



4 October, 2012

**Submission 008**

**11.1.6**

**Received 4-10-12**

**Health and Community Services Committee**

Health and Community Services Committee,  
Parliament House,  
George Street,  
BRISBANE. Q. 4000

Dear Committee,

Please find enclosed our submission to the Disability Services (Your Life Your Choice) Amendment Bill 2012.

We thank the Committee for this opportunity to provide valuable insight and understanding of issues relevant to the people with disabilities whose lives will be directly influenced by this amendment.

Yours faithfully,

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**Patron: Her Excellency, Ms Penelope Wensley, AC Governor of Queensland**

## **EXECUTIVE SUMMARY**

- Education and Support will be needed to encourage service users about the potential benefits of self-direction
- Review mechanisms for contracts
- Alliances between DSQ and entrenched service providers must be challenged, and ways found to accommodate pathways for new innovative operators
- Regulation by scaling of fees or charges by services providers
- Supports to persons with disability entering into contractual agreements
- Independent statutory body to review contracts and disputes
- There must be a statutory right for a person to leave any host arrangement or transfer when required
- The need to change other policies and practices that do not comply with the autonomy of self-direction eg: forced co-tenancy (capacity coordination) shared care and living arrangements etc.
- Supported decision making within the context of self-direction

Queensland Advocacy Incorporated (QAI) is a community-based advocacy organisation that has for the last twenty-five years campaigned for the rights of vulnerable people with disability in Queensland.

This submission is in response to the proposed Disability Services (Your Life Your Choice) Amendment Bill 2012, and should be read in conjunction with the “Your Life Your Choice” Self Directed Support Framework policy objectives.

QAI is encouraged by the proposed amendments and urges the Queensland Government to advance these amendments by providing the following advice and recommendations.

## **Human Rights**

The Framework emphasises the consideration of human rights in the development of the person-centred plans at the heart of Self-Directed Support and in the delivery of all services based on that plan. It does not address the fragility of those rights and the inability of someone who believes their human rights have been violated to obtain a remedy.

The human rights described in the *Disability Services Act* are hardly more than aspirational. Their application is only ‘encouraged’ and not mandated. The *Convention on the Rights of Persons with Disabilities* (CRPD) is hardly more helpful. It is a bona fide international instrument ratified by the Commonwealth that binds all levels of government. Even so it is considered to represent little more than a developmental guide for governments seeking to improve the status of people with disability. It suffers this humiliation because its boldly drafted injunctions are reduced to little more than plaintive entreaties by the lack of any domestic mechanism to enforce its principles. If government is serious about Self-Directed Support and about better quality lives for people with disability, it will make human rights enforceable at domestic law by enacting the relevant instruments into applicable legislation, and by empowering a tribunal to adjudicate allegations of their breach.

## **Transition towards the NDIS**

The proposed Amendments to the Bill are just the beginning of a process to enable people with disability to exercise autonomy in their lives. However, we are concerned that service providers have had an entrenched alliance with government and their concerns and logistic requirements are often considered with more priority than those of people with disability and their families.

## **Education and Support**

The Framework should make provision to equip service users with the education and support they need to take advantage of self-directed support. When self-directed support was introduced in England, uptake was initially slow. Reasons given for this include failure to understand properly what the program entailed and fear of embarking upon a new life course that was so little understood. The right kind of education and support provided to service users could help overcome uncertainties that might restrict its

uptake. Further, if service users are sufficiently equipped to manage Self-Directed Support, this may obviate altogether the need for a host provider. This would increase the level of control a service user could exercise over their support services, an undeniable aim of the Framework, and potentially reduce overall costs.

However, the cost of educating people to manage their own supports must not be taken from a service user's support package. It should come from an entirely independent source. Billing such cost to a service user would reduce and potentially debase the delivery of essential supports.

Likewise, the costs to a host provider in the form of brokerage, planning, management and administration should not be stripped out of a service-users support package. Given the vital role these supports play in ensuring the service-user's quality of life they must not be diminished in order to satisfy the pernicious and ever-growing appetite of these incidental costs.

Case examples of how lives have been enhanced and enriched by the opportunities that have arisen from enabling people with disability and their families to exercise autonomy and freedom should be offered at every opportunity to encourage and support people to avail themselves of the same.

## **Amendments to the Act**

While the Department of Communities, Child Safety and Disability Services has given some limited information about the proposed Amendments, there is a need to develop and inspire some understanding of the potential for people with disability and their families about what is possible with this initiative. Many people with disability or their family members may find the notion of 'self-direction' to be onerous and frightening, given the historical constraints, restrictions and bureaucratic paperwork imposed upon them.

**Clause 5 (Section 7)** states that the objects of the Act are *“achieved by regulating disability services funded by the department to enable consumer choice and ensure the quality, safety, responsiveness and accountability of the services.*

We assert the following in relation to this clause:

1. Service providers who fail to respond to the needs and requests of their client base are not fulfilling their funding obligations and therefore should have any contractual arrangements with the government cancelled.

This is particularly important in regional rural or remote areas where the service provider has a monopoly in absence of any other options. It also is vital where the client has no informal supports, or has a cognitive, intellectual or behavioural disability and is unable to accept full responsibility to manage their funds and is dependent on a host provider.

2. That the Department of Communities, Child Safety and Disability Services has a 'watchdog' role in the area of the scale of fees that brokers or host/service providers

can charge individuals for providing the range of planning, budgeting, recruitment, acquittal of funds etcetera.

The Department should raise awareness of a recommended range of costs to clients in the area of support worker wages, and service provider fees and charges.

**Clause 7(new sections 43A and 43B)** provides new definitions relevant to the new Part 5A i.e.: “relevant person” and “relevant disability services”

We offer this advice and recommendation:

3. “*Relevant person*” may include beyond the definitions provided, the roles of both formal and informal advocates within the adult’s support network.
4. “*Relevant disability services*” may at times include generic services. In traditional service arrangements a person with a disability may have obtained in-home support for such routine tasks as cleaning and gardening. The self-directed model should also allow a person with disability access to generic services that would not have been available to them in the past.

#### **43D Individual funding agreement**

*‘(1) If the Minister approves funding to a person under section 43C, the person may enter into an individual funding agreement with the chief executive for the funding.*

*‘(2) The individual funding agreement must—*

*(a) **include the terms and conditions the chief executive considers appropriate;***  
*and*

*(b) state the relevant disability services to be obtained with the funding.’*

While any expenditure of public funds should be appropriately and diligently acquitted and accounted for, this wording implies that the individual and or their family member has, in fact, small say in the negotiation.

Any contractual agreement between an individual with disability and/or their family and the Chief Executive should be negotiated with an equitable approach to what constitutes compliance to the funding guidelines.

A person with disability and/ or their family should have access to an independent review of the contract, or funding agreement, the terms and conditions, and a right of appeal to an independent arbiter such as QCAT.

#### **Further to the Disability Services (Your Life Your Choice) Amendment Bill 2012, QAI offers the following submission:**

Queenslanders with a disability and their families stand on the precipice as the NDIS approaches. To quote the Minister for the Department of Communities, Child Safety and Disability Services, Ms. Tracy Davis, *“This government is committed to providing Queenslanders with a disability and their families with a quality disability service system that meets their needs and helps them to live the lives they want. We strongly believe that people with a disability should have the freedom to make choices **about how they***

***live, including the supports they receive. Our disability service system needs to reflect this.***

These words offer some inspiration and hope to individuals with disability. However, in light of current government reviews and cut-backs- the Family Support Program review, the proposed Taxi Subsidy Scheme cap, the defunding of the TAAS program, the proposed congregate care options for Aging Parent Carers and their family members with disability, and the practice of 'capacity coordination' (or 'vacancy management') we are sceptical about these Amendments. It is incongruent to offer "choice and control" to a few individuals and families under a trial project while still restricting the majority of people with disability to shared care, shared housing and block funding arrangements.

### **Capacity**

Care should also be taken to ensure that people with decision-making difficulties are not excluded from the Framework, or, if taking up a position in the Framework, are not excluded from the decision-making that attaches to that position. There are presumptions both in the Convention on the Rights of Persons with Disability (CRPD) and the Guardianship and Administration Act that adults have the capacity to make their own decisions. Yet, the decision-making model regularly followed in Queensland in the event of questions about capacity involves wholesale substitution by another of an individual's rights to make their own decisions.

A more wholesome and acceptable decision-making model involves the provision of the supports necessary to ensure a person enjoys the maximum possible participation in decisions about their lives. This supported decision -making model should be fully-explored whenever issues of capacity arise, deferring to substitute decision-making only as a last and least intrusive resort.

### **Freedom of Choice and Host Arrangements**

It appears that under the Framework a host provider chosen by the service user will assist the service user to develop their person-centred plan and then provide the service user with the supports elaborated in the plan. We find this arrangement concerning. It worries us because the host providers are drawn from those service providers already approved under the DSA. This serves only to further entrench the incumbents along with the operational cultures, practices and procedures that service users have long found offensive, restrictive, self-serving and inhospitable.

The Productivity Commission recommended in its final report on the NDIS that a system of service delivery should be adopted that encouraged new entrants into the service sector. This new blood would constitute an invigorating draught that would stimulate change, innovation, and improved quality for service users. The model proposed in the Framework maintains the position of and dependence upon existing suppliers. It seems to offer no pathway in to the sector for mainstream operators. This reliance on a pool of existing suppliers would also seem likely to inhibit the flexibility and Innovation central to the Framework's success. Unfortunately, flexibility and innovation are not traits that are routinely assigned to many of the service incumbents. With no new entrants into the sector there will be little pressure on existing service providers to imagine beyond the tired responses they routinely deploy in the face of demands for change.

The proposed supply model would also seem to steal from the Framework, and from the service users hoping to benefit from it, the vital spark that gives one credibility and the other genuine hope for change, namely, real choice. For the choice offered here is in fact an ersatz blend at best, restricting service users to a pool of incumbents approved under the DSA. Restricting them, so to speak, to a selection from the hard centres left at the bottom of the box – nobody really wants them, but they are all that is available. This is hardly any choice at all.

A final concern lies with the host provider delivering both planning and managerial support, along with personal and other care services. There is a clear potential here for a conflict of interest to encourage the host provider to pressure the service user to accept the supports the host provider can deliver rather than the supports the service user wants and needs. While the Framework does insist that the host provider has a separate arm operating the self-directed support, many people with disability will potentially be offered a range of services such as recruitment, staff training, supply of staff, etcetera until such point that the host provider is in fact doing it all.

One way to overcome this potential conflict of interest would be to restrict the host providers to a planning and administration role that included packaging but not supplying the supports required. These would be obtained from service providers to which the host provider was not related.

A better way would be to amend the DSA in a way that would encourage new entrants into the sector. This would serve the additional ends of increasing choice and encouraging existing providers to embark upon a genuine program of quality improvement. It would also bring the Framework into harmony with its own philosophies, which propound as guiding principles real choice, respect, dignity as an element of a good life, and a person-centred approach.

An essential buttress to these principles is the attachment of the support package, or of the money to purchase required supports, to the individual service user, so it travels with them as they choose to move geographically and within the service sector. With an open and responsive sector this would promote real choice and the empowerment of service users that comes from choice. It would translate these Framework themes and principles into delicious reality for people who have long lived in the shadow of disadvantage.

## **Dispute Resolution**

Under the Framework a service users expectations must defer to a test of reasonableness. This is not unreasonable. However, it is only too easy to imagine that disputes may erupt between service users and host providers about what constitutes 'reasonable' supports. Contention may also break out over differing recollections about the level of services agreed upon compared with those actually delivered. It will be important in these circumstances to have an effective dispute resolution mechanism to settle these differences.

The Productivity Commission in its Final Report on an NDIS recommends the establishment of an Inspector General that would sit as an independent statutory body to adjudicate on disputes of this nature. A similar body or other impartial mechanism

should be established in Queensland to hear disputes between host providers and service users arising out of the proposed Framework.

Another issue for consideration is the ability of the service user to walk away from an agreement with a host provider where a dispute over the quality of a service has resisted all reasonable attempts at resolution. QAI appreciates the importance of honouring contractual obligations, but it would be a grievous wrong to hold a service user to the full term of a contract where the services contracted for were unacceptable. It must be remembered that in many instances the contracted services will be for intimate care and support, which, if improperly provided, could make life an intolerable misery.

It is essential therefore that the Framework incorporates both a mediation mechanism for settling disputes about these issues and, if mediation fails, an entity that can dissolve the service contracts without penalty to either party. If, however, it is the host provider that wishes to void the contract, upon such a decision being made, the host provider must continue to provide the contracted services for a reasonable time during which the service user secures another service provider.

## **The Framework**

### **2.6 Being Accountable**

*“All decisions need to be attributed to their plan and agreed to by the person and/or family and the host provider.”*

While it is commendable for people to have a life plan to which a funding agreement may be tailored, it is not in keeping with the context of ordinary citizens (and living a life that is at times spontaneous), to be held accountable to a life plan. Surely accountability is to be held to the funding agreement rather than a plan.

### **3.2 Who can self-direct their support?**

*“Once a person and/or a family decide that they wish to self-direct their support, they can request a transfer to a host provider. Financial transfers can only occur at the end of a quarter, however, there is an expectation that host providers may be brokered in the interim.”*

People with disability and their families should be able to transfer at any time and as needed, especially in the event of a dispute with the host provider. The requirement to wait for the end of a quarter is untenable, and extra brokerage costs would be unaffordable without support from an independent source.

*“Self-directed support is initially, for people and/or families who have:*

- *Ongoing (recurrent) funding*
- *Individualised funding and*
- *Support needs that are considered stable.*

Although these conditions are intended for the initial phases there should still be a stated timeframe that indicates when people may move to recurrent/individualised funding. The funding must meet their support needs so they too can self-direct and gain autonomy over their lives.



**3.3 Who can provide self-directed support?**

The intent of the Your Life Your Choice Framework appears to define ways in which a person with disability and/or their family may exercise some control over their funding arrangements, staffing and how their funds are spent within the funding agreement.

The amendments must specify essential contractual terms that will protect people entering self-directed arrangements, whether with the Chief Executive or with host providers.

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