

Review of the National Disability Advocacy Program 2016

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About Me:

I am the parent and primary carer for a gorgeous five-year-old daughter with Rett Syndrome, which affects every functional area of her life and results in complete dependency.

I am also a PhD Candidate based at the University of Southern Queensland, looking at disability advocacy in the parent carer population.

The NDAP Review discussion paper states that “*Disability advocacy support models are focused on individual advocacy, systemic advocacy, citizen advocacy, family advocacy, self-advocacy and legal advocacy.*” (p.1)

It has been my experience as a parent carer based in a major metropolitan area of Queensland that individual and family advocacy is either not readily available or just extremely difficult to locate. I say this as someone who considers herself a proactive and highly engaged advocate for my child. This lack of accessible support is particularly concerning when I put myself in the shoes of many of my peers who are perhaps not so well resourced.

It is imperative that the parent carers of children with complex disabilities are empowered and supported in developing and exercising their own advocacy skills, particularly in systemic interactions (medical, educational, etc.).

Some current research that explores advocacy issues and support options in the parent population:

<i>Author/Year</i>	<i>Title</i>	<i>Aim</i>	<i>Design/Method</i>	<i>Participants</i>	<i>Findings/Conclusions</i>
Kingsnorth, Gall, Beayni, and Rigby (2011)	Parents as Transition Experts? Qualitative Findings from a Pilot Parent-Led Peer Support Group	To study the impact of a parent-led peer support group on parents’ knowledge, skills, and level of support in planning for the future.	Qualitative - Pilot peer support group session notes, short response questionnaire, follow-up focus group.	30 parents of transition-aged (12-18) youth receiving augmentative communication support.	Themes were: (1) increased awareness of challenges and shifts in views on future orientation; (2) increased active planning; and (3) the value of experiential knowledge.
Trainor (2010)	Diverse Approaches to Parent Advocacy During Special Education Home-School Interactions	To explore the types of capital resources parents perceived were necessary to their participation in educational advocacy. To discuss the effects of parental advocacy on educational equity.	Qualitative, interpretivist. Focus groups and in-depth interviews, categorical meaning and relational themes identified and interpreted.	27 parents of children with special education needs in the US.	Four advocacy positions identified by parents but not used in isolation. Inter- and intra-cultural differences identified among participants. Resource requirements were different when advocating for a single child as opposed to advocacy for systemic change.

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Resch et al. (2010)	Giving Parents a Voice: A Qualitative Study of the Challenges Experienced by Parents of Children with Disabilities	To examine the specific sources of challenges facing parents caring for children with disabilities.	Qualitative study, focus groups. Data collected and thematic elements identified.	40 parent caregivers with disabled children.	Four main themes: (1) access to services and information; (2) financial barriers; (3) community and school inclusion; and (4) family support. Themes indicative of a mismatch between caregiver needs and services.
Ryan and Cole (2009)	From Advocate to Activist?: Mapping the Experiences of Mothers of Children on the Autism Spectrum	To consider whether a high level of advocacy involvement among the Mothers of children with Autism Spectrum Disorder (ASD) leads to activism, and if so, identify the factors that lead to the transition.	Qualitative study, in-depth interviews.	36 Mothers of children with ASD.	Most Mothers undertook enhanced advocacy activities, either independently of as a result of interactions with a peer support network. Advocacy and activism occur on a continuum but the role of parent caregivers as activists is largely unrecognised.
Dempsey and Keen (2008)	A Review of Processes and Outcomes in Family-Centred Services for Children with a Disability	To review current research and discuss the links between family-centred practise and improved outcomes for children.	Literature review.	35 studies considering independent, moderating and dependent variables in assessing services and outcomes for children.	Family-centred practises are directly linked to parental locus of control, self-efficacy, and satisfaction with the supports received. These practises are also indirectly related to improved outcomes for families and children.
Neufeld, Harrison, Stewart, and Hughes (2008)	Advocacy of Women Family Caregivers: Response to Nonsupportive Interactions with Professionals	To examine advocacy as a proactive response to negative of nonsupportive interactions with professionals among women family caregivers.	Qualitative study, in-depth interviews.	34 women family caregivers.	Negative feelings, mistrust, and powerlessness were key outcomes of nonsupportive professional interactions. Ensuing challenges were identified as catalysts for advocacy development.
Green (2007)	"We're Tired, Not Sad": Benefits and Burdens of Mothering a Child with a Disability	To explore the nature of perceived burdens as well as the ability of the Mother carer to see past the burden to the benefits of caring for a child with a disability.	Quant/Qual data drawn from a survey instrument and follow-up in-depth interviews.	81 Mothers of children with disabilities completed the survey. Seven in-depth interviews were subsequently held.	Objective (socio-cultural) burden considerably higher than subjective (emotional distress). Intensive, time-consuming contact with the medical service delivery team was identified. Advocacy activities, negotiations, and paper work a reported drain on maternal resources. Mothers consistently reported the benefits of mothering their disabled children, including maternal love and pride, appreciation and joy.

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Glang, McLaughlin, and Schroeder (2007)	Using Interactive Multimedia to teach Parent Advocacy Skills: an Exploratory Study	To examine the efficacy of the Brain injury Partners: Advocacy Skills for Parents multimedia intervention.	Quant - Randomised Trial, subsequent scales scoring	31 parents of children with traumatic brain injury	Post-intervention scores in the treatment group found improved knowledge, application, and attitudes scale scores when compared with the control group.
Crowe and Florez (2006)	Time Use of Mothers with School-Aged Children: a Continuing Impact of Disability	To compare the time use of Mothers of children with disability to that of Mothers of neurotypical children.	Qualitative data collected through time use diaries.	60 Mothers (30 with disabled children, 30 with NT children) with children aged 3–14.	The type of occupations a Mother participates in varies greatly depending on the presence of disability and the age of the child. Occupational gaps are present where disability exists and grow wider as the children age.
Hess, Molina, and Kozleski (2006)	Until Somebody Hears Me: Parent Voice and Advocacy in Special Education Decision-Making	To explore the nature of parental advocacy in special education decision making and its effect on educational outcomes for children.	Qualitative study. Focus groups	29 parents of children with a diverse range of special education needs.	Themes identified: (1) the dichotomous nature of system-led decisions and parental advocacy; (2) the teacher's role as 'bridge' between families and schools; and (3) parents' views on the struggle to find inclusive placements.
Brown, Anand, Fung, Isaacs, and Baum (2003)	Family Quality of Life: Canadian Results from an International Study	To gather preliminary data on Family Quality of Life where intellectual disability is present, and to report the findings of one part of the larger study.	Quant/Qual data collected via Family Quality of Life Survey.	34 families with an intellectually disabled child or adult member.	Spiritual and cultural beliefs, family relationships, and careers were identified as significant contributors to FQoL. Also highlighted a lack of practical support from people outside the immediate family regarding the disabled member. Families largely indicated that they were involvement in advocacy but wanted more knowledge and information.

Every one of the above studies found that the overwhelming majority of parent carers are already engaged in advocacy through a wide range of activities resulting in varying amounts of success. A sense of frustration about systemic barriers facing the families of children with complex support needs was common (Trainor, 2010; Resch et al., 2010; Ryan & Cole, 2009; Neufeld et al., 2008; Green, 2007; Hess et al., 2006).

Another common theme was the identification of advocacy engagement as a drain on parental resources, including emotional (Neufeld et al., 2008; Crowe & Florez, 2006; Brown et al., 2003), financial (Resch et al., 2010; Brown et al., 2003), and socio-cultural (Resch et al., 2010; Trainor, 2010; Ryan & Cole, 2009; Neufeld et al., 2008; Green, 2007; Crowe & Florez, 2006; Brown et al., 2003). Beyond these barriers, respondents largely reported positive feelings and experiences when parenting their children with complex needs (Green 2007; Crowe & Florez 2006; Brown et al., 2003).

Brown et al. (2003) asked families with disabled children about the family's current advocacy activity. Of the 34 respondents, 25 families said they were advocating for disability related services '*some*', '*quite a bit*', or '*a great deal*' of the time. The remaining nine families reported that their responses of '*hardly at*

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all or *'a little'* were indicative of a lack of knowledge about how to engage in advocacy rather than any disinclination to do so. Although a small sample, this result supports the position that most parent carers are either actively advocating for their children, or would be if only they knew how.

Dempsey and Keen (2008) clearly demonstrated the value of effective system-family partnerships in achieving positive wellbeing outcomes for the child/ren, their families, and the service providers themselves. In order to harness these benefits, researchers are exploring ways to educate and empower parent carers, successfully developing advocacy skills through the delivery of training modules (Glang et al., 2007) and peer-led support groups (Kingsnorth et al., 2001).

NDAP Discussion Paper Responses

1.1 How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?

Well-informed parent carers are able to target their approach to agencies designed to offer specialized supports. It is fair to expect that staff at specialist agencies should be highly skilled in providing their limited model/s of support.

1.2 What are the drawbacks?

Well-informed parent carers are logically *not* the people most in need of advocacy services, and others are unlikely to know where to look. Agencies are historically not adept at collaborative or even cooperative supports (perhaps this is related to funding models?). There is also a significant lack of knowledge among the parent carer community about advocacy supports on offer – they are not well communicated.

1.3 How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?

Advocacy coordination. Funding disparate NGOs to deliver advocacy services almost ensures a disjointed, uneven experience for Persons with Disabilities (PWDs) and their families. As service users, we often don't know where to begin. We are routinely turned away when we have approached an agency that doesn't engage in the model of support we need, but there is no advice offered unless you're lucky enough to find a sympathetic individual employee. A central point of contact for PWDs and family members could supply some local direction (if not advice). This could be provided as part of a 'hub and spoke' design (central agency with outlying services) or as an NDAP-controlled hotline that simply links to local/appropriate agencies.

2.1 How do we improve access for:

- people with disability from Aboriginal and Torres Strait Islander communities and their families?
- people with disability from culturally and linguistically diverse communities and their families?
- people with disability in rural, regional and remote locations?
- people who are very socially isolated including those with communication difficulties and those in institutional care?

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Online video conferencing (Skype/Zoom etc.) and other forms of tele-health are having considerable successes we can learn from. Tele-advocacy for remote/isolated PWDs and families offers immediacy and equitable access.

However, travelling 'clinics' should still be considered where tele-approaches aren't sufficient. Local support – particularly in the form of translation/sign and other cultural supports – can be included in this model.

3.1 What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?

A grass roots approach – it's the end users that really need to know where the services are, and those who are not already involved with service and support organisations likely to need it the most.

The obvious answer is to use the NDIS as a direct line to PWDs and families, but not every person seeking advocacy will be part of the NDIS. Other approaches (particularly among the young child populations) is to reach out through schools, child care centres, and GP clinics – the places people tend to go when issues arise – the 'first responders', if you will.

Traditional advertising is difficult because most stakeholders are agreed that funding should be used for services, not marketing. However, a central 'Advocacy Coordination' service/hotline could be directly advertised where offering agency linkage only (no services or recommendations etc).

3.2 How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as:

- disabled people's organisations (DPOs)
- the Australian Human Rights Commission
- Ombudsman organisations
- aged care advocacy organisations
- state disability advocacy organisations
- peak bodies?

Through innovative funding designs that encourage collaborative solutions. The NDAP should allow these bodies to inform their own level of cooperation, and NDAP financial support offered where rationale and outcomes are clearly identified. Universities can offer great support in coordinating innovative projects from a research and reporting perspective. Any subsequently published academic works ensure that successes and learnings are well-communicated.

4.2 How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?

As the NDIS rolls out, there are many examples of PWDs and families approaching advocacy providers to act as intermediaries when communications with the NDIS have become strained. Advocacy independent of the NDIS is required to avoid the obvious conflict of interests.

If NDIS begins to include advocacy as a 'fee-for-service' line item, the delineation will become blurred and service gaps are more likely to appear.

4.3 What policies and strategies do we need to protect the rights of people with disability?

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- Anti-discrimination policies;
- Human rights agreements around disability;
- Inclusion programs in schools, tertiary institutions, and (supported) employment;
- Strategies to support and maintain existing informal care provision.

5.1 What forms of legal review and representation do people with disability need most?

Systemic mediation. Whether this is within the medical, NDIS, educational, employment, or any other systemic interaction, it is here that many PWDs and families begin to struggle. Moving towards a US-style litigious system wouldn't help anyone (except perhaps high-fee lawyers), and independent mediation services may prevent this and support PWDs and service providers alike.

5.2 What barriers prevent people with disability from accessing justice?

- Funds – legal advice/support is expensive;
- A lack of understanding about rights and obligations on both sides; and
- The fear of retribution – systemic and personal.