Response by CASA to Draft Report and Recommendations from the Productivity Commission's Inquiry into Disability Care and Support

CASA

(Committed About Securing Accommodation for people with Disabilities)
CASA is a parent group that has over two hundred members. We came together over the lack of funding for desperately needed services. Accommodation is the core main concern of our families.
We were formed in 1999. We are a united and committed body of parents, with a vision of securing permanent supported accommodation for people with disabilities, and supporting their rights to plan to live independently in the community, when the time is right for them and not reliant on a family crisis. Our goal is to make the governments aware of the critical unmet need in accommodation, respite and therapy services for people with disabilities.

Preamble:

"The current system is underfunded, unfair, fragmented and inefficient and gives people with disabilities little choice and no certainty to access appropriate Supports."

The parents from CASA thank the Commission for this statement. As a group of committed parents and carers we have been expressing these sentiments for years and have, until now, felt that our pleas for help and reform of the system were falling on deaf ears.

The members of CASA, and thousands of people like us throughout the country, now feel that there is some light at the end of a very long tunnel that we have been stuck in for a very long time.

Funding of the proposed new system:

It is heartening to read that the Commission has recommended such a substantial increase in funding to fix this broken system.

However, although substantially increased and on-going funding is both welcome and needed, the system will remain broken unless significant reform is undertaken hand-in-hand with the increase in funding. Any reform to the system needs to take into account evidence of the aspects of current support and service provision that are working, both here and internationally, and not just reflect the current buzz words and trends from the states and territories.

It would be devastating to all disabled people and their carers if any new funding became caught up in federal/state cash grab and fight for jurisdiction. It would also be disappointing; to say the least, if this new funding was used by state and territory governments to continue business as usual. Like the members of the community and the Productivity Commission, the state and territory governments need to also acknowledge that the current system (including the parts they administer)) is broken.

Family Story:

Edward has always been a young man who has a fabulous personality and great sense of humour, but has always been very demanding with challenging behaviours. Despite never having a specific diagnosis, he is non-verbal, has distinct autistic traits, petite mal epilepsy and very mild cerebral palsy. He is over 130 kilograms and 6 ft5. Eating has become and obsession and a hobby, incredibly difficult to control. Since leaving school, despite receiving Post School Options funding and some Intensive Family Support funding, and despite my trying my best to build a stimulating and exciting program of activities, Edward has got more and more socially isolated and badly behaved. We believe he has lost hard earned skills learned at school and has becoming increasingly depressed and unmanageable. Rocky Bay refused to transport him, and we moved providers. A work experience place that I struggled to find and negotiated hard to keep, dumped us as they said he became a safety risk. His world became smaller and smaller. Late last year the neurologist put him on Resperidone, a drug generally used to control elderly patients with dementia, and Edward appears to have had an adverse reaction, and in February experienced a major psychotic incident, becoming terrified of everything in the house, appearing to hear or see things in the air conditioning vents, literally not sleeping for seven days before finally being hospitalised. That experience in itself was traumatic as there were no mental health beds available and Edward was kept in emergency, heavily sedated, for three days after having being "bought down" by eight security and medical staff – the most traumatic thing for him as he was terrified, and a most devastating thing for a parent to watch. He developed pneumonia from the heavy sedation and had to have a catheter as he stopped urinating. He left hospital with a new regime of drugs, and on top of his epilepsy medication he now has anti-psychotics, anti-depressants, and anti-anxiety medications. Of course, being non verbal, he can't tell us how these mind altering drugs make him feel, and we can only try and gauge his mood, how sedated or tired he looks and how anxious he gets, to work out how they are performing and whether to adjust them up or down. At our own expense we have bought a people mover bus at a cost of $62 000 (with a bank loan) and had it fitted with a screen between the seats and the driver, and removed the locks on the inside of the sliding door so he can't escape or attack the driver when out. We have also, for the first time ever, had to build a wall and fence with automatic gates around our property as he has become a "runner" (another $20 000 bank loan). Taking him out in the community has become traumatic, as he participates in the activity but then tries to run for a busy road, aiming for traffic lights and/or buses, but is extremely dangerous as he tries to cross roads without looking or waiting for the lights, and is so strong and heavy and irrational it takes up to six people to hold him down. The last time we took him out, more than three weeks ago, the outing on a boat went well, but afterwards it took four of us, plus three strangers, and an hour and half in the hot sun, to stop him running into the road and to get him safely into a car (not his own van) and home. His world has been reduced to our home, the garden, and going for drives in his bus, with carers coming in to play Playstation, Wii, computers and to try and get him swimming or on the treadmill. The medication now seems to be kicking in and he seems calmer at home, and we now have been pushed up the waiting list to finally receive support from a Disability Services behaviour intervention team, and we have a neuro-psychiatrist who we are seeing privately (at around $300 a visit) so hopefully things will start to improve. Thank God I work and can afford to borrow money from the bank to pay for all of this. But why has Edward had to endure the loneliness and desperation that has driven him to a psychotic state; and why have we had to endure the heartbreak of almost losing our beloved and only child? It's not from negligence on our part – we could not have done more to keep him occupied, stimulated and involved. Our psychiatrist, Professor Sergio Starkstein, says he sees this happening to autistic young men all the time – they lose the stability of school, the routine, the social interaction from staff and students, and the stimulation of lessons from properly trained teachers and assistants, and get dumped on service providers who employ young, inexperienced carers, who get sent out to wander around shopping centres with their increasingly unmanageable clients. Sergio Starkstein says it is a disgrace, and that even in third world countries they cater better for people like Edward by having secure centres with properly trained staff, that are safe, provide stimulation with wood workshops, computer rooms, gyms, gardens etc, and companionship and structure; and ultimately the State saves because families are able to keep their children at home longer, and the State does not have to pay for expensive medications to chemically manage them. The last 22 years have been difficult, tiring, and sometimes sad; the last three months have been devastating, exhausting and dangerous.

Person-centred Care:

Whilst CASA supports person-centred care, we are concerned that any rush to implement this reform may lose sight of the fact that the disabled person concerned is a special member of a family. The family has usually been caring and advocating for the disabled person. In moving to person-centred care, the family as a whole should be included. Any analysis should include an investigation of the possible savings to support the family – ie: if both parents remain in the workforce and primary care is provided, their self-esteem is maintained, they contribute to the taxation system and their retirement incomes and the disabled person stays in a loving, supportive and familiar environment.

This also reduces the stress on the family, the risk of family breakdown and their subsequent reliance on Centrelink payments.

At the moment, stress-related depression is suffered by many family members currently providing primary care. Other children in the family also often suffer from depression and fail to either succeed or complete their education.

Any new system needs to include safeguards that will prevent the other children in the disabled person's family (or the off-spring of the disabled person) becoming one of the growing number of young carers – and by doing so, prevent them from missing out on education, social interaction and developing a lack of self-esteem.

Self-directed Funding:

Individual/self-directed funding is supported, but there needs to also be safeguards in place to ensure that the person with the disability has the capacity to ensure that this new system will achieve a better outcome for the disabled person. Not all disabled people and their families have the capacity or want to be involved in the arrangement of support staff, day care options, accommodation, etc. In order for the disabled person and/or their family to make these choices they will need an extensive knowledge of the system – which services are good, etc.

Any new system will also need to include the capacity for the supports to be altered as time and circumstance requires. For example, the disabled person and their family may decide to remain as a family unit for as long as possible accessing day care support. However, when the parents become older and in need of care themselves, the support the disabled person can access will need to change to potentially include residential care. Again, there will have to be safeguards in place to ensure that the person with a disability has a good life, and one of their choosing.

NDIS:

A NDIS type scheme is what CASA and other organisations from the sector have been calling for a very long time – along with the need for the funding to be portable. The recommendation that the NIIS be consistent across state and territories is also strongly supported – at the moments that are extremely large discrepancies.

Access to Therapies:

CASA would also like to place on record our support for the recommendation relating to access to therapies. The system as it currently stands restricts a disabled person's access to therapies once the disabled person reaches the age of 18. Families have noticed a decline in their family member's abilities as they get older and their access to therapies is restricted, This often degenerates into a crisis situation, which in turn can lead to a dependence on long-term accommodation (as the deterioration has an impact on the disabled person's health and wellbeing and their family's ability to support them.). Access to crisis and emergency support will also need to be included in any new support system.

Family Story:

Going from early intervention, through school therapy services our son was able to weight bare, his legs had some muscle tone, his had learnt over one hundred and fifty signs in makaton, and was able to feed himself using a knife and fork. Once school had finish at eighteen he became more and more reliant on his family, they did what they could to keep him active member of their local community. With the lack of therapy services he started to deteriorate becoming increasingly harder for his family to cope, his weight escalated and his family also suffered back, shoulder and knee problems. They applied for out of home accommodation after nine long years they finally had funding approved. His family thought that they won the lottery, but this was short lived, at the group home he was hoisted into his wheelchair, where he sat all day. Now he has contractures in both legs, he doesn't use his communication skills because staff are not trained in Makaton causing him to be frustrated and now is label as having behavioural problems. All the great work in the early years had been lost. If therapies continued when he left school he may well be still living in the family environment or at least had the chance to choose to leave home when the time was right for him and not because his family was in crisis.

Reform of the System:

Although extremely supportive of the recommendations contained in the Draft Report, CASA would again like to place on record our reservations about exactly how the distribution of the proposed increase in funding will ensure that the system is reformed, and that these reforms remain in place in the long-term. We would also like to reiterate our view that there needs to be a comprehensive look at the sector when designing and implementing the new scheme.

We are also of the view that further attention needs to be paid to the wages and conditions of support workers, perhaps with a view to developing a tiered wages system that rewards experience, thereby increasing the chances of retaining long-term workers in the system.

Advocacy:

Finally, CASA calls for an increased focus on advocacy. Advocacy for individual disabled people and their families is going to become increasingly important if we move towards a person-centred

(Family centred) funding model. A mechanism will need to be developed that will provide for independent advice and advocacy for the disabled people and their families that decide to directly purchase services. This will be needed not only to assist with the selection of the service provider(s) but also ongoing monitoring to ensure that their needs are being met and that they are getting value for money.

CASA would close our submission by once again congratulating the Commission for actually listening to families.

Carol Franklin

Co-founder CASA