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The Hon Mal Brough MP
Chair
Joint Standing Committee on
the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600

18 November 2014

## Dear Mal Brough,

I am writing to you following a recent opportunity that we had to meet with The Hon Kevin Andrews; this was arranged with the assistance and support of our local federal Member of Parliament, the Hon Karen Andrews. We greatly appreciated the careful and attentive concern that each showed in regard to the issues we have raised.

The purpose of our meeting was to seek to discuss the key issues of concern in regard to the design and policy approach of the NDIS that have not yet been successfully addressed by the NDIA. I have included a summary of those issues in this letter. In the course of our conversation, Kevin Andrews suggested that you would appreciate the opportunity to hear about the issues that we have raised; the examples of how these issues will disadvantage the people we support; and in particular the design issues which do not address the requirements of people with high and complex care needs.

In brief, CASSI's experience is as a disability support service which specialises in the support of people with high and complex care needs. We have been operating as an NGO in SE QLD since 1989 and in Nth NSW since 2002. We have an unusual expertise that has resulted from being able to share the lives and support of people who have very complex issues at hand. The circumstances of the people that CASSI supports includes people who:

 Have a disability and are at the end stages of life but whose needs are too high to access the normal range of centre based palliative services,

- Have a dual diagnosis; and as a result are regularly excluded from public hospitals and community based mental health services,
- Have multiple disabilities that also have an overlay of health concerns,
- Have behavioural issues which are complex, episodic and still on-going,
- Have an advocate who is active and involved in the life of their family member and who relates to service providers (and funders) in a persistently adversarial way.
- Have previously lived in institutional settings and are now enjoying the benefits
  of living well in the community, with detailed and effective support from CASSI,
- Have been excluded from most other services in our region; CASSI has
  effectively become a service of last resort due to the complex nature of the
  people we are supporting.

As a result of this experience we are very well positioned to provide expert comment on the impact of the NDIS, as it is currently designed, on people who have high and complex care needs. Sadly, I wish to advise that these are the very people who are at great risk of missing out under the new NDIS arrangements. These are the people who have had to battle long and hard, with our support and assistance, to access the necessary resources that can be used flexibly and responsively by a service such as CASSI to meet the required support arrangements. As Minister Andrews commented to us, it would be very disappointing if the NDIS was rolled out in a problematic form that required many years of modification and rectification work because the design weaknesses were not addressed ahead of a roll out timetable.

CASSI has always advocated for, and in support of, people who have a high and complex care needs. These are the people who rarely fit well into a design or structure of service and support arrangements; even one which purports to be "person centred" such as the NDIS. The vulnerability of the people we support is undeniable. They are also the very people who are "troublesome" to any funding regime because of the sheer quantity of support and case management that they require for their support to work well and to be responsive to their individual needs. We are concerned about the people that we currently support and we are also concerned that people with high and complex care needs who are at this point of time not receiving formal support will be poorly accommodated by the NDIS, in its current design.

If we were given to opportunity to meet with your or your colleagues, the issues and questions that we would raise are as follows:

 People Issues; does the NDIS respond well to the needs of people with high and complex care needs? In many ways the scheme has missed the point of the detailed and complex work that our service undertakes. There is a great deal of "additional" work done by this service on behalf of our service users and a great deal of "additional" supervisory support required for staff who are called on to work in complex and difficult areas.

- Funding Arrangements; will the NDIS funding approach enable a service to work well? We believe that the so-called efficiency price and the loss of block grant funding both work against our ability to work in our area of expertise. Block funding is in fact an invaluable resource for our service that enables us to respond quickly, flexibly and effectively to issues that will not be captured and costed in a NDIS planning session. The efficiency pricing policy of the NDIA is to pitch funding at around 20% less that the funding that this service receives (per hour) from two State Governments. It would be a surprising day for us to learn that we are currently funded by a State government too generously and that we could still break even (as we do now) with 20% less funding.
- The Inefficiency Paradigm: is the NDIA's assumption that NGO's operate inefficiently and need to be "forced" into new approaches that are more efficient, a warranted approach? We strongly assert that NGO's are very experienced operators who have worked for a very long time in marginally funded environments. Our efficiency is demonstrated and is worthy of recognition by the NDIA; we in fact do not need a below par price to enable efficiency.
- Staff Issues; does the NDIS environment enable the engagement and retention of good staff? This is a key area where a service such as CASSI will need to be able to effectively supervise staff, support them while working in a challenging area, train them in the skills, competencies and concepts needed to provide a service of quality, and to pay them reasonably. The NDIS pricing policies actively works against this critical part of our work.
- When Two Systems Collide: does the NDIS operational approach recognise the entrenched clash of services (eg Disability and Mental Health services)? We are disappointed to see that the NDIS approach is underpinned by a simple demarcation declaration of responsibilities between Health and Disability services. That declaration is one that is not useful in the real world of a disability service trying to support some of our service users to access the health system. The poor access to health systems by people with a disability is well documented; the production of a simplistic demarcation document by the NDIA will not fix what has been a problem for more than 20 years.

We would be pleased and honoured to be able to speak with you directly about these important issues. We would like to be able to share with you our experiences about

how a service such as ours is unlikely to be able to respond effectively to the complex needs of the people who use our service, under the NDIS as it is currently designed. We also appreciate the time that has been taken by you and your Parliamentary colleagues to explore this extensive development of the disability services systems in an effort to ensure that the outcome of this is positive and meets the initial intent of the NDIS.

Yours sincerely,

Alan Binnie (CEO: CASSI)