

Summary of Issues to be presented by CASSI to the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme

We are pleased to be able to provide this summary of the issues we wish to raise with the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme (NDIS). In doing so we wish to focus particularly on the experience of people with a disability who have high and complex care needs, as well as making associated reference to the a experience of a Non Government Organisation (NGO) that has been involved in the disability sector for over 25 years.

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 or multiple diagnosis; and as a result are regularly excluded from public hospitals and mental health services,
- Have multiple disabilities that also have an overlay of health concerns,
- Have previously been cared for by a family member, who are either not able or willing to continue as a carer,
- Have behavioural issues which are complex, episodic, on-going and inclusive of aggression towards self and others,,
- 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.

It is our contention that there are a number of 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. Our issues of concern are based on the actual circumstances of people that we support at CASSI, as well as the operational experience of a service with our specialist approach to the support of people with high and complex care needs.

As a result of this extended and detailed 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, we wish to advise that these are the very people who are at greatest 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 their required support arrangements. The design weaknesses of the NDIS are significant and problematic when considering the circumstances of people who have high and complex care needs. It would be very disappointing if the NDIS was rolled out in its current form only to be followed by many years of modification and rectification work because the design weaknesses were not addressed ahead of a roll out timetable.

CASSI has always been a strong and determined advocate for, and in support of, the people that we support. Our extended experience has shown that people who have high and complex care needs rarely fit well into a design or structure of service and support arrangements; even one which purports to be the facilitator of a “person centred” approach 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 assistance 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 about the people who have high and complex care needs who are not yet in receipt of funded support; This is because we believe that they will be poorly accommodated by the NDIS, in its current design.

The issues we wish to raise and the matters we wish to put forward for consideration are:

- **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. The NDIS pricing structure has placed its major emphasis on poorly funding direct care; while the infrastructure of supervision and case management that has to be in place in an on-going way for quality and responsive services for people with high and complex care needs is poorly recognised by the NDIS.

- **Funding Arrangements;** will the NDIS funding approach enable a service to work well? We believe that the loss of block grant funding will actively work against our capacity to provide support 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, understood and costed in a NDIS planning session. In fact block grants are an opportunity for a service such as CASSI to be able to respond quickly to complex issues of support which typically emerge in an unplanned manner and which funders have great difficulty in responding to with the speed that is required. The NDIA is dismissive of block funding and it simply declares that the new model (NDIS) will become the source of flexibility and creativity; that declaration is made without any form of research or comparative evaluation. New found flexibility (through the NDIS) has become the mantra of the NDIA; however, it is a mantra that is not evidence based. This lack of evidence is described in their own most recent quarterly report:

*“The NDIS provides a range of supports aimed at increasing participant independence, inclusion, and social and economic participation. These supports are designed to be more flexible than the previous system, and allow innovation. Importantly, the supports are specific to an individual, and not provided through block grants to service providers. **No specific data on services received under the previous disability system is collected and comparison is difficult due to block grants.**” (NDIS quarterly report #2 for 2014 - 2015)*

- **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 long time and experienced operators who have worked extensively in marginally funded environments. Our efficiency is demonstrated and is worthy of recognition by the NDIA. We do not need an unsustainably low level of funding to be introduced to somehow force us to suddenly and somehow become efficient. It is the daily function of NGO’s in this sector to effectively draw all the value that is available from the underfunded support arrangements which we operate.

The efficiency pricing policy of the NDIA is to pitch funding at around 20% less than the funding that this service currently 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 from the NDIA.

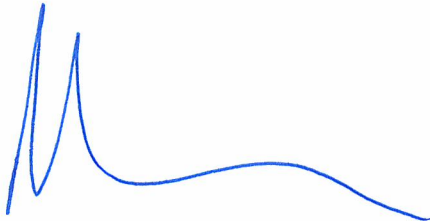
The current NDIA policy approach of temporarily and marginally increasing the levels of some funding upwards, and then drawing those levels down again, as some form of perverse lesson in efficiency, is neither warranted nor needed. The people who CASSI supports have dealt with poor funding levels for a very long time with advocacy and determination; it is disrespectful to their real and demonstrable support needs to send some efficiency message to their service provider (CASSI). That message is that somehow those who have not had the responsibility of providing high quality support services now know much more about that their operation than those who have.

- **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. Just at the very time when the community has begun to recognise the value of support staff in this sector, by shoring up an extended period of pay increases (through till 2019), the NDIA has set in place a bare bones and minimalist approach to the cost of employing and retaining staff in a service such as CASSI's and others in the sector.
- **When Two Systems Collide:** does the NDIS operational approach recognise the entrenched clash of services (eg Disability and 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, and which remains a problem to this day.

The NDIA approach is to declare that their Local Area Coordinator "...can assist the participant to make contact and discuss their needs with appropriate healthcare providers where appropriate" (quote from NDIS website). Because the new Scheme intends to not pay for support at that time. The irony is that this is the very period of time when a NGO such as CASSI expends additional (not less) resources in battling to gain access to health care for our service users, on providing support in the hospital's ward if the person with a disability does actually becomes an inpatient, on negotiating for actual treatment to occur and finally on seeking an appropriate discharge process to be achieved.

The NDIA has established a committee to look at mental health issues. This does not appear to be looking at the situations for people with a dual or multiple diagnosis. The membership is pretty well straight down the line of mental health practitioners along with a number of public servants. There is no representation of the issues that we are raising here in this paper.

We are pleased and honoured to be able to speak with the Committee 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.



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