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**SUPPORTED ACCOMMODATION
FOR ALL WHO NEED IT
A REALITY; NOT A DREAM**

A Discussion Paper

MAY 2006

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SUPPORTED ACCOMODATION FOR ALL WHO NEED IT A REALITY; NOT A DREAM

Why this Discussion Paper?

In January 2006 Minister Della Bosca released a final version of The Accommodation & Support Paper¹. The Paper was the result of a long process of consultative sessions, of input from working parties and consumers on draft models of supported accommodation and the result of a process of Roundtable Discussions with prominent stakeholders in the disability sector.

The Association for Children with a Disability NSW (“ACD NSW”) stayed close to the consultation process and prepared its own Submission to the Government in April 2005 advocating a range of options in supported accommodation for people with disabilities.²

ACD NSW has considered the Government’s Final Paper in detail. Its representatives attended a further Roundtable Discussion on the topic on 23 March at which the NSW Government’s approach was compared to the situations now existing in Norway, Sweden and the United States.

ACD NSW’s interpretation of the Final Paper is that the Government is moving further and further away from the concept of providing out-of-home supported accommodation for people with disabilities who require such care. They intend to rely on families to provide in-home care for their children for as long as those families are physically able to do so. The Government justifies this approach on the basis that it is too costly to do otherwise given the number of people in NSW to whom it has to provide disability services.

Our Vision

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

Our assessment is that this is financially achievable if the State Government, Federal Government and families work together to contribute to this vision.

¹ Now available on DADHC’s website, www.dadhc.nsw.gov.au.

² Contact ACD NSW for a copy of that Submission.

Who is ACD NSW?

ACD NSW is a non-profit organisation run by parents of children with a disability seeking to help other parents. The group's aims in general are:

- to provide support and information for all parents, carers and families of children with any type of disability; and
- to raise awareness of the issues facing parents, carers and families of children with a disability and to advocate for improved services.

Our Goal

In preparing this Discussion Paper, ACD NSW's goals were:

- to steer the NSW Government towards placing greater emphasis on out-of-home long term supported accommodation for people with a disability, thus allowing for greater choice for families and real options;
- to focus the Commonwealth Government's attention on the inadequacy of services & funding in this area;
- to generate discussion between parents the extent to which they should be required to assist financially with the long term care of their child if they choose out-of home care;
- to encourage Government and private enterprise to develop viable options for out-of-home long term accommodation for people with disability; and
- to raise public awareness of the inadequacy of services & funding in this area.

The NSW Government's Accommodation & Support Paper

First, we commend the Government on its acknowledgement that "one size does not fit all". The Government has recognized that families look for a choice of accommodation models and, whilst the group home model is likely to remain the dominant form of supported accommodation, it seems well accepted now that a range of options will be considered³ (such as the cluster and campus college models that the ACD NSW proposed in its Submission to the Government in April 2005).

Overriding reliance on Families

The overriding concern we have with the Paper is the emphasis placed on maintaining people with a disability in the family home, irrespective of whether or not that is the family's preference. Whilst we commend the Government for agreeing to provide additional support to those families who choose to care for their child at home, we are fearful that the Government is using the "stay-at-home" option as a substitute for providing additional supported accommodation places and, therefore, removing any real

³ On page 6 of the Paper the Government states "In 2005, there is a recognition that group homes work for some, but not for all, that large residences may offer greater freedom to some and that assisting people to remain at home is vitally important".

choice families may have. This is certainly the message that came through from the DADHC representative, Alex Goodwin, in her presentation at the Roundtable on Supported Accommodation held on 23 March.

Page 11 of the Paper states that one of the key focuses of the new disability system is to assist people with a disability to stay at home. Page 13 states that out of home support will be available only “when care cannot practically or cost effectively assist people to remain at home”.

The Paper highlights the high cost of accommodating people with a disability outside the home and points out that, based on currently funding, this creates a huge imbalance in the sharing of funds amongst people with a disability⁴.

All of the above points to a Government solution which is to keep people with a disability in the family home as long as possible.

ACD NSW supports the fact that families may choose to care for their child in their family home for as long as they wish. ACD NSW applauds the extent to which the Paper recognizes that those families require additional support to do this.

However, it is critical that families have a choice between in-home care and out-of-home care once their child becomes an adult.

Many 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 if those siblings have left home.

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 resident⁵.

Why should Australia not provide the same?

The NSW Government would have us believe that such a solution is unsustainable due to costs. ACD NSW believes that the Government is inflating the cost assessment to support its conclusion that families should care for their children as long as possible in the family home.

⁴ Refer page 3 of the Paper.

⁵ Refer paper delivered by Professor Jan Tøssebro at 23 March Roundtable on Supported Accommodation

The Government Paper states that there are over 200,000 people in NSW with a severe or profound disability and that currently only 3% of those people (5,000 people) are housed in supported accommodation outside the home. This costs the NSW Government approx \$500,000M p.a. (approx \$100,000 per person per year), which is almost half the current budget for disability services.

Clearly, on its face, this statement paints a picture of despair and total lack of equity for those not currently in supported accommodation. As a result, the Paper concludes:

“This is simply unsustainable for the thousands of families providing care with little or no assistance. As is the case with all government services, resources for disability services are not unlimited and we must ensure resources are allocated in an optimal way.”⁶

But let us look at the reality.

The figure of 200,000 which DADHC relies on has been obtained from the Australian Bureau of Statistics (“ABS”) but, when you examine the ABS definition of “a person who is severely or profoundly disabled”, you see that the number of people captured by the definition is significantly greater than the number who would usually be considered “severely or profoundly disabled”⁷. The ABS definition is as follows:

“Severe” means a person who sometimes needs assistance to perform a core activity;
 “Profound” means a person who is unable to perform one of the core activities listed below independently.

A “core activity” is:

Self care - bathing or showering, dressing, eating, using the toilet and managing incontinence.

Mobility - moving around at home and away from home, getting into or out of a bed or chair; and using public transport.

Communication - understanding and being understood by others: strangers, family and friends.

Hence, a person who is unable to use public transport independently would, on the ABS definitions set out above, be considered “profoundly disabled”. I suspect, however, that that person would not require 24 hour care in supported accommodation outside the home! That person is unlikely to be a candidate for long term supported accommodation.

What is needed is a real understanding of the actual number of people currently in need of such care. Is it 200,000 as DADHC asserts or does that figure misrepresent the actual reality?

⁶ Again refer page 3 of the Paper.

⁷ Compare for example the definition used by the American Association on Mental Retardation as outlined at www.setonhill.edu/academics/IDEA/severe_&_profound.htm or the definition of “profoundly disabled” in section 197(2) of the Commonwealth Social Security Act - both definitions are set out in the Appendix.

The Real Numbers

For the following reasons, ACD NSW assert that the actual reality of the need for long term supported accommodation amongst people with a disability in NSW is far closer to 20,000 than it is to 200,000:

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%⁸. 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 NSW, 0.3% of the population is 20,000 people⁹.
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 lists¹⁰.
3. A Report issued by the Australian Institute of Health and Welfare (AIHW) in 2002 entitled “*Unmet need for disability services: effectiveness for funding and remaining shortfalls*”¹¹ comments that the numbers of people identified in ABS statistics can vary markedly from one year to the other. Having examined the methodology used by the ABS, the Report states that the variation arises not due to a change in the prevalence of the disability but rather due to “changes in the design and methods” of the ABS surveys¹².

Using the figure of 20,000 as the correct representation of the number of people with a disability in NSW in need of long term supported accommodation, it is now feasible to envisage a State which has minimal-to-no waiting lists for supported accommodation for young adults with a disability as they come through the system!

The number of 200,000 used by DADHC and the Minister is unrealistic and paints a very distorted picture. It presents a problem which seems insurmountable – in DADHC’s words, “unsustainable”. The reality is that, although the objective of providing supported accommodation for all adults in NSW seeking that option is not cheap, it is certainly within the realm of possibility and is a realistic target to be obtained.

⁸ Refer paper delivered by Professor Jan Tøssebro and paper delivered by Roger Stancliffe at 23 March Roundtable on Supported Accommodation

⁹ Based on ABS data of NSW population at 6.7 million in 2004

¹⁰ Refer paper delivered by Professor Jan Tøssebro at 23 March Roundtable on Supported Accommodation

¹¹ Available for viewing at <http://www.aihw.gov.au/publications/index.cfm/title/7741>

¹² Page 137 of the AIHW Report.

The Real Costs

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 NSW seeking that option would be \$2 billion. That is \$1.5 billion more than the NSW Government currently spends on supported accommodation per annum.

Certainly, this is not an insignificant cost but when put in the context of 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.

What is needed now is a focus on how that additional \$1.5B can be obtained. We need innovative solutions that do not rely solely on the NSW Government.

Set out below is a suggested Action Plan developed by the ACD NSW. Can you improve it? Do you have other ideas? We would welcome your suggestions and be happy to work with you to put them to Government at a State and Federal level.

10 POINT PLAN:

Action	Assumptions	Calculation	Estimated cost saving/revenue
1. Review all existing residents of supported accommodation to determine if any of them would be better suited in a more semi-independent style of residence and establish those people in such facilities where identified.	Assumes 10% can be relocated to a residence costing half of current cost. NB: No account has been made for one-off cost of establishment of semi-independent style of residences	Current users: 5,000 Cost of current users: \$500 million 10% of 5,000=500 Cost of those users: \$50 million ½ of \$50M=\$25M Result: Saving of \$25M p.a.	\$25M p.a.
2. Increase NSW Government spending by 10% ¹³ (this may be funded across Govt	Assumes all the increase is diverted to supported accommodation – a	10% of \$1.1 billion = \$110 million p.a.	\$110M p.a.

¹³ It is noted as a postscript that, since formulating this 10 Point Plan, the NSW Government has pledged a large injection of funds to the disability sector, although not specifically increasing funding for long term supported accommodation to the extent suggested in this Paper. The figure of \$1.1 billion on which our calculations are done represents the Government's spend in the 05/06 financial year.

Departments, extending to the Dept of Housing and Health as well as DADHC)	better option would be to increase State Govt funding by 20% so funding to all services is increased.		
3. Establish funding model for each existing residence whereby families pay annual fee (means-tested) each year for a maximum period of 10 years ¹⁴ .	Assumes average annual fee of \$6,000 pa (equivalent to fees payable 1/3 average cost of childcare per annum).	5,000 x \$6,000 = \$25 million p.a.	\$30M p.a.
4. Establish funding model for each new placement whereby families pay annual fee (means-tested) each year for a maximum period of 10 years plus a once-off placement fee. Placement fee to be set according to tax rate of parents but fee should be tax deductible over 5 years.	Assumes average annual fee of \$6,000 pa. Assumes average placement fee of \$50,000 per person. This equates to \$750 million. It has not been factored into the Action Plan since it is a once-off fee. However, it could be used to defray the capital costs of establishing the facilities.	\$90 million p.a. This total amount may reduce slightly 10 years after the introduction of this fee but given the higher mortality rate for people with a disability ¹⁵ , the reduction should not be substantial as fees will continue to be generated by newer residents.	\$90M p.a.
5. Interest on the placement fee capital.	Assume rate of 6% p.a.	6% x \$750M.	\$45M p.a.
6. Federal funding direct to parents to be provided akin to current childcare rebate scheme to defray the annual fee referred to	Figures not included here since this payment would go directly to parents, not to Government.	N/A	N/A

¹⁴ Potentially, the annual fee referred to in this Action Point and the next could be paid out of a Special Disability Trust established for the person with a disability.

¹⁵ Article entitled "Life expectancy of people with intellectual disability: a 35-year follow-up study", Journal of Intellectual Disability Research, Volume 44 Page 591 - October 2000 found that in cases with profound ID, the proportion of expected life lost was > 20% for almost all age groups. Copy of article available at www.blackwell-synergy.com/links/doi/10.1046/j.1365-2788.2000.00280.x

above.			
7. Federal funding to be provided direct to the operator of each residence akin to current funding for nursing homes as provided for the aged by the Commonwealth Department of Health and Ageing. Existing ACAT assessment tool to be applied to determine daily subsidy from Federal Govt.	Assumes average daily subsidy of \$125 per day.	$\$125 \times 365 \times 20,000$	\$912.5M p.a.
8. Resident contribution of 85% of their disability pension.	This figure is based on the current disability pension for a single person aged 21 and over (\$499.70 per fortnight) – the additional revenue is calculated only on the disability pensions of the additional 15,000 residents.	<p>Pension is \$13,000pa $85\% \times \\$13,000 = \\$11,000$</p> <p>$15,000 \times \\$11,000 = \\$165,000,000$</p>	\$165 million p.a.
9. Newer residences to comprise a variety of accommodation models including clusters, hostels and village models, all of which are less costly to run than group homes	Assumes 1/2 of all new residents choose to live in residences which cost at least 15% less to run than a group home	<p>$1/2 \times 15,000 = 7,500$</p> <p>Saving of 15% of \$100,000 for each of those residents = \$112,500,000</p>	\$112.5M
10. Introduce \$100 levy on all births payable by parents on release from hospital. This levy is comparable to the new levy to be imposed on car insurance to fund the Lifetime Care &	Assumes birth rate of 12.7 births per 1,000 population, as per ABS figures from 2004.		\$8.5M

Support Scheme for people suffering serious brain injury or spinal cord injury in a car accident.			
TOTAL:			\$1,498.5M

Using a reasonable mix of parent contribution, State and Federal funding, the unachievable now looks manageable!

Ideas for meeting the capital costs of build would include the development of Private/Public Partnerships whereby private enterprise build the residences in exchange for a guaranteed return for, say, 20 years. This concept is being used successfully in other States to develop affordable housing for low income families.

If you are interested in ensuring there is sufficient funding to meet the need for supported accommodation for people with a disability, or in working with ACD NSW to present our Action Plan to Government, please respond to me with your comments and suggestions.

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APPENDIX

Definitions:

Commonwealth Social Security Act [section 197\(2\)](#):

A child is a profoundly disabled child if:

- the child has a severe multiple disability ([1.1.S.133](#)) OR the child has a severe medical condition ([1.1.S.130](#)), AND
- BECAUSE of that disability or condition, needs continuous personal care ([1.1.C.340](#)) for a minimum of 6 months unless the child's condition has been certified by a medical practitioner as having a terminal illness for which palliative care has replaced treatment, AND
- the child's disability or condition MUST include at least 3 of the following:
 - the child receives all food by nasogastric or percutaneous enterogastric tube,
 - the child has a tracheostomy,
 - the child must use a ventilator for at least 8 hours a day,
 - the child has faecal incontinence ([1.1.F.05](#)) day and night, AND if the child is under 3 years old, is expected to have faecal incontinence day and night at the age of 3,
 - the child cannot stand without support, AND if the child is under 2 years old, is expected to be unable to stand without support at the age of 2,
 - a medical practitioner has certified in writing that the child has a terminal condition for which palliative care has replaced active treatment, or
 - the child requires personal care on 2 or more occasions between 10pm and 6am each day, AND if the child is under 6 months old, is expected to need personal care between 10pm and 6am each day at the age of 6 months, OR
- a medical practitioner has certified in writing that:
 - the child has a terminal condition and is in the advanced phase of that condition, AND
 - the child has a life expectancy measured in weeks or months or it is possible that the child will live for more than 12 months but unlikely that he or she will live for a period substantially greater than 12 months, AND
 - because of the terminal condition the child will need continuous personal care for the remainder of his or her life.

The **American Association on Mental Retardation (AAMR)** defines Mental Retardation as:

"...substantial limitations in present functioning...characterized by: significantly sub-average intellectual functioning, existing concurrently with; related limitations in two or more of the following areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work."

The American Association on Mental Retardation (AAMR) recommends that mental retardation be classified according to level of support an individual may need:

- **Intermittent Support:** Intermittent, short term, "as needed" supports of high or low intensity during life-span transitions, i.e., job loss, medical crisis, etc.
- **Limited Support:** Supports characterized by consistency over time and time-limited, i.e., employment training, transitional supports.
- **Extensive Support:** Long-term daily support in some environments, i.e., home or school.
- **Pervasive Support:** Constant, high intensity, possibly life-sustaining support across environments.

Severe Mental Retardation:

- IQ range of 25-40
- Usually requires extensive level of support according to AAMR (regular daily assistance needed in some but not all areas)
- Accounts for 3-4% of persons with MR

- Do not function independently though they can acquire some self-help skills e.g., feeding, dressing, and toileting
- Can usually perform simple acts a grooming and personal hygiene
- Understanding of language is likely to be better than their ability to express it
- Speech may be very poorly articulated and difficult to understand
- May be able to recognize some functional words and common signs
- May know that money has value but may not be able to tell the specific values of coins
- May be capable of performing some useful work at a sheltered workshop or activity center
- Relates to adults in a childlike fashion
- Can have some peer relationships

Profound Mental Retardation:

- IQ range below 25
- Will require Pervasive level of support according to AAMR(extensive support in all areas of daily life and activities)
- Often "un-testable," however, their ability may be estimated by standardized adaptive behavior scales with caregivers providing the observational information e.g., Vineland Social Maturity Scale
- Accounts for 1 percent of persons with MR
- Will always require much supervision though some self-help skills may be acquired
- Likely to have multiple disabilities, particularly in mobility and communication

- Ability to understand exceeds their ability to speak
- May have little or no speech
- May be capable of following simple directions
- No academic skills
- May be unable to perform any useful work, though with training, may be able to achieve a work-activity level of productivity
- May appear socially isolated and pay little attention to others except as it relates to their own needs