**REVIEW OF THE NATIONAL DISABILITY ADVOCACY PROGRAM**

Submission by Deirdre Croft (parent and advocate Western Australia)

**A PERSONAL INTRODUCTION**

I write this submission in a personal capacity as the mother of a 35 year old son, Richard, who has a severe intellectual disability, and multiple other disabilities, due to birth trauma.

Richard is an only child. His father passed away in Perth in late 2013. His father’s family live interstate and are not involved in Richard’s life.

I am currently attempting to build a **Personal Advocacy Network** for my son (with membership drawn from people who know Richard well - including my own extended family, friends, supporters and other contributors to Richard’s life). My goal is to create a network that will endure and continue to watch out and speak up for Richard beyond my own capacity and lifetime. The network is supported by a paid facilitator under the auspices of WA’s Future Living Trust[[1]](#footnote-1). The early level of commitment is promising.

I also have experience of the challenges faced by people with physical disability having cared for my mother over a five year period until her death (1998-2002). My mother had right side paralysis following a life threatening stroke in 1998 but she remained intellectually competent until the last month before her death.

Having cared for both a person with intellectual disability and for a person with physical disability, I assert that the challenges experienced, both by the person with disability, and by the person providing needed care and support, are qualitatively different for these different disabilities.

To a lesser extent, my submission is also informed by my many years of advocacy on behalf of all Australians with disability and their family carers – including:

* serving on state and national disability campaign committees over a ten year period (1994-2003)
* four years on the National Disability and Carers Ministerial Advisory Council (2003-2007)
* research undertaken for my PhD thesis on the long term care needs of Western Australians with intellectual disability (2006-2010). Unfortunately, my thesis remains uncompleted due to competing personal care demands in the ensuing years.

In my capacity as a long term advocate and researcher, I would have liked to have made a more substantial submission to this review (including more comprehensive references to research reinforcing the unique needs and vulnerabilities of people with intellectual disability).

Unfortunately, my time and capacity to prepare a more detailed submission is limited due to:

* my own deteriorating health and stamina
* the personal demands of continuing to meet Richard’s high level care needs
* the organisational time and effort involved in building Richard’s Personal Advocacy Network.

**AN ADVOCACY QUESTION**

**Who is qualified to speak for those who cannot speak for themselves?**

In making this submission, I begin with a question in my own mind, which I hope your own committee may also pose, as well as answer, in the current review of the National Disability Advocacy Program.

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| **My question is:****Who is best qualified to represent and advocate for my son’s lifelong needs for support with personal care, skills development, physical activity, recreational opportunities, social engagement and other quality of life dimensions?****As an extension of that question, I also ask:** **Who is best qualified to represent and advocate for the systemic issues and obstacles facing people, like my son, who have a severe intellectual disability and complex needs and who are, in many cases, unable to speak or advocate for themselves?** |

**DOES LIVED EXPERIENCE OF DISABILITY QUALIFY A PERSON**

**TO ADVOCATE FOR MY SON?**

As well as a severe intellectual disability, Richard is sight impaired.

Would a person who has lived experience of being blind or vision impaired be sufficient to inform any advocacy they may undertake that is relevant to the lifelong needs of my son and of others like him? I think not.

Although Richard can walk, he also has mobility challenges and needs support to navigate the physical environment.

I wonder whether a person who is also restricted in their mobility, but otherwise intellectually competent, could understand and advocate for the needs of someone like my son, and other people with intellectual disability who similarly experience mobility restrictions. Again I think not.

Richard has no verbal communication. Perhaps a person with hearing impairment might understand what it may be like for someone like Richard who also faces communication challenges? No again.

**DIFFERING DIS/ABILITIES DIFFERING NEEDS**

From the range of disabilities listed above and, as an intellectually competent person, I can quite easily imagine what it might be like to be blind, or to be deaf or to have mobility restrictions. I could even use a few props to enhance my understanding.

I cannot, on the other hand, imagine what it is like to live with a severe intellectual disability as Richard has, nor do I understand how my son perceives his world.

It is only because I have a close and long term personal relationship with my son that I am able to pick up on the subtle changes in his state of equilibrium and sometimes, not so subtle, changes in his behaviour which enable me to discern how he is travelling and/or what may be disturbing or disrupting his quality of life.

For people with physical or sensory disability, I believe I also understand some of the access and inclusion issues they might face in their quest to participate and be included in all dimensions of Australian society.

I would, however, suggest that the physical and social barriers faced by people with physical or sensory disability can, in large part, be readily rectified with some accommodations in the physical environment and/or by championing changes in discriminatory public attitudes.

In a hierarchy of human needs, the “access and inclusion” and “choice and control” issues advocated by, often highly intelligent, articulate people with physical and sensory disability are nowhere near the priority issues impacting on my own son’s wellbeing and quality of life.

My son’s disability is pervasive. It impacts on every dimension of his life.

He depends on every person who comes into his life to do the right thing by him.

Richard relies on other caring people to:

* meet his most basic physical needs
* provide opportunities and support for him to engage with his physical and social environment
* provide opportunities and support for him to develop and practice skills that will enable him to maintain and increase his competence and personal independence
* speak up for him and advocate on his behalf.

The extent and breadth of my son’s multiple disabilities not only makes him incredibly dependent on the good intentions and actions of others, but also incredibly vulnerable if these good intentions and actions are not forthcoming (even in one single person who may be involved in his day-to-day life).

How could a person with a singular physical or sensory disability possibly understand what life is like for Richard, and for others like him. How does their lived experience of disability help to inform any advocacy they might undertake for the hundreds of thousands of people like Richard in our society?

And yet people with physical and sensory disability with a lived experience of their own particular disability are predominantly those who populate the current, generic disability advisory and advocacy groups.

Regrettably, there also appear to be many people with physical and sensory disability amongst this same population who deny the legitimacy of the advocacy contribution of family carers who seek to represent and advocate, not only for the needs of their own family member with severe intellectual disability, but for the needs of others like them, who, like Richard, cannot speak for themselves.

**SOME INTELLECTUAL DISABILITY STATISTICS**

According to the Australian Bureau of Statistics, there was a statistically significant increase in the number of Australians with intellectual disability reported in the 2012 Survey of Disability, Ageing and Carers (SDAC) compared to the 2009 survey (from 2.6% of the population to 2.9% of the population).[[2]](#footnote-2)

However, the 2012 figure of 668,100 people also included those in older age groups who may have dementia. When this older population is discounted, in 2012, there were 454,600 Australians under the age of 60 who had an intellectual disability.

The published ABS tables for the 2012 SDAC Survey do not make a distinction according to age for the levels of intellectual disability reported. However,

* 417,100 people (or 62.4% of the total population of people with intellectual disability had a profound or severe core activity limitation)
* 153,000 people (or 22.9% of the total population had a moderate or mild core activity limitation).

This would suggest that a substantially higher number and proportion of Australians with intellectual disability are severely affected by their disability than those who have a milder intellectual disability.

A high proportion of people with intellectual disability also need assistance with “oral communication” ie may have difficulty communicating verbally.

According to the 2012 SDAC Survey:

* 76% of the 417,100 Australians with intellectual disability who had a profound or severe core activity limitation needed assistance with oral communication
* 25.5% of 153.000 Australians with intellectual disability who had a moderate or mild core activity restriction needed assistance with oral communication.

A Special Bulletin on Intellectual Disability in Australia published by the Australian Institute of Health and Welfare (2008)[[3]](#footnote-3) reported that in the 2003 SDAC:

* 40.7% of people aged under the age of 65 with a profound or severe core activity limitation had speech problems
* 23.7% of all people with intellectual disability under the age of 65 had speech problems.

Without an age breakdown on the 2012 figures it is not possible to cross reference the 2003 figures with those reported for 2012.

However, it may be concluded that a very high proportion and number of Australians with intellectual disability are unable to speak, or to speak well, for themselves.

A media statement on the 2012 SDAC reports that “*three quarters of (Australians with intellectual disability) are getting help from family, friends and neighbours, with* ***parents the most common source of help*.**” (emphasis added).

**PERSONAL EXPERIENCE OF DISABILITY ADVOCACY**

Many years ago a ministerial advisory colleague of mine, who is blind, commented to me that the only thing she had in common with someone like my son Richard was “humanity”.

Does a shared humanity equip a person to adequately represent and advocate for the needs of my son? If so, there would be no need for any specialist disability advocacy programs.

I recall another historic conversation with a current senior disability advocate who uses a wheelchair and is also a mother of a child who does not have a disability. This advocate confided in me that she didn’t think she could have coped if she had had a child with an intellectual disability. Why not, I wonder?

Over my many years of disability advocacy, I have been aware of, and often been personally subjected to, negative attitudes towards the advocacy voice of family carers speaking on behalf of their loved ones with severe intellectual disability. Too often the assumption appears to be that only those with lived experience of disability have the right to speak on the disability platform and that family carers are seeking to advance their own need for support, rather than the support needs of the person in need of care, with a conclusion to be drawn that the care of their loved one represents “a burden” on the carer’s life.

In joint disability and carer forums, my experience is that the disability representatives have often been surprised to discover that the concerns of family carer representatives are, more often than not, focused on advocating for the needs of their family member than for themselves. And, even when family carers do seek support for their caring role it is typically motivated by their commitment to continue to provide the personal care and support their family member needs.

**DISCRIMINATION WITHIN THE DISABILITY SECTOR**

Even within the disability sector it would seem that discrimination and negative attitudes are rife - where people with severe and profound intellectual and multiple disability are too often disowned and relegated to the bottom of the disability/ability hierarchy because they do not neatly fit into the current, generic “Break Down the Barriers” or “Choice and Control” advocacy paradigm.

People like my son Richard cannot be held up as a shining example of “ability without barriers” or as some refer to as “able-ism”.

If Richard’s worth as a human being, or his contribution to society, is measured solely by his capabilities, he will surely be socially de-valued, not only within the broader community, but also within the disability sector itself.

**ON RICHARD’S SIDE**

My son Richard has featured in three documentaries charting key points of transition in his life. The latest in the trilogy is called “On Richard’s Side” reinforcing Richard’s need to have a team of people who are on his side over the course of his life and my quest, as his mother, to ensure that he does.

The film was recently selected for its world premiere screening at the Sydney Film Festival. A dedicated web-site has also been set up[[4]](#footnote-4) in which a brief description is offered as to the central themes explored:

*Filmed over three decades, On Richard’s Side charts the life-story of Richard, a young man with a complex disability since birth. The film provides intimate and poignant insights into his parents’ determined quest to establish a quality life for their son and themselves.*

*Richard’s mum, Deirdre is now ageing and she is fiercely committed to finding an answer to the questions - who will care for Richard in the next stage of his life and what will happen to her son when she is no longer around?*

The title page of the “On Richard’s Side” website includes a short trailer to the film as well as featuring a comment I made during one of the many hours of interviews we conducted. The comment reinforces the notion that human value need not simply derive from a person’s assessed capabilities or “a-bilities”.

“*If we have a notion that there is something in humanity that is intrinsically worthwhile and valuable and that people who call forth our caring and our love and our compassion are doing a service to us because those are qualities that enrich our humanity…then without people who are vulnerable, without people who need us, how do we practice our caring and our compassion?*” (Deirdre Croft, 2015)

**A VOICE FOR PEOPLE WITH SEVERE INTELLECTUAL DISABILITY**

In 2010, I wrote an article which was published by the Australian Institute on Intellectual and Developmental Disability in its Interaction Journal. The article was entitled “*For better or worse – How have people with intellectual disability fared in a whole of disability service framework*”.[[5]](#footnote-5)

My analysis confirmed that people with severe intellectual disability had lost ground in multiple domains of service provision and advocacy under the whole of disability service framework which had been implemented throughout Australia from the late 1980s to the early to mid-1990s.

In my article I quoted esteemed international expert on intellectual disability Professor Jim Mansell (2006)[[6]](#footnote-6) who coined the term “*de-differentiation*” to describe the way in which throughout the Western world there had been a “*loss of special, separate policies and services structures for people with intellectual disabilities and their replacement by general policies and structures*”.

Mansell noted that “*the consequences of de-differentiation may include greater competition for priority or resources and a lack of recognition of special issues”* while *“the idea of developmental intervention to help people overcome their intellectual disability has almost completely disappeared as a priority*” (p. 72-73).

**RECOMMENDATIONS**

With a couple of minor modifications, my recommendations below are the same ones I made in the 2010 paper I prepared for the Interaction Journal article.

**1. A distinct intellectual disability identity:**

There is a need to reclaim and define a distinct intellectual disability profile in which the unique characteristics and needs of people with intellectual disability can be clearly articulated and promoted.

**2. Intellectual disability specific data:**

Data are required to enable monitoring, informed advocacy and evidence-informed action to address the unique needs of and issues facing people with intellectual disability.

**3. A dedicated advocacy focus:**

Recognising that many people with intellectual disability cannot speak for themselves or speak well for themselves, there is a need to strengthen and adequately resource a strong intellectual disability-specific advocacy voice which can represent the needs of people with intellectual disability and their family carers based on the best available data and evidence.

In addition, and based on my own recent experience in working to establish a **Personal Advocacy Network** for Richard following the death of his father, I would further recommend:

**4. Funding support for the establishment of Personal Advocacy Networks for people with intellectual disability**

Recognising that parents provide most of the support required by their sons and daughter with intellectual disability, and that people with intellectual disability will require continuing support beyond their parents’ lifetime, there is a need to ensure that families are supported to establish personal advocacy networks to ensure the needs of their children with intellectual disability continue to be met, and their best interests advanced after their parents have passed away.

**A CONCLUDING COMMENT**

I made the following concluding comment in my 2010 Interaction article which I believe just as strongly today:

*“As a journalist/wordsmith by professional training, I am interested in how we use language and the meaning we attribute to the language we use.*

*On which basis, I experience a certain inconsistency in the use of the word “dis-ability” as a generic label to describe people who are limited in their physical or intellectual capabilities, compared to the more precise definitions we apply to people with superior physical and intellectual “a-bilities”. It seems ludicrous to assume we would group elite sportspeople with high flying academics into a singular category as if superior ability in either domain created a unifying experience. Yet we have no problem grouping people who have a physical or intellectual dis-ability on the assumption that the experience of disability must also create a common cause. To my mind, it’s lazy language and conceptually flawed.”*

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1. Future Living Trust <http://www.futureliving.org.au/> [↑](#footnote-ref-1)
2. [http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4433.0.55.0032012?OpenDocument](http://www.abs.gov.au/AUSSTATS/abs%40.nsf/DetailsPage/4433.0.55.0032012?OpenDocument) [↑](#footnote-ref-2)
3. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442452891> [↑](#footnote-ref-3)
4. <http://www.onrichardsside.com.au/> [↑](#footnote-ref-4)
5. <https://engage.dss.gov.au/wp-content/uploads/2015/09/Addendum-1-For-Better-or-Worse-D-Croft.pdf> [↑](#footnote-ref-5)
6. Mansell, J., (2006), Deinstitutionalisation and community living: Progress, problems and priorities, Journal of Intellectual and Developmental Disabilities, Vol 31 (2), pps 65-76 [↑](#footnote-ref-6)