This submission has been authorised by the ACD NSW Committee.

16 August 2010

The Association for Children with a Disability NSW (ACD NSW) is a non-profit organisation run by parents of children with a disability. We represent over 600 families across NSW. We help families gain knowledge and confidence to provide the quality of life their child deserves by:

- Providing support and information for parents, carers and families of children with any disability
- Raising public and political awareness of the issues faced by parents, carers and families of children with a disability
- Advocating for improved services and equipment for families of children with a disability.

ACD NSW is supportive of the concept of a national disability care and support scheme. The currently disability system is crisis driven and woefully inadequate. It is unfair, piecemeal, chronically under-funded and creates dependence. Families with disabled children often feel they are drifting from crisis to crisis.

ACD NSW considers that the key characteristics of a national disability care and support scheme would be:

- enshrined in legislation
- national
- consistent in application
- easily accessible
- based on a consideration of the needs of the person with the disability and their families
- provide choice of services and support
- applicable to those people already living with a disability as well as those born or incurring a disability after the introduction of the scheme.

We have not attempted to address all of the questions in the Issues Paper. We feel many other submissions will address these questions adequately. ACD NSW is an organisation focussed on children with a disability, and we have focused on those which we consider having particular relevance to children and young people with a disability, an area where we can most add value, in particular:

1. Who should be eligible
2. Assessment tests
3. Essential care costs
4. Linkages
5. Models of delivery and the need for choice
6. Benefits of the scheme

Where appropriate, we have included relevant quotes from some of our members.

1. ELIGIBILITY

We would like to see a broad eligibility criteria such that the scheme covers all people with a disability, regardless of how they received their disability. However, we would propose tiered levels of funding and support be available, according to the needs of the person with the disability and the family. We recognise that the costings of such a broad scheme may ultimately be untenable but consider it important that the costing exercise is done on that basis at some point so that a fair case can be made if it is necessary to restrict the application of the scheme to only people with, say, a severe or profound disability.

Being an organization representing parents of children with disabilities, we do feel strongly that the scheme should apply to all children with a disability, irrespective of their particular circumstances.

As we understand it, the current proposal is for the scheme not to cover people over 65 years of age who incur a disability. We would support that proposal on the basis that, whilst the current aged care system has it faults, it offers those people far more than is currently available for families with a child with a disability. Until that discrepancy is narrowed, we believe the focus of the national scheme should be on people younger than 65.

We consider it essential, however, that a person remain eligible under the scheme for the whole of their life-time if they have been eligible before they turned 65. This would ensure that people with a disability can “age in place” rather than be removed from their home and moved to a nursing home once they turn 65. Uprooting a person with a disability in that way (as is the case under the current system) is extremely disruptive for the person and their family and can lead to many unwanted behaviours.

2. ASSESSMENT

We are not familiar with the entire range of tests available for assessing disability but we would like to say very strongly that tests based exclusively on a diagnosis of a specific syndrome are not appropriate since many disabilities are not diagnosed till a child is already at school and many are never properly diagnosed at all.

It matters not whether a child has an official diagnosis of Cerebral Palsy or an, as yet, unnamed genetic disorder (or a named one for that matter). A ten year old with CP who cannot walk or weight-bear is functionally no different from a ten year old child with Rett Syndrome who cannot weight-bear or walk. Similarly, a ten year old child with mild CP who can walk and talk independently may need a minimum of help compared to a ten year old child with severe CP who is non-verbal and has no functional body control. Basing support and intervention on a tick-box diagnosis makes no sense. We suspect a combination of tests will be necessary based on the functional needs of the person with the disability and the degree of supervision required over the person on a day to day basis.

Formal functional assessment tools such as the internationally recognised Gross Motor Skills Scales should be complemented with similar assessment tools to measure fine motor skills, social skills, daily-life functionality, intellectual and learning abilities. Decisions on eligibility - and indeed the level of support and the need for therapy and equipment - should be based on such functional assessment tools.

Assessment should encompass the circumstances of the whole family, not just the person with the disability. Factors to be considered would be the health of the family members – the parent-carers but also, most importantly, the siblings of the child with a disability - and the support mechanisms the family has in place. There needs to be provision for a family or person with a disability to notify the “authorities” if a change in these circumstances arises and procedures need to be available to respond promptly to that change, for example, a crisis respite place for the person with a disability on a temporary basis.

A regular re-assessment process needs to be put in place but we are conscious that this process should be as easy as possible and it should constitute a single “point of entry” into the range of supports and services covered by the scheme. The current requirement to complete applications forms of up to 40 pages for each service, imposes an unnecessary administrative burden on families and people with a disability. Like the proposed e-Health records, we must be able to use technology more efficiently to streamline this process. For the majority of families, the needs of their person with a disability and even their own family circumstances will not change markedly from year to year. This should be the presumption on which the re-assessment process is based.

Assessment should be standardized nationally, and transferrable from state to state. Currently, families moving interstate are technically obliged to leave their child’s wheelchair and other equipment at the state border (and somehow carry them across, we assume?). Once settled in their new state, the whole assessment process for services and equipment starts all over again. As the mother of one child with Cerebral Palsy who moved interstate said "*do they expect him to be miraculously cured once we cross the borders?*"

A formal appeal process should be available to families and people with a disability about decision made concerning eligibility and assessment outcomes.

Lastly, we consider it important that the terminology used under the scheme reflects the common understanding of those terms. We believe there is currently a mis-match, for example, in the Australian Bureau of Statistics ("ABS") definition of "severely or profoundly disabled" against what the public would expect and this results in confusion when the public hears statistics relating to this group.

The ABS definition references of a "profound or severe core activity limitation" but, because of the broad definition of that phrase, the number of people captured by the definition is significantly greater than the number who would usually be considered "severely or profoundly disabled".

3. ESSENTIAL CARE COSTS

Families with a child with a disability face costs over and above those which are normative for a family with a child who does not have a disability.

We suggest that the following supports and services need to be covered by the scheme, bearing in mind that, if our tiered eligibility proposal is accepted, the funding level/entitlement to each of these supports and services would differ:

Equipment – equipment is currently very hard to get and the waitlists are lengthy (we refer to the report of the NSW Parliamentary Legislative Council General Purpose Standing Committee No2's Inquiry into the Program of Appliances for Disabled People and similar reports in the public domain outlining the inadequacy of equipment).

The implementation of a national pool of equipment could save considerable costs by allowing for the recycling of equipment and acceptance of donations of equipment. The current approach to an equipment pool is very piecemeal.

The scheme would also need to take account of the cost of maintenance of equipment.

Therapy services – A common issue for families is the lack of availability of therapy services for their child. The waiting lists for Occupational Therapists, Physiotherapists and Speech Therapists are often extensive, however very little information is available to families about how long they will have to wait to see a therapist.

> *"I've been on a waiting list for over 5 years for Speech Therapy and Physiotherapy services for my daughter, I have no idea how much longer she will be waiting, they have provided me with no information."*

Ideally, individualised funding would be available and this would allow families greater and more timely access to affordable private therapy services.

Note that the cost of therapy and equipment alone can be in the $100,000s, just in the child's pre-school and school age years.

In desperation, many families buy private services and equipment, incurring significant costs, adding to further familial stress (and increased mortgages!)

There seems to be a particular gap for families of children with disabilities due to the peculiarities of being a child. Children grow, and per definition, this means that their needs change constantly. Equipment needs regular updating to take into account physical growth. If wheelchairs are not regularly replaced with bigger ones, scoliosis of the spine is an almost inevitable result (requiring expensive surgery in later years). The current system seems incapable of planning these predictable events adequately. In addition, as children pass into different life-phases, their needs change again. Toddles, pre-schoolers, primary school children, secondary school children, young people in the workforce, they all have particular needs, especially in the transition periods.

> *My daughter was accessing services from [a major disability service provider] since her diagnosis at the age of one. We got about an hour of speech, physio and OT, which was hardly enough. Little did I realize I should have been grateful. When she turned three, she was no longer considered an early intervention priority and placed on a waiting list. We waited nearly a whole year before services resumed, and even then they are patchy. I mean, she has a lifelong disability. Do they really think she was going to grow out of it at the age of three?*

Training – families often miss out on training considered fundamental to a respite worker. For example, respite workers are trained in handling a child that needs to be transferred by a hoist but (in NSW at least) that child's parents are not allowed to have the same therapist advise them how to do that transfer in their own home.

Respite care – For many families, having a break away from the caring role is paramount in ensuring they remain healthy and avoid burn out. A priority for many families of children with a disability is the ability to access regular, good quality respite. See the discussion of various models and areas for improvement in Appendix A.

ACD NSW is aware of a number of cases where families have asked for respite and been repeatedly denied. In the end, they feel forced to leave their children at the hospital and relinquish their parental responsibilities. Other parents have had to come to the point where they threaten to commit suicide before the Intensive Family Support System kicks in.

Home modifications - There is no streamlined home modification scheme that helps parents adapt their houses to the needs of their child with a disability. Any scheme should include the garden as well as the home so the person with the disability can experience all the benefits of the property.

> *We bought our daughters electric wheelchair (cost $17,000), we modified the inside of the house (cost around $50,000) to make it accessible. We bought another car that can carry the weelchair and ramps for it ($58,000). We then wanted to build and access ramp to the front of the house, and asked our local home modification scheme. We were rejected. We then approached the Family Assistance Scheme for a small contribution towards building the ramp. They have provided washing machines etc. so why not a bit of money toward the ramp we were building? We were told that they don't fund these kind of things – but would we like some money for a Wii game console? Thanks but no thanks! I don't need a Wii, I need my daughter to be able to drive out of her house.*

Vehicle modification scheme – Most States and Territories provide no funding whatsoever for the cost of modifying a vehicle to make it wheelchair accessible (compare the UK). Modifications start at $25,000 and it is recommended that a car of no more than 3 years of age is used to justify the expense of the modification. This further adds to the overall vehicle expenses.

Post school options programs – This is an area where the services available differ markedly between States and Territories. Programs should be offered for a min 35 hrs per wk with continued opportunity for learning. The process of transitioning from school to post school option programs needs to be managed so that it is predictable and structured and allows retention of friendship groups. Providers should be required to meet best practice standards and accreditation. This area offers good opportunities for linking with private enterprise.

Accommodation for people with a disability – this is probably the most critically undrefunded area of the current disability service system and the consequences of that are the most devastating. We have outlined in Appendix B of this Submission our estimate of the need for long term supported accommodation across Australia and, in Appendix C, we provide commentary on a range of supported accommodation models.

Casework services - There seems to be an inequity for how Casework services are provided across government run (ADHC) and government funded services and big differences from one region to another. Some families report waiting a couple of years for casework services whilst others are provided casework services within weeks for very similar issues.

There needs to be greater transparency in the information available to families, such as how long they will wait for this service and how long they will receive the service for. Some parents also raised the issue of quality of the casework service. As with care workers, some caseworkers were not of an acceptable quality.

> *"I wasn't happy with how we were treated by the Caseworker, she was patronising and talked down to us, I used to end up feeling upset and frustrated after I spoke to her."*
>
> *"The Caseworker has me answer the same questions repeatedly, it's very repetitive and I feel quite traumatised by having to re-live what have been the most painful, difficult times of my life over and over again."*

In cases where parents/carers find filling in paperwork in order to access services difficult and repetitive it may be helpful if caseworkers could assist with it.

This is an area where we envisage a national disability care and support scheme could make a huge impact. A little planning would go a long way. We hear this often:

> *"Why do I sometimes feel that I'm the first person in the world to have a child with a disability? If only someone had told me to anticipate this need, I could have planned for it and been ready. Instead, I'm now in crisis mode and desperate."*

This parent may be referring to a need that has arisen for equipment, a change in the state of their child's health or their own health, or a need arising at school. Parents are often the worst person to anticipate what is ahead, either because they don't particularly want to face the future or they simply have no knowledge of what to expect. Therapists, teachers and medical professionals are often reluctant to spell out to parents what they should expect in case they are seen to be too negative. The combination of these two facts tends to leave carers in the dark.

Access to information - Carers and people with a disability are spending too much time finding their way through the system and fighting bureaucratic processes (including submissions!) to obtain basic equipment and services. It is a sad indictment of our disability system that parent bodies like ACD NSW and ACD Vic felt the need to produce a book called "Through the Maze" for parents of children with disabilities to help them find their way in the impenetrable maze of services spread over government and Charity organisations. Parents spend countless hours filling in forms to request services and in some case spend more time on waiting lists than receiving services.

4. LINKAGES

Other services and support which ACD NSW believes a national disability care and support scheme should cover (but only to the extent that they are not provided elsewhere) are:

- mental health services

- specialised sports and recreation
- educational support
- Rehab centers
- Post school options transport
- Rural area transport needs special consideration
- transport for people with a disability to travel to and from work
- Counselling for the person with the disability and family members

The link with the pensions and other payments handled by Centrelink deserves special mention. Whilst we do not consider a change in the body administering those payments is necessary, we would like to see the current system of carer allowance and carer payment replaced with one carer wage which is tiered and takes into account the level of disability of the child - based on formalized functional assessment tools – and an assessment of the caring time.

Some parts of the current system accessed by people with a disability and their families works reasonably well currently and should remain in place, although some improvements could be made in some areas. The areas to which we refer are:

- funding and availability of medication – the health care card provides reasonable discounts for medications currently.

- the health system generally – although improvements can no doubt be made to the health system, it is not envisaged by ACD NSW that a national disability support scheme would detract from any services available to people with a disability through the current health system nor the benefits available to people with a disability and their families through holding a health care card.

- health insurance – it is currently illegal to include your child on your private health insurance once they turn 25 (and some fund have a cut of age of 21). Disabled children may not earn an independent living, and yet need regular hospitalisations.

- transport to and from school – this is managed reasonably well in NSW by the Dept of Education although problems do arise in NSW (which we understand are better dealt with in other States and Territories) when a family wishes to have their child transported on a regular basis from school to a respite cottage. In addition, many parents have reported to us substantial ongoing problems trying to organise and maintain quality transport especially if the student attends a mainstream school. Not all drivers and escorts seem to be adequately vetted before awarded the contract. In addition, there is no transport available for community participation programs (many of which finish at 3pm, when parents are at work or collecting other children from school).

- Post-school options – once children have left school, they join the queue again for every service they have previously been able to access. Some services have a “cut off” age of 16, some of 18, some depend on whether the child is in an educational setting.

5. MODELS OF DELIVERY AND CHOICE

A national disability care and support scheme should provide the opportunity for people with a disability and their family/carers to manage their own funding. Self-directed funding offers the person with a disability far more choice and control within their own lives. Individual funding is more empowering for the individual than the current service system where the person with a disability is viewed as a passive care recipient.

Many families of children with disabilities would welcome the availability of self-directed funding, this would allow them to target funding to the areas of most need for their child.

A logical progression would be to provide flexible respite packages in the form of self-directed funding, some parents are frustrated with how their packages are managed by their brokerage service and allowing these families the option of co-ordinating this service themselves would be a positive development.

> *“I have enormous difficulty contacting the brokerage service that manages my flexible respite package yet I’m not allowed to phone the agency and book respite directly with them. How much easier life would be if I was! The brokerage service sometimes forgets to make the booking and I’m sitting at home waiting for a carer to turn up who doesn’t turn up who hasn’t even been booked.”*

There is a worldwide movement towards more individualised (or demand-led service) for people with a disability.

ACD NSW emphasizes however that self-directed funding should be but one choice amongst a range of service delivery models.

When a family first receives new that their child has a disability, many parents go through a stage of denial. Even where the parents initiated the search for an answer to the question why something is “not quite right” with their child, most parents hold out some hope that early intervention or a (new) medical cure will heal their child. For many parents, this is the first time they come into contact with the “disability world” and they are totally disoriented and lost. Most have no idea which services they should be requesting (as they do not know which services exist) let alone where to get them from. In moments like these, having a large service provider take on a family is a godsend.

Yet as families travel the disability road, many gain competence and would like to return to a position where they manage their child's needs. Often service providers do not supply the (level of) service parents may request, or are opposed to certain approaches the family would like to make (such as certain therapies the service provider does not like). The family may prefer to "buy" its services on the open market. Parents may find they have a better sense of timing when new equipment may be needed and do not need specialist therapeutical input (for example, when a footplate on a wheelchair is broken there is really no need to wait many months to see an OT to confirm the footplate is broken and then place an order for a replacement). In situations like this we believe it would be highly beneficial for the family to have access to an individualized funding package. However, five years down the track, the family may be falling apart, and it may decide to return to a service provider to take over management of the child's disability until the family has regrouped. As the child grows into an adult, self-directed funding should then be an option again.

ACD NSW strongly believes a national disability care and support scheme should offer families the flexibility to freely move between a model of service provision and self-directed funding. Children grow, families change, and needs need to be adapted. We believe only a flexible approach can adequately meet the needs of families with children with a disability.

6. BENEFITS OF A SCHEME

There are social and economic benefits that would flow from the introduction of a national disability care and support scheme, as follows:

- The charity model (our current system) is highly demotivating, humiliating and denigrating. It creates dependence and portrays people with disabilities as passive and incapable of contributing to wider society.

  As a consequence, general society sees people with disabilities as incapable, even useless. This is a self-fulfilling prophesy where people are written off as useless, thus justifying the low investment rate in the potential capabilities of people with disabilities, and thereby guaranteeing that people with disabilities do indeed not fulfill their potential and will continue to rely on charity. This gives society an excuse to continuously ignore people with disabilities.

- People with a disability and carers of children with disabilities could be participate more fully in the paid workforce or voluntary sector if proper supports were in place. The vast majority of carers are women, and the majority have given up work after their children were diagnosed.

- Paid work will confer superannuation entitlements on carers and people with a disability, thus assisting their financial independence into the future.

- Supporting people with a disability and carers to remain in the workforce will boost their self-esteem, encourage social interaction and mimimise skills shortages in the workplace.

- Some studies have pointed to a strong link between mental illness and caring for a child with a disability. The incidence of mental illness and other health-related issues (drug and alcohol abuse) for carers as well as siblings would reduce if proper supports were in place for people with a disability.

- Recent studies have shown that a more accessible support system is fundamental to strengthening families who have a child with a disability. See, for example, p15 of the Report on Family Resilience, released June 2008 by the Social Policy Research Centre, UNSW Disability Studies and Research Institute June 2008, which states:

  "Learning about and getting access to appropriate services is an important step in families being able to adjust to having a child with disability (the first stage of the resilience process). Most families felt ill-informed about services and supports available to them. Other carers or parents of children with disability were a primary source of information for many families. There was widespread frustration among the families that this information was not provided at the time of the assessment." *(Ref:http://www.sprc.unsw.edu.au/reports/Family_resilience_final_report.pdf)*

- ACD NSW believes that our current disability system is in violation of the United Nations Convention on the Rights of Persons with Disabilities if not in letter, then certainly in spirit. We believe a National Disability Insurance Scheme will go a long way in addressing this. Our children are our future – including disabled ones!

APPENDIX A – Respite Solutions

CURRENT MODELS OF RESPITE

1. Own home respite

1.1 Benefits:

- Minimum dislocation for the person with a disability
- Ready access to necessary equipment, food and medications.
- Ability to obtain assistance in short bursts in high stress periods of the day.

> *"Homecare services work really well for me in the morning to help get my daughter off to school. Where else could I find someone to help me for just 45 minutes at 7 in the morning?"*

1.2 Drawbacks:

- No "change of scene" for the person with a disability.
- Minimal social inclusion for the person with a disability.
- Some service providers require a person over 18 to be in the house at the same time as the paid carer. This often means that the paid carer never takes responsibility for initiating activities with the person with the disability; the paid carer waits for direction from the unpaid carer. It is also hard for the unpaid carer to relax if the paid carer and the person with a disability are in close proximity.
- Even where service providers agree to care for a person with a disability without another adult in the house, some service providers will not care for siblings of a child with a disability whilst they are in the home. This means that parents need to organise and pay for a separate carer for the other children or arrange to have them looked after outside their own home.
- Some service providers will not take the person with a disability outside the house while they are on duty. Presumably this is a risk minimisation issue but it severely curtails the value of the respite.
- Lack of privacy for the family of the person with the disability.
- Sense by family that home is a "revolving door" for paid carers, particularly where there is no consistency of carers.

- Obligation on unpaid carer to train paid carer "on site", often whilst the unpaid carer is paying for the service, at least in part.

1.3 Proposal for Improvement

- Paid carers be given the support and training required to care for a person with a disability without the presence of an adult.
- Paid carers be authorised to take the person with a disability on limited activities outside the home, subject to an Occupational Health and Safety check if necessary.
- Paid carers be authorised, at least at night, to care for siblings of a person with a disability in the family home provided that proper notice is given to the paid carer together with any additional information about the other children.

2. Centre-based respite (Day Programs)

2.1 Benefits:

- Gives unpaid carer and rest of family a real break from the person with a disability.
- Overcomes many of the drawbacks raised in relation to Own Home Respite (eg privacy, self-initiation by the paid carer, on-site training)

2.2 Drawbacks:

- The number of integrated settings willing to take a child with a disability is very limited and finding information about those which will take your child is difficult.

> *"Currently Councils appear to the sole repository of knowledge in this area but my experience with 2 different Councils over recent years indicates that they are able to offer very little assistance and the parent is really entirely on their own. I rang one after the other and was turned away again and again. It is demoralising after a while."*

- Service providers rarely have a pick-up or drop-off service so respite time is lost in travelling.

> *"I usually have to drive at least 20 mins each way to access a day program for my child."*

- Centres are often not set up with the equipment needed by the child through the day, especially in integrated vacation care centres.

> *“ As my daughter grew, she was refused access to the vacation care centre she had been attending in St Ives because the Public School where the holiday programs were run did not have the equipment needed to change her through the day (my daughter is incontinent).”*

- Even in Centres exclusively servicing children with a disability, equipment is often limited.

> *“In the Vacation Care Day Program run at Clark Road school in Hornsby, my child is not allowed to roll around on the floor through the day because the staff do not have the equipment to lift her back into her wheelchair and there is a “no lift” policy in place. This means that she is confined to her wheelchair all day.”*
>
> *“I turned up to Birrahlee one day when they were doing renovations and found that my child was unable to access the Centre at all because he is confined to a wheelchair.”*

- As far as ACD NSW is aware, there are no After-School Vacation Care Centres exclusively for children with a disability of any age. This severely restricts the ability of parents of a child with a disability to work. Bearing in mind that 87% of marriages end in divorce for parents with a child with a disability, it is tantamount to discrimination for single parents of a child with a disability to face this obstacle.

2.3 Proposals for improvement:

- Improve information available to families about availability of integrated settings willing to take a child with a disability.
- Establishment of vacation care programs and after-school care programs exclusively for children with a disability who are 12 years and over. ACDNSW believes this is being instigated on a limited basis next year in some areas and commends this approach.
- Investigate viability of a pick-up and drop-off service, even if the parents need to pay a surcharge for this service.
- Instigate individualised funding so that parents may choose which Centre is most appropriate for their child.
- Impose a duty on Centres to assist parents in transitioning from one service to another by providing to them sufficient notice of the pending ineligibility for the service and providing information about available alternates in the area.

3. Centre-based respite (Overnight)

3.1 Benefits:

- Gives unpaid carer and rest of family a real break from the person with a disability.
- Overcomes many of the drawbacks raised in relation to Own Home Respite (eg privacy, self-initiation by the paid carer, on-site training)

3.2 Drawbacks:

Access to overnight respite through the week is often limited by the fact that the transport used to get a child from home to school, and vice versa, cannot be used whilst the child is at the Respite Centre.

3.3 Proposals for improvement:

- negotiate with Special Transport in the NSW Education Department for transport to and from overnight Respite Centres.
- Alternatively, permit a child to be transported by a taxi if requested in writing by a parent.

4 Community Based Respite

4.1 **Benefits:**

- Broadens range of experiences for the person with a disability.
- Provides access to activities that it may be impossible or very difficult for the family to undertake together, eg Sailability or swimming.
- Gives unpaid carer and rest of family a real break from the person with a disability.
- Overcomes many of the other drawbacks raised in relation to Own Home Respite (eg privacy, self-initiation by the paid carer, on-site training).

4.2 Drawbacks

- Some Vacation Care Centres exclude people in a wheelchair from community based activities because they do not have access to the transport necessary to get them there and back.
- Even where Centres have access to a wheelchair accessible bus, there are no bolts in the floor of the bus to secure the wheelchair. An unsecured wheelchair on a bus is a safety hazard to the person in the wheelchair but perhaps even more so to the other passengers on the bus.
- Some vacation care centres exclude people who are incontinent from community based activities because they are unable to change the person when out and about.

- Some vacation care centres exclude people who require peg-feeding from community based activities.

4.3 Proposals for improvement

- Educate paid carers on methods for managing incontinence and special feeding requirements whilst out and about.

> *"I have to manage to change my child when I'm out shopping so surely they can do it too when there are more people to help."*

- Encourage the introduction of minimum standards in shopping centres and other public places for change room facilities suitable for people with a disability.
- Encourage the introduction of minimum "tie-down" standards for wheelchairs when travelling on trains and buses.

5. General issues:

5.1 Quality of paid carers

In an ideal world, all carers would have a passion for their job and, indeed, for the most part, care workers are committed and caring. However, all service providers that ACD NSW has spoken to advise that there is currently a huge shortage of care workers which means that families are sometimes required to accept care workers who are not of an acceptable quality, simply because no one else is available.

> *"This morning my HomeCare worker turned up a ½ hour late for a ¾ hour shift. Yesterday, the HomeCare worker (a different one) who was booked to help feed and bathe my daughter at 5:30pm called me that morning to see if she could change the shift to 3pm. I told her not to bother coming."*

> *"Last time I left my son in weekend respite, the care workers forgot to give him his lunch-time epilepsy medications. I called to complain but no-one ever called me back."*

The shortage of carers was confirmed by the keynote speaker at the Carers NSW Conference on Thursday June 11 2009, the Hon John Waltkins, CEO of Alzheimer's Australia, who referred to a recent report which Alzheimer's Australia has commissioned addressing this issue specifically for people with dementia. The report is entitled "Making Choices. Future dementia care: projections, problems and preferences" and has been prepared by Access Economics Pty Limited. It is available at http://www.alzheimers.org.au/content.cfm?topicid=348.

5.2 Consistency of paid carers

Given the shortage of care workers, turnover is high and families face a “revolving door” of different paid carers. This is detrimental to the child; nor does it allow for the paid carers to ever build a rapport with the child or a sense that the paid carer is contributing to the child’s development in the long term.

5.3 Respite whilst away from home on holidays

The only respite funding available to families travelling interstate is the Commonwealth Carer Emergency Respite funding and this is limited per block of holidays, irrespective of how frequently or how little the family has accessed that funding throughout the rest of the year.

> *“I have paid up to $30 per hour in other States to get assistance from paid carers whilst on holidays outside NSW. Holidays are a really stressful time for us as a family. I have frequently returned from a holiday in tears and more exhausted than before I left because of the difficulty in finding help when we’re away. I can see why many families of a child with a disability choose for one parent holiday separately from the other parent!”*

HomeCare funding is portable within NSW, but most other providers of respite cannot provide assistance outside their region, even within NSW.

> *“I recently used my weekly allocation of HomeCare funding successfully whilst on holidays on the Central Coast, without too much difficulty. It made a huge difference and the carers were lovely.”*

Proposals for improvement:

- national funding.
- individualised funding.

5.4 Specialised In-Centre Respite

There is very little available for children who access a medical model of respite and, even if a facility is available, access to community participation and social activities outside of the facility is restricted. Focus should be given to respite for children who require this specialized service. Also, the administration involved in using these facilities should be made easier for families by extending out the requirement to provide new medical forms (with a GP signature) from every 2 months (as it is currently) to, say, 6-monthly, unless there is a change in the medications.

5.5 Monitoring

ACDNSW is not aware of any monitoring of respite facilities to ensure they operate in accordance with the Disability Standards. We suggest this is considered for quality assurance purposes.

Alternate Respite Models

6.1 Live-in Carer Model

The concept of a "carer's visa" for people with a disability has been proposed at the Federal Government level to ease the crisis in respite for people with a disability and to address the shortage of care workers in this country. It is a solution that COSTS NOTHING to implement and it would in fact save the State and Federal Governments money overall.

In brief, it is proposed at the Federal level that unskilled workers from Asian countries would be allowed into Australia if they were to live-in with a family and provide care to a frail aged person or a person with a disability. This follows a model adopted in Canada; see www.ci.gc.ca/english/pub/caregiver for more details. Regrettably, the response from the Federal Government is that immigration laws are unlikely to implement such a visa in the short term given the current economic downturn.

The benefits of live-in help over all of the forms of respite discussed above are numerous, namely:

- Flexibility in hours
- Consistency of worker, allowing for knowledge retention and reduced training burden
- Provides care for more than one child at no additional fee
- Care available even when child is ill
- Assistance can be provided with other domestic duties like cleaning and cooking while the child is resting
- Utilises the equipment already in the home.

We understand that the main concerns with this Proposal are that:

(a) Australia should not develop a 2 tier work system;
(b) Australia must protect the jobs of existing workers;
(c) The workers may be subjected to poor conditions; and
(d) Families may try to take advantage of the immigration provisions to bring in cheap cleaners or butlers.

We address each of these concerns in turn:

(a) Need to avoid 2 tier work system

This issue can be addressed by ensuring that the carers are paid a wage commensurate with what an Australian would receive. Whilst a family may not be able to afford to do this strictly in cash terms, some families could do so if recognition in financial terms was given for the bed and board provided by the family. Furthermore, if individualized funding packages were to be made available to families, it would be possible for a family to utilise that funding to cover all or some of the cost of the worker.

Our research indicates that a childcare worker in a Centre is paid approx $40,000pa for a 38 hour week. Bed and board can be valued anywhere between $150 per week to $250 per week (Home Stay families are paid $250 per week to house foreign students). Taking the mid-range figure of $200 per week as a "credit" against wages, this leaves a cash payment of $569 per week in wages if 38 hours of work are required. This equates to approximately $15 per hour in cash terms (remembering that the bed and board is part of the worker's remuneration so the worker is not being exploited). A family's entitlement to Government assistance with these costs would depend on the care needs of the person with a disability but, clearly, the funding dollar will stretch further at $15 per hour compared to the rates currently paid to care workers. The financial benefits are even more obvious if that rate is compared to the rates paid to agency staff, and if you take into account the savings on administration costs incurred by the array of service providers upon which just one family may rely.

By way of comparison, and assurance as to the fairness of the proposed system for the overseas worker, au pairs are paid about $150 per week plus bed and board for approx 20 hours of work (see http://www.peopleforpeople.com.au/html/faq.html). The drawbacks of au pairs compared to the model proposed above are that au pairs can only stay with one family for 3 months (although that is often stretched to 6) and they are generally here to party and have limited commitment to their work.

(b) Protecting the jobs of Australians

This brings us to the second possible hurdle – will foreign care workers take the jobs of Australians?

As discussed above, it is very difficult to attract and retain good workers to care for people with a disability. Furthermore, Australian workers are rarely interested in live-in positions given that so many young workers remain living at home with their own families so long nowadays.

The shortage of care workers is predicted to increase dramatically over the next 20 years. The Access Economics report referred to at 5.1 above predicts that, just for people with Alzheimers, in the absence of any policy or other change, there will be a shortage of a further 150,000 FTE paid and unpaid carers in Australia by 2029. This is in addition to the shortages that currently exist.

(c) Conditions of the workers

This issue would require some monitoring but it is not an issue peculiar to this proposal. The issue has already been addressed with respect to 457 visas at a national level. Furthermore, research could be conducted on the Canadian carer's visa referred to above to see how this issue has been combated.

(d) Misuse of the visa by Australian families

It would be easy to identify the need of the families who choose to exercise this option simply by relying on whether a family member residing in the home is eligible for a Health Card. Interestingly, in Singapore, families are allowed a second foreign worker if they have a child who is 5 years or younger, even where the child does not have a disability.

6.2 Family Camps

As mentioned above, holiday times can be a very stressful period for families. It would be helpful to families with a child with a disability to offer a 2 or 3 day camp in the school holidays for one parent (possibly 2) plus all the children in the family. The camp would provide a cabin for each family unit and the parent would be responsible for caring for his or her children at night but, through the day, the children (those with a disability and those without) would be cared for and entertained by paid or volunteer carers. The benefits of this would be:

- allowing parents to network without the responsibility of caring for their children;
- allowing interaction between siblings of children with a disability in an environment that is fun and not forced;
- social inclusion for the children with a disability.

Meals would be prepared for the attendees, or perhaps a roster arrangement could be set up so everyone contributed their time, but this would need to be co-ordinated by the organisers. The facilities would need to be chosen carefully to ensure all necessary equipment was available.

6.3 Rebate for personal engagement of paid care worker

For a variety of reasons, many families prefer to engage their own care worker in their own home. It is recommended that tax assistance or a rebate of some other kind be made available to those families to assist them with the costs involved in that approach.

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

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[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.

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[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].

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[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.