

Barriers to effective family advocacy



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Barriers to effective family advocacy

CREATING A CONTEXT

Parents who have a child diagnosed with
an impairment
are faced with a changed reality.
Beginning a lifelong journey of
dealing with medical,
educational and
human service professionals

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Additional challenges are
gaining access to relevant information,
and services and dealing with
bureaucracy

Written and anecdotal history includes
families' stories of isolation, being
marginalised, controlled and case
managed.

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Where the 'system' sets the policy, in isolation and holds the power and the resources

With families & individuals being human service 'clients' who should be 'grateful' for a service- no matter how that 'service' is delivered.

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Leaving families in unequal power relationships with their ability and effectiveness to advocate diminishing over time.

Often irrespective of socio-economic circumstances

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Some families may be socialised into the 'tragedy model' whereby their family member is:

"A burden on society, a problem to be fixed, and without the possibility of a real future for an 'ordinary' life"

Simpson, J. Hornby, G. Davies, L. and Murray, R. (2004). Positive Parent Professional Relationships in O'Brien, P. & Sullivan, M. (Eds), Allies in Emancipation *Shifting from providing service to being of Support*. Melbourne; Dunmore

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The focus is on the deficits of their family member & medical and educational professions and by funding bodies

There is little focus on acknowledging and fostering the strengths and capacities of the whole family

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For other families there is frustration and a deep sense of abhorrence at the lack of fundamental human rights accorded their sons or daughters.

Bureaucracy in day to day life significantly enhances the challenges of the caring role

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Bureaucracy and....

- Hospitals, waiting lists & the likelihood of parent competency being questioned.
- Pre-school
- Schools
- Centre Link
- Accessing family support via Human services

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For our adult family members who cannot speak for themselves, we then encounter another set of bureaucracy involving:

- Centre-link
- Telstra
- Energy companies
- Human Services

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In Queensland the Guardianship and Administration Act 2000 cites the following around.....

“9. Range of substitute decisions makers

- (1) This Act and the *Powers of Attorney Act 1998* authorise the exercise of power for a matter of an adult with impaired capacity for the matter
- (2) Depending on the type of matter involved, this may be done---
- (3) On an informal basis by members of the adult’s existing support network.....”

(page 48 Reprint 5D effective 1 July 2010)

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As we negotiate this maze no matter our personal role in life, we are often powerless to break down the barriers of social exclusion, and the culture of inaccessibility to supports and for our daughter or son, access to the rights enjoyed by other citizens.

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Social Exclusion

Is lifelong for our family member with a disability and often for families

Relegated for life to being a Centre-link recipient

And a human service 'client'

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I am a client at an intake meeting
You move house

I have challenging behavior
You are rude

I am non-compliant
You don't like being told what to do

Author Unknown: cited in Westcott, R. (2003) Lives Unrealised; Clienthood and the Disability Industry; Australian Institute on Intellectual Disability; Canberra

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Denied in the main:

- Meaningful and .. paid employment
- A career
- Home ownership
- Intimate relationships
- The personalised assistance required to be included in and contribute to one's community

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**I wanted to talk to the nice looking person behind us in the grocery store
I was told it was inappropriate to talk to strangers**

You met your spouse at the grocery store, looking for the bean sprouts

Author Unknown: cited in Westcott, R. (2003) Lives Unrealised; Clienthood and the Disability Industry; Australian Institute on Intellectual Disability; Canberra

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The Convention of the rights of person with disabilities (2006)(CRPD) was adopted by the United Nations General Assembly in December 2007.

- Australia is party to seven of the United Nations' core human rights treaties, including:
- International Covenant on 'Economic, Social and Cultural Rights
- International Convention on the Elimination of all forms of Racial Discrimination
- The Convention on the Elimination of All Forms of Discrimination Against Women
- Convention on the Rights of the Child
- Convention on the Rights of Persons with Disabilities

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Each of which incorporate elements of the right to housing and social services

The reality however is vastly different in Queensland from the Rhetoric.

**Being party to a treaty does not make that treaty part of Australian Law
Legislation must be enacted to incorporate CRPD obligations**

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Article 19 of the convention expresses the following, ..

“...recognising the right of all persons with a disability to live in the community and participate in community life with choices equal to others,Including:

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The opportunity to choose their place of residence...and

- Where and with whom they shall live on an equal basis with others
- Have access to a range of in-home residential and other community support services....and

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the personal assistance necessary to support living and inclusion in the community,
and
to prevent isolation and segregation from community”

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**When I ask someone out for dinner
it's an outing**

When you ask someone out it's a date

**I am learning leisure skills
Your T-Shirt says you're a 'couch potato'**

Author Unknown: cited in Westcott, R. (2003) Lives Unrealised: Clienthood and the Disability Industry; Australian Institute on Intellectual Disability; Canberra

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**In Queensland an adult individual who
wishes to leave the family home,
or where their family may no longer be
able to support them, due to age, illness
or stress,**

**Personalised Supports as options as per
Article 19
are limited, in fact almost non-existent.**

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**Disability Services response is of a
crisis nature**

**If the individual has high support
requirements of 24 hours per day the
options are grim**

**Family ability to advocate for
personalisation is severely limited**

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“The upper limit of recurrent funding to be provided by the Department for direct support of any individual through funding programs is 65 hours per week plus sleepovers if required....”

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“.....Where a person requires 24 hour support on a daily basis they may also receive a maximum of seven sleepovers to be shared in a standard co-tenancy of three people”

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My Caseworker, Psychologist, Occupational Therapist, Nutritionist , Vocational Trainer & house staff, set goals for me for the next year

You haven't decided what you want out of life

Author Unknown: cited in Westcott, R. (2003) *Lives Unrealised; Clienthood and the Disability Industry*; Australian Institute on Intellectual Disability; Canberra

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The other people I live with are usually chosen according to our degree of disability-or label not about whether we like each other or have things in common

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Family and advocates will then spend countless hours/years of angst knowing that I am unhappy, and that my 'ordinary life' certainly does not even resemble

Article 19

The bureaucracy seems insurmountable, and that will mean forever being

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Someday I won't be a consumer of special services - maybe

You will move onward and upward

I'm a client

You're a person

Author Unknown: cited in Westcott, R. (2003) Lives Unrealised: Clienthood and the Disability Industry; Australian Institute on Intellectual Disability; Canberra

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**“You can only be as happy as your
most sorrowful child”**

Personal comment to speaker by a parent, original author unknown.

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