through which we can learn to be so much more than anybody ever expected – myself included. Indeed, where we can know what it is to be valued (to have inherent human dignity) within those everyday relationships.

My focus in this paper is on providing real home options. Yet, I would suggest that we can only do that when we, as a society, as professionals, as service providers, are able to fundamentally challenge a social apartheid present in every social institution, and in the norms which we hold dear, even in the narration of Australia as a nation. Do we want a story of an enabling or disabling Australian nation to be told and enacted in our homes and social policy? It is only in this way, and via the relationships in homes which ultimately are a means to an end, that we will ultimately transform people with disability from *other* to *us*.

Problem with your  
telephone, mobile phone  
or internet service?






The TIO may  
be able to help.

The Telecommunications Industry Ombudsman is a free and independent dispute resolution service for people with complaints about telecommunications or internet services.

If you have tried to resolve a complaint with your phone or internet service provider, but are not making any progress then contact the TIO.

Website	www.tio.com.au
Freecall	1800 062 058
Freefax	1800 630 614
TTY	1800 675 692
Interpreter service	131 450



Telecommunications  
Industry Ombudsman

# Nurturing Community

Associate Professor Christopher Newell, AM

Edited version of a keynote address presented to  
“Good to Great” Conference of Disability Professionals Victoria,  
Melbourne Convention Centre, 5-6 March, 2007.

## **Community: Beyond the Taken for Granted**

Recently, I had the opportunity in giving an address about “community” and disability to reflect on what this word “community” really means. This concept “community” is a word often used and even more often abused in the area of disability. Those of us with disability are integrated into the “community” and yet not well accepted. So-called “community values” (whatever they are) and appeals to the welfare of “the community” can be used to perpetuate abuse for clients with disability. In starting to think about what we mean by this word community, I did what I often do with my students and reflected on the derivation of the very words that we take for granted.

## ***Communis*: Common, public, shared by all or many**

The word community comes from the Latin *communis*, meaning “common, public, shared by all or many”. Sadly, this make a great deal of sense. When we think about community and people with disability, we can certainly think of some shared social meanings: pathetic burdens, medical mistakes, even life unworthy of living. In all of this, the accounts of disability in terms of medical deficit and charity remain essentially strong. It is all summed up in some catch-cries derived from real life:

- Thank God I don’t have a disability.
- Better off dead than disabled.
- Disability is about the other, rather than the us.

## ***Com*: With or Together**

The Latin term “communitatus”, from which the English word “community” comes, is comprised of three key elements, the first being “com” which is a Latin prefix meaning with or together. Here I would suggest that we face some significant challenges. In the first place, we tend in Australian society to conceptualise disability not in terms of valued members of society or intimate friends we desire relationship with, but in terms of the *other*, outside of our moral community. Even skilled disability professionals exist in a context where other areas of employment are much more highly valued. Families with a child with disability know only too well a negative narrative regarding disability and who belongs to valued communities.

Of course, disability is often used widely in society as a tool for promoting professional claims to expertise, but mostly in terms of the narration of disability in terms of medical deficit requiring scientific, medical, regulatory and charitable response. The rights of people with disability extend in such dominant constructions to either the right to a cure for the pathetic

body or mind, or seemingly to the right to be patted on the head in a charitable sense that leaves the status quo as it is!

Put brutally, there are a lot of negative accounts of disability around and, after many years of research and advocacy in the area, I have come to see many with vested interests in keeping the status quo as it is. If in doubt, reflect for a while on the lack of importance given by the major Australian political parties to disability in this election year.

It is not just people with disability and their families such narratives can marginalise. The perpetuation of dominant accounts of disability can also serve to devalue the very professionals who are involved in seeking to address the disadvantage and human rights of people with disability. The transformation of disability in society requires the accompanying transformation of people with disability from *other* to *us*.

### **Munis: The changes or exchanges that link**

Secondly, in continuing to explore the Latin for ‘community’, we encounter the idea of “munis” which may be seen to mean “the changes or exchanges that link”. For example, the words ‘municipal’ and ‘monetary’ may be seen to take their meaning here, both forms of exchanges and meanings. In nurturing community, and in building exchanges, I would suggest that the addressing of the everyday apartheid of people with disability<sup>1</sup> - the continuing narration as other, special needs, outside of the unexamined normal - requires the intentional, purposeful building of meanings and mutual valuing.

A real test of community is whether or not those who have less valued jobs or socially valued positions feel valued and are seen to make important contributions, in the same way as those who have highly recognised and remunerated positions and jobs. Sadly, we often see an Orwellian Australian community in the sense that everyone is equal of course – it is just that some are more equal than others.

In shaping and nurturing community, vital components include: Telling and valuing stories and contributions, and fostering relationships where people know they are valued. These are important, not just for persons with disability or even for professionals in the area of disability. They are important for all of us as humans who learn from and express our humanity in such relationships, with opportunities for building exchanges that link. For me there is also the deep longing that one of these days those of us with disability may be regarded as being worthy of being regarded as professionals of the highest value.

Everyday, I am reminded of the dominant exchanges linking and shaping within community: the taken-for-granted nature of myself as “special needs”, rigorously avoiding exploring why this is so; the requirements for medical clearance and certification; and the narration of myself as disability in terms of being a burden to others. Addressing the linkages and exchanges of disability will inevitably require not just building community within our smaller communities but helping with, and purposefully attending to, the transformation of disability in society.

### **Tatus: Small, local, even intimate**

Finally, in examining the Latin suffix “tatus”, meaning diminutive or small, local, even intimate, we are reminded of the sense of community that we all seek to nurture in our own lives.

<sup>1</sup> For an exploration of this, see for example: Goggin, G. & Newell, C. *Disability in Australia: Exposing a social apartheid*, UNSW Press, Sydney, 2005.

We all yearn for intimacy. Is it any wonder that accounts of integrating people with disability into “the community” have largely not worked, when premised upon the placing people into disconnected or large amorphous accounts of community? Given the complex social relations and negative understandings of disability, which of us really can thrive in such a negative scenario?

Of course, there are a variety of ways in which we come together as fixed and temporary communities, daring to share, to learn, to expose our fears, our joys and those most intimate of things, our very stories. For me the best example of this is found in my extended family, something that nurtures me and allows me to nurture and love. Professional associations and lobby groups can also be examples. Conference topics like disability can also be examples of temporary community, also important in our lives. For me, it is these and similar accounts of community which do not just assist to narrate disability in terms of *us*, rather than *other*, but assist in building resilient individuals able to engage in, and claim a proper account of, nurturing communities in broader society.

### **Fine in theory, but...**

“Well, it all seems fine in theory, but...” Certainly, my own life experience attests to the fundamental problems. As the noted narrative theorist Hilde Lindemann Nelson notes:

How freely we can exercise our moral agency is contingent on a number of things. Most broadly, it depends on the form of life we inhabit: the niche we occupy in our particular society; the practices and institutions within the society that set the possibilities for the courses of action that are open to us; the material, cultural and imaginative resources at our disposal; the constraints arising from the moral flaws within our roles and relationships; the shared moral understandings that render our actions intelligible to those around us. More specifically, the extent to which our moral agency is free or constrained is determined by our own — and others’ — conception of who we are.<sup>2</sup>

### **A wee smattering of theory**

There is of course a significant theoretical under-pinning to what I am suggesting. Also a lot of contested social theory regarding the nature, building and transformation of community. The German sociologist Ferdinand Tonnies has something to offer our inquiry. In his 1887 book, *Gemeinschaft und Gesellschaft*, he distinguishes between “community” (*Gemeinschaft*) and a much broader account of “society” (*Gesellschaft*). He reminds us that the building of community requires the presence of a “unity of will”, with families (at their best) being the best expression of that. Of course, other characteristics such as place and belief can also result in, or enhance, that sense of community. Even buildings help to shape community and also reflect values – for example, buildings that do not have wheelchair access. In addition, the routine lack of consideration by others with disability in thinking of “access” for people with intellectual impairment says much of our lived commitment to shared community.

Likewise, there are social theorists who point to the importance of social capital. Such social capital may be found in the sense of connectedness, the formation of social networks, the sense of community that exists, and our accounts of freedom, security and belonging. When I think

---

<sup>2</sup> Nelson, Hilde Lindemann. 2001. *Damaged Identities, Narrative Repair*. Cornell University Press, Ithaca., 2001: xi.

of the dominant narration of disability in such negative terms, where there is very little that is to be valued in the lives of people with impairments or their families, I would suggest we as a society have a long way to go in defining capital.

The account of community we have may be seen to be fostered by the degree of reciprocity we have and the desire to do things for each other. Nurturing community requires the formation of group identity, attendance to inter-personal relationships, the building of personal and cultural values, giving heed to social structures and a fostering of group dynamics where people know that they belong. It is in such relationships that we learn to know we are valued, or we learn how *other* we are.

### **Building communities**

So, how are we to build communities? That great social commentator and spiritual guru M. Scott Peck, in his 1987 book *The Different Drum* has reflected upon the importance of a process of “conscious community building,” identifying a shared story and consensual decision-making. All of this is founded upon respect for all people and an embrace of difference. Yet, when we think about it, the embrace of diversity spoken of widely within society never really seems to extend to embrace of people with disability. After all, the embrace of people with disability in terms of diversity ends up embracing the very things that we fear.

The four stages that Scott Peck suggests are as follows:

1. **Pseudo-community:** This is where participants are “nice with each other”, we play safe, we present those aspects of our personalities that we think are the most desirable but we dare not go deeper.
2. **Chaos:** When people move beyond such inauthenticity, feeling safe enough to present the depths of ourselves. This recognises that organisations are not necessarily communities. One of the significant challenges I face in community is authentically presenting an understanding of myself, and the world of disability, in terms of oppression and the structural and ideological ways in which we make people with impairments disabled. For many, such a stance is regarded as inherently dangerous. Yet, I would suggest that we live in a world where such alternative narrations are vital, where people are embraced regardless of, even because of, their different views.
3. **Emptying:** Thirdly, we face the stage of emptying, which moves us beyond the attempts we have to fix or to heal or convert that stage of chaos. It is at this point when we can acknowledge our own woundedness and brokenness, and recognise that as common to all of us as human beings. This is a major step when dominant conceptions of disability seem to be the antithesis of valued community. Dare I suggest that people with disability have much to teach all of us in an important stage of being community? I remember well when I was in hospital last year for months struggling with break-through spinal pain and life-threatening moments. I was deeply afraid of losing everything that I had managed to gain in terms of those accounts of prestige, social status and position. Colleagues in a variety of communities (professions, Church and academics) had either the opportunity to confirm that my brokenness was unacceptable or to find there was authentically a role for me in a community that dared to share its brokenness.
4. **Authentic Community:** Finally, there is that stage of authentic community, which is not really a moment in time but involves process and space of deep respect, truly

listening for the needs of all within this community. Here I think Scott Peck is truly perceptive in recognising that there is a deep yearning within every human soul for compassionate understanding from one's fellows. This is also the case not just with professional groupings but building community with and of people with disability.

### **Nurturing Community**

Accordingly, we have some significant choices to make. We can either live our lives and accounts of professionalism in ways which perpetuate the otherness of people with disability and the tragedy of such lives. Alternatively, we can build an account of community and professionalism which, in tackling the marginalisation around disability, also enhances our account of the role of people with disability and disability professionals in society. We need to make conscious choices to nurture ourselves as individuals, to grow together as fellow members of community, and purposely to nurture an account of community which sustains and embraces all people, including people with disability. In so doing we will inherently tackle a culture of marginalisation, or what I call social apartheid, around disability.

In this way, we can tackle otherness and the perpetuation of disability as outside of the normal. This is towards building an embracing account of community for fellow professionals, for people with disability and families, and indeed for a transformed Australian society. Nurturing community is really about claiming and shaping the "com" (with) in community. It's about the relationships whereby we transform disability from *other* to *us*.

## ***The Odyssey ... a journey of enrichment and possibility***

### **Family Advocacy's first National Conference**

**25 and 26 October 2007  
in Central Sydney**

**National and International Speakers!**

Hear how people with disability can live a rich, varied and secure life, open to the possibility of making friends and developing relationships beyond family - experience positive learning opportunities - be recognised as part of the wider community - have constructive, meaningful leisure time and a place to call home.

A limited number of sponsored places will be available for people with disability and/or family members. Please contact Family Advocacy directly ([familyadvocacy@family-advocacy.com](mailto:familyadvocacy@family-advocacy.com).)

Conference Contact:

Tel: 02 9869 0866 or 1800 620 588 (NSW non-metro callers)

Email: [conference@family-advocacy.com](mailto:conference@family-advocacy.com)

[www.family-advocacy.com](http://www.family-advocacy.com)

# Intellectual disability: A social movement in need of revitalisation?

Errol Cocks PhD

Presented at 13th World Congress of Inclusion International, 2002, Melbourne

## Introduction

This is the first of two linked papers. It discusses intellectual disability in terms of social movements and examines the contention that it is a social movement in need of revitalisation. This will involve identifying some of the signs that the movement is faltering and some analysis of factors that are contributing to the situation. The focus of the paper is that Australia and other countries may or may not recognise elements of this analysis.

The second paper, “Can the concept of social capital contribute to disability policies and practices?” is an exploration of the concept of *social capital* from the perspective of disability. This will involve some consideration of related concepts of social exclusion and sustainability, and also explain why disability as a social movement is a significant contributor to social capital. This analysis may help to redefine a developmental agenda for the disability sector and provide much-needed renewal. For example, by enhancing the place and contribution of people with intellectual disability in modern society and also by recognising the great contribution made by civil society, particularly in the form of *voluntary effort* such as advocacy and elements of the disability voluntary sector, important rationales can be drawn for social policy development. It is certainly time for the disability sector to look over the walls and connect with *some* of the key ideas that are transforming societies because these ideas, in addition to generating renewal, will provide rationales and “leverage” that will help to advance the interests of people with disability.

In fact, the *vitality* of voluntary effort should be a major concern of any government that is interested in the development of stronger communities. This is much more than hoping that volunteers will relieve the burden on treasuries! In recent years, the actions of governments in Australia in undermining the strength of advocacy and the voluntary sector has reflected little understanding of this issue and has weakened an important element of civil society. Somewhat belatedly, governments are beginning to change direction from a managerialist, rationalist and market-dominated ideology to a rediscovery of the vital importance of civil society, whether this is expressed as “joined up thinking” and “partnerships” in the UK, “building stronger communities” in Australia, the so-called “triple bottom line” of developers and reformed economists, or universal acknowledgment of the importance of *sustainable development*. In addition, a disability research agenda may be developed that is substantially different from the historical and much of the contemporary research effort.

## Characteristics of Social Movements

I want to begin by providing a brief history of social movements and the emergence of what

are called “new” social movements. Historically, modern social movements emerged in the context of the French revolution and Marxism (Flacks, 1995) when the division between the Left and the Right world views generated enormous social and political activity. The time has passed when social movements and, to a significant degree, political allegiances, can be described simply as reflecting liberal or conservative world views. Politically, we are aware of the “third way” and the ascendancy of populist and pragmatic centralist stances, even in the face of what appears to be the rise of the political right in some parts of the world.

Flacks (1995) accounted for the loss of relevance of the Left-Right distinction, which drove many social movements for over two centuries, with three phenomena. First, globalisation of the world economy and the development of global markets has meant that welfare states can no longer deliver on their promise, and financial pressures have meant that countries must be competitive or suffer economically. In this context, arguments that are based on class lose their appeal and their potency. Second, leftist traditions of solidarity, so clearly seen to be failing in the labour movement, have been replaced by strong individualism in which, amongst other things, people battle hard to protect their relative advantage when growing inequity is the order of the day. Finally, and of particular relevance to disability, Flacks asserted that the “silent minorities” are now mobilizing, no longer willing to endure sacrifice in order to advance the causes of others. For example, women, ethnic minorities and unskilled people are asserting their rights and needs. People with disability, especially in the context of the so-called *social model* of disability which is so strong in the UK in particular, are becoming increasingly unwilling to serve the interests of service systems.

This provides a backdrop for the emergence of what some commentators are calling “new social movements”. Johnston, Larana, & Gusfield (1995) have identified some differences between earlier cases of collective action and new social movements.

1. New social movements attract people of various social classes and structural characteristics such as age and gender.
2. Rather than reflecting overarching ideologies such as Marxism, capitalism or socialism, members of new social movements exhibit “a pluralism of ideas and values, and they tend to have pragmatic orientations and search for institutional reforms that enlarge the systems of members’ participation in decision making.” (p. 7) Constituents of these movements do not see value in becoming members of established political groups, but rather seek participation more directly through particular interest groups. This has, of course, been to the chagrin and frustration of traditional political parties.
3. Of particular relevance to viewing disability activism as a social movement, new social movements are associated with values related to pride in being a member of a social group that may have been perceived, historically at least, to be problematic. Belief in the power of the *social construction of identity* has led many such groups to essentially redefine themselves and create both private and public identities that assert their inherent value. New social movements based on “gay pride”, “celebration of difference” and a “deaf culture” thus contribute to the individual’s self-definition.
4. The focus of new social movements is often on personal or intimate aspects of human life. Consider, for example, social movements that are concerned with sexual preference.
5. As a response to political and economic conditions, such movements search for channels for participation in political, social and economic life. To a significant extent, traditional political channels and allegiances are seen as ineffective, in part a reflection of the

apparent inability of modern governments to respond successfully to a raft of social problems and the retreat into management rather than amelioration of problems.

6. Rather than a hierarchical and centralized structure, new social movements tend to promote local autonomy. This reflects an important assumption that people do have the capacity to address and solve their own problems.

Johnston, Larana, and Gusfield (1995) wrote of new social movements as attempts to “reclaim a self robbed of its identity” in response to “a self that is thwarted and assaulted in modern society.” (pp. 10-11)

The *culture* of a social movement is fundamental to its identity and existence. Lofland (1995) described six dimensions of that culture. It is interesting to think of each dimension in terms of disability as a social movement.

1. Social movements have at least one major shared *value* that may be quite distinctive and not necessarily widely shared. Social inclusion is an obvious value to which members of the disability movement are likely to subscribe.
2. Symbolism physically expresses the purposes of social movements and is reflected in people who are characterised as leaders, particular events and particular places. The disability movement has many such leaders, although one might observe that they are ageing or no longer with us, and there is a big question in regard to where future leaders may come from.
3. Every social movement has its stories that illustrate the nature of the struggle. The achievements of people with disability in overcoming prejudice, rejection and the limitations imposed by their impairments provide much inspiration. Similarly, we might view the reform of service systems as reflecting the commitments of allies.
4. Special occasions and celebrations sustain movements.
5. Social movements generate many valued social roles such as knowledge creators and disseminators.
6. Cultural styles such as openness, friendliness or aggression become associated with social movements.

Clearly, social movements that lose contact with these aspects of their culture are most likely to decline. Finally, social movements have particular characteristics that contribute to their culture. These include an historical context that is often rooted in a sense of concern or even of outrage at the treatment of a particular group of people. This may drive a concern to right perceived wrongs and also supports a strong sense of identification with those people. In addition, of course, it also drives *that* group to assert its own position. Such movements may draw on high order principles or values such as human rights or social justice and will generate a broad base of support. Crucially, social movements are *relational* and depend greatly on social networks and connections between people who are sufficiently “like-minded”. As we explore the foundational, relational aspects of social movements, we begin to perceive the link with the idea of *social capital* – the value that is created by the networks of connections between people. We also see how the culture and other characteristics of social movements may define a disability social movement.

## Characteristics of Disability as a Social Movement

A strong disability social movement can be clearly seen in the unbroken line of effort to

improve the life conditions of people with disability. Historically, this line of effort can be viewed in a long-term manner for as long as recorded history and there is great value in having some comprehension of this timeframe. For my purposes, the “modern” disability social movement could be dated from the post-World War II period when the process of reform accelerated significantly due in large part to the advocacy of the parents of people with disability.

Using some of the cultural characteristics of social movements, it is not difficult to identify a disability social movement. Disability history, particularly since the mid-19<sup>th</sup> century, is replete with examples of the poor treatment and rejection of people with disability and even a cursory knowledge of that history clearly indicates how a sense of outrage has provided much fuel for the movement. The movement has drawn from some powerful values, ideologies and concepts including human rights, normalization, social role valorization, the dignity of risk, least restrictive alternative and social justice to name some. In fact, few social movements have had such a foundation of values, theory development, literature and action strategies. The richness and strength of this movement is reflected not only in these characteristics, but also in the development of an extensive voluntary sector, advocacy movement and a substantial body of knowledge and experience in the analysis and reform of societal agencies, particularly the human service sector. This has been supported by policy development, statements of rights by international agencies and considerable legislative development. The disability social movement also has its leaders and heroes and its inspirational events. It also has a strong sense of the importance of a critical culture.

It is interesting to consider the disability movement as a *new social movement* as outlined above. Clearly, where people with intellectual disability have been concerned, for the most part, the disability social movement has been driven not by those people themselves, but by their parents, family members, advocates and allies. It is only in the past one or two decades that we have seen a more direct influence by people with intellectual disability themselves through such means as self-advocacy. In this respect, intellectual disability constitutes a somewhat different movement to that of disability as a whole where the direct influence of people with physical disability can be seen at least two decades previously. One of the contemporary challenges to the *intellectual* disability movement has been to incorporate the voice of that group more directly and influentially. Many physical disability activists and academics, especially in the UK, have also embraced the social model of disability and participatory action.

If new social movements have the characteristics of promoting identity formation and *participation*, then the intellectual disability movement has only widely adopted these objectives in recent years. Some aspects of the movement have in fact sustained features of a disability identity that are not positive. Similarly, one of the ongoing tensions in the movement has been comprehending the distinction between the physical presence of people with intellectual disability in communities and their *participation*. The *direct voice* of people with intellectual disability has not been acknowledged or easily heard. In fact, using new social movements as an example, the notion of participation must be taken much further to include participation in decision-making and more direct political participation. Similarly, the example of new social movements as promoting pride in group membership suggests that there is considerable value in acknowledging the inherent value of people with intellectual disability and the value of their contributions. *At the heart of these challenges is the need for people with intellectual disability to be part of the mainstream of the movement rather than merely its object.*

## A Faltering Social Movement?

At the heart of my contention that the *intellectual* disability social movement at least is faltering are a number of generational factors. These are partly the result of the age of movement participants and the need for new, younger leadership, and partly the result of the ageing of the movement itself. If social movements have a life-cycle, then there is likely to be a time when entropy sets in and the energy of the movement runs down.

But first, are there signs of faltering? And are these signs that can be attributable to the movement in any way or are they simply manifestations of broader social decline? I would identify five signs.

1. The connection with the early history of the intellectual disability movement has weakened considerably and, with it, the sense of outrage that provides energy to a movement. This is a function of time and distance, but it also reflects a modern decline in concern for, and interest in history. Students of human services and their teachers are more focused on the pragmatics of core competencies than they are with culture, history and ideology. A generation or so of economic rationalism and content-free managerialism has done its best to drive out the traditional person-centred values of human services and, with it, a significant degree of personal commitment to cause which is fundamental to social movements. Of course contemporary rhetoric has shifted, but the super tanker of a rationalist policy era changes direction extremely slowly. Some critics would say that nothing really has changed. We are being drowned in a sea of rhetoric and public relations which modern formal human services now use as a response to crisis. All of this contributes to a lessening of *discernment*. This means that people become less able to evaluate what is before them.
2. In Australia at least, there are major crises of support for people with intellectual disability and their families. This is partly a consequence of the ageing of the population. But it also reflects lack of anticipation, planning and/or preparation on the part of social institutions and governments. Traditional voluntary sector agencies, as well as government services, can no longer respond to the unspoken contract that they will support people with disability when families can no longer provide this. This has been a great disappointment to families who have supported voluntary organisations for many decades. The crises are across the board, but are especially impacting on older and more disabled people, and older parents. In some parts of Australia, the movement has become much more directly political as a response to this crisis and, in doing so, has publicised many heart-rending stories of the plight of families and their sons and daughters with disability. Governments seem unable to respond adequately and plead lack of funds. Different levels of government squabble over who should be responsible. They are very slow to adopt policies that could respond or at least to begin to *implement* them and bureaucratic inertia persists. The situation has been exacerbated by policies that have moved very quickly to absorb disability into generic systems. For example, in Australia, government policies in the area of employment and vocational services have continued to disadvantage people with more severe disability or high support needs.
3. A related issue here is the existence of inequity. This is a perennial issue. However, the nature of some modern reform is allowing inequity to persist. One example is the manner in which scarce resources are rationed and allocated. Another is reflected in the

contrast between people who remain locked within poor quality, congregated services that are provided by all sectors and people who have access to “leading edge” services that are highly individualised.

4. There is a growing realisation that the movement is over-dependent upon governments and formal services. It is now clear that neither can fully deliver. Governments are struggling to manage the demands of globalisation for ever-increasing efficiencies, the growth of crises in social infrastructure and the needs for social support in an ageing population. One response of government and the formal sector is to withdraw support down to the level of the essentials of care which is less costly, but unlikely to recognise the scope of human needs. Some government policies are at least implicitly supporting a return to congregate care as the costs of more individualised supports are recognised. For example, we are seeing the return of the “duplex model” of accommodation services and the squeezing of more beds in various forms of group homes.
5. Some years ago, in personal correspondence with Dr Wolfensberger, he said that a major motivation for the development of Citizen Advocacy in 1969 was a mother who said, in the face of the early development of the community living movement, “What will happen to my child when I’m no longer here?” This question still reverberates.

## Renewal

There are at least five positive signs that the intellectual disability movement may be renewing.

1. The focus on self-determination and the search for ways of supporting people as individuals, even one at a time, offers many opportunities. As Dave Hagner (1996) has written, we are progressing from a mentality that says: “There’s a special place (on the hill) for you”, through “There’s a program for you”, to “How can we support you so that you can have a good life”. The challenge is to find ways of supporting people that do not require them to hand their lives over to someone else. The challenge is also for traditional service providers to reform what they do in these directions.
2. More action is occurring that is *relatively independent of government*. The early decades of the disability social movement were marked probably by strong influence and leadership that came from *within* the movement. Governments essentially followed this lead. This occurred in Australia right up to the late 1980s when, unfortunately, the reformist initiatives of the policy and legislative changes of the 1980s, such as the Disability Services Act 1986, came increasingly under the control of a rationalist, “content free” agenda. The challenge is to find ways of supporting people that are not under the dictates of government and not vulnerable to winds of policy change.
3. In some parts of Australia, parents and families are re-asserting their influence, an influence that waned after the strong parent involvement of the first decades of the disability movement. The challenge is for this family leadership to also look beyond the immediate crises of support in order to re-build a strong direction and base of values. Family leadership is once again at a premium.
4. The participation of people with intellectual disability in decision-making and their control over their own lives is an ever-increasing priority for many groups. This underpins the

concept of self-determination. However, the challenge remains for people with disability to play a more central role in a broad movement, rather than being its object.

5. Finally, there are indications that the movement is looking over the walls of its self-containment towards ideas that have broad appeal and which have the potential to acknowledge the contribution of people with disability and their allies to society — ideas that can support the development of a stronger, more positive identity for people with disability. In my view, this requires a reaffirmation and renewal of disability as a social movement — a return to the sense of purpose and cause. So many aspects of this social movement, its inclusive values, its reliance on relationships and networks, its knowledge and experience base, its personal commitments, its achievements and its energy contribute to a better society for us all. The challenge is to look for ways to rediscover this potential within the movement, to show its value to people outside its walls and to connect with ideas that have broad appeal. In this regard, the concept of *social capital* is worth exploring. This concept is about acknowledging the importance of trust, reciprocity and relationships, and understanding how these have declined in many societies that are otherwise rich in the material sense. It is a concept that recognises the importance of social movements and of voluntary commitments and their contribution to human well-being. Connecting with these ideas may contribute to a reassessment and reassertion of the importance of the disability social movement and provide strong rationales for its renewal.

## References

- Flacks, R. (1995). The party's over – so what is to be done? In H. Johnston, E. Larana, J. R. Gusfield (eds.), *New social movements. From ideology to identity*, pp. 330-351. Philadelphia, PA: Temple University Press.
- Hagner, D., Helm, D.T., & Butterworth, J. (1996). "This is your meeting". A qualitative study of person-centred planning. *Mental Retardation*, 34(3), 159-171.
- Johnston, H., Larana, J. R., & Gusfield, R. (1995). Identities, grievances, and new social movements. In H. Johnston, E. Larana, J. R. Gusfield (eds.), *New social movements. From ideology to identity*, pp. 3-35. Philadelphia, PA: Temple University Press.
- Lofland, J. (1995). Charting degrees of movement culture: Tasks of the cultured cartographer. In H. Johnston, E. Larana, J.R. Gusfield (eds. *New social movements. From ideology to identity*, pp. 188-216. Philadelphia, PA: Temple University Press.

# Can the concept of social capital contribute to disability policies and practices?

Errol Cocks PhD

Presented at 13th World Congress of Inclusion International, 2002, Melbourne

## Introduction

My paper “Intellectual disability: A social movement in need of revitalization?” outlined the characteristics of so-called “new” social movements and argued for the importance of acknowledging the *intellectual disability* social movement. It presented some of the signs that this movement is in some degree of decline and then listed five indicators of renewal of the movement. These were:

1. The focus on self-determination for people with intellectual disability and their families;
2. Signs that elements of the movement are pursuing greater independence from government;
3. The re-emergence of parent leadership;
4. Seeking to reinforce a role and identity for people with intellectual disability not as the *objects* of the movement, but as *participants* whose influence is paramount; and
5. Looking over the walls of the movement to connect with ideas that have broad appeal — ideas that can serve to acknowledge and reinforce the contributions made by people with intellectual disability and their allies to the well-being of society. So much of the intellectual disability social movement contributes to the betterment of society: its pursuit of social inclusion; its development and strategic use of powerful values, ideologies and concepts; the development of an influential voluntary sector and advocacy movement; and the development of a substantial body of knowledge and experience in the analysis and reform of societal agencies. The movement has also galvanised support at an international level with *Inclusion International* being a good example of this.

This paper will explore the concept of *social capital* and establish its relevance to the intellectual disability movement. Social capital may well provide additional rationales to assert the contribution made by people with intellectual disability and their allies within the social movement to the building of better societies for us all. A social capital context may help policy-makers and planners to appreciate this contribution and, connecting with the ideas, may also contribute to the renewal process of the movement itself.

The paper will provide a brief overview of the scope of the concept of social capital, establish the relevance of the concept to the intellectual disability movement and consider some of the implications for policy and practice.

## What is the Scope of Social Capital?

We are somewhat familiar with financial, physical and human capital which refer to the value that is associated with money, buildings and education. Social capital is a term that has been in occasional use for some decades but which has been given much more attention in the past decade, particularly through the work of Coleman (1998) (in education), Putnam (1993, 1995, 2000), and some international organisations such as OECD, the World Bank and the UN. At the heart of this burgeoning interest is the realisation amongst policy-makers that the relationship between material wealth and the well-being of individuals and societies is more complex than had been acknowledged within some of the limited ideologies of economic development. Countries with high GDP's do not necessarily have happy populations. OECD (2002 a) surveys suggest that overall well-being is increasingly lagging behind growth in GDP and *diminishing returns may have set in*. Of course GDP is a problematic measure in the sense that it does not take into account costs and benefits that are not market-based. The concept of the *triple bottom line* is belatedly leading governments to consider not only economic benefits, but also environmental and social outcomes. International concern struggles with inequality, new forms of exclusion and poverty, and the quality of life and health of children, elderly people and disadvantaged groups. A related point is the relevance of social capital to human conflict which is ever-present, but of great concern at present.

Current international emphasis is on a much broader concept of *human development*. The United Nations Development Program (UNDP) has published a number of reports since 1990, based upon the Human Development Index (HDI) which is a combination of four measures: life expectancy, adult literacy, education enrolment ratios and per capita GNP. A recent report, the Arab Human Development Report 2002 (UNDP, 2002) proposed further broadening of the HDI to include civil and political liberties (FS – Freedom score), women's access to power in society, IT access and per capita CO<sup>2</sup> emissions. A major departure from the HDI is the exclusion of income. It would indeed be interesting to consider a Disability Development Index (DDI) as a basis for policy development and reform and impact. In these terms, social capital is an attempt to examine and measure the *social* components of human development.

Social capital refers to the value that accrues through *social networks* and the *social connections among individuals*. We recognise immediately the link between this concept and the efforts of the intellectual disability social movement to promote the participation and inclusion of people with disability. There is a vital *relational foundation* to both.

Social capital also incorporates *trust* between people and the notion of *reciprocity*. Each of these concepts is a necessary ingredient for coordination and cooperation in human effort. In Putnam's words:

*Working together is easier in a community blessed with a substantial stock of social capital.* (Putnam, 1993)

He referred to norms of generalized reciprocity as the *favour bank*. Social capital makes possible the achievement of outcomes that otherwise would be impossible. Again, we can see the relevance of this to the importance of acknowledging the *contribution* of people with intellectual disability. Reciprocity requires an expectation of both give and take.

Putnam sees social capital as being closely related to *civic virtue* whereby citizens contribute to their community. He stated:

*A society of many virtuous but isolated individuals is not necessarily rich in social capital.* (Putnam, 2000)

International agencies and programs, including the OECD, the World Bank, the Arab Fund for Economic Development and the UNDP have taken up issues around social capital. The World Bank's interest is reflected in their statement that:

*Increasing evidence shows that social cohesion is critical for societies to prosper economically and for development to be sustainable. Social capital is not just the sum of institutions which underpin society – it is the glue that holds them together.*

Social capital resides in social relationships entered into voluntarily, implying that governments will often be *facilitating or supporting* the development of social capital rather than actually creating it. Social capital focuses on the nature of the relationship between civil society and the state. This point does raise the question of what it is that governments can do to foster the development of social capital and what they do, however unintentionally, to destroy it. The German philosopher Habermas has examined this question in much detail in his consideration of *civil society*, and its relationship to the state and to commerce. His contention is that the formality and regulation of the state, what he calls the *legal administrative form* (Habermas, 1989), may undermine any stated goals of creating societies in which people can be free. This issue reflects on my earlier observation that elements of the intellectual disability movement are seeking greater independence from government. Of course, it must also be recognised that governments can do much that is facilitative. However, a knowledge of the recent era of managerialism and economic rationalism shows that governments in Australia have administered social policies that have eroded social capital in our own field. A related assault on social capital has occurred through the policies of marketisation that have turned human services into businesses and vulnerable people into market commodities.

It is of interest to note that many knowledge generators in our movement, for example, John McKnight, John O'Brien, and Wolf Wolfensberger, have held similar positions for a long time.

Putnam has made a distinction between *bonding social capital* and *bridging social capital*. Bonding social capital is generated by the close ties and relationships between members of closely-knit groups, families being the clearest example. Bridging social capital is generated when relationships develop that are extended over distance. An international social movement such as *Inclusion International* is an example of bridging social capital at work. Social capital is not by definition positive. For example, some forms of bonding social capital might create antagonism between in-groups and out-groups, or may foster sectarianism, ethnocentrism, corruption or some other form of anti-social outcome. Bridging social capital is seen as fostering linkages to external assets and information diffusion. Social movements would likely rely on both forms. However, bridging social capital may be particularly useful in renewal processes.

In the context of bonding and bridging social capital, we can reflect on the meaning and implications of Margaret Thatcher's notorious statement that *there is no community, only individuals and families*.

Putnam's analysis of the situation in the US concluded that social capital is declining. In his book *Bowling alone*, he analysed a wide range of social indicators in areas such as engagement in politics and public affairs, membership and participation in clubs, community associations,

religious bodies, work-related organisations and professional societies, philanthropy and volunteering in order to support his case. He also examined a range of possible causes of the decline he documents. His list features many of the characteristics of modern society. It includes pressures of time and money, mobility, urban sprawl, changing family structures, big government, the welfare state, technology and the mass media and marketisation. He attributes much of the decline in social capital to *generational effects*. Thus he contends that an unusually civic pre-World War II generation was replaced by successive generations of less civically-minded people in the guise of the *baby boomers* and the *generation Xers*. Television was also identified as a major culprit. These conclusions obviously need further study. However, the generational issue is interesting from the perspective of the development of social movements.

There has been a considerable quantity of research on social capital carried out internationally by academics and international agencies, such as the OECD (2002 a) and the World Bank. One interesting observation from some of those studies is the relationship between high income and inequity in income and wealth distribution that is seen most starkly in countries such as the US, the UK and Australia, and low levels of trust.

The literature suggests links between social capital and many social issues. The World Bank, for example, has databases relating social capital to crime and violence, economics and trade, education, the environment, finance, nutrition, population, information technology, poverty, economic development, rural and urban development, water supply and sanitation. A clear problem with the concept of social capital is that it may be a panacea for explaining anything. There are methodological issues in the way social capital is measured, with a very heavy reliance on social indicators and drawing from data sets taken retrospectively from research. Nevertheless, the concept has great face value in validating the common experience of modernity – radical individualism and the loss of community.

Both Putnam and the OECD have stated that the most convincing evidence of the positive impact of social ties and connectedness that characterises social capital is in the area of personal health. Research evidence supports the following connections:

- The more connected and integrated we are with our community, the less likely are we to experience colds, heart attacks, strokes, cancer, depression and premature death.
- As social connectedness has declined, rates of depression and suicide have increased.
- Social isolation tends to precede illness.
- There is a positive link between supportive relationships and mental health.
- Isolated elderly people have greater risk of Alzheimer's disease and dementia.

Campbell (2000) concluded that *social capital provides a fruitful starting point for filling the current gap in our understanding of community-level determinants of health*. Social capital may provide the integrating concept to unite a range of fragmentary concepts such as “a sense of community”, “community competence or capacity”, “collective efficacy” and “empowerment”.

### **What is the Relevance of Social Capital to the Intellectual Disability Movement?**

In considering the relevance of social capital to the intellectual disability movement, four

broad issues are examined:

### **1. Disability, social movements, voluntary associations and social capital**

To return to my major theme about the connection between social capital and the intellectual disability social movement, many writers and researchers have concluded that social movements and voluntary engagements are the stuff of social capital. Social movements build social capital and also are built upon social capital, creating a “virtuous circle”. Social movements foster new identities and extend social networks. They promote civic engagement.

Putnam referred to voluntary civic associations as *schools for democracy*, places where social and civic skills are fostered. They are places where civic engagement helps to create trust, reciprocity and cooperation with positive spin-offs for local communities.

The modern intellectual disability social movement is over a half-century old and, in social capital terms, must be seen as an excellent example of both bonding and bridging social capital. The current emphases on valued social roles, citizenship and inclusive communities in this movement can *potentially* contribute to the discourse about social capital and building stronger communities. This contribution needs to be made more clear, obvious and relevant to policy-makers.

### **2. Disability, social exclusion, poverty, risk and social capital**

In a major review of the literature, Elwan (1999) from the World Bank could find little systematic examination of the linkages between poverty and disability. She concluded that the link between social exclusion and poverty is seen acutely with people with disability *in both developed and developing countries*. Consideration of these issues for people with disability also clearly illustrates that social exclusion means more than poverty. It is also associated with high risks of lack of access to social institutions such as education, housing, health and employment. Evidence from both developed and developing countries is that people with disability run substantial risks. On average, they:

- Are less educated and more illiterate.
- Have lower socioeconomic status.
- Reside in rural or poor areas.
- Have poorer nutritional status.
- Have lower inoculation and immunisation coverage.
- Have higher unemployment rates, lower occupational mobility and higher under-employment.
- Are more vulnerable to “mental illness”.
- Have lower marriage prospects.
- Have high risks of physical and mental abuse.

Social exclusion appears to go hand-in-hand with lower levels of trust and civic engagement. This is particularly the case with bridging types of social capital where there may be high levels of trust and cooperation *within* a group, but low levels of cooperation and trust *between* groups. This is a situation in which bonding forms of social capital may work towards the *exclusion* of some citizens. This could occur directly, whereby some groups such as people with intellectual disability are excluded from important social institutions such as education. It could also occur

indirectly whereby a social movement may effectively isolate itself from the mainstream of society. Arguably, this is an issue for the intellectual disability movement and leads to the conclusion that it is time to create *new* bridging social capital and forge *new* links and alliances in order to renew and revitalise the movement.

### 3. The Focus on Relational Aspects

The particular relevance of a social capital perspective to social exclusion is illustrated by an interesting study, Baron, Riddell, and Wilson (1998). Using a social capital framework, they studied the “life worlds” of 30 adults with intellectual disability who lived in Scotland. They examined the relationship of people with intellectual disability to *sources of social capital*. To determine this, they essentially mapped social contacts of this group. These were their conclusions:

1. Access to needed services was limited by the location of services and the domination of *segregated services*.
2. The adults experienced no developmental progression through a transition stage to adulthood.
3. Lack of work severely limited their personal development and wider social engagements.
4. Social integration was limited by the dominance of special social networks and lack of work.
5. Participative citizenship was limited by closed social networks and segregated service provision.
6. Inequity was suggested in exclusion from mainstream social, economic and personal life chances.

In mapping the relationship of these adults with disability with their community, the researchers clearly illustrated how the limited relationship to social capital maintained them in negative social roles. Equally, of course, their limited social roles served to restrict their access to social capital, creating a “vicious circle”.

The lesson here for self-determination is the fundamental importance of the relational aspect and the danger that these ideas could become merely another expression of formal services.

### 4. Sustainability and social capital

There are substantial threats to both sustainability and social capital. A recent OECD study defined sustainability as:

*Development that satisfies the needs of the present generation without compromising the capacity of future generations to satisfy their needs.* (OECD, 2002 b)

Understanding the social aspects of sustainability are much more rudimentary than for environmental aspects.

The report concluded that there is great pressure on the sustainability of social institutions, including the family. A number of influences were described, some of which help to explain the current pressures in the disability sector:

- A major factor here is demographic. All countries are undergoing transition from high mortality and fertility rates to low mortality and fertility rates as a result of public health improvements. The OECD (2002 b) reported that birth rates are below replacement in 61 countries which have a total of 44% of the world's population.
- Decline in the size of families and the break-up of extended families create living and working arrangements that affect the capacity of families to support their members. This is a critical issue for people with disability who have support needs.
- There is a declining proportion of young people that will create considerable pressures on living standards from 2010 onwards.
- Social exclusion of elderly people is an escalating problem.
- Immigration in its various forms places strain on the political and social capacities of many countries and is seen to be contributing to the growth of the political "new right".
- There is growing inequity in wealth and income distribution that is almost universal.
- Education gaps between developing and developed countries remain substantial, especially in higher education where access is clearly linked with wealth.

### **Implications for Policy and Practice in Disability**

Social capital provides an integrative framework for exploring the relationship between vulnerable groups, including not only people with disability, but also other groups such as the elderly, people with "mental illness", and people from some racial and ethnic groups and communities. Social capital also integrates a wide range of social indicators and social dynamics that are closely related to human development, including health and well-being, education, economic well-being and social inclusion. It focuses on the contribution of social networks, partnerships, social movements and voluntary associations that are seen as important elements of strategies to address social exclusion and the creation of stronger and more inclusive communities. Social capital also incorporates an analysis of the relationship between civil society, the state and the market, and draws attention to the effectiveness of government policies and practices.

Some policy and research implications have been expressed within the growing literature on social capital. They include:

- Support for families and family friendly policies.
- Support for voluntary initiatives.
- Government decision-making processes that encourage participation (rather than merely consultation) and empowerment.
- Support to learning and leadership development.
- Linking efforts to enhance well-being to local communities.
- Better understanding of what works to promote social capital and what erodes it.
- Greater links between social capital and economic outcomes.
- Understanding the inequalities that are embedded in social capital and how social capital is related to social inclusion/exclusion.

These implications need to be better understood within the disability social movement and should form a foundation for strategy and policy development. They certainly present a challenge

to the preoccupation of much current research effort in intellectual disability which is inward-looking and repetitive. All the indications are that the time ahead will be very challenging indeed.

## References

- Baron, S., Riddell, S., & Wilson, A. (1998). The best burgers? The person with learning difficulties as Worker. In T. Shakespeare (ed.). *The disability reader*, pp. 94-109). London: Cassell.
- Bloom, D. (1999). *Social capitalism and human progress*. Paris: OECD.
- Campbell, C. (2000). Social capital and health: Contextualising health promotion within local community networks. In S. Baron, J. Field, & T. Schuller. *Social capital: Critical perspectives* (pp. 182-196). Oxford, UK: Oxford University Press.
- Coleman, J. (1998). Social capital in the creation of human capital. *American Journal of Sociology*, 94 (Supplement), S95-120.
- Elwan, A. (1999). *Poverty & disability. A survey of the literature*. Geneva: World Bank.
- Field, J., Schuller, T., & Baron, S. (2000). Social capital and human capital revisited. In S. Baron, J. Field, & T. Schuller (eds.). *Social capital. Critical perspectives*, pp. 243-263. New York: Oxford University Press.
- Habermas, J. (1989). *The new conservatism. Cultural criticism and the historian's debate*. Cambridge: Polity Press.
- OECD (2002 a). *The well-being of nations. The role of human & social capital*. Paris: OECD (CERI).
- OECD (2002 b). *The social aspects of sustainable development*. Paris: OECD (DEELSA/ELSA).
- Putnam, R. (1993). The prosperous community: Social capital and public life. *The American Prospect*, 143, 35-42.
- Putnam, R. (1995). The strange disappearance of civic America. *The American Prospect*, 7(24).
- Putnam, R. (2000). *Bowling alone. The collapse & revival of American community*. New York: Simon & Schuster.
- Temple, J. (2000). *Growth effects of education & social capital in the OECD countries*. Paris: OECD (Economic Department).
- United Nations Development Program (2002). *Arab Human Development Report 2002*. New York: Author.
- World Bank: [www.worldbank.org/poverty/scapital/whatsc.htm](http://www.worldbank.org/poverty/scapital/whatsc.htm)

# BOOK REVIEW

## **Learning Re-enabled: A Practical Guide to Helping Children with Learning Disabilities**

2<sup>nd</sup> Ed.

Susan N. Schriber Orloff

This book by Orloff is about children with the label “learning disability”.

In the recent review of the *Teaching of Reading* by the Australian Government, the authors of the report rejected the usage of such labels as *learning difficulties*, *learning disabilities*, *special needs*, *reading disabilities*, *dyslexia* and *students at education risk*. These terms have been used interchangeably, and research based on such labels provide little in terms of efficacy.<sup>1</sup>

We know, however, that it is enough of a label to know that a child is not reading. Enough to know what intervention and resources apply. The lesson from the research is that good instruction is good for all – requiring only variation in intensity and design informed by regular assessment of skill.

In many ways, Orloff’s book suffers from this labelling difficulty.

Notwithstanding, Orloff is clearly empathetic with the plight of many children who are struggling with learning. And this is a good thing. However, it is a mistake to base our intervention or analysis on a “disability” label. In the field of development, this is an error of scientific proportions.

To illustrate this point, there is a “myth” in the teaching of reading that has been around for several decades and continues to exist despite the evidence. The argument goes: “wouldn’t it be wiser to tailor instructional process and materials to children’s perceptual styles or dominant modalities”. In 1990 Adams reported that 95% of special education teachers believed that the modality argument was supported by research. **Yet, it is not supported by the data.**

The idea that one can teach reading skills by training perceptual skills such as spatial relations, visual memory, visual discrimination, visual motor integration, gross and fine motor coordination, tactile-kinesthetic activities, auditory discrimination and auditory-visual integration is without any measurable evidence of positive effect. Bouncing on trampolines may be lots of fun and great exercise, but it is not a scientific reading method with any positive research effect.

While many of the physical activities in the book may be of benefit to the physical development of a child, it is difficult to account for the book’s claims of such activity linked to educational skill or development. The book would be somewhat improved by presenting the research evidence upon which Orloff relies.

Therein lies the difficulty in reviewing this text. I think of such writing as belonging to a different era when we believed in a false science that individual difference requires a different developmental science<sup>2</sup>. On the bright side, Orloff is clearly a practitioner and author of immense good will. Yet this is only one half of what children need.

Paul Cain

**(Endnotes)**

<sup>1</sup> Dr Rowe et al (March, 2005).

From the outset, it is important to recognise the lack of clarity surrounding prevailing definitions of *learning difficulties*, and the continuing controversy about how identification should proceed. Over the past few years, theorists and practitioners have highlighted the necessity for definitional changes that reflect contemporary understandings and allow for easier and more consistent identification (e.g., Kavale & Forness, 2000; Scruggs & Mastropieri, 2002). Despite increasing efforts to cope with definitional problems plaguing the term *learning difficulties* by researchers and practitioners (e.g., Shaw, Cullen, McGuire, & Brinckerhoff, 1995), there is little consensus in the literature on definitional issues, especially in respect of the role played by intelligence (or IQ). The inherent complexity in reaching definitional consensus is characterised by Lyon (1996, p. 3) as follows: *Which instructional reading approach or method, or combination of approaches or methods, provided in which setting or combination of settings, under which student–teacher ratio conditions and teacher–student interactions, provided for what period of time and by which type of teacher, have the greatest impact on well defined elements of reading behaviour and reading-related behaviours, for which children, for how long, and for what reasons?* The question, posed by Lyon with respect to children with reading difficulties, is equally applicable to children with a range of other learning difficulties. In particular, it highlights the challenge faced by educational researchers and practitioners as they seek to find effective ways to cater for the educational needs of children who find it difficult to learn.

[And]

In a review of the current international situation in relation to this issue, Gale (2000, p. 130) notes:

*Although there have been literally thousands of studies concerned with learning disabilities, particularly focused on primary and secondary education, what the literature generally shows is that researchers are no nearer to a common understanding of what is meant by such terms.*

<sup>2</sup> In Dr Rowe et al (March, 2005). Rowe poignantly makes the point that only a small portion of variance was accounted to individual difference of students; that outmoded forms of biological or social determinism whilst still pervasive are “little more than religious dogma”.

## **TASH 2007 Conference**

# **Equity, Opportunity and Inclusion**

**Workshops, Conference and Exhibits**

**5 - 8 December 2007**

**Washington State Convention and Trade Center  
Sheraton Seattle Hotel and Tower  
Seattle, Washington**

For Highlights, Registration and News, visit TASH's website:  
[www.tash.org](http://www.tash.org)

TASH is an international membership association leading the way to inclusive communities  
through research, education and advocacy

# CONFERENCES

## **19-22 October 2007**

### **National Advocacy Conference 2007**

Ability Incorporated

Valla Beach Resort

Nambucca Heads, NSW

Tel: 02 6628 8188 or 1800 657 961

Email: aiadvoc@bigpond.net.au

## **22-23 November 2007**

7th Annual ASSID Conference for

Disability Support Workers

University of Melbourne

Tel: 03 9925 7899

Email: dswconference@rmit.edu.au

Web: www.assid.org.au

## **25-26 October 2007**

### **"The Odyssey ... a journey of enrichment and possibility"**

Family Advocacy National Conference

Central Sydney

Tel: 02 9869 0866 or 1800 620 588

Email: conference@family-advocacy.com

Web: www.family-advocacy.com

## **5-8 December, 2007**

### **"Equality, Opportunity and Inclusion"**

Washington State Convention & Trade  
Center

Seattle, Washington, USA

Web: www.tash.org

## **5-7 November 2007**

### **"In Tune"**

42nd ASSID Conference

Fremantle, WA

Email: assidconference@dsc.wa.gov.au

Web: www.strongercommunities.curtin.edu  
.au/assid2007/

## **6-8 February 2008**

### **"Being the Change"**

Having a Say Conference 2008

Deakin University

Geelong, Australia

Tel: 03 9416 4003

Email: office@valid.org.au

www.valid.org.au

**DO YOU SUBSCRIBE TO  
AIID'S JOURNAL *INTERACTION* or *INFORMATION SERVICE*?**

*Interaction is the premier journal in Australia with a focus on issues affecting people with intellectual disability and their families.*

**Only \$35 for four(4) issues per year or \$40 for overseas subscribers!  
e-Interaction is available online for \$20, or free if purchased with hard copy.**

- ← Topics covered include: Employment; Education; Accommodation.
- ← Articles for publication in *Interaction* are always welcomed.

\* \* \* \*

**Alternatively, you may wish to subscribe to**

**AIID's Information Service**

**The Service costs \$150\* per year and is available within Australia only.  
In addition, e-Information Service is available from AIID's website for \$75\*.**

**Features of the Service**

When you become a subscriber, you will receive 11 packages a year, consisting of a quarterly generic package, journal content lists, newspaper clippings, press releases and other material relevant to intellectual disability.

- ✓ Your subscription also includes AIID's journal *Interaction* (four issues per year).
- ✓ You can order copies of articles for personal research for the cost of photocopying and postage.
- ✓ We sell publications from Australia, Britain, Canada and the United States — members are entitled to 10% discount.
- ✓ AIID also has a range of videos covering intellectual disability. These are suitable resources for staff training, presentations, teaching skills, etc. As a subscriber, you pay \$10 per 10 working days, plus mailing costs, instead of the normal charge of \$20.

*\* Cost to individuals only – please contact AIID for cost to organisations.*

**Payment Details:    *Interaction* - \$35 (\$40 overseas)                      *Information Service* - \$150**

**Cheque/Money order**                       **Bankcard, Mastercard or VISA**

**Credit Card Number:** \_\_\_\_\_

Expiry Date: \_\_\_\_\_                      Signature: \_\_\_\_\_

Name: .....

Address: .....

.....

Australian Institute on Intellectual Disability  
PO Box 771, MAWSON ACT 2607 AUSTRALIA  
Tel/Fax: 02 6296 4400 / Email: [guna.adens@ncid.org.au](mailto:guna.adens@ncid.org.au)



*Australian Institute on Intellectual Disability*  
*PO Box 771*  
*Mawson ACT 2607*  
*Tel/Fax: (02) 6296 4400*  
*ISSN 0818/6286*