Submission to the Australian Productivity Commission on behalf of The Onemda Association Family Advocacy Network

Preamble

Onemda is an adult disability service provider located in the eastern suburbs of Melbourne. Onemda – indigenous for *"With loving care"*, was established in 1968 by a group of parents in sheer desperation for the critical need of day service support for their significantly physically and intellectually disabled sons and daughters. During this period, there was next to no recognisable services for this population within the local and surrounding areas with most day services only supporting mildly *disabled* adults. The government of the time was doing very little in actual recognition within this field and less so in responding to the dire needs of their families.
From the early days of volunteer support and primitive facilities and resources, Onemda today now boasts a population of over 100, employing over 65 staff and has large, well resources facilities to support the significantly disabled.
Onemda has and always had strong family links from the early pioneers of the service to these days having a formal Family Advocacy Network (FAN) which directly reports to and from the Onemda Committee of Management. The network primarily is an opportunity for families to share experiences and ideas, offer mutual support, is an avenue for families to remain informed of sector developments and lobby for the rights and needs of people with a disability and their supporters. We speak here for these families, we need to have a voice and be heard.

On behalf of these families and the Onemda community, we submit the following chronology of our experiences over the past 40 years and provide our suggestions of the key features for a long-term care and support plan for Australia's future.

Where from

1. *De-Institutionalisation*

The relocation of clients to Community Residential Units has seen a significant improvement in behaviour both in the areas of self care and social inter-action and has provided dignity to clients. There has been a movement into the provision of flexible daily service options, better training programs, varied leisure activities and more regular contact with parents, family and the general community.

2. *Community Housing*

The establishment of CRUs and the development of the program from 1980-2000 gave hope to clients, parents and carers that a service plan would be available to address the individual needs of clients and to target and service those requirements. <u>However the breakdown in the capital program for new housing for community based clients over the years 2001-2010 has placed the system in crisis</u>.

3. *Respite Services*

Although some respite services exist for physically and intellectually disabled clients, the lack of planning and funding to cater for present and future demands has seen a cut in service provision and increased stress on ageing families.

4. *Workforce*

Committed and professional staff are an integral part of the Disability field. However the physical and mental stress placed on staff combined with a general underpayment of salary does engender a higher turnover of staff with a subsequent loss of expertise and the flow on effect of providing quality training and development of clients.

5. *Attitude towards people with disability*
Community attitude and expectations have changed dramatically over the last 40 years. Modern Australia no longer believes in the "out of sight, out of mind" prejudices that previously existed, but supports and demands a "fair go" and equality of life for all and the necessary provision of services to enable those goals to be achieved.

6. *Medical advancements*
Over recent years medical advancements have played a key part in enhancing life expectancy for most intellectually and physically disabled clients. These improvements have also strained current resources.

7. *Advocacy for the rights of people with a disability.*
Parents are increasingly better educated than previous generations and combined with a higher standard of living know they have a right to demand, expect and achieve proper outcomes for their sons and daughters.

Where to

1. *Whole of Life Planning*
Whole of life support plans are essential for each person as soon as they are assessed with a physical or intellectual disability. Unfortunately most clients assessed as medium to severely disabled will require various levels of support throughout their entire life. Whole of life plans, with regular reviews detailing every area of their anticipated need, will not only give some comfort and direction to clients and families but will ensure that programs /goals can be detailed and co-ordinated as needed. Additionally the resultant information encompassed in each plan will build a data base for government departments and service providers to prepare to meet those needs with proper infrastructure and finance over forthcoming years.

2. *Ongoing Need for Day Services*
To ensure that the fabric and inherent need of disability day services are acknowledged and empowered for the critical function which they serve within community. The recognition that day services provide the most efficient and effective method in achieving individual outcomes for clients with significant life long disability is assumed, and that the value they provide in disability support must neither be ignored nor forgotten.

3. *Review of Accommodation Model*
Families need the right to have some peace of mind regarding what will happen to their disabled family member when they are no longer able to care for them. We feel powerless and want to be able to work towards preparing them for a future without us. The Government strongly encourages family members to fulfil the role of carers, but does not provide them with legal standing or adequate support. Supported accommodation models should be examined /reviewed to give some choice or options to clients and their families to meet their individual needs. Community Residential Units have provided a huge change in providing quality living and community participation and must be expanded to meet current and future demands. Small settings of cluster housing for persons who, due to their social network/ living patterns ,health and medical needs or level of disability should be a viable option for clients and families to consider. If aged or retiring couples are given that choice of life style, why not our disabled fraternity?
The exploration of a residential transition program which creates smoother orientation to future semi and/or independent living needs. This will assist to appropriately match individuals with the desired supports, environments and infrastructure for successful transition.

4. *Workforce Development and retention*
The provision of increased funding in the Disability Budget to the lifting of wages and putting greater incentives in place for all carers and disability employees are essential. There must be an injection of investment into the sector's professional status which is reflective of the current day values of a modern Australia. A society intrinsically committed to the rising of the oppressed and disadvantaged.

5. *Increased Respite Options for Carers*

Respite care in accommodation, day programs and home care are key elements in supporting family and community living for disabled clients. This must not only be seen as just a break for families but a positive, social and enjoyable experience for the disabled family member. Respite needs not to be perceived as a form of a luxury item, but to be truly recognised as an integral component to the ongoing wellbeing, care, support and personal development of both the person with a disability and the carer. All workers are entitled to 4 weeks annual leave per year, families should have access to quality overnight respite for the same period for the person in their care.

Governments must seek better understanding of carer need with increased data collation which is wide scoping and targets the areas in most need. To keep families/ carers better informed about their rights, choice and options.

6. *Health*

Any person born or who acquires disability must be appropriately supported and have fully subsidised access to the Australian health system. It must be one of the great modern moral obligations we have as a fully developed nation, that this disadvantaged population have the right to the appropriate health services to meet their on-going medical needs. In addition, with the much overdue shift towards increased funding and social de-stigmatising of the mental health sector, this has unfortunately not extended to the junction between mental health and pre-existing disability. This requires as much attention for disabled members of our society who deserve the same benefits of those being experienced by the non disabled.

In Closing

A National Disability Insurance Scheme would underpin a whole of life plan for each person requiring support .The Insurance Scheme would provide the necessary funding to enable Australian society to provide a high level of care to those that need it most. Government policy and planning at the Federal and State level needs a complete review to address the needs of a rapidly expanding population and to overcome infrastructure and resource meltdowns inherent in the current system of disability care. The better use of finite budget funding to ensure each client is given a chance to live, engage and develop within the community is vital.

In conclusion we thank and applaud the Government for launching this inquiry and hope this is the beginning of a new era where families and government departments can work together in ensuring the best of care for our children's futures.

Family Advocacy Network
The Onemda Association