RESPONSE TO PRODUCTIVITY COMMISION'S DRAFT REPORT

on

Disability Care and Support

by

THE ASSOCIATION FOR CHILDREN WITH A DISABILITY NSW

30 April 2011

The Association for Children with a Disability NSW (ACD NSW) made a Submission to the Productivity Commission in August 2010. We have reviewed the Draft Report published by the Commission and are supportive of the majority of the recommendations made by the Commission. However, there are a couple of key areas in our original Submission that we believe warrant more detailed consideration and, potentially, more immediate action, namely:

1. Supported Accommodation; and

2. Workforce Issues.

We address each in turn.

1. Supported Accommodation

The primary area of concern for ACDNSW is the current crisis in long term supported accommodation for people with a disability. Appendix B of our original Submission outlines the research we have conducted to assess the present need for accommodation of this kind in Australia. The research compares the incidence of disability in other countries and concludes that Australia needs approximately 60,000 long term accommodation places and yet currently only approximately 20,000 exist. We see no reason why the need in Australia should be any less than that in other countries where disability is better serviced so we are very concerned by what we consider as a lack of planning and forward thinking in the Draft Report to address this shortfall.

This matter was raised with one of the Commissioners as a question in an open forum at a Conference run by Carers NSW in Sydney earlier in the year and the response received was that it was not considered that a shortfall of the degree we have outlined existed. We believe further research needs to be done in this area if the figures we have furnished are to be discounted.

ACDNSW understands that a pilot is necessary to test the proposed scheme and that it may take until 2018 for the scheme to be rolled out across Australia. However, our concern is that, unless work on identifying sites and constructing buildings commences within the next 2 years, there is absolutely no way that sufficient housing can be available for the scheme to become fully operational by 2018.

Connected to this issue is the debate about what that housing should look like. Appendix C of our original Submission advocates that a range of choices of accommodation should be made available. For your ease of reference we have included both Appendices again here.

2. Workforce Issues

Finding good paid carers is very difficult toaday; we can only imagine how this problem will be exacerbated when more funding available for the provision of services. This is of course not an argument against an increase in funding, but it does mean that we have to look to more innovative solutions to find carers. One of the suggestions made in Appendix A (para 6.1) of our

original Submission to the Productivity Commission is the introduction of “carer’s visa” such that unskilled workers from other countries would be allowed into Australia if they were to live-in with a family and provide care to a person with a disability.

We were heartened to see this line of thinking considered in the Draft Report but concerned that it was subject to the caveat that it must first be established that there is an “acute and persistent shortage” of workers. Given the current difficulties faced by service providers and families in the aged sector as well as the disability sector and given the likely increase in the number of aged people and people with a disability even in the period only to 2018, and taking this together with the fact that the objective here is to make more services available, we believe it can already be shown that there will “acute and persistent shortages” and it is unfair on families to hold up the efficient operation of this proposed scheme by not addressing this problem head on and well in advance.

Our proposal is for a carer’s visa to be introduced within the next 12 months so that families have some ability to manage the demands upon them before the NDIS becomes fully operational in 2018. As mentioned above, whilst we recognize the need to implement such a complex scheme slowly, there are families currently in crisis and others struggling daily under the weight of their caring responsibilities who would be well served by taking immediate action in an area such as this.

This policy change would not be difficult to implement, is not only low cost but is potentially a cost saving device for current Governments and would have immediate benefit to families. As mentioned in our original submission, there are precedents to look to for guidance: see www.ci.gc.ca/english/pub/caregiver for more details.

This proposal has been put to the Howard Government and the current Government by ACDNSW but both Governments have been reluctant to make any changes affecting immigration laws. We believe a strong recommendation from the Productivity Commission may encourage them to act, particularly if they can see it as a cost saving exercise and if they recognize that the proposal fits well with the relatively recent trend towards individualised funding, a concept they are going to have to come to terms with eventually anyway.

We are grateful for the opportunity to provide further comment to the Commission.

APPENDIX B
Long Term Supported Accommodation – The Need

There is a chronic lack of out-of-home long term supported accommodation for adults with a disability in Australia.

In some States, it is impossible to obtain a place in long term supported accommodation without relinquishing your rights over your child in order to satisfy the authorities that your child is "homeless or at risk"[1]. No parent wants to do that.

Even then, the likelihood is that your child will end up simply blocking a bed in a respite services, or your child will be placed in a nursing home because there will not be a permanent bed available.

This situation is inhumane and has to be remedied.

ACD NSW's vision for the future is that all families with an adult child with a disability should have the option to access out-of-home long term supported accommodation for their child when they require it.

The Current Situation

Governments are moving further and further away from the concept of providing out-of-home supported accommodation for people with disabilities who require such care. They are relying on families to provide in-home care for their children for as long as those families are physically able to do so. Governments justify this approach on the basis that it is too costly to do otherwise given the number of people to whom they have to provide disability services.

ACD NSW supports the fact that families may decide to care for their child in their family home for as long as they wish. However, the members of ACD NSW believe that it is critical that families have a **choice** between in-home care and out-of-home care once their child becomes an adult.

The vast majority of parents find that providing in-home care for their adult child places enormous stress on their relationship with their partner, significantly restricts their ability to gain employment and imposes an excessive level of responsibility on any siblings of the adult child, even when those siblings have left home.

The most current data on disability services is that recorded by the Australian Institute of Health and Welfare ("AIHW") in its Report entitled "Disability Support Services 2007-08" released December 2009. That Report states that out-of-home long term supported accommodation is

[1] Refer ADHC requirements in NSW.

provided to 18,476 people in Australia.[2] See the below Table for a breakdown of that figure across various accommodation models:

Large residential	3,126
Small residential	912
Hostels	410
Group Homes	12,923
Alternate family placement	246
Other accommodation support	859
TOTAL	**18,476**

Table compiled from data from Table 2.1 AIHW Report on Disability Support Services 2007-08

The exact cost of this kind of service is not recorded in the AIHW data but, what the data does state, is that the cost of that service plus the cost of providing attendant care and personal care and of providing other in-home accommodation support totaled just under $2.3 billion in the Financial Year 07-08[3]. Assuming out-of-home supported accommodation represents two thirds of that expenditure, the total cost of long term supported accommodation for people with a disability across Australia in the Financial Year 07-08 was $1.5 billion.

Dividing $1.5B by the 18,476 people equates to a cost of just over $80,000 per annum per person. Given that cost, it is easy to understand why Governments resile from committing further resources to this area.

However, bearing in mind that families have already saved Governments these costs by keeping their children at home for the first 20 years of their life, our proposal to Governments is that they cannot refuse to expand the provision of long term supported accommodation to adults with a disability without first conducting a thorough analysis of the actual cost of making such care available to those who need it.

[2] Refer AIHW Report on Disability Support Services 2007-2008 Table 2.1 – this figure represents the total of the funded services listed under "accommodation support" excluding attendant care/personal care and excluding In-home accommodation support.

[3] Refer AIHW Report on Disability Support Services 2007-2008 Table 1.3

What should we reasonably expect?

Other countries, such as Sweden and Norway, are currently meeting the demand for housing for all people with a disability who seek that kind of accommodation. In Sweden, every person with a disability has the legal right to be housed and cared for outside of their family home. In Norway, although no legal obligation has been imposed on the Government, the Government pays the full cost of supported accommodation save only for a nominal rent charged to the resident[4]. In the UK, a legal obligation has been held by the Courts to fall on the Councils to provide adequate supported accommodation for people with a disability and at least one Council has been successfully sued for failure to do so.

Why should Australia not provide the same?

The Costs

To understand the costs of providing long term supported accommodation to those who need it, we have to determine the "potential population".

Table A1.1 of the AIHW Report on Disability Support Services 2007-08 states that the "potential population"of people always needing basic support is 36,991. It is reasonable to expect these people would all require long term supported accommodation.

ACD NSW considers this estimate to be low and, for the following reasons, considers a more realistic estimate of the number of adults with a disability in Australia with the need for long term supported accommodation is approximately 65,000:

1. Statistics in Norway, Sweden and the United States show that the percentage of people with a disability who currently require or will require supported accommodation outside the home is 0.45%[5]. Assuming one third of that number are still children, and assuming we do not seek to place children in supported accommodation, the housing need can be said to exist for 0.3% of the population. In Australia, 0.3% of the population is 67,239 people[6].

2. 0.3% of the population is consistent with the demand which exists in countries such as Norway and Sweden. Norway provides supported accommodation at a per capita rate of 0.24% (i.e. 24 places for every 10,000 people) and, in that country, demand equals supply for the most part – there are virtually no waiting lists. Sweden provides supported accommodation at a per capita rate of 0.18% (18 places for every 10,000 people) and also has minimal waiting lists[7].

---

[4] Refer paper delivered by Professor Jan Tossebro at 23 March 2006 Roundtable on Supported Accomodation
[5] Refer paper delivered by Professor Jan Tossebro and paper delivered by Roger Stancliffe at 23 March Roundtable on Supported Accomodation
[6] Based on the reading on the ABS "population clock" data for the Australian population at 11am on 6 August 2010, which was 22,413,232.
[7] Refer paper delivered by Professor Jan Tossebro at 23 March Roundtable on Supported Accomodation

Australia currently offers only 8 places per 10,000 head of general population. The target of 30 places per 10,000 (ie 0.3%) results in a requirement for approximately 65,000 places. On that basis, we could envisage a country which has minimal-to-no waiting lists for supported accommodation for young adults with a disability as they come through the system.

The reality is that, although the objective of providing supported accommodation for all adults in Australia seeking that option is not cheap, it is certainly within the realm of possibility and is a realistic target to be obtained.

So what would it cost?

Leaving aside build costs for the moment, since they are a one-off capital cost, based on the current spend per person in supported accommodation, the cost of providing supported accommodation for all adults in Australia seeking that option would be $5.2 billion. That is $3.7 billion more than Governments (on a combined basis) currently spend on supported accommodation per annum.

Certainly, this is not an insignificant cost but, when put in the context of the Government budgets, it is not unrealistic to expect this money to be made available for a service which is considered in other countries to be a basic legal right of a person with a disability.

ACD NSW supports the introduction of national disability care and support scheme to fund this urgent need.

In closing, ACD NSW cites pleas for help that it has received from its members:

> *"I have devoted my life to the care of Alex to the detriment of my family, especially my other son Peter who suffered in his early years from my neglect. I feel guilty about this, but I don't know what I could have done differently. My relationship with my husband is very difficult because in order to keep going I have shut down all aspects of my life except the essential. I know he misses the happy, optimistic person I used to be, a person with a sense of humour. I have become a machine who every now and then breaks down and cries.*
>
> *I don't know how long I can continue to live my life like this but I know it is not long as there are cracks appearing in the walls of my will. Every day I cry more often and I have become completely antisocial. I fear these are signs of a deep depression, a depression caused by a lack of hope that my future might be different."*
> Mother of a 26 year old boy

“I am the mother of an intellectually disabled son he is now 22 years of age and was born with cerebral palsy. For the first ten years there were numerous specialists and trips to hospitals and wandering if when I went in to wake him in the morning he would still be alive. It has made a huge impact on my two other children, like no family holidays and constant working around Chris, it has also made a huge impact on my marriage. As I had no parents or family to help out the responsibility was always on my shoulders, Chris is now working with supported help so we get up at 5.30 am and I drive him to his work and pick him up again so my petrol bill a week is $100 just for driving him. I don’t get any respite with no hope of getting any!!!. I don’t have supported accommodation for my son and no hope of getting any!!!, What happens to him when I die. “

Mother of 22 year old boy

“Like all parents of intellectually disabled children who grow up, we are anxious about our son's future when we can no longer provide the care he needs. He needs round the clock supervision and our dream has always been to see him settled in a suitable venue at a time when we can assist with the transition. As we are both in our sixties, the time when we will no longer be able to carry on our task of caring for our son, is not far away. We desperately seek to find a solution not only for ourselves but for so many people in similar situations.

We agree that children with a disability, even in adulthood, may be best served by being at home with a loving family; but only to a point.

Once the loving family starts to wear out, that family needs to be able to retire like any other person. We urgently request that more supported accommodation be provided to prevent many older parents from becoming seriously ill or dying prematurely.”

Mother of 33 year old boy.

“When I think of the job ahead of me - for the next 40 years or so, I just feel overwhelmed. Courtney is so difficult to look after that we have few friends or family prepared to take on the challenge, which begs the question: who looks after her when we can't? We just never *seem to get a break, and it is relentless hard work.*

I have emailed State and Federal MP's about the inadequate respite and accommodation facilities, and the response is always the same: blame the other party, and/or the other level of Government. It seems that we just don't matter, beyond a token payment and a pat on the back. If this situation does not change soon, there are going to be thousands of families driven to all sorts of desperate outcomes, and unfortunately, that's what may have to happen before they start listening to us.”

Mother of 15 year old girl

APPENDIX C – LONG TERM ACCOMMODATION - MODELS

One of the predominant themes that comes through from speaking with parents of children who have experienced any form of supported accommodation is that everything turns on the quality of the care. Where the carers take the time to get to know the clients and to create a sense of family atmosphere in the home or hostel, everybody benefits. Presumably, the Group Home was developed with this theme of family in mind. However, evidence suggests that this atmosphere can similarly be created in environments which house far more people than can be accommodated in a Group Home. The Models proposed by us below are three examples of supported accommodation in which we believe that a family atmosphere can be created.

The other predominant theme that comes through from the parents with whom we have spoken is that Group Homes have the following disadvantages:

- clients may feel isolated if they are not frequently taken into the surrounding community
- there is often inadequate supervision of the carers
- incompatibility of clients can create problems which cannot easily be overcome in a small environment
- the needs of one client may tend to dictate the activities of the others in the house.

These disadvantages have also been identified in the publication by Roger J. Stancliffe and K. Charlie Lakin entitled "Costs and Outcomes of Community Services for People with Intellectual Disabilities", refer p130. (Paul H. Brookes Publishing Co, 2005.)

It is our contention that the Models of supported accommodation proposed by us below offer opportunities to overcome the difficulties that have been identified with Group Homes.

Key Requirements of all Models

We have sought to identify Models of supported accommodation that will ensure a safe and long-term secure environment for our often vulnerable group.

In doing so, we have identified the following as key requirements which need to be satisfied by any model:

- Accommodation to be wheelchair accessible, within and outside the premises
- Some bathrooms to be fitted with hoists and other equipment suitable for moving non-mobile clients
- Ducted reverse/cycle air-conditioning
- Shaded outdoor space

- Communal indoor and outdoor space
- Mini-bus
- Double garage to accommodate bus, plus parking for staff./Visitors.
- Maintenance services to maintain equipment/buildings/grounds
- Regular cleaning service
- Close to transport or walking distance to local village of shops
- On-site Manager responsible for administration and staffing
- Staffing levels appropriate to client individual needs
- Emergency response system with "hands on" support. This need may be met by a nurse if medical care needs of residents are required, or in the case of people with challenging behaviour, a specialist in that field.
- Regular visits by specialist health professionals i.e. doctors/physiotherapists/occupational therapists/recreation officers/dieticians/speech pathologists.
- Support to assist in improving independent living skills
- Carers to facilitate community interaction to minimise social isolation
- Full compliance with Occupational Health and Safety requirements, fire regulations and any other relevant legislation.
- Management of the Cluster by a Board comprising a large percentage (approximately 80%) of interested parents and a lesser percentage of independent persons with an interest in disability services.
- At least one bedroom dedicated to Respite. This would be used for emergencies but also to transition people with disabilities from their family home to the supported accommodation.
- A guaranteed right to remain in suitable accommodation once the initial placement is awarded with ongoing assessment of the person's needs.
- Each disabled person has the right to be assessed at the request of their parents, guardian or primary carer to determine suitability of the person for out-of-home care. (This right has been afforded to carers in the United Kingdom by legislation – see www.cafamily.org.uk.)

Our Preferred Models

From the above list of Key Requirements, we have developed three Preferred Models which we have named:

(a) Cottage Clusters
(b) The Campus College Model; and
(c) The Village Model.

We outline below the key indicia of each of these Preferred Models.

(a) Cottage Clusters

The “Cottage Cluster” Model is based on the groups of cottages available to students at some Universities, such as the cottage-style, on-campus accommodation at Canberra University. It also conforms with cluster models already in the community for the general population seeking medium density housing with minimal maintenance, security, independent living, cost effective accommodation.

We propose that “Cottage Clusters” would comprise 4 or 5 purpose-built 3 to 4 bedroom single story villas on a large suburban block, plus a Manager’s Office or Live-In accommodation.

Each Villa to contain:

- 3 or 4 large bedrooms; each client to have own bedroom. Bedroom to accommodate wheelchairs/hoists/access to orthopaedic bed. Built in wardrobe; personal furniture etc
- Lounge/Recreation Area; with easy access from eat-in kitchen. Must facilitate movement of hoists/wheelchairs and physiotherapy equipment with suitable seating for residents and staff. Entertainment unit.
- Kitchen: Eat-in kitchen to accommodate four wheelchairs and bench tops at heights to facilitate client observation/participation in food preparation, plus table for meals. Medicine Safe
- Bathroom/Toilet: designed to accommodate physical aids, including hoists for spa bath/toilet chairs/change table/large shower recess with hand held shower/ vanity cabinet.
- Separate Toilet: – large enough for wheelchair/toilet chair access.
- Laundry: large washing machine/dryer/double laundry tub
- Villas built with wide hallways and doorways to accommodate wheelchairs/hoists
- Each Villa in cluster to function individually with staffing levels appropriate to client needs.

Facilities shared between the Villas would include:

- Shaded outdoor space for each villa, plus large communal space for cluster to facilitate weekend BBQs Christmas/Birthdays etc.
- A Network Manager located at the Cluster Office would be responsible for administration and staffing. Office to include computer/fax/photocopier.
- The Office would act as an emergency response system for each cluster and would be open at all times with a Manager on duty who can act as “hands on” support in case of emergency.

(b) The “Campus College” Model

The “Campus College” Model is based on the hostels commonly available to students at many Universities, for example, the Robert Menzies College Hostel at Macquarie University, Sydney.

In formulating this model, we considered the similar forms of supported accommodation available in Holland and in Israel and the premises previously run by AFFORD in Penrith, Sydney but which is now closed.

We propose that the "Campus College" Model would comprise 2, 3 or 4 purpose-built single or two-storey buildings each sleeping up to 10 residents, with one or more Manager's Offices and some Live-In accommodation.

Each level of each College building to contain:

- 8-10 bedrooms; each client to have own bedroom. Bedroom to accommodate wheelchairs/hoists/access to orthopaedic bed. Built in wardrobe; personal furniture etc plus small area to relax in.
- 2 small, cosy lounge areas
- One larger Lounge/Recreation area
- Eating Area with two tables to seat 6-8 people. To retain the sense of family, tables should be no larger than the everyday dining table and there should be no more than 2 tables in the Eating Area.
- Kitchen: Suitable for preparation of meals in large quantities. Alternatively, meals could be prepared in bulk in a separate area and delivered to the College. In that case, each College building should nevertheless contain a small kitchen suitable for training residents in independent living and for providing access to snacks between meals and tea and coffee for residents and visitors.
- Medicine Safe
- 2 Large Bathrooms: designed to accommodate physical aids, including hoists for spa bath/toilet chairs/change table/large shower recess with hand held shower/ vanity cabinet.
- 2 Separate Toilets: large enough for wheelchair/toilet chair access.
- Laundry suitable for basic emergency washing (of soiled clothing etc) and training residents in independent living.
- Colleges built with wide hallways and doorways to accommodate wheelchairs/hoists
- Each College to function individually with staffing levels appropriate to client needs.

Facilities shared between the Colleges would include:

- Outdoor space central to all College buildings with communal space for cluster to facilitate weekend BBQs Christmas/Birthdays etc.
- Ideally, a fenced pool or spa area.
- General store
- Cafe
- Music room
- Sensory room
- Large Community room
- Gym

- Larger Laundry for the bulk of the washing. Alternatively, this washing may be contracted out.
- A Live-In Manager responsible for administration and staffing. Office to include computer/fax/photocopier.
- 24 hour Registered Nurse

(c) The Village Model

The Village Model conforms with models already in the community for the general population seeking medium density housing with minimal maintenance, security, independent living, cost effective accommodation.

We propose that the Village Model would comprise up to 20 purpose-built 3 to 4 bedroom single story villas of the kind described in the "Cottage Cluster" Model, plus a Manager's Office and, possibly, Live-In accommodation for the Manager.

Villas would be positioned in the grounds in groups of 4 or 5 and would share outdoor facilities as per the Cottage Cluster Model described above. Given the number of residents housed in the Village, additional facilities available to residents would include:

- Walking tracks suitable for pushing wheelchairs
- Bike tracks suitable for modified bicycles
- Fenced Pool or spa
- General store
- Cafe
- Music room
- Sensory room
- Large Community Room
- Gym
- 24 hour Registered Nurse

Conclusion

The NSW Association for Children with a Disability is focused on providing choice to families of people with disabilities, particularly for those with moderate to severe disabilities. Whilst the current practice of using Group Homes predominantly to accommodate people with disabilities works well in many instances, it certainly also has its drawbacks as identified earlier in this paper and, of course, the acute lack of places for people with disabilities is a separate issue in its own right.

In this paper we have proposed a variety of models which we consider suitable for people with moderate to severe disabilities. We believe that each of these models:

- minimises social isolation by facilitating socialisation outside the home with minimal effort/cost
- enables more appropriate matching of clients than is possible in a Group Home setting
- due to the larger numbers of clients in each setting, allows greater flexibility of activities to suit a wide range of needs
- allows for improved supervision of staffing when compared to Group Homes
- provides back-up for carers allowing for support in an emergency as well, ideally, a broader group of carers with familiarity with the clients
- provides a more efficient base for visits by specialize staff i.e. Physios/OT/Speech Therapists etc.

We recognise that some of our Preferred Models may be considered by some advocacy groups as having too many similarities with the institutions they have worked so hard to dismantle. In response to that, we would submit:

(a) There are people in the community without disabilities aged 18 and older currently living in residences comparable to each of those set out as our Preferred Models;

(b) Those Models have been proven to work successfully in other countries; and

(c) The atmosphere of a residence is formed as much by the carers who work there as by the physical environment provided.