

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY  
THE DEPARTMENT OF AGEING, DISABILITY AND  
HOME CARE**

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Partially Confidential

## Submission to ADHC inquiry

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.

In this submission we will attempt to cover some of the issues currently affecting families of children with a disability in NSW, we have included relevant quotes from some of our members.

### RESPITE

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. The availability of a number of different options is important so that families can access the model/s of respite that best suit their needs and the needs of their child. We have outlined some of the issues below:

- Many families claim that there is just not enough respite available and of the respite models that are available they are not flexible enough to allow the family to tailor the service to meet their child's individual needs. Some services are very structured according to the time the respite can be provided, some services do not allow the parent/carer to choose the staff member or agency they prefer and some services are very strict around whether or not the care worker can take the child out into the community or on a social activity.

*"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?"*

- 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.
- There is a sense by some families that their home is a “revolving door” for paid carers, particularly where there is no consistency of carers. There seems to be a difficulty in providing carers of a consistent standard or quality and often families are sent a new carer that they have never met, this is especially problematic if their child has complex medical needs. The parent often has to spend a lot of the time explaining the needs of their child, this can be exhausting in itself, particularly if you are provided with a new carer each time you book respite.
- A common difficulty is finding respite away from the home that provides carers with a proper break away from the caring role and also provides a ‘change of scene’ for the person with a disability. Families would like to see greater availability of respite that doubles up as an activity (social inclusion) for the person with a disability as well as an increased availability of centre-based respite.

*“There simply isn’t enough centre-based respite available for my two boys who have a severe disability and access a medical model respite centre.”*

- 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 very restricted. Focus should be given to respite for children who require this specialised 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. The child’s social needs need to be recognized as important within medical model respite and every attempt should be made for the child to access the community. Medical model respite should be expected to adhere to the Disability Standards in the same way that non-medical respite is.

*“I feel terribly guilty sending my children to their medical model respite unit because they really don’t like going, there is no community access available like there is for other centre-based respite and my children love going out and accessing the community. I feel guilty the whole time they are there, it’s not much of a break.”*

- 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. This could be remedied if ADHC negotiated with Special Transport in the NSW Education Department for transport to and from overnight Respite Centres.

### **Monitoring of Respite**

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. We also suggest that ADHC investigate whether there is scope for including the monitoring of respite units within the scope of responsibilities of the Community Visitor.

There is a need for more transparency in terms of the police checking procedures within the Homecare service, ACD NSW suggest that as standard procedure families are informed if staff have not undergone police checking, this would enable the family to make an informed decision as to whether or not they use carers that have not undergone the police check. This is of particular importance in the case of vulnerable children.

*"I had used Homecare for a couple of years when I was informed by someone that not all workers were police checked, that those who were employed prior to the introduction of police checking in 2004 were not compelled to undergo a check. I was shocked. Why had no-one ever told me?"*

### **Before and After School Care and Vacation Care**

The difficulty in accessing After-School and Vacation Care makes employment very difficult for parents of children with disabilities this often means that families of children with a disability become a single-income family by default. And 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. We have outlined some of the issues below:

- As far as ACD NSW is aware, there are no After-School Vacation Care Centres exclusively for children with a disability of any age. The number of integrated settings willing to take a child with a disability is very limited and finding information about those that will take your child is difficult to find.

*"Currently Councils appear to be 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 and some families do not own a vehicle.

*"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 \_\_\_\_\_ 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 \_\_\_\_\_ 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 \_\_\_\_\_ 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 ACD NSW is aware, there are no integrated settings available at all for children over 12 years of age to mix with children of their own age because children without a disability who are over 12 do not need such a service. Theoretically, a parent could choose to send a child with a disability who is over 12 years to an integrated Vacation Care Centre or After School Centre but, even if the transport and equipment issues identified above could be overcome in an integrated setting, the suitability of that setting for the child would be questionable. If the child is the same size physically as a normal child of that age, they will soon look (and perhaps feel) out of place amongst the other children. This is ironic since Inclusion Support Funding is accessible until the child with a disability is 16 years of age. In effect, that funding is redundant for children over 12 years of age.

*"I live walking distance to \_\_\_\_\_ which, several years ago, was running a week-long holiday program in January. Being a Special Needs School, it had all the play equipment as well as personal care equipment necessary for my child. The ratio of children to paid carers was 5:1, which was too high for my daughter due to her high support needs, but I was told that I could access the Centre if I sent a carer along specifically for my daughter. I had SUPPS funding approved for my daughter to cover the costs of employing an additional carer but it couldn't be used at the \_\_\_\_\_ school because the service they offered was*

*not an integrated service. In other words, I had funding for an extra carer but no appropriate service at which it could be used."*

- There needs to be improved access to the information available to families about the availability of integrated settings willing to take a child with a disability.
- Inclusion Support Funding for children 12 years and over should be redirected to Centres providing vacation care exclusively to special needs children.
- 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.
- 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.
- 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.
- Paid carers need to be educated 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."*

- Liaise with other relevant NSW Departments to encourage the introduction of minimum standards in shopping centres and other public places for change room facilities suitable for people with a disability.
- Liaise with NSW Department of Transport to encourage the introduction of minimum "tie-down" standards for wheelchairs when travelling on trains and buses.

## Recreation services

Some recreation services for children with disabilities exclude children with more severe disabilities and/or children who use a wheelchair as they do not have high enough staffing levels or the ability to transport kids in wheelchairs.

*"I inquired about the . . . and was told my son was not able to use this service as he uses a wheelchair and transportation would be difficult. It's really hard to find recreational activities for a child with mobility difficulties."*

## 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 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.

A common problem raised by families is that of care workers who do not put the needs of the child and their family first.

*"I explained the importance of not smoking around my two children who have Chronic Lung Disease and Asthma but the care workers ignored my wishes and the welfare of my children and smoked anyway."*

In addition to this there seems to be no state-wide standard for training and education for care workers, all disability services need to provide their staff with good quality training programs that educate the staff on the importance of anti-oppressive practice and supporting individual needs.

*"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."*

- 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.

## **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."*

- Instigating individualised funding would enable families to use services when they are away on holidays and make a holiday feel more like a holiday.

**In conclusion on respite**, ACDNSW put forward a variety of solutions to the problems identified above in a paper prepared recently. A copy of that submission is included herewith as Appendix A.

## **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."*

There is a need for ADHC to improve the transparency of this process by providing families with more information about how long their child will need to wait for services. This gives families the information needed to make informed choices about whether they will seek services elsewhere.

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



## 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.

Again 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.

## SELF-DIRECTED FUNDING

ACD NSW want the state government to 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."*

## **LONG TERM ACCOMMODATION**

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"<sup>1</sup>. 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.**

Responsibility for funding long term supported accommodation for people with disabilities rests jointly with the States, Territories and Federal Governments.

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

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<sup>1</sup> Refer ADHC requirements in NSW.

December 2009. That Report states that out-of-home long term supported accommodation is provided to 18,476 people in Australia.<sup>2</sup> 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
<b>TOTAL</b>	<b>18,476</b>

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<sup>3</sup>. 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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<sup>2</sup> 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.

<sup>3</sup> 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<sup>4</sup>. 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%<sup>5</sup>. 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<sup>6</sup>.
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<sup>7</sup>.

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<sup>4</sup> Refer paper delivered by Professor Jan Tøssebro at 23 March 2006 Roundtable on Supported Accommodation

<sup>5</sup> Refer paper delivered by Professor Jan Tøssebro and paper delivered by Roger Stancliffe at 23 March Roundtable on Supported Accommodation

<sup>6</sup> 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.

<sup>7</sup> Refer paper delivered by Professor Jan Tøssebro at 23 March Roundtable on Supported Accommodation

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 a National Disability Insurance 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 to the detriment of my family, especially my other son 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 wondering 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 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, 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. 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

We have plenty more of these stories if you need them unfortunately.

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Approved by ACD NSW Executive Committee

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6 August 2010

## **APPENDIX A**

# **RESPONSE TO DADHC DIRECTIONS PAPER ON NEW DIRECTIONS FOR DISABILITY RESPITE SERVICES IN NSW**

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 500 families around 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.

In responding to DADHC's Discussion Paper, ACDNSW elected to step through a variety of current respite models and provide submissions with respect to each as to how the service could be improved, and then propose new models for consideration by DADHC. To support our proposals we have provided relevant quotes from parents from time to time.

### **CURRENT MODELS**

#### **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.
- As a matter of courtesy, the unpaid carer is required to interact with the paid carer and take some responsibility for their welfare by, for example, offering a cup of tea. There are times that unpaid carers do not even have the energy to socialise with their friends, let alone making small talk with a relative stranger who is in their home to help.

## **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.
- Respite fees are waived for the first 2 hours each time a new paid carer is introduced to the family home.

## **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 be 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 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 \_\_\_\_\_ school in \_\_\_\_\_, 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 \_\_\_\_\_ 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 ACDNSW 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.
- As far as ACDNSW is aware, there are no integrated settings available at all for children over 12 years of age to mix with children of their own age because children without a disability who are over 12 do not need such a service. Theoretically, a parent could choose to send a child with a disability who is over 12 years to an integrated Vacation Care Centre or After School Centre but, even if the transport and equipment issues identified above could be overcome in an integrated setting, the suitability of that setting for the child would be questionable. If the child is the same size physically as a normal child of that age, they will soon look (and perhaps feel) out of place amongst the other children. This is ironic since Inclusion Support Funding is accessible until the child with a disability is 16 years of age. In effect, that funding is redundant for children over 12 years of age.

*"I live walking distance to \_\_\_\_\_ school which, several years ago, was running a week-long holiday program in January. Being a Special Needs School, it had all the play equipment as well as personal care equipment necessary for my child. The ratio of children to paid carers was 5:1, which was too high for my daughter due to her high support needs, but I was told that I could access the Centre if I sent a carer along specifically for my daughter. I had SUPPS funding approved for my daughter to cover the costs of employing an additional carer but it couldn't be used at the \_\_\_\_\_ school because the service they offered was not an integrated service. In other words, I had funding for an extra carer but no appropriate service at which it could be used."*

### **2.3 Proposals for improvement:**

- Improve information available to families about availability of integrated settings willing to take a child with a disability.

- Inclusion Support Funding for children 12 years and over should be redirected to Centres providing vacation care exclusively to special needs children.
- 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:**

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

## **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."*

- Liaise with other relevant NSW Departments to encourage the introduction of minimum standards in shopping centres and other public places for change room facilities suitable for people with a disability.
- Liaise with NSW Department of Transport to 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, DADHC care workers are committed and caring. However, all service providers that ACDNSW 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:**

- Implement "debit/credit" arrangements with other States (and between service providers within NSW) so funding is portable for families.
- Instigate 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](http://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.

Recognising that the NSW Government cannot change the Commonwealth immigration system, ACDNSW's proposal is that DADHC work within the limits of the existing Federal system by assisting families attract live-in workers to Australia by sponsoring overseas citizens who have, or are able to gain, a skilled occupation on the Federal Government's Skilled Occupations List. State sponsorship confers an additional 10 points on a person applying for permanent residency, thus making it easier for the person to satisfy the otherwise relatively strict criteria.

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 may be 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 DADHC 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.

**CONCLUSION**

ACDNSW values the opportunity to respond to the DADHC Discussion Paper and would be happy to discuss any aspect of the above at any time.

Contact details: