



Queensland Advocacy Incorporated

Our mission is to promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

Systems and Legal Advocacy for vulnerable people with Disability

16 December 2016

Australian Government
Department of Social Services

Re: A draft Service Delivery Model for a proposed new carer support service system

We thank you for this opportunity to make a submission in relation to the draft Service Delivery Model for a proposed new carer support service system.

Yours sincerely

Michelle O'Flynn
Director

Ph: (07) 3844 4200 or 1300 130 582 **Fax:** (07) 3844 4220 **Email:** qai@qai.org.au **Website:** www.qai.org.au

2nd Floor, South Central, 43 Peel Street, STH BRISBANE QLD 4101

QAI endorses the objectives, and promotes the principles, of the Convention on the Rights of Persons with Disabilities.

Patron: His Excellency The Honorable Paul de Jersey AC

About QAI

QAI is an independent, community-based, systems and individual legal advocacy organisation. Our mission is to promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

QAI extends beyond the defence of civil and political rights to the defence of rights without a legal foundation, rights to self-respect and respectful treatment embodied in the simple quality of human dignity. Our organisation is held to account by including membership base of people with disability, as key board positions, and as paid staff. Our board members have experience in advocacy, the lived experience of institutionalization, community legal services, private legal practice, academia and community work. QAI is a member of the National Disability Advocacy Network of Australia (DANA) and Combined Advocacy Groups Qld (CAGQ).

As well as core systems advocacy QAI provides individual legal advocacy to people with a disability at risk of human rights abuses, particularly around guardianship and restrictive practice matters, and assists people required to appear before the Mental Health Review Tribunal. We also provide non-legal advocacy to people with disability at risk from the criminal justice system by working with legal and community services that help the person with a disability remain in the community.

1. Introduction

QAI's believes that disability is impacted by the interaction between an individual's impairment and the social environment. We also believe that the disabling effects of the social environment are a collective, national responsibility, and that the state is the mechanism by which we reform it, and not to eliminate part of our humanity, but to address the myriad ways in which social structures and institutions fail to adjust to impairment and so exclude, demean and devalue people with disability.

The Australian Commonwealth has ratified a number of international conventions, particularly the *Convention on the Rights of Persons with Disabilities* (CRPD) in formal recognition of its obligations to ensure that people with disability are guaranteed certain fundamental rights. One of those formal rights is access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community (Article 19). The National Disability Insurance Scheme is part of the Commonwealth's substantive commitment to the fulfilment of that right.

QAI's starting point, is that support is a collective responsibility - not the duty of unpaid carers formerly compelled to step-in because the state has failed to meet its human rights obligations or because the measures offered have been inappropriate.

QAI also believes that the needs of unpaid carers are best met by ensuring, by matter of right, the public provision of appropriate supports to people with disability and to anyone else who needs them, including elderly and or ill people.

We, in Australia have not yet fully resourced the rights to which we have formally committed. They are a work in progress, but the National Disability Insurance Scheme promises to meet the support needs of over 400 000 Australians. My Aged Care promises to do the same for people over 65 years.

Together they will reshape the lives of people who need support, and the lives of the unpaid carers who have until now, endeavoured to provide it. The new integrated carer support service will need the flexibility to adapt to this reformed social environment, and this new era of independence for people with disabilities, who will now be able to make their own decisions about what support they choose, and where, how and who will provide it.

The good news for carers is that their caring role will become less a matter of duty and more a matter of choice. If the National Disability Insurance Scheme and My Aged Care fulfil their promise, demands for respite, 'carer fatigue' and the 'burden of care' will be much less common and less urgent, if not consigned to the past.

2. Overall Comments

3.1 Preliminary - Use Plain Language

The co-design principle has not extended to the language used so far in the consultation. The authors of the draft concept and draft service delivery model have not addressed their language to ordinary everyday non-specialists. Here is an example of unfriendly writing:

The challenge will be delivering education and counselling interventions specific to the needs of the carer cohorts - without the interventions becoming over specialized and too varied to support economies of scale.

The authors of the draft model and draft concept over-use clichés and bureaucratic jargon like 'caring journey', 'carer cohorts', 'proactive support' and 'normalise uptake of services'; too much of the passive voice, making it difficult to know who is speaking or doing; and too many depersonalized, alienating terms like 'cohort' and 'target group'.

The words themselves become an access barrier for carers, guaranteeing that many readers will struggle to get past the first paragraph of the introduction. No matter what the final structure, the literary content associated with the new model must use plain, respectful, jargon-free language. Here are some alternatives expressions that mean the same thing as those used in the draft:

- 'Co-design process' = collaboration
- 'be dependent on' = depend on
- 'developing a new integrated carer support service system through a co-design process' = collaborate to improve carer supports
- 'Identify high-risk cohorts' = find people who are not yet connected

Language conveys values, not just information, and depersonalized language like 'cohorts' diminishes people as it describes them and reduces them to a type or group.

3.2 Integrate with the National Disability Insurance Scheme and My Aged Care

About 42.5% of NDIS participants have intellectual disability. Add to this another 35% of participants who have autism, psychosocial disability, acquired brain injury and other neurological impairments. Altogether, about 77.7% of NDIS participants have disabilities that may require them to need, a decision-supporter - that is, a carer who could support them to make their own decisions, including decisions about support itself. Not everyone will have or want an unpaid carer but many will, including NDIS participants and older people.

It is contrived and inefficient, for government to replicate services to carers, people with disability, and older people. A lot will depend on the extent of a person's decision-making ability, but when a participant with an unpaid decision-supporter/carers wants contractual advice about an agreement with a service provider, so, often, does the carer. Again, depending on a person's decision-making ability, whenever participants want advice the carer does too, because they both participate in the decision-making. The default setting should always direct the service towards the person with disability, or older person.

Carers and the people they support are often a team that can work together to improve the lives of both, or all (if there is more than one carer). The more paid support is available to the participant, the more time will be available to the carer/s for other pursuits, including paid work.

3. Comments on the Structure

a. Three Tiers- or Two?

As yet the Draft Model lacks detail, particularly at the bottom end where detail most matters, so it is difficult to visualize the final structure.

QAI supports the national level goals. The regional level goals and activities too heavily rely on the underdeveloped 'Hubs'. The local level detail either does not yet exist, or tends to refer back to the Regional Hubs.

As others have said in the earlier consultation, the three-tier framework may be an unnecessarily complex one to create from scratch, given the nature of the services it will deliver and the demands of the carer end-users it will support. QAI is concerned that the 'Hubs' will drain money and resources at the expense of services direct to people with disabilities. A dollar spent on direct services to people they support will give carers better value than the same dollar spent on supporting regional hubs.

QAI agrees with the suggestion made by others that existing or projected regional services could coordinate support, such as Carer Associations, Commonwealth Respite and Carelink Centres, My Aged Care Regional Assessment Services, and the National Disability Insurance Agency's Local Area Coordinators. There is likely to be other support coordination services that will also meet the needs of people with disability and their carers. In Queensland agencies such as Community Resource Unit, Parent2Parent, Pave the Way and 'host

provider services' such as Bespoke Lifestyles Australia provide support coordination along with educational sessions about maximizing potential of NDIS supports and services.

The commissioning framework for the Hubs would need to safeguard against conflicts of interest. The danger is that a single organization could have a stake in both a regional hub and one or more of the grassroots services to which the hub may refer potential clients, giving that organization a competitive advantage and undermining carers' freedom of choice.

2.2 Avoid Duplication of Services

There is nothing more 'grassroots' than caring for someone you love, and loving someone you care for. It's a visceral, emotional undertaking; not an abstraction. A carer support framework means nothing if it is not grounded in local networks of carers and people with disabilities.

Much of the carer framework need not be carer-specific. Apart from unnecessary duplication, carer-specific groups and services in general may fail to attract carers: many carers do not identify as such, or at least not to the extent that they will join a carer group. Government must not reinvent the wheel, but offer carer support as a part of a range of services and by boosting existing informal and semi-formal networks.

However, government should not create carer groups simply to fulfil the service model. Linking people together because they share the carer function does not work if they do not share values or vision. The experience of the former systems and family advocacy group Queensland Parents for People with Disabilities (QPPD) was that carers and families find the connections they prefer when building a vision with and for the person for whom they care. At the grass roots level there is much to be done by way of strengthening or even establishing currently weak unpaid care supports. Unknown numbers of marginalised people have no natural community or family support. QAI represents many of the most vulnerable people with disabilities in the criminal justice system. The cruel combination of disadvantaged life history and complex support needs has meant that many have no-one at all.

QAI is aware of a number of people in state or territory forensic systems whose only support comes from someone thousands of kilometres away who may be from a different educational, familial, ethnic and cultural background. Or, they may have family who care, but complex issues related to their incarceration restricts any face to face contact.

Not every carer has ready access to the person for whom they care. Up to 30 percent of people in prison have a disability, usually some kind of intellectual or cognitive impairment associated with acquired brain injury or Foetal Alcohol Spectrum Disorder. To see their loved ones face-to-face, many carers must often use public transport and overnight accommodation. Some carers live on remote or in regional communities. The carer strategy must focus on supporting carers' most basic needs for everyday services, and be prepared to support innovative and culturally-specific supports. The Forensic Disability Service (FDS) here in Queensland, for example, has an arrangement with local Aboriginal elders that allows in-person relationships between inmates and the local community. The FDS is a *de facto* prison, but an unpaid relationship with the local Aboriginal mob is for some of the detainees

the only connection with culture, and the outside world. Whether the culture and the connection are relevant to the person is unknown to us.

2.3 Carers and The National Disability Insurance Scheme

The NDIS and My Aged Care will transform the lives of carers too. The highest priority is providing people with disabilities and older people with reasonable and necessary supports. If this approach is delivered appropriately and adequately the bonds of duty and obligation on carers will ease. Reasonable and necessary supports mean that carers move from 'have to' to 'want to'. Some carers will need support to finish their education, or reskill.

4. Awareness and Community Linkages

The Gateway and Peer Support online are a step-up from the Carer Information and Support Service. For any carer, finding the relevant information needed, and learning to navigate the system is often the most difficult obstacle. Ensuring that information is directed to the issues that have most meaning and relevance to carers is most effective. Government must continue to 'block' fund (for example, through ILC funding) grassroots parent, family and carer organizations. They build word-of-mouth connections grounded in those shared experiences, providing mentoring and potentially offer opportunities to engage as a collective advocacy voice. The currently defunded Queensland Parents for People with Disability (QPPD) is a great example. It would, if still funded to do so, provide non-professional services and mutual development for and by carers. It would - and did for over 30 years - do this more efficiently than any other mechanism by:

- Connecting carers and parents
- Building community
- Allowing rapid information sharing
- Providing systems and family advocacy
- Developing skills of families as advocates for their loved ones and for all people with disability, including those who do not have families, and
- Offering parent to carer strategic advice, mentoring and inspiration.

In Queensland, the Community Resource Unit is another source of development for families and community by provision of information, education and 'change agency' leadership for families and carers who seek new and alternative means of support provision.

5. Information and Advice

Counselling, support, information, carer support and advocacy can be delivered online using peer-to-peer platforms, but it may be worth looking into developing mobile-based peer-to-peer information applications as well as /internet-based portals. Carers and people with disabilities are in general very skilled in the use of technology not least because

communication technologies have so much more to offer people who may have more than average physical and access challenges.

One of the key findings of research into communication technologies and social strata is that for marginalised people, including carers, mobile phones are the technologies of choice because they have a low technical and financial threshold to participation. Mobiles are used primarily for voice calls and text messaging rather than for internet access, so information is sourced from others in preference to the internet.

This has profound implications for how online content and information services ought to be designed to be more human-centred, simple and succinct. Pages of online content have limited value to the 46% of Australians who are not prose literate. Information needs to be packaged in short, sharp grabs. It should be pictorial, have text-to-speech capabilities, be compatible for the software and hardware used by people who are both deaf and blind, and should link easily to voice-to-voice or face-to-face interpersonal communication.

- Finding carers means finding people with disabilities too
- Early contact through Health practitioners, child-care, and schools and quickly link to peer support

6. Peer Support

Many carers, family members and supporters are currently accessing the NDIS Grassroots Discussion Facebook page to gather information, discuss issues, learn and share experiences. We believe that online peer support is a terrific way for carers, people with disability and others to share experiences, news, inside information, and strategic advice for negotiating with service providers and bureaucracy. Disability Loop's Face Book [site](#) is an exemplary carer-to-carer-to-people with disabilities online forum, as is the Face Book National Disability Insurance Scheme Grass Roots discussion site. Forums are a quick and easy way, too, to gauge the quality of services, and a great way to offer analysis and constructive criticism.

They must be moderated for abuse and to keep on topic. There may be value in experimenting with Aboriginal and Torres Strait Islander and CALD-specific forums.

7. Safeguards

Unpaid carers often do a huge and sometimes thankless job, sacrificing their own careers, relationships and financial opportunities to care for a loved one who needs support. In part, the draft integrated carer support framework is a public acknowledgement of that fact. Unfortunately, the high moral purpose can get in the way of an objective assessment of the standard of care delivered by unpaid carers.

Sometimes, when it is clear that the person with disability is not receiving adequate or appropriate funded supports or services, the quality of care may be eroded and eventually provided grudgingly, or primarily out of self-interest. In-kind compensation may be a motivator, together with modest Commonwealth allowances, concessions and supplements, freedom from the work test, and eligibility for state-based schemes, programs and provisions

for which the carer might otherwise have been ineligible. While self-interested care is not necessarily incompatible with good care and good outcomes for the person with disability, in a minority of cases, care may be negligent, abusive or exploitative.

Here in Queensland, the application of chemical, mechanical or physical restraint, containment or seclusion of any person with a disability who is supported by a service operating with state-government funds is regulated by legislation. In relation to support by unpaid carers there is no such regulation and no such scrutiny unless they are in the receipt of funds which are self-directed and managed. Care that is not delivered as part of a publicly-funded program by a publicly accountable service supported by state, territory or Commonwealth funds is not regulated any more than the relationship, for example, between parent and child.

While government should do everything it can to support carers so that people with disabilities, elderly or ill people can stay in their own homes and be looked after by people they love, the state has a duty under the UN conventions it has ratified to guarantee that the rights of persons with disabilities and the elderly are upheld, respected and protected. The state must not be ignorant of abuse and neglect merely because it is happening behind the picket fence.

From time to time QAI is made aware of carers who either intentionally or unwittingly abuse their position of trust or disregard the interests of the person for whom they care. While cases of outright physical abuse or neglect are not common, some carers may be condescending about their adult children with disabilities, referring to them as if they actually are children. QAI is aware of some carers who have colluded with health professionals to undermine or ignore the choices of people with disability. A tribunal appointed guardian has a statutory responsibility, in Queensland, to abide by certain human rights principles set out in Schedule One of the *Guardianship and Administration Act 2000* (Qld). The Act does not provide a mechanism for the enforcement of those principles, but our recent contact with the office of the Public Guardian suggests that statutory guardians are under-resourced and hard-pressed to include people with disability in decision-making.

The law is of no assistance here to the person with disability. If an unpaid carer makes a decision that runs over-rides the rights of the person for whom they care, who is available to challenge it? The framework must explore ways to balance the needs of people with disabilities for safeguards against families' needs for privacy. Ensuring that people with disability have access to advocacy is a means to this end.

QAI intends to develop Human Rights Indicators for the Last Resort Use of Restrictive Practices as a resource for carers, guardians and service providers. It will provide a clearer understanding of the human rights implications of the use of such extreme measures against a person with disability. Our organisation has sought funding assistance to develop this tool as we have experience with the Human Rights Indicators for People with Disability (a resource for disability activists and policy makers) – Convention on the Rights of Persons with Disabilities.

Education and Training for Carers

As National Disability Insurance Scheme supports are accessed by people with disability many unpaid carers of people with disabilities will look for training, education and jobs.

The focus of education and training for carers must be congruent with expectations and aspirations of any other community citizen, including online training so that carers can maintain their caring roles. Education and training does not need to be 'carer-focused', but needs to be 'carer-sensitive' rather than formalising carer 'qualifications'. A combination of feedback, weekend intensives, and face-to-face meetings will motivate and encourage people, and offer opportunities for networking. Some carers are already connected to organisations such as Community Resource Unit or Parent2Parent etcetera and will be offering mentoring and training to other carers and also consultancy to service providers and support workers.

- Government can provide labour market programs and other mechanisms to enable/reduce barriers to the above, but carer-specific programs would be stigmatising and an inefficient duplication of effort.
- The framework can encourage those programs to be sensitive to carers' needs rather than inventing new training institutions.
- The Integrated Carer Support Service need offer no more than referrals to those services.

8. Counselling

The National Carer Counselling Program should enable carers to access the services they want in a way that works for them. Counselling should be available face-to-face for carers who do not use or would not benefit from online services. There must be continuing education around the benefits of counselling to address the stigma associated with it, and the sense that by seeking it carers have failed.

9. Respite - Short-term and Emergency

The National Respite for Carers Program is the umbrella for a number of targeted short term and emergency services.¹ It is a good program, but it needs a different name.

Respite is a disappearing concept - in more ways than one. The word itself is archaic and belongs in the history books along with institutional living arrangements. From the Latin *respectus*, or 'refuge', it means 'a short period of rest or relief from something difficult, such as an unpleasant obligation or punishment; the Google example is "refugee encampments will provide some respite from the suffering"'.

¹ The National Respite for Carers Program includes Short term and emergency respite (delivered by Commonwealth Respite and Carelink Centres), Respite Support for Carers of Young People with Severe and Profound Disability, Mental Health Respite (Carer Support) and Consumer Directed Respite Care.

Respite implies that unpaid support is so distasteful that any person so engaged is entitled to relief before returning to the fray. Caring can be hard, at times, but calling a break 'respite' is value-laden and prejudices the caring relationship. How must a person with disability feel as the instrument of their mother/father/sister/brother's punishment?

Nor does the notion of break from punishment reflect the reality that the majority of carers are not unhappy with their role. Carers' levels of 'Personal Wellbeing' and 'Satisfaction with Caring and Leisure', on average, are below the normal range, but not so far below that carers are unhappy.²

The 'dirty word' aspect of respite lies not in its meaning but in its function as an indicator that rights to reasonable support are not being met. As long as people with disabilities and others who need them are denied reasonable and necessary supports, unpaid carers will need to have breaks, the demand for which rises in inverse proportion to the public provision of support.

10. Targeted Financial Support

Compared to a general population sample, carers have lower rates of satisfaction with ability to pay for household essentials, with their ability to afford the things they would like to have, with their ability to save money, their financial security, and their ability to not worry about income covering expenses.³

Household income is a double jeopardy for carers. Their average household income is lower than is normal within the general population, and their wellbeing is more depressed than is normal due to low income.

Carers must be entitled to the same or more financial compensation as any other pensioner in the welfare system. It must be acknowledged that historically, governments and systems have relied upon the contributions of carers as an unpaid workforce, and as an economic saving grace. This is not the respectful or sustainable treatment of carers and families that have fractured under the pressures of financial and emotional hardship due to lack of funded supports and services that would otherwise have negated these issues. However, as people with disability, carers, and families transition to the NDIS, many will still be required to continue their caring role due to the reasons outline earlier in this submission, and therefore financial remuneration to carers, particularly for those who are single parent families must be increased.

11. Carers in the NDIS

Providing useful and timely advice to people with disability and their carers is part of the role of National Disability Insurance Scheme Local Area Coordinators. They could be responsible

² Robert A Cummins, Joan Hughes & Adrian Tomin. 2007. Special Report: Australian Unity Wellbeing Index Survey 17.1. Report 17.1. "The Wellbeing of Australians – Carer Health and Wellbeing". Melbourne: Australian Centre on Quality of Life, Deakin University.

³ Robert A Cummins, Joan Hughes & Adrian Tomin. 2007. Special Report: Australian Unity Wellbeing Index Survey 17.1. Report 17.1. "The Wellbeing of Australians – Carer Health and Wellbeing". Melbourne: Australian Centre on Quality of Life, Deakin University.

for giving carers of people with disability appropriate and timely information and referral. So too, could parent groups.

Carers of people with intellectual impairments frequently will become Plan Nominees. As such, carers need information, advice, resources and support to enable the people for whom they provide care to self-direct their supports and services. 'Support Coordination' such as that by "host providers" has been used successfully in Queensland. Organisations such as Community Resource Unit, Pave the Way and Parent to Parent have been important capacity builders for people with disability and carers.

12. Supported decision-making

Carers often provide decision supports. Supported Decision-Making can operate as a less restrictive and less costly alternative to guardianship or the involvement of a public trust, and many carers have instigated this over time. Many carers have done this by ensuring that the people for whom they provide care are empowered by the same means as people without disabilities. This includes bank accounts in the person's name that they operate even with support; information and education about their income source (eg - Disability Support Pension), budget, housing options and tenancy advice; to name a few.

QAI submits that formalising informal decision support merely replicates the current guardianship regime and is unnecessary. However, advocacy at a commonwealth government level to peak representative groups for telephone companies, banking institutions, business councils, and retail associations about the legitimacy of support for decision making will advance acceptance of and vigilance in regard to the status of people with disability in exercising their rights to control and choice in their lives.

13. Conclusion

The Carer support structure should commit to and promote some bottom-line principles around carer/cared-for relationships.

- Commit to the elimination of conflicts of interest in service delivery across the three tiers of the structure
- Expressly commit to Supported Decision-Making and support for the National decision-making principles set out by the Australian Law Reform Commission
- Formally acknowledge that the best way to support carers is to fulfil the rights of persons with disabilities.
