Inquiry into Disability Care and Support
Australian Government Productivity Commission

My submission is based on the dual experiences of being the mother of 31 year old young lady with an intellectual disability, combined with that of a CEO of a community service organisation and in excess of 30 years experience working in the health and disability field.

Our families' journey began with the arrival of our daughter, to all intents a perfectly normal baby. As we passed one developmental milestone after another, with little 'normal' progress, the reality of our special child dawned. At two years of age we were informed that she had developmental delay due to an unknown cause. During these years there was a myriad of medical appointments, assessments and hospitalizations. We were advised that our daughter would probably not walk, talk or be able to attend regular kindergarten or school; and that we should consider placement in a residential facility where she could receive the care she required. At the time we lived on the family farm, deep in the Otways, two hours drive over the mountain range to any support services. Being young, determined and optimistic, we refused to consider the option of alternate care; and chose instead to leave the family farm (where my husbands family have farmed for 4 generations) and move closer to an regional area where access to supports and services would be available.

We actively participated in early intervention programs, spent hours at home implementing activities and exercises as advised, and knew progress. Our daughter began to walk by the time she was six years of age, and was making some progress with her communication. We saw the dawn of the 'deinstitutionalization' process, studied Wolfensberger, championed integration into kindergartens and schools and read the Cullen-Brown Report into educational services for people with a disability. The world for our daughter and our family was about to change, and it was exciting! We understood that a nurturing family life was the best environment in which our daughter could flourish and develop to her ultimate potential; and that at an appropriate time in adulthood she would be able to leave the family home and live with support with a group of her peers, preferably within the community where she had grown up.

How disappointing to find ourselves in 2010 writing a submission to your commission, in the vain hope that at some point in the future we will see light at the end of the tunnel.

From our families' experience and perspective, a NDIS must address the following:

- Eligibility needs to be determined by a thorough, independent assessment and must include a process for review and dispute
- The needs of the person with the disability must be central to the decision making processes; but not at the exclusion of the needs of parents and siblings. All family members' needs are of equal importance.
- Early intervention is critical, and has the capacity to significantly alter and improve outcomes for the person with a disability, and the family unit.
- The notion of an 'insurance scheme' conjures the possibility of creating yet another lawyer's picnic – and must be avoided at all cost. Any tangible benefits of what will ultimately be a taxpayer funded response however disguised, must be directed towards the people for whom it was intended.
- People with a disability and families must be able to choose the services and providers who can best meet their needs. This does not mean that they should or

must have complete control of the 'funding bucket'. Not all families want this level of involvement or responsibility.
- The needs of people with a disability currently identified on state government waiting lists or registers must be addressed in the early stages of implementation. To only focus on newly eligible persons would be a travesty of natural justice.
- If eligibility under the NDIS is confined to those deemed to have a severe/profound disability, there will be many people and families with support needs that will not be met within the scheme. A parallel response will be required.

My earlier reference to Cullen-Brown report into educational services, whilst part commentary, was intentional. As an amateur historian, I draw your attention to a couple of salient recommendations made in this report drafted over 25 years ago into what had been the most significant shift in public policy at the time – educational services based on a human rights and social justice platform. Recommendations of relevance to the current debate included:

- The policy that parents are free to choose the educational placement for their child should be supported by balanced and comprehensive information. (**Information and Communication)*
- Uncertainties and inequalities in funding to be removed through the creation of the resource index. (**Equality in access)*
- Recommendations in relation to teacher training and professional development. (**Workforce development and training)*

If we fail to learn the lessons of history, we will continue to make the same mistakes, and we don't always need to look beyond our own borders for some of the answers.

I consider my children my 'best work', including my daughter who has a disability. Her influence on all our lives has been profound, and we have learnt many lessons — perseverance, tolerance, patience to name a few. We have always endeavoured to provide her with the same opportunities as her siblings, and are grateful to live in a community where she is embraced and included. But it is time now for her to leave home, and commence the next part of her journey while we are here and able to provide the support and security that will be required to ensure a successful transition.

Respectfully yours

Jacqui Suares